

Ethics of developing autonomy in child healthcare

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Summary

The hypothesis of this dissertation is that respect for the children's developing autonomy in paediatric healthcare, especially with regards to national vaccination programs, may be expressed differently across Europe. Despite the differences, common ethical patterns and good practices may be identified and transferred across the region. Although the paediatrician's role may be decisive in addressing ethical dilemmas regarding the respect for developing autonomy in childhood, it is unclear if ethics teaching is adequately included in their resident curricula.

The thesis consists of two ethical conceptual chapters (Chapters 3 and 4) and two social sciences chapters (Chapters 2 and 5). Each of them reveals different challenges from the field of vaccination ethics, identifies and explores different levels of respect for the child's developing autonomy in paediatric healthcare and discusses them in a European and an international context.

Chapter 1 provides an introduction to the field of vaccination ethics and defines the research questions and hypothesis. Chapter 2 presents a systematic literature review and metasynthesis, regarding paediatric resident ethics curricula and depicts the current situation in the didactic of medical ethics among physicians specializing in child healthcare. It identifies recurrent teaching patterns, portrays common difficulties and summarizes solutions to address these difficulties

Chapter 3 focuses on the context of vaccination ethics. Utilizing a methodological approach currently proposed by the World Health Organization, this chapter examines and addresses ethical dilemmas regarding the provision of a prophylactic seasonal vaccine in childhood to reduce the burden of influenza-related morbidity. The Hippocratic ethos, several expressions of utilitarianism such as the harm principle, perspectives from liberty and autonomy, as well as justice and solidarity perspectives are analysed in this case. Finally, decisions regarding the ethically most suitable interventions with regards to seasonal influenza vaccination programs are drawn, using a modification of the intervention ladder, a tool to facilitate ethical decision-making, proposed by the Nuffield Council on Bioethics.

Next to the traditionally accepted and well-established forces of medical and parental paternalism, Chapter 3 focuses on the concept of the children's developing autonomy as a new emerging force in ethical discussions in child healthcare. Chapter 4, further, presents an extensive literature review in an attempt to clarify and address this emerging ethical pattern. It also introduces an ethical model including the triad of the child, as patient, the parents and the physician, interacting in a frame of justice and respecting the child's right to autonomy of choice, while acting for the child's medical good. A

tool that should facilitate ethical discussion among these three actors accompanies the proposed model.

The respect, or non-respect, to children's rights to autonomy of choice is differently expressed throughout Europe. Continuing the navigation in the field of vaccination ethics, Chapter 5 presents the findings of an exploration of differences regarding expressions or respect for children's developing autonomy throughout Europe, using the human papillomavirus (HPV) vaccination offer as indicator. A mixed methods approach was used, utilizing an expert survey within the frame of the "Models of Child Health Appraised" Project (MOCHA). The data analysis addresses the following themes: (i) provision of informed consent, (ii) parental and medical paternalism, (iii) relevance of the child's chronological age or maturity, and (iv) vaccination programs targeting boys. These themes are being handled differently across the region. Chapter 5 also explores associations of the implemented practices with the national HPV vaccine coverage rate across the European Union, discusses and identifies the most suitable ethical approaches to be transferred and implemented across Europe.

In Chapter 6, the Discussion of this dissertation, the general findings of this dissertation are discussed, with an emphasis on strengths and limitations. This should foster and guide future research, provide recommendations for policy and decision-makers in the field of vaccination ethics on a national, European and international level, and also provide helpful input for ethical discussion among and between physicians, ethicists, parents and, of course, the children as patients themselves. Furthermore, a Child's Rights-based approach, proposed by the American Academy of Pediatrics, is introduced as an alternative to discuss vaccination ethics in childhood and is compared with the "developing autonomy approach", introduced and implemented in Chapter 4. The similarity of the conclusions reached using the two approaches, confirms the validity of the "developing autonomy approach".