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W kręgu rodziny i szkoły
In the circle of family and school

Karolina Czerwiec
Uniwersytet Pedagogiczny w Krakowie
ORCID: 000-0002-3774-6901

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Positive Experiences of Parents of Intersex Child – Case Study

Pozytywne doświadczenia rodziców dziecka intepłciowego – studium przypadku

ABSTRACT: The objective of the research was to diagnose parents' experiences with treatment of an intersex child. Disorders of sex development (DSD) represent a wide scope of rare congenital disorders with diverse pathophysiology, which affect the development of chromosomal, gonadal or anatomical sex and which often require specialist help from the early childhood. The study was conducted by means of individual semi-structured interview. The results are presented as a case study. It was revealed that parents of intersex children need the support of doctors, psychologists, family as well as safe social environment. Parents who participated in the study had positive experiences in this regard.

KEYWORDS: intersex, parenting, disorders of sex determination, society, acceptance.

STRESZCZENIE: Celem badań było zdiagnozowanie doświadczeń rodziców związanych z leczeniem interseksualnego dziecka. Badania przeprowadzono techniką wywiadu indywidualnego częściowo ustrukturyzowanego. Wyniki zaprezentowano w formie studium przypadku. Wykazano, że rodzic w sytuacji posiadania interseksualnego dziecka potrzebuje wsparcia lekarzy, psychologów, rodziny, jak również bezpiecznej przestrzeni społecznej. Rodzice objęci badaniem mieli pozytywne doświadczenia w tym zakresie.

SŁOWA KLUCZOWE: interpłciowość, rodzicielstwo, zaburzenia determinacji płci, społeczeństwo, akceptacja.

Introduction

One of the determinants of personal identity is gender identity. It can be assumed that individuals are determined by their body and sexually marked – from cells to all physiology. The awareness of gender identity is, in turn, formed based on the awareness of one's own body with which one functions throughout life (both for themselves and for the world) and through which he or she expresses the self. Corporeality has impact on personal identity, the awareness of this identity and self-perception, what is also connected with different configurations of this corporeality, its typical characteristics and individual differences. This is the context in which gender identity emerges, as it is recognized later than corporeality, even though the body is sexually determined from conception. One can even say that it is others who grasp the aspects of the person's identity before he or she is able to recognize it, which means, for example, that parents become obliged to respect the identity of their children by choosing their names, clothes or teaching them certain behaviors (Grabowski & Sztramski 2014). Gender identity development is the result of a complex interaction between genes and environment. It is impossible to predict with complete confidence what gender any child will eventually come to identify with (Consortium on the Management of Disorders of Sex Development, 2006).

Answering the question whether a child is a boy or a girl seems easy but sometimes, after birth, there may be clear clinical uncertainty regarding this. Uncertainty can be disturbing: uncertainty regarding the reliability of symptoms, diagnose accuracy or evidence supporting the necessity of certain intervention on the newborn genitalia (Karkazis, 2008). Intersex conditions (IC), disorders of sex development (DSD) are biological variations which cause difficulties in determining whether a person is male or female at birth (Lenhart, 2015). Birth of a child with an intersex condition is almost always unexpected. About one in 1,500 children is born with atypical genital or reproductive anatomy that raises the question about cosmetic „correction". As is the case when any child is born with unforeseen condition, health professionals and parents are often ill-prepared to deal with psychological consequences (Leidolf et al., 2008).

Intersexuality is a problem for those whose bodies are labeled this way, however, not because of inherent "difficulties" with biological or anatomical manifestations of intersexuality (Holmes, 2008). If an intersex newborn is considered uncanny, freakish, mythic or monstrous, it often leads to what some call "sexually mutilating' genital surgeries (Harper, 2007). A newborn with atypical genitalia presents a challenging clinical scenario and requires expert input. There has been a significant progress in knowledge about the underlying causes which may lead to mere differences or more serious disorders of sex development, descriptions of history of certain conditions and short- and long-term complications together with the clinical interventions. Thanks to this information, experts in interdisciplinary teams should be able to support the family of the intersex children and individualize the management plan so that it considers the shifts in social attitudes and expectations regarding the concepts of diversity and openness. Thus, it is likely that gender assignment practice, especially in cases where sex assignment is unclear for the experts, will continue show temporal, social and geographical differences (Markosyan & Ahmed, 2017). In the context of the above, the goal of the study presented herein is: to diagnose the experiences of parents regarding the treatment of their intersex child.

Theoretical Background

There are individuals who are biologically „intersex', which means their sexual anatomy is ambiguous, usually due to genetic abnormalities. Their biological gender is hard to determine even for a long time after birth (Colapinto, 2000; Reiner & Gearhart, 2004; Mayer & McHugh, 2016). The term *intersex* evokes various images, usually of people who are both male and female, neither male nor female. None of these visions is accurate. Millions of intersex individuals are males or females whose sex chromosomes, gonads or sexual anatomy do not fit clearly into the binary male/female norm. Some intersex conditions involve inconsistency between internal and external sexual characteristics. For example, some persons with IC may have female-like external genitalia and testes but they not have internal female sex organs. Other intersex individuals may be born with genitals which seem neither male nor female. Some persons with IC may also have chromosomal pattern which does not meet XX/XY norm. Most experts agree that about 1–2% of people are born with sexual characteristics that differ from the medically defined male and female norms (Greenberg, 2012; Preves, 2003).

Medicine is only part of the culture. It surely serves the society by "fixing' intersex persons but it cannot be solely responsible for the representations of intersex persons as deviant. Intersex individuals are usually constructed as "exotic", "other" or "monsters". These representations are meant to restore the borders between the norm (normal, heterosexual male and female body) and abnormal bodies (intersex persons' bodies) (Holmes, 2008). As a heteronormative society that uses science to create differentiation in bodies to reinforce heterosexual behavior, other variations or ambiguities in sex are overlooked, ignored, or "corrected" when noticed, in order to fit into the accepted male-or-female binary (Lee Schofield, 2013). Gender identity development is the result of a complex interaction between genes and environment. It is impossible to predict with complete confidence what gender any child will eventually come to identify with. Like all other children, children with DSD are given an initial gender assignment as boys or girls. But team members should be aware — and advise parents in relevant instance — that children with certain DSD are more likely than the general population to feel that the gender assignment given to them at birth was incorrect. The role of health care professionals in initial gender assignment is to interpret test results concerning the etiology and prognosis of the intersex child and concerning the status of the child's anatomy and physiology (e.g., hormone production, hormone receptors, gross anatomy), so as to inform the parents' decision about gender assignment. Thus, initial gender assignment (boy or girl) is made by the parents after the parents have been fully informed about the results of tests and what is known about gender identity development in patients with similar conditions (Consortium on the Management of Disorders of Sex Development, 2006). Even though both, parents and clinicians often resort to surgical interventions in order to eliminate atypical sexual characteristics, believing that such procedure will help the child to adapt and mitigate the stress of the parents, it has been noticed that there is no evidence supporting this belief. Therefore, it is important to investigate the grounds of doctor's recommendations and parents' values as this may help with considering advantages and disadvantages of different treatments. These values may include protection of the child from being ashamed or stigmatized, avoiding unnecessary interventions, leaving decision about surgical intervention for the future, ensuring the best possible physical and psychological health, supporting the development of healthy sexual and gender identity of the child, preserving the child's fertility (Karkazis, 2008; Karkazis & Rossi, 2010; Karkazis et al., 2010). More recent studies show that cosmetic (rather than life-saving) genital surgery in infancy is frequently not wholly wholly successful and the secrecy of many such diagnoses has been described as damaging and destructive for sexual and erotic life of intersex persons as well as their emotional health (Harper, 2007). In 1950s, plastic surgery to „normalize' infant bodies has become the standard of care when an intersex child is born. Many adults who were operated as infants, have begun to complain that these surgeries had caused them tremendous, long-term physical and emotional pain. Despite new standards of care proposed in the medical circles, the practice of normalizing surgeries was continued, partially due to demands of the parents. The birth of an intersex child is a source of great stress and anxiety for parents and doctors. Surgery is seen as quick-fix which provides immediate relief. But there are no data which would support normalizing treatments as a proven therapy leading to a long-term satisfaction of the child. These irreversible surgeries result in heavy scarring, loss of sensitivity and are a great source of shame. In addition, the initial surgery usually requires several other surgical interventions during the person's life. The mechanisms that drive these surgeries are parents' anxiety and social intolerance for ambiguity (Lenhart, 2015). Rationales for surgical intervention include the risk of cancer. However, there is evidence that issues such as sex of rearing are interpolated into decision making processes and, undermining their neutrality. Risk assessments are variable, subjective and based on small sample sizes and the repetition of outdated data. It is unclear whether or not widespread early surgical interventions have undermined the ability to perform accurate risk assessments associated with ageing (GATE, 2015).

At present, intersex patients and their families have insufficient access to psychosocial care. Study by Bennecke et al. (2015) showed that only half of parents of children with DSD, who need emotional support received psychological assistance they evaluated as adequate. It is disturbing because it can be stated that the main challenges faced by the parents are information and psychosocial rather than medical or surgical. Families struggle with many challenges beyond understanding complicated medical and genetic information, including fear of stigmatization, coping with anatomical differences (whether or not the surgery has occurred), post-surgical complications, lack of clarity regarding the gonadal tumor risk, uncertainty regarding the stability of the child's gender identity, potential infertility as well as disruptions and burdens connected with numerous medical visits. Detection of intersexuality at birth is usually the time of severe suffering; parents report high level of emotional distress and cognitive confusion which often occurs concomitant with medical and surgical decision-making (Ernst et al., 2018; Feder, 2014).

Research methodology

The paper presents a subset of data, a part of a bigger research project which focuses on intersex children and adults, parents of intersex and transsexual youth and social attitudes towards intersexuality and transsexuality.

Based on the suggestions by Creswell (2014), it was decided that qualitative study is the most adequate method to investigate and understand meanings that constitute one of the social problems. Using this method, experiences of parents of intersex children were described and analyzed (phenomenological study). Qualitative study is effective in case of phenomena which have not been investigated much and when the sample consists of 3 to 10 respondents, what is typical for phenomenological research. Such approach allows to obtain rich descriptions from the sample, explores the importance of experience and does not define the phenomenon but rather allows the respondents to define it, making them experts in their own experiences while the researcher learns from them. The data obtained cannot be generalized but they help to understand the importance and the nature of the studied phenomenon.

A semi-structured guide to interviews was used, with open-ended questions to allow the respondents describe their experiences freely. Once the interviews had been conducted, significant statements were noted and classified as coded. Then, the data was grouped into categories. Data analysis was made based on the following experience categories: identification with own gender, safety and relationships, difficulties in school (including preparation of teachers to interact with intersex student), health care, professional career of the parents.

The project involved the analysis of experiences of parents with treatment of their intersex children, seeking support and social relationships. The sample consisted of the parents of eight intersex children. Each family was the so called complete family Four families lived in Poland, two in the United States and two in the United Kingdom. All respondents were Poles. During the interviews, they were informed about the goals of the project. This paper presents a case study of parents of an 9-year old child with DSD, who have positive experiences regarding the child's treatment. The family has been living in London for 5 years, the mother is an economy graduate and at present, stays home with the children, the father works in a logistic company. They have 3 children: 9-year old intersex boy and 3-month old twins (boy and girl).

All participants of the research gave their written consent to participate in the research and to publish the research results. The research results and conclusions from the research were consulted with them.

Results

Gender identification

Experiences of the parents show that choosing what gender should they raise their child with is very difficult if the biological sex is not clear.

The mother recalled when she first faced the problem of intersexuality of her child:

> *Right after our child was born, the doctors told us that we would get more information about the gender once they do more tests. Waiting for the results was hard but they tried to inform us about the progress every day. After 6 days, we were told that our child has a rare condition – is intersex. We were told that diagnosing their gender will take several months and only then the decision about the sex of rearing will be possible. Since then, every day we learn more about intersexuality.*

Decision cannot guarantee that during puberty the child will not begin to identify with the sex opposite to that which was assigned by doctors and parents. The parents are still afraid that they have made wrong decision about the child's gender, though their 9-year old son's behaviors are typical for male sex. According to the parents, the most important fact in this context is that

> *gender identity expressed by the child should be treated with respect because it is a great struggle for the person who feels a boy to be treated as a girl, and the opposite.*

The child is aware of their condition. The boy understands that his internal organs look somewhat atypical and that in a while he will likely have to have a surgery to remove the vestigial female reproductive organs from his abdominal cavity, which are found together with properly grown male organs.

The parents did not encounter any difficulties as they were looking for help for their child. However, they are aware that they were very lucky as they read the stories of other parents of intersex children in the Internet, which are not that optimistic.

Safety and relationships

The parents emphasized their strong bonds with their family and closest friends, which helped them to survive the worst — the time of waiting for the diagnosis. Their loved ones provided them with a great support. Family and friends asked them many questions and gave them many advices and this motivated the parents to search for information about intersexuality every day.

They also began to search for support in the Internet. First of all, they were looking for information about what is intersexualism, what are the types and how to treat it. They also browsed for information about the life of intersex children, their functioning in the the society and among peers. Most websites dedicated to these issues as well as blogs and online forums published by intersex persons were in English.

Thanks to the doctors who treated their child, they were able to contact parents of intersex children in Poland. Meeting with two other couples helped them to calm the negative emotions and thoughts about the future of their child.

Already outside Poland, the parents found support from a social worker who became their family gender therapist. They point out that it was not necessary but the awareness that there is someone to whom they can turn to anytime, helped them feel safe.

The respondents clearly stated that parents who raise an intersex child have a great need for psycho-social support. What has helped them to survive the most difficult moments was mutual support. They both emphasized that it would have been very hard if, for some reason, the other parent was absent.

Difficulties in school (including preparation of teachers to interact with intersex student)

The parents said that their child had began education in Poland. At the age of 3 he began attending pre-school. The kindergarten teacher and psychologist knew about the child's situation and cooperated willingly with the parents, observing the child in terms of its gender-related behaviors. For both the teacher and the psychologist it was a first encounter with an intersex child. At first, they did not know what intersexuality is about but they were ready to take part in a series of meetings with the parents who explained the key issues regarding the condition of their child.

The child functioned as a boy since the beginning. He got engaged in behaviors culturally understood as typical for boys. It is so until now.

At present the boy goes to primary school in London. Nobody knows about his intersexuality because his parents, psychologist, social worker and practitioner decide that there is no need to inform the teachers about the child's history. The child develops male identity and has no problems with classifying himself as male.

Health care

The parents decided that, as they look back, one of the most important thing was the fact that doctors had always talked to them openly and honestly about their child's condition. Also, they had never said that the situation is easy. It turned out to be very helpful as they were dealing with it.

It was crucial that the doctors had never forced the parents to agree on quick genital surgery in order to normalize their child. They emphasized that

> *from the health perspective, there was no such need so the doctors informed us that we should wait with the decision until our child will be aware enough to take part in the decision making process.*

Once they had made all the tests, the doctors concluded that the child will most likely develop male gender identity and the parents can register the child with a male name and gender.

For 8 years, the child has been under the regular care of specialist. He only has regular check-up as from the medical and biological point of view, he does not show any pathological changes. In few years the boy will undergo a surgery to remove the vestigial ovaries which may be vulnerable to cancer in the future.

The child does not visit psychologist because he is aware of his condition and fully accepts the situation. The parents, in turn, are in regular contact with a psychologist who will be available for the boy when necessary.

Professional career

Since the birth and the diagnosis, the parents focused on searching for help for the boy. In the first year of his life the mother was on maternity leave and the father often took sick leave of days off work to take part in numerous doctor's appointments. Thanks to early diagnosis and determination of treatment, the father could go back to the normal mode of work quite soon. Two years later, the mother went ack to work and the boy could begin to attend a kindergarten. At present, the mother is on maternity leave and takes care of the 3-month old twins.

Society

The parents pointed out that it is extremely important to talk to people and teach them about that what they do not know. Their closest friends did not know what intersex is about and asked very surprising questions about the child's sexuality, which initially seemed rude. But the parents explained what it means to be intersex and what it means for the child's functioning. It turned out to be the best solution as it changed the way of thinking of those who lacked awareness in this regard. The parents declared:

> *Contacts with others were never a struggle. We know we were very lucky. We helped our loved ones to understand what is intersexuality and then they took their own initiatives to learn more. So, at first we supported them and then, they supported us. Parents of intersex children need support. It is also important that social reactions were not hostile, that the environment does not blame parents for the child's condition.*

Conclusions

Once they get the diagnosis, parents of children with DSD seek support in very different ways. But they all need support. In the case presented herein, the parents received help from many different sources – from doctors, psychologists, social workers, family, friends and Internet as a source of information and answers to many ethical questions.

Educating parents is surely one of the priorities which should be implemented during treatment of an intersex child. It is extremely important that parents are aware of their responsibility to create a safe space for their children. It means, among others, that the child and its intersex condition is fully accepted and involves the awareness that his or her gender identity may turn out to be different than initially assigned. Therefore, social atmosphere and attitudes play important role in facilitating or hindering implementation of these principles. The sense of support and trust empower parents to fight for the health of their intersex child.

All participants of the research gave their written consent to participate in the research and to publish the research results. The research results and conclusions from the research were consulted with them.

There is no conflict of interests.

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