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Research Article

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Abstract

This is an ethnographic study of decision-making concerning tube feeding in the acute phase after a severe stroke. It is based on 6 months of ethnographic research in three stroke units in the Netherlands, where the decision-making on life-sustaining treatment was studied in 16 cases of severe stroke patients. Data were collected through participant observation and interviews. For this article, the analysis was narrowed down to the decision whether or not the patient should receive tube feeding. The data on tube feeding were assembled and coded according to different modes of dealing with this decision in clinical practice, which we refer to as "repertoires." We discerned three different repertoires: choice, necessity, and comfort. Each repertoire structures clinical practice differently: It implies distinctive ethical imperatives, central concerns, sources of information, and temporalities. We hope our findings can improve decision-making by uncovering its underlying logics in clinical practice.

Keywords

ethnographic research; tube feeding; end-of-life decision-making; severe stroke; palliative care; qualitative research; The Netherlands

Introduction

In 2015, the Royal Dutch Medical Federation published a report about appropriate end-of-life care under the heading "Not everything that can be done has to be done [niet alles wat kan, hoeft]" (Stuurgroep Passende zorg in de laatste levensfase, 2015). This title refers to the societal objectives of preventing life-sustaining treatments for patients who have little to gain from it and of considering palliative care as an alternative. These objectives apply best to situations in which patients have a clear prognosis and are able to express their wishes. However, in the case of patients in the acute phase after a severe stroke,[1] the opposite is the case: prognostic uncertainty, time pressure, and the fact that patients are often incapacitated make the decision-making process particularly complex (Visvanathan et al., 2017). To include an incapacitated patient's will in the decision-making process, doctors frequently make use of advance directives and surrogate decision-making (de Kort et al., 2017; Shalowitz et al., 2006). However, in the acute phase after a severe stroke, the uncertainty of prognosis raises doubts as to what extent these decisions can be planned for in advance. Therefore, our aim was to ethnographically study how these complex decisions are taken in clinical practice.

As most research on decision-making after a severe stroke has been interview-based (de Boer et al., 2015; Eriksson et al., 2014; Payne et al., 2010; Seeber et al., 2014), we sought to contribute to this field with ethnographic research that observes *how* decisions on life-sustaining treatments are taken in clinical practice. Ethnographic methods are suitable for studying multifaceted, complex social situations and are therefore particularly useful to bioethics (Gordon & Levin, 2015; Muller, 1994; Willems & Pols, 2010). In the case of decision-making after a severe stroke, ethnography had several advantages: it enabled us to study decision-making

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prospectively, not just retrospectively; it allowed us to study a multiplicity of actors and their interaction; and it included the incapacitated patient in the observation (see Pols, 2005).

This study is based on 6 months of ethnographic research in three stroke units in the Netherlands, where two researchers followed 16 patients in the acute phase after a severe stroke. In the course of the fieldwork, we encountered several treatment decisions, ranging from nearly standardized "do not resuscitate" decisions to decisions of treating a hypothetical lung infection with antibiotics. After fieldwork, we decided to narrow down our analysis to one particular treatment decision: whether to start or stop tube feeding.[2] We found this a particularly interesting case for several reasons: (a) it is a decision with direct consequences, rather than being dependent on hypothetical complications such as a cardiac arrest; (b) it is more invasive than, for example, the prescription of antibiotics; and (c) the fact that patients have the right to refuse tube feeding in the Netherlands (KNMG Royal Dutch Medical Association, V&VN Dutch Nurses Association, 2014) raises considerable ethical dilemmas when dealing with incapacitated patients, who are not able to express their will.

Our theoretical approach is informed by empirical ethics (Willems & Pols, 2010) and practice theory (Reckwitz, 2002), and makes use of the concept of "repertoires" (Pols, 2005) to describe how tube feeding was discussed, handled, and understood in our case studies. With this approach, we sought to do justice to the ethical complexity of the situation by exposing the multiplicity of meanings, functions, and consequences that tube feeding can acquire for acute severe stroke patients. Rather than providing a blueprint of what to do, we hope our analysis will contribute to clinical practice by unraveling the decision-making process and its underlying logics.

Method

The methods of this study are ethnographic and involved 6 months of fieldwork in 2017 in three stroke units in the Netherlands. In this period, two fieldworkers followed the decision-making process on life-sustaining treatments for patients with a severe stroke from the day of admission until the day of discharge (with a maximum of 4 weeks). They followed the decision trajectories, conducting observations, interviews, and collected additional medical records. The fieldworkers were neither medically trained nor familiar with the field and could therefore observe the decision-making process from a relative distance—as far as possible in such an emotionally burdening field.

Patients included were those who had suffered a stroke and had an uncertain but poor prognosis of either low chances of survival or a low quality of life in case of survival. Whenever a patient was admitted to the hospital within these 6 months, who fit the inclusion criteria, the treating doctor would contact the fieldworkers to review the patient's inclusion anonymously and to ensure sufficient variation in the case studies. Data saturation was reached after 16 patients, when no new treatment decisions occurred.

Ethics and Informed Consent

This research was approved by the Medical Ethics Review Committee of the VU University Medical Center (number 2017.173). They reviewed the informed consent procedure and the privacy measures, and suggested improvements where necessary. The committee also concluded that our research—since it only involved observations of the patients—did not fall under the conditions of the Medical Research Involving Human Subjects Act (WMO) and that the strict conditions of this law did not apply to our research design. The researchers signed a statement of integrity with the participating hospitals, ensuring the privacy of all patients and staff in the ward.

The procedure to establish informed consent was carried out by senior staff at the participating hospitals. Patients were initially identified on the basis of inclusion criteria by senior staff at the neurology departments. Once a patient was considered eligible for the research, a senior physician of the stroke unit would ask the patient directly, or in case of incapacitation, their legal representative, for informed consent to participate in the research. It was ensured that this physician was not the patient's treating physician to minimize the risk of coercion. Whether or not a patient was capable to give informed consent was established by the treating physician. If the patient recovered in the course of the fieldwork and could be addressed again, consent to participate in the research was retrospectively established by the researchers.

Patients or their legal representatives were provided with an official consent form and an information folder about the research. In addition, they received information in person and were given the opportunity to ask more questions before signing the consent form. The form included a clause that patients had the right to withdraw from the research at any point in time, in which case all their data would be deleted. One of the participants made use of this option, but opted for the data to be kept.

The researchers only contacted the patient once informed consent had been established with the physicians. All participating physicians and care professionals were also asked for their informed consent to participate in the research. Prior to fieldwork, information sessions were held at each stroke unit, after which the professional participants were asked to sign consent forms. The researchers

spent 2 weeks in the stroke unit before data collection to give staff the opportunity to ask questions about the research and establish additional consent in person.

Data Collection

The main ethnographic method used in this study was participant observation, which was complemented with interviews and informal conversations. Additional triangulation was provided by studying medical records.

Participant observation in the stroke units served as the primary research method. Once a case had been included, researchers attended as many morning transfers and rounds, staff meetings, and family consultations as possible. The data were collected in the form of a structured observational coding scheme with fixed items (e.g., which decision was being discussed, who participated in the discussion, what was the outcome of the decision, who took the decision if no decision was taken, by when did the decision need to be taken) as well as open field notes. The researchers developed these field notes into more extensive ethnographic vignettes, distinguishing between observational notes (detailed descriptions of observations), interpretative notes (the researcher's interpretations of the observations), as well as personal notes (describing the emotional process and personal feelings of the researcher). If the participants consented, the family consultations were audio recorded in full and transcribed verbatim.

The field notes were complemented with interviews with family members and informal conversations with the hospital staff. The purpose of the interviews with family members was to further understand the considerations of the family when taking decisions on life-sustaining treatments (e.g., what decisions had to be taken, which considerations played a role in this decision, whether it felt like their decision, what they think the patient would have wanted, who helped them with taking this decision). These interviews were audio recorded and transcribed verbatim. As in-depth interviews were not an option for the physicians at the stroke unit for lack of time, the researchers made use of informal conversations and unstructured, ad hoc interviews, asking the physicians to reflect on their reasons for taking a specific decision. The notes from these conversations were typed out as soon as possible into more extensive reports. In case the patient was transferred to a nursing home after her or his time in the stroke unit, the researchers followed up with phone calls and conducted an additional in-depth interview with the elderly care physician to hear about the rest of their trajectory. These interviews were also recorded in full and transcribed verbatim.

In addition to the field notes and the interviews, the researchers also studied relevant medical records for each case. These included reports of morning rounds, summaries of family consultations, and medical assessments and policy decisions. This was only done in situations in which there were doubts about the observations and further triangulation of the data was deemed necessary. To ensure confidentiality, all data were archived in a secured folder on the university database that was only accessible for the researchers.

Analysis

After the fieldwork period, the fieldworkers chronologically reassembled the field notes, reports, and transcriptions of each case and compiled them into extensive case reports, which formed the basis for the analysis. Due to personnel changes, the analysis was conducted by different researchers than the fieldwork and the compilation of the case reports.

The case reports were openly coded using memos and comments in Microsoft Word. The first round of coding consisted mostly of codes such as types of decisions, who participated in the decision and various themes that appeared in the concerns and arguments made by the participants. After a first round of coding, we decided to narrow our analysis down to the decision on whether to start or stop tube feeding, as this was the most pressing issue in most of our cases. We compiled all data on decision-making about tube feeding and openly coded considerations that came up in the decision-making process (e.g., gaining more time, following advance directives, a patient pulling out the tube). We then grouped these considerations into three higher order concepts: choice, necessity, and comfort.

As the majority of our data were observational and not interview-based, we chose to describe these concepts as "repertoires" (Pols, 2005), to distinguish the different ways in which tube feeding is proposed, discussed, handled, and understood in practice. We preferred "repertoires" over "themes"—an attempt to balance the border between narrative and ethnography (see Gubrium & Holstein, 1999). This approach is informed by practice theory (Reckwitz, 2002), which allows for an analysis of the *how*—the modes of interaction—rather than the *what*—the thematic content. By making these repertoires explicit, we aim to make "the often inexplicit patterns of value, knowledge and actions" (Pols, 2005, p. 80) visible. The concept of repertoires functioned both as a descriptor and as an analytical tool, as we were already analyzing our data through that lens during the coding process.

Results

We found that tube feeding is configured in a number of ways and does not always involve the same values, actors, and understandings of what should be done. Instead, each repertoire stages the decision of tube feeding differently.

Table 1. Summary: Three Repertoires of Tube Feeding.

Description of Repertoire	Choice	Necessity	Comfort
Ethical imperative	Respect for autonomy	Not letting die	Reduce suffering
Central concern	Representations of patient's will	Medical indication	Signs of discomfort
Temporality	Past	Future	Present
Source of information	Family as surrogates	Doctors and care professionals	The patient

We identified three repertoires of tube feeding from our data: choice, necessity, and comfort. These repertoires are not confined to particular actors, institutions, or even cases; different repertoires can be at play at the same time, sometimes complementing one another, conflicting or clashing at other times (See table 1).

First Repertoire: Choice

In the first repertoire, tube feeding is configured as the individual choice of the patient. Here, the decision on whether to start or stop tube feeding depends on the patient's will. This repertoire invokes the principle of respect for autonomy, in which feeding someone against their will becomes a violation of that principle:

> Case 13: woman, 85–90 years old, infarct right hemisphere; patient is aphasic and semi-paralyzed
>
> Upon intake, the doctors want to start tube feeding, but the family is convinced that the patient "would not have wanted" this. During the family consultation, the son-in-law tells the doctors, "But she explicitly said she did not want to be artificially fed." "No," the daughter adds. "So, I think that you have to respect that," the son-in-law continues. "So, my idea is, let her lie in a quiet room, because she does not want to drink and she does not want to eat. So, if you respect that, then it should be over soon."

In the repertoire of choice, it poses a problem that patients are often incapacitated due to aphasia or disturbed or lowered consciousness and unable to express their will directly after a severe stroke. Therefore, families play a crucial role in informing doctors about what the patient "would have wanted," drawing on a variety of material to represent the patient's will. For example, the patient may have completed advance directives:

> Case 8: man, 55–60, infarct left hemisphere; patient is aphasic and semi-paralyzed
>
> During an interview the patient's wife says: "[We have] all the documents for an emergency, and we brought them with us. We have been able to see very clearly . . . that he wants food and water, so he does not want to starve, but that he does not want procedures done, to extend life in the condition that he is in. So, that was comforting for all three of us—we knew that, because of how he had talked about it. But it was comforting to see it black on white—with his signature on it."

In other situations, references were made to past statements of the patient in comparable situations:

> Case 10: woman, 70–75, infarct right hemisphere; patient is aphasic, semi-paralyzed and semi-comatose
>
> During the family consultation, the sister's partner tells the resident[3]: "She has been in this [situation] before, when she was still at home in her flat, eh . . . she had broken her hip, and was . . . incredibly dependent on everyone actually, and then she also said: 'If this doesn't get better, then I don't have to continue like this' . . . These were literally her words. And I do think that if she . . . stays paralyzed and tube fed and . . . is not able to enjoy things anymore, well that then . . . that she would also not choose that option."

These examples illustrate how the repertoire of choice is concerned with the accuracy and the authenticity of representation of the patient's will; it helps when it is written "black on white" or that these were "literally her words," because the reconstruction of the patient's will is never fully certain.

One of the ways in which patients' relatives made a case that the patient would not have wanted to be tube fed is by referring to the cultural stereotype of the "vegetable" [kasplantje]. This is a metaphor of a severely disabled patient in a nursing home who is kept alive with food and water despite having a severely low quality of life. Both relatives and doctors sometimes fell back on this metaphor. One of the residents expressed his concern with this term:

> Case 10: woman, 70–75, infarct right hemisphere; patient is aphasic, semi-paralyzed and semi-comatose
>
> "I have a bit of a problem with the term 'vegetable,'" says the resident to researcher XX. "It completely disregards the nuance of such a situation." He tells XX that he finds the vegetable term too subjective and relative. "Whereas a sportive man, who is very active, might find that 'this is no life,' this might be completely different for someone who is fine with being in a wheelchair." He says he wants to know from people whether they have "thought about this question"

> [whether they want to continue life with severe disabilities], because often that is not the case. But for him the phrase "she does not want to be a vegetable" is not sufficient. "Well," he adds in a sarcastic tone, "of course, no one wants that."

According to this resident doctor, the term "vegetable" is useless in end-of-life decision-making. Rather than confronting the dilemma between life with severe disabilities and death, it refers to a cultural stereotype of a vegetating patient. The metaphor is often used as a rhetorical device to devalue the option of life-sustaining treatment. However, the fact that the other option is death is not brought to the fore. Although the metaphor of the vegetable fits within the repertoire of choice, it offers only an illusion of choice because the image it conjures is generally considered undesirable—as the resident said, in the end, "no one wants to be a vegetable." This resident points out that choice, as it is handled in clinical practice, is not always as well-informed and reflected upon as it should be ideally.

If the patient is incapacitated, the choice repertoire depends on a reconstruction of the patient's will. Taking a decision in the present therefore involves drawing on the past. However, sometimes families and care professionals came up with creative compromises on how to still include an incapacitated patient in the present decision-making process. In the following example, the patient's will was not expressed cognitively, but staged through the patient's body:

> Case 13: woman, 85–90, infarct right hemisphere; patient is aphasic and semi-paralyzed
>
> During the family consultation, the resident suggests: "We can also try a middle way and see whether she wants to eat . . ." ". . . And then see whether she opens [her mouth]," the daughter says. "See whether she wants that . . .," the resident adds. . . . ". . . So it is a process that she has to do herself, that's what it comes down to," the son-in-law concludes. "Yes," the resident agrees. "Okay, so then we can tell her this emphatically. That it is up to her," says the son-in-law. . . . The resident replies, "I like what you said, that she has to do it herself."

Here, patient choice is enacted in a way that assumes the patient is capable to express their decision on life-sustaining treatment. It is an effort to include the patient in the present time in the decision-making process. But within the repertoire of choice, it is necessary to assess whether the patient is capable of taking and expressing such a decision. In the case of incapacitation, most of the agency in this decision-making process remains with the family, who are the primary source of information in the process of reconstructing the patient's will from the past rather than the present.

Second Repertoire: Necessity

In the second repertoire, tube feeding is treated as a necessity, as living is necessary for everything else. It can be necessary for several reasons, for example, giving a better prognosis, giving the patient a chance to survive, creating more time for the family to take decisions, or enabling the patient to recover their speech function and participate in the decision themselves. When refraining from tube feeding, none of this would be possible anymore, as it would result in the patient's death.

Whereas the choice repertoire draws on advance directives, personal relationships, and shared experiences, the necessity repertoire draws on clinical knowledge. Whether tube feeding is necessary or not depends on its medical indication and a diagnosis of dysphagia, the inability to swallow. In most of our case studies, this was assessed by dieticians and speech therapists, who measured the patient's ability to swallow and dietary intake. The necessity of tube feeding was established once it has been indicated by a professional.

> Case 14: man, 70–75 years old, infarct right hemisphere; patient is aphasic, semi-paralyzed and has pneumonia
>
> During the morning round on the second day, the resident informs the neurologist that there will be a family consultation today to discuss tube feeding. The neurologist seems surprised. "Medically speaking there is barely any doubt about tube feeding," she says. She explains that she believes the decision on tube feeding has already been taken, and that there is nothing that has to be discussed with the family. The resident agrees with her, but also adds, "we still have to discuss this with the family." "But this is not a question that we will discuss," the neurologist replies. The decision about tube feeding is clear, also because the dietician has already made a statement about this. "There is no doubt," she adds. The researcher asks the neurologist what she means by that. She replies, "Well, medically speaking there is no doubt about this, if the man is not able to swallow, well . . . then there is no doubt about the appropriateness [juistheid] of starting to tube feed."

The disagreement between the two doctors in this excerpt illustrates the different role of the family in the necessity repertoire. In the choice repertoire, it is mostly up to the family to assemble personal knowledge about the patient's will, but in the necessity repertoire it is up to doctors to assemble medical knowledge. This shifts the dynamic between doctors and family: Instead of the family informing the doctors about the patient's values, it is the other way around—the doctors inform the family about medical facts.

In our cases, we encountered the necessity repertoire mostly in terms of gaining time. The only way to give a prognosis of how much and in what condition the patient might recover during the acute phase is to "wait and see."

In these situations, tube feeding is not a medical treatment that could improve the patient's condition, but a necessity to keep them alive to give a better prognosis. Here, hope that the patient might recover plays an important role, which also depends on other factors such as age and the current state of the patient. In contrast to the reconstruction of the past in the choice repertoire, the temporality of the necessity repertoire is oriented toward the future and toward giving a prognosis.

> Case 6: man, 55–60, third cerebral hemorrhage; patient is aphasic and semi-paralyzed
>
> During the family consultation, the patient's wife asks the co-assisting physician, ". . . If you do give him . . . how do you say, food . . . then he will continue as a, eh . . . vegetable. Do you get me?" the doctor nods in agreement. "Yes, I get what you mean. And that is something which we cannot say anything about yet." "But then I also cannot take a de . . . cision yet either," the wife replies. "Then we have to wait and see," the sister adds, "The doctors also said, tomorrow we will try with a tube. We will give some food and then we will have to wait three days and see how it goes . . . And then we can always still say: we will continue feeding, or we stop it. That is also possible."

In this case, the wife was asked to take a decision between options that are uncertain. This points toward the interdependence between choice and necessity: For a choice to be made, there needs to be a prognosis, for which tube feeding is a necessity.

When tube feeding is configured as a necessity rather than a choice for patients with a severe stroke, it invokes different ethics because its status as a medical procedure is not always evident. As tube feeding is considered a medical procedure in the Netherlands (KNMG Royal Dutch Medical Association, V&VN Dutch Nurses Association, 2014), patients have a right to refuse it. However, according to the logic of the necessity repertoire, tube feeding is sometimes handled not as a treatment in its own right but as a precondition to treatment—one that is not up for discussion and cannot be refused:

> Case 10: woman, 70–75, infarct right hemisphere, aphasic, semi-paralyzed and semi-comatose
>
> The patient was initially admitted for an epileptic seizure and only diagnosed with an infarct a week later. The doctors agreed with the family to refrain from treating any complications related to the stroke, but to still try to treat the epilepsy. When the researchers asked the resident about why the patient was still being tube fed, the resident said: "You can't stop feeding people if you are still treating them, we are still trying to make her better."

In this example, tube feeding is not up for discussion, because it is a prerequisite for treating the patient. It would be paradoxical to treat someone while also letting them starve.

When tube feeding is not treated as a medical procedure, but as a precondition, refraining from the treatment may become an unethical act because it disturbs the "natural course" of the disease:

> Case 13: woman, 85–90 years old, infarct right hemisphere; patient is aphasic and semi-paralyzed
>
> The resident tells the researchers during an informal conversation: "Yes, what the neurologist said [earlier] . . . we are not God . . . And what she means by that is that you can't say 'okay now we stop feeding at this and this point' . . . sometimes you just have to let nature run its course . . . In an ideal situation, or at least our ideal situation, we would have a patient with less strongly articulated ideas [about end-of-life treatment] and that the family says she is old and do we really have to do everything for her at this point . . . And that we then say, 'we give her food and drink, we give her a tube and we wait and see.'"

This resident considers not using the tube is "playing God," disturbing "letting nature run its course." It is necessary to artificially feed the patient for her to die a natural death. Although this logic fits within the repertoire of necessity, it turned out to be quite an exceptional case. What we encountered more often in other cases were allusions to the idea that starting tube feeding would be "playing God."

Third Repertoire: Comfort

In the third repertoire, the decision on whether to start or stop tube feeding depends on whether tube feeding causes a patient suffering or discomfort. Its ethical imperative is to reduce suffering. As many severe stroke patients are incapacitated and cannot communicate whether they are suffering, this repertoire requires an attentiveness to signs of discomfort.

> Case 13: woman, 85–90 years old, infarct right hemisphere; patient is aphasic and semi-paralyzed
>
> On the fourth day, the team of doctors has changed. During the morning round, one of the nurses says, "To be honest, I have difficulties with this treatment policy. . . . I think that we have to call the palliative team. . . ." The new resident replies, "If I understand correctly, then I see that she is uncomfortable." "Yes, when I touch her she pulls a face and then stiffens completely," the nurse agrees and adds, "I don't think this is ethically responsible."
>
> The resident tells the rest of the staff that the family wants to stop with everything and that they care most about the patient not suffering. "And we do see a woman that is suffering," he declares. The new neurologist pauses and

thinks for a few seconds and then says that it is most important to prioritize the comfort of the patient. "And we have to act in accordance with that," he adds.

When tube feeding is configured as a matter of comfort rather than a necessity, it is not handled as a means to an end but also as an end in itself. Comfort can both be a treatment goal and an attribute of treatment itself.

Case 1: woman, 85–90 years old, infarct right hemisphere; patient is unapproachable and semi-comatose

During the family consultation, the neurologist asks: "Another important question, at the moment she is getting fluids . . . through an IV, and the question now is . . . should we feed her with a tube in her nose?" "May I ask a question?" the son-in-law asks, ". . . Is it necessary at the moment? For her comfort . . . that is the most important." "Does it have any use . . .," says the daughter. "At this point, not really . . . but it is something to keep in mind," the neurologist replies. . . . "Because if you don't do that . . . feeding . . .," the daughter interrupts, "do you then start a certain process [dying]?" "In the end yes," the neurologist replies, "If someone does not get any food for weeks . . . then yes . . ." "But she does not feel any of this herself . . .," says the daughter. "We [the family] are with the four of us, and so if one of us says: 'I want her to be fed,' then we will feed her and then the other three have to give in . . . but we do have to discuss this well . . . your mother has to be comfortable . . .," says the son-in-law. "That is the most important [thing]," the daughter adds.

As opposed to the choice repertoire, where the family is the source of information regarding the patient's will, and the necessity repertoire, where doctors are the source of information on whether tube feeding is indicated, the source of information in the comfort repertoire is more diffuse. Whether or not a patient is suffering and what to do about it has to be established collectively by care professionals and relatives. This repertoire is unique because it involves the patient in the present moment. Even if a patient is not able to express their will, they might still be able to pull out the feeding tube, for an unknown reason—maybe because they are in pain, agitated, uncomfortable because the tube is displaced or signaling that they don't want the tube at all. When this happens, and it did frequently in our cases, it often poses an ethical challenge for care professionals, because there is no way of knowing why the patient pulled out the tube:

Case 6: man, 55–60, third cerebral hemorrhage; patient is aphasic and semi-paralyzed

"He can't say that this doesn't feel nice, so if he can't express himself then it's really difficult to say that he pulls it out because he finds it annoying . . . of course you can't know, because he can't say so . . . why he pulls it out," says the sister. The resident replies: "No, and very often it's also the case that when people have severe neural damage, they react directly to internal stimuli—for example if they are in pain or uncomfortable, they react immediately without being able to regulate this in their mind."

This situation is a deadlock between two differing interpretations of the patient's action from the choice and the necessity repertoire: the infusion of a will versus the reduction to a symptom. Seen from the choice repertoire, this is as an act of self-determination and a signal that the patient does not want to live any longer. In the necessity repertoire, this could be interpreted as a symptom of the stroke: The patient cannot think beyond their immediate discomfort, cannot understand that the tube is necessary for their survival, and therefore must be restrained to prevent them from pulling it out. And at the center of these conflicting interpretations, we find a patient who is visibly suffering—for reasons that are impossible to establish.

The comfort repertoire, however, offers another way of handling this situation that avoids this deadlock:

Case 8: man, 55–60, infarct left hemisphere; patient is aphasic and semi-paralyzed:

When the resident comes by for the morning round, the patient is awake and sitting in a wheelchair. His eyes are open and he is wearing a fastening glove [to prevent him from pulling out the tube]. He looks around and glances at the glove several times while slowly twisting his hand in it. . . . The nurse reports that the thorax image looked good, but that the patient pulled out the tube several times already, which is also the reason why he has a fastening glove. "Is the tube not placed too low?" the resident asks and suggests that they might have to consider changing its position. The nurse replies that the tip of the tube was not as visible in the thorax image and that she doesn't know in what position it is. While she says this, she pulls a part of the tube from the patient's nose and tests it with a syringe of food. "Look, now it's in a good position," she says, while watching the syringe. . . . "Do you feel any pain?" the resident asks the patient. He nods his head. But when the resident asks where he feels pain he just nods again and then stares at the fastening glove in bewilderment.

Instead of interpreting the patient's act of pulling out the tube as either a will or a symptom, the doctor asks whether it is placed in a good position. This question is both an interpretation of the situation (the tube is causing the patient pain if misplaced) and an impetus to act (adjusting the position of the tube). Therefore, the comfort repertoire differs from the other repertoires in its temporality: rather than being oriented toward the future or reconstructing the past, its effects can be perceived in

the here and now. If a patient is visibly suffering, this gives an impetus to act. However, the immediacy of comfort also implies that the question of "what to do" is a pragmatic one—one in which situations can sometimes be improved by a bit of adjustment of the tube.

Often it is difficult to establish where the boundary has been reached when tube feeding is causing a patient too much suffering. A patient pulling out the tube can certainly be seen as a sign of discomfort, but when is that reason enough to decide to stop it? One response to this problem we encountered was setting a protocol for how many times maximum the tube can be reinserted, as was the case in one of the hospitals where one of the patient's files contained the statement:

> Policy of the unit is to refrain after the probe is removed 3x.

This policy is largely specific to the nasogastric tube: As it can be easily pulled out (unless the patient is fastened), the question arises whether to *temporarily refrain* from using it. With the percutaneous endoscopic gastrostomy tube, this question does not arise as easily. As it is somewhat more permanent and difficult to remove for the patient, the question is rather whether to *stop* feeding. Thus, the specific material attributes of each tube, how invasive or permanent they are, also play an important role in considerations of comfort.

In our stroke units, the comfort repertoire often implied the transition to a palliative policy, in which case the patient would not be tube fed and be given morphine, which suppresses hunger. Although comfort can sometimes be ensured by adjusting the position of a tube, it more often implies a decision about life and death in itself. Once comfort is established as the highest priority, there is very little that can legitimize keeping someone alive by means of tube feeding.

Discussion

From our ethnographic data, we were able to discern three repertoires of how tube feeding is handled in clinical practice: as choice, as necessity, and as comfort. These repertoires help us make sense of at least a part of the large amounts of data we collected during the research. It is important to note that the choice to narrow the analysis down to tube feeding was only made after the data were collected. Although this enabled us to conduct an exploratory, open-ended study, it also limits our analysis. The data would probably look different had we already entered fieldwork with that particular research question in mind. Furthermore, the repertoires are only based on a limited sample of cases and not generalizable to other stroke units or fields. They should not be taken as "social facts," but rather as an analytical tool to make sense of such a complex decision-making process that link empirical phenomena with central concerns and debates in research on end-of-life decision-making.

The repertoire of choice is the most researched: Biomedical ethics has long dealt with the problem of how to treat incapacitated patients while also respecting the principle of autonomy (see Community Engagement Core, 2016). Empirical findings on patients after a severe stroke show that proxy decision-making and advance directives are used most frequently to respect patient autonomy (de Kort et al., 2017). Proxy decision-making has also been studied in terms of its accuracy in representing the patient's will (Shalowitz et al., 2006). However, other studies have shown that families of severe stroke patients are not only involved as proxy decision-makers, but take on a multiplicity of roles (Seeber et al., 2014) whose experiences should be included in research on the decision-making process (de Boer et al., 2015; Meeker, 2004). These studies resonate with our findings, in which families took on different roles in each repertoire, and we agree that the involvement of the family should not be reduced to proxy decision-making alone.

More fundamental critiques of choice in end-of-life decision-making go beyond these concerns and question the assumption that good care equals patient choice, for example, in the case of advance care planning (Robins-Browne et al., 2014) or "good death" (Black & Csikai, 2015). A central argument in this literature is that many of the end-of-life decisions patients are presented with in practice are choices between equally bad or futile options, and therefore meaningless (Borgstrom, 2015; Callahan, 2002) or not even real choices at all (Drought & Koenig, 2002; Kaufman, 2005; Slomka, 1992). Although our findings resonate with some of these critiques, the problems that arose in our cases were not that the options were equally bad but that they were uncertain. We encountered the choice between life as a "vegetable" and death only as a metaphor, not as a reality—one which we believe employs a "misleading simplicity" (Hertogh, 2011) that neither takes the uncertainty of prognosis nor the disability paradox (Albrecht & Devlieger, 1999) into account. We therefore underline the importance of improving communication between physicians and families, a call that has been made in numerous studies on end-of-life decision-making (de Boer et al., 2015; Payne et al., 2010; Quinlan & O'Neill, 2009), especially in the context of prognostic uncertainty (Ridley & Fisher, 2013) or once a patient's status is considered terminal (Aldridge & Barton, 2007).

One of the pitfalls of critiquing choice in end-of-life decision-making is that the question of alternatives remains unanswered. Dichotomies, such as choice and care (Mol, 2008) or choice and compassion (Borgstrom & Walter, 2015), or analyses of decision-making as primarily occurring between physicians and patients (Lippa

et al., 2017) risk positioning choice as either the opposite or as the definition of good care. By proposing three rather than two repertoires, we hope to constructively contribute to critiques of choice "putting autonomy in its place" (Callahan, 2002)—by relativizing it instead of discarding it altogether. In the case of patients after a severe stroke, the choice paradigm is not always misplaced. It is one of several repertoires, one of many ways to handle decisions about life-prolonging treatments and ethical dilemmas about death.

The necessity repertoire forms a counterpoint to the choice repertoire, one that is reminiscent of medical paternalistic authority as opposed to patient autonomy. However, we found that in the context of prognostic uncertainty in the acute phase after a severe stroke, decisions on life-sustaining treatments may follow different ethical imperatives, such as "waiting and seeing" or "giving nature a chance," a finding echoed in other qualitative studies on decision-making after a severe stroke (Eriksson et al., 2014). Another factor that supports the necessity repertoire is time pressure in decision-making, which we encountered not as a subjective experience of the family (de Boer et al., 2015) but as a factor that actively shapes how decisions are made and the ethics they imply.

The third repertoire, comfort, resonates with efforts to integrate palliative care in stroke units (Gardiner et al., 2013) and the societal objective of limiting unnecessary life-sustaining treatments in end-of-life care (Stuurgroep Passende zorg in de laatste levensfase, 2015). It bears similarities to other ideals of good care such as compassion (Borgstrom & Walter, 2015) that center on a patient's best interest rather than patient choice. In our attempt to describe comfort not just as a treatment goal but as a mode of handling tube feeding in its own right, we found that there are multiple ways of how comfort might be incorporated into decision-making after a severe stroke. These might include an attentiveness to immediate signs of discomfort, attempts at improving comfort with minor adjustments, as well as protocols and searches for alternatives on how to deal with a situation in which a patient repeatedly pulls out the feeding tube.

Although we are aware that this repertoire is the least fleshed out of all three, we believe it carries the most importance, as it incorporates the patient in the present moment. It therefore contributes to studies on voiceless patients in critical care and the search for alternative forms of communication (Happ, 2000) as well as nonverbal and embodied incorporations of the "patient perspective" (Pols, 2005). As most research on decision-making after a severe stroke has been interview-based and focused on either doctors or relatives, we hope to have contributed to this field by including incapacitated patients as observed through the ethnographer. The importance of this topic calls for further research on how other factors, for example, the age of the patient or institutional policies, shape these repertoires, as well as possible interventions on how to incorporate incapacitated patients into decision-making after a severe stroke.

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Notes

1. Resident doctors are treating physicians, who are under the supervision of a senior physician.
2. We refer to a severe stroke when a patient has an uncertain but poor prognosis (either as a consequence of the stroke or as a consequence of the patient's general health status) and is in a state in which decisions about life-prolonging treatments and the start of palliative care are on the agenda.
3. In nearly all cases, the decision about tube feeding concerned the nasogastric tube (NGT) and not the percutaneous endoscopic gastrostomy (PEG), as the NGT is most commonly used in the acute phase after a stroke.

References

Albrecht, G. L., & Devlieger, P. J. (1999). The disability paradox: High quality of life against all odds. *Social Science & Medicine*, *48*(8), 977–988. https://doi.org/10.1016/s0277-9536(98)00411-0

Aldridge, M., & Barton, E. (2007). Establishing terminal status in end-of-life discussions. *Qualitative Health Research*, *17*(7), 908–918. https://doi.org/10.1177/1049732307299995

Black, K., & Csikai, E. L. (2015). Dying in the age of choice. *Journal of Social Work in End-of-Life & Palliative Care*, *11*(1), 27–49. https://doi.org/10.1080/15524256.2015.1021072

Borgstrom, E. (2015). Planning for an (un)certain future: Choice within English end-of-life care. *Current Sociology Monograph*, *63*(5), 700–713. https://doi.org/10.1177/0011392115590084

Bortgstrom, E. & Walter, T. (2015.) Choice and compassion at the end of life: A critical analysis of recent English policy discourse. *Social Science and Medicine*, 136–137, 99–105. https://10.1016/j.soscimed.2015.05.013

Callahan, D. (2002). A commentary—Putting autonomy in its place: Developing effective guidelines [Special issue III]. *The Gerontologist*, *22*, 129–131. https://doi.org/10.1093/geront/42.suppl_3.129

Community Engagement Core. (2016). *Medical decision-making for unknown and unrepresented patients*. Harvard Medical School.

de Boer, M., Depla, M., Wojtkowiak, J., Visser, M. C., Widdershoven, G. A. M., Francke, A. L., & Hertogh, C. M. P. M. (2015). Life-and-death decision-making in the acute phase after a severe stroke: Interviews with relatives. *Palliative Medicine*, *29*(5), 451–457. https://doi.org/10.1177/0269216314563427

de Kort, F. A. S., Geurts, M., de Kort, P. L. M., van Tuijl, J. H., van Thiel, G. J. M. W., Kappelle, L. J., & van der Worp, H. B. (2017). Advance directives, proxy opinions, and treatment restrictions in patients with severe stroke. *BMC Palliative Care*, *16*(52), 1–6. https://doi.org/10.1186/s12904-017-0234-8

Drought, T. S., & Koenig, B. A. (2002). "Choice" in end-of-life decision-making: Researching fact or fiction? [Special issue III]. *The Gerontologist*, *42*, 114–128. https://doi.org/10.1093/geront/42.suppl_3.114

Eriksson, H., Andersson, G., Olsson, L., Milberg, A., & Friedrichsen, M. (2014). Ethical dilemmas around the dying patient with stroke: A qualitative interview study with team members on stroke units in Sweden. *Journal of Neuroscience Nursing*, *46*(3), 162–170. https://doi.org/10.1097/JNN.0000000000000049

Gardiner, C., Harrison, M., Ryan, T., & Jones, A. (2013). Provision of palliative and end-of-life care in stroke units: A qualitative study. *Palliative Medicine*, *27*(9), 855–860. https://doi.org/10.1177/0269216313483846

Gordon, E. J., & Levin, B. W. (2015). Contextualizing ethical dilemmas: Ethnography for bioethics. *Advances in Bioethics*, *11*, 83–116. https://doi.org/10.1016/S1479-3709(07)11004-9

Gubrium, J. F., & Holstein, J. A. (1999). At the border of narrative and ethnography. *Journal of Contemporary Ethnography*, *28*(5), 561–573. https://doi.org/10.1177/089124199129023550

Happ, M. B. (2000). Interpretation of nonvocal behavior and the meaning of voicelessness in critical care. *Social Science & Medicine*, *50*, 1247–1255. https://doi.org/10.1016/s0277-9536(99)00367-6

Hertogh, C. M. P. M. (2011). The misleading simplicity of advance directives. *International Psychogeriatrics*, *23*(4), 511–515. https://doi.org/10.1017/S1041610211000184

Kaufman, S. (2005). *And a time to die: How American hospitals shape the end of life*. Scribner.

KNMG Royal Dutch Medical Association, V&VN Dutch Nurses Association. (2014). *Caring for people who consciously choose not to eat and drink so as to hasten the end of life*. http://docplayer.net/10054859-Caring-for-people-who-consciously-choose-not-to-eat-and-drink-so-as-to-hasten-the-end-of-life.html

Lippa, K., Feufel, M., Robinson, F., & Shalin, V. (2017). Navigating the decision space: Shared medical decision making as distributed cognition. *Qualitative Health Research*, *27*(7), 1035–1048. https://doi.org/10.1177/1049732316665347

Meeker, M. A. (2004). Family surrogate decision making at the end of life: Seeing them through with care and respect. *Qualitative Health Research*, *14*(2), 204–225. https://doi.org/10.1177/1049732303260501

Mol, A. (2008). *The logic of care: Health and the problem of patient choice*. Routledge.

Muller, J. H. (1994). Anthropology, bioethics and medicine: A provocative trilogy. *Medical Anthropology Quarterly*, *8*(4), 448–467. https://doi.org/10.1525/maq.1994.8.4.02a00070

Payne, S., Burton, C., Addington-Hall, J., & Jones, A. (2010). End-of-life-issues in acute stroke care: A qualitative study on the experiences and preferences of patients and families. *Palliative Medicine*, *24*(2), 146–153. https://doi.org/10.1177/0269216309350252

Pols, J. (2005). Enacting appreciations: Beyond the patient perspective. *Health Care Analysis*, *13*(3), 203–221. https://doi.org/10.1007/s10728-005-6448-6

Quinlan, C., & O'Neill, C. S. (2009). *Practitioners' perspectives on patient autonomy at end of life*. Irish Hospice Foundation.

Reckwitz, A. (2002). Toward a theory of social practices: A development in culturalist theorizing. *European Journal of Social Theory*, *5*(2), 243–263. https://doi.org/10.1177/13684310222225432

Ridley, S., & Fisher, M. (2013). Uncertainty in end-of-life care. *Current Opinion in Critical Care*, *19*(6), 642–647. https://doi.org/10.1097/MCC.0000000000000030

Robins-Browne, K., Palmer, V., & Komesaroff, P. (2014). An unequivocal good? Acknowledging the complexities of advance care planning. *Internal Medicine Journal*, *44*(10), 957–960. https://doi.org/10.1111/imj.12556

Seeber, A. A., Pols, A. J., Hijdra, A., & Willems, D. L. (2014). How Dutch neurologists involve families of critically-ill patients in end-of-life care and decision-making. *Neurology Clinical Practice*, *5*(1), 1–8. https://doi.org/10.1212/CPJ.0000000000000091

Shalowitz, D. I., Garrett-Mayer, E., & Wendler, D. (2006). The accuracy of surrogate decision makers: A systematic review. *Arch Intern Med*, *166*, 493–497.

Slomka, J. (1992). The negotiation of death: Clinical decision making at the end of life. *Social Science & Medicine*, *35*(5), 251–259. https://doi.org/10.1016/0277-9536(92)90021-H

Stuurgroep Passende zorg in de laatste levensfase [Steering committee Appropriate care at the end-of-life]. (2015). *Niet alles wat kan, hoeft*. KNMG [Royal Dutch Medical Association].

Visvanathan, A., Dennis, M., Mead, G., Whiteley, W. N., Lawton, J., & Doubal, F. N. (2017). Shared decision making after severe stroke—How can we improve patient and family involvement in treatment decisions? *International Journal of Stroke*, *12*(9), 920–922. https://doi.org/10.1177/1747493017730746

Willems, D. L., & Pols, A. J. (2010). Goodness! The empirical turn in health care ethics. *Medische Antropologie*, *22*(1), 161–170.

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