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How we involve patients and relatives in palliative ethics consultation

Ralf J. Jox, Andreas Schaider and Gian Domenico Borasio

Ralf J. Jox, MD PhD, Interdisciplinary Center for Palliative Care, Marchioninistraße 15, D-81377 München, Tel: 089-4140-5216, Fax: 089-7095-4939
Ralf.jox@med.uni-muenchen.de
www.izp-muenchen.de

Background. The practice of clinical ethics consultation (CEC) is highly diverse. Some clinical ethicists favour involving patients and/or relatives in the consultation process, others keep them away and concentrate on discussions with the health care professionals. Palliative care is a discipline that constantly faces ethical problems concerning end-of-life decisions. Because of its unique culture of communication, it might offer significant contributions to the question how CEC should deal with the question of patient and relative involvement.

Methods. We reflect on the philosophy of palliative care and the experiences at our inpatient palliative care unit. In addition, we review the protocols of ethics consultations done by our palliative care staff in other hospital departments.

Results. Modern palliative care is founded in the 60s of the 20th century and is grounded on the value of patient autonomy. Its origins show striking parallels with that of medical/clinical ethics. Palliative care regards patient and relatives as a "unit of care", which is expressed in the World Health Organization definition of palliative care. At our inpatient palliative care unit, end-of-life decisions are made in a communicative setting that is designed to prevent conflicts and foster consensus. The first important point is that patient and relatives should make a free and informed decision to come to our unit (many visit the unit before they decide to come here). On the unit, the patient and relatives are encouraged to make many "small" decisions on their own (e.g. on the design of their room, the timing of the day), being sensitized to use their autonomy. It is essential that patients and relatives have confident talks with different contact persons for different interests (physician, nurse, social worker, chaplain, psychologist etc.). Thereby, the team gets a more holistic view of the patient and relatives. The style of communication that has proven to be most helpful is characterized by realism, honesty, reliability and empathy. The palliative care staff is often called to ethics consultations on other wards, particularly intensive care units. In the years 2006 and 2007, 17 consultations were done. Even in the cases of coma, the consultant always went to the patient first and tried to establish communication with the patient. In 15 cases, relatives were present in round-table discussions (most of them were legally acknowledged substitute decision makers). These discussions had a median of 6 participants, 2 relatives, 1-2 physicians, 1 nurse and 1-2 other significant professionals (e.g chaplains, social workers, psychologists, therapists). Chaplains often acted as advocates for the patients and relatives, and their holistic approach has been very valuable for honouring the patient's will and finding a consensual decision.

Conclusion. In palliative care, the involvement of patients and relatives in decision making is indispensable and has proven to be helpful in practice. These are good arguments for CEC to do similarly.

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