



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”

Beauchamp 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.

Goodlander EC, Berg JW, Core Issues in Pediatric Ethics, Cambridge 2011

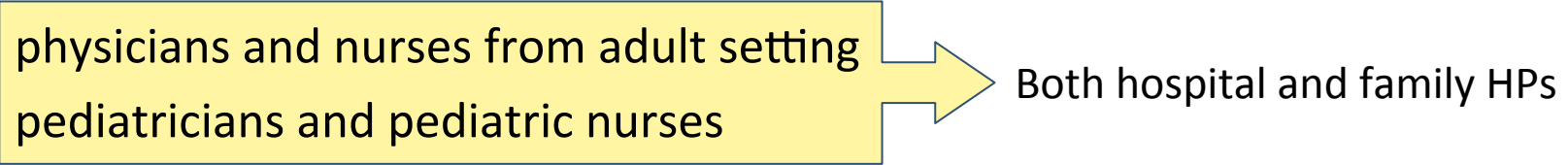
- Few studies investigated end-of-life (EoL) care of children between neonatal and adolescent age.

Pousset G, et al. Arch Dis Child 2011
Vrakking AM, et al. Acta Paed 2007

Aim

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

Methods

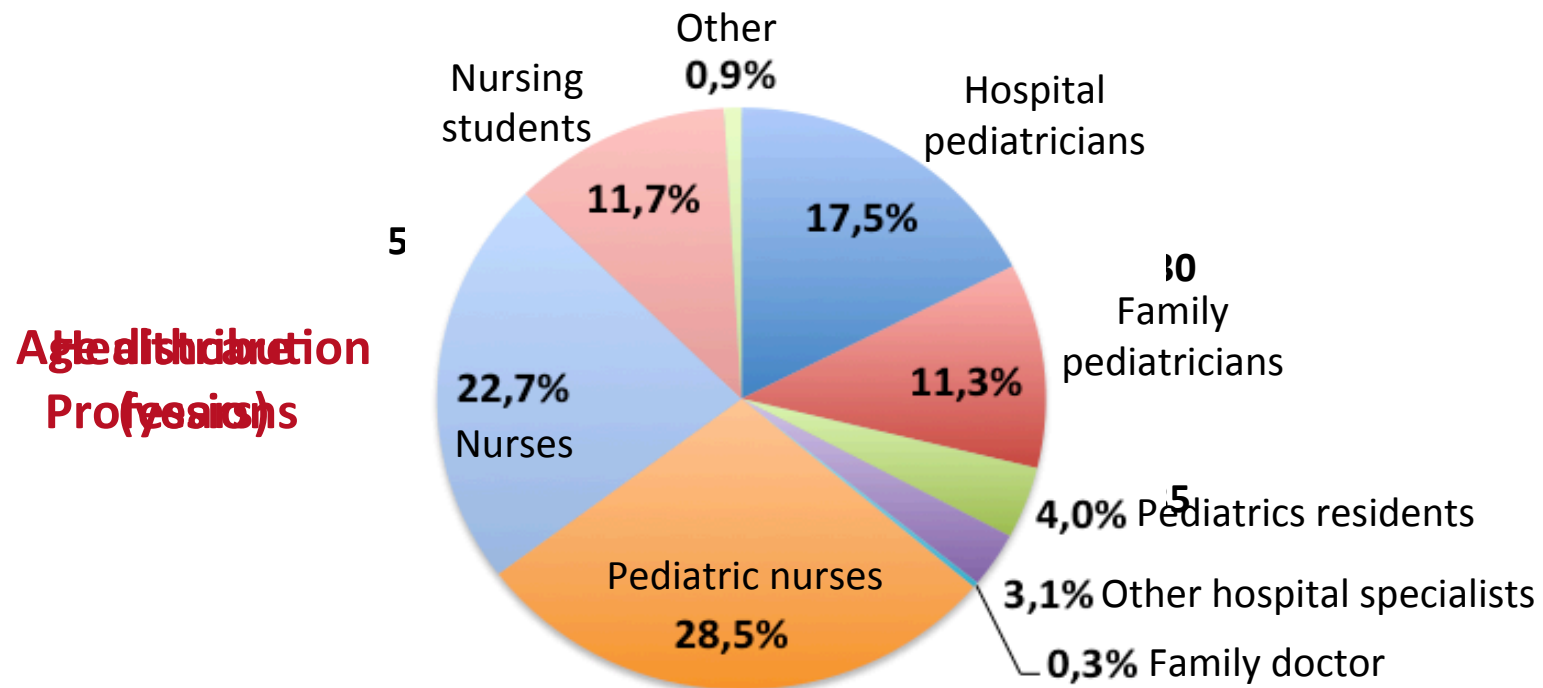
- *Ad hoc* on-line anonymous survey (18 multiple-choice questions about children's autonomy at the EoL and 12 questions on social and demographic features) between May and July 2016
- Population of the study: **592 Italian HPs**
 - ✓ physicians and nurses from adult setting
 - ✓ pediatricians and pediatric nurses
 - ✓ a class of nursing students at the last day of course

Both hospital and family HPs
- Descriptive and multivariate analysis

Results

326 questionnaires returned (response rate: 55.1%)

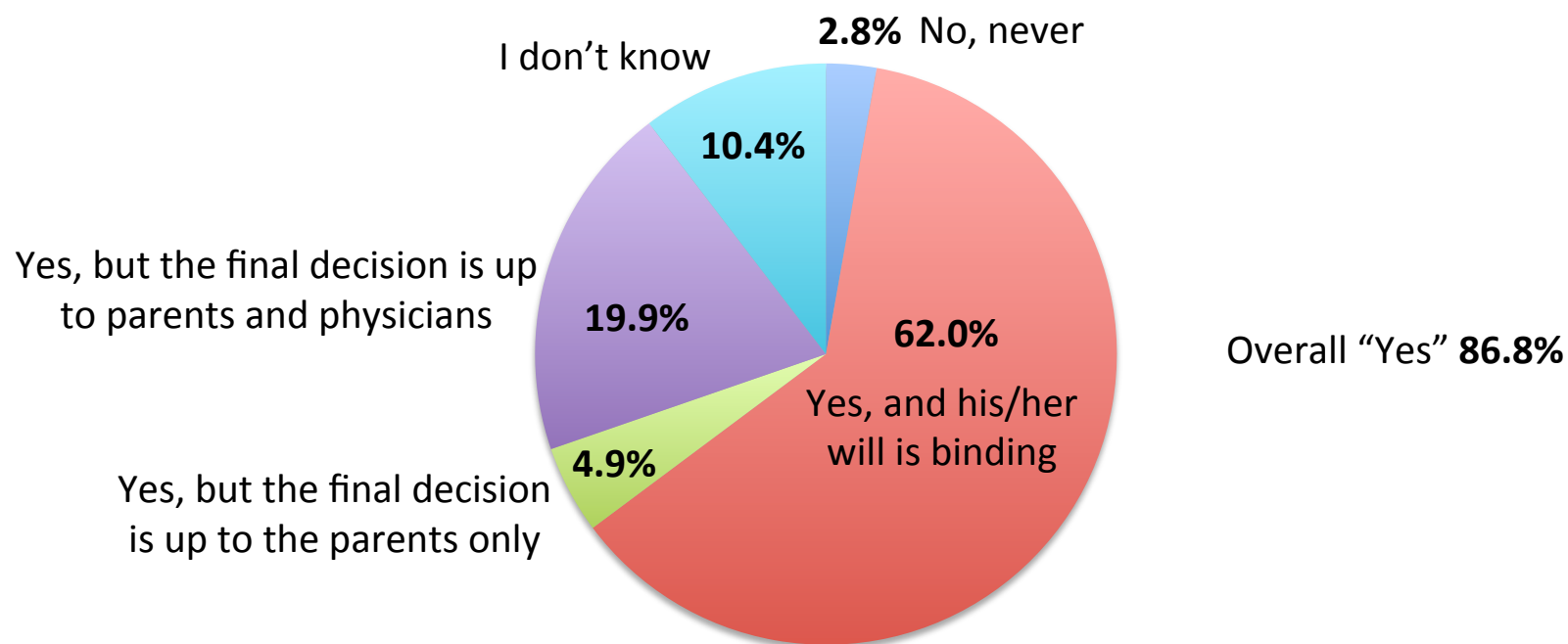
- 261 females (80.1%)
- 187 had children (57.4%)
- 118 physicians (94 pediatricians), 167 nurses (93 pediatric), 38 nursing students, 3 other



- 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%)

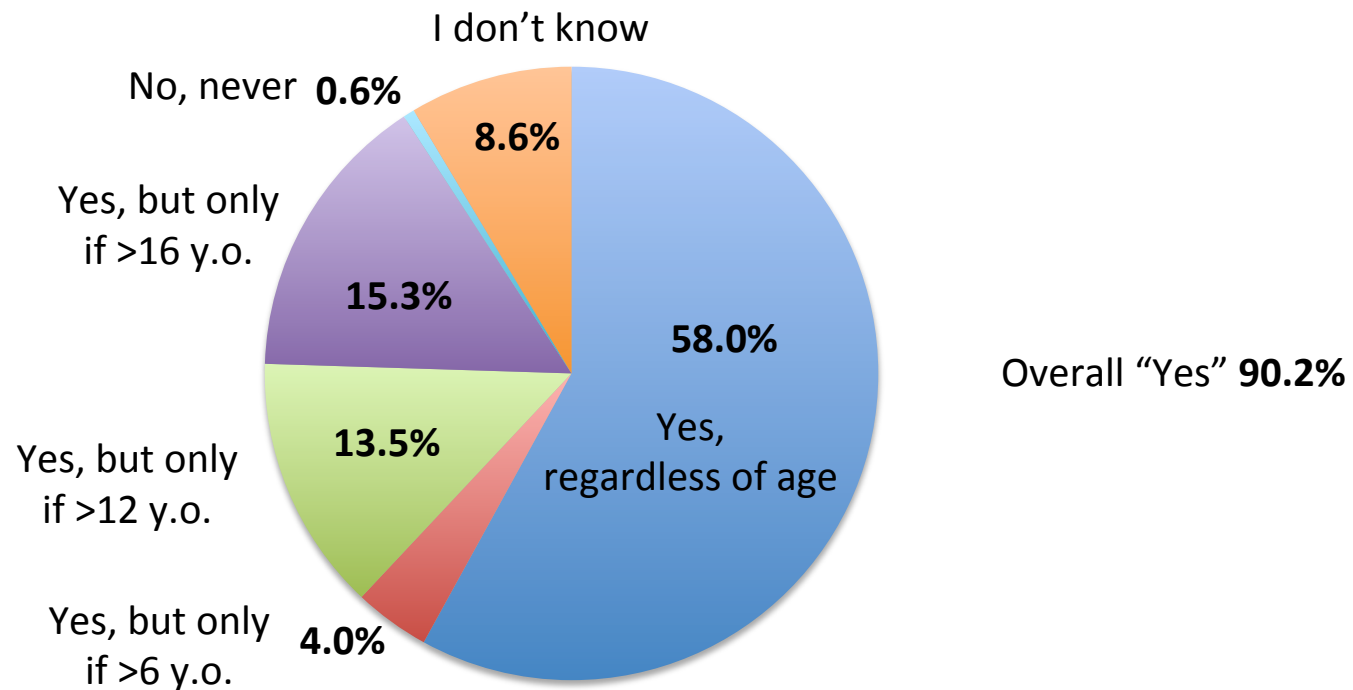
- Out of 178 HPs who worked with terminally ill children, 107 (60.1%) had never participated to discussions on anticipate dispositions about EoL with children and their families.

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



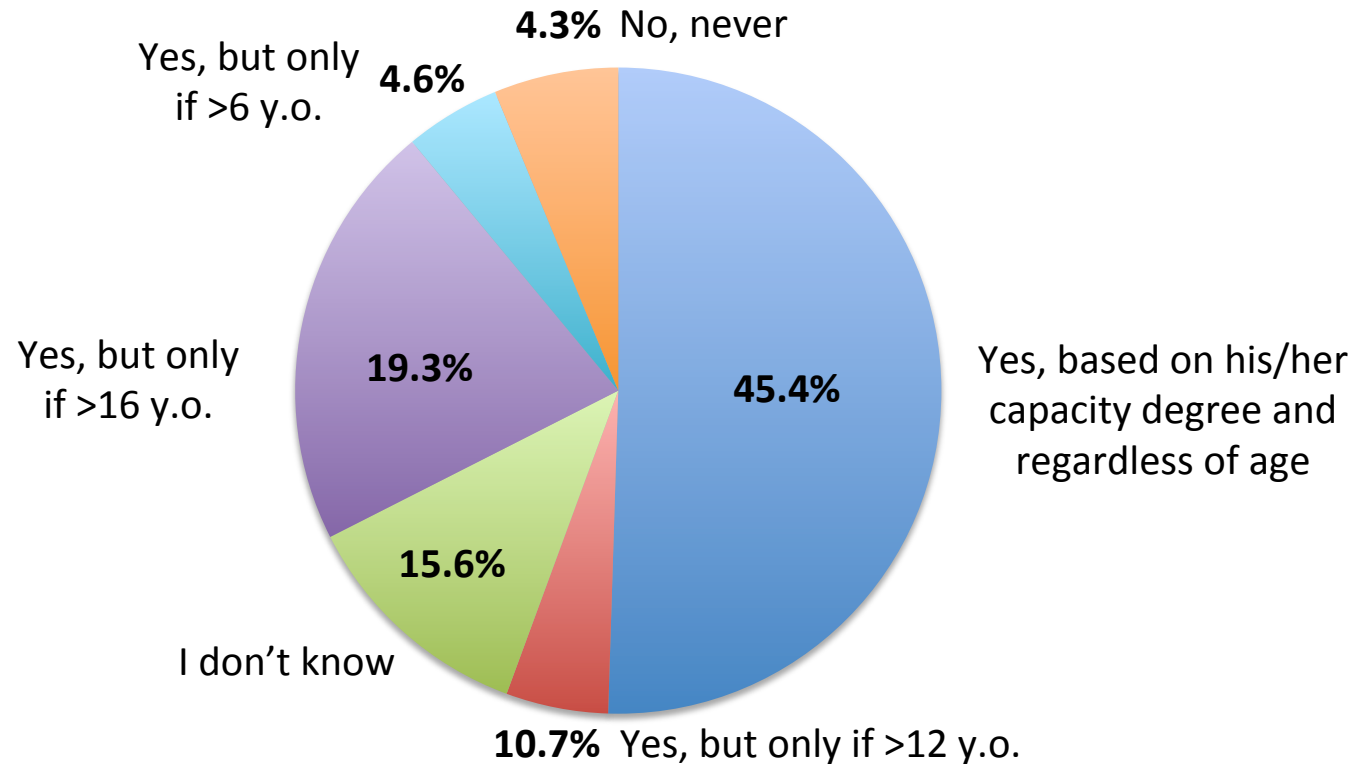
“Yes” was significantly associated with HPs’ **young age** ($p=0.02$) and **previous bioethical studies** ($p<0.001$), but not with spiritual believe ($p=0.74$).

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?



- "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 beliefs.

Cohen J, et al. Int J Public Health 2014

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

Sahler OJZ, et al. Pediatrics 2000

Giannini A, et al. Pediatr Anesthes 2008



Gold Medal
of Merit for services
to Public Health
2013

CHARTER OF THE RIGHTS OF THE DYING CHILD THE TRIESTE CHARTER

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”

Acknowledgments

- Regina Margherita Children’s Hospital and Sant’Anna Women’s Hospital - A.O.U. Città della Salute e della Scienza di Torino, Turin, Italy;
- Department of Pediatrics, Ospedale Martini (ASL TO1), Turin, Italy;
- Department of Pediatrics, Ospedale Agnelli, Pinerolo (TO), Italy;
- Department of Pediatrics, Ospedale Cardinal Massaia, Asti, Italy;
- Paediatric Palliative Care-Pain Service, Padua, Italy;
- physicians of the Medical Association (OMCEO) of Turin, Italy;
- physicians of the Italian Federation of Pediatricians (FIMP) of Piedmont, Italy;
- physicians and nurses of the Italian Association for Pediatric Hematology and Oncology (AIEOP);
- nursing students (III class), University of Turin – Rosmini Institute, Turin, Italy.

Thank you