MEDICALIZATION OF INTERSEX AND VARIATIONS OF SEX CHARACTERISTICS: AN ANALYSIS OF THE MEDICAL PROCEDURES THROUGH NARRATIVES OF CLINICIANS AND INTERSEX INDIVIDUALS IN TURKEY

by

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ABSTRACT

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Keywords: intersex, disorders of sex development, medicalization, variation of sex characteristics, gender, sexuality

This thesis analyzes the medical treatment procedures of intersex children and their implications based on the data I collected from interviews with clinicians who are involved in medical treatment of intersex children in research and teaching hospitals in Istanbul as well as intersex individuals who went through these treatments. I explore why, or to what extent, the early, non-consensual, and medically questionable hormonal and surgical interventions currently continue despite the challenges that have been raised against them in the last decades on the basis of principles of informed consent and respect to bodily autonomy. I argue that the conventional medical procedures rely on superficially coherent narratives of treatment based upon a biologically deterministic understanding of intersex traits and variations of sex characteristics that is separate from personhood. Furthermore, I suggest that in the context of Turkey, the dichotomy of “biological” versus “subjective” is associated with the dichotomy of “advanced” versus “backward,” in which medicalization becomes a measure of being “advanced”, or “Westernized.” This research shows the ways in which these dichotomies do not hold and argues that the medical treatments fail to provide what they promise in practice. Finally, I show how the intersex individuals’ experiences can help deepen the discussions around current controversies about medical treatment procedures.

ÖZET

İNTERSEKS VE CİNSİYET ÇEŞİTLİLİĞİNİN MEDİKALİZASYONU: KLİNİSYENLER VE İNTERSEKS BİREYLERİN ANLATILARI ÜZERİNDEN MEDİKAL SÜREÇLERİN BİR ANALİZİ

Ceren Aydın

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Anahtar Sözcükler: cinsiyet gelişim farklılıkları, cinsiyet özellikleri, çeşitlilik, interseks, medikalizasyon, tıbbileşme, toplumsal cinsiyet, cinsellik

Bu araştırma, interseks çocukların tıbbi tedavi süreçlerine dahil olan, İstanbul'daki araştırma ve eğitim hastanelerinde görev yapan klinisyenler ile interseks bireylerle yaptığım görüşmelere dayanarak, interseks çocukların tıbbi tedavi prosedürlerinin ve bunların uygulamalarının eleştirel bir incelemesini sunmaktadır. Son yıllarda aydınlatılmış onam ve bedensel otonomi prensiplerine dayalı olarak gündeme getirilen itirazlara karşın, erken yaşta uygulanan, onama dayalı olmayan, tıbbi açıdan gerekliliği tartışmalı hormonal ve cerrahi müdahalelerin günümüzde ne derece ve neden devam ettiğini araştırmaktayım. Geleneksel tedavi süreçlerinin, interseks özellikleri ve cinsiyet özelliklerindeki çeşitliliklerin bireyden ayrı ve biyolojik deterministik yorumuna dayalı, yüzeysel bir tutarlılık gösteren bir tedavi anlatısına dayandığını iddia etmekteyim. Ayrıca, Türkiye bağlamında, "biyolojik" ve "öznel" arasındaki ikilik, medikalizasyonun "ileri," veya "Batılı" olmanın bir ölçüsü haline geldiği "ileri" ve "geri" ikiliğiyle bağdaştırılmaktadır. Bu araştırma bu ikiliklerin isabetli olmadığını ve uygulamada tıbbi tedavilerin vaatlerini karşılayamadılarını göstermektedir. Son olarak, interseks bireylerin deneyimlerinin tıbbi tedavi süreçleri etrafındaki mevcut tartışmaları derinleştirmeye nasıl yardımcı olabileceğini tartışmaktayım.

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CHAPTER 1

INTRODUCTION

According to the definition of OII (Organization Intersex International), “Intersex people are born with sex characteristics that do not fit typical binary notions of male or female bodies.”[1] These sex characteristics include external genitalia, internal genitalia such as ovaries or testes, hormones, chromosomes, and secondary sex characteristics such as the patterns of body hair and voice. In the typical constructs of female and male bodies, these categories are assumed to come in packages; however, in intersex bodies these traits might exist in various combinations, disrupting the typical categories of male and female.

“Intersex” was used “to refer to a wide range of sexual ambiguities including what had previously been known as hermaphroditism” for the first time by geneticist Richard Goldschmidt in a 1917 article, after which “the term ‘intersexual’ slowly gained popularity among medical professionals” (Dreger 1998, 31). Before, the term existed, but “some authors had used the term ‘intersexuality’ to refer to what we would call homosexuality and bisexuality, and even Goldschmidt himself suggested that human homosexuality might be thought of as one form of intersexuality” (Dreger 1998, 31). Historian Elizabeth Reis suggests, on the other hand, “doctors have never fully incorporated ‘intersex’ into their vocabulary” (2009, 155) because of the lack of consensus on the definition and scope of intersex. “Starting in the early 1990s, activists instead advocated ‘intersex.’… Some parents, though, were uncomfortable with the “intersex” label for their affected children. To them,

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[1] OII international is a “decentralized global network of intersex organizations”(http://oiiinternational.com/, accessed on 05.09.2018). It was established in 2003 by Curtis Hinkle in order to create a platform for intersex activists who are outside of US. Today, the online network includes Intersex Human Rights Australia (formerly known as OII Australia), OII Austria (VIMÖ), OII Belgium (Genres Pluriels), OII Chinese, OII Europe, OII Francophonie, OII Germany (IVIM), OII Hispanoparlante, OII Italia, Intersexioni, Intersex Iceland, Intersex Scandinavia, Intersex South Africa, Netherlands Intersex/DSD Network (NNID), OII Philippines, and OII United Kingdom. The US branch of the network, formerly known as OII-USA, continues as Intersex Campaign for Equality (IC4E) since 2015 (https://www.intersexequality.com/mission/).

‘intersex’ meant a third gender, something in between male and female” (Reis 2009, 155). In 2006, “Disorders of Sex Development” was suggested to replace “intersex,” with the *Consensus Statement on Management of Intersex Disorders* (2006) published as a result of the International Consensus Conference on Intersex held in 2005 by the US-based Lawson Wilkins Pediatric Endocrine Society and the European Society for Pediatric Endocrinology. The argument of the *Consensus Statement* was that “terms such as ‘intersex,’ ‘pseudohermaphroditism[2],’ ‘hermaphroditism,’ ‘sex reversal,’ and gender-based diagnostic labels are particularly controversial. These terms are perceived as potentially pejorative by patients and can be confusing to practitioners and parents alike” (Lee, et al. 2006, e488). Thus, DSD was defined as “congenital[3] conditions in which development of chromosomal, gonadal, or anatomic sex is atypical” and proposed as a term that is suitable for the clinicians to use when communicating with the parents (Lee, et al. 2006, e488).

Today, it can be argued that the dominant umbrella term for atypical sex development in the medical nomenclature is “Disorders of Sex Development” (DSD), while “intersex” has been reclaimed by the activist groups and thus has political connotations. On the other hand, both terms can be used by both activist and medical communities, since these communities often interact, intersect and collaborate with each other.

In this thesis, I use “intersex” as the default term, whereas I sometimes use “DSD” or “intersex/DSD” in order to convey the medical narrative more accurately. I also use “Variations of Sex Characteristics” (VSC) in addition to “intersex” because “intersex” is a contested term, especially in the medical context. The term “intersex” has been mainly abandoned in the medical nomenclature since the dominant medical view is that “ambiguity” of sex traits is a manifestation of incomplete development of sex, and there are only two sexes; this is what the term “Disorders of Sex Development” implies. Even if some doctors may use the term “intersex” as a synonym of “DSD,” it does not cover some atypical sex traits that I refer to in this thesis. One such trait is one that is known as hypospadias, or

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[2] Please see section 2.2.2 for the explanation of the term.

[3] Existing from birth

as *"peygamber sünneti*[4]*"* in Turkey, in which urinary opening is located not at the tip of the penis, but somewhere below it. Hypospadias can be a symptom of some DSD conditions, which are mainly genetically rooted; however, it can also exist independent of a condition. When it occurs without a DSD diagnosis, in a body that is otherwise typically male, it is merely regarded as a "genital anomaly" that can be surgically "fixed." Hypospadias is quite common; it is observed around 1 in every 50 to 500 male-assigned births[5]. In short, I use VSC as a general term that applies to atypical sex traits for the sake of clarity.

"The birth of a child with ambiguous genitalia constitutes a social emergency," according to the statement of The American Academy of Pediatrics (AAP) (American Academy of Pediatrics, Committee on Genetics, Section on Endocrinology and Section on Urology 2000). In other words, intersex is considered both as a medical and social condition that demands urgent medical intervention, which may include surgical and hormonal intervention in order to alter the sex characteristics of the body so that it will fit only one of the binary sex categories - male or female. In recent decades, however, this medical view has been challenged by the intersex individuals who were subjected to medical intervention against their consent on the basis that the overwhelming majority of the medical interventions are not necessary or urgent from a physical health perspective, that they violate the bodily rights of intersex people, and that they can lead to physical and emotional harm for the individuals who go through them.

Currently, the main cause of the intersex movement is to end early, non-consensual, and non-vital surgeries that aim to "normalize" sex traits in intersex children by forcing them into one of the binary categories of sex. This emphasis of the movement on early surgeries also determined my choice of focus for this research. While I do not view medicalization as

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[4] English translation of this term would be "prophet's circumcision." A common symptom of hypospadias is lack of foreskin, and it is said that Mohammed was born without a foreskin, which was interpreted as a holy sign. I talk about cultural perception of hypospadias in Turkey more in Chapter 3.

[5] In "Sexual Development and Disorders of Sex Development in Children: Facts for Families" published on the website of Society for Sexual Development and Hypospadias (Cinsel Gelişim ve Hipospadiyas Derneği), the frequency rate of hypospadias is given as 1/250 - 1/500 in male-assigned births (Çocuklarda Cinsel Gelişim ve Cinsel Gelişim Kusurları: Aileler için Genel Bilgiler 2011). However, a study conducted in a teaching hospital in Istanbul found the rate as approximately 1 in every 52 live male-assigned births, based on the screenings between September 2007 and December 2008 (Akın, et al. 2011). Among others, a worldwide literature review study concludes that mean rate of hypospadias in "Arabic countries, Turkey, [and] Islamic Republic of Iran" is around 1 in 459 in all "live births", based on 36 studies conducted between 1964-2013, and it states that "numerous studies showed an increasing prevalence; on the other hand, there were a lot of contradictory data on the prevalence of hypospadias" (Springer, van den Heijkant and Baumann 2016).

only related to surgery, it constituted a special focus in the interviews I conducted, as well as occupying a significant place in my thinking and theorizing throughout this project.

1.1 Fieldwork

1.1.1 Methodology and Positionality

For my fieldwork, I conducted one-to-one, semi-structured interviews with 12 clinicians[6] from various fields and 4 intersex individuals, 3 of whom are also activists. The interviews with the clinicians lasted from approximately 30 minutes to 3 hours, and the interviews with the intersex individuals lasted approximately from 3 to 5 hours; in total, I had approximately thirty hours of recording. I recorded and transcribed all the interviews except the ones I conducted with two of the clinicians who did not give consent to be recorded. During the interviews that I could not record, I took notes. I reached both the clinicians and the intersex individuals mainly via snowball method. I conducted all the interviews with the clinicians in the hospitals or clinics they work, except one who works outside of Istanbul -I interviewed her in a cafe- and since they usually have a busy work environment, sometimes I conducted two short interviews rather than one long interview. This time concern caused some disadvantages; for instance, I was not able to ask all the questions I planned to ask the clinicians. But it might have also had some advantages such as forcing me to revise and narrow down my interview questions to the topics I considered most important as well as to customize my questions for the next interview based on the first. Also, my fieldwork included some other sites and activities such as attending a theoretical class on DSD offered to medical students who are in their clinical stage of education, conferences, and meetings, as well as internet resources such as blogs and websites. The intersex individuals I interviewed live in different parts of Turkey outside of Istanbul; so, I traveled to the cities they live in, and conducted the interviews at places of their choice, which were cafes or restaurants in three interviews, and the house of the informant in one case. These interviews were rather long, and usually more open-ended than the interviews with the clinicians.

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[6] One of them was a medical student who was at the internship stage at the time of the interview; however, since she had direct contact with the patients, I refer to this informant as a “clinician” as well.

I use pseudonyms for all of my informants; I randomly picked first and last names for all clinicians; I use both when I first mention their names, and afterwards I refer to them as “Dr. (first-name)” throughout the thesis. For two of my intersex informants, I use pseudonyms that they picked for themselves; one of them asked me to use a “unisex name,” and I picked a name in line with that criteria. I chose a random pseudonym for the last intersex informant. All the pseudonyms that I picked by myself are in line with the gender expressions of the informants.

Throughout the thesis, I use the pronoun “they” in order to refer to a hypothetical patient. As forcing intersex children into binary gender categories came up as one of the most problematic aspects of the intersex treatment procedures during my research, I decided to avoid using the singular pronoun “he or she,” when referring to children with “ambiguous sex.” I also use “they” for the intersex individuals I interviewed, in accordance with their preference.

At the beginning of my research, I planned to conduct equal numbers of interviews with clinicians and intersex individuals, but later I decided to focus my research on the medical narratives and the clinicians. One reason for this was the difficulty I had accessing intersex individuals, whereas access to clinicians was easier. Furthermore, as I continued my fieldwork, the interviews with the clinicians became more interesting for me since I was rather familiar with the issues of the intersex activists, and I was able to understand their arguments and sympathize with them. Yet, I could not understand why the clinicians continued with the conventional treatments despite the global backlash of the intersex individuals, and I was curious about their views.

One other reason for this choice was that my positionality as a researcher posed challenges during my fieldwork. As I show in Chapter 4, one of the problems intersex individuals emphasize regarding the treatment procedures is being objectified as patients during medical examinations. They talked about how they were used as research subjects without their consent by the doctors during their treatment and how it contributed to the trauma the treatment has caused. Moreover, the experiences of being fetishized, exoticized, and objectified by social, cultural, and medical mechanisms throughout history form a collective memory for intersex people. So, from the very beginning, I was aware that my position as a non-intersex person and a researcher could be triggering to intersex individuals, which led me to limit my fieldwork. As a result, I put the clinicians' narratives to the center of this thesis, using the interviews I conducted with the intersex individuals as reference points to form questions for both the theorizing and the interviews I had with the clinicians.

I had concerns about interviewing clinicians as well, thinking that they might perceive me as a dissenter and the interviews might be tense, and I expected interviews to be challenging for me. To the contrary, most of the clinicians welcomed me warmly, and they offered to help me despite the fact that they work with quite busy schedules. A couple of clinicians even expressed open support for my research and helped me find medical resources on the topic. Despite being willing to help me, some clinicians frequently reminded me of their authority on the topic in various ways as they spoke with me. For instance, one pediatric surgeon Dr. Ziya Çelik said, "I can always help you, but these matters are delicate matters. I mean, the medical side of this thing is very complicated. These are thorny matters,"[7]and he repeated it several times during the interview. He avoided using any medical terms, and when I asked, "is there a medical term for …?" once, he said "there are many, but I'm trying to explain it to you in a way that you can understand,"[8] which I interpreted as a boundary-setting statement. Pediatric endocrinologist Dr. Ayfer Demir had a similar attitude; when I asked her "how does the process work when a patient with difference of sex development comes?"[9]for instance, she emphasized that the existing medical procedures are standard:

> "Now, when a patient that has a difference of sex development arrives, we ask for medical examination, etc. There is an underlying cause, so we need to first find that underlying cause…. After we make a diagnosis, again, according to this opinion, or rather according to the published scientific data, we have a council that determines what to do about this diagnosis…. We get together and we find the best way of treatment together…. The treatment for each diagnosis is more or less self-evident anyway, changing sex is out of the question; it depends on the underlying disease."[10]

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[7] "ben sana her zaman yardımcı olurum ama bu konular hassas konular, yani bu işin tıbbi yönü çok karışık, bunlar çetrefilli konular"

[8] "çok var da… ben senin anlayabileceğin şekilde anlatmaya çalışıyorum"

[9] "cinsel gelişim farklılığı olan bir hasta geldiğinde süreç nasıl işliyor?"

[10] "Şimdi cinsel gelişme farklılığı olan bir hasta geldiğinde biz ne yapıyoruz, tıbbi tetkik istiyoruz, altta yatan bir neden var, dolayısıyla önce o tıbbi nedenlerini, altta yatan nedenini bulmamız lazım…. Tanısını koyduktan sonra da yine bu tanıya göre, daha doğrusu yayınlanmış olan bilimsel verilere göre bu tanıda ne yapılır ona yönelik olarak bir konseyimiz var….. Bir araya geliyoruz ve en uygun tedavi şekli ne ise birlikte yapıyoruz…. Zaten her tanının tedavisi aşağı yukarı belli, cinsiyet değiştirmek sözkonusu değil, altta yatan hastalığa bağlı."

By emphasizing the medical aspect and the straightforwardness of the subject, Dr. Ayfer implied that it was not open for non-medical discussion. As I show in the next chapter, however, the medical decisions can be open to discussion.

It could be that Dr. Ayfer avoided talking about the medical details because it would be hard to explain to someone outside of medicine in the short time she was available for the interview. However, most other clinicians talked about medical details with me even when they had little time, which is why I read her narrative as an expression of authority. In my view, reminding me of their medical authority was a way of refusing to be challenged for some of the clinicians I interviewed.

I perceive the variations among the positionings of the clinicians as shaped by the power relationships that they are situated in. For example, male doctors, who constitute the majority, tended to feel more comfortable with me; I see it as a sign of that they did not perceive someone like me as capable of challenging their authority on the topic. On the other hand, women doctors may be feeling that their authority is more open to be challenged in a male-dominated field. A general endocrinologist, Dr. Serap Deniz, referred to this issue more openly. During the interview, which we held in her office at the hospital, someone knocked the door and asked a question to Dr. Serap. Suddenly her attitude changed, and she replied to the person in a more authoritative tone than she was talking to me. When the person who asked the question left and closed the door behind, she immediately went back to her previous relaxed tone. Later in the conversation, she explained her behavior:

> Ceren: If I ask you how many sexes you think there are, what would be your approach?
> Dr. Serap: Two, I mean, it is of course difficult to make such a differentiation of sex, as to how many sexes there are. I mean, for instance, they call women doctors the third sex; I mean, there are things like that. In order to hold on in the working life, you can’t help but get men’s characteristics, attributes…. I act like that since I believe I settle things easier if I act that way. Otherwise I’m not like that in my personal life.[11]

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[11] Ceren: Sizce kaç tane cinsiyet vardır diye sorsam ne gibi bir yaklaşımınız [olur]?
Dr. Serap: İki tane. Yani, böyle bi cinsiyet ayrımı yapmak tabii ki zor, kaç tane cinsiyet vardır diye, işte ne biliyim mesela doktor kadınlar için üçüncü cins derler, yani böyle işler vardır. Çalışma hayatında tutunmak için ister istemez erkek karakterlerini, özelliklerini kapıyosunuz…. Böyle davranırsam işimi daha kolay hallettiğime inandığım için öyle davranıyorum, yoksa özel hayatımda öyle biri değilim.

Dr. Serap is critical of her working environment because she thinks that it forces women to "lose their womanhood," in her words. In addition, the interviews I had with two male clinicians reinforced my impression. In an anecdote, one of them referred to how an "emotional" woman clinician almost prevented the "correct" medical treatment of an intersex infant, because she thought the child was too young to go through surgery. Another male clinician referred to a woman clinician's views as "extreme," saying, "she is interested more in the humanistic side" of the issue.[12] I further discuss how the dichotomies between "subjective" and "objective" knowledge, and the alignment of medicine along with "objective" influence medical decisions in favor of a more surgical approach in Chapter 2.

Around half of the clinicians seemed surprised that I wanted to interview them. Several of them expressed this by asking questions such as "So, what do you want to learn from me?" with surprise, or disbelief in their tone. Dr. Ayfer expressed this explicitly; I had an appointment with her saying that I wanted to interview her for my thesis, but she thought that I wanted to interview the patients and she was very surprised when she realized that I intended to have her as an informant. She repeatedly asked what my purpose is and was not convinced that interviewing her could be any beneficial for my thesis. I recognized a similar approach in a couple of other interviews with the clinicians, which I attribute to those clinicians' views about the objectivity and neutrality of their medical views.

The clinicians did not regard their personal backgrounds as relevant to my questions. When I asked them demographic questions such as their age, where they grew up, or about why they chose to be a doctor, or to work in the specific field they do, they usually dismissed my question either by saying that it was not relevant to our conversation or giving other non-personal information about the development of their interest. This was the only question category that consistently received such open and abrupt dismissal in my interviews, and I decided to not to ask these questions after several such encounters. In one instance, a pediatric surgeon touched upon the issue of why he chose his specific expertise, without my asking the question. Dr. Ziya said that one reason he chose this area was because "it provided answers to some questions he was curious about" while he was studying general surgery, although he did not mention what these questions were. And in another instance, another

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[12] "O daha çok işin insani yönüyle ilgileniyor"

pediatric surgeon Dr. Engin Bulut said that he specialized in this area because he was simply fascinated with it.

My being a graduate student in one of the top universities in Turkey was probably an important factor that allowed me to interview the clinicians. For instance, after asking detailed questions regarding my educational background, Dr. Ali Korkmaz said, “I see, nice… I mean, I suppose that you are raised well,”[13] nodding his head in an approving way. As I discuss more in detail in Chapter 2, education level of the patients can be an important factor that influences the communication between the clinicians and the patients; clinicians often complain that most of their patients are not educated enough to understand them. Thus, I assume that the fact that I am someone whom the clinicians would perceive as educated was an important factor that influenced my conversations with them. I do not claim, however, that it is an accurate representation of the patients or of me. As I will discuss further in Chapter 3, I suggest that the categories such as “educated” and “not educated” are constructed; for instance, the clinicians might have seen me in a different way if I talked to them as one of their patients, and my positioning as a researcher might have made it easier for them to see me in the category of “educated.” Moreover, the fact that I am a student allowed me to position myself as a learner and might have made the clinicians sympathize with me because they saw me like their own students. One clinician implied this when I asked a question about medical procedures, which I understood that he perceived as too general to explain in a short time. In response, he smiled and said, “Our students are like that, too, though.”[14]

During my fieldwork and the process of the data analysis, my views of the clinicians changed as well. As I listened to the differences in their views and positionings and as I started to realize some mechanisms I discuss in the following chapters, I became more able to see them as individuals who are situated in the power mechanisms and structures they operate in, and not merely as sources of authority, regardless of whether I agree with their opinions or not. As a result of both this realization and the clinicans’ friendly approach, I started to feel more relaxed during the interviews. This is also likely to have contributed to

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[13] “anladım, güzel.. yani iyi yetiştiğinizi tahmin edebiliyorum,”

[14] “Bizim öğrenciler de böyle gerçi.”

my analysis by enabling me to focus on various mechanisms at play that result in the current controversies about medical management of intersex and variations of sex characteristics.

1.1.2 Representativeness of the Study

I am likely to have talked to clinicians who have relatively unorthodox ideas about the recent paradigm shift in medical treatment of intersex, which is in favor of a less surgical approach. Not all clinicians I contacted were equally open to talk to me, and I did not pursue some clinicians who did not return my emails or calls further, partly because of practical concerns and partly because documenting the average doctor's opinion was not among my priorities; rather, I wanted to see what more critical and open doctors think about the shifting paradigm, in order to be able to understand why they would avoid change. As I will show, many clinicians I interviewed stated that they support the postponement of the early surgeries, for instance, but this might not represent the opinion of the majority in the field. Also, I conducted my research in two major research and teaching hospitals in the largest city in Turkey, and thus it is likely that they offer higher standards of care compared to many other hospitals in Turkey. Some clinicians mentioned this as well. Geneticist Dr. Alper Şimşek says, for instance, "our people [doctors] are still very very good, you know… maybe they're not too patient-centered; I think that an individualized counselling is not really done, but still very… of course compared to the overall [situation], in Turkish standards, it's a 'crème de la crème' thing, I mean… They receive a service that they can't really get in Turkey."[15]

When we were discussing the recent changes in the treatment procedures, intern clinician Irmak Güler, who works in a hospital in a city other than Istanbul, mentioned that her hospital is quite up-to-date on treatment of intersex children, but she was pessimistic about a large-scale change happening. So, I brought up the issue of clitoral surgery, since I had the implication that some surgeons could be growing more cautious about it:

> Ceren: But, for instance, they used to cut the clitoris before?
> Dr. Irmak: Yes, some do it now, too.
> Ceren: But at least less?

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[15] "yine bizimkiler çok çok iyiler yani…. hasta bazlı olması anlamında belki çok şey değildir, çok hasta bazlı değildir belki, tıbbi nosyon içerisinde bireyselleştirilmiş bir konsey yapılmadığını düşünüyorum, ama yine de çok tabii ki genele nazaran, Türkiye standartlarında 'creme de la creme' bir şey yani….Türkiye'de çok alamayacakları bir hizmeti alıyorlar."

> Dr. Irmak: In fact, there are many; many of them cut it.
> Ceren: They do?
> Dr. Irmak: Yes.
> Ceren: So, there are none at your hospital?
> Dr. Irmak: Not here but outside, there are many that we know of, cause, when, instead of coming to a university hospital, they go to a state hospital, the person they meet is someone who got their education in the eighties or the nineties. They do it just like that, without asking or anything.[16]

Moreover, this study does not include clinicians who work in private hospitals. The treatment decisions are made in teams, which I will call "DSD committees," that include specialists from various fields such as pediatric surgery, pediatric endocrinology, and depending on availability and need, psychiatry or psychology, and radiology. The clinicians I interviewed did not have any knowledge of an existing team in a private hospital, and they presumed that clinicians would probably avoid performing surgeries on intersex children without a team decision because of legal and ethical concerns. For this reason, I limited my research to the public hospitals. The only exception to this is Dr. Ziya, who started working in a private hospital after his retirement but spent his previous working life in a public research hospital as well. However, if a team decision is received, then the patient can go to a private hospital in order to have the treatment. In short, intersex treatment, including surgeries, occurs in private hospitals as well, yet I did not include them in my research because they do not have DSD committees. In addition, some parents might decide to take their intersex children to hospitals abroad, as reported by some clinicians; my study does not include those patients as well.

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[16] Ceren: Ama mesela eskiden klitorisi kesiyorlarmış?
Dr. Irmak : Evet, şimdi de kesen var
Ceren: Ama en azından daha az?
Dr. Irmak : Aslında çok var, çok kesen var
Ceren: Var mı?
Dr. Irmak : Var
Ceren: Sizin hastanede [mi] yok?
Dr. Irmak: Bizde değil ama yani dışarıda çok, bildiğimiz çok var, çünkü üniversite hastanesine gelmek yerine bir tane devlet hastanesine gittiklerinde karşılarına çıkan kişi seksenlerde eğitim almış, doksanlarda eğitim almış, sormadan etmeden çat diye yapıyorlar.

1.2 Literature Review

This thesis is at the intersection of several fields. Firstly, it touches upon questions that the medical anthropology literature raises. For instance, Arthur Kleinman's *Writing at the Margin: Discourse between Anthropology and Medicine* presents medicine as a specific area of study and practice that has its own specific culture. In his critique of medicalization, Kleinman emphasizes how "to change the border between a social and a health problem" is connected to the moral and the political, and "the deep cultural processes that are at work within biomedicine...limit biomedicine as a science and form of practice" (Kleinman 1997, 16). He further emphasizes that "while giving the sufferer the sick role, medicalization can stigmatize as well as protect; it can institute a misguided search for magic bullets for complex social problems; and it can obfuscate the political and economic problems that influence these behaviors" (Kleinman 1997; 38). In this thesis, I adopt a similar approach to the medicalization of intersex and variations of sex characteristics; however, I view the "social problem" not as intersexuality itself, but rather as the stigmatization of it. Anne Fadiman's brilliant journalistic work *The Spirit Catches You and You Fall Down* (2007) has also been helpful for me to understand what it would look like to approach both the clinicians and patients as culturally situated subjects. Telling the story of a Hmong patient's encounters with modern medicine following their immigration to the US, Fadiman denaturalizes the universality of modern medicine and shows how assumption of rational, universal authority can create catastrophic consequences. Fadiman's account thus allowed me to recognize the implications of these underlying assumptions more easily in my own research. This recogniziton also enabled me to see beyond the binary of disease/non-disease when the discussion is on intersex since Fadiman's research subjects were concerned with epilepsy, a conditon that is non-controversially considered a disease; still, for them, "the crisis was the *treatment*, not the epilepsy" (Fadiman 2007, 53). While I do not argue that intersex is a disease, I argue that the fact that some intersex individuals might need medical help should not compromise the critique of medicalization.

From a global health perspective, Paul Farmer's account emphasizes the drastic inequality in access to high quality health care, and it points out how part of this inequality stems from that policy implementers do not see some populations, such as poor populations, as deserving enough and thus set low standards. Although Farmer's account is based on very different contexts than the context of this study, it provides a convincing account of how often inequalities in access to healthcare arise more because of "failures of imagination" than lack of available options (Farmer 2013), which encouraged me to challenge the arguments about the impossibility of setting higher ethical standards for intersex patients in Turkey, as I discuss in Chapter 3. Also, *Medical Anthropology at the Intersections,* which enabled me to problematize a purely medical approach to intersex that "leaves out… the anthropological insight that relationships and practices imbued with meanings are a life lived, not merely a symptom of an underlying physical truth" (Inhorn and Wentzell 2012, 37), and *Commodifying Bodies*, which shows how the objectification of body parts works as dehumanization (Scheper-Hughes and Wacquant 2002), were among the sources from the medical anthropology literature that inspired this thesis.

Another related field is feminist science studies, which point out to the cultural and political nature of scientific discourses about sex, gender, and sexuality. For instance, Emily Martin (1991) deconstructs the conventional scientific discourse of human fertilization, which associates the sperm and egg's behavior with traditional gender roles, suggesting that the widely known story of sperm as the penetrator and the egg as the passive receiver of sperm is more culturally constructed than being scientifically accurate. In his *Making Sex: Body and Gender From the Greeks to Freud*, Thomas Laqueur provides a detailed historical analysis of how the scientific and cultural constructions of sex developed parallel to each other for many centuries (Laqueur 1990). One of the early accounts that challenge the biological, binary construction of sex from a scientific perspective is Fausto-Sterling's article "The Five Sexes: Why Male and Female are Not Enough" (1993), in which she argued that there are biologically five sexes, not two, because intersex people exist. Seven years later, she published an update, "The Five Sexes, Revisited" (2000), and this time she argued that her previous categorization of five sexes was too narrow to account for the variety of bodily embodiments of sex, again referencing the wide variety of intersex bodies. In this article, she also responded to Suzanne Kessler's critique of her 1993 article (Kessler 2000 [1998]), which suggested that Fausto-Sterling's "five sexes" argument was based on a strictly biological understanding of sex and gender and thus ignored the performative nature of gender, by stating that "[she] now agree[d] with Kessler's assessment" (Sterling

2000, 22). Also, it should be noted that a crucial point that opened such debates on sex and gender was the publication of Judith Butler's *Gender Trouble* (1990), which argued that gender is performative, that is, gender is constructed through the repetition of actions, rather than being a stable or coherent marker of identity. Rebecca Jordan-Young's *Brain Storm: The Flaws in the Science of Sex Differences* (2010) provides a more recent challenge to the dominant scientific accounts of sex. Reviewing a vast body of scientific literature on biological sex differences, Jordan-Young illustrates that most of these studies include methodological fallacies that would weaken their conclusions on sex difference. She also points out that this body of research both relies on the studies that are conducted on intersex individuals and in return justifies the conventional medical treatment procedures for intersex children in a self-referential way: "These studies ... have contributed to a systematic disregard for how medical intervention harms women with CAH and other intersex individuals who are subjected to cosmetic, but medically unnecessary, genital surgeries" (244). For instance, she points out that in these studies, the negative consequences of the treatment on sexual funciton, such as lack of sensation, libido, and sexual activity, are attributed to biological factors, such as brain masculinization in women, which obscures the necessity of considering other potential reasons such as treatment itself.

An underlying theme that I problematize throughout the thesis is the dismissal of medical procedures of the personhood of the patient, and objectification of the body. Geertje Mak's historical analysis of how the concepts of sex, body and self has changed from the nineteenth century to the twenty-first century helped me to historically contextualize the medical treatment procedures of intersex. Mak (2012) shows how the concept of "true sex" in intersex management emerged as a result of the separation of the "body" from the "person." When it comes to treatment of people with "doubtful sex," the clinicians' role has changed from being "guardians of morality" to discovering their patients' "inner truth," which, in the case of hermaphrodites, meant finding the "true sex." However, it did not mean that moral policing was completely abolished. It only changed form, for this time, understanding and expressing one's "inner self", which is a sexed self, became a moral responsibility in its own right, and doctors who treated hermaphrodites started encouraging their patients to "find their inner truth" for their own good, rather than seeing themselves as agents of moral policing. Mak's account is a helpful reminder that the idea that everyone should have one "true sex" is a historically constructed, and a morally charged concept. Alice Dreger provides another historical account that is helpful to understand how the medical categorization of intersex is historically situated (Dreger 1998). On the other hand, these accounts are based on European history and thus cannot be argued to provide a universal history of intersex. In order to have a deeper understanding of the social perception of intersexuality in Turkey, a historical review of how hermaphrodites, or "khuntha," in the Middle East, for instance, would be very useful. For instance, Gesink (2018) argues "studies on intersex persons (*khuntha*) in premodern Islamic societies often underestimate the nonjudgmental character of legal and medical discourse.... The dominant strand of this discourse tolerated ambiguity and flexibility regarding nonbinary sex embodiments" (152). By revealing that the "West" has not always been more "advanced" or "open-minded" than the "East," such a historical reading can help subvert the widely held beliefs about the irreversibility of this trend.

Also, this thesis draws heavily on several major works of a relatively recent field of intersex studies, including Katrina Karkazis's *Fixing Sex: Intersex, Medical Authority, and Lived Experience* (2008), sociologist and Georgiann Davis's *Contesting Intersex: The Dubious Diagnosis* (2015), and Morgan Holmes's collection *Critical Intersex* (2009). These works not only deepened my understanding of the topic but also shaped the questions I raised during this research.

A challenge for this thesis was the lack of literature on intersex issues in Turkey, although there is a significant body of medical research on the topic. Hülya Türker's unpublished master's thesis is a rare example that examines the current debates around the medical intervention in intersex children from the perspective of medical ethics and law (Türker 2015). Berfu Şeker's article (Şeker 2011) and her interview with intersex activist Belgin İnan (Şeker 2013), and an issue of the Kaos GL magazine (İnterseks 2017) are also among the scarce publications on intersex issues in Turkish other than medical publications. Yet, the existing literature on trans people's medical experiences can provide a useful comparison to understand the implications of medical construction of sex. For example, as Aslı Zengin (2014) describes, medical institutions play a gatekeeping role for surgical sex reassignment for trans people, unlike the intersex. Zengin states that as part of the medical testing that is required for “the scientific evaluation of one’s sex and gender,” “medical genetics … monitors trans people’s chromosomal combination to see whether they are intersex or not” (2014, 59). In his unpublished master’s thesis, Emirhan Deniz Çelebi states that penis reconstruction surgery can be demanded from trans men during the judicial process despite the high risks that the surgery involves (2018), which is striking considering that the high risk of penile reconstruction surgeries is often cited as a reason why intersex children are assigned more often as females than males. Lastly, there is a body of literature on LGBTI+ politics in Turkey, to which the issues raised in this thesis are inevitably linked (Savcı 2016; Zengin 2015; Bereket and Adam 2006; Özyeğin 2015). This thesis differs from these studies in both methodology and scope; it is based on one-to-one interviews, and it brings together clinicians’ and intersex individuals’ perspectives together. In this sense, this research aims to contribute to constructive conversation between the main “sides” of the controversies in Turkey.

1.3 Thesis Outline

In the following chapter, I first discuss some of the questions that arise from the rationale of medical treatment. Second, I summarize my findings about use of terminology and the debates surrounding it among clinicians, and then I point out to two practical implications of using the language of “disorder.” In the final section, I discuss the possibilities of change in relation to the positionalities of the clinicians in these debates. In Chapter 3, I discuss how the communication process between the clinicians and the patients and families shape how intersex is framed in the clinical setting as well as how this might affect treatment process. In particular, I discuss the power dynamics in the decision-making process, follow-up mechanisms, and I analyze the role of a particular understanding of the concept of “culture” among clinicians in these processes. In Chapter 4, I present the stories of intersex individuals who were subjected to medical treatment and discuss their implications for the debates around the medical procedures. Finally, after providing an overview of the history of intersex activism in Turkey, I discuss the intersections of the intersex/LGBT movement with the clinicians.

CHAPTER 2

MEDICALIZATION

In the following section, I critically analyze the logic of medical treatment procedures that came up during my fieldwork and which challenge the notion that medical management procedures, and especially early surgeries, offer a “quick fix” to intersex.

2.1 Fractures in Medical Logic

2.1.1 Medicine as a Scientific Endeavor and the Hierarchies of Evidence

One of the most surprising and confusing things for me during my interviews with the clinicians was that they often advocated for less intervention to intersex children, yet at the same time they stated that they nevertheless continue to perform operations for different reasons. One of the implicitly expressed reasons for continuing operations is the dichotomy established between “objective” and “subjective,” in which medical opinions are classified as objective, and non-medical opinions are classified as subjective. In this dichotomous classification, “objectivity” is naturally prioritized because it is implied that “objective” opinions are above any “subjective” or “personal” opinions in a scientific endeavor such as medicine. Thus, one of the ways in which clinicians justified the treatment procedures was to emphasize the “objectivity” of medicine, and to present it as devoid of any cultural or political positionality. Specifically, clinicians employed this distinction to explain why they practice non-intervention less than they advocate for.

One of the most striking examples of how this dichotomy is utilized can be seen in the following excerpt. When we were talking about cliteroplasty and vaginoplasty in children with CAH, Dr. Bülent Özcan said:

> "The general opinion is that, individuals who have not been intervened in, -I'm talking about Congenital Adrenal Hyperplasia, not the others-, the individuals that have never been intervened, with a vagina, after they arrived the adult age, that was opened only enough for bleeding, to allow the menstrual blood to come out or to allow sexual intercourse, with a clitoris that was never intervened in are the ones that lead their lives most happily. The ones that are intervened in the least end up very happy both in terms of sexual pleasure and in terms of perceiving life in general."[17]

This was a very unexpected statement for me to hear, because Dr. Bülent also told me that he continues performing cliteroplasty in most of his patients with CAH who have "large" clitoris. So, I became even more curious about why, and continued to ask questions on this topic as it came up in our conversation. At first, he gave me such reasons as Turkey being a conservative country and therefore the prospect of children without intervention suffering socially, or the parents pressuring him for operations, which was a reasoning offered by all the clinicians I interviewed. However, later in the conversation we came back to this issue when he mentioned the lack of medical studies which provide information on long-term effects of surgery and talked about it being "hard to decide what to do." I referred to what he said before about his opinions on the correlation between non-intervention and long-term happiness:

> Dr. Bülent: I am supposed to tell [the family]: "we have done this for a thousand patients and their body perception score was this, this much in 1000 ones…" There is not enough research, it is very subjective.
> Ceren: But you said that, based on limited data, there is a perception that the least intervened ones are the happiest…
> Dr. Bülent: I said it entirely subjectively.[18]

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[17] "Genel kanı o ki hiç dokunulmamış bireyler -Konjenital Adrenal Hiperplazi'den bahsediyorum diğerleri için değil- hiç dokunulmamış, vajen erişkin yaşa geldikten sonra [sadece] kanamaya, adet kanının akmasına izin verecek kadar açılmış veya cinsel birleşmeye izin verecek kadar açılmış, klitorisine hiç dokunulmamış bireyler en mutlu yaşamlarını sürdürenler. En az dokunulmuş olanlar hem cinsel haz açısından hem de genel hayatı algılama açısından çok mutlu oluyorlar."

[18] Dr. Bülent: Ben [aileye] diyeceğim ki "bin tane hastada böyle yaptık daha sonra kendi bedenine algılama skoru şu oldu, 1000 tanede şöyle.." şey [yeterince çalışma] yok ki, çok subjektif.
Ceren: Peki şeyi dediniz ya hani hani kısıtlı verilere dayanarak daha az dokunulanlar daha mutlu oluyor gibi bir algı var…
Dr. Bülent: Tamamen subjektif olarak söyledim

This dialog was striking to me because Dr. Bülent dismissed his *own* opinions and observations on the grounds that they were subjective, since there were not enough follow-up studies that show long-term harm. Thus, one of the implications of the dichotomy between medicine as an “objective” field versus “subjective” opinions is dismissing non-medical voices as invalid, even if they are the opinions and observations of the very surgeon who performs those operations.

Anthropologist and bioethicist Katrina Karkazis mentions that this dichotomy has implications also in how medical studies are conducted and interpreted in the first place. For instance, the voices of patients are lacking in these studies, because they are counted as subjective data (Karkazis 2008, 167). Moreover, if the evidence that is based on self-report is not published in a medical journal, it’s not considered as evidence; rather, it is considered as anecdotal data. However, clinicians regularly depend on anecdotal data in their own practice and in the medical papers they publish. And whether considered scientific or anecdotal, in general “the only available evidence seems to contradict surgeons’ and others’ belief that early genital surgery both preserves sensation and provides cosmetically appealing and functional outcomes...As long as these hierarchies of acceptable evidence persist...there will be no consensus over what counts as credible evidence, and the truth claims that each side derives from these. This is the primary reason why outcome studies are unlikely to resolve these debates” (Karkazis 2008, 168).

In this picture, it should not be surprising, then, that activist voices or data produced by social scientists can be dismissed easily as non-medical opinions. Indeed, when I interviewed Dr. Ayfer, a pediatric endocrinologist, she cautioned me against using the activist voices as representative in my study, claiming that they represent a minority whose operations went wrong, but that there is a silent majority who are happy about the surgical operations they had. Furthermore, she also established a contrast between social sciences and medicine and positioned social sciences as unscientific. She emphasized this point when I asked her if there are instances where opinions differ between clinicians about the sex-assignment of an intersex child:

> Ceren: So, does dissent ever occur?
> Dr. J: Of course it does. So, what happens in that case, I mean, look, in all positive sciences we have some guidelines or data, so we first try to act according

> to those, so the dissent is not like in social sciences. Here, we have more positive data at hand, such as "a thousand articles were published on this disease" or "this and this happened in our experience" and then, according to this, according to the scientific, latest up-to-date data, we decide to do it in a certain way. Dissent occurs rarely, but not much; I mean, we try to reach an opinion in the end. After all, when five or six people get together, ultimately everyone… Like I said, positive science, positive data are very important here. I mean, we are supposed to always act according to evidence-based medicine; wherever the up-to-date knowledge takes us, not however we please.[19]

In this narrative, Dr. Ayfer employs the hierarchy of evidence Karkazis mentions; for her, for data to be considered scientific, there is the criteria of being strictly collected by medical researchers, dismissing the evidence provided by the testimonials of intersex people themselves or evidence collected by social scientists.

In her discussion of Evidence-Based Medicine (EBM), Karkazis points out several weaknesses with the term, which was coined as part of an effort to move "toward outcomes-based medical treatment which began in the 1990s" (Karkazis 2008, 280). She points that EBM promoted standardization based on the existing medical study outcomes, and thus was meant to minimize the individual judgments of the clinicians based on cultural or personal views. Yet, when there is not enough reliable evidence, EBM might promote the continuation of reliance on insufficient data, such as in the case of intersex treatment. Currently, the lacking outcomes are being standardized with the discourse of EBM, which means that EBM makes it more difficult to challenge these outcomes. In short, "[w]hile some argue that EBM attempts to limit individual clinical authority, it actually reinforces medical authority in general at a time when health movements have presented contemporary challenges to this authority" (Karkazis 2008, 283).

Not all clinicians, on the other hand, are as strict as Dr. Ayfer on this matter. For instance, pediatric surgeon Dr. Engin is critical of the discourse of Evidence-Based Medicine. When

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[19] Ceren: Peki fikir uyuşmazlığı ortaya çıktığı oluyor mu?
Dr. Ayfer: Tabii ki oluyor yani o durumlarda nasıl ilerliyor, yani elimizdeki, şimdi bak pozitif bilimlerin hepsinde elimizde bir takım ya guideline"lar vardır ya veriler vardır dolayısıyla önce onlara göre hareket etmeyi deneriz, dolayısıyla fikir uyuşmazlığı sosyal bilimler gibi değil. Burada daha pozitif verimiz var elimizde, "bu hastalıkta bak 1000 tane yazı yayınlanmış" ya da "bizim de deneyimimizde şu şu şu şu şöyle olmuş" dedikten sonra biz de buna bunlara uyarak elimizdeki bilimsel, son güncel verilere dayanarak "böyle yapalım" diye konuşuruz. Fikir uyuşmazlığı nadiren oluyor ama çok olmuyor yani bir fikre varmaya çalışıyoruz sonuçta, zaten beş-altı kişinin bir araya geldiği bir yerde sonunda herkes.... Dediğim gibi burada pozitif bilim, bilimsel veriler çok önemli yani her zaman güncel bilgi bizi nereye götürüyorsa, evidence-based medicine, ona göre hareket etmek durumundayız hani canımızın istediği gibi değil.

I asked the factors that contributed to changes in the standard procedures in recent years, he answered by saying that he was mostly affected by the outcomes of his own patients over the years, and then he followed:

> Dr. Engin: So, this is a university hospital, we're trying to practice medicine that's based on evidence. That said, I always laugh at that, 'evidence-based medicine'… *(laughs)*
> Ceren: Why?
> Dr. Engin: Because you do it over and over as evidence-based, and then, 10 years later, when we look back, we say: 'we did it that way but it was faulty'. It's like that. So I laugh because of that, I mean, there is no such thing as evidence-based. I guess there's experience-based. A lot of things can change. Eggs, for instance, increase cholesterol… What do we say now? We say: 'No, it does not.' We even say: 'eat them' *(we laugh)*, mean, it's like that. So they said: 'butter is dangerous', but my grandparents all ate butter. Now we say: 'eat butter'.[20]

In this quote, Dr. Engin blurs the boundaries between scientific evidence and ordinary people's experiences, challenging the view that strictly distinguishes between the two. Also, by establishing parallels with a topic that is much more popularly known than intersex, he generalizes his argument to other medical issues as well. I will discuss how comparing intersex with other medical conditions and presenting it as "just like any other disease" is another way of establishing medical authority and legitimizing the treatment procedures in 2.2.2. In the following part, I will show how clinicians might employ their own cultural values and assumptions regarding gender, sexuality and social morality in their clinical decisions.

2.1.2 Clinicians' Personal Values on Gender, Sexuality and Social Morality in Medical Decisions

Although some clinicians tend to maintain the strict division between the objective and the subjective in their discourses, they, as everyone else, are part of the society and thus are not

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[20] Dr. Engin: yani burası üniversite hastanesi, kanıta dayalı tıp yapmaya çalışıyoruz. Hoş, ben ona da hep gülerim, "kanıta dayalı tıp…" *(gülüyor)*
Ceren: Neden?
Dr. Engin: Çünkü yaparsın yaparsın kanıta dayalı, sonra 10 yıl sonra geriye baktığında deriz ki "biz bunu öyle yapıyoduk ama hatalıymış," böyledir. Yani gülerim o yüzden, yani kanıta dayalı diye bişey yok, tecrübeye dayalı esasında var herhalde, bisürü şey değişebiliyo. Yumurta mesela, kolesterolü arttırır… şimdi ne diyoruz, hayır arttırmaz hatta yiyin diyoruz [gülüyoruz], yani onun gibi, yani şu anda işte tereyağı zararlıdır dendi, e benim dedemler filan hep tereyağı yerdi, şimdi yiyin diyoruz

exempt from making culturally situated decisions in their medical practices (Kleinman 1997). In my fieldwork, this was most obvious in the discussions on the reasons for performing cliteroplasty. These discussions came up in two ways: first, and more commonly, when the clinicians expressed empathy with the patients and applied their own values while empathizing. Second, although less commonly and implicitly, some clinicians expressed concern about the implications of sex assignment on social morality.

The decision to perform cliteroplasty on a female-assigned intersex child is made when the clitoris is deemed too large by the clinicians. As Karkazis (2008) states, "[t]he first table for female neonate clitoral size was published in 1980" (150), and even if there were studies published during the 80s that suggested some average sizes for the newborn clitoris, "Neither study specified, however, at what point the clitoris of an infant could be considered enlarged" (151), which means that the decisions are based on subjective criteria. Pediatric surgeon Dr. Engin supports this by saying "There's nothing to measure the clitoris with, there's no size thing, I mean, like 'it should be this big at this age' or anything like that. We make somewhat an eyeball estimation, to be honest."[21]

The following conversation with another pediatric surgeon Dr. Bülent might provide further insight on how the "eyeball estimation" decisions work in terms of deciding cliteroplasty. As I mentioned in the previous section, I was struggling to understand why Dr. Bülent is continuing cliteroplasty operations even though he believes that those who escape surgery are the happiest; so, I continued to ask him:

> Ceren: So, if the ones that are intervened in less end up happier, can't you just say 'let's not do it'?
> Dr. Bülent: A girl doesn't want to go around with that clitoris. I mean, I think about it too; when the mom undoes the diaper near others, when she goes to the pool, or to the gym, etc., near other girls, or at school, in the toilet, cause it is really big...
> Ceren: But why, then, are the ones that are intervened in less, happier?
> Dr. Bülent: Because their pleasure rates are higher…
> Ceren: Should there be a choice between two things here, cause there will be a negativity in any case?
> Dr. Bülent: Maybe there will be, but, in fact, without really finding it in my heart, since that child will suffer like that, knowing they won't be happy in the future,

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[21] "Klitorisin ölçüm şeyi yok, yaşa göre büyüklük şeyi yok, yani "şu yaşta bu kadar olur, bu yaşta bu kadar olur [gibi]…" birazcık göz kararı yapıyoruz açıkçası."

> I am in a position to do [this]. But think about the Turkish society; she became a normal, fertile woman and she got together with a man, they undressed, he saw that there, I mean, really, if you saw it as a man, erect, you'd run away. I mean, it's really a clitoris like a penis; not something a man would easily accept.[22]

Here Dr. Bülent assumes two things: first, that a girl-assigned child with an atypically large clitoris would be disturbed by it as she grows up; second, that she would prefer to have the clitoris surgically altered at the expense of reducing its sensitivity. Neither of these assumptions are informed by scientific evidence; rather, Dr. Bülent imagines the child as an adult and applies his culturally informed views about how a female body should look like and what a person with a female body should desire. Moreover, his culturally informed views are specifically shaped by his subject position as a heterosexual man, assuming the heterosexuality of the future adult.

In her book *Doubting Sex*, Geertje Mak shows how a major transformation of perceptions of sex, self and body at the turn of the twentieth century in Europe influenced the social and medical treatment of hermaphrodites[23]. According to Mak, apart from factors such as increasing access to physicians, the very role assigned to medicine changed profoundly around this time. Earlier, clinicians undertook the role of preserving social morality while making decisions about hermaphrodites. For instance, individuals could go to a clinician to be examined in order to get permission to marry to a certain person on the basis of their sex. Starting from the last quarter of the nineteenth century, however, clinicians' role began to change from guardianship of social morality to a more morally distanced position of discovering the "true sex" (Mak 2012).

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[22] Ceren: peki eğer daha az dokunulanlar daha mutlu oluyor ise yapmayalım deseniz mesela olmuyor mu?
Dr. Bülent:kız çocuğu o klitorisle dolaşmak istemiyor, yani ben de düşünüyorum bu çocuk başkalarının yanında anne altını açtı, o zaman havuza girdiği zaman, spora gittiği zaman falan filan, diğer kızların yanında okulda tuvalette filan, çünkü öyle böyle [büyük] değil ya..
Ceren: ama o zaman niye daha mutlu oluyorlar az dokunulanlar?
Dr. Bülent: Çünkü haz alma oranı daha büyük, ona bakıyor…
Ceren: burada iki şey arasında seçim mi yapmak mı gerekiyor, hani her türlü bir negatiflik olacak?
Dr. Bülent: olacak belki ama aslında gönlüm çok razı olmadan o çocuk öyle sıkıntı çekecek diye ilerde onun mutlu olmayacağını bile bile şey yapmak durumunda kalıyorum; ama yani bir Türk toplumu düşün, normal doğurgan bir kadın haline geldi, bir erkekle bir araya geldi soyundular erkek orada gördü, yani hakkaten onu ereksiyon halinde görsen kaçarsın erkek olarak yani öyle böyle değil, bayağı ciddi penis gibi bir şey klitoris o yani her erkeğin çok kolay kabul etmeyeceği şekilde

[23] Here, I use "hermaphrodite" instead of "intersex" because it was the term being used in the historical context referred

Even if morality can be ingrained in their medical decisions I agree that the clinicians do not mainly consider moral policing as part of their job. The main discourses they build their arguments upon are scientific objectivity, as I show in the previous section, or the prospective happiness of the patient, rather than morality. During the interviews, even if they commonly referred to the conservativeness of Turkish society, moral implications associated with it came up only as an external factor which might force them into making decisions that they are not entirely comfortable with; however, clinicians did not express an explicitly moralistic stance. Rather, they consider themselves as primarily concerned with the "happiness" of the patient. Yet, there were two instances which showed that some might still consider themselves as guardians of social morality.

As I mentioned before, I had a long discussion with Dr. Bülent about why he continues to perform cliteroplasty even if he thinks that it is harmful. As part of this discussion, he brought up the issue of how "people with genital anomalies" can make a lot of money in porn and sex work. Apart from other reasons he suggested for operating on the clitoris, this argument was based on a concern about moral consequences on social order rather than a concern about individual happiness, which implicitly means that he might also feel responsible about the social morality when making decisions about whether or not to perform cliteroplasty on his intersex patients.

In a similar vein, Dr. Ziya brought up *hijra*s, giving an anecdote about how intersex children are in danger of abduction by *hijra*[24] communities in India:

> "For instance, one of the countries that this matter is a problem in and that it keeps people, medical and judiciary mechanisms busy the most is India. Around 1999 or 2000, I was invited to India twice. Once I gave a speech on the topic and then, the second time, I performed two or three surgeries and I was at a workshop as an operator. I performed this surgery of feminization that we call clitoroplasty and vaginoplasty… When groups that are called hijras, that live secluded, find out about a baby that is born with ambiguous genitalia -as it was called at the time-, they usually kidnap the baby. I mean, I don't know in which cities this occurs the most, but they kidnap and raise the kid. When the kid reaches the age of 13 to 15, they sell the kid as a very expensive sex object… This is, for instance, a big problem there. All municipalities, etc. try to find a solution to this. There was an important health institution in New Delhi… I mean, they have patients

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[24] *Hijra* is used as an umbrella term for some transgender and intersex people in India; it is also legally recognized as a "third gender" category with a court ruling that passed in 2014 in the country.

> there all the time, cause the ones that save their patients from the hijras take their patients there so that these kids become acceptable by the society."[25]

Before this anecdote, Dr. Ziya had given another anecdote from the US, and conceded that it might be a good idea to let people decide for themselves. Yet, he continued, "but of course it is difficult to take such as risk for both the parents and the doctors in societies like ours."[26] Giving these two anecdotes, Dr. Ziya contrasts US with India, presenting the US as an "educated society" as opposed to India, where non-intervention might have severe consequences. In this contrast, Dr. Ziya also places Turkey next to India, and therefore implies that similar consequences that disrupt social morality might await an intersex child, unless intervened.

Even though clinicians might often construe their role as one of scientists who rely solely on objective data that are devoid of cultural and moral influences, it may not always be the case. This is not to say that the clinicians cannot distinguish between scientific and unscientific data well, but rather to point to the necessity of questioning what the dichotomization of categories such as "objective/subjective" and "medical/non-medical" imply on a practical level. While the dominant medical discourse suggests that we can strictly distinguish between medical and non-medical evidence, at a closer look, maintaining these categories as such means prioritizing the evidence collected by medical professionals over evidence collected by activists and social scientists, obscuring the fact that these hierarchies of evidence are created by the power imbalance between the patients and the medical professionals. Thus, voices of the intersex people themselves can easily get lost in these debates. In the following section, I will explore the role of psychiatry, which occupies a unique position in the medical narrative between the "objective" and the "subjective."

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[25] "Mesela bu konunun en çok problem olduğu en çok insanları ve tıbbi ve adli mekanizmaları meşgul ettiği ülkelerden bir tanesi Hindistan. Hindistan'dan 1999-2000 falan o civarlarda 2 kez peş peşe Hindistan"a davetli gittim bir tanesini de bu konuyla ilgili bir konuşma yaptı mı ikincisinde gidip iki üç tane ameliyat yaptım oturup bir workshop"ta ameliyatçı olarak bulundum. İşte bu kliteroplasti vajinoplasti dediğimiz dişileştirme ameliyatını yaptım….O zamanki ismi ile ambiguous genitalia ile doğan bir bebekten haber alınınca bu bebeği genelde kaçırırlarmış hicralar denen, kendi içlerinde kapalı yaşayan gruplar, yani hangi şehirlerde en fazla bilmiyorum ama kaçırıyorlar ve büyütüyorlar, böyle işte.. 13-15 yaşlarında gelince çok pahalı seks objesi olarak satıyorlar… işte yani orada Mesela bu bayağı problem Yani bütün belediyeler vesaire bu işe bir çare bulmaya çalışıyorlar, Yeni Delhi'de önemli bir sağlık kurumu vardı …. yani oraya devamlı hasta geliyor, çünkü hicralardan kurtaranlar hastalarını oraya getiriyormuş topluma kabul edilir hale gelsin bu çocuklar diye."

[26] "ama tabi bizim gibi toplumlarda öyle bir riski almak anne baba için de zor, doktor için de zor yani."

2.1.3 Medicalization as Lack of Psychiatric Consultation and Care

Medical anthropologist and psychiatrist Arthur Kleinman points out how medicalization has been mainly construed as "overmedicalization" in medical anthropology, ignoring psychiatry as a subject of study. In pointing out this lack, he also raises the question, "[w]hat happens when we see the state not primarily as the source of powerful control over the … society at large, but rather as fragile, constrained, and almost powerless to provide the most basic care for its most … vulnerable members?" as one of the five questions pertaining to the future of medical anthropology (Kleinman 2012, 123). Following this question, in this section, I examine the role attributed to the psychiatric care in the discourses as well as in the practices of the clinicians I interviewed.

Based on the data I gathered from my interviews with the clinicians, in the process of sex assignment to a child diagnosed with DSD, psychiatry is usually attributed a secondary role compared to the role of endocrinology and surgery. If the child is under two years old, and if the condition is a well-known condition, then "there is not much doubt" about which sex to assign. For instance, the established medical view for a child with CAH and XX chromosomes is always to assign them as a girl if the child is under two years old at the time of the diagnosis. Also, clinicians stated that in many other cases as well, it is easier to assign sex when the child is under two years old, since it is assumed that gender identity does not fully develop before that age, and thus it can be influenced by "appropriate" rearing. The logic follows that when the child is under two years old there is usually no need for psychiatric examination. However, psychiatrist's role is considered more important for children who are above this age. For those children, many of the clinicians I interviewed emphasized the important role of the psychiatry in the sex assignment process of a child. At the same time, they expressed concern about the lack of availability of psychiatric consultation, especially the lack of psychiatrists who are qualified enough - or rather who have sufficient familiarity with this special group - to help intersex children.

In one of the two major hospitals where I conducted my fieldwork, there were no psychiatrists or psychologists in the DSD commission, at the time of the interviews (2017 June). There was one pediatric psychiatrist in the other hospital, Dr. Nilgün Yılmaz, who was specifically involved with the DSD commission in that hospital. When I asked her about how the DSD council works, and how they decide the sex assignment, she said: “Sometimes they are not sure, so they come to us, and other times if they are organically certain, we abide by their decision.”[27]

This indicates that, in two major research hospitals in Istanbul, the decisions regarding sex assignment are predominantly made by surgeons and endocrinologists, who are most of the time “organically certain” about the proper sex assignment. Yet, as I discuss at the end of this chapter, clinicians may not feel certain in their decisions; to the contrary, they may have a conflicting relationship with their own power over the destiny of the intersex children, indicating that they need a different kind of expertise to be able to make “technical” decisions regarding intersex children.

Dr. Nilgün was very friendly and welcoming towards me, but she seemed a bit uneasy about the topic of my questions, and she did not allow me to record the interview; instead, I took notes. She expressed concern about how “there isn’t much research on this topic, very little on children and adolescents; for instance, there are separate clinics for them abroad. Unfortunately, there aren’t really any in Turkey *(in an upset tone)*. [At the first hospital] there’s Dr. Ayşe Kaya. We don’t know what happens in the long run, for instance,”[28] indicating that she might be feeling inadequate in her role as a psychiatrist in the case of intersex children, and someone like Dr. Ayşe could know more about it. Dr. Ayşe is a prominent psychiatrist who is well known for her groundbreaking role in helping trans individuals in Turkey gain their rights and improving the standards of care for them. Since I did not know any psychiatrist whose name is associated with intersex individuals, I had requested an interview with Dr. Ayşe when I was beginning my research, hoping that I can learn more from her. However, Dr. Ayşe said that she almost never encounters intersex individuals and she gave the names of a couple of pediatric surgeons, stating that they will know more about the topic. As I continued my research, I continued to realize how inadequate psychiatric consultation and care for intersex individuals has been.

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[27] “Bazen emin olamıyolar o zaman bize geliyorlar, bazen de onlar organik olarak eminlerse biz onların kararına uyuyoruz.”

[28] “bu konuda çok çalışma yok, çocuk ve ergenlerde çok az, yurtdışında onlar için ayrı klinikler var mesela, malesef Türkiye’de pek yok (üzülüyor), [ilk hastanede] Dr. Ayşe Kaya var, uzun vadede ne oluyor bilmiyoruz mesela.”

Even in cases where the endocrinologists or surgeons might want to refer the child to a psychiatrist before assigning sex, it is often up to the parents whether to take their child to the psychiatrist or not, and if they do not want to, there is no mechanism to force them to do so before surgery. For instance, Dr. Ali told me the story of a teenager for whom he disagreed with the rest of the committee about sex assignment; the child had been raised as a girl until the time she was brought to the hospital, and the committee had decided to assign the child as a female, and to perform gonadectomy on the child to take out the testes. But Dr. Ali insisted that the child should be assigned as male, and that the testes should be left in the body, refusing to sign the concluding report. The committee's decision was followed anyways, and the child was assigned as a female and therefore the testes were taken out. Dr. Ali tells this story as:

> Dr. Ali: [There was a kid] that played football and provided for the family. My colleagues here operated them. And I said that I was against them being operated, cause when the testicles are removed… A child that was supposed to be a boy was raised as a girl, plays at a girls' team, plays well, why? Cause there are testicles. What is androgen? It provides strong physique but the family reluctantly raised their child as a girl. They lost their testicles, in order to pass as a girl.
> Ceren: So, that child was a big child, one that could express themselves, right?
> Dr. Ali: Must be 13 or 14.
> Ceren: Did they, themselves say something?
> Dr. Ali: No, it was a family where family pressure was very strong. They didn't give the child the right to speak.
> Ceren: Here, if the psychiatrist or the psychologist sees them, can't they take their [statement on the subject]?
> Dr. Ali: They can, but, how to say, of course it can be taken but the family has the last word.
> Ceren: But couldn't they take the child's consent, even if the family has the last word?
> Dr. Ali: No, they didn't have the kid talk, or they probably didn't have them talk to the psychologist.[29]

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[29] Dr. Ali: Türkiye'de top oynayan, aile ailenin geçimini sağlayan [bir çocuk vardı] onu da mesela buradaki meslektaşlarım ameliyat ettiler. Ben de dedim edilmesin taraftarıyım çünkü testis alınınca… erkek olması gereken çocuk kız olarak yetiştirilmiş, kız takımında top oynuyor, iyi top oynuyor, neden çünkü tesisler var androjen nedir kuvvetli fizik sağlar ama aile istemeden çocuğunu kız olarak yetiştirmiş, kız olarak geçsin diye testislerinden oldu.
Ceren: Peki mesela o çocuk büyük bir çocuktu, kendini ifade edebilecek bir çocuktu değil mi?
Dr. Ali: 13-14 yaşında filandır herhalde
Ceren: Kendi hani bir şey söyledi mi?
Dr. Ali: yok aile baskısı çok kuvvetli bir aileydi yani çocuğa hiç söz hakkı vermediler
Ceren: burada Mesela psikiyatrist görürse ya da psikolog, onlar şeyini alamıyor mu?
Dr. Ali: Alabilir ama nasıl diyeyim, tabii alınabilir ama son kararı aile verir mesela yani
Ceren: Peki çocuğun şeyini alamaz mıydı yine de son söz ailede olsa bile?
Dr. Ali: yok konuşturmadılar çocuğu, konuşturmadılar veya psikologla büyük ihtimalle konuşturmamışlardır.

Despite the importance that is attributed to psychiatric consultation and care in the medical discourse, in practice it can be seen that it is a bit arbitrary to obtain the view of a psychiatrist or a psychologist, even when the child is old enough to speak for herself, and even when there is a disagreement on the sex of a child in the committee. Regardless of whether this story is representative of the majority of the cases or not, it indicates that there is no mechanism which ensures that a 13-year-old can have their own say in a sex assignment process that includes irreversible surgical operations. The lack of such a mechanism further reinforces medicalization of intersex and contributes greatly to the possibility of suffering of children with intersex traits.

Karkazis notes, "[a]lthough clinicians have expertise -about the endocrine system or surgical techniques, for example- many have received only basic training in determining gender assignment" and shows how confusing it can be to make sex assignment decisions for the clinicians (Karkazis 2008, 93). Dr. Alper, a medical geneticist, pointed out the gap between the expertise of surgeons and endocrinologists and their assumed role in sex assignment:

> Dr. Alper: The most I can say is 'yeah, medically it has been shown that, you know, one must pay attention to this at this surgery. The surgeon already knows about that, or, you know, information can be given such as 'with patients like that, with this genetic result, we must pay attention to hypertension', or 'when these people are assigned female gender, they go through sex change operation again' but there's no real connection there, you know, no follow-up with that family.
> Ceren: They say they follow up until they grow up?
> Dr. Alper: They do, they do, they follow up very closely but for what? One follows their hormones, another follows whether they can pee or get an erection, so that's something else, there's no connection there…
> Ceren: There's no obligation for psychiatric follow-up, for instance…?
> Dr. Alper: Of course not, of course not…[30]

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[30] Dr. A: ben en fazla şunu söyleyebilirim "a evet tıbbi olarak böyle böyle gösterilmiştir ki, işte şu ameliyatta şuna dikkat etmek lazımdır," cerrah zaten bunu bilir, ya da işte "şu hastalarda bu genetik sonuçta işte yüksek tansiyona da dikkat etmek lazım," ya da işte "bu insanlara ileride dişi yönünde gender assign edildiğinde tekrar cinsiyet değiştirme operasyonu geçiriyorlar" gibi bilgiler verilebilir ama hani orada tam olarak bir bağ yok ki yani hani o ailenin takibi yok
Ceren: büyüyene kadar takip ediyoruz diyorlar?
Dr. A: ediyorlar, ediyorlar, çok yakın takip ediyorlar da neyini takip ediyorlar? biri hormonunu takip ediyo, biri işeyebiliyo mu erekte olabiliyo mu onu takip ediyor, dolayısıyla o başka bir şey yani orda bir bağ yok yani..
Ceren: öyle psikiyatrik bir takip filan zorunluluğu yok mesela gibi..?
Dr. A: tabii ki, tabii ki..

Dr. Alper emphasizes the need for a *connection (“bağ”)* between “technical” decisions made by clinicians such as what kind of surgery or hormone treatment should be employed in order to achieve physical sex assignment and the social world the patient lives in. In doing so, he proposes psychiatric consultation and care as part of an “interface” between the clinicians and the intersex individuals’ non-medical experiences. In Chapter 4, I come back to this issue in terms of the possibilities such an interface can offer in closing the gap between the burden of “organic certainty,” in Dr. Nilgün’s words, and a more socially informed approach that values the non-medical information as much as medical information. In the following section, I discuss in further detail what “organic certainty” might look like in practice.

2.1.4 “Organic certainty” of Sex and Surgery

The ways in which medical studies are interpreted by the clinicians raises the question of how the clinicians can be “organically certain” about the sex of a child, considering that even children born with typically-sexed bodies can develop a different gender identity than they were assigned at birth as they grow up. In the sex assignment process of intersex children, the clinicians refer to previous medical studies that are conducted on the specific condition of the patient. For example, according to existing studies, the majority of children who are born with 5-alpha reductase deficiency (5-ARD) later develop male gender identity in puberty[31] due to physical virilization; so, when a child is diagnosed with this condition, they are assigned as a boy, and in that case, clinicians can be “organically certain” about the assignment.

The medical studies on which these decisions are based upon usually include statistics such as “%80 of the children born with 5-ARD develop a male gender identity,” or “%95 of the CAH children with XX chromosomes develop a female gender identity”; the decisions are made in favor of the large percentages in these studies. This raises the question of why %95

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[31] Children born with this condition have typical female phenotype at birth, so they are raised as girls if they are not diagnosed. In puberty, the body virilizes and they develop masculine sex characteristics.

“success’ rate in sex assignment justifies the sex assignment to the remaining %5 of these children, let alone the early surgical operations that come with it.

In *Brain Storm: The Flaws in the Science of Sex Differences*, Rebecca Jordan-Young points out that the studies that are conducted on sex difference on humans are by definition “quasi-experiments,” namely, they cannot be ideal scientific experiments that include control groups and experimental groups due to obvious ethical concerns. And “the interpretation of every quasi experiment depends on carefully placing that study within the overall body of evidence. So, a synthetic analysis of quasi experiments can actually be done with mapping the *structure* of studies, to see how well the studies fit together” (Jordan-Young 2010, 3). Since there are not many studies to compare with each other on long term effects of current gender assignment procedures on intersex children to begin with, these statistics become even more dubious and open to interpretation.

The narrative of “organic certainty” gives the message that sex assignment is finalized once the surgeries are done. Therefore, the child who is inter-sex is transformed into a single-sex person, the dis-order is put into order, and the child is no longer in a liminal state because s/he has reached the final destination. However, because of the questions the interpretation of studies raise, as well as fact that people born with typically sexed bodies do not always develop a “matching” gender identity later, it is impossible for clinicians to make a “correct” sex assignment in each and every case, including the conditions where “success rate” is very high, such as CAH. However, because the medical narrative obscures uncertainty, the early sex-assignment surgeries can be justified more easily on the premise that the child would suffer less psychologically.

One consequence of this is the elimination of other alternatives that can potentially respect the child’s bodily autonomy as well as minimize social suffering[32] for the child. For instance, this narrative does not allow for a scenario in which a child can be raised with gender assignment *and* without surgery, as some intersex activists would suggest. Such a scenario requires abolishing the binaries between “intersex” and “single-sex,” as well as binaries between gender roles, since it would mean providing a space to the child in which

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[32] Social suffering is a term that is used by Arthur Kleinman to define pain caused by social circumstances, as opposed to, say, mental illness

gender and sexuality can be recognized as more fluid rather than being fixed once and for all once the child reaches two-years-old. In the second scenario, gender would not be a "done deal," and gender roles could be bent more easily. However, because sex assignment process is construed as a coherent, linear scenario rather than one with a lot of room for uncertainty and ambiguity, alternative scenarios cannot find space for discussion.

2.1.5 Temporal Distance Between the Surgical Methods and Outcome Studies

Karkazis notes that another obstacle in the way of change in medical procedures is the temporal distance between the applications of newly invented surgical methods and observing the long-term effects of these methods (Karkazis 2008, 158). During the interviews, many clinicians brought up the lack of evidence about the long-term effects of current methods and presented it as a problem. In this section I show the implications of this obstacle through the examples of frequently performed operations in children with Congenital Adrenal Hyperplasia (CAH): vaginoplasty and cliteroplasty.

CAH is the most common condition among intersex children; pediatric surgeon Dr. Bülent estimates that approximately %80 of his intersex patients have CAH. He explains the two corrective surgeries that are typically operated on CAH children, vaginoplasty and cliteroplasty:

> "Now, there's a closed vagina, maybe part of it is open, and a huge clitoris, now, what we're going to do is to open the vagina and turn it into a vagina that is fit for intercourse, fit for birth, and somehow turn that clitoris into a normal clitoris; when you think about it like that, it sounds logical. It all went wrong with the vagina. No matter how much you fix the vagina, it tightens and shrinks."[33]

This is not only his experience, but an internationally acknowledged drawback; so, currently the global tendency is evolving toward postponing vaginoplasty until later when sexual activity starts, he explains, and continues:

> "So the general opinion is… very… Sometimes there's just a very thin membrane that closes it, and we cut those open but with the ones that need harder

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[33] "Şimdi kapalı bir vajen var, belki bir kısmı açık, kocaman da bir klitoris var, şimdi yapacağımız iş vajeni açıp birleşmeye uygun, doğurmaya uygun bir vajen haline getirmek, o klitorisi de bir şekilde normal klitoris haline getirmek, böyle düşündüğün zaman mantıken böyle geliyor. Vajen ile ilgili başımıza gelmeyen sorun kalmadı, vajeni istediğin kadar sen yap vajen daralıyor küçülüyor, istediğin kadar yap daralıyor küçülüyor."

> surgeries, we don’t touch the vagina at all. Otherwise, if you perform the operation at 3 or 4 years old, you need to constantly dilate it and keep it large until the period of adolescence, and this is something that is done constantly, every day, or every other day, so it becomes a very serious sexual trauma for a girl at an age when she doesn’t understand what’s what.”[34]

Here, there are several issues to be discussed, among which is the assumption that the child will be heterosexual and will desire penile-vaginal intercourse in the future, and also that she will give birth. But for the purposes of this chapter, I would like to point out the mechanism that caused change in this specific surgical procedure, vaginoplasty. Dr. Bülent states that observing the long-term effects of the former surgeries played a key role in changing this procedure in favor of a non-intervention policy, postponing vaginoplasty, both on a global scale and also in his own practice.

Cliteroplasty poses a similar problem. If a child has a large clitoris and is going to be assigned as a girl, then clitoris reduction is common practice. On the other hand, the fact that clitoris is crucial to sexual pleasure has recently forced surgeons to abandon the practice of cutting the “excess” part of clitoris, and instead to develop new surgical techniques in order to preserve the tissues with high nerve density while preserving innervation. For instance, pediatric surgeon Dr. Bülent explained that he follows this principle in the cliteroplasty operations he performs: the clitoris is separated into its parts (corpus cavernosum), some of this erectile tissue is removed if it is “too large,” and they are buried inside of the labia. And then the tip of the clitoris is stitched back. It is presumed that the sexual pleasure will be preserved with this technique since the tip of the clitoris, the part with the higher density of nerves, is preserved. It is also thought that this is a reversible surgery; the parts that are buried could be taken out and the clitoris could be resumed to its former shape, in case the child wants to have it back in the future. However, the problem is that it is not known at the moment if this is possible, and what kind of consequences will await the person if this kind of reversal happens.

Dr. Birsen Koç, a pediatric endocrinologist, says:

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[34] “Onun için genel kanı… çok… sadece bazen incecik bir perde kapatıyo oluyo onları kesip açıyoruz ama daha zor ameliyat yapılması gerekenlere de hiç dokunmuyoruz vajene. Yoksa dört yaşında 3 yaşında yaparsan adölesan döneme kadar sürekli onu dilate ederek geniş tutman lazım, bu daha bir kız çocuk için sürekli her gün gün aşırı yapılan bir şey çok ciddi bir cinsel travma haline geliyor daha neyin ne olduğunu anlamadığı yaşta.”

> "I don't know, I mean, you should ask surgeons that; talk to the surgeons. But burying a clitoris is reversible. Besides, even if they're going to remain as a girl, … There's fibrovascular bundle, namely fibers that organize pleasure, etc. during sexual intercourse. Even if they become a girl, we should protect them, so it's protected that way… But 99.9 per cent of the ones that go through clitoroplasty are Congenital Adrenal Hyperplasia; they're all karyotype girls, they have uteruses, the ovaries are in place and function normally. There's something wrong there, I mean, there's a problem with the adrenal so the androgens are high, and in our treatment, those androgens get out of the system, so there's no doubt there, they are raised as girls."[35]

Dr. Birsen first gives the theoretical justification for this practice, and then moves on to discussing practical application. Theoretical justification for clitoral reduction is that it is a reversible surgery. Yet, Dr. Birsen is cautious in asserting the reversibility, and the main justification she provides is that almost all of CAH children are assigned as girls, and therefore the possibility of reversal is not a main concern. This points that in practice, the operation is based on the assumption that the child will not demand reversal in the future.

However, Dr. Bülent, who has over twenty years of experience as a pediatric surgeon, is even more cautious about this technique; after explaining the details of this procedure, he continues:

> Dr. Bülent: If they ask at an adult age: 'where is my clitoris?' we cut these off and we give them to them, saying: 'there's your clitoris!'
> Ceren: Does that happen?
> Dr. Bülent: Sure, it does, we hope it does; since there's no one yet who reached that age… It's been five years since these operations started.[36]

Dr. Bülent directly points to the problem of temporal distance between the operations and the observing of the results, implying that they may not obtain the desired results. Also, he is not only concerned about reversibility, but also about the ability of preserving sensitivity and the sexual function of clitoris with this method:

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[35] Bilmiyorum yani gerçi onu cerrahiye sormak lazım cerrahi ile konuşmak lazım ama klitorisi gömmek geri dönüşümlü bir şey. Ayrıca da hani kız olarak bile kalacaksa …. o klitorisin içinde fibrovasküler bundle, yani o cinsel orada ilişki sırasında zevk alma bilmem ne hani orayı düzenleyen yapılar var, kız olsa bile korumak gerek, o sayede korunmuş oluyor…. Ama kliteroplasti yapılanların yüzde 99.9"u Konjenital Adrenal Hiperplazi oluyor; onlar hep karyotip kız, rahimi var, overleri yerinde ve normal çalışıyor. Orada yanlış bir şekilde yani böbrek üstü bezinde sorun olduğu için androjenler yüksek, bizim tedavimizde de o androjenler sistemden kalkıyor, o yüzden oradan hiç şüphe yok, onlar kız olarak yetiştiriliyor

[36] Dr. Bülent: İleride erişkin yaşta nerede benim klitorisim derse bunları kesip al sana klitoris diye çıkarıp veriyoruz
Ceren: Olabiliyor mu öyle?
Dr. Bülent: oluyor tabii, olacağını ümit ediyoruz, daha o yaşa gelen olmadığı için.. bu ameliyat başlayalı 5 sene oldu.

> "But no matter what, when these [people] become adults, they become people who don't enjoy or who even fear sexual intercourse, big majority of them; there is crazy research about these. You'll see as you research; the cutting of the clitoris [takes away] all the sexual pleasure. All this genital mutilation, etc. which is done also in Africa is aimed at this anyway, by cauterizing the clitoris… They can get vaginal orgasm but when there's no clitoris, the vaginal orgasm is endangered too."[37]

Similarly, pediatric surgeon Dr. Ali explained the importance of the integrity of clitoris to his students during class:

> "Normally, the clitoris was being amputated; I'm the first to do the surgery while protecting the tissue on it. The surgery lasted for three hours. They said: 'What's Doctor Ali. doing down there [in the operation room]?' There was no one doing that here. Now I don't do that anymore either, cause this tissue is very sensitive, no matter how much you pay attention…"[38]

Based on his own experience, Dr. Ali realized that no matter the surgical method, clitoris is too sensitive to be operated on, and therefore he stopped performing cliteroplasty on his patients.

While these examples can be considered as part of a development toward enhancing the practice of informed consent, Karkazis states that this is one of the general problems in medical treatment procedures of intersex children: a great number of surgical methods exist, they are constantly updated, and therefore long-term effects are not known at the time of the application because they are newly developed methods. It takes many years before the children grow up and long-term effects can be observed. In many cases, negative consequences are observed later, and more new methods are developed, yet the cycle continues. Meanwhile, the operations are justified by the claims that they fix the problems that exist in the former methods, and thus the potential harm that can be caused by the surgeries is overlooked because it cannot be proved at the time of the operation.

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[37] "Ama ne olursa olsun bunlar erişkin birey haline geldikleri zaman cinsel birleşmeden zevk almayan, hatta korkan bireyler haline geliyorlar çok büyük çoğunluğu, acayip araştırmalar var bununla ilgili. Sen de araştırdıkça göreceksin klitorisin kesilmesi bütün cinsel hazzı… zaten bu genital mutilation falan Afrika'da da yapılan işte tamamen buna yönelik, klitorisi dağlayarak, vajinal orgazm olabiliyor ama klitoris olmadığı zaman vajinal orgazm da tehlikeye giriyor."

[38] Klitoris normalde ampute edilirdi, üzerindeki dokuyu koruyarak ameliyatı ilk yapan benim, ameliyat 3 saat sürdü, 'Dr. Ali aşağıda [ameliyathanede] ne yapıyor?' dediler, bunu burada yapan yoktu, şimdi onu da yapmıyorum çünkü bu doku çok hassas, ne kadar dikkat etseniz de…"

2.1.6 Selective Application of Theories

Another point that was striking to me was the use of multiple theories that often contradicted each other, to justify ongoing early surgical interventions. There are two main theoretical frameworks that influence gender assignment procedures in the current treatment paradigm; to put it simply, one prioritizes social constructionism over biological determinism, and vice-versa.

The social constructionist view contends that the gender identity of a child is mainly determined by socialization process, as opposed to biological factors; it is associated with the psychologist John Money, who played a crucial role in setting the dominant paradigm of medical treatment of intersex infants starting from the 1950s. While having great fame and influence in the field until the 1980s, by the mid-1990s he was being harshly criticized due to his infamous "failure," which became publicly known as the John/Joan case,[39] as well as because "changing cultural understandings of sex, gender and sexuality (and their relationships), concomitant movements for the acceptance of non-normative sexualities, gendered ways of being, and bodies, the decreased authority of the medical profession, and the rise of principles of medical ethics were changing the context in which intersexuality was understood and treated" (Karkazis 2008, 64). As a reaction to these developments, biological deterministic views, which hold that the gender identity is mainly determined by biological factors such as chromosomes and hormones, began to gain more legitimacy in the field against social constructionism. Nevertheless, this did not mean that Money's views were to be abandoned altogether - he did not entirely reject biological factors anyways. Rather, most theories he proposed continue to be popular today among clinicians. One theory that is reminiscent of Money's legacy is the idea that genital appearance has a large

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[39] While he was a psychologist at Johns Hopkins in mid-1960s, John Money encountered a male infant whose penis was accidentally amputated during circumcision, and he suggested that the child could be reassigned as female and can develop a female gender identity through appropriate socialization. David underwent sex-reassignment surgery and was renamed as Brenda; the operation was kept secret from him. For a long time, Reimer case was reported as a "successful case" that substantiated Money's approach. As Reimer grew up to become an adult, however, it turned out that it was not a "successful case"; David Reimer reclaimed his male identity, and the sex-reassignment caused him significant psychological damage. Unfortunately, Reimer committed suicide in 2004, at the age of 38. Money was accused of using Reimer as an experiment subject -Reimer also had an identical twin, so it made Reimer a perfect candidate for such an experiment, since the twin could be the "control case"- to build up his own reputation. For an extensive analysis of the Reimer case and its relevance to the origin and development of Money's theories on intersexuality, see (Karkazis 2008). For a broader critical analysis of Money's diagnostic concepts "hermaphroditism," "transsexualism," and "paraphilia," see (Downing, Morland and Sullivan 2015).

influence on determining gender identity. Because of this belief, for instance, children who had micropenis -who are otherwise typical males- were reassigned as females, since it was though that an atypically small penis would impair the male development of gender identity. This practice is largely abandoned today; however, the idea that genitalia is of crucial importance to gender identity remains popular among clinicians and is a legitimate reason for surgical intervention.

In connection with this idea, in a study he published in 1985, John Money concluded that boys who have atypically small penises are more likely to be homosexuals. I found out that this idea still circulates among the clinicians I interviewed and influences their decisions. This reasoning especially applies to male-assigned children, that is, male-assigned children who have small penises or no penises are believed to be more likely to have "same-sex" attraction if they grow up without surgical or hormonal interventions to enlarge the penis. Therefore, male-assigned children who have penises that are considered atypically small are likely to go through penis reconstruction surgeries - if not assigned as girls any more. Pediatric surgeon Dr. Engin explains how this reasoning works in children with 5-ARD:

> "In the disorder that we call 5 alpha-reductase, the penis is small, but we try to turn it into a penis somehow. The group with heavy hypospadias, you know, the willy is very small, etc., in these… I mean… Like this… The sexual identity is under so many different factors; I mean, ranging from your anatomic structure to… you know, hormonal… I mean, I don't know… a small penis, a very very small penis can push you towards a very different direction… it can affect, ranging from depression to your sexual preference."[40]

Children who have 5 alfa reductase conditions are believed to develop male identity, and therefore assigned as males when they are diagnosed. Dr. Engin means that they perform penis reconstruction surgeries on these children against the odds that they might grow up with an "error" of sexual orientation.

Although no one explicitly mentioned among my informants, Karkazis notes that one reason that clitoris reduction surgeries are so common is the concerns of masculinized sexuality; for example, it is believed that if the clitoris is left in its original size, a girl is more likely to

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[40] "5 alfa redüktaz dediğimiz bozuklukta penis boyu küçük oluyor, onu biz bi şekilde penis haline getirmeye çalışıyoruz ağır hipospadyaslı grup, hani pipi boyu çok ufak bilmemne… Bunlarda mesela…Yani.. Şöyle… Cinsel kimlik o kadar farklı etkenler altında ki, yani senin anatomik yapından tut, işte hormonal, yani ne biliyim… küçük bir penis, çok çok küçük bir penis seni çok daha farklı yönlere itebiliyor, depresyondan tut, cinsel tercihine kadar etkileyebiliyor."

become lesbian, or to embrace “masculine behavior” (Karkazis 2008, 149). In the next chapter I will further discuss the hetero-normative construction of sex, gender and sexuality ingrained in the medical paradigm. For now, I would like to show another way in which Money paradigm is effective in current medical treatments.

According to Money’s paradigm, sexual identity develops during the first 2 to 2,5 years of a child’s life, and socialization is extremely important in this development. However, as I mentioned above, when Money’s paradigm began to be abandoned, dominant medical opinion started to shift toward biological determinism, distancing itself from Money’s social constructionism. One major consequence of this shift has been the increasing importance attributed to “brain organization theory,” which includes the argument that gender identity is constructed during prenatal period, and it is fixed immediately after birth, which means that gender identity reaches its final stage long before the age of two. Brain organization theory is quite popular and influential in determining the treatment procedures of intersex children. On the other hand, the social constructionist idea that gender identity is flexible until the age of two and it can be shaped by social rearing still provides a strong justification for early intervention in clinicians’ narratives. According to this view, children are much more flexible in developing gender identity in accordance with their social rearing, and therefore clinicians believe that they should “catch” children before this age in order to be able to assign their gender “correctly,” in accordance with their “true sex.”

A brochure that is prepared for the parents in one of major research hospitals in Istanbul, includes the following statement:

> “It is very important that disorders of sex development are determined right after birth or before 1.5 to 2 years old when the sexual identity is formed. Because a severe defect that is not noticed or admitted can cause the family to be mistaken about the sex, and the child to be raised according to the behavioral model that pertains to the opposite sex.”[41]

This brochure was published recently when I was doing my fieldwork in the summer of 2017. On the one hand, the brain organization theory and biological determinism dominates the theories of sex and gender in the medical community at large; on the other hand,

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[41] “Cinsiyet gelişim bozukluklarının, doğumdan hemen sonra ya da cinsel kimliğin oluştuğu 1,5-2 yaşından önce tespit edilmesi çok önemlidir. Çünkü fark edilmeyen veya kabul edilmeyen ileri derecedeki bir kusur, ailenin cinsiyet konusunda yanılmasına ve çocuğun karşı cinse özgü davranış modeline uygun yetiştirilmesine yol açabilir.”

clinicians assume that they have flexibility before roughly two years of age because they believe that gender identity is not fully set before that age, enabling them to ensure the development of the correct gender identity with the right kind of intervention. While they seem conflicting with each other, both of these theories were quite prevalent among the clinicians I interviewed. However, they were not used randomly, but rather utilized selectively and strategically in the way that would best maintain heteronormative values. I do not argue that clinicians use the theories selectively and with the intention of manipulating the patients, but I argue that heteronormativity is so deeply ingrained in these medical theories about gender, sexuality and body that they are considered to work that way "naturally." Jordan-Young mentions that "key scientists repeatedly assured [her] that the constructs they work with in the realm of sexuality are "common sense." Thus, measures for most traits, especially in the domain of sexuality, have not been seriously debated," which is one of the criticisms she brings to the brain organization research (Jordan-Young 2010, 58).

Finally, it is worth noting that the hierarchical structure in medical communities may contribute to the continuation of theories even if they are outdated. This hierarchy works both internationally and domestically; the North American influence is very high in medical theories, and also seniority is extremely important in determining whose opinion counts in any given hospital. And since decisions about sex assignment and surgery are made by a team, the opinions of the senior surgeons and endocrinologists might dominate the others' opinions. This is both bad and good news. The bad news is that the clinicians who have more unorthodox thoughts among my informants were the younger and less influential ones. On the other hand, this might be good news too, because when a prominent surgeon thinks that cliteroplasty is harmful and decides to abandon this surgery in his own practice, he is likely to influence many others in the field.

2.2 Medical Language on Intersex

2.2.1 Debates around “Disorders of Sex Development”

In 2006, *Consensus Statement on Management of Intersex Disorders* was published, introducing the term “DSD” (Disorders of Sex Development) in order to replace “intersex,” which had become a term that represented “a positive marker of non-normative and queer identity, rather than a medicalized term denoting pathological or disordered status” as a result of intersex activist movement in the US (Spurgas 2009, 98). The intersex activist movement started to become visible in the US in the 90s, especially with the foundation of Intersex Society of North America (ISNA)[42] in 1993. ISNA, in its early years, completely rejected medicalization of intersex and positioned itself within a radical queer politics. In later years, divisions began to emerge among ISNA members around the issue of whether or not the intersex movement should engage with medical community, and those who wanted to engage with the medical community were accused with going against the queer politics of early ISNA (Spurgas 2009, 98-100). Regardless, eventually their views came to dominate the organization, and ISNA moved towards a politics that favored collaboration with medical professionals in its later years.

A cornerstone in the road to the *Consensus Statement on Management of Intersex Disorders* (2006) was the Intersex Consensus Meeting held in Chicago in 2005 to discuss various issues around medical management of intersex, with the attendance of “50 ‘experts’ from 10 countries, and two intersex activists” including the founder of ISNA, Cheryl Chase (Spurgas 2009, 101). Cheryl Chase and historian Alice Dreger along with other researchers and clinicians considered it necessary to conjoin a new terminology for intersex. Their argument was that the existing nomenclature did not reflect the medical realities of intersex individuals in terms of classificatory groups, which made it difficult for them to access

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[42] ISNA is the first large intersex activist group that posed medical treatment of intersex as a political issue. It was founded by Cheryl Chase (Bo Laurent) in 1993 as a support group. Cheryl Chase states, “ISNA’s most immediate goal [had] been to create a community of intersex people who could provide peer support to deal with shame, stigma, grief, and rage as well as with practical issues such as how to obtain old medical records or locate a sympathetic psychotherapist or endocrinologist” (Chase 1998, 197), and that the long-term goal was to “change way intersex infants are treated, ... that surgery not be performed on ambiguous genitals unless there is a medical reason (such as blocked or painful urination), and that parents be given the conceptual tools and emotional support to accept their children’s physical differences” (Chase 1998, 198). ISNA’s online archive is available at http://www.isna.org/.

proper medical care when they needed it. As Spurgas cites from Alice Dreger, a re-classification was also deemed necessary to "[sort] patients into diagnostically meaningful groups if sound, evidence-based research [was] to be conducted" (Spurgas 2009, 101).

While the proponents of DSD terminology argued that this move would make intersex individuals' access to medical care easier, Spurgas argues that it contributed to the medicalization of intersex, reconsolidating the authority of medicine over the issue of intersex: "pro-DSD contingent's primary interest [was] in distancing intersex activism from queer and transgressive sex/gender identity politics and instead in supporting Western medical productions of intersexuality," (Spurgas 2009, 101-102) and that "the language of *disorder* goes hand-in-hand with this approach to intersex -the idea that there may be physical disorder present in an intersex body, but that this physical atypicality in no way compromises normative gender identity and certainly does not compromise heteronormative sexual desire and lifestyle" (Spurgas 2009, 106). As some intersex activists (e.g. Koyama 2006) mention, there are many individuals with intersex traits who do not embrace intersex as something that "queers" their identities. On the other hand, the two views -one that embraces "intersex" and distances "DSD" and positions itself in queer politics, and one that embraces "DSD" rather than "intersex"- are often presented as binaries, they do not have to be so, and in fact they are not. Both views persist among intersex communities; there are also many people who would embrace both terms and/or use them strategically in different contexts for different reasons (Davis 2015).

Nevertheless, DSD terminology has drawn substantial criticism from scholars. In her book *Contesting Intersex*, intersex scholar Georgiann Davis argues that "the linguistic shift from *intersex* to DSD served as a perfect vehicle for medical professionals to reassert their authority and maintain their exclusive jurisdiction over intersex traits. It allowed medical professionals simultaneously move beyond the John Money debacle and to respond to intersex activism and feminist critiques that were successfully claiming intersex was not a medical problem" (Davis 2015, 70). In other words, "DSD clinicians' established themselves in opposition to John Money, who is considered the symbol of the "pre-DSD" era and is associated with the publicly known failures of medical treatment of intersex. In a similar vein, Spurgas argues that the DSD treatment logic will mainly serve to "open up the possibility of a new and even more encompassing "intersex treadmill,"" which is a term coined by Cheryl Chase to refer to the "never-ending drive to fit within a normative sex category" which requires a "lifelong "management" in order to continue to pass as [the ascribed] sex" (Spurgas 2009, 113). Further, according to this view, it promotes a stigmatizing language which assumes the existence of an original sex in every person, as well as presenting the individual, rather than the existing social norms, as the main source of problem. The activism that the language of DSD allows focuses on the bodily rights of the individual, while failing to adequately problematize the social and cultural norms (Holmes; Spurgas; Morland 2009). Spurgas further criticizes the way in which the decisions were made on the road that ended with the 2006 Guidelines, pointing out that mainly the US-based medical community determined these debates and the decisions, whereas those who are affected by it in the rest of the world were not consulted during this process (Spurgas 2009, 111-112). However, Davis also emphasizes that using the DSD language can be necessary to access biological citizenship, and she advocates using both terms strategically, as they are needed (Davis 2015).

2.2.2 Clinicians' Use of Terminology

Currently, DSD (Disorders of Sex Development) is the umbrella term that is used to define intersex conditions in the medical literature. The classification system used before the 2006 Consensus was based on a distinction between "male-pseudohermaphrodites," "female-pseudohermaphrodites," and "true hermaphrodites," in which gonads indicated which group the person belongs to. According to this system, someone who has ovaries would be classified as a "female-pseudohermaphrodite," and someone with testes as a "male-pseudohermaphrodite." And the term "true hermaphrodite" was left for the rare condition Ovotesticular DSD, in which both ovarian and testicle tissues exist. As a result, the overwhelming majority of the conditions were classified under one of the "pseudo-" groups. However, because the term "hermaphrodite" came to be considered offensive, the term "intersex" was often used as an umbrella term by medical professionals, even though "clinicians have never fully incorporated intersex to their vocabulary...there has never been agreement on what intersex means or on what conditions constitute intersex" (Reis 2007, 537). Indeed, the most common way in which the 2006 *Consensus Statement* came up during my fieldwork was how it made classification much easier for the clinicians. When I asked Dr. Ayfer if the consensus caused any changes in practice, she replied, "The new consensus classified everything more clearly; it was very complicated before; there are still some vague things, but it is much better now."[43] Several other clinicians gave similar answers to this question. For the clinicians, it means that they can be now more confident in their decisions about the treatment process than before, confirming the view that the 2006 Consensus Statement and the DSD language contributed to medical authority over intersex. Since the 2006 Consensus Statement replaced "intersex" with "DSD," the new terminology and the Consensus Statement in general have been highly contested by many intersex activists, who reject the label of "disorder" to define intersex conditions. According to this view, the language of "disorder" defines a natural bodily variation as a medical abnormality to be fixed; in this way, the "disorder" language helps unnecessary medical interventions - especially the early surgeries- to be justified.

Not surprisingly, I found that DSD language is quite popular among the clinicians I interviewed. The Turkish translation of "Disorders of Sex Development" is *Cinsiyet Gelişim Bozuklukları (CGB*), but the terms my informants used also included *Cinsel Gelişim Bozuklukları* (*Disorders of Sexual Development*), *Cinsel Gelişim Farklılıkları (Differences of Sexual Development), Cinsel Gelişim Sorunları*[44]*, and Cinsel Gelişim Kusurları*[45]; they referred to the latter two of these terms only in Turkish and to the former two with English translations. Several of the clinicians touched upon the debates on the term "disorder." Three of them, pediatric endocrinologist Dr. Ayfer, pediatric surgeon Dr. Bülent and intern clinician Dr. Irmak (who is also an LGBTI+ activist) mentioned their preference of the term "difference" instead of "disorder," and therefore preferred to use DSD as "Differences of Sex Development" or "*Cinsel Gelişim Farklılıkları.*" I did not ask clinicians specifically whether they prefer the term "difference" or not; these three clinicians brought it up themselves. Other informants either used "CGB" or names of the specific conditions, rather

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[43] "Yeni consensus herşeyi daha net sınıflandırdı, eskiden çok karışıktı, şimdi daha oturttu, şimdi de bazı vague durumlar var ama çok daha iyi."

[44] "Sorun" can be translated to English as "problem."

[45] "Kusur" can be translated to English as "defect."

than using an umbrella term. A couple of clinicians also brought up the old terminologies such as "pseudo" and "true hermaphrodites," either because they found it easier to explain or it made sense to them, which shows that this classification system might still be influential in their thinking. Also, many clinicians indicated that they use the name of the specific diagnosis among each other, instead of DSD or any umbrella term.

Among these terms, *Cinsel Gelişim Sorunları (CGS)* is promoted by the Society for Sexual Development and Hypospadias (Cinsel Gelişim ve Hipospadiyas Derneği), which is a medical association that aims to "diagnose, treat, and follow-up individuals with disorders of sexual development and hypospadias and support their families[46] (Cinsel Gelişim ve Hipospadiyas Derneği)." An announcement on the website that is published on 2014 October explains one of the reasons for this preference as, "It should be noted that characterizing problems of sexual development as defects or disorders is refuted, first of all, by the people who have these traits, and their views should be respected[47] (Cinsel Gelişim ve Hipospadiyas Derneği'nin Duyurusu 2014)." [48]

The least popular terms among the clinicians are "hermaphrodite" and "intersex." They cited similar reasons for the inappropriateness of these terms: "hermaphrodite" means having "both male and female sexual organs," while "intersex" implies being "in-between sexes." Neither of them is in accordance, however, with the predominant medical view that everyone has one "true sex," either male or female. Several clinicians also suggested that these terms are offensive to patients for the same reasons; therefore, "intersex" is positioned as a derogatory term similar to "hermaphrodite," according to these clinicians. Also, most clinicians emphasized in particular that the term "*çift cinsiyetli*," which is close to the term "hermaphrodite," is wrong to use. They complained that the patients "somehow pick up this term" and they try hard to convince the patients that their child is not "*çift cinsiyetli*," but only has a "disorder," or "difference," of sex development, and otherwise "s/he is a normal girl/boy."

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[46] Translation from Turkish belongs to me.

[47] Translation from Turkish belongs to me.

[48] "Cinsel gelişim sorunlarının bir kusur ya da bozukluk olarak nitelenmesinin öncelikle bu özelliklere sahip bireyler tarafından reddedildiği bilinmeli ve görüşlerine saygı gösterilmelidir."

"Intersex" as a term is used more in the context of activism in Turkey, as well as globally, and it is unfamiliar to the larger population compared to "hermaphrodite" or "*çift cinsiyetli*." Also, the fact that the word "sex" only refers to sexual activity in Turkish language might create difficulties for using this term. For instance, activist intern clinician Dr. I, who is strongly against the term "disorder," mentioned that she nevertheless avoids using the term "intersex" with the patients for this reason:

> "Intersex is not used much anymore; it's a little bit to do with demographics but it is very difficult for our patient or the families to understand that, and the word 'sex' is something that creates problems, you know, since people think about it not in the sense of gender but directly sexuality."[49]

However, this is not a problem only in Turkey; intersex activist and scholar Georgiann Davis shows that it might be an issue in the North American context too; even if 'sex" refers to bodily characteristics, the term "intersex" might be perceived as embarrassing (Davis 2015, 102).

Dr. Ali also brought up the debates about the terminology when I asked him about why "intersex" is not used in the medical nomenclature any more:

> "I mean, for instance, intersex, you know, inter-sex, you know, like sex is between two things… it sounds like it's torn between two sexes. We abandoned that. I mean it's been abandoned; now it's called '*cinsel gelişim kusurları,*'[50] namely, '*disorders* of sex development.'"[51]

Dr. Ali here emphasized the words "kusurları" and "disorders" in order to imply that the word "kusur" is a correct translation of the word "disorder," and therefore should not be perceived as offensive, even if it might sound offensive, as it also has the meaning of being "defected." He continued:

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[49] "interseks çok kullanılmıyor birazcık demografik ile ilgili bir şey ama hastamızın ailelerin falan onların anlaması çok zor ve seks kelimesi sıkıntı yaratan bir şey hani cinsiyet anlamında değil direk cinsellik anlamında düşündüğü için insanlar." (Dr. Irmak)

[50] Because this quote is about translation, I left this part in the original language, Turkish. The literal translation of this phrase would be "defects of sexual development," but Dr. Ali used it only in Turkish. He translated the phrase into English as "disorders of sex development." As I explained above, the Turkish translation of "defect" (*"kusur"*) was suggested by some clinicians in Turkey instaed of "disorder."

[51] "Yani mesela interseks, işte inter-sex, işte cinsiyetin iki arada bir şey.. iki cinsiyet arasında kalmış gibi bir ifadesi var, bunu terkettik, yani terkedildi, cinsel gelişim *kusurları*, yani *disorders* of sex development olarak geçiyo şimdi." (emphasis belongs to the speaker).

> Dr. Ali: I mean, this is the goal here… so that people are not disturbed by the expression of a disease about them.
> Ceren: Are they disturbed by intersex?
> Dr. Ali: I mean, yes, yes, yes… [a term] that includes intersex… or even *cinsel gelişim kusurları* (*defects* of sexual development) … For instance, when the person thinks of themselves as "we're not defective", they're sometimes disturbed by that name of disease, I mean, someone with a defect of sex development… I mean, *defect*ive… Since it is not nice for people to perceive their children as someone that is sexually defective, or for people to talk about the children that way, they tried to change that too. Now, instead of Disorders of Sex Development, … The 'D' at the beginning of DSD [is used as] "differences" (*farklılıklar*) instead of "disorders," I mean the terminology got all the way there.[52]

Dr. Ali indicates that "intersex" is perceived as even more offensive than "disorder" by the patients. While he agrees that intersex is not a good idea to use because of its implication of an "in-between" state, he finds the reactions to "disorder" a bit of an exaggeration, implying that those who are offended by the language of "disorder" might be a bit oversensitive.

While it is true that both "disorder" and "intersex" are highly contested terms, there are many different views among different groups. The majority of intersex activists, including those in Turkey, argue against the term "disorder" and embrace "intersex." Although there are activist groups and intersex individuals who embrace, or at least who do not completely reject the term "disorder" (Davis 2015), the intersex activists and allies predominantly use "intersex" rather than "DSD." According to Davis's US-based study, most parents tend to prefer "DSD" to "intersex," since they are comforted by a medical explanation for the atypicality of their child, in addition to their discomfort with the association of "intersex" with LGBT (Davis 2015, 143). On the other hand, according a clinical study conducted in Turkey, "DSD" is even less preferred than "intersex" is by the parents, who usually prefer using the Latin-origin name of the specific condition rather than an umbrella term. The authors concluded that their "study was consistent with the earlier ones showing a lack of acceptance of the term DSD by the families despite the worldwide use of it among clinicians

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[52] Dr. Ali: yani burada amaç şu.. kişiler kendileriyle ilgili kullanılan hastalık ifadesinden rahatsız olmasınlar diye.
Ceren: 'İnterteks'ten rahatsız mı oluyorlar?
Dr. Ali: Yani evet, evet, evet.. içinde interseks.. hatta cinsel gelişim *kusurları*.. mesela kişi kendisini "biz kusurlu değiliz ki.." diye düşündüğü zaman, o hastalık isminden de rahatsızlık duyabiliyor yani cinsel gelişim kusuru olan birisi.. yani "kusur"lu, cinsel açıdan kusurlu birisi gibi çocuklarını algılaması insanların, veya çocukların kendilerinden böyle bahsedilmesi hoş olmadığı için o da değiştirilmeye çalışıldı. Onu da şimdi Disorders of Sex Development değil de.. DSD'de baştaki "D" "disorders' yerine, "differences," "farklılıklar" [olarak kullanılıyor] yani, oraya kadar geldi terminoloji.

(219-20)," and pointed out that parents avoid using any term that contains the word "sex" in it (Tiryaki, et al. 2018)[53]. Thus, Dr. Ali's narrative seems reflect the dominant clinical perspective, which is challenged by these studies.

Davis mentions that clinicians often compare DSD to other diseases or medical conditions in order to "balance the dominating perspective that focuses almost exclusively on gender-related aspects of DSD with one that conceptualizes DSD as a congenital and chronic condition, akin to other pediatric conditions' (Davis 2015, 93)." In fact, Dr. Ali also used a similar way to imply that DSD is a medical condition:

> "well… a problem[54] means a problem, in fact… [Like] stomach or intestinal problems but when… when it's 'disorders of sex development', sexual… I mean… when the word… 'sex' is involved, gender thing is involved, it can be off-putting, that's why making it a little bit more… I'd said at a meeting, that the word that really needs to change here is not 'disorder' or 'differences', etc. but the word '-sex' must be removed; I think that will be removed soon."[55]

Even if Dr. Ali is sympathetic to those who are offended by the term "DSD," he nevertheless maintains that it is a disease.

Moreover, I found out that when a clinician advocates for the term "difference" instead of "disorder," it does not mean that they do not consider this difference as a problem. But instead, the term "difference," when used in a medical context, might mean that the difference is still a disease. For instance, Dr. Ayfer indicated preference for the term "difference" over "disorder," yet perceives DSD as "just like any other disease." I asked her what she thinks about the argument that any intervention except non-vital interventions should not be done during childhood, including conditions such as hypospadias[56]:

> Ceren: You know, they say that [it should not be intervened] for non-vital surgeries such as hypospadias, either.
> Dr. Ayfer: But you know, for hypospadias… there's mild hypospadias and then there's severe hypospadias. Severe hypospadias can cause a lot of disturbance to

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[53] According to the study, out of the 79 parents inquired, only 2 mentioned "DSD" and 5 mentioned "intersex" to define the condition of their children, whareas 40 of the parents were familiar with the term "DSD" and 42 with "intersex."

[54] Here Dr. Ali refers to "disorder," but he used the Turkish word for "problem," ("*sorun"*).

[55] "ee.. sorun, sorun demek aslında… Mide bağırsak sorunları hastalıkları [gibi] ama işin içine… disorders of sex development olduğu zaman cinsel.., yani… işin içine… seks kelimesi girdiği zaman cinsiyet şeyi girdiği zaman itici olabiliyo, onun için onu birazcık daha… bir toplantıda ben burda asıl değişmesi gereken kelime 'disorder,' 'differences' vesaire değil '-seks' kelimesi kaldırılmalı demiştim, sanırım yakında da o kaldırılacak"

[56] A condition in which the opening of the urethra is on the underside of the penis.

> the patient. I mean that's still a man, but there can be a hypospadias correction surgery, I mean, they cannot pee.
> Ceren: Can't they pee sitting down, for instance?
> Dr. Ayfer: They can do it sitting down, but there's the psychology of that, etc., it won't be like other men… I mean, it's harder to say so hundred per cent.[57]

Here, when Dr. Ayfer says "they cannot pee" she actually means that a child with hypospadias cannot urinate in a standing position, which would create the problem of difference, as "he won't be like other men." Thus, even if she perceives DSD as a "difference," it is a difference that should be "fixed" in early childhood.

2.2.3 Practical Implications of Understanding Intersex as a Disorder

One other criticism that was brought to the DSD language was that, as a result of positioning intersex as an abnormality that should be fixed or avoided, it might provide justification for eugenics with the help of medical technologies (Spurgas 2009). In my fieldwork, medical genetics expert Dr. Alper talked about his role in intersex management procedures in terms of providing prenatal testing and genetic risk determination, and he mentioned that as a result, some people decide to have an abortion after they learn that the fetus has DSD during prenatal screening, or some others might avoid pregnancy altogether if they find out that they carry a gene that causes DSD:

> "Families… sometimes, they come to us when they're going to have a sibling for a previously diagnosed and treated child, and because they find out that there's a risk. Or an indication is detected that makes one think of sex anomaly in their existing pregnancy; then tests are planned, and when the sex that is observed in the ultrasound and the chromosomal sex don't match, we also evaluate if there may be other diseases there and… this is called prenatal diagnosis. Let's say a couple that made a kin marriage has a child and this is a child that was diagnosed with 5 alpha-reductase deficiency. They ask us if the same thing will happen in their following child, and yes, they have a risk of 25%. Or an individual was diagnosed with androgen receptor defect; the appearance is female; they are diagnosed at around 16 to 18 years of age since they can't

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[57] Ceren: Hani şey için de diyolar [müdahale edilmesin diye], hayati olmayan cerrahi operasyonlar için, mesela hipospadias gibi
Dr. Ayfer: Ama hipospadias'ın bak… hafifi var ağırı var, ağır hipospadyas hastaya çok rahatsızlık verebilir. Yani yine erkektir o, ama o hipospadias düzeltme operasyonu yapılabilir, yani çişini yapamaz.
Ceren: Oturarak yapamıyo mu mesela?
Dr. Ayfer: Oturarak yapabilir ama onun psikolojisi var bişeysi var, öbür erkekler gibi olmayacak …. Yani %100 öyle söylemek daha zor.

> menstruate; the mother is also a carrier for this disease, cause this is inherited based on X and they realize they are a carrier too, … there they have a 50% risk, for instance. When there's a child in the family, for various diseases, there can be 25% to 50%, and for some rare diseases, 1% to 3% risk for the following child."[58]

When an intersex trait is a "disorder," it is interpreted as a risk factor in reproduction, along with many other congenital conditions. Dr. Alper observed that "people find out about these risks; they sometimes do nothing and sometimes decide not to have a child but usually they decide to do nothing, our families; for instance, they're not as sensitive here as they are with diseases that are to do with mental deficiency." [59]

However, Dr. Alper also stated that one reason for this relative "tolerance" of parents toward DSD might be the relatively narrow time-window during which prenatal diagnosis and abortion are both possible: the prenatal testing is done around the 11th week of pregnancy, and abortion is allowed approximately up to the 14th week of pregnancy if a fetus is diagnosed with DSD. However, abortion is possible until later phases of pregnancy in other "more severe" conditions such as Down Syndrome. Not everyone receives, or knows about prenatal testing, so some people may receive it only when it is too late for abortion. A second and more important reason, however, might be that the patients are told that if their child is born with DSD, it can be "fixed":

> "Some of the ones that know about early termination, of course, come [terminate the pregnancy], but some might say, for instance, you know, 'there's a 75% chance that it won't be like that [sick], let me take my chance.' Like 'my child can be operated', etc.… They sometimes think like 'Good, there's a treatment',

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[58] "Aileler … bazen daha önceden tanı koyulmuş ve tedavi edilmiş bir çocuğa çocuğa kardeş yapacaklarında ve bunun riski olduğunu öğrendikleri için bize geliyorlar, ya da var olan gebeliklerinde cinsiyet anomalisi düşündürecek bir bulgu saptanıyo, ondan sonra testler planlanıyo, gözlenilen cinsiyetle ultrasonda kromozomal cinsiyet birbirine uymadığında orada başka hastalıklar aslında olabilir mi diye de değerlendiriyoruz ve.. bunun adı prenatal tanı. Diyelim ki akraba evliliği yapmış olan bir çiftin çocuğu var ve 5-alfa redüktaz eksikliği tanısı almış bir çocuk bu, bir sonraki çocuklarında aynı şeyin olup olmayacağını soruyorlar bize, ve evet %25 riskleri var, ya da androjen reseptör kusuru olan bir birey tanı almış, dış görünümü dişi, 16-18 yaşlarında adet göremediğinden dolayı tanı alıyo, annesi de bu hastalık için taşıyıcı, bu çünkü x"e bağlı geçiyo ve kendisinin de taşıyıcı olduğunu fark ediyor, … burada %50 riskleri oluyor mesela. Çeşitli hastalıklar için %25-%50, ya da bazı nadir hastalıklar için yüzde 1 ile 3 arasında risk olabiliyor ailede bir çocuk olduğunda bir sonraki çocuk için."

[59] "insanlar bu riskleri öğreniyorlar, bazen hiçbir şey yapmıyorlar, bazen çocuk yapmamaya karar veriyorlar ama genellikle bir şey yapmamaya karar veriyo bizim aileler, mesela zeka geriliği ile ilgili hastalıklar kadar burada hassas değiller."

> you know, maybe if that weren’t [an option], they would [have an abortion], I don’t know…”[60] (Dr. Alper)

Thus, defining an intersex condition as a “disorder that can be treated” has the paradoxical result of more “tolerance” in the context of genetic testing.

One of the striking examples of what it means to perceive intersex as a “disorder” was how clinicians talked about it in contrast with transsexuality, and sometimes homosexuality. Even if I did not ask any questions involving transsexuality during the interviews, several of the clinicians started the conversation by distinguishing intersex from transsexuality, worried that I might have confused them with each other. This might be read as only a caution on their side to eliminate any misunderstandings; perhaps they were surprised that I was specifically interested in intersex as a social scientist and wanted to make sure that we were talking about the same thing, for example. Yet, all of the clinicians who emphasized the difference did so in one specific way: by emphasizing that DSD has “organic roots,” and therefore it requires medical intervention. This implied that the early medical interventions cannot have any political or cultural reasons, because of the underlying assumptions that body is the domain of medicine, and medicine is objective and therefore above politics. I perceive the clinicians’ careful distinguishing of intersex from transsexuality as an attempt to de-politicize the discussion by implying that DSD/intersex is a medical condition that requires medical intervention based on “objective,” “organic” criteria, as opposed to some archaic beliefs about gender and sex.

Pediatric psychiatrist Dr. Nilgün explained the difference between intersexuality and transsexuality by stating “gender dysphoria does not have an organic foundation, but the intersex is different; both organic and psychological; different, of course, since it has a more organic foundation.”[61] The fact that there is a bodily element that can be found out through existing medical technologies makes all the difference between intersex and trans. Because there is not any known “organic foundation” of transsexuality, it is considered only as a

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[60] “Erken terminasyondan haberdar olanların bir kısmı tabii ki geliyorlar [hamileliği sonlandırıyorlar], ama bir kısmı şey diyor mesela hani “yüzde 75 böyle [hasta] olmayacakmış zaten, şansımı deneyeyim” diyebiliyorlar … ‘yani çocuğum ameliyatını olur bilmem ne olur’ falan… ‘iyi, tedavisi var,’ gibisinden de düşünebiliyor yani, o olmasa belki şey yapacak [kürtaj olacak] bilmiyorum..”

[61] “gender disphoria’nın organik bir temeli yok, ama interseksler daha farklı, hem organik hem ruhsal, daha organik bir temeli olduğu için daha farklı tabi.”

"psychological" issue. Rather, the fact that intersex is associated with "organic roots" turns it into a condition that needs to be fixed. This view, however, erases the non-medical experiences of intersex. For instance, in this narrative, there is no place for a person who is both intersex and trans; from a medical point of view, such a person would not be considered as trans, but rather as an "error of sex assignment." On the other hand, a non-intersex trans person would not be considered as a case of "error of sex assignment," since the "mismatch" between the body and person would be considered as a psychological issue.

During his class when he gave a lecture about DSD to medical students, Dr. Ali said:

> "A very important point: we shouldn't confuse it with transsexuality or homosexuality that is seen in adults. Some of your professors in psychiatry may say that DSD is not a disease; DSD is a disease. In fact, no one should be disturbed by this 'disorder' here; if there's a disorder in the enzymes, etc., this is, of course, a disease."[62]

Dr. Ali contrasts DSD with transsexuality and homosexuality in order to emphasize that it is a disease, because as opposed to the latter, the former has a biological indicator in the body which can be measured and managed with current medical technologies. According to this narrative, transsexuality and homosexuality are not considered diseases from a medical point of view only because no "organic reason" could be discovered, despite a tremendous amount of research devoted to this end. But what if it were found? The current medical management procedures of intersex might give an idea of the answer to this question.

It is worth to note that in this context "organic" means, "discoverable by the existing medical and scientific tools," considering the fact that scientific developments in endocrinology, surgery, and genetics were crucial to how intersex and sex variations came to be classified as medical conditions (Mak 2012). It means that variations of sex characteristics became medical conditions as a result of historical developments that allowed it to happen, and not because they "organically" cause suffering and pain to the person. In other words, medicine asserts authority over variations of sex characteristics because it *can*. Hence, it can be argued that defining intersex as a disease becomes a choice, as opposed to an objective reality.

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[62] "Çok önemli bir nokta: bunu yetişkinlerde görülen transseksüellik veya homoseksüellikle karıştırmamak lazım, psikiyatrideki bazı hocalarınız DSD hastalık değildir diyebilirler, DSD hastalıktır. Aslında kimse buradaki 'disorder'dan rahatsız olmamalı, enzimlerde vesaire bir bozukluk varsa burada bu tabii ki hastalıktır."

Nevertheless, the fact that several clinicians brought up transsexuality and homosexuality in our conversations and compared it with intersexuality indicates that they do see the connections that they are trying to de-emphasize:

> "But now, we hear about gender dysphoria and others - homosexuality, transsexuality, etc. - more; worldwide, there's a shift towards postponing the intervention, both in the world and here…" (Dr. Nilgün)[63]

Here Dr. Nilgün made a connection between de-medicalization of homosexuality and transsexuality, and de-medicalization of intersex, which indicates an awareness that intersex is on the way of de-medicalization for the same reasons that homosexuality and transsexuality have been de-medicalized.

2.3 Changes (not) taking place

According to the clinicians' narratives, there is some tendency in general towards postponing the surgical operations until the age of consent.

> "There was a family, for instance; it was a family that made me very happy. They absolutely didn't care about the child's sex. They didn't give a name to the child, just because of this. Choice of clothes… Never [they said] 'my son,' or 'my daughter,' just like 'my dear child, my baby,' etc., a state of love like that… We saw that the baby could go either way with our intervention. We didn't know its development, it was little, like 1 year old and… Since the family was favorable too, we decided to wait. We made a decision to observe the child, not do anything and see which one will be more dominant, which direction it will go, since the family is also favorable, to postpone the operation as long as possible." (Dr. Irmak)[64]

When I asked Dr. Engin what changes occurred in recent years in the treatment procedures, he said -in addition to developing new surgical techniques- "Also, we started to make more decisions to wait for some situations, such as 5 alpha reductases. [We thought] 'let's not intervene and wait until 13-14 years old and see how the genital structure, the child's

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[63] Ama artık gender disphoria ve diğerleri homoseksüellik, transseksüellik vs. daha fazla olduğu duyuluyor, dünya genelinde biraz daha müdahaleyi ertelemeye yönelik bir gidişat var, dünyada da burda da... (Dr. Nilgün)

[64] "Bir aile vardı mesela beni çok mutlu eden bir aileydi kesinlikle umurlarında değildi çocuğun cinsiyeti çocuğa isim vermemişler sırf bu yüzden tamamen böyle ne tür kıyafetler hiç oğlum kızım değil böyle canım çocuğum bebeğim falan diye bir sevgi hali …. bizim müdahaleyle iki yöne de gidebileceğini gördük kendi gelişimini bilmiyoruz küçüktü çünkü 1 yaşında filandı ve….biz aile de uygun olduğu için bekleme kararı aldık çocuğu izleyelim bir şey yapmayalım bakalım hangisi daha baskın olacak hangi yöne doğru gidecek aile de müsait madem mümkün olduğu kadar operasyonu erteleyelim diye bir karar aldık." (Dr. Irmak)

tendency, or things like that will turn out.'"[65] Similarly, Dr. Ayfer said, "If possible, to do the operations later,… avoiding irreversible surgeries as much as possible, reduction of in some operations, not eliminating/reducing the clitoris in CAHs."[66] When I asked about how often he performs clitoris reduction surgeries, Dr. Engin stated, "We usually don't intervene, because with hormones, when the endocrinology started a certain hormone [treatment], it already tends to get smaller; I mean when the testosterone levels diminish, it also tends to get smaller. My preference is 1,5 or 2 years old to do these operations. So, I performed reduction surgery perhaps in 15 patients out of 60; with others, there is no need to make it smaller."[67] It is important to note that Dr. Engin cites medico-normative reasons for the cases when he did not perform cliterodectomy, rather than lack of informed consent. Indeed, the eliminations in the surgical operations do not happen uniformly; it can be easier to push the current treatment paradigm toward a non-interventionist approach in some cases than others.

Hypospadias, a condition where the urethral opening is not on the tip of the penis but somewhere in the lower side of it, is a very common condition that is still regarded as requiring intervention by the majority of the clinicians. Especially if it is a more "severe" form, the person cannot urinate in a standing position, and the ability of impregnation is decreased if the child reaches adulthood without having surgery. The penis shape can have curvature that is atypical compared to non-hipospadiac penises. These are commonly cited reasons why, in Turkey as well as among international medical communities, it is widespread to regard hypospadias operations as medically necessary, even in contexts where other types of operations such as cliteroplasty and vaginoplasty can be regarded as contestable. The failure of someone with hypospadias to perform ideal masculinity makes hypospadias a condition that is more serious than others. The operation can be done when the person reaches adulthood if they desire. There is no consensus among surgeons on that

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[65] "Bi de, işte bazı şeylerde bekleme kararını daha fazla almaya başladık işte bu 5-alfa-redüktazlarda filan, ellemeyelim, 13-14 yaşına kadar bekleyelim, genital yapı ne olacak, çocuk eğilimi ne olacak, hani bazı şeylerde."

[66] "Yapılabiliyosa ameliyatların mümkün olduğunca geç olması, ... geri dönüşümsüz ameliyatların mümkün olduğunca yapılmaması, bazı ameliyatların azalması, CAH'larda klitorislerin artık alınmaması/küçültülmemesi."

[67] "Genelde pek de ellemiyoruz, çünkü hormonlarla, belli bir hormon şeyi başladığında endokrin, zaten o küçülme eğilimde oluyo, yani testosteronu vücuttan kaldırmaya başlayınca sonuçta o da küçülme eğilimde oluyo. Benim tercihim de 1 yaş, 1,5 yaş civarı benim bu ameliyatları yaptığım yaş. O yüzden.. 60 hastanın belki 15'inde filan küçültme yapmışımdır, diğerlerinde hiç küçültmeye gerek kalmıyo yani."

early surgery gives better results; yet, it is common practice to do the operations in infancy and childhood mainly because of the perceived “psychological damage” it can cause to the child growing up.

Furthermore, it is difficult to measure how these changes are applied in practice. For instance, the concepts such as “unnecessary,” “cosmetic,” “irreversible” or “if possible,” can be subjective; clinicians may not use these concepts as the same with other groups even when they use a similar language with them:

> Ceren: Can we say that operations with solely aesthetic purposes might not be made, you know, like, operations of this kind shouldn’t be done…?
> Dr. Ali: Absolutely we can, I mean, since the child cannot have an aesthetic concern, it’s not right to intervene in a child’s genital area with the aesthetic concern of the parents; we can say that. This has already appeared in the USA with court decisions; in most countries in Europe, even circumcision is forbidden in many countries so that it’s not done with the family’s wish.[68]

Dr. Ali is indeed one of the most unorthodox clinicians; he reports that he completely eliminated clitoral surgery in his own practice, and he takes pride of advocating for change towards a less interventionist approach among his colleagues. On the other hand, Dr. Ali still regards hypospadias, for instance, as one of the traits that should be fixed by surgery. Later in the conversation I asked him whether he would maintain his approach for hypospadias:

> Ceren: And do you argue that to be postponed until puberty?
> Dr. Ali: No, this [should be] … surgically fixed. Of course, when good, experienced people do it, really good results are achieved. If you obtain the good results when the child is little, the child grows up without going through psychological problems, I mean, they don’t go through problems related to this during that youth, childhood, school age, young adulthood periods, but if it’s done well…[69]

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[68] Ceren: Şey diyebilir miyiz sadece estetik amaçlı ameliyatlar yapılmayabilir gibi bir şey diyebilir miyiz mesela hani şu tarz ameliyatlar yapılmamalı..?
Dr. Ali: Kesinlikle söylenir yani çocuğun estetik kaygısı olamayacağına göre anne babanın estetik kaygısıyla bir çocuğun genital bölgesine müdahale etmek kesinlikle doğru değil, onu söyleyebiliriz, bu Amerika’da zaten mahkeme kararı olarak da çıkmış vaziyette Avrupa’da çoğu ülkede sünnet bile yani ailenin isteğiyle yapılmasın diye birçok ülkede yasaklı. (Dr. Ali)

[69] Ceren: Peki ergenliğe kadar onun da ertelenmesini savunuyor musunuz?
Dr. Ali: Yok, yok, bunu düzeltmek… cerrahi olarak düzeltmek [lazım], tabii iyi, tecrübeli kişiler yaptığı zaman hakikaten iyi sonuçlar elde ediliyor. Eğer iyi sonuçları çocuk ufakken elde edersiniz çocuk psikolojik sorunları yaşamadan büyüyor yani o gençlik, çocukluk, okul çağı, genç erişkin dönemlerinde bununla ilgili sıkıntıları yaşamaz, onunla ilgili psikolojik şeyleri olmaz, ama iyi bir şekilde yapılırsa…

Hypospadias operations are also known as *"peygamber sünneti"*[70] or "congenital circumcision" in Turkey, since an indication of hypospadias is lack of foreskin. It is a very common condition; one in every 200 to 300 male-assigned children are born with this trait. Overwhelming majority of children born with hypospadias are operated in infancy or early childhood. In an ideal case, it is supposed to take maximum two surgical operations to complete the typicalization. However, in practice, a lot of complications occur which require further surgeries. A child with hypospadias can spend his entire childhood with hospital visits and can have up to five-six surgeries in the process. These surgeries can cause severe lifelong consequences such as loss of sensation, pain during urination and so on, in addition to the psychological damages. "The comparatively robust evidence of the success of hypospadias repair has meant that criticism of this intervention has not had as much effect as criticism of other normalizing interventions for atypical sex anatomies. [Still,] there are also a number of patients who have had repeated and unsuccessful repair, leaving them with significant functional problems. 'Hypospadias cripples' has remained a term of art in the medical literature since its introduction in 1970." (Feder 2014, 203-204). In short, hypospadias operations remain controversial for similar reasons as other cosmetic operations, such as cliterodectomy and vaginoplasty are.

Gonadectomy operations are contested because on the one hand, there is a medical view that suggests testicular tissues that remain inside of the body are likely to cause cancer, and therefore they should be removed without waiting long. On the other hand, especially for some specific diagnoses than others, opponents claim that the cancer risk is not significantly higher than in non-intersex individuals who have testes and therefore the removal should not be considered as a medical urgency, especially before puberty. Dr. Irmak, after criticizing early, non-consensual operations, discriminates between the different diagnoses when she expresses her position on this controversy:

> "There's just this… in some types of intersex individuals, risk of cancer is high. There's a kind of cancer that we call gonadoblastoma… in some of the intersex individuals, this [gonadal development] is in-between, half-developed or developed 80 per cent. In these in-between gonads [between an ovary and a testicle] or this thing that we call string gonad which is rudimentary, in pieces, the possibility of incidence of this cancer we call gonadoblastoma is one in ten,

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[70] Please see footnotes in page 3 for the explanation of the term.

> according to the literature and it's higher in some kinds of it. One in ten is a high possibility and it's not functional anyway in most people, I mean, it doesn't have the capacity to produce hormones… I mean, I approach a bit conservatively in these situations, you know, I think it should be removed if there's risk."[71]

However, in other cases, such as AIS[72], the risk of cancer is more contested among medical professionals. Since AIS is one of the most common variations of intersex, the controversies on gonad removal mostly stem the experiences of İndividuals with AIS. Pediatric endocrinologist Dr. Birsen mentioned a case where she had two sisters who had AIS as her patients. When the older sister was diagnosed, her gonads were removed. However, when her little sister was diagnosed with AIS several years later, Dr. Birsen decided not to remove her gonads immediately, and decided to wait:

> "For instance, there was a child that I was seeing, that had AIS. They told her after the gonadectomy; she says: 'my parents had my older sister's ovaries removed'. You know, she thinks that they did harm to her, like she was sterilized. She had a fear that we would do the same thing to her, for instance… I mean, she has the same disease, the younger one… I didn't let the younger one get gonadectomy, you know, I said: 'in your sister's period, things were like that, but, you know, we're not in a hurry with you now, you can decide for yourself if you want.'" (Dr. Birsen)[73]

The older sister was a patient of another clinician, not Dr. Birsen, yet Dr. Birsen associates the change between the treatment of the two sisters with the move towards the new paradigm, as opposed to a difference between her approach and another colleague's approach. Moreover, the fact that Dr. Birsen mentions the older sister's fear of sterilization implies that her decision might be influenced by the little sister's feedback.

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[71] Sadece şey var bazı tür interseks bireylerde kanser riski yüksek, gonadoblastoma dediğimiz bir kanser türü var …. interseks bireylerin bazılarında bu [gonadal gelişim] arada kalır yarım gelişir veya yüzde 80 gelişir gibi değişik değişik şeyler var, bu [over ve testis arasında] arada kalmış gonadlar veya bu tam gelişmemiş parça parça kalmış string gonad dediğimiz muhabbette gonadoblastoma dediğimiz kanserinin görülme olasılığı onda bir literature göre ve bazı türlerinde daha da yüksek, onda bir yüksek bir olasılık, ve zaten fonksiyonel değil çoğu insanda hani hormon üretecek kapasitesi yok yani….yani ben biraz konservatif yaklaşırım böyle durumlarda hani risk varsa alalım diye düşünüyorum."

[72] In individuals with Androgen Insensitivity Syndrome and XY chromosomes, androgen receptors of the body do not respond to testosterone; therefore the body has the appearance of a typical female body. Internally, there are undescended testes and there is no uterus and cervix. The vaginal canal is also short.

[73] "Mesela bir tane gördüğüm çocuk vardı AISi olan, gonadektomiden sonra söylemişler, 'annemler benim ablamın yumurtalıklarını çıkarttırdılar' diyor, hani zannediyor ki ona kötülük yaptılar, kısırlaştırıldı gibi şey yapıyordu, bana da aynı şeyi yapacaklar korkusu vardı mesela … Yani aynı hastalık var çocukta yani ikincisinde de ….. ikinciye gonadektomi yaptırmadım da yani dedim ki 'ablanın döneminde o işler öyle oluyordu ama hani şimdi senin acelesi yok, istersen kendin karar verirsin' falan diye söyledim." (Dr. Birsen)

In addition, several other clinicians reported postponement in gonadectomies, especially in AIS patients. Pediatric endocrinologist Dr. Bülent says: "Yes, there is such a drift, or rather, there is also a view like 'let the testicles stay, let's remove them later, after puberty'."[74] Another pediatric endocrinologist Dr. Ali reported a patient whose gonads were not taken out: "Risk of cancer is low for gonads; we don't remove them anymore, anyway. We used to, before. There's even a patient that's waiting now."[75] Pediatric endocrinologist Dr. Ayfer says: "We used to remove them more easily before; the current approach is to rather wait till the age that the child can express themselves, but sometimes, you know, the family doesn't want that; the family can be involved."[76]

On the other hand, as can be seen in these reports, the dominant view is still to remove the gonads once the child reaches puberty. Theoretically, puberty is perceived as an age when the child can express informed consent. Yet, in practice, this does not necessarily mean that informed consent principles are followed. As I show earlier in this section, the medical treatment procedures are not structured in a way to ensure the patient's informed consent, even if the patient is old enough. The following conversation I had with pediatric endocrinologist Dr. Ayfer indicates that postponing gonadectomies until puberty can be based on a superficial understanding of informed consent:

> Dr. Ayfer: You remove the testicles at one point. Leaving the testicles inside causes cancer, so the testicles are removed. The testicles that come out don't have an effect in many ways anyway, androgen insensitivity…
> Ceren: Hmm, didn't you say just now, that [they are not removed] until the child, the person reaches an age that they can express themselves?
> Dr. Ayfer: Right, they did reach, and they were removed; they're removed one way or another in disorders of androgen receptor.[77]

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[74] "Evet öyle bir gidişat var, daha doğrusu tesisler gelişme döneminde dursun daha sonra ergenlik döneminden sonra testisleri alalım şeklinde bir görüş de var."

[75] "Gonadlarda kanser riski düşük, artık almıyoruz zaten, eskiden alıyorduk, öyle hasta var hatta şu an bekleyen."

[76] "Eskiden daha kolay alırdık, güncel yaklaşım daha çok çocuğun kendini ifade edebileceği yaşa kadar beklemek, ama işte bazen aile istemiyo, aile işin içine girebiliyor."

[77] Dr. Ayfer: Testisleri de alıyosun bi aşamada, içerde kalması kanser yapar testislerin, dolayısıyla testisleri alınıyo zaten ordan çıkan testisler etki edemiyo bisürü şekilde, androjen duyarsızlığı..
Ceren: Hmm, biraz önce şey demediniz mi, çocuk, insan kendini ifade edebilecek yaşa gelene kadar.. [alınmıyor]?
Dr. Ayfer: Tamam, geldi, alındı, bi şekilde alınıyo androjen resptörü kusurlarında.

Dr. Ayfer did not elaborate further on the details about how consent of the patient plays into this process. In Chapter 3, I show how a patient who reaches puberty can go through gonadectomy without being informed about the content of the intervention, and therefore without being given information on possible risks and complications, which is shaped by the dynamics between the patient and the clinicians.

2.3.1 Clinicians' Positionalities

"We've been performing these operations for so many years; from time to time… not from time to time, very often, I ask myself: 'so what?' Why am I doing this? I mean, everyone that I [operate] is unhappy, everyone is unhappy; there's no individual that is happy when I perform my operation."[78] said Dr. Bülent, during our conversation on his doubts regarding the benefits of the surgeries. So, why is he continuing?

All the clinicians I interviewed are aware of the rising global tendency to eliminate and/or postpone early, non-consensual, non-vital surgeries on children with intersex traits and variations of sex characteristics. Most of the clinicians embraced the shift toward this new treatment paradigm at least in the interview narratives. Although this does not mean that it reflects the actual practices of the clinicians on a large scale, it seems like there is a continuing medical shift toward postponing the operations until the age of consent. Still, this change seems to be slower than one might expect. In this section, I discuss the clinicians' positionalities vis-a-vis the intersex treatment procedures to shed light on why this might be the case.

Both medical opinions and ethical stances vary among and within the clinicians' practices. They question, revise, and update their views and practices in different degrees, mainly due to gaining awareness of some of the ethical problems with the currently dominant treatment paradigm. A pediatric surgeon explains his inner conflict about the ethical implications of the issue:

> "I mean, my conflict is this; I'm interested in the surgical aspect of it. I mean, if somebody says to me: 'Pal, we've taken care of the social/cultural aspect of it

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[78] "Bunca yıldır bu ameliyatları yapıyoruz, zaman zaman… zaman zaman değil çok sık kendime soruyorum: so what? Niye yapıyorum ki yani yaptığım herkes mutsuz oluyor, herkes mutsuz oluyor; benim ameliyatını yaptığımda mutlu olan bireyim yok"

> and this clitoris will be cut and they will be made into a girl'… The thing I love the most; I can work as a technician there. But when I start thinking about what they will be in the future, how will their adaptation to social life be, how will the societal culture perceive this, etc., then I cannot perform my surgery. I mean, there's a truth that I see as a surgeon there; there's a big clitoris that needs to be cut. I say, they cannot live with this, but it is difficult for me to deal with their problems 30 years after it's been cut; then I don't know what to do… But no one can decide that; you're not going to be able to decide that as cultural studies, go into it and see; you won't know what to do either, no one has known… In fact, if I could lay it on the family, if the family says to me: 'I want that', then it will be all over for me." (Dr. Bülent)[79]

There could be some obvious answers to Dr. Bülent's questions and concerns, such as the argument that intersex individuals and activist groups have been raising their voices, and that their voices should be prioritized. But for now, I would like to point out that this quote is important in showing that from the perspective of an established pediatric surgeon who has over twenty years of experience, the medical procedures are highly open to contestation, and there is indeed plenty of room for discussion, precisely because these are not only medical decisions, but also social decisions. It is also important in showing that how clinicians are distanced from both the social realities of their intersex patients, as well as non-medical resources such as activist groups, civil society organizations, and social science research. In the absence of information and support these kinds of resources can provide, it becomes easier to delegate the burden of decision to parents. It is also safer for the clinicians since the parents are the legal guardians of the patient; if a clinician who goes against the will of the parents makes a "mistake," the family is more likely to complain, or even sue. But if they comply with the family's desires, especially in cases where a medical decision is hard to make, then the risk is minimized for the clinicians.

The medical procedures can be contested from the viewpoint of clinicians not only on ethical, but also medical grounds. Pediatric surgeon Dr. Ali told me about a disagreement he had with the rest of the DSD committee in the medical diagnosis of the sex of a patient;

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[79] "Yani benim sorunsalım şu, ben işin cerrahi yönüyle ilgileniyorum yani biri dese ki bana arkadaş biz bu işin sosyal kültürel yönüyle ilgilendik, bu klitoris de kesilerek kız haline getirilecek.. en bayıldığım şey tekniker olarak ben çalışayım orada. Ama bu ilerde ne olur, sosyal yaşama adaptasyonu nasıl olur toplum kültürü bunu nasıl algılar filan ben girmeye kalktığım zaman o zaman ben ameliyatını yapamıyorum, yani benim cerrah olarak gördüğüm bir doğru var ortada büyük bir klitoris var kesilmesi gereken bununla yaşayamaz diyorum ama kesildikten 30 sene sonraki sorunlarıyla baş etmem de zor ne yapacağımı bilmiyorum o zaman….ama buna kimse karar veremez, buna kültürel araştırmalar olarak sen de karar veremeyeceksin, içine gir bak ne yapacağını sen de bilemeyeceksin, hiç kimse bilememiş…aslında aileye yıkabilsem, aile bana "şunu istiyorum" dese benim için iş bitecek." (Dr. Bülent)

the patient was a teenager who was raised as a girl, yet Dr. Ali believed that the patient was male. Both the appearance and attitudes, and the medical condition of the patient - 5 alpha reductase deficiency (5-ARD) - were among the reasons Dr. Ali cited for his diagnosis. Since the parents did not allow for their child to speak to him, he does not know the patient's perspective. This is the same patient Dr. Ali refers to in section 2.1.2.1; he also referred to this patient in his class:

> Dr. Ali: A patient came to me at the age of 14 or 15. I refused to operate them. I said that the child was introverted, etc. I told them: 'Wait for another two or three years, the child hasn't discovered themselves yet', but the family refused that, saying: 'What does the kid know?'… It was a girl, but totally masculine. Their friends noticed that too. The council decided: 'girl', but I didn't sign it.
> (A student): But, sir, isn't this child abuse?
> Dr. Ali: Yes, but we can't do anything, I can't; I can't object to the decision of the council. Their testicles were removed, and a vagina was made, [that person] will come [back] to us, I'm waiting.[80]

This quote shows that the medical view in sex assignment is not always coherent and objective, which is a common misconception, as discussed in section 2.1.1.1. In the absence of proper psychiatric care, non-medical resources, or protective mechanisms, the clinicians -and the parents- rely on the clinicians' medical(ized) views of sex, gender and sexuality to make decisions, bypassing the subjectivity of the patients themselves.

Moreover, this case suggests that clinicians who disagree with the opinion of the majority can be powerless because of the structural lack of protective mechanisms. Even when clinicians want to follow the principles of informed consent, they may not be able to enforce it because they do not have the tools and resources that support them. In fact, from the interviews with the clinicians, I had the impression that more critical clinicians might be marginalized from the medical community because of their advocacy for a non-interventionist approach, even though I do not have direct proof. Also, in a recent conference on Intersex Studies, one of the researchers mentioned a similar observation in their own research, which is not published yet. Since Intersex Studies is a newly emerging field, I

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[80] Dr. Ali: bana 14-15 yaşında bir hasta geldi, ameliyatı reddettim, çocuk içe dönük vs. dedim 2-3 yıl daha bekleyin, kendini keşfedememiş henüz, ama aile reddetti, o ne bilecek diye….kız ama tamamen erkeksi, arkadaşları da fark etmiş, konseyden kız olarak karar çıktı, ben imzalamadım.
(a student): Hocam ama bu çocuk suistimali değil mi?
Dr. Ali: Evet ama bir şey yapamıyoruz, yapamam, konseyin kararına itiraz edemiyorum. Testisleri alındı, vajen yapıldı, o [geri] gelecek bize bekliyorum.

could not find any other published resources to support this point. Nevertheless, keeping in mind that clinicians are not a uniform group in their positionalities could be useful in general.

Another sign of the clinicians doubts about the medical narrative is that some clinicians showed hesitation -such as pauses, diminishing tone of voice, or correcting themselves- with using terms like “girl/boy,” “women/men,” or -in one case- “treatment,” when referring to the sex assignment processes of individuals with intersex traits. This shows that they are not entirely comfortable with the definition of sex and its medical treatment as it is formulated in the current intersex treatment paradigm. The dominant medical discourse of sex is founded upon an understanding of gender identity, sex, and sexuality in which they are inevitably tied to each other in a way that they would make up a cis[81]-heterosexual person with a single sex and single gender identity. Sex, gender identity and sexuality come as “package deals” in an unquestioned “heterosexual matrix” (Butler 1990). As these packages are inadequate to account for bodies with intersex traits and variations of sex characteristics, the medical language of sex is also inadequate to talk about them. In this sense, the hesitations of clinicians show that they feel the inadequacy of their language.

Clinicians work on a slippery slope; they frequently point out the “difficulty of their job,” which comes from that they are expected to make medical decisions about non-medical problems when it comes to children with intersex traits and variations of sex characteristics. Although they are aware of the global tendency to avoid early, non-vital interventions and they are influenced by it to a certain extent, the change does not come easy. Even if medicalization of intersex is relatively recent in human history, in terms of the life span and medical practice of the clinicians I have interviewed, it is a well-established procedure. Hence, many feel comfortable with following long-established principles as they are taught in medical school. Moreover, as I have tried to show, it is not only a matter of individual decision for clinicians, but also a structural matter; even if some clinicians may be more in favor of postponing the treatments, they may not be able to convince the parents and other clinicians, and hierarchies may play into the decision-making processes to determine whose

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[81] Someone whose bodily sex at birth matches with their gender identity.

opinion dominates. The main issue is that there is a lack of a protective mechanism that would ensure the child's consent against the familial and medical authorities who choose to dismiss it. Clinicians work in a structure which cannot provide them the kind of information and support they need to view their patients' concerns from a non-medical point of view, whereas non-medical decisions are integral to the overall process. As a result, they often feel stuck and confused, and the safest way to follow becomes complying with what they already know as the "medical truth."

On the other hand, despite these factors, I maintain that clinicians as a group have significant power and agency in the decision-making processes for the treatment of children with intersex traits. For instance, as I will show in Chapter 3, clinicians' narratives indicate that parents of children are usually willing to comply with the clinicians' instructions, since they consider the doctors as a strong authority. Since clinicians are the main decision-makers, they constitute an important force that can cause a change forward, even if they can be uncomfortable with the responsibility they undertake.

In this chapter, I showed some elements of the logical reasoning behind the treatment procedures, and their practical implications. Clinicians' claims of objectivity obscure the socially and culturally shaped logics in the treatment procedures and legitimize dismissing the challenges raised by the activist movement by positioning them as "subjective." Nevertheless, clinicians rely on their own culturally shaped views of femininity, masculinity, social acceptability and morality in their medical decisions. Lack of a sufficient psychiatric consultation and care mechanism leaves the important decisions mainly to the "technical" experts such as endocrinologists and surgeons, failing to prioritize the patient's long-term psychological wellbeing over the clinical or parental authorities. As a result of these mechanisms, subjectivities of the patients are ignored in the medical decision-making processes, and standardized treatments are followed. Thus, for many common conditions, it is thought that the "true sex" of the child can be identified correctly through medical examination. Meanwhile, two competing theories that have determined the intersex treatment paradigm since the 50s, social constructionism associated with John Money and biological determinism associated with Milton Diamond, are employed selectively to support this reasoning. Even if biological deterministic views gained more popularity after the fall of Money’s reputation, the social constructionist view that gender identity is flexible before the age of two, and the emphasis put on the influence of the appearance of genitals on gender identity development remains strong, whereas the existence of a “true sex” is theorized upon the biological deterministic idea that gender identity is mainly developed and fixed during the prenatal period. Combining these specific points from two incommensurable theoretical approaches, the logic follows that genital surgeries should be completed in the first two years of life, ensuring healthy gender identity development in accordance with the “true sex.” Thus, the link between gender assignment and sex assignment surgery is envisioned as unbreakable, eliminating any discussion of alternative possibilities “in-between” the traditional treatment procedures and non-intervention, such as temporary gender assignment without surgical intervention. Surgery remains as the most appropriate response, and the focus of debate is often shifted to the quality of the surgical methods, and surgical methods are constantly updated to achieve presumably better results, as a response to the challenges from activists. Because of the temporal distance between the newly developed surgical methods and emergence of their long-term effects, evidence proving the harmful effects of earlier surgeries can be dismissed as “outdated,” and the surgical approach continues.

Second, I showed how the dominant medical terminologies help establish medical authority on intersex. I summarized how the terminology of Disorders of Sex Development (DSD) emerged along with an update on the classification scheme of intersex conditions in 2006. I presented the discussion around the new terminology and the criticism it drew from intersex activists and scholars. Then, I described terminological choices of the clinicians I interviewed, and showed how their stances on different kinds of terminologies are in congruence with the medical logic of the traditional treatment paradigm. I also analyzed two other practical implications of viewing intersex as a disorder: providing grounds for selective abortion via prenatal testing and hindrance of discussion of intersex as a political issue, distancing it from transsexuality.

In the last part, I discussed the implications of the shifting treatment paradigm for the clinicians. I presented data from my interviews regarding the changes that have been occurring in the clinicians’ narratives and practices as part of the shift towards a less interventionist approach, and I discussed the challenges they face in relation to this shift. In the interviews, most clinicians embraced the new paradigm verbally, yet they reported relatively minor changes in their medical practice. Several of them reported a decrease in certain interventions such as cliterodectomy, vaginoplasty or gonadectomy; one pediatric surgeon -out of four- reported the complete elimination of cliterodectomy from his own practice. Finally, I analyzed the clinicians' struggle with the paradigm shift; they view many aspects of the traditional treatment paradigm as open to debate, while hesitating in applying the paradigm shift to their practices, which can lead to inner conflicts and anxieties, as well as conflicts with other clinicians and families.

CHAPTER 3

DYNAMICS OF THE PATIENT-CLINICIAN RELATIONSHIP AND INFORMED CONSENT

In this chapter, first, I lay out the dynamics of the relationships between the clinicians and the patients based on clinicians' reports on how they talk about their conditions with the patients. I argue that clinicians often avoid communicating patients' conditions to them as variations of sex characteristics (VSC). They can withhold information from the patients or misinform them about their sex characteristics, emphasize the medical aspect of their condition by establishing parallels with other diseases, and place the responsibility to inform the patient and to make decisions about treatment on the parents. I suggest that clinicians employ these strategies because they do not view the principles pertaining to respect for autonomy, such as informed consent or nondirective counseling, as necessarily relevant to the wellbeing of their patients.

In the second part of the chapter, I analyze a very common narrative among clinicians regarding the impossibility of change due to the cultural and socioeconomic context that their patients live in. I contextualize this discourse in the political and economic context of Turkey particularly in relation to neoliberalization. Then, I show how the new paradigm of treatment envisions intersex patients as neoliberal subjects, and how this might be narrowing the discussions around informed consent, as well as slowing down effective change in the long term. Finally, I discuss different questions that can be raised in relation to informed consent in relation to the importance of peer-based information.

3.1 Establishing the Medical Truth of Sex

During the interviews, in response to the questions regarding how they communicate their conditions to the patients, clinicians usually gave general and blurry answers. For example, pediatric endocrinologist Dr. Birsen said, “we’re trying to explain our decision at the council, why we did that, what happened, what’s wrong with the child.”[82]

Even when I pressed them to provide more details or examples, either they repeated the general answers they already gave, or their answers varied greatly. Sometimes, the clinicians gave contradictory answers. For example, an endocrinologist and a pediatric surgeon who work at the same hospital provided very different narratives of how they communicate to the patients. In this hospital, I first interviewed pediatric endocrinologist Dr. Birsen; when we were talking about the medical paradigm’s recent shift in favor of postponing the surgeries, Dr. Birsen stated that they -as the DSD team- have recently been more likely to avoid irreversible surgeries at an early age and gave CAIS as an example: “we follow up like that, keeping the gonads as much as possible, I mean, trying not to touch the gonads until they reach an age that they can decide for themselves.”[83]

Later, I interviewed a pediatric surgeon, Dr. Engin, who works at the same hospital. To my surprise, Dr. Engin openly said that they keep their conditions secret from their patients with CAIS, because it would be too traumatizing for the patient to learn the truth. This is the dialog we had with Dr. Engin:

> Dr. Engin: Adult… with children, you know, so that they don’t hear about it… For example, a girl or a boy, I just mentioned it, complete androgen insensitivity, for instance; there’s male chromosomal structure but the external genital system is completely a girl, the behaviors are those of a girl’s, everything is of a girl’s. In situations like this, an effort is made so that it is not heard. You know, there are patients that are at this age; I have kids who go to university right now. To some, you know, we say, like: “there was a problem with your reproductive system, we tried to repair that” or “we tried to fix that.” We do our best, so they don’t hear about it.
> Ceren: Oh, so that they, themselves don’t hear about it?
> Dr. Engin: Yes, cause you know, think about it, you’re 14, you’re a girl, you don’t menstruate, you come, and they tell you: “you’re really a boy.”
> Ceren: Both telling them they’re XY and… I don’t know… like, [cause] it demoralizes them?
> Dr. Engin : Sure, sure, sure… I mean… They cannot place that [information] anywhere… That’s why we, you know, try not to tell them, for them not to be aware…

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[82] “konseydeki kararımızı, niye böyle yaptığımızı, ne olduğunu, çocuğun nesi olduğunu anlatmaya çalışıyoruz.”

[83] “gonadları olabildiğince koruyarak, yani gonad mevzusunu tamamen kendi karar verecek yaşa gelene kadar hiç ellememeye çalışarak o şekilde takip ediyoruz.”

> Ceren: And, you know, for instance, how do you explain the testicle removal surgery?
> Dr. Engin: Since we remove it by surgery, and at that point, we also make a vagina and we say, you know: ‘there was something in your reproductive system, we fixed that’.
> Ceren: Oh, but [how do you say that] before? … For example, if I were to have an operation at the age of 14, you know, I’d ask…
> Dr. Engin: We say: “there were some tissues that weren’t supposed to be there, so we removed them.”[84]

Contrary to Dr. Birsen, Dr. Engin sticks to the view that keeping information from the patient can be a medically ethical behavior in the name of protecting the patient emotionally. Both Dr. Birsen and Dr. Engin are part of the DSD team of the hospital, and Dr. Engin mentions that they work harmoniously as a team: “Since the endocrinology [department] of ours here is *(with emphasis)* very firm, a very good endocrinology [department], they receive a lot of patients and they forward them to me. We [work] exactly as a team,”[85] which makes it difficult to interpret their contradictory narratives. Later Dr. Engin went on about how his patients are happy with the results, and how they appreciate him. He even proposed to introduce me to one of his patients for an interview. He clearly considers himself as a clinician seeking the best interest of his patients, and he was not apologetic about his approach favoring secrecy.

The contradiction between the narratives of the two clinicians may be because - as both Dr. Engin and Dr. Birsen, and many other clinicians mentioned - the communication process varies greatly from patient to patient, and they had different examples in mind when they

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[84] Dr. Engin: Erişkin.. çocuklarda, aman hani duyulmasın diye.. mesela kız, erkek çocuk, demin söyledim, total androjen insensitivitesi mesela, erkek kromozom yapısı var, ama tamamiyle dış genital sistem kız, davranışları kız, her şeyi kız, böyle durumlarda duyulmasın diye çaba harcanıyo. Hani bu yaşlarda olan hastalar var, şu anda üniversiteye giden çocuklarım da var. Bazılarına hani işte “senin üreme sisteminde sıkıntı vardı, onu tamir etmeye çalıştık” veya “düzeltmeye çalıştık” şeklinde yorumluyoruz, duymaması için elimizden geleni.. yapıyoruz
Ceren: Ha kendisinin de duymaması için mi?
Dr. Engin: Evet, çünkü yani, düşünsene 14 yaşındasın, kız çocuğusun, adet görmüyosun, geliyosun, diyolar ki “sen esasında erkeksin.”
Ceren: Hem XY olduğunu söyleyip hem.. ne biliyim.. hani onu demoralize eder.. [diye mi]?
Dr. Engin: Tabii ki, tabii ki, tabii ki.. Yani.. hiç bir yere koyamaz yani.. O yüzden hani biz söylememeye, farkında olmamasına çabalıyoruz..
Ceren: Peki şey mesela, testisleri alma operasyonunu nasıl açıklıyosunuz?
Dr. Engin: Ameliyatla aldığımız için, bi de işte o sırada da vajen yapıyoruz, ve diyoruz ki hani senin üreme sisteminde bir şey vardı, onu düzelttik
Ceren: Ha, ama önceden [nasıl söylüyorsunuz?].. mesela 14 yaşında bi ameliyata gircek olsam hani sorarım..
Dr. Engin: “Orda olmaması gereken dokular vardı onları aldık” diyoruz.

[85] “Bizim burdaki endokrinoloji de çok [vurgulu] sağlam, çok iyi bir endokrinoloji olduğu için oraya da çok hasta geliyo, onlar da bana yönlendiriyo, biz tam bi ekip olarak [çalışıyoruz]”

were talking to me. Perhaps, they have different opinions about which strategy is the general rule and which one is an exception to the rule. Also, it might be because their specialties are different; usually endocrinologists, more than the surgeons, do the talking with the patients and follow the management of the treatment in general. However, it is still striking to see such a difference from two closely working clinicians about the same group of patients. This situation nevertheless shows that an established procedure does not exist in practice; the strategies of communication are highly variable and can at times lead to misinformation of the patient.

With a closer look, however, the contradiction may not be as strong as it seems; because, what is considered "truth" or "knowledge" in the first place can vary when the "truth" of sex/gender is concerned. When I further investigated what exactly the clinicians say to their patients and/or the parents, I found out that the clinicians usually avoid posing DSD as a condition that has relevance to gender and sexuality. Even if the medical decisions are inevitably gendered, the condition is communicated as a medical disorder, as opposed to a variation of sex characteristics. Even though Dr. Birsen emphasized that they try to postpone the gonad operations, what she said later shows that it does not mean that the relevant information is given to the patient: "You know, we don't really talk about gender or bring up those subjects, you know, the family doesn't either. We don't really … to the child either but at the beginning when holding the council, we give detailed information to the family."[86] The "detailed information" given to the parents is also likely to not include the gendered nature of the medical decision-making.

Dr. Birsen gave an example to further explain, mentioning a patient with AIS:

> "For example, we told them this way: 'the chromosome tests of some girls come out like this.' I mean, cause the child is already a girl, I mean, in fact in all aspects, you know, we want the child psychiatrist to see them too, but you know, I mean, all of the person is really a girl. 'There's no problem with you being a girl; and we will cure it, you know, there are some things that are broken, and we will fix them. You know, there may be trouble with you having a child, um… At this day and age, with the available technology, you may not have a child very easily but assisted reproductive techniques are developing, healthy girls, or for instance, some girls with no problem whatsoever might also not be able to

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[86] "hani cinsiyetle ilgili pek konuşup o konuları açmıyoruz, hani aile de açmıyor, çocuğa da çok şey yapmıyoruz ama, başta konseyi yaparken falan detaylı bilgi vermiş oluyoruz aileye."

> have children'… You know, for instance, without confusing them, or we don't say: 'you're *çift cinsiyetli*[87] or you have this, or that; your karyotype is, in fact, male', you know."[88]

Here, Dr. Birsen does not mention how she knows that her patient is "definitely a girl"; nor do we hear the patient's own voice in this narrative. In fact, it is considered dangerous to involve the patient in this conversation because it can "confuse" her. Furthermore, Dr. Birsen's narrative implies that she does not completely believe in what she told her patient, when she said, "there's no problem with you being a girl[89]." This is because the patient has XY chromosomes and testicles, which compromises the medical diagnosis of sex, according to Dr. Birsen. In a similar vein, when pediatric surgeon Dr. Bülent was talking about a girl with AIS, he said "for example, a girl who is at the age of 13, 14, extremely levelheaded, hardworking, top of her class, etc.… But she's really a boy; it's not [right] to tell her: 'you're a boy' at those stages."[90]Because Dr. Birsen and Dr. Bülent believe that "male" karyotypes and gonads can prevent a child from being a complete girl, they consider affirming their patient's gender identity as a "white lie." In this logic, telling the "truth" is considered unethical because it would go against the child's own understanding of her gender identity.

As a result, Dr. Birsen did not tell her patient that she had testicles rather than ovaries, and instead she said, "there are some things that are broken, and we will fix them,"[91] and further she talked about implications of AIS on reproductive capacity. In this narrative, the information that would disclose that the patient has a variation of sex characteristics is selectively concealed, and the condition is strictly defined as a disorder *("bozukluk").*

Hence, although Dr. Engin's and Dr. Birsen's accounts may sound contradictory to each other, what they mean in practice may not be tremendously different from one another.

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[87] Local version of the term "hermaphrodite" in Turkey; the literal translation would be "double-sexed."

[88] "Mesela ona şöyle anlattık yani 'bazı kızların kromozom testi böyle çıkıyor,' yani çünkü zaten çocuk kız, yani aslında herşey olarak, hani çocuk psikiyatristi falan da görsün istiyoruz ama hani yani her şeyi aslında kız. 'Senin kız olmanla ilgili bir sorun yok, biz de onu tedavi edeceğiz, hani bozuk olan bir takım şeyler var onları da düzelticez, işte çocuğun olmasında sıkıntı olabilir, ee.. bu dönemde bu mevcut teknolojiyle hani o kadar kolay çocuğun olmayabilir, ama yardımcı üreme teknikleri gelişiyor, sağlıklı kızların da mesela bazı hiçbir problemi olmayan kızların da çocuğu olmayabiliyor…' Hani mesela kafasını da karıştırmadan, sen çift cinsiyetlisin ya da işte şuyun var buyun var senin karyotipin erkek aslında falan demiyoruz yani."

[89] "senin kız olmanla ilgili bir sorun yok."

[90] "mesela 13-14 yaşlarında son derece aklı başında çalışkan sınıf birincisi filan bir kız çocuğu… Aslında erkek, ona o aşamalarda tutup da sen erkeksin filan demek şey [doğru] değil."

[91] "bozuk olan bir takım şeyler var onları da düzelticez"

Whereas Dr. Engin advocates for hiding information in the name of saving the patient from being traumatized, Dr. Birsen advocates for informing the patient, but this information is given in a highly medicalized language which conceals that the treatment aims to "normalize" the sex characteristics, and in effect it conceals crucial information regarding what was or is to be done to the patient's body.

The avoidance of the clinicians to talk about the conditions in relation to variations in sex characteristics prevents a deeper discussion of what categories such as femininity and masculinity mean beyond their medico-normative definitions. This results in taking these categories for granted even in the face of living evidence that disrupts these categories. In order to avoid dealing with this incongruity, the clinicians avoid talking about the gendered nature of the condition altogether at the expense of withholding important information from the patient.

In cases when information is not withheld, perceiving sex/gender as a medical truth rather than a subjective experience can still result in the manipulation of the information given to the patient, as in the case of male adults with CAH. Individuals with CAH are believed to be females "in reality," and they are assigned as females when they are diagnosed at infancy. However, sometimes people born with CAH can escape diagnosis and can be reared as males. This is considered a mistake in sex assignment by the clinicians, and the male identity of the adult person is considered highly fragile. Moreover, one side-effect of most cases of CAH is having insufficient levels of cortisol, so most people with CAH need to take cortisone supplements to compensate for the lack, which in return decreases their pre-medication levels of testosterone. Therefore, if a person with CAH identifies as male "despite" their lowered testosterone levels and their female "true sex," then they are prescribed additional testosterone supplements. However, this is a situation that is not endorsed by the clinicians. Dr. Birsen's description of communication with such a patient illustrates this view:

> "But if he feels *very much* like a man, I mean, saying there's an organic reason to this, and that is such and such… *but if the child persistently wants to be that way [a man] during the treatment*… For instance, you know, he wasn't our patient, but recently, a guy in Hatay who has 21-hydroxylase deficiency, adrenal insufficiency; the doctor there consults us; you know, the man gets married, he has a wife, he goes to the doctor cause he can't have children. He probably knows

> it too, but, you know, he doesn't use his medication. We should put him on medication, and when the medication starts, his male hormones will drop and maybe he won't feel that much like a man, and then… so… but he's got married… I mean… You know, telling him all about this… like 'but you need to use this medication in order to live, *but if you still want to be a man in spite of this*, then we need to give you manhood hormones *in addition from the outside*'."[92] (emphasis added)

In this narrative, the words and phrases such as "if he persistently wants to be a man," "if you still want to be a man in spite of this," "in addition from the outside"[93] imply that Dr. Birsen finds it difficult to believe that an adult with CAH can be a man; rather, he can only "want to be a man." It communicates to the patient a mistake was made, and the patient himself is insisting on this mistake by identifying as male.

Categorizing intersex variations as medical conditions leads to an avoidance on the part of the clinicians from talking about the gendered/sexed aspects of these conditions when they are communicating with their patients. While the clinicians might consider it as an innocent attempt to protect the patient's emotional wellbeing, or an attempt to guide the patient to their "natural" sex, it can also mean withholding crucial information from the patient about their body and the interventions made, as well as communicating to the patient that their existence is a "mistake." As illustrated in the Chapter 4, this may cause a trauma by itself.

In the communications between the patients and the clinicians, DSD can be compared to other medical conditions, including severe diseases such as cancer. Several clinicians stated that they use these comparisons to tell the patient that their condition is "just like any other." This comparison emphasizes further that DSD is a disease as opposed to be a variation of sex characteristics, and thus it should be treated. For instance, when I asked pediatric endocrinologist Dr. Ayfer about it, she said,

> "It's true for many other diseases; we need to tell the truth somehow about their disease. But it's the same for all diseases, not just for this, of course. There are

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[92] "ama *çok* kendini erkek gibi hissediyorsa hani bunun bi organik sebebi var o da bu falan diyerek… *ama çocuk tedavide ısrarla kendisi öyle [erkek] olmak istiyorsa*… Mesela işte bizim hastamız değildi ama geçende Hatay'da bir 21 hidroksilaz eksikliği, adrenal yetmezliği olan bir çocuk, oradaki doktor bize danışıyor mesela işte adam, evleniyor karısı var, işte çocuğu olmuyor diye gidiyor doktora, muhtemelen kendisi de biliyor ama, hani ilaçlarını da kullanmıyor, çocuğa ilaç başlamak lazım, ilaç başlayınca erkeklik hormonları düşecek ve belki kendini aslında o kadar erkek hissetmeyecek, o zaman da ee... ama evlenmiş.. yani.. hani bütün bunları anlatarak.. ama senin yaşaman için bu ilacı kullanman lazım, *gene de buna rağmen erkek olmak istiyorsan* o zaman *ekstradan* sana *dışarıdan* erkeklik hormonu vermemiz lazım diye."

[93] "ısrarla erkek olmak istiyosa," "gene de buna rağmen erkek olmak istiyorsan," ekstradan…dışardan"

> patients that can't have children; you can tell them too. There are children with tumors, they don't come to us, I mean, to endocrinology, but… Again, the child's age, their level of maturity; in these cases, psychologists are very important; they often come into play while talking about tumors. All this is individualized and told according to the child's age and cultural maturity level."[94]

Also, in a recently published brochure that is prepared for the parents, it says,

> "Disorder of sex development is not something to be ashamed of. Just as there can be an abnormality or a disorder in the other organs of a person and it can be treated, the abnormalities in genitalia are also ordinary and they can be treated to a great extent. Your biggest responsibility as parents is to accept and love your children as they are. Tell them about this situation at the right time and in a proper way and do what is needed for their treatment."[95]

In these examples, the comparison of DSD to other diseases is emphasized to prevent an embarrassment on the part of the patient and the parents. Similar to the narratives of Dr. Birsen and Dr. Engin analyzed above, these narratives consider concealing the sex-variation aspect of the condition as a means of protecting the patient. On the other hand, by establishing parallels between DSD and other diseases, the treatment procedures of DSD and treatment procedures of, say, cancer are also paralleled to each other, concealing the fact that cultural assumptions regarding gender and sexuality play a major role in defining the treatment as necessary in the case of DSD. When children with intersex traits are reduced to sick patients, their needs are reduced to medical treatment, which comes in the form of early, non-consensual surgeries and treatments that can leave them in long-term pain and suffering rather than feeling loved and accepted.

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[94] "Başka bisürü hastalıklar için de geçerli bu, hastalığı hakkında….yani bi şekilde doğruları söylemek gerekiyor. Bütün hastalıklar için aynı şey ama, sadece bunun için değil tabi; çocuğu olmıycak hasta da var ona da anlatabilirsin, tümörleri oluyo çocukların, onlar bize gelmiyo yani ama endokrine, yine çocuğun yaşı, olgunlaşma düzeyi, buralarda psikologlar çok önemli tümörlerde, mesela çok devreye giriyolar anlatırken. Bütün bunlar çocuğun yaşına ve kültürel olgunluk düzeyine göre bireyselleştirilip anlatılıyor."

[95] "Cinsiyet gelişim bozukluğu utanılacak bir durum değildir. Nasıl bir insanın diğer organlarında anormallik veya bozukluk olabiliyor ve tedavi edilebiliyor ise, cinsel organlardaki anormallikler de olağandır ve büyük oranda tedavi edilebilmektedir. Anne ve baba olarak en önemli sorumluluğunuz çocuklarınızı olduğu gibi kabul etmek ve sevmek, onlara bu durumu uygun zamanda ve uygun şekilde anlatmak ve tedavileri için gerekeni yapmaktır."

3.2 Decision, Treatment and the Aftermath

3.2.1 Who makes the decisions?

As explained in Chapter 2, how much information the child will be provided during the treatment can be up to the parents' decision. If the parents do not want their children to know the details of their condition, in many cases clinicians comply, since there is no structural obligation, such as legal obligation, against it. Pediatric endocrinologist Dr. Birsen explains how it works in practice in their hospital: "if they're at a reasonable age, and if the family says it's OK for the child to know, we speak to the child, too, but some families, for instance, want to be more cautious, they want to meet with the psychiatry [department], etc. You know, we decide individually how to give information."[96]

Dr. Birsen says that the parents should agree if the child is going to be informed, even if the child is at a suitable age to be told. Thus, a standard procedure about informed consent does not exist; whether to follow informed consent principles is based on "individual decision." In my interviews, some clinicians complained about this situation, saying that they actually want to delay the operations, or obtain the informed consent of the child, but their parents would not let them. For instance, intern clinician Dr. Irmak, who works in a hospital located in a city other than Istanbul, explained that at her hospital, unlike many other hospitals in Turkey, there is a high standard of care for patients with intersex traits; the clinicians advise delaying the operations and providing informed consent as much as possible, according to her observations. However, she continued, the situation is still far from being ideal because of the parents' attitude: "I mean, there are also cases where families cause problems, but the families' problems are mostly unfavorable for the child; they're, like, completely about their social circles, problems in their heads."[97]Thus, parents are seen as the force that is holding the progressive clinicians back. At the same time, as I showed in 2.3.1, the authority they have on the sex/gender assignment of their patients can be a huge burden on the clinicians,

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[96] "mantıklı bir yaştaysa çocuğun bilmesinde bir sakınca yok diyorsa aile, çocukla da konuşuyoruz, ama bazı aileler mesela daha tedbirli olmak istiyor, bir psikiyatriyle görüşmek istiyorlar falan, hani bireysel karar veriyoruz nasıl bilgilendireceğimize."

[97] "yani ailelerin sıkıntı çıkardığı durumlar da var ama çoğunlukla çocuğun aleyhine biraz ailelerin sıkıntısı, tamamen kendi sosyal çevreleri, kendi kafalarındaki sıkıntılar falan gibi."

and they might want to delegate this burden to the parents, especially in cases in which they find it difficult to decide.

On the other hand, Dr. Irmak and many other clinicians expressed that most parents still comply with the clinicians' recommendations; because, most parents do not have any knowledge on the issue, they are stressed about their child's condition, and they see the clinician as the only authority who can provide an answer to their questions. There are also cases in which this is not true; some patients can be reactionary and can refuse to follow the clinician's instructions; however, these cases are more exceptions than the rule. Pediatric psychiatrist Dr. Nilgün says, "all of them [the patients] are conservative but I never heard 'oh, no, no way'. Families care about what the doctor says."[98] Pediatric surgeon Dr. Engin says, "Families rather listen to us. Frankly, I have never met anyone so far who says: 'this shouldn't happen, that should happen', or 'why are you doing this?' You know, at this point they are awfully desperate, you know, like 'whatever you say doctor', especially with newborns."[99]

Dr. Irmak also emphasized that in most cases clinicians can use their authority to convince the family to follow their advice; the example she gave about the decision-making process of an infant patient with CAH -whose parents insisted on raising as a boy- in her hospital illustrates how this can work:

> Dr. Irmak: My professor's approach was, to my great happiness, rather than the family's insistence, regarding how the child would live most healthily according to the data we have… but, you know, the family saw what they wanted to see, I guess; I mean, they wanted to have a son. It's a young couple, 19 or 20 years old. Anyway, our professors' position is like: 'I don't care what the family wants. The situation of this child is obvious'… I heard the professor say things like: 'I'm writing the child's report like this, I mean, I can't make the child's life miserable just because the family wants so'; I watched this at the back, heart emojis coming out of my eyes.
> Ceren: I see. But does the family not need to give consent for any intervention to the child?
> Dr. Irmak: It does, but as you can imagine, this is a situation that can scare a lot of families; it's a very ambiguous thing. It's not something they have witnessed

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[98] "[hastaların] hepsi muhafazakar ama ben hiç 'ay yok olmaz' duymadım, aileler doktorun ne dediğine önem veriyolar."

[99] "Aileler daha çok tabi bizi dinliyolar, şu ana kadar bize 'şu olmasın da bu olsun,' veya 'niye böyle yapıyosunuz' diyene açıkçası rastlamadım. Zaten hani bu noktada acayip çaresiz kalıyolar, hani 'doktor bey siz ne derseniz o olsun' şeklinde, özellikle yenidoğanda."

> or have knowledge on, and most of the time, families have the tendency to trust the doctor… Because there's a doctor before them, you know, 'Professor Doctor such and such,' like, they have an apron, you know, their hair turned grey, they have glasses, etc. So, when they say, 'we're doing this', they usually follow [the doctors].[100]

On the one hand, clinicians might want to rely on the parents for the decision making; on the other hand, families' "backwardness" might be seen as an obstacle to the right treatment. In any case, clinicians are quite powerful in the decision-making process whether they are comfortable about it or not, as intersex scholar Georgiann Davis points out: "Although clinicians claim that they are merely information providers, it is important to keep in mind that they make treatment recommendations from a position of power and authority over the intersex "emergency" they create. This leaves parents inclined to accept medical recommendations and simultaneously allows providers to evade responsibility for their actions" (Davis 2015, 124).

3.2.2 Treatment as Taking Action

My interviews with the clinicians supports an observation made by Ellen Feder; "it seems that the choice with which many parents of children with atypical sex are confronted is this: *do something* about your child's condition, or *do nothin*g" (Feder 2014, 149; emphasis belongs to author). When parents find themselves between choosing one of these options, it makes more sense to them to choose to "do something" about their child's condition.

This is not to say that clinicians intentionally make this formulation; in fact, as I have shown, they can feel highly conflicted about the authority assigned to them by this medical formulation. Yet, it is deeply ingrained in the medico-normative language of intersex traits; defining intersex and variations of sex characteristics (VSC) as disorders to be fixed

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[100] Dr. Irmak: Hocamın yaklaşımı beni çok mutlu eden bir şekilde ailenin ısrarından çok elimizdeki verilere göre çocuğun en sağlıklı nasıl yaşayacağı yolunda oldu….ama işte aile görmek istediğini biraz görmüş sanırım hani oğulları olmasını istemişler, genç bir çift, 19-20 yaşlarında falan, neyse bizim hocalarımızın tutumu da hani "ailenin ne istediği beni ilgilendirmez bu çocuğun hani durumu ortada"….''ben de çocuğun raporunu bu şekilde yazıyorum yani ailenin gönlü olsun diye çocuğun hayatını karartamam" gibi laflar ettiğini ben duydum, arka tarafta gözlerimden kalpler çıkarak falan izledim
Ceren: Anladım, peki çocuğa yapılacak bir müdahalede ailenin consent vermesi gerekmiyor mu?
Dr. Irmak: Gerekiyor ama tahmin edersiniz ki bu çok aileyi korkutabilecek bir durum, çok belirsiz bir şey, şahit oldukları, bilgi sahibi oldukları bir şey değil, ve çoğu zaman ailelerin hekime güvenme eğilimi var…çünkü hekim var karşısında hani profesör doktor bilmem kim işte önlüğü var ne bileyim saçı beyazlamış gözlüğü var falan yani, "şunu yapıyoruz" dediğinde yapıyorlar genellikle.

inevitably leads to a purely medical formulation against which action should be taken. For instance, the language Dr. Bülent uses when complaining about how difficult it is to motivate the parents toward a "wait and see approach" is a good example:

> "Some say: 'Professor, we first trust in God and then in you'. I say: 'Look, if you trust in God first, God created that way, then keep your child like this. But if you say that I'm better than God and can do what he can't, then I'll fix this'. They say: 'I repent, of course not, professor'; some say, 'faithless doctor' and take the child away *(we laugh)* … But it's like that, cause they [think] it can be fixed… Its shape and all is never the original, anyway, it doesn't work; it doesn't end up like a real vagina. We do something that resembles it, sometimes the clitoris is still big, or sometimes it disappears completely. Since the family doesn't know the technical details, they think it will be something totally normal. We try to explain that it won't be like that, but of course, a good part of our people [don't understand] … I mean, I tell them every time, but they don't understand anything."[101]

In this narrative, Dr. Bülent expresses how big a burden he is undertaking since surgical intervention does not provide what it promises. Knowing this, he wants to be saved from this burden by explaining the parents the reasons why it is better to wait. However, the categorization of intersex as a disease is limiting the possibilities of his language; he says they he can "fix" it, even while he is trying to explain why he actually cannot. In the end, what is communicated to the parents is a choice between "fixing" and "not doing anything" about their child's medical condition. In such a formulation, it is not surprising that parents choose the "fixing" option, even if they understand that there might be some "side-effects." Indeed, when I push him more, asking "But don't more conscious (*bilinçli*[102]) families come to you too?"[103] he responds, "I mean, relatively conscious families do come but… What kind of a decision do you want the family to arrive at? What should the family say now?

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[101] "Bazıları hocam önce Allah'a sonra size güveniyoruz diyorlar, diyorum ki bak önce Allah'a güveniyorsan Allah böyle yaratmış, o zaman böyle sakla çocuğunu, yok sen Allah'tan daha iyisin onun yapamadığını yaparsın diyosan ben bunu düzeltirim diyorum. "Tövbe estağfurullah hocam" filan diyor, bazen dinsiz doktor diye alıp götürüyorlar [gülüyoruz].. Ama öyle çünkü senden yani düzeltileceğini [düşünüyorlar].. Zaten şekli mekli hiçbir zaman orijinal değil olmuyor, orijinal vajen filan olmuyor, benzermiş gibi yaptığımız bir şeyler yapıyoruz, bazen yine büyük kalıyor klitoris, bazen tamamen kayboluyor, aile teknik detayları bilmediği için son derece normal bir şey olacak zannediyor, öyle olmayacağını anlatmaya çalışıyoruz ama tabii halkımızın önemli bir kısmı [anlamıyor]…. yani ben her seferinde anlatıyorum ama hiçbir şey anlamıyorlar."

[102] I explain the Turkish term "bilinçli" in Section 3.3 of this thesis.

[103] "Peki öyle daha bilinçli aileler de gelmiyor mu size?"

‘Professor, leave the vagina as it is’; neither the mother nor the father wants to take such a responsibility, cause they don’t know.”[104]

Thus, even if the parents “understand,” they still are not in a position to take the responsibility of the ultimate decision, because of the medicalized context in which intersex traits are defined and discussed. In the last section of this chapter, I will further discuss how the absence of peer-based information in the medical context leads to construction of the patients as inadequate to take responsibility of their own treatment, and how it reproduces the narrative of “cultural factors” as justification for maintaining the traditional, surgical approach.

3.2.3 Following-up with the Patients

Finally, insufficiency of follow-up procedures may constitute another obstacle to fulfilling the principles of informed consent. Especially because there is little evidence about the long-term effects of surgical operations on children with intersex traits, follow-up of the patients is crucial in seeing the results of the treatment for the clinicians; for instance, several of them mentioned their clinical experience among the factors that caused them to change their practices toward a less interventionist direction. Yet, when I asked the clinicians about their follow-up mechanisms, they gave either general answers such as stating that they do follow-up and they consider it important, or they stated that the follow-up procedures vary greatly depending on the patient. Their responses were in many ways similar to the responses they gave to the questions about how they communicate their conditions to the patients, as explained at the beginning of this chapter. For instance, pediatric endocrinologist Dr. Birsen explained her approach as following:

> “You know, in every case that I see, at every follow-up, at adolescence, I personally [say]: ‘how are things?’, etc., you know, ‘do you have a complaint?’; if they want to speak to me or if I don’t get answers to my questions the way I want to, you know, if the person that came with them, their mother, or father says to me: ‘can I speak with you?’ and wants to tell me something, you know,

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[104] “yani nispeten bilinçli aileler geliyor ama….ailenin nasıl bir karara varmasını istiyorsun, aile ne desin şimdi “hocam vajene dokunmayın”; böyle bir sorumluluğu ne anne ne baba almak istemez, bilmiyor çünkü.”

> I can do things that are aimed at that; I say: 'let's talk to the child psychiatrist again; let's do this and that'…"[105]

The first thing Dr. Birsen mentions about the follow-up procedure is related to heterosexuality being an indicator of success; that the patients are attracted to the "opposite sex/gender" is considered a proof of that the correct sex/gender was assigned. Second, as mentioned earlier, there is no obligation for a long-term psychological support; it is up to the parents, or the endocrinologist's perception of the need, to refer the child to a psychiatrist or psychologist. Third, the emphasis is more on the parents' need to talk, rather than the child, whereas it is the child who is facing the consequences directly. A question such as "how is it going?" is very general, the child is at the clinician's room with her parents, and she is speaking to an endocrinologist in an extremely busy hospital setting, knowing that there are tens of patients at the door waiting for them to leave the room. In these conditions one could raise questions about how much the patient would be able to express herself. For instance, can the child feel safe in such a context? How can the child give feedback for a treatment that she does not know the content of? Does the follow-up procedure include criteria such as complications, pain, or loss of sensitivity? Can these be captured with the kind of general question that Clinician F asks? What about other possible consequences that is more difficult to measure, such as feelings of shame that is caused by the experience of treatment?

Feder (2014) states that "clinicians working with parents of children with ambiguous genitalia report an increasing use of a kind of consultation that has come to be called "nondirective counseling." A nondirective approach involves the provision of information a healthcare provider believes to be important for weighing various possible interventions in a given medical situation and what is known of the outcomes without directing the person counseled to make a particular decision… Under the model of nondirective counseling, decisions regarding treatment rest ultimately with the patient and not with the healthcare provider" (Feder 2014, 134). Most of my informants implied that they try to follow these

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[105] "Hani bireysel olarak ben her gördüğüm vakada her kontrolde adölesan dönemde kız/erkek arkadaşı var mı "nasıl gidiyor işler" falan filan hani "bir şikayetin var mı" gibi, eğer benimle konuşmak isterse ya da benim sorularıma hani istediğim gibi cevap alamazsam, o sırada mesela annesi ya da babası yanındaki gelen kimse, hani sizinle konuşabilir miyim deyip bana bir şey anlatmak isterse, hani ona yönelik şeyler yapabiliyorum, çocuk psikiyatristi ile tekrar konuşalım diyorum, şunu yapalım bunu yapalım…"

principles in their clinical practice, although they cited the parents' inability or unwillingness to receive this kind of counseling and to be the main decision-makers - as I will discuss further in the following section- as an obstacle to achieving this. Still, they generally regarded the principles of nondirective counseling as the "ideal situation."

However, as I showed, clinicians often use multiple narratives strategically to present the condition of a patient as a purely medical issue that demands medical intervention. They often avoid talking about the facts that would disturb the medical definition of sex, they can conceal or misrepresent what the surgery involves, they can present the intersex trait as a serious condition by establishing parallels between the intersex condition and other diseases, and they commonly present treatment as "doing something" as opposed to "doing nothing." Based on my interviews, it seems to me that clinicians often go against the principles of nondirective counseling despite their high regard of it.

In her research, Feder observed a similar pattern: "[clinicians'] accounts of discussions with parents … indicate that, paradoxically, at least some degree of the urgency that parents feel may be result of the formally nondirective methods of providing information to parents" (141). Clinicians often view the principles of nondirective counseling as "abstract principles" that are not relevant to real life problems of real people; they do not think that these principles will bring the patients happiness and relief, as Feder observed (135). My interviews with clinicians also support these findings, as I show in this chapter; clinicians can move around the ethical rules in different ways, using multiple strategies in order to justify what they think is the most appropriate thing to do in their context. However, because "abstract principles" of ethics represent a morally superior position, most clinicians feel the need to respond in ways that would prove their own ethical stances in their existing practices, rather than seriously considering changing their practices (Morland 2009).

In the following section I show how clinicians' view of their patients is shaped by the larger political context and how it influences clinicians' positions about the shifting paradigm of treatment in the recent years. Next, I present some suggestions made by scholars on how we can discuss the ethical concerns such as informed consent in ways that will allow us to move beyond the moral competition imposed by some "abstract principles."

3.3 “Culture” as a Barrier to Change: “It’s not possible in Turkey”

In clinicians’ narratives, medicalization and “advanced countries” *(“ileri ülkeler”)* often go hand in hand. On the other side of the coin, under-medicalization and “backwardness’ also go hand in hand. For example, several clinicians cited the fact that nowadays newborn infants go through a detailed examination immediately after birth and thus it is much easier to detect intersex conditions at birth as one of the good and desired developments. In this way, they suggested, it is easier to “catch” an intersex condition at birth and intervene “before it is too late.” For instance, pediatric endocrinologist Dr. Ayfer stated that there are fewer intersex people who are not diagnosed until adulthood in advanced countries, because “in the advanced countries, this kind of problem is seen less, cause it is diagnosed early. In our country, sometimes it goes unnoticed.”[106]

When I asked general endocrinologist Dr. Serap if she encounters with adult people who have intersex traits that have not been diagnosed before, she says:

> “Sure, it used to be in the past; now there are pediatricians everywhere, etc., families are more conscious compared to before, it’s easier to access doctors, so, I mean, when 30 years ago these cases were more prevalent, now it’s almost never seen. I mean, like with thyroids, in the past, we used to see huge thyroids, but we don’t see them anymore. I mean, doctors are numerous, and many doctors go to the periphery due to mandatory service; I mean, like I said, you know, due to the change in health policies, it isn’t hard to reach doctors, so it is very unlikely to encounter such overdue cases, but we used to see them before.”[107]

Clinicians often suggested that “civilized” or “Western” countries provide higher standards of care for intersex children. It is therefore not surprising that when I asked the clinicians what they think about the growing global advocacy for the postponement of surgeries until the patients come to an age that they can give consent, most of them, if not all, agreed that it is a better way of treatment. However, then they quickly brought up the issue of “culture” and how it is an impediment to change in the way of being like those “advanced countries.”

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[106] “ileri ülkelerde bu tip sorun daha az çünkü erken tanı konuyor, bizde bazen gözden kaçıyor.”

[107] “Tabii, yani eskiden olurdu, şimdiden zaten her yerde çocuk hekimi var vesaire, aileler daha eskiye oranla bilinçli, doktora ulaşma daha kolay,dolayısıyla yani bundan 30 yıl önce bu vakalara daha çok rastlanırken, şimdi artık hemen hemen hiç rastlanmıyo, yani tiroidde olduğu gibi eskiden kocaman kocaman büyük tiroidler görürdük, görmüyoruz artık onları. Yani hem hekim sayısı çok, hem zorunlu hizmet sebebiyle çok fazla hekim perifere gidiyo, yani dediğim gibi işte sağlık politikalarının değişimiyle hekime ulaşmak zor değil, dolayısıyla böyle geç kalmış vakalara rastlama ihitmali de çok az, ama eskiden görürdük.”

They said that they wish they could apply these principles to their patients, but "unfortunately" they cannot, either because the social pressure would be too much for the patients to deal with, or because the patients have "socioeconomically low" status and therefore they cannot "understand" enough to make decisions for themselves. As a result of the patient's perceived inability to participate in the medical decisions that concern them, the "safest" choice is considered to be performing the operations, in accordance with the long-established medical protocols however outdated they are according to "Western standards." When I was talking to the pediatric endocrinologist Dr. Birsen about the growing tendency in the world to postpone the surgical operations, she said:

> "In fact, the approach all over the world is like that. In our country, people, especially families still want this thing to be clarified, you know; for the child to be able to recognize themselves, you know, rather than making a big change later and, with their own expression, 'being disgraced', there's an expectation like, 'let them be a girl or a boy, let this be concluded right here'. This is something that rather relieves the family but, regarding the legal and moral aspect of it, we prefer and the whole world prefers the other way."[108]

In this quote, Dr. Birsen positions herself as a clinician and as a representative of the "modern mindset"; she positions herself as a representative of the objective and scientific view, thus, against the patients who are subject to societal and cultural pressures around them. However, in our next conversation, when the same issue came up, she made the dichotomy between "modern/western mindset" and Turkey's social context a bit blurrier:

> "I mean, you're right; there are things like: 'don't perform any surgery that isn't of vital importance', but this is very hard to do in Turkey… For example, you… said: 'let it be a boy'… The mother says: 'Are you going to let it like that? I mean, one day they'll grow up and see their penis and say, 'where's my penis, I'm a man''; you put yourself in the family's place and you feel the need to do something… put your own child [in their place], for instance."[109]

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[108] "Aslında bütün dünyadaki yaklaşımda öyle, bizim ülkemizde hala insanlar, özellikle aileler, bu işin çabucak netleştirilmesini istiyor, hani çocuğun kendi bilebilmesi, hani eş dost akrabayas sonradan büyük değişiklik yapıp hani kendi tabirleriyle "rezil olmaktansa" küçükken kız ya da erkek olsun, o işi orada kapansın, böyle bir beklenti oluyor. Bu daha çok aileyi rahatlatan bir şey, ama kanuni hukuki ve ahlaki boyutuyla biz öbür türlüsünü, bütün dünya öbür türlüsünü tercih ediyor"

[109] "Yani dediğiniz doğru hiçbir ameliyat yani "hayati önemi olmayan hiçbir ameliyatı yapmayın" gibi şeyler var, ama bunu Türkiye'de yapmak çok zor... mesela siz …. erkek olsun dediniz …. diyor ki annesi "böyle mi bırakacaksınız, yani yarın öbür gün büyüyecek bu pipisini görecek hani diyecek ki nerede benim pipim ben erkeğim," orada hani ailenin yerine de koyup kendinizi bir şey yapma ihtiyacı hissediyorsunuz….kendi çocuğunuzu koyun mesela."

In this narrative, Dr. Birsen can justify the early surgical operation - in this case penile reconstruction - *only* when she steps out from her role as a “modern” clinician and empathizes with the parent who has a socioeconomically low position in society and who lives in under high social pressures in her everyday life. By maintaining the dichotomy between her views as a science person who adopts the “western” thinking and as an ordinary citizen who can empathize with her patients, Dr. Birsen can continue to promote early surgical operations while at the same time advocating for “advanced” standards such as informed consent.

During interviews, clinicians invariably mentioned and complained about their patients’ low socio-economic status. Among all, only one clinician - Dr. Irmak, despite her relatively little experience as an intern clinician - mentioned a positive example in which the parents agreed to rear the child genderless for a few years, even though she also mentioned similar things about how the socioeconomic status of her patients are very low in general. When I asked Dr. Irmak why this might be the case, she answered:

> “It’s more likely for a person who is relatives with their spouse to have a lower socioeconomic status, to be ignorant, hence they’re more likely to be sick, I mean, more likely not to use the pills. Most of the patients that I see are elementary school graduates. I mean, there’s really a relation there. I mean, yes, maybe university graduates go to private hospitals and not come to me, the state hospital; there’s that. And there’s also really a state of consciousness; it’s less likely for someone with a master’s degree to marry their relative, or to be forced to that by their environment, compared to someone who is an elementary school graduate.”[110]

This represents a common view among the clinicians who deal with intersex patients; there is a collective perception of the intersex patients as belonging to a less educated, socioeconomically lower class. Sometimes, this can be presented as an explanation of patients’ avoidance of medicalization, too. When pediatric surgeon Dr. Engin was explaining his stance against the term “çift cinsiyetli,” he complained that patients hold on to this term because they “cannot understand” the medical “truth” explained to them by him:

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[110] “Eşi ile akraba olan insanın sosyo ekonomik durumunun düşük olma olasılığı, cahil olma olasılığı daha yüksek, bu yüzden hasta olma olasılığı daha yüksek, yani ilacı kullanmama olasılığı daha yüksek. Benim gördüğüm hastaların çoğu ilkokul mezunu hani bunun bir ilişkisi var gerçekten, hani evet belki üniversite mezunları özel hastaneye gidiyordur, bana gelmiyordur devlet hastanesine o var, bir de gerçekten bir bilinç hali var, akrabası ile evlenme olasılığı daha düşüktür master mezunu birinin bir ilkokul mezunu kişiye göre, veya çevresinden böyle bir baskı görme olasılığı daha düşüktür.”

> "And sometimes, it goes like this; you know, the person you encounter, according to their socioeconomic level, let's say cultural level; no matter how much you explain, somehow, you can't. I mean, they keep it in their mind as if their child is *çift cinsiyetli*. So, how come…? And unfortunately, this group is, for some reason, the group with lower socioeconomic level. I mean, very few of these patients are from a higher level of income or higher cultural level"[111]

Dr. Engin thinks that parents obsess over the term "çift cinsiyetli" for the sole reason that they are not able to understand the medical "truth." As I explained in the previous section, clinicians are opposed to the terms "çift cinsiyetli" and "intersex" because they represent a status of the sex of the child as "both" or "in-between" respectively. However, the medical view of DSD maintains that every child is born with one "true sex," and any sign of ambiguity is a bodily "error" that needs to be fixed in accordance with the "true sex" of the child. Thus, while DSD language is a medicalized language, "çift cinsiyetli" remains a term that indicates how the person is perceived socially, a language that belongs to a pre-modern, or pre-medicalized, era. Thus, that patients insist on using the non-medical term "çift cinsiyetli" rather than the DSD language is attributed to their low socioeconomic status; in other words, having lower socioeconomic status is framed as "undermedicalization."

In line with this view, several clinicians I interviewed - including 3 out of the 4 pediatric surgeons- emphasized the need for more specialization of medical care for intersex individuals, referring to European countries. Two of these three surgeons were Dr. Engin and Dr. Ali, both of whom are well known names especially in hypospadias operations, and who take pride in their professional success in this form of surgery. Both of them expressed a moderate approach about postponing surgeries until the child grows up to give consent - in fact, Dr. Ali takes pride in being an advocate for elimination of cliteroplasty completely-, yet their moderate approach did not apply to hypospadias. Even if they were more open considering postponing other types of surgeries, they said that they cannot advocate for postponing "all the operations," and gave hypospadias as an example that they would not want to postpone. Instead, they brought up the issue of expertise:

> "There has to be referee centers about this; that's how it works abroad; for instance, in England, France, that's how it is. They set up the system, they solved

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[111] Bazen de şöyle oluyor, hani karşıdaki sosyoekonomik düzeye göre, kültürel düzeye göre diyeyim, ne kadar anlatsan da bi şekilde anlatamıyosun, yani o kafasında benim çocuğum çift cinsiyetliymiş gibi akılda tutuyolar, ee hani.. ve malesef bu grup sosyoekonomik düzeyi düşük grup nedense.. Yani bu hastaların çok azı böyle gelir düzeyi, kültürel düzeyi yüksek hasta grubundan oluyor."

> it. This is a matter that not everyone should deal with. There must be a few main centers and there, [people who know their stuff] must direct… Unfortunately, that's not how it is in Turkey. That's why there can be bad outcomes, unfortunately. I mean, these surgeries need to be performed well." (Dr. Engin)[112]

> "Abroad, for instance in England, these operations are limited to certain centers. I mean, people who are experienced in that subject perform it. People outside those don't have the authority to perform such surgeries. In fact, it has to be like that; it's true for all surgeries. Experienced surgeons had better perform these operations so as to minimize the results that might negatively affect the child's life." (Dr. Ali)[113]

According to this view, the major problem lies in that there are too many unqualified surgeons who conduct intersex operations which create bad results. Therefore, there should be specified centers that have qualified surgeons, and no other surgeon should be allowed to do these operations. This view places the problem at the unqualified surgeons, rather than the violation of right to consent; in other words, the pain and the suffering that is caused by early surgical operations is a result of *under*medicalization, rather than medicalization, of intersex in Turkey, as opposed to "the West."

As a result of these perceived dichotomies between "West" versus "Turkey," "civilized" versus "backward," and" medicalized" versus "undermedicalized," early surgical operations continue to be justified even when the clinicians feel like they might be doing the wrong thing. When he was talking about whether or not postponing the surgeries, Dr. Engin said:

> "For example, [Dr. Ali] thinks differently; he says: 'let's postpone, let them decide for themselves when they're 18'. It might be like that in other countries, but I argue that, in every disease, it should be approached according to the culture of the country. I mean, OK, let's not intervene but what will that child be until they reach 18? It may be like that in other countries but here, according to the

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[112] "Bununla ilgili referee merkezlerin olması lazım, yurtdışında böyle işliyor, mesela İngiltere'de Fransa'da bu böyle, sistemi kurmuşlar, onlar halletmişler. Bu iş herkesin uğraşmaması gereken bir konu, birkaç ana merkezi olması ve oralarda (işi bilenlerin) yönlendirmesi gerekiyor …. Malesef Türkiye'de böyle değil, o nedenle kötü sonuçlar alınabiliniyor malesef, yani bu ameliyatların iyi yapılması lazım." (Dr. Engin)

[113] "Yurt dışında bu tür meliyatlar, mesela İngiltere'de belli merkezlerle sınırlıdır, yani o konuda tecrübeli olan kişiler yapar , onun dışındaki insanların yetkisi yoktur bu tür ameliyatları yapmaya. Aslında bu olmalı bence, bu her ameliyat için geçerli, çocuğun hayatını olumsuz etkileyebilir sonuçları minimuma indirmek için ameliyatları tecrübeli cerrahların yapmasında fayda var." (Dr. Ali)

> culture… For instance, we go to international congresses and they protest us, saying: ‘don’t touch my organ’. But here, people change city because of that.”[114]

This quote by Dr. Engin is exemplary of the line of reasoning of many clinicians in terms of thinking the intersex issue locally. Yet, he does not attribute the absence of protests in medical conferences in Turkey to the silencing and stigmatizing culture around the issue; rather he attributes it to the lack of complaint. Thus, Dr. Engin - and many other clinicians - perceive “culture” in a very specific and limited way, one in which justifies the continuation of early surgeries.

When I asked pediatric surgeon Dr. Ziya about the same issue, Dr. Ziya gave an anecdote from a medical conference on intersex that was held around fifteen years ago. An intersex activist from the US sent a video to be shown at this conference, whose audience was medical professionals. Dr. Ziya still remembers the message in this video:

> “At a video that was shown at the end of a conference, ‘did you ask me when removing my testicles? Maybe I want them?’ I mean*… (an expression like ‘this is really shocking’)*, really… There’s a levelheaded, educated person in front of you, and I also think that a person like that should be able to make their own decision… I mean, when I put myself in their shoes, they’re right. I want to make my own decision, too. Everybody should be let be.”[115]

Dr. Ziya is one of the oldest in the profession; he also has the most conservative ideas regarding gender and sexuality, as well as the postponement of the operations. Thus, it was very surprising for me to hear this anecdote and his support for the activist who sent the video. His tone of voice implied that the question of “did you ask me when removing my testicles? Maybe I want them?” had a profound effect on him, which he still remembers after such a long time. Then, he added:

> “But if you let such a person in an uncultured environment… [it’s not good]. For example, in Sweden, Germany, they might be doing that; they might say: ‘let them decide for themselves’. Those are societies that think in a civilized way.

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[114] “Mesela [Dr. Ali] farklı düşünüyor, o ‘erteleyelim’ diyor, ‘18’e gelince kendi karar versin’ diyor. Başka ülkelerde öyle olabilir, ama ben her hastalıkta ülkenin kültürüne göre yaklaşılması gerektiğini savunuyorum. Yani tamam ellenmesin de 18’e gelene kadar o çocuk nolucak? Başka ülkelerde öyle olabilir, ama burada kültüre göre…. Mesela biz uluslararası kongrelere gideriz, bizi protesto ederler, ‘organıma dokunma’ diye. Ama burda, insanlar şehir değiştiriyo ya bu yüzden.”

[115] “Bir konferansın sonunda gösterdiğimiz bir videoda, ‘siz benim testislerimi alırken bana sordunuz mu? Ben belki onları istiyorum…?’ Yani böyle… (şok ifadesi), hakkaten… karşında aklı başında eğitimli bir insan var, ve öyle bir insanın kendi kararını alabilmesi lazım bence de... Yani ben kendimi onun yerine koyup düşündüğüm zaman haklı, ben de kendim karar vermek isterim, herkesi kendine bırakmak lazım.”

> But think, for instance, someone in Elazig[116]… us letting them be… that doesn't work. What would this child go through in their school life and after? But it's important for a person that received education to make their own decision. Everybody wants to be happy; it's the only goal for everybody, in the end."[117]

3.3.1 Neoliberal Responsibilities and the New Paradigm of Treatment

What is the difference that is so deep between someone who is "educated" and who is not, so far as to justify performing surgical operations on the genitals for cosmetic reasons on the latter? On the one hand, "West" is associated with medicalization, which is manifested as more early surgeries in Turkey. On the other hand, "West" is moving towards postponing the operations; clinicians are aware of this, and at least in discourse they position themselves in alignment with this new "West."

In fact, medical anthropologist Ayşecan Terzioğlu states that the alignment of the clinicians with "the West" has its roots in the history of Turkey. Terzioğlu points out that during the late Ottoman and early Republican era, clinicians played a major role as apparatus of modernization. They embraced modern republican values and became important collaborators of the state in public health projects such as vaccine campaigns or proliferation of local health clinics. During this period, public health, preventive medicine and population control were on the agenda of the state. However, things started to change dramatically in the 1980s because of the neoliberal policies implemented that resulted in privatization of health care institutions and increase in inequality between social classes. In accordance with these changes, cultural discourse around health also changed; no longer a primary responsibility of the state, health became a "personal responsibility" as opposed to be a basic human right. This also affected clinicians' relationship to the state; their "social mission of modernizing the country, cultivating new generations who believe in the superiority of science and medicine" was also being taken away (114). When they realized this, "many clinicians embraced the role of 'guardians of modernity' instead of 'pioneers of

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[116] A city in the southeast of Turkey

[117] "Ama sen böyle bir insanı kültürsüz ortamda bırakırsan... [olmaz]. Mesela İsveç"te, Almanya'da yapıyorlardır belki, kendi karar versin diyebilir, oralar medeni bir şekilde düşünen toplumlar, ama düşün mesela Elazığ'da biri, biz bırakalım olmaz, bu çocuk okul hayatı ve sonrasında neler yaşar... Ama eğitim almış bir insanın kendi karar vermesi önemli. Herkes sonunda mutlu olmak ister, herkesin tek amacı budur sonunda."

modernity,'" and they started to distinguish between "good" *("bilinçli")* and "bad" *("bilinçsiz")* patients as part of this new role (117). Being a "bilinçli" patient included criteria such as accepting the authority of the clinician, showing complicity, and having received higher education; at the same time, it was an indicator of being a "good and modern" citizen. Most importantly, "bilinçli" patient was the patient who took personal responsibility for her illness (Terzioğlu 2011).

The references my informants made to the patients' education levels and occupational status show a similar kind of distinction. Taken in this light, my informants' distinction between "more advanced countries" and Turkey, or between educated and the less educated patients can be read as part of this historically and politically rooted positionality. According to the clinicians, intersex patients constitute the "bilinçsiz" patients who are not able or willing to take responsibility for their own medical treatment. In other words, the clinicians think that they cannot apply the new paradigm to their patients not because they are against it in principle, but because their patients do not represent the type of patient that is defined by the new paradigm. By categorizing patients into groups, the clinicians in Turkey measure their patients' ability and willingness to take the personal responsibility of self-management of their own medical treatment. The overwhelming majority of the patients, however, cannot pass this test. Therefore, the clinicians continue to practice early surgeries because they do not "trust" in their intersex patients' ability and willingness of undertaking this neoliberal responsibility.

The delegation of the responsibility of treatment to the patient is not peculiar to Turkey, however. Alyson Spurgas (2009) talks about how the shift to DSD language is also a shift towards making intersex treatment a personal responsibility. Based on her research in the US, she argues that intersex people -along with the broader neoliberal shifts in medicine and culture - are forced to become "patient-consumers," who are more "free" in their decisions about their bodies, whereas this "freedom" comes with a responsibility of self-disciplining of the body, attached to morality (Spurgas 2009, 114-115). Thus, the medical paradigm that forces early surgeries is shifting towards one that forces a moral responsibility of self-medicalization.

Intersex scholar Iain Morland criticizes mainstream intersex activism by suggesting that the new paradigm places individual responsibility on the patient, similar to Spurgas; however, Morland poses the critique toward the mainstream intersex movement, suggesting that the dominant activist views, as represented by ISNA, contributed to the imagination of the patient as a neoliberal subject, who considers taking responsibility as a moral duty. He offers a critical reading of "Notes on the Treatment of Intersex," a document published in ISNA's website in 2000[118], that summarizes how ISNA envisions the changes in the treatment model of intersex by comparing the old treatment model with the new, patient-centered, model. Morland suggests that in the new treatment paradigm as suggested in this document, it is not clear how "informed consent" can fully work; no matter how conscientious the clinicians are, it is impossible for them to provide the patients and patient families all the necessary information they need to make their own decision, he suggests, because of the complexity of the mechanisms that play role in the treatment procedures: "[i]n this model, instead of being presented with a menu of clinical interventions from which to choose, a family would be provided with a gender theory reading list. To give them anything less would be to conceal from them the true rationale for reforming treatment" (204). He further points out that "patients sometimes desire neither to make decisions about their treatment, nor even to be fully informed about their treatment options" (202) and reminds that the "patient-centered" model, which places great importance on personal responsibility, can be as authoritative as the medical approach. Morland poses the problem as the moral competition created by the language in which the new paradigm is framed: "Activism cannot avoid paternalism so long as its patient-centered agenda is narrated as morally superior to not only conventional intersex medicine, but also to the desires of patients" (206).

As the analysis of Spurgas and Morland points out, the intersex activist movement and the shift it advocates towards a new paradigm of treatment is shaped by the broader neoliberal political context in which health becomes personal responsibility rather than a basic human right. In this framework, both the patients and the clinicians gain new responsibilities; the clinicians are responsible with informing the patient fully and offering all the medical

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[118] Morland states, "In March 2003 'Notes' underwent subtle revision and was renamed 'Shifting the Paradigm of Intersex Treatment'" (Morland 2009, 193); this is the version available today at the website of ISNA, through the hyperlink http://www.isna.org/compare.

options, and in return, patients are responsible for absorbing this medical information and taking charge in the medical decision-making. In the specific political and historical context of Turkey, this formulation results in categorization of intersex patients as lower-class; the patients who are not willing or able to take this responsibility do not “deserve” to be treated according to the new paradigm. Thus, in order to raise better questions at this historical moment in which intersex rights movement is gaining global momentum, I suggest that it is necessary to pay attention to various kinds of inequalities as well as moral competitions that is perpetuated in congruence with the neoliberal logic of our age in different contexts, whether it is in the medical or activist narratives. One such inequality is the one that created by the class position of the patients. Perceiving DSD as a lower-class disease, the clinicians in Turkey can continue to promote early surgical operations while at the same time aligning themselves with the rising global advocacy of intersex rights. On the other hand, the dominant language of the new treatment paradigm and the activist movement assigns a moral inferiority to those who do not, or cannot, take personal responsibility of their own medical treatment as well as to the clinicians who do not expect their patients to do so.

3.3.2 Discussing “Culture” in the Medical Context

As Renato Rosaldo states in his *Culture and Truth*, a major contribution of cultural anthropology as a field of study has been making “culture” the central focus as an object of analysis. However, the anthropological view of “culture” changed drastically around the 80s. Previously, “culture” was considered unitary, homogeneous, bounded, static and only applicable to those who are “below.” During the 80s, the term went through a major transformation; a new understanding of “culture” emerged in which it is defined as multiple, heterogeneous, fluid, historically contingent, as well as relevant to those who are “up” (Rosaldo 1989). As Lawrence Cohen (2012) states, by the 1990s, territory-bounded analysis was considered old fashioned because of anthropology’s critique of the term “culture”; it leads to oversimplification of the social worlds people live in through an overemphasis on territory. However, as the term “culture” became old-fashioned for anthropology, it became increasingly more popular in other fields. One of these fields was clinical research, since “[p]art of the power of culture has been as a site of recognition for clinically marginalized populations through proliferating pedagogies of cultural competency in patient care" (Cohen 2012, 68). Cohen does not deny that taking geographical area as a focus of analysis can still be relevant to our problems; however, he reminds that medical anthropology should take the anthropological critique of "culture" seriously while reincorporating the area into its analysis.

I argue that apart from the neoliberal shifts in the larger political context, another impediment to change is the interpretation of "culture" as unitary, homogeneous, bounded, static, and as only applicable to those who are "below," in clinical research. This kind of reading of culture prevents the clinicians from seeing their patients as part of the changing world, and it prevents seeing themselves as "cultured" beings.

For instance, despite the clinicians' insistence that Turkey is different because of its cultural environment, the paradigm shift in the "West" is facing similar challenges as in Turkey. Both in the US and many European countries, children with intersex traits and VSC continue to be imposed the treatments that go against their rights to bodily integrity and informed consent; and activist groups and allies in those countries face similar challenges from medical authorities.

Second, the import of medical theories from "the West" is not historically recent; the traditional treatment paradigm also originated in the US and developed and became widespread throughout the world mainly through the collaboration of the US and Europe-based medical professionals. As historian Alice Dreger informs, one of the two medical experts of "doubtful sex" in Britain in the late nineteenth century Lawson Tait "examined two children sent from Turkey specifically for the purpose of having their sexes diagnosed" in 1879 (Dreger 1998, 82). If the historical pattern continues, the paradigm shift is also likely impact medical and activist practice in Turkey.

Third, clinicians referred to the ways in which their patients are influenced by the social and cultural conditions that they live in as a reason to hold on to the traditional paradigm; yet, they did not frame their own life and work conditions as factors that might be relevant to change. For example, a couple of clinicians referred to their harsh working conditions such as their busy work loads and the increasing violence toward clinicians and concerns of safety. For instance, pediatric surgeon Dr. Engin says, "As opposed to the World Health

Organization that says: 'you can see 20 patients a day', how many patients are seen here? 100 patients *(bangs hand on table)* are seen. And can you make mistakes? You definitely can… I mean, I'm doing the job of three people. Other than that, I'm trying to write articles, I'm trying to do science, I'm trying to raise pediatric surgeons, and I'm trying to raise doctors."[119]

Indeed, I was bewildered by how crowded it was when I first stepped into the hospital Dr. Engin works. On the other hand, none of the clinicians framed these drawbacks as "cultural" reasons to avoid unnecessary treatments, which could potentially minimize both their work load and risk of "making mistakes."

Fourth, the idea that a non-intervened intersex trait would necessarily cause suffering because of the cultural context could simply be wrong. In order for a physical difference to cause psychological problem, the person needs to be aware of it and frame it as an inferiority. Yet, many people learn they -or their child- have an intersex trait for the first time from the clinicians. In other words, medicine produces intersexuality; a trait that is not considered bad or unusual can be so after the diagnosis (Eckert 2009).

For example, hypospadias is one of the most frequent conditions, and it is commonly known as "*peygamber sünneti,*"[120] which is a holy sign, in Turkey; the children born with this trait can be defined as "congenitally circumcised," as one of the indications of hypospadias is lack of foreskin. In a webpage[121] of a pediatric surgeon who is known for his success in hypospadias operations, comments of families whose children had hypospadias operations show how medical diagnosis changed their perception of their children's condition tremendously:

> "My son was born with *peygamber sünneti*. I didn't know that this was a disease. I found out that this was a disease when I went for circumcision. Of course, we

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[119] "Günde 20 tane hasta bakabilirsin diyen Dünya Sağlık Örgütü"ne karşı, burda kaç hasta bakılıyo 100 hasta *(elini masaya vuruyor)* bakılıyor; peki hata yapabilir misin, kesinlikle hata yaparsın…. Yani ben üç kişinin işini yapıyorum. Onun dışında makale yazmaya çalışıyorum, bilimsellik yapmaya çalışıyorum, çocuk cerrahı yetiştirmeye çalışıyorum, doktor yetiştirmeye çalışıyorum."

[120] Please see footnotes in page 3 for the explanation of the term.

[121] (http://www.peygambersunneti.com/aile-yorumlari)

> were very scared but thank God… We went to a doctor such as the professor"[122] (parent - 1)
>
> "I was very happy when my son was born circumcised, [thinking] my dear is born *peygamber sünnetli*. Later on, I heard the word hypospadias. Whichever doctor I go to, they tell me something. I don't understand, but my fears and my worries grow. Of course, then, … we were forwarded to our doctor"[123] (parent - 2)
>
> "Yeah, we were also happy when they said *peygamber sünnetli,* but then, when we found out about the truth, we were quite worried. Then, like everybody else, we looked for a doctor"[124] (parent - 3)
>
> "When my son was born, I was happy to see he was *peygamber sünnetli*. And my dream was to have him circumcised as soon as he was born. Of course, it's called *peygamber sünnetli* in colloquial language; its other name is hypospadias. When he was only 3 months old, we found out that this circumcision couldn't be like a normal circumcision, and that it had to be through surgery. We got an appointment and went to Professor …. We learned that hypospadias had three kinds, as light, medium and severest and that ours was the severest."[125] (parent-4)

A physical trait that is considered positively or neutrally becomes a source of tremendous fear and anxiety for the parents because of the diagnosis, rather than the culture. To the contrary, the cultural norms that favor male circumcision allows hypospadias to be framed as a naturally-circumcised penis, and therefore a source of contentment for the parents. Definitely, culture plays into the anxieties of the parents after the diagnosis as well. Dr. Alper observed that among his patients' families, "some of the clitoromegalies don't have their child operated… But I didn't see… incomplete masculinization, you know, like in situations where the male sexual organ isn't really completed in shape,"[126]meaning that families are especially sensitive about the diagnosis when it is about the penis. When a

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[122] "Oğlum peygamber sünneti ile doğdu bunu bir hastalık olduğunu bilmiyordum sünnet için gittiğimde bunun hastalık olduğunu öğrendim tabiki çok korktuk ama çok şükür … Hoca gibi bir doktora gittik"

[123] "Oğlumun sünnetli doğduğunda cok sevinmistim peygamber sünnetli doğdu kuzum diye sonrasında hipospatias kelimesini duydum hangi doktora gitsem biseyler anlatiliyo anlamamakla beraber korkumda artiyor endişemde tabiki sonrasında … doktorumuza yönlendirildik" (parent - 2)

[124] "Aynen bizde peygamber sünnetli denildiginde sevinmiştik ama sonrasında işin aslını ögrendigimizde bayagı sıkıldık Sonrasında herkesin yaptıgı gibi dr aradık" (parent - 3)

[125] "Oğlum dünyaya geldiğinde peygamber sünnetli olduğunu gördüğümüzde sevinmiştim. Hayalimde ilk doğduğunda hemen sünnet yaptırmaktı, tabi halk dilinde peygamber sünnetli diğer adı hipospadias. Daha 3 aylıkken bu sünnetin normal bir sünnet şekliyle olamayacağını ameliyatla olması gerektiğini öğrendik. …. Hocam'a randevu alarak gittik. Hipospadias'ın hafif, orta ve en ağır olmak üzere 3 çeşidi olduğunu bizimkinin en ağır olduğunu öğrendik." (parent - 4)

[126] "kliteromegalilerin bir kısmı ameliyat ettirmiyor…ama şey görmedim, inkomplet maskülinizasyon, yani hani erkek cinsel organının şekilsel olarak tam tamamlanmamış olduğu durumlarda görmedim"

clinician tells the parents that their child's penis should be "fixed," it triggers the anxieties around the masculinity of the child, and the parents gain a sense of urgency for performing the operation. Yet, one can argue that it is the medical diagnosis rather than the "culture" in the first place that creates desperate parents in fear and anxiety.

Georgiann Davis points out that parents' feelings of guilt play a major role in their compliance with the medical procedures, and many parents later regret surgery. She further shows that once parents get involved with the intersex community, they start to think differently about their child's condition; Davis's "interviews with parents revealed that parents who consented to medically unnecessary interventions tended to express decisional regret" (Davis 2015, 125), after receiving peer-support and non-medical information from the intersex community. As I showed, the clinicians I interviewed agree that their guidance plays a predominant role in determining parents' choices. Although they attributed it to low socioeconomic status of their patients shaped by the context of Turkey and patients' lack of ability to understand the medical information, Davis's research shows that there is a similar situation in the US. Davis concludes: "[Parents] thus need as much information as possible before consenting to procedures, or else they may eventually experience guilt and decisional regret. But parents do not need more medical information - they have enough of that. Instead, … they need a different kind of information, which comes from peer support" (Davis 2015, 126).

If we follow Davis in reconsidering the concept of "informed consent," one of the crucial questions we should ask about informed consent in treatment procedures is "what kind of information is provided?" rather than "is all the relevant information provided?" Highlighting the importance of the kind of information that comes from intersex individuals' experiences - in other words, peer-based information - framing the question this way can take from the patients the responsibility to absorb a lot of medical information to make their own decisions, and rather can allow them to rely on other people's experiences defined in a non-medical language. This question can also be very useful for the clinicians; sharing the responsibility with others can provide them a language to express the problems they perceive in their practices without being positioned as scapegoats and take off some of the burden of being the only authority in making difficult decisions.

3.4 Respect for Autonomy

In this section, I will discuss the findings of my research in relation to the discussion of the principle of Respect for Autonomy, one of the four basic ethical principles that can guide decision making processes in biomedical processes as presented in the Beauchamp and Childress's seminal work *Principles of Biomedical Ethics (2001)*.

The other three principles presented in the book are Nonmaleficence, Beneficence, and Justice, and Beauchamp and Childress do not argue that any one of these criteria is more important than others; in the end, the ethical question boils down to determining which principle(s) should have priority over others in specific cases. However, I will be discussing only the autonomy principle since it is the most contested principle in decision-making processes of intersex individuals. Since I will only provide a brief introduction on this topic, my aim is to discuss how we can use the principle of autonomy to raise questions on intersex treatment procedures based on my research outcomes.

Although Beauchamp and Childress state that autonomy can have a wide range of meanings, they maintain that "Personal autonomy is, at a minimum, self-rule that is free from both controlling interference by others and from limitations, such as inadequate understanding, that prevent meaningful choice....[and] virtually all theories of autonomy agree that two conditions are essential for autonomy: (1) liberty (independence from controlling influences) and (2) agency (capacity for intentional action)" (58).

I mentioned in section 3.3 that clinicians often referred to the lower socioeconomic status of their patients and the cultural norms of the Turkish society as factors that prevent them from prioritizing the patient autonomy in the decisions they make. Since the patients often do not have the necessary educational background, clinicians argued, they cannot adequately understand the medical explanations and therefore cannot make informed decisions. This view also implicitly associated having lower socioeconomic status with conforming to cultural norms about gender and sexuality. In my analysis, I argued that the clinicians employ the concept of culture in a rather simplistic way that reifies patients as a group that inherently lacks the ability or willingness to take charge of their own treatment. In other words, clinicians might be downplaying their patients' agency, which, according to the definition provided by Beauchamp and Childress, would provide justification for not prioritizing the autonomy principle in the decision-making process, whereas it should have been prioritized had they accepted the patient's agency.

Furthermore, suggesting that "no theory of autonomy is acceptable if it presents an ideal beyond the reach of normal choosers," (59) Beauchamp and Childress stress that the principle of autonomy cannot be considered as an all-or-none situation, but rather that the autonomy should be considered as a continuum. This is because "normal choosers" can have various degrees of understanding of the topic and they might be influenced by external circumstances to various degrees. However, in their arguments regarding the socioeconomical level and the cultural status of their patients, the clinicians often referred to patients as a uniform group, which led to the idealization of the concept of autonomy as an unattainable goal for their patients. Moreover, in Chapter 3, I showed that doctors can withhold information from the patients, especially in a way that would conceal the fact that they have variations of sex characteristics, in order to prevent anticipated emotional distress. It means that patients can undergo irreversible surgical operations such as removal of gonads without being provided any information regarding the content. Even if the doctors' concerns about the emotional status of their patients can be valid, this approach can also be drawing some of its justification from a dichotomous understanding of autonomy; if the patients are not able to be fully autonomous, then it follows that they cannot be autonomous at all, which would justify dismissal of the concept of autonomy altogether. However, embracing an understanding of autonomy as a continuum could mean that keeping it on the table as much as possible in any situation, as opposed to categorizing the patients in as either "autonomous" or "non-autonomous." For instance, it would allow an approach that views patients as people who can both experience distress about their intersex status and also have a certain capacity for autonomy at the same time.

Since the competence to make decisions is a prerequisite for the application of the principle of autonomy, Beauchamp and Childress point out that the doctors often have a gatekeeping role in determining who is competent and who is not competent to make decisions. They particularly emphasize that competency should be regarded as a continuum, and may change according to the topic, or particular circumstances under which the decision is made. To evaluate competency, Beauchamp and Childress provide a list of various kinds of "inabilities" that could be used to determine the extent of incompetence of a person to make an informed decision. One of these "inabilities" is the "inability to understand relevant information" (73). As I showed, this is a main "inability" that the clinicians associated their intersex patients with. However, at the same time, clinicians tend to interpret the "relevant information" in a limited way that focuses on the medical information, whereas it could include other kinds of information that is still relevant to patient's concerns about the treatment procedure.

For example, in her article on the obligatory psychotherapy process that trans people undergo before sex reassignment surgery (SRS) in Turkey, Aslı Zengin (2014) states that from the perspective of psychiatrists, "some trans people have a strong belief that the surgery will radically change their lives by resolving every problem they have had to cope with regarding their gender identity," and "first goal of these therapies is to temper these expectations and to ensure psychological well-being by putting other anxieties and tensions at ease" (60). This is also one of the points that is raised by intersex activists regarding the surgeries – that the surgery does not magically make their intersex status go away and intersex people should not have over the top expectations about the results of surgery. As the psychiatrists who run the SRS therapy state, this would be an extremely important information to provide intersex people with before they undergo surgery, for instance. Yet, to the contrary, as I argued in Chapter 2, intersex treatment procedures can be represented as if they fix the individual's sex once and for all after the hormonal and surgical treatment procedure.

On the other hand, it should be noted that Zengin (2014) also mentions that the obligatory nature as well as the strictness of the psychotherapy process are criticized by some trans people who attend SRS therapy, because they think that the therapies reinforce hetero-norms in way that is too restrictive to represent their reality and thus turn into a repressive environment. Thus, rather than suggesting that the SRS therapy model should be applied to intersex people, I merely point out that there can be many ways to provide "non-medical information" to patients in ways that will contribute to their wellbeing. This information can come from various resources other than the surgeons and endocrinologists; psychiatrists specialized in intersex issues can be only one example. In section 2.1.3, I showed how there is no mechanism of protection for teenagers, for instance, who are forced to treatment without their consent. The fact that the SRS therapy is obligatory for trans people, who are adults by the time of surgery, and that such an obligation does not exist for intersex people most of whom are children or adolescents presents a stark contrast that should raise questions on the purpose, and efficacy on the gatekeeping roles of clinicians.

So far, I discussed the principle of autonomy as it applies to the patients themselves. However, the majority of intersex children undergo the treatment process when they are too young to give consent. In that case, the decision-making is undertaken by the clinicians and the parents, which makes it necessary to discuss the ethics of surrogate decision-making for intersex children.

In the case of "never-competent" patients - such as little children as opposed to, say, someone who was formerly competent but became incompetent at a later stage of a disease - Beauchamp and Childress present two options for surrogate decision-making, first of which is "substituted judgement," which means that the surrogate makes a "decision the incompetent would have made if competent" (2001, 102). Beauchamp and Childress criticize the use of "substituted judgement" for patients who were never competent; they believe, "the standard of substituted judgement should be used for once-competent patients only if reason exists to believe the decision can be made as the patient would have made it" (2001, 100). Among my informants, some clinicians proposed arguments in favor of some treatment procedures in line with this principle. For instance, some suggested that a child assigned as a girl/female who has a "large" clitoris would not want to have it when they grow up, and thus it is appropriate to remove the clitoris surgically. Also, in general, it is a widespread view among clinicians that non-intervention in intersex children would cause a bigger trauma for them during their school life and adolescence. The prevalence of this belief raises the question if clinicians hold this belief because they believe that no person would want to be intersex. If, or when, so, this view can also be considered in alignment with the substituted judgement principle and should be discussed as such.

The second suggestion of Beauchamp and Childress (2001) for surrogate decision-making is using "best interest standard, [which] .... protects another's well-being by assessing risks and benefits of various treatment and alternatives to treatment, by considering pain and suffering, and by evaluating restoration or loss of functioning” (102). Some clinicians explicitly referred to this principle in their decision-making, claiming that surgical intervention can be in the best interest of a child, even if the child cannot give consent. While stating that the best interest standard could be appropriate for some cases, Beauchamp and Childress note that “the best interest standard has sometimes been interpreted as highly malleable, thereby permitting values that are irrelevant to the patient’s benefits or burdens,” and as one example, they point out that adults sometimes project their own feelings to their children without being aware of it (103). In case of intersex individuals, it could be argued that the clinicians rely on a medical definition of sex that is highly heteronormative, which is also in alignment with societal norms and therefore with most parents’ views. Thus, when a narrow, heteronormative understanding of sex, gender and sexuality, is regarded as a neutral reference point, the “best-interest principle” should be questioned.

Beauchamp and Childress argue that for surrogate decision-making, “substituted judgement” principle should have priority over the “best-interest” principle, implying that autonomy principle should be applied to the extent it is possible. It should also be noted that Beauchamp and Childress do not discuss a category such as “will-be-competent,” a category of patient who is not competent at the moment, but who will be competent in the future. The examples they discuss under surrogate decision-making principles are medically urgent cases. Therefore, the question remains if intersex conditions would qualify for applying the surrogate decision-making principle at all, depending on the validity of the urgency attributed to these conditions. It could be argued that the majority of the interventions in intersex children are not medically urgent and it would be possible to wait for the time when the patient is competent by delaying the decision-making.

CHAPTER 4

INTERSEX STORIES, ACTIVISM, AND FUTURE STEPS

4.1 Medical(ized) Experiences of Intersex

According to the intersex adults I interviewed, medical treatment procedures caused more harm than benefits to them, both psychologically and physically. In this section, I will focus more on their discussion of psychological harm; because, the traditional treatment paradigm is mainly justified based on the assumption that erasing the variations of sex characteristics increases the child's psychological wellbeing, whereas physical harm caused by surgery can be regarded as mere side-effects that can be fixed by further medical intervention. While it is well known that intersex operations may cause tremendous physical pain and suffering, a discussion of physical harm caused by surgeries alone may further medicalize the discussion, posing the problem as one of whether the surgeons are qualified enough, or if the patients are compliant enough. Moreover, even if they are experiencing physical disturbance or pain as a result of the operations they had, my intersex informants did not position the physical harm as a main source of their suffering. Instead, they talked about how the medical treatment they were subjected to further reinforced the secrecy and stigma they experienced, rather than alleviating it.

A main problem that came up in the narratives of intersex adults is secrecy. Generally, both the clinicians and the families advise the child to keep their condition as secret, and this can lead to psychological harm in several ways. First, it can be an obstacle to self-acceptance, and thus, psychological wellbeing. As I showed in Chapter 3, the clinicians and parents can withhold information from the patient regarding their bodies, as well as what is done to their body during the treatment procedures, including surgery. When this happens, the information is mainly withheld in a way that would conceal the variations of sex characteristics and construe the condition as a disorder. However, intersex narratives show that this silence itself can be a source of anxiety and stress to the patients, since they nevertheless perceive that there is something that is silenced. Moreover, when they find out what happened later, they tend to feel betrayed.

The following excerpt from our conversation with Meral portrays the consequences of secrecy:

> "These doctor-hospital processes started in my adolescence; I was… around 14 or so. They wouldn't tell me anything. They would take me to doctors in order to understand why I wasn't menstruating; you know, ultrasounds, blood tests, etc. First, we went to a gynecologist, and then to endocrinology, genetics at the Faculty of Medicine in Akdeniz University; I mean, my high school years passed by with all this, you know; the period when you're the most fragile, I mean, a really difficult time even for heterosexual people; and on top of that, I lived all this. Of course, there was secrecy in the family; they weren't telling me anything about this. We're going to the doctor's, my mother is withdrawing to a corner with the doctor, whispering. I don't understand what's going on, you know; I'm scared of that thing, the chair and it passed by like that; they were bad times. And then, on top of that, I had a surgery in the summer that I finished high school. I was turning 18; I guess there were a few months left. I was operated, again, there, not knowing what's going on, very much being tricked, you know, being told: 'there is a cyst in your ovaries, we'll remove that'. Then I found out that I didn't have ovaries by birth, anyway… I didn't know that I was intersex and all. The procedure that was done was the removal of the undeveloped testicles and the reduction of the clitoris. So, that was a completely unnecessary, just a cosmetic intervention anyway. That surgery stupefied me a lot, of course; I fell apart at the seams; I got alienated from my body, etc. They were bad times. Right with that state of mind, I started university. I went to Ankara. I was separated from my family for the first time. It was a department that I really wanted and liked, but despite that, I had to quit."[127]

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[127] "Bu doktor-hastane süreçleri ergenliğimde başladı, on..dört yaşında falandım, bana bişey söylemiyolardı, neden regl olmadığımı falan anlamak için doktora götürüyolardı işte ultrasonlar kan tahlilleri vs., jinekologa gittik ilk önce, ondan sonra endokrinoloji, genetik, Akdeniz Üniversitesi Tıp Fakültesi"nde, yani lise yıllarım hep bunlarla geçti, hani insanın en böyle kırılgan hassas olduğu dönem, hani, heteroseksüel insanların bile gayet zorlu bi dönemi, bi de üzerine ben bunları yaşadım, ee tabi hani hep böyle bi gizlilik vardı ailede, onlar böyle hiçbi şey anlatmıyodu bu konuda zaten, doktora gidiyoruz, annem böyle doktorla bi köşeye çekiliyo fısır fısır konuşuyo filan böyle neler olduğunu anlamıyorum böyle, korkuyorum o şeyden, koltuktan falan, öyle geçti, kötü zamanlardı yani. ee, onun üzerine işte liseyi bitirdiğim yaz ameliyat oldum, 18 yaşına gircektim heralde bikaç ay kalmıştı, orda da hani yine ne olduğunu bilmeden gayet böyle kandırılarak, işte 'yumurtalıklarında kist varmış, onu alıcaz' denerek ameliyat edildim, sonra da öğrendim ki hani yumurtalığım yokmuş zaten doğuştan… interseks olduğumu falan bilmiyodum, yapılan işlem şeymiş, içerdeki gelişmemiş testislerin alınması, ve klitorisin küçültülmesi, ee, o zaten tamamen gereksiz sadece kozmetik bi müdahale, o ameliyat beni çok afallattı tabi, her şeyim alt üst oldu, bedenime yabancılaştım filan, kötü zamanlardı. Tam o psikolojiyle işte üniversiteye başladım, Ankara'ya gittim, ailemden ilk defa ayrı kalıyodum falan, çok böyle isteyerek severek gittiğim bi bölümdü ama ona rağmen yarım bırakmak zorunda kaldım."

For Meral, the silencing and being lied to was the primary reason behind their alienation to their own body, as well as the psychological problems they had later during the university years, rather than their intersex condition, and even more than the surgery itself:

> "You know, cause there's, um… constantly a wall in front of you… since you don't know anything, you know, you feel that there's something different about you, but what it is was hidden from you; you don't know. You know, there was constantly a wall in front of me; I was struggling with it. The stage of not knowing what you should do, who you are. So, it was a period when I was really stuck. Anyway, that's why I quit school."[128]

Meral specifically emphasized the feeling of being cheated as a major cause of trauma in their narrative:

> "When I came out the surgery and woke up, I was, you know, expecting that a cyst would be removed from my ovaries; you're expecting something different from the surgery, but when I woke up, there was a bandage on my clitoris… It's horrible, I mean, imagine, you have a problem with your appendix; they admit you related to your appendix, for instance, and you wake up to find your arm cut; there's a bandage on your arm. This is what I went through."[129]

The comparison Meral makes between appendix and arm, as representations of cyst and clitoris shows how Meral perceive the difference between what is told and what is actually done. Meral was told a non-vital organ was going to be taken out because it was causing trouble, but instead a healthy, vital organ was removed from their body without their information. Meral continues to explain why their clitoris was so crucial:

> "And I had had my first sexual experience before I was operated; right before the surgery, even; two or three months before the surgery. Such a traumatic thing, I mean, you lose your sexual organ that you had your first sexual experience with, just a few months ago; and, I mean, without being told, it was so bad... You know, I had experienced it, I had had a relation with a partner that

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[128] "Hani şey oluyo çünkü, ee.. önünde sürekli bi duvar.. hiç bi şey bilmediğin için, hani kendinde bi farklılık olduğunu hissediyosun, ama ne olduğu senden gizlenmiş, bilmiyosun, hani sürekli bi duvar vardı önümde onunla mücadele ediyodum, ne yapman gerektiğini, kim olduğunu falan bilememe aşaması, ee çok o yüzden tıkandığım bi dönemdi. Neyse işte o yüzden okulu yarım bıraktım."

[129] "Ameliyattan çıkıp uyandığımda ben hani yumurtalıklarımdan kist alıncak diye bekliyorum, ameliyattan farklı bişey bekliyosun ama uyandığımda işte klitorisimin üzerinde bandaj vardı... Çok korkunç bi şey yani, düşün mesela seni alıp diyelim apandisit sorunun var, senin apandisitle ilgili yatırıp mesela uyanıyosun senin kolun kesilmiş, kolunda bandaj var, böyle bi şey yani yaşadığım."

> way, and I hadn't received a reaction like 'you're not operated, what's this?' If I wasn't operated, I'd go on with my life the same way."[130]

This narrative directly refutes the justifications clinicians offered for operating clitoris, such as providing caution against bullying by peers, or improving sexual relationships. Furthermore, Meral emphasizes how the operation was traumatic because their relationship to their clitoris as an organ that provides sexual pleasure was damaged. This focus, however, was completely absent from the narratives of clinicians I interviewed; even when they talked about the importance of preserving the nervous tissues -two of the surgeons concluded that they cannot fully preserve it no matter how careful they are-, none of them mentioned the possibility of clitoris having a significance on its own, as an organ that could be essential to one's sense of being. According the clinical narratives, non-consensual reduction of clitoris would be justified if the sensation could be fully preserved, since, a female body does not need a large clitoris in the heteronormative imaginations of sexuality.

> Deniz went through surgical operations when they were 6 years old, but their condition was kept secret from Deniz. Still, Deniz tells how they knew about their condition even if it was silenced: "I found out that I was intersex more or less when I was 6, cause the doctors keep talking. They think that the child doesn't understand anything. They talk about everything near me, anyway."[131]

However, Deniz was silenced when they brought it up later with their parents:

> "Now we're talking, but when I was little, they said nothing. In fact, when I said [something], [they said]: 'don't tell anyone anything'. Cause as a child, you're more like, you know, you speak your mind; frankly, you don't feel the need to hide anything. For example, I used to talk near my cousins; I used to talk near my brother, etc. When they heard about it, they were very angry with me, [saying]: 'don't tell anyone'… Other than that, they didn't talk to me when I was little, not at all, not by any means."[132]

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[130] İlk cinsel deneyimimi de ameliyat olmadan önce yaşamıştım, ameliyattan hemen önce hatta, ameliyattan 2-3 ay önce falan, o kadar travmatik bi şey yani, daha bi kaç ay önce ilk cinsel deneyimini yaşadığın cinsel organını kaybediyosun, ve yani sana söylenmeden, çok fena… Hani yaşamıştım mesela, hani o şekilde bi partnerle bi birlikteliğim de olmuştu mesela, 'ameliyat olmamışsın bu ne' falan şeklinde bi tepkiyle karşılaşmamıştım mesela, ameliyat edilmeseydim yine aynı şekilde öyle devam edecektim hayatıma."

[131] "Hani ilk interseks olduğumu öyle böyle 6 yaşında falan öğrendim çünkü doktorlar devamlı konuşuyor, 'çocuk bir şey anlamıyor' diye düşünüyorlar, yanında konuşuyorlar her şeyi zaten."

[132] "Şimdi konuşuyoruz ama küçükken hiç bir şey söylemediler, hatta ben söylediğimde 'sakın kimseye bir şey söyleme' falan, çünkü çocukken daha böyle şey oluyorsun hani ağzına geleni söylüyorsun açıkçası bir şey saklama ihtiyacı duymuyorsun, hani mesela kuzenlerimin yanında söylüyordum, abimin yanında söylüyordum falan, bunlar kulağına gittiğinde bana çok kızıyorlar ve hani 'kimseye söyleme' falan diye… benimle onun haricinde konuşmadılar küçükken hiçbir şey hiçbir şekilde."

Both Meral and Deniz learned about the details of their conditions and treatment procedures with their own efforts in their late teenage years, after they went through surgery and hormone treatments for many years. Both of them, however, construe the years-long silencing as something that "blocked" them by alienating them from their own bodies, rather than as something that protected them. Meral learned it through a psychologist who decided to disclose information against Meral's parents' wishes:

> "I went to a psychologist of my own accord, asking them [my family], saying I don't feel well… Of course, then, like with all doctors, the psychologist spoke to my family first. …I was 18 then. The period I'm talking about is when I finished high school… In spite of that, they still don't tell me anything about my own body. Then, the psychologist, completely on their own initiative, told me about the situation, although my family told them not to, and that was after about three months of therapy consultation; they told me at the end of that process… They didn't have much information either but, you know, *çift cinsiyetli*, etc. … I heard from them for the first time that it was a condition that was called hermaphrodism, etc. *I was really astonished and shocked and all, but on the other hand, that wall came down by them telling me.* I learned there, but despite that, it took me quite a long time to accept myself."[133] (emphasis added)

Deniz was not informed in any way about the details of their condition and about the reasons of the treatment they received during many years, until they coincidentally found out at nineteen years old, about twelve years after going through surgery:

> "Then they gave something like a referral; it tells all about what I've gone through. The night we were going to the hospital,… I saw my dad put this in his coat [pocket], cause they were hiding it from me… I said [to myself]: 'why are they putting it, and secretly, at a time when everybody's sleeping'; I see it, and… I study biology; I speak English, too; so, I know more or less what it says there… Then I understood the situation, cause some things are spoken since childhood;

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[133] "Ben kendi isteğimle onlardan [ailemden] talep ederek psikologa gittim, kendimi iyi hissetmiyorum falan diye …. tabi o zaman bütün doktorlarda olduğu gibi ilk önce ailemle konuştu psikolog…. Artık 18 yaşındayım, bunları anlattığım zaman liseyi bitirdiğim dönem… ona rağmen hala benim kendi bedenimle ilgili bi şey bana anlatılmıyo. Ondan sonra, psikolog tamamen kendi insiyatifiyle, ailem söylememesi gerektiğini belirttiği halde bana anlattı durumu, o da üç aylık filan bir terapi danışmasından sonra, o sürecin sonunda söyledi….onun da çok bilgisi yoktu ama işte 'çift cinsiyetli' filan.. hermafrodizm denen bi durum olduğunu falan ilk ondan duydum öğrendim. *Çok hani afalladım şok oldum falan ama bi yandan da o duvar ilk onun söylemesiyle yıkılmış oldu*, orda öğrendim yani, ona rağmen hani benim kendimi kabullenmem uzunca bi süre aldı."

> *you feel it too, anyway, but, you know, you can't name it somehow, but after seeing that, you say: 'yes, so, that's what I am'*."[134]

Both Meral and Deniz were well aware that there was something hidden from them about their bodies before finding out that they are intersex, and their experiences became meaningful to them only after finding out. Even if it caused an initial shock, Meral likens the moment to 'demolition of a wall," which cleared their vision. Deniz also had a moment of shock, but they still position it as the beginning of a processing and self-acceptance:

> "Later on, I saw this report, but I was very upset. I still couldn't tell it [to my family]. I had a friend; I said it to them, and they supported me a lot… How to say, I shouldn't be ashamed but after I found out about that, I felt so bad. You know, I was like a freak, I mean, I was this oddball of a person. You know, 'what difference does my existence make?'; I was thinking that way… I mean, I wasn't like other people and you experience ostracism since childhood; you think they are right; you say: 'yes, people were right to ostracize me'… At first, I'd felt very different, but then I got over it, of course thanks to my friend, and then my other friends, then my intersex friends, and then I told my family… I remember this; I was sitting opposite the TV, in the chair, you know, and my face went red, and numb, when I found out, when I read. You know, questioning comes later anyway. At first you put things into place; I did that. Then came the period: 'why am I like this, why am I like that' and all. And after that, you accept it anyway. I mean, I'm glad to be intersex; I couldn't think [of myself] any other way."[135]

As can be seen in the narratives of Deniz and Meral, because of undergoing surgery, frequent hospital visits, and hormone treatments that lasted many years, as patients, they were well aware that something was kept secret from them. The secrecy and the silencing around the intersex condition and the treatment did not necessarily protect them from feeling different; yet, it seems like it increased the distress later. Most importantly, both Meral and Deniz

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[134] "Sonra böyle sevk gibi bi şey verdiler, bütün yaşadığım şeyleri anlatıyor, hastaneye gideceğimiz akşam …. babamın montuna bunu koyduğunu gördüm, çünkü benden saklıyorlardı…. bunu dedim acaba niye koyuyorlar, bir de gizlice herkesin uyuduğu bir vakit bunu görüyorum ve…. Biyoloji okuyorum, İngilizce de biliyorum, aşağı yukarı ne olduğunu biliyorum yani orada yazanın…. ben sonra durumu anladım çünkü küçüklükten beri zaten bir şeyler konuşuluyor, *zaten kendin de hissediyorsun ama hani bunu bir şekilde adlandıramıyorsun ama bunu gördükten sonra diyorsun ki 'evet ben buymuşum'* falan diyorsun."

[135] "Daha sonra ben bu raporu gördüm ama çok üzüldüm, yine [aileme] söyleyemedim, bir arkadaşım vardı ona söyledim o da çok destek olmuştur….nasıl diyeyim utanmamak gerekiyor ama ben onu öğrendikten sonra o kadar kötü hissettim ki hani ucube gibiydim yani böyle saçma sapan bir insandım hani benim varlığım olsa ne olur olmasa ne olur bu şekilde düşünüyordum... hani diğer insanlar gibi değildim ve zaten küçüklükten beri bir dışlanma yaşıyorsun hak veriyorsun evet insanlar haklıymış beni dışlamakta falan diyorsun….başta çok değişik hissetmiştim ama sonrasında atlattım tabii ki bunları arkadaşım sayesinde, sonra diğer arkadaşlarım, sonra interseks arkadaşlarım, sonra aileme anlattım….şeyi hatırlıyorum televizyonun karşısında oturuyordum koltukta hani yüzümün böyle kırmızı olduğunu yüzümün uyuştuğunu hatırlıyorum öğrendiğim zaman okuduğum zaman; hani daha çok zaten sorgulama sonradan oluyor, ilk başta bir şeyleri yerine koyuyorsun o oldu, sonradan "ben niye böyleyim ben niye şöyleyim" falan süreci başladı, ondan sonra da zaten kabul ediyorsun yani interseks olduğum için de mutluyum zaten, başka şekilde düşünemezdim."

position their finding out as a necessary point to move on with their lives and overcome the feelings of alienation and loneliness created by the years-long secrecy. The concealment of information did not serve to protect them, but rather further added to the feelings such as shock and embarrassment that the disclosure caused, and delayed the start of the acceptance process, whereas finding out marks the beginning of their psychological healing by opening up to their loved ones and accepting themselves as they are.

Another point that is worth pointing out is that in these narratives, the main reason of the feelings of difference, or shame, is the frequent hospital visits that are not known why. In other words, knowledge of “difference” comes from, or is at least reinforced, by medical diagnosis. Paradoxically, medical treatment procedures become the main reason of the shame and stigma they intend to prevent.

Even if the person knows their condition before the medical intervention, because of reasons such as social stigmatization, the medical treatment can still reinforce the feelings of difference, rather than curing them. For instance, Berfin, who was born in a small village, was exposed to a lot of discrimination and social stigma because of their condition. Thus, Berfin knew “what they were” for as long as they can remember:

> “One day, my mom held me by the hand and, with four old women, they took me in; forced me to lie down; looked at my privates; they checked like doctors; they said: ‘there’s that, they’ll open a channel from here, it’s a girl’, etc. That was the first… I’d fainted in their hands then. My aunt’s daughter came to my screams and took me from them, etc. So, then… Um… At the age of 6 or 7, a part of my body was alienated, shown like a bogey; they made me feel that I had a part of me that I was supposed to be scared of. I learned this when I was 6 years, 7 years old. After that, you know, due to kids’ nicknames, othering, ostracism, etc. they made me feel different all the time.”[136]

Later, Berfin was diagnosed around the age of twelve, and went through surgery shortly after the diagnosis, around the age of thirteen. This, however, was far from being an answer to their socially rooted problems; to the contrary, in Berfin’s narrative, the surgery

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[136] “Bir gün baktım annem elimden tuttu 4 tane yaşlı kadınla beraber, içeriye aldılar beni, zorla yatırdılar, apışlarıma baktılar, işte doktor gibi kontrol ettiler, bak işte şurda şu var dedi bak burdan kanal açılacak işte kızdır da şudur da budur da böyle konuştular, ilk yani öyle, ellerinde baygınlık geçirmiştim ben o zaman, ee çığlıklarımı duyan halamın kızı gelip beni ellerinden almıştı vesaire, şimdi öyle olunca... ee… daha ben 6-7 yaşlarında bedenimin bir tarafının bana yabancılaştırıldığını, öcü gibi gösterildiğini, korkmam gereken bi tarafım olduğunu bana hissetirdiler, 6 yaşında 7 yaşında ben bunu öğrendim, onun devamında da zaten ee işte çocukların lakaplarından ötekileştirmeden dışlamadan şundan bundan dolayı da her dakka farklı olduğumu hissetirdiler.”

represents an extension of the discrimination and the stigmatization they were exposed to. When I asked them, what is it like to live in an intersex body, Berfin replied:

> "I can say it's a bed of nails; I mean, for one thing, since the society doesn't offer you a chance to live as yourself…; for one thing, you see a hypocritical imposition in the society; I mean, you don't talk like yourself, you don't act the way you are, so what do you do? Whichever [side is] given to you, male or female, whichever you're seen as in the society at that time, you kill your other side and you turn towards the other side, just for the sake of the society, just in order not to draw people's doubts on yourself… I mean, you can't be yourself, from the way you talk to your demeanor, and everything, everything. … Let's say you feel like a man, not like a woman. … Since it's difficult to make a penis, they, for example, want to turn the intersex into women; they don't let them be. I mean, the modern age hits like that, and the backward age, the religionist age hits in another way. And worship, the worship that is seen fit for the intersex is different; washing your corpse is different."[137]

In this quote, Berfin talks about the social policing and the sex assignment surgery at the same time, aligning them together as obstacles to be their authentic self. In Berfin's experience, there is not much difference between the "modern" medicine and cultural rules such as religious rules in terms of discrimination and stigmatization against intersex individuals.

Further, according to Berfin, the main reason that they were subjected to surgery was to protect social morality, rather than their own happiness:

> "In the village life, oxen's testicles are removed, so that they can [focus] only on their bodily force; they're cut off and removed in a primitive way, and their manhood is killed. Now, they do the same to us, the intersex… If you're a woman, they kill the womanhood, and if you're a man, they kill the manhood; I mean, they kill it somehow; I mean, the intersex are somehow degendered; these are killed… I mean, they have to protect the morality of the society, you know… The goal there is to kill your sexual desires; it's over; after that, you don't have

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[137] "Ateşten gömlek diyebilirim, yani bi defa toplum sana kendin gibi yaşama fırsatı sunmadığı için bi defa toplumda ikiyüzlü bir insan dayatması görüyosun, yani kendin gibi konuşmuyosun, kendin olduğun gibi davranmıyosun, e napıyosun, sana verilmiş, eril veya dişil, hangisinde toplumda o anda görünürsen diğer tarafını öldürüp diğer tarafa sırf toplumun hatırı için yönelip insanların şüphe ve kuşkularını üstüne çekmemek için…. Yani konuşma biçimi olarak, hal ve hareket ve davranış ve her şey olarak, her şey olarak, olduğun gibi olamıyosun.… Diyelim ki kendini erkek hissediyosun, kadın hissetmiyosun… Penis yapmak falan zahmetli iş olduğundan dolayı interseksleri hep kadın yapmak istiyolar mesela, kendi hallerine bırakmıyolar. Yani modern çağ böyle darbeliyo, geri çağ, dinci çağsa ayrı bi darbeliyo. Ve, ibadet, intersekslere uygun görülen ibadet durumu farklıdır, cenaze yıkaman farklıdır."

> a sexual life anyway… They take away your source of life, they take away your force, they emasculate you."[138]

Contrary to medical narratives that suggest pursuing the best interest of the patients, Berfin defines the surgical operations as "castration."

Meral and Deniz, too, perceive the medical diagnosis and the gender assignment procedures as gender policing, rather than being a cure to their problems. Meral says:

> "After [the surgery], I used the pills and the injections, etc. and with the effect of those pills, I started menstruating, although I didn't have ovaries, cause, um… But that's not a normal menstruation; it's created with pills. So that I go like: 'oh, look, I'm a girl, I hit puberty, I'm menstruating', etc. Just so I see that. That's the only reason why I was using those pills. You know, I had menstruated for a while. And my mom had even called the doctor with great joy, [saying]: 'our daughter has menstruated, thank you'… You know, [there's] always this effort to be put into a box of girl/woman; that's how I grew up. At the same time, my mom was trying to visually raise a girl, you know; like trying to force me into waxing my hair, trying to make me wear more feminine clothes, etc. On one hand, I go through all this…"[139]

At the time, Meral did not know that they had an intersex body, and they were prescribed hormones as part of the clinicians' attempt to be psychologically relieved. Yet, as can be seen in this narrative, for Meral, these treatments only brought more pressure, rather than being relieving. Meral thinks of themselves as being policed, not treated, as a result of the hormone prescriptions that were aimed to make them look more feminine.

Similarly, Deniz states that the pressure caused by gender-policing was increased on Deniz as a result of masculinizing surgery: "For example, when I was operated at the age of 6 or so, I was acting very femininely anyway, and my friends were making fun. Since I was

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[138] "Köy hayatında öküzlerin güçlerini sadece bedensel güce verebilmeleri için testisleri alınır öküzlerin, çıkartılır, ilkel… bir şekilde kesilir çıkartılır, erkeklikleri öldürülür. şimdi biz de böyle yani interseksler de aynısını yapıyolar.... Kadınsan kadınlığı… erkeksen erkekliğini öl… yani öldürüyolar bi şekilde öldürüyolar, yani bi şekilde interseksler cinsiyetsizleştirliyo yani, bunlar öldürülüyor…. Toplumun ahlakını korumak zorundalar yani anlatabiliyo muyum…. Orda amaç, orda amaç senin cinsel arzularını öldürmek, bitiyo, ordan sonra zaten bi cinsel hayatın olmuyo yani… Senin yaşam kaynağını alıyo senin gücünü alıyo seni iğdiş ediyo."

[139] [ameliyattan] sonra ilaçları iğneleri filan kullandım, o ilaçların etkisiyle yumurtalığım olmadığı halde regl olmaya başladım çünkü şey…. ama hani normal bi regl değil o da, ilaçlarla yaratılmış, ben hani işte "aa bak ben kızım, ergenliğe girdim, regl oluyorum" filan, göriyim diye sırf hani sırf o yüzden o ilaçları hani kullanıyodum hani bi süre regl olmuştum falan, hatta annem büyük bi sevinçle doktoru aramıştı işte "kızımız regl oldu sağolun teşekkürler" filan tarzı… hani hep böyle bi işte kız, kadın kutusuna konma çabası, onunla büyüdüm yani. Bi yandan da annem de şey olarak da, şekilsel olarak da böyle bi kız olarak yetiştirmeye çalışıyo falan, işte hani tüylerimi zorla böyle ağda filan yaptırmaya çalışıyo, daha böyle kadınsı kıyafetler giydirmeye çalışıyo vesaire, bi taraftan da bunları yaşıyorum işte..."

operated now, my mom’s expectation was going up. She was telling me: ‘act more like a boy now.’ I was forcing myself that way, you know.”[140]

As a male-assigned child with CAH and XX chromosomes, the diagnosis and medical treatment increased the anxiety around the masculinity of Deniz, which made their feminine behaviors more noticeable, and created pressures for them to behave in a more masculine way. In her book *Brainstorm: The Flaws in the Science of Sex Differences*, Rebecca Jordan-Young points out that there is a similar dynamic for girls with CAH, whose femininities are considered under threat by their high levels of testosterone. However, Jordan-Young suggests that it is a self-fulfilling prophecy: the behavior of girls with CAH are read as overly masculine not because the high levels of testosterone, but because “Girls with CAH are *expected* to be more masculine, and it is well established that expectations of this sort influence behavior; and anxieties and/or simple expectations among girls with CAH may lead to *overreporting masculine behavior* by both parents and the girls” (Jordan-Young, 247; emphasis belongs to author). Because of the gendered expectations that are created by the diagnosis, even the sort of behavior that is considered normal for their peers is considered deviant for the children with CAH. In other words, gender-policing is reinforced, not alleviated, by medical diagnosis and treatment.

When the gender-policing comes together with secrecy, it can lead to even more damaging results:

> “Since my family was in an effort to isolate me from others, they would say things like: ‘you sit at home’, or for example, ‘speak lower when you’re outside’, etc. I tried to make my voice lower. I didn’t do that with my cousins. When I acted a bit more femininely, my mom would say: ‘you’re acting like this here too’; like ‘I told you to be careful with your friends, but be careful with your cousins too’”[141] (Deniz)

No one except their parents knew about Deniz’s condition, including their brother, as well as other family members, or close friends. Thus, Deniz had to force themselves into gender

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[140] “Mesela 6 yaşında falan ameliyat olduğumda çok hani zaten çok feminen davranıyordum arkadaşlarım da hani dalga falan geçiyordu, hani artık ameliyat da olduğum için annemin beklentisi de artıyordu “artık biraz daha oğlan çocuğu gibi davran” diyordu mesela o şekilde zorluyorum kendimi falan hani.”

[141] “Ailemin hani diğerlerinden beni izole etme çabası olduğu için ‘sen evde otur” işte mesela “dışardayken sesin kalın çıksın” falan derlerdi, sesimi kalın çıkarmaya çalışırdım, kuzenlerimle çıkarmazdım böyle biraz daha feminen davranınca ‘burada da böyle yapıyormuşsun’ falan derdi annem, hani ‘sana arkadaşlarınla dikkatli ol dedim ama yani kuzenlerimle de dikkatli ol’ falan…” (Deniz)

roles everywhere except home. This is a case in which secrecy not only creates shame and trauma, but also encourages the child to isolate themselves from their social environment.

4.1.1 Mistrust and Resistance to Medicine

In addition to the psychological trauma caused by secrecy and concealment, another key issue that came up during my interviews with intersex adults was the dismissal of the intersex person's subjectivity and the objectification of the body during medical treatment. For instance, my informants talked about experiences of being an object of scrutiny and curiosity, along with the violation of privacy as very disturbing experiences in a context in which they had no information or authority over their treatment procedures. Medical students and colleagues who were called to the examination rooms, non-consensual photography and video-recordings, non-consensual participations in medical research projects are some of the common experiences my informants shared. Combined with the lack of information, their subjectivities were ignored, and they were reduced to passive bodies to be treated, rather than individuals who have agency over their bodies. In this section, I will show how this can lead to a lack of trust in the medical establishment, and how reading intersex narratives in this context can offer new insights about the patient-clinician relationships.

During an interview, a pediatric surgeon admitted that clinicians do not know much about what happens to the intersex children who are operated during their childhood in their adult lives. He suggested that these children do not come back to the hospital after they become adults because "the surgeries are probably successful, and they continue with their normal lives." After a moment of pause, he continued, "Well, actually we would like them to come back. A couple of years ago we decided to call them back and conduct a study [about the long-term effects of surgeries], but none of them wanted to come" (Dr. Bülent). His tone was a little reproachful. As the surgeons who performed the operations, they were curious about the results they caused, and they wanted to conduct a study about it. Yet, their efforts were not well-received by their patients.

When I met Deniz, I brought this conversation up. Deniz said "Oh yes, they called me too, some time ago. Of course, I did not go, why would I? I am not going to be their guinea pig."

This was during the very beginning of our meeting, and even though I had some idea of why they would not want to go back for such a study, Deniz's response still confused me a little. After all, now they were an adult who is sufficiently informed on the subject, and furthermore they were an activist who is advocating against surgical operations on intersex children. Why would Deniz refuse such an opportunity to speak back to the main targets of their advocacy? Later in our conversation, I noticed that behind Deniz's refusal there was a huge mistrust against the medical professionals.

Deniz's condition is CAH (Congenital Adrenal Hyperplasia), which is manifested by a break in the adrenal glands' hormone production chain. This break causes lack of cortisone, as well as production of more-than-average levels of androgen precursors. Because CAH emerges in prenatal stage, XX infants who have this condition are usually born with virilized genitalia, and they can be assigned as males if not diagnosed at birth. Since cortisone is essential for vital bodily functions, individuals with CAH need medical help to continue with their lives. However, lack of cortisone can be cured by simply taking cortisone supplements on a regular basis, and there is no other medical emergency typically caused by CAH.

Deniz was not diagnosed at birth, and they were raised as a boy. At six years old, Deniz was brought to the emergency room because they had a crisis due to the cortisone deficiency. After examination, Deniz was diagnosed as CAH, and the clinicians suggested Deniz's family that Deniz should be assigned as female. Deniz's mother refused, saying that she raised a boy child and she does not want it to change. Therefore, the final decision was to assign Deniz as male. It was decided that they needed to remove the uterus, because "it had tumor cells." Deniz was kept at the hospital for nearly one year for the treatment of cortisone deficiency as well as sex assignment surgeries. During this time, at the age of seven, they were subjected to countless tests and examinations.

Deniz, like many other individuals with intersex traits who sought medical help, was included in medical studies without being informed. During our conversation, Deniz showed me the article published by their clinicians in a medical journal as a result of a study they were included. They identified the study by recognizing their own medical history. Part of the reason why so many tests and examinations were conducted on Deniz's body was this study, and perhaps other studies like this one. However, Deniz's family did not know that the tests were going to be used in a study. Deniz says,

> "It was to such an extent that, you know, they had tricked my family like 'let your child come to class'. They would take only me in there; they hadn't taken my family in. I had cried, and all. They're taking off my clothes, but I was crying my eyes out. Then when my family saw this nonsense, they, of course, took me out, but they didn't expect something like that either… After that, they didn't let such nonsense stuff; cause, there would be a doctor's dissertation, or their projects, or researches, and they would ask: 'can I take some blood?', or 'can I do this, can I do that?' There was also this kind of exploitation."[142]

Furthermore, Deniz has a lot of memories about being stripped off in front of many people, because the professors were taking this "opportunity to encounter such a rare case" and they were calling their interns to the examination room to show them this "interesting case":

> "I mean, you know, the thing that upset me the most was this; the examinations were troublesome. You go once in around three months for examination and every time, there would be a doctor you don't know; an intern probably. They make their interns see me, you know, like 'there's something interesting, you look too, so that you gain experience'… OK, maybe I was sick, I had something wrong according to them, but every time, I had to open my genital area and show it to them, and every time, I would cover my face, like I had something to be ashamed of. I mean, for instance, my dad never went in there, anyway; my mom did. And my mom never looked my way. She acted like she was ashamed of me too, or maybe she wasn't pleased with the situation. So, it was really a trauma for me, frankly, what else can I say…"[143]

During this time, Deniz had no idea about why they were there, and no one explained or consulted them anything during the course of the treatment. Neither Deniz nor their family did not know that they were going to publish a study on Deniz, and even though Deniz mentions that they have a very protective family, they could not prevent their child being

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[142] "Öyle bir boyuta geçmişti ki ailemi şey diye kandırmışlar işte "çocuğunuz derse gelsin" falan diye, tek beni sokuyorlardı içeriye ailemi almamışlardı içeri, ağlamıştım falan, işte üstümü falan çıkarıyorlar ama ben yani hüngür hüngür ağladığımı bilirim. Sonra ailem bu saçmalığı görünce ailem tabii ki çıkardı ama onlar da böyle bir şey beklemiyolardı. …ondan sonra hani böyle saçma şeylere izin vermediler; çünkü bitirme projesi oluyordu doktorun, veya ona yakın hani projeleri mi oluyor çalışmaları mı oluyor, ve diyolardı ki "bir kan alabilir miyim" ya da "şunu yapabilir miyim bunu yapabilir miyim" diye, ayrıyeten böyle sömürü olayı oluyor."

[143] "Yani şey ben benim en çok her zaman üzüldüğüm nokta şu, muayeneler çok sıkıntılı geçiyor, küçük olduğunda üç ayda bir falan gidiyorsun muayene olmaya ve her defasında tanımadığın bir doktor oluyor, stajyer doktor muhtemelen, stajyerlerine baktırıyorlar hani "ilginç bir şey var siz de bakın, tecrübe olsun" diyerek….tamam ben hastaydım belki onlara göre yanlış bir şeyim vardı ama her defasında ben yani genital bölgemi açıp onlara göstermek zorunda kalıyordum ve her defasında böyle yüzümü kapatıyordum sanki bende utanılacak bir şey varmış gibi yani, mesela orada hiçbir zaman babam girmezdı içeri zaten annem girerdi, annem de hiçbir zaman benim tarafıma bakmazdı o da benden utanır gibi yapardı ya da belki durumdan hoşnut olmazdı, hani o bende cidden bir travmadır açıkçası başka ne diyebilirim…"

exposed to medical experts and students in crowded rooms “like a zoo animal,” in Deniz’s words.

When Deniz started to tell me their medical story, they mentioned that “There was cancer in my uterus, so they removed it.” Then, later in the conversation, they were talking about how clinicians assign unnecessary medical operations on intersex children in order to fit them into a binary sex system: “For example they remove your uterus saying that there is a risk of cancer, but the real reason is that, so you will think that you are a man in your adult life,” Deniz said. At that point, I was not sure if Deniz was also referring to their own story or not, since they mentioned before that they actually had tumor cells. So, I asked, “But you did have tumor, right?” Deniz paused, and then showed me the medical article which they were included in. They said “Look at the title, it means that I had tumor cells, right? What do you think?” From the title it seemed like the article was about a group of CAH patients who developed tumor cells. Further, Deniz is a doctoral student in biology and understands fluent English; considering their skills as well as interest in the topic, I found it hard to believe that Deniz did not really understand the article. Deniz continued, “I mean, they said so but I’m not quite sure. If I had tumor cells, why did not any of them of them spread to other parts of my body? Perhaps it was a specific group of cells that is normal to have in a body with my condition?” At that point, it started to make more sense to me why Deniz did not go back to talk to the clinicians who were curious about what happened to their patients. This narrative shows the tremendous lack of trust in the medical establishment.

Later, Deniz elaborated further on why they did not accept the invitation of the clinicians who called them:

> “When they’d called, they’d asked like: ‘what are you doing, are you studying?’ and I’d told them that I was studying. They said: ‘Among them, you’re the only one who has a regular life, like, who studies. We have to meet with you’. Maybe that’s why they were surprised… I don’t know, maybe that’s why, or maybe they’d stick something in my head.”[144]

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[144] “Aradıklarında şey demişlerdi, işte, ‘Ne yapıyorsun, okuyor musun?’ diye sormuşlardı, ben de söylemiştim okuduğumu, ‘Aralarında en düzenli yaşamı [olan], en böyle okuyan sen varsın, seninle mutlaka görüşmeliyiz” falan diyorlar. Belki onun için şaşırmışlardır…. Bilmiyorum belki de onun içindir, belki de kafama şey takacaklardır.”

Deniz refers to a kind of a brain-scanning test they went through when they were diagnosed during childhood. Deniz envisions going back to talk to the clinicians as being objectified again, rather than being listened to; thus, Deniz does not see a point in going back:

> "There's something like that; they think the intersex's brain functions are not like other people during childhood… They took me somewhere for a mind test. There were two computers; they put something in my head and I'll listen to the sound for an hour. I mean, you know, they must realize that we are not stupid, that we are even smarter than them. I mean, you are used like commodity, not like a human… But you form a life… I mean, this life is not for 15 years, it lasts for a long time; I mean, they must think about that… Yes, they are curious about what are the intersex, what do they do… They must realize that we are not people who go willy-nilly and open up when they say 'open', that we are also informed…"[145]

As I show in 3.3, clinicians perceive most intersex patients as lacking the ability of taking personal responsibility about their medical treatment, and they see it as a justification on treatment without informed consent. Echoing this, in their own treatment process, Deniz felt that clinicians perceived them as intellectually lacking, and therefore incapable of exercising agency, which, for Deniz, is a reason to think that they would not be heard by the clinicians even if they accept to talk to them. Emphasizing forming a "life," Deniz points out that the objectifying approach of medicine does not take intersex indivuduals' personhood into account and calls out the clinicians to imagine their intersex patients as subjects with agency, and not as victims of their intersex conditions.

As opposed to Deniz, Berfin knew about their body condition since they were a child, but only because they were raised in a small village, where rumors spread and Berfin heard many insults and nicknames from other kids in the village all the time. These nicknames included "*çift cinsiyetli* and a hundred other names." Berfin has a different condition than Deniz; but they never told me the medical classification of their condition, even while explaining the details of their physical traits or the operations they had. Even if I have an idea about what it can be, I will not include their condition with its medical name here;

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[145] Şöyle bir şey var intersekslerin beyin fonksiyonlarının diğer insanlar gibi olmayacağını düşünüyorlar küçüklükte…. bir baktım şey akıl testi için bir yere götürdüler, bilgisayarlar var iki tane işte kafama şeyi koydular bir saat boyunca sesi dinleyeceğim falan, yani hani bizim salak olmadığımızı, gayet onlardan daha da akıllı olduğumuzu fark etmeleri lazım, hayır yani böyle insan değil mal gibi kullanılıyorsun….ama bir yaşam oluşturuyosun sen….hani bu yaşam on beş senelik değil uzun yıllar sürüyor, hani bunu düşünmesi gerekiyor….evet merak ediyorlar interseksler nasıldır ne yapıyor….orada tıpış tıpış gidip "aç" dediğinde açan insanlar olmadığımızı anlamaları gerekiyor artık, hani bizim de bilinçli olduğumuzu…"

because, I perceive Berfin's refusal to use the name of the condition as resistance to medicalization. I will only mention some physical traits they have when relevant.

At birth, Berfin was assigned as a girl and raised as a girl. Yet, their parents found out that there was something "wrong" with Berfin's genitals. Later, their family took Berfin to the hospital, and they ended up in a hospital in Istanbul when they were twelve. Here, it was decided that Berfin's "real sex" was female and therefore Berfin needed to have two surgical operations; one for removing the testes, and another one involving the clitoris. When I asked what kind of operation it was, they said "They cut my clitoris like this, and also like this, and then like this...," showing with hand gestures as if they cut it in several different directions. When I asked why they did it, Berfin responded "to protect social morality, so that I do not get pleasure." Even if I tried to ask what she thought was the logic of the clinicians, I could not get a different answer.

Even though Berfin was twelve years old at the time of these operations, clinicians had decided with Berfin's father to assign them as a female without involving Berfin in the conversation. After the second operation, Berfin was told "to come back before getting married" to open the vaginal canal. Berfin also remembers that the clinician gave some pills, and explained how to use them, but did not explain what they were for. Berfin explains, "one side of it was orange, the other side was white, you start with the white side first, then you switch to the orange side, then you stop for 10 days. Since I did not know, I was just using wherever side I wanted to... Then I stopped using it after I learned that they were hormone pills." [146]

At the age of thirty-nine, around twenty-seven years after the operations, Berfin decided to seek medical help to get their vaginal canal opened, because they wanted to get married. During the examinations, in a room of six specialists, one of the specialists asked Berfin to show them their genitals, saying "open, open it so we can look[147]" in a rude and condescending manner, in front of the other clinicians. The room also had very big windows that looked towards the hospital yard, and they were not covered by curtains. Berfin

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[146] bir tarafı portakal renkliydi, bir tarafı beyazdı, önce işte beyaz'dan başlıyosun sonra portakal rengine geçiyosun sonra 10 gün bırakıyosun, ben tabi bilmediğim için, aldım hangisinden neresinden başlayacağım… kullanıyodum gidiyodum.. sonra hormon ilacı olduğunu öğrenince onu da artık kullanmadım.

[147] "Aç, aç da bakalım"

hesitated, and the same specialist repeated his words. Berfin was extremely offended by this request and resisted the clinician who asked it. Later, one of the other specialists in the room defended Berfin and apologized. After this event, Berfin decided to stop seeking medical help, and not to get married. Berfin told me this story as soon as we started to talk in our first meeting, repeated the story later, and also gave many references to it while they told me other stories. Berfin also tells this story during the panels and events. Clearly, this story and what it represents holds a central place in Berfin's criticism of the medical establishment.

As I quote above, Berfin also claims that they did not use the hormone pills because they did not understand what they were and how to use them. When I tried to ask about the medical terms during our conversation, Berfin seemed like they did not hear my questions. Thinking that maybe they really did not, I tried to ask again, but the same thing happened.

How should we read Berfin's resistance to speak the medical language? At the time of our interview Berfin was 44 years old. 32 years after surgical operations, they are one of the few intersex activists in Turkey who is publicly visible and doing advocacy as well as consultancy to other intersex people and their families. Considering their relationship to the issue, I read Berfin's avoidance of medical terms as an active refusal to use the medical language, rather than simply as lack of information, or lack of ability to use the medical terms. Berfin went through a difficult childhood with a lot of stigmatization, had two surgical operations at the age of twelve which left them in pain for life -Berfin stated that they have pain while urinating still today, 32 years after the surgery- and when they willingly sought medical help after many years, they were humiliated. Both psychologically and physically, medical treatment caused tremendous harm on Berfin. For Berfin, there is no point in speaking the medical language anymore, because it did not help them. In this context, I believe that Berfin's refusal to use the medical language should be read as resistance to medicalization of their body, and an indicator of the mistrust in the medical authority.

When we read Deniz's and Berfin's stories together, we see that the main reason behind their resentment to medical establishment is the objectification of their bodies and dismissal of their subjectivities. In Deniz's words, "you don't exist there… in fact, you do, but you don't."[148] As intersex individuals, their bodies became objects of scrutiny and curiosity; they were looked at, examined, tested, experimented and operated on, while their opinions and feelings were completely ignored. Based on "objective" explorations, treatment decisions were made for them and imposed upon their bodies. Deniz refuses to speak to the clinicians because they refuse to be positioned as an object of medical study. Medical language does not have a place in Berfin's story, because it cannot tell their story as a *person*, as someone with emotions and agency.

4.1.2 Implications and Discussion

As a result of early, non-consensual surgical operations and medical treatments, Meral, Deniz and Berfin feel a lot of resentment to the medical establishment today. The main source of their resentment is that they were never offered an alternative scenario in which they would be able to take the responsibility of their own decisions. When I asked what they would like to say to their clinicians, Deniz pointed it out as:

> "I would say this; they're trying to fix us in some way, they tried to fix us at the time, but I wasn't fixed, I'm still this. I'd especially talk about the fact that those treatments and examinations were child abuse, rather than treatment, cause you are seriously harassed, I don't know… Traumas arise, cause there are things that appear before your eyes in snatches; you're trying to forget anyway, you know… How should I put it; you have your sex transition, you have surgery, etc., no psychological support is provided for you. Your family says 'hush' anyway… That's why I don't think we're psychologically very healthy … You're put aside, being told: 'I fixed you'. In fact, you're not fixed. In fact, you end up worse since they wear you down. You know, maybe if it weren't for these surgeries, the child wouldn't be worn down so much. I mean, this has to be somehow brought to an end."[149]

According to Deniz, medical treatment procedures caused more harm than benefits. This means that not only medical treatment failed to prevent psychological difficulties, but it

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[148] "sen orda yoksun… aslında varsın ama yoksun."

[149] "Şöyle derdim, bir şekilde düzeltmeye çalışıyorlar, bizi düzeltmeye çalıştılar zamanında ama ben düzelmedim, hani ben buyum hala, özellikle oradaki tedavilerin muayenelerin tedaviden çok çocuk tacizine girdiğinden bahsederdim çünkü ciddi anlamda tacize uğruyorsun ya bilmiyorum… travmalar oluşuyor çünkü böyle kesik kesik gözünün önüne gelen şeyler oluyor unutmaya çalışıyorsun zaten hani …. nasıl diyeyim, cinsiyet geçişini yapıyorsun ameliyat oluyorsun falan, sana hiçbir psikolojik destek verilmiyor, ailen zaten sus diyor…. ruhsal anlamda hani onun için psikolojilerimizin de çok sağlıklı olduğunu düşünmüyorum…. "seni düzelttim" diyerek köşeye koyuluyosun, aslında düzelmiyorsun, seni aslında yıprattıkları için daha kötü oluyorsun, hani belki bu ameliyatlar olmasa çocuk o kadar yıpranmayacak yani buna bir şekilde son verilmesi lazım."

added to them, which disempowered them to cope with the stigma and discrimination they face.

Meral also thinks that an alternative scenario could turn out much better for them, because it would give them more options:

> "They could have waited till I reached 18. Um… they could have told me about the situation. I could have had these surgeries if I wanted them myself, after the age of 18, … or I would leave my body as it was, not having anything done, or just like I accept my intersex identity now, I could have accepted my body the same way… I mean, I don't see my big clitoris as something wrong, something bad. I was born with it anyway. It's an organ of mine. I mean, I'd accept it and if I'd have a relationship, I'd have it the way my body was. I'd have it with a partner that would accept me that way anyway and I wouldn't be with them if they didn't accept it… You know, just like I overcame these now, just like I'm able to talk to you, I'd overcome again and, you know, I'm sure I'd be psychologically a much healthier person."[150]

An alternative scenario could also have protected Meral against life-long physical side-effects:

> "You know, for instance, if those testicles weren't removed, even if there's a small risk of cancer, I'd regularly go to my doctor follow-ups, but my testicles would remain and keep producing testosterone, so what would happen? Right now, I wouldn't have a risk of osteoporosis… Now, for example, if I go to a gynecologist, since I have a pink [female] ID card, they won't give me testosterone, they'll give me estrogen. But if my testicles weren't removed, my body's own natural hormone balance wouldn't be upset; that testosterone would protect me from the risks that need to be eliminated by estrogen replacement."[151]

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[150] "Ben 18 yaşıma basana kadar beklenebilirdi, ee, bana durum anlatılırdı, 18 yaşından sonra kendim istiyosam bu ameliyatları olurdum, ….ya da hiç bi şey yaptırmayıp vücudumu olduğu halde bırakırdım, veya şimdi interseks kimliğimi nasıl kabullendiysem bedenimi de yine o şekilde kabullenebilirdim…. yani ben o büyük klitorisimi yanlış bi şey olarak, kötü bi şey olarak görmüyorum, zaten onunla doğmuşum, o benim bi organım yani hani ben bunu kabullenicektim, bi ilişki yaşıycaksam da bedenimin o haliyle yaşıycaktım, zaten beni o şekilde kabul eden bi partnerle yaşardım, kabul etmese zaten onunla birlikte olmazdım…. hani bunları şu an nası aştıysam, senle nası konuşabiliyosam yine aşardım yani ve, hani ruhsal olarak da çok daha sağlıklı bi insan olucaktım eminim ki."

[151] "Yani mesela o testsiler alınmasa, ufak da olsa bi kanser riski varsa bile ben düzenli olarak doktora kontrollerime giderdim, ama testislerim dururdu ve testeteron üretmeye devam ederdi, dolayısıyla nolurdu benim mesela şu anda bi kemik erimesi riskim olmazdı…. şimdi mesela ben jinekoloğa gidersem pembe kimlik sahibi olduğum için bana testesteron vermiycek, östrojen vericek, ama benim testislerim alınmasaydı zaten vücudumun kendi doğal hormon dengesi bozulmamış olcaktı, o testosteron beni östrojen replasmanıyla giderilmesi gereken risklerden koruycaktı."

4.1.2.1 Lack of Access to Medical Care

Meral, Deniz, and Berfin share a mistrust in the medical establishment as a result of their experiences of medical treatment. The biggest reason of their mistrust in medicine is that their own experiences of, as I showed above, do not match with what medicine envisioned for them. Traditional treatment paradigm of intersex defines sex in a strictly binary way and imposes this definition on intersex bodies at the expense of causing harm. Thus, Meral, Deniz, and Berfin do not believe that clinicians' motivations are purely medical, and they avoid seeking medical help in relation to their intersex condition, even if they would like to. For example, Meral says:

> "These surgeries are so far from being medical; in fact, in my syndrome, Xo-XY Turner, there's risk of uterine cancer, but with me, during the surgery, in spite of this, my uterus wasn't removed… They just removed the testicles and fixed the clitoris. I mean, why don't they remove my uterus? Cause, you know, I'm supposed to think that I menstruate, taking hormone pills. They didn't remove it although there's cancer risk. If they asked me, in fact, I wanted to get rid of that. Right now, I'm living with a time bomb in my body, you know; I'm living with the risk of that uterine cancer right now. I passed 30, there's even higher risk. For instance, normally, I should go to the doctor right now and have it checked and keep it under surveillance, and maybe have it removed, but, you know, I can't go, I mean, because of the phobia of doctors, unfortunately… [breath]… It's like that, you know…"[152]

Referring to the controversy around the removal of testes based on the risk of cancer they pose, Meral means that the testes are removed easily in female-assigned intersex people, because it disturbs the sex binary, rather than because it carries a risk of cancer. The fact that their uterus was left inside whereas testes were removed is a proof of it for Meral.

Berfin also avoids hospitals: "Due to all the fear and situations I went through at hospitals, unfortunately, I'm, you know, 44 years old and I never went; I was scared."[153]

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[152] "Bu yapılan ameliyatlar o kadar tıbbi olmaktan uzak ki aslında, benim sendromumda, Xo-XY Turner'da rahim kanseri riski var asıl, ama bende ameliyatta buna rağmen rahmim alınmadı…. sadece testisleri alıp klitorisi düzelttiler, yani neden almıyo rahmimi, çünkü işte regl olduğumu zannetmem gerekiyo ya hormon ilaçlarını içip falan, kanser riski olduğu halde onu almadılar, ben asıl bana sorsalar ondan kurtulmak istedim, şu an hani bedenimde bi saatli bombayla yaşıyorum, vücudumda o rahim kanseri riskiyle yaşıyorum şu an, 30"u da geçtim, daha da yüksek bi risk var, mesela normalde benim şu an doktora gidip onu kontrol ettirmem, takip altında tutmam lazım, belki aldırmam lazım falan, ama işte gidemiyorum yani, doktor fobisi yüzünden ne yazık ki..[nefes].. böyle yani…"

[153] "Hastanelerden yaşadığım onca korku ve durumdan dolayı malesef işte 44 yaşıma geldim, asla gitmedim, korktum."

Other than the lack of access to healthcare created by mistrust in medicine, in some cases, medical professionals reject patients who seek medical help based on moral reasons. For instance, after Berfin had surgery, they were prescribed with hormone pills, and told that they should "come back when getting married," in order to open a vaginal canal; Berfin was not provided with the option to have their vaginal canal opened before getting married. Similarly, another intersex person with whom I met during an informal gathering and who has a similar condition to Berfin's was told the same thing after she had surgery. She was 15-16 years old when she had surgery, and she was told "to come back before marriage." When she specifically asked about the option to have her vaginal canal opened without getting married, she was rejected by the response "not possible,"[154] without being provided further explanation. This person is now in her early twenties, which means that this happened around 7-8 years ago. Thus, while early, non-consensual medical interventions continue to constitute a problem for intersex people, some medical interventions can be denied even if the patent demands it, based on moral reasons.

Lastly, an intersex person may not be able to reach medical help due to structural reasons, because of organization of sexual health based on sex binary, as in the case of Deniz:

> "About a month ago, I went to the [ward of] internal medicine and said: 'I'm having a terrible pain in my… chest…' They said: 'we can't see you, go to the endocrinology'. I went to the endocrinology, but they didn't know what to do. If it were a woman, they could go to gynecology due to chest pain, but I can't. Where should I go then, what should I do? There are problems of this kind."[155]

4.1.2.2 Intersex Voices and the Medical Narrative

Like Dr. Bülent, some clinicians I interviewed suggested that their intersex patients must be doing well because they do not come back to complain. Thus, there is a perceived lack of complaint from the viewpoint of the clinicians. Based on this perception, they argue that only few people are harmed by the medical procedures because of surgical side-effects or because they went to a "bad clinician," but otherwise there is a "happy majority" who do

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[154] "olmaz"

[155] "Yaklaşık bir ay önce ben burada dahiliyeye gittim dedim ki çok fena şey sancısı çekiyorum dedim göğüs sancısı çekiyorum dedim ….biz sana bakamayız dedi endokrine git dedi, endokrine gittim bir şey anlamadı. Eğer bir kadın olsaydı göğüs sancısından kadın doğuma gidebilirdi ama ben gidemiyorum, ben nereye gideceğim o zaman ne yapacağım? Bu tarz problemler oluyor."

not bother to talk about their medical history. This is why medical professionals tend to prioritize the discussions on surgical methods and the quality of the clinicians when they are challenged about the possible harmful consequences of medical procedures. However, as I show here, physical pain is not central to the narratives of Meral, Berfin, and Deniz; rather it is the experience of having to go through surgery and medical treatment that caused most harm to them.

My data also shows why intersex individuals may not want to speak back to the clinicians. Let alone going back to complain, Meral, Deniz and Berfin do not even want to go to the hospital for their health problems. Moreover, they may perceive the asymmetry of power between them and the clinicians as a major barrier to speaking to them directly. As Deniz's story shows, they may think that they would not be able to express themselves in a medicalized context which does not recognize them as subjects with agency. Deniz's narrative also reminds us that children who go through treatment never have the chance to have an alternative experience of growing up without going through medical treatment to compare with; so, the patients may internalize the medicalized viewpoint and frame their suffering as the normal state of things:

> "For example, even though I was aware of some things, I wasn't, you know, reflecting it to my family, cause I thought that they were already spending a lot of effort for me; I'm already a sick person according to them, someone who needs to be fixed, I'm already a big burden to them, so I didn't want to worry them, so I acted the way they wanted me to, and I acted as if I didn't hear some things, even though I did."[156]

As a child, Deniz could not resist medical and parental authorities, because they internalized the medical point of view. This shows that patients can internalize the role they are attributed, which might be another reason behind the lack of complaint. If someone regards themselves as "just like any other patient," then they are also likely to see their suffering because of their condition, not because of the medical treatment procedures. In short, the silence of many intersex individuals does not necessarily mean that they are happy with the

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[156] "Mesela ben bir şeylerin farkında olsam da şey yapmıyordum hani bunu aileme yansıtmıyordum çünkü zaten benim için çok fazla emek harcıyorlar diye düşünüyordum, zaten onlara göre hani ben hasta biriyim düzeltilmesi gereken biri, ya zaten ben onlara büyük bir külfet oluyorum, bir de onları üzmek istemiyordum, onun için onların istediği gibi davranıyordum, bir şeyleri duysam da duymuyor gibi davranıyordum."

results of their medical treatment. There might be many other reasons including stigma, discrimination and medicalization that silence them. Meral puts it as:

> "This is, you know, like a domino effect; if you're intersex, you're ostracized, and when you're ostracized, you might not be able to finish your education, cause there are problems at school, too. Your education is left half finished, and when your education is left half finished, you can't gain a profession that you can stand on your own two feet with. When you can't gain that profession, you're unemployed and then your status of class lowers. When your status of class lowers, the rate at which you're taken seriously diminishes, you're shier, or you can't reach the places you're supposed to reach. You know, it's such a spiral that once you fall into it, it's hard for you to get out of it, so in order to carry out activism, you have to have reached a point where you can get a little bit out of that spiral; unfortunately, this is the truth. So, you know, the people who need this activism the most are, in fact, the people who are at a position that cannot make that activism, right now."[157]

Deniz, Berfin and Meral's stories are not just exceptional stories where the medical treatment went wrong. Even if their medical conditions and social backgrounds are different from each other, they recognize similar patterns in each other's stories:

> "There are various different biological situations, syndromes within the scope of intersex; very different from each other; some genetic, some hormonal, etc., but the medical processes are always the same… No matter what the syndrome, their personality or age is, the medical process is always the same; it worked very similarly with everyone. In that respect, we understood that the things we went through and felt related to those medical processes are very similar; that those feelings are very similar… [Another intersex activist] and Berfin wrote articles that told about their own pasts. When I read those articles, I remember feeling sometimes like: 'But this is the article that I wrote. Did they steal it from me?' I mean, it's so much the same feeling… We went through the same things; we felt the same feelings because of those medical processes. In fact, that is the point that brings us together the most; I mean, those damages that medicine made or left on our bodies, their psychological repercussions on us… As we got to know each other, we understood that that was our strongest common point. Even

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[157] Bu hani zincirleme bişey, intersekssen dışlanıyosun, dışlandığın zaman eğitimini tamamlayamayabiliyosun, okulda da çünkü sıkıntılar oluyo, eğitimin yarım kalıyo, eğitmin yarın kalınca sana kendi başına ayakta durabileceğin bi meslek kazanamıyosun, o mesleği kazanamayınca işsiz kalıyosun, o zaman da işte sınıfsal konumun düşüyo, sınıfsal konumun düşünce ciddiye alınma oranın daha azalıyo, daha çekingen oluyosun, ya da ulaşman gereken yerlere ulaşamıyosun, hani bu öyle bi sarmal ki, onun içine bi kere düştün mü ordan çıkman zor yani, dolayısıyla hani aktivizm yürütebilmen için birazcık daha o sarmalın dışına çıkabilcek bi noktaya gelmiş olman gerekiyo hayatında ne yazıkki hani bu gerçek, dolayısıyla hani aslında bu aktivizme en çok ihityacı olan insanlar o aktivizmi yapamayacak konumda olan insanlar şu anda."

> though all our personalities and pasts are very different, we looked very much like each other in that sense."[158] (Meral)

As activists, they are also connected with many other intersex individuals from different parts of the world, and they recognize similar patterns in their stories as well; in Berfin's words, "Wherever you go around the world, the story of the intersex is always the same." [159]

From the viewpoint of medical professionals, I interviewed, intersex treatment procedures are highly variable, and they are in constant change; they are highly individualized according to the patient as well as according to the clinician, and the medical technologies. Yet, from the point of Deniz, Meral and Berfin, the consequences of these treatments are very similar.

As I showed in Chapter 2, clinicians tend to dismiss the personal testimonies of intersex activists and individuals who challenge the treatment procedures based on arguments such as they just represent an unlucky minority who suffered exceptionally much from the "side-effects" of the treatment. Yet, as I show in this chapter, Berfin, Meral, and Deniz mentioned the "side-effects" of surgery, or hormone treatments only as of secondary importance of their suffering. Rather, they mentioned the consequences that stem from the very process of going through those treatments: they feel humiliated, ignored, and objectified.

These are stories that are not visible in clinicians' narratives, not so much because clinicians' narratives are contrary to Berfin, Meral, and Deniz's stories as because they are the stories that can only be told from their subject position. They are also the stories of *persons* who have feelings, emotions and social lives outside of the clinic. Many things in clinicians' and intersex activists' personal stories actually correspond to each other; yet, the intersex

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[158] "İnterseks kapsamında çok farklı biyolojik durumlar, sendromlar var, birbirinden çok farklı, kimisinin genetik, kimisinin hormonal vs., ama tıbbi süreçler hep aynı….sendrom ne olursa olsun, kişiliği ne olursa olsun, yaş ne olursa olsun, tıbbi süreç hep aynı, çok benzer işlemiş herkeste. O açıdan o tıbbi süreçlerle ilgili yaşadığımız, hissettiğimiz şeylerin ne kadar birbirine çok benzer olduğunu, o duyguların birbirine çok benzer olduğunu anladık…..[başka bir interseks aktivist], Berfin, kendi geçmişlerini anlatan yazılar yazdılar, o yazıları okuduğumda bazen böyle şey hissettiğimi hatırlıyorum, "e bu benim yazdığım yazı, benden mi çalmış acaba" hissine kapılıyosun, yani o kadar aynı duygu ki.. aynı şeyler yaşanmış, aynı duygular hissedilmiş o tıbbi süreçler yüzünden, aslında bizi en çok ortaklaştıran nokta o, yani o tıbbın bedenimiz üzerinde yaptığı, bıraktığı hasarlar, onun bizdeki ruhsal yansımaları, en en.. güçlü ortak noktamızın o olduğunu anladık birbirimizi tanıdıkça, hepimizin hani kişilikleri, geçmişi filan çok farklı olsa da o açıdan birbirimize çok benziyoduk. (Meral)

[159] "Dünyanın neresine gidersen git intersekslerin hikayesi hep aynıdır."

individuals were affected in quite different ways than most clinicians think they would be. For instance, most clinicians consider assigning the “correct gender” as one of most important measurements of success in treatment. In the narratives of Meral, Berfin, and Deniz, however, it was not mentioned. While being assigned the wrong gender can be a problem, there are also many other problems that are largely ignored by clinicians even if the “correct gender” is assigned. Deniz, Berfin, and Meral do not complain as much about their gender category as they complain about the narrow category of gender they were forced into. Another example is that as I show in Chapter 3, clinicians can hide crucial information regarding the intersex status of the patients, because they think it would be “traumatizing” or “confusing” for the patients. This information was also kept secret from Deniz and Meral until they found out later in their lives; yet, it did not protect them, but rather it contributed to their feelings of shame and confusion, and it alienated them from their bodies. Moreover, finding out marks the beginning of a process of empowerment and healing in their stories, no matter what their initial reactions were. Berfin knew their intersex status, yet they did not know the term “intersex” until they specifically asked a clinician at the age of thirty-nine. Knowing themselves by the terms “intersex” enabled Berfin to reach the community and marked the beginning of their activism. Third, as a justification for clitoris reduction, surgeons suggested that it would be embarrassing for a girl child to have a large clitoris because it could be noticed by other girls. Meral, who had clitoris reduction in in her teenage years, already had gone through childhood with their clitoris when they had the operation. Meral was traumatized because their clitoris was operated, not because it existed. Fourth, as I show in the Chapter 3, clinicians make a distinction between their patients based on their socioeconomic status and education levels, and they can attribute non-compliance of the patient to reasons such as inability to understand and low level of education. From this point of view, Berfin, who grew up in a village, and who did not attend higher education, would be considered as such a patient. Yet, as I show in this chapter, Berfin did not comply with the clinicians’ instructions of hormone treatment, because they did not have an interest in conforming to the social norms of the gender they were non-consensually assigned; additionally, they are one of the leading activists today. Fifth, the process of medical examinations holds a large place in the intersex stories as a source of trauma, and because of their intrusive nature, physical examinations can be defined as “child abuse,” whereas a discussion of the effects of examinations is almost absent from the clinicians' narratives. From the viewpoint of the clinicians, the effects of the medical procedures are evaluated only in terms of their physical results, or sometimes in terms of the contentment of the parents; however, the effects of the very experience of going through the treatment are usually not taken into account. Last but not the least, from the medical viewpoint, the patient reaches a non-intersex state as a result of the treatment, whereas Deniz, Meral, and Berfin do not feel less intersex as a result of the medical procedures they went through. Rather, medical procedures only contributed to the amount of pressure to conform to gender roles for them.

4.1.2.3 Peer-Based Information

If the early, non-consensual medical treatments do not help intersex individuals cope with social discrimination, there is one thing that does: community. For Berfin, Meral, and Deniz, meeting each other has been very empowering, because community provided them non-medical information and support, which was crucial in making their experiences intelligible to them. Meral explains how peer-based information was crucial to them in embracing their identity as intersex, by comparing it to embracing their identity as lesbian:

> "I've first tried to accept myself through… You know, like 'I'm probably gay. Am I a lesbian?', etc. You know, slowly, right at that time, the internet was becoming widespread, etc. You know, I was entering gay websites, looking at associations' websites, etc. I started corresponding with some people. You know, at first, I started out by accepting my homosexuality. I still couldn't find sufficient resources about the intersex in those years anyway. The word intersex wasn't used much anyway, and when I put in hermaphrodism, always medical stuff would come up and you can't understand anything from that… For many years, although I knew I was intersex, I couldn't do anything about it, I couldn't talk to anyone, etc., cause I didn't know. Neither could I reach someone else about it, nor were there resources, etc. So, I got to accept and know myself as I learned."[160]

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[160] "Hep işte ilk önce şeyden kabullenmeye çalıştım kendimi …. hani işte eşcinselim heralde, lezbiyen miyim ben vesaire gibi, işte yavaş yavaş, hani tam o dönem de internet de yaygınlaşıyodu filan, işte eşcinsel sitelerine giriyodum, derneklerin sitelerine bakıyodum filan, birileriyle yazışmaya başladım filan işte, hani ilk öyle bir eşcinselliğimi kabullenmekle başladım, hala interseks hakkında zaten yeterli kaynak bulamıyodum internette o yıllarda, interseks kelimesi de fazla kullanılmıyodu zaten, hermafrodizm yazdığım zaman da zaten hep tıbbi şeyler çıkıyodu karşımıza, ondan da bişey anlamıyosun….baya uzun yıllar interseks olduğumu bildiğim halde bunun üzerine bişey yapamadım, kimseyle konuşamadım vs. …. bilmiyodum çünkü, bu konuda ne başka birisine ulaşabilmiştim, ne kaynak vardı vesaire, dolayısıyla öğrendikçe hani kendimi kabullendim, tanıdım."

Meral defines “learning” as having access to peer-based information. Even if Meral conducted a lot of research about the medical details of their condition, does not count as “learning” for Meral since it did not really help them make sense of their experience as an intersex person, while Meral accepted their sexual orientation more easily because they could reach peer-based information over the internet. Yet, it took longer to accept being intersex because they could reach only medical information for a long time. Reaching peer-based information and learning from them is a turning point for Meral in processing their intersexuality and come to terms with it.

Accessing peer-based information not only transformed Meral, but also transformed their family relationships. Meral’s parents, too, had received only medical information about Meral’s condition, which made it difficult for them to talk about it:

> “They were shy. They wouldn’t talk about the fact that the medical process that I went through could have created a trauma in me… They just saw it like, let’s say ‘you had a mole on your face and we had it removed, it’s over, it’s done’; that’s how my parents saw it.”[161]

After Meral started reaching community over the internet, they were able to share their non-medical view of their experiences with their parents as well:

> “Then I decided to talk to my mom; I told her: ‘I know that I’m intersex. I’m now trying to accept it and I don’t see myself as wrong. I like women…’ I told her all about it. For the first time, after many years, really [with emphasis] me and my mom ended up having such a conversation, you know, for the first time, we talked between us and all… Despite that… Even then, I couldn’t tell my mom how much trauma the surgery caused in me, how it scarred me. Just newly we can talk about it a little, my mom and I; and she says, you know: ‘we were ignorant back then. I wouldn’t have it done if I knew. I’m sorry.’”[162]

Meral’s mother, after listening to the non-medical version of the story from Meral’s perspective, regrets the decision of surgery. Thus, Meral’s story shows how important peer-

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[161] “Çekiniyolardı, onlar o geçirdiğim tıbbi sürecin bende bi travma yaratmış olabileceği üzerine konuşmuyolardı….bunu sadece şey gibi görüyolardı işte, atıyorum “yüzünde ufak bi ben vardı, benini aldırdık, bitti gitti, kapandı” gibi, bu şekilde bakıyolardı annemle babam.”

[162] Annemle konuşmaya karar verdim sonra, anlattım işte, “ben işte interseks olduğumu biliyorum, bunu işte artık kabullenmeye çalışıyorum, ve hani kendimi yanlış olarak görmüyorum, işte kadınlardan hoşlanıyorum…” bütün hepsini işte anlattım, ilk defa hani annemle çok.. uzun yıllardan sonra gerçekten[vugulu] böyle bi paylaşımda bulunmuş olduk, hani böyle ilk defa kendi aramızda konuştuk falan….ona rağmen…. o zaman bile tam anneme ameliyatın bende ne kadar travma yarattığını, ne kadar yaraladığını tam anlatamamıştım, daha bunu birazcık yeni yeni konuşabiliyoruz annemle yani, o da şey diyo yani, işte “cahildik o zaman, bilseydim yaptırmazdım, özür dilerim” falan dedi bana yani.

based information, as opposed to medical information, can be in supporting both intersex individuals and their parents.

Meral, Deniz and Berfin were subjected to social pressure, discrimination and stigma because of their intersexuality; yet, the medical treatment they received did not provide help with dealing with these problems. Still, they were able to open the spaces in their lives to be themselves thanks to their own strength and struggle, even in the face of the social and medical pressures that they faced. Their stories show that the only way to help them enhance their lives as intersex people would be to support them in their struggle to be themselves.

4.2 Activism, Echoes from the Medical Community, and Possibilities toward Change

4.2.1 Intersex Activism in Turkey

Meral, Berfin, and Deniz are among the first intersex activists who started the intersex movement in Turkey. Meral was involved in Lambda in the late 2000s, first with their lesbian identity. Then, finding motivation and support from the community, Meral decided to write a piece about their experiences as an intersex individual in order to be published in Kaos GL website. This was as important for Meral as much as it was important for the start of the intersex movement in Turkey: "You know, writing that article and pouring it out…; That article was when I first expressed myself entirely, with all of myself, saying 'I'm intersex'. It was very transforming for me,"[163]Meral says. In 2011, Meral opened a blog "İnterseksüel Şalala[164]," where they collected such written pieces. İnterseksüel Şalala thus became the main source of information in Turkish, and a tool for intersex individuals around Turkey to find each other; Berfin and Deniz also found Meral thanks to this blog. With Meral's involvement in Lambda, LGBT movement started to learn more about intersex, and shortly after the abbreviation started to be used as LGBTİ with the addition of "İ." Meral tells the story of addition of "İ":

> "At that time, as the article drew attention when it was read, and after meeting the people at Lambda, we started organizing meetings within Lambda. You

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[163] "hani o yazıyı anlatıp dökmek, ilk defa benim hani tam olarak, bütün her şeyimle interseksim diye kendimi ifade ettiğim şey oldu o yazı, çok dönüştürücü olmuştu benim için"

[164] https://intersexualshalala.wordpress.com/

> know, I went there two or three times to tell the LGBT activists about intersex; 'what is intersex, where do we live, how can the LGBT activism help the intersex activism, what can be done?' We held meetings about this within Lambda. Thus, LGBT activists learned some things about intersex and this way, 'I' was added at the end of LGBT. Thanks to those meetings I did at Lambda, all those Kaos GL, you know, in those gay and lesbian publications, etc. the expression 'LGBTI' started being used."[165]

By the summer of 2013, also with the help of the increasing visibility during the Gezi movement, the abbreviation LGBTİ was adopted more widely, including mainstream media organs in Turkey:

> "The first time that it became widespread was during the Gezi period; you know, in Hurriyet newspaper, when Gezi events were mentioned, when it said LGBT, the 'I' was added and it became widespread; that was 2013. But in Kaos GL, etc., you know, saying LGBTI had started right after those meetings; and that was 2010 or 2011. Lambda released a press statement about that meeting; you know, a press statement that said: 'we apologize for not including intersex within the LGBT activism all this time. From now on, we will include the intersex in the scope of our own struggle', etc. We even wrote the mutual text together; we wrote a statement like that and that was a first in Turkey. For the first time, intersex was thus included in the LGBT movement. While all this was being done, I didn't know any intersex person, other than myself *(laughs)*. You know, we're writing these fancy press statements with Lambda and all that, but there is only one intersex there *(laughs)*."[166]

Later, Berfin and Deniz, among others, reached Meral via the blog İnterseksüel Şalala, and they have been active in the movement since then. With another activist, Berfin held the first intersex panel during the Istanbul Pride Week in 2013. Since then, Berfin has been involved in more than twenty events including panels and interviews in various media

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[165] "O dönemde, yazı da okununca ilgi çekince, Lambda'daki arkadaşlarla falan tanışınca, Lambda"nın kendi içinde toplantılar yapmaya başladık, işte iki üç sefer ben gittim ordaki LGBT aktivistlerine interseks'i anlattım, interseks nedir ne değildir, nerde yaşıyoruz, LGBT aktivizmi interseks aktivizmine nası yardımcı olabilir, neler yapılabilir, bu konuda toplantılar yaptık Lambda"nın kendi içinde. Böylece LGBT aktivistleri de interseksle ilgili bişeyler öğrenmiş oldular, o şekilde artık LGBT'nin sonuna İ de konmaya başladı. Benim o Lambda'da yaptığım toplantılar sayesinde bütün o işte Kaos GL filan işte, gey-lezbiyen yayınlarında falan işte LGBTİ ibaresi kullanılmaya başlandı."

[166] Medyada filan ilk yaygınlaşması Gezi döneminde oldu, hani Hürriyet gazetesinde falan Gezi olaylarından bahsedilirken LGBT denirken İ"nin de konmaya başlaması, yaygınlaşması 2013, ama Kaos GL'de falan hani böyle LGBTİ denmeye hemen, o toplantılardan hemen sonra başlamıştı, 2010-2011 o zamanlarda. O toplantıyla ilgili Lambda bi basın açıklaması yayınladı, işte "bu zaman kadar LGBT aktivizmin içine interseks dahil etmediğimiz için özür diliyoruz" minvalinde bi basın açıklaması yayınladılar, bundan sonra interseksleri de kendi mücadelemizin kapsamına alıcaz vesaire, ortak hatta metni de birlikte yazdık, öyle bi açıklama yazdık, o da Türkiye'de bi ilk oldu yani, ilk defa o şekilde LGBT hareketinin içinde interseks de dahil edilmiş oldu. Bütün bunlar yapılırken ben daha hiçbir interseksi tanımıyorum kendimden başka [gülüyor], hani Lambda'yla filan şeyli böyle süslü basın açıklamaları filan yazıyoruz ama ortada sadece bir tane interseks var [gülüyor].

organs, both in Turkey and abroad. Among other panels, Berfin positions the panel they held for medical students at Istanbul Çapa Medical School in May 2016 as “the most important panel.” The activist group also provides support and consultation to parents of intersex children, who reach them via other LGBTI+ organizations.

For the future, Berfin mentions their vision as “First of all, the fate of intersex children need to be saved from the doctors’ and the family’s hands; there must be state protection.”[167] Meral says that they envision an intersex movement that reaches other groups beyond the LGBTI+ movement: “we need to establish contact with the people that we need to win over in the fields of law and medicine. You know, I say: ‘I wish we could do that’ at the moment.”’[168]

4.2.2 Echoes of the Intersex and LGBTI+ Movement in Clinicians’ Narratives

All of the clinicians I interviewed are aware of the increasing global tendency toward eliminating or postponing the early, non-consensual, cosmetic surgical operations performed on children with intersex traits and variations of sex characteristics. As I show in Chapter 3, a common manifestation of this awareness is to refer to the socioeconomically lower status of the patients as a justification to hold on to the old treatment paradigm. Even if it shows the resistance, it also shows the need to respond to the intersex rights movement on the part of the clinicians. In Chapter 2, I show other ways in which the movement is influential; the clinicians try more to avoid irreversible surgeries, and at least in discourse most of them embrace the new paradigm. In this section, I will show how the intersex movement echoes in the clinicians’ narratives in more explicit ways.

For instance, during his class in which he gave a lecture about DSD to medical students, pediatric surgeon Dr. Ali allocated some of the slides in his presentation to talk about the lack of informed consent of the patients and the challenges that are posed by the intersex activist groups on this ground. He also included several slides with the pictures of the

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[167] “Öncelikle interseks çocukların doktor ve ailenin iki dudağı arasından kurtarılması gerekiyor, devlet koruması olmalıdır.”

[168] “hukuk ve tıp alanında yanımıza almamız gereken insanları yanımıza almamız için onlarla bi temas kurmamız lazım, hani onu da yapabilsek keşke diyorum şu anda.”

protests by the activist groups. In this framework, he talked about how he abandoned performing clitoris reduction surgeries completely during the course of his practice, stating that it also inspired some others to do the same. Even if he does not fully agree with the activists who advocate for eliminating all types of cosmetic surgeries, the lecture nevertheless perplexed the students and elicited many questions regarding the ethics of the issue at the end of the class.

Among my informants, Dr. Bülent is the only clinician who explicitly referred to the LGBTI+ movement in relation to the rising challenges to the early cosmetic surgical operations. While he was explaining the treatment procedures to me, he posed it as the main challenge he faces in his practice: "The real problem is whether we should intervene or not… we are under immense pressure from the LGBT, especially about the cosmetic[169] side of the issue. There are serious problems about that."[170]

Dr. Bülent is quite social with his students. I was referred to him by one of his students who is a member of an LGBTI+ group of the university he currently works at; this student described him as a professor who is open-minded and also open to conversation, referring to debates he had with Dr. Bülent on the issue. Dr. Bülent also invited a group of his students to attend and listen to one of our interviews, which turned into an interesting discussion session later. In this discussion, one of the students in the room referred to fluidity of gender, saying: "Professor, I had heard that there are people who feel like a woman one year and then like a man, the next; they name themselves a bit like that; people who say: 'I don't want to define myself, cause I feel that I change'…"[171] Dr. Bülent responded: "We started out [the conversation] there… Since I started doing this, I [realized] that there is no such thing as male sex and female sex; that it is a spectrum and there are a lot of transitions from place to place, anyway."[172] I find this conversation important because Dr. Bülent steps out

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[169] Here, I use this word as a translation of "pertaining to physical appearance."

[170] "asıl sorun dokunalım mı dokunmayalım mı….işin görünüş kısmı ile ilgili LGBT'nin korkunç baskısı altındayız, onunla ilgili ciddi sorunlar var."

[171] "Hocam bir de kendini bir yıl kadın gibi hisseden bir yıl erkek gibi hisseden, yani o insanların kendileri söylüyor bunu, insanlar da olduğunu duymuştum kendilerini biraz öyle adlandırıyorlar. 'Ben kendimi tanımlamak istemiyorum çünkü değiştiğimi düşünüyorum' diyen insanlar…"

[172] "Başta ordan başladık…. Zaten ben bu işi yapmaya başladığımdan beri artık erkek cinsiyeti dişi cinsiyeti gibi bir şey olmadığını, bir spektrum olduğunu, oradan oraya bir sürü geçişler olduğunu [anladım]."

of the medical narrative of "true sex"; instead, he discusses intersex in relation to the subjective experience of gender and sexuality.

Several of the clinicians - including three of four surgeons - brought up legal concerns even if I did not pose any questions to them in this topic, which shows that it is an issue at the back of their heads. A pediatric endocrinologist referred to legal concerns as one reason why they try to postpone gonadectomies: "I mean, you know, normally it's more suitable that they decide for themselves, cause otherwise, they may, you know, bring the doctor into question and, you know, say: 'Why did I undergo gonadectomy? That was my gonad'. I mean, a legal process may start there, so, not to go into that thing, since that's what's right, too." (Dr. Birsen)[173]

One pediatric surgeon was concerned that he might be more vulnerable to legal action because the details of the surgeries are not decided on the DSD team reports in the hospital he works; only the assigned gender is: "We decide the sex all together [at the council]; there's no problem there, cause we have the Sexual Research Council and everybody signs under that… But all the surgeries that will be performed after a decision is made to turn into female, … there are a lot of different kinds of surgery and they're all in my [initiative], and when I enter the surgery, I'm by myself. In everything I do, individuals are going to sue me."[174]Another pediatric surgeon brought it up during the class he was teaching on DSD: "Another aim of the council is to protect the doctors. In areas where it is difficult to make a decision and where there is possibility to make a mistake too, you share the blame."[175]Similarly, another pediatric surgeon said, "I mean, these are not decisions that you can make by yourself. I mean, this is really something that brings judicial responsibility."[176]

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[173] "yani hani kendisinin karar vermesi daha uygun normalde çünkü aksi de yarın öbür gün şey yapabilir doktoru zan altında bırakıp hani niye gonadektomi yaptırdım, hani o benim gonadımdı diyebilir yani orada hukuki bir süreç başlayabilir, o yüzden hiç o işe de girmemek, doğrusu da o olduğu için" (Dr. Birsen)

[174] "(konseyde) oturup hep birlikte karar veriyoruz cinsiyetine orada bir sorun yok, çünkü CAK kurulu var cinsel araştırma kurulu var bizde, onun altına herkes imzalıyor …. ama dişiye çevirmeye karar verildikten sonra yapılacak ameliyat, bir sürü ameliyat şekli var, hepsi benim şeyimde [insiyatifimde], ameliyata girdiğim zaman ben yalnız başımayım, yapacağım her şeyde bireyler ilerde beni dava edecekler" (Dr. Bülent).

[175] "Konseyin bir amacı da doktorları korumaktır, karar almanın zor olduğu, yanlış yapma ihtimalinin de olduğu yerlerde bu suçu paylaşmış oluyorsunuz." (Dr. Ali)

[176] "yani bunlar tek başına alacağın kararlar değil, yani bu gerçekten adli sorumluluk getiren bir şey (Dr. Engin).

However, legal concerns might not be as effective as other factors -such as gaining a genuine awareness about the consequences of the early surgeries- in leading to change towards postponing the surgeries, since the clinicians can find ways around these legal imperatives. For instance, as explained in the 2.1.3, surgical techniques vary tremendously not only among the surgeons but also among the patients of an individual surgeon. They are updated constantly, with the purpose of solving the problems observed in the former methods, and by the time the patients grow up and open court cases about the harmful consequences, new methods are already developed. So, there is always a time lapse between the surgeries and the collection of evidence about their harmful consequences. For example, pediatric surgeon Dr. Bülent referred to a court case in the US to explain why he -along with others in the medical community- started to use a new method in clitoris reduction operations. Before, clitoris was cut from the top, including the part with high nerve density. After a court case brought against this kind of operation, Dr. Bülent says:

> "With that, we had great difficulty… And I always perform these surgeries. What should we do, what should we do? We found another method. Remember I said: 'The penis can be divided in three as corpus cavernosum and glans'; we divided it in three… we divide this *(shows by drawing)* these and this, too… And we take and bury this thing that we divided, into the labia majora."[177]

Here, Dr. Bülent explains the new method of clitoris reduction operations, where the tip of the clitoris including the higher density of nerves is preserved, and the clitoris is "buried" instead of being cut, as explained in section 2.1.3. However, later in the conversation he also said that different kinds of side-effects were observed as a result of the surgeries in which he used this method, and so he ended up having to operate again and remove parts of the clitoris in these patients. In other words, the new method developed as a caution to legal action did not necessarily provide a better outcome for the patients.

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[177] "Bunun üzerine biz de büyük bir sıkıntıya düştük… Ben de hep bu ameliyatları yapıyorum, ne yapalım ne yapalım diye… başka bir yöntem bulduk, dedim ya iki tane corpus cavernosum ve glans şeklinde penis üçe ayrılabiliyor diye, onu üçe ayırdık …. bunu ayırıyoruz *(çizerek anlatıyor)* şunları şunu da …. şöyle ayırdığımız şeyi de şu getirip büyük dudakların içine gömüyoruz. (Dr. Bülent)

4.2.3 Lack of Interface between the Medical and Activist Communities

In a later conversation with Dr. Bülent, he referred to another pediatric surgeon Dr. Ziya, and told "a very interesting story" about Dr. Ziya attending to an LGBT panel in Istanbul around fifteen years ago. Dr. Ziya is one of the first pediatric surgeons and one of the founders of the field in Turkey. Dr. Bülent suggested me to interview Dr. Ziya and added: "If you talk [to him], there may be very interesting things in his memories about other patients."[178] Excited about interviewing him, I made an appointment with Dr. Ziya in the private hospital he started working after his retirement. To my surprise, Dr. Ziya was anxious to meet me. He asked me if I were a journalist; he let me record the interview, but he seemed more uncomfortable when the recording started, so I turned it off after a while and did not record the rest of our conversation. After asking me a few questions about why I do this research, he started summarizing the standard medical treatment procedures of some common conditions. When I asked a question to him about a seeming paradox, he nervously smiled, and added, "See, these are not such simple matters; these are very complicated matters, but you, for instance, come and *interrogate me*."[179]

After I turned off the recording, once again he said: "How are you going to write now exactly? You know, maybe you're a journalist and come to me, saying it's a thesis. There's nothing [suspect] in what I tell you anyway, but…"[180]I offered to provide official proof of my status as a researcher, but he rejected immediately. I was surprised to see him in a defensive position; after all, he is one of the most well-respected pediatric surgeons in Turkey, and I did not understand why he felt anxious. Still, he had a kind and friendly attitude, and he was willing to help me. So, I decided to keep the rest of the interview as unstructured as possible, in order to avoid asking him questions that might be perceived as "interrogation."

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[178] "Konuşursan onun anılarında başka hastalarla ilgili olan çok ilginç şeyler de olabilir."

[179] "İşte bak gördün mü bunlar bu kadar basit konular değil, bunlar çok karışık konular ama şimdi sen mesela gelip *ifademi alıyorsun*" (emphasis added)."

[180] "Sen şimdi tam nası yazacaksın, hani gazeteci olursun belki tez diye geliyosun, gerçi hani bu anlattıklarımda bir şey yok ama…"

Thus, Dr. Ziya shared with me a few anecdotes which he thought would be important for this thesis, considering my position as a social scientist. One of these anecdotes is the one I mention in section 3.3, where he talked about the video-attendance of an intersex activist in a medical conference about intersex, held in 1996, about twenty-one years ago from the time of the interview. The activist posed the question, as Dr. Ziya reports, "did you ask me when removing my gonads?" in this video, which left a profound impact on him. Later, he told me a second anecdote, which was the story I listened from Dr. Bülent earlier:

> "Back in the day, when I was dealing with these matters; and I don't remember what year it was, but, one day, I was going in the car and the radio was on. It was Acik Radio, or something. On the radio, they were talking about a speech at Bilgi University, and I realized I was near there, so I thought, 'let me go there'. The topic of the speech was homophobia, meaning fear of homosexuals. I went there. Professor (name of a prominent psychiatrist) was there too. When she saw me, she said: 'Oh, come, professor. Look, they're talking about your subject', so I went and sat at the side, somewhere nonassertive. … The speech was finished and finally they asked if there were any questions. No one asked a question. Then they looked at me, asking if I had a question and I, just for having asked a question, stood up and said: 'it was a nice speech, thank you', etc. And then I said: 'We are not afraid of homosexuals, but we want our children to be normal". Just then, someone from the back or something started yelling: 'Who are you calling abnormal? You are abnormal!' … That person took their viraginity out on me like that. In fact, I… in such an innocent way… just so I asked a question…"[181]

Dr. Ziya is now retired, and this is a "very funny and interesting story," which is still remembered and circulated among his students after many years. Unfortunately, a meaningful communication could not be established between Dr. Ziya -and clinicians who came after him- and the Intersex/LGBT movement until this day.

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[181] "Ben zamanında bu işlerle uğraşırken, o da kaç yılı hatırlayamıyorum şimdi ama, bir gün arabada gidiyorum, radyo açık, Açık Radyo mu çalıyordu neydi, radyoda Bilgi Üniversitesi"nde bir konuşmadan bahsediyor, baktım yakınmışım da, haydi gideyim dedim, konuşmanın konusu homofobi, yani homoseseksüellerden korku anlamında, gittim Arşaluys Kayır hoca da oradaydı, beni görünce "aa gel hocam bakın sizin konuları anlatıyorlar" dedi, ben de gittim kenara iddiasız bir yere oturdum. ….konuşma bitti, en son soru var mı dediler, kimse soru sormadı, sonra bana baktılar, sorunuz var mı falan diye, ben de sırf soru sormuş olmak için kalktım, dedim "güzel bir konuşmaydı teşekkürler" filan, sonra dedim "biz homoseksüellerden korkmuyoruz, ama çocuklarımızın normal olmasını istiyoruz" dedim, o sırada arkadan mı ne oturan biri, …. 'sen kime anormal diyosun, sensin anormal!" diye bana bas bas bağırmaya başladı, ….içindeki şirretliği o insan öyle çıkardı benden. Halbuki ben orada ne kadar masum bir şekilde... sırf soru sormuş olmak için...."

CHAPTER 5

CONCLUSION

The main purpose of this research is to provide an overview of the medical processes that children with intersex traits and variations of sex characteristics are subjected to and discuss them from a non-medical perspective in the context of Turkey. My aim is not to dismiss the merits of medical perspective but rather to denaturalize its authority over other perspectives and to demonstrate that management of intersexuality should be open to discussion of different stakeholders, especially of the subjects themselves.

The underlying theme that links the the issues I present in Chapter 2 is prioritizing biological deterministic views of sex and gender over the subjectivities of the intersex individuals, while ignoring the ways in which cultural discourses might be inherent in some of these views. By laying out some of the inconsistencies in the logic of the existing treatment procedures, I suggest that the medical procedures cannot provide what they pledge. The lack of discussion of the subjectivities of the patients is so profound that most conversations I had with the clinicians were founded upon on the seeming assumption that the patients do not have a reliable sense of their gender and that it can only be determined by careful medical examination of their bodies, attitudes, and desires. Even if the major medical guidelines and the clinicians I interviewed stress the importance of psychology and psychiatry for sex/gender assignment, my research results suggest that psychiatry and psychology are practically regarded as of secondary importance since the irreversible, non-lifesaving hormonal and surgical interventions continue even in cases where qualified psychological or psychiatric supervision is not available or if the parents of a patient reject consultation, for instance. This is one of the most alarming outcomes of my research.

A seeming reason for the secondary importance attributed to psychology and psychiatry is the overemphasis on the biological nature of sex characteristics and their connection to gender identity. When sex and gender are interpreted as merely biological facts, a restrictively rational language of “underlying causes,” “statistics,” and “success rates” take over the conversation, and treatment is reduced into an attempt of approximation of the physical appearance to one of the two medically accepted definitions of sex, female or male. The sex question is automatically connected to some -less common- real concerns that may require urgent treatment, such as hormone imbalances that affect the vital systems of the body and treated as such. Thus, surgery becomes the natural response to “ambiguous sex,” just as cortisol supplement is a response to cortisol deficiency. However, today, we know that the nature of sex, gender, and sexuality is too complex to establish this kind of parallelism. First of all, no matter how high the “rate of success” may be in predicting the future gender identity of a person based on previous data, the existence of trans people tells us that it is impossible to predict an individual’s gender identity correctly every single time. Existence of people with non-binary gender identities further complicates the picture. Furthermore, the overly biological interpretation of the links between sex traits and gender identity normalizes the link between gender assignment and medical intervention such as genital surgery, whereas they are two different steps. This also normalizes the risks of early genital surgery, including loss of function and sensitivity, and pain. In this framework, aiming for the highest possibility of “success” based on previous data means not only accepting that some people will be assigned the wrong gender and will be surgically assigned the wrong sex, but it also means taking away the chance to avoid medical intervention from those who would like to.

As a result of normalization of medical intervention, the issues of autonomy and consent are overshadowed. Because of the constant update of surgical methods and methodical variations among surgeons, the quality of the methods dominates the conversation among the clinicians, especially surgeons. There are two main problems caused by this situation; first, it takes as long as years to measure the effects of the newly developed methods, so there is an ongoing problem of lack of evidence on the harms of the current surgical methods at a given moment. But perhaps more importantly, focusing on surgical methods or qualifications of the surgeons shifts the focus of the conversation away from the issues of consent and autonomy, which are at the root of the current controversies about the treatment procedures. Thus, intersex subjects who are harmed by non-consensual interventions are diminished to a position of victim of “old, bad methods,” or “bad surgeons,” which legitimizes ignoring their voices.

Although I did not spare a separate chapter on analyzing the relationship between the dominant medical procedures and heteronormative ideologies of sex, gender and sexuality, I tried to show their connection throughout the thesis. For instance, in Chapter 2, I suggest that medical theories on intersex conditions are interpreted in ways that comply with heteronormative, binary notions of sex and gender; to this end, even contradictory theories can be utilized together to construct coherent narratives of treatment, whereas questions that could complicate sex/gender assignment decisions are ignored or less emphasized.

In the second section of Chapter 2, I present an overview of the clinicians' approach to terminology, and I provide some examples of how terminology can influence the lives of intersex individuals on a practical level. While clinicians' approaches to terminology vary, a general tendency is to distance themselves from the term "intersex"; this distancing makes sense since the implication of the term "intersex" is not commensurate with the medical idea of sex - that everyone has one "true sex," either female or male, and an in-between state does not exist. "Disorders of Sex Development (DSD)" finds wider acceptance, although some clinicians advocate using terms such as "difference" or "problem" (*sorun*), instead of the controversial term "disorder." However, these terms still define intersex traits as deviances from the norm, as opposed to being, for instance, variations of sex characteristics. This idea of deviation, however, is what justifies the "normalization" of the intersex traits, and therefore the terms such as "difference" do not seem to have practical effects on the medical procedures. I suggest that two of practical implications of adopting a language of DSD -or some version of it, as opposed to "intersex"- are providing a basis for selective abortion and de-politicization of the issue since "intersex" is associated with the activist movement today.

In response to the global intersex activism that has been gaining momentum in the last decades and the controversies it caused around the conventional treatment procedures, the clinicians I interviewed reported a growing avoidance from intrusive and irreversible interventions. On the other hand, the general support for early surgery and intervention is still quite strong among clinicians. Also, the tendency toward a less intrusive approach is not distributed equally among specific medical conditions or physical traits. It can be selective based on the extent to which the specific trait would “disturb” the binary heteronormative imagination.

In chapter 3, I discuss the communication between the clinicians and the patients and/or patient families based on the data I gathered from my interviews with the clinicians. I conclude that the underlying logic that DSD is a disorder, or a deviance from normative sex, also shapes the communication process between clinicians and the patients and their families. Clinicians often fail, or avoid, to convey intersex traits as variations of sex characteristics, but rather they convey the condition as a disease or a disorder that needs medical attention. They might do this by withholding information from the patients or misleading them about their sex characteristics, comparing DSD with other medical conditions, and delegating the duties such as informing the patient and decision-making to the legal guardians of the patients. I suggest that clinicians may utilize these strategies because they do not always believe that promoting the autonomous choice of the patients as fundamentally pertinent to the welfare of their patients.

In the medical decision-making processes for intersex children, both the clinicians and the parents are involved. My interviews with the clinicians suggest that clinicians have the upper hand in decision-making, because of the authority assigned to them by their professional titles, even in cases that they might be willing to relinquish some of their authority to parents. Once the decision is made about the sex/gender assignment and the treatment procedures are followed, the patients are asked to pay regular visits to the hospital for follow-up. However, the follow-up mechanisms seem to be inadequate, especially to follow-up the psychological wellbeing of the patient as well as issues such as the sexual functioning and intimacy matters.

A question that emerged during my research process was about why the clinicians did not seem to have changed their practices as much as could be expected since many of them expressed sympathy for the new paradigm that promotes the bodily autonomy of the patients. A common response among clinicians was that cultural and socioeconomic status of the patients in Turkey would not allow them to be competent for decision-making, as they should be in order to be considered autonomous. Thus, the clinicians continue to follow a more conventional, surgical approach, asserting that non-intervened children would suffer emotionally because of the cultural norms. Furthermore, clinicians associate medicalization of intersex with being “advanced” or “Western,” implying that those who suffer from harmful consequences of the medical treatment are the victims of factors such as lack of medical reference centers and legal regulations that would prevent unqualified surgeons to operate the patients, or lack of availability of medical tests to “catch” intersex newborns in more rural parts of Turkey, rather than violation of the right to autonomy. Thus, even though the intersex treatment paradigm is shifting toward a less interventionist approach in the “West,” clinicians view it as inapplicable to patients in Turkey because of the idea that Turkey is not as “advanced” and the patients in Turkey cannot take the responsibility of their treatment processes. Instead, their suggestions for solution focus on further medicalization, rather than promoting respect for the autonomy of the patients. I argue that this view is based partly on a neoliberal understanding of health as an individual responsibility as opposed to a fundamental right, and partly on a rather simplistic incorporation of the concept of “culture” into the clinical context, which constructs the patients as passive objects of treatment, rather than subjects with agency.

Surprisingly, in my research, religion did not come up as a central issue that directly affects the lives of intersex individuals in terms of the medical decisions made during the treatments. However, intersex individuals have been recognized in Islam as “khunsa,” and there are specific rules that knhunsas are required to follow in relation to issues such as how to determine the sex/gender, prayers, inheritance rights, and bathing the deceased. An obstetrician-gynocologist from Malaysia, Ani Amelia Zainuddin, explains the categorization rules of khnunsas and states that they are “collaborating with Islamic scholars and other medical experts in DSD to update these Islamic definitions to align with modern understanding of anatomy” (2017, 355). Thus, further research needs to be conducted in order to find out how religion factors into the treatment process in Turkey.

It is worth emphasizing that clinicians do not form a uniform group; they diverge among their approaches to many issues discussed in this research, and the issues raised in this research do not point to individual clinicians, but rather to the collective results of some medical conventions and common practices, as well as structural issues that result in harm to intersex individuals. As I have shown, many issues I raise in this research were also raised by clinicians during the interviews. As some clinicians pointed, established medical practices can be insufficient to support the clinicians in their pursuits of the best results for their patients. Currently, however, even though the change may not be easy to adopt for clinicians since it goes against the long-established practices, these practices are being challenged globally by many different groups including intersex activists, bioethicists, social scientists, and medical professionals, and the intersex medical treatment is moving toward a new paradigm that prioritizes autonomy and consent.

In this phase of transformation, I would like to suggest that we can reconsider some ways in which these principles can be incorporated to decision-making processes. If the discussion of ethical principles may be considered too abstract, however, as one practical solution to different concerns around decision-making, I suggest that peer-based information should be promoted because it can be of tremendous help to both intersex individuals - since it would provide them a valuable source of information from someone who went through a similar process - and the clinicians - since it would take some of the burden of decision-making for their patients by sharing the responsibility with others. In the absence of peer-based information, efforts on the side of medical professionals might remain insufficient and even turn the debates into a moral competition that can damage the process.

As I intend to demonstrate in Chapter 4, including intersex individuals' voices in these debates among medical professionals has the potential of shifting the questions in ways that would account for a wider range of real-life experiences than the dominant treatment narratives presume. Such an inclusion can be a "simple" starting point of conversation before delving into more "complex" dynamics of medical decision-making. I hope that this research will contribute to a meaningful conversation among different communities including intersex activists and medical professionals as well as other groups.

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