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Experiences of parents of an intersex child – A case study[**]

Summary

Intersexuality represents a wide range 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 issue of intersexuality is rarely discussed outside the clinical environment. Meanwhile, the social situation of intersex people is often particularly difficult, which is largely due to ignorance and social unawareness about human biodiversity. Therefore, a pedagogical approach to these issues, taking into account the experiences of parents of intersex children, seems to be a necessity. The research aimed to identify and reconstruct parents' experiences regarding the treatment of their intersex child. The study used the interpretative paradigm and the case study method, and it focused on the individual, future-oriented action and understanding of social interpretations. The findings show that parents of intersex children need the support of doctors, psychologists, family as well as safe social environment.

Keywords: intersex, parenting, sex determination, society, acceptance

Introduction

Gender identity is one of the determinants of personal identity. People are determined from cells to all physiology by their own bodies and sexually, sex and gender. The awareness of gender identity is, in turn, is formed by awareness of their

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own bodies which are one of the most important elements of their life functions (both for themselves and for the world) and through which they express themselves individually. Corporeality, different configurations of this corporeality, its typical characteristics as well as individual differences have an impact on personal identity, identity awareness and self-perception. In this context, gender identity emerges and what is important to emphasise, it is recognised later than corporeality, even though the body is sexually and genitally determined from fertilisation. It could be assumed that it is others who grasp the aspects of the person's identity before he or she is able to recognise it, which means, for example, that parents should realise that they become obliged to respect their children identity by choosing their names, clothes or teaching them certain behaviours (Grabowski & Sztramski, 2014). Development of gender identity is an outcome of a complex relationship and interaction between chromosome complement (genes) and environment. Whereby it should be noted that it is impossible to prefigure with complete certainty with what gender child will finally identify with (Consortium on the Management of Disorders of Sex Development, 2006).

Answering the question about children's sex, whether a child is a boy or a girl seems to be easy but sometimes, after birth, there could appear clinical uncertainty regarding this. Hesitation and insecurity in the area of reliability of the symptoms and the accuracy of the diagnosis, as well as the evidence supporting the need for surgical intervention on the genital organs of the newborn, could be disturbing (Karkazis, 2008). Intersex conditions (IC), sometimes defined as disorders of sex development (DSD) are biological variations which cause difficulties in determining a child's sex – whether the child is male or female at birth (Lenhart, 2015). Birth of a child with an intersex condition always seems to be unexpected. About one in 1,500 children is born with atypical genital or reproductive anatomy which raises the question of cosmetic "correction". Health professionals, doctors and parents are often ill-prepared to deal with psychological consequences of this situation, as is the case when any child is born with an unforeseen condition (Leidolf, Curran, Scout, & Bradford, 2008).

Intersexuality is a problem for those whose bodies are labelled this way, however, not because of inherent defects or "difficulties" with biological or anatomical manifestations of intersexuality (Holmes, 2008). If an intersex newborn is considered freakish, uncanny, monstrous or mythic, it often leads to what some call "sexually mutilating" genital surgeries (Harper, 2007). A newborn with atypical genitalia is a very challenging clinical case and requires experts' input and involvement of their medical experience and open-mindedness. Nowadays, 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, as well as short- and long-term complications including the clinical interventions. All this information are very useful for experts in interdisciplinary teams because should be able to support families of the intersex children and know how to individualise the management plan so that it considers the figure and changes in social attitudes and expectations regarding the concepts of diversity and openness. Thus, it is likely that gender assignment practices, especially in cases where sex assignment is unclear for the experts, still and for years will continue 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

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

It should be noted that medicine is only one part of the culture. It surely serves the society by "fixing" intersex individuals but it is not solely responsible for representing them as deviant. Intersex persons are usually portrayed as "exotic", "other" or "monsters". These representations are meant to restore the borders between norms (normal, heterosexual male and female bodies) and abnormal bodies (intersex persons' bodies) (Holmes, 2008). Heteronormative society use science to create differentiation in bodies to reinforce heterosexual behaviours, other variations or ambiguities in sex and gender are overlooked, ignored, or "corrected" when noticed, in order to fit into the accepted and the only right one male-or-female binary system (Lee Schofield, 2013). Complex interaction between genes and environment determine development of gender identity. Nobody can predict what gender an individual child will identify with; complete confidence in this area is impossible. That is why doctors and parents give an intersex child an initial gender assignment as a boy or a girl – exactly the same as other children. In this situation, medical team members should be supportive of the parents and should be aware that intersex children are more likely than the general population to experience gender incompatibility, to feel that they have been incorrectly assigned their gender at birth. Therefore the role of health care professionals when assigning initial gender is to correctly and deliberately interpret test results related to etiology and prognosis of the child with intersex conditions, e.g. gross anatomy, physiology, hormone production, hormone receptors, among other to inform the parents' about gender assignment decision. Thus, initial gender assignment (initial diagnosis /prognosis whether a child is a boy or a girl) is made by doctors and parents – doctors fully inform parents about medical tests results and actual state of knowledge in the area of development of gender identity in patients, persons with similar conditions (Consortium on the Management of Disorders of Sex Development, 2006). However, both parents and clinicians often resort to surgical interventions in order to eliminate atypical sex characteristics and traits, believing that such procedure will help the child to adapt and ease parental stress, there is no evidence supporting this belief. It is therefore important to investigate the basis of the doctor's diagnosis and recommendations as well as the parents' beliefs, because this may help with considering the advantages and disadvantages of different treatment methods. These values may include protecting the child from being ashamed or stigmatised, avoiding unnecessary interventions, postponing the decision about surgical intervention for the future, ensuring the best possible physical and psychological health, supporting the development of healthy child's gender identity, preserving their fertility (Karkazis, 2008; Karkazis & Rossi, 2010; Karkazis, Tamar-Mattis, & Kon, 2010). The results of more recent studies show that cosmetic (rather than life-saving) genital surgery in infancy is frequently not always and fully successful and the secrecy of many such diagnoses is often described as damaging and destructive for emotional health as well as sexual and erotic life of intersex persons (Harper, 2007). In 1950s, "normalising" infants' bodies with plastic surgery became the standard procedure whenever an intersex child was born. Unfortunately, many of the adults who underwent surgery as infants, bring to the public's attention the fact that these surgeries caused them immense, long-term pain, both physical and emotional. Parents' and doctors' great stress and anxiety caused by birth of an intersex child, often disturb and interrupt rational approach, especially due to demands of the parents who do not to want notice that new medical standards of care and medical practices of normalising surgeries recommend postponement of all surgical and cosmetic procedures. Surgery is seen as a quick-fix which provides immediate relief, solution and answer, but it is noticeable. All the more, there is no data or any evidence that normalising treatment and therapy support long-term well-being and satisfaction of the child. Whereas, it is known that results of irreversible surgeries could be terrifying, e.g. heavy scarring, loss of sensitivity, or great source of shame. It is worth mentioning that the initial surgery is not the only one because it usually requires further operations in the following years of life. Unfortunately, this mechanism of decisions about surgeries is caused by parents' anxiety of ambiguity as well as social intolerance for otherhood (Lenhart, 2015). It is obvious that the risk of cancer is a rational decision about surgical intervention. However, there is evidence that issues such as sex of rearing are interpolated into decision making processes and, undermining their objectivity and neutrality. Risk assessments are generally subjective, variable and based on small sample sizes, as well as outdated research results and data. It is also unclear whether or not widespread early surgical interventions have undermined the ability to perform accurate risk assessments associated with aging and health discomfort (GATE, 2015).

At present, intersex patients and their families have insufficient access to psychosocial support and care. A study conducted by Bennecke and colleagues (2015) showed that only half of parents of intersex children who need emotional support received adequate psychological assistance. It can be seen that it is disturbing because the main challenges parents face concern access to reliable psychosocial information rather than medical or surgical information. Parents and entire families face many problems and challenges related not only to understanding complicated medical (including genetic) information, but also to fear of social rejection and stigma, the need to cope with anatomical differences (both, without and after surgery), complications after surgery, lack of comprehensive knowledge about the risk of gonadal cancer, uncertainty about the stability of the child's gender identity in the future, uncertainty about potential infertility, as well as fatigue, strain and burden related to numerous medical visits and consultations. Furthermore, diagnosis of intersexuality at birth is ordinarily the time of severe suffering; parents report high levels of emotional distress and cognitive confusion which often occurs concomitant with medical decision-making (Ernst et al., 2018; Feder, 2014).

In the Polish legal system (as in most countries around the world) intersex people practically do not exist. Information about the birth of a child should be reported to the Registry Office within 14 days. In the case of an intersex child, at the written request of the parents and with the presentation of a medical certificate, in order to conduct a full medical diagnosis in terms of the child's gender, consent may be obtained to extend the deadline by several months. During this time, the child does not have a birth certificate, and this time is too short to give a chance to observe the child's gender identity. Moreover, there is a great societal pressure on the early normalisation of the genital organs (Ziemińska, 2017). On the other hand, the United Kingdom allows the issuance of a temporary birth certificate stating that the child's gender is unknown (unknown sex) and consent to treatment is made on a case-by-case basis without reference to a specific age – this approach may put pressure on children to adapt to decisions made by their families. This requires verification and making sure that children are not being forced to have surgery (Garland et al., 2018; The fundamental rights situation of intersex people, 2017). Since 2011, IntersexUK has been fighting for the prohibition of corrective procedures, which it considers cosmetic and aimed at adapting the child to the binary ideology of society through genital mutilation. In 2016, the organisation called on the House of the EU Parliament to investigate restorative operations by the British government and played a key role in persuading the UN Committee on the Rights of the Child to admonish the United Kingdom to perform procedures on children. The move has made more and more British parents decide not to have their children undergoing surgery (Kleeman, 2016). Actions related to these aspects are also undertaken in Poland. At the same time, the medical Polish language adopted the term ZRP (gender development disorders) (Ziemińska, 2017; Bajszczak et al., 2014). This type of approach suggests that a person's development is disrupted and should be treated. In some cases, this is indeed the case, but many intersex people are perfectly healthy and struggle only with the social feeling of "otherness" (Ziemińska, 2017).

Research Methodology

The aim of the research was to diagnose the experiences of parents in the field of intersex child treatment. The research problem was the question: What experiences do parents of intersex child have in terms of shaping the child's gender identity in the context of social and educational conditions? The research was carried out on the basis of an interpretative paradigm focusing on the individual, future-oriented action and understanding social interpretations. What is important here is the assumption that the research is carried out on a small scale and reflects social life and negotiating meanings through the subjective experiences of the respondents.

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[1]. 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 analysed (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 an approach allows for 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 generalised but they help to understand the importance and the nature of the studied phenomenon.

This paper presents a case study of parents of a 9-year-old child with DSD who have had positive experiences regarding the child's treatment. The family has been living in London for 5 years, the mother is an economics graduate and at present stays home with the children, the father works in a logistic company. They have three children: a 9-year-old intersex boy and 3-month-old twins (boy and girl). The names of the participants have been hidden to keep them anonymous. The participants were recruited through the author's private contacts; they were provided with a comprehensive explanation of what the project was all about and chose their preferred form of contact. All research participants consented to participate in the research and to have the research results published. The data analysis, research findings and conclusions from were consulted with them.

The research material was collected using the technique of open, categorised, individual, free, partially structured interview. The condition was to collect data in accordance with the established questionnaire without changing the order and content of the questions, but with the possibility of using supplementary explanations. Additionally, the researcher's statements, kept to a minimum, did not contain any suggestive content. Once the interviews had been conducted, significant statements were noted and classified as coded. Then, the data was grouped into categories. Data encoded with the use of the content analysis method (analytical categories were derived from the research concept) (Rubacha, 2008) constituted the construction of the biographies of the respondents. The topics were analysed in the light of research problems focused on gender identity in biological, social

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[1] The entire research project, including the analysis of the research results and their discussion, was presented by the author in the monographs *Pedagogiczne aspekty tożsamości płciowej człowieka* and *Funkcjonowanie osób interpłciowych w przestrzeni społecznej*".

and pedagogical contexts. Data coding took two steps: initial coding and targeted coding; which ensured that the analysis was based on the data and did not impose the interpretation of the researcher. Table 1 shows the coding examples.

Data analysis was conducted based on the following categories of experience: identification with the child's own gender, safety and relationships, difficulties in school (including preparation of teachers to interact with intersex student), health care, professional career of the parents. Table 2 shows how to create the codes.

Table 1. Coding examples

Transcription element	Initial coding	Targeted coding
School curricula contain little content regarding the broadly understood human sexuality.	Lack of education in the field of broadly understood human sexuality.	The need to supplement curricula with the issues of gender identity, both in the biological and social dimension.
There is no knowledge of intersexuality in the traditional media and very little of it on the Internet.	There are no reliable sources of knowledge about intersexuality.	The necessity to take actions to spread reliable content on intersexuality in the media.

This study aims to contribute to contemporary empirical knowledge about the lives of intersex people. The main advantages of the study include drawing attention to gender issues in terms of biological, social, professional and educational determinants. But also to indicate the point of view of intersex child parents, interpreted through objective situations, personal history and subjective experiences. Moreover, what is important in qualitative research, during the interviews, efforts were made to create an atmosphere of honesty and lack of tension in order to be as sure as possible that what was said by the respondents was true. Undoubtedly, the identity of the author of the article as a pedagogue and a cisgender woman had an impact on the research design, data collection and its interpretation. Therefore, the interpretation of the results is a detailed review of the findings resulting directly from the collected data. While it was planned to interview intersex children, it was dropped because of ethical concerns about talking with them about their sex and gender identity in the context of the challenges society attitudes for them. Interviewing parents has some limitations, as it does not allow to fully access the child's perspective – but thanks to parents it is possible to understand how an intersex child is conceptualised by families and society. The interviews also allowed access to the points of view, statements and feelings that the children shared with their parents. It should be noted that

Table 2. Codes constructed in each category

Categories	Codes					
Identification with child’s own gender	• prejudices • pressure • limitations • social reactions • gender stereotypes • understanding	►	Consequences for the intersex child: • the role of psychologists • proactive interactions • individualised approach • practicality	►	Individual system resources for stakeholders: • specialist of education in the area of gender and gender identity • family • resources of knowledge about gender and gender identity	Results: • understanding of knowledge of intersex issues or lack of it • accessibility and the type of understanding that schools, workplaces, people have or not have about it
Difficulties in school (including preparation of teachers to interact with intersex student)	• information for those involved in education • the current situation in education • sharing knowledge about intersexuality • developing awareness					
Safety and relationships	• popularisation of knowledge about intersexuality in order to promote a proper attitude to gender difference					
Professional career of the parents	• evaluation of the employee on the basis of his competences and qualifications • counteracting gender stereotypes in the workplace					
Health care	• changes in medical procedures • training for medical staff in the field of interaction with the patient					

the sample is not representative of the parents of intersex children. Consequently, their stories do not reflect the experiences of all families who struggle with their children's identities.

Findings

Gender identification

Experiences of the parents show that choosing what gender they 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 behaviours 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 emphasised 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 intersex is, what are the types and how to treat it. They also browsed for information about the life of intersex children, their functioning in 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 emphasised 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 an intersex student)

The parents said that their child had begun education in Poland. At the age of three 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 behaviours. 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 behaviours 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 normalise their child. They emphasised 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." After all the tests had been carried out, the doctors concluded that the child would most likely develop a male gender identity and the parents could register the child with a male name and gender.

For eight 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 a 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 back 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 intersexuality is 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.

Discussion of the results

The issue of gender identification of an intersex child turned out to be very difficult for the participants of the research. They were afraid of the initial selection of the child's gender in a situation where his biological sex was still diagnosed and thus uncertain. Moreover, such fear does not even pass over the years. Sieradzan (2009) states that the gender category itself is hypothetical, not scientific, as there are no scientific methods of determining it. Gender is infallibly determined neither by the doctor nor by the parents of the newborn. The only competent person here is the person concerned himself, but he can do this only when he is a few years old. Meanwhile, just after birth, doctors arbitrarily assign a newborn to one or another sex, guided by their own and accepted ideas about the normativity of the sexual organs. Ainsworth (2015) emphasises that the idea of two genders is simplified and that there is a broader spectrum of defining it. For example, Paul James, a geneticist at the Royal Melbourne Hospital in Australia, had to interview a 46-year-old woman in her third pregnancy about her gender. The woman had both cells containing two X chromosomes as well as X and Y chromosomes. So, gender may be much more complicated than it seems. A simple scenario assumes that the presence of the Y chromosome determines the male sex, and its absence the female. But doctors know that there are people whose sex chromosomes say one thing and their gonads (ovaries or testes) or sexual anatomy say otherwise. Therefore, parents of an intersex child face difficult decisions as to whether to raise them as a boy or girl. It is also worth adding that it is assumed that as many as one person in one hundred has some intersex form.

Respondents had no difficulty finding help after the birth of their intersex child, but knew that online stories indicated that other parents had multiple problems in this regard. Karkazis (2008) emphasises that the analysis of multiple perspectives supports parents in discussions and problem-solving. This is important because examining the parents' experiences of intersex children shows that they experience shock, shame, fear, sadness, guilt, anger, anxiety, and alienation. Medical team members should talk to parents carefully. Communication includes reassuring parents and making sure decisions about a child's gender are not made without examining the parents' emotional responses. Psychosocial support should come from psychologists, social workers, support groups, and other parents with similar problems. In the case of intersexuality, little research has been done on health and well-being and, moreover, there are conflicting results from existing research. While everyone agrees that the best interests of the child come first during treatment, the lack of long-term research into this makes it difficult to determine what is best for a given child. Therefore, it is important to make an informed decision to discuss different solutions, consulted with different groups experienced in the issue of intersexuality (Karkazis & Rossi, 2010; Karkazis et al., 2010). Whether parents find out about their child's intersex characteristics after birth or during adolescence, they may receive very contradictory information from different sources. Furthermore, the pressure to perform genital surgery to conform to the "typical" socially accepted pattern of a female or male body can be overwhelming. Parents interviewed by Human Rights Watch spoke of being lost, suffering, seeking support and reliable information, and the relief that comes from receiving support. Some parents were overwhelmed by the insensitive behaviour of doctors, the uncertainty of the child's gender; others felt harassed by doctors and loved ones. That is why it is so important to seek support from various sources, including those on the Internet (Human Rights Watch, 2017).

The results of this study have shown that one of the most important factors in coping with a difficult situation related to the uncertainty of a child's gender is the bond and support of the closest family and friends. Contact with parents with similar experiences is also a support. According to Carpenter (2018), recognising the uniqueness of individual intersex cases and, above all, individual decisions and actions in this area assume that the needs of individual families are different. It is important to pay attention to their isolation, lack of contact with their family, the closest community or their peers. Affirmative support should be integrated and include multidisciplinary teams supporting families with intersexuality. Barriers are related to the small number of specialists in this field, the lack of specialised training and the lack of sharing experiences, and inadequate hierarchy of psychosocial priorities in medical and social care (Délot et al., 2017; Ernst et al., 2018).

The respondents found that the Internet is a good source of information on intersexuality, but there is definitely not enough Polish websites devoted to this subject. Carpenter (2018) gives the example of intersex parents who quickly discovered that groups of parents focused as support groups were not a sufficient form of support and source of knowledge. They also recognised that social media or online searching for parents of children with similar health conditions is also not easy. Moreover, there is concern that existing groups may have narrow clinical perspectives, or fears driven by clinical narratives that encourage genital surgery as the only form of child support. Many parents do not understand the functions of surgery and therefore the most important thing is to search for detailed information about all aspects of the disease and possible solutions. Part of the source of such knowledge is the Internet; sometimes parents are overwhelmed by too much information they read on the internet. However, this does not change the fact that thanks to the Internet, most parents have a higher level of knowledge about intersexuality and thus are able to ask doctors more specific questions about the treatment of their child (Human Rights Watch, 2017).

Parents participating in this study had positive experiences with teachers of preschool education, but emphasised that they lacked knowledge in the field of various aspects of the functioning of an intersex child in the health, social and, above all, school dimensions. Orr (2018) and O'Keefe (2016) emphasise in this context that questions about intersexuality, due to the work performed by activists, scientists and representatives of various professions, are the subject of consideration of many disciplines. Greenberg (2012) believes that addressing the topic of intersex people creates a space for political and social negotiations in the field of intersex education. Education should concern the whole of society, as the legal reform itself will not change the mistreatment of intersex people. Moreover, intersexuality should be seen as a topic that fits into the school curriculum (Garland, Samuelsen, & Travis, 2018). The more so as the knowledge of these issues helps students understand that the perception of gender changes in time and culture. Students should learn that many cultures around the world have different concepts of gender. This approach will help them to critically consider how gender expectations affect their lives and the world as a whole. Students who are knowledgeable about the diversity of human gender experiences, especially the complexity of the human body, will have a better understanding of their own bodies and development. Failure to provide them with this knowledge makes them unprepared to effectively navigate the world around them, and they are unaware that gender atypicality is a natural part of human diversity. Recognition of natural, biological variability allows them to accept themselves and others as they are (Gender Spectrum, 2019). There is also the issue of well-intentioned teachers who want to question accepted norms but are often afraid to talk about something they have not mastered sufficiently. Then they avoid discussing these issues and consolidate the adopted norms. The sense of guilt and shame displayed by the participants of the Ollivier (2017) study was very evident in terms of the ability to use the appropriate language to describe gender identity. These are their perceptions of the need to learn and transform towards challenging oppressive discourses and promoting the inclusion of marginalised people, including in educational discourses and teacher training.

According to the parents participating in the research described in this article, it is important that an intersex child is aware of its biological atypicality and of the possibility of future surgery. They also concluded that if there was no such necessity, there was no need to inform the school community about the intersexuality of a given student. An important issue is also the situation where an intersex child has siblings. Then, parents are obliged to teach all their children how to deal with possible aggression from their peers. They should also be aware that anyone who learns about their child's intersexuality, including their immediate family, needs time to accept the new situation and, above all, to acquire reliable knowledge about the characteristics of intersexuality. Information provided to them by parents should be reliable, specific, but at the same time limited to a minimum – it should not include intimate details about the functioning of their child. The same principle is used to provide their information to teachers at school. There is usually no need to discuss the child's intersexuality with them; exceptions are situations when a child wants to tell them about himself or requires special conditions in terms of his functioning (IGLYO, OII Europe and EPA, 2015). Human Rights Watch (2017) cites the example of an 8-year-old intersex girl who did not undergo genital surgery, as neither the girl nor her parents were concerned about the ambiguity of her genitals. This example shows how important adaptation is to reduce anxiety levels. At the same time, it should be remembered that society is a difficult place for people who are different. But even so, having the baby undergo irreversible surgery without her consent does not seem to be the best solution. It should also be taken into account that fear for the future of the child, perception of him by school friends, ridicule after discovering the unusualness of his sexual organs. On the other hand, the declaration of the mother whose 13-year-old son did not undergo surgery was unequivocal and indicated that the child had never experienced any mistreatment – even in situations where he had to disclose his intersexuality. Other parents interviewed by Human Rights Watch confirmed that peers generally need simple messages when they ask questions about the unusual nature of their intersex colleagues. The answer that such a child was born is often enough.

Parents said that one of the most important things in the field of healthcare is good contact with competent doctors. In their opinion, the approach that allows postponing surgery on the child's genital organs until the diagnosis of the child's sex is certain and unambiguous is of great importance. In fact, human rights standards for intersex people are evolving rapidly, and the United Nations has addressed this issue in the thematic reviews. Regarding child surgery, the Commissioner called for postponing invasive and irreversible surgical interventions that are not necessary, but painful and risky (Human Rights Watch, 2017). In 2015, Malta adopted the Gender Identity, Gender Expression and Sex Characteristics Act, which states that doctors cannot perform any gender assignment treatment for a child's sex characteristics if the intervention can be postponed until the child is made aware and gives informed consent to it. The act also states that medical intervention caused by social pressure violates the law (McDonald, 2015). In turn, in 2014, OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO published a joint consensus on the elimination of forced sterilisation and recognised it as a violation of the human rights of intersex people, unless such intervention is medically justified, e.g. reducing the high risk of cancer genital organs (GATE, 2015).

Research has shown that not every child needs psychological support, especially those who accept their situation of being intersex. This does not mean, however, that parents should not be aware of making contact with a psychologist whenever they need it. AIS Support Group Australia (2008) emphasised many years ago that intersex children should receive the protection and care necessary for their well-being. In turn, governments should enact laws on administrative, social and educational measures to protect such a child from all forms of physical or mental violence, both by the organisation and by parents and from immediate action. Paying attention to increasing the number of research and the scope of knowledge on intersexuality should be a priority in preventing intersex rights violations in the future (Lancing, 2018). Access to specialist psychological knowledge is becoming more and more important here. Preparing the family to recognise the emotional and behavioural health needs of a child or undertaking psychosocial interventions are of key importance here (Ernst et al., 2018; Lossie & Green, 2015). It should be remembered that not all mental health professionals have a sufficient level of knowledge about intersexuality. Therefore, parents should pay attention to their behaviour. Parents should also observe their child's reactions to specialists, and if they find that the child does not want to see the person, they must change the specialist (IGLYO, OII Europe and EPA, 2015).

Parents emphasised that it is important to educate people about human sexuality, especially those from the closest circle of an intersex child. Aoi (2018) points out that the considerations on the human rights of intersex people make it possible to identify problems faced by an intersex person in terms of gender insecurity, social contacts, or changes in public policy. Therefore, international human rights organisations pay attention to promoting a different social approach in this regard in all areas of public life, including educational programs that raise awareness of the natural diversity of bodies and their specific health needs. Such action is aimed at bringing about change that allows society to recognise the general needs of the "Other", paying attention to inclusiveness, and not only pretended political correctness. Furthermore, Lancing (2018) emphasises that children's rights should not be about society's expectations, but about what is best for the child, as well as about his self-determination. However, it also notes that this approach requires fundamental changes in social and political institutions and an understanding that change is only possible if society understands the causes of inequality. Unfortunately, discriminatory beliefs and the social mechanism of normalising gender stereotypes hinder the implementation of initiatives in this area (Lancing, 2018). Another obstacle is the fact that people forget that the development of gender identity is the result of a complex interaction between genes and the environment; that it is possible to predict with certainty what gender an intersex child will identify with despite the initial gender assignment. Thus, gender assignment is a social and legal process not always requiring surgical intervention (Consortium on the Management of Disorders of Sex Development, 2006).

Conclusions

Once they get the diagnosis, parents of intersex children 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.

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