The Body/Secret Dynamic: Life Experiences of Intersexed People in Israel

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Abstract
Intersexed subjects experience their bodies through the repercussions of treatment policies implemented in their bodies at birth and throughout their lives. Secrets and secrecy comprise a major element of the treatment policy toward intersexed subjects in Israel and act as a disciplining and normalizing force in the life experience of intersexed subjects. This article presents case studies of intersexed adults, subjects through whom we can learn about both historical and contemporary treatment policy toward intersexed people as well as about the perpetual conflict between the particular corporeal existence of individuals and the experience of the secret and secrecy in their lives. The purpose of this article is to shed light on the dynamics that exist between the secret and intersexed bodies and the paradoxical consequences of body/secret relations.

Keywords
intersexed people, body, secret, min-guf process, Israel

Introduction
I have a secret, I have a secret. [cries] We don’t talk about it. . . . It’s not diabetes where you need regular treatment, and it’s not TERT syndrome or any other known syndrome. The very fact that it’s not spoken about means that I have a secret—a secret I’m aware of because it wasn’t repaired from birth and I had to live on pills. I’m telling you that from birth they hooked me up to a “respirator” that I can only be disconnected from when I’m 18. (Or, November 6, 2009)

Hearing this testimony represented a foundational, insightful moment for me as a person who has been researching the intersexed body for the past 7 years. This was the moment at which I first understood the significance and profound power of the secret in the everyday living experience of many intersexed people. I had known that intersexed people were told lies and lived with secrecy (Chase, 1998; Cote, 2000; Ford, 2000; Harper, 2007; Holmes, 2002, 2008; Preves, 2003), yet, even when for years the secret and secrecy surrounding intersexed people made it difficult for me to collect research data and contact intersexed people and parents of intersexed children and adults in Israel, I accepted this situation as a given, assuming that the phenomenon itself was an extremely private matter, kept within the confines of hospitals to maintain patients’ privacy.1 But when Or cried and explained how the secret controls and damages her social and familial life and how suicidal thoughts ran through her head, I realized that I needed to reframe the secret as a forceful social agent that threatens the very being of intersexed people. In my doctoral dissertation Meoded Danon, 2012), I examined the ways in which the secret is a significant part of the medical treatment of intersexed people in Israel and other countries (Audi, 2014; Karkazis, 2008; Kerry, 2008) and explored the ways in which the secret is reproduced by parents of intersexed children and becomes part of family lives.

In this article, I focus on the embodied particular experience of the secret in the narratives of three intersexed adults. I chose to focus on only three narratives to explore in depth each individual’s experience of living with an intersexed body and the secret that surrounds it. While every participant in this study experienced the powerful secrecy that surrounds their bodies and is manifested in the complexity of the body/secret relationship, the narratives of these three participants in particular highlight the complexity of living with the secret and secrecy as well as the practice of body/secrecy in familial, medical, and personal relations. Hence, I chose to focus on each of these narratives to reveal the particular, unique living experiences that they portray.

In these narratives, the motifs of secrets and secrecy are prominent, as they are in narrative studies and other kinds of studies that focus on the life experiences of intersexed people. Secrets and secrecy characterize both treatment policies and the behavior of the parents of intersexed people, thus comprising an integral element in their life stories. Secrets

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and secrecy encourage stigma, shame, low self-esteem, loneliness, lack of trust in others, difficulty in creating intimate relationships, and a host of other problems (Feder, 2006; Karkazis, 2008; Kerry, 2008, Meoded Danon, 2012, 2014; Lev, 2006; Preves, 2003). Paradoxically, treatment policies have historically attempted to prevent these negative phenomena, so they have often attempted to normalize the body through surgery and hormones, tailoring it to one of the two typical sexes/genders: male/female, man/woman.

The moment of discovering the secret, that is, their particular “intersex” physical condition and their treatment history, was perceived by intersexed people as a significant, life-changing event that not only legitimized their emotions both in the past and in the present but also opened many questions and left them with a great deal of anger and frustration toward their doctors and parents, who had concealed information from them. Studies of the life experience of intersexed people, such as those of Sharon Preves (2003), Katrina Karkazis (2008), and Stephen Kerry (2008), have often related to the intersexed body as a discursive, medical body, a passive product of biomedical science. Unlike previous studies, this one aims to demonstrate how the material intersexed body, like any other human body, is dynamic, and senses, experiences, and even opposes attempts to normalize it in its own unique ways. Moreover, this study describes the complex relationship between the body and the secret and reveals how the secret is experienced as a foreign object that the body cannot tolerate. It also interrogates the ways in which the secret is established in the body and its effects on the embodied subject, and explores what causes intersexed people to feel alienation from their lives in general and their bodies in particular.

The existence of the intersexed body and the act of keeping it secret have been linked, in an institutionalized manner, through the traditional protocol outlined by Johns Hopkins Hospital in the 1950s. At the time, John Money and his colleagues were conducting pioneering clinical and psychological studies on “hermaphroditism,” and were considered the leading authorities on the subject. The Johns Hopkins professionals believed that gender role and gender identity (Gender R/I) should establish and guide the treatment policy of “hermaphrodite” children. According to this perception, the core problem of “hermaphrodite” adults was being assigned to the “wrong gender,” which caused social alienation, stigma, and psychopathological problems. Hence, they claimed, hermaphrodite children should be assigned a coherent gender role as early as possible (no later than 18 months of age), and raised in accordance with it, while those with ambiguous external genitalia should undergo surgical correction. Money and his associates asserted that normal looking external genitals are more crucial than chromosomes, gonads, and internal and other sexual characteristics for establishing a “normal” gender role/identity (Money, 1955; Money, Hampson, & Hampson, 1955, 1957). The Johns Hopkins medical team focused on diminishing and concealing bodily ambiguity as quickly as possible, which would allow “hermaphrodite” children to be socially accepted and unstigmatized. In fact, Money et al. (1955) encouraged doctors to “talk frankly” with hermaphrodite children, and claimed that “truth is seldom as distressing as the mystery of the unknown” (p. 294). Theoretically, they argued in their article that “hermaphrodite” children should not be kept in the dark regarding their physical state, but, unfortunately, we revealed that only four decades later, there is a tremendous gap between their theory and the actual realities of intersexed people.

Since the 1990s, much criticism has been voiced against the “Money Protocol,” especially regarding the problematic connection between gender identity and the “true sex” of intersexed people. For example, Suzanne Kessler claimed that Money and his colleague evaluated penis size (“a good-sized penis”) as the sole condition for raising a newborn as a boy. Chromosomes and other physiological characteristics were less relevant than penis size, so babies with penises smaller than the ideal of the medical staff, with hypospadias, with XY46 sex chromosomes and testes were forced to undergo “corrective” genital surgery and raised as girls (Kessler, 1990, pp. 12-13). Anne Fausto-Sterling (1993) argued in her pioneering article “The Five Sexes: Why Male and Female Are Not Enough” that the biomedical professionals at Johns Hopkins disciplined intersexed bodies according to stereotypical gender norms, instead of seriously and deeply studying the many (at least five) sexes of the human body. In the summer of 1993, soon after the publication of “The Five Sexes,” Sheryl Chase, an intersexed activist, established the Intersex Society of North America (ISNA), the first organized group of intersexed activists. Chase, like most ISNA members, had been treated and operated on according to the “Money protocol,” for 60 years, which was internationally recognized and followed. ISNA began to voice its criticism of this protocol on the Internet, in the popular media, and in literature. The writings presented in the book *Intersex in the Age of Ethics* (Dreger, 1999) brought to light the living experience of many intersexed people, revealing that they had grown up unaware of their physical diagnosis and the significance of their physical–surgical histories, as their physicians and families had lied and concealed this information from them, and they had to discover it on their own. For most of them, this discovery was traumatic. They felt that they had been living a lie for years and were forced to cope alone with the consequences both of the surgeries carried out on their bodies, which caused much physical and emotional damage, including lack of genital–sexual sensation, and of the revelation of their bodily secret. As more studies were published and an increasing number of intersexed people revealed their stories, the secrets and secrecy surrounding their bodies have become known as a familiar feature of the dominant narrative and an integral element of traditional treatment policy (Chase, 1998, 2003; Dreger, 1999; Feder, 2002, 2006; Hillman, 2008; Holmes, 2002; Lev, 2006; Morland, 2001, 2009; Preves,
1998, 2002, 2003; Sutton et al., 2006). The Chicago Conference of 2005, organized by the ISNA and other intersex advocates and biomedical professionals, aimed to change the traditional and problematic “Money Protocol.” The main changes of the medical treatment concerned clinical and pathological nomenclature, with the term Disorder of Sex Development (DSD) replacing the old terms “hermaphroditism” and “intersex conditions” (Lee, Christopher, Faisal, & Leuan, 2006). The new guidelines are more centered on patients and families. Experts advocate sharing information on patients’ physical condition and treatment with parents, and the optimal sex/gender of the newborn is determined by multidisciplinary teams that consider the best interests of patients and families. Interestingly, these teams do not include intersexed subjects who could talk about their experiences and the consequences of treatment. Other changes primarily involve improved biomedical diagnostic technology and better surgical techniques (Ganka et al., 2010). Nonetheless, the new DSD guidelines are still motivated by concealing bodily ambiguity, especially ambiguous external genitalia, and assigning “normal” sex/gender to “DSD” children. The bodily autonomy of intersexed children is still in great doubt under the terms of current treatments. Furthermore, the very term DSD, as Davis (2011) claimed, “constructs ‘sex’ as a scientific phenomenon” in ways that maintain biomedical authority over intersexed bodies.5

Theorizing Intersexed Bodies and the Power of the Secret

“Intersexed” bodies include a broad range of physical states that challenge the significance, components, and development of the sexual body. They comprise various configurations of sex chromosomes and different structures of the external and internal genitalia. Just as the body cannot be defined as male or female in a separate, stand-alone category, and the one always depends on and is compared with the other, so it is impossible to define and diagnose the intersexed body except in comparison and in relation to typical female or male bodies. Male and female are sexes that were established in the past continue to be established by the bi-social establishment and are not disconnected from cultural biases and heteronormative perceptions of sex, gender, and sexuality.

Michael Foucault’s (1973, 1990, 1995, 2006) poststructuralist discursive view of the human body, established through power relations (especially the biopower of human science) and the discipline of knowledge, influenced writers such as Judith Butler (1990, 1993, 2004), Myra Hird (2004), Anne Fausto-Sterling (1993, 2000), and others, who challenge the normative Western discourse on sex and gender categories. Poststructuralism critiques the notion that sex categories are natural, claiming that, like other social categories, they are the result of a discourse based on and formed through power relations. Biomedical science is not disconnected from social power relations and a heteronormative perception of gender, so its research, gaze, and perception of the body are all filtered through language, through a system of meanings that mark the body as female-feminine or male-masculine. The paradox is that the normative sexual order is imaginary; physical-sexual reality is not organized into two unambiguous sexes. Science, in its attempt to characterize or assess the factors or characteristics of the development of sex in the body, repeatedly encounters “undesirable” results in bodies (whether those of mice or people) that challenge its assumptions.6

In contrast to poststructuralism, which perceives the human body as “discursive,” a product of construction and social power relations, the phenomenological approach to the body, established through the work of Maurice Merleau-Ponty (1978), relates to the “subjective” body, focusing on corporeal, sensory experience. Merleau-Ponty claims that our perceptions, consciousness, knowledge, and understanding of the world are manifested through our own bodies, which are situated in the world as the heart is in the organism, breathing life into it, carrying it inside itself, and shaping our perception and understanding of the world around us. In other words, our flesh, our material, sensual body constructs our living experience, our being in this world. A phenomenological approach allows us to analyze the experience of intersexed people through their own feelings, senses, and ways of adjusting to social norms through their own particular bodies.

A secret, like a human body, is difficult to define and frame theoretically. It is elusive and hard to estimate according to any measure, because it is multidimensional and multifaceted. The secret depends greatly on the different contexts and social interactions within which it exists. Sissela Bok notes that the Latin source of the word secrecy (secretum) is secernere, to separate, to create a kind of boundary between the external, those who do not know the contents of the secret, and the internal, those who conceal it (Bok, 1984). This word actually implies the kind of internal conflict inherent in all secrets. Evan Imber-Black (1998) described different types of secrets, including positive ones, which strengthen interpersonal relationships; negative, toxic ones, which poison relationships, limiting our lives and our ability to make clear and effective decisions; and dangerous ones, which pose immediate physical or emotional danger and can cause damage to others and even lead to suicide (Imber-Black, 1998). These toxic and dangerous secrets are the ones relevant to our context of intersexed people, because they poison bodily experience and make the existence and experience of intersexed people extremely difficult. For Georg Simmel (1906) and Erving Goffman (1963), secrets and secrecy are positive and essential in social life, and help to protect us from stigma and keep us from harm while we interact with others. Simmel describes what he calls the dialectic of the secret, in which, for example, the secret creates boundaries and increases diversity among people, but, however, entails
the temptation to break down boundaries and blur differences, especially when it is revealed. On one hand, the secret acts as a protective sheath that gives power to those who know it, but on the other, it produces the tension and danger associated with its revelation (Simmel, 1906). Unlike Simmel, Bok (1984) claimed that holders of secrets experience negative tensions and conflicts that are embodied in everything they do.

The dynamics of power can be destructive, as Mark Karpel (1980) explained with regard to family secrets, claiming that holders of secrets have a sort of “nuclear bomb” that is saved for later use, and the only way to be saved from the cruel secret and its destructive repercussions is to reveal it (p. 296). In a more particular, practical, embodied way, cognitive researchers such as Julie Lane and Daniel Wegner (1995) describe the difficulty of keeping a secret, explaining how much energy and effort we need to expend to manage our thoughts, our behavior, and especially our body language when keeping a secret. Paradoxically, the more we try to conceal it, the more we reveal the existence of the secret, because techniques for discovering secrets improve over time and constantly threaten the shell of secrecy, and also because our own bodies struggle with the secret. To theorize the relationship between intersexed bodies and the power of the secret, I embrace both the poststructuralist and the phenomenological approaches to the body and demonstrate the tension that exists between them. While these two approaches differ from one another, combining them provides a theoretical perspective that focuses on the phenomenology of social power that describes how the subjective body experiences the power exerted upon it through the agents of social power in general and the power of the secret in particular. This approach corresponds with that of Chris Shilling (2005), who coined the term “corporeal realism” to describe both the connection between body and society and the distinction between them. Shilling’s approach ignores neither the established social forces, their influence on the experience of the body, nor the body’s unique power, development, and material traits. Therefore, this article adopts Shilling’s perspective, and both offer an analysis of the power relations that discipline the body, in our case the intersexed body, and consider the particular bodily experience of individuals and their reactions to social power relations.

**Method and Secrecy**

This article is part of a comprehensive study conducted in Israel between 2005 and 2012. It examined the attitude and treatment of intersexed people and the life experience of intersexed adults. It included 22 semistructured interviews with biomedical and other professionals in Israel. The most difficult task was to reach intersexed people. Fortunately, a support group for intersexed people began to operate at the same time that I started my research. One of the endocrinologists gave me their brochure and suggested I speak with the moderator of this group, who had been born intersexed and would be happy to help. It took me 3 years to find other intersexed people for my study. After publishing calls for participants on various Internet sites and forums, in particular endocrinology, parenting, and fertility forums, I eventually made contact with 11 intersexed adults and 7 parents of intersexed children and adults. All of the names of the participants have been changed to maintain their anonymity, and each of the participants signed a consent form, which described the purpose of the research, their right to stop and leave the study at any time, their right to secrecy and anonymity, and my contact information, including phone number and email address. All the participants chose the locations and times of their interviews, to ensure a relaxed and pleasant atmosphere. With seven of the intersexed adults, I conducted follow-up interviews to learn more about the changes in their lives and to examine many aspects and themes that were absent in the first interview. During the study, I realized that the secret and secrecy were integral parts of the treatment policy and the life experience of intersexed people, so I played a role in keeping their secrets. I had to build their trust in me and provide a comfortable and safe space in which they could expose their lives to me. To foster their trust, during the interviews I informed all the participants about the various stages of the study, its purpose, and what I had learned so far.

During the research process, as I conducted the interviews and analyzed my findings, I used the stages and ideas of grounded theory (Charmaz, 2006; Corbin & Strauss, 1990). Grounded theory makes it possible to focus on the dynamics and changes of the research field, and data from the field form the core of the theory. The processes of sampling and finding participants were actually part of the fundamental theme of this research. Only after several interviews with intersexed people did I understand that the reason for the great difficulty involved in finding intersexed people in Israel was the forceful social agent of the secret. In contrast to the public activism of intersex support groups in North America, the United Kingdom, Germany, and other countries, in Israel this group and intersexuality in general are shrouded in secrecy. There are few participants, not because of the number of intersexed people in Israel, but because the secret surrounding intersexed bodies is reproduced and manifested beyond hospital walls, assimilated into and practiced in everyday social interaction. There are very few (closed) group meetings during the year, and there is no critical activity that challenges the biomedical discourse. As in other Western countries, the biomedical system in Israel is authoritative and asserts its power over intersexed people.

The term I coined to describe the whole treatment process of intersexed people is “the min-guf process” (Meoded Danon, 2012). Min in Hebrew means sex, kind, or type. Guf means body. My term, min-guf, implies both the separation (the human body is more than the sum of its sexual organs) and the connection (intersexed bodies treated by the medical
establishment as unfixed sexual bodies) between sex and body. In English, it could be understood as “the sexing process” or the sexual transformation of the body. I chose this term to focus on the sex category and its various manifestations in the human body and on the bodily consequences of medical treatment. Rather than considering the gender category as the main frame for normalizing and disciplining intersexed people, I claim that sex and gender categories, much like the body and society (sex–body/gender–society), are intimately integrated and historically manifested in one another; that there is no actual, clear line between them. The stages of the min-guf process that intersexed people undergo throughout their lives embody the blurring of the boundaries between sex/gender and body/society. These stages include diagnosing the sexual characteristics of the body, shaping the body according to one of two typical sexes (female or male), and performing clinical follow-up of the development of the body according to its new conditions. The secret is an inseparable part of the min-guf process, as I will describe in the following three case studies of intersexed adults. Each of these stories presents a unique example of the problematic and paradoxical living experience engendered by the min-guf process, which aims to conceal intersexed bodies. Despite the fact that the experiences described in these stories took place decades ago, and biomedical technology in many countries, including Israel, has changed considerably in the meantime, the secrets and secrecy surrounding intersexed bodies still have not changed and continue to exist alongside urgent physical intervention at a very early age.

Through the stories of the intersexed subjects of this study, I will explore the ways in which the secret is established in the body and examine the dynamics of the secret in each particular, embodied subject’s life. It is important to emphasize that these stories are not intended to reflect the life experience of all intersexed people; on the contrary, they aim to expose the subjective embodied experience of individual subjects to emphasize the particular struggles with the social forces that act on each body. Bodily particularity informs us, casting doubt on the existence of any universal or unisexual physicality.

Shai: “A Hospital Child” (August 22, 2008)

Shai was born in Israel in 1955. Despite his age, his body looks like that of a young boy. Large green eyes illuminate his face, his hands and feet are small, and he is short. At the beginning of our meeting, Shai showed me a 1958 medical document that described his physical diagnosis and the decisions his doctors made about his body. This is the only medical document Shai has obtained from his own medical file. Shai does not know about everything that happened to his body during his childhood and is interested in reading his medical file, but the hospital where he was treated is concealing his records, despite his legal right to see them and his attempts to obtain them. Before I introduce the contents of the document, let us connect to Shai’s experience of childhood and adolescence:

I always felt unusual, different, let’s say, from infancy, but I didn’t understand why. I looked like a girl... I was in the hospital all the time, sometimes for long periods, which automatically makes you feel different... To the outside world, I showed that I was a boy in an extreme way, being the epitome of what a bad boy was and pushing this to the limit, because I felt different... For example, from a very young age I felt attracted to boys, but I realized that it was forbidden, that you were not allowed to talk about it and no one should know. I used to play secretly with dolls. I loved playing with dolls.

Social responses to Shai’s appearance sometimes led people to mistake him for a girl and treat him like one, which caused him frustration, pain, and a counterreaction that manifested itself in a radicalization of his “boy” behavior. Thus, his behavior toward the world was extreme, extroverted, and interpreted by him and those around him as “boyish,” in contrast to his behavior in his own world, without peer pressure, where he could express his feelings and desires. His physical appearance as a boy–girl caused a contradiction, a dialectic between his inner world and the outside world, as he explains,

You have to understand that all my life I’ve simply been acting, and I’m a very, very honest person, so it always bothered me that I had to act... Outside, I looked different. Even today, when everyone knows me, they call me “Shai, a man with balls.” In point of fact, I have no balls at all [laughs], “Shai with the ostrich eggs” everyone calls me.

Shai was unaware of the cause of the hospitalizations and his physical characteristics, but he understood his body as “sick.” The third important issue in the context of Shai’s sense of difference is his sexuality and attraction to boys, which was perceived as forbidden in his social environment and never spoken of. Thus, Shai learned to conceal his sexuality and keep it secret.

Secondary sex characteristics, the growth of the penis and pubic hair, appeared in Shai’s body at a very young age (5-6), and he was ashamed of them. His communication with his parents was minimal, and he did not ask questions about his physical condition or share with them the physical changes he was undergoing. This surprised me because parents are usually aware of physical changes in their children’s bodies, but Shai claims that he learned to be independent at a young age, to shower alone, and take care of his own needs.

During his childhood hospitalizations, he felt that his body was perceived by doctors as something rare, but he was not sure why:

You’re a little kid and all day they strip you and dress you and look at you; that’s how it was. I understood that mine was a rare, special case, so they all wanted to see, they all wanted to touch, that’s how it was. Just like an exhibit in a museum.
Despite Shai’s otherwise excellent memory, his recollection of the years when he was hospitalized has been erased. During these years, a number of surgeries were performed on his body, including one to remove his uterus, ovaries, and fallopian tubes.

By the time he was 13, Shai’s body had developed in accordance with its material terms (due to increased androgen secretion, he underwent puberty very early, but from age 13, he stopped growing and remained quite short). Each month, Shai would arrive at the hospital for monitoring. He describes how the doctor treated him like an object, without asking how he felt. He would ask him to strip and check the length of his bones, limbs, and penis. For some reason, even when it was obvious that his bones were not growing, the doctor ignored this fact.

At 17, Shai received his first draft notice for compulsory military service and underwent a physical examination, including an examination of his scrotum. During the examination, it became clear to Shai, through the body language of the doctors as they looked at another, that something was amiss with his genitalia. They said nothing to him. He dressed and went home. One month later, he received a letter stating that he was exempt from military service (on grounds of being “permanently unsuitable”). He attempted to appeal the decision and asked to volunteer, in any capacity, “just to wear a uniform,” but without success. In retrospect, Shai says that he understands why the military doctors never told him anything, as this would have been an extremely difficult task and a great responsibility to assume, considering that the doctors who treated him during his childhood had not told him anything. So the military doctors maintained his civilian doctors’ rules of secrecy.

Two years later, Shai was surprised to receive a draft notice for 3 years’ service. He now refused to join both because the army had rejected him in the past and because he had continued with his life and now had a job and plans for the future, so he appealed the recruitment and was subsequently summoned to a meeting of the Medical Committee. Before the meeting, he unexpectedly received a large package containing all his medical documents. This is how Shai describes his experience of discovering the secret:

It said “female pseudohermaphrodite,” but one sentence deeply shocked me. I’ll remember it to my dying day. . . . It said they were making me into a boy because my parents were primitive Moroccans. . . . I remember that I went to the committee and like an idiot gave them all the documents. . . . I understood why I felt different and what was different and what was wrong with me. . . . I didn’t want to talk about it, I was ashamed. . . . I buried it in some corner of my body and covered it with stones and didn’t want to talk about it.

Among all the medical documents in the package was the document Shai presented to me early in our meeting. It includes a description of the min-guf process that Shai underwent during his childhood, and reflects both the medical-technological conditions in Israel at the time and the biosocial perceptions of Shai’s physicians. The document notes the following:

Empty right scrotum. On the left side a small mass can be felt, large penis, uterus, ovaries are present. In conclusion, the child is genetically female, gonadal sex female with completely male external genitals, the penis is large, urethral tube inside the penis, a well-structured but empty scrotum. Regarding the child’s future, of course he will have to live as a male, and this is due to the following: the external genitalia are completely male. Constructing a proper vagina to allow a normal sex life as a female is a complicated and difficult thing, and the results are doubtful. The condition of the ovaries cannot be determined with certainty. Will there be fertility? If he continues to live as a male it would be possible to stop administering cortisol. Increased androgenization will ensure the development of menstrual periods. In the meantime, we will not perform any surgery, and if there is a need, we will perform the following required surgeries: partial or complete hysterectomy and removal of the ovaries. We see no justification for shocking [words deleted from the document] the parents and telling them about our findings. We released the child with a recommendation to administer 25 mg of cortisone and instructed the parents to bring him back for a follow-up visit in 10 days.

Shai’s physical characteristics are described here in a way that presents different kinds of sex: genetic sex, gonadal sex, and external sex. His multisexual body shocked the doctors, so they could not justify telling his parents about his physical characteristics. The medical document suggests that the doctors were being considerate of the parents and preventing them from being shocked, but in the document that Shai read and is now unable to obtain the doctor wrote that his parents were “primitive Moroccans,” so the reason for concealing the information from them was the prejudiced perception of his doctors, who assumed that because of their ethnicity, his parents would not be able to understand and cope with Shai’s physical condition. Keeping Shai’s intersexed body a secret caused his physicians to perform the min-guf process on him without sharing it with his parents and without their permission. Shai became a “hospital child,” a child who belonged to the world of those who treated him and its perceptions.

Shai was born with classical congenital adrenal hyperplasia (C CAH), which involves a lack of salt in the body and hormonal imbalances that result from an increased secretion of androgens. Shai’s doctors sexed his body as masculine, the reason for this decision being the appearance of his penis, in particular its size. Shai’s uterus and ovaries were removed, silicone testicles were implanted in his body, and cortisone was administered to balance his hormones.

In a conversation I had with Prof. B., one of Shai’s doctors, he related the following:

I remember a patient who came from Pediatric Surgery at age two and a half. In a general exam, the doctor said his penis was large. The person who conducted the Barr body test [used for detecting the X chromosome] said, “You know, it’s female.
What shall we do with him now? Cut him? He has a functioning uterus, ovaries. If he’s treated with cortisone he’ll reach sexual maturity and then what? The ovaries will wake up, estrogens will make breasts, and then there will be menstruation, he’ll ‘urinate’ blood. It has to drain into something. It will accumulate in the uterus. What can we do to remedy the problem?” So if you decide to raise the child as a male, you remove the uterus. . . We told the parents there was an “incompatibility.” [long silence] At the age of two and half, the child was already big—there was no choice. I believe we made the right decision. Here you have to decide whether to amputate this penis. I remember my boss said, “You don’t amputate a penis like this!”

The doctor’s words indicate that treatment practices in Shai’s case—that is, the process of sexing him as masculine—were carried out because of his large penis. This is in line with the Johns Hopkins University approach of the time, the phallocentric approach, according to Kessler (1998), which related to penis size. However, there is ambiguity regarding the process of the medical monitoring of Shai’s body, the ramifications of the surgery for his body, and what all the doctors did when they noticed during follow-up that Shai’s bones had stopped growing. his body had stayed the same size, and his “large penis” was now relatively small, as he stopped growing at age 13. Shai is angry at his doctors, who prevented his body from growing and did not prescribe hormone replacement therapy for him. He realizes in retrospect that the reason for this was to keep the secret from him:

In order not to reveal the truth, [the doctor] would not give me hormones so I wouldn’t ask questions. . . . If you decide to make me a boy, let me look like a boy! For G-d’s sake, give me the hormones on time! Everyone in our family is tall, so if you see . . . that I have stopped growing, give me [the hormones], help me grow. . . . So, you see that all the signs show that he simply did not want this secret to be revealed.

At the age of 22, when Shai discovered the secret, he concealed it from his friends and family, maintaining the rules of secrecy and hoping that it would disappear. He did not share the discovery with his parents and was especially angry at his father because he thought that he (who had accompanied him to the hospital during his childhood) had known about everything and been involved in the doctors’ decision making. Only in 1997, years after his father’s death, when Shai was able to read all the medical documents, did he realize that his parents actually had not been informed.

Shai decided to tell Dr. H., the new endocrinologist who replaced the doctor who had treated him throughout his childhood, that he knew what had happened to him and that it bothered him that people mistook him for a girl. Dr. H. never spoke to Shai about his physical history, but he was kind to him, explains Shai, and prescribed testosterone, which Shai has taken ever since. He describes the changes in his body:

I started shaving, which made me very happy. [smiles] I also grew a beard. For years I had a beard to show that I was male and not female. . . . I had a somewhat feminine voice, but relatively low. The hormones made my voice much lower.

Today, Shai undergoes hormonal monitoring in the adult endocrinology department, with a kind new endocrinologist of whom he is very fond. She arranged for Shai to have surgery to replace the small silicone testicles implanted when he was a child with larger ones.

As Shai began to deal with the secret of his life and learn about his medical past, he became severely depressed and required psychological and psychiatric treatment. The more he investigated, the more new things he discovered, including flashes of negative experiences from the hospital and physical and emotional abuse by his doctors. Shai’s coping alone with the discovery of the secret, while he continued to hide it from others, threatened his life to the point where he considered suicide, but he decided not to bury his secret with him. Several years ago, he began to suffer extreme pain in his lower abdomen and underwent a series of tests that revealed the stump of a uterus in his body, a kind of historical, material remnant through which the body signaled, in its own way, the physical secret it held inside.

The bodily secret, that is, the social, material product of the min-guf process, caused Shai to live in a world divided between the external and the internal. These divisions, the same separation that produces the secret, as Bok (1984) claimed, are experienced by the body. The differences between his internal and external worlds caused Shai to learn to become an excellent actor, especially in highlighting his so-called “masculine” features in his social environment as opposed to his “feminine” features in private. Shai was seen by his friends as a “man with balls,” a kind of “bad boy” who acted violently and stood out. My intention in pointing out this behavior is not to distinguish between “masculine” and “feminine” features and to perceive them as given, or to reproduce gender stereotypes, but rather to show how Shai distinguishes between these two worlds and to demonstrate how this separation establishes embodied negative emotions, frustration, and loneliness. Here, the body itself undermined the concealment of the secret, especially in the external “boy–girl,” appearance that caused people to mistake Shai for a girl. The more people mistook him for a girl, the more extreme were his reactions—“bad boy” behavior and changing his appearance as an adult, growing a beard, and having larger silicon testicles implanted. However, the concealment game is exhausting and frustrating. For Shai, the hormones are “a sham,” not a part of him. He says that he would like to rest from his frustrating struggle with the bodily secret and social conservatism.

Shai’s min-guf process established a bodily secret that transformed his body and poisoned its being. The treatment policy, together with the bodily secret, led to Shai’s body being neither female nor male, but rather a different kind of body, a body without internal sex organs, with a small penis and silicone testicles, a body that depends on synthetic hormones.
Shai physically experiences resistance to the bodily secret in various ways. For example, the body remembers its missing organs, as evidenced by the experience of physical pain that caused Shai to discover the stump of the uterus in his body. In addition, Shai has always experienced the bodily secret in his own unusual nature and difference, through his frequent hospitalizations and through the way in which his doctors looked at his body as though it were an object in a museum. Thus, even when he was unaware of the contents of the secret, it was palpable and real in his life, like a foreign body.

Ronnie: “I Once Had Testicles” Is Similar to “I Have Testicles” (October 7, 2005, November 21, 2008)

Ronnie’s story is very different from Shai’s; they grew up in different environments, at different socioeconomic levels, with different cultural values and different intersex conditions. Yet, a similarity exists between them in terms of their embodiment and their bodily experience, which are closely linked to the secrets that surround their bodies. The course of Ronnie’s life intersects with that of her sister, who is 4 years older. Both were born with Complete Androgen Insensitivity Syndrome (CAIS). Although her sister did not participate in the current study, her presence was felt in Ronnie’s story, because she experienced the min-guf process and the establishment of the bodily secret first, and Ronnie later went through the same process. This is how Ronnie began her life narrative:

I was twelve, and my older sister was sixteen and hadn’t gotten her period, and my parents took her to all kinds of tests because of this matter. Later, they also took me for tests. Everything she went through, I went through, and they didn’t explain why and I didn’t ask too many questions. . . . They told me I had been born without a uterus and couldn’t have children and I wouldn’t menstruate. They even took the trouble to tell me that studies prove that the girls who have this syndrome are pretty, tall, and not hairy. I remember that I didn’t believe them and thought it was nice of them to tell me this, but it was clear they had done it to be kind, to make me feel good after the blow they had just dealt me.

When Ronnie describes the “matter,” and what she calls “this syndrome,” there is a sense of alienation, a certain distance—alienation that I feel as a listener and alienation and distance experienced by Ronnie. The common perception is that androgen insensitivity syndrome produces “beauty”—girls who are pretty, tall, and not hairy. This is how doctors present the characteristics of this physical condition to parents. This myth of “beauty” is also reflected in popular literature, for example, in the novel Middlesex by Jeffrey Eugenides (2002) and in the media (in one of the episodes of the television series House).

Ronnie cannot describe in words what she felt after her parents told her she would not menstruate or bear children. She felt terrible and cried all night. Until that evening, she had expected to menstruate—Menstruation was something everyone was talking about as teenagers. Later, Ronnie lied to her friends said she had gotten her period. She bought sanitary pads and kept them in a cupboard. When her mother saw them she asked Ronnie why she had them, Ronnie was embarrassed and explained that if a friend needed a pad, she would have one. Ronnie lied to decrease the social pressure around her, thus participating in the establishment of the bodily secret.

Ronnie began to undergo examinations by the gynecologist who treated her older sister with no explanation about the nature of the tests or the reason for them. She underwent the examinations as part of her routine, asking no questions. After examining her, the gynecologist told her mother that Ronnie could have normal sex—that is, heterosexual sex—because she had a vagina. In some cases of CAIS, the vagina is narrow and doctors recommend expanding it with surgery.

Ronnie and her sister each experienced the min-guf process alone. Ronnie’s sister underwent surgery at this time to remove her testes. This process was not shared with Ronnie. When Ronnie began to mature, the physical examinations were geared toward surgery to remove her gonads. This is how she describes the experience:

In the summer between eighth and ninth grade, I had surgery. My mother told me to say that it was hernia surgery, and that’s what I said. . . . I was told that they were removing my residual ovaries, so I wouldn’t get cancer or something. I didn’t know it was something else. . . . I have scars on my lower abdomen [from the surgery].

Ronnie’s parents lied, concealing the real reason for her surgery; instead of telling her that testicles were being removed, they told her that residual ovaries were being removed to prevent them from becoming cancerous. Ronnie told her friends that she had hernia surgery, as her mother asked her to. The scars from her surgery remain on her lower abdomen, a sign that her body remembers what happened to it, a mark of its physical history. Following surgery, Ronnie began to take synthetic hormones. In this way, through medical treatment and her parents’ cooperation with it, the secret was established in Ronnie’s body.

One day her sister sent her an email with a link to the Androgen Insensitivity Syndrome (AIS) group in England. Ronnie kept the email in a folder and did not open it. When I asked her why, she replied,

When I saw that in the initials “AIS” the first word was androgen, my only familiarity with that word was that it had to do with someone whose biology and gender are undefined, something between a man and a woman, and it was very frightening to me. . . . I put it in a folder and forgot about it. After about two years . . . I told my friend, a doctor. . . . I told her what I tell everyone, and then she asked me, “So when did have your testicles
removed?" and I felt like I’d been punched in the stomach, just 
as ashamed that I didn’t know. So I told her at age fourteen, as if I 
suddenly had made all the connections to the surgery I had had 
then. Then she left, and I went to the website that my sister had 
sent me . . . and only then did everything become clear to me.

Ronnie experienced the moment of the secret’s revelation 
in her body as a punch in the stomach, a feeling directly 
connected to her abdominal surgery, which the body remembers 
through a scar. Ronnie immediately made the connection 
between her surgery at 14 and the removal of her testes. The 
secret, now revealed, that her body had contained testes, and 
not damaged ovaries, frightened and deeply troubled Ronnie, 
because the organ she most associated with masculinity had 
been part of her body. She explains,

The subject of the testicles was the most problematic for me then 
and has been ever since. I didn’t tell my boyfriend about the 
testes, but only that I don’t have a uterus, and he took it with 
indifference. I don’t want to tell him about the testicles, because 
I think this would have been a sexual turn-off for him.

After uncovering the secret, Ronnie began to explore her 
physical condition; she read studies and wrote an academic 
paper on the different forms of AIS, which she gave to her 
sister and parents to read. Ronnie also recognizes the bene-
fits of her physical condition, such as being tall and not being 
hairy. Ronnie expresses her discomfort with the term 
“intersex”:

I don’t think of myself as intersex. . . . I don’t have any problem 
with my sex. I also think it has to do with the form of the 
syndrome that one has. The physical appearance of those with 
complete AIS is that of a woman and it’s different from other 
syndromes, where there are elements of both sexes. . . . Despite 
my condition, it’s clear to me that I’m a woman; my sex was 
confused, but my gender was not. I will elaborate. Yes, I had 
problems when I was younger. I was flat-chested and had short 
hair, so people would mistake me for a boy and I was very 
insulted. My hands are not feminine either, but I cannot imagine 
living life as a man.

Ronnie’s “physical reality” is dialectical, expressed in the 
tension between her internal corporeality and the external 
corporeality resulting from her “syndrome.” The dialectic is 
between her internal “masculinity” (testes, XY46 sex chro-
mosomes) and phenotypical femaleness (female external 
genitalia). On one hand, Ronnie says that her corporeality, 
her outer appearance as a woman with CAIS, is that of a 
woman, unlike what outer appearance may be in other physi-
cal conditions of intersexuality. On the other hand, she says 
that her physicality as a child made people mistakenly think 
she was a boy, and that she had been offended by this. 
Similarly, she adds that her “sex” is confused, but her “gen-
der” is stable, clear, and decidedly feminine. When I asked 
Ronnie to describe what it means to her to “feel like a 
woman,” she responded that she had no idea, but that she still 
knew she was a woman and not a man in the existing social– 
gender dichotomy.

Ronnie, like Shai, experienced the physical dialectic. This 
took place during the surrogacy process, 3 years after our first 
interview. Ronnie told me that she had married her partner and 
they had begun the surrogacy process, during which she was 
required to undergo general medical examinations and provide 
medical documentation confirming her inability to conceive:

When I do an ultrasound there is something comfortable in the 
doctor just writing “uterus and ovaries not detected” and not 
“but testicles were detected” . . . because there is still a 
dissonance between the self-concept, the gender I chose, and the 
fact that I once had testicles. It’s a dissonance that needs to be 
dealt with, and this solves the problem of the need to deal with 
it. It doesn’t completely solve it because, bottom line, “I once 
had” is similar to “I have,” but it still allows me to deal with it 
and explain myself to myself and not explain it to the ultrasound 
technician, let’s say.

Ronnie’s bodily secret continues to exist, even when there are 
no testicles in her body. Ronnie says that she deals with 
the secret by keeping it to herself. Thus, she maintains the 
dissonance—the bodily dialectic. In retrospect, Ronnie 
explains that the secret has affected her life, her social abili-
ties, her interpersonal relations, and her trust in others.

The min-guf process that Ronnie underwent created a 
physical secret that, in turn, produced a dialectic in her life 
between her body and her gender. The bodily secret here is 
actually a family secret, shared by her older sister, their par-
ents, and their doctors. The secret no longer depends on 
the material physical characteristics of the intersexed body; even 
after Ronnie’s testes were removed, she experienced the ten-
sion produced by the bodily secret. The removal of the testes 
did not produce a blurring or disappearance of intersexed 
corporeality, but rather strengthened it and preserved it as a 
bodily secret. The body is the secret, but at the same time it 
also undermines the secret. The feeling that Ronnie describes, 
the self-dissonance, threatens to reveal the secret. In other 
words, on one hand, the physical secret, concealing the inter-
sexed physicality, protects Ronnie from the threat and the 
response to the disturbing physicality associated with masu-
culinity. But, on the other hand, the body cannot conceal the 
secret, and leaves the physical scars of the min-guf process. 
There are also emotional scars that are experienced physi-
cally, for example, the sense that the testicles exist even in 
their absence. The secret provides power, presence, and exis-
tence to the particular intersexual corporeality.

Or: “I Was Hooked Up to a 
Respirator” (November 6, 2009, 
December 25, 2009)

Or, 28, is an academic. She is interested in researching the 
genetics of her physical condition—congenital adrenal 
hyperplasia (CAH). Or is active in the CAH community on a
well-known Internet site and often provides biomedical information to parents of intersexed children and to intersexed people with CAH. She begins with the story of her birth:

I was born prematurely, in the eighth month, and it was a breech birth. I’ve always been kind of contrary. They noticed something strange and my mother told me that there was a doctor who . . . recognized the syndrome. Actually I was, I am, a classically difficult case. The term is CAH due to 21OH deficiencies, which means CAH due to damage to enzyme 21 accompanied by the loss of salts. I have all the problems. Aside from that, he recognized that I did not look normal and so they monitored me closely, so I did not become dehydrated.

Immediately after birth, Or underwent a series of tests to monitor levels of hormones and salts in her body. Her external genitals included an “enlarged clitoris” and closed labia, and this situation brought about the initiation of the min-guf process and diagnostic tests to determine her physical condition. She and her parents were referred to the best hospital available at the time—Johns Hopkins University, which specialized in these surgeries. She recalls,

By age 5, I actually already realized that I was different. I didn’t go to change clothes in the locker room at the pool. At five I underwent the first surgery. And then they arranged the external form [of my genitals], arranged what needed to be arranged.

Or reveals here that at an early age, she had become aware of the physical differences reflected in the appearance of her external genitals. She describes the difference she sensed at a very young age when she saw that the women in the locker room did not have the same organ as she did. Or explains how she experienced her difference: “From the day I first knew who I was, I knew somehow that I was not normal. To have surgery at age five pretty much establishes this fact.”

Or’s statement attests to the fact that genital surgeries themselves increase the sense of difference in intersexed children and do not facilitate their adaptation or sense of social belonging, as biomedical experts claim. Or does not remember many details of the meeting with the psychologist at the clinic before her surgery, but she recalls that her mother talked with the psychologist, and she mainly played with toys she defines as “boys’ toys”—tractors and trucks. During her childhood, Or remembers, she had to take medications, which increased her sense of difference and alienation regarding her corporeality.

At 12, Or underwent a second operation to continue the construction of her external genitals. While the first surgery constructed the outer labia, corrected the urethra, and reduced the size of the clitoris, the second was aimed at constructing a vagina and allowing the passage of menstrual fluid from the cervix. Or reports her recollection of learning from her mother about the second surgery: “I remember she explained that I had to have surgery so I could lead a normal life. I remember I asked why they hadn’t removed my uterus during the first operation.”

Or was aware of her corporeality early on. Her response to her mother’s news about the impending surgery can be seen as an attempt to resist ordinary life, a uterus, fertility, the kind of life her mother wishes for her. Or traveled to the United States with her mother to undergo the second operation. She does not remember pain, but recalls that she recovered quickly and was released early. After surgery, she had to preserve the vagina in her body and to use different expanders to widen it. As this was very painful for Or and for her mother, who tried to help her, in time they stopped. After the second surgery, Or increasingly shut out her friends. When I asked her why she thinks she isolated herself, she replied,

The main reason, I think, is that when I was born the doctors advised my parents not to tell. They told the grandparents, aunts and uncles, and that was it. I mean, they knew what I had, but it didn’t come up. . . . The parents didn’t tell. You understand, they didn’t talk about it. My siblings don’t know.

At age 17, Or had a third operation and later an additional one to open and expand the vagina, which her body had closed over time. The purpose of the operations was to encourage her sexuality, especially the act of penetration. Or claims that, although she is not in a relationship and does not want to be in one, she still preserves the opening of the vagina because it is threatening to close again.

Or’s min-guf process and the establishment of her physical secret caused her alienation and self-hatred. She does not like to be photographed or to see herself in pictures, and is revolted by psychologists. Her sense of alienation is increased and reproduced both by the expansion of her vagina and the operations she underwent and through her bodily secret, which is not spoken of. This is a kind of vicious circle—a bodily secret that is not mentioned, but which controls her life and threatens its existence.

Or attempted to escape this vicious circle. When she was drafted into the army at age 18, she decided to stop taking the dexamethasone (a type of cortisone) she had taken all her life. Or decided to get, as she says, “off the respirator” to which she had been attached since birth, which meant breaking free from her bodily secret. When her doctor called her in for a blood test, Or told her that she had stopped taking the pills. The doctor informed her parents at once, and they asked her to resume taking the medication. Thus, the doctor violated medical confidentiality, and Or claims that if she had filed a complaint, the doctor would have lost her license. But she did not file a complaint. The physical effects of stopping her medication included fatigue, depression, and facial hair growth.

Or and her parents conceal the secret from her siblings, and thus the physical secret becomes a family secret that creates a boundary between those who share it and those who do not within the family system. The secret sabotages family
relationships and communication between family members. The relationship between Or and her siblings and her parents is cool and distant. When I asked Or about love and intimate relationships in her life, she explained that she has never experienced love that it is impossible for her:

How can I tell someone I was born different, that what you see now is the result of a successful plastic surgeon, more or less? I have no idea what I look like compared to someone normal. I would argue that the work they did wasn’t one hundred percent perfect, that I’m quite different. I don’t know, I mean they forgot to tattoo an orientation map on my genitals [laughs].

Or asks how she can develop a relationship with another person when she is unable to accept herself. She has a great deal of anger that erupts dramatically when someone annoys her. Or’s anger is directed at herself, and she often sinks into depression and talks to no one.

Or’s most dominant conflict is the struggle between the body and the secret. Throughout her life, the secret was established in her body with the aim of concealing the body and its physical history. It thus undermines and suppresses the particular experience of the body, its appearance, its being in the world, and particularly its interaction with its environment and with others. Throughout her life, Or learned that her body was a secret, something different, and therefore everyone was concealing it. The medications she takes, the surgeries she has undergone, and keeping the secret all reaffirm and intensify her difficult feelings. The bodily secret poisons her existence and causes conflicts and alienation from herself and others.

Conclusion

The min-guf process of intersexed people, the surgical, hormonal practices, the deliberate concealment of the intersexed body, and the attempt to make it “disappear” all establish a bodily secret. The secret is embodied as an organic feature through treatment practices. Over time, it becomes a foreign object that undermines the body’s orientation and existence. The bodily secret is a force that surrounds the body and produces stress, frustration, and the alienation of intersexed subjects from their bodies. Physical secrets, like other toxic and dangerous secrets, cause the subjects who experience them to occupy opposing worlds. On one hand, intersexed subjects live in a world run and disciplined by the rules of the secret and its agents, a world whose social, gender, and sexual norms are reproduced, filed under an imaginary sexual/gender ideal. On the other hand, they experience in their bodies a world that opposes both the rules of the secret’s game and the secrecy and social norms regarding sex/gender. The body does not “know” how to conceal the secret and treats it like a “foreign body,” causing tension and unease. Thus, it reveals the secret through pain, inflammation, scarring, residual internal genitalia, and the side effects of synthetic hormones, producing a kind of dialectical “corporeal realism” (Shilling, 2005) experienced by the intersexed subject, according to which his or her body simultaneously exists/does not exist, is present/absent, is hidden/visible. This dialectical corporeal realism produces a vicious circle; when intersexed subjects reveal the physical secret and become aware of the difference between their bodies and social sex and gender norms, they become its agents and reproduce the rules that conceal it. Thus, Or, Shai, and Ronnie conceal their physical secrets from their siblings and other relatives, just as individuals with conditions such as CAIS, ovotestis, or gonadal digenesis may conceal their chromosomal and gonadal characteristics, or CAH individuals conceal their presurgery genital characteristics, from intimate partners. But the body objects and responds in its own particular terms, a situation that creates tension and conflict with the rules of concealment and often leads to a continuation of the “normalization” of the body into a particular sexual ideal. And yet, the more the bodily secret continues to operate in the lives of the intersexed, the longer they try to conceal it from those around them and from themselves, the more they experience alienation from the body, alienation caused by the body and experienced in the body. The bodily secret disconnects and separates body and mind, and distinguishes between them as well as between consciousness and being and between society and its norms and the material body. Bodily secrets produce a constant conflict that makes the existence of embodied subjects impossible, as they are caught between conflicting worlds. The only way to escape the vicious circle in which intersexed people are imprisoned is to end the paradoxical attempt to conceal the intersexed body in the public space in general and from intersexed subjects in particular. That is, the surgical practices and the secrecy that surround them, whose goal is to reproduce some kind of typical sexual/gender ideal and not necessarily to save lives or prevent physical danger (except in rare cases in which gonads become cancerous), do not ensure the welfare and happiness of intersexed subjects. On the contrary, they endanger their lives and undermine their social, familial, and intimate relationships. The intersexed body has existed since the dawn of history. Attempts to make it disappear or to conceal it are damaging not only to intersexed people and their families but also to biomedical science, which, instead of attempting to normalize intersexed bodies, could learn much from them about the different ways in which the human body develops and the many challenges that it presents.

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Notes

1. I understood the difference between privacy and secrecy at a later stage of my research. While privacy and secrecy are similar in that they both include an element of concealment, researchers who differentiate between these two concepts claim that privacy is legitimate and ethical because every person has a right to protect his privacy as long as it does not harm others. While secrets and secrecy are supposed to be concealed, this concealment is directed at people from whom the secret is concealed, to whose lives the secret is connected. When information connected to the life, emotions, or body of another person is involved, the secret is unethical and damages the lives of others, from whom it is kept and to whose lives it is connected (Bok, 1984).

2. This traditional protocol was also called the “Money Protocol” (Davidson, 2009, p. 63).

3. Hermaphroditism was the traditional clinical term for intersexed patients and was replaced in 2005, following the Chicago conference, to “Disorder of Sex Development” (DSD).

4. Intersex Society of North America (ISNA) fell apart following its support of the term “DSD” and Chase, now called Bo Laurent, became the head of Accord Alliance group, which is devoted to supporting research and clinical cooperation with biomedical professionals.

5. Currently, various intersex and interdisciplinary groups are acting to raise awareness of intersexed peoples’ rights and to change medical treatment. Among these are the Organization of Intersex International (OII), European Network for PsychSocial studies in Intersex/DSD (EUROPSI), Accord Alliance, and others.

6. Joan Fujimura (2006) analyzed the protocols of genetic studies and the attempt of science to determine which genes cause the formation of female and male sex. It was found that science is deliberately ignoring findings that are inconsistent with the dual sexual perception. For example, while scientists suggest that SRY is the gene that causes the formation of male characteristics such as testicles, they ignored a fertile female mouse with an XX chromosome bearing the SRY gene, possibly because they could not explain this finding.

7. Can we separate the human body from social forces, language, and norms? Examining and researching human bodies, the medical discourse makes no separation between sex and gender norms. How can we capture the gender category and its manifestation in the sexual body? Parents use gendered language with their babies, but could they really predict that their babies will grow up to be a cis-gender person? Where does sex (body) begin and gender (socialization) end? Intersexed people become “intersexed” immediately after integrating with the biosocial gaze, which characterizes and defines them according to normative sex/gender frames. I would like to thank the reviewers for their insightful comments on this point.

8. This is an outdated medical term that indicates a situation in which the internal sex organs are “female,” and include uterus, ovaries, and fallopian tubes, while the external physical characteristics (phenotype) are male and the external genitals appear “male.” In Shai’s case, this took the form of a penis with a “normative” urethral opening at the tip of the penis and not elsewhere as happens in similar conditions (adrenal hyperplasia) and the structure of a scrotum, but no testes.

9. I interviewed Shai’s endocrinologist to get a historical perspective on treatment methods in cases of the intersexed in Israel. Without being asked, the doctor began to tell me about a unique case that he had treated and I understood that he was talking about Shai.

10. This syndrome is attributed to people with XY46 sex chromosomes. There are two forms of “androgen insensitivity syndrome”—complete and partial. In the complete form, the body does not respond to androgens and does not develop as male. The gonads—testicles—are undeveloped and remain in the groin (in some cases creating a hernia) or abdomen. The phenotype appears “female,” with female external genitalia—external labia, vagina, and clitoris. Frequency is 1 in 13,000 to 20,000 births. In the partial form, the body responds to androgenic hormones partially, testes develop, and the phenotype is integrated—“ambiguous genitalia.” The older term for AIS was “testicular feminization syndrome” (Harper, 2007).

11. For example, Ronnie told me about a woman with Complete Androgen Insensitivity Syndrome (CAIS) whom she met, who told her she had vaginismus, a condition in which the vagina is tight or shrinks during intercourse (with penetration), and that it caused her pain and discomfort.

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