

Long-term Cosmetic and Functional Outcomes of Feminizing Genital Surgery

Feminizan Genitoplastinin Uzun Dönem Kozmetik ve Fonksiyonel Sonuçları

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ABSTRACT

Background: In this study, long-term cosmetic and functional results, quality of life, emotions, and feelings of patients who underwent feminizing genitoplasty were evaluated.

Materials and Methods: Twenty-two disorders of sex development cases who underwent feminizing genitoplasty were retrospectively evaluated. The primary pathology of the cases, the age of the operation, and the operations performed were recorded from the patient files. Cosmetic evaluation was performed. The sensitivity of the clitoris and vagina was evaluated. A questionnaire was administered to the patients to evaluate gender role and quality of life.

Results: The age of 22 cases included in the present study ranged from 12.33 to 26.02 years, and the mean age was found to be 18.50±4.23 years. Except for three cases, all cases perceived a heat difference of 2 °C below and above 37 °C. All patients stated that they were cosmetically satisfied. In the present study, it supports the behavior similar to male subjects. It was found that the quality of life was not affected in patients with disorders of sex development.

Conclusion: In most studies, it remains a subjective assessment because of the small number of cases and the absence of standardized scales. The fact that the culture of each country is different and the living standards are different can also change the treatment and prognosis of the patients. These patients face multiple life-long problems, from urinary tract infections to psychiatric problems. As the treating team, we should carefully evaluate the needs of these cases, keeping this in mind.

Keywords: Feminizing genitoplasty, outcome, cosmetic, longterm, disorder of sex development

ÖZ

Amaç: Çalışmamızda feminizan genitoplasti yapılan olguların uzun dönem kozmetik, fonksiyonel sonuçları ve yaşam kalitesi değerlendirildi.

Gereç ve Yöntemler: Feminizan genitoplasti yapılan 22 cinsiyet farklılaşma sorunu olan olgu retrospektif olarak değerlendirildi. Olguların birincil patolojisi, ameliyat yaşı ve yapılan ameliyat hasta dosyalarından kaydedildi. Kozmetik değerlendirme hasta ve cerrah tarafından ayrı ayrı yapıldı. Klitoris ve vajina hissi değerlendirildi. Cinsiyet rolü ve yaşam kalitesi anketler ile değerlendirildi.

Bulgular: Çalışmaya katılan 22 olgunun yaş aralığı 12,33 ila 26,02 yıl arasında değişmekteydi. Ortalama yaş 18,50±4,23 yıl olarak bulundu. Üç olgu dışında diğerlerinde 37 °C'nin 2 °C altı ve üstü ısı farkını algıladı. Tüm olgular kozmetik olarak memnundular. Olguların davranış değerlendirmesi erkek yönü desteklemekteydi. Cinsiyet farklılaşma sorunu olan olgularda yaşam kalitesinin bozulmadığı görüldü.

Sonuç: Cinsiyet farklılaşma sorunu olan olgular çok yönlü değerlendirme gerektirmektedir. Çoğu çalışmada hem olgu sayısı azlığı hemde standart ölçeklerin olmayışı nedeniyle subjektif değerlendirme olarak kalmaktadır. Her ülkenin kültürünün farklı oluşu hayat standartlarının farklı oluşu da olguların tedavi ve prognozunu değiştirebilmektedir. Bu olgular idrar yolu enfeksiyonundan, psikiyatrik sorunlara kadar yaşam boyu çoklu sorunlarla karşılaşmaktadır. Tedavi veren ekip olarak bunu akılda tutarak bu olguların gereksinimlerini iyi değerlendirmeliyiz.

Anahtar Kelimeler: Feminizan genitoplasti, sonuç, kozmetik, uzun dönem, cinsiyet farklılaşma sorunu



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Introduction

Disorders of sex development (DSD) are a broad definition that includes hormonal, metabolic, and chromosomal abnormalities that result in abnormal genital development (1). Its incidence has been reported as 1:4,500 in the literature (2).

A case with a sex development problem should be diagnosed by a multidisciplinary team as quickly as possible, but without making a hasty decision. Gender should be determined, and treatment should be planned (2-4).

In infants of female sex, gonadectomy may be required in addition to hormone replacement therapy, genitoplasty, and genital surgery. Genital surgery varies from vaginal reconstruction or dilatation of the vaginal opening to clitoral reduction and labioplasty. The primary purpose of surgery is to make the masculine external genitalia look female and provide sexual intercourse in adult life (5). Research in the 1950s showed that sex development was based on environmental factors after birth. It is accepted that babies are psychosocially neutral at birth and that sex develops with the behavior of families and the environment, based on whether they are male or female genitalia (6). According to this, as the most appropriate sex policy, early genital cosmetic surgery was recommended based on male or female external genitalia appearance that is suitable for sexual function. Today, sexual identity differentiation is a multifactorial and complex process that includes genetic, prenatal and postnatal hormonal, psychological, and sociological effects. The importance of external genitalia appearance in this process is unknown, but it is argued that it may be minimal. Feminizing genitoplasty is also believed to have a positive effect on psychological outcomes (7). In a study conducted on cases with congenital adrenal hyperplasia, it was found that good surgical results and satisfaction with genital appearance reduced behavioral problems (8).

Although signs of progress have been observed in long-term results in genital repair and establishing a diagnosis in recent studies, the timing of sex determination and genital surgery remains controversial (9,10). Some authors recommend delaying genital surgery and sexual decisions until the child is old enough to make his own decision (10,11). Despite improvements, some patients still face difficulties and traumatic experiences for treating DSD (12).

In the present study, long-term cosmetic and functional results, quality of life, emotions, and feelings of patients who underwent feminizing genitoplasty were evaluated. This study aimed to evaluate the long-term results of the operation and especially the clitoris sensation in patients who underwent nerve-sparing clitoroplasty.

Material and Methods

After institutional review board approval (2012-023) and obtaining informed consent from the patients and their parents, 22 DSD patients aged 12 years and over were evaluated. The patients were those who had previously undergone feminizing genitoplasty in our clinic or had feminizing genitoplasty in another center and were followed up in our clinic. The primary pathology of the cases, the age of the operation, and the operations performed were recorded from the patient files.

A cosmetic evaluation was performed by genital examination, by the categories clitoral length (normal/none-long), glans-clitoris length (normal/none-long), the distance between the clitoris and urethra (normal/none-long), labia majora normal/none-long), labia minora (normal/none-long), whether the labia majora covers the clitoris (normal/none-long), perineal distance (normal/none-long), whether there are two separate orifices (yes/no), whether the urethra vaginal entrance is in its normal place (yes/no), and whether the vaginal width is appropriate (yes/no). This scale was scored separately not only by the surgeon but also by the third person (nurse) who was not present during the operation and by the case, giving 1 point when normal. It was evaluated whether there was a difference between the scores.

The sensitivity of the clitoris and vagina was evaluated. As in the "Genitosensory Analyzer", 2 instruments with adjustable temperatures were made. One of them was between 24 °C and 50 °C, and the other was between 24 °C and 10 °C, which could be adjusted with buttons and had metal plugs at the ends. Starting at 37 °C, the patient's clitoris and anterior vaginal wall were touched, and the patient's sensation of heat and cold was questioned. The sensation of the patient was examined by increasing or decreasing 1 degree each time. A maximum of 40 °C and a minimum of 20 °C were set as the confidence limits. The sensation was evaluated by touching the clitoris and vagina of the patients with cotton. The correlation between the type of operation performed and clitoral sensation was evaluated.

In this study, a questionnaire including 19 health-related and 27 gender-role-related questions was administered to the patients to evaluate gender roles and quality of life. The answers of the patients were evaluated in five parameters and were scored from 1 to 5 (1: never, 5: always). For this purpose, the questionnaire that Julka et al. (13) used to evaluate the quality of life and gender role was translated into Turkish and used.

Statistical Analysis

In this study, statistical analyses were performed using (the Number Cruncher Statistical System) 2007 Statistical Software (Utah, USA) package program. Alpha Cronbach values were calculated to determine the reliability of the scales used. In the evaluation of the data, in addition to descriptive statistical methods (mean, standard deviation, frequency, percentage distributions), a one-way analysis of variance test was used in comparisons between groups, Pearson's correlation test was used to determine the relationships of variables with each other, and the weighted Kappa test was used to determine doctor and nurse evaluation concordance. The results were evaluated at a significance level of $p < 0.05$.

Results

Twenty-one of our cases were followed up with a diagnosis of congenital adrenal hyperplasia (CAH) and one with a diagnosis of mixed gonad dysgenesis. One of the CAH cases had a 46XY genetic structure and 17 β -Hydroxysteroid Dehydrogenase deficiency. Others had a 46XX genetic structure and 21 hydroxylase deficiency.

The age of 22 cases included in the present study, ranged from 12.33 to 26.02 years, and the mean age was found to be 18.50 ± 4.23 years. Eleven cases were older than 18 years. The body weight of our patients ranged from 38.5 to 80 kg, and the mean was 56.25 ± 11.02 kg. Height ranged from 140 to 162 cm, with an average height of 150.75 ± 6.33 cm.

Of the cases, 4 (18.18%) were university graduates, 13 (59.09%) were high school graduates, and all (100%) were secondary school graduates or still continuing their studies. Twenty- of 22 cases (95.45%) in the study group were receiving hormone replacement therapy.

Clitoroplasty was performed in 21 patients. Although the age range of these cases varied between 1 and 16 years, the mean age of clitoroplasty was found to be 4.48 ± 4.83 . The age range of 21 patients who underwent vaginoplasty ranged from 1 to 16 years. The mean age of vaginoplasty was found to be 5.76 ± 5.34 (Figure 1).

Of 21 patients who underwent clitoroplasty, 3 underwent clitoroplasty without preserving the neurovascular structure, and 18 underwent clitoroplasty with preservation of the neurovascular structure. None of the patients had a history of sexual experience. In the evaluation of the sensation of the cases, 2 of 22 cases (9.09%) had no clitoris sensation. It was found that in 1 (4.55%) of the cases, there was no vaginal or tactile sensation. The temperature difference in the clitoris was not found in 3 (13.63%) cases (Table 1).

The normal evaluation rates of the surgeon and nurse in the cosmetic evaluation are given in Table 2. The cases

evaluated the cosmetic appearance as normal at a rate of 100%. The width of the vagina and the distance between the clitoris and the urethra were found to be the most inadequate by the surgeon and nurse in cosmetic evaluation. Clitoral length, glans- clitoris width, labia majora, labia minora, glans clitoris covering of labia majora, perineal distance, having two separate orifices, evaluation of the urethra, and urethra entrance were evaluated as normal at rates ranging from 60% to 100%. The evaluation of the operating doctor and the non-operating person (nurse) was found to be statistically significant ($p = 0.0001$).

Nocturnal and/or daytime urinary incontinence was in 5 of 22 (22.72%) cases. Four cases (8.18 %) describe urgency. Postvoid dribbling was found in 2 cases (9.09%). Of these, only 3 cases (13.63%) were found to affect life. Urinary tract infection history was found in 4 (18.18%) of the cases.

The total number of answers of 22 cases to 18 questions about quality of life ranged from 25 to 43. The mean was found to be 35.27 ± 4.77 . The total number of answers of 22 cases to 27 questions about gender roles varies between 41 and 79. The mean was found to be 59.13 ± 11.28 . The general assessment of quality of life was answered between 5 and 10 out of 10. The mean value was 8 ± 1.92 .

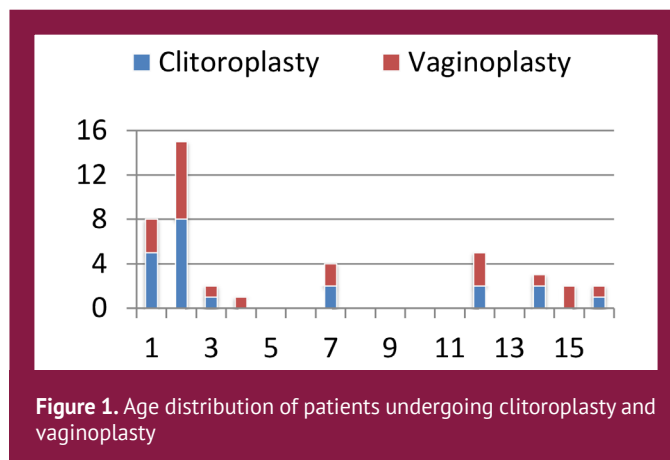


Figure 1. Age distribution of patients undergoing clitoroplasty and vaginoplasty

Table 1. Distribution of postoperative sensation assessment measurements in the study group

		n	%
Sexual experience	No	22	100.00
	There is	0	0.00
Clitoris sense	No	2	9.09
	There is	20	90.91
Vaginal sensation	No	One	4.55
	There is	21	95.45
Sense of touch	No	One	4.55
	There is	21	95.45
Temperature difference in the climate	No	3	13.63
	There is	19	86.36

Table 2. Comparison of physician and nurse postoperative cosmetic evaluation measurements

		Doctor		Nurse		p
		n	%	n	%	
Clitoral length	None-long	5	22.73	6	27.27	$K_w=0.879$ $p=0.0001$
	Normal	17	77.27	16	72.73	
Glans clitoris width	None-long	8	36.36	10	45.45	$K_w=0.814$ $p=0.0001$
	Normal	14	63.64	12	54.55	
The distance between the clitoris and urethra is sufficient	None-long	12	54.55	8	36.36	$K_w=0.645$ $p=0.001$
	Normal	10	45.45	14	63.64	
Labia majora	None-long	0	0.00	0	0	$K_w=1$ $p=0.0001$
	Normal	22	100.00	22	100.00	
Labia minor	None-long	4	18.18	4	18.18	$K_w=1$ $p=0.0001$
	Normal	18	81.82	18	81.82	
Does labia majora cover clitoris?	None-long	5	22.73	5	22.73	$K_w=1$ $p=0.0001$
	Normal	17	77.27	17	77.27	
Perineal distance	None-long	5	22.73	4	18.18	$K_w=0.861$ $p=0.0001$
	Normal	17	77.27	18	81.82	
Are there two separate orifices?	No	6	27.27	6	27.27	$K_w=1$ $p=0.0001$
	Yes	16	72.73	16	72.73	
Urethra vagen entry	No	6	27.27	6	27.27	$K_w=1$ $p=0.0001$
	Yes	16	72.73	16	72.73	
Vagen width suitable	No	12	54.55	12	54.55	$K_w=1$ $p=0.0001$
	Yes	10	45.45	10	45.45	

Discussion

Cases that reached puberty were included in the study to evaluate sexual development and sexual experience. However, although there were 11 patients older than 18 years in our study, no patient had sexual experience.

According to the 2012 data from the Turkish Statistical Institute, the average height of girls in Turkey is 162.8 cm. Accordingly, DSD cases are 12 cm shorter than the average. In an article in which the results of 35 different studies conducted with CAH cases were evaluated, it was found to be 3.5 cm shorter than their peers (14). In this study, it was argued that the short stature was related to the drug treatment that the patients received. The higher rate of short stature in our study may be due to poor planning of the treatments or other factors (quality of life, surgery, depression) besides the treatment. When the quality of life and stature of the patients were compared, no statistically significant correlation was observed. In Turkey, cases with sexual development disorder hide their diagnoses because of cultural reasons, and they hesitate to talk about it. Therefore, there may be a predisposition to depression, as

well as life-long treatment. Surgery may affect the quality of life and may be a predisposition to depression.

According to the 2012 data from the Turkish Statistical Institute, the average weight of girls in Turkey is 58.1 kg. According to this, the weights of the cases are below the average. Although there is no study directly related to weight average in the literature, obesity is expected in CAH cases due to insulin resistance (15). The low mean weight in our study may be because the weights of the patients ranged widely from 38.5 to 80 kg.

Recent publications have recommended clitoral surgery in infancy (16,17). In our clinic, it is preferred to perform clitoroplasty in patients under the age of 2 years. However, the average age of clitoroplasty was found to be high because of late admissions. There is still no consensus on the age of vaginoplasty. However, it is advocated that it should be performed under the age of 1 or starting from adolescence (18,19). In our clinic, vaginoplasty is also preferred for patients under the age of 2, but the cases performed in the past years and the late admission age increase the average vaginoplasty age.

There is no standard scale to evaluate the cosmetic results of patients who underwent feminizing genitoplasty.

Most of the evaluations were made by the surgeon's examination as a good or bad cosmetic result. This causes evaluations to be subjective most of the time. In an article published in 2007, the cosmetic results of 82 patients who underwent feminizing genitoplasty were evaluated by the patient herself or her family and by the surgeon. The cosmetic results were excellent. The mothers of all cases stated that they were satisfied with the cosmetic results, but the surgeon did not use any objective criteria in the evaluation (20).

In our study, all patients stated that they were cosmetically satisfied. The evaluations of the surgeon and the third person were compatible with each other, but they were not as satisfied with the cosmetic results as the cases. This may be because the cases could not be compared. In our study, the evaluation of the third person who did not undergo surgery allowed us to obtain a more objective result. In another study performed with different techniques and at different ages, the clitoris was evaluated as 59%, vaginal opening 18%, vaginal length 73%, and labia 61% normal. The evaluation was made only by the surgeon, but the evaluation was made using a scale they created (21). The Fortunoff vaginoplasty technique was used in our study, and we could say that our cosmetic results are better than these results.

There are very few publications that evaluate the sensitivity of genitoplasty. In a study by Crouch et al., they evaluated 28 cases of genital sensitivity with the Genitosensory Analyzer (GSA) in cases who underwent feminizing genitoplasty compared with the control group.

The threshold of clitoral warmth perception of the cases to whom feminizing genitoplasty was applied was found higher (42.8 °C, the control group: 39.2 °C) and the threshold of coldness perception was found to be lower (28 °C, the control group: 33 °C) than the control group (8). CAH cases participated in the vaginal sensitivity test, and no difference was observed compared with the control group of 4 people. There are 2 separate probes giving heat and vibration in this device. When the patient felt the heat, she stopped the test by pressing the button in her hand. Thus, the threshold values for hotness and coldness were determined. Different techniques were used in the surgery of the patients, but no comparison was made (22). Again, in a similar study, which Lesma et al. conducted with 12 cases and 12 control groups, it was found that sensitivity in the clitoris was lower than in the controls. He found no difference in vaginal sensitivity compared with controls. Only the Passerini Glazel technique was used in this study (23). In this study, we used 2 devices, similar to the GSA device, with which we can adjust the desired temperature. When the patients felt the heat difference, they gave verbal

feedback. Except for three cases, all cases perceived a heat difference of 2 °C below and above 37 °C. In our study, there was no control group, and we did not have the opportunity to use decimal degrees while increasing the temperature. In 3 of our cases, clitoroplasty was performed without preserving the neurovascular structure. It was found that 3 patients without a clitoris temperature difference did not undergo nerve-sparing surgery.

In a study conducted by Nabhan et al. (24), urinary infection history was found to be 8.5% in patients operated on before 36 months and 3% in patients operated on after 36 months. It was stated that this was consistent with the same age group without health problems (24). In the study by Lesma et al. (20), no urinary infection was found. In the study of Canalichio et al. (25), urinary infection was found to be 10% and urinary incontinence 19%. The incidence of urinary tract infection and urinary incontinence in our patients was higher than that in other studies.

The evaluation criteria of the publications evaluating the quality of life in patients with DSD are different from each other. Some have made qualitative evaluations and some have made quantitative evaluations. Qualitative evaluations show that sexual functions and sexual satisfaction of DSD cases decrease (26,27). In the quantitative evaluation, the cases were evaluated using scored questionnaires. Outcomes ranged from a better quality of life than controls to severely affected (28-31). In the evaluation of Julka et al. (13), the mean score of quality of life was found to be 39.5±6.8 in DSD cases, 34.3±7.6 in healthy controls; in the present study, the score of DSD cases was found to be 35.27±4.77. As in the study by Julka et al. (13), it was found in this study that the quality of life was not affected in DSD cases.

Studies have argued that the rate of male-type behaviors is high in female patients with CAH (32-34). In only one of our cases, the mother complained of male-type behavior. Julka et al. (13) found the mean score of gender role to be 84±5.4 in female DSD cases, 51.2±6.0 in male DSD cases, 82.5±8.7 in healthy female cases, and 53.2±7.1 in healthy male cases. In this study, all cases were raised as females, and the mean score was 59.13 59.13±11.28. The study by Julka et al. (13), supports that female DSD cases behave like healthy females. On the other hand, in this study, it supports behavior similar to male subjects. Julka et al. (13) included 8 female and 5 male DSD cases. This reduces the reliability of the study. Having 22 cases in this study may provide more reliable results.

Study Limitations

However, because of the lack of a control group in the present study, it could not be evaluated whether the results obtained were different from those of healthy individuals

in our society. The lack of a standard scale to evaluate the cases and the cultural, structural, and religious understanding of each society may lead to different results in each study. In addition, because of the high number of cases and the use of a quantitative scale in the present study, its reliability is higher than that in other studies.

Conclusion

In the present study, as in other studies, it was found that patients who did not undergo nerve-sparing clitoroplasty did not perceive the temperature difference and had no sense of touch. This is an indication that neurovascular structures must be protected while performing clitoroplasty.

In addition, DSD cases require multidisciplinary evaluation. In most studies, it remains a subjective assessment because of the small number of cases and the absence of standardized scales. The fact that the culture of each country is different and the living standards are different can also change the treatment and prognosis of the patients. These patients face multiple life-long problems, from urinary tract infections to psychiatric problems. As the treating team, we should carefully evaluate the needs of these cases, keeping this in mind. There is a need to use standard scales and studies with control groups to evaluate DSD cases.

Ethics

Ethics Committee Approval: Ankara Child Health and Diseases Hematology Oncology Training and Research Hospital Non-Pharmaceutical Clinical Research Ethics Committee (decision date: 20.06.2021/decision no: 2012-023).

Informed Consent: Retrospective study.

Peer-review: Externally and internally peer reviewed.

Authorship Contributions

Surgical and Medical Practices: Z.A.K., T.T., Concept: T.T., Design: T.T., Data Collection or Processing: T.T., Analysis or Interpretation: T.T., Literature Search: Z.A.K., T.T., Writing: Z.A.K.

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