Reflective Accounts on Secrecy and Uncertainty in the Field of Intersex Bodies

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This article reflects on the dynamic of secrecy surrounding intersex bodies and the ways secrecy is a significant social player that operates in social interactions, physical experiences, and decision-making processes. Based on interviews with medical professionals, parents and intersex people in Israel and Germany, which aim at understanding the meanings, medical practices and experiences of intersex bodies, I will describe the ways the dynamic of secrecy establishes and reestablishes intersex bodies. The secret operations and achievements depend on the degree of concealment of significant information, but at the same time, its actual existence often creates tension, changes peoples' behaviors, creates uncomfortable and tense social interactions that reveal its existence to some extent. The dynamics between concealment and disclosure is the heart of the game of secrets. This dynamic often creates multiple realities and experiences of uncertainty. In the context of intersex people, the dynamic between concealing and revealing controls their social, familial and subjective-somatic experiences. By keeping intersex physical characteristics and intersex peoples' medical history (genital and many other surgeries to "normalize" their bodies) in secret, doctors and parents often believe that they are protecting the children and helping them to be socialized as "normal" as possible, as healthy female or male children. However, at the same time, these concealing practices and the concealing/revealing dynamic convey negative feelings, toxic messages towards children's "deviant bodies", and thus also towards their self-images, their actual existence and their sense of belonging. These messages are an integral part of their growing up process, of their embodiment experiences, similar to the corporeal experience of their surgical scars.

Introduction

«Secrecy can harm those who make use of it in several ways. It can debilitate judgment, first of all, whenever it shuts out criticism and feedback, leading people to become mired down in stereotyped, unexamined, often erroneous beliefs and ways of thinking. Neither their perception of a problem nor their reasoning about it then receives the benefit of challenge and exposure» (Bok 1984, 25).

Sissela Bok highlights the main challenges of conducting research in fields surrounded by secrecy, such as the field of intersexuality/different sex development. Although today, intersex people, or people born with variation of sex characteristics (chromosomes, gonads, reproductive organs and genitalia which are not typical as female or male bodies) are more outspoken in many places around the world, especially in social media, and in some places, there are laws that acknowledge their bodily autonomy, still, intersexuality is largely concealed behind hospitals walls and familial spaces, far from the public awareness. The purpose of this article is to describe the methodological and socio-political barriers in this field that stem from the dynamic of secrecy. As I began my research journey in 2005, in Israel, I wondered why this field was constructed by secrecy. Perhaps it was because physical sexual development is a private matter related to the doctor-patient relationship and should be confined to the clinical space. Perhaps intersex bodies are concealed because they threaten and

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undermine sex/gender binary norms. Who wants to keep these bodies in secrecy and why? In the varied studies I conducted between 2005-2021, in Israel and in Germany, I learned that secrecy affects and sometimes controls the participants involved in this field: the bio-medical-professionals, health care providers, parents, siblings, intersex children and adults. Each of these "agents of secrecy" are dealing with, or sometimes struggle with the dynamic between revealing and concealing, embodied within the secrecy.

As a sociological researcher, who was not born with intersex characteristics (as far as I know of) and who is not a health care professional nor a parent of an intersex child (as far as I know of), I was and I still am an "outsider", with both the advantages and disadvantages that such a status entails. The separation between the inners and outsiders in any "secret field" is crucial to keep the secret. The inners seek to create a sense of identity and belonging, highlighting the differences between "us" and "them", far from the outsiders. In this field, the term intersex, which became a political term in the 1990s, embodied the history and contemporary struggle of people with different sex developments who share the same meta-narrative of the medicalization of their bodies. This includes the surgical and hormonal intervention to "feminize" or "masculinize" their bodies, the systematic concealment and secrecy surrounding their bodies, and the physical, psychological and social suffering caused by these medical practices, and living in secrecy and shame (Davis 2015; Karkazis 2008; Preves 2003). An 'outsider' position challenges the access to information and data, in this context, medical-statistical data on the number of newborns, pregnancies, abortions, medical outcomes, etc.; or access to support groups, close groups of parents and/or adults with intersex variations. On the one hand, I was unencumbered by any personal or political interest and uninvolved in the conflicts in this field. It enables me to be open to learn and listen to the varied experiences, issues that exist among intersex people, parents and doctors. A major disadvantage of being an outsider was my dependency on the willingness of the participants to take part in my study.

Sometimes I had to pass certain "tests" to be accepted, and, of course, I needed to build trust otherwise I would remain on the outside. I knew that it would be difficult to find intersex people in Israel, but I was unaware of the boundaries that secrecy creates and how they control the participants' lives and inevitably affected my relationships with them as well as my methodology. First, I would like to describe the boundaries that secrecy establishes in the research field and the blurry, ambiguous line between privacy and secrecy in the context of intersex people. Next, I will discuss the dynamics between revealing and concealing, and the uncertainty which exists in different experiences and practices, and from different points of view.

1. *Methodology*

This article is based on my journey in studying intersex bodies, my ethnographic accounts and the findings of different qualitative studies (narrative interviews with intersex adults and parents, semi-structured interviews with medical and healthcare professionals) I conducted between 2005-2021, in Israel and Germany. In the appendix the chart describes in detail each of my study's goals, methods and outcomes. Each of the study's goals is the outcome of the previous study and the changes in the field, including human rights and laws for bodily autonomy, such as they exist in Germany,

and it has trigged the comparison study between the German and Israeli socio-political aspects on intersexuality. In addition, findings on lack of psycho-social support for intersex patients and families in Israel, as revealed in my first study (Meoded Danon 2015), motivated the German-Israeli collaborative project which focuses on establishing awareness and better care within the public and health professionals spheres (Meoded Danon, Schweizer 2020).
The long-standing perspective in this research field enables me to examine the trends of change versus the trends of conservation in different socio-medical aspects. Secrecy embodied within the dominancy of the pathological discourse on intersex bodies and the normalization of medical practices. In some places (Germany, Greece, Australia) there are significant changes and more openness and awareness of the damages caused by secrecy, concealment and irreversible genital surgeries, but in many places the concealment and secrecy surrounding the existence and medical practices towards intersex babies/children are dominant policy.

2. *Secrecy, privacy and intersex bodies*

«We are used to thinking of power as what presses on the subject from the outside, as what subordinates, sets underneath, and relegates to a lower order… But if, following Foucault, we understand power as forming the subject as well, as providing the very condition of its existence and the trajectory of its desire, then power is not simply what we oppose but also, in a strong sense, what we depend on for our existence and what we harbor and preserve in the beings that we are» (Butler 1997, 2).

A secret, according to Simmel, is a kind of a living entity that exists through the tension of concealment, and in this sense, the secret is both a material and an intangible entity (Simmel 1906). We usually sense the existence of the secret through the tension it creates, but at the same time it is an abstract figure. It has the power to create destructive actions, distorted perceptions, and negative emotions (within its holders and outsiders, and in their interactions). At the same time, it stimulates creativity, challenges social boundaries, and creates mystery that arouses curiosity. The multiplicity of secrets makes it difficult to empirically study and analyze their effect on people's lives, however it must be considered in all research conducted in the field of intersex. The "dynamic of secrecy" refers to the inner tension between concealing and revealing practices. Simmel described this tension as follows:

«Secrecy sets barriers between men, but at the same time offers the seductive temptation to break through the barriers by gossip or confession…from the play of these two interests, in concealment and in revelation, spring shadings and fortunes of human reciprocities…» (Simmel 1906, 466).

Following Simmel's argument, Tefft (1980) referred to the dynamic of secrecy as an ongoing tension or conflict that creates a chain of actions and reactions between the "holders", those who keep the secret, and the "outsider" who wants to reveal it (ivi, 37). The importance of secrecy in the research context is that it keeps the privacy, anonymity and participants' confidentiality, respect and promise to protect them from harm, and in general establishing a relationship of trust and cooperation (Bogdan, Biklen 1982; Guillemin, Gillam 2004; Sabar Ben-Yehoshua 2001). Moreover, there is a blurry line between privacy and secrecy that we must acknowledge in our research process. As Bok explains:

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«Privacy, the condition of being protected from unwanted access by others, often generates secrecy. Secrecy protects privacy, personal space, families, and territory from unwanted others, and the more efforts to control their privacy rely on concealment, the more privacy and secrecy overlap. However, privacy does not necessarily conceal, and secrecy hides things that go far beyond what it is private. We usually associate secrecy with what we perceive as private, sacred, silent, forbidden, and stealthy» (Bok 1984, 11).

While privacy is a moral value of one's right to protect by concealing one's personal matters, physical issues, emotions, feelings, if it does not harm other people, keeping secrets and secrecy are usually the deliberate concealment of information that related to other peoples' lives, bodies, their histories, future actions, and perception of reality. Beside surprise parties or other gestures that involve concealing information that are relevant to other people, most of the secrets usually have negative, harmful effects on other people's lives, even those who seek to protect others from the information concealed (Imber-Black 1993). Hence, to practice any form of concealment in our studies, we need to ask these essential questions: what kind of information we conceal and why? Who pays the highest price (in social, familial, and physical-emotional terms) for concealing or revealing the information concealed?

Secrecy, unlike privacy, is an essentially paradoxical phenomenon. Benziman (2011) suggests that there are three main paradoxes concerning secrets. The first is the logical paradox. That is, the secret becomes a secret only through a process of representation; it must be reproduced to become a secret, and by means of the process of reproduction, it is revealed and ceases to exist. The second is the paradox of existence. While the secret is simultaneously abstract and material, we sense the tension and discomfort that it creates in social interaction, and although we do not reveal its content, we do reveal its presence. The third paradox is the illusion of control. When we decide to disclose the secret to a certain person and ask her/him "not to tell", we unconsciously convey the message that we have violated the law of concealment and the hearer might do the same (*ibidem*). These paradoxes create a dynamic of secrecy, practices that both reveal and conceal the secret, filled with tension, uncertainty and paradox.

What is the line between privacy and secrecy in intersex peoples' lives? It is a complex question because it embodies issues related to bodily autonomy and socio-cultural control. On the one hand, our body is our most private, precious asset, and any information regarding our physical characteristics, our feelings, emotions, passions, memories, etc. should be our own private matters. However, on the other hand, human bodies are public; our genitals and sexual characteristics become our social status after we are born, and in many places even before (through prenatal testing). Our sexual characteristics, especially our genital appearance, our most private parts, are our social tickets to be part of community/public life; it will signify our names, registration, the ways others will communicate with us and treat us in our social environment, in the context of gender's dimorphic norms.

Intersex bodies include many sexual characteristics, sex chromosomes, gonads, reproductive organs, genitalia that challenge the traditional line between female/male bodies (Fausto-Sterling 2000), hence, the automatic relation between social gender status and one's body/genitals is in doubt. Intersex babies, especially those with nontypical genitalia usually become a familial matter and not a private, individual matter of one's body, and various medical and familial acts carried out to conceal the

characteristics of intersex bodies, especially the "ambiguous genitalia" from the public sphere, public knowledge, family members until the babies' bodies will be "normalized" (Carpenter 2018). The medical practice of secrecy embodied within the genital surgeries practices aim at normalizing 'ambiguous genitalia' as early as possible to prevent psychopathologies among children (Money, Hampson, Hampson 1955; Kessler 1998). This practice is known as the "optimal gender policy". In order to conceal the physical difference of intersex children, parents move to different cities, hide their children's birth certificates, conceal medical records (such as pictures taken in surgical and clinical settings), tell lies, etc. (Chase 1998; Coventry 1999; Cote 2000; Davis 2015; Ford 2000; Holmes 2002, 2008). The attempts to conceal bodies that challenge body-gender binary norms paradoxically emphasize the existence of secrets and the will to reveal it. For intersex adults the secret was always vivid and present, its presence was tangible, it was experienced through somatic feelings of negative tension, uncomfortable, distressful atmosphere, fear, etc.
What are the consequences of these practices on intersex people's lives? And how does the dynamic of secrets affect their lives?

3. *Living with secrets and somatic knowledge*

«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, 29 Israeli with CAH).

When Or cried during our first interview (there were 2 more in different times), and explained how the secret controls and damages her social and familial life, and how suicidal thoughts ran through her head, that was the moment I realized how toxic and dangerous secrets can be. I was very naïve back then, at the beginning I didn't understand her negative feelings, after all, on the face of it, everything looks fine with Or, her body looks "normal", she grew up in a loving and supportive family, she studies at the university and is a brilliant person, works in a biological laboratory, what is the problem? I did not understand the depth of the physical-emotional damage of living with 'the secret'.
I will never forget the first "intersex" conference I took part at. It was in Oxford, in March 2005, the Androgen Insensitivity Support Group (AISSG) organized a conference there and in order to take part in (as outsider) I was required to prepare a lecture on my research purposes and explain my interest in this topic. I agreed, of course, although I was only at the beginning of my research. When I arrived at the conference hotel, I had to use a secret code in order to get permission to enter the conference room. In my (naïve) mind I had anticipated meeting mostly androgynous, gender-queer-looking people, but most of the participants "passed" as (very tall) women. Amazing and brave women. As an outsider, I was asked many questions. Why was I researching intersex? Did I have a boyfriend? I found myself "coming out of the closet" as a lesbian more than ever before. My ambivalent relationship with my mother and her difficulties in accepting my way of life were the highlight of many conversations. I felt free and comfortable sharing my feelings and did not feel at all like an outsider. I conducted two pilot interviews to learn more about the themes and

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issues that concerned their living experience. In retrospect these interviews enlightened the power of the secret which establishes the dominant narrative of intersexed people. Ann was the first to agree to participate, and, as many other narratives that will follow, her story begin with revealing her physical condition:

« […] I was 26 when I found out the truth. I felt terrible, I could not handle it. I always felt different growing up and I didn't know why […] My family was a very hard family to grow up in. I have a difficult relationship with my parents […] I felt quite happy and stable in my lesbian identity. I came out when I was 17 and when I found out the truth about my medical condition it really messed up my head because I suddenly questioned why I was gay. Was it because of my Y chromosome? What was motivating me? I had seen my sexuality as a cool thing up to that point. I felt that I was not like the mainstream lesbians. And suddenly I felt that my partner was rejecting me and thought that I was a male […] and that my belonging in that community was in danger and that lesbians would reject me if they knew that I had a Y chromosome. I suddenly rejected myself […] I couldn't believe that my partner would still love me and my relationship with her deteriorated very quickly and I used drugs and drank».

Anne taught me that the difficult experience of discovering the secret, which completely undermines the perception of reality, causes the desire to escape from this reality and thus also endangers life. In the second interview I met Shane, 23 years old, also born with AIS, who told me a different experience of concealment and revelation:

« […] my parents told me that I was intersexed when I was 11 years old and I didn't talk or think about it and carried on with my life […] I was young then so I didn't think about it really. So the things that I didn't discuss were feelings. I have got all the information about my condition, so I don't regret it. […] All my friends and family know. […] I came out when I was 15, I had boyfriends before, but I realized that it wasn't right for me. But now I think of my sexuality also as a continuum, like my gender».

Shane's story was exceptional and inspirational. I thought that this is the moral goal we need to achieve in this field, that intersex bodies, children and people will come out of the closet and reveal the ways human bodies and sex development are not dimorphic nor binary as assumed, and intersexuality should be socially recognized rather concealed.

Nevertheless, there was one time in the research that I had to take part in concealing the secret from intersex children and it felt awful. I met Naama, an Israeli mother of 12-year-old Omer. Omer knew nothing about her physical characteristics (born with AIS). When I arrived at her home, Naama explained that Omer was in her room and we should sit in the garden, where she wouldn't be able to hear us. At the beginning of the interview, when she talked about the process of Omer's diagnosis and her interaction with the medical professionals, Naama whispered, and I had to strain to hear what she said. She was tense, her body language conveyed unease, and her face looked sad and hurt. She stopped talking several times during the course of the interview, when she heard a noise coming from the house. As the interview progressed, her body language changed. The more she revealed, the more her body looked at ease. She raised her voice, laughed, and made more eye contact. She explained that Omer was born with AIS, which she had never heard of before. Naama told me that following the diagnosis she cried a lot and was devastated to know that her daughter would not be able to bear children. Our interview, she told me, was one of the few times that she discussed this matter, since she and Omer's father conceal this secret from everyone. They are afraid of ruining Omer's happy childhood. On the one hand, in this interview

I became an agent of secrecy, joining Omer's parents' and doctors' acts of concealment, but, on the other hand, I sensed the paradox of the secrecy. I felt that my presence, even though Omer remained in her room, and we did not meet, probably conveyed a sense of tension, especially through her mothers' body language. She probably knows something was being concealed from her. By keeping intersex condition concealed only gives this condition, physical difference an entity of itself, a strong and significant of one's destiny; but, on the other hand, the more we break each condition and its physical characteristics we (must) realize that sex development is complex, messy and we naïve to assume binary dimorphic bodies in the first place. The more we accept this complex the more the paradox of secrecy becomes. Towards the end of the interview, Naama challenged her own assumptions about sex development and fertility issues: "I do not know if my boys are fertile or infertile, why do I assume their fertility?", by breaking down sex characteristics and sex-gender different relation, the act of concealment challenged. What is the big deal? So the body develops in different sexual ways, what is so unusual about that? Naama asked me questions regarding her daughter's body, such as whether Omer would develop male secondary sexual characteristics; how other parents reveal the physical condition of their children; and what the best way to reveal this secret is. In exchange I asked her what she knew about Omer's diagnosis, and what her main fears about revealing the secret were. The interview space invited Naama to practice the disclosure to Omer and she only imagined the negative consequences of Omer's revelation.

The lack of support groups and public awareness only strengthens the power of secrecy controlling both children and parents. Secrecy surrounding bodies is deeply intertwined with the treatment policy. Genital surgeries and operations for the removal of internal organs take place during infancy – between age six months and one year – with the assumption that the babies will not remember and their bodies will adjust and recover. When the children grow up, parents and physicians are reluctant to talk about the physical facts, and hope that the children will only ask questions at a much older age. In reality, children sense that their bodies contain a secret, a negative thing that requires medical intervention. The physical secret becomes an inseparable part of their feelings of shame and strangeness and their experience of alienation. Many describe how they knew that there was something missing, hidden because of the tension they aroused in interactions with doctors and parents. Dr. Ralph, a German psychologist, described how his patient discovered her physical secret through a psychotherapy session:

«Emma (pseudonym) was probably 25 years old … she was very intelligent and active, but there was always a depressive cloud over her soul, she always had the feeling that she had lost something. We couldn't solve that, and then (after many therapy sessions), I asked her to close her eyes and describe what she saw. She saw a child in bed before surgery. I asked her what she felt and what was happening to her. And then she seemed detached, and said that she saw this baby had testes and it was quite clear what she had lost…for the first time, she realized that this had been the beginning of many problems and issues in her life».

Emma's experience is similar to the experiences expressed in many intersex narratives that show how the secrecy surrounding their bodies create tension and communicational barriers between them and their parents, siblings, and peers. The secret ironically conveys negative messages regarding their bodies, turning them into

a source of threat and fear. These experiences signify the meaning of somatic knowledge which is our unique corporeal sensual perception. This is a phenomenological knowledge of an inner feeling of being-in-the-world, the ways immediate objects and people are revealed to us, experienced by our unique corporeal senses (Merleau-Ponty 1962, 1968; Csordas 1999; Shusterman 2008). Somatic knowledge constitutes through the body-world relation, in the space of "in-between" the body and the objects of attention. This knowledge is not organized, nor systematic but it is temporary and temporal, it includes among others bodily communication and non-verbal messages, facial expression, voice, dreams, illusions, intuitions and so forth.

To conclude this part, living with secrecy and the ongoing practice of concealing information from others (by both parents and intersex adults) create mistrust, separation, and miscommunication between those who know the secret and those who do not. In addition, living with secrecy creates liminal somatic experiences, a kind of living in-between, not here, not there, always searching for a non-judgmental place, searching for home.

4. *Learning from somatic knowledge*

Increasingly, many parents are raising their children as intersex, having learned lessons from intersex adults. Verena, is the mother of 11-year-old Lena, who was born with gonadal dysgenesis. Verena decided to raise Lena as intersex, and while she gave Lena her mother's name, the gender assignment is open and not stereotypical. Lena meets with other intersex children in Germany and they travel, play, and share stories. Verena takes Lena for follow-up checkups and hormonal testing to determine whether there are signs of puberty, Verna is curious to know how Lena's body will develop. She describes her conversation with Lena about the physical changes of puberty and the reasons for medical checkups:

«I told her we had to go there because puberty would arrive and her body would change, and she would change, and if she wants to change to a boy or if she doesn't want that we will have to do something, she has to decide. She didn't like this... [and] for her it wasn't a nice idea to change. She said "I want to stay as I am… because there are not so many people who are like me" ».

Lena, as any other intersex child, during the socialization process, receives overt and covert messages towards their body, their body parts, and their physical development. Positive or negative messages are remembered, embodied, and become an integral part of the children's body image. Taking part in support groups enables parents to learn and have deeper understanding about varied intersex conditions, knowledge that is not always available to many doctors in this field. Including the long-term effects of hormonal treatments, different dosage, etc., Alex, a German father of an intersex child, describes his experience with support groups for intersex children and their families:

«There are multiple encounters with this group. First you meet intersex adults…we can learn a lot from their experiences. There is a 20-year-old who went through hormonal therapy, tried testosterone, tried estrogen. We can learn a lot. They explained what was not working for them… You don't see only one person, you see many with the same (physical) condition, but with different experiences. There is not a single answer to it. And then you meet other parents who have kids, who are a little bit older or a little bit younger, and see how these kids are developed… and it is quite interesting to see the range of

possibilities, and the final important things is that kids meet each other, and they see that they are not alone, they see themselves as a group».

While secrecy and genital surgeries are intertwined with one another in intersex children and adults' experiences, changing this dynamic is challenge for parents and doctors in Israel, where parents are usually struggle with socio-medical constraints that do not tolerate physical differences, as we can see in the issue of circumcision ceremonies for Jewish boys (Meoded Danon 2021). For instance, a young Israeli mother of a six-month-old baby with minor hypospadias, re-examined the doctors' advice to agree to early corrective genital surgery. She searched on social media for adults who had experienced this surgery. She talked with the 40 years old man with hypospadias (his mother mentioned above), who posted his personal experience on Facebook last year. She learned how the surgeries he had undergone did not correct his hypospadias, but actually created serious functional and health-related issues. When she went to different doctors to learn more about the surgery, she openly discussed her concern regarding surgical complications. However, the doctors' reactions were not what she had expected.

«They started telling me I was making problems for the boy, and in adolescence he would have problems, because that is boys' most important organ. My feeling was actually: okay, whom am I going to consult? A person who does this for a living… you pay them and they treat you as if you're mentally challenged. What are these questions anyway? Get the boy, we will operate on him, have him fast for six hours, we'll perform a two-hour surgery, after that a two-week catheter, and it's not a big deal. If worse comes to worst and the surgery isn't successful, we'll do another surgery, take skin from the cheek, it's nothing. Without blinking, in a second, just have him undergo surgery and that's it. Why are you coming to ask me about it, anyway? I know better. I'm the professor».

She decided to postpone the hypospadias repair, but then she was conflicted over the matter of circumcision. However, many Israeli parents who choose not to circumcise their children have an available option, unlike parents of children with atypical genitalia. Despite family pressures, parents who had chosen not to circumcise their children, especially when both partners agreed with this decision, faced the social pressures together, often without any dramatic issues arising. However, for parents of children with atypical genitalia, the possibility of not performing the surgery is very limited, because of the invisibility, secrecy, and lack of public discourse on the meaning and consequences of these surgeries, and because parents are reluctant to challenge gender and physical norms. To raise and acknowledge physical differences requires parents and medical professionals to pause, hesitate for a moment, and take the time to raise doubts and question the automatic, mechanical "correction" of the body.

Conclusion

Secrecy is usually intended to hide information that is perceived as the "truth" of something or someone, a significant and precious information about something or someone. Secrecy in the context of intersex bodies intended to conceal the gap between organized gender social norms and the chaotic development of the human body, human organism. Hence, the surgical and hormonal treatments seek to establish a "certainty" regarding the babies' sex- gender socialization in a binary society.

Concealing these practices is usually assumed by parents and doctors to be essential in this process of socialization, so that children would adjust to their new bodies with a sense of certain body-gender identity; but secret creates paradoxes, as I mentioned above (Benziman 2011), caused by its inner concealing/revealing tension. The first paradox is in its reproduction logic. Secret must be reproduced to become a secret, and through the process of reproduction it ceases to exist. While the continuity of medical practice that relies on concealing and socializing babies' intersex bodies through early surgical intervention, aims at keeping intersex bodies in secret from public and from the affected patients, in practice, however, intersex bodies cannot be concealed, doctors usually reveal/share and document their patients' bodies and the medical treatment, they are conducting and publishing studies; the parents usually know and sometimes reveal the secret to other family members, and the revealing intersex bodies and the treatment by the patients themselves and by the public depend on time, the social interactions and the will to know. The second paradox relates to its actual existence, its abstract and material characteristics. Although the content of the secret is concealed from the children (their sex characteristics and the various treatments they underwent in infancy), they always knew that there is a secret related to their bodies. This knowledge is related to their somatic feelings, somatic emotions, and intuitions. They read doctors' and parents' body language, facial expressions, their communication style, and which topics are sensitive and cause tension in family dynamics. The third paradox of the secret is the illusion of control. Secrets become the property of the owner of the secret, the owners want to protect their valuable and precious secret from others. But, as soon as the secret is discovered, the owners lose the control over it and it slips away, becoming the 'property' of many. In this sense, intersex people continue and are continuing to keep the secret as a family property, something precious related to their family that keeps them safe and protects them from others. But, at the same time, they might reveal the secret to significant others, friends and relatives and thus also release the secret to the world. In this context, the line between privacy and secrecy (the deliberate concealment of the secret) is blurry. The secret becomes private when intersex people choose to tell or not to tell others about their physical characteristics or the treatments they have undergone; but, privacy becomes secrecy when intersex people are involved in intimate relationship and the question of whether, when and how to tell about their physical characteristics, about issues of fertility for example, is no longer a private matter, because this information is also related to the other person involved, and the ways they both imagine their future relationship.

There are two more paradoxes of secrets I would like to add to Benziman's work, which evolved from the field of intersex, the paradox of the secret aura, and the paradox of uncertainty. The paradox of the secret aura relates to the fact that secrets have significant force, they create a kind of magnetic fields and light around them, and the keepers of the secrets turn the secrets to unique and transcendent truth; but, in the moment of revelation, the aura of the secret weakens or disappears. Thus, keeping intersex bodies a secret creates a kind of an aura around these bodies, turn this bodies to unique, mysterious, unnatural, or supernatural bodies, but, when the secret is revealed and the more people learn about these varied bodies, especially the complex biology of human bodies, the aura around these mystery bodies disappears, and instead

these bodies are perceived as another aspect of human's bodies. And, the other paradox I suggest is the paradox of uncertainty. This paradox is based on the assumption that by keeping a secret from others, the holders seek to preserve and reproduce a kind of certainty and order in their everyday lives, in their routine and actions. However, the very existence of the secret creates uncertainties in many aspects and areas of secret holders' lives, for instance, they invest a lot of energy to conceal their secret which makes them alert and their communication styles and interaction with others becomes distant, alienated, and restrained. Also, the secret holders struggle to focus and achieve their daily tasks and goals, all of which create a reality of uncertainty. Thus, while the normalization process of intersex body and intersex characteristics kept in secret from patients/children to establish a sense of certainty for their parents and (maybe) for the children in a binary society, the concealment practices created uncertainty in the lives of intersex people, in the ways they communicate with their parents, lack of trust in doctors and the medical system, their sense of isolation and separation from other family members, peers etc. All of which establish a living experience of uncertainty, for both, the parents (secret holders) and the children. By ending the concealment practices of intersex bodies and making them increasingly visible, the dominant narrative of secrecy will change, and also the meanings of intersex bodies.

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Appendix

Years and Context of the Study	Goals	Methods	Main Findings and Issues
2005-2011 **PhD study, the first sociological study on intersex in Israel**	To study the bio-medical and parental discourse on intersex bodies and the living experiences of intersex people in Israel	Qualitative study: half-structured interviews with 22 medical professionals. Narrative interviews with 7 parents and 11 intersex adults. IRB approval, Ben-Gurion University	The "Minguf Process": the soma-sexual socialization of intersex people. It includes the diagnosis stage, design and follow up. The medical discourse and the "Minguf" process is surrounded by secrecy. Lack of statistical, quantitative data on intersex in Israel. Ambiguous meanings, terms and interpretations of intersexuality and intersex people. The use of the term Disorder of Sex Development (DSD), instead of intersex. High terminations of pregnancies of intersex fetuses. Genetic counselors apply Pre-implantation Genetic Diagnosis (PGD) to families with a history of intersex-genetic conditions. Early genital surgeries. Parents are lack of info, highly depended on medical information, lack of social support, and concealed the physical facts from children or family members. Intersex adults are living with the vicious circle of secrecy, the ongoing dynamic between concealing/revealing their physical truth. Some experience their gender aligned with the gender given at birth, others express gender fluidity and non-binary. Many experiences physical, psychological, and social alienation and loneliness
2015-2018 **A comparison study on medical and social discourse on intersexuality in Israel and Germany.** **In 2013 a law passed in Germany which enable to live the Geschlecht gender/sex status at the birth**	To learn about the significance and implications of the new law in Germany and compare the medical discourse and activism in Germany and Israel	Mixed qualitative methods, including discourse analysis of medical publication, and intersex activists' publications. Narrative interviews with 82 Israeli and German participants, including 52 biomedical professionals, and psychologist, 15 parents and 15 intersex adults	In Germany: The German law allows only "temporary" recognition of intersexed bodies, depending on the different interactions between parents and the medical system and between the body and the professionals. More public awareness in Germany, cooperation between support groups for parents and intersexed adults and doctors and psychologists. Fragile achievements of bodily autonomy for intersex in Germany, depend on parental courage. Genital surgeries are widely taking place. Many German parents are raising their children with intersex identification. In Israel:

certificate open. I was curious to learn the socio-medical outcomes of this law		IRB approval, The Hebrew University of Jerusalem	More and more use of PGD to prevent the birth of intersex babies. Termination of pregnancies Parents are struggle with secrecy, fear, and long-term side effects of surgical and medical intervention. Lack of psychosocial support for intersex people and families
2018-2019 **Inter-care and awareness, a German-Israeli collaborative project, to improve the psychosocial care for intersex patients and families. The context is the lack of psychosocial support for intersex people in Israel and Germany. Funded by the Zukunft German-Israeli Future Forum**	To establish German Israeli collaborative projects for health professional. To increase public, medical professionals' awareness and knowledge on intersexuality and living experiences. To improve the care for intersex children, adults and families	An action study with 28 psychologists, social workers and intersex activists from Israel and Germany. Participated observations in two workshops, questionaries, and thematic analysis of the collaborative projects. IRB approval, The Hebrew University of Jerusalem	Seven small thematic groups collaborated and developed these following projects: Positive Intersex Information: incorporated three subprojects (intersex in the military, children's book and illustrated booklet). Each subproject dedicated to integrating new knowledge and information on intersex in different fields. Education on DSD/Intersex: this group created an educational lecture and workshop for German and Israeli healthcare professionals. Intersex and the Jewish Discourse: the group studied and analyzed Jewish theological texts on intersex with the aim of raising awareness of it in Israel's Modern Orthodox Jewish communities and supporting the acceptance of intersex people. TED-style lecture the group created a lecture for biomedical professionals, healthcare professionals, and lay people aim to establish an "interview", to understand intersex people perceptions and views of sex/gender. Parents' Group this group recognized and outlined the need to establish support groups for parents of intersex children in Israel. Implementation group focused on establishing a network consisting of professional caregivers, parents, intersex people, and the LGBTQA+ community. Sex Therapy for Intersex People: address intersex people's sexual needs and experiences. The participants are conducting a systematic literature review on intersex peoples' sexual health and well-being and aiming to create tools and guidelines for healthcare professionals and publish their outcomes
2018-2020 **A comparative study be-tween parents who did not**	To learn about the parental meanings, strategies, and actions for	The study included narrative interviews with 41 parents of children with nonnormative genitalia. Of these,	There are many similarities be-tween the discourse of intersex activism and the discourse of Israeli parents who choose not to circumcise their children. First, they both challenge the notion of "normative" genitalia and believe that it is socially constructed.

circumcise their children and parents of children with non-typical genitalia in Israel. The context is the issue sur-rounding genital autonomy in Israel	genital autonomy in Israel. To compare the discourse and experiences of parents who did not circumcised their children and parents of children, with non-typical genitalia	18 parents had children born with atypical genitalia, 14 parents lived in Israel and 4 in Germany (15 mothers and 3 fathers), and 23 were secular Israeli Jewish parents (3 fathers and 20 mothers) who had not circumcised their sons, so within the Israeli-Jewish social context, these children are considered to have nonnormative genitalia. IRB approval, The Hebrew University of Jerusalem	Second, intersex activists and parents who have not circumcised their children perceive genital autonomy and informed consent as significant ethical values and children's right. Third, both claim that genital surgery causes irreversible genital mutilation and long-term emotional damage. Fourth, both clearly differentiate between surgeries necessary for physical health and cosmetic, socialized surgeries. Limited resources available to Israeli parents of children with non-typical genitalia, regarding genital surgeries, including the (deliberate) concealment of data on the complications and dam-ages associated with circumcision, the data on the immediate and long-term side effects and health issues associated with genital surgeries, and the marginalization of voices that challenge the genital socialization process
2020 - continued **The geneticization of intersex bodies and the us-es of Assisted Reproductive Technologies for diagnosing and treating intersex people, in Israel and other places**	To study the genetic discourse of intersex/DSD and the socio-political is-sues surrounding it, in Israel and Germany. To examine the consequences of early genetic diagnosis on the birth rate of intersex babies in Israel and Germany. To analyze the public and activists' position towards issues of geneticization	Mix qualitative and quantitative methods, statistical analysis of clinical data, on birth of intersex fetuses, termination of pregnancies, PGD cycles in central hospitals in Israel. Interviews with geneticists, gynecologists, in both countries. IRB from the medical faculty of Bar Ilan University and Helsinki approval from three hospitals in Israel	Mix qualitative and quantitative methods, statistical analysis of clinical data, on birth of intersex fetuses, termination of pregnancies, PGD cycles in central hospitals in Israel. Interviews with geneticists, gynecologists, in both countries. IRB from the medical faculty of Bar Ilan University and Helsinki approval from three hospitals in Israel

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