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# Do It Yourself
# Hormone Replacement Therapy

In Dissonance with State-Sanctioned Constructions of Gender

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# Abstract

Although the field of transgender studies has grown exponentially during the last decades, little is still known about gender affirmative medication outside institutionalized settings. Based on group interviews and autoethnographic accounts, this thesis sheds light on the experiences of practitioners of unprescribed hormone replacement therapy. The focus will be put on how the Swedish welfare state is active in processes of legitimization and precarization of gender through medicolegal discourses.



**Keywords:** Cisnormativity, Transgender, Biopolitics, Public Health, Social Anthropology

# Table of Content

## Acknowledgements

This thesis is written as a result of a collective struggle, as I am radically dependent on other beings. There is never a single author, neither am I. Some deserve a special mention.

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# 1. Introduction

"I know someone, I could ask them for testosterone if you'd like," my partner said. It was the middle of the day and we were still in bed. I was too ashamed of my body to get to work. Gender affirmative treatment was years away, according to estimations. Unprescribed hormones became my remedy. While I hear others in the trans community talking about putting their life on hold in desperate waiting for gender affirmative treatment, I feel as if I got the chance to take a short-cut, to let my life continue. Instead of waiting, I wrote this thesis. These words are funded by criminalized testosterone.

Sweden is dominantly constructed as inclusive towards people identified as LGBTQ (Kehl, 2018). Yet, in this thesis I will bring forth how the Swedish state is perceived as a producer of cisnormative[1] gendering through state-sanctioned medicolegal regulations of hormone use. Through an investigation of how self-medication with hormones - also known as do it yourself hormone replacement therapy (DIY HRT)[2] - is used as a gender affirmative practice among people with trans experiences I will bring forth how dominant understandings of the practice make gender deviance highly precarious. Sweden was one of the first countries to offer state-funded gender affirmative healthcare (GAH) (Transformering, 2020a) but today it is highly contested both by transgender movements and gender-critical voices. While established media has reported that GAH is too accessible (SvT, 2019), people in this study explain that they turn to DIY HRT due to the inaccessibility of GAH. I will suggest that, if we are to understand the contradictions in current debates and problems within GAH, we need to take a closer look at subject formation and processes of power/knowledge. Therefore, in this thesis I aim to discuss how cisnormative gatekeeping works and how the state is active in producing and legitimizing certain ways of doing gender.

Basing my thesis on an understanding of how power constitutes all relationality, I aim to bring forward how medicolegal regulations of sex hormones not only limit but also produce

[1] A cisnormative system makes it seem natural and desirable to adhere to the gender you were assigned at birth. See page 25 for more about the concept.

[2] Self-medication will throughout this thesis be used as synonymous with DIY HRT. Hormones will refer to estrogen and testosterone.

subjectivity. Instead of evaluating health and risk from a supposedly objective perspective I am inspired by scholars who seek to deconstruct claims to knowledge (Abu-Lughod, 1991;Butler, 1990;1997; Foucault, 1976; Haraway, 1988; Mohanty, 2003; Preciado, 2013; Stryker, 2006). Hence, rather than pointing out recommendations to avoid side effects from DIY HRT I am discussing how certain knowledge is able to proliferate through institutional legitimacy than. Yet, it does not mean this thesis is not interested in health. I would claim these issues are at the core of what produces livability[3] and vulnerability in contemporary society.

While a lot of attention has been paid to health inequality during the last decades (Green et al, 2019) the understanding of how ideas of pathologized gender deviance constitutes part of this broader pattern, has received little attention. Despite being pointed out as a recurring phenomenon both in Sweden and other places (Linander, 2018; SOU, 2017:92 pg. 669ff; Rotondi et al, 2013), there is not much research looking on self-medication with hormones as a gender affirmative practice. WHO (2020) warns that marginalized groups are forced to carry out healthcare practices by themselves without being able to access medical professionals. This is confirmed to be applicable when it comes to gender affirmative self-medication in Canada by Rotondi et al (2013). Still, when it comes to the Swedish context, no study is able to shed light on how gender affirmative self-medication is perceived by its practitioners. My objective is hence to write another perspective on gender affirmative practices into academic existence.

With this in mind, I aim to answer the following questions:

- How does the medicolegal regulations of sex hormones produce trans subjectivity?
- How do users of DIY HRT perceive the transformative potential of the practice and its dissonance towards the medicolegal regulations mentioned above?

[3] I understand liveability in this context to refer to an ontology of vulnerability in which we as humans need certain conditions to be fulfilled in order to sustain life. I consider this concept useful to think about which lives are made possible and which are eradicated, not by active killing but through taking away the conditions that make life possible.

Preciado (2013) argues that the fiction of gender is upheld through state regulations of biocodes, including estrogen and testosterone - the focus for this thesis. He suggests that the possibility of bending gender norms is reduced by the cisnormative legal frameworks of substance administration. Following this argument, I have chosen to put focus on how these regulations work in the case of DIY HRT in Sweden. When it comes to thinking about state control, I have been inspired by Spade (2015:8) not to think of laws as realities, built on the power of the sovereign who gets what he wants. Instead, I see state regulations as working through discursive systems of meaning that produce the legitimacy of the enforcement. Yet, to emphasize the discursive constructions is for me not to lose focus from our flesh and bones. As Edenfield, Holmes & Colton (2019) suggest, state institutions do not only act as abstract ideas but as materialized entities with serious consequences for human bodies. Throughout this thesis I will make visible the interconnectedness of regulations as discursive constructions, the enforcement in material terms and the consequences for subject formation.

As an increasing amount of people are born and raised in (neo)liberal hegemony, few come to question the notion of the individual body as property of the subject (Schwarzmantel, 2005). Yet, in the construction of the Scandinavian welfare state, coercive law enforcement has been a crucial element to take care of 'vulnerable' citizens (Nilssen, 2005). Since the participants in this study perceived these regulations as part of the precarization of trans subjectivity, I will discuss the ways that the construction of vulnerability is bound to legitimize coerciveness, even within a (neo)liberal state system. Following Stryker's (2006) and Repka & Repka's (2013) analysis of dominant understandings of transgender subjects as based on discursive processes of psychopathologization, medicalization and objectification, I will point out how these constructions work to discursively form trans subjects as people in need of welfare interventions rather than as autonomous citizens.

**Disposition**

In the next section you will be introduced to my main sources and to the field of transgender studies. Following this, in chapter 2, you will be able to read about how I arrived at the choice of research methods and some methodological concerns. The participants will be presented. Here I will also reflect upon the intersections of my own role as researcher and

community activist. In chapter 3 I will discuss in depth how I understand gender deviance and furthermore put trans into a historical context. Especially I will linger on the medicalization process as I see it as crucial to understand the wider discussions surrounding trans identities. By reading this chapter it will be a lot easier to understand the different positionalities of the participants in this study. In the following chapter I will explain what HRT entails as well as present the participants motivation for turning to DIY alternatives. In the fifth chapter, I explore the participant's relationship to the Swedish state and how institutional trust was transformed in the process of assuming a trans positionality. Here I will also explain what the state-sanctioned gender affirmative healthcare (GAH) consists of and briefly touch upon why the participants did not find this an accessible alternative. Thereafter, in chapter 6, I will go deeper into the state administrative processes of medicolegal regulations of hormones. Here I will discuss how different seemingly neutral laws can work in a cisnormative manner from the perspective of DIY HRT practitioners. In chapter 7 the focus will be on different ways of speaking of self-medication. I will bring up perspectives from general trans communities, Swedish civil society organizations and the ways that medical professionals within the state-sanctioned GAH speak. I will discuss how discourses of silence and danger are crucial to legitimize and withhold cisnormative standards within state-sanctioned regulations. Thereafter I will discuss how participants were able to create systems of solidarity and resistance by sharing knowledge and resources with other DIY practitioners. The 7th chapter will be devoted to a more theoretical discussion of the construction of autonomy in a welfare state and the construction of coercion in a liberal state. I will here analyze how Swedish biopolitics has been able to seem neutral (even progressive) despite its cisnormative production of gender. My point here is to show how the categorization of trans as a mental illness has been crucial for legitimizing coercion through processes of pathologization and stigmatization of psychiatric illnesses. In chapter 8 I will discuss the epistemological basis of GAH and how this is constructed differently through DIY-alternatives. For example, I will show how auto-experimentation (experiments made on oneself) become dissonant towards the medicolegal regulations. Furthermore, I will show how black boxing can work to diminish the knowledge of the users of GAH. I will argue that the Foucauldian concept of knowledge/power helps us to take apart the different claims and dismantle what they are basedon. In the conclusion I will try to finalize this project by pointing forwards. I will make some suggestions of further research and address the subjugation of this arena of knowledge in general.

## Previous research

In this section I will present the main secondary sources used for this thesis. I will provide a motivation for why I have prioritized certain sources over others. Also, I will give a brief presentation of the interdisciplinary field of transgender studies.

This thesis would not have been the same without the inclusion of the book Testo Junkie (2013), an investigation of sex, gender and biochemical substances, written by Paul B. Preciado. According to a review by Pellegrini (2016), Testo Junkie is already deemed to be a classic within gender and queer studies. Just like Butler's Gender Trouble, this book really causes us trouble with its gender-bending and genre-blending composition. Preciado blends autoethnographic accounts with deep delving into the history of substance regulation and subject formation. Through this, he manages to bring forth a theoretical framework, in dialogue with other critical scholars such as Foucault and Butler, that puts an explicit focus on the medico-technical production of sex. With Preciado's focus on how state systems produce gendered subjects through biopolitics, I find the book useful to ground my analysis of how DIY HRT enables a subjection different from what the state-sanctioned GAH offers.

As Preciado points out the importance of how the state regulates the access to hormones, it has been necessary for me to gain an understanding of legal procedures surrounding the practice of self-medication. To understand law at a theoretical level I have been using the introduction to the book Normal Life by Dean Spade (2015), who is a scholar, lawyer and a trans activist. I find his reflections to be especially useful as he highlights the dissonance between what the law says and what the law does, something that was pointed out by the participants of this study as well. In most cases I have been able to use the original sources for laws and regulations, though there are some instances in which I have instead used informative web pages set up by the relevant authority to guide citizens. In some cases, I have also been in correspondence with state authorities to make sure that I have made the right interpretation of the law.

Although this thesis is written in social anthropology, I also want to situate myself in the interdisciplinary field of transgender studies. Similarly to other feminist disciplines, it combines research with an explicit political stance and critical analyses of power (Stryker, 2006). Yet, while feminist studies often take the categories of binary sex/gender[4] for granted, transgender studies seek to dismantle how man and woman are constructed. This background makes it similar to queer studies, which can also be seen as ancestor or an umbrella category, but transgender studies puts its focus on gender deviance rather than on sexuality. As such, the field pays attention to epistemology just as much as embodiment and identity. For an overview of this field and a historic contextualization of claims to knowledge about transgender lives I have used Stryker's introduction to the anthology *The Transgender Studies Reader* (2006). Included in this anthology is also Stone's famous article *The Empire Strikes Back - a Post-Transsexual Manifesto* (1992) that I use in a similar manner. I find the epistemological ground and deconstructive aims to be very useful in relation to my own research questions. Additionally, albeit their relative invisibility in this thesis, my thinking about the world has been heavily influenced by Foucault (1976) and Butler (1990;1997) who both also form part of the wider theoretical framework within transgender studies.

Since I am interested in how gendered subjectivities are produced, I have aimed to find sources that build on a framework that acknowledges how power becomes productive. Instead of focusing on how things are, as a stable matter of fact, I am interested in authors who highlight the social processes that construct our world. In line with other feminist and post-colonial scholars (see for example Mohanty, 2003; Rich, 2003) I find it important to pay attention to the specific history and configurations of a place to avoid universalization of hegemonic accounts. Since my thesis is also focused on the construction of the welfare state and how regulations produce subjectivities, I find it crucial to point towards sources that have focused on the same context. In other words, I do not want to uncritically apply what is said about self-medication in one context where the state plays a totally different role. Hence, I have prioritized accounts that come as close as possible to the Swedish context. Yet, for my theoretical framework I have been using material from other times and locations.

[4] Within trans studies, the distinction of gender as social and sex as material is blurred following the argument of Butler (1990) that sex cannot be seen as a given but is also socially constructed.

Although there is much work done within social anthropology that discusses the body, bodily modifications and gender (forexample Kulick, 1998) I have not been able to find relevant work in the Swedish or Scandinavian context. Since my own background is interdisciplinary within social sciences and humanities, I have found it hard to motivate a singular focus on authors explicitly working in an anthropological tradition. Instead, I have used a combination of disciplines, some of them that are themselves a combination of more traditional categorizations. Yet, for my methodology I have relied more on anthropology as this discipline has for a long time discussed different issues of relationality, trust and procedural ethics - which are all areas that I find crucial for this work. Nevertheless, I still find my thesis to be relevant for the field of social anthropology as it brings in theoretical insights from other disciplines into a methodological framework that I find to be relevant to anthropology.

Generally, there is not a vast amount of published material to choose from when it comes to the intersection of gender affirmative practices and the construction of the welfare state. I have not been able to find more than one article focusing on self-medication as a gender affirmative practice in a Swedish context despite reaching out to the Nordic Transgender Studies network and several tries through different search engines. This means that I have balanced on slippery ground when it comes to choosing my sources of information. Some material is not adapted to the context of the Swedish welfare state, some isnot concerned at all with the violence of gender essentialism and some seems to be outdated already.

Repka & Repka (2013) have left an important mark since they produced the only article I have been able to find about trans people's self-medication in a Swedish context. They write from an activist point of view, bringing community insights into the academic world. These reflections also tie in with what I perceive as a more general discourse within the Swedish trans community, and what participants also spoke of. Apart from their more loosely defined experience as trans activists they base their article on a Swedish radio program about trans people's self-medication with hormones. They highlight parts of the radio program to illustrate how the stigma of self-medication is linked to wider structures of cisnormativity, psychopathologization, medicalization and ideals of rationality. What I find lacking in the article is a clear line of thought when it comes to who said what. Which parts of the article are based on community discourse and which parts are the author's own opinions? In part, the

article forms a picture of a united trans community. Though I would have wished for a more thorough work to put as one of my pillars for this thesis, I find it crucial to use a source that links self-medication to the Swedish context.

Ida Linander has published several articles about the Swedish healthcare in relation to people with trans experiences. Several of these articles formed the ground for Linander's dissertation in public health, published in 2018. In this thesis I include references both to one of the articles (Linander et al 2017), written in cooperation with other scholars, and the dissertation as such. Since the article was part of the dissertation project, the article and dissertation rely on the same methods and theoretical ground. Linander based their work on interviews surrounding the access to gender affirmative healthcare with 18 persons that all have a trans experience[5]. Self-medication is mentioned in several instances, even though it is never the main focus of the texts. What I find helpful in Linander's work is the combination of critical analysis, stemming from an epistemological ground in transgender studies, and a rich empirical material. I have used Linander's work both to complement and emphasize what I have concluded in my study.

In 2016 the Swedish government made the decision to order a state public report (in Swedish statlig offentlig utredning) (SOU), about the lives of transgender people in Sweden. It acquired the official number SOU 2017:92. Ulrika Westerlund was appointed to lead the investigation and gathered a team consisting of government officials. She also appointed a reference group with medical professionals, lawyers and researchers. To map out all different aspects of transgender life within a country is quite an impossible task. Yet, the material gathered in the 889 pages long document has been of great use to me both in my studies and my work with Transammans[6]. SOU 2017:92 both relies on secondary sources such as government reports and published academic articles but also on primary data through various methods. On a website dedicated to the state public report, people were able to submit their testimonies about different aspects of transgender life. They were able to gather 122

[5] For a discussion on what a trans experience might mean and how that differs from being a trans person, please see the beginning of chapter 3.

[6] I have been an activist in the Swedish federation called Transammans since 2018 and the chairperson since March 2019. Transammans works to challenge body and gender normativity. The federation will be mentioned several times throughout this thesis since it has had an (in)direct effect on my work

submissions this way, mainly, but not only, from people with trans experience. They also did interviews with key persons, such as civil society representatives and medical professionals within the GAH. Additionally, they organized community forums at popular trans-related events. The report includes a section (pg. 669-676) about self-medication with hormones and hormone blockers, a big part of which is dedicated to discussing the information given out by the Health and Welfare Department (2015) which I also discuss on page 44 in this thesis. They conclude that the lacking accessibility to GAH is at the core of people's decision to start self-medicating. I have used the state public report 2017:92 both to create an overview of the field and to make comparisons between their writings and mine.

## 2. Methods

As Hastrup (2009) notes, the delimitation of something is not much more than a cognitive construction. What has informed this research project is not only the methods I will describe here but the whole intersection of lives that collided in time-space, and then got mashed up into this text - written in intra-action with the corona-outbreak, germinating seeds and my own clinical evaluation within the state-sanctioned gender affirmative healthcare.

Yet, this thesis is mainly based upon the information gathered in group discussions online. I will start to discuss my motivation and practical proceedings for these discussions. I will then present the participants of this study. The last section of this chapter contains a discussion of my own role as an insider/outsider and some methodological reflections on my work.

From my experience within the organization Transammans, through feedback on events and community discussions, I have seen how people become empowered by meeting others in similar situations. Many times, people have told me how they thought there was no one else "like them" or "in their situation". By establishing a network surrounding non-conforming gender identities, people can exchange both practical advice and make sense of their world. I was hoping my interviews could bring people together in a similar way. Maybe together we could feel a little bit less lonely.

So, I started thinking about empowerment through interviews. After conducting my first interview, which was my only solo interview, the participant brought up that the conversation, despite being respectful and rewarding, also gave them a feeling of sorrow. Something that had been hidden inside of them suddenly entered the stage again. Even though I did try to focus my interview guide on what the participants *think* of something rather than what they have experienced, these two are obviously linked. And some of the experiences linked to self-medication are experiences of neglection, desperation, waiting, longing, unintelligibility and outright violence. I realized that, as Ross (2017:35) nicely puts it, "finding moments of empowerment is far more likely than creating fully empowering processes". I have strived toward making research a valuable experience for everyone involved, but I also want to acknowledge the painful emotions that have also formed this text.

While anthropologists have always engaged in group conversations in the field, today the concept of focus groups, stemming from marketing research, is dominating the group-based qualitative research. According to Montell (1999) there were few feminist approaches to group interviews or focus groups, despite the fact that consciousness-raising groups had been used extensively during decades at that time within feminist activism movement. Montell proposes that a feminist focus group would entail a lot of opportunities for similar empowerment while also achieving valuable data for research. In contrast to individual interviews, the researcher is not the only one making follow-up questions and comments to participants' answers. Instead, the participants themselves might start to lead the conversation. This can serve to disrupt the hierarchy and dichotomy of the researcher and the researched. Additionally, the interactions in the groups themselves might provide useful information about the research topic. What Montell writes has been similar to my experience. Sometimes, the informants have hijacked the conversation to start sharing advice about levels of erythrocytes or how to get hormones through the customs. I have not stopped them. Rather, I have engaged in the kind of small talk that facilitates livable lives and biohacking revolutions. For me, this has not only been a process of rapport building but a sharing of political strategy among activists. My methods have not only been instrumental, but also performative.

Because of the sensitive nature of the topic, confidentiality becomes crucial. Almost half of the Swedish population is worried about how companies such as Facebook handle their personal information, according to an investigation by the Internet Fund (Internetstiftelsen, 2019). Still, when I started hanging out in Swedish trans communities I was introduced to a number of very active Facebook groups. I doubt that Facebook is the best choice for confidentiality, but since I saw so much activity from individuals with trans experiences in Facebook groups I still thought it was my best option to find participants. My original plan was that nothing else would take place on that platform. Yet, working with an approach where participants are allowed to be participants and not just passive respondents, means that I needed to listen to the opinions of my collaborators. Hence, I ended up having everyone, except one participant, reaching out to me on Facebook. I even conducted one chat interview through Facebook after requests from participants. My primary plan was to use skype for all interviews, but only half of them were actually carried out that way.  Due to technical

breakdowns, suggestions from the participants and other adjustments we ended up on different platforms. Yet, all except one was made through video calls (synchronous oral conversations with cameras on)

In each of the discussions there were 2-4 participants. I had prepared questions to facilitate the discussion, but I was not seeking to strictly follow the manuscript. My task was to make sure everyone was heard, make the discussion flow and that the conversation kept some focus on the meaning of self-medication rather than the latest tv-show. Some of the conversations took the shape of semi-structured interviews. Yet, all of the groups also had some interaction among the participants themselves.

### The main characters of this story

This study has been informed by 12 participants. They were all recruited through self-selection via a call for participants posted in trans-separatist groups on Facebook. To gain some demographic information about the participants I sent out a questionnaire before we had the conversations. My aim was never to gain a sample that could be seen as representative of DIY HRT among people with trans-experiences in Sweden. I did not include or exclude anyone based on their answers to the questionnaire. However, based on the answers submitted I would like to point out some ways in which this study might have captured the picture of some groups and not others.

The majority of the participants were women using estrogen, diagnosed male at birth, and on average 29 years old. SOU 2017:92 (pg. 674) noticed that more people using estrogen were willing to speak about their DIY practice. They speculated on how the heavier regulations on testosterone, which are brought up on page 42, might affect the sample. Either it could be more common to self-medicate with estrogen or people using estrogen might be more inclined to speak about their experiences (ibid). Since estrogen is generally used by women and estrogen is not illegal to possess, this could be an explanation behind how a majority in this study were women. Yet, there are no quantitative studies that make further insights possible. Still, my sample included a myriad of gender identities and positions in society. The

oldest one had turned 52 and made jokes about her age since she ended up being in the same group as two of the youngest participants who both were 18 years old. Some were fed up with life and stayed at home even before COVID-19 while others flourished.

Importantly, according to the answers of the demographic questionnaire, none of the participants considered themselves to surely[7] have experience of being racialized and/or of racism[8]. If I would remake the questionnaire, I would probably ask people about their ethnicity or race instead of asking for an experience of racism. Race is not a concept widely used in a Swedish context, but I am also critical towards the use of ethnicity as an essentializing demarcation, following the arguments of Hylland Eriksen (1999). Generally, I was not sure of how to put the question and in hindsight I am skeptical towards my own phrasing. This is mostly due to how the questions makes it seem like racism is an individual experience rather than a social structure. The formulation of the question, and my own insecurities about how to ask questions about racism when no participant addressed it, has made it hard for me to discuss the implications of whiteness in relation to DIY HRT. I find this to be a crucial flaw in this research project since racism is such a foundation for how social experience is stratified.

I only included people who live in Sweden. Still I published my call for participants in both English and Swedish to make it possible for at least a small part of the non-Swedish speaking population to participate. In the end, I had two participants who preferred to do the interview in English. Both of them had moved to Sweden during the recent years. Many of the participants also deviated from norms regarding body functionality in ways that was not linked to sex/gender. I did not ask them to specify in which way, yet during the conversations several participants described themselves as neurodivergent[9]. Furthermore, there was a

[7] One participant answered "I am not sure" on the question asked

[8] In the Swedish version I wrote: "Do you have an experience of racism and/or of being racialized as non-white?" In the English version I wrote "Do you have a personal experience of racism?" The difference in formulation exist because I did not manage to find out whether racialization is being used in an English-speaking context similarly as in a Swedish context

[9] To be neurodivergent is when you do not fulfil the norm of how the brain is supposed to work. If you for example have ADHD or bipolar disorder, you are neurodivergent. To be neurotypical is to fulfil the norm of how a 'normal' brain works.

tendency towards having higher education in my sample. In my call for participants, I reached out for people with trans experiences rather than transgender people[10]. I added an asterisk to further down describe that I have a pluralistic view on what trans experiences can be (for a further discussion on the meaning of trans, see following chapter).

In the call for participants in Swedish, I wrote that participants should be self-medicating, consider self-medicating or previously having self-medicated. In the English version I used self-medication in the title but then wrote using, consider using or previously having used unsubscribed hormones in the criteria of participation[11]. I still find it hard to decide upon one word to encompass the practices I write about. I struggle, stuck in between intelligibility, representative descriptions and the politics implied in the utterance of specific words. When I started to hang out in the trans community self-medication and its Swedish equivalent 'självmedicinering' was the only word I heard that described the practice of using hormones outside the official GAH. So, when I started to apply testosterone gel on my stomach, I told people I was self-medicating. It was not until I was reading academic texts that I heard of any other terms. With this experience in mind, I thought the best way to make sense to people was to use the word self-medication/självmedicinering in my call for participants.

Most of my participants took some advantage of either private or public healthcare, as I will explain in detail in chapter 5. In that sense, their HRT was not entirely self-managed. Still, they perceived themselves as responsible for it and described their own practice as self-medication. One of the participants was hesitant to start self-medicating due to their wish to preserve their fertility. This is the only person in the group that has clearly not had any personal experience of self-medication. Still I found it interesting to include her in the study since she had a plan for how to go about it and could help me understand the motivation for DIY HRT. Another participant had not yet been able to access the substances normally used

[10] In the discussions, most participants referred to themselves as being 'trans' and in these instances I will refer to them as 'trans'. Yet when speaking about the whole group I cannot claim to be speaking about a group of trans people. All of the participants did, however, at some point in their lives have an experience of dissonance in relation to cisnormativity - a trans experience.

[11] I used unsubscribed instead of unprescribed due to a mistranslation. I used self-medication in other instances in the English call for participants but not in the bullet points describing who was able to participate. Please access the appendix to see the full call for participants.

for HRT but had tried other substances in order to regulate their hormone levels - yet without any perceived affect. I still perceived her experience to be important for the study since she inform me about the problems to access hormones without a prescription.

### Acknowledging the cyborg writing this text

As Abu Lughod (1991) notices, anthropology, with its emphasis on fieldwork, departed from the idea of total disentanglement to the research subject long ago. In a typical study you would arrive as a stranger but then get committed, attached, and become "one of them" (Bell, 2019). So, what about this situation when I was, in some ways, already an 'insider'?

O'Reilly (2009:114) states that 'outsiders' might be seen as less trustworthy, which can make it harder to build rapport. Additionally, she writes, outsiders are often less sensitive to which words to use and are more likely to construct the research subjects into stereotypes. Similarly, Adams et al (2017) emphasize the role of shared experiences and knowledge of which terms to use when conducting research with transgender and gender diverse participants. Before I started this project, I asked some friends within the local trans community what they thought about my tentative research project. One of the answers that I got was that my own experience with DIY HRT would be crucial for anyone to talk to me. This comment confirms the suggestion by both O'Reilly (2009) and Adams et al (2017).

Kivits (2005) suggests that self-disclosure is important to be able to create a sense of trust. I find it crucial that the participants are able to feel as comfortable as possible. Therefore, I wrote in the Facebook post that I have myself been taking unprescribed hormones for two years and that I am agender/transmasculine. I have also made my purpose clear, which is to bring forth stories that are seldom heard in dominant debates on the matter. It is also possible to link my Facebook post to my personal profile where it is possible to find a lot of personal information. Some people did already know me as the chairperson of Transammans.

Yet, what kind of an insider can I claim to be? Importantly, Abu-Lughod (1991) and Narayan (1993) problematizes the distinction between insider and outsider by pointing towards the

intersections and hybridizations of both categories. O'Reilly (2009:115), mentioned above, writes that researchers are still outsiders in the way that they see the case through a theoretical lens. I would like to further deconstruct the professionalization of knowledge and refrain from saying that my participants do not have any theoretical framework. Still, I doubt we share the same one. We all brought with us a chaotic set of discourses to this project. As Mohanty (2003) writes, there are so many more aspects of our identity than gender. I cannot claim to represent transgender people as a whole. I might consider myself to belong to some kind of trans community, but the plurality of people's perspective makes it impossible to declare myself an insider without hesitation. I preferably follow Abu-Lughod's (1991) suggestion of making explicit the particularities of our positionality in relation to the wider context of the research.

To be committed, not only to the research, but to be tied to people emotionally is not a reason to refrain from claiming scientific results. In line with many others (Owton & Allen-Collinson, 2013), I rather see emotional involvement as an advantage for ethnographic processes. When speaking of relationality in research, Bell (2019) describes that people commonly highlight that forming trust in the researcher brings forth more valuable and 'true' data. I find Adams et al (2017) to bring us an example of this when they emphasize sampling problems as a result of failing to build dialogue with transgender and gender diverse participants. Bell (2019) argues that trust in this discourse becomes a mere instrument for research goals. Similarly to Bell, I would rather like to turn it into a question of ethics and epistemological stance, but also of acknowledging the way that humans are bound together. Rather than claiming objectivity in relation to the field, I want to be clear that relationships already existing were part of how the research was formed.

In conventional research, there has been no (explicit) place for the researcher's personal experience (Hastrup, 2009). It has even been thought to pollute the results, rather than adding something to them. Pease (2012) agrees to this picture and then brings forth how personal and passionate writing is crucial for developing a feminist writing practice. If we are serious about having our research make an impact on the world, we need to make it matter for the people who read it. In this thesis you will find personal accounts of some of the worst moments of our lives. I would like my writing to be just as disruptive as those experiences

ask of me. My limits, however, lie not only in the conventions of academic writing. Since I am not a native English speaker, I find my vocabulary too limited to write all feelings into existence. Still, I hope that the black box[12] of academic knowledge-power might be a little bit demystified by trying to construct myself as part of thinking-feeling humanity.

[12] This concept will be described and discussed in chapter 8.

# 3. Identity formation and body modification

This chapter will be devoted to make sense of trans subjectivity. I will put a specific focus on how gender deviance became trans and how trans in turn became connected with bodily modifications. This chapter will not focus on HRT but rather bring forth a wider picture to make it possible to understand the kind of arguments and references the participants use in their accounts.

## Categorizing the body - cis and trans

When someone is born, most people are diagnosed[13] as either female or male according to a professional, medical interpretation of the outer genitalia. The rest of your life you are expected to perform[14] your given diagnosis. Another word for this is cisnormativity.

There are people who do not want, or simply do not manage, to perform their assigned gender. This cannot be reduced to one single narrative. Around the world there are plenty of words that describe someone who does not comply with the assigned gender[15]. Transgender, trans or trans* has been proposed as umbrella terms to include all dissonant gender positionalities (Stryker, 2006; Singer, 2014). RFSL, RFSL Ungdom (Transformering, 2019), FPES (N.D.) and Transammans (2020) define trans or transgender (transperson, in Swedish) in a similar way. To move away from the word trans as a marker of a stable identity, Linander et al (2018) instead uses the concept 'trans experiences' to describe people with an experience of not fulfilling expectations of gender conformity. I have also seen it used within the trans community to also include people who might not identify as trans for the moment but have had a period in their lives in which they identified as such. Throughout this thesis, I will use different concepts depending on context. For example, I will use transsexual when I refer to a time during which that was the primary concept for people under the current trans

[13] This expression is made famous by Anne Fausto-Sterling who has written extensively about the medical system of biosocial gender assignment.

[14] Here I draw on the notion of gender performativity, as developed by Butler, 1990.

[15] Although Western hegemonic knowledge production has long been marginalizing those who did not fit in to cisnormativity as a part of colonial power relations. See for example Camminga, 2018; Jarrín, 2016 or Hinchy, 2014.

umbrella. Since words are part of our identity formation just as much as identity formation is part of the words we use (Butler, 1997), there is no way to find out the 'right' word. Yet I find it important to make visible the genealogy of the concepts I use to also dissect the implicit power dynamics produced with the utterance of that specific concept.

To be able to understand dominant perspectives on gender deviance I find it crucial to make visible the history that forms basis for current discourses. During the 19th century the state-sanctioned medical expertise became obsessed with categorizations related to sex (Foucault, 1976:126; Svenaeus, 2003:25). Phenomena became interpreted from a biomedical point of view and new concepts developed into diagnoses (Preciado, 2008:75). Previously unnoticed practices turned into defining criteria of subject formation (ibid). There was a special interest in categorizing those deemed Other[16] (Foucault, 1976). Increasingly, the abnormal became defined as sick and unhealthy - cases for medical interventions (ibid). Within this specific context, the word transsexual was first written into existence as a curable condition (Preciado, 2008:28). In 1955, the term gender was coined and made it possible to separate what previously was known as sex into different aspects. This further constructed transsexuality as an intelligible condition since it was now possible to explain how sex and gender could differ from each other. With the birth of transsexualism, gender deviance became homogenized into stable categories rather than chaotic contextualized phenomena.

Within the biomedical context, the goal for a new-found disorder is to find its cure. Surgeries aimed at correcting problematic sex/gender positions were refined during the 20th century (Preciado, 2008:28ff). The scientific discovery of the hormone made the base for the development of hormones for commercial use. Preciado suggests that the interventions to "cure" transsexualism are often thought to be derived from a genuine medical need. However, he wants to emphasize how the technical possibilities for gendered bodily configuration also was the founding condition for the wish to undergo the same interventions. Here, he is not trying to delegitimize gender affirmative treatments but rather pointing to how any desire must be put into its context. What I find important in relation to this study is how the discursive-material construction of trans was based on interactions of technical

[16] I use Other similarly to Lee (2014:16-17) as a way to denote excluded subjectivities without having to specify how the process of exclusion was legitimized.

development, biomedical thought and an increased attention towards sex/gender. Despite current struggles to demedicalize the concept (AKAHATÁ et al, 2018), the link between trans and the need for bodily transformations has been well established throughout the history of the concept.

Since trans has been understood dominantly from a medical perspective, I find it important to introduce some of the main points in debates of biomedicine and the medicalization critique. According to Baronov (2008), biomedicine is the dominant underlying model of thought in current Western health practices. Biomedicine is linked to the project of modernity. With its roots in enlightenment thought it shares the same ideals of rationalism and objectivity. Larson (1999) agrees and suggests that biomedicine is based on dominant positivism. With methods for curing conditions that were previously a sure path to death, biomedicine has gained legitimacy among both professionals and lay people (ibid). As Svenaeus writes, we now have the possibility to survive, but that also makes us dependent on medical techniques. Biomedicine becomes the foundation of our existence - whether or not we agree to its underlying epistemology.

### Medicalization critique

Yet, biomedicine has been under critique from several angles. Importantly, from a feminist perspective, Haraway (1988) has emphasized the impossibility of value-free objectivity in her famous article about situating knowledge. Within public health, others criticized the mechanistic view on the human body and pointed out how not everything could be solved by an individually targeted cure (Blaxter, 2010:16ff). Illich (1974:918, cited in Blaxter, 2010:16) was significant in forming a critical perspective on power. He claimed that the current medical system was bad for human health because it fostered a dependence on medical experts rather than allowing for human autonomy. Lupton (1997) traces this critique back to the second half of the 20th century and the field of medical sociology, which during this time developed a critique of how an increasing number of phenomena became structured and interpreted as medical cases. Also transsexualism came under scrutiny during this uprising. Raymond (1979) argued that transsexualism is a mere intervention by the medical establishment and, based on the importance of the material body, that transsexual women are

not real women. Instead, she claimed that transsexual women were a malicious portrait of femininity carved out by patriarchy. Although the sociological medicalization critique brought up important issues about power inequalities in modern society that were long thought to be 'natural', the medicalization critique in turn became criticized for its dichotomous and essentializing construction of patients as passive recipients and doctors as almighty and evil (Lupton, 1997).

Sandy Stone (1991) was pioneer to point out how this essentializing dichotomization worked to spread biomedical narratives of gender deviance. Stone puts herself into dialogue with Raymond (1979), previously mentioned, and shows how Raymond has constructed a uniforms narrative of the transsexual based on dominant accounts legitimized by medical institutions. Stone points out that Raymond's account fails to encompass the diversity that exists under the trans umbrella. To support her arguments, Stone brings forth the historical and social context of the transsexual. To become eligible for "gender reassignment surgery"[17] you had to present yourself as fitting into the criteria that the clinics posed for you. It was an interaction in which medical professionals tried to find out what a transsexual was, while at the same time, the people who wanted to undergo gender affirmative healthcare constructed themselves as transsexuals in order to become intelligible towards the medical apparatus. However, it was the medical apparatus who had the last say in defining who was a 'real' transsexual. For example, they would not accept anyone who did not want to undergo all kinds of treatment available to adjust their body to resemble a cis person of the 'opposite' sex (Stone, 1991). Stone argues that this narrow picture was uncritically adopted by radical feminists such as Raymond since they failed to analyze the implicit power relations in this construction and instead came to the conclusion that transsexuals were not "real".

As will be further discussed in this thesis, whether or not trans subjects are constructed as capable of agency lies at the core of the discussion between Stone (1991) and Raymond (1979). Similarly to Lupton's (1997) description of how the medicalization critique constructed patients as passive, Stone notes that:

[17] This term reflects the picture of the transsexual as someone who wanted to change sex which has long been the dominant narrative of the trans subject. The gradual change to "gender affirmative healthcare" reflects the changing perception of what it means to be trans and seek bodily modifications.

> The people who have no voice in this theorizing are the transsexuals themselves. As with males theorizing about women from the beginning of time, theorists of gender have seen transsexuals as possessing something less than agency.

Stone points out how the knowledge production regarding transsexualism has been dominated by anyone but transsexuals themselves. She calls for trans-visibility and the creation of counter-discourses to the dominant medical narrative of what trans is. Lupton (1997) brings forth the increased usage of a Foucauldian framework of power as a main factor for how patients are now also thought to have agency, since power can be seen as something working in all social relations rather than a possession of the medical expertise. With this new focus on patient's perspectives there has been an increased focus on how patients are active in constructing themselves as subjects for medical investigation.

### Uncoupling trans and medicine

To understand oneself from a medical perspective cannot be understood as either good or bad but must rather be seen in all its complexity. Internationally, trans-related civil society organizations and networks have called for depathologization of trans identity (Asia Pacific Transgender Network et al, 2018). However, simultaneously, they argue that everyone should be able to access gender affirmative treatments. One of my participants suggested that gender identity should be held separate from gender dysphoria. He thought that a medicalization of gender dysphoria[18] was not at all problematic, while trans identities needed to be depathologized. Also in wider discussions within trans communities I have seen the argument for a separation of gender dysphoria and trans to enable those with dysphoria to get access to different treatments while not pathologizing the term as it has now become an identity category more than a medical diagnosis. Yet others claim that it should be possible to have medically assisted gender affirmative treatments without having a suffering of clinical significance. These discussions were further actualized with the creation of the new diagnostic manual ICD-11. Important in these discussions is to avoid a stereotypical generalization of trans people, imagining a homogenous group with unison claims. As I will

[18] Gender dysphoria is a suffering or hinderance in everyday activities because one's gender identity does not match the gender assigned at birth.

further emphasize in my description of the participants' understanding of their sex/gender, there are a myriad of understandings of what trans is and how this relates to adjustments of the body.

What has helped me to think in terms of trans, the necessity of medical treatment and identity formation is Butler's theories of subjection (1997). She puts forth how intelligibility is a core element of the human condition. Those who perform gender in a way that others do not understand are exposed to increased amounts of violence and precarity (ibid). Hence, if medical treatments might increase the intelligibility of a gendered subject, they might increase the livability of people's lives. Yet, most of my participants did not see their HRT as a means to avoid violence, but as a necessity for themselves. Therefore, I think about the postmodern critique of how systems of meaning are seen as outside of ourselves, as described by Butler (1997). She argues that discourse is not something that pre-exists outside of us which we then internalize despite it being in contradiction with our best interest. Rather, we are founded on the existence of discourse - we are discourse. There is no possible way to reject language altogether, since language is our way to make ourselves intelligible, and in language, power structures already exist. Thus, the belief in such systems of meaning is what keeps us alive. Rather than seeing medicalization as internalized transphobia, I want to acknowledge the agency of every human subject to make use of discourse and find a way for themselves to make sense of their world. That is not to say that everything is based on a deterministic reproduction - as we use the words, we put them into new orders and meaning change in constant interaction with surrounding agents.

Before moving on, I want to make sure that you are with me. There is a myriad of understandings of what trans is or should be. There are competing discourses on how we should understand gendered embodiment. These are struggles of power that constitute the (un)livability of human lives. That is how we create each other.  Let's continue.

# 4. The motivation for using hormones

I will now move on to how the participants constructed their motivation to start HRT in relation to their gender. Keep in mind that each and everyone has a unique understanding of themselves, while here there will only be space for a few examples that I find important to highlight. Further on in the thesis I will touch upon this topic again and it will be possible to distinguish more factors related to the production of the self. After explaining HRT and my participants' motivation for HRT in general, I will present some of the reasons why they started self-medicating instead of waiting for state-sanctioned gender affirmative healthcare (GAH). This will be further explained in the following chapter that focuses on the state-sanctioned gender affirmative healthcare.

## Sex/gender and hormones

Before I move on to participant's motivation for HRT, I find it necessary to explain what HRT is. Sex hormones are bioinformation that the body needs to develop secondary sex characteristics (Hembree et al, 2017). These characteristics include vocal pitch, hair growth (how much and where), breast tissue augmentation, muscle structure, growth of clitoris/penis and more. In puberty, the gonads (testicles or ovaries) start producing more sex hormones and therefore develop secondary sex characteristics (ibid). To develop secondary sex characteristics seen as masculine, testosterone is the main driver while estrogen is the force behind the secondary sex characteristics thought of as feminine (Transformering, 2020b; Transformering 2018). However, most bodies produce both estrogen and testosterone, yet in different amounts. HRT or gender affirmative hormone treatment means that you add medically produced hormones in order to elevate the level of the sex hormone your body produces less of (Hembree et al, 2017). For someone with testicles producing testosterone, it might be necessary to take testosterone blockers in addition to estrogen to gain any effect. The effects are similar to those during puberty, although some things are not susceptible to change after going through a first puberty. For example, once you have gone through a puberty driven by testosterone, your vocal cords have been growing, which means you have

gained a deeper vocal pitch[19]. Through HRT you are not able to decrease the size of your vocal cords and therefore get a higher vocal pitch. Similarly, if you add testosterone for an increased period of time, you will not be able to reverse the effect on your vocal cords even after stopping the treatment. As participants will discuss further down, no noticeable physical changes will appear during the first months of hormone treatments. (ibid). Within the official healthcare system, which I will describe further down, you may get help from an endocrinologist (a doctor specialized in hormones) to carry out HRT (Transformering, 2020c).

Most participants construct their need for HRT as a part of their trans identity. I want to start with a quote from one participant who described HRT as a part of herself. When I asked her why she started DIY HRT she said:

> Yeah, that I was like… I thought before that during all these years, even though things were good, and I felt comfortable and satisfied with life, there was always something wrong. And then, when I knew… That I was trans. That was more of a positive feeling in the beginning. That I realized this is what has been missing, that this is what I need. That this is what… I have been neglecting a part of myself for many years. That this is what is needed. This is what I owe myself. Then I have to do it. Whatever might happen. And it has been going well so far. Four months now. [Smiles]

In this answer she constructs her trans-identity as something that she already had before discovering it, a part of herself that has been neglected. She does not make much of a distinction between her identity and HRT. The hormone treatment is spoken of as an intrinsic part of being trans, and hence as a part of herself - something that she could not avoid. The hormone use in this case is not understood as an eligible add-on but part of one's being - an ontological necessity for a livable life.

[19] For adolescents however, there is a possibility to undergo a treatment to suppress pubertal development which delays the evolvement of secondary sex characteristics. For example, this makes it possible for someone with testicles that produces testosterone to never go through a testosterone-driven puberty (Hembree et al, 2017)

For another participant, HRT was her medicine to cure a hormone imbalance that she was born with. I read this as a way to queer[20] the medical discourse, referring to what I previously mentioned about putting words in new orders. Rather than seeing her body's production of testosterone as a natural determinant of her sex/gender, she saw it as an aberration from her normal bodily functions as a woman.

> Participant 1: I have a pretty medical view of myself. I have also met quite a lot of cis women with different hormonal aberrations. And that's basically how I see myself. That I think that… Well, now it is actually really that… I sort of identify as a transwoman, but in a way, I see myself as… I would almost say intersex[21]. That I'm just like any cis woman, just that I have had hormonal disturbances during the embryonic state.
>
> Participant 2: Oh yeah! Lovely! [nods intensively]
>
> Participant 1: And that's actually how I see it. It is really the most boring, stereotypical, normative scene. This approach is not actually... But I think it feels really wrong to apply that perspective to other transgender people because I am a woman with emphasis on, sort of. And period. This is how I see my own identity. So for me it feels like my body has been producing too much testosterone and too little estrogens and that's why I subscribe to a hormone treatment. It's just like any cis woman during menopause who needs medicaments really.

Here, we can read how the participant identifies with other women who need to add hormonal medicaments in order to function normally. Within dominant constructions, normality for a person assigned female at birth is different from the standards for someone assigned male (Blaxter, 2010:4). For example, in Sweden if you are assigned female at birth and produce more testosterone than a woman is expected to produce you are able to access hormonal treatments from the state-funded healthcare without a 'gender identity disorder' (GID) diagnosis[22] (Friedmann, 2018). The participant was assigned male at birth which makes her

[20] Queer is here used as a verb, meaning that a discourse has been modified and interpreted in a way that disturbs dominant power relations.

[21] Intersex is an umbrella term for different kinds of body characteristics that make it hard to unambiguously categorize the body as male or female according to cisnormative standards.

[22] For more about the trans-related diagnoses, see page 31-32.

unable to take this path, instead she needs to wait for the gender investigation to see if she is eligible for gender affirmative treatment. By putting herself into the discourse of female hormonal dysfunctions she is able to become intelligible as a woman in a cisnormative system despite her bodily incapacity to produce enough estrogen. Also, it counteracts the picture of the transsexual as "born in the wrong body". Here we rather get a view that her body *is* a woman's body, yet with a hormonal dysfunction - which the participant understands as something relatively common in general society. The relation to hormones becomes a matter of constructing a livable life, since she otherwise sees herself as malfunctioning.

Similarly, another participant stated that she saw her HRT as taking antidepressants. She explained that without it, she did not see any point in living, since it all got too painful for her to cope with. For her, it was the body that caused a strong anxiety, since she perceived it as being the wrong body. A third participant described it as being a dissonance between the brain and the body, and that his brain needed to get the testosterone he was taking. Before starting on HRT, he states that there was something "wrong" with him. In his narrative, he did not at all emphasize the importance of identity, but rather thought of hormones as something that his brain was in need of in order to cope with a body that did not match the neurological aspects of gender identity. Hence, he also saw it as a kind of medicine to correct a bodily dysfunction.

However, there was a resistance from some participants to put themselves in a medical framework. For example, one of the participants stated that they[23] did not experience any discomfort with their assigned gender. For them, the HRT practice was an option rather than a necessity. Similarly, Preciado (2013:55-56) places himself into a movement of 'gender benders', who do not subscribe to a medical protocol of transsexualism but experiment with their gendered bodies in the ways they like. Another participant resisted the medical perspective as well, but still described the use of hormones as a necessity. She pointed towards the social intelligibility as a main reason for undergoing gender affirmative treatments. She described the acts of everyday discursive violence: "And that is just really heavy when people are misgendering and kind of point out that you are wrong, like 'you are

[23] 'They' is used in English as a gender-neutral, singular pronoun (similar to the Swedish use of 'hen'). All participants are referred to by the pronoun they submitted in a questionnaire during early spring 2020.

not a woman, haha, anybody sees that'!". Here she refers to the suffering caused by invalidating comments. She believes this kind of misgendering was much due to a bodily appearance that according to cisgender ideals is read as masculine. As people generally do not reveal their genitals to strangers, dominant strategies for determining if someone is male or female (the only sexes that exist in cisnormative thinking) are based on other clues. Vocal pitch, size/shape of the chest and facial hair growth are some of the main clues that people use to determine which sex someone has. Hence, hormones play a big role in the validity of one's gender performance. This social perspective can be another way of looking at the use of hormones.

### Turning to DIY

Initially, many thought of self-medication as risky, hard and beyond reach. Several of the participants tried to endure the long process of accessing state-sanctioned HRT but ended up in a situation in which they feared they would commit suicide before reaching their remedy. One participant said:

> I then managed to find a way to access testosterone and then I did it [start DIY HRT] because I thought that there was not really much that could… I mean, it is either taking that risk or die, so it is not really…

In this quote, the participant describes that he did not consider the risk of managing his own HRT to be too high, since he was determined to commit suicide if he did not get access to HRT. Hence, it became the lesser of two evils. Similarly, another participant framed her start of unprescribed HRT in terms of necessity. She said:

> I also started self-medicating not so long ago, last October the 25th. And I guess it is a situation in which you have to do what you must. Do what you have to do. Because there are no other options.

In this statement we can read how HRT is perceived as an acute necessity, a necessity that has no other remedies than start self-medicating. She simply did not see it as possible to wait for professional supervision. WHO (2020) points out that self-care interventions should only be proposed when the user feels confident about the practice. In most cases in this study, the participants did initially not feel they had the competence to practice HRT without the

assistance of a medical professional. Rather than *choosing* self-medication, the majority of the participants perceived themselves as *forced* to it. Due to the inaccessibility of GAH, to which I will return, the medicolegal regulations make it impossible for someone in acute need of HRT to depend on the welfare state.

Still, the participants in this study perceived their health to be substantially better after starting DIY HRT. Also WHO (2020) acknowledge that, when no other alternative is available, self-care is often a better practice than abstaining from care altogether. As they felt better while practicing DIY HRT, they started to question why the state would not allow them to do it. As they formed their own understanding of HRT, expert advice did not seem as rational anymore. The experience of being forced into going against the medicolegal regulations and then realize that one's health was improved transformed these participant's views of the state altogether.

Yet, some did already have a critical view of the state. Generally, these participants did not postpone self-medication as long as described in this section. One participant told she came in contact with self-medication communities rather quickly after she realized she was trans. She then believed more in what the community told her than in what experts and regulations subscribed. Another participant was offered testosterone by a friend before they even considered going through a clinical evaluation for GAH. In the last sections of chapter 6 I will return to the importance of community and write more about different ways to get introduced to DIY HRT.

# 5. In the state we trust

I thought I was making a study about self-medication and therefore I did not ask much about the official state-sanctioned gender affirmative healthcare (GAH). The participants in the study told me I was wrong. Self-medication is all about the state-sanctioned GAH - or rather, the conditions of the same. Their decision to start self-medicating was very much grounded in their perception of the state-sanctioned GAH as inaccessible. This goes in line with previous research by Rotondi et al (2013) and Repka & Repka (2013), who suggest that the inaccessibility of healthcare is the main reason for self-medication.

This chapter will first give you a description of what the state officially offers with regards to GAH before I move on to explain in which ways it is perceived as inaccessible. The last part of this chapter will be dedicated to a discuss the context of institutional trust and the Swedish welfare state as ways of producing gender normality.

## State-sanctioned gender affirmative healthcare

Since the gender affirmative healthcare[24] in Sweden is considered to be specialized healthcare (Linander, 2018:45), the first step is to get a referral - a process which can take several years[25]. Thereafter, to access any gender affirmative treatments, you need to go through an evaluation process in which a medical team determines if you fulfill the criteria for any of the 'gender identity disorder' (GID) diagnoses (Linander, 2018:19-21). The evaluation process before any diagnosis should, according to the health and welfare department (Socialstyrelsen, 2015), be adapted towards the need of the individual. Yet, both according to the participants in this study and results from other empirical studies (see for example SOU 2017:94 pg. 578ff; Linander et al, 2017) the evaluation process is not perceived as fulfilling any need that the care recipient has, but is rather (mis)used as a tool for gatekeeping the gender affirmative

[24] Generally in a Swedish context, gender affirmative healthcare refers to both the clinical evaluation and the treatments. If I just refer to a part of it, I will instead write 'evaluation' or 'treatments'.

[25] Several of the participants spent years in the primary healthcare or at psychiatric clinics before getting a referral. Some clinics within the gender affirmative healthcare accept referrals written by the person seeking care which makes the waiting substantially shorter. Still, many need to go through the process of convincing a doctor in the primary healthcare to send a referral, which increases the total time before accessing any treatments (see for example SOU 2017:92 pg. 704).

treatments. During my own clinical evaluation, I was asked in detail about which toys I used to play with as a kid and whether I liked to play with girls or boys. Others speak of how they have been subjects of Rorschach inkblot tests. This model is criticized for its cisnormative gatekeeping by both scholars and activists (see for example Linander et al, 2017). Within the GAH clinics, there is a lack of consensus regarding how much time the evaluation should take. For the SOU 2017:94, one of the clinics stated that an evaluation can be carried out in 6 months. Yet, the average time for a clinical evaluation was 3,8 years during 2001-2010 (ibid, pg. 705ff). According to the clinics, this is both due to internal waiting times and diagnostic insecurities. In chapter 8 I will further discuss the ways of knowing whether someone is transgender.

Sweden is now in the process of updating its official diagnostic system but still uses a nationally adapted version of ICD-10[26], in which the primary diagnosis is called transsexualism (Socialstyrelsen, 2019). This diagnosis is defined as:

> A wish to live and be accepted as a member of the opposite sex, often accompanied by a feeling of discomfort or inadequacy of one's own anatomical sex and a wish for hormonal or surgical treatment to physically resemble the preferred gender as much as possible (Socialstyrelsen, 2020:200)[27]

In this construction, it is implied that one *is* not really the gender one identifies with, but rather the gender one has been assigned, since the criteria is based on a wish to become something else than one already is. The use of the word *opposite*, indicates a binary view on gender. This diagnosis is only applied to those who identify within binary gender constructions - man or woman (Transformering, 2020d). For those who adhere to a non-binary identity, there is a possibility to attain either 'Other gender identity disorder' or 'Unspecified gender identity disorder', which are both placed within the same category of GID. Yet, with the latter diagnoses you cannot access all medical and legal gender affirmative procedures.

[26] ICD-10 was accepted by the World Health Assembly in 1990 (Reed et al, 2016)

[27] My translation from Swedish. Original "F64.0 Transsexualism En önskan om att leva och bli accepterad som en medlem av det motsatta könet, ofta åtföljt av en känsla av obehag eller otillräcklighet med det egna anatomiska könet och en önskan om hormonell eller kirurgisk behandling för att kroppsligen likna det prefererade könet så mycket som möjligt.

Once a diagnosis is acquired, there are several possibilities for gender affirmative treatments, but all are centered on the primary or secondary sex characteristics. Some of the interventions are:

| **Surgery** | **Logopedics** | **Endocrinology** | **Supportive gear** | **Fertility preservation** |
|---|---|---|---|---|
| Chest (mastectomy, breast augmentation) | Voice coaching | Hormone blockers | Chest (binder, breast prosthesis) | Egg/sperm freezing |
| Genitalia (gonad removal, construction of outer genitalia) | | HRT (testosterone, estrogen, testosterone blockers) | Outer genitalia (penis prosthesis, tucking/gaff) | |
| | | | Hair (wigs, hair removal) | |

It differs widely which of them each person wants to take part of, and, to certain extent, the availability depends on which region you live in. It is common that someone does HRT but never undergoes any genital surgery (Anova, 2020). You need to be a Swedish citizen or have a permanent residence to gain access to any part of the gender affirmative healthcare, unless you already started HRT (Linander, 2018:86).

Historically, the general Swedish healthcare has gained high marks in quality (Burström, 2009). Yet, during the last decades, there has been a trend of decline in healthcare provision. Despite an explicit focus on health equality, there has been a growing disparity between different social groups. Under current neoliberalization of healthcare management, more and more private actors have entered the market of healthcare services. Yet, most of the healthcare services are still tax-funded and available to all citizens (ibid).

In an agreement between the Swedish government, the counties and the municipalities in 2019, the actors identify shorter waiting times as a key factor for accessibility to state-funded healthcare (Socialdepartementet & Sveriges Kommuner och Landsting, 2019). According to Swedish law[28] there is a guarantee that any care recipient should be given care within a maximum of 90 days. Still, in several parts of the healthcare system, this standard is not being met (ibid). This has been the background for further allocations to fulfill the guarantee regarding waiting times. Importantly, clinical evaluations are not included in the guarantee[29] (Waldenström, 2020), which means that the most time-consuming aspect of the gender affirmative healthcare (GAH) is not included. According to figures from 2017, the time from the date of the referral to the first meeting in the process of the clinical evaluation may vary from 2 months in Linköping[30] to 17-18 months in Lund, with an average of 8 months[31]. In addition, once the evaluation process has started, there are internal waiting times between the visits. The clinic in Lund stated in 2017 that it would be necessary to wait for two years to meet a psychologist. If you are diagnosed, you can have a referral sent to start HRT with the help from an endocrinologist. At most clinics, this process does not take more than a couple of months. However, at the clinic in Alingsås it would be necessary to wait for 15 months before getting access to professional supervision (ibid).

In current debates surrounding the GAH, gender critical voices have suggested that it is going too fast to get access to gender affirmative treatments (See for example SVT, 2019). SOU 2017:92 has in its compilation not been able to find any evidence for the claim that a longer clinical evaluation would lead to more accurate diagnostics. Rather, it points to several sources that emphasize the health benefits of having begun treatment (ibid). The suffering caused by the long waiting times in the GAH has not only been highlighted in my study but also by SOU 2017:92, Repka & Repka 2013 and Linander, 2018 among others. According to SOU 2017:92 (pg. 707), the clinics point out a lack of financial resources and educated staff as the cause of the long waiting times.

[28] see for example SFS 2017:30 9 kap. 1 §

[29] With a few exceptions, for example for evaluations of dyslexia.

[30] Though, one of the participants had to wait for two years before starting his evaluation in Linköping.

[31] My calculation, based on the figures from SOU 2017:92 pg. 710.

### Expectations of the relationship with the state

Most participants in this study had tried to gain access to the state-sanctioned GAH. Though my sample consisted of people who either were self-medicating or were interested in starting to self-medicate, the majority of them thought that gender-affirmative healthcare should be provided, at least to certain extent[32], by the official healthcare system.

> Participant 1: Regarding the question, my relation to self-medication is that I was forced into it, and I am now advocating for it. Of course, the best thing is to have it prescribed, but I honestly think that people who self-medicate will be the ones that make the healthcare rethink their position.
>
> Participant 2: I agree with [participant 1]

Here we can see that participant 1 constructs a self-evident hierarchy, in which it is better to have a prescription than to manage your own HRT. He further states that he was forced to self-medication, implying that he would not have chosen it if he would have had access to supervised HRT.

Not only did several of the participants think that the state should be responsible for GAH, they *expected* that it would be provided to them. One of the participants describes that they[33] did not start self-medicating due to their trust in that the state would handle it.

> First I thought it [self-medication] was not something that I need, because I thought the state would arrange that [HRT] for me and it would be easy. It will only take a year, as they say on [inaudible], but then it takes a year [for them] to even know that I am trans. And then they make an investigation! So they make an investigation to know if there is a need for an investigation. And that is when I lose faith.

[32] For example, most were critical towards the clinical evaluation but thought that they should be provided access to an endocrinologist to handle their HRT.

[33] Gender-neutral, singular pronoun, as explained in footnote 24, page 31.

In this quote, we can see how this participant initially expected the public system to provide them with the healthcare they needed. They had perceived HRT as accessible and formed a trust in that. After facing an enlarged and arbitrary process during the phase of gender investigation, their perception started to change and at last they gave up their hopes for to get any help from the official system.

My participants spoke of their trust in the state in past tense. Several participants had experienced a change in their perception of the social support systems due to their encounter with the state-sanctioned GAH. One of the participants described it with a reference to state-critical philosophers:

> And also the funny thing, for me personally, is when you read Foucault or Agamben or people like them and you read and they paint a very dark picture of reality and you feel like, this is not really how it works – until you get into the shadowy corners of modern society and then you realize it does work like that. I think this is the case. For example, I'm here, I'm not exactly stupid, I'm very proud of my independence and then I meet this person who has the right to decide if I live or die. That's very horrible.

She refers to literature that she started to read before she started investigating how the Swedish GAH works and how she first thought that the authors were exaggerating the extent of the problems. After her experience as a transgender person in the healthcare system, she now identifies her own reality in the descriptions in these books. She now argued that there is no state-sanctioned GAH in Sweden, only a chimera of it. Although it was not said, I understand this by connecting to the old juridical principle and legal maxim saying, "justice delayed is justice denied"[34]. Since there is no help to get *now*, when I need it - there is no help at all. She was not able to construct a livable life without turning to DIY alternatives.

Another participant had a very harsh experience with the official medical systems, both in Sweden and Great Britain. When she realized how long it would take to access the Swedish GAH she decided to put her money into a private clinic in Great Britain, to be able to get

[34] My understanding of the legal maxim is based on Burstyner & Sourdin (2014)

faster access to hormones. After some time of poor treatment and then the threat of Brexit, taking away her possibility to have hormones sent easily, she decided to give it up. Hence, her motivation for unprescribed HRT was very much grounded in her perception of being abandoned by the official healthcare system. When I asked her why she started, she told me:

> Because the British clinic, they don't give a shit about me. Anova [one of the clinics providing gender affirmative healthcare in Sweden] don't give a shit about me. No doctor at the health care center [vårdcentralen] gives a shit about me. So, this is what I have to do.

Here, she describes that after reaching out to several healthcare facilities she lost faith in that anyone else would be able to help her. She perceived it as the only way forward was to take responsibility for her own health. The safety net of the state was not there for her.

Some participants pointed out that the waiting times are prolonged if you do not fit in to the narrative of what a transsexual is. They pointed out neurodiversity (especially diagnoses of autism), young age and being assigned female at birth (AFAB) as positions that were seen as suspicious by the GAH clinics. Specifically, the intersection of these became constructed as problematic and was used as a motivation to prolong the clinical investigations. This is partially pointed out in SOU 2017:92 (pg. 656ff) although they do not highlight AFAB as much as my participants did. The state public report describes how several healthcare professionals divide the care recipients into two groups. One group is seen as part of a historically established transsexualism. The other group is characterized by young age and neuropsychiatric diagnoses and is pictured as less capable of understanding the consequences of GAH (ibid). This narrative has been further established through the wide-spread documentary *The Trans Train and the Teenage Girls* (SvT, 2019). Importantly, the accessibility of the official GAH is unequally distributed according to wider societal power dynamics.

Repka & Repka (2013) points out how the Swedish healthcare system is generally seen as functional and based on a principle of equality. Therefore, people with no personal experience of the GAH have a hard time seeing that there could be marginalizing processes within the system. Repka & Repka (2013: 113) describe that, in dominant accounts: “People who need treatment with hormones seem to be choosing between two, equally viable options;

either get medical care free of charge, legally, safely, and comfortably, or self-medicate in an illegal, expensive way with accompanying health risks." They propose that the general expectation, or symbolic construction in dominant discourses, of what the state-sanctioned healthcare is capable of differs substantially from the materialized experience of it. Similarly, one participant in this study highlighted that people around her thought it was easy to access the Swedish GAH, which made it hard for them to understand why she had not yet undergone any medical interventions.

These expectations and the institutional trust must be understood in relation to the wider image of the Swedish state. Calmfors describes the dominant view of Nordic society as based on a: "generous welfare state based on universalist principles, [...]," that furthermore, "offers generous social protection" [...] (2014:17). He further states that the Nordic societies have high levels of trust in societal institutions. I see this as the context the participants come from when they expect the state-sanctioned healthcare to provide them with what they need. Yet, among the demographic group of self-defined trans people, the trust towards both healthcare and other social support systems is very low (SOU 2017:92 pg. 642). Since I am interested in the process of subject formation, I find it important to pay attention to the role of subject formation in building and destroying trust towards the state. In this case we need to look closer to how trust is being lost in the process of subjectification.

Assuming a trans position in relation to the world might imply a radical shift in power relations. I see the relationship with the state as one of these relations that was drastically altered for several of my participants. Most of my participants were seen, and saw themselves, as cis gender for a long time. Their expectations on the world were based on this experience. When they then declared themselves as transgender subjects through trying to access GAH, the state turned a different kind of gaze towards them. They experienced an increased vulnerability as they experienced the public healthcare system from a position of being trans. Still, depending on which other social markers of Otherness that the participants had, not everyone had formed a positive expectation of the state while positioning themselves as cis gender. Trust in the state might be read as a part of a privileged subject position. The image of the state changes with subjectification through experiences of medicolegal institutions. This becomes fundamental both to understand what trans subjectivity means in the Swedish context and to understand the DIY HRT practice.

# 6. State administration of hormones

In this chapter I will discuss which laws and regulations acted to form a precarization of DIY HRT. The focus will be on the regulations that participants pointed out as hindrances for their DIY HRT. The first part concerns the access to hormone while the second part discusses issues of monitoring DIY practices.

## Accessing DIY HRT

According to Swedish law (SFS[35] 2015:31) Läkemedelsverket is responsible for defining which drugs are allowed to be sold over the counter, and for which drugs you need a prescription. The medicaments needed for HRT are only available at the pharmacy if you have a personal prescription. Only a certified doctor is able to write a prescription (HSLF-FS 2016:34 2 kap 1§). When a prescription is made, the doctor is responsible for the consequences of the medication (Manninen, 2018). It is illegal to sell the substances necessary for HRT to anyone who does not have a prescription (Läkemedelsverket, 2019a). Furthermore, according to SFS 1991:1969 §2, testosterone cannot be owned or used other than for documented and accepted medical or scientific purposes because of its classification as a doping substance.

With background in these regulations, getting access to hormones became one of the biggest concerns for the participants. Not only did people not know where to start looking for it, but additionally they were afraid of not getting the *right* thing - that the packages they bought would contain something else than the substance they were searching for.

First of all, one needs to know exactly what one is looking for and where you can find it. The name of the medicaments is not the same as the name for the active substance nor the actual hormone type. One participant told that she had tried several substances that she had been told would make a hormonal difference but that ended up having no effect:

[35] SFS stands for Svensk Författningssamling, which refer to Swedish law.

> Participant 1: The most gross thing was "BO"[36]. i.e. dried ovaries from cows...
>
> Participant 2: I…. Have no idea what "PM" "BO" or "SP" are
>
> Participant 1: No, but if you search for MTF[37] HRT you find it. But there is no scientific evidence that it works.

Participant 1 in this conversation wanted to access the *right* substances, but since she did not know where to find them, she tried whatever she could get, even though it was unclear whether it would work or not. Unfortunately, she did not get the results that she hoped to attain. Another participant was searching for hormone blockers to delay his puberty and then be able to come to terms with his gender identity before having changes made to his body. However, since he did not manage to get access to puberty blockers, he instead had to start with testosterone since he felt desperate to somehow lessen the dysphoria that his bodily produced estrogen gave him.

Several participants were afraid that they would get deceived by the online sources they bought the medicine through so that the packages would contain the wrong substance. Since they were not able to buy it from the pharmacy, due to the illegality of selling the substances to someone without a prescription, they could not benefit from the pharmaceutical control mechanism carried out on a pharmacy (Läkemedelsverket, 2019b). Given that none of them had the necessary equipment to carry out similar controls, they could not know what was the actual content of the substance they used. In several cases, the inability to buy the substances at the pharmacies caused the participants' health risks.

Also in the position of consumers, the regulations made the access more precarious. When the participants bought things from unofficial sources, they did not have a guarantee that what they ordered and paid for would arrive safely. Some feared that the things they bought would end up getting stuck at the customs or that the police would confiscate it. Furthermore, they never knew if there would be any supply. One participant described that during the first

[36] Since I did not perceive it as relevant for the aims of my study, I never asked what these abbreviations stand for. Neither do I know in which language they are.

[37] Male-to-female. Participant 1 is referring to that participant 2 is a transman, and probably do not know as much about HRT for transfeminine people.

year, she ran out of hormones, since she did not know that it was impossible to order things during December. It required both knowledge, time and money to have a steady supply.

If you live in Sweden, you have the right to get subsidies on prescribed medicines (SFS 2002:160 4-5§). This is, however, not applicable if you do not have a prescription. The prices of buying HRT substances outside the state-regulated system might vary. Participants in this study reported prices from approximately 20 Swedish Krona/month to 1000 Swedish Krona/month[38] depending on source, substance and dosage. Hence, the cost for HRT may be high, especially in comparison with the state-funded alternatives accessible to those with a GID diagnosis.

Importantly, not everyone is able to access unprescribed hormones. In Linander's dissertation study (2018), the participants describe it as something that only privileged people could afford. It is also discussed in Linander et al (2017) where the authors highlight that both medical and technical knowledge is unequally distributed in society. Since both financial means, computer-skills and advanced health literacy is required to access hormones, DIY HRT only becomes an opportunity for those who are already relatively privileged. Additionally, Linander et al suggest that similar resources are making it easier to access the state-sanctioned gender affirmative healthcare (GAH). Hence, the access to hormones is generally stratified.

In this study, only one out of 12 participants considered themselves to have a good financial situation. This participant was previously nervous about running out of hormones and therefore postponed her HRT, but after she had been working for a while she had managed to save enough money to build up a bigger supply so that she did not have to worry about standing without. 6 persons said their economic situation was average while 5 participants defined it as bad. Most participants in this study did not stress the economic factor as an obstacle for their HRT, but neither did I ask them outright about this aspect.

What happens to those who cannot access DIY HRT? A study made in the United States on imprisoned transfeminine people shows that, when no other option is available, some cut of

[38] In euro, this would currently (July, 2020) translate to 2 €/month to 96 €/month

their testicles to reduce testosterone levels (Brown, 2010). This was undertaken firstly after repeated attempts to access safer gender affirmative treatments. My participants also brought up ideas and/or plans for removing gonads by themselves as a solution when not getting access to HRT. Hence, we can see that there is a risk that people carry out even potentially lethal procedures when no other alternatives are available. Repka & Repka (2013) agree to this, saying that denying trans people safer options is no way to prevent them from undergoing gender affirmative procedures. With regards to the way that knowledge about DIY HRT is marginalized (as I will speak more about in next chapter), we need to ask what this entails in terms of health consequences. Further research on this topic is crucial.

### Monitoring DIY HRT

In the endocrinological recommendations for monitoring HRT, it is stated that you should carry out both blood tests and physical exams in addition to interviews about the patient's condition (Hembree et al, 2017). The side-effects are not very well studied but includes liver dysfunction, thromboembolic disease and excessive weight gain, depending on which kind of hormone you use. The main risks appear when exceeding healthy levels of any sex hormone. Hence, the need for blood tests is motivated to decrease the risk for side effects and/or to discover them early (ibid). In the recommendations from the Health and Welfare Department for people with gender dysphoria, it is stated that healthcare professionals might take over the supervision of an ongoing self-medication and that they should consider the risks of not doing so (Socialstyrelsen, 2015:48). In the radio program analyzed by Repka & Repka (2013), the psychiatrist being interviewed states that blood tests are generally made if they find out that someone is self-medicating. Based on this, I agree with Repka & Repka (2013) that it might appear as if monitoring was easily available to those who want it. Yet, both Repka & Repka (2013) and my study show that the access to blood tests are highly precarious. In Linander's (2018) study, some participants were not given access to any follow-ups for their unsupervised hormone use while others were referred to an endocrinologist and then given access to state-funded hormones.

For the participants of this study, the access to blood tests as a safety measure was a matter of both economical and knowledge resources. One alternative was to turn to private healthcare facilities. The participant that had managed to save money from her job used that money to

carry out blood tests from a private company. Another participant mentioned that it was crucial to her to use a similar private company for blood tests to be able to not worry too much about her health. Others tried to get blood tests through the state-funded healthcare in different ways. This was a less costly procedure but required both knowledge and confidence. I told one group that I had been able to convince a health center to take blood tests, but that they still did not know *what* to test nor how to evaluate the results. Another participant had a similar experience as he had to give the doctor instructions for exactly what to do and then evaluate the results himself. Here the access to knowledge becomes crucial for ensuring your well-being, since the trained endocrinologists are locked behind the gatekeeping mechanisms of GAH.

That DIY HRT practitioners do not have a prescription put them in a situation of precariousness. If you are in acute need of HRT, it is impossible to stay within the limits of the law. Through this, certain ways of being trans are criminalized. To access HRT and to monitor any side effects that might occur during HRT required different forms of labor or capital. Since money and/or intellectual abilities was helpful in this matter, the safety of practicing DIY HRT seems to be stratified into already existing patterns of domination. This makes me think of what Spade writes about discriminatory laws (2015). He argues that too much attention has been given to anti-discrimination laws while the normative workings of the state system through administrative violence has been relatively untouched. In this way states have been able to present themselves as 'LGBTQ-friendly' while gender deviance is still marginalized within the same state construction. Similarly to Preciado (2013), I would argue that we need to look right here, in the regulation of hormones, to find core elements of cisnormative legislation. This legislation excludes those who do not present themselves as subjects of investigation, those who cannot afford to wait patiently for the judgement of the medical expertise, from the social support systems. Health risks are in this way not only placed upon those who self-medicate, but on certain modes of being. In other words, I find this to be an example of what Preciado (2013) argues to be the biotechnological production of sex/gender through state administration. Those who submit to medicalized versions of transsexualism present certain modes of doing gender that are legitimized and gain state support. As this support might be vital, the gender ideology of dominant institutions is active in constituting life and death. In this way, it is possible to view the criminalization and precarization of DIY HRT as a matter of keeping the sex/gender system intact.

# 7. Dominant and subjugated discourses of DIY HRT

In this section I will discuss how participants' perception of DIY HRT was constructed. I will highlight discourses both within online communities, civil society organizations and among medical professionals. I will not dig deep into each arena, but rather give an overview that can serve to understand the ways in which DIY becomes invisible and/or dangerous in dominant narratives. I have no intention of making a supposedly objective judgement of whether the practice should be deemed risky or not. Rather, my aim is to bring forth how discourse is constructed as a marginalization process. I propose that speaking of danger is part of how DIY is constructed as an impossibility. In the second half of this chapter I will discuss subjugated discourses on self-medication by showing how participants gained access to knowledge and support related to DIY HRT.

## Silence and danger

Several of the participants told me they were really happy that I brought up the subject of DIY HRT. They felt there were very few spaces where they were allowed to speak openly about it. Furthermore, I became aware of the restrictiveness by a comment I got from a group moderator when I asked if I could publish my call for participants in their group. They[39] told me it would cause a lot of trouble if I published it and that I was definitely not allowed to promote self-medication. I was surprised since I did not perceive my call for participants as a promotion of the practice (to read the full call for participants, see appendix). I asked a fellow trans activist, who is moderating several trans-related groups on Facebook, and he did not perceive my post as promoting hormones in any way. He said, however, that some people are afraid to even come close to the subject of self-medication. In this case, the moderators are able to act as gatekeepers for what is appropriate to speak about or not.

[39] Gender-neutral, singular pronoun as explained in footnote 24, page 31.

The participants told me that fear-inducing comments from members of different forums can make it hard to share experiences of self-medication, even if the moderators would allow the post. One participant describe how she started to gather information through internet forums for trans people. It did not take long until she saw comments on how you would die from DIY HRT. She explained: "There are always some devoted people who say WATCH OUT! No! One might die!" That she encountered this kind of response made her wary of what could happen, and she decided to put her hope to the official system for a little while longer. She said that it is probably out of care that people try to prevent others from risking their health. Another participant faced the same reactions from online trans communities and then tried to seek help from abroad, instead of managing her own medication.

I find the silence to be continuous in the external communication from trans-related civil society organizations. There are several civil society organizations currently working with trans rights in Sweden. Some of the more established organizations are Full Personality Expression Sweden (FPES)[40] The Swedish Federation for Lesbian, Gay, Bisexual, Transgender, Queer and Intersex Rights (RFSL)[41], RFSL Ungdom[42] and Transammans[43]. Neither of these frequently discuss self-medication in available material on their webpages. Transammans (2020) mention self-medication in one instance in their political program, in which they state that it is "unacceptable that a lot of people today feel forced to self-medicate as they wait for [gender affirmative] healthcare."[44] The organization states that it is crucial that everyone should be able to get (gender affirmative) healthcare within a reasonable timeframe. Also RFSL brings forth that everyone should be able to access state-funded

[40] FPES was founded in 1966 but did from the start only include heterosexual transvestites assigned male at birth (Edenbrink, 2016). For decades, the organisation expressed its disdain towards anyone who claimed to have another gender than what they were assigned at birth. Yet, following intense discussions during the beginning of the millennia, they now aim to include and work for the rights of all transgender people (ibid.).

[41] With their 7000 members around the country, RFSL are today the biggest organisation working for transgender rights. The organisation decided to include transgender rights in their work 2001 (Transformering, 2020a).

[42] Since 2003 RFSL Ungdom is an independent organisation, yet in close collaboration with RFSL.

[43] Transammans is a relatively new organisation, founded as a national federation in 2015, that works with transgender people and their closely acquainted to challenge normative assumptions about bodies and genders (Transammans, 2019). I was elected chairperson for Transammans in 2019 and re-elected for the year 2020.

[44] My translation, original in Swedish: Det är oacceptabelt att många idag känner sig tvungna att självmedicinera i väntan på vård.

gender affirmative healthcare (GAH) but does not explicitly mention self-medication other than as a point of information (RFSL, 2019). I have not been able to find any material mentioning self-medication on the webpage of RFSL Ungdom.

There are furthermore several instances in which the risks of self-medication are highlighted. At the webpage of RFSL (2015) they state that self-medication might be a risky practice. Also at Transformering (2020c), a web page hosted by RFSL in cooperation with their youth league RFSL Ungdom, self-medication is described as potentially dangerous. On the webpage of FPES, the only text available mentioning self-medication is an article from the news archive describing a members' gathering in October 2011 (Nylund, 2011). During this meeting, an invited endocrinologist talked about the risks of self-medication and advised people to wait until the regulations of hormones would get less restrictive. The organization as such does not state their perspective on the matter.

Neither the participants picture of discourses within trans community nor my analysis of civil society organizations external communication are fully representative of the arena of communication as such. As I will show later in this chapter there are parts of the trans community that are centered around HRT and actively opposing doctor's involvement in HRT. In the same way, I know from my own experience that there can be opportunities to discuss DIY HRT during activities within the previously mentioned civil society organizations. Still, following the argument in the sections above, I want to emphasize how the perception of the participants was formed out of their first encounters. The most visible arenas of trans subjectivity produce invisibility for DIY HRT.

Several participants emphasized that medical discourses highlighted the dangers of DIY HRT. One participant claimed that the risks with HRT were exaggerated and that some of the points made by medical professionals were not in line with what is published in endocrinological scientific journals. In the radio program analyzed by Repka & Repka (2013), a psychiatrist explains that medical professionals normally inform people about the risks whenever they meet someone who practices DIY HRT. In the light of what the participants in this study stated, I see this as an example of how self-medication is

constructed as dangerous, which creates a stigma around the practice.

As Repka & Repka (2013:115) point out, people with trans experiences who engage in self-medication are dominantly pictured as "disordered, irrational, selfish, and desperate". Self-medication transgresses boundaries of how the power relations are supposed to be constructed among doctor-patient. To do something considered medical without the supervision of a medical professional is a dis-order in itself, a matter out of place[45]. Considering this picture, DIY HRT carries a subject position of irrationality. Not that the practice would make you stupid, but through becoming part of the practice you are subsumed to the same discourse of irrationality.

To further map out the discursive subjugation of DIY HRT should be a project for further research. It would be important to pay attention to official communication from institutionalized biomedicine as well as narratives within different parts of the trans community. How is risk used as a motivation for silence and how does that relate to the production of cisnormativity? How do we treat each other in the trans community when dominant institutions are monitoring our lives? There are questions that must be asked about how people construct the discourse of DIY HRT and how that is related to health consequences. This requires a critical analysis of power/knowledge processes and the subordination of certain bodies.

### Accessing subjugated knowledges

If we see the accounts above as a part of the dominant knowledge production about DIY HRT, we need to ask what other kinds of knowledge are being subjugated. As pointed out by several scholars, it is important to pay attention to the resistance in all relations of power (see for example Foucault, 1976; Butler, 1997). Since many of my participants did not see the state-sanctioned GAH as an alternative they were driven to seek out other options.

[45] Matter out of place in the same sense as Douglas (1966) famously wrote, though she was not talking about this particular context

Subjugated knowledge about DIY HRT became a crucial element for both empowerment and practical guidelines about HRT.

The process of building knowledge about HRT was different to everyone, both in terms of how much, when and how. Most started to research the matter even before they really considered doing it themselves. None of the participants, nor me, have any formal medical education. Instead, most of us dug deep into digital resources. Some went to online forums dedicated to DIY HRT while others ended up reading scientific journals of endocrinology and neurology.

The research carried out to be able to start DIY HRT implied both an emotional struggle and unpaid time-consuming work for most participants. One participant shared his frustration by saying:

> It is wicked and tough that many trans persons over the world, but especially where there are doctors available, that we, as care recipients, need to study ourselves instead of just letting the anxiety, the stress, go. And just receive the gender affirmative healthcare and put the responsibility on the endocrinologists and let them do the work…

He points out the irony in having formally educated people but still not get the access to their knowledge as a care recipient Instead he feels the need to take the responsibility upon himself to provide sufficient knowledge for his medication. This is not specific for practitioners of self-medication. Linander et al (2017) describe how people with trans-experiences even within the GAH had to "become their own project managers" and do research in order to gain access to necessary healthcare.

Although the search for knowledge was primarily pictured as a matter of necessity, several of the participants also argued for a decentralization of the knowledge surrounding HRT. One of the participants claimed that it would never be possible to depend on the nation state for

provision of gender affirmative practices. Instead they[46] argued that queer people should build up social support systems of mutual care and solidarity. They said: “I think it's not safe to depend on medical or healthcare system completely. We should be able to care about ourselves, in our communities.” They raise the issue of safety in relation to having access to gender affirmative treatments and caution against putting trust in the official system. This should be read in the light of the cisnormative state-building and how state violence has been commonly occurring towards those deemed deviant. Another participant told it was of big importance to her to access more knowledge about HRT. She even thinks that she would have started earlier if she had known more, which would have caused her less suffering. Her wish is that information about hormones would be open and accessible to everyone.

### Decentralizing medical knowledge/power

The aforementioned participant is not alone in her strive towards a decentralization of knowledge of hormone use. Edenfield, Holmes & Colton (2019) discuss the information sharing on DIY HRT among trans communities. Similarly to the participants, they state that instructions from peers are crucial for the ones practicing DIY HRT. On public web pages they found both user-generated knowledge and references to secondary sources that provided useful information. When the secondary, often medical, sources were presented they were recontextualized to fit the purpose of DIY HRT. Many of the guides that were referred to were aimed at medical professionals. Therefore, it became necessary that some people could understand how to access and translate the institutional information to make it available to other users. The study additionally describes online forums in which users can ask questions, discuss and provide knowledge for each other, for example about adjusting dosages or accessing different substances.

Edenfield, Holmes & Colton (2019) suggest that the discourses presented in the user-generated material constructed a hybrid in which a professional, medical language was manifested alongside rants, celebrations of queerness and personal anecdotes. They do not perceive the communication as queer because of the identity label of the ones who made it,

[46] Gender-neutral, singular pronoun as explained in footnote 24, page 31.

but because the discourse in itself presents a queer way of knowing. They conclude their article by saying "these practices work outside of institutions precisely because institutions are necessarily invested in the heteronormative project." Hence, they argue that, to a certain extent, the communication is constituted by the way in which it works through subjugated arenas.

During the chat interview I asked whether they had engaged in sharing their knowledge of DIY HRT with others in the trans community. One participant said that he had received help from one of the other participants in the group and started to mention some of the things he remembered. Then the other participant breaks in and tells him that he got it wrong.

> Participant 1: Not me but when I needed information [Participant 2] helped me by mentioning all that is important to measure for a blood test, even if I did not manage to have a blood test made on everything it is still good to know… HCG [...] [mentions several types of hormones[47]] and so on.
>
> Participant 2: So uh… I don't know if this is the right moment, but it is actually neither of those things you should test xD [laughing]

After this interaction participant 2 explains what should be measured during a blood test for someone on HRT. They both laugh about how participant 1 got the different abbreviations mixed up with what is necessary for a pregnancy test. In the end, participant 1 reassures participant 2 by saying that he actually has everything written down on a note, though he did not have it present at the moment.

Instead of having everyone answering my question, I got a concrete example of how knowledge about DIY HRT is shared. As Edenfield, Holmes & Colton (2019) suggest, I see how this sharing of knowledge goes beyond the limits of what is possible inside dominant medical institutions. Participant 2 does not carry the legitimation of the state like a certified doctor has[48]. He does not even have the age required to be one. Through this type of

[47] A participant asked me to not include the hormone types in the published version of this thesis since someone might read it and think that they should (or should not) include these in a blood test for monitoring DIY HRT.

[48] According to 4§ kap. 4 2010:659 only someone with an authorization from the state has the right to call themselves a doctor.

knowledge sharing, bodies otherwise deemed incapable of knowing, because of their status as insane, lay people and unintelligible (Repka & Repka 2013), are treated as legitimate sources of information.

However, it is not an easy task to know who to trust when it comes to unauthorized instructions found online. As one participant described her search for knowledge in online forums:

> One of the main issues of being in DIY I guess is that you need to be able to... On these platforms there is a lot of people that think they understand it, some of them actually do, some of them are doctors, but anyway. You have to read up to 50 people, what they say and then create your own statistics and draw a conclusion based on x amount of people said this and x amount of people said that and so on. So it's an interesting mental game actually and I enjoy it in certain extent. It would be easier if it would not be illegal, but yeah...

Here she refers to how the lack of support from state institutions makes it hard to access correct information. Through the system of certified doctors, one is able to know that someone has education in the field they are in. It is theoretically possible to execute processes of accountability since it is possible to take away the certificate from a doctor who has not followed the guidelines for how to provide safe and reliable healthcare. However, these institutional practices are not available to those who are not able to wait for state-sanctioned GAH.

### Creating trans solidarity

Though it was hard to access and evaluate information, the sharing of knowledge and experiences created a strong connection between people and a sense of solidarity within the community. Two of the participants even formed a romantic relationship after getting in touch through their interest in DIY HRT. As most felt they had been let down by the state, they constructed an alternative safety net built on an ethics of care. One participant described it like this: “I never really felt this kind of responsibility when it comes to any community until I became more aware of my trans identity and started to walk around… Yeah, it's very

important to care about each other.“ She describes how she never really felt the need to belong to a group previously. Yet, this changed when she became part of the DIY community. In December 2019 she ran out of hormones and was not able to buy more of them. In desperation she reached out to other DIY HRT practitioners and was sent hormones from a person that she had never talked to before. In this way the community became a social support system that for a while made her life livable.

To have friends already practicing DIY HRT is a way to take a short-cut into the community. In my case, I got access to both hormones and all the instructions I needed from friends or the friends of my friends who all had been practicing DIY HRT during some period of their lives. Just like in my case, the participants told that most of these advisors were peers - trans people who already were self-medicating.

This kind of help often resulted in reciprocity. To be offered resources in times when one does not have any seemed to contribute to a wish to give back. One participant describes that they[49] use to give away testosterone for free when they encounter someone who wants to try.

> I think my way of sharing has been giving testosterone to people who wanted it. I give it for free or just for the same cost that I pay, which is very little. [...] First of all I think it is part of how I got it. So, at first, I got it like that, so it's my way of keeping the chain.

Here they describe how they consider it important to keep reproducing the act of giving away hormones. As it was crucial for them to be able to access hormones from the start, they want to give the same possibility to others. They furthermore point out the importance of sustaining this kind of community-based system so that people are not forced to subsume themselves to the conditions of the state-sanctioned GAH.

By repeating the acts of sharing both knowledge and access to DIY HRT, alternative structures of gender affirmative healthcare are built up. These lack the resources and legitimacy of state-sanctioned healthcare which puts the users of it in a position of precarity.

[49] Gender-neutral, singular pronoun as explained in footnote 24, page 31.

Yet, these structures become empowering to participants who are not able to access supervised HRT. I would argue that this community-based healthcare system is crucial in making possible Other ways of being in the world. The state-sanctioned GAH asks you to subsume yourself to the decisions of a biomedical and juridical system that makes room only for a narrow interpretation of what it is to be trans. In the community-based system there is wider room for experimentation and demedicalization. Bycontrasting these systems, we are able to gain clarity about which gendered subjectivities gain legitimacy from dominant institutions.

# 8. Whose body?

Here I want to focus on deeper questions of autonomy and coercion. What kind of body is thought to be autonomous in the Swedish state construction? Who can be an owner of a body and when is that right taken away? I will discuss how gender normality imposes restrictions on body modifications as I put subjectification in relation to the nation state

When the participants were confronted with the state-sanctioned gender affirmative healthcare (GAH) they felt a dissonance in their perception of their bodies as their own and of the state management of hormones. Firstly, the gatekeeping of the diagnostic makes them unable to decide for themselves whether they want GAH or not. Instead of themselves, a medical team was supposed to make decisions about their bodies, which was frustrating to many of the participants. Secondly, once they started DIY HRT they experienced a lot of obstacles set up by state regulations, as I have described in chapter 5. These circumstances made several participants reflect on their body in terms of ownership. Some of them thought the medicolegal governance denied them their bodily autonomy. One participant expressed her frustration by saying:

> As long as I keep it [DIY HRT] under control and don't hurt myself - what right do they have to judge me? If you are able to keep it [DIY HRT] under control I think - no, no, but it [the body] is mine. I'm actually allowed to do whatever I want - but of course I can't! I know that. So… Then I just get frustrated. I am already frustrated, but yeah…

This participant reflects about her perception of the body and who owns it. She thinks that she should be able to do whatever she wants with her body, as long as she does not hurt herself. However, she also refers to a reality in which she is not allowed to do what she wants with her body. This dissonance causes her a lot of frustration.

For some, DIY HRT became a way to overcome that frustration and reclaim the right to their own bodies. In this way, DIY HRT, transformed their relationship to their body. During one of the group discussions I asked if and how DIY HRT was in any way political and one participant answered: "[in the way] that I have the right to my own body. [...] So it becomes political in the way that I gain control over my own process." Here she links the practice of bodily rights to DIY HRT. She further states that it becomes political in the way that she is taking control despite having been denied the right to her own body through medicolegal processes. In this way, DIY HRT can form a resistance towards the dominant ways of GAH. Yet, I would like us to stay with the question about the body as the property of an owner. What I find important here is the dissonance between a discourse of bodily integrity and experiences of restrictions towards the body. I find it interesting to linger upon how participants felt that the body was supposed to be theirs, but that the capacity to act as if it actually was their property was limited. To be able to understand this position I would like us to focus once again on the medicolegal institutions of the Swedish welfare state.

**Bodily integrity in the Scandinavian welfare state**

Drawing on Foucault's description of modernity, as I mention in chapter 3, Johannisson (1991) explains how biopolitical mechanisms developed in Sweden. In the 19th century the government started to gain interest in the quality and not only the quantity of bodies within its borders. At this time the field of medicine was relatively unregulated, and the existence of quacks was widely debated (Eklöf, 2001). The governing institutions and the medical elite saw a possibility to cooperate in order to increase the health of the population (Johannisson, 1991). Simultaneously, the medical field became legitimized by state procedures and biomedicine gained hegemonic status. Built on this cooperation the idea of public health flourished, and the body increasingly became part of the social body of the state through biopolitical interventions. Through this project mortality rates dropped drastically, while the extent of state coercion increased. Institutionalizations and forced sterilizations became essential to maintain the hygiene of the nation (ibid). With this historic contextualization, we might ask ourselves; how might anyone think of the body as individual property?

Preciado (2013:117) points out that the current construction of individuality and the idea of the body as private property are based on a neoliberal discourse[50]. Schwarzmantel (2005) agrees that the notion of individuality has become naturalized, though he attributes it to liberalism. He states that a hollow version of liberalism has gained a hegemonic position, making it hard to challenge its assumptions about human ontology. He writes "Liberalism has lost out as a critical philosophy and triumphed as a contemporary 'common sense'" (ibid:90). When I asked my participants why they thought that they had the right to autonomy, most did not know what to answer. They referred to it as being an obvious fact. I understand this as one of the ways in which hegemonic (neo)liberalism might work.

Yet, (neo)liberalism is not the only thing at work here. According to Nilssen (2005) the Scandinavian welfare state is built on principles that, in part, stand in conflict with each other. He claims that there is a dissonance between the right of self-determination and the ethical imperative to protect others, built into the Swedish juridical system. During the 20th century there has been an increased emphasis on individual autonomy at the same time as there has been a stronger justification for involuntary interventions against deviants. I connect the dissonance and frustration felt by both me and the participants to the welfare state dilemma described by Nilssen.

Several participants emphasized that trans people are not included into a general discourse of bodily rights, both within feminism and within official institutions. The state-sanctioned GAH and the restrictions made on self-medication were only seen as examples of a broader pattern. To understand the workings of this structure, I want to point to an example, also mentioned by several participants. In 1999 the Swedish state allowed an economic compensation for those who had been sterilized against their will (SOU 2000:20, pg. 7) despite the fact that trans people were still required to undergo forced sterilizations[51] (SOU 2007:16, pg. 172). This did not end until 2013, which makes it quite a recent event that many

[50] Others might attribute similar ideas to modernity rather than neoliberalism. Boas & Gans-Morse (2009) point out that neoliberalism is commonly used as "a conceptual trash heap" (ibid:156). It is possible that Preciado has not thought through his use of the concept. In any case, my point here is to denaturalize ideas about the body by linking them to systems of meaning. To discuss the usage of the terms neoliberalism and liberalism lies outside the scope of this thesis.

[51] In general, forced sterilizations based on the fear of that the children of a deviant person would show similar characteristics (Weindling, 1999). Also in the case of transgender subjects, the question of whether the children would turn out the same way was given extensive consideration (SOU 2007:16 pg. 179) though other reasons was also brought forth. A wider discussion of the matter lies beyond the scope of this thesis.

of the participants still remember. First in 2018 it was recognized that also transgender people have the right to economic compensation for the assault (Kammarkollegiet, 2020). That the state declared forced sterilizations as an act of illegitimate coerciveness while still carrying out the same practice towards people seeking GAH I read as an example of how transgender people have been treated as the Other. We must then ask how this Otherness is constructed and legitimized in dominant discourses.

To understand how limits of the neoliberal subject are understood in the context of the Swedish welfare state I turn to Nilssen (2005). He conceptualizes these limits as strong and mild paternalism respectively. I will first explain how we can understand the mild paternalism in the context of HRT and then move on to a discussion of the strong version.

In Nilssen's conceptualization (2005), mild paternalism aims to protect anyone who is not capable of deciding for themselves. He derives the argumentation for mild paternalism back to Mill's influential harm principle, which states that anyone "in the maturity of their faculties" (Mills, 1859:14 & 54) should be able to enjoy freedom as long as it does not limit the freedom of anyone else. That is to say, anyone considered sane, should be able to enjoy autonomy. The right to decide over oneself is for Mill dependent on the notion on sanity[52]. Larsen (2005) puts this into the context of the current welfare state and claims that the same kind of criteria is used today to denote who can be rightfully put under protection of the state. He proposes that it is based on an "ethics of care", that we have an obligation to take care of those who are not able to take care of themselves.

In the construction of the "ethics of care" the notion of sanity or capability seem to be a stable one, based on objective measures. Yet, if we follow a constructivist line of thought we need to question the category of sanity and form a discussion on who has the ability to remain sane. Which bodies and subjectivities are made intelligible? We need to critically investigate what it means to normalization of subjects if bodily autonomy is dependent upon the notion of sanity, as opposed to deviance. Foucault (1976) points out how deviant subjects

[52] The inherent racism in Mill's argument should be noted. Only those who are able to reason and argue in a civilised manner should be included. According to Mill, children and 'primitive' societies are out of question for this kind of self-determination.

increasingly, during the 19th century and onwards, became constructed as mentally ill. This is further discussed by Repka & Repka (2013) who claim that the psychopathologization of trans subjectivity is constructing gender deviant people as mentally ill and therefore incapable of rational thinking. If further linked to the construction of sanity as a requirement for making one's own decisions, the psychopathologization of gender deviance allows the state to legitimize the use of coercion and circumscribe the bodily integrity of trans subjects.

Furthermore, we need to look at the power relations assumed in the construction of the doctor-patient. Similarly to what participants in this study told, Repka & Repka's (2013:114) state that a practitioner of self-medication wanted to take control over their own body by turning to self-medication rather than the official healthcare. A physician comments on this by saying "it is hard to take charge fully of one's body if you do not have a medical training". Repka & Repka thereby point out how the body is thought to be the domain of the medical expertise. I read this sentence as a construction of the care recipient as not-fully a subject and hence not capable to exercise autonomy. Similarly, Conrad writes that when an issue becomes medicalized, the medical professionals are in a position to define and control the subject (1992). This relation of power implies an act of relinquishing autonomy and becoming subject to the doctor's decision. Yet, it does not only work as a materialized act when visiting the clinic but spreads discursively onto trans subjectivity as long as the phenomenon is understood from a medicalized perspective. I see this as another way in which the deprivation of autonomy from transgender people is legitimized.

I do not aim to construct a dichotomy in which cis people are allowed autonomy and trans persons are deprived of it. We are all embedded in sociality, in systems of meaning, that we cannot escape. Yet, if we constitute a society in which certain subjectivities are constructed as needy and helpless while others are seen as capable experts, this inequality must be recognized. We need to ask ourselves what kind of injustices a seemingly neutral law might legitimize through these discursive constructions.

What I have described so far is by Nilssen (2005) described as mild paternalism. Now I will move on to what he refers to as strong paternalism, meaning that the limits on the subject are not motivated by someone's incapability but on the nature of the activity that they strive

towards. How are certain bodily practices constructed as illegitimate and how does that relate to the imaginary of the state? Which ideas that have been able to spread as part of hegemonic production of knowledge surrounding the body?

Preciado argues that different parts of the body are surrounded by different discourses. While you are free to reconstruct your nose through cosmetic surgery you cannot transform the genitals without permission from the medicolegal establishment. He writes: "[...] the genitals are still imprisoned in a premodern, sovereign, and nearly theocratic power regime that considers them to be the property of the state [...]." Yet, Preciado does not offer much of an explanation for why this mode of thought has been able to proliferate. I turn to other authors to find out how the genitals became such an explosive matter. Yuval-Davis (1997) points out that the reproductive capacity of women is essential for the nation state. She claims that (certain) women's bodies become important as they are thought to carry the future of the nation. To regulate the reproductive capacity hence becomes a central part of state administration[53]. Similarly, Foucault points out the fear of degeneration if people were allowed to reproduce freely. In the Swedish context, the couple Myrdal became famous when they published the book *Crisis in the Population Question*[54] (1997[1934]). They argued that we would need a stricter control on people's sexuality in order to maintain a social democratic state. How would we be able to care for each other if everyone was in need of care? This kind of argument constructed legitimacy for the eugenic programs in Sweden, as the welfare state was celebrated for its notions of equality and care.

Based on this, genital control became crucial for the maintenance of the welfare state. Hence, to let anyone fiddle around with hormones, affecting the reproductive capacity, would be constructed as irrational. Furthermore, reproduction is taken out of the private sphere of the individual body. It becomes part of a collective body rather than an individual one.

[53] One relevant example is pointed out by Kulick (2003) as he describes how sex workers were deprived of their right to self-determination through the 1998:408 law prohibiting the purchase of temporary sexual relationships.

[54] Original in Swedish "Kris i befolkningsfrågan".

Yet, as several participants pointed out, there seem to be another dimension to why gender affirmative treatments are so heavily guarded. While abortion is seen as a matter of rights, HRT is generally accepted as a medical decision. Repka & Repka (2013) link both the psychopathologization and cisnormativity to the marginalization of trans subjectivity. Following their line of argument, I find that any desire to change your gendered appearance might be seen as pathological and insane. As I have previously argued, acts perceived as belonging to the sphere of medicine need legitimization from a medical professional to be seen as reasonable. Adding to that, cisnormativity constructs all forms of gender deviance as unnatural. To apply the hormones of the 'opposite' sex hence becomes an irrational act in itself. The only rational explanation would be a case of medically defined transsexualism. Yet, without a doctor, you end up just being crazy - which gives the state all rights to intervene.

In this section I have analyzed the dissonance felt by the participants when encountering how they as trans subjects do not experience the kind of bodily integrity and personal freedom that has been discursively created as a natural state of things. By relating this to the welfare state, ideas of public health and the ethics of care (as conceptualized by Nilssen, 2005) I have discussed potential ways of constructing a legitimate ground for limits to the bodily integrity otherwise assumed. Following the conceptualization of strong and mild paternalism I mapped out different ways of constructing the regulation of hormones as rational. There are still questions to ask. How does the state apparatus work to legitimize a coexistence of autonomy and coercion in other cases? How does racialized othering work in this context? To build a theory of the state from a perspective of gender deviance might open up for new conceptualizations of how liberalism and paternalism are interlinked.

# 9. Who knows?

In this section I will discuss how the participants started to question the medicolegal system of state-sanctioned gender affirmative healthcare (GAH). First, I will discuss the ways of knowing if you are transgender. In the dominant understanding of trans there is an underlying construction of gender as an essential part of the self. Gender identity is imagined as a stable object, possible to discover (or, at worst, hidden in the unconscious). I will bring forth different understandings of trans ontology and what kind of knowledge about the self that is required to claim such a subject position. One of the important points that I will linger on is the way that auto-experimentation has been a useful strategy to several participants. Yet, in dominant, institutionalized understandings of trans, auto-experimentation is not a legitimate way to knowledge. Secondly, I will move on to discuss the critique raised by several participants as they questioned the competence of the medical professionals working at the gender clinics. Generally, a dichotomy is created that puts those who self-medicate as unknowing while those who supervise HRT in medical institutions as knowing. I will discuss in which ways this dichotomy has gained recognition while also putting into context the unknowing of the medical professionals.

## Trans epistemology

The clinical evaluation processes are made to find out who is actually in need of GAH. The ones responsible for this decision are doctors, psychologists, and other medical professionals (and maybe a social worker). Many of my participants considered this process to be illegitimate since they perceived it as impossible for anyone else to know whether they needed GAH or not. When we discussed the official process of the gender evaluations and the diagnostic criteria, one woman said:

> You asked me if I thought it was possible for a doctor to know if I am trans, with regards to the evaluation and so on. And, no - obviously, I don't think they can. I am the only one who can know. Also, this is a reason that it is a good thing to start [HRT] by yourself, so that you are not put a situation where you are really insecure, like I was one and a half year ago. And then just think that I have to say certain things to my therapist. I am the one who knows. And now I

> know even better. I guess it's a charade, just like a lot of other things in the world…

Here she states firmly that it is impossible for anyone else to know who is trans. Furthermore, she brings up the gatekeeper position of the medical professionals and how the positionalities change when one has already started HRT without a prescription. This refers back to what Stone (1991) writes about how subjectivities are formed by the diagnostic criteria to become eligible for gender affirmative treatments. When one is not bound to fulfill diagnostic criteria there is no necessity to perform the medical narrative of who is trans. Now the participant rather refers to the clinical evaluation process as a charade.

Another participant points to the cisnormative construction in the clinical evaluations made to find out whether someone is eligible for a GID ('Gender Identity Disorder') diagnosis. She puts forth the absurdity in how medical professionals are supposed to tell whether one is transsexual or not by saying:

> That is just so stupid! Imagine that a cis person would enter [the clinical evaluation] and then they say "no, I actually think you are a transwoman, sorry [laughing] and not the cis man you claim to be". It would be just totally absurd! And that is really just the same thing.

She imagines a world in which cis people would need to undergo a clinical evaluation similar to the one within GAH but finds it hard not to laugh while doing it. She points out that a cis person would never be questioned in their gender identity while trans people need to go through an evaluative process. Another participant agrees but puts it with a hint of irony: "Yeah exactly, its indeed funny! It feels as if you have to wait to prove your gender, to prove your gender identity to the Swedish state, in order to get hormones. Wouldn't it be enough if I want it?" In this quote she emphasizes what she sees as the absurd conditions of the clinical evaluation. Implied is the conflict between the epistemology of positivism, in which everything should be possible to prove (and/or falsify) empirically, and the ontology of gender identity as something that cannot be proven. The clinical gender evaluation process is here constructed as an impossible mission. It is trying to find something it cannot find because gender identity does not manifest as a measurable entity. Also Preciado (2013:102ff) recognizes this epistemological clash in the construction of the transgender condition. He claims that the dominant knowledge production favors what can be seen. Hence, genitals are

generally read as an empirical truth, impossible to question. Within the same epistemology, gender identity becomes impossible to find. The construction of the transgender condition is based on a vague notion of the psychoanalytical kind, constructed in dissonance with the biomedical discourse.

If it is not possible to know objectively, to prove, your gender, how do you then know? This was hard to explain for most of the participants and some ended up with the conclusion that you cannot actually know. One participant reasoned like this:

> Well yeah, how do you actually know if this [transitioning[55]] is right? Actually, it is not possible to know, I think. What I know is that it has made a huge difference to take away this fog of misunderstandings through stopping to… Through presenting myself in accordance with my gender identity and be clear about who I am. Both verbally and in my gender expression. And then I think the medical transition helps, hopefully, in terms of my bodily dysphoria. To some extent, anyway.

Here she states it is impossible to know if HRT is going to make life any better. Yet, she experienced earlier in life that sociality became easier when she was able to express her gender identity in a way that made her more intelligible to others. This makes her think that a medical transition (gender affirmative treatments in different forms) can make it even easier. Hence, she grounds her decision for HRT in a subjective feeling of how her life was transformed by presenting herself differently, not by a belief in the certainty of objective diagnostic criteria. To find this kind of knowledge, based on experience and gut feeling, she sees no point in having a medical team investigate the question for her.

Preciado further sheds light on cisnormativity by suggesting that the feeling of having a specific gender identity should be just as scientifically valid as claiming the objectivity of sex based on biological facts. To support this claim, he argues for the flexibility of matter and the constructedness of sex, not for gender identity as part of our innate selves (as has previously been done by other theorists). He writes: “Male and female are terms without empirical

[55] Transitioning in a trans context generally refer to make changes (physical, social, juridical) in order to be able to live in accordance with one’s gender identity.

content beyond the technologies that produce them" (pg. 101). Preciado claims that even from an empiricist perspective it should be clear that binary gender norms are maintained through a constant (re)making of the body. Hence, he denaturalizes both the idea of sex and gender. By taking Preciado's perspective we are opening up for an understanding of sex/gender as uncertain and we may learn to think differently about the legitimacy of medical gender evaluations.

**Auto-experimentation**

To be able to let gut feeling decide whether HRT was the right thing, some of the participants decided to try it out rather than to start it as a definite decision. To do experiments on one's own body was common practice until the beginning of the 20th century (Preciado, 2013:348ff) During a long time, before the development of state-sanctioned biomedicine, the only way to see if a substance gave the effect you searched for was to try it. In the case of my participants, it was not so much that they did not know what the substance would do to them but rather that they did not know how they would feel about it. Several participants described that they were not fully sure if HRT was the right thing for them before they started. Some knew that they wanted to change their bodies somehow, but they were not sure if hormones were the right way. Others doubted everything. To come closer to an answer, some of them *tried* HRT to feel what is was like. This was not seen as a final decision but rather as an experiment. One of the participants had been thinking a lot about whether she could manage to continue with her previous bodily appearance when she finally decided to try HRT. She describes her decision like this:

> And I think that I just thought that I actually have a month to make a decision before anything permanent happens. Because that was people told me, that nothing will happen the first month. So, if it has been a month and you don't feel really into it, you can just stop without any side effects.

To try it out hence became a way for her to handle the insecurities of having to make a decision. She was told to listen to her gut feeling after already having started the practice. Once she was on HRT, she describes that she felt her confidence increasing since her body were no longer actively masculinized by testosterone. It somehow became easier for her to make the decision once the anxiety of having things "going the wrong direction" stopped -

for her this was signified by the testosterone in her body that she perceived had a masculinizing effect.

Something similar happened to me. Once I started to take testosterone it felt like I could breathe deeper. Instead of the panic I previously had of being stuck with a sign saying “I am a woman” I started to see how I could redesign that signifier. There were possibilities that I always thought were out of reach. Somehow it did not sink in before I actually applied the testogel[56] unto my body for several weeks in a row. This transformed the way that I relate to my body in terms of ownership. By making that choice by myself, the body remained mine.

One of the participants stated that they[57] did not experience any gender dysphoria before starting HRT. In contrast to many of the other participants they did not even consider hormones before they got access to it. Rather, they felt open to experiment with gender expressions.

> When I started actually, I was not thinking about taking hormones, I just got them from a friend who had too much and I was like "hmm, why not? I could try ". But it wasn't on my mind to take hormones. More like, I could try, now when I have it. And then, because it didn't feel bad, I said ok.

Here the participant describes that they felt it was worth trying when they had access to it anyway. They did not think of it as *starting* HRT but rather as an experiment. Similar to Preciado, they did not try to mimic a medical protocol for how to apply the substance in order to perform a gender transition. Rather, they took testosterone whenever they felt like it. They describe this as very much influenced by the time/place that they were in at the time. In the trans community of Barcelona there were strong anarchistic influences which opened up for a pluralistic understanding of what it can mean to be trans. The participant did not feel any need to appear in a certain way to fit into a certain mode of gendered being.

By making use of auto-experimentation, practitioners of DIY HRT transform the way in which hormones are used. They go beyond the narrative of transsexuals who have always

[56] Testogel is the form of testosterone that I have been using.
[57] Gender-neutral, singular pronoun as explained in footnote 24, page 31.

known they were born in the wrong body (Stone, 1991) and form another way of being trans. Today this would not be legitimized within the framework of the Swedish healthcare regulations as it is tied to the biomedical paradigm. All healthcare should be "in accordance with science and established practice"[58] (SFS 2010:659 1§ 6 kap) which links it to the empirical research and canon of biomedical literature. Hence, it would be against the law for any doctor to prescribe a substance as an experiment (outside the frames of an institutionally approved research project) or based only on personal belief. Similarly to what is said in Edenfield, Holmes & Colton (2019), what I have described here could not happen inside of dominant institutions because of the heteronormative framework they are built upon. Hence, DIY HRT becomes part of forming a different kind of trans subject that does not need to be sure but can use the body to find out what is right.

**Deconstructing expert power/knowledge**

Not only did the participants question the ability of the medical system to decide whether they were in need for GAH or not, but some of those who were more experienced with DIY HRT also questioned the ability of the medical professionals to carry out HRT in a safe manner. One participant told:

> Ironically, for example in Hungary, the official care basically makes people overdose testosterone blockers - which is one of the true ways to get side effects. So yeah, one of my statements would be that, depending on country and depending on doctor, because I've also heard stories like this from Germany, DIY is not necessarily more dangerous than doing it officially.

This participant brings forth an example that made her doubt the legitimacy of the medical professionals responsible for carrying out HRT. She does not specifically question the ability of the doctors inside the Swedish medical system but constructs a general critique against the assumed dichotomy that puts DIY HRT as dangerous while medically assisted HRT is seen as safe.

[58] My translation, original in Swedish: "i överensstämmelse med vetenskap och beprövad erfarenhet"

They are not alone in their criticism of the GAH for lacking knowledge about its practices. When the State Advisory Committee for Medical and Social evaluation (Statens beredning för medicinsk och social utvärdering, 2020) evaluated the scientific evidence available for GAH they found several knowledge gaps, especially when it comes to treatment for young people. Yet, as pointed out in Bauer et al (2009) it is necessary to understand that the medical knowledge production is and has historically been based on cisnormative assumptions. The lack of legitimate medically produced knowledge about HRT is not constructed in a political vacuum. Bauer et al (2009) state that the lack of knowledge about transgender lives must be seen as an informational erasure. I find it to be true, for example with regards to the lack of education about GAH and trans positionalities (see for example Koiparsan & Safer, 2018; Parameshwaran et al, 2017; Dubin et al, 2018;Lindroth, 2016) Yet, while the knowledge is lacking in some areas, it is flourishing in others. Informal exchange between people with trans experiences form subjugated knowledges. Yet, the medical canon privileges the accounts of medical professionals in state-sanctioned cisnormative institutions. As the State Advisory Committee for Medical and Social evaluation points out knowledge gaps about the topic, they only consider sources they find legitimate. I suggest that we must pay attention to what kind of knowledge counts as legitimate and who is able to be included within state-sanctioned processes of legitimization. Paying attention to subjugated knowledge might be a way to find break the informational erasure outlined by Bauer et al (2009).

Another participant sheds light on how information is not shared with medical professionals, but rather kept within the trans communities.

> Some people, other people that I've heard that, between us, they know more than the doctors really do because we don't tell them so much. So, I actually feel that self-medicating and deciding by yourself can actually be even safer. Instead of trying out what the doctor says.

In this quote, the participant is questioning the dichotomy of supposedly *safe* HRT while getting supervision and *unsafe* DIY HRT. They[59] emphasize that personal details are seldom shared with medical professionals. I partly link this unwillingness to open up to the dependent position of the one in need of GAH, as several studies have highlighted (Stone,

[59] Gender-neutral, singular pronoun as explained in footnote 24, page 31.

1991; Linander et al, 2017; SOU 2017:92 pg. 595ff). This configuration tends to construct trans narratives that are intelligible and valid to the medical professionals, which means that stories that go beyond what the institutional framework expects are often not told in the medical setting (ibid). In this way, the knowledge and perspective of what trans can mean remain relatively narrow within the healthcare system.

According to this participant the trust put in medical competence might affect the safety of the treatment. When you listen to the doctor and assume that they know what to do you are not as inclined to make your own analysis. I find this similar to what Von Busch (2009, drawing on Bruno Latour) conceptualizes as blackboxing. He argues that in modern society specialization processes have made it impossible for us to actually understand most products delivered to us. For this to work out we need to put our trust in experts. The legitimation processes are often based on dominant institutions like the state. I read this as an extension of Foucault's (1976) theorizations about power/knowledge. In this context this mechanism works to enforce the opposition between medical professionals as knowing and the trans subject as unknowing. If we adhere to this framework it seems reasonable to put the decision-making power to the medicolegal institutions.

On the other hand, when practicing DIY HRT, you need to open the black box. It is not an easy project and puts you in a precarious position since you are not given the support of medical institutions that for example a student of medicine would get. Once the black box was opened some of the participants were disappointed with its content. One man described how he during his teenage years started to read endocrinological scientific journals and quite soon felt that he knew more than the medical professionals that he encountered. He started to question what professionals in the healthcare system told him when he encountered studies that were claiming the opposite. His conclusion was that they used their position as experts to claim their knowledge and decisions as legitimate while in fact their primary function was to maintain a cisnormative system and prevent people from undergoing gender affirmative treatments. He said the risks “[...] are exaggerated to keep us under control, so that we are more inclined to follow the directives of the evaluators and adjust to their boxes, at their terms.” For him, acquiring knowledge during DIY HRT could be a strategy to unbox the power/knowledge of institutional medicine.

# 10. Concluding this project, pointing forwards

One week ago, the psychologist conducting my clinical gender evaluation told me that they might be ready to put a diagnosis on me. The psychologist paused for a moment and then said: "Do you mind if I ask, why did you actually come to the gender affirmative healthcare? You seem to be pretty sure of your identity and furthermore, you already have testosterone."[60] The answer to their question is hopefully to be found in this thesis. I did not come in search of gender affirmation. I came to take part of the welfare society again. After years of precarious access to expensive bottles of testogel I gave up. I was tired of trying to get blood tests taken in the primary healthcare and spending my spare time trying to interpret them correctly[61]. I want the privilege of accessing a state-funded endocrinologist that gives me guaranteed access to testogel. And so, I had to let you evaluate me. By sharing this story, I hope you see that whatever resistance might be built on the practice of DIY HRT, it is also built on the precarization of our bodies.

This research never claimed to be objective. It was made possible through my position as a gender-bending biochemical experiment, connected with people involved in similar projects. My methods emanated in trans solidarity, an acknowledgement of vulnerability and an aim to make the research valuable already in the making - not just a result in an exclusive journal hidden away from its participants[62]. This study did not in any way claim to be representative for all who practice DIY HRT and I hope no one tries to gain any quantitative insights from it. What you have found is, rather, a first step to shed light on how practitioners of DIY HRT perceive their own practice, their relationship to the state-sanctioned gender affirmative healthcare and, in some sense, to the state as a broader imaginary.

There is a myriad of understandings of these questions. People had very different reasons for starting HRT, yet most of them used it to construct a livable life for themselves when the

[60] Since I did not record the interaction, this quote is a free interpretation from my memory.

[61] As described in chapter 6, the doctors in the primary healthcare seldom know how to interpret a blood test for monitoring HRT. Both me and participants in this study needed to evaluate the results of the blood tests ourselves.

[62] Hence, creating empowering research methods rather than having a strict focus on the research outcome. Read chapter two for more thoughts about this.

official healthcare system had turned them down. Hence, my study confirms what Repka & Repka (2013) & Rotondi et al (2013) suggest in their articles about self-medication among trans people - that the shortcomings of the state-sanctioned system are reflected in people turning to other alternatives with less resources and safety. Yet, there was initially a high level of trust in official institutions and social support systems. I have suggested that the loss of faith in dominant institutions can be seen as a part of trans-becoming. For otherwise relatively privileged subjects, assuming a trans identity can entail a drastic change in power relations.

When trans subjectivity is constructed within dominant medicolegal institutions, the queerness of the subject is put into fixed definitions. The regulations of hormones legitimize and materially enforces a cisnormative understanding of gender. They favor a trans subjectivity that yields itself to the medical expertise, that is capable of waiting and presents the narratives expected of them. Meanwhile, the ongoing precarization of DIY HRT practitioners is motivated by the assumed danger of the practice and the irrationality of psychopathologized subjects. A life within the boundaries of state-sanctioned understandings of gender becomes more livable. Yet, it also enforces the legitimacy of medicolegal control. Trans subjectivity is created in interaction with medical professionals within institutional practices that are built on an understanding of difference as pathological. The same understanding gains spread within trans communities and we soon start reproducing the same gatekeeping experienced within medical frameworks. This is not to argue for any kind of false consciousness. It is rather to acknowledge how different subjects are produced through interaction with different systems of meaning.

Through DIY HRT, Other[63] lives are made possible. Inside communities of self-medicating transgender people Other knowledge is made important. When not following the guidelines of the clinical evaluation of the gender affirmative healthcare, Other methods are used for knowing which way to take in life. When you are not bound to the gatekeeping of the gender affirmative healthcare you are able to start treatments faster, which participants found to be lifesaving. Forming an understanding of gender and embodiment, DIY HRT might become a

[63] As previously stated, Other is used to denote marginalization in a broad term with respect to the intersections of overlapping power structures.

revolutionary project as practitioners get in touch with other gender deviants. Auto-experimentation might be a way to deal with feelings of uncertainty; a practice that is made possible in the absence of medical professionals that expect you to narrate a linear path towards transition. Furthermore, perceiving the decision to start HRT as your own might be empowering in itself. By repeating acts of solidarity, through sharing of knowledge and material resources, the space is increased for us who did not manage to adapt to institutional frameworks. Simultaneously, the legitimacy of expert-knowledge might be dis-ordered.

I would like to reach into the future and put some concepts in the hands of coming projects. I have been looking at the state administration of hormones from a perspective of DIY HRT practitioners. I was able to conclude that medicolegal processes make gendered normality more livable. I made a tentative analysis of how these systems gain legitimacy through the making of trans subjectivity as insane (psychopathologization), as defined by medical professionals (medicalization) and as unnatural (cisnormativity). There is a dire need to dig deeper into these processes. What beliefs make it possible to limit trans subjectivity? Researchers, inside and outside academia, we need to dwell upon the importance of these processes, the intersections, their limits. Following feminist scholarship, we are fully equipped to dismantle the workings of hegemonic power. To question the natural should be business as usual by now. To look at the administration of biotechnical possibilities puts us at the core of life and death of humanity.

The marginalization of trans-produced knowledge and gender deviant practices makes us dependent on resources from dominant institutions. Yet, in interaction with alternative understandings of gender and bodily modifications the subjectivity of medical professionals is also being queered. As I am forced to tell them about my life in exchange for hormones, my psychologist is bound to listen to my convincing stories of an ungendered society/ my theoretical drivel[64]. If discourses of gender deviance are brought inside medical institutions and alliances of solidarity are built across the borderlands of professionality, there could be a way forward. For that to happen, we further need to investigate what kind of gender affirmative healthcare is made possible through institutional frameworks. How do we gain

[64] I once turned a session at the gender evaluation clinic into a lesson in guerrilla gardening.

legitimacy for a queer making of the healthcare without having us all dismissed as victims of dis-order? How far can a psychiatrist go in their support for gender deviance before they lose their professional authority? Though I might be skeptical, the state-sanctioned gender affirmative healthcare still has the potential to make trans lives less precarious.

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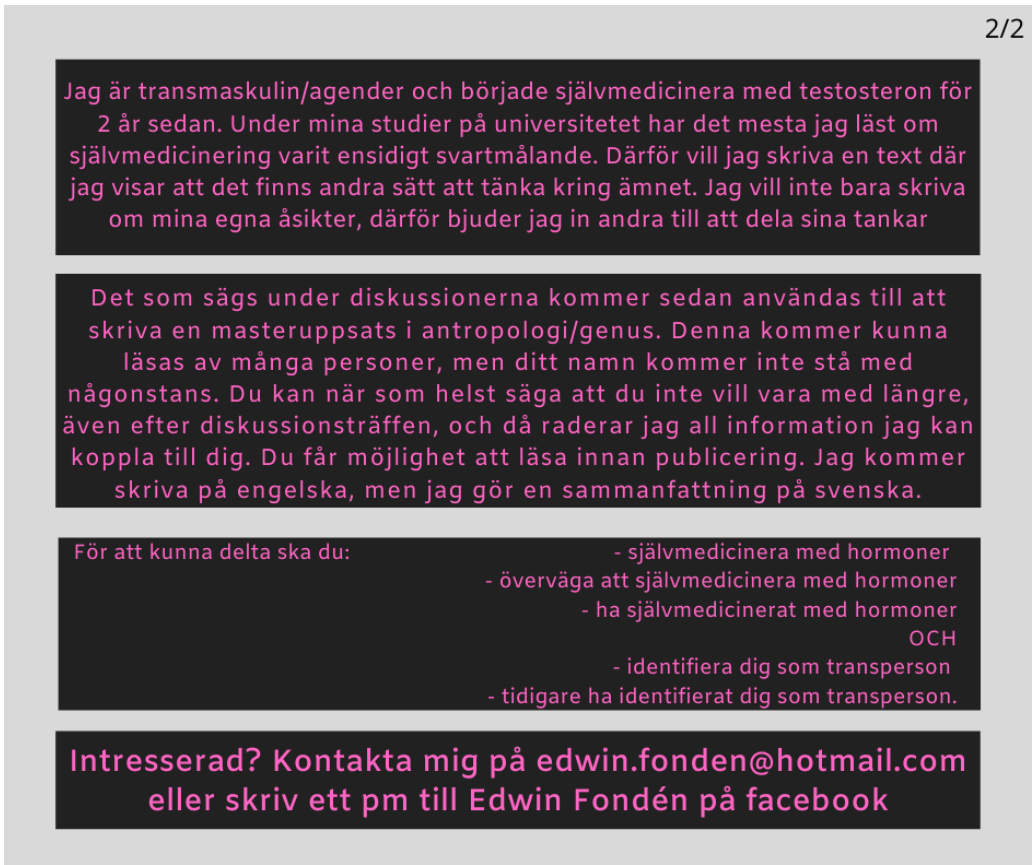
# Appendix

Call for participants in English and Swedish, including a Facebook post.

1/2

# Would you like to discuss selfmedication in a group of transpeople*?

To gather information for my thesis I invite you to a discussion about unsubscribed hormone use. The discussions will primarily be held online but might also be held "in real life" if we happen to live close to each other. Example questions: Should it be easier/harder to get access to hormones? What is hormones for you? Do you think there is a difference between hormones and (other kinds of) medication?

**Interested? Feel free to contact me on edwin.fonden@hotmail.com, or write a pm to Edwin Fondén on Facebook.**

*non-binary, agender, genderfluid, cross-dresser or gender questioning? Everyone is welcome. I consider transpeople to be a wide term for all of us who don't fully identify or express ourselves in line with our assigned gender.

2/2

I am myself transmasculine/agender and started self-medicating with testosterone two years ago. During my university studies most of what I have read about self-medication has pictured the practice as dangerous and irresponsible. Therefore I would like to bring other perspectives to the academic debate.

What is being said during the discussions will be used for a master thesis in gender studies/anthropology. It will be available for a lot of people to read but your name will not be in it . You will be able to withdraw your participation at any moment. I will then erase all the information that I can link to you. You will get the possibility to read through before publication. The thesis will be written in English.

To participate, you should

- be using unsubscribed hormones
- consider using unsubscribed hormones
- previously have used unsubscribed hormones

AND

- identify as a transperson
- have identified as a transperson

**Interested? Feel free to contact me on edwin.fonden@hotmail.com, or write a pm to Edwin Fondén on Facebook.**

Trans

Privat grupp

Om

**Diskussion**

Meddelanden

Medlemmar

Evenemang

Videor

Foton

Filer

Videoparty

Sök i den här gruppen

Genvägar

**Edwin Fondén**
21 tim

For english scroll down!

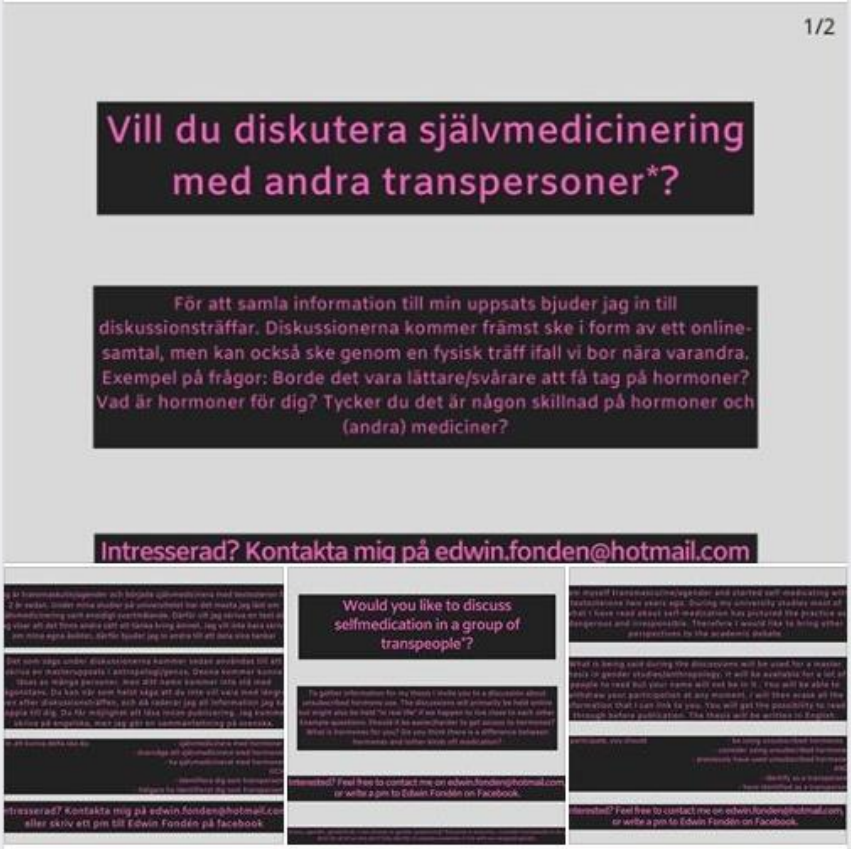
**Vill du diskutera självmedicinering med andra transpersoner*?** 💉💊

För att samla information till min uppsats bjuder jag in till diskussionsträffar. Diskussionerna kommer främst ske i form av ett online-samtal, men kan också ske genom en fysisk träff ifall vi bor nära varandra. Exempel på frågor: Borde det vara lättare/svårare att få tag på hormoner? Vad är hormoner för dig? Tycker du det är någon skillnad på hormoner och (andra) mediciner? 💻📞

**Intresserad?...**

Visa mer

1/2




1 kommentar

Gilla Kommentera