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Social Uncertainty in Disorders of Consciousness: Shedding Light on the Various Perspectives of Family Caregivers and Surrogates

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Johnson and Lazaridis (2018) encourage their readers to acknowledge, communicate, and consider uncertainty in health care decisions for patients with disorders of consciousness (DOC). We agree that a distinctive feature of DOC is a high level of uncertainty. We also agree that uncertainty should be openly acknowledged by health care professionals in order to allow well-founded, responsible decision making. Yet when the authors describe four sources of uncertainty in DOC—scientific, personal, practical, and ethical sources—they miss out on a fifth major source: social uncertainty. In this commentary, we elaborate on social uncertainty with a focus on subjective DOC theories and surrogate decision-making frameworks.

A SOCIAL SOURCE OF UNCERTAINTY

Social uncertainty refers to the social environment of the patient. Throughout their article, Johnson and Lazaridis already refer to surrogate decision makers and family members but as rather passive recipients of information, neglecting their active and pivotal involvement in health care decision making. By adding a social source of uncertainty, we draw attention to the complex, dynamic interaction between patients with DOC, health care personnel, and especially family members.

Subjective theories, coping styles, and decision-making frameworks contribute to social uncertainty

Those who care for the patient, including the patient's family members, develop a subjective theory about DOC during their care. This subjective theory includes their own explanations of the etiology and the meaning of DOC, and, more importantly, about the presence or absence of consciousness, the ability to communicate,

and the probability of neurocognitive rehabilitation. Subjective theories not only influence the emotional coping of family members with the disabled state of the patient, these theories also impact family members' surrogate decision making for the patient. There is a plethora of different subjective theories of DOC, and it is hard to predict which one the family member will adopt. This translates into social uncertainty.

Individuals who want to plan ahead for an anticipated situation of DOC (e.g., by issuing advance directives) cannot be certain about how their family members will understand DOC and whether they will be willing to incorporate previously expressed preferences. For health care professionals it is difficult to predict—and sometimes to accept—how family surrogates develop and apply their DOC theories.

Family members develop subjective theories about the patient's condition

A subjective theory develops over months and years in a complex way that is only partly influenced by medical information about the patient's condition. Other factors influencing subjective DOC theories are the family members' personal backgrounds, their relationships with the patient, their interactions with other caregivers, and the cultures of the care environments. Movements of information, for example, are one important source of information that family members interpret and build into their subjective theory. Those theories can be expressed with metaphors. One participant in our interview study that we reported partly in 2012 described her daughter's condition as follows: "She is in a wood, in a nice wood. She likes it there and she doesn't have the urge to get out of there."

We base our assumptions on our research group's socio-empirical studies with family members of patients with DOC, including an ongoing qualitative study about

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family members' attitudes toward the use of new diagnostic and prognostic technologies in DOC (Jox et al. 2015; Kuehlmeier, Borasio, and Jox 2012). There are other research articles that support our hypothesis, although the role of the family in DOC is a rather neglected field of research. Jacobs and colleagues studied family reactions to the "persistent vegetative state" more than 30 years ago (Jacobs, Muir and Cline 1986). They described "response patterns" of each family as a unique process that depends on many interrelated factors. Edgar, Kitzinger, and Kitzinger (2015) described how lay people and medical professionals draw on different "interpretative resources" in their response to chronic DOC (Edgar et al. 2015). They assumed that relatives require an "interpretative framework" that encompasses the uniqueness of the patient and their relationship with them. Subjective theories can explain disagreement between medical professionals and lay people. In our quantitative survey among family members of patients with DOC we found significant discordance between family members' perspectives and medical assessment in about one-quarter of the cases (Jox et al. 2015).

Family members' hope and denial play a crucial role in the processing of medical information

There are a depth and range of emotional reactions commonly experienced by families with a severely brain injured relative (Kitzinger and Kitzinger 2014). Two core mechanisms that concern the psychology of caring for patients with DOC and that are incorporated in caregivers' subjective theories are hope and denial. The hope for a remarkable recovery of the patient has been considered crucial for the caregivers' successful coping with the acute phase traumatic coma on an intensive care unit (Verhaeghe et al. 2007). Some of the interviewed family caregivers in our study hoped that the patient might eventually be able to communicate verbally again, others accepted that the current condition would be the best possible condition to be achieved, and a third type was preparing themselves for the patient's death (Kuehlmeier, Borasio, and Jox 2012). Wijdicks and Rabinstein describe three types of family caregivers: (1) "realists," who "understand the gravity of the situation and know that prolonged care would be futile"; (2) "fighters," including "those who were willing to sacrifice themselves for the patient" or "those who put trust in a miraculous recovery"; and (3) "procrastinators," who were unsure or have heard about unexpected recoveries (Wijdicks and Rabinstein 2007). Despite the patients' long-standing severe DOCs in the cases that were included in our survey, family members' belief in future improvement was surprisingly high, especially with regard to the hope that the patient may one day regain the ability to communicate (Jox et al. 2015). In an older study in Israel, denial was described as one of the most prevalent reactions to post-coma unawareness

(Tzidkiah, Sazbon, and Solzi 1994). In our current study, we elaborate how next of kin of patients with DOC who have high hopes for the patient's recovery repress negative test results and medical evaluations of the patient's condition, irrespective of their presumed degree of certainty. Hope and denial play a crucial role in maintaining the psychological stability of family members, which seems important to keeping on caring and making sense of their own investment. Diagnostic or prognostic uncertainty can be used to reinforce the hope for recovery or the denial of negative evaluations.

Family members adopt different decision-making frameworks as surrogate decision makers

Being put in a situation of acting as a surrogate decision maker can be a very challenging task for family members of patients with DOC. Family members have to interpret their role as surrogate decision makers, and there are various possibilities for how to approach this. In our qualitative interview study with family members of patients with unresponsive wakefulness syndrome, we examined their attitudes toward decision making. They were making reference to two kinds of representations of the patient's will: (1) previously expressed patient preferences, such as a written advance directives or oral statements, or the patient's prior identity, and (2) a will constructed and interpreted from the course of the patient's condition and minimal behavioral signs, including reflexes and vegetative signs. The second representation of the patient's will, and the high hopes for improvement of the patient's condition, the caregivers' definition of life-sustaining treatment, and the moral obligation not to harm the patient were used as justifications to disregard previous treatment wishes of the patient (Kuehlmeier, Borasio, and Jox 2012). In our survey among family members of patients with DOC, the family members' perspectives on patient well-being and behavior, as well as their own needs and interests, were judged more relevant than the patient's advance directives or orally expressed treatment wishes (Jox et al. 2015).

CONCLUSION

Since family caregivers' medical and moral assumptions can outweigh the patients' autonomous treatment preferences, their subjective illness concepts and their frameworks on how to approach surrogate decision making are a relevant additional source of uncertainty in DOC. Even when patients have previously written advance directives for the case of unresponsive wakefulness syndrome (UWS), they cannot be certain how surrogates will use these documents and on which theories and values they will base their surrogate decisions. This is a strong argument to buttress advance directives by a comprehensive model of advance care planning (ACP) that fosters mutual understanding of the future patient and his or her family members. Even when the former has indeed acquired a DOC and lost

decisional capacity, professional ACP as a longitudinal process of communication and support can help family caregivers cope better with the situation, reflect on their subjective DOC theories, and mitigate the social uncertainty that accompanies decision making. Especially in cases where ACP has not taken place, specialist counseling for family caregivers and surrogates is warranted, although guidelines on how to apply it and research on its effectiveness are widely missing.

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REFERENCES

- Edgar, A., C. Kitzinger, and J. Kitzinger. 2015. Interpreting chronic disorders of consciousness: Medical science and family experience. *Journal of Evaluation in Clinical Practice* 21(3): 374–379.
- Jacobs, H. E., C. Muir, and J. Cline. 1986. Family reactions to persistent vegetative state. *The Journal of Head Trauma Rehabilitation* 1(1): 55–62.
- Johnson, L. S. M., and C. Lazaridis. 2018. The sources of uncertainty in disorders of consciousness. *AJOB Neuroscience* 9(2): 76–82.
- Jox, R. J., K. Kuehlmeier, A. M. Klein, et al. 2015. Diagnosis and decision making for patients with disorders of consciousness: A survey among family members. *Archives of Physical Medicine and Rehabilitation* 96(2): 323–330.
- Kitzinger, C., and J. Kitzinger. 2014. Grief, anger and despair in relatives of severely brain injured patients: Responding without pathologising. *Clinical Rehabilitation* 28(7): 627–631.
- Kuehlmeier, K., G. D. Borasio, and R. J. Jox. 2012. How family caregivers' medical and moral assumptions influence decision making for patients in the vegetative state: A qualitative interview study. *Journal of Medical Ethics* 38(6): 332–337.
- Tzidkiah, T., L. Sazbon, and P. Solzi. 1994. Characteristic reactions of relatives of post-coma unawareness patients in the process of adjusting to loss. *Brain Injury* 8(2): 159–165.
- Verhaeghe, S. T., F. J. Van Zuuren, T. Defloor, M. S. Duijnste, and M. H. Grypdonck. 2007. How does information influence hope in family members of traumatic coma patients in intensive care unit? *Journal of Clinical Nursing* 16(8): 1488–1497.
- Wijdicks, E. F., and A. A. Rabinstein. 2007. The family conference: End-of-life guidelines at work for comatose patients. *Neurology* 68(14): 1092–1094.