



**Article title:** Stories of Arab Intersex Individuals

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## **Introduction**

Intersex people, as defined by the UN Free & Equal, “are born with sex characteristics (including genitals, gonads and chromosome patterns) that do not fit typical binary notions of male or female bodies”.<sup>1</sup> Intersexuality is, however, highly variable with some intersex features being visible at birth while others might not appear before puberty. It is estimated that 0.05 to 1.7% of the population is intersex.<sup>1</sup> Intersexuality is related to biological sex characteristics and is different from gender identity,<sup>1</sup> the internal and inherent feeling of being a man, woman, or another gender (gender non-conforming) regardless of the person’s sex.<sup>2</sup> Clinically, intersex individuals have heterogeneous presentations which range from genital atypia, pubertal differences, or concerns for fertility.<sup>3</sup> Hence, many may be discovered as intersex in their infancy while others may never know before adulthood.

That being said, intersex individuals face stigma and discrimination<sup>4</sup> to the extent of being considered a curse or a bad omen in certain areas, leading to infanticide.<sup>5</sup> In the medical community, there is an ongoing debate on whether intersexuality should be viewed as pathology and medicalized under “Disorders of Sexual Development” or whether it should be considered as a “third sex”, a natural variant along a non-binary sex spectrum.<sup>4,6</sup> This debate raises the issue of “normalization” interventions, the practice of subjecting intersex children to sex-reassignment surgeries (SRS) intended to change the biology of intersex individuals to fit the binary standards of male and female.<sup>7</sup> The UN Convention on the Rights of the Child, Article 3 states that in all actions concerning children, “the best interest of the child shall be a primary consideration”<sup>8</sup>. But what is the best interest of the child? While some advocate for early “normalization” interventions in the first months or years of life, others call for a stop to these interventions, questioning their beneficial effects and advocating for the postponement of any intervention until the minor is of decision-making age and is able to assent or decline such surgeries.<sup>7</sup>

In the Arab world particularly, knowledge and medicolegal frameworks about intersexuality seem inexistent with no publications to date on the matter. Therefore, this study aims to highlight certain experiences of intersex individuals in this region as well as physicians’ practices. Hence, the authors suggest this first-of-its-kind study as a first step to fill the enormous gap on the practices performed on intersex individuals in this region.

## **Methods**

A total of eleven non-governmental and civil society organizations related to sexuality and LGBTQIA+ health were contacted in Lebanon and the Arab region through email.

While most responded, many reported to have either no information on the matter or showed no interest in the subject. Only one non-governmental organization (NGO), Helem, had direct involvement with intersex individuals, showed interest in this research, and agreed to an interview. The interview was semi-structured. Helem took oral consent from intersex individuals or their parents (if they were a minor) beforehand to share the information they provided.

## **Results**

Helem (Arabic for “dream”) is one of the first-ever LGBTQIA+ advocacy NGOs in the region, based in Lebanon, aiming to eradicate discrimination.<sup>9</sup> It provides services to the queer community including casework, medical services, and psychosocial support. The authors were joined by Helem’s Manager and the Senior Protection Officer for Case Management. Helem’s representatives started by stating that there is virtually no published data in the Arab world about intersex individuals nor a legal framework. Laws in Lebanon contain articles that are deliberately misinterpreted to criminalize LGBTQIA+ individuals especially gender non-conforming individuals, for example, under “impersonation of another person”. They shared three stories of intersex individuals they helped, arbitrarily named Nour, Rayan, and Farah.

### 1. Nour’s Experience

Nour is an intersex individual in his late thirties that identifies as a man. He is a non-Lebanese Arab that sought Helem’s assistance in Lebanon after fleeing his home country due to death threats. He had been forced to quit his job when his coworkers discovered he was intersex, calling him “a demon sent to earth”. Nour had not known he was intersex until he was in his early thirties. In fact, his parents had taken him to his doctor for a “regular check-up”, as they told him when he was nine. At the doctor’s, he was forcibly anesthetized and underwent SRS into a biological female. The reason is that the doctor “felt” that Nour would “become a girl” later on, based on a non-scientific analysis of the hormone panel and general exam. Nour’s parents never told him about what happened that day and prohibited him from talking about it. When he sought Helem, doctors’ assessments showed deteriorating health including brittle bone due to extremely low estrogen, very low testosterone even for a biological female, PTSD, and severe depression with suicidal ideations. Upon further evaluation, the surgery seemed to be experimental as the surgeon seemed to have “no experience in what they were doing”. Of note, the surgery was done in a hospital setting, therefore, it is unlikely that it was just the action of one doctor. Helem’s representatives hypothesize that multiple health professionals, as well as the hospitals’ ethical board, may have been involved.

On the subject of the surgery being “experimental”, Helem’s representatives affirmed that this is not uncommon. They had once worked with an intersex person who had

undergone 6 failed surgeries and subsequently, had resultant physical problems like infections and bleeding. They conceptualize that this is partially due to physicians' lack of knowledge of the procedure, the willingness to unethically experiment despite that, and the "pride" of some Arab physicians of never admitting they do not know what to do.

## 2. Rayan's Experience

Rayan was a 2 months-old infant whose parents were non-Lebanese Arabs. They were in Lebanon when they took Rayan to get vaccinated. Upon conducting a routine physical examination of the patient, Rayan's doctor was overtly shocked and "in panic" when she saw Rayan's genitals. Consequently, she took a photo of the child's genitals without parental consent and called multiple healthcare personnel from the hospital to come to check the baby's genitals. Based solely on the visual appearance, and without ordering any tests, she informed the parents that Rayan needed immediate surgery or else negative health outcomes would develop. She even unsolicitedly booked an appointment for their next visit. Naturally, Rayan's parents were anxious and scared for their baby. They were unsure what to do and went back to their home country where they sought a second opinion. This second doctor also stated that Rayan is in need of surgery. At that time, Rayan's parents were put in contact with Helem who recommended a third physician in their country. The latter, after running tests, stated that Rayan is healthy and there is no threat to their life. The parents still felt uneasy as two doctors had given a surgical recommendation versus one who gave no such indication. After that time, the extended family discovered that Rayan was a "Khuntha" (Arabic for hermaphrodite) and started pressuring the parents to surgically "fix" them, citing multiple cultural and religious reasons. One of the reasons was: "God will hold you accountable". Rayan's parents went back to Lebanon where they sought Helem. Helem provided the parents with educational sessions on intersexuality and relayed Rayan to a Lebanese pediatric endocrinologist. The latter also confirmed that Rayan is in good health with the exception of a minor urological problem. No SRS was needed and so, it was not done. The decision of doing it or not will rely on Rayan's decision when they grow up, the parents affirmed. Currently, the mother is still acting as if Rayan is a girl because "there's already another girl in the house" but acknowledges and accepts that, when Rayan grows up, they might identify differently. However, the parents are still worried about bullying and mental health consequences especially suicide non-conforming individuals face in their society.

When asked why they think the first doctor reacted this way, Helem representatives stated that it might be related to the fear of biological consequences, lack of knowledge, and socio-cultural reasons. They added that many times, sex is assigned based on the need of the parents. For example, an intersex individual could be assigned as a male because "they will help the family economically in the future" or a girl because "that's what they want". Sometimes, a doctor may suggest a surgery based on what is most

profitable financially, which is usually an assignment of sex to females in the case of Lebanon.

### 3. Farah's Experience

Farah is a 9-year-old Lebanese intersex child referred by another organization to Helem a few months after they had been subject to SRS. Originally, Farah's parents thought the child was biologically a male, however, when puberty began, changes typically associated with female biology started to develop. This led the parents to seek a doctor that decided to conduct an SRS without any evidence-based reason. The surgery was "totally experimental". Farah's laboratory tests before the surgery indicated that they were healthy. Currently, The parents are feeling guilty and regret the decision to approve the surgery. One of the reasons for this guilt is the mental health consequences Farah suffered after the surgery. Farah stated that, after the surgery, they feel mentally worse and "uncomfortable" towards their body. They are also having multiple questions about the surgery. Farah is also currently discovering their gender identity. Their parents state that they highly regret the decision and will support Farah in whatever gender they identify with later on.

On the question of the cut-off age for decision-making, Helem representatives state that 18 years old is a "safe" mean age. The question resides in whether the individual can give informed consent and a psychologist, in this case, can be helpful in assessing that capacity.

The interviewers wrapped up with a question on why don't parents of intersex individuals that SRS sue offending physicians. A major reason cited was stigma and the social repercussions on intersex individuals and their parents. Another reason is the lack of LGBTQIA+ protection laws in Lebanon. However, if parents were to sue, Helem representatives believe that provided evidence could, at least, pave a way for a series of recommendations, issued by a judge, concerning intersex individuals in Lebanon. These recommendations could be used to advocate for a change in policies and seize the attention of the Lebanese Order of Physicians. As a final note, Helem representatives reflected on the lack of knowledge about intersex individuals in the region. Parents typically share their concerns with religious authorities, extended family members, and neighbors. If they seek medical help, they are likely to fall upon a physician that is ill-equipped in handling intersex individuals or a queer-phobic physician that would, many times, give non-scientific advice violating human rights principles.

### **Discussion**

The complete inexistence of data around intersex individuals in this region showcases the obscurity attributed to this subject, whether deliberately due to stigma, religious, and

cultural reasons or non-deliberately due to lack of knowledge. For Lebanon, which has no mention of LGBTQIA+ individuals in law, a history of subjectively interpreting legal articles to fit the socio-cultural narrative comes as no surprise. As with Article 534 which is sometimes used to criminalize homosexuality, depending on the judge's ruling,<sup>10</sup> it seems intersex individuals if their gender expression does not fit the stereotypical masculine and feminine expressions may also be subject to criminalization. In other Arab countries, where being LGBTQ can lead to imprisonment or the death penalty,<sup>11</sup> it is possible that intersex individuals are subject to a similar fate. This is definitely something to consider when deciding against SRS surgeries in the Arab world.

### 1. Nour's Experience

Nour's experience is common to many individuals who have been lied to about their identity.<sup>12</sup> It showcases the extreme measures parents and doctors can resort to when a child is discovered to be intersex, abusing them and then denying them an explanation. It is clearly evident that the gap in physicians' knowledge is immense but many doctors may be unwilling to admit it which explains the interpretations of laboratory results without any basis in evidence as well as the recurrent theme of multiple failed surgeries. This could be due to the "ego of the Arab physician" as many perceive doctors to be all-knowing and willingly subscribe to the paternalistic approach.<sup>13</sup> To preserve this construct, physicians may find themselves hesitant to admit their lack of knowledge which could lead them to non-scientific inhumane decisions. Additionally, being discriminating against intersex individuals is common.<sup>14</sup> Nour losing his job, even after SRS, shows how deeply rooted the fear of intersex individuals is. Of note is the long-term health consequences that resulted from Nour's parents and the doctor's actions. In addition to the debilitating endocrine and psychiatric sequelae, Nour is stuck in the body of a female even though he is a man.

### 2. Rayan's Experience

Rayan's story shows parents' struggles when they have an intersex child. Taking an infant for routine vaccinations could lead to a life-threatening diagnosis and emergency surgery. Additionally, the infant's genitals are treated like "exotic" medical findings, photographed, and shared. In just one encounter, the doctor managed to break ethical principles of autonomy, confidentiality, non-maleficence, and justice. Her anxious attitude might reflect internalized fear from intersex individuals. Moreover, the mental turmoil Rayan's parents went through is consistent with the psychological stress intersex parents experience, as overall anxiety is much higher in this population which could sometimes be as high as anxiety in caregivers of heart failure and stroke patients.<sup>15</sup> Additionally, the sociocultural stress from being told that their child is "broken" and the cultural and religious repercussions of not "fixing" them is a common theme, especially in the middle east where LGBTQIA+ individuals are considered as

diseased.<sup>16</sup> Finally, the anxiety towards the future of their child is rooted in reality, as intersex individuals are more likely to be bullied at school.<sup>17</sup> Rayan's case also clearly shows the lack of education and consensus in handling intersex children. No medical school properly prepares future physicians in the Arab world to handle LGBTQIA+ individuals and this is especially true for intersex individuals. The proper management seems to differ from one physician to the other based on economical and socio-cultural reasons more than evidence-based approaches. Despite all the barriers, Rayan's story is one that you don't hear often in the Arab world where the SRS was not performed.

### 3. Farah's Experience

As for Farah, their case shows the paternalistic approach that physicians use when parents are worried or confused. The doctor, in this case, opted for a "know-it-all" attitude that had negative health repercussions on Farah and their parents. Farah's parents will have to live with the guilt for providing arguably uninformed consent to a surgery that proved detrimental. While the parents' intentions were to help their child, Farah ended up having psychiatric symptoms as well as unanswered questions. This is expected as "normalization" surgeries have long been shown to negatively affect mental health, to the point of being associated with suicidal ideations.<sup>18</sup> Add to that, PTSD, depression, and anxiety are prevalent in intersex individuals, especially in people who discovered their intersexuality late like in Nour's case.<sup>19</sup> In this case, if the physician had educated the family about the possible options and had waited for Farah to grow up, these irreversible repercussions on Farah's body, health, and life could have been avoided. While literature shows no clear optimal age for intersex individuals to make the decision of undergoing surgery or not, it is clear that surgeries should be delayed until the child can give informed consent.<sup>5</sup> Puberty blockers may be used for the purpose of giving more time for gender identity exploration, but the evidence is still minimal regarding their use.<sup>20</sup>

### **Conclusion**

Reiterating what Helem said, there is no medicolegal framework that protects intersex individuals in the Arab world. In fact, people scarcely know about their existence. Therefore, a conversation needs to be initiated that would, later on, be reinforced by policies that protect intersex individuals. Relevant authorities representing the medical body, like the Lebanese Order of Physicians in Lebanon, should release a statement about the medical and ethical considerations when managing intersex individuals to protect them from abuse. Up-to-date guidelines for physicians on what is considered best practices, ethically and medically, should also be made available. Importantly, physicians should be held accountable, if not in the eyes of the law, then in the eyes of this relevant authority. Practicing medical procedures that are not backed by evidence nor by ethical and human rights principles, like unnecessary SRS should be prohibited.

Moreover, medical schools should include intersex issues, and LGBTQIA+ issues in general, into their curricula. Finally, in the fight for LGBTQIA+ rights in the region, advocacy groups should aim to include intersex individuals on the frontlines. This may prove beneficial in increasing exposure and destigmatization of intersexuality.



## References

1. UNFE-Intersex.pdf [Internet]. [cited 2021 Jan 13]. Available from: <https://www.unfe.org/wp-content/uploads/2017/05/UNFE-Intersex.pdf>
2. American Psychological Association. Guidelines for psychological practice with transgender and gender nonconforming people. *Am Psychol*. 2015 Dec;70(9):832–64.
3. Vora KA, Srinivasan S. A guide to differences/disorders of sex development/intersex in children and adolescents. *Aust J Gen Pract*. 2020 Jul;49(7):417–22.
4. Zeeman L, Aranda K. A Systematic Review of the Health and Healthcare Inequalities for People with Intersex Variance. *Int J Environ Res Public Health*. 2020 Sep 8;17(18).
5. Behrens KG. A principled ethical approach to intersex paediatric surgeries. *BMC Med Ethics*. 2020 Oct 29;21(1):108.
6. Carpenter M. The “Normalization” of Intersex Bodies and “Othering” of Intersex Identities in Australia. *J Bioethical Inq*. 2018 Dec;15(4):487–95.
7. Harris RM, Chan Y-M. Ethical issues with early genitoplasty in children with disorders of sex development. *Curr Opin Endocrinol Diabetes Obes*. 2019 Feb;26(1):49–53.
8. crc.pdf [Internet]. [cited 2021 Jan 13]. Available from: <https://www.ohchr.org/Documents/ProfessionalInterest/crc.pdf>
9. Lebanon’s gays struggle with law. 2005 Aug 29 [cited 2021 Jun 11]; Available from: [http://news.bbc.co.uk/2/hi/middle\\_east/4154664.stm](http://news.bbc.co.uk/2/hi/middle_east/4154664.stm)
10. Lebanon: Same-Sex Relations Not Illegal [Internet]. Human Rights Watch. 2018 [cited 2021 Jul 3]. Available from: <https://www.hrw.org/news/2018/07/19/lebanon-same-sex-relations-not-illegal>
11. Audacity in Adversity [Internet]. Human Rights Watch. 2018 [cited 2021 Jul 3]. Available from: <https://www.hrw.org/report/2018/04/16/audacity-adversity/lgbt-activism-middle-east-and-north-africa>
12. Davis G, Wakefield C. The Intersex Kids are All Right? Diagnosis Disclosure and the Experiences of Intersex Youth. In: Neff Cluster P, Lee Blair S, Bass LE, editors. *Sociological Studies of Children and Youth* [Internet]. Emerald Publishing Limited; 2017 [cited 2021 Jul 3]. p. 43–65. Available from: <https://www.emerald.com/insight/content/doi/10.1108/S1537-466120170000023004/full/html>
13. Saade Riachy C, Nemr E. Medical professionalism in Lebanon: between doctors’ perception and patients’ satisfaction. *Int J Med Educ*. 2020 Aug 21;11:171–2.
14. Zeeman L, Sherriff N, Browne K, McGlynn N, Mirandola M, Gios L, et al. A review of lesbian, gay, bisexual, trans and intersex (LGBTI) health and healthcare inequalities. *Eur J Public Health*. 2019 Oct;29(5):974–80.
15. Szymanski KM, Salama AK, Whittam B, Frady H, Cain MP, Rink RC. Beyond changing diapers: stress and decision-making among parents of girls with congenital adrenal hyperplasia seeking consultation about feminizing genital restoration surgery. *J Pediatr Urol*. 2019 Dec;15(6):653–8.
16. Abdessamad HM, Fattal O. Lebanese Medical Association for Sexual Health: Advancing

Lesbian, Gay, Bisexual, and Transgender Health in Lebanon. *LGBT Health*. 2014 Jun;1(2):79–81.

17. *Bullying-and-Violence-in-School.pdf* [Internet]. [cited 2021 Jul 3]. Available from: <https://www.unfe.org/wp-content/uploads/2017/05/Bullying-and-Violence-in-School.pdf>
18. Weidler EM, Linnaus ME, Baratz AB, Goncalves LF, Bailey S, Hernandez SJ, et al. A Management Protocol for Gonad Preservation in Patients with Androgen Insensitivity Syndrome. *J Pediatr Adolesc Gynecol*. 2019 Dec;32(6):605–11.
19. Rosenwohl-Mack A, Tamar-Mattis S, Baratz AB, Dalke KB, Ittelson A, Zieselman K, et al. A national study on the physical and mental health of intersex adults in the U.S. *PloS One*. 2020;15(10):e0240088.
20. Rew L, Young CC, Monge M, Bogucka R. Review: Puberty blockers for transgender and gender diverse youth—a critical review of the literature. *Child Adolesc Ment Health*. 2021;26(1):3–14.