DIY Transition

Informal Hormone Use and Transgender Community Care in The Netherlands

Elise Aimée Alkemade —— 6256597
MSc History & Philosophy of Science
Thesis —— 1st November 2023

Supervisors:
Hieke Huistra
Domitilla Olivieri

Utrecht University

Contents

Acknowledgements

Completing this thesis marks the end of my time as an HPS student. I am extremely grateful to have been a part of a wonderful community of enthusiastic, intelligent and inspiring academics who taught me that everything is more complicated than it seems.

I have worked on this thesis for over a year. It has been a difficult project at times, but I have thoroughly enjoyed the months of reading, interviewing, writing and rewriting. I have had help from many people, a few of which I want to thank in particular:

Hieke Huistra, for keeping me on track and giving me such good advice. Each of our meetings gave me new ideas and my thesis is much better for it. Domi Olivieri, for her helpful feedback and for giving me a non-HPS perspective on my writing. My parents, sisters and friends for their support, and for listening to my half-formed ideas along the way. All the koele kikkers of the HPS room, for keeping me company during more than 200 lunch breaks and motivating me to do some work every day. Finally, Marien, for countless BoTaTu walks, proofreading my work and all the kind words.

Elise Alkemade, 1 November 2023

Introduction

On the 18th of September 2022, a demonstration for better transgender healthcare was organized in Nijmegen by activist group TransZorgNu. Despite the pouring rain, about 150 people gathered to listen to speeches by activists and organizers, dance and make themselves heard. This protest was one of several that had been organized by the same group the year before. They had spread their demands in Amsterdam, Utrecht and Rotterdam already. The activists asked for four things:[1]

1. No waiting lists
2. No diagnosis; complete self determination
3. Decentralize trans care, break the monopoly
4. Transgender care in transgender hands

All of these demands touch upon problems trans people experience in the formal healthcare system. In Nijmegen, a demand of a different type was added to the list. Now, the activists also asked health policy makers to "Ensure that the steps people take outside the gender teams are safe."[2] In contrast to the previous four demands, this one explicitly mentions that trans people take action outside of the system. Whereas the demands above are aimed at institutional improvement, and getting more trans people into professional care, the new one recognizes that care is given informally as well. This thesis will explore what these informal care practices look like, with its main focus on informal hormone use.

---

[1] TRANSZORGNU, "Statement (English)," June 8, 2021, https://transzorgnu.noblogs.org/post/2021/06/08/statement-english/.

[2] TRANSZORGNU, "Statement En Eisen Trans Zorg Nu Nijmegen," accessed October 3, 2022, https://transzorgnu.noblogs.org/post/2022/08/07/statement-en-eisen-trans-zorg-nu-nijmegen/.

Historically, medical transition has mostly been organized within trans communities.[3] In the beginning of the 20th century, the first hormone replacement therapy (HRT) trials were conducted. Using this technique, trans people could use estrogen or testosterone to feminize of masculinize their bodies.[4] During this time, however, very few people had official access to HRT as it was administered in hospitals. Therefore, trans healthcare was mostly organized on the streets, and knowledge was spread under the radar. These knowledge networks developed over time, as trans people let each other know how to use make-up to feminize your face, how to lower the pitch of your voice, or which doctor to go to for hormones.[5]

Only in the second half of the 20th century did official ways of accessing trans healthcare become more available. During this time, the Amsterdam academic hospital started offering medical transition procedures.[6] At the time, transitioning required a psychological assessment, mandatory divorce, sterilization and genital surgery to complete.[7] Nowadays, more medical transition options are available, and care is offered in several locations.

Despite the increase in conventional healthcare, informal knowledge networks among trans people are as prevalent as ever. At the protest in Nijmegen, people were handed flyers made by an anarchist group hosting a resource exchange on informal hormone use.[8] The flyer advertised "Trans harm reduction for self-medication", "self-injection support", "info and exchange about DIY HRT" and "hanging out". This grassroots organization is just one example of the ways in which trans people have organized themselves to care for each other and exchange information on how to safely access HRT.

Another example of information exchange on informal hormone use is the satirical artwork "Housewives making drugs", by Mary Maggic. This video, modeled after a cooking show, shows a duo of transfeminine presenters performing "a simple 'urine-hormone extraction recipe' while amusing the audience with their witty back-and-forth banter about body and gender politics, institutional access to hormones, and everything problematic with heteronormativity"[9]. While the tone is light, quasi-scientific methods are shown on screen, as the presenters use chemical equipment and laboratory methods to extract estrogen from their urine. And although the video ends with a song about getting drunk on hormone-infused 'estro-gin', genuine scientific information is shared in the video.

---

[3] Jules Gill-Peterson, *Gender Underground: A Trans History of DIY*, Forthcoming.

[4] Alex Bakker, *Transgender in Nederland: een buitengewone geschiedenis* (Amsterdam: Boom, 2018), 9–11.

[5] Bakker, 32–33.

[6] Bakker, 272.

[7] Bakker, 178.

[8] Trans Healthcare Network, "T-RREx: Trans Radical Resource Exchange," 2022, Personal collection of the author. Personal collection of the author.

[9] Mary Maggic, "Housewives Making Drugs — Mary Maggic Official," accessed October 4, 2023, https://maggic.ooo/Housewives-Making-Drugs.

Both these instances, although different in tone, show the wealth of knowledge that is held and shared within the trans community when it comes to transition. By combining their experiences with literature research, trans people have built networks and catalogues of information that are used by many to shape their own transition, independently or in combination with formal healthcare. Studying practices of self-medication is interesting for societal and scientific reasons.

Relevance

Studying self-medication is societally relevant because knowing more about what methods people use in practice can help us with providing healthcare that is better suited to the people it intends to help. Studying what care practices people organize amongst themselves can be a productive way to find new solutions that can also be implemented in an institutional setting.

Self-medication practices can be studied from many different angles, and therefore can also provide insights in different areas of science studies. I will use self-medication as a case study for three different fields related to patients, trust, and the healthcare system.

First of all, trans communities are an example of a patient group. Patient groups and health movements have been studied extensively over the past few decades, inspiring discussions about expertise, health activism, and the politics of knowledge.[10] Trans people advocating for better access to care are a patient group that can give more depth to these conversations. In contrast patients suffering from other conditions, trans people already form a community outside of a medical context, and thus are better situated to organize together. Similar to gay activists contributing to AIDS research, trans people are uniquely able to advocate for better trans healthcare.[11] Especially those who self-medicate, and thus have experience with this care in practice, have knowledge to share about how patient groups organize and operate.

Next, looking at people who self-medicate can also clarify how trust is formed in an informal medical context. Many scholars have studied the role trust has in the relationship between doctor and patient, and how that trust is formed.[12] Studies have also been done on

---

[10] For an overview, see: Steven Epstein, "Patient Groups and Health Movements," in *The Handbook of Science and Technology Studies* (Cambridge, UNITED STATES: MIT Press, 2007), 499–539.

[11] Steven Epstein, *Impure Science: AIDS, Activism, and the Politics of Knowledge*, 1 online resource (xiii, 466 pages) vols., Medicine and Society (Berkeley: University of California Press, 1996), https://search.ebscohost.com/login.aspx?direct=true&scope=site&db=nlebk&db=nlabk&AN=4620.

[12] Michael Calnan and Rosemary Rowe, *Trust Matters in Health Care* (Maidenhead, UNITED KINGDOM: McGraw-Hill Education, 2008), http://ebookcentral.proquest.com/lib/uunl/detail.action?docID=369496; Lucy Gilson, "Trust and the Development of Health Care as a Social Institution," *Social Science & Medicine* 56, no. 7 (April 1, 2003): 1453–68, https://doi.org/10.1016/S0277-9536(02)00142-9; G. F. M Straten, R. D Friele, and P. P Groenewegen, "Public Trust in Dutch Health Care," *Social Science & Medicine* 55, no. 2 (July 1, 2002): 227–34, https://doi.org/10.1016/S0277-9536(01)00163-0.

why people turn to alternative healthcare practitioners, and trust them instead of conventional doctors.[13] Trans people who use informal care methods are located on the intersection of both these lines of research. As will become clear, people who self-medicate often combine formal and informal sources of knowledge, and make use of them based on a mix of trust, convenience and personal preference. Thus, knowing more about informal care practices can shed new light on how people engage with medical knowledge.

Finally, trans healthcare can be used as a case study to further explore Annemarie Mol's concept of the logic of care.[14] Mol has developed two frameworks to analyze how healthcare is understood in society. In the logic of choice, patients should be emancipated and free to choose which treatment option is right for them. In the logic of care, doctors and patients work together to form a personal and changeable care approach. While Mol uses diabetes patients as a case study, it is interesting to see how these ideas apply to trans healthcare. This case offers new insights, as trans people's relationship to the healthcare system is more contentious. Trans people identify with their 'condition', and activism by the trans community shows that their ideas about medical care might be distinct from those of other patient groups.[15]

Existing research

Self-medication in trans people has mainly been studied from a public health perspective. Scholars have studied the practice in different locations to determine what self-medication practices exist and how many people make use of them.[16] Others have tried to determine where people obtained their medication, and whether they were sufficiently informed of the risk of self-medicating.[17] Sometimes, these findings are adapted to warn healthcare providers of the dangers of self-medication, and to advise them to change their approach.[18]

---

[13] Inge Kryger Pedersen, Vibeke Holm Hansen, and Kristina Grünenberg, "The Emergence of Trust in Clinics of Alternative Medicine," *Sociology of Health & Illness* 38, no. 1 (2016): 43–57, https://doi.org/10.1111/1467-9566.12338.

[14] Annemarie Mol, *The Logic of Care: Health and the Problem of Patient Choice*, MyiLibrary (London ; Routledge, 2008), https://www.loc.gov/catdir/toc/ecip085/2007047374.html.

[15] Austin H. Johnson, "Rejecting, Reframing, and Reintroducing: Trans People's Strategic Engagement with the Medicalisation of Gender Dysphoria," *Sociology of Health & Illness* 41, no. 3 (2019): 517–32, https://doi.org/10.1111/1467-9566.12829.

[16] Nooshin Khobzi Rotondi et al., "Nonprescribed Hormone Use and Self-Performed Surgeries: 'Do-It-Yourself' Transitions in Transgender Communities in Ontario, Canada," *American Journal of Public Health* 103, no. 10 (October 2013): 1830–36, https://doi.org/10.2105/AJPH.2013.301348.

[17] Nick Mepham et al., "People with Gender Dysphoria Who Self-Prescribe Cross-Sex Hormones: Prevalence, Sources, and Side Effects Knowledge," *The Journal of Sexual Medicine* 11, no. 12 (December 2014): 2995–3001, https://doi.org/10.1111/jsm.12691.

[18] Kate Nambiar et al., "Hormone Self-Medicating: A Concern for Transgender Sexual Health Services," *International Journal of STD & AIDS* 29, no. 7 (June 2018): 732–33, https://doi.org/10.1177/0956462418773213; Nelson F. Sanchez, John P. Sanchez, and Ann Danoff, "Health Care Utilization, Barriers to Care, and Hormone Usage Among Male-to-Female Transgender Persons in New York City," *American Journal of Public Health* 99, no. 4 (April 2009): 713–19, https://doi.org/10.2105/AJPH.2007.132035.

These different studies provide an approximate answer to the question of how many trans people self-medicate. Most of them mention a prevalence of 23-26%, although the methods to determine this number are not consistent. The studies were done at different times and locations, and participants were audited in various ways, with surveys given to people who visited a particular gender clinic or spread through social media. Some studies inquired whether people had ever used hormones that were not obtained through an official doctor, while others asked about current informal hormone use. Some based their percentages on all self-identified trans people and others compared self-medication to everyone on HRT. Therefore, the conclusions varied from "Cross-sex hormone use was present in 23% of gender clinic referrals [in Nottingham], of whom 70% sourced the hormones via the Internet",[19] to "Overall, 43.0% of trans Ontarians were currently using hormones, and an estimated 26.8% had ever used nonprescribed hormones".[20] So, although the percentages are all remarkably close together, they do not necessarily communicate the same data.

Another limitation present in these studies is that they are likely to underrepresent self-medication. Anecdotal reports suggest that using informal trans care is much more widely used than these studies claim.[21] This has several reasons. Due to the informal character of self-medication practices, it is difficult to contact a representative sample of subjects for a study. Additionally, trans people might not be honest about their use of self-medication. Some of these practices, such as importing testosterone, are illegal, and people might not want to risk losing access to their medication. Hence, numbers reported by academic studies might not cover all informal hormone use.

To estimate how many people in the Netherlands self-medicate, we need to know the prevalence of self-medication as well as the number of trans people. The prevalence was determined by two recent studies. Both have surveyed self-identified trans people about their experiences with trans healthcare. The first study, done in 2016 by patient organization Transvisie, reported that 18% of respondents "had used hormones before they were provided by a healthcare provider"[22] A second study was done in 2022 on behalf of the Dutch ministry of health.[23] This study reports that 15% of their respondents said to use self-medication. An additional 41% said they have considered it. The researchers noted that self-medication was a sensitive topic among their participants, and that therefore the true prevalence of the practice was higher than they had estimated.[24] From both these studies, it

---

[19] Mepham et al., "People with Gender Dysphoria Who Self-Prescribe Cross-Sex Hormones."

[20] Rotondi et al., "Nonprescribed Hormone Use and Self-Performed Surgeries."

[21] *I Emailed My Doctor 133 Times: The Crisis In the British Healthcare System*, 2022, https://www.youtube.com/watch?v=v1eWIshUzr8.

[22] E.M. Boom, van den, "Onderzoek Transgenderzorg Nederland" (Transvisie, 2016), 19, https://www.transvisie.nl/wp-content/uploads/2016/12/onderzoektransgenderzorgnederland.pdf.

[23] Zorgvuldig Advies, "Ervaringen En Behoeften van Transgender Personen in de Zorg," November 2022, https://open.overheid.nl/documenten/ronl-b8614f82bc58342fdd4a40d396385004c86dcfc3/pdf.

[24] Zorgvuldig Advies, 57–58.

seems safe to conclude that at least 18% of trans people have used hormones informally during their transition.

The total number of trans people in the Netherlands has been hard to determine as well. A recent report investigating the perceived increase of trans people in the Netherlands concludes that relevant numbers are not available. There is a lack of recent surveys, no uniform approach, and reported numbers of trans people rely on proxies instead of self-identification.[25] Recent research done by Rutgers, a Dutch expertise center on sexuality, noted that 2.2% of Dutch people identify as transgender.[26] Their sample was representative, but it is unclear whether all these people actively take steps to transition. Nevertheless, taking 18% of 2.2% of the Dutch population results in more than 60.000 people having used self-medication during their transition. This number is by no means guaranteed to be close to the true amount, but it does indicate that self-medication is prevalent enough to study.

Because all aforementioned studies have a similar research method, they might not be able to describe the nuanced relationship trans people have to self-medication accurately. The researchers have tried to sample a large group of trans people to survey them about their experiences with trans healthcare and/or self-medication. While this approach makes it possible to find trends in behavior, it limits the amount of detailed information that can be gathered. Personal situations cannot be taken into account, and people are not able to describe their experiences in their own words. From my analysis of the literature, this seems to facilitate assumptions on how people experience informal healthcare. Characterizing self-medication as "A concern for sexual health services", or as a negative consequence of long waiting times, might not do justice to the diverse and contrasting attitudes trans people have towards the practice.[27]

The study that, in my opinion, has best been able to describe trans people's experiences with trans healthcare, was published when I was already working on this thesis. The *Mijn Gender Wiens Zorg* report was issued in February 2023, and aimed to contextualize the increased demand in, and changing nature of trans healthcare in the Netherlands.[28] By means of theoretical literature, media analysis and focus groups with trans people and healthcare professionals, the researchers investigated how and why the demand for trans healthcare has changed recently. The report also describes a future vision on trans healthcare based on the wishes of trans people. Their participants propose more acceptance of trans people, shorter waiting times for care, and more knowledge about trans care in the

---

[25] E. Das et al., "Mijn Gender Wiens zorg," Onderzoeksraport (Radboud Universiteit, February 2023), 17, https://www.ru.nl/onderzoeksekseengender/project-transgenderzorg/.

[26] Fayaaz Joemmanbaks and Hanneke de Graaf, "Kiezen Voor Een 'X': Onderzoek Naar de Behoefte Aan Een Non-Binaire Geslachtsregistratie" (Rutgers Expertisecentrum Seksualiteit, April 30, 2023), 8.

[27] Nambiar et al., "Hormone Self-Medicating: A Concern for Transgender Sexual Health Services"; Boom, van den, "Onderzoek Transgenderzorg Nederland."

[28] Das et al., "Mijn Gender Wiens zorg."

whole medical community as possible improvements.[29] However, the study does not specifically focus on self-medication, and might disregard the considerations of this particular group.

My research

I this thesis, I record self-medication practices among trans people in the Netherlands, from the perspective of people who engage in them. As explained in the previous section, little is known about why and how people use self-medication. By letting trans people describe their experiences in their own words, I have been able to get detailed descriptions on how people's personal circumstances influenced their transition. Depending on people's age, social circle, location, and other factors, the way people approach informal healthcare can change drastically. Therefore, highlighting individual stories can be especially useful when trying to study the motivations of this group.

To achieve this goal, I will answer the following questions:

1. How do people experience informal hormone use while transitioning in the Netherlands?
2. What structures have been set up share information about DIY transitions, and how are they used?
3. How do people care for each other within the trans community?
4. What type of care are people looking for, and how can that it be adequately provided?

Answering these questions can help to inform the conversation about trans healthcare. For many people, trans healthcare is an unfamiliar topic, and especially self-medication can cause an averse initial reaction. By documenting transition stories of people who have used hormones informally, I hope to convey a sense of what going through the trans healthcare system can feel like. I hope that sharing personal experiences can cause a more well-informed discussion about trans healthcare, where people who self-medicate are taken seriously in their practices.

Additionally, studying people who self-medicate can give interesting insights in how trans healthcare can be improved. I will complement the research done in the *Mijn Gender Wiens Zorg* report by specifically looking at how informal care practices can inform conventional healthcare. Within the trans community, a lot of knowledge about transition has been exchanged, and valuable experiences have been recorded. People have cared for each other and developed techniques for exchanging information and practical knowledge on self-

---

[29] Das et al., 42.

medication. By taking these practices seriously, we can learn about what types of healthcare are wanted and needed, and how to match them to people's wishes.

I have used qualitative methods during my research. My main data comes from a series of semi-structured interviews, with six trans people and a doctor. Interviewing has several advantages when trying to answer my research questions. First of all, it gives me the opportunity to record people's stories as completely and authentically as possible. My interviewees get the freedom to describe their practices and motivations in their own words and on their own terms. This means there is a lower risk of misrepresenting their experiences than if I had used pre-determined categories in a format like a survey. In addition to this, interviewing gives me the option to study practices and motivations simultaneously. I can ask people about what they do, and have them reflect on their choices at the same time. This means I can go into detail about how people make decisions about their healthcare. This is especially useful when investigating the formation of trust in informal healthcare sources. Finally, interviewing allows me to ask follow-up questions on the particulars of people's transition. I get the chance to ask if and how the method of acquisition changed over time, and specify whether 'ordering hormones online' means using an online pharmacy, buying home-brewed estrogen from a person on Reddit, or getting a prescription after a virtual screening by a GP abroad. These nuances are harder, if not impossible, to catch in a different format.

In this thesis, I specifically focus on informal hormone use as an example of self-medication. It is the most common instance of informal healthcare, and a clearly defined category. When looking for interview candidates, I included those who had used or currently use medication for their transition that they had not acquired through a conventional healthcare provider. This definition, which is similar to the one used in other studies, includes hormones ordered on the internet and acquired through friends or acquaintances. I have not made a distinction between medication that is proven to be effective in changing hormone levels, and alternative options such as phytoestrogens. This way, the focus remains on the decision-making process people employ when using informal medication.

To gather my data, I have conducted six in-depth interviews with trans people who had experience with informal hormone use as in the definition above. My participants have been gathered through convenience sampling, and comprised four trans women, one trans man and one transmasculine non-binary person. Four were found through my own network, and two responded to a call I placed on the Dutch forum T-Nederland, which centers around trans issues.[30] I asked participants about their experiences with transition and self-medication, which sources they trusted when gathering information about informal hormone use, and what their ideal trans healthcare system would look like. The interviews took between 45 minutes and 1,5 hours each, and were conducted on location. They were

---

[30] "T-Nederland," accessed October 9, 2023, https://t-nederland.nl/.

recorded and transcribed to facilitate analysis. The names I have given my interviewees in this thesis are fictitious to preserve anonymity.

Although my interviews have been useful for answering my research questions, the selection of my interviewees limits my research in several ways. Due to the fact that most participants were gathered through my own network, there was limited diversity in the sample. My interviewees were predominantly well-educated, and most lived in major cities in the Netherlands. They were mostly in their late twenties, and had started their transition as adults. More importantly, none of my participants were currently fully reliant on self-medication. This is unsurprising, because people might not be comfortable reflecting on self-medication and exposing its particular processes when still actively being dependent on it. Nevertheless, this means I have not heard the stories of people in the most precarious circumstances, as they will likely not volunteer to discuss their situation.

In addition to interviews with trans people, I have also talked to Camiel Welling, a doctor employed by the Trans United clinic. Several of my interviewees had used the clinic's services during their transition. Trans United offers hormonal care without diagnosis, based on strong informed consent.[31] This is unusual in the Netherlands, and Welling was able to clarify the motivation behind using this method, as well as offer a professional perspective on the practice of self-medication.

Structure

In my first chapter, I will write a detailed account of the transition path of a single person, Charlie. By following one unique story, I hope to provide insight in the deeply personal choices and idiosyncrasies that so greatly influence transition. Although this story is by no means representative, it does give a characteristic image of what transitioning can look like, and how self-medication can be a part of navigating the Dutch trans healthcare system. During Charlie's account, it becomes clear how important community care is for people transitioning informally. Because Charlie did not have access to professional guidance, they relied on structures set up by the trans community to organize their care. Although this was appreciated, Charlie would rather have been able to use formal care from the start.

In my second chapter, I aim to give a more general outline of what types of information and care are exchanged within the trans community. I describe websites and forums dedicated to sharing experiences with transition and informal hormone use. I also mention offline spaces where trans people care for each other. Next, I explore why people use of these sources, and when they trust them. I will show that community bonds are crucial in

---

[31] The precise definition of 'strong informed consent' is given in: Florence Ashley, Colton M St. Amand, and G Nic Rider, "The Continuum of Informed Consent Models in Transgender Health," *Family Practice* 38, no. 4 (July 28, 2021): 543–44, https://doi.org/10.1093/fampra/cmab047.

fostering trust between trans people. Finally, I describe how the Trans United clinic uses some of these trust-building mechanisms in their own practice.

In the final chapter, I describe the ideal trans healthcare as envisioned by my interviewees. I argue that they are mainly looking for care in Mol's definition.[32] The current system, with a gatekeeper structure and mandatory diagnosis, is ill-suited to provide that care. This is the main reason people have organized informal healthcare structures in their own communities instead. I show that using a strong informed consent model can be a good alternative to diagnosis. By using this method, more people can access trans healthcare that suits their wishes and needs.

---

[32] Mol, *The Logic of Care*.

Chapter 1: Charlie's informal care chronicles

In this chapter I will focus on telling the transition story of one of my interviewees: Charlie. Charlie is a transmasculine nonbinary person in their twenties, and lives in a major Dutch city. Charlie describes their own transition path as "a bit of a mess" [33], as they have used hormones and other care from different sources, ranging from extremely informal access through friends, to a prescription from a gender team. Although their story is not average or easily generalizable, I think that sharing it will illustrate what navigating the Dutch trans healthcare system can look like. I also show how different forms of self-medication can play a role during transition.

By unpacking a single story in detail, I show how complex motivations and experiences during transition can be, especially when informal hormone use is involved. Charlie has positive as well as negative experiences with both formal and informal healthcare providers, sometimes simultaneously. Their transition path shows that the lines between formal and informal care can be blurred, and that every transition is unique. Charlie combines care from their community with official diagnosis to shape their transition in a way that works for them.

Charlie's story is especially interesting because it highlights many themes that are relevant throughout this thesis. I will focus on three in particular. First is the importance of trans community spaces, both on- and offline, for spreading information about self-medication methods. Throughout their transition, Charlie relies on trans people for different types of care. Without this community and the structures it has set up, Charlie's transition would

---

[33] "echt een zooitje"

have been very different. Secondly, I want to show the contested role a gender dysphoria diagnosis has for many trans people. It is a useful way to access formal healthcare, but the process of getting it is not always smooth. Finally, I argue that Charlie, like most of my other interviewees, is essentially looking for formal healthcare, and makes use of informal methods mostly because formal care is not available.

Trans Healthcare in the Netherlands

I will start Charlie's story just as they started it: with their addition to the waiting list of a Dutch gender clinic. In the Netherlands, it is recommended to access psychological, hormonal and surgical trans healthcare by visiting a gender clinic. There are about 15 locations offering psychological and hormonal care, with a capacity ranging from a few dozen to a few hundred patients each. Locations for gender-affirming surgeries, such as mastectomy or vaginoplasty are more scarce, with six available hospitals[34]. Most transgender healthcare is covered by basic health insurance. For many people, the waiting list for psychological care is a first step in their medical transition.[35]

Every gender clinic has a different approach and objective. The fifteen locations mentioned above are the ones offering a certified diagnosis for gender dysphoria or gender incongruence.[36] Having one of these diagnoses is necessary to get access to hormonal care. The procedure for getting diagnosed differs across clinics. Some require thirteen conversations over half a year, while others are satisfied with six sessions during nine months.[37] In 2017, a quality standard of transgender healthcare was published, which recommended standardizing the requirements for diagnosis, as currently there is no consensus on what approach works best.[38] Next to clinics offering diagnosis, there are many other places where trans people can get psychological care, for example to help them explore their gender identity or to come out to friends and family.[39]

---

[34] Kwartiermaker Transgenderzorg, "Overzicht Transgenderzorg in Nederland," accessed June 28, 2023, https://open.overheid.nl/documenten/ronl-1ba2426d6fb29898e3a0530575bfd927b6bf476c/pdf; Welzijn en Sport Ministerie van Volksgezondheid, "Ontwikkelingen in de wachttijden, aantal wachtenden en capaciteit van transgenderzorg - Rapport - Rijksoverheid.nl," rapport (Ministerie van Algemene Zaken, March 31, 2022), https://www.rijksoverheid.nl/documenten/publicaties/2022/03/31/ontwikkelingen-in-de-wachttijden-aantal-wachtenden-en-capaciteit-van-zorg.

[35] Transition has a major social aspect as well. Usually, trans people change their gender presentation, name and/or pronouns before visiting a gender team. This social transition likely follows only after the person took months if not years to think about their gender identity. See: Boom, van den, "Onderzoek Transgenderzorg Nederland," 15.

[36] Both diagnoses are currently in use, although their definition is different. See: Jack Drescher, Peggy Cohen-Kettenis, and Sam Winter, "Minding the Body: Situating Gender Identity Diagnoses in the ICD-11," *International Review of Psychiatry* 24, no. 6 (December 1, 2012): 568–77, https://doi.org/10.3109/09540261.2012.741575.

[37] Michiel Lugt and Michiel Langman, "Wachttijden genderzorg," December 16, 2021, 13, https://transvisie.nl/wp-content/uploads/2021/12/rapport-wachttijden-genderzorg.pdf.

[38] Alliantie Transgenderzorg, "Kwaliteitsstandaard Transgenderzorg," December 18, 2017, 20–21.

[39] "Transgender Wegwijzer," accessed October 2, 2023, https://transgenderwegwijzer.nl/.

All these different options means that access to hormonal care is inconsistent. Within clinics, the waiting times differ from a few weeks to over two years.[40] However, the clinics with shorter times often have patient stops, meaning patients cannot register there for weeks or months at the time. This increases the experienced waiting time. Depending on your timing, location, and knowledge about the possible options, access to psychological care and diagnosis can vary wildly.

Waiting times and trust

Charlie first registered with a gender clinic called Stepwork in 2018. Although Stepwork was one of the bigger gender clinics, their limited capacity meant Charlie was on their waiting list for over two years. This is not far out of the ordinary, with waiting times for psychological care averaging about 75 weeks during this period.[41] Unfortunately, Stepwork went bankrupt in late 2021. At this time, 350 people were being treated there, and 430 others were on their waiting list. Charlie was one of the latter. All these people had to be transferred to another healthcare provider, and to avoid overburdening the existing locations a new clinic was founded: Genderhealthcare.[42]

As a new institution, Genderhealthcare had to prove that they were able to provide quality care to their patients. As Charlie explains, they did not feel it was evident that this new clinic was trustworthy:

> Charlie: Ze hadden natuurlijk een nieuw project opgestart, dat heette dan Genderhealthcare. Maar na het lezen van wat paniekerige berichten die rondgingen door transpersonen op social media over deze overname, en een bericht van Transvisie,[43] groeiden ook mijn twijfels tegenover deze organisatie: wat is deze organisatie, en wie zijn de mensen die erachter zitten?; waar komt die negatieve berichtgeving van? Stepwork was natuurlijk met een soort drama uit elkaar gegaan, en nu leek deze overname ook stroef te gaan. Ik twijfelde: oh, moet ik hier in mijn vertrouwen leggen? Sommige dingen, ik weet niet of je er wat van hebt gehoord, maar toen dacht ik: oh mijn god oké, wat moet ik doen? Ik ga niet opnieuw bij de VU inschrijven want dan kun je weer helemaal opnieuw beginnen. Dus nou, ik me maar ingeschreven bij die nieuwe, de gender healthcare, hopend dat het gewoon zo spoedig mogelijk zou gaan. Ik had een indicatie gekregen dat ik een jaar geleden, in januari 2022, had moeten beginnen aan de hormonen.

> Charlie: They had started a new project, that was called Gender Healthcare. After reading some panicked messages that were spread on social media by trans people, and a press release

---

[40] Kwartiermaker Transgenderzorg, "Overzicht Transgenderzorg in Nederland."

[41] Lugt and Langman, "Wachttijden genderzorg," 13.

[42] "Overnamekandidaat gevonden voor failliet Stepwork Transgenderzorg," accessed June 29, 2023, https://www.cooperatievgz.nl/cooperatie-vgz/nieuws-en-media/nieuwsoverzicht/genderhealthcare-neemt-failliet-stepwork-transgenderzorg-over.

[43] Transvisie, "Persbericht: Zorgen om de overname Stepwork door GHC.," *Transvisie* (blog), November 5, 2021, https://transvisie.nl/persbericht-zorgen-om-de-overname-stepwork-door-ghc/.

> by Transvisie, my doubts about this organization grew: what is this organization? Who are the people behind it? Where does the negative messaging come from? Stepwork had ended with some drama after all, and now the takeover seemed to be difficult as well. Some things, I don't know if you heard anything about it, but it made me think: oh my god okay, what should I do? I'm not going to register with the VU, because then I'll have to start all over again. So, yeah, I just registered with the new Gender Healthcare, hoping it would all go as quickly as possible. I had gotten the indication that I should've started hormones a year ago, in January 2022.

This quote shows a first example of how unknown organizations are trusted out of necessity. Charlie mentions specifically that they decided to register at GenderHealthcare, despite their skepticism caused by the negative messaging going around about the clinic.[44] The alternative, waiting even longer for care, was even less desirable. Although the above situation refers to formal healthcare, throughout the rest of the chapter it will become clear that this mechanism of making use of non-ideal care out of necessity is present in more informal situations as well. In the context of trans care, to 'trust' a healthcare provider is often not a freely made choice. Instead, people take action as best they can in suboptimal circumstances.

Spaces and self-medication

As shown in the quote above, Charlie expected to start their treatment quite quickly once the transfer to Genderhealthcare had been completed. During the few months until their promised intake date, they had the opportunity to start using hormones informally for the first time.

> Charlie: Een vriend van me, die zit zelf aan de testosteron, die had in november 2021 wat testosteron aan mij gegeven, een fles met Androgel, en toen was ik lekker in november of in december begonnen daarmee voor mezelf, en ik dacht: oh, dat is leuk, want dan heb ik voor die drie maanden zelf nog wat, om het zelf even te proberen en dan word ik hopelijk gebeld door die andere organisatie waar ik officieel zou beginnen.
>
> Charlie: A friend of mine, who is using testosterone himself, gave me some testosterone in November 2021, a bottle of Androgel, and then it was nice to get started with that myself in November or December, and I thought: oh, that's fun, because then I have some of that stuff to try it myself for those three months, and then hopefully I'll get a call from the organization where I would get started officially.

---

[44] GenderHealthcare has proven to provide adequate transgender health care in line with the required standards. Transvisie has apologized for their reaction and recognizes how their response has made the transferral more difficult: Transvisie, "Update na eerdere berichtgeving over zorgaanbieder GenderHealthcare.," *Transvisie* (blog), April 29, 2023, https://transvisie.nl/update-na-eerdere-berichtgeving-over-zorgaanbieder-genderhealthcare/.

Here, Charlie expresses that they would ideally have access to official care, and that they see the self-medication as a temporary measure. It was only meant to bridge the gap until they could start their treatment at Genderhealthcare. The main reason that they started using testosterone at that specific moment was because they got the opportunity at the right time. In my other interviews, I noticed that personal connections and luck were crucial component in finding care as well.

The personal connection to the person providing the hormones helped Charlie to trust them. Charlie initially had some doubts about starting the Androgel, but after doing some research on its effects they felt comfortable using the product. Overall, the experience was positive for Charlie. They saw the act of sharing hormones as community care, and Charlie appreciated being able to share a positive moment with their friend.

> Charlie: Ik had [de fles Androgel] gekregen met een heel lief briefje erbij, want hij wist dat ik graag ook, dat ik er ook al heel lang mee bezig was. Hij had dat ook van iemand gekregen voordat hij begon, dus hij wilde dat graag door blijven geven, als een soort van T4T.
>
> Charlie: I'd gotten [the bottle of Androgel] together with a very sweet note, because he knew that I also wanted, that I was thinking about it for a long time. He had also gotten it from someone before he started, so he wanted to pay it forward, as a type of T4T.[45]

This is one example of community care that shows the close-knit nature of the trans community. I've encountered this topic in nearly every interview I've conducted. People rely on each other to provide them with advice and recommendations, and generally trust other trans people to give accurate information. I will go into detail on this in chapter two, but for now I want to highlight the importance of trans community spaces for providing this care.

In Charlie's case, a good example of a trans community space is the queer gym they visit. Aside from being a welcoming and non-judgmental space to work out, this gym is a physical location where medical advice and hormones are made accessible.

> Charlie: Ik krijg ook vaak vragen van andere vrienden, van nieuwe mensen die ik [in de gym] ontmoet, van: hé, jij zit aan de testosteron toch? Hoe ben je daaraan gekomen? En dat is heel fijn, omdat je elkaar kan helpen, qua resources en qua informatie die er is, en hoe je met zo'n systeem kan spelen om er zo snel mogelijk doorheen te komen, en dus ook dingen aan elkaar door kan geven. (…) Ik offerde het laatst ook aan iemand van, hé ik heb testosteron voor je, en die zei: ja, ik heb dat echt al van heel veel mensen aangeboden gekregen. Ja, dus ik denk dat iedereen wel *ready and willing* is momenteel.
>
> Charlie: I often get questions from other friends, from new people I meet [at the gym], like: hey, you're taking testosterone, right? Where did you get that? And that's very nice, because you can help each other, with resources and with the information there is, how you can play

---

[45] T4T stands for 'Trans for Trans', and is often used in the trans community to describe trans people caring for each other.

> the system to get through it as quickly as possible, and can maybe pass on some things. (…) I also offered it to someone recently, like: hey, I've got testosterone for you, and they said: yeah, I've gotten that offer from so many people already. Yeah, so I think everyone is ready and willing at the moment.

This quote shows that many people rely on physical locations, such as a gym, to discover how others manage their transition. Having a social space to meet peers gives trans people access to information they would not have been able to gather otherwise. Especially in an environment that is specific to trans or queer people fosters these kinds of exchanges.

Community care

The next step in Charlie's transition further illustrates how important trans community spaces are for exchanging knowledge and care. Although Charlie had been promised they could start their treatment at Genderhealthcare in January, there was a significant delay. When Charlie ran out of the original bottle of Androgel, they did not have access to another one immediately. As they did not want to stop taking testosterone, they had to look for alternatives.[46] Through a friend, Charlie found the Instagram account of a group in a nearby city, which was able to help with a temporary supply.

> Charlie: Zij bleken bij een soort anarchistisch boekenwinkeltje te zitten en dat waren dan vrijwilligers die daar werkten. Met een van die mensen had ik afgesproken 's avonds een keertje en dat was eigenlijk heel fijn, dat was echt een hele fijne ervaring. We hadden een paar uur de tijd om alles een soort van door te nemen. We hadden eerst thee gedronken, over van alles gepraat: wat je dan wil, wat de risico's waren, of je al bekend was met testosteron en wat de effecten een beetje zijn. Daarna gingen we injecteren, want ze hadden al die dingen dus daar. Dat was een heel liefhebbend speciaal moment eigenlijk. Natuurlijk was het een beetje spannend, jezelf injecteren, want ik had dat nog nooit gedaan en dat is toch wel wat heftiger dan een gelletje smeren, maar diegene heeft mij echt stap voor stap uitgelegd wat de stappen waren: een naald vullen, je hele tafel schoonmaken, gewoon het hele proces. (…) Ik heb mezelf ook daar ter plekke geïnjecteerd en diegene deed dat ook, maar dan met een lege naald, om samen te zijn en te laten zien hoe het echt moet. Ja, dan zit je ergens in een achterkamertje, maar dat was een heel cool, een heel fijn moment en heel lieflijk eigenlijk.

> Charlie: They were located in a kind of anarchist bookshop and there were all volunteers working there. I met with one of those people one evening and it was a very good experience. We had a few hours of time to talk through everything. We had some tea first and talked about all kinds of things: what I wanted, what the risks were, if I was familiar with testosterone and what the effects would be. After that we started the injections, because they had all the equipment there. It was a very loving moment actually. Of course it was kind of scary, injecting yourself, because I'd never done it before and it's a bit more drastic than just applying some gel, but this person explained every step to me: filling a needle, cleaning your whole

---

[46] After starting HRT, your body enters a second puberty. Going back and forth between high levels of estrogen and testosterone is a very unpleasant experience, and can slow down transition significantly.

> table, the whole process (…) I injected myself there on the spot, together with the other person, who used an empty needle to really be together and show me how it's done exactly. Yeah, you're sitting in some sort of back room, but it was a very cool, a beautiful moment and very lovely actually.

Charlie thus was able to get their next dose of hormones through personal connections and self-organized support groups. The above quote is an excellent example of how the trans community cares for its members. Although most trans people have not had formal medical training, many have taught themselves a lot about the effects of hormone therapy and transition. Combined with their lived experience, trans people are able to share extensive knowledge on informal hormone use. When trans people feel like conventional healthcare is not accessible to them, they thus have the resource to organize informal alternatives among themselves.

Charlie mentioned several times that they felt cared for, and had a good experience when learning how to inject themselves. This is partially caused by the informal setting in which the instruction took place. Because the volunteer was able to take their time when teaching Charlie, they had the opportunity to get to know each other. Therefore, their relationship became more personal than the one a doctor and patient usually have. The fact that Charlie and the volunteer were both part of the trans community, and had gone through the same transition process, made the injection instruction into a positive experience for Charlie. Although they started their injections out of necessity, they were still able to experience a "beautiful moment". Thus, although informal hormone use can be intimidating at times, community care can improve the experience trans people have when accessing it.

Despite this careful process, Charlie had some worries about their informal hormone use from the start. Before starting to apply the Androgel, they had done research online, reading everything from "guides on how to do self-medication, to all the medical documents about the effects of T and the risks". This attitude is one that I saw in all my interviewees. Everyone had spent weeks or months doing research on hormone replacement therapy in many different ways, reading these guides or looking at dedicated forums and websites. This supports claims made in earlier research. A recent report on self-medication notes that 94% of people who use self-medication had gathered information on possible risks.[47] The people I spoke to were aware of the risks that informal hormone use entails, and took precautions to stay as safe as possible.

Diagnosis

In the meantime, Charlie worked to get a diagnosis from a recognized gender clinic, so they could start their hormone therapy officially and be considered for surgeries in the future. As mentioned before, different clinics can have different waiting times, so Charlie tried a

---

[47] Zorgvuldig Advies, "Ervaringen En Behoeften van Transgender Personen in de Zorg," 59.

different one while still on the waiting list with Genderhealthcare. At the suggestion of a friend, they got into contact with a psychotherapist further away. This therapist was not covered by basic insurance, but Charlie was able to get an appointment for diagnosis quite quickly. The diagnostic process was successful and fast, but it did take a toll on Charlie.

> Charlie: Ik had echt vier uur gereisd en ik was echt in de middle of nowhere, aan zijn huisboerderij. We zaten ergens ook weer in een klein zijkamertje, dat was ook zijn office, dat je denkt: oh, mijn god, waar ben ik? Twee honden erin, alles rook naar hond, dat ik denk oh my gosh, waar de fack ben ik weer beland? (…) En toen hadden we een gesprek, hij was hartstikke aardig, maar hij doet psychotherapie dus hij was me heel erg aan het challengen over dingen, en dan waren we ook heel erg academisch, ook soort van intellectueel aan het sparren, wat heel erg leuk was. Maar op een gegeven moment werd ik het ook wel helemaal zat, omdat hij me een soort van... Hij test je natuurlijk of je wel echt weet wat je wilt. En enerzijds kom je daar met het idee, en hij weet ook al dat ie wel gewoon gaat geven wat je wilt, dus je weet sowieso dat je [de diagnose] gaat krijgen. Maar het hele gesprek daaromheen werd soms wel een beetje heftig, ja, ik kwam er wel huilend uit, weet je, dat was niet zo fijn. (…) Ik dacht op zo'n moment: ik ben blij dat ik ouder ben en dat ik stevig in mijn schoenen sta. Ik denk, als ik een jonger persoon was geweest, had ik dat niet zo kunnen opvangen.

> Charlie: I had been travelling for four hours and I was in the middle of nowhere, at his housefarm. We were sitting somewhere in a small backroom, that was also his office, so you're like: oh my god, where am I? Two dogs in there, everything smelled like dogs, so I was like oh my god, where the fuck did I end up now? (…) And then we had a conversation, he was super nice, but he's a psychotherapist so he was challenging me a lot on things, and we were very academically, also sort of intellectually sparring, which was a lot of fun. But at a certain point I became sick of it, because he was sort of… Of course he tests you to find out if you know what you want. And on the one hand you go there with the idea, and he also already knows that he's gonna give you what you want, so I definitely know that you're gonna get [the diagnosis]. But the whole conversation around that became quite intense at times, yeah, I did leave crying, you know, that wasn't very nice. (…) At some point I thought: I'm happy I'm older and am able to hold my ground. I think, if I had been a younger person, I wouldn't have been able to take it like that.

For Charlie, the process to get their diagnosis was not an easy one. The conversation was challenging and intense, but Charlie was able to see it partly as an intellectual challenge or a game they had to engage in to get their diagnosis. They also described that it was clear from the beginning that they would get the diagnosis they wanted, and this conversation was a necessary hurdle to take to get it. They felt it was worth it to put themselves through this conversation, as there were no other options available them in a similar timeframe.

Charlie's mixed feelings about this gender care specialist and his procedure are articulated further in the next quote. Although Charlie did not have the best experience themselves, they did recognize that the psychotherapist had good intentions, and did not want to deprive other people of the choice to access this care.

> Charlie: Hij had mij ook gemaild: "hé, kan je alsjeblieft en een recensie achterlaten. Dat zorgt voor mijn banden met de zorgverzekeringen." Dat ga ik niet doen, nee, ik wil niet iemand anders… Ik heb dan ook weer niet het lef om iets slechts te zeggen, want je hebt toch een afhankelijkheidsrelatie met zo iemand. (…) Hij wil het beste voor transmensen, dat weet ik dus wel. Zijn politiek leek overeen te komen met de mijne [links] en hij vertelde ook over zijn zorgen tegen het hele zorgsysteem zoals het er nu uitziet en leek in te zien dat het zo inaccessible is voor transmensen, dus ik geloof ook wel, hij heeft het beste met de mensen voor. Hij moet het systeem natuurlijk ook een beetje spelen, weet je, ertussendoor glippen. Dus dat gun ik hem ook, omdat ie wel goede intenties heeft. Alleen bij mij voelde dit gesprek dus niet denderend, nee.

> Charlie: He had emailed me: "hey, can you please leave a review? That will help my ties to insurance companies." I'm not gonna do that, no, I don't want anyone else… I don't have the guts to say anything bad, because you are in a dependency relationship with someone like that (…) He wants the best for trans people, I do know that. His political ideas seemed to match mine [left-wing], and he told me about his worries about the healthcare system as it is now. He seemed to realize it is inaccessible to trans people, so I do believe he has people's best interests at heart. He has to play the system a bit, of course, you know, slip through it. So I grant him that, because he has good intentions. It's just that for me, the conversation didn't feel amazing, no.

Charlie has a complicated relationship with their therapist. On the one hand, they had a negative experience getting their diagnosis and did not feel like they could leave an honest good review. On the other hand, they did not want to take away the option of a relatively accessible diagnosis from other trans people. Charlie recognized that it is necessary for their therapist to play the system a bit, and wanted to work together against the bureaucratic institutions that might not be able to recognize what care trans people need. This particular healthcare provider seemed to be an ally against the system, who wants the best for his patients, although his approach might not be the best for all of them. This attitude, while justifiable from an individual standpoint, keeps intact a system that does not optimally serve its patients.

Conventional care

After Charlie got their diagnosis, they were able to start supervised hormone replacement therapy at the Maasstad hospital in Rotterdam. Charlie shared their history of informal hormone use with their endocrinologist, and her reaction was better than they anticipated. The endocrinologist was very interested in self-medication practices, and wanted to know exactly what was being done "underground".

> Charlie: Ze snapten het, maar ze waren er niet zo blij mee. Ik zit nu bij een hele fijne, bij het Maasstad in Rotterdam. Die zijn net nieuw, dus ik denk dat zij nu veel verhalen horen van alle trans mensen die zo lang aan het wachten zijn. Dus ik was niet de enige, maar ze zei dat ik wel een beetje met mijn gezondheid had gespeeld, en ook dat je misschien toch wel bij je

> huisarts aan kan kloppen of had kunnen kloppen om zo'n nulmeting [van bloedwaarden] te laten doen. Maar m'n endocrinoloog was ook heel erg geïnteresseerd in wat het eigenlijk was, wat ik had ingespoten, dus eigenlijk wil ik dat binnenkort een keertje meenemen voor onderzoek. Zodat ze een soort database hebben van informatie die er underground is, dat zij weten of het goed spul is.
>
> Charlie: They understood, but they weren't very happy with it. I'm now with a great, with the Maasstad hospital in Rotterdam. They're very new, so I think they hear a lot of stories from all the trans people who've had to wait for such a long time. So I wasn't the only one, but she said I had gambled with your health a bit, and also that I could've maybe approached my GP to do a baseline measurement [of blood values]. But my endocrinologist was also very interested in what it actually was, that I had injected, so actually I want to take it along with me for research soon. So they have a kind of database of information going around underground, so they know if the stuff is any good.

Here, Charlie's endocrinologist accepted their informal hormone use. This was not what Charlie expected. Because their friends had had bad experiences with doctors, Charlie had not wanted to contact their GP to be referred to a gender clinic. Elsewhere in the interview, Charlie said the following about that choice: "it felt like a very big step, I thought, I'd rather do it myself. I'm not sure why. Those things are just scary. I'd rather go to a stranger."[48] This reluctance to talk to a GP about gender questions is not uncommon. It has been reported in literature, and I've also encountered it in the other interviews for this thesis. The most common reasons are previous experiences of transphobia by GP's or other healthcare workers, or a lack of knowledge by GPs.[49] As the above quote shows, however, there are hospital workers who accept the use of self-medication, and incorporate it in their treatment.

After Charlie noticed that they would be treated well in the hospital, they made the following observation: "The hospital probably doesn't really work against you, it's more the whole system before that".[50] This comes to the core of the difficulties in trans healthcare, which I will further elaborate on in chapter three. Charlie, as well as my other interviewees, were mostly looking for formal healthcare, but had trouble with accessing it.

---

[48] "Dat voelde als een hele grote stap, dan dacht ik nou dan doe ik het liever zelf. Ik weet niet waarom. Dat soort dingen zijn toch spannend. Dan ga ik liever naar een vreemde."

[49] Audrey Heng et al., "Transgender Peoples' Experiences and Perspectives about General Healthcare: A Systematic Review," *International Journal of Transgenderism* 19, no. 4 (October 2, 2018): 359–78, https://doi.org/10.1080/15532739.2018.1502711; Deborah McPhail, Marina Rountree-James, and Ian Whetter, "Addressing Gaps in Physician Knowledge Regarding Transgender Health and Healthcare through Medical Education," *Canadian Medical Education Journal* 7, no. 2 (October 18, 2016): e70-78, https://doi.org/10.36834/cmej.36785.

[50] "Ik denk dat het ziekenhuis werkt misschien niet zo tegen je, het is meer het hele systeem daarvoor"

Too little too late

At the time of the interview, in April 2023, Charlie still received hormonal care in the Maasstad hospital, and they were happy with their transition. Coincidentally, they had gotten a call from Genderhealthcare the week before the interview, after they had been on their waiting list for more than a year.

> Charlie: Een week geleden belden ze mij pas, van hé, ben je nog geïnteresseerd, je kan nu aan de gang. Ik stond op plek nummer 50, ze zeiden dat ze er 30 mensen per maand doorheen zouden gooien. We zijn nu meer dan een jaar verder, nu ben ik pas bij hen aan de beurt dus. (…) Ik zei: nou ik heb geen interesse meer nee, ik ben ondertussen al een jaar verder en ik ben al een jaar bezig. Ik hoop dat iemand na mij nu een plekje eerder krijgt en ik hoop dat ze goed behandeld worden.

> Charlie: A week ago they finally called me, like, hey, are you still interested, you can start now. I had been in spot number 50, they said they would process 30 people a month. We're a year down the road, and now it's finally my turn. (…) I told them I'm not interested anymore, no, we're a year down the road and I've been doing this myself for a year now. I hope the next person can move up a spot and I hope they get treated well.

This poignant ending story shows that, at least in this case, the trans healthcare system was falling short. By taking initiative and accepting certain risks, Charlie was able to organize their transition much more quickly than the clinic specialized in delivering it. This means that many people, who might not be as determined, do not know where to look, or are simply less lucky, are not able to access trans healthcare nearly as quickly. This creates unfair situations, and pleads for a different organization of trans healthcare. In chapter three I go further into what such a system might look like.

———

In this chapter I have followed along with Charlie's medical transition. Though they have used informal methods, I argue that they have been looking for formal healthcare throughout their transition. This is shown by their initial registration with Stepwork, and the fact that they are currently happily transitioning under medical supervision. Charlie is not alone in this, and in the following chapters I hope to show that more trans people want access to formal care, but are limited in their access to it. Many self-medication practices are a result of this lack of access.

I have also shown that the trans community has played a big role in Charlie's transition. In the next chapter, I will zoom out and give a more general overview of how the trans community has organized itself with regards to sharing knowledge on informal hormone use. Like in Charlie's case, several online and offline spaces are relevant for this organization. In addition to this, I will go into various mechanisms for trust in different informal sources. Again, the trans community is crucial in fostering trust.

Chapter 2: Organizing in the trans community

In this chapter, I aim to give a more general overview of the different practices of self-medication I have encountered. I will also outline the structure in which they are organized. As I have shown in the previous chapter, trans people can access information on self-medication, and the medication itself, in many different ways. Everyone uses a different method for their transition, and approaches can change over time. Sources for medication range from extremely informal, such as acquaintances met online, to almost formal, like a GP abroad who writes a prescription. Although the overview will not be complete, my aim is to illustrate how varied informal practices are in informal trans healthcare, and that everyone mixes and matches methods to shape their own transition.

In addition to this, I will explore how people determine which sources are trustworthy, and what information they act on. I will show that information spread through the trans community is deemed more trustworthy. When formal advice is not available, people rely on other trans people to share their experiences sincerely. If possible, however, people prefer to get their information from scientific sources. They trust medical evidence, and look for verifiable information when possible. Only when these sources are not available, do people rely on knowledge circulated by the community.

I will first describe some online community spaces where information on trans healthcare is given, and show why people trust advice that is shared there. Next, I will look at trust formation in real-life spaces. At the end of the chapter, I will describe two alternative clinics my interviewees have used to access hormonal care, and show how these clinics make themselves trustworthy to their patients. Whereas the last chapter was fully focused on Charlie's story, I will now be drawing on all of my interview data. I will combine my interviews with other sources, such as forums and websites related to trans healthcare. I hope creating a patchwork of experiences allows me to show the variation in practices and draw some more general conclusions at the same time.

One of the common ways people find informal hormones is through their friends. In the last chapter, Charlie mentioned that they got their first dose of testosterone gel from a friend who knew they wanted to start transitioning. And Charlie is not the only one: according to the Transvisie report, 25% of trans people who self-medicate get their hormones from other trans people.[51] Another example of this is given by Aiden:

> Aiden: It was really just happenstance. I met this guy, he was talking about going to a different prescription or something (…) So he had leftovers of his old prescription. And he was like, I need to find someone who needs it. And yeah, I was like: yo, yeah, that's me. I was cycling like an hour and a half to go get it as well. I was not going to let anything get in my way about it.

Both Charlie and Aiden trusted the source of the hormones they used: they came from friends or acquaintances they knew, and the hormones were prescribed by a conventional doctor. However, starting hormones by yourself is not an easy task: there are many different options for regimens and dosages, and the effects are different for everyone. Therefore, all my interviewees looked for more information before starting their self-medication.

Informal sources online

Usually, trans people find information about the effects of hormones online. There are many websites, often in a social media or forum format, where people share experiences and advice about trans healthcare. Some are semi-private, such as closed Facebook groups or Discord servers, while others are openly accessible on websites like Reddit. In some groups, general experiences with transition are shared. People might talk about the effects of different hormone dosages, or what bodily or mental changes they notice over time. Other groups focus specifically on self-medication, and people might share where they order their hormones, or discuss what the optimal blood levels for testosterone or estrogen are. During my interviews, everybody reported visiting these types of websites.

The information shared on these websites is extremely informal. People share their own experiences and anecdotes, and ask for advice from others. In this setting, there is no real division between the people looking for information and those sharing it. Several of my interviewees mentioned that they had also shared their experiences online, or even given advice on posts. One of them had even ran a blog for a few years where she kept track of her transition and shared her experiences. These examples illustrate that looking for and

---

[51] Boom, van den, "Onderzoek Transgenderzorg Nederland," 20.
Getting hormones through friends is especially common for transmasculine people: 50% compared to 20% of trans women. This is because testosterone is included in Dutch doping law, and therefore much more difficult to order online than estrogen is.

sharing experiences online is common, and there is a lively community adding to websites related to this topic.

One example of a space that focuses specifically on self-medication is the Reddit board /r/TransDIY.[52] On this forum, there are many posts with practical questions, such as how deep to insert a needle when injecting testosterone, or how to dispose of leftover medication. People also ask about their personal health situations, like whether their estradiol levels are normal or when they can expect their nipples to change shape. Advantages of different hormone applications are discussed. Furthermore, people share and ask about details of hormone delivery from different sources and to different countries. In all these cases, people share intimate and detailed information, and generally seem open to each other's advice.

The interactive forum environment might encourage sharing personal stories. Patricia Radin, who did research on how trust is formed on a forum for breast cancer patients, suggests that an interactive community space is conducive for fostering trust[53]. She argues that the ability to observe people's posts over time, the positive reaction to other people sharing intimate information, and the possibility to form connections to specific people enables interpersonal trust between the users of the forum. This makes the forum users comfortable enough to share intimate details about their illness, as well as their personal lives.

On the /r/TransDIY board, similar mechanism are at play. Reddit can be used to read other posts, and people react quite positively to the transition pictures others share there. This interaction increases the community feeling, as people are able to actively be part of something, as is the case on the forum Radin describes. A big difference, however, is that Reddit profiles are mostly anonymous. People are unlikely to share their name and precise location, and discussions will be focused on the topic the board is for, rather than general personal information. This is in sharp contrast to the forum Radin describes, where people are encouraged to write a biography section, upload pictures, and share their personal email address to get into contact with other users.[54] On Reddit, this level of personal connection is impossible, so another factor for fostering trust is likely to be present, especially if people are to trust each other with medical advice.

I argue that the existing trans community takes the role of the forum-specific community Radin describes. In contrast to other patient groups or organizations, which form around a specific disease, trans people already feel in community with their peers. In the early 21st

---

[52] "R/TransDIY," Reddit, accessed December 15, 2022, https://www.reddit.com/r/TransDIY/.

[53] Patricia Radin, "'To Me, It's My Life': Medical Communication, Trust, and Activism in Cyberspace," *Social Science & Medicine*, Patient Organisation Movements, 62, no. 3 (February 1, 2006): 591–601, https://doi.org/10.1016/j.socscimed.2005.06.022.

[54] Radin, 598.

century, trans people started seeing themselves as part of the LGBT community, and became proud of their identity.[55] Nowadays, trans people find each other for social gatherings, and are used to sharing experiences outside of a medical setting. Within this trans community, people are used to rely on each other to make sense of their transness and explore their identity.[56] From my research suggests that this process translates to medical advice as well. Benthe, a trans woman who frequently visited forums for medical advice, said: "I would say, if I read something online, I trust it more easily if the person is trans themselves, instead of taking it from a random cis person".[57] It seems like sharing an identity makes people more trustworthy. Although it is difficult to determine how knowledgeable someone is in a setting like a forum, lived experience communicates expertise to those looking for advice.

Another factor that helps credibility of advice posted on forums is the number of posts confirming similar experiences. /r/TransDIY is a very busy forum, with over fifty thousand subscribers and about 30 posts per day. Similar boards, such as /r/askMtFHRT, also have multiple new posts a day, and there are many other spaces and dedicated websites where people share such experiences. Altogether, people are able to find an enormous amount of information on what transition results they can expect at what time, which medication has which side-effects, and how people feel at each point in their transition. Posts are often incredibly detailed, with people sharing long lists of effects they feel within the first day after their first dose of hormones, and noting differences in things such as skin sensitivity, emotional wellbeing and appetite. This amount of information allows people who want to start their own DIY transition to decide which information is trustworthy and which is not. If experiences are shared by many others, it is more likely that the effects will be similar for the next person. Even though the evidence is still anecdotal, consistent experiences confirm that certain treatments might be reliable.

In my interviews, the credibility of shared experiences was evident as well. One of my interviewees, Eva, had based her hormone regimen on information she found on a Dutch transgender forum. She tried a method advocated by a specific doctor after hearing positive experiences, and said:

> Eva: Ja, ik geloof dat ik via het Nederlandse forum van die naam gehoord had, van die arts. Na een tijdje zag ik gewoon dat die community zo groot was en dat zoveel mensen het over hem hadden. En ja, ik heb ook presentaties van hem gezien, maar het waren wel vooral de

---

[55] Bakker, *Transgender in Nederland*, 67–68.

[56] Avery Dame, "'I'm Your Hero? Like Me?': The Role of 'Expert' in the Trans Male Vlog," *Journal of Language and Sexuality* 2, no. 1 (January 1, 2013): 40, https://doi.org/10.1075/jls.2.1.02dam.
Also an interesting source on how expertise in online communication is determined through language use.

[57] "Ik zou eigenlijk wel zeggen, als ik iets online lees, dan vertrouw ik het sneller als die persoon zelf trans is dan als dat een random cispersoon is"

> verhalen van mensen die zeiden: dit werkt echt voor mij. Ik heb alles geprobeerd, niks werkte. Maar nu ik zijn methode volg heb ik opeens resultaat.

> Eva: Yeah, I think I heard that name on the Dutch forum, that doctor. After a while I just saw that the community was so big and so many people were talking about him. And yeah, I've also seen presentations of his, but it was mostly the stories of people who said: this really works for me. I've tried everything, nothing worked. But now that I'm following his method I suddenly see results.

Here, Eva specifically mentions being convinced by the number of people seeing results from this particular approach. Although the doctor's professional expertise was a supportive factor, she was finally moved to action after she saw that his method worked for so many people. For her, the inherent reliability of the trans community was enhanced by the amount of people speaking out, making her confident in trying a new way of administering hormones.

Eva was happy with her results, and felt grateful for the amount of information trans people shared online:

> Eva: Zonder mensen die hun verhalen en ervaring en kennis hadden gedeeld, had ik echt niet geweten waar ik had moeten beginnen. En dan was ik waarschijnlijk, ja gewoon via de officiële weg, via het ziekenhuis begonnen, en dan was ik niet echt blij met m'n transitie en resultaten geweest. Ik heb zo'n beetje alles geprobeerd wat via de officiële weg kon in Nederland, dus ik ben heel blij dat die gemeenschap er is en zoveel kennis onderling deelt.

> Eva: Without people who shared their experience and knowledge, I definitely wouldn't have known where to begin. And then I would have started probably through the official route, through the hospital, and I wouldn't really have been happy with my transition and my results. I've tried just about everything that's possible through the official route in the Netherlands, so I'm very happy that community is there and shares so much knowledge among themselves.

This shows that people appreciate the knowledge trans people exchange online, and are happy to be able to find so much information about transition. This is partly because this type of information is not accessible anywhere else. A GP or other healthcare provider will not be able to provide anyone with such detailed and personal stories. Although there are guidelines and average timelines available to doctors, reading about others' experience can make trans people more familiar with what to expect when transitioning.

Especially when organizing informal hormone use, this shared knowledge can ease anxiety about possible consequences. Although she realized advice from people online was not generalizable, Benthe did mention that she felt comforted after reading others' experiences online:

> Benthe: Het kan voor mij ook geruststellend zijn om een ervaring van iemand anders te lezen die succesvol is geweest, ook al weet ik dat ik niet 100 procent moet vertrouwen op dat dat ook voor mij succesvol zou zijn. Ja, die geruststelling vind ik een belangrijke factor soms.
>
> Benthe: It can also be reassuring for me to read about an experience by someone else that has been successful, although I know I cannot trust 100 percent that that will also be successful for me. Yeah, I find that reassurance to be an important factor sometimes.

In summary, it seems that informal contacts are valuable to many trans people in determining what transition path is right for them. In addition to listening to general advice on what to expect during transition, trans people rely on anecdotal information when determining their self-medication routine. People are cautious when listening to this advice, but do appreciate it. People feel like they can trust trans people because they feel part of the trans community outside of a medical context as well. Because many trans people are used to organizing together and listening to each other in different situations, they are more likely to rely on each other for medical advice.

Risks

Despite the mechanisms to increase trust I described above, my interviewees were aware of the risks they were taking when starting self-medication. They realized that sources online were not always reliable, and might contain false information. Nevertheless, some trusted their own judgment when selecting credible sources:

> Denise: Ja, dat is toch waarschijnlijk een beetje dat ik in de IT zit en daar heel veel ervaring mee heb en redelijk goed weet hoe ik onderscheid kan maken tussen onzin informatie en echte informatie. En ja, of ik daar een wetenschappelijk stroomdiagram aan kan koppelen weet ik niet. (…) Ja, het is vrij normaal voor mij om inderdaad zin en onzin van elkaar te scheiden wat dat betreft.
>
> Denise: Yeah, it probably has to do with the fact that I’m in IT, and have a lot of experience with that and am quite good at differentiating between nonsense information and real information. And yeah, I don’t know if I can spell out the scientific process there (…) Yeah, it’s quite normal for me to separate sense from nonsense, in that respect.

To Denise, her experience working with computers helped her to decide what sources to trust when looking for information online. Other interviewees also generally trusted their own abilities to differentiate between reliable and unreliable information. They were, however, aware that their lack of medical knowledge meant they did not always know how to apply this information to themselves. However, in the absence of alternatives, they acted anyway.

> Benthe: Omdat het best wel een heftige keuze is en je bijvoorbeeld medische kennis ervoor moet hebben om het op een betrouwbare manier te doen, zag ik mezelf er eigenlijk niet heel erg voor aan om dat te doen eerst. (…) maar toen ik besefte dat ik nog zeker twee jaar zou moeten wachten op hormonen, toen heb ik eigenlijk heel stapsgewijs de overgang naar DIY

> genomen. (…) het is ook niet echt te vertrouwen eigenlijk, en ik weet ook zeker dat ik het nooit gedaan zou hebben als ik niet het gevoel had dat het absoluut noodzakelijk was.
>
> Benthe: Because it's quite a major choice and you need to have medical knowledge for example, to do it in a reliable way, I didn't really think I was capable of doing this at first. (…) but when I realized I would have to wait at least two years for my hormones, I took the step to DIY very gradually. (…) It cannot be trusted, really, and I am sure I would never have done it if I didn't have the feeling it was absolutely necessary.

Benthe, for example, realized that she was not fully equipped decide what medication would be right for her, as she lacked medical knowledge. However, her perspective changed when she found out how long she would have to wait to get hormones the official way. Acting on uncertain information was preferable to waiting for hormones for another two years. Lacking other options, people thus resort to 'trusting' incomplete or flawed information when starting self-medication. This is an important factor that I encountered in several of my interviews.

Offline care practices

In addition to the online sources I mentioned above, people also find care in their real life environment. This can be by getting hormones from friends, but there are some more organized initiatives that provide trans healthcare as well. Trust in these organizations forms differently than in an online environment. The main difference is that the care is delivered in a physical space, by a person standing in front of you. This enables different mechanisms for trust formation. In a medical setting, physical interactions are vital for establishing trust between doctor and patient.[58] I argue that this is also true in an informal setting such as trans healthcare.

Whereas doctors can rely on a certain amount of public trust, the trans people organizing care for their peers do not have that advantage. Therefore, informal healthcare providers have to compensate for their lack of authority. In a study on trust in alternative medicine clinics, Pedersen et al. argue that trust is established on relational, bodily and material grounds.[59] Many clients trust specific practitioners, and base their choice of clinic on recommendations from friends. The practitioner builds trust through talking and listening to ailments. Bodily reasons that convince clients that treatment will be effective include the ability of the practitioner to "gain insight into their bodily and physical conditions through, for example, the manipulation of reflex zones".[60] Finally, the material space the treatment takes place in plays an important role. The presentation and character of the clinic, specific

---

[58] Patrick R. Brown et al., "Actions Speak Louder than Words: The Embodiment of Trust by Healthcare Professionals in Gynae-Oncology," *Sociology of Health & Illness* 33, no. 2 (February 2011): 280–95, https://doi.org/10.1111/j.1467-9566.2010.01284.x.

[59] Pedersen, Hansen, and Grünenberg, "The Emergence of Trust in Clinics of Alternative Medicine."

[60] Pedersen, Hansen, and Grünenberg, 50.

objects being displayed, as well as the physical appearance of the practitioner influence whether the patient feels the practitioner will provide genuine treatment. Together, these factors increase the trust in practitioners of alternative medicine.

In the following paragraphs, I will show that these three elements for establishing trust are present in informal trans healthcare as well. However, my case is different from the one described in Pedersen et al.'s article. Whereas they study alternative medicine, meaning treatments that have not been scientifically proven by biomedical research, my interviewees were often looking for medication and care that explicitly had been proven to be effective. They were thus not looking for alternative medicine, but instead for accessible alternatives to proven hormone therapy. Some of my interviewees mentioned looking for 'medical testosterone', and preferred being able to get medication from a pharmacy instead of an unknown source. Despite this difference, however, the relational, bodily and material factors present in establishing trust are still relevant for trans people navigating a space where they receive non-conventional hormone treatment.

I claim that the shared identity between 'doctor' and 'patient' makes the former more trustworthy in the case of informal trans healthcare. Advice given by a doctor who has gone through a similar experience is more likely to be trusted. [61] For trans people, it is therefore easier to accept input from people how have transitioned themselves. To illustrate this, I will reexamine the anarchist volunteer group Charlie visited to learn about hormone injections.

> Charlie: Zij bleken bij een soort anarchistisch boekenwinkeltje te zitten en dat waren dan vrijwilligers die daar werkten. Met een van die mensen had ik afgesproken 's avonds een keertje en dat was eigenlijk heel fijn, dat was echt een hele fijne ervaring. We hadden een paar uur de tijd om alles een soort van door te nemen. We hadden eerst thee gedronken, over van alles gepraat: wat je dan wil, wat de risico's waren, of je al bekend was met testosteron en wat de effecten een beetje zijn. Daarna gingen we injecteren, want ze hadden al die dingen dus daar. Dat was een heel liefhebbend speciaal moment eigenlijk. Natuurlijk was het een beetje spannend, jezelf injecteren, want ik had dat nog nooit gedaan en dat is toch wel wat heftiger dan een gelletje smeren, maar diegene heeft mij echt stap voor stap uitgelegd wat de stappen waren: een naald vullen, je hele tafel schoonmaken, gewoon het hele proces. (…) Diegene had een setje met dingetjes en ik ook. Ik moest die gewoon nadoen en die vertelde bij alles wat je moest doen en waarom je dat moest doen. Dus dat was super duidelijk. Ik heb mezelf ook daar ter plekke geïnjecteerd en diegene deed dat ook, maar dan met een lege naald, om samen

---

[61] This mechanism is recognised more widely, which is why experience experts are often deployed in mental healthcare. See: Maja Haanskorf, "Ervaringsdeskundigen in de praktijk: 'Vaak is een half woord genoeg om elkaar te begrijpen,'" *AS - Maandblad voor de activiteitensector* 38, no. 8 (August 1, 2017): 36–39, https://doi.org/10.1007/s41188-017-0095-4; Marijn Kester and Olivier Lingbeek, "Herstel En Vertrouwen: Professionals, Ervaringswerkers En de Herstelvisie in de Nederlandse Geestelijke Gezondheidszorg," *Beleid En Maatschappij* 45 (September 1, 2018): 246–67, https://doi.org/10.5553/BenM/138900692018045003002.

> te zijn en te laten zien hoe het echt moet. Ja, dan zit je ergens in een achterkamertje, maar dat was een heel cool, een heel fijn moment en heel lieflijk eigenlijk.

> Charlie: They were located in a kind of anarchist bookshop and there were all volunteers working there. I met with one of those people one evening and it was a very good experience. We had a few hours of time to talk through everything. We had some tea first and talked about all kinds of things: what I wanted, what the risks were, if I was familiar with testosterone and what the effects would be. After that we started the injections, because they had all the equipment there. It was a very loving moment actually. Of course it was kind of scary, injecting yourself, because I'd never done it before and it's a bit more drastic than just applying some gel, but this person explained every step to me: filling a needle, cleaning your whole table, the whole process (…) The other person had a set of supplies and I had one too. I just had to copy them, and they told me at every step what to do and why to do it. So that was super clear. I injected myself there on the spot, together with the other person, who used an empty needle to really be together and show me how it's really done. Yeah, you're sitting in some sort of back room, but it was a very cool, a beautiful moment and very lovely actually.

The first passage of this quote shows relational aspects of trust building. The long conversation Charlie had with the volunteer built interpersonal trust, by including casual topics to break the ice. Because the volunteer took the time to answer Charlie's questions, they established that they were knowledgeable about trans healthcare. In this way, Charlie was able to verify the volunteer's expertise, as the latter had no official credentials. As mentioned before, this process was a positive and loving experience for Charlie, and they felt cared for by this volunteer. Thus, the interaction between the two people helped to build relational trust.

The next step of the process shows how bodily aspects of trust are established. During the encounter, Charlie performed their first testosterone injection on themselves. They mentioned being nervous about this, as it was a more complicated procedure than simply applying the gel they had used before. Charlie had to trust that the volunteer was able to teach them how to do injections safely. The cleaning process that preceded the injection, and the step by step explanation of how to do it, reassured Charlie that the volunteer had the necessary expertise to show them the procedure. An important addition here is the fact that the volunteer instructing Charlie could show them how they injected their own testosterone. Because the volunteer had done this exact thing to themselves before, they were able to show Charlie 'how it's really done'. Again, their shared identity is crucial for building trust in this situation.

Finally, material aspects played a role as well. First of all, the setting and location of the meeting were relevant. It was held in a back room of an anarchist bookshop, which immediately distances the procedure from conventional medical practice. As mentioned by Pedersen et al, this can increase comfort with a procedure for some patients. For Charlie, who is comfortable in anarchist spaces and mentioned several times that the experience was ‘lovely’, this seems to be the case.[62] Secondly, the identity and physical presentation of the volunteer are significant. The fact that the volunteer was transmasculine and an anarchist, similar to Charlie, meant that they were more trustworthy. Thus, the combination of the setting of the instruction and the identity of the volunteer assured Charlie that they would be treated well.

In short, trust in informal healthcare can be increased by several factors present during face-to-face encounters. The relationship between the instructor and the instructed, physical interactions, as well as the material environment can play a role in establishing trust. Although these circumstances are often created unintentionally, we will see that they are also consciously employed by more formal healthcare providers.

Grey healthcare

In addition to the informal options mentioned thus far, trans people use multiple other ways to organize their healthcare outside of the official system. In this section, I will discuss two organizations: GenderGP and the Trans United Clinic. Both exist on the boundary between informal and formal care. These clinics offer treatments that are verified and medically supported, and they employ certified doctors. But as their approaches differ from those practiced by most Dutch doctors, they are not recommended by gender teams and not covered by insurance. Therefore, these clinics fit into a category I call ‘grey healthcare’. Their existence shows that in many cases, it is difficult to categorize care as strictly formal or informal. Because several of my interviewees used these clinics in combination with informal methods described above, I find them interesting to discuss.

GenderGP

GenderGP a private online transgender clinic that is based in the United Kingdom.[63] It offers a variety of trans healthcare services, including counselling sessions, prescriptions for hormones, and surgery referrals. The clinic uses an informed consent system, which means people do not need a diagnosis before starting treatment. After an intake session people will receive a hormone prescription they can file in their own country. Regular blood tests are mandatory to monitor the health of the patients. So are psychological follow-up sessions, but the total amount of support is still lower than recommended by Dutch healthcare providers. For many trans people, this clinic offers an opportunity to acquire hormones from a trusted source, as they can be picked up from their local pharmacy. This does come at a cost though, as GenderGP charges an intake fee and a monthly subscription fee, and the follow-up checks are not included in those costs. The medication also has to be paid by the patient themselves.

---

[62] Pedersen, Hansen, and Grünenberg, “The Emergence of Trust in Clinics of Alternative Medicine,” 51–52.

[63] “GenderGP.Com,” GenderGP Transgender Services, accessed June 20, 2023, https://www.gendergp.com.

GenderGP thus fills a gap in healthcare, as trans people are able to order their hormones with fewer hurdles than they would have to overcome when using Dutch gender clinics. Several of my interviewees mentioned they had used GenderGP services for a while. Denise, a trans woman, bought progesterone pills from GenderGP while she was on medication through the official Dutch system already. In contrast to some other countries, like the UK, Dutch doctors do not prescribe progesterone to trans women, instead relying on estrogen-only treatments for feminization. It has been suggested that progesterone might help with later breast development, including shaping of the breast tissue.[64] This is the reason Denise added these pills to her regimen.

> Denise: Sinds zes-weken heb ik nu progesteron erbij en dat voelt goed. (…) Mijn endocrinoloog heeft ook gezegd: heb gewoon een beetje geduld. Als we twaalf of 24 maanden verder zijn, mag ik jou waarschijnlijk ook gewoon progesteron voorschrijven, dus ik heb zoiets van ja, dan betaal ik gewoon twee, drie, vier jaar wat. GenderGP loopt gewoon via de apotheek en c'est la vie.
>
> Denise: Six weeks ago I added the progesterone and that feels good. (…) My endocrinologist has told me to have a bit of patience. In 12 or 24 months she can probably prescribe me progesterone herself, so I was like, well, then I'll pay GenderGP for two, three, four years, I get my medication through my pharmacy and c'est la vie.

For Denise, genderGP was thus a welcome addition to her official regimen, and it was a source that is trustworthy enough to use for an extended time period without significant worries. This is mainly because GenderGP can rely almost fully on public trust in healthcare. Its main difference to Dutch gender clinics is the use of the informed consent model, which I will go into further in chapter 3. This example shows again that the line between official and unofficial care can be hard to draw, as people often combine different methods to tailor their own transition plan.

The Trans United Clinic

Another form of grey healthcare is the Trans United clinic in Amsterdam. The clinic offers trans- and sexual healthcare to people who do not have access to the Dutch healthcare system for various reasons, like homeless people and refugees[65]. Like GenderGP, it uses an informed consent model and is therefore not covered by Dutch insurance policies. Trans United was set up by a trans woman, and now employs a doctor, several social workers and a group of volunteers to provide social and medical help to trans people and others. In

---

[64] Charalampos Milionis, Ioannis Ilias, and Eftychia Koukkou, "Progesterone in Gender-Affirming Therapy of Trans Women," *World Journal of Biological Chemistry* 13, no. 3 (May 27, 2022): 66–71, https://doi.org/10.4331/wjbc.v13.i3.66.

[65] "Trans United Clinic – Trans United Europe," accessed December 16, 2022, https://transunitedeurope.eu/?page_id=255.

their practice, the employees of the clinic are consciously working to gain the confidence of the people they are treating.

This became clear during my interview with Camiel Welling, the doctor working with the Trans United clinic. Although he could partly rely on his medical training to inspire trust, Welling was also aware of the fact that many trans people had previously had bad experiences with healthcare providers. Therefore, he was actively working to combat the lack of trust that resulted from that mistreatment.

> Welling: We herkennen dat gevoel van onveiligheid bij zorgverleners en we vinden dus ook een belangrijke taak om juist te laten zien dat mensen wel een veilige plek kunnen vinden, waar ze zowel voor hun zorg terecht kunnen, maar ook beseffen dat ze begrepen worden, met als doel mensen weer vertrouwen te geven in de zorg en daardoor meer mogelijkheid hebben om gezondheidsdiensten aan te kunnen bieden. Voor ons is de belangrijkste vorm van veiligheid dat de transgemeenschap in de bredere zin je accepteert waardeert en aanwijst als veilig team. (…) Als we de rolmodellen al niet eens kunnen overtuigen dat we inclusieve zorg willen bieden, hoe ga je dan individuen goede zorg bieden? Dus door de transgemeenschap aan het stuur te zetten en een coördinerende rol te geven, zien mensen van oké, dit is een team waar de transgemeenschap vertrouwen in heeft, waar sleutelfiguren een vertrouwen in hebben. En dat zal dan wel goede zorg zijn, denken veel mensen uit de community.
>
> Welling: We recognize that feeling of unsafety with healthcare providers and so we think it's an important task to deliberately show that people can find a safe space, where they can go for healthcare, but where they also feel understood, with the goal of restoring people's trust in healthcare in order to have more opportunities to deliver healthcare services. For us, the most important form of safety is that the trans community in a broader sense accepts and appreciates you and recognizes you as a safe team. (…) If we cannot even convince role models that we want to offer inclusive care, then how are we going to provide that care to individuals? So by putting the trans community at the wheel, and giving them a coordinating role, people see that okay, this is a team that the trans community has confidence in, that key figures have confidence in. So that has to be good care, many people from the community think.

In this quote, Welling highlights the mechanisms by which the Trans United clinic inspires trust. The clinic's main goal is to profile itself as a safe space for people looking for care. The employees do this by engaging with the trans community, and having them be actively involved in the way care is offered. Welling specifically mentions engaging with "key figures". These are people who are well-known in the local trans community, and who others are likely to listen to. If key figures can be convinced that the Trans United clinic offers quality care, then others will follow suit. The Trans United clinic is able to identify and reach these key figures because of its unique position. The founders and employees of the clinic are local, and often trans themselves, and therefore know who the key figures to involve are. Thus, being embedded in the trans community is beneficial in medical contexts as well.

People

This community aspect is further developed by the people the Trans United clinic employs. Its team exists mainly of queer people, and all the volunteers working at the clinic are trans themselves. According to Welling, this creates a basis of interpersonal trust, as being in a space with a majority of trans people gives patients the feeling that "these people at least know what kind of barriers I run into, and intrinsically understand, and to whom I don't have to explain myself"[66]. As we have seen earlier on in this chapter, this is in line with the experience of my interviewees. They are more likely to trust trans people with healthcare advice, especially in an informal setting. By creating a trans-dominant space, the Trans United clinic generates a feeling of safety and acceptance that is not present at an average doctor's clinic. Taking away the necessity of having to justify your identity in addition to the medical issues you came for makes the experience of asking for healthcare more comfortable for patients.

The feeling you have to justify your identity to healthcare providers is shared by many trans people. It is a major hurdle to accessing healthcare, and makes trans people reluctant to go to conventional healthcare providers.[67] We already saw this sentiment in chapter 1, when Charlie said they were hesitant to approach their GP with questions about gender. Next to this, Fien said that she specifically did not go to a gender poli because she did not want them to verify whether she was trans enough:

> Fien: Je moet, als je dan bij zo'n genderpoli komt en wil gaan beginnen met hormonen, allemaal vragen doen en dan moeten zij bepalen of je wel echt "trans genoeg bent" om eraan te beginnen. En dat heeft me altijd zó erg tegengestaan, daar had ik altijd zó ontzettend weinig zin in.
>
> Fien: If you go to a genderpoli and want to start using hormones, you have to do all sorts of questions and they have to verify whether you're "trans enough" to start with them. And that has always bothered me a lot, and I was dreading it immensely.

Hosting trans healthcare in a space where being trans is the norm means that mistakes such as using the wrong pronouns for someone will not be made as often, or at all. Having a majority trans staff thus can reduce the pressure put on trans people looking for care. Recent research has come to the same conclusion, and it is recommended that more trans people are employed throughout the whole of trans healthcare.[68]

---

[66] "Dit zijn personen die in ieder geval weten tegen wat voor barrières ik aanloop, en dat echt intrinsiek begrijpen en waar ik me sowieso niet aan hoef uit te leggen"

[67] Robin Bos, ""What Are Your Pronouns?": General Practitioners' Open-Mindedness Mitigates a Knowledge Gap When Communicating with Transgender and Nonbinary People" (Utrecht, Utrecht University, 2022), 2.

[68] Das et al., "Mijn Gender Wiens zorg," 5.

Spaces

In addition to the people working at the clinic, the space it is hosted in also helps to build trust. The monthly office hours of the clinic are held in the Trans House, located in the center of Amsterdam. It is a space that is used primarily for social activities, such as café evenings and coaching sessions.[69] Patients will often have visited this space for non-medical reason, and therefore feel more comfortable asking for medical help when they need it. Welling describes this as follows:

> Welling: [Het transhuis] is een locatie die vooral voor sociale en maatschappelijke activiteiten benut wordt, waar ook een kledingbank is, waar mensen voor andere vragen terecht kunnen en waarvan mensen weten van: oh, ik kom hier voor sociale situaties, maar ik kan hier dus ook voor zorgvragen terecht. Dus in plaats van dat mensen zelf over bruggen heen moeten om zorg te vragen waarvan ze eigenlijk niet eens zeker weten of dat wel veilig is, of ze met een pasje bij de receptie moeten staan en alsnog met de verkeerde pronouns omgeroepen worden, denken ze: nu kom ik op een locatie waar ik mezelf mag zijn en waar de zorgverlener te gast is.
>
> Welling: [The Trans House] is a location that is mostly used for social and societal activities, where we also have a clothing bank, where people can also come for other questions and of which people know: oh, I come here for social situations, but I can also come here with healthcare questions. So instead of people having to cross bridges themselves to ask for healthcare of which they aren't even sure it is safe, or having to stand at reception with a card and still get called up with the wrong pronouns, here they think: oh, now I'm in a location where I can be myself and where the healthcare provider is a guest.

To Welling, the fact that the Trans House is also a social space makes people more likely to go there for medical care. The interior design of the space, with large couches, a bookcase and a dining table, supports this argument. By showcasing themselves as safe in informal situations, they hope to remove some of the barriers trans people experience when accessing care. Both material and relational factors are important to that.

This conscious shaping of the environment seems to be worthwhile, as the three interviewees who had experience with the Trans United clinic all described their experiences as very positive. The attention that had been put into creating a safe location was appreciated, and so was the procedure of accessing treatment. One of my interviewees made the following comment about the clinic:

> Aiden: The level of care put into recognizing it as a community space as well as a medical necessity was incredible. It was brilliant. I think that's what the basis of Trans United is, is that first it's a community project. It's community outreach. The clinic in which they're doing the prescriptions was just one aspect of that. Community outreach is: okay, we see what's needed in the community and it's someone writing prescriptions. So we'll fulfill that. But also we just

---

[69] "T-Huis – Amsterdam," accessed July 21, 2023, https://t-huis.transunitedeurope.eu/.

> need to get together and sit down and have a cup of tea and chat about shit. You know, we need to have that sort of binding experience. And that was nice. It also felt like a very safe space because they were very, very careful about who they let in to that room. (…) I think because a lot of them are also trans themselves, they know exactly what's needed and exactly where those missing links are in the medical field.

This experience supports the claims made by Welling, and shows that the care put into making the Trans United clinic welcoming is recognized by visiting patients. Aiden stressed multiple times how important community is in this, and that he appreciated the option to socialize as well. He also realized that this was in part due to the large amount of trans people present. The combination of a social and a medical space, as well as the incorporation of the trans community, seemed to work well for him.

———

In this chapter, I have described some of the organizational structures that have been set up by trans people to provide care. I have argued that at in all these structures, the trans community plays an important role, for organization, sharing experiences and fostering trust. People trust their own trans friends to give them safe hormones for example. In online environments, reading stories of other people’s experiences with certain hormones can help people decide what regimen would be right for them. Although the people posting usually have no medical background, the fact that they have gone through transition themselves is sufficient to trust them.

In more formal settings, such as the Trans United clinic, the involvement of the trans community also improves the care being provided there. Trans employees can more accurately identify what care is needed, which results in a better alignment with the wishes of the visitors. Having trans staff present also causes an environment in which people are more comfortable asking for care, without having to be afraid of unpleasant interactions.

Thus, it is important to not underestimate the importance of the trans community in the establishment of informal and formal healthcare systems. This community holds a great deal of knowledge on how trans healthcare can be provided, and is willing to share it. This is not only useful for people looking to self-medicate, but can also inform conventional healthcare policy. In the next chapter, I will go into what trans people would ideally like to see in healthcare, and how some of these ideas could be implemented.

Chapter 3: Caring for trans people

In the previous chapters I have described the different ways in which trans people have organized themselves outside of the conventional healthcare system. Because of long waiting times, bad experiences with healthcare providers or inaccessible care, people have found ways to transition on their own terms. However, as I will show, this informal system is not ideal either. It is set up partly out of necessity, as people lack reliable sources for their hormones or the supervision of a professional to safeguard their health. This begs the question of what trans people would like to see instead.

In this chapter I will first examine what an ideal trans healthcare system would look like to my interviewees. I argue that what they want most of all is good care: treatment that fits their personal situation, and knowledgeable healthcare professionals who are able to guide them through their transition. In the second part of this chapter I will go into reasons why the current healthcare system is not suited to delivering this type of care. I argue that too much emphasis is put on the diagnosis of gender dysphoria, and that it might be a good alternative to use an informed consent model instead. This approach might be better suited to the deliver the care that trans people are actually looking for.

The logic of care

The definition of care as I used it above is one described by Annemarie Mol.[70] In her book *The Logic of Care*, she describes two logics present in the Dutch healthcare system to find out what good care is. She distinguishes between the logic of choice and the logic of care, which

---

[70] Mol, *The Logic of Care*.

both frame the questions and relevant answers in how to provide good healthcare in a different way. Mol argues that the logic of choice is too often taken for granted, and that offering the logic of care as an alternative framework might help in providing better care to those who need it. I am interested in these two logics because they can help me disentangle what my interviewees and others are looking for in trans healthcare.

In the book, Mol presents the logic of choice as the one that is at the basis of the Dutch healthcare system. It is a product of western society, and expects emancipated patients to be actors who can make conscious choices on what care is right for them.[71] In this system, doctors take a guiding or managerial role, but patients are ultimately required to make an active choice about what care is best for them. In this framework, care is good if all patients are given equal opportunity to choose their ideal treatment.

As an alternative to this, Mol presents the logic of care. This is a materialist perspective to healthcare, which is based on the process and action of caring. Doctors and patients both actively 'doctor together' to design a treatment that takes the patient's specific circumstances into account. Care is good when it is perfectly adjusted to the patient's needs. Within the logic of care, the goal is not to be healthy again, but to work towards a good life.[72]

The logic of choice is widespread in trans healthcare. It is present in the idea that diagnosis is the right way to determine who gets access to care, and that hormone therapy is the cure to a condition called gender dysphoria. Many activists frame their arguments in the logic of choice as well. The TransZorgNu statement, for example, asks for complete self-determination.[73] This emancipatory ideal, where people get the freedom to choose that treatment is right for them, matches the logic of choice. However, this approach might not be the most useful one. From my interviews, it follows that most trans people do not want free choice, but good care instead.

Care over Choice

I will argue that my interviewees primarily want to be cared for, and that the wish to choose freely is secondary. In Mol's framework, good care is characterized by attentiveness and specificity. Patients are seen as whole people with complex lives, which need to be taken into account when figuring out what care practice suits them best. To Mol, the opposite of this good care is neglect, which means patients are not treated in a sufficient manner. In my interviews, I saw a clear need for care in this sense: people want to be taken seriously when requesting help, and appreciate guidance and input from a professional on how to best

---

[71] In this chapter, I deliberately use 'patients' to describe trans people receiving care. This is because they have become patients in the context of the medical system.

[72] Mol, *The Logic of Care*, 22–23.

[73] TRANSZORGNU, "Statement (English)."

implement hormonal care in their daily lives. They do not want to be neglected, but ask for accessible care and easily available information.

Neglect

Currently, people trying to make use of trans healthcare often experience some form of neglect. Oftentimes, this neglect is not deliberately brought about by unsympathetic healthcare professionals, but rather a result of systemic causes. The main way this neglect manifests is through a lack of available healthcare. This makes trans healthcare inaccessible in several ways. One example of this inaccessibility is the long waiting times that were already discussed in chapter 1. Aiden thought that "for everyone the waiting times are always the thing that they want to get rid of", and that seems to reflect the attitude I've seen during my other interviews as well. Everyone mentioned the waiting times as one of their major struggles with the current system. In the absence of proper care, people turned to self-medication as an alternative.

> Benthe: Ik kwam er meteen achter dat er een heel lange wachtlijst was en toen heb ik de keuze genomen online illegaal hormonen te bestellen, omdat ik dacht dat ik die lange wachtlijst eigenlijk zonder zorg niet door zou komen.
>
> Benthe: I immediately found out that there was a very long waiting list, and then I made the choice to order hormones online illegally, because I thought I would not get through that long waiting list without any care.

To Benthe, there is a clear link between the lack of formal care and her choice to order hormones online. Although she would have preferred to have been treated by a doctor in a timely manner, this option was not available to her. As a result, she chose the only other feasible method to start her transition. Taking the risk of using hormones from an unverified source was preferable to not receiving any care at all.

In addition to the waiting times, the lack of available care also causes other problems. After enduring the waiting lists, people still have trouble finding healthcare that is affordable and within reasonable travelling distance. Eva, for example, specifically mentioned that the travel time was too long for her to go to a psychologist as often as she would have liked. For Charlie, travel time was only one of the reasons psychological care was inaccessible to them.

> Charlie: Maar ik werd letterlijk verwacht om naar Groningen te gaan. (…) a. het was duur, b. het was ver, weet je. Het is echt heel ver lopend door weilanden letterlijk gewoon, dat je denkt: oh, dat moet je maar kunnen (…) ik vraag me af hoe het voor mensen is die niet in de Randstad wonen, hoe het daar zit voor mensen die niet de fysieke of monetaire middelen hebben om deze acties te ondernemen, omdat het ook tijd, energie en mentale resilience kost om dat te doen.
>
> Charlie: I was literally expected to go to Groningen (…) a. it was expensive, b. it was far away, you know. It was a really long distance to walk through fields, literally. It makes you think:

> oh, you have to be able to do that (…) I wonder what it's like for people who don't live in the Randstad[74], what it's like for people who don't have the physical or monetary means to take these actions, because it costs time, energy and mental resilience to do all this.

Here, Charlie describes the process of getting a gender dysphoria diagnosis. As was mentioned in Chapter 1, Charlie's psychotherapist was willing to diagnose them, but the process was not without trouble. Charlie had to pay for expensive health insurance, and had to travel for hours to get to their appointment. Next to this, they had to withstand an unpleasant diagnostic process. Charlie realized this makes this route inaccessible to many people who might not have the same privileges.

Finally, there is a lack of accessible information about possible transition options and surgeries. Although there are some initiatives to make an overview of available healthcare providers, my interviewees felt they were dependent on their communities for this information.[75] Instead of being able to turn to a reliable source, people felt like they had to be in the right place at the right time, and get lucky to access healthcare.

> Fien: Het is gewoon heel raar dat het echt een community effort is om al die informatie door te geven en op de juiste plekken te krijgen, maar dat daarbuiten die informatie gewoon totaal niet goed toegankelijk is.

> Fien: It is just very strange that it's really a community effort to spread all that information and get it to the right places, but that outside of that the information is just not accessible at all.

In this case, the trans community was crucial to mitigate the lack of available information. As I have shown in chapter 2, a lot of advice on trans healthcare is spread by the community. However, this community is not accessible for everyone. Many people have to be lucky enough to stumble across a useful tip online, or to run into someone who can help them get hormones. Therefore, a lack of trustworthy information creates inconsistencies in access to healthcare.

The past examples of inaccessible care show that trans people experience neglect caused by the trans healthcare system. They have to wait very long for healthcare, and have to be lucky to find a provider that is accessible to them. These cases show that my interviewees' ideas of bad healthcare match with Mol's logic of care. Trans people feel worst when they are neglected, and not necessarily when they do not have freedom to choose.

---

[74] The Randstad is a collection of cities in the Netherlands, with a high concentration of facilities. Trans people are more likely to find care and community there.

[75] Kwartiermaker Transgenderzorg, "Overzicht Transgenderzorg in Nederland"; "Transgender Wegwijzer."

Attentiveness and specificity

To Mol, the way to organize good care is by being attentive and specific to the person being treated.[76] In this section I will show that the ideal sketched by my interviewees matches this idea of good care. People want to receive care that suits their personal situation, ideally given by someone with a medical background. They want the option to change their hormone therapy if they feel it does not fit their needs, and would like a professional to guide them in this. To the people I interviewed, this was preferable to being cared for by people from the trans community.

Interestingly, Charlie expressed this wish for guidance as well. Although they have had positive experiences with community care, and expressed they were grateful for the option, they would still prefer the opportunity to be treated by a medical professional:

> Charlie: Idealiter kan je door je huisarts gewoon doorverwezen worden naar het ziekenhuis (…) Die community care, wat natuurlijk ook iets heel intiems en speciaals is, ja, dat zou wel verloren gaan. Maar ik denk, als het systeem gewoon goed werkt, dan had het in de eerste instantie niet hoeven te gebeuren. Want die community care die is heel mooi, maar het is eigenlijk te gek voor woorden dat we gevaarlijke medicijnen aan elkaar moeten geven, waar je speelt met je lichaam, omdat je zelf geen zicht hebt op hoe je lichaam in elkaar zit. (…) Ik heb dan liever dat iedereen gewoon zonder risico's access heeft.
>
> Charlie: Ideally your GP can just refer you to the hospital easily. (…) The community care, which is of course something very intimate and special, yeah, that would be lost. But I think, if the system works well, this wouldn't have had to happen in the first place. Because the community care is very nice, but it's outrageous that we have to give dangerous medication to each other, where you're gambling with your body, because you have no insight in how your body works (…) I would prefer everyone to just have access without risks.

Charlie thus was aware of the risks they were taking when using informal hormones during their transition. The community care, although "lovely" at times, was a last resort to them. Charlie only made use of it because professional care was not available. This is a sentiment that was shared by more of my interviewees, and most used self-medication out of necessity.

Other interviewees also asked for professional guidance during their transition. They wanted help to determine what care was available and what would suit them best. An example is given by Aiden:

> Aiden: I don't know, maybe everyone should get a caseworker to help guide you through the process. You meet each other once every two weeks (…) I think having that holding hand maybe for young people, not gatekeeping, just… like a librarian, I suppose. A librarian slash therapist.

---

[76] Mol, *The Logic of Care*, 85.

This librarian/therapist combines the ideas of attentiveness and specificity in trans healthcare. This caseworker would be up to date on the specific situation of their patient, make time for them, and be available for any questions. This setup is a good example of Mol's idea of 'doctoring together' that is applied in a logic of care context. This concept describes the process of finding a suitable treatment, and involves active participation from both doctor and patient. Instead of finding the right choice to make, the goal is to balance the lifestyle and material circumstances of the patient to create a tailor-made treatment for them.[77]

This option to customize care is one that is appreciated by my interviewees. Eva, for example, would prefer to be able to experiment with different treatments, to find out what fit her best. This included the option to try out hormones for a while, and stopping if she did not like them:

> Eva: Ik denk ook weer van, is het heel erg als mensen het gewoon even proberen en daarna denken: het is niet voor mij? Misschien ermee stoppen, dat is geen enorme ramp, als je natuurlijk geen vergaande dingen zoals operaties hebt gehad.
>
> Eva: I also think like, is it so bad if people just try it for a while and then think: it's not for me? Maybe stop using them, that's not such a big deal, if you haven't done anything huge, like operations.

The idea of trying out hormones and possibly stopping again is not often considered in the conventional healthcare system.[78] As we will see later on in this chapter, the Dutch system is organized in such a way that trans people have to be sure of what they want before starting hormone therapy. This means there is no room for experimenting with hormones. Nevertheless, the idea not worth considering, and fits well with the 'doctoring together' idea.

Knowledge

To achieve the high level of professional support described above, doctors need to be more knowledgeable about trans topics than many are today. This is something that has been suggested by earlier research, and is expressed by my interviewees as well.[79]

A big point of improvement is the knowledge of GPs. They are often the first point of contact is people have questions about their gender identity, but many trans people are hesitant to approach them. Like Charlie mentioned in chapter 1, this can be because GPs

---

[77] Mol, 65.

[78] A radical defence of experimenting with hormones can be read in: Laboria Cuboniks, *The Xenofeminist Manifesto: A Politics for Alienation* (Verso Books, 2018).

[79] McPhail, Rountree-James, and Whetter, "Addressing Gaps in Physician Knowledge Regarding Transgender Health and Healthcare through Medical Education"; Das et al., "Mijn Gender Wiens zorg."

might not be used to treating trans people, and do not know what steps to take when they come in with questions. Denise noted another improvement for GPs as well:

> Denise: Ja, dan denk ik dat er een grote rol ligt voor huisartsen. Mijn vrouw heeft diabetes type twee, en als je ziet hoe huisartsen daarmee omgaan en dat je daarvoor niet naar het ziekenhuis toe hoeft, en als je dan weet hoe eenvoudig hormoontherapie eigenlijk is, dan zouden eigenlijk gewoon alle huisartsen op de hoogte moeten zijn van hoe ze hormoontherapie kunnen voorschrijven
>
> Denise: I think GPs have a big role to play. My wife has type two diabetes, and when you see how GPs deal with that, that you don't have to go to the hospital for it, and if you know how easy hormone therapy actually is, then I think all GPs should be informed about how they can prescribe hormone therapy.

Here, Denise is asking for GPs to be able to administer hormone therapy themselves. Currently, Dutch GPs are not allowed to do this. GPs generally are a first point of contact, but are recommended to refer trans people to an expert for diagnosis and hormone treatment.[80] However, Denise is not the only one who would like GPs to provide hormone therapy. It has been recommended by activists, and in a recent survey 83% of trans people said they found this role important or very important.[81] Thus, allowing GPs to start hormone treatment, and teaching them how to do so safely, might improve trans people's experience.

Next to GPs, more knowledge is needed in psychological trans care. Charlie mentioned being skeptical towards their gender psychologist, as they might not know enough about the topic to be able to help them. Here, Charlie refers to a newsletter they had received from GenderHealthcare, which had just been set up when they were on the waiting list there.

> Charlie: Ik kreeg een nieuwsbrief met de mensen die daar dan werkten. Dat je denkt: ja, jullie hebben geen idee wat de transzorg is, dat is helemaal niet jouw specialisme weet je wel Ik kan me voorstellen dat het moeilijk is om veel gekwalificeerde werknemers te vinden voor een nieuwe organisatie, maar als trans persoon is het fijn om duidelijk te weten dat je hulp krijgt van mensen die weten waar ze het over hebben. Misschien heb ik ook wel te veel vooroordelen, maar bij vorige therapeuten bleek vaak dat ik hun bijvoorbeeld moest uitleggen wat non-binair nou precies betekende, terwijl zij dan zogezegd gender en seksualiteit als een van hun expertises hadden. Het is niet zo gemakkelijk als het denken van "Ik heb veel lhbt mensen om me heen, daarom kom ik nu werken bij deze instelling", dat je denkt, ja, sorry ja, *what are you gonna do*? en je moet natuurlijk ergens beginnen, maar…

---

[80] "Kwaliteitsstandaard Transgenderzorg Somatisch - Richtlijn - Richtlijnendatabase," Richtlijnendatabase, 2018, 44, https://richtlijnendatabase.nl/richtlijn/kwaliteitsstandaard_transgenderzorg/startpagina_-_transgenderzorg.html.

[81] Principle 17, "Trans* Zorg Anders," September 2022, 55; Zorgvuldig Advies, "Ervaringen En Behoeften van Transgender Personen in de Zorg," 33.

> Charlie: I got a newsletter with the people working there. I thought, yeah, you have no idea what trans healthcare is like, it's not your specialty at all, you know. I can imagine it is difficult to find enough qualified employees for a new organization, but as a trans person it's nice to know for sure that you get help from people who know what they're talking about. Maybe I'm too prejudiced, but with previous therapists I'd had to explain to them what being non-binary means exactly, while they said to be specialized in gender and sexuality. It's not as easy as thinking "I've got a lot of lgbt people around me, that's why I'm working at this institution", makes you go, yeah, sorry, but *what are you gonna do?* And of course you have to start somewhere, but…

This example shows that Charlie has a background of observing a lack of expertise in their psychologists. They were hesitant to trust these psychologists because the latter did not have relevant experience in trans healthcare.[82] Thus, having special trainings available for psychologists as well as GPs might help to increase their knowledge on these topics.

The experiences described above largely match those reported in earlier research. The 'Mijn Gender Wiens Zorg' report, which has been referenced before, is the most suitable to compare to my work. The trans people that were interviewed for this report also noted that they disliked the long waiting times and the lack of support while waiting. Like my interviewees, they would like to receive care matched to their specific situations, and more knowledge on trans issues among healthcare providers.[83]

Formal care

Altogether, the examples in the previous section show that in an ideal situation, trans people often look for relatively formal care. Most would appreciate guidance from a professional during their transition. This idea is not only an abstract wish, but already put into practice. In chapter 2, I showed that many people used conventional medication, and reached for scientific sources for information, if they could find those. Furthermore, all my interviewees had tried to access conventional care before starting self-medication. Everyone had put themselves on a waiting list first, and at the time of their interviews, they were all under medical supervision. Many remarked that they felt like they were in good hands once they were able to get into the system.

These experiences suggest that the formal healthcare system can be adapted in such a way that trans people feel comfortable making use of it again. The practice of self-medication is not a rebellious act of a group that has lost faith in modern medicine, but rather a result of the inaccessibility of the system. The problem is summarized nicely in the following observation, made by Charlie: "The hospital might not work against you so much, it's rather

---

[82] Note that this does not match Charlie's actual experience with the care they received in the Maasstad hospital. They were happy about the endocrinological care they received, and so were many other people. See: Zorgvuldig Advies, "Ervaringen En Behoeften van Transgender Personen in de Zorg," 37–49.

[83] Das et al., "Mijn Gender Wiens zorg," 42.

the whole system before that."[84] In the next section I will explore what this system is, and which aspects of it might give people the feeling that it works against them.

Diagnosis

My interviews suggest that the main concept that interferes with the process of receiving healthcare is diagnosis. Diagnosis of gender dysphoria has been a topic of debate amongst trans people for a long time. Although many reject the pathologization that a diagnosis entails, they do recognize its use in navigating the healthcare system.[85] In this section, I argue that diagnosis embeds trans healthcare in the logic of choice. Diagnosis is antithetical to trans peoples' wish for care as described in the previous section. The focus on diagnosis prolongs the process of getting access to hormone therapy and further alienates trans healthcare. In addition to this, getting diagnosed was also simply a bad experience for the people I have interviewed.

A useful characterization of diagnosis was given by Charles Rosenberg. His article "The Tyranny of Diagnosis", describes how diagnoses have become central to our modern medical practice, as it became "increasingly technical, specialized, and bureaucratized".[86] Rosenberg argues that diagnosis has become a bureaucratic tool to legitimize physicians' authority over disease treatment. As a result, a diagnosis now provides a starting point for a predetermined treatment path that a patient can smoothly follow within the structures of the hospital.[87]

I would like to argue that Rosenberg's characterization of diagnosis is relevant in the case of gender incongruence as well. In the case of trans healthcare, the gender incongruence diagnosis at its worst fulfils exactly the role Rosenberg describes. Instead of a way to establish whether a patient has a certain conditions, it has become a bureaucratic necessity that enables patients to be treated in the medical system. Diagnosis has been so embedded within the hospital structure, that doctors use it even when they are not convinced of its inherent benefit. Camiel Welling, the doctor working for the Trans United clinic, gave an example of that:

> Welling: wij gebruiken bijvoorbeeld wel diagnostische codes zoals de ICD 11 code en de DSM code. Dat is dan niet omdat wij geloven in het ziekte model, maar gewoon omdat we weten dat zonder die codes vervolgstappen bij verzekering en andere zorgverleners complex zijn. Je

---

[84] "Het ziekenhuis werkt misschien niet zo tegen je, het is meer het hele systeem ervoor"

[85] Mary C. Burke, "Resisting Pathology: GID and the Contested Terrain of Diagnosis in the Transgender Rights Movement," in *Sociology of Diagnosis*, vol. 12, Advances in Medical Sociology (Bingley, UK: Emerald, 2011), 183–210; Johnson, "Rejecting, Reframing, and Reintroducing."

[86] Charles E. Rosenberg, "The Tyranny of Diagnosis: Specific Entities and Individual Experience," *The Milbank Quarterly* 80, no. 2 (2002): 237, https://doi.org/10.1111/1468-0009.t01-1-00003.

[87] Rosenberg, "The Tyranny of Diagnosis."

> doet een persoon geen dienst door het niet te labelen volgens een systeem waardoor ze toegang krijgt tot de rest van het systeem. Dus dat is de uitdaging die we soms hebben.
>
> Welling: We do use the diagnostic codes such as the ICD 11 code and the DSM code, for example. That's not because we believe in the disease model, but just because we know that without these codes the next steps at the health insurance and other healthcare providers are complex. You don't do someone a favor by not labeling it according to a system, which gives them access to the rest of the system. So that's a challenge we have sometimes.

Here, Welling explains that he has to diagnose patients to be able to treat them well.[88] He recognizes the importance of a diagnosis to move forward in the system, even though he does not 'believe in the disease model' that he is required to use. As the Trans United clinic uses a different treatment model than most, Welling's views on diagnosis might seem like an exception. However, my interviews show that more mainstream gender psychologists have similar objections to diagnosis.

A good example of these objections was given by Fien. She was diagnosed at a recognized gender psychologist while already using hormones informally. The psychologist trusted her to know whether she wanted to continue, and did not see the added value of a diagnostic process for Fien:

> Fien: Ze zegt ook: ja, eigenlijk heb ik niet de capaciteit om iedereen echt individueel te begeleiden, maar als jij zegt wat je wilt, dan ga ik dat proberen te regelen en dan verwoord ik dat misschien op een andere manier naar de zorgverzekeraar toe, maar dan krijg ik het tenminste voor elkaar.
>
> Fien: She says: I might not have the capacity to supervise everyone individually, but if you say what you want, then I'll try to arrange it, and maybe I'll phrase it differently for the health insurer but at least I'll make it work.

The 'different phrasing' Fien mentions here means that her psychologist tells the health insurer that she has gender dysphoria, although the recommended diagnostic process has not been followed. Instead, the psychologist chooses to use her professional position to 'make it work', and get Fien her medication.

These two examples show that Rosenberg's description of diagnosis is accurate in this case: doctors use diagnosis to work with the system and to help their patients, even though they are not fully convinced of its intrinsic use. Diagnosis has become so embedded in our

---

[88] People are made into patients by means of their diagnosis as well. Diagnosis increases medicalisation, see for example:
Peter Conrad, *The Medicalization of Society: On the Transformation of Human Conditions into Treatable Disorders*, 1 online resource (xiv, 204 pages) vols. (Baltimore: Johns Hopkins University Press, 2007), http://site.ebrary.com/id/10256349.

healthcare system that it is difficult to escape. This results in doctors and patients inadvertently maintaining a system they do not support.[89]

Patients

The focus on diagnosis is not helpful to trans people themselves either. As we saw in the previous section, trans people want to access good formal care, but diagnosis could work against that. During my interviews, people said they had experienced the psychological evaluation prior to diagnosis as tedious and unhelpful. The necessary conversations with a psychologist did not give people more perspective on their desired transition path, but were seen as a formality:

> Benthe: Ik merkte dat mijn gesprekken met mijn psychologen eigenlijk een soort van opvulling waren meestal, omdat er zes gesprekken moesten plaatsvinden en er moest een gesprek plaatsvinden met een ouder erbij en ik moest mijn levensverhaal typen en zo, terwijl eigenlijk vanaf het begin al duidelijk was voor mezelf en voor de psychologen dat ik die diagnose zou krijgen.
>
> Benthe: I noticed that my conversations with my psychologists were a kind of filler, usually, because we had to have six conversations, we had to do a conversation with a parent present and I had to type my whole life story and stuff, while from the beginning it was clear for both me and the psychologists that I would get the diagnosis.

In this case it is clear that this diagnostic process does not add anything to the care delivered to the patient. The diagnosis does not help the doctors determine whether the patient needs care, nor does it encourage the patient to think about their needs. Instead, the process takes up time and resources to get people into the system. For some people, the experience was not merely useless but also unpleasant. They had the feeling they had to prove themselves to their doctor, while they already were sure of what they wanted:

> Charlie: Het kost hartstikke veel tijd. Het is al een hele stap om je überhaupt aan te melden. Je gaat het niet voor je lol doen, weet je wel, mensen die trans zijn weten dat ze trans zijn. (…) Ik ben hier en nu al acht of negen jaar mee bezig, dat ik denk ik heb ook geen therapie meer nodig. Ik weet gewoon wat ik wil.
>
> Charlie: It takes an extremely long time. It’s a big step already to register in the first place. You don’t just do that for fun, you know, people who are trans know they are trans. (…) I’ve been thinking about this for eight or nine years by now, I’m like: I don’t need therapy anymore. I just know what I want.

Both these quotes show that diagnosis does not serve its purpose from the perspective of trans people. Ideally, the diagnosis serves as a confirmation that the patient is in need of gender confirming care, and the conversations beforehand clarify which type of care that

---

[89] This also further increases the medicalization of trans people, something most of them reject. See: Johnson, “Rejecting, Reframing, and Reintroducing.”

would be. However, patients experience having to convince their psychologist of something they already know. If they are already sure of what they want, the diagnosis only slows them down, without adding any value for them.

When people are not sure of what they want yet, the diagnostic process can even become actively harmful. While Charlie and Benthe were already fairly certain of their wishes, other interviewees did appreciate some time to go over the treatment options. In these cases, the diagnostic process can have adverse effects. Because diagnosis is mandatory for receiving care, people feel a lot of pressure to prove to their psychologists that they deserve to be treated. They are acutely aware of the weight that diagnosis holds, and were afraid of saying the wrong thing and forfeiting their access to care, especially after waiting for so long. Because of this, they did not dare to express their doubts.

> Eva: Ik wist zeker dat ik het wilde, maar ik durfde geen enkele twijfel te bespreken daar, omdat ik gewoon dacht van, ik wil dit, ik wil het zo snel mogelijk en alles wat ik misschien zeg, kan eraan bijdragen dat het langer duurt of dat ik het misschien niet eens krijg of zo. Dus daar was ik wel bang voor. (…) Ik heb op een bepaald moment een uitbarsting gekregen dat ik opeens gewoon moest huilen, dat ik al die twijfels heb besproken toen. Toen hebben ze me ook verteld dat dat echt niet de bedoeling is, en dat ze gewoon willen dat je eerlijk bent. Dat heeft toen wel veel verbeterd, maar je hebt alsnog wel het gevoel dat je echt beoordeeld wordt en dat je jezelf moet bewijzen.
>
> Eva: I was sure that I wanted it, but I did not dare to discuss any doubts there, because I just thought like: I want this, I want it as quickly as possible and everything I might say could contribute to it taking longer, or maybe not even getting it at all. So I was scared of that. (…) At one point I got an outburst, I just started to cry out of nowhere, and I discussed all my doubts then. They did tell me that that's not the intention at all, that they just want you to be honest. That did improve things a lot, but you still have the feeling that you're really being judged and that you have to prove yourself.

Here, diagnosis clearly defeats its purpose. Because Eva felt like expressing doubts would limit her access to care, she did not feel comfortable being honest. The crucial status diagnosis has, means that it cannot fulfil its purpose of determining who deserves access to trans healthcare.

I claim that this focus on diagnosis further embeds trans healthcare in the logic of choice. It makes gender dysphoria an independent disease entity that can be identified at a single point in time. The goal becomes determining whether a patient has a disorder that needs to be treated, instead of caring for a person. When diagnosing patients, it is assumed that there is a distinction to be made between people who are really transgender and thus deserve care to alleviate their dysphoria, and those that no not.[90] This hard border does not match

---

[90] These ideas are also situated in 'wrong body' and 'born this way' discourses, which further support the necessity of diagnosis. See for example:

the experience of trans people, who often prefer to have the option to explore their gender identity without being forced into a diagnostic process.[91] Thus, diagnosis and the logic of choice seem to prohibit people from getting what they are actually looking for: quality care.

Alternatives

This begs the question of whether there are alternatives. Can we step out of the logic of choice paradigm, and move into something more closely resembling the logic of care? Is there a way to give people access to quality care that is specific to their situation? Can we avoid lengthy waiting times, and the ensuing neglect? Can people be allowed the space to explore their gender identities and transition goals more freely? Can we not just try to cure patients, but focus on caring for people instead? And is there a way to do all of this without relying on a mandatory diagnosis?

Fortunately, it seems like there is such an alternative. Using the methods of shared decision-making and informed consent, most of these demands can be met. These methods are an alternative to using diagnosis as described above. With this approach, patients and doctors determine together what type of care is suitable for them. The doctor informs the patient of what transition paths are possible, and what the results of different options are. Together with the patient, a fitting care plan is established, which can be modified as time goes on and circumstances or wishes change.

This method has been advocated for from different directions. Several activist groups and other studies that I have referenced before, suggest informed consent as a useful alternative to mandatory diagnosis. The TransZorgNu activists want no diagnosis and complete self-determination to obtain "control over our own care and our own bodies".[92] Principle 17, and activist alliance who published a report with an alternative vision for trans healthcare, wants trans healthcare to be non-pathologized, and presumes that trans people can determine for themselves whether transition is right for them.[93] The study done by patient organization Transvisie recommends more research into informed consent as it is already practiced in the US, Canada and the UK.[94] Although some of the phrasing used in these statements match the logic of choice, I argue that informed consent and shared-decision making are worthwhile alternatives to diagnosis, situated in the logic of care.

Ulrica Engdahl, "Wrong Body," *TSQ: Transgender Studies Quarterly* 1, no. 1–2 (May 1, 2014): 267–69, https://doi.org/10.1215/23289252-2400226; Sahar Sadjadi, "Deep in the Brain: Identity and Authenticity in Pediatric Gender Transition," *Cultural Anthropology* 34, no. 1 (February 22, 2019): 103–29, https://doi.org/10.14506/ca34.1.10.

[91] Das et al., "Mijn Gender Wiens zorg," 9.

[92] TRANSZORGNU, "Statement (English)."

[93] Principle 17, "Trans* Zorg Anders," 50.

[94] Boom, van den, "Onderzoek Transgenderzorg Nederland," 38.

To explore the consequences of informed consent, I will use the Trans United clinic as a case study. Because this clinic is not covered by insurance, and therefore not bound by the strict regulations regarding diagnosis, their employees are able to use a shared decision-making approach. This means their conception of diagnosis is very different than the one described so far. The clinic's doctor, Camiel Welling, says:

> Welling: Er is geen enkele identiteit die je met een diagnose volgens vakjes vast kan leggen. Dus je kan zeggen van: ja, we moeten wel echt een diagnose en klachten hebben, maar uiteindelijk gaat het om zorg die past bij Iemands genderidentiteit.
>
> Welling: There's not a single identity that can be diagnosed by ticking boxes. We can say we need a diagnosis and certain complaints, but ultimately it's about providing care that suits someone's gender identity.

In this quote, there is a clear focus on providing care in line with someone's wishes, instead of relying on diagnosis to decide what is the right approach. Welling rejects gender dysphoria as a disease category, and instead sees transness as an identity, which demands a different type of treatment.

In shared decision-making, the role of a doctor changes from manager to collaborator. This is in line with Mol's idea of 'doctoring together' which is a key concept in the logic of care.[95] As implied by the name, determining the right type of treatment is a cooperative process, where doctor and patient continuously work together to find care that suits their specific situations. This is in contrast to other clinics, which often have to follow set protocols:

> Welling: Één van de endocrinologen van het VU geeft wel eens aan van dat ie eigenlijk jaloers is, dat wij door minder hoepels hoeven te springen en echt meer kunnen kijken wat bij de persoon past, en ook meer op basis van ervaringen, in plaats van hele lange onderzoeken, kunnen zeggen van oh, ja, deze, deze weloverwogen stap kunnen we samen maken.
>
> Welling: One of the VU endocrinologists sometimes mentions that he's a bit jealous that we have to jump through fewer hoops, and can also look more carefully at what suits a person, based on experiences instead of lengthy examinations, and can say: yes, this deliberate step is one we can take together.

This attention to specifics is facilitated by the shared-decision making process. Tailored care can be provided with the specific patient's situation and wishes in mind. As we saw in the previous section, trans people appreciate this attention to detail, and the option to tailor care to their personal situation.

This specific care is only possible if true attention is paid to a patient. Because the Trans United Clinic is a social space as well as a healthcare provider, it is possible to get to know patients more personally, and to observe how they develop over time. This focus on process

---

[95] Mol, *The Logic of Care*, 65.

instead of fixed points is important in the logic of care, and it is clearly present in the method used by the clinic. In another interview, Welling said the following:

> Welling: Er zijn zoveel momenten van transitie waar je juist heel positief naar kan kijken, en waardoor je je transitie iets heel bijzonders en waardevols kan maken, en dat wordt heel vaak in de reguliere zorg vergeten. Het gaat echt om dat einddoel, en tot die tijd ben je niet goed, pas je er niet bij. Ik merk wel dat het zo leuk is om mensen te zien bloeien en enthousiast te worden over het proces in plaats van het einddoel.
>
> Welling: There are so many moments in transition that you can look at very positively, and which make your transition something special and valuable, and that is often forgotten about in regular healthcare. It's really about the end goal, and until you reach that you're not right, you don't fit in. I notice that it is a lot of fun to see people blossom and to be enthusiastic about the process, instead of the end goal.[96]

This approach recognizes that transition is a positive experience for many trans people. It reframes transition as a process of self-expression, instead of a cure to dysphoria. Many trans people already experience it as such, but as Welling says, this is not often acknowledged in trans healthcare. The TransZorgNu activists, for example, have also noticed this misinterpretation.[97] Appreciating that transition is something worth celebrating might bring healthcare more in line with how trans people see the process themselves.

The shared decision-making process, at least as it is used in the Trans United clinic, is not suitable for all trans people. Although is helpful for people who are already reasonably sure they want to transition, people with more questions or doubts might benefit from conversations with a psychologist instead. As with all mayor decisions, children and adolescents might also need more guidance when arranging their transition. According to Welling, however, shared decision-making could be the standard approach for adults over approximately 25 years of age, unless they request otherwise. According to the Transvisie report, over half of trans people are over 25 when starting their transition.[98] This means a significant amount of trans people might benefit from shared decision-making.

If some of those suited to informed-consent would use the system, this could also improve conditions for other trans people. Everyone over twenty-five who is confident about their transition plans could be taken off the waiting lists for diagnostic care. This drastically decreases the waiting times for everyone who does appreciate psychological guidance. Overall, offering an informed consent approach can thus reduce waiting times for all trans people, even those who elect not to use it.

— — —

---

[96] "Trans United Clinic – Trans United Europe." 8:33-9:02

[97] TRANSZORGNU, "Statement and Demands Trans Zorg Nu Nijmegen," August 7, 2022, https://transzorgnu.noblogs.org/post/2022/08/07/statement-and-demands-trans-zorg-nu-nijmegen/.

[98] Boom, van den, "Onderzoek Transgenderzorg Nederland," 11.

In this chapter I have argued that there is a mismatch between trans healthcare and the wishes of trans people. Trans people mostly want to be cared for, ideally by a professional who can help them determine the transition path that is right for them. However, the focus on diagnosis in conventional healthcare ensures that there is no room for exploration. People feel uncomfortable expressing doubts about their gender identity, out of fear that they might lose access to healthcare. Therefore, this model is not suited to delivering quality care.

Instead, it might be interesting to explore if a shared decision-making model can be more widely adopted in conventional healthcare. This model changes the framing of trans healthcare: instead of offering a cure for gender dysphoria, the goal is to care for trans people in a way that is right for them. Shared decision-making is better suited to the type of care trans people have called for. In addition, shared decision-making has the potential to reduce waiting times in trans healthcare, and thus addresses the biggest hurdle people experience.[99]

At a broader level, this chapters shows that the opinions of trans people are worth listening to when solving problems in healthcare. Lived experiences can be incorporated alongside theoretical knowledge to improve trans healthcare policy. This also ensures that the services are more in line with what trans people actually want: good care.

---

[99] Boom, van den, 2.

Conclusion

In this thesis, I have shown some of the practices of informal hormone use in the Netherlands. By incorporating interviews with trans people, I have been able to include their perspective to self-medication. Using this approach has allowed me to reveal some of the varied ways trans people shape their transition. Using a combination of formal and informal care practices, my interviewees have constructed their own transition path in a way that suits them. I hope this thesis has been able to illustrate what DIY transition can look like, and how ingenuity, care and community come together to create it.

In Chapter 1, I followed Charlie's transition path and their experiences with informal hormone use. Throughout their transition, Charlie has relied on the trans community to care for them. This care ranged from friends helping them to acquire hormones to an organisation teaching them how to inject testosterone safely. Although organizing their own transition was far from easy, Charlie also had some positive experiences along the way, mainly because of this community care. However, Charlie would ideally have had easier access to conventional healthcare, so they would not have had to go to their friends for medical advice. Ultimately, Charlie used informal healthcare mostly because there was no alternative available to them.

The importance of the trans community is shown again in chapter 2, where I gave an outline of informal networks that have been set up to spread information about self-medication. Both online and offline, people find each other to share their experiences. Although people are aware that these experiences are different from conventional medical advice, they are cautiously trusted. This is mainly because the trans community is already well-developed outside of a medical context. Trans people are used to rely on each other, and are thus more likely to go to their peers for medical advice as well. Despite this appreciation of community, people do generally look for solid medical advice. My interviewees had done extensive research, and looked for scientific sources when they were available.

In chapter 3, I examined what the ideal trans healthcare system would look like to my interviewees. I further explored why trans people use self-medication, whilst most of them preferred formal care. I used Mol's framework of the logic of care to explain that there is a mismatch between what the Dutch healthcare system offers and what trans people actually want. The current system, with its protocols and diagnoses, leans too heavily on a logic of choice. This leaves no room for doctors to provide the care that trans people are looking for. Using a different approach, such as shared decision-making, could be an improvement on that front.

Throughout my research, it became clear that most of the experiences of my interviewees agreed with those expressed by other trans people. In earlier studies about experiences with trans healthcare, people said they wanted shorter waiting lists, more knowledge about trans issues among all healthcare providers, and more room for personalised care.[100] People would also like to see more trans people working in trans healthcare. In all these areas, the opinions of my interviewees agreed with those of a more general population. Thus, it seems that there is no fundamental mistrust of medical science at the basis of self-medication practices.

The main reason people do give for starting self-medication is one that has been mentioned in many other studies: necessity. The excessive waiting times for trans healthcare mean formal healthcare is not accessible to many trans people, and they resort to informal hormone use as an alternative. There is therefore a straightforward way to lower the rates of self-medication. If trans healthcare is made more accessible, it is likely that many people who use hormones informally will embrace formal healthcare instead.

I have also learned that the boundary between formal and informal care is not as distinct as I assumed when I started this project. Trans people do not always make a clear decision on whether to transition formally or informally. Instead, people mix and match methods and approaches, relying on their friends in one situation and on medical advice the next. By looking at both formal and informal methods, and everything in between, a more comprehensive understanding of trans care can be developed.

Further research

Further research in this area could include an analogous study with a more diverse sample of interviewees. Due to the small number of interviews and similarities between the participants, the conclusions drawn in this thesis are limited. A higher diversity in interviewees, across factors such as age, location, education, and income would be interesting to analyse. This could especially improve the understanding of trust in informal sources for medical information. The people I have interviewed were al relatively privileged, which might have increased their trust in medical institutions. Including

---

[100] Das et al., "Mijn Gender Wiens zorg," 42; Zorgvuldig Advies, "Ervaringen En Behoeften van Transgender Personen in de Zorg"; Boom, van den, "Onderzoek Transgenderzorg Nederland"; Lugt and Langman, "Wachttijden genderzorg"; Principle 17, "Trans* Zorg Anders."

experiences of marginalized groups could show different mechanisms and reasons for not using conventional medical care.

Another aspect that deserves closer attention is the way in which political orientation influences choices around self-medication. People with different political backgrounds might have different ideas about the role of official institutions and community in trans healthcare. Especially anarchists and other left-wing collectives would be interesting to study. Anarchists are by definition distrustful of institutions, and thus might express different opinions on how trans healthcare should be organised. Anarchist groups are also used to organise together in the face of systems they deem unjust. Thus, looking at their organisational structures might give us insight in how trans community care is organised on a practical level.

On a more theoretical level, it might be interesting to explore how the logics of care and choice relate to processes of medicalisation and demedicalisation of transness. Earlier research has shown that trans people engage with diagnosis and medicalisation strategically.[101] Whereas other patient groups are generally unified in their call for (de)medicalisation, trans people are more divided on this topic. It has been argued that the main divide is about the role of diagnosis in trans healthcare. Although most people resist pathologisation of transness diagnosis entails, some do recognise its use for legitimizing trans identity and accessing medical resources.[102] It could be investigated how the logic of care can be combined with these concerns about diagnosis, identity and medicalisation.

Recommendations

For activists, it is worth considering how the logic of care can be incorporated into their messaging. As I mentioned in chapter 3, many activist demands are rooted in the logic of choice. People advocate for complete self-determination and autonomy.[103] During my interviews I did see these values being expressed, but the wish for care was even stronger. Having the option to determine your own transition path is an attractive prospect, but it does ask a lot from people. Being fully informed about the options is a lot of work, and might not be feasible for everyone. Therefore, advocating for proper guidance from healthcare professionals is an alternative theme to address. This might also have more impact on health policy makers. Radical autonomy will be hard to incorporate into a bureaucratic healthcare system, but providing well-educated doctors should be feasible.

My recommendations to policy makers are similar to those proposed by earlier research. Most of all, it is worth considering informed consent as a serious alternative to diagnostic trans healthcare. As shown in chapter 3, offering a shared decision-making approach to

---

[101] Ana Patrícia Hilário, "Contestation, Instrumental Resistance and Strategic Conformation within the Diagnostic Process of Gender Dysphoria in Portugal," *Health* 21, no. 5 (September 1, 2017): 555–72, https://doi.org/10.1177/1363459317708826; Johnson, "Rejecting, Reframing, and Reintroducing."

[102] Burke, "Resisting Pathology."

[103] TRANSZORGNU, "Statement and Demands Trans Zorg Nu Nijmegen."

trans people can cut waiting times for everyone. This type of care would also better suit the wishes of trans people than the diagnostic system we have now.

At a broader level, I would advise to listen to trans people when they talk about trans health care. This includes listening to what is being said at protests, and taking those demands seriously. It involves looking at self-medication practices, and considering whether they could inform healthcare policy. It also means employing more trans people in healthcare professions. They will be more easily trusted by the people coming in for care, and might have good ideas for improvement. On all levels of policymaking, trans people have valuable knowledge to share on how care can be made better for them. By including them, trans healthcare and transition can be made more enjoyable for everyone.

Bibliography

Alliantie Transgenderzorg. “Kwaliteitsstandaard Transgenderzorg,” December 18, 2017.

Ashley, Florence, Colton M St. Amand, and G Nic Rider. “The Continuum of Informed Consent Models in Transgender Health.” *Family Practice* 38, no. 4 (July 28, 2021): 543–44. https://doi.org/10.1093/fampra/cmab047.

Bakker, Alex. *Transgender in Nederland: een buitengewone geschiedenis*. Amsterdam: Boom, 2018.

Boom, van den, E.M. “Onderzoek Transgenderzorg Nederland.” Transvisie, 2016. https://www.transvisie.nl/wp-content/uploads/2016/12/onderzoektransgenderzorgnederland.pdf.

Bos, Robin. “"What Are Your Pronouns?”: General Practitioners’ Open-Mindedness Mitigates a Knowledge Gap When Communicating with Transgender and Nonbinary People.” Utrecht University, 2022.

Brown, Patrick R., Andy Alaszewski, Trish Swift, and Andy Nordin. “Actions Speak Louder than Words: The Embodiment of Trust by Healthcare Professionals in Gynae-Oncology.” *Sociology of Health & Illness* 33, no. 2 (February 2011): 280–95. https://doi.org/10.1111/j.1467-9566.2010.01284.x.

Burke, Mary C. “Resisting Pathology: GID and the Contested Terrain of Diagnosis in the Transgender Rights Movement.” In *Sociology of Diagnosis*, 12:183–210. Advances in Medical Sociology. Bingley, UK: Emerald, 2011.

Calnan, Michael, and Rosemary Rowe. *Trust Matters in Health Care*. Maidenhead, UNITED KINGDOM: McGraw-Hill Education, 2008. http://ebookcentral.proquest.com/lib/uunl/detail.action?docID=369496.

Conrad, Peter. *The Medicalization of Society: On the Transformation of Human Conditions into Treatable Disorders*. 1 online resource (xiv, 204 pages) vols. Baltimore: Johns Hopkins University Press, 2007. http://site.ebrary.com/id/10256349.

Dame, Avery. “‘I’m Your Hero? Like Me?’: The Role of ‘Expert’ in the Trans Male Vlog.” *Journal of Language and Sexuality* 2, no. 1 (January 1, 2013): 40–69. https://doi.org/10.1075/jls.2.1.02dam.

Das, E., M. Wasservauer, C. Loopuijt, I. Plug, A. Uilhoorn, A. van der Vleuten, and C. Verhaak. “Mijn Gender Wiens zorg.” Onderzoeksraport. Radboud Universiteit, February 2023. https://www.ru.nl/onderzoeksekseengender/project-transgenderzorg/.

Drescher, Jack, Peggy Cohen-Kettenis, and Sam Winter. “Minding the Body: Situating Gender Identity Diagnoses in the ICD-11.” *International Review of Psychiatry* 24, no. 6 (December 1, 2012): 568–77. https://doi.org/10.3109/09540261.2012.741575.

Engdahl, Ulrica. “Wrong Body.” *TSQ: Transgender Studies Quarterly* 1, no. 1–2 (May 1, 2014): 267–69. https://doi.org/10.1215/23289252-2400226.

Epstein, Steven. *Impure Science: AIDS, Activism, and the Politics of Knowledge*. 1 online resource (xiii, 466 pages) vols. Medicine and Society. Berkeley: University of California Press, 1996.

https://search.ebscohost.com/login.aspx?direct=true&scope=site&db=nlebk&db=nlabk&AN=4620.

———. “Patient Groups and Health Movements.” In *The Handbook of Science and Technology Studies*, 499–539. Cambridge, UNITED STATES: MIT Press, 2007.

GenderGP Transgender Services. “GenderGP.Com.” Accessed June 20, 2023. https://www.gendergp.com.

Gill-Peterson, Jules. *Gender Underground: A Trans History of DIY*, Forthcoming.

Gilson, Lucy. “Trust and the Development of Health Care as a Social Institution.” *Social Science & Medicine* 56, no. 7 (April 1, 2003): 1453–68. https://doi.org/10.1016/S0277-9536(02)00142-9.

Haanskorf, Maja. “Ervaringsdeskundigen in de praktijk: ‘Vaak is een half woord genoeg om elkaar te begrijpen.’” *AS - Maandblad voor de activiteitensector* 38, no. 8 (August 1, 2017): 36–39. https://doi.org/10.1007/s41188-017-0095-4.

Heng, Audrey, Clare Heal, Jennifer Banks, and Robyn Preston. “Transgender Peoples’ Experiences and Perspectives about General Healthcare: A Systematic Review.” *International Journal of Transgenderism* 19, no. 4 (October 2, 2018): 359–78. https://doi.org/10.1080/15532739.2018.1502711.

Hilário, Ana Patrícia. “Contestation, Instrumental Resistance and Strategic Conformation within the Diagnostic Process of Gender Dysphoria in Portugal.” *Health* 21, no. 5 (September 1, 2017): 555–72. https://doi.org/10.1177/1363459317708826.

I Emailed My Doctor 133 Times: The Crisis In the British Healthcare System, 2022. https://www.youtube.com/watch?v=v1eWIshUzr8.

Joemmanbaks, Fayaaz, and Hanneke de Graaf. “Kiezen Voor Een ‘X’: Onderzoek Naar de Behoefte Aan Een Non-Binaire Geslachtsregistratie.” Rutgers Expertisecentrum Seksualiteit, April 30, 2023.

Johnson, Austin H. “Rejecting, Reframing, and Reintroducing: Trans People’s Strategic Engagement with the Medicalisation of Gender Dysphoria.” *Sociology of Health & Illness* 41, no. 3 (2019): 517–32. https://doi.org/10.1111/1467-9566.12829.

Kester, Marijn, and Olivier Lingbeek. “Herstel En Vertrouwen: Professionals, Ervaringswerkers En de Herstelvisie in de Nederlandse Geestelijke Gezondheidszorg.” *Beleid En Maatschappij* 45 (September 1, 2018): 246–67. https://doi.org/10.5553/BenM/138900692018045003002.

Kwartiermaker Transgenderzorg. “Overzicht Transgenderzorg in Nederland.” Accessed June 28, 2023. https://open.overheid.nl/documenten/ronl-1ba2426d6fb29898e3a0530575bfd927b6bf476c/pdf.

Laboria Cuboniks. *The Xenofeminist Manifesto: A Politics for Alienation*. Verso Books, 2018.

Lugt, Michiel, and Michiel Langman. “Wachttijden genderzorg,” December 16, 2021. https://transvisie.nl/wp-content/uploads/2021/12/rapport-wachttijden-genderzorg.pdf.

Maggic, Mary. “Housewives Making Drugs — Mary Maggic Official.” Accessed October 4, 2023. https://maggic.ooo/Housewives-Making-Drugs.

McPhail, Deborah, Marina Rountree-James, and Ian Whetter. “Addressing Gaps in Physician Knowledge Regarding Transgender Health and Healthcare through Medical Education.” *Canadian Medical Education Journal* 7, no. 2 (October 18, 2016): e70-78. https://doi.org/10.36834/cmej.36785.

Mepham, Nick, Walter P. Bouman, Jon Arcelus, Mark Hayter, and Kevan R. Wylie. "People with Gender Dysphoria Who Self-Prescribe Cross-Sex Hormones: Prevalence, Sources, and Side Effects Knowledge." *The Journal of Sexual Medicine* 11, no. 12 (December 2014): 2995–3001. https://doi.org/10.1111/jsm.12691.

Milionis, Charalampos, Ioannis Ilias, and Eftychia Koukkou. "Progesterone in Gender-Affirming Therapy of Trans Women." *World Journal of Biological Chemistry* 13, no. 3 (May 27, 2022): 66–71. https://doi.org/10.4331/wjbc.v13.i3.66.

Ministerie van Volksgezondheid, Welzijn en Sport. "Ontwikkelingen in de wachttijden, aantal wachtenden en capaciteit van transgenderzorg - Rapport - Rijksoverheid.nl." Rapport. Ministerie van Algemene Zaken, March 31, 2022. https://www.rijksoverheid.nl/documenten/publicaties/2022/03/31/ontwikkelingen-in-de-wachttijden-aantal-wachtenden-en-capaciteit-van-zorg.

Mol, Annemarie. *The Logic of Care: Health and the Problem of Patient Choice*. MyiLibrary. London ; Routledge, 2008. https://www.loc.gov/catdir/toc/ecip085/2007047374.html.

Nambiar, Kate, Nicolas Pinto-Sander, Julia Davis, Tamara Woodroffe, and Daniel Richardson. "Hormone Self-Medicating: A Concern for Transgender Sexual Health Services." *International Journal of STD & AIDS* 29, no. 7 (June 2018): 732–33. https://doi.org/10.1177/0956462418773213.

"Overnamekandidaat gevonden voor failliet Stepwork Transgenderzorg." Accessed June 29, 2023. https://www.cooperatievgz.nl/cooperatie-vgz/nieuws-en-media/nieuwsoverzicht/genderhealthcare-neemt-failliet-stepwork-transgenderzorg-over.

Pedersen, Inge Kryger, Vibeke Holm Hansen, and Kristina Grünenberg. "The Emergence of Trust in Clinics of Alternative Medicine." *Sociology of Health & Illness* 38, no. 1 (2016): 43–57. https://doi.org/10.1111/1467-9566.12338.

Principle 17. "Trans* Zorg Anders," September 2022.

Radin, Patricia. "'To Me, It's My Life': Medical Communication, Trust, and Activism in Cyberspace." *Social Science & Medicine*, Patient Organisation Movements, 62, no. 3 (February 1, 2006): 591–601. https://doi.org/10.1016/j.socscimed.2005.06.022.

Reddit. "R/TransDIY." Accessed December 15, 2022. https://www.reddit.com/r/TransDIY/.

Richtlijnendatabase. "Kwaliteitsstandaard Transgenderzorg Somatisch - Richtlijn - Richtlijnendatabase," 2018. https://richtlijnendatabase.nl/richtlijn/kwaliteitsstandaard_transgenderzorg/startpagina_-_transgenderzorg.html.

Rosenberg, Charles E. "The Tyranny of Diagnosis: Specific Entities and Individual Experience." *The Milbank Quarterly* 80, no. 2 (2002): 237–60. https://doi.org/10.1111/1468-0009.t01-1-00003.

Rotondi, Nooshin Khobzi, Greta R. Bauer, Kyle Scanlon, Matthias Kaay, Robb Travers, and Anna Travers. "Nonprescribed Hormone Use and Self-Performed Surgeries: 'Do-It-Yourself' Transitions in Transgender Communities in Ontario, Canada." *American Journal of Public Health* 103, no. 10 (October 2013): 1830–36. https://doi.org/10.2105/AJPH.2013.301348.

Sadjadi, Sahar. "Deep in the Brain: Identity and Authenticity in Pediatric Gender Transition." *Cultural Anthropology* 34, no. 1 (February 22, 2019): 103–29. https://doi.org/10.14506/ca34.1.10.

Sanchez, Nelson F., John P. Sanchez, and Ann Danoff. "Health Care Utilization, Barriers to Care, and Hormone Usage Among Male-to-Female Transgender Persons in New York City." *American Journal of Public Health* 99, no. 4 (April 2009): 713–19. https://doi.org/10.2105/AJPH.2007.132035.

Straten, G. F. M, R. D Friele, and P. P Groenewegen. "Public Trust in Dutch Health Care." *Social Science & Medicine* 55, no. 2 (July 1, 2002): 227–34. https://doi.org/10.1016/S0277-9536(01)00163-0.

"T-Huis – Amsterdam." Accessed July 21, 2023. https://t-huis.transunitedeurope.eu/.

"T-Nederland." Accessed October 9, 2023. https://t-nederland.nl/.

Trans Healthcare Network. "T-RREx: Trans Radical Resource Exchange," 2022. Personal collection of the author.

"Trans United Clinic – Trans United Europe." Accessed December 16, 2022. https://transunitedeurope.eu/?page_id=255.

"Transgender Wegwijzer." Accessed October 2, 2023. https://transgenderwegwijzer.nl/.

Transvisie. "Persbericht: Zorgen om de overname Stepwork door GHC." *Transvisie* (blog), November 5, 2021. https://transvisie.nl/persbericht-zorgen-om-de-overname-stepwork-door-ghc/.

———. "Update na eerdere berichtgeving over zorgaanbieder GenderHealthcare." *Transvisie* (blog), April 29, 2023. https://transvisie.nl/update-na-eerdere-berichtgeving-over-zorgaanbieder-genderhealthcare/.

TRANSZORGNU. "Statement and Demands Trans Zorg Nu Nijmegen," August 7, 2022. https://transzorgnu.noblogs.org/post/2022/08/07/statement-and-demands-trans-zorg-nu-nijmegen/.

———. "Statement En Eisen Trans Zorg Nu Nijmegen." Accessed October 3, 2022. https://transzorgnu.noblogs.org/post/2022/08/07/statement-en-eisen-trans-zorg-nu-nijmegen/.

———. "Statement (English)," June 8, 2021. https://transzorgnu.noblogs.org/post/2021/06/08/statement-english/.

Zorgvuldig Advies. "Ervaringen En Behoeften van Transgender Personen in de Zorg," November 2022. https://open.overheid.nl/documenten/ronl-b8614f82bc58342fdd4a40d396385004c86dcfc3/pdf.