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PAPER

How family caregivers' medical and moral assumptions influence decision making for patients in the vegetative state: a qualitative interview study

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ABSTRACT

Background Decisions on limiting life-sustaining treatment for patients in the vegetative state (VS) are emotionally and morally challenging. In Germany, doctors have to discuss, together with the legal surrogate (often a family member), whether the proposed treatment is in accordance with the patient's will. However, it is unknown whether family members of the patient in the VS actually base their decisions on the patient's wishes.

Objective To examine the role of advance directives, orally expressed wishes, or the presumed will of patients in a VS for family caregivers' decisions on life-sustaining treatment.

Methods and sample A qualitative interview study with 14 next of kin of patients in a VS in a long-term care setting was conducted; 13 participants were the patient's legal surrogates. Interviews were analysed according to qualitative content analysis.

Results The majority of family caregivers said that they were aware of aforementioned wishes of the patient that could be applied to the VS condition, but did not base their decisions primarily on these wishes. They gave three reasons for this: (a) the expectation of clinical improvement, (b) the caregivers' definition of life-sustaining treatments and (c) the moral obligation not to harm the patient. If the patient's wishes were not known or not revealed, the caregivers interpreted a will to live into the patient's survival and non-verbal behaviour.

Conclusions Whether or not prior treatment wishes of patients in a VS are respected depends on their applicability, and also on the medical assumptions and moral attitudes of the surrogates. We recommend repeated communication, support for the caregivers and advance care planning.

BACKGROUND

Some patients show signs of wakefulness as demonstrated by eye opening, but are incapable of a meaningful reaction to stimuli. This condition is known as the vegetative state (VS).¹ Decisions on life-sustaining treatment for patients in the VS have been an issue of intense discussions over the last 40 years. Life-sustaining treatment can be defined as any treatment without which the patient would die from a life-limiting disease within a foreseeable time frame.² Such decisions are extremely challenging for professional care personnel and surrogate decision makers, who are quite frequently the patient's next of kin. Cases that were legally contested by the patients' next of

kin have led to controversial public debates about the moral justification of the withdrawal of artificial nutrition and hydration (ANH) for patients in a VS.³ Meanwhile England, Wales, Germany and other countries have laws stipulating that a valid and applicable advance refusal is binding and that surrogates have to acknowledge the patient's expressed will.⁴ The legal regulation in Germany is such that a dialogue between the doctor and the legal surrogate forms the basis for the legal surrogate's decision to agree or disagree with the application of treatment. The doctor has to suggest which treatment goals can be achieved by means of therapeutic measures, which is often referred to as the medical indication of a treatment. Then it has to be investigated with the legal surrogate whether the proposed treatment is in accordance with the patient's advance directive or presumed will. Treatment omission or withdrawal in accordance with the patient's will is lawful in Germany.

Treatment decisions for patients in a VS have to be made despite a high level of uncertainty regarding diagnosis,⁵ therapeutic success and prognosis.⁶ Even though it used to be a core diagnostic criterion, it has recently been challenged by neuroscientists whether all patients in a VS have actually lost consciousness.⁷ Consequently, diagnostic classification has been questioned and bedside examination alone does not seem sufficient to make a reliable diagnosis. An accurate diagnosis has implications for the course of a potential recovery⁸ and for symptom control treatment.⁹ Traditionally, recovery from VS more than a year after a traumatic brain injury and 6 months after a non-traumatic brain injury is regarded as highly improbable¹⁰ but not totally impossible, seeing as some cases of late recovery have been published in the literature.^{6, 11} Decisions on limiting life-sustaining treatment should be made with reference to the ethical principles of the patient's autonomy and best interests.¹²

Usually the next of kin are advocated as surrogate decision makers, because they are thought to know the patient's wishes and values best and are most interested in the well-being of the patient.¹³ Yet, studies using hypothetical case scenarios have shown that surrogate decision makers may inaccurately represent the patient's treatment wishes.¹⁴ It remains unclear whether surrogates in fact decide according to the patient's will, especially in cases of VS where uncertainty is so prominent. We explored this question in a qualitative interview study.



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METHODS AND PARTICIPANTS

From 2009 to 2011 a total of 14 next of kin, who were taking care of 12 patients in a VS from throughout Germany, were recruited with the help of the following gatekeepers: (1) the head nurse of a nursing home ward specialising in the long-term rehabilitation of patients in a VS, (2) a doctor working for a nationwide outpatient care service, (3) the case manager of a nationwide outpatient care service and (4) a counsellor for family caregivers for severely disabled patients. Gatekeepers either distributed invitation letters or contacted family caregivers directly to inform their clients of the study. Criteria oriented, purposeful sampling was conducted in order to have the maximum variety of cases according to the following characteristics: patient–caregiver relationship (parents, children and partners), duration of being in the VS (short, medium and long term) and care institution (professional care institutions and private homes). Interviews were conducted until a satisfactory sample of perspectives on limiting life-sustaining treatment was found (rejection of treatment limitation, consideration of treatment limitation under circumstances, agreement with limitation of treatment). Inclusion criteria, with reference to the patient, was being in a condition where recovery was highly improbable, so at least 6 months after non-traumatic brain injury and 12 months after traumatic brain injury.¹⁰ Participants were required to be able to speak German fluently. The interviews were carried out by two interviewers: the first author, a psychologist, and the second author, a doctor, both skilled in qualitative interview methods. The interviews were conducted with three mothers, eight spouses (one fiancée, one ex-wife) and three sons of mothers in a VS. Except for one relative, all were the legal surrogates of the patient. Table 1 shows the demographic data of the sample group. The local research ethics committee granted ethical approval for this project. Participants were approached according to local research protocols and informed consent was obtained.

The patients lived in the following settings: (1) a nursing home ward specialising in the long-term rehabilitation of patients in a VS, (2) community homes for patients requiring 24-h respiratory or intensive care service and (3) private homes. At the time of the interview, the patients had been in a VS for 9 months (in a case of hypoxic brain injury) to 15 years. We conducted semistructured interviews on the participants' decision making about life-sustaining treatment. We also investigated the caregivers' understanding of the illness and their burden, which will not be reported in this article. The caregivers

Table 1 Demographic data of the sample

	Patients, n=12	Next of kin, n=14
Ages, in years		
Median	50	54
Range	36–71	34–74
Gender, %		
Female	50%	50%
Care institution, frequency		
Private home	n=4 (33%)	
Nursing home	n=8 (67%)	
Relationship, frequency		
Parent–child	n=2	n=3
Child–parent	n=3	n=3
Partner	n=8	n=8
Time spent in vegetative state, months		
Median	52	
Range	9–183 months	

were asked, among other questions, the following: 'Have you ever asked yourself, if it would be better not to administer life-sustaining treatment in his/her [ie, the patient's] case? Please narrate'. The interviews took place at the institutions where the patients were in care or at a neutral place in the University Hospital where the authors worked. They were audio recorded, transcribed following adapted transcription rules and verified by one of the interviewers. The transcripts were analysed by means of the MAXqda software (VERBI GmbH, Berlin, Germany) using the qualitative content analysis method according to Mayring.¹⁵ Meaningful parts of the material were selected inductively to answer the research question: 'How do family surrogates of chronic VS patients deal with previously expressed wishes and the presumed will of the patient regarding life-sustaining treatment?' The participants' key statements in answer to the research question were selected. Repetitive statements were reduced, paraphrased to a general declaration and abstracted. The entire material was analysed and sorted according to the abstract categories by using a coding guide. For the purpose of this publication, selected quotes were translated by an English native speaker. The interview guide, transcription rules and coding guide can be obtained from the authors upon request.

RESULTS

Knowledge of patients' wishes

The results of the content analysis of the patients' wishes and their representations are illustrated in table 2. In half of the studied cases, family caregivers reported statements made prior to VS by the patient that could be applied to the current situation.

Those family caregivers that did not report knowledge of prior wishes interpreted a will to live in the patient's survival or non-verbal behaviour. The following comment was made with reference to a moment in which a doctor, while standing at the patient's bedside, made the suggestion to discontinue life-sustaining treatment, and at that moment, the patient opened her eyes.

'The decision was actually there from the beginning, because I know my daughter and at the moment when he [ie, the doctor] said, she can't do that [ie, opening the eyes], and she did it, as though she had heard it, I knew: No.'

(Mother, P. 2a)

How the expectation of recovery overrules an advance directive

In two interviews conducted with the sons of a patient, one reported knowing of an advance directive and orally expressed wishes by his mother, in which artificial nutrition had been refused without explicit reference to a VS condition. At the time of the interview both of her sons shared the view that artificial nutrition should be maintained, yet resuscitation may be withheld.

'(...) With regard to her advance directive, yes it exists. It actually prohibits artificial nutrition, so yes, she crossed that off (...). Her position was pretty clear on that, to me at least. I think to all of us children (...). But this situation we have through this acute, through this unforeseen, through this brain haemorrhage as well as (...) through the uncertainty of how the condition is progressing, like how can it be. (...) We have never seen the situation that way, as an actual artificial way of maintaining life, but rather as a recovery process or a kind of process where I think to myself: that makes sense. And that is still not neglecting her wishes.'

(Son, P. 3b)

Table 2 Categorical analysis of the representation of the patient's wishes in interviews with family caregivers

Form of representation	Wish	Tendency of wish
Written advance directive	No artificial nutrition and hydration (P. 3) No enduring life sustaining treatment, if a 'normal' life isn't possible (P. 1) No tubes (P. 9)	Refusal of life sustaining treatment
Anticipatory oral statements	No life-prolonging treatment (P. 6) No tubes when I'm in a VS (P. 7) No life in a wheelchair (P. 10) No life-prolonging treatment in a condition like after a stroke (P. 11)	
Presumed will based on the patient's prior identity	She wouldn't have wanted to live like this (P. 8) He wouldn't have been able to deal with illness or disability (P. 12) If she could kill herself for example, jump from a bridge, she would do it (P. 11)	
Presumed will based on the patient's survival	He is a 'fighter' because he survived a crisis (eg, a sepsis) (P. 4; P. 6) He is not dissatisfied with his situation, otherwise his condition would deteriorate (P. 9) He decides himself: If he wants to die he will just die (P. 4; P. 9)	Ongoing will to live
Presumed will based on the patient's current behaviour	She gives 'signs' (eg, open eyes) that she wants to live (P. 2a) Through participation in physiotherapy she shows her will to live (P. 3a) He wants to live because he participates in the care process and reacts to appeal (P. 5)	

The type of representation of the patient's wish, the content of the wish and the tendency for or against life sustaining treatment are shown. The numbers mark the interview participants (not the patients).
VS, vegetative state.

This particular son had difficulties explaining his thoughts, which became evident by the interrupted grammatical structure and his repetition of words. He weighed his mother's wishes against his own impression of the illness and his own assessment of her recovery potential. The patient was continuously artificially nourished and hydrated. He reached the decision that he would not accept intensive care measures or surgery for his mother in case of complications or comorbidity. Yet, if there was a treatment option that would improve her condition, for example neurosurgery, he would agree to it. That resembles the next argument that was also present in two other cases.

How defining life-sustaining treatment measures guide decisions

A family caregiver had previously spoken with his wife about life-sustaining treatment measures while the patient's father had been care dependent. The patient's wish was clear to the spouse, even though the topic of their discussion was not the VS. He was determined to comply with her wishes. He was convinced that if she had a chance to end her life, 'to jump from a bridge', she would do it.

'So we actually spoke about what if this and that would happen. Well she didn't want life-prolonging treatment under any circumstances.'

(Husband, P. 11)

This patient was continuously artificially nourished and hydrated, but the relative did not perceive the ANH as being a form of life-sustaining treatment. He was of the opinion that because healthy people would also be nourished, ANH was neither artificial nor invasive. To him it was not a treatment measure at all. He said, he would consent to antibiotics that could cure pneumonia, but not if there was a more serious and complicated infection. Thus, the effectiveness of the treatment also influenced his decision on where to draw the line.

'Now we have to differentiate between life sustaining and life prolonging, am I right? (...) It depends on what her chances are in each concrete situation. In case of a lung infection one agrees [ie, with the administration of antibiotics], but if the condition deteriorates severely I would decide according to her wish.'

(Husband, P. 11)

Instead of considering having the ANH withdrawn, he thinks back counterfactually to his standpoint; if he could have foreseen the outcome of the surgery, he would not have agreed to it. In contrast to ANH, surgery was a treatment measure that he could have rejected.

'If I had known back then when they operated (.) known what the the consequences would be...(.) how the condition would be, I would not have agreed to it. Because I'm quite sure that she wouldn't want what she has now under any circumstances.'

(Husband, P. 11)

In a similar case, the husband of a patient rejected artificial respiration after his wife had a sepsis. He assumed that this treatment measure was life prolonging. Meanwhile he agreed with all other treatment measures and hoped for her survival.

How the moral obligation not to harm the patient prevents a decision

A family caregiver used a double standard in making surrogate decisions for the patient and making decisions for herself. She reported that the hospital referred her to a lawyer who could have advised her on the possibility of discontinuing nutrition.

'Many family members do that now, they stop the nutrition, and only provide fluids. That takes about 2–3 months, but I mean no! I couldn't do something like that. (...) I think it's inhumane. Because, I don't know, I still don't know if he is able to perceive things. And he already had problems with his stomach and still for me it is starvation. So I wouldn't do it. If his heart were to fail now and he wouldn't be brought back, that's something different. But apart from that everything will proceed as it was. I couldn't do that.'

(Wife, P. 10)

It is most important for her that the patient is not harmed and does not have to suffer from either treatment or treatment withdrawal. Later, she was asked by the interviewer (I) what she would want if she had the same condition. What the respondent (R) had termed inhumane for her husband is exactly what she wished for herself:

R: 'Unplug everything.'
I: 'Everything?'
R: 'Everything.'

I: 'Including the artificial nutrition?'

R: 'Yeah, everything. Well I wouldn't want to live like that. Mm Mm [negation]. Before, you haven't made up your mind. But if you experience something like that for yourself, then no.'

I: 'But you've just said that starvation is inhumane.'

R: 'Yes, for others. For myself, phh [non-verbal expression, to say I don't mind].'

(Wife, P. 10)

The patient's will was not precisely against living in a VS. According to his wife he never wanted to live in a wheelchair. The wife justifies this wish by deciding to withhold resuscitation treatment, if the patient were to experience cardiac arrest again. She would not like to inflict pain upon the patient and sees resuscitation as a measure that would not cause him pain if omitted. She also refuses artificial respiration. In her eyes, the patient's condition is not burdensome to himself. She is a relative who no longer has any great hope of the patient recovering.

DISCUSSION

For the family caregivers we interviewed, patient autonomy had only a minor impact on them and did not guide treatment decisions. We found a discrepancy between patients' wishes against prolongation of treatment in severe conditions such as the VS and the surrogates' decisions to continue ANH and other forms of life-sustaining treatment. The caregivers in our study considered ANH as a form of basic care that could not be rejected. All patients were artificially nourished and hydrated. The patients' wishes were overruled by three types of reason: (a) the expected recovery of the patient, (b) the family caregiver's definition of life-sustaining treatment and (c) the moral obligation to not cause the patient harm or pain. We found a type of family caregivers who was ambivalent towards decisions about life-sustaining treatment. They try to balance their own moral and medical assumptions and the patients will and come to inconsistent decisions for and against treatment measures.

A lack of representation of patient autonomy in decisions about life-sustaining treatment was also described in an interview study with older patients in nursing homes in Norway.¹⁶ The authors argued that relatives wanted to continue life-sustaining treatment to avoid the loss or to avoid a bad conscience not having done enough for the patient. In an early study with family caregivers of patients in the VS it was reported that even when family caregivers did not expect the patient to improve, the majority wanted the patient to undergo almost all therapeutic interventions including surgery.¹⁷ Another qualitative study identified how surrogates come to their decisions on life-sustaining treatment. The majority of the surrogates based their decisions on knowledge of the patients' wishes or advance directives. A minority planned to make decisions based on a sense of shared values or on their own personal beliefs about acceptable quality of life of the patient, which in some cases did not match what they knew about their loved one's beliefs.¹⁸

It is remarkable that half of the family caregivers reported knowing the treatment wishes of their patients, mostly referring to advance directives or previous oral statements. However, not all wishes were exactly related to the VS and needed interpretation and application by the caregivers, who were the legal surrogates in all cases but one. Especially when there was a lack of knowledge about the patient's expressed wishes, the family caregivers interpreted the patient's non-verbal behaviour as purposeful expressions of a will to live. The problem of inter-

preting aversive or cheerful behaviour with regard to end-of-life decisions is well known from dementia patients.¹⁹ Loved ones of patients in a VS may be especially tempted to read meaning into the patient's involuntary behaviour to recognise the patient's identity and in order to share or even delegate the responsibility to the patient. However, it could be possible that some of the patients are misdiagnosed as being in a minimally conscious state (MCS) or incomplete locked-in syndrome and thus being able to show purposeful behaviour or even to communicate rudimentarily. Misdiagnosis rates of 40% have been reported before.⁵ Yet being in a MCS does not necessarily mean the patient has a higher quality of life,¹² but has a better prognosis.⁸ The differential diagnosis is also relevant for attitudes towards end-of-life issues. It was shown in a recent European survey that doctors and nurses have different beliefs about patients' pain perception²⁰ and different attitudes towards end-of-life decisions for patients in the VS compared to patients in the MCS, considering it more acceptable to stop treatment in a chronic VS.²¹

The hope for a remarkable recovery of the patient has been described in the literature and is considered crucial for the caregivers' successful coping with the situation.²² It can partly be explained by the uncertainty of prognosis. Although the current guidelines see only a small probability for the recovery of patients in a VS in the chronic state, like the ones we referred to in this study,^{10 11} there are scientific reports of late recovery, as well.⁶

Wijdicks and Rabinstein described three types of families dealing with decisions about life-sustaining treatment: (1) realists that understand the gravity of the situation and know that prolonged care for a patient in a VS would be futile, (2) procrastinators who were unsure or have heard of unexpected recoveries and (3) fighters who were willing to sacrifice themselves for the patient and put trust in a miraculous recovery.²³ Some of the interviewed family caregivers in our study hoped that the patient might eventually be able to communicate verbally again, others were in acceptance of the current condition as the final stage of recovery and a third type was preparing themselves for the patient's death. It has been investigated in prior studies that family caregivers of patients in the VS go through phases of shock, bereavement and finally adaption in which the family caregivers develop an increased ability to let go of the patient.²⁴ We found a fourth type of family caregivers being ambivalent between hope, anticipatory grief and acceptance of the condition.

The term 'life-sustaining treatment measures' was often interpreted differently than how it would be defined medically. ANH or administration of antibiotics was not seen as a medical but 'normal' or 'basic' treatment by the family caregivers in this study. Conversely, respiration, surgery and resuscitation were seen as technical or invasive medical procedures that may be omitted. A moral distinction between various forms of treatment is well known from studies of clinical practice.²⁵ One of the reasons underpinning the reluctance to forego ANH is the fear of letting the patient 'starve to death'. Another fear of withdrawing ANH or artificial respiration is the fear of legal consequences, which reveals a lack of knowledge of the legal framework in Germany that actually allows omission and withdrawal of treatment. Suffering from starvation could only be the case if the patient was indeed aware. But even then, the evidence from studies about the withdrawal of food and fluids in older people or dementia patients argue against suffering and show that dehydration can even be a palliative means leading to a peaceful death.²⁶ Removing foods but not fluids leads to a prolonged dying phase with cachexia that

may indeed cause severe suffering in those patients able to perceive it.

Interventions fostering advance care planning have been recommended for dementia patients.²⁷ Advance care planning is usually understood as an alliance with the patient (or future patient). It may also be applicable to the situation of incompetent patients, like patients in a VS, where the family surrogates could be the main target of this process and the result is an 'advance directive by proxy' or a 'prospective care plan'.²⁸ We identified a high uncertainty regarding the legal framework of limitation of treatment measures. To inform family caregivers on legal matters and the ethical weight of patient autonomy a brochure could be a successful and sustainable intervention. In addition, counselling and access to psychological support for surrogates could be an important factor in improving their decision-making process for the sake of the patients and for their own sake. It should be investigated more closely whether decisions on life-sustaining treatment are made intuitively or rationally, and whether the arguments we found are reasons or justifications for the surrogate's intuitive decisions. A prospective study should look at how caregivers' perspectives change during the course of the illness.

LIMITATIONS

This qualitative interview study did not investigate a representative sample. Gatekeepers might have selected role model caregivers that were engaged in the care of the patient. There was a cultural bias in excluding participants that did not speak German fluently. In that we encouraged the participation without further incentives other than helping to improve knowledge on the issue, we were unable to reach disengaged caregivers. Legal guardians of other patients in a VS might have decided during the early stages to discontinue life support. Furthermore, we do not know if the participants were always willing to reveal their knowledge of the patients' wishes in the interviews. We also do not know if their interpretations really represented the patient's wish. Even advance directives are not always easy to interpret and we did not investigate the patients' advance directives, but depended solely on the participant's narration. Prospective study designs would be necessary in order to provide a representative picture of caregivers of patients in a VS. Our sample was too small to investigate whether the social roles in the relationships between caregivers and patients had an impact on decision making. It can be hypothesised that mothers of patients are more reluctant to forgo treatment than husbands of patients, but this has to be confirmed in quantitative studies with larger samples. The VS diagnoses of the patients in this study were not examined by the researchers. In Germany, VS and MCS²⁹ are not yet consistently discerned, so it is possible that the patients in our study may in fact be in a MCS, but are labelled as being in a VS.⁵

CONCLUSIONS

We identified a gap between the legally and ethically justified norms and current practice. Theoretically, family caregivers should inform about the patient's wishes. Practically, the family caregivers of several patients in a VS in the long-term care made their own decisions and did not necessarily base them on the patients' will. There was a discrepancy between the patients' wishes against prolongation of treatment and the surrogates' decisions to continue ANH and other forms of life-sustaining treatment. The caregivers considered ANH as a form of basic care that could not be rejected. We also identified a group of

ambivalent caregivers who are hesitant to make irreversible decisions. Surrogate decision makers require support in the form of active information and structured communication.

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Contributors KK designed the interview grid, conducted the sampling, collected the largest part of the data, verified the interview transcripts, analysed the data, drafted and revised the paper. She is guarantor. RJJ initiated the project, revised the interview grid, participated in the data collection, revised the results, drafted and revised the paper. GDB supported the initiation of the project, revised the interview grid, revised the results and revised the paper.

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