

## Is the transition possible?

### *A transição é possível?*

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The long-term survival and higher quality of life for children with severe congenital malformations is a novelty of the in the last 30 years. Some reconstruction techniques are quite recent: the magnifying cistoplastias started to be used in children in the 70s; the modern techniques of reconstruction of the anorectal malformations were proposed in the 80s; the life expectancy of patients with myelopathy increased from the second to the fourth decade since the 70s. The support treatment for severe diseases has improved greatly. Children with posterior urethral valves survive today without urinary diversion; children with hypoxic-ischemic encephalopathy reach adulthood thanks to the best physical therapy resources and nutritional and respiratory support.

The Children and Adolescent Statute (Law 8069/90) bequeathed the care of patients younger than 18 years of age to pediatric specialists, but there are problems. The logistics of caring for adolescents is not (or should not be) the the same one used in the treatment of infants and children before puberty. Problems related to privacy and autonomy need to be dealt immediately. In a children's ward separation by gender is unnecessary and common toilets for all patients are acceptable. In a teenage ward this care is essential for respecting the individual and preventing problems caused by the attraction between patients of different genders, who are emotionally and legally immature, or by the physical exposure during procedures, including the simple physical examination and daily dressings change. Issues related to autonomy and decision-making rights on conducts have a different approach in children (in which they have a more informative character, the legal responsible having the burden of decision) and older adolescents, who are able – and legally supported – to participate more effectively in the decision-making process.

Despite the law prescription, and from the managerial point of view, an undisputed control mechanism, it is difficult for a 16-year-old patient in full postpartum, breastfeeding her baby, to accept being admitted on a typical pediatric ward for a cholecystectomy; she will identify much more with the accompanying mothers than with the other patients. Or a 17-year-old lad, with STD due to promiscuous sexual activity, being treated at an urology clinic for pediatric patients amid prepubertal children who enjoy drawing and painting portraits of princesses and superheroes. I have lived both situations and it's hard not to admit the ethical, logistical and technical conflicts involving them. Without a

proper support structure, around 1/5 of care in quaternary specialized outpatient pediatric urology are for teens older than 14 years and adults (unpublished personal data), divided between patients in late follow-up (2/3) and initial visits, often involving typical adult diseases (STDs, varicoceles).

Another problem, this one related to the long survival of patients with malformations, relates to transition of their care to adult medical professionals, which has been called clinical transition in the recent, abundant literature. The technical training of professionals specialized in children's medicine is fragile in the specific approach of the health aspects at maturity. Obstetric problems, issues directly related to work, contraception and STD prevention, prostate diseases, routines of prevention and early detection of tumors typical of adulthood are among the ordinary themes in the practice of "adult" physicians, in which the pediatric professionals are usually not involved. On the other hand, professionals trained for adult care very rarely have full seasoning, sufficient experience and security to address the long-term sequelae or consequences of congenital diseases. For the proctologist receiving an adult with anorectal malformation, or for the urologist receiving a male survivor of a posterior urethral valve with stage-3 renal insufficiency and severe bladder dysfunction, these patients are a major problem and a source of stress and insecurity.

To complicate things further, acceptance of the transition to adult medicine is poor by the patient, who is much used to the treatment methodology and interaction with the same staff for 18 years, whilst considering the social and family complex relations of children with serious chronic diseases. These "former children" range from those early mature and capable of a huge degree of self-knowledge and cooperation, and those late immature and chained to a great deal of family overprotection, for whom the psycho-social approach can be very difficult, sometimes leading to high-risk behaviors, drug use and sexual promiscuity.

The literature has suggested models for the transition clinics in which the patient lives for a period, usually focused between 16 and 18 years, with professionals from both reference areas (child and adult medicine) at the same time. That way we can offer patients a smooth transition of the doctor-patient relationship, with the gradual development of trust and intimacy with the doctor who will clinically follow them during adulthood. Personnel

qualified in medical congenital diseases have the chance to build a relationship and a great cooperation with colleagues specialized in adults, with common projects and recognition of data of late clinical outcome of such patients. Doctors responsible for the treatment of adult patients have the chance to acquire ideal knowledge about specific congenital diseases and the consequences and technical nuances of pediatric reconstructive surgeries, and share an action plan to monitor patients in many cases throughout their lives and expectation of future complications (up to 1/5 of patients with posterior urethral valves progress to terminal kidney disease as young adults, fertility problems

and sexual inadequacy are common in men with bladder exstrophy, female patients after reconstruction of anorectal malformations frequently have serious gynecological and obstetrical problems, for example).

It is a very good idea. But can we build this admittedly complex structure in the Brazilian health system? At a time when the authorities focus more and more on basic health issues and support fewer initiatives related to highly complex care, it seems quite difficult. A pity, since around 3% of children have congenital malformations and, as a sign of success in modern pediatric surgery in Brazil, a large proportion of them survive to adulthood.