The Concepts of Personhood and Autonomy as they apply to end-of-life decisions, especially to palliative sedation

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In this presentation I would like to discuss the concepts of personhood and autonomy as they apply to end-of-life decisions. In the article titled "Concepts of personhood and autonomy as they apply to end-of-life decisions in intensive care", the authors Walker and Lovat propose broadening the classical concept of autonomy – as the ability to make independent decisions based on conscious and rational choices – to include the relational aspect of human nature. A person who is able to make his/her own decisions would make them in consultation with his/her family and close friends. Being in relationships with other persons would be the reason to make end-of-life decisions together. Based on the concept of *relational autonomy* (Mackenzie and Stoljar 2000), Walker and Lovat propose a broader concept of patient autonomy in the context of end of life decisions in intensive care. According to this concept, end-of-life decisions would be made with family and close friends not only in the light of social customs, but also according to law and clinical standards. (Walker, Lovat, 2015, 311-314). In my presentation, I would like to analyse this concept in relation to palliative care [PC], in particular the procedure of palliative sedation.

The idea of holistic patient care is included in the philosophy of PC. Hence, relatives can be involved in this type of care. However, as for decisions on deep palliative sedation, the patient's own autonomy should come before other factors. In this presentation, I will argue for the widest possible autonomy of the patient in decision-making in situations of death and dying. I believe that each patient has the right to die in accordance with her/his own personal preferences, even when they are not in line with the preferences of those closest to him/her. The right to a dignified death should be closely tied to respect for the autonomy of the dying. My position is not an expression of opposition to accompanying the dying, however. On the contrary, I believe that accompanying persons should have a far-reaching understanding and acceptance of the patient's preferences, even when those choices are difficult for them.

In the concept of personhood and autonomy as they apply to end-of-life decisions in PC, the optimal situation would be a decision based, on the one hand, on the personal preferences of the patient, while on the other hand taking into account the preferences of his / her family and loved ones. In order to come to such a decision, it is necessary to fulfil the conditions of two-way communication based on the mutual acceptance of choices and preferences combined with courage and openness to conversation about dying and death, and the patient must be accompanied. In making such decisions, the recommendations developed by the medical teams undertaking them may prove useful. I propose a similar development of recommendations for the families and loved ones of the dying. Education in this field is a prerequisite for the development of the concept of personhood and autonomy as they apply to end-of-life decisions in PC, which is also an expression of the principles of IT, as holistic care is not just for the patients themselves, but also for their families at the time of death, and later during the mourning period.

The French recommendations for medical staff may be a helpful example in deciding whether to put a patient in a state of palliative sedation. The authors of "La sédation pour détresse en phase terminale. Recommandations de la Société Française d'Accompagnement et de soins

palliatifs" propose that the entire care team making the decision answer the three following questions:

1. Why are we making this kind of decision? (This question concerns discernment of intentions accompanying this sort of decision)
2. For whom we intend to make this decision? (This question is related to ensuring that the patient's autonomy is respected)
3. For what reasons are we making this decision? (In this question, the most important thing is the values which form the basis of the care staff's decision; this question is also connected with standards of clinical practice, the law of the country where this decision is made, and the scope of responsibility of the person providing palliative sedation) (p.39).

Similar indications are included in the EAPC recommendations and other documents.
In this presentation I will argue that, on the basis of existing recommendations, it is necessary to develop standard recommendations for the relatives of patients who have entered into a state of deep sedation in PC, as an aid in making a joint decision in this regard [in the sense of the concepts of personhood and autonomy].

References

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