How Dutch neurologists involve families of critically ill patients in end-of-life care and decision-making

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Summary

When critically ill neurologic patients are cognitively incapacitated, decisions about treatment options are delegated to surrogates, usually family members. We conducted qualitative interviews with 20 Dutch neurologists and residents in neurology varying in age, work experience, and workplace to investigate how they involve their patients' family members in decision-making. Their reports revealed that they ascribed 3 different, yet tightly interwoven roles to families: (1) informants about values and preferences of patients, (2) participants in care and care planning, and (3) sufferers themselves. Neurologists regarded decision-making as an integral part of end-of-life care rather than an isolated process, changing the meaning of what decision-making entails. All different roles of family members were important in end-of-life care and decision-making, instead of the single one of legal surrogate. Neurologists need to support family members in these various roles.

The care of critically ill patients without decision-making abilities is common in neurologic practice. Medical decisions for these patients are ideally made by surrogates, and include decisions to forego certain treatments, such as resuscitation, artificial ventilation, artificial feeding, and antibiotic treatment. Surrogate

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decision-making, usually by family members, is laid down in the health law in the Netherlands, and in most other Western countries.^{1–3}

The idea of self-determination through representation is, however, not unproblematic. Empirical evidence shows that families often do not represent patients' preferences accurately.^{2,4} Family members may not understand the patient's condition, prognosis, and treatment options.^{5–7} Their considerations may be influenced by the desire to pursue any chance of recovery, by grief, and by their own views on the usefulness or futility of treatment.^{8–10} Patients may never have uttered opinions concerning end-of-life questions, and family members may be confronted with their own fears of death and dying.^{11–13} Therefore, physicians treating incompetent patients should not regard family members only as surrogates as defined by law lest they shift responsibility for decisions completely to family members, or disregard the care needs of the families themselves. Though the literature stresses the complexity of surrogate decision-making in practice, it does not address the various and potentially conflicting roles family members may have in care.^{2,14,15}

Given the discrepancy between idealistically and legally aspired surrogate decision-making and its potential limitations in care practice, we interviewed neurologists in order to learn how they involve family members in the process of care and decision-making for incompetent patients at the end of life. We especially aimed to elucidate their handling of the potential conflicts between the legal role assigned to surrogates and the other roles they have.

METHODS

In-depth interviews

We approached practicing residents and consulting neurologists for in-depth interviews by purposive sampling. We first selected 2 university hospitals and 3 nonacademic hospitals from urbanized areas and 3 nonacademic hospitals from rural areas of the Netherlands, with possibly different patient populations. From these hospitals, we selected consultants and residents from different age groups, implying variable durations of clinical experience, and with different areas of special interest. We stopped recruiting neurologists when interviews did not yield new information anymore (thematic saturation).¹⁶ Though family is usually considered to be the individual's closest biological relations or spouse, in the context of our study it could be whomever the neurologists we interviewed considered as such.

Between August 2010 and April 2011, 20 neurologists were interviewed (table), using a topic guide to provide a structure for the interviews. Interviews lasted between 35 and 75 minutes. The interviewer (AAS) asked for a description of at least 2 recent or memorable cases in which treatment restrictions were discussed with families, one case that went well, and one that was problematic. Ethics approval was not needed under the Dutch Medical Research Involving Human Subjects Act (WMO).

Analysis

Interviews were audiorecorded, typed out verbatim, and anonymized. The transcripts were analyzed using MAXqda version 10 software.¹⁷ In each transcript, topics were coded according to the topic guide used, such as "characteristics of patients," "timing of discussions," and "dilemmas," and according to the themes that emerged during the interviews, such as "good care for patients," "good care for families," and "responsibility in decision-making." The interviewer coded the material and discussed coding with other investigators (AJP, DW) until consensus was reached. The lists of codes under each topic served as the basis for the empirical ethical analysis.¹⁸

RESULTS

Neurologists ascribed 3 different, yet tightly interwoven roles to families, those of (1) informants, (2) participants in care and care planning, and (3) sufferers.

Table Characteristics of interviewed neurologists

Sex	
Male (residents/consultants)	11 (3/8)
Female (residents/consultants)	9 (3/6)
Socio-ethnic background	
Secularized native Dutch	20
Age, y	
<40	6
40–50	7
>50	7
Workplace	
Urban	
University hospital	9
Regional hospital	5
Rural	
Local hospital	6
Consultants	14
Special area of interest ^a	11
^a Special area of interest: neurovascular disease (2), movement disorders (1), neuromuscular disease (1), neuro-oncology (1), dementia (1), neuroinfectious and neuroinflammatory disease (4), psychosomatic disease (1).	

Informants

Families were viewed as primary informants about the patients' values, because families had known the patient for many years and were supposed to know his or her treatment preferences.

If an important decision has to be made, I want to meet with the patient and his family. I want to hear from the family what kind of person he used to be and what kind of view he had on life. Especially when I am in doubt myself about whether I should still treat a pneumonia, just to give an example. "Should we try or not?" In that case I really want to see the family myself... (Neurologist 6).

Advance directives were rarely available, and if so, they often did not fit properly with actual treatment considerations and dilemmas. Medical knowledge alone was considered insufficient to make proper treatment plans. Clinicians needed information about patients' views and preferences.

The family members are the ones who know him best. And even if the patient has never talked about it [treatment preferences], they can tell you what his view on life was, what he considered valuable (Neurologist 13).

Families were not the only valuable informants. Neurologists also often contacted general practitioners or home care nurses. However, families' attachment to and involvement with the patients gave their reports about the patients' wishes special importance.

If there is someone who knows the patient well and loves him and says "well, if he has a chance of 10 percent [of being able to manage a wheelchair and eat without help] then we should go for it," yes, that's decisive (Neurologist 1).

Emotional attachment made family members good informants, but not always. Respondents reported cases with conflicts within families, or where families lacked solidarity with patients

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and put their own interest first. When this happened, the neurologists disregarded families' views and fell back on their duty not to harm.

Well, that you will not harm the patient in the broadest sense. That's absolutely the main thing, that's always the main thing. [...] It's important to do the patient no harm with all the actions you could possibly take (Neurologist 9).

Neurologists aimed to provide care in line with the patients' preferences and views on life. They experienced knowledgeable and concerned families as the most valuable, yet not the only possible and surely not infallible source of information when far-reaching treatment options had to be considered.

Participants in care and care planning

All neurologists involved families in decision-making about treatment restrictions. They called families negotiators on behalf of the patients and strove for their agreement with all far-reaching medical treatment plans.

They represent the patient, they are the ones with whom you more or less negotiate. This sounds serious, but that is what it sometimes pretty much comes down to... They are the ones with whom you determine the treatment policy (Neurologist 9).

Apart from negotiators, families were also active participants in care. The capacity of the patients' network to engage in future care could have an effect on the choice of reasonable treatment options.

I couldn't make that judgment because I couldn't figure out who that 57-year-old junkie was...- When it became evident that there was a safety net, support, when I heard from those people that they would provide care for him, the situation became completely different (Neurologist 17).

Interviewees said to stimulate families to participate in care and care planning by carefully informing them about the condition and prospects of the patient and about medical treatment options. Medical explanations had to be adapted to families' abilities to comprehend the information, taking the disrupting effects of families' stress and grief into account.

You should sketch it as clear and concise as possible for the family, not too much information. For the family members such a situation is extremely difficult. They are in distress... While we have the experience, they experience such a situation for the first time (Neurologist 4).

Neurologists emphasized the importance of sufficient time and quiet when discussing treatment options with families. In many cases, the medical condition and prognosis of patients were not fixed and stable, which made repeated discussions necessary.

You can't rush through such a conversation, you should certainly take time for it and that's not always convenient. It is not an ordinary conversation, so you should hand over your pager and you should be aware it could take some time. [...] It is very important that you then get the idea

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of being on the same wavelength as the people who you are talking to, that they understand what you are telling them (Neurologist 3).

All interviewees considered families' assessment of and agreement with proposed treatment plans important, not only to guarantee that the patients' views had been taken into account, but also for the families' reconciliation with the course of events.

They will have to recognize themselves [in what is decided]...They are the ones who have to live with the decision to fight [for the patients' life] or not (Neurologist 8).

Interestingly, the neurologists explained that although families had an important voice in care and care planning, families never got the final vote. They felt they had to take the ultimate responsibility for the care of their patients.

When a difficult decision has to be made, I enter the conversation with a clear treatment plan on my mind. And then I tell the family why I think it is important, necessary to stop—or start...anti-biotic treatment, for example (Neurologist 1).

This apparent conflict with the legal requirement “to seek consent from the representative for all interventions and treatment decisions”¹ is mainly explained by the clinicians' recognition of the representatives as sufferers.

Sufferers

Clinicians felt that the care of their patients included care for their families as well. In seeking consent for treatment decisions, they therefore tended to frame treatment options carefully, so as to allow family members to agree.

When the situation threatens that the family is forced to decide, you should always try to avoid that, people should not get the feeling that they have to decide about the death of their father or husband. We should take those feelings of guilt away, one way or another...Yes, it is our decision, that's always the trick (Neurologist 14).

Keeping final responsibility for treatment decisions did not mean that neurologists simply took over. They rather tried to guide families through the decision-making process. Again, they emphasized the importance of sufficient time to allow suffering families to digest and accept the patients' condition and its consequences.

They are emotional, and these emotions are of course about their going to lose someone...This needs time. (Neurologist 13) I will have known the family for a few days and together we will have worked towards, yes, really worked towards a certain decision (Neurologist 11). They will have to live with it [the treatment decision and its consequences] (Neurologist 1).

The neurologists described various strategies to reach shared agreement on certain medical decisions without putting the burden of deciding on families. They sometimes employed persuasion, for instance, by using their professional authority.

People are aware of your experience and then of course you have more authority, which surely makes it easier...I am aware of my seniority and my grey hair and I make use of it (Neurologist 4). You show a scan for instance. That is what I usually do when large abnormalities are visible. "Look, a large hemorrhage, nothing can really be done about it." Then of course, it sinks in, then they [the family members] put 2 and 2 together (Neurologist 11). If the family does not understand it completely or becomes worried or nervous, I sometimes refer to the *vegetable*, "so that your father doesn't become that *vegetable*, that's not what he would have wanted, would he?" (Neurologist 15) I don't think it's good to present your plan bluntly and to say "that's how we are going to do it," but on the other hand you should stay in the lead (Neurologist 13).

To reconcile families with the situation at hand, neurologists thought it important to avoid conflicts. As long as patients were cared for properly and did not suffer, neurologists said they would postpone medical decisions if that supported families' process of acceptance.

This family was from the Balkans, they were completely overwhelmed by the proposal of the resident to abstain from further treatment, because father was in such a poor condition. I told them that it was obvious to us that further treatment did not make sense, but that if they found this difficult to accept, we could wait and see how the situation developed for another 24 hours. So I gave them some time (Neurologist 12).

In fact, neurologists built relationships with these families that did not end after the definite treatment plan had been figured out.

Even if you have agreed to simply wait for the end, I keep on seeing how the family is faring and take some time to talk things over with them. As a doctor you are a certain character to them with certain rituals that go with it. You remain the contact person for the family. For instance when the patient has trouble breathing, you try to take away the families fears, ask the nurses to stay involved with them (Neurologist 13).

When neurologists talked about families as sufferers, appropriate patient care included care for these families. The conclusion of the decision-making process was then not only in the interest of patients, but also in that of the families.

DISCUSSION

From our interviews, we could infer 3 different but tightly interwoven roles for families of incompetent patients in care and decision-making toward the end of life. As informants about patients' views and as participants in care and care planning, family members were said to support neurologists in their striving to provide good, individuated care. However, families were also seen as sufferers themselves. Neurologists felt responsible not only for the appropriate care for patients, but also for the patients' families, whom they experienced as struggling with conflicting interests during decision-making.

Opinions expressed in interviews may of course not necessarily reflect actual practice accurately. However, the reports we documented show a strong conformity between neurologists of different ages, working in different hospitals and various regions of the Netherlands. Moreover, similar views were reported in a recent nationwide study on surrogate decision-making for cognitively impaired patients among Dutch physicians working on intensive care units and in nursing homes and in a national television documentary about Dutch physicians' views on their moral standards.^{19,20} Judging from all these observations, we conclude that the opinions are likely to reflect current standards of Dutch neurologists, and that a significant discrepancy between report and practice in this case seems improbable.

According to the ideal of self-determination and according to legal regulations of many Western countries, family members are surrogate decision-makers for incompetent patients. In practice, however, the most pertinent principle Dutch neurologists voice is not to have family

members make decisions. They do not understand families as decision-makers, but involve them in care as informants about the patients' values, as participants in care planning, and as sufferers themselves. Good care involves not forcing the family to decide about the end the life of their relative, so as not to induce the guilt of responsibility for a loved one's death.²¹ At the same time, the neurologists take care that families can live with what is, implicitly or explicitly, the doctor's decision about their loved one, for instance by giving them more time, talking to them, explaining, making it look as if it was their own decision, and so on. Thus, the neurologists view family involvement and decision-making from a perspective of care for all concerned. By now, we hardly know whether this practice is different in other Western countries. The few empirical data on the subject mainly focus on the position of the physician in surrogate decision-making and not on the various roles family members may have in this process.^{14,15,22,23} As the role of families as sufferers appears to be pivotal in clinical practice, a restrictive (or legalistic) approach to the involvement of family members in decision-making could deprive families of the acknowledgement of their grief and the care they need to play a meaningful role in the end-of-life decisions for their loved ones.^{24–26} The clinical practice described may provide more and more varied benefits than the restrictive approach, from the perspective of both incompetent patients and their families. For the patients, it may bring forth protection from too hastily taken decisions, colored by grief, other emotions, and self-interest. For family members, it provides recognition of their emotions and need for support.¹⁴ On the other hand, it is possible that the neurologists we interviewed may not leave enough room for families to participate in the decisions that are so crucial for the fate of their loved ones. Though the neurologists try to repair this by seeking the families' approval of treatment plans, there are situations—as discussed in the Results—in which families' potential decisions legitimately diverge from those of the neurologist. The restrictive approach, and especially the law, may adjudicate in such situations. Our findings highlight the fact that—in the Netherlands—the clinical practice of end-of-life care and the involvement of family in care and decision-making is primarily driven by a comprehensive clinical morality, and not by a more restricted legalistic approach. Morality of care is strengthened from within, rather than enforced from outside. This suggests that reflection on and empirical studies of medical practices are better ways to improve care than juridification.

REFERENCES

1. Dutch Medical Treatment Act (Wet op de geneeskundige behandelingsovereenkomst, WGBO [in Dutch]). Statute of the Dutch Ministry of Health, Welfare and Sports. The Hague: The Dutch Ministry of Health, Welfare and Sports; 1994.
2. Berger JT, DeRenzo EG, Schwartz J. Surrogate decision making: reconciling ethical theory and clinical practice. *Ann Intern Med* 2008;149:48–53.
3. Lautrette A, Peigne V, Watts J, Souweine B, Azoulay E. Surrogate decision makers for incompetent ICU patients: a European perspective. *Curr Opin Crit Care* 2008;14:714–719.
4. Shalowitz DI, Garrett-Mayer E, Wendler D. The accuracy of surrogate decision makers: a systematic review. *Arch Intern Med* 2006;166:493–497.
5. Abbott KH, Sago JG, Breen CM, Abernethy AP, Tulskey JA. Families looking back: one year after discussion of withdrawal or withholding of life-sustaining support. *Crit Care Med* 2001;29:197–201.
6. Azoulay E, Sprung CL. Family-physician interactions in the intensive care unit. *Crit Care Med* 2004;32:2323–2328.
7. Majesko A, Hong SY, Weissfeld L, White DB. Identifying family members who may struggle in the role of surrogate decision maker. *Crit Care Med* 2012;40:2281–2286.
8. Schenker Y, Crowley-Matoka M, Dohan D, Tiver GA, Arnold RM, White DB. I don't want to be the one saying "we should just let him die": intrapersonal tensions experienced by surrogate decision makers in the ICU. *J Gen Intern Med* 2012;27:1657–1665.
9. Sonnenblick M, Friedlander Y, Steinberg A. Dissociation between the wishes of terminally ill parents and decisions by their offspring. *J Am Geriatr Soc* 1993;41:599–604.
10. Turan B, Goldstein MK, Garber AM, Carstensen LL. Knowing loved ones' end-of-life health care wishes: attachment security predicts caregivers' accuracy. *Health Psychol* 2011;30:814–818.
11. Marks MA, Arkes HR. Patient and surrogate disagreement in end-of-life decisions: can surrogates accurately predict patients' preferences? *Med Decis Making* 2008;28:524–531.

12. Moorman SM, Hauser RM, Carr D. Do older adults know their spouses' end-of-life treatment preferences? *Res Aging* 2009;31:463–491.
13. Vig EK, Taylor JS, Starks H, Hopley EK, Fryer-Edwards K. Beyond substituted judgment: how surrogates navigate end-of-life decision-making. *J Am Geriatr Soc* 2006;54:1688–1693.
14. Weinstein E. A piece of my mind: on caring for those who will remain. *JAMA* 2012;308:1749–1750.
15. White DB, Malvar G, Karr J, Lo B, Curtis JR. Expanding the paradigm of the physician's role in surrogate decision-making: an empirically derived framework. *Crit Care Med* 2010;38:743–750.
16. Lucassen PLBJ, olde Hartman TC. Qualitative Research: Practical Methods for Daily Practice (Kwalitatief onderzoek: Praktische methoden voor de medische praktijk [in Dutch]). Houten: Bohn Stafleu van Loghum; 2007.
17. MAXqda. The Art of Text Analysis: VERBI Software: Consult. Berlin: Sozialforschung GmbH; 2010.
18. Willems D, Pols J. Goodness! The empirical turn in health care ethics. *Medische Antropologie* 2010;22:161–170.
19. Exploring the Soul. Doctors, episode 4 (Kijken in de ziel. Artsen [in Dutch]). Dutch Public Service Broadcaster for Information, Education and Culture "NTR"; 2012.
20. Akerboom CPM, Dute JCJ, Gevers JKM, Nijis H, Winter HB, Woestenburg NOM. Thematische wetsevaluatie: Wilsonbekwaamheid en vertegenwoordiging. Zoetermeer: Schulten Reproservice; 2011.
21. Tauber AI. Patient Autonomy and the Ethics of Responsibility. Cambridge, MA: MIT Press; 2005.
22. Azoulay E, Pochard F, Chevret S, et al. Family participation in care to the critically ill: opinions of families and staff. *Intensive Care Med* 2003;29:1498–1504.
23. van der Steen JT, Kruse RL, Ooms ME, et al. Treatment of nursing home residents with dementia and lower respiratory tract infection in the United States and the Netherlands: an ocean apart. *J Am Geriatr Soc* 2004;52:691–699.
24. Dubler NN. The doctor-proxy relationship: the neglected connection. *Kennedy Inst Ethics J* 1995;5:289–306.
25. Torke AM, Alexander GC, Lantos J, Siegler M. The physician-surrogate relationship. *Arch Intern Med* 2007;167:1117–1121.
26. Tronto J. *An Ethics of Care: Moral Boundaries: A Political Argument for an Ethics of Care*. London: Routledge; 1993:125–155.

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