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INTERSEX IS NOT EXACTLY 'BREAKING NEWS'

By Ardit Kika - 26.10.2019

CONFUSION STILL SURROUNDS MISUNDERSTOOD TOPIC.

At noon on a Wednesday in early September, journalists packed into a small room in the University Clinical Center of Kosovo (QKUK) for a hastily arranged press conference.

“This is the second case of [newborns] with this syndrome [Congenital Adrenal Hyperplasia, CAH] only this year, and it shows in symptoms of ambiguity in genitalia,” announced Xhevdet Gojnovci, director of Neonatology. “Therefore, there has been news circulating in the media, which I would say is not definitely confirmed, but it is CAH syndrome.”

Within a few questions from journalists, QKUK doctors simultaneously announced and denied the birth of what they termed a “double-gendered child.” Following the conference, which was also live-streamed over social media, various media outlets subsequently reported on the birth of the “double-gendered child” and the “story” spread like wildfire in both online outlets and television stations.



Hajrullah Fejza, who has a PhD in Human Sexology, says that the birth of an intersex baby is far from an extraordinary event and to make a press conference out of it is “scandalous.” Photo: Ferdi Limani.

But Hajrullah Fejza, who holds a PhD in Human Sexology, highlights that the birth of an intersex child — to use the commonly accepted term for people born with genitals that “do not fit the typical definitions for male or female bodies” — is hardly a breaking news story for human biology.

“It is a frequent phenomenon — international statistics show that 1.7% of people are born intersex,” he says. “Neither the media or physicians should make an extraordinary event out of it. As a reporting [press conference] it’s scandalous, unnecessary and unprofessional.”

Gojnovci says that he was pushed by the media to speak about the birth of the intersex baby, after the information had leaked from QKUK.

A day earlier, a relatively small online news outlet, Front Online, had reported the birth of the intersex child citing a single off-record source. On top of breaking the journalistic conventions of confirming information with other sources, the outlet also wrongly reported that “such a birth is not remembered in Kosovo.”

A 2015 report by Australian medical personnel stated that during five short visits to Kosovo between 2011 and 2015 alone they had reviewed the cases of “5 intersex youngsters.” According to Gojnovci, QKUK’s Gynecologist-Obstetrics Clinic sees the birth of approximately 11,000 babies a year, with one intersex baby having been born in each of the last three years.

However these figures do equate to just 0.01% of all births which, when compared to the global rate of 1.7%, suggests that instances of babies born intersex in Kosovo is likely to be considerably under-recognized.

What happens when an intersex baby is born?

According to the Law on Civil Status, parents need to register the birth of a newborn child within 15 days of birth, or in “exceptional” cases within 30 days — the law is not clear on what is considered an exceptional case. The birth certificate then states the sex of the child, which in Kosovo’s law means either female or male.

In the case of intersex babies, the law gives doctors the power to determine the sex.

Once the doctor has determined the sex, it is clear that surgical intervention in Kosovo is not uncommon. The visiting medical personnel from Australia carried out surgical interventions on the five young intersex children whose cases they reviewed;

pediatric surgeon Defrim Kocinaj also previously told K2.0 that — as a result of these visits plus training in hospitals around Europe and Turkey — doctors in Kosovo are now able to carry out surgery in more common cases.

Gojnovci says he has no information as to whether there are any intersex children whose sex is not reassigned to male or female as this was a matter for endocrinologists, geneticists, pediatric surgeons and plastic surgeons. “I can only speak of the neontological part,” he says, referring to the care provided in the first 28 days after birth.

BOTH THE UN AND THE COUNCIL OF EUROPE HAVE CALLED FOR A REPEAL OF LAWS THAT ALLOW SURGICAL INTERVENTION ON YOUNG INTERSEX CHILDREN.

In recent years, there has been a backlash from human rights activists and international bodies on the international tendency to conduct surgery on intersex babies, with a UN campaign titled “Free and Equal” stating that medical intervention is typically unnecessary from a medical perspective and can cause “permanent infertility, pain, incontinence, loss of sexual sensation, and lifelong mental suffering.”

Both the UN and the Council of Europe have called for a repeal of laws that allow surgical intervention on young intersex children, insisting that any such intervention should only take place with the consent of the individual once they are old enough to make an informed decision.

According to a Council of Europe report, it is estimated that anywhere between 8.5% and 40% of intersex people “end up rejecting the sex they were assigned at birth demonstrating the major infringements of their psychological integrity.”

However, despite UN experts warning that parents pressured into agreeing to surgical intervention on their intersex child “have often reported having regrets because it did not benefit their child, harmed them, and created difficulties in the parent-child relationship,” there is little evidence that parents in Kosovo are given enough information to make any sort of informed choice.



Xhevdet Gojnovci, director of Neonatology at QKUK, says that parents are informed about their baby being intersex piecemeal by various specialists.
Photo: Atdhe Mulla / K2.0.

Gojnovci claims that parents are informed by Neonatology about the general health condition of the intersex baby, “without any detail about the sex of the baby, because it needs confirmation.”

The doctor says that parents are informed by his department of the baby’s “anatomical changes” in genitalia as well as the next steps in terms of which specialists will be consulted for verification of the diagnosis.

However, he says there is no standard process by which parents are told that their baby is intersex or no doctor explicitly giving them this information or explaining the meaning of it. Instead, a group of physicians including an endocrinologist, geneticist, radiologist and pediatric surgeon tell parents piecemeal about the different elements that link to their own specialisms.

“Each shares his or her part [of the information],” he says. “The information remains incomplete, meaning that it will be consulted and completed in the future.”

Determining whether a child is intersex, male or female immediately after birth can necessarily include the input of different specialists, with Fejza highlighting that various tests, including using radiography, should be carried out.

But Linda Gusia, a sociology lecturer at the University of Prishtina, says that parents have the right to information on their newborn, and that this information should be clearly contextualized so that parents understand what it means in practice. Not clearly informing a parent that their newborn is intersex, and what this means, is a “fundamental violation of rights, a breach of ethics” and flagrant abuse, she says.

“It is the right to know. The right of parents to know what this means,” she says. “If the surgery is to be conducted, what does that mean? Does it mean that this child will feel like a girl, [for example]? What does that mean? Does it mean that the child could need additional attention? What does this mean?”

Two genders vs. two sexes

Both Dr. Gonojvci and much of the media used the term “*me dy gjini*” (“double-gendered” or “with two genders”) to describe the newborn child, rather than the correct term, intersex.

Confusing the words “sex” with “gender” is quite common in Albanian discourse, and even Kosovo’s laws tend to use the two words interchangeably. Only the Law on Gender Equality differentiates between the two, defining sex as “biological and physiological characteristics that define men and women” and gender as a role or identity “that is learned, changed over time, and varies widely within and across cultures.”

The mix-ups extend to administrative mistakes, with courts and personal documents using “gender” when they are referring to “sex” and vice versa.

INTERNATIONAL APPROACHES TO INTERSEX

Many countries have taken measures to respect the human rights of intersex people.

Finland and Portugal do not impose a time limit on the registration of a baby’s sex in cases of intersex babies.

Australia, Malaysia, Nepal, New Zealand and South Africa have included the option of “X” as a passport entry for sex, while passport applications in India allow for three categories, “Female,” “Male” and “Others.” Germany’s ID cards do not have any reference to sex/gender.

Malta was the first country to pass legislation banning non-consensual surgery to modify sex characteristics. Its 2015 law protects the bodily integrity and physical autonomy of intersex minors by banning medical procedures and treatments until they are of age when they can provide informed consent.

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Parliaments, courts, bioethics bodies and/or ministries of a few other countries such as Australia, Switzerland, Colombia, Chile and Germany have addressed the need for full informed consent of the intersex individual prior to surgery.

recent decision by the Constitutional Court wrongly referred to “gender marker” when referring to male and female, which is actually a sex marker. Similarly, Kosovo IDs, with categories named in three languages, have *Gjinia* (“Gender” in Albanian), *пол* (“Sex” in Serbian) and “Sex” (in English).

Fejza says it is important to clearly differentiate between sex and gender, because when they are mixed up by institutions “you get a mish-mash of statements, laws, procedures and everything else.”

Gusia meanwhile says that society as a whole is very harsh toward difference.

“Each difference that is considered as a handicap by our society is punished by society,” she says. “Our society is very rough toward all people who are a bit different. Different meaning gay, or disabled, looking a bit different. It is very uncomfortable with difference.”

According to Gusia, society and institutions should be less hung up on difference and instead should move toward making the lives of each person easier.

“I think that science has at least tried to put itself in the service of making people’s lives easier, but I think we should [frame social issues and medical science] in a way that asks: How much do we know?” she says.

Gusia points to the way human anatomy and genitalia is taught, arguing it is framed by prevailing social norms and highlights as an example the major inaccuracies in the way genitalia was taught in the past.

“Physicians in the 18th century thought that a woman’s body was a man’s body turned upside down,” she says. “[At that time] we only had the anatomy of the man because it was the norm. Women’s anatomy wasn’t taught.”



Sociologist Linda Gusia says there are still huge misconceptions about gender and sex in Kosovo. Photo: Majlinda Hoxha / K2.0.

Gusia also says the role and significance of genitalia tends to be widely misunderstood.

“I ask my students where our gender predispositions come from. Do they come from our genitals?” she says. “And most of them say yes...”

She insists that we need to move beyond such ideas and to understand ourselves on many different levels. “To understand gender ... beyond genitalia, because recent research has shown that genital organs are secondary features [for human beings].”

The indications, however, are that such a societal shift in attitude is still a long way off, not least because what is being taught in Kosovo’s schools and universities is not generally keeping up with global developments when it comes to understanding such matters.

Nexhmi Hyseni, a pediatric surgeon at QKUK and lecturer at the University of Prishtina, says that their students do not learn about intersex either in textbooks or lectures in the Department of Surgery.

In fact, intersex seems to be left out of school and university textbooks on human

bodies.

This year, the Ministry of Education, Science and Technology introduced new school textbooks, which still make no mention of intersex. For instance, 6th grade pupils have a new Biology textbook, which includes human sexuality. One section of the book talks about homosexuality, heterosexuality and bisexuality as “different sexualities,” but the part on human bodies refers only to the male and female bodies, without including intersex.

According to Hajrullah Fejza, books like this one, should include a definition of intersex.

“It shouldn’t be a taboo; just like sexual orientation and gender identity, which should not be taboos,” he says. “It should be spoken of, and it shouldn’t be a shame to write a simple definition: ‘All people with genital organs not fitting into the definition of being male or female are intersex.’”

Linda Gusia similarly proposes that it’s time to simply embrace difference.

“I think that we are complex beings and we should accept [this fact] as it is — to accept the diversity and fluidity of being,” she says. “Our experiences aren’t the same, our sufferings aren’t the same, and how we’re built [physically] is not the same. The idea is not to normativise, discipline and punish all the other people who do not fit those norms.” K

Feature image: Majlinda Hoxha / K2.0.

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