



Karolina Czerwiec*

Pedagogical University of Cracow

Intersex child's parents' negative experiences – case study

KEYWORDS

intersex, parenting, disorders of sex determination, society, social pressure

ABSTRACT

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Intersexualism is often treated as a secret in medical and family systems. According to the thesis that intersex body is pathological and requires immediate surgical and hormonal regulation, intersex persons are subject to the process which involves rapid production of normative masculinity or femininity through invasive clinical practices. The goal of the study was to diagnose the experiences of parents of an intersex child with searching for support during the treatment for both the child and themselves. The study was conducted by means of individual semi-structured interview. The results are presented as a case study. It was shown that parents do not always receive the necessary social and medical support, and their children are treated as sensations and pathologies, regardless of the fact that empathy and acceptance are critical for making the right treatment-related decisions.

Introduction

Human relations are fundamental when it comes to developing individual identity, self-confidence, self-respect, self-actualization and self-esteem. These aspects of practical attitude towards the self are considered the ontogenetic developmental

* ORCID: <https://orcid.org/0000-0002-3774-6901>.

stages on the path to a good life. The sense of self-worth and emotional safety can be achieved if a person feels that he or she is seen as an important contributor to the development of the society and their individual abilities are valued (Sørli, 2016). Barring ambiguity at birth, parents and caregivers seamlessly begin the socialization process that molds their child's behavior to coincide with the child's prescribed gender role, that is, the set of actions or mannerisms that are considered culturally appropriate for a person of a certain gender in a certain time and place. Unfortunately, this process is not without obstacles such as misogyny or heteronormativity. However, contrary to popular belief, the possession of a vagina or a penis does not determine gendered behavior, as there is no behavior that occurs only in one gender without exception (Lee Schofield, 2013). When sexual development is atypical during fetal development, the child often has atypical genitalia in the neonatal period. This may lead to disorders of sex development (DSD; intersexuality [Markosyan and Ahmed, 2017]).

About 1:2000 cases are children born with reproductive organs so atypical that they have to be consulted with a gender differentiation specialist and surgical interventions are considered (Greenberg, 2012). The existence of people with intersex conditions, whose bodies combine the aspects of male and female anatomy, proves unequivocally that we should take up the challenge and undermine traditional concepts of gender (which suggests that traditional concepts of normative gender should be challenged). Until recently, intersex conditions were shrouded in shame and secrecy; many adults were unaware that they had been born with an intersex condition and those who did know were advised to hide the truth. Current medical protocols and societal treatment of intersexual people are often based on false stereotypes about gender (Greenberg, 2012). Parents grieve the loss of their anticipated "normal" child and try to make informed decisions regarding the treatment. In addition, as an intersex child matures, he or she may experience permanent stress regardless of their health condition and sex of rearing. Confusion regarding gender roles and interventions can be overwhelming. It results, among others, in surgeries at a young age, surgery without informed consent and lack of disclosure from parents and health care professionals who keep diagnoses and details of treatment secret (Leidolf et al., 2008). Respecting the above, the goal of the study was to identify the experiences of parents of an intersex child with searching for support during the treatment for both the child and themselves, as well as to identify and categorize the experiences of the parents of an intersex child throughout their child's life, and highlight the challenges that they faced along the way.

Theoretical background

As soon as an intersex condition – the possession of physical sex markers (genitals, gonads or chromosomes) which are neither female nor male – is suspected and diagnosed, social institutions are mobilized to sustain the two, seemingly objective, sexual categories. Bodies of newborns are modified and what was “ambiguous” becomes “normal”. Child surgeons and endocrinologists often emphasize that parents want to normalize the child’s intersex state at a push; additionally, the way intersexuality is managed by medical professionals and psychologists reveals deep beliefs about gender and genitals established in our culture. Even though doctors teach parents how to think about the condition of their children, not all are ready to accept atypical reproductive organs. It may result from the wrong approach of physicians what, in turn, brings the necessity to adopt a new approach to physicians to be used in talking with parents and children (Kessler, 1998; Mayer & McHugh, 2016).

According to Harper (2007), about 25% of newborns with intersex conditions have visibly ambiguous genitals. Since 1950s, many of those infants born in the Western medical culture have been subjected to early genital surgery, often reinforced by hormone treatment. Surgeries include: removal of clitoral tissue considered overlarge; reconfiguration of penises with “openings” other than at their tip; removal of ovarian or testicular tissue diagnosed as inappropriate to the sex assigned etc. These procedures may sound like reassuring correction of errors but they entail numerous problems. Medical convention developed, for example, guidelines on non-disclosure of details about the conditions and treatment of intersex patients during puberty. Some intersex persons discover only in adulthood that they are intersex, that they underwent surgical intervention as infants, that their sex was determined surgically and that there might have been other treatment options which are no longer available to them as adults. Their bodies become uncanny signifiers, at one familiar and unfamiliar. A considerable number of adult intersex individuals express their rage and despair as they had not consented to be deprived of erotic experiences and self-determination (Harper, 2007). As reported by Harper (2007), respondents described the feeling as if they had been mutilated, resulting in a sense of anger because of the procedures they had been subjected to in their childhood. They were mutilated undergoing a normalizing operation as children; and it took them a lot of time to contain and control their anger because of the procedures they had been subjected to in their childhood (Harper, 2007).

Karkazis and Rossi (2010) claim that gender assignment must consider the diagnosis, hormonal functioning, the condition of internal and external sex organs, potential for fertility as well as psychosocial and cultural factors. Parents should know all the available evidence regarding the likelihood of a given gender identity of the child in the light of the diagnosis. For more complicated cases, parents may want to consult a specialist in gender identity development for intersex patients. Timing, necessity, benefits and risk associated with the planned genital surgeries of intersex children are intensively discussed. There is no doubt that surgeries to save the newborn's life are necessary, for example creation of a urinary opening. Although parents and clinicians may wish to attend to genital atypicality as quickly as possible once the child has been assigned a gender (and surgical possibilities may inform gender assignment decisions), gender assignment is a social and legal process that may proceed irrespectively of medical or surgical intervention. Decisions about genitoplasty are challenging due to lack of clinical evidence regarding their long-term psychological and physical outcomes (Karkazis & Rossi, 2010; Karkazis et al., 2010).

The birth of a child with ambiguous genitals unfortunately causes an unjustified crisis in society and unnecessarily causes discomfort to some people. But it also raises the question about the role of medicine in solving the issues which are more socially than medically urgent (Feder, 2014). Healthcare professionals have been debating as to what extent full disclosure during intersex treatment may help or disturb psychical well-being of the intersex person and whether resignation from surgical intervention is generally less harmful than the surgery (Alderson et al., 2004). Throughout the provision of services to the family, it is critical that the team is supportive of atypical anatomy and behavior in intersexual children, and that they model this acceptance for family members. Flexibility is the key to making patients and parents feel valued and accepted; i.e., it is the key to reducing a sense of stigma. Parents should not be blamed when children express behavior atypical for their gender assignment. They should be supported in recognizing that each child is unique and lovable in their own right (Consortium on the Management of Disorders of Sex Development, 2006).

Normalization surgery offers the promise to relieve the discomfort of parents of the child whose body does not conform to the cultural standards of binary gender. But, according to Cornwall (2012), most parents are motivated by love to their children, and fear as they decide about the medical care, especially in relation to intersex area. They are perfectly aware that their children will have to function in the society in a way that may not be welcomed (Cornwall, 2012; Tamar-Mattis, 2006). Intersexual persons still struggle with medicalization, secrets and general

lack of awareness of their condition. Parents of intersex children are usually responsible for the decision whether the child will undergo surgery and what information about the treatment he or she will receive. However, medical environment is not free from cultural biases (Lane, 2018). For all these groups, the problem with intersex persons is definitely a social issue but the problems with the social system affect mainly infants and intersexual children. Intersexuality is a problem because intersex persons have little hope that medical environment will see their bodies as expressions of difference. Instead, intersexual adults are often presented as freakish crises or medical emergencies – often with the only intention to correct them surgically as an evidence of the wonders of medicine, examples of sexual dimorphism and the correctness of the “heterosexual matrix” (Holmes, 2008). In this process, the absolute secret is the key factor for the success of normalization – the “secret” of intersex bodies becomes not only an active factor in the normalization of sex (Meoded-Danon & Yanay, 2016). The secret and stigma surrounding intersex conditions preserve the perception of monstrosity, suggesting intersexual persons that their “defect” is so monstrous that it should be removed (Harper, 2007). However, intersexuality should not be considered mutation or anomaly (Brossi et al., 2012).

Materials and methods

The research was carried out within two paradigms – essentialism and constructivism, due to the fact that within these two paradigms there were transformations in the perception of femininity and masculinity, and gender identity. Biological essentialism refers to gender identity as an innate construct, and social constructivism assumes that culture has a huge impact on shaping human identity.

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 the 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 a 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.

The research used the non-probability sampling of research participants. Non-probability sampling was used due to the fact that the objective was to create a close representative sample and the respondents were selected on the basis of an arbitrary decision of the researchers. The features characteristic of a specific social category, namely features characteristic of persons of the same specific group, were important here. Additionally, the researcher had adequate knowledge of the study population (Babbie, 2012; Babbie, 2016; Kothari, 2009). The deliberate selection of study participants was used by searching the websites of intersexualism and internet forums about it, as well as using snowball sampling – a method of non-random sampling consisting of recruiting participants by other participants (Castillo, 2009). Respondents received a link with the interview questionnaire via the e-mail. Interviews conducted using social media, such as Messenger, as well as phone call.

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. All interviews included discussion and informed consent of the participants, and respondents were informed about how the information they shared would be used in publications.

The paper presents the results of the study – an interview with the parents of a 10-year old intersex child, a boy whose sex was determined as female right after birth and who underwent feminizing surgery. The family have been living in London for 20 years, the mother is a stylist, the father works in a bank. They have 3 children: 10-year old intersexual boy and 14-year old boy and 11-year old girl. The parents have negative experiences with treatment of their intersex child.

The qualitative research was conducted in a specific context, both spatial and temporal, which means that these findings cannot be generalized, but are intended to provide in-depth knowledge about the experiences of specific respondents

struggling with problems in the field of broadly understood health problems of their child. The article deliberately decided to present a case study of only one family in order to describe comprehensively these unique experiences and describe their individuality. The interview comprised several thematic categories: identification with one's own gender, security and relationships, educational implications, health care, parents' professional implications, and society. It was recognized that the functioning of a family with an intersex child is multidimensional and in each of these situations, parents encounter difficulties. It is not possible to refer only to the sphere of interpersonal or educational relations without reference to other aspects of life. It was concluded that the case study of a specific family should reflect all those spheres in which the family encountered problems.

It should be noted that this case study is not a representative sample of parents all over Poland or all parents with intersex children. Consequently, their stories do not reflect the experiences of all families who struggled with their children's intersexuality. However, there are some generalizations that can be made about this particular sample related to this research project. In this article, the case study is understood as the research approach that Gerring (2006) states is most preferably defined as the intensive study of an individual or a small number of units (cases) in order to understand a larger class of similar units (case population); in addition, in many cases in-depth knowledge of a single case may be the key to a deeper understanding of the whole, although limited generalizability of the course also exists.

Figure 1 presents the research procedure.

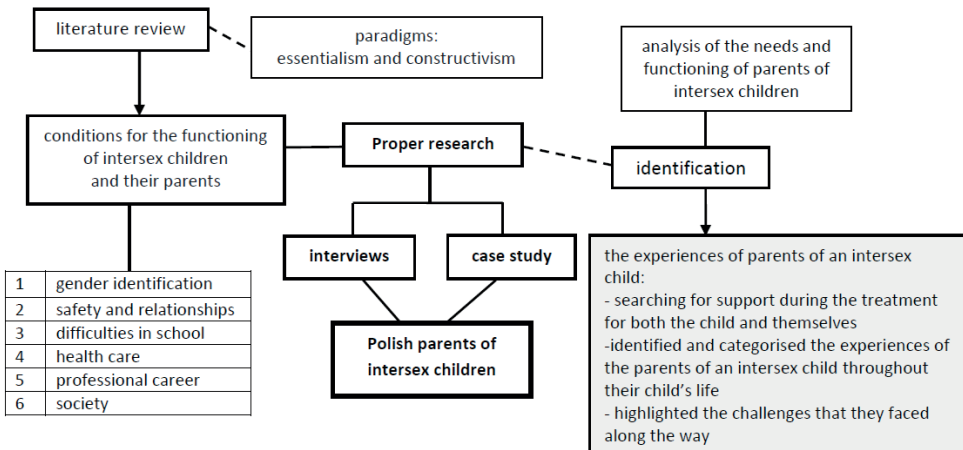


Figure 1. Research procedure

Source: Authors conception.

Results

Gender identification

The parents emphasized that their child was born with some variation, however not as rare as it might have seemed. The doctors made series of tests and concluded that the child will most likely be a girl rather than boy. The parents recalled:

We were aware that no test gives one hundred certainty about the child's gender and what gender he or she will show in a few years. But the doctors clearly persuaded us to make surgery to correct the external sex organs towards female.

The parents had agreed to the surgery but very soon regretted their decision because not much later the child began to show clear signs of male identity.

The parents' feelings are surely the key determinant during gender assignment. The parents were aware that they were responsible for their child's future and comfort, also in terms of functioning in the child's gender identity (right gender). They knew that they were the active participants in the development of the child's gender identity. Therefore, they quickly began to search for help to enable their child function as a male.

At present, the boy is 10 and functions as a male in every aspect of life. His parents and siblings also treat him as if he has been always a boy. For more than 5 years, they have been looking for ways to physically restore his male sex anatomy.

Safety and relationships

Apart from individual learning and searching for resources and support groups, the parents found some help online. They found other parents with whom they could talk via the Internet about their experiences and who gave them some advice and guidance. The parents said:

Online support groups were a salvation for us. They were the only support in the most difficult period. It was a great mental and social support. The only one we had when it comes to external institutions.

Other children also turned out to be a support for the parents. The siblings of the intersex child were very supportive. The parents emphasized:

our children addressed our son the way he wanted – both in terms of his name and pronouns. For them, it was not a problem at all.

It happened when the boy was 5 and declared that he was a boy. The other children were 11 and 14 at that time.

For the family members the whole situation was a source of great shame and it was decided that it should remain secret forever. The parents said that family members did not accept their child, which caused a great discomfort and the sense of having no support.

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

At the age of 2–3 the child was attending kindergarten as a girl. Other children in the group and the teachers knew him as female. When the process of reassigning the child to his proper gender began, the parents decided to withdraw him from the kindergarten. At the age of 5, the child returned to the same kindergarten but as a boy. He was placed in a different group and other children naturally treated him as their male friend. But the problem was with the group teacher and other staff members who remembered the child as a girl. At first, they could not understand the reasons for this change and the parents had to spend a lot of time to help them understand what intersexuality is about and how they should treat the boy. The parents said that

the teachers accepted the fact that the child who they used to know had functioned with a wrong gender and that, despite of what they were used to, they should treat him as a boy. They tried hard but sometimes they happened to accidentally address our son using female pronouns.

It was a difficult situation for the parents but it was encouraging that neither their son nor his kindergarten friends paid any attention to the teachers' mistakes.

At present, the child goes to primary school as a boy. None of his teachers and friends knows about his difficult past.

Health care

Right after the child was born, the parents worked with a team of professionals – psychiatrists, pediatricians, surgeons, endocrinologists, urologists, therapists and psychologists. Very soon, the experts concluded that immediate feminizing surgery is necessary. The external genitalia of the child were ambiguous whereas the internal included ovaries and all male sex organs. The surgery was performed quickly; the parents were almost forced to sign the proper documents. The parents said:

A big group of people often gathered in the hospital room. Doctors, nurses, medical students. Everyone talked about our child as a problem and a sensation. The doctors showed the students weird sex organs and explained that they had the opportunity to see what tricks biology can play to a human body. We kept hearing that our child had a defect and needed to be fixed as soon as possible.

Two years later, it turned out that the doctors did not perform genetic tests. Seeing that their 3-year old behaves like a typical boy, the parents decided to make, at their own expense, a series of specialist tests which showed that the child is genetically a boy, his proportion of sex hormones is typical for boys and the vestigial ovaries must be removed as soon as possible as they are highly carcinogenic.

The boy needed support so the parents provided psychological help for him. But it turned out that the psychologist was not a specialist in this field and tried to convince the child by any means that he is a girl. Parents' explanations that the child had been assigned the wrong gender were futile. After two visits the parents resigned from the psychologist but it was enough for the boy to start to withdraw. Only the next psychologist took care of the child so well that he soon reached the state he is in now – he functions as a boy and is happy with who he is.

Professional career

After the birth, the mother gave up her job to be able to take care of the child and his siblings. For financial reasons and the rules in his workplace, the father could not even switch to part-time job but he was on holiday or sick leave whenever it was necessary. The situation changed when the child was 3 years old, when it turned out that the past genital surgery was a mistake and then the child began to demonstrate clear male identity. The father set up his own business and hired few employees to be able to spend time with his family. This situation lasted for about 2 years during which the parents intensively searched for help for their child. When the situation stabilized, both parents returned to full-time jobs. At present, the child's condition and his treatment do not require from the parents to give up their professional career.

Society

The parents decided to educate everyone who is not aware, what intersexuality is about, what is some sort of protection for their child. It was important for them because many of their friends who seemed to be rational people, broke off contacts with them when their son was born. Thus, the parents decided that they had to

create the most possible safe environment for the child, both in his closest environment, at school and in the wider community. They declare that for them, the most important is to

help people understand what intersex is about. People are often intolerant because they do not have proper knowledge. They would rather attack the unknown and do not try to understand it. It is important not to get discouraged when one hears an unfavorable comment. One needs to remember all the time that these people are not educated in this area.

The parents met with critical comments about their child's condition – words like pathology or deviation often occurred. At first, it was difficult for them because they thought about their child's intersexuality only in terms of a disease, something that will prevent their child from normal functioning in the future. Later, they understood that many misunderstandings result from the lack of awareness. They also emphasized the importance of the support from parents of other intersex children and they regretted they could not rely on such support from their family, doctors, friends or their closest environment. The only support they got was through online contacts with other parents who shared similar experiences.

Conclusions and summary

Empathy and understanding are crucial when it comes to supporting parents of intersexual children. Acceptance and tolerance of that what is different, is the key. When they are lacking, it is mainly due to social ignorance (for example, the behavior of kindergarten staff when the child returned to kindergarten after treatment), lack of basic education regarding sex determination (for example, the way of treating a child and the approach of medical staff to the child's intersexuality; or family members and their sense of shame caused by an intersexual child in the family), social indifference towards expanding this knowledge (for example, the lack of competence of the psychologist who was to help the child; or parents' experiences with people who openly refuse to listen about intersexuality), blaming the parents of intersex children for the situation (for example, friends broke off contacts with parents when their son was born). This attitude still functions in the social discourse. It is necessary to support the children and their parents actively, showing acceptance and educating that intersexuality does not equal crisis and

tragedy. The support from the closest family and friends is crucial, however, they often turn their back to the parents in this difficult situation.

Representatives of different social groups, including health care professionals and psychologists still treat intersex children as a sensation. The parents whose history is presented herein, experienced many unpleasant situations in the hospitals – places where they should have felt the safest. The unnecessary genital surgery was the situation through which they lost their trust to the doctors completely. Medical experts and psychologists should adopt the affirmative attitude and help the parents by giving them advice and showing interest, as well as by emphasizing moral and ethical values. Constructive feedback is of extreme importance.

It must be remembered that genital mutilation is irreversible. For this reason, individuals should have the right to decide about their bodies. Even more so, as parents very often make such decisions unaware and led by emotions. This may result in situations that damage family relationships, which sometimes never gets restored.

It should also be clearly emphasized that the problems of families with intersexual children are not related only to the accuracy of medical diagnoses, but also – and perhaps above all – to medical treatment, surgical interventions, the lack of social knowledge about intersexuality and misconceptions about it. This is also consistent with the Consortium on the Management of Disorders of Sex Development (2006) claiming that parents should not be blamed when children express behavior atypical for their gender assignment.

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