



**BSc Psychology**  
**Department of Psychology**

**A Phenomenological Study on the Lived Experiences of Intersex  
Individuals in Iceland**

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### **Foreword**

Submitted in partial fulfillment of the requirements of the BSc Psychology degree, Reykjavik University, this thesis is presented in the style of an article for submission to a peer-reviewed journal.

### Abstract

The objective of this qualitative study was to explore the lived experience of intersex individuals in Iceland. The intersex population in Iceland is estimated to be around 6,000 and this is the first study of this kind in Iceland. The recruitment of participants took place online through a combination of convenience and purposive sampling and yielded two participants. This study utilized a descriptive phenomenological research design, using semi-structured, in-depth interviews. The interviews were recorded and transcribed verbatim. Following transcription, the interviews were analyzed, revealing notable themes and experiences. Both participants talked openly about their intersex variation yet had distinct experiences of how they discovered and came to terms with being intersex. A notable shared theme between participants pertained to physical health and well-being; other noteworthy themes included distrust of adults, acceptance of intersex identity, social feedback, controlling the narrative, and negative experiences in healthcare settings. The results of this study are in line with previous research and underscore the importance of further research on intersex individuals in Iceland.

*Keywords:* Intersex, qualitative study, lived experiences, well-being

### Útdráttur

Tilgangur þessarar eigindlegu rannsóknar var að rannsaka upplifun intersex einstaklinga á Íslandi. Fjöldi intersex einstaklinga á Íslandi er talin vera í kringum 6000 og er þetta fyrsta rannsókn sinnar gerðar á hér á landi. Leit að þátttakendum fór fram á internetinu með hentugleika- og aðgengisúrtaki og fengust tveir þátttakendur í rannsóknina. Rannsóknin fylgdi fyrirbærafræðilegri hugmyndafræði og voru hálf-stöðluð, ítarleg viðtöl tekin við þátttakendur. Viðtölin voru tekin upp og skrifuð niður orðrétt. Eftir að viðtölin höfðu verið skrifuð upp, voru þau greind og komu í ljós eftirtektarverð þemu og upplifanir. Báðir þátttakendur töluðu opinberlega um að vera intersex en áttu ólíkar upplifanir um hvernig þau uppgvötuðu að þau væru intersex og tóku það í sátt. Sameiginleg þemu milli þátttakenda sneru að líkamlegri heilsu og líðan; önnur þemu sem komu fram voru vantraust gagnvart fullorðnum, að taka í sátt intersex sjálfsmýnd, félagsleg viðbrögð, að stýra orðræðunni og neikvæð reynsla innan heilbrigðiskerfisins. Niðurstöður þessarar rannsóknar eru í samræmi við fyrri rannsóknir og undirstrika mikilvægi frekari rannsókna á intersex einstaklingum á Íslandi.

*Lykilorð:* Intersex, eigindleg rannsókn, upplifanir, líðan

### **A Phenomenological Study on the Lived Experiences of Intersex Individuals in Iceland**

Over the past few years, the discussion of sex and gender has been a noteworthy topic (Godman, 2018). Although some people debate whether there are more than two genders, it is generally acknowledged that there are two biological sexes: male and female (Encyclopædia Britannica, n.d.-b; Godman, 2018). The sex of an individual is usually determined at birth by the presentation of an infant's external genitals. Infants born with a penis are identified as male and those born with a vulva are identified as female. But not all infants are born with typical genitals; some are born with atypical genitals, making sex identification more difficult. This is where the concept of intersex comes into play (Amnesty International, 2017; Lambda Legal, 2018).

Intersex is often used as an umbrella term to describe individuals with sex characteristics that do not align with those of either biological sex, male or female (Amnesty International, 2017; Lambda Legal, 2018; Lundberg et al., 2018). An individual's intersex variation might affect their genitals, chromosomes, hormones, and/or gonads, which refers to the reproductive organs, i.e. testes and ovaries (American Psychological Association, n.d.; Amnesty International, 2017). In the medical field, intersex variations are often referred to as "Disorders of Sex Development (DSD)", although DSD sometimes stands for "Differences of Sex Development" (Lambda Legal, 2018; Lundberg et al., 2018). Given some intersex individuals perceive DSD as a negative and stigmatizing term (Lambda Legal, 2018; Lundberg et al., 2018), the term intersex will be used throughout this thesis.

### **Previous Research**

Due to a distinction in sexual anatomy, doctors have often found themselves compelled to perform surgeries on the genitals or reproductive organs of young intersex individuals without their consent (Amnesty International, 2017). The aim of these surgeries is to align their physical

characteristics to societal norms and expectations regarding sex and gender (Amnesty International, 2017; Haghghat et al., 2023). In recent years, researchers have conducted studies aimed to explore shared experiences of intersex individuals within healthcare settings, which have revealed upsetting results (Haghghat et al., 2023; Lampalzer et al., 2021). Participants commonly experienced medical trauma resulting from inappropriate procedures, traumatizing effects of undergoing surgeries as children, and being omitted from binary frameworks regarding gender and sex (Haghghat et al., 2023).

Both previously mentioned studies (Haghghat et al., 2023; Lampalzer et al., 2021) utilized a qualitative research design, which provided a deep understanding of participants' experiences. However, there were some limitations worth mentioning. Haghghat and colleagues' study failed to address cultural differences and lacked racial diversity, as most participants were white. Lampalzer and colleagues (2021) study noted concerns regarding subjectivity due to the nature of qualitative data. Furthermore, the small sample size limits generalizability, therefore researchers recommended replicating the study with a larger sample size.

Previous research has also shed light on the psychological well-being of intersex individuals, revealing distressingly high rates of suicide attempts, thoughts of self-harm, and engagement in self-harm (Jones et al., 2016; Rosenwohl-Mack et al., 2020; Schweizer et al., 2016). Mental health diagnoses were also frequent among participants, with the most common diagnosis being depression, followed by anxiety and PTSD (Jones et al., 2016). Jones and colleagues (2016) also found a correlation between gonadectomy in childhood and suicidal prevalence. However, having a childhood best friend was revealed to be positively correlated

with a lower prevalence of suicidal thoughts, suggesting the importance of friendships on intersex individuals' mental health (Schweizer et al., 2017).

All three studies mentioned above (Jones et al., 2016; Rosenwohl-Mack et al., 2020; Schweizer et al., 2016) utilized a qualitative research method. All studies provided significant results about the well-being of intersex individuals in the United States (Rosenwohl-Mack et al., 2020), Australia (Jones et al., 2016), and Germany (Schweizer et al., 2016), contributing to the existing knowledge of well-being of intersex people worldwide. There were however notable limitations, such as the lack of representation of multiple ethnicities in all studies, small sample size (Schweizer et al., 2016), a skewed age distribution (Rosenwohl-Mack et al., 2020), and sampling bias (Jones et al., 2016). These are all factors that can affect the generalizability of results.

Earlier research also explored relationships among intersex individuals. Lundberg and colleagues (2021) explored how young intersex individuals discuss their intersex variations and it was revealed that participants found parents and other family members were able to provide support during difficult situations. Others found it uncomfortable to talk about their intersex variation to their parents or family members, leaving them feeling isolated. In those circumstances, connections with partners and friends were a vital source of support.

Lundberg and colleagues' study (2021) also explored romantic relationships among intersex individuals. Many participants experienced concerns when it came to romantic relationships, fearing their partner's reactions to learning about their intersex variations. Researchers Sanders et al. (2015) also described a similar theme in their research, where participants in their study voiced their concerns regarding telling a partner about their intersex

variation, fearing their rejection. Participants who had not been in relationships expressed it was a distressing topic.

Both studies mentioned above employed a qualitative research design, providing an in-depth exploration of relationships among intersex individuals in the United Kingdom (Lundberg et al., 2021; Sanders et al., 2015) and Sweden (Lundberg et al., 2021). However, these studies had some limitations: they included only young, female-identifying participants and had small, homogeneous sample sizes, which limited their generalizability.

### **The Context in Iceland and the Current Study**

Previous studies outside of Iceland have provided valuable insight into the lived experiences of intersex people, however, such research has not yet been conducted in Iceland. In 2019, Amnesty International reported on intersex people's right to healthcare in Iceland. In their report, Amnesty International highlights the human rights violations intersex individuals face in Iceland. They additionally shed light on the lack of multidisciplinary care, clear protocols, and social support within healthcare settings, which limits their access to quality healthcare. Amnesty International's report primarily addresses the human rights violations intersex individuals face in healthcare in Iceland, while also touching on how difficulties faced in healthcare affect intersex individuals and their families.

A study on the lived experiences overall of intersex people in Iceland has not yet been conducted, therefore, little is known about the lived experiences and well-being of intersex people in Iceland. Consequently, this study serves as a foundation for further research on the topic. This study moreover adds to the existing knowledge of experiences of intersex individuals worldwide, drawing upon successful qualitative studies previously conducted. The research questions this study aims to answer are: What are the lived experiences of intersex individuals in

Iceland and how have their experiences shaped them and influenced the difficulties they might have faced?

## **Method**

### **Research Design**

The objective of this study was to gain a better understanding of the lived experiences of intersex individuals in Iceland. With the estimated population of intersex individuals in Iceland a mere 6,000 people (Amnesty International, 2019), it was presumed difficult to recruit multiple participants, therefore, a qualitative research design was chosen. Specifically, a descriptive phenomenological research design was utilized to gain a better, deeper understanding of human experiences (Willig, 2022).

### **Ethical approval**

Participants signed an informed consent before the interviews were conducted. There were no ethical implications for one having participated in the study. Both participants read and signed an informed consent form before the interviews and agreed to have the interviews recorded. Participants were informed of their right to withdraw at any time. Furthermore, participants were informed that their identity would be protected using pseudonyms. Anonymity was protected throughout the study, including during transcription and analysis. All recordings and transcriptions were securely stored and only accessible by the researcher.

### **Participants**

The criteria for study inclusion were that participants had to have reached at least 18 years of age, be a native Icelander, and have an intersex variation. The sampling method used in the study was a combination of convenience and purposive sampling. An advertisement for the research was posted on Facebook and emails were sent to two organizations in Iceland: *Intersex*



*Ísland*, which is an organization that provides resources for intersex individuals and allies, and Samtökin 78, a queer activism organization in Iceland. Through these efforts, two participants who met the criteria were recruited to partake in the study. Both participants were given pseudonyms, which they chose for themselves. Jóna is 42 years old and female, Katla is 28 years old and non-binary. Both participants have an intersex variation called Androgen Insensitivity Syndrome (AIS). Individuals with AIS are born with XY chromosomes, but their bodies cannot respond to male hormones, known as androgens. The insensitivity to androgens consequently affects the development of external genitals and internal reproductive organs during fetal development (Amnesty International, 2019; Encyclopædia Britannica, n.d.-a).

### **Measures**

Semi-structured, in-depth interviews were conducted, guided by ten open-ended questions developed by the researcher, with assistance from their thesis supervisor (see Appendix A). A semi-structured interviewing method allows for a deeper exploration of the participants' experience, as it can follow their priorities and areas of interest (Smith & Osborn, 2015). The interviews were recorded, one on a smartphone voice recorder application and the other using Microsoft Teams. Recordings were stored in a locked computer and phone and only accessible by the researchers. Recordings will be deleted a year after the study has been published.

### **Procedure**

Prior to meeting, the participants were asked which time and place suited them best for providing interviews. Participants were asked to read over the informed consent forms before the interviews and were informed that the interview would most likely last between 30 and 90 minutes. The interviews took place on March 27<sup>th</sup> and April 4<sup>th</sup>, with the first interview taking

place in a meeting room at Reykjavík University and the latter online. The length of the interviews ranged from 76 minutes to 116 minutes. Following the interviewing process, the interviews were transcribed verbatim, where anonymity was protected. The interviews were then analyzed, using a descriptive phenomenological approach and thematic analysis.

## **Results**

Following the analysis of interviews, notable themes emerged for participants. Below, each participant's story is presented, along with key themes identified during thematic analysis.

### **Jóna's Story**

Jóna is a 42-year-old who lives with her husband in Reykjavík. She recently became a grandmother and enjoys spending time with her grandchild, family, and friends. Jóna was born and raised in a small town in Iceland and grew up in a close-knit family, where she met her relatives frequently. When Jóna's mother gave birth to her, there was no indication that she was anything but a typical baby girl. However, during a hernia repair surgery at around three weeks old, doctors realized Jóna was intersex. Jóna has Androgen Insensitivity Syndrome (AIS), she has XY chromosomes but did not develop male sex characteristics. However, Jóna did have male gonads, or testes. In infancy, during a second hernia repair surgery, Jóna's testes were removed, since, at the time, doctors believed they would increase her risk of getting testicular cancer. Jóna's mother was advised by doctors to delay telling her daughter about her condition, since it could negatively affect the youth's self-awareness.

Jóna's mother told her she was intersex when Jóna was twelve-years-old, although that term was not used at the time. Jóna said this is probably the worst time to tell someone they are intersex, as so much is going on at that age: "You are starting to think, 'Oh I can have children when I grow up' and you have started thinking about the future." She described her experience

of learning she was intersex as being very difficult and that she no longer trusted her mother after keeping this hidden from her.

### **Distrust of Adults**

Jóna explained how the experience of learning she was intersex negatively affected her relationship with her mother: “This had a very negative effect on the relationship between me and my mother; there was a certain breach of trust. I just stopped trusting my mother at that time and stopped trusting men completely.” Jóna explained that her distrust towards men stemmed from it being a male doctor who had told her mother to keep her condition a secret. Soon after learning she was intersex, Jóna was diagnosed with ADHD and oppositional defiant disorder, and was sent to a youth psychiatric ward in Reykjavík. All the psychiatrists at the facility were male, which she recalls being an interesting experience, as she had decided she did not trust men: “So I showed my oppositional defiant disorder quite strongly and refused to talk to all men”. Eventually, all the psychiatrists gave up on trying to get through to her, and Jóna was referred to a female psychiatric nurse, with whom she was able to open up. Jóna’s nurse, along with an art therapist, helped her discuss the trauma she had been through, which also included the domestic assault Jóna had experienced, perpetrated by her father. Such had increased her distrust in men: “There was domestic violence, so it was another point, I don't trust men because they resort to violence”.

Jóna’s strained relationship with her mother following the breach of trust remained unchanged until she was 15-years-old and a younger relative of hers was born intersex, this younger relative will be referred to by their pseudonym: Emma. When that happened, Jóna’s mother and Emma’s mother came to Jóna and asked her what should have been done differently regarding her situation. She told them she should have always known she was intersex and that

they had not had any right to keep this from her. Therefore, Emma's mom took Jóna's advice and brought Emma up knowing she was intersex. She reflected on how having her mom and Emma's mom reach out to her with this changed her perspective regarding her mom's decision not to tell her she was intersex sooner and had a positive effect on their relationship:

They made a mistake, but they realized they made a mistake, and they corrected it, changed it. So, if they had known better, they would not have done it. It was somehow enough to fix this breach of trust that was between me, and my mother and we are very close today.

### **Accepting Intersex Identity**

Gaining a relative who was intersex also changed Jóna's perspective on being intersex. Jóna had been having a tough time with her self-image since learning she was intersex: "I had started breaking myself down, like 'I am not a real woman' and 'I am a freak'". One time her mother heard her talk about herself that way and told her that if that was true about her, it must also be true about Emma. Jóna recalled that this changed her thinking in that regard:

So, I was put in a position where, unlike a lot of people I've met who share the same biology as me, I couldn't think negatively about myself when it came to this. You know, I could think negatively about myself in other ways.... But when it came to this, it happened very fast, the negative thoughts popped up and I thought, no, Emma isn't like this, so I can't be either.

This change of attitude had a very positive effect on how Jóna thought about herself. Jóna stated that during this time, from around 15-17 years old, she was able to build up her self-image.

Right before Jóna turned 18, she went to study abroad and decided to be more open about being intersex. At the time, only her mostly female relatives and one close friend knew she was

intersex, so this was a rather big step for her. As she was going so far from everyone who knew her, she figured she could use this opportunity to see what it would be like:

Because I was going to the other side of the world, if it all went to hell, it was a limited time, it was a year. If it was terrible, I would go home in a year and then I could just forget about it, I would have tried it and known how it was.

Hence, most of the people around her, the year she studied abroad, knew she was intersex, and nothing bad happened. When she came back home, she started being more open about being intersex and told her friends.

Jóna talked about one of her most empowering moments, which happened when she was around 23-years-old. She, along with a few family members, was visiting a support group in England for intersex people and their family members. One night, she went to a bar with three friends she had met in the support group. They danced, had fun, and, on their way back to the hotel, started singing: „We are AIS, I’ve got my XY’s out with me“ to the melody of the song *We Are Family*. People on the streets of Oxford started joining them, and no one questioned them about the lyrics to the song. This moment changed Jóna’s perspective: “I just completely stopped being afraid to talk about it and caring about what people thought about it.”

### **Social Feedback**

When Jóna has told people she is intersex, she has usually experienced positive reactions. She said the most ignorant comments have been men who have asked her “Are you a man, then?”, after she told them she had XY chromosomes. In such situations, she has explained to them:

No, you can pump me with endless amounts of testosterone, and nothing will happen, I am biologically incapable of transitioning to a male body, no matter what I do. This is my body, and it will just be like this.

She stated that most of the time, people realize it is a stupid question. Jóna then explains to them the difference between gender identity, gender expression, and sex characteristics.

Jóna also recalls a couple of instances where she has received negative reactions. One time, at her previous workplace, she was having a conversation about her stepson and niece, who, at the time, lived part-time with her and her husband. A former coworker asked: “But when are you going to have your own children?” Jóna stated: “At that time, I had reached a point in my life where I wasn't hiding this, I wasn't telling people this unprompted, unless it came up in the discussion, but I wasn't hiding this, so I explained it” to which her coworker answered: “How awful that you can never have your own children.” This made Jóna very upset: “I remember it made me really angry when she said that my children were not my children”. Thankfully, her other coworkers did not let these comments go unnoticed and stood up for her, which gave Jóna some reassurance.

Another uncomfortable situation Jóna experienced involved her ex-boyfriend. He did not have a negative reaction to her telling him she was intersex, but soon after she told him, he started talking about surrogacy. He talked about surrogacy for a couple of weeks after she told him but, ultimately, that relationship did not last very long. Her ex-boyfriend's reaction affected how she felt about telling her current husband she was intersex:

I had decided that I was going to tell him this in a public place because if he didn't take it well, I could just leave.... It was fully planned, and I told him about this, and I was really

stressed that it would be something negative, because I had told my ex about this, and it was like...

Telling her husband, however, provided great relief: “He was just like ‘yeah okay’, and we finished our food and then went to his house“. A couple of hours later he asked her how being intersex affects her:

All of a sudden, he starts asking: ‘but how does this affect you?’ ‘Does it have any effect on your health?’ ‘No’, at that time I thought not. He started asking a few questions, but they were all just about me, it was never about how it affected him, there was never an issue and then it was just over, and he just knew about this.

### **Physical Health and well-being**

In her adult years, Jóna has experienced hormonal imbalances, resulting in a decline in physical health. Around the time she moved in with her husband, Jóna was on hormonal implants, that were created for women going through menopause. Although these implants helped for a duration of time, she experienced intense hormonal fluctuations, as she explained herself: “I went through menopause 30 times in 10 years”. Along with other physical health issues, the negative effects of these hormonal fluctuations had on her body, resulted in her having to go to rehabilitation and receive disability benefits.

When these implantations were no longer in production, Jóna received hormones through injections, which improved her symptoms, and she was able to build herself up again. However, what helped Jóna the most was receiving testosterone: “Then I got started on a small dose of testosterone and then I started building myself up even more and then the dose was increased, and I started building myself up even more”. The doctor who first prescribed her testosterone then moved out of the country, and Jóna went to a series of doctors who would not prescribe her

testosterone because she is a woman and “women should not be on testosterone.” Fortunately, her general practitioner continued to prescribe testosterone, as he saw how much it helped her. Things, however, got more complicated when her general practitioner retired, and Jóna ended up importing testosterone from Serbia, where no prescription was needed for it, for about two years. In 2020, Jóna finally got a new specialist who put her on “full-blown testo” which improved her physical health greatly.

Jóna stated that following her change of hormone treatment, her well-being started improving as well:

Basically, while I was on estrogen I always had low-grade anxiety, very low-grade, not so much that anxiety meds were needed but there was always a little underlying low-grade anxiety, and after I started testo it went away.

### **Katla’s Story**

Twenty-eight-year-old Katla was born and raised in a small remote town in Iceland, where they have lived most of their life. Katla has a very close-knit family; they live at their parents’ house and their younger sister lives close by. When Katla’s mother was pregnant with them, a test detected the presence of XY chromosomes, indicating that she was carrying a boy. Upon birth, however, it was clear that Katla was not a boy, as they had the anatomy of a newborn girl. Katla has a close older relative who has the intersex variation AIS, so their mother was convinced Katla also had the same intersex variation. It was later confirmed that Katla did in fact, have AIS.

When deciding how to go about telling their child they’re intersex, Katla’s parents researched online support groups and read about people who raised their children knowing they were intersex. When Katla was 3-years-old, the decision was made to speak openly about their



intersex variation. Katla has, therefore, always known they're intersex. Consequently, they have always experienced being intersex as normal. Katla felt comfortable telling others about being intersex. In elementary school, for example, their entire class knew they were intersex, and most people in their small town knew as well. They never experienced being outcast, e.g., bullied or talked about behind their back. So, their experience of growing up intersex was rather positive.

### **Controlling the Narrative**

As stated above, Katla was always open about being intersex and informed about what their intersex variation meant for them. They explained how being in that position, benefited them when it came to discussing being intersex with other people. By speaking about their intersex experience positively, they influence how others perceive the topic: "Whenever I have spoken to people, I describe it as a positive thing and I mean, I don't mind it and so people basically get the same attitude as I do."

Although Katla has always been confident in their intersex identity, they have been told by doctors to not talk about being intersex:

I remember one time I was going to give a presentation to my class about intersex and stuff and he was not comfortable with it at all. He didn't just say straight out 'You can't do this' and 'It's not good for you' but he was like 'You now have to consider what you're doing, this can have consequences and as soon this is out in the open you can't take it back' and some bullshit like that.

Katla also recalls her older relative, who went to the same doctors, being told to keep this a secret: "He literally just said 'go about this as murder', which is some heavy shit." Regardless, Katla remained open about being intersex and did not let their doctor's comments affect with whom they shared this information.

### **Negative Experiences in Healthcare Settings**

Being told by doctors to keep quiet about their intersex variation has not been the only negative experience Katla has had in healthcare settings. Katla stated: “Actually the main prejudices I have received have been from doctors” The same pediatric doctor who told Katla to be quiet about being intersex, constantly tried to convince them they were a woman, to which Katla responded: “No I am intersex”. This doctor also had a problem with Katla questioning the hormone treatment they were on:

I was basically just asking him ‘Hey, the meds you have me on, the ones I’m on right now, is this really the way it should be?’ and I mentioned the idea of getting testosterone instead of estrogen and he just said, ‘no it’s not available and this is not okay and you’re 18 so goodbye’.

Following this, Katla was left without a doctor and proper medication: “So for almost two years I didn’t have any doctor and I was only on crappy drugs that just didn’t work for me”. Eventually, after a family member had called the Icelandic Ministry of Health every day for about a month to file a complaint about their doctor, they were finally referred to a new doctor, although they had specifically asked not to be referred to this specific doctor:

Actually, the doctor we said I didn’t want to see, because we had a bad experience with her, but we were just told that this was the only doctor who could see us, so a bad doctor is better than no doctor.

While their new doctor was not their first choice, she did attend to them better than their previous doctor: “I’ll give her this, the doctor I got after my previous doctor, she was not great but at least she did her job”.

There were no hormones measurable in Katla's system when they went to see their new doctor, which Katla contributed to them only being on birth control pills. Since their hormone levels were this low, their doctor was convinced they had not been taking their hormones and could not be trusted to do so. When Katla asked to get regularly scheduled hormonal injections, as it would be more convenient than taking medication daily, their doctor was at first hesitant. However, their doctor then saw it as an opportunity to monitor their hormonal intake. Katla recalls: "So I did, in fact, get what I wanted because I wanted to be on the injections, but I only got it for the wrong reasons".

### **Physical Health and Well-being**

Due to the lack of hormones Katla received during the time they had no doctor, Katla experienced osteopenia, which means their bone density had decreased. This was discovered after they sustained a broken wrist and a broken collarbone, within a short timeframe. Katla explained how they experienced a drastic decline in physical and mental health during this time:

This period where I was without a doctor and just before that, it was actually just kind of hell, because I was really sick, in a way my body wasn't getting what it needed and then it wasn't functioning properly. I had very little energy, I was always tired, I slept a lot, I couldn't concentrate on anything, and on top of that, I fell into depression because I just thought to myself, 'Is this my life?'

Katla then described it as "life-changing" when they finally started getting hormones again:

The hormones were kicking in and I think the best description for it is that you kind of realize that you've been seeing everything in black and white all the time and then suddenly you realize that there are colors".

Because they had been sick for so long, Katla kept a health journal, to keep track of their physical health. This aided them in realizing the periodic changes their body went through after receiving the hormonal injections and they noticed a pattern:

When I had estrogen injections, it would take a few days or a while and then I was doing good, then when it started to wear off and I had to get injections again, I would basically get sick, I got tired and all the things I experienced before I got the injections, it started to come back, until I got the next injection.

At around the same time, Katla brought up the same idea they had brought up with their previous doctor: to get testosterone. At first, their new doctor was hesitant: “She was like ‘um no, we can’t really do that, you need to get estrogen because that is what women get’.” Ultimately, she agreed to try giving Katla a small dose of testosterone. After getting testosterone, Katla started noticing changes:

By adding a little testosterone, I had more stamina and then these fluctuations became more even, but she was still steadfast on the fact that I was a woman, and women get estrogen, so I wasn't allowed to get testosterone except a tiny, tiny bit.

When Katla’s doctor switched to a private practice, they got a new doctor, who did not see a problem with them being on testosterone. Katla was very pleased with their new doctor and stated:

This was the best doctor I have ever met because he just said ‘okay’, he knew something about this and said, ‘Yes I’ve heard that it's all right to be on testosterone’ and agreed I could get just testosterone. Since then, it has just been a whole different life.

Katla no longer experiences the same fluctuations in their physical health as they used to and their physical health has improved greatly, although it is not at 100% yet.

In infancy, Katla's testes were removed, a procedure they wish had not been performed. Katla did not have a say in the matter, due to their young age:

I was about to turn 9 months old when my testes were taken, and there was no informed consent there. My parents were told I would get cancer and die, so it was just a matter of taking them before I got cancer and died, which was just as soon as possible.

Although Katla wishes their testes had not been removed, they recognize that their doctors most likely had good intentions. Katla stated that had those testes not been removed, they would not have had to go through the troubles with hormonal imbalances they went through in the past: "Had I been allowed to have those testes, I would have produced testosterone, because that's what a male body would do, but because I'm immune to it, my body would have converted it into estrogen". They suspect a possible reason their health is not perfectly good yet is that their body is not naturally controlling the hormone production: "It would actually be more natural if the body would produce, by itself, more when more is needed and less when less is needed".

Although Katla still struggles to go to doctors' appointments, their recent doctors have been more understanding, they feel like they listen to their opinions a little more now than they used to, especially younger doctors. Katla also attributed it to growing up: "Perhaps it's because I've grown up and learned to stand strong on my own, maybe that helps".

### **Discussion**

The objective of this study was to gain insight into the lived experiences of intersex individuals in Iceland, focusing on how their experiences have shaped them and influenced the difficulties they might have faced. Results of the study revealed several notable themes, including the shared theme of physical health and well-being, as well as distrust of adults,

acceptance of intersex identity, social feedback, controlling the narrative, and negative experiences in healthcare.

The main distinction in participants' experiences relates to how they found out they were intersex and how that affected their experience of being intersex. Jóna was told she was intersex in her teens, which she recalls being a difficult experience. It negatively affected her self-image and created trust issues with her mother and men. In contrast, Katla was aware of their intersex variation since early childhood, they always viewed it as normal and had a positive experience growing up intersex.

Both participants had surgeries done on their reproductive organs in childhood, without consent. This was a common experience among participants in previous research (Amnesty International, 2017; Haghghat et al., 2023). Both participants also talked about their struggles with getting prescribed testosterone. Most of their doctors were reluctant to do so as they perceived them as female and argued that women should get estrogen, not testosterone. This is in line with previous research, where it has been revealed that intersex people are commonly excluded from binary frameworks regarding sex and gender in healthcare settings (Haghghat et al., 2023).

Regarding well-being, both participants struggled with mental health issues, such as anxiety and depression, which previous research has shown is common among intersex individuals (Jones et al., 2016). Previous studies have also addressed the high prevalence of suicide and suicidal thoughts among intersex people (Jones et al., 2016; Rosenwohl-Mack et al., 2020; Schweizer et al., 2016). Participants in this study, however, did not report instances of suicide attempts or suicidal thoughts.

Previous research has also highlighted the positive impact of a close relationship with family members (Lundberg et al., 2021), which both participants in this study have. Although Jóna experienced a lack of trust for her mother, after finding out she was intersex, they now have a close relationship. Both participants are in great contact with their family members, which appears to have a positive impact on their well-being. Jóna also addressed worries she had regarding telling her partner about her being intersex, which is in line with previous studies regarding romantic relationships among intersex individuals (Lundberg et al., 2021; Sanders et al., 2015).

There were themes in this study, which have not been widely addressed in previous studies, particularly those related to controlling the narrative and accepting intersex identity. Katla had an experience that is rather unique in the intersex community: they learned about their intersex variation at a very young age. As a result, Katla viewed being intersex as normal and was not afraid to talk openly about it. This allowed them to have a positive impact on other people's perceptions of intersexuality. The theme of Jóna accepting her intersex identity was also not commonly discussed in previous research. It demonstrates the possibility of gaining a positive outlook on one's intersex identity, regardless of the difficulty of doing so initially.

### **Strengths and Limitations**

This qualitative research provided a valuable in-depth understanding of the lived experiences of two intersex individuals in Iceland. This is the first qualitative research of this kind in Iceland and, therefore, provides a geographic context and broadens the cultural knowledge of intersex people's experiences worldwide. This research allows for a comprehensive analysis, where, through in-depth interviews, the researcher can identify noteworthy themes, which might not have been apparent with a quantitative research design.

However, there are some limitations worth mentioning. The lack of diversity is a notable limitation. As there were only two participants, who both had the same intersex variation. There is therefore a lack of representation of individuals with other intersex variations. Both participants were also born and raised in rural parts of the country, which might have played a role in their experiences. Another noteworthy limitation is the possibility of sampling bias. Both participants self-selected to take part in the study and, therefore, the sample might not be representative of the whole intersex population.

Lastly, it is important to address the subjective nature of a qualitative methodology. Despite efforts to remain unbiased, personal experiences and preconceptions of both the researcher and participants regarding the subject may have influenced the data obtained. Furthermore, it should be taken into consideration that the researcher's personal biases might have affected the interpretation of the findings.

### **Direction for Future Research**

It would be beneficial to conduct a similar study with a larger and more diverse sample, as there were only two participants in this study, and both had the same intersex variation. As both participants in this study came from rural parts of Iceland it might be informative to conduct a comparative study with intersex individuals in the capital area and rural areas. As a participant in this study mentioned, it might also be more beneficial to conduct a study like this in partnership with a well-known organization. That way, participants might be more motivated to participate and educate people about their lives as intersex individuals. Lastly, conducting quantitative research might provide generalizability and valuable insight regarding important aspects of intersex people's lives in Iceland.



**Conclusion**

This study provided valuable insight into the lived experiences of intersex individuals. Notable themes emerged which shed light on the challenges faced by participants as well as positive outcomes regarding their intersex identities. Participants had very different experiences of learning they were intersex, which greatly impacted their journey. The findings of this study are in line with previous research while also highlighting themes that have not been widely addressed before, such as controlling the narrative and accepting one's intersex identity. Overall, this study contributes to the existing knowledge of intersex individuals' experiences. There is however a clear need for continued research on intersex individuals in Iceland to provide more information and to meet the social and psychological needs of this underrepresented group.

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## Appendix A

### Interview Questions

1. Gætir þú byrjað á segja mér aðeins frá sjálfu þér?
2. Gætir þú sagt mér frá fjölskyldu þinni og heimilislífi
3. Hvenær komstu að því að þú værir intersex og gætir þú sagt mér nánar frá þeirri reynslu
  - a) Vissir þú hvað intersex var áður en þú komst að því að þú værir intersex?
4. Hvaða kyni var þér úthlutað við fæðingu og hvernig skilgreinir þú kyn þitt í dag
5. Hvernig hafa viðbrögð fólks verið þegar þau komst að því að þú værir intersex
6. Hvernig upplifir þú þekkingu fólks í kringum þig á hvað intersex er?
7. Hvernig upplifir þú að vera intersex einstaklingur á Íslandi?
  - b) Er eitthvað sem samfélagið á Íslandi gæti gert betur í tengslum við intersex málefni.
8. Þegar þú lýtur til baka, er eitthvað sem þú vildir að hefði farið fram öðruvísi í kjölfar þess að í ljós kom að þú værir intersex
9. Er eitthvað sem ég spurði þig ekki um en þú myndir vilja deila með mér?
10. Ein spurning að lokum, nú reyndist erfitt að finna þátttakendur fyrir rannsóknina, ert þú með einhverjar ályktanir um hvers vegna það gæti verið?