AUTONOMY OF COMPETENT CHILDREN ABOUT END-OF-LIFE DECISIONS: ATTITUDES OF ITALIAN HEALTHCARE PROFESSIONALS

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Autonomy

“At a minimum [...] self-rule that is free from both controlling interference by others and limitations that prevent meaningful choice”

Beachamp TL, Childress JF, Principles of biomedical ethics (7th edition), 2013

Essential conditions for autonomy:

- **Liberty**: independence from controlling influences
- **Agency (capacity)**: capacity for intentional actions
• Essential conditions for **capacity**:  
  ✓ Can **understand a procedure**, including risks, benefits and alternatives  
  ✓ Can ask **appropriate and relevant questions**  
  ✓ Can **make decisions consistent** with his/her values

• Acquired by law with the age of majority, but neurophysiological studies show that it is often acquired after 20 y.o.  

• Few studies investigated end-of-life (EoL) care of children between neonatal and adolescent age.  
Aim

To explore the attitudes of healthcare professionals (HPs) towards competent children’s autonomy about EoL decisions.

Methods

- *Ad hoc* on-line anonymous survey (18 multiple-choice questions about children’s autonomy at the EoL and 12 questions on social and demographic features) between May and July 2016

- Population of the study: **592 Italian HPs**
  - physicians and nurses from adult setting
  - pediatricians and pediatric nurses
  - a class of nursing students at the last day of course

- Descriptive and multivariate analysis
Results

326 questionnaires returned (response rate: 55.1%)

• 261 females (80.1%)
• 187 had children (57.4%)
• 118 physicians (94 pediatricians), 167 nurses (93 pediatric), 38 nursing students, 3 other

• 180 never attended bioethical studies (55.2%)
• 240 Roman Catholic (73.6%), 36 agnostic (11.0%), 33 atheist (10.1%), 4 Protestant (1.2%), 1 Christian Orthodox (0.3%), 1 Muslim (0.3%), 11 other (3.4%)
• Out of 178 HPs who worked with terminally ill children, 107 (60.1%) had never participated to discussions on anticipate dispositions about EoL with children and their families.

Do you think that a competent terminally ill child should be involved in decision-making about his/her own end-of-life?

“Yes” was significantly associated with HPs’ young age \( (p=0.02) \) and previous bioethical studies \( (p<0.001) \), but not with spiritual believe \( (p=0.74) \).
If a competent terminally ill child asked not to be resuscitated with the consent of his/her parents, do you think his/her will should be accepted?

- “Yes, regardless of age” was significantly associated with young age ($p=0.03$), nurse profession ($p=0.008$), and hospital vs family practice ($p=0.01$).
Do you think that a child could understand what "euthanasia" means and could ask for it for him/herself?

- 45.4% Yes, based on his/her capacity degree and regardless of age
- 19.3% Yes, but only if >16 y.o.
- 15.6% Yes, but only if >12 y.o.
- 10.7% Yes, but only if >6 y.o.
- 4.3% No, never
- 4.6% I don’t know
- 4.3% Yes, but only if >16 y.o.

- “Yes, regardless of age” was significantly associated with pro-euthanasia \((p<0.0001)\), nurse profession \((p=0.02)\), and hospital vs family practice \((p=0.01)\).

- Overall 289 HPs (88.7%) asked for a law on euthanasia and 260 (79.8%) thought it should consider competent children.
Conclusions

• Italian healthcare professionals (nurses above all) declare respect of competent children’s autonomy about end-of-life decisions.

• Age and profession, but surprisingly not gender, parenthood and religion, seem to play a key role driving personal believes.


• Bioethical studies should be implemented to achieve higher awareness and constructive debate.

Art. 4

“The child is a person in all respects and is entitled to fundamental rights such as the right to life, dignity, freedom of expression and equality”

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