



Decision-Making and Implications of Genital Surgery in Intersex Individuals in the Arab World: A Case Series

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Abstract

Background: Knowledge, clinical guidelines, and medicolegal frameworks regarding intersex individuals are inexistent in the Arab world. Some medical professionals view intersexuality as a disorder of sexual development that often needs genital surgery to correct while others view intersexuality as a natural variation along the sex spectrum. No study to date addresses the vast gap in the literature.

Methods: We contacted eleven non-governmental and civil society organizations involved in matters of sexuality and gender in the Arab world through email. Eight organizations answered but only one, Helem, had been directly involved in supporting intersex individuals and agreed to an interview. We conducted a semi-structured interview with Helem after consent was taken from intersex individuals or their legal guardians to share their experiences.

Results: We studied three cases of intersex individuals, of which two underwent genital surgery (GS) at a young age. The surgeries were experimental in nature and had negative health consequences. Decision-making is influenced by physician factors, notably lack of knowledge, and parental factors, like stigma. Sociocultural reasons factor in the decision more than scientific evidence. Physicians, in the cases presented, dealt with intersexuality as a rare pathology requiring urgent surgical intervention. Parents of intersex individuals suffer significant psychosocial stressors.

Conclusion: Medical professionals are ill-equipped to deal with intersex individuals in the Arab world, often performing unethical and abusive practices for which they are not held accountable. Parents' education and referral to intersex-knowledgeable physicians seem to deter parents from opting for genital surgery. Intersexuality is severely understudied and ignored in the medical field. Guidelines and medicolegal frameworks are required to address this issue.

Keywords: *Intersex, Disorders of Sex Development, Surgery, Ambiguous Genitalia, Genital, Arab*

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Introduction

Intersexuality, medically denoted as disorders/differences in sex development, is characterized by a difference in genitals, gonads, or anatomic sex that are not typical of male or female bodies. Intersexuality is highly heterogeneous with currently different medical management strategies [1]. Intersexuality is related to biological sex characteristics and is different from gender identity, the internal and inherent feeling of being a man, woman, and/or gender non-conforming regardless of the person's sex [2]. Intersexuality results from unusual differences in the development of the endocrine and reproductive systems resulting from chromosomal differences (e.g. Turner Syndrome), monogenic mutations (e.g. congenital adrenal hyperplasia), or complex differences or syndromes [3]. Clinically, intersex individuals have heterogeneous presentations which range from genital atypia to pubertal differences, or fertility concerns. Hence, many may be discovered intersex in their infancy while others may never know before adulthood [4].

That being said, intersex individuals face stigma and discrimination [5] to the extent of being considered a curse or a bad omen in certain areas, leading to infanticide [6]. In the medical community, there is an ongoing debate on whether intersexuality should be considered a pathology under "Disorders of Sexual Development" or whether it should be considered a "third sex", a natural variant along a non-binary sex spectrum [5,7]. This debate raises the issue of genital surgeries (GS) intended to change the biology of intersex individuals, usually children, to fit the binary standards of male and female [8]. 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" [9]. While some advocate for early GS in the first months or years of life is the best course of action, 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 [8].

In the Arab world particularly, knowledge and medicolegal frameworks about intersexuality are inexistent with no publications to date on the matter. Therefore, to the best of our knowledge, this is a first-of-its-kind study aiming to fill the gap in the literature around intersexuality in this region of the world. We aim to highlight the experiences of three Arab intersex individuals, physicians' attitudes towards intersexuality, and variables factoring in the decision-making process of genital surgeries and their implications.

Methods

This is a retrospective single-center non-consecutive case series. We contacted eleven non-governmental and civil society organizations involved in matters of sexuality and gender in the Arab world through email. Eight organizations answered but only one, Helem, reported being directly involved in supporting intersex individuals and agreed to an online interview. Helem (Arabic for "dream") is one of the first-ever LGBTQIA+ advocacy Non-Governmental Organizations (NGOs) in the region, based in Lebanon, aiming to eradicate discrimination [10]. It provides services to the LGBTQIA+ community including casework, medical services, and psychosocial support. We conducted a semi-structured interview with Helem's Manager and the Senior Protection Officer for Case Management. The interview consisted of questions regarding intersex individuals' experiences, parental experiences, doctors' knowledge and attitudes, societal views, and current laws. Helem had taken consent from intersex individuals or their legal guardians to share their experiences before our interview. This study was approved by the Lebanese University Institutional Review Board and was done under Helem's confidentiality policies. In a de-identified manner, Helem representatives shared three cases of intersex individuals they worked with, arbitrarily named Nour, Rayan, and Farah. All three authors were present during the interview. Two of the authors were

responsible for transcribing the conversation which was directly compared following the interview.

Results

Case 1: Nour

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". When he was nine, his parents took him to undergo GS into female biology. The surgeon thought that Nour would "become a girl" later on based on an analysis of the hormone panel and physical exam. Nour was prevented by his parents from talking about the incident and did not discover he was intersex until his early thirties. When Nour sought Helem's doctors, he showed deteriorating health including brittle bone, low estrogen, low testosterone, post-traumatic stress disorder (PTSD), and severe depression with suicidal ideations. The surgery seemed to have been experimental. Helem's representatives affirmed that this is not an uncommon practice. They conceptualize that this is partially due to physicians' lack of knowledge of the procedure, the willingness to unethically experiment, and the "pride" of some Arab physicians in never admitting they do not know.

Case 2: Farah

Farah is a nine-year-old Lebanese intersex child referred to Helem a few months after they underwent GS. Originally, Farah's parents thought the child was biologically male. However, during puberty, Farah started developing female secondary sexual characteristics. This led the parents to seek a doctor that decided the child was in need of GS which was experimentally performed. Farah's laboratory tests before the surgery had shown no abnormalities. Currently, the parents are feeling guilty and regret the decision to approve the surgery. A major reason for this is the mental health

consequences Farah suffered after the surgery. Farah felt depressed and uncomfortable with their new body. Additionally, Farah is still currently discovering their gender identity. The parents state that they will support Farah in whatever gender they identify with later on.

Case 3: Rayan

Rayan is a two months-old infant. His parents, non-Lebanese Arabs, were in Lebanon when they took Rayan to get vaccinated. Upon conducting a routine physical examination, Rayan's doctor was overtly shocked and panicked when she saw Rayan's genitals. Consequently, she took a photo of Rayan's genitals without parental consent and called multiple healthcare personnel from the hospital to see the infant. Based solely on the visual appearance and without ordering any tests, she informed the parents that Rayan was in need of urgent surgery or else negative health outcomes would develop. Naturally, Rayan's parents were anxious, scared, and confused. They sought a second opinion in their home country which also ended in a surgical recommendation. Rayan's parents were then put in contact with Helem who recommended a third physician in their home country. The latter, after running laboratory tests, stated that Rayan is healthy and there is no threat to their life. The parents still felt uneasy from the conflicting recommendations. This was exacerbated by the extended family that discovered Rayan was a "Khuntha" (Arabic for "hermaphrodite", used as a derogatory term) and pressured the parents to surgically "fix" Rayan, citing multiple cultural and religious reasons like "God will hold you accountable". Consequently, Helem provided the parents with educational sessions on intersexuality and relayed Rayan to a Lebanese pediatric endocrinologist which confirmed that Rayan is in good health with the exception of a minor urological problem. No GS was needed, and therefore, the parents declined the surgery. The choice of doing it or not will rely on Rayan's decision when they grow up, the parents affirmed. However, Rayan's parents are still worried

about the bullying and mental health consequences non-conforming individuals face in their society.

Other Inquiries

When asked why Nour's first doctor reacted this way, Helem representatives stated that it might be related to the fear of biological consequences often unfounded, 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". 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. When we asked why don't parents of intersex individuals sue physicians for unethical experimentation, a major reason they cited was stigma and the social repercussions on intersex individuals and their parents. Another reason is the lack of LGBTQIA+ protection laws in the region as well as the lack of clinical guidelines. For example, 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". On 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 managing intersex individuals.

Discussion

Both physician and parental factors are considered when choosing for or against GS. Physician factors include often unfounded fear of biological consequences, sociocultural perceptions, lack of knowledge and guidelines, and pride of the Arab physician. Parental factors include the parents' preferred sex depending on their needs, stigma and discrimination, lack of intersex protection laws, inaccessibility to

intersex-knowledgeable physicians, and community socio-cultural and religious pressures.

1. Laws & Data

The complete inexistence of data on intersex individuals in this region can be seen as a result of stigma, religious, socio-cultural reasons, and lack of knowledge. Additionally, it could be related to the laws of the countries, where LGBTQ people are criminalized [9]. While there are no laws concerning intersexuality, there is a history of interpreting existing laws to fit the socio-cultural narrative [11].

2. Perception of Intersex Individuals

Similar to Nour's, it is common for many individuals to be lied to about their identity [12]. Discrimination and demonization are common practices against intersex individuals [4,13], which was evident in Nour's and Rayan's cases. They showcase how society often deals with intersex individuals with misunderstanding and fear. Parents often initially encounter doctors who view intersexuality as a rare pathology needing fixing (often urgently). Physicians' lack of knowledge is evident in all three cases presented, whether on intersex health or genital surgery. Decisions seem to be influenced by socio-cultural reasons rather than evidence. There is a theme of doctors not acknowledging their limitations, often a symptom of the paternalistic approach that many patients often willingly subscribe to [14]. Finally, as evidenced in Rayan's case, there can be a clear breach of ethical principles like confidentiality without consequences. When it comes to intersexuality, there are no guidelines, accountability, or oversight in the Arab world.

3. GS-Related Harm

Nour and Farah, who underwent GS at an early age, reported poor mental and physical health. This is expected as 20% of intersex individuals reported these procedures to have a very negative effect on their life. This is especially true for clitoridectomy and gonadectomy. Common complications of these surgeries are vaginal or urethral

stenosis, urethral fistula, loss of clitoral or glans sensation, shortened penile length, and dissatisfaction with anatomical appearance or function. Satisfaction varied depending on the type of surgery done [15,16]. Additionally, fertility preservation options are limited [17]. Following GS, dissatisfaction with sexual life is common with consequences like dyspareunia, arousal, and sexual anxiety [18]. Moreover, PTSD, depression, and anxiety are prevalent in intersex individuals, especially in people who discovered their intersexuality late like in Nour's case [19]. GS seems to confer more harm than benefit in the cases presented. This may be partially due to the experimental nature of the surgeries. Moreover, as with Nour, inadequate gender affirmation is another common consequence of GS [20].

4. Psychosocial Consequences for Parents

In the cases of Farah and Rayan, the parents of these intersex children suffered notable psychological stress. This is common as overall anxiety is much higher in this population and could be as high as anxiety in caregivers of heart failure and stroke patients [21]. 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 [22]. Finally, the anxiety about the future of their child is rooted in reality, as intersex individuals are more likely to be bullied at school [23]. Another thing to highlight is the financial strain intersex parents in the Arab world are under, as they often have to pay for travel, multiple physicians, and the GS. Despite that, Rayan's story is rare in the Arab world where the GS was not performed. This is likely attributed to Helem's education and interventions. Unlike Farah's parents, who intended to help their child but were not adequately informed by the physician on the matter, Rayan's parents had the opportunity to make an informed decision.

5. Strengths and Limitations

This study is to the best of our knowledge,

the first in the region to discuss the experiences of intersex individuals, the effects of genital surgeries, and the psychosocial consequences on both the individual and their guardians. It highlights the issue of genital surgery from a holistic and patient-centered view beyond clinical diagnoses and medical and surgical interventions. However, the study only looked at three cases that were reported by a single organization. While the study results offer valuable insight, the experiences of three people can not be generalized to the experiences of intersex individuals in the Arab region. Further multi-centered quantitative research in hospital settings looking at the variables we presented (e.g. parental attitudes, doctor attitudes, interventions done) and other variables (e.g. cultural background of parents, hospital policies, doctor's professional background) could offer a more robust view of the situation of intersex individuals in the region and could serve a basis for future guidelines and recommendations.

Conclusion

From the cases we presented, we hypothesize that most medical professionals are ill-equipped to deal with intersex individuals in the Arab world. They often perform unethical and abusive practices for which they are not held accountable. Intersexuality is still viewed as a pathology that seemingly needs urgent interventions. Often, GS is recommended without informing parents of alternative options or explaining the risks. A multitude of factors plays a role in deciding on GS. In the three cases we studied, GS proved severely detrimental to physical and mental health. Additionally, parent education and referral to intersex-knowledgeable physicians seem to deter parents from opting for GS. In conclusion, intersexuality is severely understudied and ignored in the medical field which is leading to questionable, unethical, and abusive practices towards intersex children. Further multi-centered quantitative studies are needed. Guidelines and medicolegal frameworks are required to address this issue.

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