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To cite this article: Tanvir Alim, Md. Shihab & Adnan Hossain (2022) Experiences of intersex individuals in Bangladesh: some reflections, *Sexual and Reproductive Health Matters*, 29:2, 2149054, DOI: [10.1080/26410397.2022.2149054](https://doi.org/10.1080/26410397.2022.2149054)

To link to this article: <https://doi.org/10.1080/26410397.2022.2149054>



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Published online: 20 Dec 2022.



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Experiences of intersex individuals in Bangladesh: some reflections

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Keywords: intersex, surgery, justice, advocacy, Bangladesh, South Asia, Hijra, LGBTIQ+

“When I was an adolescent back in 2012, there was no change in my body, which was a topic of discussion in my family and school. My younger brother started growing facial hair, but I had no facial hair, which was a shame. As I am from a well-reputed family with political affiliation, we had to attend many social get-togethers, and my father always introduced me as his elder son. People used to give me a look, and I remember I was uncomfortable all the time. My parents wanted a permanent solution to this situation as they worried about my future. They also thought of the loss of the family reputation and thus took me to a hormone specialist for the first time. The whole experience was one of trauma for me. The doctor undressed me in front of others to inspect my genitalia, which was a very shocking moment. I had to undergo a series of diagnostic tests, and after the ultrasonography report, the doctor proposed to convert me into a girl through surgery. My parents did not like his suggestion. They took me to other doctors for second opinions, and I was subjected to similar procedures repeatedly. Such check-ups were always a very tiring and humiliating process for me. One of my relatives who knows about the issue recommended to my parents that I should see an endocrinologist at Bangabandhu Sheikh Mujib Medical University Hospital (BSMMU), a well-known hospital in the country. When I went there, other patients approached me and asked: ‘What is your problem, you do not look sick at all. Why are you here? I was fifteen years old at that

time. Before the surgery, there was a board meeting of urologists and endocrinologists, but there was no psychosexual counselling. I was very uncomfortable during the doctors’ consultation with my parents as they always asked my parents: ‘How would you like to see your child? As a boy or a girl?’ My parents took me for the surgery, saying it would be a laparoscopy. Neither the doctors nor my parents informed me that they were removing the uterus and the ovary from my body.”

The vignette above concerns the lived experiences of Shihab, the second author of this paper. This collaboratively authored essay draws on Shihab’s experiences and the experiences of four other intersex persons. The essay is a set of reflections emerging out of prolonged conversations in which we, the authors, compared notes on our respective experiences as activist-scholar (Tanvir), activist (Shihab) and researcher-activist (Adnan) working among gender/sexually marginalised communities in Bangladesh. Based on interviews with five intersex people, we attempt to bring into view the social stigmatisation and medical violence to which intersex bodies are subjected. We show that intersexuality is predominantly conceived as a bio-medical problem that can be corrected with surgical intervention. There is neither any advocacy nor activism in sight to contest the authority of bio-medical and cultural discourses that sanction and perpetuate a dimorphic model of gender and sexuality.

Background

Intersex refers to individuals born with sex characteristics which are not typically male or female. Intersex people live and identify their gender in a variety of ways, just like non-intersex people, including women, men, intersex women, intersex men, intersex persons, and non-binary, intersex persons. Intersex people have existed throughout history and across cultures. However, for a long time, intersex issues remained invisible. The very term intersex was not used until recently to describe differences in sex characteristics. Importantly, not everyone born with differences in sex development identifies as intersex.

There is very little knowledge about the various kinds of harassment and violence that intersex people experience in Bangladesh. While public knowledge about people that are neither men nor women is widespread in South Asia and the media are often flooded with images and stories of such “liminal figures”, very little attention has been focused on people that are intersex or the violence of surgeries and socio-medical traumas that they experience. Part of the problem here, as we argue, stems from the way intersex people are often conflated with hijras, a long-established sub-culture of people typically assigned a male gender at birth who later identify themselves as either women or non-men in Bangladesh and beyond.^{1,2} The politics of this popular representation of the hijras as intersex and vice versa is beyond the scope of this paper but suffice it to say here that people with the intersex condition are marked as special beings in Bangladeshi hijra cosmologies. However, intersex people are rarely part of the hijra community in Bangladesh.¹ The mainstream society, however, makes no distinction between the two, a conflation that generates cultural confusion, obscures sources of power inequalities and naturalises the social marginalisation of intersex persons and hijras.³

That the mainstream society, including the Bangladesh government, deems hijras to be born with an intersex condition is further evident in how hijras in Bangladesh were legally recognised as a distinct sex/gender through a policy decision adopted by the Government of Bangladesh in 2013.⁴ In the aftermath of their recognition, a policy paper guiding the implementation of the livelihood development programme of the hijras by the Ministry of Social Welfare defines the hijras as “congenitally sexually

handicapped people who, because of either genetic or physical conditions, cannot be classified as either male or female. Chromosomal anomalies are the main cause for the birth of such sexually defective people” (Adnan’s translation).

The cultural conflation of people born with intersex conditions with hijras further invisibilises the specific issues of intersex persons. It also has implications for how families and society treat children born with an intersex condition. For example, there is a tendency among people across the social classes to hide intersex children from society, which often reads intersexuality as a form of disability likely to have resulted from sins committed by the parents. The belief that people with the intersex condition will not be able to form heteronormative families or beget children further adds to the stigmatisation of the families in which they are born. Although efforts are made to align such children with a gender often chosen by medical doctors at an early stage of the child’s development, very little research or knowledge is available on what happens to them when they grow up in the context of Bangladesh.

However, more recently, global intersex initiatives and regional mobilisation of intersex persons in Asia have resulted in a growing understanding of intersex being a distinct constituency separable from the hijras.

In 2012, the United Nations developed the “Born Free and Equal”^{*} campaign that sets out the scope of the legal obligations of Member States in respect of the rights of LGBTI people, and also integrates, for the first time, recommendations in respect of the rights of intersex persons.^{*} Across the Asian region, a new group of intersex activists has emerged as a regional network of member organisations and intersex voices called Intersex Asia.[†] Its role as a regional organisation is to empower and build the capacity of intersex activists and communities, enhance intersex visibility, spread awareness about intersex issues within and outside the intersex community and advocate for law and policy reforms in Asia.

The Bangladesh Intersex Forum, an emergent intersex activist group in Bangladesh, is a member

^{*}The latest version of the document is as follows: https://www.ohchr.org/sites/default/files/Documents/Publications/Born_Free_and_Equal_WEB.pdf.

[†]<https://intersexasia.org/>.

of Intersex Asia. It is a community-based organisation established in 2021 to advance intersex justice in Bangladesh. Some of the Bangladesh Intersex Forum members first chanced upon the term “intersex” via the internet or LGBT activist circles in Bangladesh. Other members of the Bangladesh Intersex Forum came to learn about the term after they became part of this forum. A national consultation with intersex people in 2020 was organised by the Bandhu Social Welfare Society, one of the largest NGOs working on gender and sexual diversity in Bangladesh.⁵

Against such a backdrop, we position this paper as a preliminary attempt to produce knowledge that will help counter social prejudice and systematic othering of intersex people in Bangladesh and beyond. We believe that expanding the popular understanding of the various challenges that intersex people face is the first step towards advancing intersex wellbeing and justice.

The reflections and discussion that follow are based on interviews with five intersex persons, including the second author, identified through the Bangladesh Intersex Forum (BIF). Shihab, the second author of this perspective paper, is currently the president of this network. Ethical clearance for this project was obtained on 6th July 2021 from Research Initiative Bangladesh (RIB), a Bangladeshi research organisation. The guideline for ethical and good research practice adopted by RIB was followed throughout the research process.

All three authors were involved in these interviews at various levels. The interviews focused mostly on the social and medical experiences of the interviewees. Out of these five persons, three had been subjected to surgical procedures, and two participants had gone through several

diagnostic tests. Below is a summary of some basic information about the research participants to help the readers get a sense of the context and background of the research participants (Table 1). Various aspects of their interviews are also taken up for analysis in the latter part of this paper.

Social experiences of stigma and their consequences for intersex persons and their families

All the interviewees reported that confusion and disappointment followed their birth because of their intersexual condition. Despite being too young to recollect the actual events, they all heard their parents talk about how they felt ashamed when the sex of the newborn children could not be determined. Such stories spread like wildfire among relatives and neighbours. Neighbours and relatives gossiped about how these children would grow up to become hijras and social pariahs.

In Shihab’s case, it was mainly due to the social pressure from the relatives that their parents were forced to take them to doctors to find a possible cure. Part of the issue from the onset was the fear that Shihab’s family would be unable to find a family ready to accept Shihab’s sister as a bride because of Shihab’s intersexual condition. Families may back off from marrying children into families with people with the intersex condition because of the assumption that the children born to parents with intersex siblings may end up with similar conditions. Families with intersex children are at constant risk of being stigmatised in the social and public eye. This, however, turned out to be true in Shihab’s case, as on several occasions, their

Table 1. Profile of the interviewees

Name	Preferred pronoun	Current age	Location	Economic status
Nobin	They/them	29	Dhaka	Middle class
Monisha	He/him	19	Rajshahi	Lower class
Shathi	She/her	40	Rajshahi	Lower middle class
Lily	She/her	18	Rajshahi	Lower middle class
Md Shihab	They/them	23	Barisal	Upper middle class

Note: The participants have stated these economic status during their interview.

sister's weddings were called off after the groom's families found out about Shihab's condition. Consequently, intersex people often have to bear the brunt of social prejudice for which blame is placed squarely on them. According to Shihab, such incidents undermined their social position within their immediate and extended family.

In their interview, Nobin talked about the enormous pressure from the neighbours and society at large, which made their existence a continuous battle with social humiliation and shame. They further asserted how it was all too much for them as they were growing up and that their having to deal with such a situation from an early age resulted in having various psychosocial stress and disorders.

"In keeping with the doctors' advice, I was raised as a girl till I was 5. Then the doctors told my parents that I was a boy. The female name given to me and by which I was known by then was suddenly changed to that of a male name to the utter consternation of the neighbors. The news spread, and ordinary people and journalists would come from all over the place to see me as if I were an animal in the zoo. From then on, fear and shame became permanent companions in my life. Consequently, I started to develop difficulties dealing with my emotions."

When Monisha was born, the midwife in their village tagged him as a hijra as, according to her, his "genital was more like that of a woman". Monisha, however, pressed on being seen as a male as he was growing up. He used to love wearing male clothes and keeping short hair like a man, as it is socially understood in Bangladesh. However, his family forced him to keep long hair and wear a sari and bangles from when he turned 14.

Shati's story also speaks to Nobin's case, as there was confusion over whether Shati was male or female based on genitals. Shati's sibling earlier was also born with a similar condition. The village midwife told the parents that Shati, too, was born a hijra.

Lily was 14 years old when she was married to a man in their locality, but she was still staying with her parents rather than with her husband. She did not attain menarche, which made her parents anxious, and she was taken to the doctor. The consultation with the doctor revealed that Lily was a person with DSD (disorders of sexual development). Later Lily's sex identity was revealed to

others in the local community, for which she had to endure constant bullying. People suddenly started to stigmatise and tease her as a hijra. She became the talk of the town as someone with genital ambiguity. Lily's parents tried to speak to her husband's family, but they showed no interest in continuing the relationship, and Lily's marriage was terminated.

The social stigma and harassment that intersex people experience persist in their formal schooling settings. Although the economic and social background of the families determine whether intersex children will end up in schools or not, being intersex or born with intersex lowers the chances of attending school. On the one hand, many families choose not to put their intersex children into school because of social stigma and the desire to hide them from society. On the other hand, these children are routinely bullied and teased once they start attending school and may drop out. This was revealed in the following quote from Nobin's interview.

"Although the doctors told my parents that I was a boy, my physical developments contradicted such a reading as I started to develop breasts when I was thirteen. As a result, I did not want to go to school anymore. Earlier I used to be bullied and harassed as a hijra in my school. The physical changes just made it impossible for me to continue my education which also affected my ability to gain employment as I cannot produce certificates."

Medical experiences

Labelling as sexually handicapped

All the doctors that saw our interviewees characterised their conditions as DSD. They further explained DSD to be some kind of a genetic problem and/or the state of being sexually handicapped.³ Our interviewees found such characterisations of their conditions deeply humiliating, even though they may not have perceived such naming as problematic when they were first taken to the doctors. Being diagnosed as sexually handicapped from early childhood made two interviewees so traumatised that they contemplated committing suicide on several occasions.

Social pressure from close relatives forced Shathi's parents to take their two intersex children to seek medical help. There was a maternity clinic in the area where the two children were first taken for medical consultation. The doctor checked their

bodies and asked them to undergo some diagnostic tests. Based on the reports, the doctor then referred Shathi and her sister to Dhaka Medical College. There, the doctor diagnosed Shathi and her sister as DSD patients. The doctor explained that it was due to the problem of the sex chromosome during birth that the two of them were born this way. He further asserted to Shathi's parents that *"Your two daughters are sexually handicapped. They will never be able to get married, never be mothers, but through surgery, we will be able to bring them back to normal life."*

The trauma of medical procedures and their aftermath

All the interviewees spoke about their experiences undergoing several diagnostic tests prescribed by their doctors. One interviewee stated that they had to undergo forty diagnostic tests, including cortisol, radiology, haematology, complete urine analysis, biochemistry and ultra-sonogram. As some of the tests were not available in the nearby diagnostic centres, some families had to travel long distances to find the right centres that provided the required tests. Two participants stated that they had to go through the same tests repeatedly, which was physically and mentally tiring for both their parents and themselves. They further opined that the fact that they were asked to repeat the same tests over and over again raises a doubt as to whether the doctors were clueless about what the issue was and whether they were not very familiar with intersex bodies.

In the first five years of their life, Nobin was brought to Dhaka regularly for medical check-ups and procedures, including four surgeries. At one point, the surgeons removed Nobin's testicles, suggesting that it was a hernia, but later it was realised that it was the testicles that the doctors had *accidentally* removed. Later, Nobin underwent two more surgeries when they turned nine. In their interview, Nobin mentioned that one of the surgeries took 73 hours. They were unconscious for 63 hours after the surgery. These surgeries – which were so critical that there were doubts about whether they would survive the surgery – remain for them to this day a traumatising memory. Nobin is still living with the after-effects of the surgery; they can no longer walk fast as fast body movement causes their skin to stretch, which is painful.

Monisha was taken to a doctor by his parents at the age of 10, and the doctor identified him as a

DSD patient. Conventionally, society expects adolescent girls to undergo many physical changes (breast development, menstruation, genital structure). There were no such changes in his case. The doctor assured his parents that he would have physical changes if he underwent some surgeries. However, the surgeries failed to produce the desired changes. He now has difficulty urinating and, at times, serious loss of physical energy and occasional pain at the surgical site.

In their interview, Shihab stated:

"I was given testosterone hormone for a long time after my surgery, but this did not change anything. I have anxiety and other health-related issues now, which I believe have been caused by that hormone therapy."

The interviews revealed that the doctors rarely followed up on how the patients were doing. All the interviewees endured enormous suffering as a consequence of their surgeries. They all had difficulty walking or using the toilet and were not given any advice on possible infection or other risks associated with the procedures. When patients visited the doctors after a few years, the doctors could not even recall the details of the patients, nor did they have the medical files stored in the clinics.

Violations of patients' right to information and privacy

Those who had surgery in childhood said that the doctors removed their body parts, such as ovaries or testicles, about which they had no clue before the surgery. Their parents were given explanations in such a manner that they were left with no choice but to consent to these medical decisions with the hope that their children would become either male or female via these surgical procedures.

All the research participants felt that the doctors did not protect their privacy. Often, the doctors asked them to remove their clothes in front of their parents and other people during the consultation. Being asked to undress in front of parents and others emerged as a significant trope of trauma in the interviews.

One interviewee stated that the doctor spoke with the nurse in the presence of other clients, which was embarrassing and shameful for her. Shathi mentioned that she felt ashamed as a few of her relatives and acquaintances were working in the diagnostic centre and could easily find

out about her intersex condition. Because of the nature of the tests, relatives and villagers asked if she had had premarital intercourse. She added that the doctors were touching her genitals while making remarks about why her genitals were the way they were. While Shathi did not know how to react to such a remark, the silence that ensued from these remarks tore her self-respect to pieces.

According to one research participant, their doctor asked a nurse to check their genital condition as the doctor was uncomfortable doing it himself. Another interviewee disclosed that her pants were taken off, and the nurse checked her genitals in front of everyone in the chamber, which was a horrifying experience that eventually resulted in trauma and stress.

Lily's parents took her to a doctor at a time when she had no understanding of her own body. But she still recalled that the doctor looked at her genitals in the nurse's and cleaning staff's presence. She also remembers being embarrassed and scared when the doctor examined her genitals and described her condition to the nurse. The doctor recommended some further tests and checked her genitals twice more, during which no privacy was maintained.

The high cost of medical interventions

Although there is a dearth of data on the number of intersex children that are taken to doctors, what emerges from our interviews is that only families with financial abilities can bear the expenses associated with such surgeries. For example, in the case of Monisha, whose family was engaged in agriculture, a piece of their land had to be sold for the surgeries to take place.

Shati's family could not afford surgery. Their only property was a herd of cows and a house. They had to sell their cows to pay for the diagnostic tests. Later the surgery had to be postponed due to financial difficulty.

All the money that Lily's parents had gathered for Lily's wedding had to be spent on her treatment. Although expenses associated with such surgeries vary depending on the case and the type of surgery, Shihab's interview indicates that the cosmetic surgery cost Shihab's family US\$ 5993, and this was just one of the surgeries in a series of operations performed on their body. Nobin indicated in their interview that the multiple surgeries they had to undergo had cost their family about US\$ 7000 since their childhood.

Concluding thoughts

The discussion above shows how intersex bodies are subject to various types of social and medical violence in Bangladesh. Such violence, however, is not merely physical but rooted deeply in the dominant dimorphic model of gender and sexuality. Even though hijras, with whom intersex bodies are confused and conflated, are publicly recognised as a third liminal category, neither the legal recognition of hijras as a distinct sex/gender nor the cultural accommodation of such a "thirdness" works to engender a socio-cultural process that accepts intersex bodies in practice. The concept of a third gender/sex that permeates Bangladeshi society can be seen as a form of ridiculed liminality to which those failing to be either sufficiently male or female are relegated. Because such a thirdness is not on an equal footing with the so-called first and second gender/sex, it paradoxically reinscribes the binary notion of a two-gender system.^{4,6}

The interviews also establish a lack of treatment and care protocols for intersex children. Although further research is needed to understand the various medical practices toward intersex children, what seems clear, based on our interviews, is that decisions taken by the doctors and surgeons take precedence over those of the parents and children. While it is difficult to say whether these surgeries often conducted on intersex bodies are medically necessary, such surgeries are often advertised in the media in Bangladesh as examples of exceptional surgical feats. The recent launching of a specialised outpatient department in Bangabandhu Sheikh Mujib Medical University Hospital, a front-ranking medical establishment in Bangladesh, to perform corrective surgeries, and its media coverage, testifies to the way surgeons are celebrated for aligning ambiguous bodies with a binary sex/gender system.[‡]

There is, however, no activism or advocacy effort in sight in Bangladesh today that contests such surgeries or the dominance of binary configuration of sex/gender. Even though the term intersex is being taken up in some sexuality and gender-based circles where "I" is added to

[‡]Television news on corrective surgeries for aligning ambiguous bodies with binary sex/gender system https://www.youtube.com/watch?v%3DZIJNaQbRrI0&sa=D&source=docs&ust=1663010771647496&usg=AOvVaw3Uz9X4_i-xHmS32pLEw1LT.

LGBTQ, such inclusion is merely tokenistic, as intersex perspectives and voices are missing. As previously indicated, the recently formed intersex groups are still in a very preliminary stage of maturation. They have limited capacity to engage in activism and advocacy or to campaign to challenge the rampant social stigmatisation and medical violence that intersex persons routinely suffer in Bangladesh. Further research that foregrounds

the voices of intersex persons, is needed to better understand the medical and social aspects concerning intersex people so that intersex wellbeing and justice can be advanced.

Disclosure statement

No potential conflict of interest was reported by the author(s).

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