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9 **Disorders of Consciousness: An embedded ethnographic approach to uncovering the** 10 **specific influence of functional neurodiagnostics of consciousness in surrogate decision** 11 **making**

12
13 **Abstract:** A recent qualitative study published in *Neuroethics* by Schembs and colleagues
14 explores how functional neurodiagnostics of consciousness inform surrogate decision making
15 in cases of disorders of consciousness. In this commentary, we argue that the chosen
16 methodology significantly limits the scope of the potential conclusions and suggest an
17 embedded ethnographic approach of co-presence as an alternative.
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20 The novel methods of functional neurodiagnostics for patients with disorders of consciousness
21 (DOC) have yet to see wider implementation in routine care. However, in their paper “How
22 Does Functional Neurodiagnostics Inform Surrogate Decision-Making for Patients with
23 Disorders of Consciousness? A Qualitative Interview Study with Patients’ Next of Kin”[1]
24 Leah Schembs and colleagues present exciting new research that to our knowledge brings the
25 first insights from qualitative studies on how functional neurodiagnostics inform surrogate
26 decision-making when such experimental assessment is closely implemented into routine care
27 of patients with DOC. Given the great promise of results from functional neurodiagnostics in
28 a clinical setting [2, 3], the results presented by Schembs and colleagues that functional
29 neurodiagnostics, when implemented in routine assessment, play a limited role for the patients
30 next of kin, are surprising and of relevance for further discussion.
31

32 **The results and limitations of the methods**

33 The qualitative study by Schembs and colleagues explores the experience of surrogate decision
34 makers with the experimental use of functional neurodiagnostics, employing the methods of
35 high definition-EEG, aiming at detecting hidden awareness. The EEG examination included
36 both active and passive tasks. Specifically, it included an auditory oddball paradigm and a
37 motor imagery task. Schembs and colleagues interviewed seven next of kin in the homes of the
38 participants between one and nine months after the EEG examination. The participants were
39 next of kin to patients, who had suffered a wide range of durations of DOC (between 3,5 months
40 and 7 years). Schembs and colleagues specifically included next of kin with high hopes for the
41 recovery of the patient. Out of ethical considerations, they chose not to include next of kin
42 where a decision about change of treatment goals to palliative care or suggestions for
43 terminating life-sustaining treatment was being made. Schembs and colleagues provide a
44 thorough and detailed description of methods and carefully limit their conclusions to the
45 relevant subgroup of participants, being next of kin with high hopes for recovery of the patient.
46 However, despite the initial objective of the study and the specific focus on functional
47 neurodiagnostics in their title, their main results seem to relate to the influence of clinical
48 assessments in general rather than to functional neurodiagnostics specifically. The main
49 conclusion is reported to be that next of kin “deal with the results of examinations according
50 to their belief system aided by different strategies (such as avoiding certain medical personal)

1 *to restabilize the system when unfavorable evaluations were presented.*”[1](p. 1), and the
2 authors outline a plausible psychological model for these strategies. Conclusions on the
3 specific influence of the results of the EEG examinations were challenged by the fact that four
4 of seven participants did not remember the EEG examination having been conducted and none
5 mentioned it spontaneously in the interviews. However, to the extent that the lack of
6 recollection also reflects on the influence of the EEG examination, Schembs and colleagues
7 summarize this finding in the following way:

8
9 *“From the perspective of our participants, in many cases the HD-EEG*
10 *examination was interpreted as one datum or one example of an external evaluation of*
11 *the patient by a medical expert. Participants described it as not substantially different*
12 *from other examinations for the purpose of an evaluation of a patient’s condition by*
13 *experts”*[1](p. 5).

14 This result is surprising, especially in cases where there had been no observations of clear
15 clinical signs of consciousness (such as engaging in yes/no communication by nodding, or
16 shaking of the head appropriate to context). The clinical rationale for the EEG assessment is
17 the potential to uncover covert awareness, and thereby change a diagnosis from the detrimental
18 diagnosis of Unresponsive Wakefulness State (UWS) to the more promising diagnosis of
19 Minimal Conscious State [4], which would be assumed to have a core interest to participants.
20 It is also surprising given the fact that coverage of systematic misdiagnosis of such patients,
21 and cases of sudden recoveries from UWS, have received considerable attention both in the
22 medical literature [5, 6] as well as in public media [7, 8].

23 While recognizing the importance of the work of Schembs and colleagues, and the highly
24 sensitive setting of the study, we are concerned that the reliance on interviews, the timing of
25 interviews, and the selection of participants in the study severely limits potential conclusions
26 about the specific influence of the EEG examinations.

27 Firstly, the large time gap between the EEG examinations and the interviews leaves their
28 findings open to classical recall biases [9]. It is likely that the current status of the patient will
29 affect the interview with regard to how the assessment is recollected and experienced. The
30 patient’s level of consciousness may have changed, affecting the context significantly for the
31 actual interview. Based on a single interview and these limitations, uncovering whether the
32 EEG examination generated hope, or had a larger influence on surrogate decision making
33 around the time of the disclosure of results, is purely retrospect and limited.

34 Secondly, while Schembs and colleagues do recognize the issue of recall bias and state that
35 their *“research approach supposedly underestimated the vanishing short-term-effects*
36 *of neurodiagnostics disclosure”*[1](p. 15), they assert that it was *“still sensitive to a long-term*
37 *effect in cases, where the disclosure immediately had a significance to the participants”*[1](p.
38 15). However, cases where the disclosure plausibly had immediate significance, i.e. cases
39 where a decision was made to discontinue treatment, were excluded from the study at the
40 outset. The decision by Schembs and colleagues to exclude next of kin where a decision for
41 palliative care or suggestions of terminating life-sustaining treatment had been made may, from
42 the very outset, have excluded important knowledge about the process of recognition in
43 relatives of assessments, insights, and decisions by clinical staff. This could explain that *“in*
44 *their retrospective description of the conversations, none of our participants expressed*
45 *considering the possibility that the negative evaluation could have been accurate nor that a*
46 *change of treatment goal could be an option to consider”*[1](p. 9). We suggest that this

1 illustrates why, in order to uncover the influence of EEG assessments on surrogate decision
2 making, it is crucial to include cases where decisions about change of treatment goals were
3 actualized. In some of these cases, hopes or beliefs about potential recovery may have been
4 challenged and changed due to the EEG assessment. Knowledge of such processes are essential
5 in uncovering the role of functional neurodiagnostic assessments in surrogate decision making.

6 In our ongoing anthropological study of knowledge-making among clinicians and researchers
7 in the process of developing new neurodiagnostic tools (fMRI and EEG) for patients with DOC
8 in critical care, we have observed that the ethnographic method of co-presence with
9 stakeholders in the situation; patients, clinicians, scientists, and relatives, provides multifarious
10 insights to the decisions made throughout the patient trajectory in early neuro rehabilitation
11 and care. Moving beyond unidirectional observation, co-presence is a relational endeavor
12 where a shared meaning may develop through interaction of participants and researchers [10].
13 While the focus of our study is the knowledge making of clinicians and researchers, we believe
14 that experiences from our work provide valuable methodological insights applicable to the
15 research by Schembs et al. (2020). We argue that an ethnographic method of participant
16 observation in the form of co-presence produces an experience and understanding in the
17 researcher of the actual setting and interaction which situates the dialogue and decision making,
18 opening a potential for insights beyond what can be verbalized exclusively through interviews.
19 This makes it an important supplement to interviews.

20

21 **Including the perspective of next of kin where decision has been made to discontinue** 22 **treatment**

23 Our experience and suggestion of ethnographic co-presence as an embedded and
24 supplementary research strategy runs counter to the anticipation by Schembs and colleagues
25 that including relatives where treatment was discontinued and asking about their experience
26 will bring additional distress. Ethnographically engaging in the clinical setting as decisions
27 around patients with DOC unfold, the researcher forms relations with different participants in
28 such decision processes, including surrogate decision makers. These interactions mediate an
29 ethical sensitivity, which makes it possible to approach relatives for an interview, more as a
30 continuation of an existing conversation than as a disturbance. Accordingly, interview
31 interactions with such relatives, which Schembs and colleagues decided to exclude, are indeed
32 possible and can be productive spaces for reflection, giving insight into the experience of, and
33 give voice to, a highly vulnerable group. Being present not only enables the opportunity of
34 spontaneous and informal conversations with the relatives, but co-presence produces an outset
35 for addressing topics which could be ethically sensitive to a particular interviewee, because of
36 the familiarity already established with the researcher.

37

38 **How being co-present facilitates crucial knowledge about context and framing**

39 In our ongoing work, we combine an ethnographic study with qualitative interviews, letting
40 the reflections and actions of the clinic inform the questions asked. Such interrelation of the
41 material produces a productive outset for knowledge making, as the ethnographic co-presence
42 opens insights into interactions in the clinic where assessments of the patient's state of
43 consciousness are discussed by the clinical staff. It may also facilitate key insights into how
44 relatives adjust their expectations to the situation and the results conveyed by the clinical staff,
45 sometimes by defying the assessment. An example from our research illustrates how the
46 immediate co-presence in the clinical space opens access to knowledge of the interactions of
47 clinicians and relatives and how they may form contextual perceptions prior to the neuro
48 assessments:

1 In our fieldwork at an intensive care unit, providing early neuro rehabilitation at a Danish
2 hospital, we followed the clinical staff to understand their practice and reasoning around
3 assessments of consciousness. On this particular day we follow the treatment and care
4 interactions around patient B, who is behaviorally unresponsive and intended to undergo
5 experimental fMRI and functional EEG examinations in the afternoon. Leaving the patient
6 bedroom, we greet the parents who have come to visit. Alone in the hallway, the attending
7 physician shares her concerns about the family’s lack of comprehension of the situation with
8 the ethnographic researcher:

9 “[...] it’s strange with that family – it’s like they are completely distanceless in terms of the
10 gravity and seriousness of the situation. It’s all just smiles and how do we move on from here.
11 Their son is in there with a very serious brain injury and then he [the dad] asks, ‘did he sleep
12 well?’ - and the other day the mother came into his room and said: ‘oh look there is [name]
13 he is such a handsome man’, and she said that he had squeezed her hand and looked at her.
14 ‘I’ll be damned if he had. We are not even close to that.’ The physician seems concerned by
15 the seeming lack of realization in the family of the seriousness of the situation.... ‘There’s still
16 some recognition to be done there’, she says. [Fieldnotes, September 2017]

17 What we suggest by this illustrative example is that the ethnographic co-presence allowed an
18 emergence of important insights into the context and framing of the neuro assessment that
19 followed. The interpretations made by the clinical staff of the hopes and assumptions held by
20 next of kin may influence how they choose to disclose the result of the neuroscientific test.
21 This kind of knowledge may contribute significantly to understanding the complex interactions
22 at play in decisions on treatment trajectories in patients with DOC; insights that cannot be
23 obtained through interviews, as they are contextually situated in the moment of co-presence.
24 While our observations in our current project are focused on clinicians and researchers, a future
25 study on the decision making of next of kin could disclose such insights of framing and contexts
26 from the perspective of the next of kin and could also include co-presence at meetings with
27 families where information on test results were disclosed. This would further broaden an
28 understanding on how functional neurodiagnostics affect surrogate decision making.

29 **Further Considerations**

30 Employing embedded ethnographic methods readily overcome two further challenges faced in
31 the study by Schembs and colleagues. Firstly, the challenge that the conceptions of EEG results
32 of surrogate decision makers could be mediated by how results were disclosed due to the lack
33 of standardized ways of informing the next of kin of results [11]. Being present in the situations
34 of care and decision-making means that the context and framing of information and
35 communication in the clinical context is directly available to the researcher, as illustrated
36 above. Secondly, Schembs and colleagues were not able to determine whether the EEG results
37 were indeed mentioned during discharge conversations [1](p. 15). While such uncertainties
38 could be addressed by other means in a study relying exclusively on interviews, they are
39 straightforwardly avoided through ethnographic co-presence.

40 The ethnographic approach of co-presence, suggested here, does not preclude the use of semi-
41 structured interviews. However, we strongly suggest that such interviews are developed and
42 carried out in a contextual synergy of the ethnographic observations and that they take place
43 much closer to the time of disclosure of the neuro assessment results. We envision the
44 ethnographic fieldwork as facilitating such interviews, which is a common strategy for
45 interview sampling in ethnographic fieldwork. We suggest that the research team establish a

1 presence at the clinic, allowing them to follow the next of kin before, during, and after the
2 neuro assessments. This would lead to recruitment of as many participants as possible, while
3 being aware of and avoiding potential biases in systematic inclusion and exclusion of
4 participants (such as participant's hopes and expectations of recovery for the patient).

5
6 While the ethnographic method of co-presence has the potential to deal with significant short
7 comings experienced in the study by Schembs and colleagues, it is important to note that this
8 research methodology also have inherent ethical and epistemological challenges. As a vast
9 body of ethnographic methods literature [12–14] reflects, research insights developed through
10 participant observation as co-presence in the clinic does not come without challenges. These
11 include issues regarding potential loss of control over privacy for participants and patients,
12 issues of potential loyalty conflicts, and issues of validity of observations¹. While such
13 concerns are not unique to the ethnographic method, they may take a different form in relation
14 to this.

15
16 When the researcher becomes a seamless part of the ongoing life at the clinic, and no longer
17 perceived as a disturbance, it may be challenging for participants to retain control over their
18 own and the patient's privacy. Knowing when something is an object of observation, and when
19 it is not, may be difficult in the settings. However, the strength of the ethnographic research
20 lies exactly in the navigation of this dual position, as both researcher and participant in the
21 local context[15], where the experience of unfamiliarity with the complexities of everyday life
22 in the clinic, makes it possible to discover the way decisions emerge between clinicians and
23 relatives. In ethnographic participant observation access must be continuously negotiated as a
24 relational practice[12], and it is the responsibility of the researcher to clearly outline the limits
25 of the observations. Methods such as explicit note taking is a good way of clearly signaling the
26 role of the researcher. However, continuous presence at the clinic may result in the researcher
27 gaining information that is not available to the participant, potentially creating issues regarding
28 loyalty. Such issues can be addressed by explicitly participating from one specific perspective;
29 being present alongside either the relatives or the professionals. Other ways to address issues
30 of privacy and loyalty are specific techniques of member-checking, or co-creation of research
31 accounts with research interlocutors. Nonetheless, specific techniques, all rest on a reflexive
32 practice of the ethnographer with a series of ethical responsibilities within all stages of analysis
33 and representation [15, 16]. Questions of validity in ethnographic research is a commonly
34 raised concern, which repeatedly has been recognized and extensively discussed[15–17]. We
35 argue that this can be dealt with on a practical level through highly detailed field notes,
36 transparency of research processes[13], as well as by aligning the fieldnotes with results from
37 interviews. Furthermore, shared access to fieldnotes and shared processes of analysis in a
38 research team is recommendable and a core practice in our ongoing study.

39 **Conclusion**

40 We suggest that in order to draw wider conclusions on the specific influence of functional
41 neurodiagnostic assessments on surrogate decision making in routine care of patients with
42 DOC, a broader methodological approach should be considered, both in terms of design
43 strategy and selection of participants. An embedded ethnography co-presence facilitates a way
44 to integrate ethical challenges and a nuanced understanding that may serve to develop clinical
45 approaches to inform next of kin of functional neurodiagnostic results.

¹ We thank an anonymous reviewer for drawing our attention to these issues.

1 Despite the methodological limitation of the study, we commend Schembs and colleagues for
2 this pioneer research, which may inspire future research into the dynamic and complex nature
3 of decision making as a highly sensitive and contested part of clinical practice. It attunes our
4 understanding of medical diagnostic as multi-faceted, highlighting the dynamic nature of
5 diagnostics and decision making as processes shaped by dialogue and interpretation.

6

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