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Research Article

Adolescents with Disorders of Sex Development: A 3-Year Psychosocial Follow-Up Before and After Gender Reassignment

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Abstract

Objectives: Psychosocial interventions have been increasingly proven to play a key role in a holistic team-oriented approach to disorders of sex development (DSD) care. This article examined the influence of cultural and religious factors on the acceptance of the decision for gender-reassignment surgery. Next, how this patient accepted herself and her body image, and invested in her femininity, was analyzed.

Methods: The study is based on a 3-year follow-up (from 2013 to 2015) of an adolescent with 46,XX DSD, in the mental health department of FANN National University Hospital in Dakar, Senegal. The patient and his/her parents and other family members underwent 12 sessions of counseling and supportive psychotherapy before and after surgical treatment. On average, each session lasted 55 min.

Results: Raised as a boy until the age of 15, the patient initially refused surgical intervention. The parents were also confused, owing to the societal preference for males and the fear of stigmatization. The role of the grandfather was instrumental in the counseling and supportive psychotherapy, as he attributed a masculine and religious given name to the child. The postsurgical anatomy reduced the patient's distress. However, the psychic integration of her bisexuality was ambivalent and accompanied by depressive feelings and intense dream activity. Feminine socialization and environmental learning, conditioned by Wolof traditions and upbringing, were some constraints that affected post-gender reassignment outcomes.

Conclusion: While gender reassignment affects the patient, but it can even more profoundly affect the parent of that is the same sex to whom as the child's sex has been as identified at birth. Counseling and supportive therapy should take into account cultural constraints and transformations within and across the psychological developmental stages.

Keywords

Disorders of sex development; Gender-reassignment; Gender-role behaviors; Adolescence; Developmental psychology; Counseling and supportive therapy; Culture

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Introduction

Disorders of sex development (DSD) are infrequent congenital disorders that are defined as a discrepancy of chromosomal, gonadal, or anatomic sex. DSD are characterized by ambiguous genitalia, and are classified as:

- 46, XX (masculinization of a female),
- 46, XY (under masculinization of a male),
- 46, XX ovotesticular (XX sex reversal) and 46, XY complete gonadal digenesis (XY sex reversal).

The management of DSD is complex and it requires a multidisciplinary team of healthcare professionals [1,2]. Beyond medical or surgical treatments, psychosocial interventions have been increasingly proven to play a key role in a holistic team-oriented approach to DSD management [3]. These latter interventions are provided by mental health workers. A diagnosis of DSD affects the patient and his/her family. A recent longitudinal study [4] and systematic review and meta-analysis [5] reported psychological symptoms and high psychiatric morbidity and suicide rates after gender reassignment. In particular, male-to-females had significantly increased risks for suicide attempts [4]. One role of the mental health workers is to identify and treat the comorbid psychiatric symptoms of both the patient and his/her parents or family members. In addition to this "classic" role, they have to manage many mediating factors, such as appropriate information about the diagnosis, the treatment, and its psychosocial and educational implications [6]. This involves a pre- and post-diagnostic counseling process that must take into account the psychological developmental stages of the child or adolescent born with DSD as well as the cultural context (i.e., the traditional and religious values of the parents).

Some researchers have pointed out the economic, cultural, and religious constraints when managing care for DSD [7,8]. In developing countries, access to care is limited by low per capita income, geographic distance between the parents of the child born with DSD and standard hospitals, and the under-resourcing of technical facilities in hospitals and laboratories. In such cases, an accurate diagnosis is made later. Furthermore, due to the preference for sons in traditional societies, a child born with ambiguous genitalia due to 46, XX DSD (previously termed female-pseudo-hermaphrodites) is raised as a boy. This makes a gender-reassignment medical decision extremely difficult. In addition, even though the parents may consent to gender reassignment, they may experience guilt, anxiety, and depressive symptoms [9].

Although cultural and religious factors have begun to be outlined in studies of DSD management, their implications for the psychosexual developmental of a child or adolescent with DSD have been documented less. In this article, which is based on a follow-up case of an adolescent with 46, XX DSD, the influence of these factors on the acceptance of the decision for gender-reassignment surgery is first examined. How this adolescent accepted herself and her body image, and invested in her femininity, is then analyzed. At every turn, methods that can be used to rise above cultural constraints and to explore transformations within and across the psychological

developmental stages are emphasized. The therapist's approach was guided by both the developmental psychology and psychodynamic perspectives.

Method

The patient was followed up from 2013 to 2015 by the mental health department of FANN National University Hospital in Dakar, Senegal. He/she was referred to us by the urology-andrology service at Aristide Le Dantec University Hospital (Dakar, Senegal). The given names used in this article are fictitious names. Gendered pronouns ("he/she") have been simultaneously used as outlined by the consensus recommendations for when the gender reassignment has not yet been performed [1,10].

Profile of the patient and his/her family

Ali was born into a monogamous family. He/she is 15 years old and is the eldest of five uterine sibling children who are alive and healthy. He/she has three brothers aged 12, 8, and 3 years, and a younger sister aged 18 months. His/her mother is a homemaker and his/her father is a car mechanic. Ali began education at the age of six. His/her schooling was normal until the last class of primary level education. He/she stopped his/her studies in this class when his/her first menstrual period appeared and his/her chest began to develop.

Diagnosis of DSD and its evolution

After several months of pregnancy, ultrasound images had not determined the sex of the child. At birth, the midwife told the mother that her child might be a girl. She referred them to the urology-andrology service for more information. The urologist confirmed to the parents that their child might be a girl but they had to conduct a karyotype test and wait one year before the surgical intervention. The parents said that they were stunned by this information. According to Islam, they had to name the child after the child's sex was assigned. They were confused and the father said he cautiously wanted to give a neutral Muslim name to their child (neither male nor female). On the religious ceremony day, the maternal grandfather brought an Imam who decreed that the child was a male; hence, the male name "Ali" was given to the child.

At the age of 18 months and at 3 years, Ali underwent two exploratory laparotomies in order to see if the internal genitalia were female. The doctors were not reassured and asked for a karyotype test. Due to lack of financial resources, the karyotype test was done after several years, which revealed ambiguous genitalia in line with 46, XX DSD (masculinization of a female). Surgical treatment for gender-reassignment was recommended by the urology-andrology service. To prepare them to accept this treatment, the patient and his/her parents were referred to the mental health service.

Follow-up procedures

The mental health service met the patient 12 times: five times before and seven times after the surgical treatment. The team also met his/her parents and other family members (maternal grandfather and uncle). On average, each session lasted 55 minutes (35 to 120 min). The approach consisted of counseling and supportive psychotherapy. After the surgery, drawing was used as a therapeutic technique in order to help the patient to express his/her feelings and imaginary activities. The contents of the sessions are briefly described below, and analyzed and discussed further.

Observations

Before gender-reassignment surgery

First session: Ali was accompanied by his/her mother. He/she looked deprived, with his/her head down and watery eyes. He/she was dressed in blue jean pants, a T-shirt, and a baggy jacket. His/her mother reported that despite the heat, he/she had to dress in this way to avoid people being aware of his/her breasts. The contact with him/her was difficult. He/she did not answer any questions.

Second session: Accompanied by his/her mother, he/she was dressed in the same clothes as at the first session. He/she was first met alone. He/she managed to express his/her malaise: "The doctors told me they must remove my sex organ, but I want my breasts removed instead even though I will continue to have my monthly menses." The onset of his/her first menses was discussed, which he/she described as a moment of shame. His/her mother reported that he/she no longer went to school, and added that she was tired of seeing her child suffer, hiding his/her body under baggy clothes. However, Ali retorted that he only wants to be a boy.

Third session: Ali came with his/her parents. His father stated: "Ali refuses to have the surgical intervention. I often talk with him/her to get him to accept it. Since his/her childhood, the small size of his/her sex organ has always bothered us and the fact that he/she does not urinate in the same way as his/her friends. I am very confused. When I see him/her playing with his/her friends, I see that he/she is a girl." Ali was mute, with eyes misted with tears. His only words were that he/she rejected the surgery.

Fourth session: Ali came with both of his/her parents and grandfather. The latter and the Iman insisted at birth (seventh day religious ceremony) to give to the child a male name. He reported: "I agree that my grandson undergo surgery." He then addressed Ali: "You must accept the truth, it's not worth crying." The meeting with Ali continued, with Ali finally agreeing to the medical decision, stating, "I accept it because my grandfather asked me."

Fifth session: Ali came with his/her mother. Supported by his/her mother, he/she said that he/she was ready for surgery. The mother said she accepted the fate of her child because it is God's will and added that her husband is still in shock about the surgical intervention. The urologist was informed about the patient and his/her parents' decision and the necessity for post-surgery supportive therapy.

After gender-reassignment surgery

The surgery took place after nearly 8 months of counseling. After surgery, the adolescent left her parents to live with her maternal grandmother in another district. Her mother reported, "We had to hide her to avoid rumors and discrimination." The grandmother gave her the name of "Mariama." Ali became Mariama. Then, the parents began the administrative procedures to change her birth certificate. For the next sessions, Mariama came with her mother or her maternal uncle.

Sixth session: She wore a traditional dress, with a long skirt and fabric loincloth. She had a headscarf, earrings, and nail polish. She said, "Nothing pleases me in my current change. My father often comes to visit me. But when he sees me, his head is down. He keeps calling me 'Ali'." She expressed nostalgia about seeing her old friends.

Seventh session: She wore a feminine dress, with high-waisted skinny jean pants. She had long braids and earrings. She was quiet

and smiling. She said that she now has friends who are girls: "We talk about things such as girls 'outfits'." Her mother added that she likes talking about clothing. She often pays her visits but her father rarely visits her. The mother indicated that the father said he could not look Mariama in the face. His younger brother of 8-years-old also visited her. During this visit, he said "But it's Ali! I recognize him. Why does he wear girls' clothes and shoes?" The grandmother and mother asked him to shut up.

Eighth and ninth sessions: At the eighth session, Mariama looked sullen. She said that she had dreams in which she always saw herself as a boy. She was asked to make drawings to let her thoughts and feelings emerge. During these sessions, she made many drawings. Among others, she drew a market bucket containing vegetables and fishes (Figure 1). She learnt to help with the housework. She said that in the future she would learn sewing or hairdressing.

Tenth session: Mariama was dressed appropriately and wore makeup. She was asked to come with her maternal uncle with whom she lives along with the maternal grandmother. Her uncle reported, "Mariama fits in better and better socially. But, she misunderstands a lot." He also said, "Given our precarious financial situation, we have failed to meet some of her needs, such as female jewelry or clothes." At that session, she drew a spoon that looked like an erect phallus (Figure 2).

Eleventh session: She was accompanied by her mother and younger sister. She had gone to spend the end-of-year holidays with her parents and went back to her grandmother. Her mother said, "She came home at dusk and went back at night to avoid being seen. After her departure, her brothers asked me why Ali wore female clothes. I told them Mariama is a girl." From her perspective, Mariama found that seeing her brothers and sister made her feel positive.

Twelfth session: She became more and more feminine displaying her femininity through her hairstyle with long braids and her clothing. She wore earrings and lipstick. She was smiling. Interpersonal contact was much improved. At this session, she quickly made many drawings. She drew, among other subjects, a mortar with a pestle (Figure 3) and a furnace (Figure 4). She said that she would like to return to her parents and to start training.

After surgical treatment, the relationship between the mother and father of Mariama deteriorated. Gradually, he no longer visited his daughter or took care of her needs. Seven months after the surgery, he married a second wife with whom he spent half the days of the week.

Figure 1: A market bucket containing vegetables and fishes.

Figure 2: A spoon.

Figure 3: A mortar with a pestle.

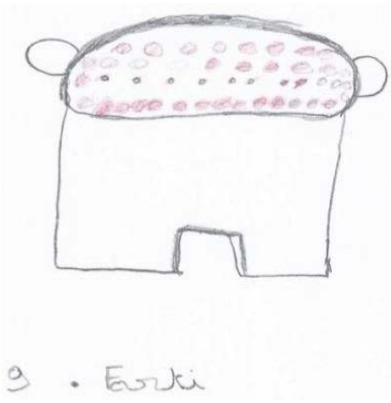

Figure 4: A furnace.

Discussion

Later diagnosis and gender-reassignment surgery in children with DSD can lead to severe disturbances in gender identity and in the identification of the parents with their child. When gender identity has been established under social pressures, and been influenced by cultural and religious factors, the medical decision for gender

reassignment is extremely stressful for both parents and family members [11]. This stressful situation does not spare healthcare professionals.

The purpose of the counseling and supportive psychotherapy was twofold. The first aim was to support the patient in the process of acceptance of the surgical intervention. This assumes the acceptance of the physiological sex change by the patient with DSD and his/her parents. This complex process needed professionalism and dexterity from the team. At first, the patient refused surgical intervention. "He" wanted to stay a boy, and wanted "her" breasts removed instead of having vaginoplasty. The parents' position was also confused. This parental confusion could be, at least in part, due to the fact that the parents received incomplete information at the birth of their child. Diagnostic and post-diagnostic counseling was not offered to the parents. In addition, their confusion hid social factors regarding the preference for a male. Gender reassignment can lead to social stigmatization or rejection. In this situation, the team's counseling and psychotherapy was focused on the patient but also extended to the parents and core family members. Their involvement in this was highly important in many ways. In collectivist societies, the child belongs to the whole clan. Grandparents, uncles, and aunts generally have more decision-making power over the child than the biological parents. As shown, at birth, the masculine given name was attributed by the grandfather and, at the gender reassignment; the feminine given name was attributed by the grandmother. As outlined, the involvement of the grandfather was decisive in the acceptance of the operation by the child and also probably by his/her parents. However, as indicated by Ozbey and Etker [11], there is an overlap between gender reassignment and gender-role behaviors.

After the surgery, the second aim was for Mariama to accept her female-gender identity and invest in her female body. Gender reassignment for Mariama occurred later at puberty. The transition to gender-role behaviors is a complex period, which is embedded in a complex process of psychosexual differentiation (gender identity, gender role, and sexual orientation). Until age 15, Mariama was raised as a boy. In such a case, gender transition can have heightened risks for trauma (e.g., sex trauma and identity disorders). For the patient, this period involved multiple losses, such as the loss of the peers and friends he/she frequently played with and a loss of family atmosphere. To avoid social stigmatization, the parents changed the family setting for their child. This parental decision also led to the abandonment of their child's school education. For Mariama, the masculine gender-role to female gender transition did not pose insurmountable problems. In addition to psychotherapeutic intervention, fostering open communication between Mariama and her grandmother contributed to this successful transition. She experienced less distress with her postsurgical anatomy. As it has been demonstrated, over weeks and months she invested in and assumed her sexual identity and femininity. Her self-image steadily improved. She became smart and developed a good interpersonal ability. Her maternal uncle confirmed her greater improvement in psychosocial functioning.

The analysis shows that two relatively difficult stages were experienced by the patient. Of note, these stages were not psychopathological. As illustrated in (Figure 2), the psychic integration of her bisexuality could be ambivalent. Mental health professionals should pay more attention to this stage, which can be accompanied by depressive feelings. As with Mariama, dream activities can reflect the profound identity reshuffle within this psychosexual stage. From this standpoint, drawings have an important therapeutic value. They provide a therapeutic way for the child to express his/her intrapsychic conflicts, to restructure imaginary activities, and to alleviate anxieties. The second relatively difficult stage for Mariama was the environmental learning. This refers to the pattern of feminine socialization conditioned by Wolof traditions and upbringing, such as getting up early in the morning, saying her prayers, doing the cleaning, and household activities. These female gender-roles are binding in traditional societies. For Mariama, learning these roles and activities evidently took a lot of time with moments of oversight. In sum, gender reassignment during adolescence implies many losses and rearrangements, including changes in the parents' rearing styles.

While gender reassignment affects the patient and his/her parents, it can even more profoundly affect the parent that is the same sex as the child's sex as identified at birth. The clinical experience in this study necessitates also stressing the psychosocial management of this parent. Gender reassignment triggers parental confusion in particular for this parent. It causes disturbances in the identification and sex-related roles of this parent with his/her child. In Wolof communities, girls' education engages the mother and boys' education engages the father. The eldest of the siblings is expected to be a male. This often strengthens the social image of the father in the community [12]. The patient's father undoubtedly met hard difficulties in adjusting to gender changes in his/her child. He had feelings of shame and embarrassment when he saw Mariama. The disengagement from his parental responsibility revealed his discomfort and meant the reversal of the parental roles. This discomfort reflected the collapse of expectations projected onto the child. Furthermore, he reacted to the gender reassignment by taking a second wife. Regarding the parents' reactions, Sirol [13] found that mothers often reacted with a moderate to severe depressive mood and fathers often adopted escape behavior through excessive alcohol consumption. Basically, this behavior is a way to struggle against depressive feelings. Sirol [13] also noted that the couple's sexual relationship was disturbed. The observations in the current study supported these results, except for alcohol consumption. For the father, symptomatology took a non-prohibited religious route; that is, polygamy.

Conclusion

In sum, the team's counseling and supportive psychotherapy was almost similar to the systemic therapy approach. Parents should not only be co-actors in the therapy process in order to help their child but also be the target of the therapy. Cultural, religious, and economic factors should not be underestimated [7,8,11] because they cover feelings of shame and reinforce secrets.

Earlier accurate diagnosis and counseling would prevent the trauma of gender reassignment later in life. They would decrease the effect on the health-related quality of life of the patient and his/her family and reduce the parents' anxiety in adjusting to their child's development [6]. Parents of the patients need psychoeducation programs, which could also prevent disturbances in the couple's relationship.

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