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Developing autonomy in pediatric healthcare: towards an ethical model

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Background

- Triangle of actors in social pediatric care
(child - pediatrician - parents)
- Lack of knowledge about the moral rights of children and adolescents
- Ethics education rarely exists in pediatric resident curricula
- The "four principles" approach (justice, respect for autonomy, beneficence, non-maleficence) as base for our ethics analysis
- Children's right of inclusion in the decision making processes and the respect to the child's developing autonomy



Developing autonomy

- Autonomy as absolute value of the individual
- Autonomy related to the age-driven process of reasoning and competent decision-making development

Aim:

Frame developing autonomy in child healthcare

Underline the pediatric task to empower child autonomy

Systematic literature review in year 2016

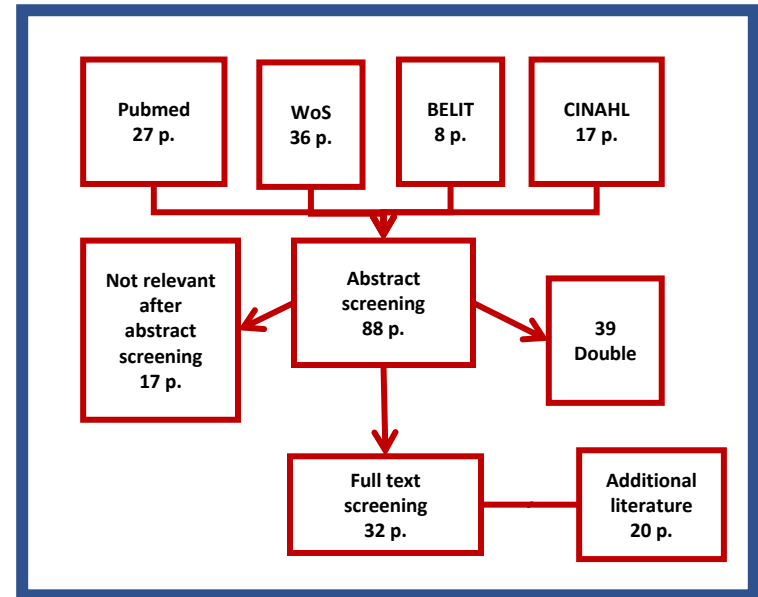
Study themes:

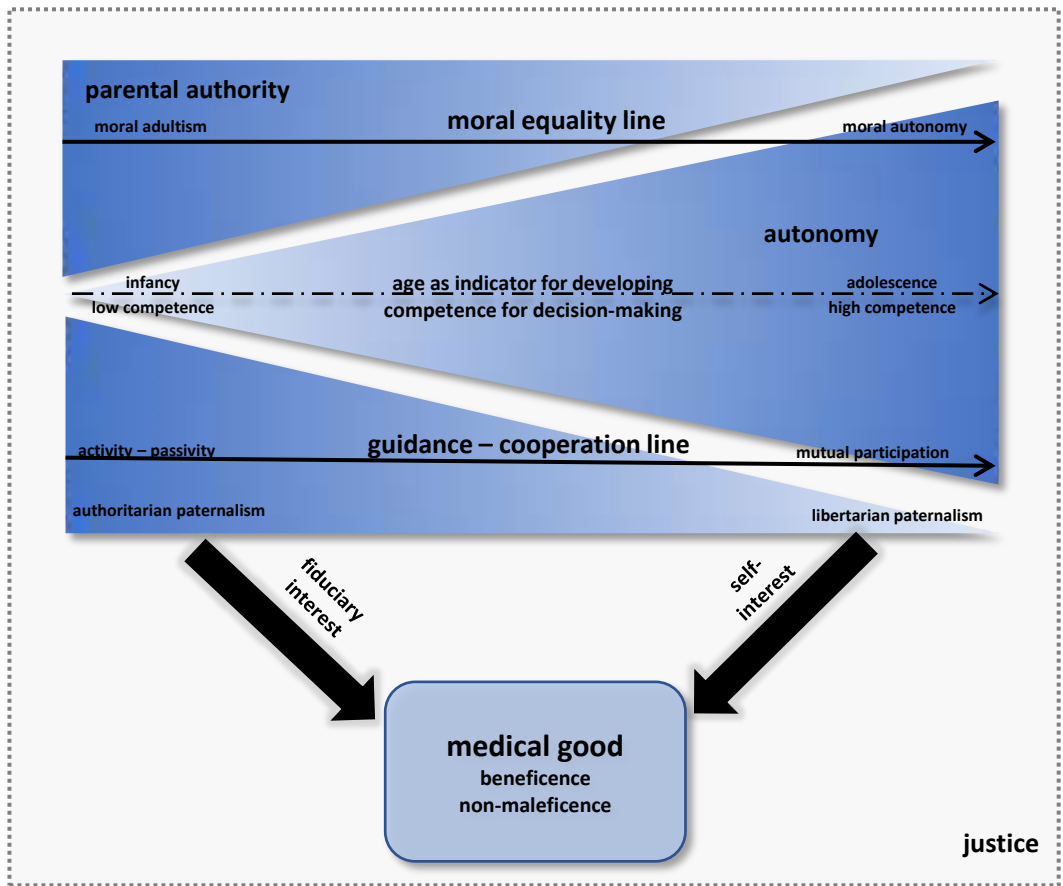
Autonomy and moral completeness

The parental role

The pediatric role

Beneficence and the medical good





Conceptual model for developing autonomy in child healthcare

Martakis, Brand, Schröder-Bäck, Arch Argent Pediatr, 2018

REVIEW

Open Access

Medical decision-making in children and adolescents: developmental and neuroscientific aspects



Petronella Grootens-Wiegers^{1,2*}, Irma M. Hein³, Jos M. van den Broek^{1,2} and Martine C. de Vries^{4,5}

	Age	0	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	Adolescence
(1) Language																		
(2) Intelligence																		
(2) Attention – Alerting																		
(2) Attention – Orienting																		
(2) Attention – Executive control																		
(2) Memory – Recall																		
(3) Reasoning																		
(3) Weighing risks & benefits																		
(4) Abstract thinking																		
(4) Mentalizing																		

Example of the implementation of the model

HPV-driven cancer is frequent in women of reproductive age. Since 2011 the HPV vaccine is offered as part of the national vaccination program in Argentina and the coverage rate is high.

Wenzeslava is a fifteen-year-old migrant girl from Bulgaria. Her family moved to Argentina a few months ago. Her parents wish that she receives the vaccine. She refuses though, arguing that she is not sexually active yet.

In a private talk with the pediatrician, she admits being scared of potential side-effects. Wenzeslawa has heard that a girl in Bulgaria developed a lethal Wegener's granulomatosis after HPV immunization. Although there was no causal relation between the two events, vaccination criticism in the media has strengthened the already high vaccine skepticism in Bulgaria.

Argentina's paradigm change:
National Civil and Commercial Code
Decision making competence for their health with the 13th year of life

Exemplary conditions to be addressed when applying the model

(based on Pellegrino & Thomasma, 1987)

Contextual conditions

Context variability:

Nature and properties of the disease, the diagnostics and therapies (plus alternatives)

and **consequences** for developing autonomy

Health-literacy issues and **decision-making competences**

False generalizations

Health illiteracy-driven fear

HPV-driven cancers not adequately curable, but preventable

Herd immunity ↑

Prevention of vaginal transmission, does not prevent from oropharyngeal manifestations.

Sexual inactivity is presented as alternative from the girl herself. (restrictive alternative)

Private talk with the pediatrician

Existential conditions

How the **disease itself or the treatment** may change ideas or decision-making competences

The effect of **prior knowledge**

Consider **institutional or societal differences**

No underlying condition or **prior experience**

Exposition to **false information**

Societal differences between the two settings

Intercultural communication

Lack of trust



Exemplary conditions to be addressed when applying the model

(based on Pellegrino & Thomasma, 1987)

Conceptual conditions

Paradigm shift: from cure to care
Respect for non-maleficence,
if not for **beneficence**
Respect for **EBM**

Respect for non-maleficence
Inform about ALL true side-effects (also rare)
Cancer prevention = respect for beneficence + EBM
Apparent paradigm shift
Don't vaccinate for the sake of the treatment
Patient shall **understand** personal & societal **benefits**
Vaccination in the future
Negotiation

Socio-ethical conditions

Individual good vs. common good?
Interests or motives or all actors
Exposition of family or third-party information?
Financing? Absolutisation of autonomy?
Frame of justice being respected?

No further socio-ethical concerns
The **frame of justice** has always been respected



What to do

- Address health illiteracy-driven fear
- Respect issues related to the language barrier, the intercultural interaction, or the lack of trust towards the new pediatrician
- Sexual inactivity as an option, but also a restriction in her developing autonomy
- Education, negotiation and empowerment
- Plan a follow-up appointment
- Application of the vaccine even without the involvement of the parents

Developing child autonomy in pediatric healthcare: towards an ethical model

Kyriakos Martakis, MD, MSc,^{a,b,c} Helmut Brand, MD, PhD^a and Peter Schröder-Bäck, PhD^{a,d}

Summary

- Introduction of a model to explore issues of developing autonomy and paternalism (medical or parental)
- Initiation and facilitation of an interdisciplinary dialogue between all involved actors
- Contextual, existential, conceptual and socio-ethical conditions shall be exhaustively considered
- Central role of the pediatrician in the facilitation of the dialogue and the empowerment of the child



Credit: Samuel Zeller



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Contextual conditions	<p>Health illiteracy-driven fear</p> <p>HPV-driven cancers present a serious risk for an often not adequately curable condition, that can be effectively prevented.</p> <p>High vaccine coverage in Argentina. It is expected to lead to a significant increase of the herd immunity in the coming decades.</p> <p>Prevention of vaginal transmission, e.g. using condoms, often does not prevent from oropharyngeal manifestations.</p> <p>Sexual inactivity or abstinence is presented as alternative from the girl herself. This alternative is restrictive for her future personal and social development, as well as her developing autonomy.</p> <p>The private talk with the pediatrician is a very important tool to be utilized.</p>
Existential conditions	<p>No underlying condition or prior experience that could influence the girl's decision-making competence or level of autonomy.</p> <p>Exposition to false information regarding potential side-effects of the vaccine.</p> <p>There are apparent societal differences between the two settings. The HPV vaccine is a successfully implemented program in Argentina, but this is not always the case in a lot of other countries. Problems in the communication or lack of trust, associated with the intercultural character of this pediatrician-patient interaction need to be addressed very thoroughly.</p>
Conceptual conditions	<p>The respect for non-maleficence (no such side-effects) of the girl is crucial. However, she shall be informed about all true side-effects, including the extremely rare serious ones.</p> <p>The prevention of HPV-driven cancers reflects the respect for beneficence as well as for evidence based medicine.</p> <p>Apparent paradigm shift from cure to care. Wenzeslawa shall not be vaccinated for the sake of performing the treatment immediately. She shall understand the personal and societal benefits of this decision and she may receive it in the future.</p> <p>Negotiation with the girl could be a useful tool.</p>
Socio-ethical conditions	<p>No concerns further socio-ethical concerns.</p> <p>The frame of justice has always been respected.</p>