



Ethical Aspects of End-of-Life Decisions

Turkish and Intercultural Perspectives

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Content

- **Truth Telling**
- **Medical Futility**
- **Role of Family in End-of-Life Decisions**

Truth Telling

Ethical Background of Truth Telling

Human Dignity



Patient Autonomy



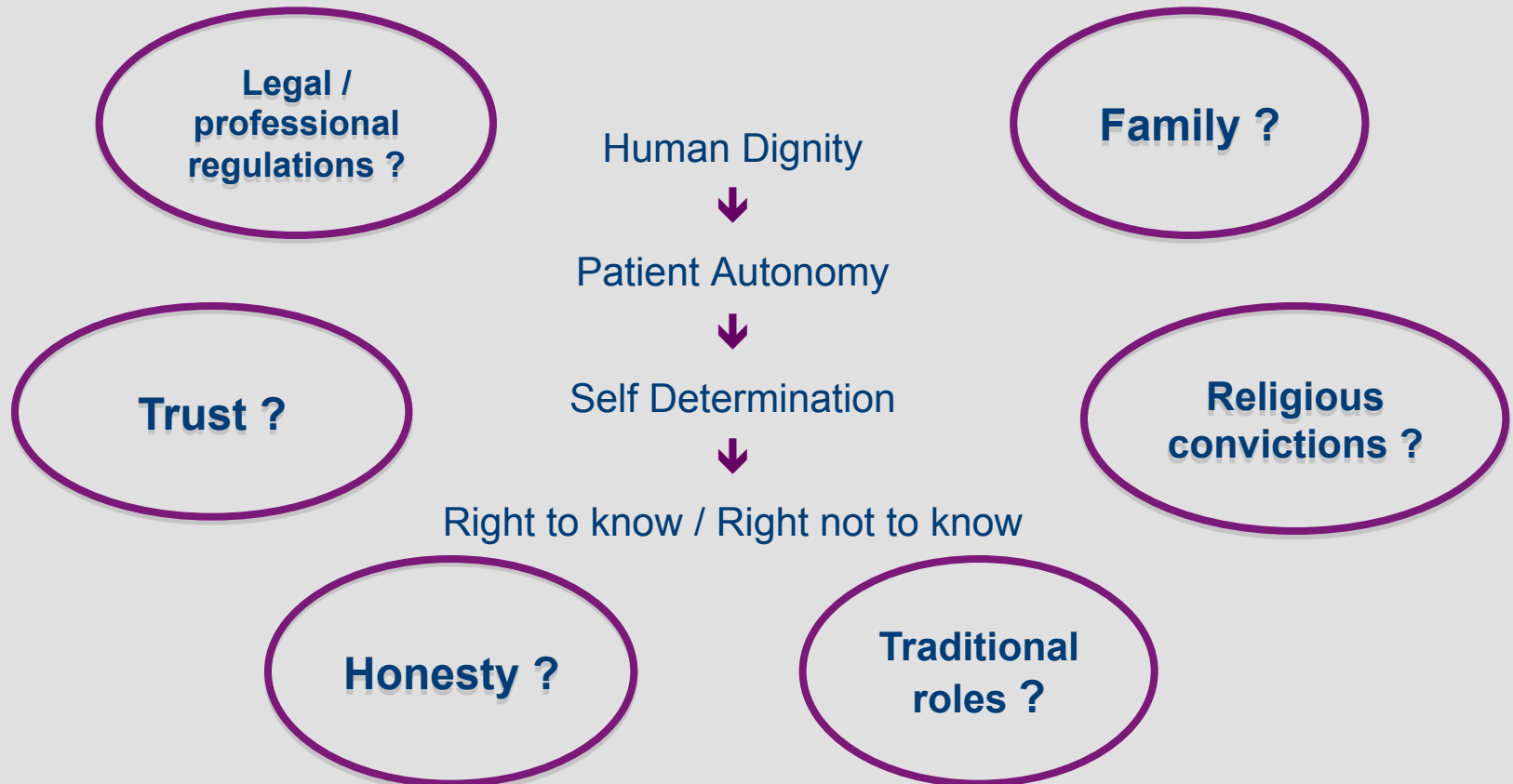
Self Determination



Right to Know / Right not to Know

Truth Telling

Ethical Background of Truth Telling



Truth Telling

Empirical Data:

In a cross-sectional study, 270 caregivers accompanying cancer patients during outpatient chemotherapy sessions were asked.

Table 2 - Preference on disclosure of diagnosis to patients and relatives

	Diagnosis disclosure		
	To the patient n (%)	To the relatives n (%)	To the relatives only n (%)
Yes	130 (48.2)	236 (87.4)	84 (80.8)
No	104 (38.5)	25 (9.2)	18 (17.3)
Hesitant	36 (13.3)	9 (3.4)	2 (1.9)
Total	270 (100)	270 (100)	104 (100)

Öksüzoğlu et al. (2006)

Similar results in *Samur et al (2000), Aksoy (2005), Ozdogan (2006) a.o.*

Truth Telling

■ Role of Family at End-of-Life Decisions:

‘My father had a cancer diagnosis one year ago. He underwent chemotherapy and surgical therapy. He is feeling good now. I think he improved because we didn’t tell him the diagnosis of cancer.’

A university professor in Turkey

‘My mother died of breast cancer. We (family member and physician) never informed her about this diagnosis. Until her death she believed in healing. Until her last day, she had a happy life.’

A top-ranking officer in the Turkish government

Truth Telling in an Intercultural Setting

CASE

A 23-year-old Turkish Muslim man living in Germany was diagnosed with malignant cancer. The patient's health conditions deteriorated increasingly, with a growing probability of his demise being imminent. Neither the patient himself nor his parents spoke German very well. With the help of an interpreter, the physician informed the patient about his current health condition and its expected course, though the patient's parents had been opposed to giving him this information. Death occurred two days after this conversation. Later on, the parents tried to hold the physicians responsible for the death of their child, claiming that by giving him such information they had contributed to a deterioration of his health condition and thus hastened the death of their child.

Ilkilic (2007) *Deutsche Medizinische Wochenschrift*

Conclusions

Truth Telling

- Patient Autonomy is not the central ethical principle for decisions at the end of life.
- 'Protecting' the patient from bad news is seen as the best interest of the patient.
- Family members and physicians see themselves as authorised to make such decisions.
- Turkish professional regulations are open for different decisions and actions and they give no clear answers.

Medical Futility

Definition:

- “Futile care refers to medical care that either prolongs suffering, does not improve the quality of life, or fails to achieve a good outcome for the patient.”

Romesberg (2003)

- “Since definitions of futile care are value laden, universal consensus on futile care is unlikely to be achieved.”

American Medical Association (1999)

Medical Futility

Approaches:

- Quantitative approach
- Qualitative approach
- Community approach

Literature: Callahan (1991); Jonsen (1994); American Medical Association (1999); Clark (2002); Glannon (2005) etc.

Medical Futility in Intercultural Settings

Empirical Data:

- One survey asked 136 doctors specializing in pediatrics working in medical faculties in the Netherlands about the parameters and conflicts arising in decision-making at the end of life.
- It was shown that in 20% of the cases under study (a total of 116 cases), a conflict of interest and decisions arose between the team and the parents.
- In almost all of these cases (22 out of 23), parents requested maximal therapy or continuation of the current level of medical treatment, while the healthcare team did not prioritize such a treatment strategy.
- It was shown that Muslim parents were significantly more frequently involved in those conflicts (58%) than non-Muslim parents (12%).

The Process of End-of-Life Decision-Making in Pediatrics: A National Survey in the Netherlands

Mirjam A. de Vos, Agnes van der Heide, Heleen Maurice-Stam, Oebele F. Brouwer, Frans B. Plötz, Antoinette Y. N. Schouten-van Meeteren, Dick L. Willems, Hugo S. A. Heymans and Albert P. Bos

Pediatrics 2011;127:e1004; originally published online March 14, 2011;
DOI: 10.1542/peds.2010-2591

De Vos et al. (2011)

Medical Futility in an intercultural setting

CASE

A six-day-old child of Turkish Muslim parents is suffering from type 2 oto-palato-digital syndrome (OPD), a rare genetic disease leading to severe anomalies in the formation of several organs. The child can only live on invasive life support, but even on a ventilator it is bound to die within a very short period of time. The German medical team suggests refraining from providing maximal therapy and limiting the extent of therapy. The parents however insist on maximal therapy, emphasising that this decision results from their Muslim faith, according to which they would be held responsible in the afterlife if they agreed to any other option.

Ilkilic / Schmidtke (2007) *Pädiatrische Praxis*

Conclusions

Medical Futility

- More intensive care possibilities increase ethical problems at the end of life involving medical futility questions.
- Lack of palliative care nationwide additionally complicates decisions on medical futility.
- Financial, social and religious arguments are not analyzed and discussed sufficiently.

Thank you for your attention!