

Ethics of developing autonomy in child healthcare

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Valorisation Addendum

The aim of this addendum is to summarize ideas and suggestions for knowledge and value creation in practice, which can be generated from the presented thesis.

Indeed, three main ways of value creation deriving from the results of this thesis are suggested:

1. Solving didactic and administrative problems when teaching ethics to paediatricians

Teaching ethics in paediatric residents, underlining the emerging issue of developing autonomy, is a main appeal in this thesis. Results of the research of the thesis are relevant to address relevant recurrent problems in teaching ethics in evidence-based resident curricula.

Thus, time constraint, lack of resources, problems due to complex residential duties or maturation effect of the residency, lack of continuity of attendance or interest, scepticism could be effectively overcome using a thoroughly planned ethics curriculum, which shall be adequately supported and funded by the department direction. Indeed, inadequate quality or limited effect of previous ethics teaching experiences present a very important problem when dealing with clinical residents. This thesis summarizes relevant didactic barriers in teaching ethics to paediatric resident and provides medical teachers with potential solutions to address them.

2. Providing paediatricians and child healthcare professionals with a tool to address developing autonomy in their daily routine

This thesis introduced a novel ethical model to address dilemmas associated with the grade of respect, or lack of respect, for the children's developing autonomy, in a healthcare setting. Not many practical tools and models have been published towards this direction, with a main alternative the Children's Rights-Based approach presented by the American Academy of Pediatrics (AAP) (AAP, 2010). The tool presented in this thesis should function complementary to the approach of the AAP and could be actually more effective for the discussion of cases in which there is a lack of alignment in the decisions of children and their parents in a child healthcare setting.

The model has been presented in the Annual Meeting of the International Society for Social Pediatrics and Child Healthcare, 27-29 Sept. 2018, Bonn, Germany as well as in the annual conference of the project "Children's well-being and child-protection: An analysis of the normative principles of children's well-being", 4-6 Oct. 2016, Göttingen, Germany and received very positive feedback. The model has already been cited in peer-reviewed papers. Finally, the publication of this chapter in English and

Spanish language, in a bilingual, open-access journal, can further increase the impact of the presented model and tool. The tool is already in use in research among paediatricians and ethics master students in Latin America.

3. Identifying transferable health ethics practices related to vaccination strategies in Europe

It is obvious that the study of contextual factors is crucial for the transferability of good ethics practices in different settings. Harmonization of these practices within Europe will need changes of the procedures of healthcare practices, including vaccination programs. This thesis portrays ethical dilemmas regarding respect to the child's developing autonomy, emerging in different vaccine settings, including the initiation of a general seasonal influenza vaccine in early childhood, as well as the treatment with a vaccine preventing the transmission of sexually transmitted agents (HPV) in late childhood. Different methodologies have been implemented in order to reach conclusions that could function as ethical guidelines to facilitate harmonization of ethics practices in child healthcare services in Europe. Results of the research presented in this thesis are relevant for policy makers and other respective ethical actors, functioning nationally, regionally and internationally. The International Society for Social Pediatrics (ISSOP) has already been used as a platform to disseminate the findings of this thesis, while the association of parts of the thesis with the EU MOCHA Project (Models of Child Health Appraised) (Blair, 2017) can multiply the impact of these findings in identifying and implementing good ethics practices in Europe and internationally.

Offering a clear overview of the phenomenology of autonomy development in childhood and adolescence can provide a robust fundament to support an ethics-based interaction between children, parents and physicians and can also serve as relevant background for child ethics research. Indeed, the study group has currently initiated the implementation of an ethics approach in treating a German cohort of paediatric patients with cerebral palsy with botulinum toxin and has extended the research field including the assessment of decision-making competences, as suggested by Hein et al (Hein et al., 2019). This patient cohort includes children with congenital postural and movement disorders, who partially suffer from intellectual disability. The comparison of decision-making competences among patients with or without cognitive dysfunction may reveal relevant findings regarding different patterns of autonomy development in childhood and adolescence of these patients. The approach has been welcomed by the patients, their parents, as well as the acting physicians.

All in all, the paradigm change underlining the importance of respect to autonomy in paediatric patients, as well as the lack of education of the physicians to respond

to this emerging need, are the main underlying values and appeals this thesis brings forward. The thesis does not only identify the problems, but also provides solutions and approaches to address them successfully.

Finally, influenced by the spirit of this thesis, but also of similar literature referring to the role children may play in vaccination programs in times of a pandemic, a group of academicians, including the author of this thesis, prepared a policy brief with ethics recommendations for a potential Sars-CoV-2 vaccine, regarding the prioritization of health workers, children and vulnerable groups (Schröder-Bäck et al., 2020). The Policy Brief aimed at health policy advisors, public health institutions and health policy makers on different levels of governance within Germany and Europe. It has been submitted to the German Standing Committee on Vaccinations, the WHO Europe and the European Commission, receiving very positive feedback.

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