

Caring for patients with disorders of consciousness: Highlights from the perspectives of healthcare professionals on communication and end-of-life decision making

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Several ethical and medical issues have been identified in and associated with the care of patients with disorders of consciousness (DOC) such as coma, the vegetative state (VS), and the minimally conscious state (MCS) (Racine, Rodrigue et al. 2010; Bacon, Williams et al. 2007; Bernat 2008; Bernat 2009). For example, the diagnosis of DOC has a fascinating and complex history marked by the constant challenge of establishing sound diagnostic categories and appropriate clinical examinations (Koehler and Wijdicks 2008). Current neuroscience research on DOC could improve our knowledge of DOC and eventually improve the accuracy of diagnosis, prognosis and enable better treatments (Gofton, Chouinard et al. 2009; Tshibanda, Vanhaudenhuyse et al. 2009). However, the integration of these advances could be complicated given the longstanding challenges associated with research and care in DOC such as lack of

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familiarity of healthcare professionals with DOC (Young, Blume et al. 1989; Youngner, Landefeld et al. 1989; Tomlinson 1990) and medical misdiagnosis (Andrews, Murphy et al. 1996; Gill-Thwaites 2006; Schnakers, Vanhaudenhuyse et al. 2009). The allocation of healthcare resources is another important issue because DOC patients are maintained alive artificially and require prolonged care (The Multi-Society Task Force on PVS 1994).

Despite the obvious importance of ethics in the care of patients with DOC especially in an evolving neuroscience context, important gaps remain in our understanding of issues in providing bedside care for patients with DOC. In particular, there is little data on how healthcare professionals deal with medical and ethical decisions concerning patients suffering from DOC. Our principal objective in this study was to understand the experiences and perspectives of healthcare professionals toward ethical issues and end-of-life (EOL) decision making in patients suffering from DOC and, through qualitative data, to provide insights into the practical challenges of providing care and making medical decisions.

Methods

We conducted a qualitative study involving healthcare professionals with different backgrounds, (e.g., medicine, nursing, clinical ethics, spiritual care, nutrition) from an acute care university medical center. A short questionnaire captured demographic data as well as type and level of experience of participants with DOC patients. A semi-structured interview was used to explore attitudes toward ethical issues identified in a previous literature review (Racine, Rodrigue et al. 2010). Qualitative content analysis content of interviews was conducted with the NVivo software.

Highlights of results

We recruited 21 participants involved with adults and pediatrics DOC patients from four hospitals within a modern tertiary hospital system. Participants had

backgrounds in medicine, nursing and other healthcare professions (e.g., social work, spiritual care).

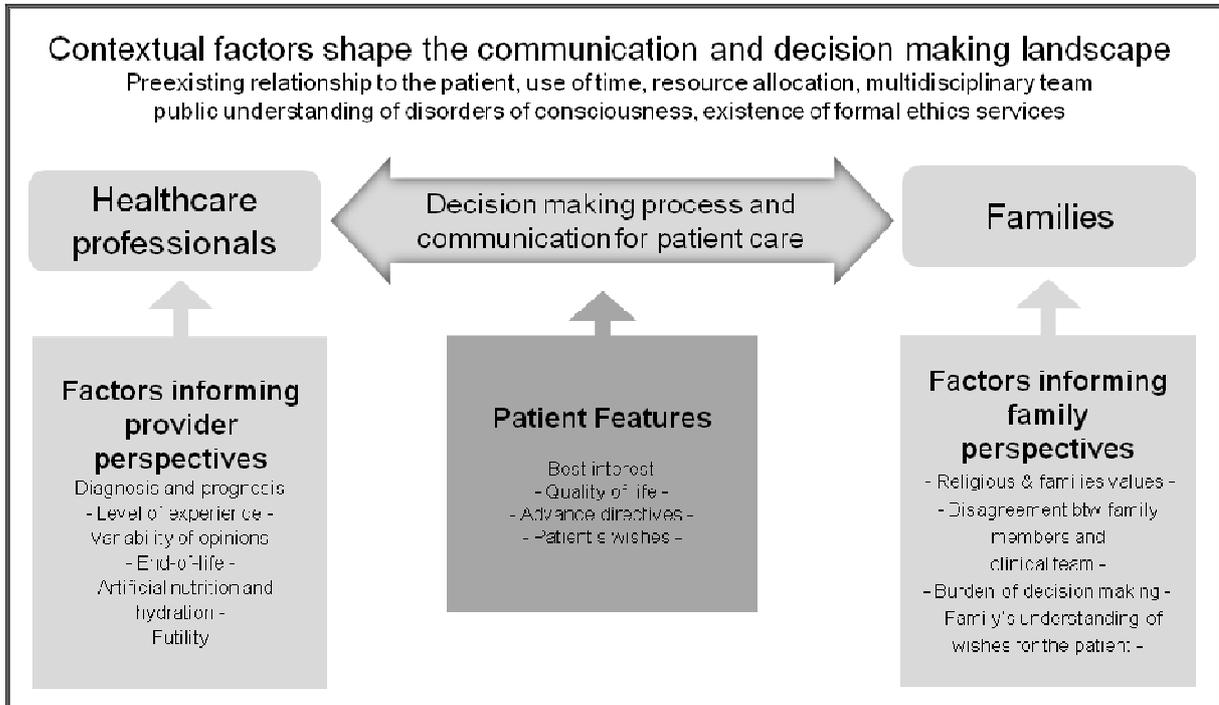
Our study identified and characterized social and ethical issues experienced by healthcare professionals in the management, care, and decision making for patients with DOC in a tertiary healthcare environment. Figure 1 illustrates that, overall, two key sets of stakeholders (healthcare professionals and families) interact through communication and decision making for patients with DOC. (The family designates either the biological family or, in rare occasions, another close person acting as a proxy for the patient.)

We found that several contextual factors shape the clinical context itself. These factors include time management, challenges in the public understanding of DOC, and the multidisciplinary team environment. Contextual issues like resource allocation and rotating staff in multidisciplinary teams create additional challenges for healthcare professionals.

The perspectives of healthcare professionals were shaped by diverging attitudes towards end-of-life care (including artificial nutrition and hydration, futility). For example, although most participants agreed that artificial nutrition was a treatment like others, a few disagreed with this common view. Healthcare professionals generally considered that diagnosis of DOC is not a major issue, but they admitted struggling with prognosis. The multidisciplinary nature of clinical teams was recognized as carrying challenges for the coordination of messages and clinical approaches and for decisions related to end-of-life.

Family perspectives were reported as being shaped by religious, cultural, and family values, possible disagreements between family members as well as the burden of proxy decision-making. The unconscious patient is only indirectly involved through the pursuit of his best interests and quality of life sometimes through advance directives but most often through an appreciation of previous wishes without formal written notification. Disagreements between family members, and/or between family members and the clinical team, can occur and greatly complicate clinical care and the ethical decision making processes. These observations are summarized in Figure 1.

Figure 1: Factors shaping communication and decision making for DOC patients according to healthcare professionals



Discussion:

Factors shaping the context and influencing the relationship between healthcare professionals and family

As illustrated in Figure 1, we found that the very context of the healthcare setting affects the relationship between the clinical team, family members, and the decision making process. Factors, such as time available to health care professionals and needed by family members, resource allocation, rotation of clinicians in the acute care environment, and public understanding were identified by healthcare professionals as context-shaping, and as having an effect on the relationship between the clinical team and family members. These contextual aspects are sometimes a source of discomfort for healthcare professionals because they report having little or no control over them; they are a feature of the environment in which they work. As a result, not only do they feel

the pressure of these factors but these factors are seldom discussed explicitly. Our data also exhibited a tension between giving time to family members and the lack of time and resources. Participants were aware that the news of having a family member suffer from a DOC is consequential and that, accordingly, time is required to digest this news. But participants also reported feeling pressure (e.g., need for a bed in intensive care) to get things done promptly (e.g., end-of-life discussion with family). Societies like the Canadian Critical Care Society have recognized the necessity of time for the family to be at peace with the fact that their loved one is in a critical neurological condition. The decision to withdraw treatment should not be done hastily (Rocker and Dunbar 2000). Nevertheless, the tension between the clinical reality and the clinico-ethical ideal can be the source of stress for healthcare professionals and does not easily dissipate.

Variability and pluralism within healthcare teams

Our observations indicate that variability exists between clinicians, including between physicians, in their dealings with patients with DOC. The practice of each individual is no doubt subjective to some extent because healthcare professionals bring with them their own experience, values, training, and personality. These subjective influences, in turn, affect how they communicate and make decisions (Racine, Dion et al. 2009). However, as reported by our participants, variability (e.g., in prognoses, in messages conveyed to the family about EOL decision making) has a direct impact on the relationship between the clinical team and family. It can lead to a serious misunderstanding between parties. The divergence of physician opinion and prognostication practices has been noted in several other papers on severe brain injury and EOL decision making (Randolph, Zollo et al. 1997; Christakis and Iwashyna 1998; Shevell, Majnemer et al. 1999; Rebagliato, Cuttini et al. 2000; Marcin, Pretzlaff et al. 2004; Rocker, Cook et al. 2004; Andrews, Azoulay et al. 2005; Rocker, Cook et al. 2006; Racine and Shevell 2009). This variability may complicate EOL decision making and interfere with consistent communication with members of the family and other healthcare professionals (Jox, Krebs et al. 2010; Tomlinson and Brody

1988; Bowman 2000). As previously discussed by one of us (J.L.B.), physicians, despite their best efforts, can convey prognosis and other messages that engage their own subjective perspective. They must acknowledge and be careful not to bias the framing of questions, notably those that involve opinions regarding outcomes, potential recovery, and quality of life (Bernat 2004).

Conclusion

We reported highlights from a qualitative study on the experiences and challenges encountered by healthcare professionals caring for patients with DOC. We found evidence of substantial challenges in diagnosis, prognosis, end-of-life care (e.g., communication) as well as vexing issues related to resource allocation. Healthcare professionals working in acute care facilities and/or family members, find themselves in an environment in which their behaviours are influenced by several factors, some of which are beyond their control. Dedicated training in EOL care and DOC is supported by our findings.

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