

Research Project

Invisible bodies. Narratives of intersex youth, their parents and physicians

Third-party funded project

Project title Invisible bodies. Narratives of intersex youth, their parents and physicians

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Intersex or Disorders of Sexual Development (DSD)* is an umbrella term for a series of congenital conditions in which the development of the chromosomal, gonadal or anatomical sex can be deemed atypical. Although it is not uncommon to be born with DSD, intersexuality is still relatively unknown among the general public. Until the 1990s, early normalizing hormone and surgical treatments for intersex infants were considered the norm. Near the turn of the 21st century, thanks to the efforts of advocacy groups, a major shift occurred in the approach to the care of patients with DSD. Under the new approach, established by the 2005 International Consensus Conference in Chicago, medically unnecessary interventions are deferred until the child is old enough to decide for him/herself and full disclosure to both parents and children is the norm. The recent growth of publications and national and international research projects on DSD highlights the positive impact of the Chicago meeting on the perception, evaluation, and awareness of this issue, both in the Swiss context and abroad. Still, this interest has mostly been confined to the medical perspective. When attention has been given outside the clinical setting, discussions have often been limited to the topic of early medical interventions. Such a narrow focus on surgical outcome ignores some of the more pressing everyday problems that people with DSD face. The magnitude of these challenges is often amplified for adolescents and young adults (AYA) for whom sexuality, intimacy and appearance are sensitive subjects. The project aims to provide insight into the lived experience of AYA (aged 13-29)** with DSD by conducting semi-structured interviews. Since AYA's experiences are influenced by that of their caregivers, the study will also explore the attitudes of parents and physicians. Interpretative phenomenological analysis (IPA) is chosen to analyze the empirical data as the aim of IPA is to understand how persons make sense of their life-experiences, keeping in mind the particular context of each singular case. The major aim of the project is to contribute to the development of professional guidelines to further improve the support to this group in a holistic and sensitive way.

Financed by

University of Basel

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Published results

4488817, De Clercq, Eva; Ruhe, Katharina, The Best Interest Standard: An Exhaustive Guide for Medical Decision Making in Pediatrics?, 1526-5161, The American journal of bioethics, JournalItem (Kommentare, Editorials, Rezensionen, Urteilsanmerk., etc. in einer wissensch. Zeitschr.

4514434, De Clercq, Eva; Streuli, Jürg, Special Parents for "Special" Children? The Narratives of Health Care Providers and Parents of Intersex Children, 2157-1740 ; 2157-1732, Narrative Inquiry in Bioethics, Publication: JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

4655824, Reber, Nina; De Clercq, Eva, Enduring uncertainties. Medical accounts on caring for young people with variations of sex characteristics, Dialogues in Health, Publication: JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

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