





How Does Functional Neurodiagnostics Inform Surrogate Decision-Making for Patients with Disorders of Consciousness? A Qualitative Interview Study with Patients' Next of Kin

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Received: 12 April 2019 / Accepted: 9 December 2019 / Published online: 11 January 2020
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Abstract

Background Functional neurodiagnostics could allow researchers and clinicians to distinguish more accurately between the unresponsive wakefulness syndrome (UWS) and the minimally conscious state (MCS). It

remains unclear how it informs surrogate decision-making.

Objective To explore how the next of kin of patients with disorders of consciousness (DOC) interpret the results of a functional neurodiagnostics measure and how/why their interpretations influence their attitudes towards medical decisions.

Methods and Sample We conducted problem-centered interviews with seven next of kin of patients with DOC who had undergone a functional HD-EEG examination at a neurological rehabilitation center in Germany. The examination included an auditory oddball paradigm and a motor imagery task to detect hidden awareness. We analyzed the interview transcripts using structuring qualitative content analysis.

Results Regardless of the diagnostic results, all participants were optimistic of the patients' meaningful recovery. We hypothesize, that participants deal with the results of examinations according to their belief system. Thus, an unfavorable evaluation of the patient's state (e.g., a "negative" HD-EEG-result) had the potential to destabilize the participant's belief system. To re-stabilize or to prevent the destabilization of their belief system, participants used different strategies. Participants accepted a "positive" HD-EEG result since it stabilized their belief system.

Conclusion We hypothesize, that a group of next of kin of patients with DOC deals with functional neurodiagnostics results on the basis of the result's value and their high hope that the patient will recover meaningfully. A psychological mechanism seems to

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moderate the impact of functional neurodiagnostics on surrogate treatment decisions.

Keywords Unresponsive wakefulness syndrome (UWS) · Persistent vegetative state (PVS) · Minimally conscious state (MCS) · Functional neuroimaging · Electroencephalography (EEG) · Family care givers

Introduction

Recent advances in functional neurodiagnostics have sparked a new interest in the clinical assessment of conscious awareness in patients with disorders of consciousness (DOC). DOC entail the unresponsive wakefulness syndrome (UWS), and since 2002, the minimally conscious state (MCS) (or minimally responsive state, MRS) [1–3]. Patients are considered to be in UWS when they are awake and show preserved autonomic and hypothalamic functions as well as sleep-wake cycles and cranial nerve reflexes, but do not show any signs of awareness of themselves or their environment [3–5]. In contrast, patients in an MCS show globally impaired responsiveness and limited but discernible evidence of awareness of self and of the environment [1]. Patients in MCS can emerge from the state when interactive communication, functional use of two different objects, or both are established [1].

Distinguishing between UWS and MCS can be of great importance to the further course of treatment since patients in an MCS are supposed to have a higher chance of recovery of cognitive functions, especially the ability to communicate [6–8]. The ability to communicate about needs and preferences with a patient matters greatly to most families and matters ethically with respect to the patient's agency in treatment decisions. Clinically, it can be very challenging to recognize signs of conscious perception of the self and of the environment. Voluntary movements may be very small and inconsistent; the patient can easily be exhausted; and the examiner and the environment can bias the examination [9, 10]. Forty percent of patients who were formerly diagnosed as showing UWS in a clinical bedside examination were subsequently diagnosed as being in an MCS when tested with a standardized neurobehavioral assessment scale [11].

Functional neurodiagnostics therefore hold promise to improve diagnostic and prognostic accuracy without

being limited to the detection of a patient's motor responses [12]. It includes two different types of measures: imaging tests or scans (e.g. positron emission tomography (PET), photon emission computed tomography (SPECT), blood-oxygen-level-dependent (BOLD), functional magnetic resonance imaging (fMRI)) and electrophysiological measurements (e.g. electroencephalography (EEG), magnetoencephalography (MEG)). They allow researchers and clinicians to examine changes in brain activity at defined localizations and time points [13].

Among other techniques, “active” or “command-following” paradigms including motor imagery tasks are used in functional neurodiagnostics research [13–15]. In a landmark fMRI study in 2006, Owen and colleagues asked a woman diagnosed with UWS to imagine playing tennis or walking through her house [16]. The patient showed cortical activation patterns that were indistinguishable from the patterns of healthy participants [16, 17]. Monti et al. used a similar paradigm to successfully build an fMRI-based communication module for yes-no questions with one patient [14, 18]. Similarly to fMRI studies, functional EEG studies showed analogously promising results with regard to detecting hidden conscious awareness for patients with DOC by means of motor imagery, spatial navigation or own name recognition tasks [20–25]. While generally both measures are criticized for their considerable potential to produce false negative and false positive test results (type I and II error), some applications involving EEG have been considered to have a lower test specificity than those involving fMRI [14, 19].

Patients who show signs of hidden conscious awareness only detectable by functional neurodiagnostics can be considered to be in a functional “locked-in syndrome” (LIS), a diagnosis that applies to patients who are consciously aware but unable to react to stimuli because of paralysis [26, 27]. Recently, the term “cognitive-motor-dissociation” (CMD) has been suggested to describe the clinical conditions of such patients without having to use the term locked-in syndrome, which is typically reserved for patients with brain stem lesions or advanced ALS [28].

The correct assignment of a diagnosis and the prediction of a patient's prognosis under a certain treatment strategy is a prerequisite for medical decision-making [12, 29]. Surrogate treatment decisions about life-prolonging treatment for patients with DOC are often made under considerable diagnostic and prognostic

uncertainty [11, 30–32]. Although functional neurodiagnostics is not yet a part of routine care, some researchers recommend using this approach to improve diagnostic and prognostic accuracy and therefore reduce this uncertainty [7, 14, 18]. There is, however, a lack of data about how patients' next of kin interpret functional neurodiagnostics results and which conclusions they draw for their part in decision-making on behalf of the patient. Researchers and clinicians have expressed concern about how the results of functional neurodiagnostics might influence the next of kin's perspective on intensifying or reducing the patient's medical treatment [12, 19].

We aim to explore how the next of kin of patients with DOC interpret results of a functional neurodiagnostics (HD-EEG-) examination to detect residual cognitive function, how these interpretations influence their surrogate decision-making, and how this influence can be explained. Other publications on family members' perspectives on functional neurodiagnostics broadly examined their attitudes, expectations, knowledge, and receptivity without exploring the real-world perceptions of the technology implemented in clinical health care [33, 34]. We found two study protocols with similar approaches, one regarding neurodiagnostics in Canada and the other in France [35, 36]. We were unsuccessful in identifying publications about the results of these studies.

Material and Methods

Design

Since we aimed to investigate how the next of kin of patients with DOC assign meaning to the results of a functional neurodiagnostics examination in the context of health care, we chose a qualitative research design to explore their perspective in a naturalistic setting (field research). We conducted qualitative interviews with the next of kin of patients who had received care in a neurological rehabilitation center in Germany, during which researchers and clinicians performed a HD-EEG-supported examination of the patients' conscious awareness. To ensure a comprehensive and complete description of the qualitative research methods that we used in this exploratory study, we base this section on the consolidated criteria for reporting qualitative health research (COREQ-Checklist) [37].

Methodology

Our research focused on the participants' interpretations, attitudes, and opinions. We used interviews as a structured form of conversation to explore these issues. We applied qualitative content analysis (QCA) following the approach described by Margrit Schreier to interpret our participants' comments and hypothesize about their deeper meaning [38]. QCA—also referred to as “qualitative oriented category-based text analysis”—is a method that is especially suitable for the analysis of conversation protocols [39]. Using this method, one can go beyond coding the “manifest meaning” and detect the “latent meaning” of conversations [40]. It allows deductive as well as inductive analysis of the material [40]. QCA has been developed across different fields of study which lead to an eclectic methodological foundation rooted foremost in communication theory, hermeneutics, linguistics, the psychology of text processing [41]. While it is discussed if QCA should be located in quantitative or qualitative research methods (or in both methods at the same time being a “hinge” between the two), in this study we understand QCA as a qualitative research method [39].

Diagnostic HD-EEG-Examination to Detect Residual Conscious Awareness

The HD-EEG examination of the patient included a measurement of the auditory p300 and a mental motor imagery task (see [Appendix 1](#) for more detailed information). It was performed in order to test which cognitive functions were preserved and was part of research implemented into the clinical routine of the rehabilitation center. Doctors suggested patients to the researchers in cases where they considered the test to be relevant.

Reporting of the HD-EEG-Examination

The results of both examinations were disclosed in written reports and in oral doctor-next-of-kin-conversations. They included a detailed description of the examinations, the individual patient's results and a discussion of these results in comparison with a population of healthy individuals (see [Appendix 1](#) for more detailed information).

Sampling and Recruitment

Between March 2015 and July 2016, we approached the next of kin of patients with DOC who had received a functional HD-EEG-examination in a rehabilitation center in Bavaria, Germany. The study recruitment was conducted by a study nurse and the co-author AB, head physician at the rehabilitation center. The study nurse approached only emotionally stable next of kin who were the patients' lawful surrogate decision-makers that she had encountered personally during the patients' rehabilitation stay. Further, participants had to speak German fluently.

Following a purposive sampling strategy, we asked for cases where the initial diagnosis was confirmed as well as disproved by the HD-EEG examination. Given their especially vulnerable situation and the exploratory nature of our study, we decided to protect participants from the additional burden of research when a decision about terminating life-sustaining treatment was being made during the stay at the rehabilitation center. LS and KK arranged the interviews, obtained verbal informed consent, and conducted the interviews. Participants could withdraw from the study at any point until data anonymization was completed. The interviewers had no prior relationships to the study participants except in one case: Because of LS's one-week internship at the rehabilitation center, she had participated in one doctor-surrogate conversation.

Data Collection

We conducted problem-centered, semi-open qualitative face-to-face interviews with a semi-structured interview grid. We developed the grid based on a method reported by Cornelia Helfferich [42]. It was informed by previous studies with next of kin of patients with DOC [43, 44]. With the help of the interview grid, we explored the participants' perceptions of (1) the current and the expected condition of the patient and (2) the HD-EEG examination at the rehabilitation center and its consequences. The interviewers did never disclose results of the HD-EEG examination to participants themselves nor did they suggest to review the written reports. They neither had the knowledge nor was it part of their role to reveal information about the patient.

Additionally, we collected data from the participants about their age, the age of the patient, the relationship between the participant and the patient and the place of

care of the patient, the cause of the brain injury, the duration of the DOC and the clinical diagnosis. We enriched our data collection with field notes where the interviewers described the interview-setting, conversations before and after the recorded interviews, and their subjective impressions of the interviews.

All interviews took place at the participants' homes. Usually, participants introduced the patients to the interviewers prior to or after the interview when they lived in the participants' homes. Usually, the participant was the only person interviewed. In one case, the patient was present during the interview, but did not participate in the conversation. Interviews were conducted either by the first (LS) or last author (KK), or both (for training purpose). KK is a psychologist and research associate who is experienced in conducting qualitative interviews in the field of DOC. She is also experienced in the training of novice researchers in qualitative methodology. LS is a medical student who was in her second and third year of medical school during the data gathering phase. She read literature about qualitative interviews and was trained by KK.

The interviews were audio recorded and transcribed verbatim by research assistants with a Masters or Bachelors degree in Sociology (MR and Silke Ohlmeier) using simple transcription rules and a computer transcription software (f4transkript) [45]. LS conducted the proof-reading and anonymization of all interview transcripts. After completion, we deleted the audio files to ensure the protection of the anonymity of our participants.

Data Analysis

We analyzed the data material using structuring QCA based on the approach described by Margrit Schreier with the help of MAXQDA software [38, 46]. At first, two authors (LS, MR) separately and then jointly coded the complete interview material inductively according to its topics (Descriptive Coding) [47]. After discussing their codes with KK, LS and MR focused their analysis on jointly selected codes that were considered suitable to inform the main research questions: "How do next of kin of patients with DOC interpret the results of functional neurodiagnostics and, how and why do their interpretations (not) change their (attitudes towards) surrogate treatment decisions?"

Qualitative research is sensitive to the perspectives and relevance setting of research participants, since it aims at describing an action "from within", from the

perspective of the aging subject [48]. The coding frame as an instrument to structure the data according to a research question has to match the material and can be driven partly by data for this purpose [38]. Since the HD-EEG examination at the rehabilitation center was not an issue that many participants talked about in length (see results), the first round of categorization contained a very small amount of interview data. From the perspective of our participants, in many cases the HD-EEG examination was interpreted as one datum or one example of an external evaluation of the patient by a medical expert. Participants described it not substantially different from other examinations for the purpose of an evaluation of a patient's condition by experts. Therefore, in the next step, LS and MR constructed the main category "reactions to an external evaluation of the patient" capturing not only reactions to the HD-EEG examination but also to other forms of evaluation. We defined evaluation as any form of statement expressed in connection to the description of the patient's condition and assigned with a significance to the patient's prognosis. Receiving statements that entailed evaluations was an ordinary experience for our participants. Reports about evaluations were mentioned in different parts of the interview. This category allowed for a broader analysis of larger, interrelated sections of the interview transcripts and was the basis for the development of a model for the psychological mechanism which could explain the (high/low) meaning of the neurodiagnostics measure to participants in our study. The analysis of this main category is at the core of this article together with categories that describe participants' background assumptions about the patient's condition and rehabilitation potential.

After the coding grid was completed, LS and MR categorized the data again separately from each other followed by consensual coding following Hopf and Schmidt [49]. Preliminary findings were discussed and affirmed in a qualitative research workshop enlisting RJJ, KK, LS, MR, a professor for general medicine, and a medical student with experience with qualitative research methods. For the purpose of this publication, selected quotes were translated by KK, LS, and an English and German native speaker and medical student. We edited grammatical irregularities, neologisms, and colloquial language for readability. We present the results based on key codes and categories supported by illustrative examples when relevant. Truncation to citations are indicated using brackets [...] as well as explanatory comments introduced by the authors.

Research Ethics

We obtained participants' written informed consent, ensured anonymization and data protection of the study material. The study accordingly received ethics approval of the Research Ethics Board (REB) at LMU Munich (512–14). Since the interviews had the potential to evoke discomfort or burden, we ensured that experienced researchers conducted the interviews. We asked participants to evaluate their experience to capture any adverse effects. None of them reported experiencing the interview as uncomfortable or burdensome, and a few responded that they felt relieved after the interview. During the research process, we reflected on our own assumptions and how we might have influenced the results of this study. We have provided a brief summary of our self-reflection at the end of the discussion section.

Results

Descriptions of the Sample, Patients, and Interviews

We conducted seven interviews with patients' next of kin. All participants were female spouses and mothers of the patients, most of whom were male (see Table 1). The average duration of the interviews was 70 minutes. The patients had received an HD-EEG-examination between one and nine months before the interview.

Main Findings of the Qualitative Content Analysis

Four of the seven participants did not remember that the medical team had conducted a functional HD-EEG examination during the patient's last stay at the rehabilitation center. Across all interviews, the examination or its results was only talked about briefly. Participants did not mention it spontaneously. They only brought it up when interviewers asked to describe the examinations performed on the patient. This stands in contrast to the interview grid, where 50% of the questions referred to the functional HD-EEG examination. In most of the cases, participants changed the subject quickly, even though the interviewer tried to bring the conversation back to that topic.

Overall, we mostly found an absence of a differentiated consideration of the neurodiagnostics measure except in one interview where the mother of a patient had hoped for the revelation of a MCS diagnosis through the

Table 1 Description of the sample

Interview	1	2	3	4	5	6	7
Attributes of the patient							
Age	26	59	67	23	69	56	33
Gender	female	male	male	male	male	male	male
Cause of brain injury	trauma	hypoxia	trauma	trauma	hypoxia	hypoxia	hypoxia
Duration of DOC	7 years	5 months	11 months	9 months	3,5 months	9 months	4 years
Participants described strong clinical signs of consciousness in the interview ^a	No	No	Yes	No	Yes	No	No
HD-EEG result	UWS	MCS	Not known	Not known	Not known	UWS	UWS
Attributes of the next of kin							
Age	50	59	58	42	65	51	55
Gender	female	female	female	female	female	female	female
Family relationship to the patient	mother	wife	wife	mother	wife	wife	mother

^a for example, context appropriate yes/no communication through nodding or head shaking, speech attempts, command following, or other directed complex motor behavior

functional neurodiagnostics examination. One participant, who did not remember that the examination had taken place, decided to fetch the report from her files and read the report supposedly for the first time during the interview. Two of the participants who did not remember that the measure had taken place were the next of kin of patients who showed obvious behavioral signs of consciousness at the time of the interview (and supposedly before). Hence, we assume that overall neurodiagnostics during the stay in the rehabilitation center is a topic of little importance in the lifeworld of our participants.

To explore its low importance, we provide data from two related main categories. The following sections first describe (1) participants' assumptions about the patient's condition and (2) reactions to professional evaluations of the patients' condition (of which the result of a functional HD-EEG is one example).

Participants' Assumptions About Their Loved One's Condition

The participants in our study seemed to share certain beliefs underlying their attitudes towards medical treatment and care for their family member with DOC. Irrespective of the diagnosis, they all appeared to be highly engaged in the care for and rehabilitation of their family members. They emphasized that their family member was awake and aware of what was going on around him and stated, that he/she was making

observable progress towards recovery. Often, they described a contrast between their perception of his/her potential for further improvements and the evaluations of specific medical experts.

Participants sometimes struggled to communicate their own perception of the patient's awareness, which can be illustrated by a quote from a mother of a 23-year-old patient, who was asked whether her son had made any progress since his stay at the rehabilitation clinic. She described how she saw and felt, that her son was responsive to his environment.

"[...] So his alertness has improved significantly. I mean (.) I don't dare say he is awake even though I suspect he is awake. [...] It's very difficult to explain to you how it feels. Yes. You see something and you think maybe it is not what you see, but you see it. But in my opinion he's already awake and he notices everything." (Interview 4)

She continued her description by giving examples where she had observed that her son had reacted emotionally adequately to social situations. In her perspective, his prior progress was proof that he will be making further progress.

In their narratives, participants related to their prior and current relationship with their family member and still felt connected with him/her despite the struggles, e.g. to build-up a code for reliable communication. This, for example, was the case in interview 6 where the wife of a 56-year-old person told us that she almost felt

attacked by the diagnosis that her husband's current doctor – a general practitioner who attends to him in the nursing home – had given him.

"[...] Meanwhile he is brutally classified as a 'Wachkoma' patient [colloquial German for UWS, literally "awake coma"] [...] and it is still in the back of my mind that I simply still perceive him as the one he was before. [...]". (Interview 6)

She pointed out, that there were moments where she was sure, that her husband was still there but it was due to his personality that he had participated selectively in the interaction with others. She worried, that he suffered without the ability to share his suffering verbally.

Over the course of the interviews, participants also revealed spiritual or religious assumptions underlying their caregiving approach. Participants expressed high hopes for their family member's recovery, which was sometimes framed as "knowledge" of further rehabilitation and improvement of the patient's capabilities. For example, this was the case in interview 7 where the mother of 33-year-old person described the course of illness of her son as a "path of progress".

"[...] At the moment it is simply the case that he is making progress even though doctors and nurses all say that nothing will change, that he won't stand up, but I know that he'll stand up one day and be able to walk; that I know. [...]". (Interview 7)

The reason for her "knowledge" (or belief) was an "inspiration" (a kind of vision) that she had after his condition had deteriorated due to a cardiac arrest. In an inner picture, she saw him walking with a walking aid and therefore she expressed being certain that he will walk again.

A belief in the recovery of their loved ones seemed to be very important for participants' own psychological well-being. Participants did not only explicitly mention it in the interviews, but it was an underlying – latent – theme of large parts of the interviews. With their efforts, they pursued the goal of establishing communication with the patient. In interview 1, the meaning of that goal became particularly clear when a mother of one of the youngest patients, a woman at the age of 26, described the purpose of her meanwhile professionalized engagement in the care for her daughter.

"[...] I see that as my job. Not that I do her care and that I go to rehab and that I give injections, but that everything aims at her being able to have an independent life. If that is what happens, that she can, uh, fix it by saying yes and no, just this code alone and then the world will be open to her. Then she can handle everything. That's what I want. Then someday I can leave without worries. [...]". (Interview 1)

Our participants' belief systems strongly influenced their attitudes towards treatment strategies. Her efforts made sense, because of their belief that improvement was possible. All of the patients were invested in a strategy that consisted of long-term care and rehabilitation measures.

Reactions to Professional Evaluations of the Patient's Condition

When the participants spoke about the neurodiagnostics examination, their meaning seemed related to the value that the results had for them. They considered it information that had either a "positive" value (in cases where doctors/researchers detected signs of conscious awareness) or a "negative" value (in cases where doctors/researchers detected no signs of conscious awareness).

Information Processing Strategies in Light of the Findings of Functional Neurodiagnostics

There were three cases where the HD-EEG examination confirmed or revealed a result that did not match the expectation of the next of kin. In these cases, participants themselves seemed not to consider it as being more persuasive than the results of other examinations.

Participants described other negative results of evaluations including comments about a low probability of meaningful recovery. In some cases, they received suggestions to refrain from rehabilitation as an achievable goal of treatment and changing the treatment goal. This could include the introduction of the option of providing palliative care and suggestions of limiting life-sustaining treatment.

The participants seemingly saw the delivery of information as such as an attack on their system of beliefs (see Fig. 1). The initial reactions to negative results of evaluations were mostly expressions of negative emotions like

sadness or disappointment. Participants seemed to apply different shielding strategies to reject the negative evaluation and keep the system of beliefs stabilized. If shielding strategies were not used or were not sufficient to protect against the threat, the system of beliefs was destabilized. As a result a number of restabilization strategies were pursued. Multiple shielding and restabilization strategies were identified in different combinations. In the next sections, we provide more insights into participants' "restabilization" and "shielding" strategies.

In summary, to maintain their system of beliefs and their hope of recovery of basic communication, the participants seemed to have accepted information selectively. They highly valued information that

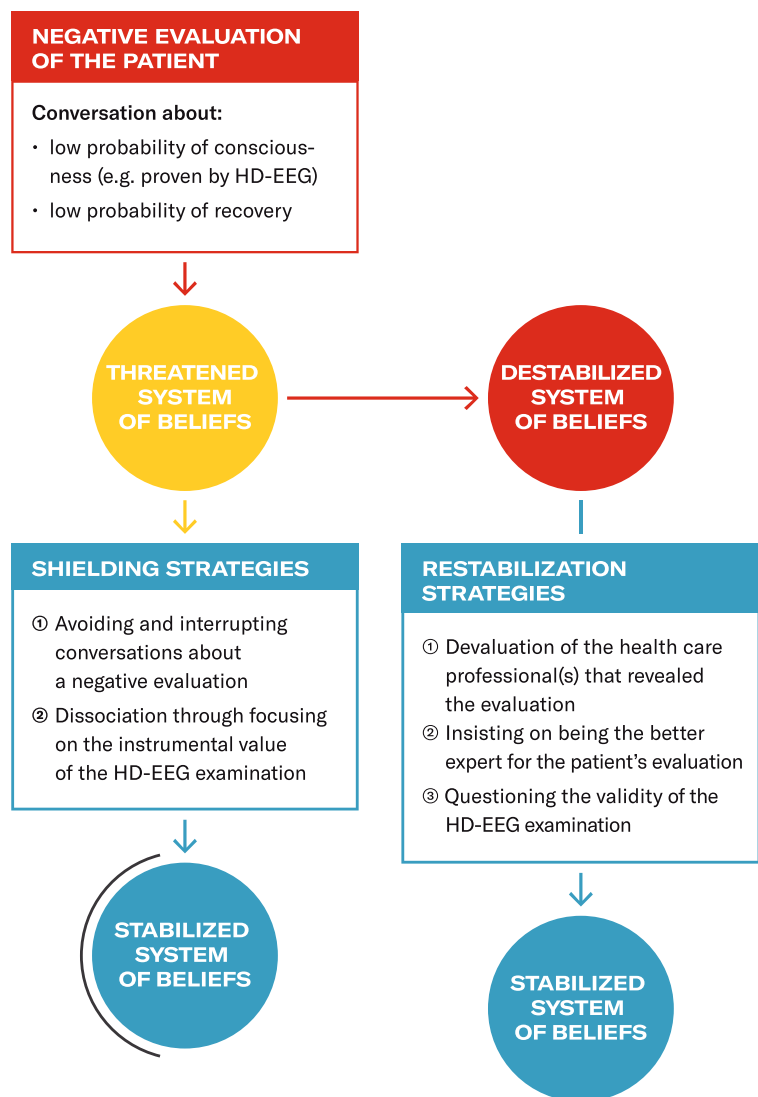
corresponded with their system of beliefs but assigned a lower value to or rejected other information.

Shielding Strategies to Protect from Destabilization

- 1) Avoiding and interrupting conversations about a negative evaluation.

Participants reported that they avoided conversations with health care practitioners who had revealed a negative evaluation of the patient. This can be illustrated by the following quote of a mother who had a conversation with a neuro-psychologist about the patient's future outlook. He

Fig. 1 Heuristic method for the information processing of a negative evaluation of the patient based on participants' strong system of beliefs including the high hope for a patient's recovery of the ability for basic communication: When the belief system gets threatened by a negative evaluation of the patient, participants seemingly use shielding strategies to keep it stabilized which is symbolized by the black line on the left side of the left blue circle. If the belief system is destabilized, participants use re-stabilization strategies



had “painted the worst picture” which upset her and she told us:

“[...] I never went back to him then because, like I said to him, I don't want to hear your theories. They scare me, and I don't believe it or I hope not and I just don't want to hear it. [...]”. (Interview 4)

When a conversation was heading in the direction of a revelation of a negative evaluation, participants reported that they interrupted the conversations.

- 2) Dissociation through focusing on the instrumental value of the HD-EEG examination.

One participant had planned to use a positive HD-EEG-result as evidence for physicians, therapists, and the insurance company in order to get better access to therapies and health aids. The negative evaluation did not affect her system of beliefs. She never doubted that her daughter was conscious. Nevertheless, the negative evaluation evoked negative feelings because the participant could not prove her daughter's (presumably) high potential for recovery to others. In this case, the participant was protected or even isolated from the negative evaluation as she expresses here:

“[...] Basically, I couldn't give a damn if that's what it [the HD-EEG result] says. I know what she can do, but it is important for the upcoming therapy because the next doctors don't know their way around patients and only see 'Wachkoma' [colloquial German for UWS, literally “awake coma”] no, MCS yes. [...]”. (Interview 1)

In her perspective, a different result should have brought about a change in the belief system of health care professionals who are not familiar with her daughter or other patient's like her.

Restabilization Strategies to Restore Stability

- 1) Devaluation of the health care professional(s) that revealed the evaluation.

When confronted with a “negative” evaluation, participants devalued the health care professional that revealed this information, most often a physician, a case

manager, or a neuropsychologist. Participants' reactions to those conversations took the form of strong anger.

While expressing their anger during the interviews, participants mostly concentrated on the context of the conversation: the moment in time when they were spoken to, the place where the conversation took place, and the terms and concepts used. They recounted phrases or sentences, which in their opinion were morally unacceptable. Participants described the health care professional who spoke with them as being not empathetic and not able to understand their difficult situation. This can be illustrated by the quote of a mother of a patient talking about a neuropsychologist who displayed a pessimistic outlook:

“[...] First, you don't treat relatives that way by scaring them and by showing them the worst possible, so psychologically, I find it to be completely out of line, completely out of line. [...]”. (Interview 4)

Another participant recollected conversations about the option of withdrawal of life-support and she considered it to be “at the limit of legality.” Other participants described feeling pressured by conversations about the possibility of changing the treatment goal and treatment strategy to palliative care. There were participants who accused the health care professional of acting upon secondary (e.g. monetary) interests. Participants reported a loss of trust after these conversations, referring to losing trust either in the health care practitioner, the health care organization, or in medicine as a whole. In one case, the participant had lost trust to the extent that she feared life-sustaining treatment might be withdrawn during her absence without her permission. She therefore did not feel comfortable with letting the patient be admitted to that specific hospital anymore. In their retrospective description of the conversations, none of our participants expressed considering the possibility that the negative evaluation could have been accurate nor that a change of treatment goal could be an option to consider.

- 2) Insisting on being the better expert for the patient's evaluation.

With regard to the evaluation of a patient's condition, most participants considered themselves as being the better experts for that evaluation. They justified their

claim by stating that they knew their spouse or child much longer, better, and deeper than a health care professional could ever know him/her. They referred to the short time that physicians and other professionals had seen or known the patient. They considered that medical methods fell short of grasping the patient's true presence. This can be illustrated by the quote of the wife of a patient whose MCS diagnosis was first revealed through the functional HD-EEG examination but who previously received a pessimistic description of the patient's prognosis in a conversation with a neuropsychologist:

"[...] So, I believe that we know each other very very well, in a way in which no doctor and no neuropsychologist can tell me anything. And I'll say, because of the energies, I feel like he communicates with me and perceives me. [...]". (Interview 2)

Many participants referred to the evaluations of trusted professionals to support their opinions. Several participants used informal verbal statements given by certain health care professionals of how the patient was making progress to support their argument that the patient is conscious and that there was a realistic chance of recovery. In one interview, the participant read the written report of the HD-EEG examination during the interview. She commented it by describing how her son reacted when the occupational therapist entered the room, how she experiences her son's affection to his therapist during occupational therapy. In short, she points out:

"[...] Yes, it just says there that he could not solve the tasks and could not give any answers to it, yes, and I find that just a bit too bad because it is not really so [...] and the occupational therapist can also prove that it is just not so. [...]". (Interview 7)

3) Questioning the validity of the HD-EEG examination.

Participants furthermore questioned the HD-EEG examination and listed reasons for the invalid nature of the examination results. They argued that the HD-EEG only captured the patient's awareness in a certain moment and missed out on better moments. One participant knew that the measurement could be distorted by movements, medication, or by other context variables in the situation of the examination and assumed that these influences caused the negative test result. She came to the following conclusion:

"[...] And I think it was a kind of thing, which just wasn't analyzable. Where it just wouldn't work. And that really is too bad. [...]". (Interview 1)

Participants also argued the examination might have caused stress to the patient because it was invasive or because of its timing (during the patient's usual sleep-time), which could have led to the patient's "bad performance."

Positive Evaluations of the Patient Through the HD-EEG Examination

One participant accompanied a patient who had received a UWS diagnosis before the HD-EEG examination and an MCS diagnosis afterwards. The information confirmed her own evaluation of the patient and encouraged her to engage more in activities that aimed to improve her spouse's condition. She stated that it helped her not to give up on the patient.

She described that the attitudes and the behavior of the health care professionals at the rehabilitation center changed because of that result. Health care professionals stopped suggesting changing the treatment strategy to palliative care and the staff seemed to put a greater effort into the patient's rehabilitation. It is interesting how she described her perception of this change:

"[...] From the moment this HD-EEG showed that something was happening there, the posture of the face changed visibly by the doctors and the nurses, and suddenly the therapies also took a completely different course. [...]". (Interview 2)

In two other cases, the patients' meaningful reactions had already been obvious to the participants before the examination. These patients were either able to communicate through nodding and shaking their head or even through verbal "yes" and "no" signals or following commands or eating for themselves—all indicating emergence from MCS. Both next of kin did not remember the result of the HD-EEG. One of them was initially interested in the result until the interviewer explained that the purpose of the examination was to measure conscious awareness. Since her husband communicated with her and consciousness was neither doubted by her nor the

medical staff, she considered the examination of low importance.

Discussion

Our study gives voice to the next of kin, who are key in the surrogate decisions for patients with DOC. They will be affected if functional neurodiagnostics is implemented into routine care. In this article, we describe a heuristic according to which next of kin in our study seemed to make sense of the results of professional evaluations (including HD-EEG examination results).

Our results only apply to a subgroup of next of kin with great hope for the patient's recovery. We understand hope as a cognitive-motivational-system that seemed to give our participants the energy "to carry on". According to Snyder (2000), hope can be theoretically understood as a form of active goal-related thinking, in which a person perceives a) agency (goal-directed energy) and b) pathways (planning to meet goals) [50]. In our study, next of kin were active in so far that they seemed highly engaged in the care for their loved ones. All participants in our study expressed that the patient with DOC was aware, present and "somehow the same" despite of his/her diagnosis, that his/her condition will improve considerably, and that he/she will have a meaningful recovery. To protect their hope and its underlying belief system the participants of our study considered the functional neurodiagnostics results according to its value (positive or negative). They seemed to perceive negative evaluations of the patient as a threat to their belief system and hope. Sometimes they even have experienced moments of insecurity in relation to their system of beliefs, which we refer to as an experience of destabilization. These perceptions were often accompanied by the (subsequent) expression of negative emotions, like disappointment, sadness, or anger. Participants described different strategies to prevent further destabilization of their beliefs system (shielding strategies) or to foster its restabilization (restabilization strategies) including a devaluation of experts who revealed negative evaluations and questioning of the validity of the functional HD-EEG measure.

Other studies with the next of kin of patients with DOC also describe next of kin as optimistic with regard to the recovery of a basic ability of communication, despite the pessimistic results of the evaluations performed by physicians [43, 51, 52]. This downsized hope

for improvement rather than a full recovery was also salient in a study about family accounts of the minimally conscious state [53]. Another study about family members' perspective of chronic DOC characterized hope as a precondition to give the patient's situation meaning and to interact with him/her as a person [54]. Shared hope could create support, understanding, and trust among family members [55]. As time goes by, often there seems to remain only one family member as the "deputy of the family" who is maintaining hope [55, 56]. Boyd (2010) described that "factors other than what the doctor has told them" such as "hope, optimism, or a belief in miracles" were "critical pieces of surrogate's perspective on a loved one's prognosis" [57]. Given the uncertainty in the care for patients with DOC (especially MCS), it is difficult to decide whether to attribute the judgement of "false hope" or "realistic hope". Musschenga (2019) argued "that false hope is hope that cannot be justified epistemically" (S.432) [58]. False hope is based on ignorance of an expert's estimation of the probability of an event. If a person knows of its low probability, but – reasonably – accepts it as a (good-enough) reason to maintain hope, it can be seen as justified or realistic hope. We did not analyze the interviews according to this differentiation, but we recommend that future studies incorporate it in their analysis of hope-based information processing. It is possible, that in some cases participant's judgments relied on a form of self-deception. Some participants considered the possibility themselves.

Other studies included next of kin with no expectations of further improvement [59]. Mwaria hypothesizes that next of kin of patients with DOC can be distinguished by the answer to the question "Is there anyone in there?" and that if a next of kin would not think that there still is "a trapped soul" in the body, hope for recovery would be very unlikely. The resulting behavior would be avoidance of the patient [60]. Such beliefs are consistent with the common belief that UWS could be a state worse than death [61]. Different beliefs between next of kin can lead to conflicts in the decision-making process, as in the case of Terri Schiavo, where unlike her hopeful parents and siblings, her husband expressed no hope for recovery [62, 63]. The analysis of the media coverage of this case suggests that the diverging views about Schiavo's prognosis were the crux of the tension [63]. The results of our study only apply to a subgroup of next of kin of patients with DOC. We had previously observed that despite the diagnosis of the patient, family

caregivers of patients in a rehabilitation center had medium to high hopes of reestablishing communication with a patient [43]. This finding was consistent with other findings about the overly optimistic prognosis of UWS in the general public [63] in contrast to clinicians [31]. We assume that the subgroup of next of kin in this study occurs frequently in studies that recruit their participants through personal encounters in rehabilitation centers.

Another possible reason for the low subjective significance of functional neurodiagnostics could be that the functional HD-EEG paradigm in our study was used among many other technologies in the rehabilitation center. It is also possible that health care personnel did not point out the meaning of the examination during the patients' stay. We assume, that relatives do not differentiate so strongly between single diagnostic methods, but rather take along a more general impression of the medical evaluation of a patient's condition and potential. Furthermore, the written report contained technical and scientific information (see Appendix 1). This could have led to the impression that the report was rather a communication device from one medical expert to another instead of a communication device from a medical expert to the patient's next of kin. We need to reconsider how we inform next of kin about complex study results as these. A study with caregivers of patients with DOC showed that lay people could come to a deep understanding of the possible consequences of functional neurodiagnostics when they are provided with more extensive information [33].

In contrast to the two study protocols of qualitative studies that aimed to analyze the next of kin's reactions to functional neurodiagnostics [35, 36], our naturalistic qualitative study accompanied a functional neurodiagnostics study that was strongly implemented into routine care. We only interviewed participants retrospectively, sometimes considerable time after the actual HD-EEG examination, and did not prime them through interviews about their expectations prior to the examination, which could bias their perceptions in experimental laboratory studies.

Results in the Light of Cognitive Dissonance Theory

The behaviors and presumed motives that we describe in this study can be discussed in light of the theory of cognitive dissonance, proposed by Leon Festinger [64]. Festinger argues that every person aims for consistency in his beliefs, values, attitudes, and behavior. If

consistency cannot be achieved, people experience a feeling of discomfort—a cognitive dissonance—and will immediately be motivated to resolve it. The degree of dissonance will vary with the importance of a person's belief/value/attitude and with the degree of inconsistency between the two conflicting cognitions. People can adopt three strategies when they want to resolve dissonance: they can change their prior cognition (e.g., a belief/attitude/value), the conflicting cognition (e.g., their own behavior or a revelation of information), or their perception of a cognition (e.g., rationalization of a behavior or information). Festinger assumed, when dissonance is present, "in addition to trying to reduce it, the person will actively avoid situations and information which would likely increase the dissonance" (page 3) [64]. The theory of cognitive dissonance has been confirmed by observational and experimental studies [65–67]. We assume that the revelation of an evaluation of the patient that was not consonant with our participants' strong system of beliefs caused a considerable dissonance that could have led to a devaluation of this information. Consequently, our participants were actively avoiding similar conversations. We hypothesize that certain next of kin even choose medical staff or medical institutions according to their system of beliefs and preferred to involve those whose evaluations are compatible with those of the patient's next of kin. We are not the first researchers to apply cognitive dissonance theory to medical decision-making [68]. However, we are not aware of other studies that explain the processing of information of the next of kin of patients with DOC with reference to the cognitive dissonance theory. Cognitive dissonance theory explains some of the strategies we found in this interview study but does not explain why next of kin do not change their beliefs/attitudes/behavior altogether. This may be because the preservation of hope is of central importance to their ability to "carry on", seemingly being the cognitive-motivational system behind their commitment to caring for their loved ones [50].

Implications of our Findings for the Ethics of Medical Decision-Making for Patients with DOC

Functional Neurodiagnostics and Uncertainty of the Patient's Capability of Conscious Awareness

Uncertainty plays a key role in DOC and has been described as a multidimensional concept with scientific,

personal, practical, ethical, and social sources [32, 69]. In patients previously evaluated as being in an MCS, the use of functional neurodiagnostics could increase certainty when MCS is confirmed. Similarly, in cases where behavioral measures point to UWS, functional neurodiagnostics assessments that indicate an MCS or functional LIS could reduce uncertainty. However, functional neurodiagnostics could increase uncertainty in cases with contradictory test results in different diagnostic sub-tests. For those formerly diagnosed as being in a UWS and confirmed as UWS by functional neurodiagnostics, the measure could slightly decrease uncertainty or cause no change in uncertainty, depending on the estimated probability of change in the future.

The next of kin of patients with DOC might not share the assumption that an “objective assessment” of consciousness is possible or valid. In our study, they focused on signs that their relative is still the person he/she was before brain injury and their relationship is ongoing, not on the absence or the presence of reproducible reactions to stimuli as a sign of consciousness awareness. We found a subgroup whose hope for recovery strongly influenced how they processed statements stemming from a professional evaluation of the patient. The result of an HD-EEG examination could not reduce uncertainty for them, and instead, the uncertainty in DOC was used to counter-argue against the professional evaluation. Only if the result is contingent with the next of kin’s expectation, certainty could be increased as opposed to a reduction in uncertainty. This result is not that surprising given that a similar phenomenon has been reported in situations of death determined by neurological criterion (brain death), where this condition can be considered as a sign of life for next of kin while it is a sign of death for clinicians [70]. Furthermore, in relation to confirmation bias, it has already been reported that neurodiagnostic results are more valued when they confirm previous beliefs. [71]

Coming to a shared evaluation of the patient’s condition and potential is a necessary precondition for shared decision-making – the current (normative) paradigm underlying medical decision-making for patients with DOC in Germany. The results of this study suggest that there are different perspectives, cultures, or almost different realities in which the evaluations of the patient’s awareness and his/her rehabilitation potential can take place, consistent with previous findings about the attitudes of the general public and of clinicians [31, 63, 72–74]. In their joint evaluation, either doctors and

next of kin could try to understand their different perspectives or their perspectives could clash with each other, possibly leading to conflict and precluding further conversation. If health care professionals focus too much on communicating the “objective evidence,” they might jeopardize the next of kin’s trust in them or in medicine as a whole. If they focus too much on stabilizing the next of kin’s belief in recovery, they are in danger of exposing the patient to burdensome treatment based on flawed judgment. Musschenga (2019) discussed whether it was justifiable to cause false hope in the context of medical treatments. He argues it is morally wrong to withhold information in order to keep someone ignorant but spare him of disappointment and so, he argues, is not exposing false hope [58]. Especially, where false hope is based on ignorance and may harm the interests of others, maintaining false hope is morally wrong [58].

If we assume that a next of kin’s judgement is based on false hope we should reflect on the way to reveal information. If we take into account the probable ineffectiveness and negative consequences of direct confrontation in cases like some in our study, different approaches to informing next of kin are needed. A form of psychological counselling could offer a wider or deeper approach to reconsider the possibility of false hope, yet so far a specific approach to counselling for next of kin of patient’s with DOC is lacking. Similarly, there could be “false despair” that could demand an analogous approach.

Considerations for the Routine Application of Functional Neurodiagnostics to Detect Conscious Awareness

The co-authors of this study and others have assumed that functional neurodiagnostics paradigms to detect residual awareness might have ethically relevant effects on medical decision-making [12]. In this study we examined next of kin’s attitudes towards one example of such functional neurodiagnostics. Jox et al. hypothesized that patients’ next of kin might see the result of functional neurodiagnostics as the ultimate proof, “the procedure that will allow them definitively to establish whether the patient is aware or predict the time of recovery” (page 735) [12]. They argued that tests that show less brain activity might have beneficial effects in that the result would help the next of kin to understand

clinical realities and cope with the limited prospects of recovery. The harmful effects of this approach may include a loss of hope, purpose, and meaning of life in the next of kin [12]. Based on our findings in this study, we hypothesize that for the next of kin with a strong belief that the patient's condition will improve, unexpected (and in their perspective "negative") functional neurodiagnostic test results could have contrary effects. In support of this hypothesis, an HD-EEG result that was dissonant with their system of beliefs did not influence the next of kin's perspective in this study. They did not lose hope but rather reacted with anger and loss of trust in the evaluation by medical professionals and sometimes even in medicine itself. Instead of seeing the result as the ultimate proof, participants of our study seemed to perceive the results as an outcome of one of many limited diagnostic approaches. Our participants have not reported diminishing their commitment to care after getting the HD-EEG result. They did notice in several cases, that the accessibility to rehabilitation measures and the amount of support they have gotten from medical personnel has changed. Based on our results we pose the question whether the results of functional neurodiagnostics can have any impact on the patient's situation, when next of kin already assume a more favorable condition and are highly engaged in the care of the patient despite the patient's diagnostic category. Further studies on the matter should distinguish participants with regard to their general attitudes and beliefs to test the hypotheses that resulted from this exploratory study.

The low effect of a neurodiagnostics measure that we found in this study might be observed differently in studies that involve other neurodiagnostics measures, most of all fMRI. Among other factors, HD-EEG and fMRI come with different costs with regard to time, effort and money, different availabilities in the clinical context, different potential for harm, different complexities in their production of results and different potentials for the visualization of brain activity. Brain images provide their recipients with a simple and catchy visualization of complex cognitive processes [75]. Both – the more elaborate measure and the perceived higher credibility of its result might (or might not) influence next of kin's perceptions of the relevance of a measure and increase its persuasiveness [75–77]. Studies suggest that functional EEG as well as fMRI can be used to identify patients with hidden awareness but there is also a considerable risk for test errors in both applications

which has been rated slightly higher in studies using EEG [14, 19–25].

Furthermore, in cases of next of kin with a different belief system, the examination may well have a different impact on the patient's situation. If the next of kin is not strongly involved in the rehabilitation or if treatment decisions are made by a professional guardian, the doctor's evaluation of the diagnosis could have a strong influence on the treatment strategy [78]. The relationship between neurodiagnostics and hope should be considered not only in research but also in clinical care. Based on our findings, we hypothesize that next of kin with high hopes organize more rehabilitation aids for the patients, care more intensively for them, stimulate patients more, and take extra effort in finding the best (fitting) health care personnel for the patient. For patients on the border between UWS and MCS, this could be a crucial influence factor. This might also apply to the engagement of clinicians [72, 74]. In cases where the patient's next of kin is present, his/her relationship with the patient, his/her belief system, and the presence or absence of hope could therefore be included more explicitly into prognostic considerations.

Limitations

Our results are not representative for all next of kin of patients with DOC. We studied a specific subgroup of next of kin. This group of women – foremost wives and mothers of mainly young patients – maintained strong hope for the further recovery of the patient. We accessed this group personally through a study nurse at a rehabilitation center in a rural area of Bavaria, Germany. Since rehabilitation is mostly linked to the progress and the treatment goals of rehabilitation and improvement, patients' next of kin might be more optimistic for their loved one's recovery during and after a stay in a rehabilitation center than with regard to other phases or settings. It is very likely that we recruited only next of kin that were often present. Our study nurse only approached participants who were engaged enough in the care that they could be (a) informed about the study and that they (b) took on the effort to participate in a 1–2-h interview after the patient's discharge. To protect them from additional burden, we did not approach potential participants who were emotionally unstable or who considered a palliative care approach, including limiting life-sustaining treatment for the patient. It is possible that the next of kin that our study nurse

evaluated as unstable would have had more negative views about the patients' prognosis. Apart from the sample studied here, next of kin with different attitudes towards recovery exist and they might as well differ in their appreciation of functional neurodiagnostics [43, 44, 79].

Some of our participants were not able to talk with us about the HD-EEG examination, as they could not remember it. The time interval between the date of the discharge and the interview was between one and nine months, which might be too long to allow specific recall. In the meantime, participants could have received more information about the patient's status, his status could have changed significantly over the time or their feelings about the patient's stay at the rehabilitation clinic could have changed. However, research showed that people can remember very important conversations even years after they have taken place [80, 81]. Especially in cases where results of functional neurodiagnostics question the patient's prior diagnosis or where functional neurodiagnostics put weight on a redirection of the treatment strategy we can expect that participants remember its revelation even after a considerable time has passed. In comparison, a confirmation of a diagnosis (or more general a confirmation of an expectation) is rather an ordinary event that probably gets forgotten quickly. Hence, we assume that our research approach supposedly underestimated the vanishing short-term-effects of neurodiagnostics disclosure, but was still sensitive to a long-term effect in cases, where the disclosure immediately had a significance to the participants.

Although it was expected that the results were explained to the next of kin upon the patient's discharge conversation verbally on top of standardized written reports, we did not gather data on how this information was conveyed in the cases that we investigated. The framing of the neurodiagnostic results during the discharge conversation could have had an impact on its remembrance. It is possible, that the functional HD-EEG-examination was not mentioned at all or only mentioned as a side note, leading to its low remembrance. On the other hand, a framing of the information as being of great importance and an emphasis on the value of the findings during a conversation could have had the opposite effect and possibly leading to an overemphasis of its value. In our naturalistic study, in comparison to experimental studies, we minimized an experimental research bias in the study findings. Hence, our study might give a first glimpse on how a full implementation of

neurodiagnostics measures could be dealt with on an everyday basis. Nevertheless, we need a thorough consideration on how the disclosure of neurodiagnostics should be performed [12]. We also need more research on the impact of the framing of the disclosure of neurodiagnostics findings on surrogate decision-making.

Our data allows us to describe the participants' attitudes that were expressed at the moment of the interview. Their answers have been elicited by the interview questions in an artificial setting, but at least interviews were conducted in a familiar environment. Like every artificial data collection, our naturalistic study could have had an interventional effect and trigger the reflection about issues that would not have taken place otherwise.

Possible changes in the participants' perspectives over time were not targeted in this cross-sectional study. A high hope for recovery might be a transient phase and not a stable belief in accompanying patients with DOC. Longitudinal studies are required to investigate how belief systems change over the course of time and which forms of doctor-surrogate communication are successful in establishing a shared perspective of the patient's rehabilitation potential.

Self-Reflection and Qualitative Research Ethics

Since qualitative research uses subjectivity and interpretation in all steps of the research process, self-reflection is a prerequisite to ensure its quality [82]. The choice of our research focus was strongly influenced by the discourse on ethical issues in DOC, especially the discourse about the potential role of functional neurodiagnostics in the detection of conscious awareness in patients with DOC. Most researchers in our group had conducted previous studies with the next of kin of patients with DOC, which also informed this study indirectly. Our research interest was supposedly not at the center of the interest of our participants. In the interviews for the study, participants rather preferred to talk about their daily struggles, especially the struggles with health insurance companies, professional caregivers, and physicians. Some of them expressed feeling as if medicine had given up upon their relatives. Sometimes, it was hard for those who conducted the interviews to be confronted with these struggles, and feelings of helplessness occurred. The presence of the patient in one interview created a challenging situation that we would avoid in future studies. In another case, the

interviewer was unsure whether to question the answers of a participant during one interview. The next of kin's suggestions for the treatments that would help the patient differed considerably from the interviewer's perspective that she gained during her medical studies. Some of our research team had multiple roles, as the role of researcher and a clinician. Throughout our study, researchers struggled with a triple loyalty: to our participants on the one hand, the medical team that cared for the patients, and to the patients who were not able to have a say in our research as well as in their medical care.

Conclusion

The participation of next of kin to the care of patients with DOC is commonplace and plays a pivotal role. Ethical evaluations of the implementation of new medical technologies into routine health care increasingly take into account the perspectives of patients' next of kin. Yet, their attitude toward advanced diagnostic procedures such as functional neurodiagnostics remains to be better understood. In this qualitative interview-study, we found that the next of kin of patients with DOC deal with the results of functional neurodiagnostics in accordance with the value of the results and their system of beliefs. In some cases, functional neurodiagnostics examinations of the patient's conscious awareness are hardly able to inform surrogate treatment decisions and do not reduce uncertainty, but uncertainty is instead used to rule out the validity of its results. Further research with next of kin with high hope needs to pay more attention to whether they rely on true or false hope for the patient's recovery.

Acknowledgements This article is part of LS's cumulative dissertation (Dr. med.) at the Medical Faculty of LMU Munich. The assistance provided by Marion Arndt in approaching the participants and ensuring their informed consent, by Silke Ohlmeier for transcribing interviews and sharing her insights during early stages of the analysis with us, by Lukas Martinez who translated some of the interview quotes from German into English and by Lars Schrodberger who finalized the layout of the figure is very much appreciated. We are grateful to participants of different research meetings where we were able to discuss our study, foremost in Germany at the rehabilitation center where the examinations of the patients were conducted, the Qualitative Workshop [Qualitative Werkstatt] at LMU Munich, the Institute for Ethics, History and Theory of Medicine at LMU Munich, the Palliative Medicine Research Network under the lead of Prof. Dr. Gian Domenico Borasio in Munich and in Canada a meeting with the Montréal

Neuroethics Network and a Journal Club at the Neuroethics Research Unit at the IRCM and a poster presentation at the 21st International Congress on Palliative Care. Last but not least, we would like to express our great appreciation to the participants of this study who shared their personal experiences with us. We also express our gratitude to the Friedrich-Baur-Stiftung who funded our study (Grant Number: 12/14, funding period 8/2014 to 07/2016) and the Max Weber Program who funded LS's research stay at the IRCM, Montréal, Canada and her visit to the 21st International Congress on Palliative Care. Furthermore, ER receives a career award from the Fonds de recherche du Québec – Santé (FRQ-S).

Compliance with Ethical Standards Research involving Human Participants: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

Disclosure of potential conflicts of interest All authors declare no conflict of interest.

Appendix 1

Functional HD-EEG-Examination to Detect Residual Conscious Awareness

The functional HD-EEG examination consisted of a protocol with two sections. The researchers performed both examinations with each patient. The first part was an auditory oddball paradigm using 4 blocks of standard and target stimuli with 10 target and 40 standard stimuli per block, which were presented randomized within each block. Stimuli consisted of 1500 Hz and 1000 Hz tones, respectively, with 500 ms duration and a 500 ms inter-stimulus interval. The main experiment was preceded by the presentation of 2 target and 8 standard tones as demonstration. Patients were instructed to listen to the target tones attentively. The experimental procedure was identical to the one described in a prior publication by one of the authors of this study and colleagues [83].

The second part involved a command-following paradigm. Using a randomized block-structure, a resting condition and a mental motor imagery condition were tested in 6 blocks per condition with 15 trials per block. Each block was preceded by a verbal instruction and each trial was announced by an auditory trigger signal. The method was based on the experiment by Cruse et al.

(2011) [21]. It tested command-following using an ERP-based mental motor imagery, instructing participants to either squeeze their right hand or to wiggle the toes. Yet, the paradigm, which was used in the rehabilitation clinic, entailed different movements than in the experiment of Cruse et al. (2011), in order to achieve a higher activation of the motor cortex following the instruction: For the motor imagery task, the patient received the instruction to imagine raising his/her arms and lowering them again when an auditive trigger-sound appeared. This condition was statistically compared to the findings obtained during a resting period, which was also indicated by auditive trigger-sounds. For the resting periods, patients were instructed to listen to the auditive trigger-sounds. The examination was repeated on a second day to reduce the influence of possibly confounding factors like tiredness. All exams were conducted by research personnel (a psychologist and a study nurse) specifically trained in conducting HD-EEG exams and data analyses. The mental motor imagery condition was statistically compared to the resting condition. The examination was repeated on a second day to reduce the influence of possibly confounding factors like alertness or tiredness. All exams were conducted by research personnel specifically trained in neurodiagnostics measures.

Standardized Written Report of the Findings of the HD-EEG Examination

In addition to the scientific purpose of the study, the results of the HD-EEG exams were always communicated in a standardized way using a written report. The reports were prepared by the researchers and revised by physicians experienced in the field of neuro-rehabilitation and trained in the interpretation of the functional HD-EEG paradigm by one of the head physicians. The HD-EEG report included a detailed description of the examinations, the individual patient's results and a discussion of these results in comparison with a population of healthy individuals. In respect to the auditory oddball paradigm (p300), the report included the extracted waveforms and topographies of the stimulus groups (standards and targets). Based on the waveform (amplitude and latency) as well as the topographical distribution of the p300 component, the quality of the brain response to the presented stimuli was rated. In respect to the mental motor imagery paradigm, the accuracy of the machine learning classifier was reported,

expressing the performance of the patient to follow the instructions. Additionally, the statistical difference between the resting and the mental motor imagery condition was reported. The report then stated if and how well the patient was able to follow the instructions and compared the performance to a control group of healthy controls. The report concluded with an overall evaluation of the patient's level of consciousness. Here it compared the results of the HD EEG with the results of the structured clinical examinations with the Coma Recovery Scale Revised (CRS-R) [84]. In case that the results of both measures were at odds with each other, this was stated and explained with regard to a variability of a patient's arousal during the exams. Reports described the HD-EEG as an experimental scientific measure and stated that results would never be used alone to guide medical decisions. Doctors attached the HD-EEG-reports to the patient's medical chart and sent them out to the patient's general physician as well as to his/her legal representative within one to two weeks after the patient's discharge. The process of oral disclosure of the results was not standardized. Usually, the results of the examinations were mentioned in the medical discharge conversations between doctors and patients' next of kin, embedded in a more general evaluation of the patient's condition and prognosis.

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