



SURVEY

17

**Trans Health Care
in
The Netherlands**

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About Principle 17

Principle 17 (P17) is a Dutch activist collective that dedicates itself to customized transgender health care. Health care if you need it, when you need it, and how you need it. We named ourselves after Yogyakarta Principle 17, in which the highest attainable standard of care is described.

In 2006 human rights specialists, including two trans-activists, set up the international declaration of LGBTI human rights. These human rights are made up of existing declarations, such as the Universal Declaration of Human Rights by the United Nations (UN), and are specific to issues concerning gender identity and sexual orientation. This document is called the Yogyakarta Principles. These Principles concern issues such as the right to life, legal gender recognition, the right to non-discrimination in diverse circumstances, the right to recourse, the right to privacy, the right to good health, etc. Principle 17 specifies the right to the highest attainable standard of health:

“Everyone has the right to the highest attainable standard of physical and mental health, without discrimination on the basis of sexual orientation or gender identity. Sexual and reproductive health is a fundamental aspect of this right.”

Principle 18 concerns protection from medical abuses, it states:

“No person may be forced to undergo any form of medical or psychological treatment, procedure, testing, or be confined to a medical facility, based on sexual orientation or gender identity. Notwithstanding any classifications to the contrary, a person’s sexual orientation and gender identity are not, in and of themselves, medical conditions and are not to be treated, cured or suppressed.”

For many transgender health care recipients, these rights are (unfortunately) not a given. Not even in the Netherlands. P17 is convinced that trans people, medical professionals and politicians alike are too often uninformed about these human rights. This is the vantage point with which P17 was created and set out to do research to improve this.

Terminology



This report uses the gender neutral pronouns they/them when not referring to a specific male or female health care recipient.

Trans people: An umbrella term for people whose gender identity or expression does not coincide with what is expected of people with their sex marker at birth. This term includes a spectrum of gender diverse people, amongst whom transmen, transwomen, cross dressers and many others that do not (only) identify themselves as men or women.

Cisgender: An umbrella term for people whose gender identity or expression coincides with what is expected of people with their assigned sex at birth.

Gender Dysphoria: The deep emotional, mental and sometimes physical strain one can experience, being transgender. This is not necessarily the conventional definition.

Gender identity: The deep rooted intrinsic conviction that each human has of belonging to a certain gender. This can be male or female, both male and female, or neither male nor female. For trans people gender identity is incongruent with the gender assigned at birth.

Gender expression: Also known as gender role. The entirety of mannerism with which one gives form to their gender. This can be through voice, clothing, jewellery, haircut and so on.

Informed consent: The process that ensures that the health care recipient fully understands the contents of the procedure. It exists in two forms, of which the more detailed one is preferred.

Intersex people: People with sex markers that vary from the norm of male and female.

Transition: All aspects of the medical and/or social transition of trans people.

Transition care: All necessary care for a gender transition: psychosocial, legal, medical and/or social support.

Transgender health care: Health care offered to trans people in the context of their need to be satisfied with their gender identity and expression. This can include psychological and medical care and is certainly not always limited to a transition or gender reassignment surgery.

Standards of Care: The internationally recognized guidelines for transgender health care

Introduction



Research Motivation

In 2014 a private group was started on Facebook to make an inventory of all complaints and wrong assumptions by care providers in transgender health care in the Netherlands. There were so many reactions that this inventory quickly resulted in a poster presentation at the 2015 EPATH conference in Gent, Belgium and the website www.betterassumptions.nl. We found so many complaints about transgender health care providers that we, as Principle 17, decided to dedicate a formal research to it. The result is this report.

Problematic Treatment

This research by Principle 17 clearly indicates that care recipients have experienced many problems with received or available care. The complaints fall in line with results from previous research such as 'Becoming Who You Are' ('Worden wie je bent') from the SCP (2012), in which questions about care only made up a minor part of the research, as well as Patient's Association Transvisie (Patiëntenorganisatie Transvisie) research (July 2016) that limited their research to actual care recipients. Principle 17's research is unique in the fact that we additionally sought respondents that did not receive any care nor the care that they still wish to receive. Furthermore, we distinguish ourselves by focussing on the question of what respondents think the ideal Dutch transgender care should be like. Lastly, we do not limit ourselves to medical care but extend our research to the broader scale of required trans care.

Most Important Results

In this research, we signalled the following most important and most commonly reported positive and negative experiences with Dutch transgender health care and the following most important elements for an ideal transgender health care:

- An end to the long waiting lists;
- Agency, an end to psychiatric diagnosis;
- Informed consent as the basis for medical treatment.

Negatives:

- Very long waiting lists (before and during treatment);
- Deficient respect, amongst others being wrongfully named and gendered;
- Lack of knowledge and insight concerning non-binary genders.

Positives:

- Presence and compensation of (partial) health care;
- Support from independent health care providers.

Improve Health Care

In short, the dissatisfaction concerns very basic characteristics of the offered health care. We hope that the results from this research indicate that these can no longer be considered 'individual complaints', but that there is indeed a widely-shared feeling of (sometimes grave) discontent from many transgender care recipients. With this report, we are prepared to speak to the Dutch Center of Expertise on Gender Dysphoria of VU Medical Center (KZcG) and other care providers with the common goal of improvement of the current care and quality customized transgender health care. Health care if you need it, when you need it, and how you need it.

Terminology and Current State of Affairs

To understand the importance of this research, three aspects must be clarified:

1. The difference between the terms 'transgender' and 'gender dysphoria'.
2. The current health care regime concerning treatment of people with gender dysphoria.
3. The developments around legal sex change in the Netherlands.

Transgender versus Gender Dysphoria

Transgender and gender dysphoria are not synonymous terms. Gender dysphoria is defined as the deep emotional, mental and sometimes physical problems that one can experience from being transgender¹. A transgender person is someone whose physical sex and experienced gender identity do not entirely or entirely do not match. In short, transgender is the identity and gender dysphoria is the burden. The burden of gender dysphoria is moreover mostly caused by a society that is unable to deal with trans people, which leads to a lot of trans related discrimination.

Gender dysphoria (in older manuals, such as the International Statistical Classification of Diseases (ICD-10) and the Diagnostic Statistical Manual of Mental Health Disorders (DSM-IV), referred to as 'gender identity disorder') can usually be treated medically. How, depends on the person seeking help, being that not everyone has the same needs. Hence, the call for customised care for this group of care seekers². As you will read, this report shows that there is still much to be won.

Gender Teams

Those who wish to adjust their bodies to their perceived gender identity in the Netherlands, generally go to one of two locations under the KZcG: the VU University Medical Center (VUmc) in Amsterdam or the University Medical Center Groningen (UMCG) in

¹ This definition avoids the heinous question of whether gender dysphoria or being transgender is something one is born with. This question moreover assumes a cisgender-centric viewpoint that isolates trans people.

² We speak of health care recipients and health care providers because this exacerbates the autonomy of the care recipient, contrary to popular terms such as patient/clinician, which still holds the outdated stigma of the all-knowing clinician versus the layman/patient.

Groningen. Underage trans people can go to the VUmc in Amsterdam or the Leiden University Medical Center (LUMC) in Leiden, which supports Amsterdam. The UMCG does not treat teenagers or children. A growing number of trans people is choosing to take their own route, by approaching experienced therapists and surgeons outside the KZcG.

Treatment Protocol

The treatment protocol used by the KZcG still assumes a linear approach. The treatment always starts with an interrogative talk during which it is being decided whether the 'patient' is at the right desk. If the KZcG believes that gender problematics probably are at play, the care recipient is placed on an, often long, waiting list. Once their turn is up everyone receives -regardless of individual wishes or needs- a diagnostic process lasting a minimum of six months up to a few years. Throughout this process a psychologist or psychiatrist decides whether gender dysphoria truly is at play and if so, if the care recipient has sufficient capacity to endure the treatment. If the answer to both of these questions is yes, and no further complications arise (labelled 'comorbidity'³), the care recipient may proceed with the treatment for which they came. The medical treatment commences with hormone replacement therapy and at a later phase surgery on primary and (some) secondary sex markers. It includes:

- Facial laser hair removal for those who have a stubble and wish to be rid of it.
- Chest reconstructive surgery through breast removal (mastectomy) for those with breasts who wish to be rid of them.
- Breast reconstructive surgery through breast implants for those who don't have breasts and wish to have them.
- Uterus and ovary removal (hysterectomy) for those who have them and wish not to.
- Metoidioplasty or phalloplasty for those who wish to have a penis and scrotum.
- Vaginoplasty for those who wish to have a vagina.

Surgery to (other) secondary sex markers is not usually included in basic treatment protocol, but can often be granted upon request by a health care recipient. This includes:

- Facial reconstructive surgery for feminisation of appearance.
- Medical tattooing to cover up scars.
- Hip liposuction for manlier hips.

Furthermore, most of these latter surgeries, as with the breast reconstructive surgery, are not covered by basic health insurance as these are considered elective cosme-

³ The term comorbidity is strictly speaking incorrect, because it implies the existence of additional symptoms. Therefore it assumes that gender dysphoria or being trans is also a disorder or disease. This has been widely denied. Being trans is a form of gender diversity, just as homosexuality or bisexuality are forms of sexual diversity.

tic operations, even though the SOC-7 ⁴ classifies breast reconstructive surgery as necessary. The KZcG locations do not offer any psychotherapeutic or psychosocial guidance because this falls outside of their realm of tasks c.q. ability. This type of care can be received from specialized therapists such as Transvisie Care (Transvisie Zorg) or other offices from PsyQ, Psycho Informa Group (PIG) or De Vaart.

Legal sex change

Because a legal sex change without medical intervention was not possible until July 1st 2014, the assumption remains that all trans people aspire a medical transition. This requirement has been removed because it was a human rights violation to enforce sterilization. As if to say that a medical transition 'fixes' trans people. The new legal approach that no longer requires a gender dysphoria diagnosis, and thus does not require medical treatment, indicates that the ideas about the transgender phenomenon are changing. These days all you need is a statement from a specialized therapist, that confirms the person in question is mentally competent (as far as this topic goes, anyhow) and aware of the consequences of a legal sex change. Furthermore, Dutch law still only recognizes two genders ('M' and 'F'). A third option, as it exists in a few other countries, is not as of yet recognized under Dutch law.

The research: who and what



The research consisted of an online questionnaire that was dispersed throughout the Dutch trans-communities ⁵ and was available from April 7th to May 22nd 2016. This questionnaire consisted of demographic questions, scale survey questions and open-ended questions and was available in both Dutch and English. Respondents were recruited through a snowball sampling method: each respondent brought in the next. Social media was also a major tool in recruiting respondents as well as spreading flyers at get-togethers, to reach the less accessible groups. With its 241 respondents, the sample is sufficiently representative. The data was analysed with SPSS and meets all ethical requirements for psychological research as per the requirements of the ethics committee at the Psychology department of the University of Amsterdam (2016 SP 6449).

Although transgender health care exists for children, teenagers and adults alike in the Netherlands, Principle 17's research focusses entirely on the 18 and above cluster. This is due to approval from the aforementioned ethics committee along with the effect of including underage trans people would have on the nature of our questions.

In this research report we look at experiences that trans people have had in transgender health care, both positive and negative. We distinguish ourselves, certainly in the Netherlands, by asking not only those who have enjoyed trans health care, but specifically also those who considered this health care and -for whatever reason- did not receive it. Additionally, we explicitly asked what respondents considered to be the ideal transgender health care. We set no framework and thereby allowed them the full freedom to write about their utopic health care by means of open-ended questions. This was often seen as the other side of the coin: the current health care system needs significant change with more freedom and agency.

In the end all of this rendered 241 valid respondents of which the majority (98.4%) resides in the Netherlands. The rest lives in Germany, the UK and the USA. The largest portion of respondents consists of those who enjoyed health care (78.3%). 8.6% considered receiving health care and 13.1% did not consider receiving health care. Of those that considered receiving health care, a part actually went on to do so.

When examining the demographics, we can conclude the following: of the 241 respondents, 98 (41.16%) identify themselves as trans women, 80 respondents (33.6%) consider themselves trans men, 36 participants called themselves trans* (15.12%), 30 see themselves as women (12.6%) and 27 as men (11.3%). Also, 24 respondents (8.2%) consider themselves to be 'other', for example none, non-binary, intersex,

⁵ We use the plural form here to indicate the variety of communities of trans people. Trans people are a diverse group of people, who each gather in their own groups. We recognize that we were only able to reach some of these communities because we do not have contacts in all of them.

gender neutral, trigender; 15 are genderqueer (6.3%), 8 are gender non-conforming (3.36%), gender fluid (2.94%), agender (2.1%), 2 androgynous (0.84%) and 1 bigender (0.42%) (see diagram 1). It was possible to give multiple answers.

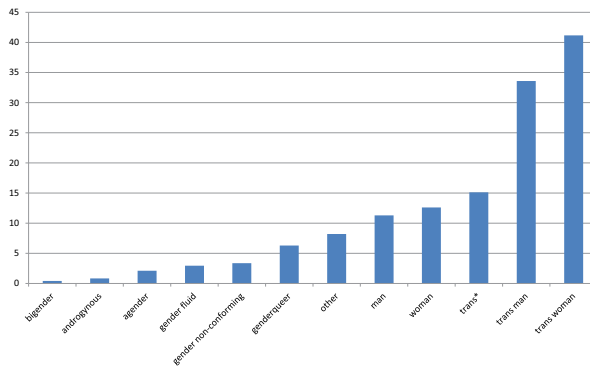


Diagram 1: Genderidentity

The participants were asked to indicate on a scale from 0 to 5, how out they are about their trans identity to different subpopulations. The respondents turned out to be most open to their friends (M = 4.57, SD = 0.94) and family (M = 4.56, SD = 1.01), and less so to colleagues (M = 3.89, SD = 1.56), fellow students (M = 3.60, SD = 1.71) and neighbours (M = 3.22, SD = 1.71).

Furthermore, they were asked how strong they experience their social network, on a scale from 0 (very weak) to 100 (very strong). The average (M = 67.77) suggests a reasonably strong support system, although the standard deviation indicates that this can vary between people (SD = 27.62). In other words, there are many trans people with strong bonds as well as many with weak bonds and everything in between. This demonstrates that in this area, everyone is represented.

When asked about relationship status 116 people (48.1%) disclosed not having an intimate relationship at the time of the survey. 77 participants are in a monogamous relationship (32%), 21 are in an open relationship (8.7%), 17 had sex dates (7.1%) and 8 had multiple relationships (3.3%). It was possible to give multiple answers.

In terms of income, it appears that a large group is dependent on social welfare (20.3%) or has no income at all (16.6%). Of the rest of the respondents 14.9% earn up to €15,000, 10.8% earn between €16,000 and €25,000, 17.4% earn between €26,000 and €50,000, 3.71% earn €51,000 or more and 3.3% is retired. 12.9% did not wish to disclose any financial information.

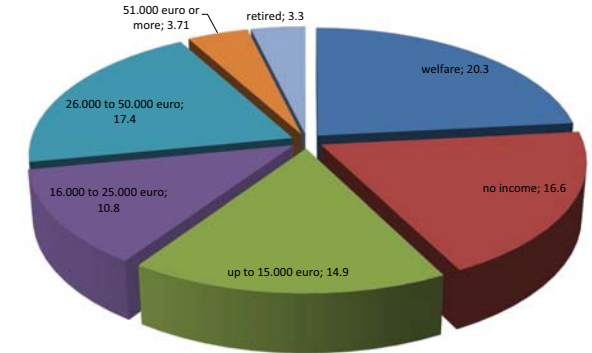


Diagram 2: Income

We also inquired about the highest completed education of the respondents. 2.9% did not complete any education, 2.9% completed elementary and middle school education, 32% completed high school, 18.3% completed vocational training, 14.5% received a bachelor's degree, 13.7% has a Master's degree and 2.1% has a Ph.D. 5.8% of the participants was educated otherwise, for instance by home schooling.

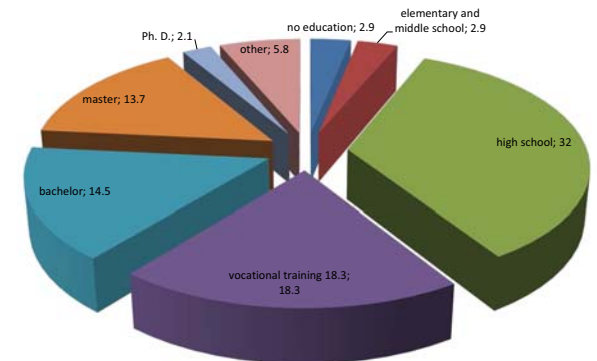


Diagram 3: Education

Health Care Experiences



In our open-ended questions, we asked specifically about positive and negative experiences in transgender health care: what went well? What were people satisfied about? Were there specific things they noticed? And on the other hand: what were the biggest problems they encountered? What were the road blocks? These questions were asked to both those who enjoyed (transition) health care and those who considered it. It is important to realize that good experiences can lead to greater satisfaction and greater compliance. Just as disappointments can lead to bad experiences, lower well-being, delay of treatment or seeking it elsewhere and in both cases with the accompanying consequences.

From our sample, 78.6% received health care, 8.3% considered health care and 13.1% has not sought nor received any health care (see diagram 4). 51.5% of the respondents received counselling or therapy, 56.8% received hormone therapy, 27.4% received facial hair removal treatment, 17.4% got breast surgery (implants or removal), 22% underwent genital surgery and 4.6% got facial reconstructive surgery (see diagram 5).

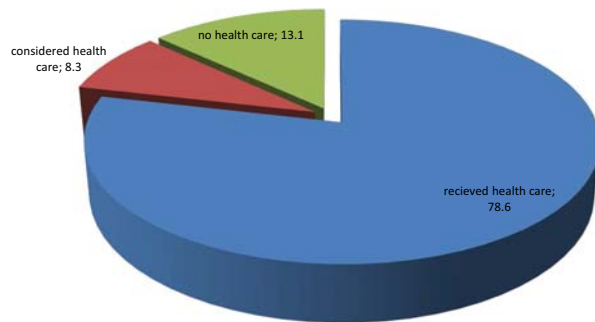


Diagram 4: Received health care

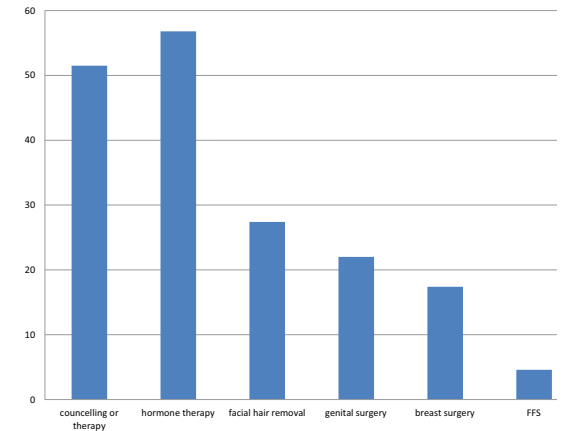


Diagram 5: Type of health care

Moreover, 14.1% of the respondents reported to have received other treatment such as uterus removal, cryopreservation of eggs, pubic hair laser removal as mandatory preparation for surgery, or attending support groups. The vast majority received their transgender health care at the VUmc (54.8%), 11.2% from their GP, 5.8% from the UMCG and 7.1% self-medicated. Furthermore, 32.4% has received care outside the KZcG at other institutions such as PIG, De Vaart or somewhere outside of the Netherlands (see diagram 6).

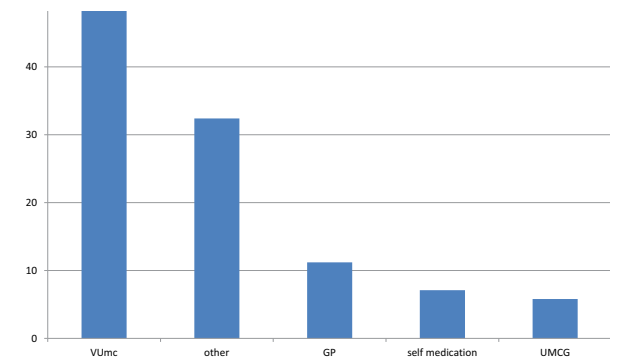


Diagram 6: Health care institutes

What Is Going Well?

When looking at the positive experiences that were mentioned, we can surely ascertain that there is much relief in having any transgender health care at all and that it is usually partially paid for. Additionally, many respondents (primarily those that considered care) mentioned how vital support from their GP and other independent practitioners had been. Some of the respondents are satisfied with the available help and its quality. This is particularly true for those who received this help over 10 years ago. Recent years have seen a growing critique due to both the worsening health care situation and an increasingly critical stance amongst care recipients. Satisfaction is experienced in more suitable health care such as from the PIG and Medical Center Slotervaart.

Many people utter objections about the one size fits all approach to transgender health care: one type of procedure that contains a fixed process, that is offered in a fixed order, which negates the option to an individual approach. Hereby, control over their own body is completely ignored.

If transgender health care were customized, it would be much easier to, for example, undergo facial feminisation surgery (FFS) without getting genital surgery, with or without hormone replacement therapy and not necessarily needing to decide that in advance. Despite improvements, this still remains the status quo.

The background to this rigid approach is linked to the old legislation that prevailed from 1985 to 2014. Under this law legal gender change was only possible after one had completed their sex reassignment surgery. The heteronormative mainstream mind frame loathed the possibility of manly mothers and feminine fathers. By opening the institute of marriage to same-sex couples in 2001, the legislative basis for the legal sex change law was deconstructed and the Ministry admitted it had been an omission not simultaneously adjusting this law (art. 1:28 BW). The future lies in solutions such as those in Argentina, Malta and Norway that do not make requirements of age, reason or even an 'expert' statement: whoever wishes to, can change their gender.

What can improve



There are separate waiting lists for the intake, diagnostic phase, the beginning of hormone therapy and for each operation. This is because each department has their own waiting list. Health care recipients are only put on the waiting list for the endocrinologist after the psychologist has discussed the specific health care recipient in the monthly team meeting, but there even seems to be a list for this.

When one is finally put on the waiting list, it seems one still has no clarity. After the waiting period has been determined it is often extended multiple times. This means that the original date can be shifted by weeks or even months. Various care recipients reported that people that were placed on a waiting list after them, were in fact helped sooner.

In the Netherlands waiting times are officially measured by a so-called standard ('Treeknorm')⁶. These refer to the agreements made between health care providers and health insurance companies about the maximum acceptable waiting periods per sector. Hospitals are additionally required to make their waiting period known for somatic procedures. The largest bottle neck in transgender health care occurs during the psychological diagnosis, which every care recipient must pass. No difference is made whether the care recipient has already gone through psychological diagnosis before or not: everybody starts at step one.

The absurdly long waiting lists also exist in other countries, and there too they are being scrutinized in research reports. Thus, an NHS clinic in London is receiving serious critique following their inspection due to overly long waiting lists. And Scottish research about the mental health of trans people points to problems with the long waiting lists. In New Zealand, the waiting time for surgery is a mere 20 years. Clinics working with informed consent have a much shorter waiting time (about six weeks⁷), such as in San Francisco.

Besides recognizing problems with the waiting lists before and during the medical process, Principle 17 is entirely in disagreement with the current model in which trans people must first endure a psychological diagnostic phase lasting an average of half a year, during which they are being checked on whether they are considered mentally stable enough to undergo transition. The concept that being trans or the usually accompanying suffering, is a mental disorder, is a knife in our backs. Currently, the DSM-5 as well as the ICD-10 still define it as a mental disorder but this is being partially revised.

Currently, 'transgender' is increasingly being considered a form of gender diversity

6 <http://www.vergelijken-zorgverzekering.net/treeknorm>

7 Personal communication with Dr. Dan Karasic M.D. (01-09-2016)

and no longer as a psychiatric identity disorder. All people have a gender identity. However, trans people often need to fight for the recognition of theirs because gender identity and sex are falsely seen as synonymous.

Western society has a unique perspective on gender identity by having only two genders. In many other cultures, a third gender is often culturally accepted. The KZcG, that present themselves as the expert about gender dysphoria in the Netherlands, has an important (exemplary) role in this.

Rigidity of Practitioners

Often, problems with the inflexibility of psychologists are brought up during semi-structured interviews. One care recipient mentioned in a conversation with their psychologist that their parents are not accepting of their transition. The psychologist insisted on speaking to the parents. This was not what the care recipient desired and it was only after denying the request over and over again that the psychologist let it go.

An example of the generally strict approach is that of care recipients that started the diagnostic phase elsewhere: they must start anew with the KZcG gender team. The consequences are thus that the subsequent waiting time and duration of the diagnosis will create a delay of at least a year. It is very frustrating to be set back, solely because the clinic refuses to assume the assessment of colleagues or even take it as a point of departure, even though in principle all transgender clinics globally use one and the same guideline (namely the Standards of Care). This should facilitate transfer and definitely not stagnate it. This is all aside from the fact that transgender health care becomes unnecessarily expensive by this procedure, due to the fact that they are knowingly repeating processes. Most people wait until they are at their wit's end before asking for health care, which makes this course of events quite burdensome. Foreign trans people suffer from this the most and as a migrant worker this can be even more tedious because these decisions have a direct effect on their personal well-being and their employability.

Those that opt for self-medication do so out of distress and because the clinics have a clear lack of capacity. The VUmc has recently decided to start checking blood levels but this bring along a new waiting list of three months for the intake. The clinic advises to have blood levels checked by the GP, but this creates a vicious cycle for most because many GPs are uncomfortable executing this check. Until the KZcG stops discouraging GPs and instead shares their lab data-analysis knowledge, this issue will not be resolved.

The VUmc Protocol Above All

The (VUmc) protocol is written for practitioners, who use this protocol as a shield and are unable to vary from it. The protocol is not available for care recipients. The gender team has no understanding for the client council's access to the protocol nor to their feedback on it.

Broadly speaking the protocol describes how to handle a psychological diagnosis, hormone replacement therapy and sex reassignment treatment. It covers everything

from application and screening to life-long hormonal follow-up treatment. The introduction states that the patient's individual needs are the focal point but in practice this does not ring true. It's not for nothing that one of the most common complaints is a lack of agency. This is strange considering that all care protocols state a focus on the needs of care consumers. Care recipients sometimes have the feeling that they are at a police interrogation, that is how opposing one experiences the role that the psychologist plays in the process: not facilitating but instead monitoring to ensure that you are not cheating.

One cannot waver from the strict conditions for treatment, which suggests that it is used as an instruction manual rather than guidelines: an exact how-to protocol instead of a roadmap with indications for what to watch out for. The protocol establishes certain requirements that the care recipient must meet, and cannot digress from. These requirements are about the Body Mass Index (BMI), quitting smoking and drinking for surgery, and comorbidity that must be under control, otherwise treatment can be denied. But comorbidity (such as depression or anxiety) is often related to the gender dysphoria. Gender identity is so fundamental to a person's existence that when that is out of balance it will be impossible/mighty difficult to tackle any other problem. Of course it is important to make these risks known to the care recipient, but denying surgery takes it a step too far.

The way in which gender teams deal with co-existing problem is absolutist and discriminating. One respondent said: "My first appointment at the VU [was] also the last. I left with a 'go solve your self-harming problems first before you come back again'". It is good to help heavy smokers and drinkers quit, but in a few cases the body aversion is so strong that this has priority before the person is even able to begin decreasing tobacco or alcohol addiction. And this means dealing with gender dysphoria first.

Weight, a high BMI, is approached in a fat phobic manner. Fat bodies - especially on women - are viewed as problematic and sick in our society. The ICD is no exception to this. Being fat - having a high BMI- is considered a problem without any regard for the relevant factors such as the state of the heart and vessels, which are factors unrelated to weight. Besides, transgender health care is the only medical field where a high BMI is an absolute contraindication. With other surgery, this does not lead to withholding surgery even though the risks are entirely identical.

Communication Shortcomings

Aside from the long waiting times before and during the medical process, many complaints are aimed at serious communication and patient management problems primarily at the VUmc: at the reception and administration of the polyclinic, at the doctors, at occurrences outside the premises. For example, appointments being cancelled frequently, sometimes even while the care recipient is already on their way to it, the absence of promised letters and outright unfriendly treatment.

Another problem is that health care recipients are not taken seriously when indicating a desire to undergo the process partially or wanting to switch the order from what the

protocol prescribes. The consequences are unnecessarily offered health care, which in turn makes the health care unnecessarily expensive. For example, some people ask for breast reconstruction without wanting testosterone. Or others want a FFS and no other surgery. Other consequences are unnecessarily long waiting times for this unnecessary health care, and this is a substantial breach of the right to freedom from unnecessary health care as also stipulated in Yogyakarta Principle 18 (see page 2).

Here is an example of the judgemental attitude of the psychologist: a particular care recipient considers it a step too far to have their vagina removed. The psychologist insists that he is not a real man as long as he has his vagina and that he will (continue to) be having sex as a woman. This is a baffling type of binary thinking by the gender team.

Because trans people do not intrinsically have a disorder, it is considered rude and degrading to act as if this were the case. Hence, Principle 17 explicitly pleads for an informed consent approach, in which a mutual understanding is essential. The care recipient indicates they are aware of what they are about to embark upon and the clinician recognizes this. A statement with the points discussed and possible questions lies at the base of this approach. Research conducted in New York⁸ for example, demonstrates that this informed consent approach creates a very low percentage of regret cases. The evident (human) rights violation in the Dutch transgender health care calls for action.

Very recently the VUmc has started to experiment with shorter turnarounds for the diagnostic phase and a more compressed process. This turns out to consist of two hours of contact every two weeks. Although the thought of compressing is great, this doesn't actually shorten the procedure. Principle 17 aims to negate the entire section of the process involving forced psychiatric assessment and to replace it with one intake appointment during which the informed consent method is explained and a medical history is recorded. Additionally, there should be quality psychological support throughout the country (aside from potential medical help) for those who need it. This depathologisation only relates to the assumption that trans people are disturbed.

Lack of Acceptance

The lack of acceptance is expressed in, amongst other ways, the consistent wrong indication (gender, first names) of care recipients. ("misgendering") This is done by the entire gender team, from receptionists to practitioners. In particular, the psychologists indicate: "We don't always know, we can't always tell [the care recipient's gender]". This is easily solved by simply asking at the first appointment: "What name and gender do you prefer?". But such a straightforward solution does not seem to occur to the gender team (anymore). Strangely enough, this used to be customary. Yet now, care recipients are only able to achieve being addressed correctly by continuous

insistence and expressing anger. And gender neutral pronouns are definitely too much to handle. In our research this therefore came up as a grievance. The current practice is not only creating unnecessary grievance, but is an outright violation of the (human) right to recognition of who you are (Yogyakarta Principle 3). Possibly this was stimulated by the health insurance law ('Zorgverzekeringswet') from 2006, but that would mean it is grounded in false interpretation. Hospitals are indeed legally required to identify care recipients by means of legitimation, however the law does not specify anything about registration. So, the professional at hand can simply ask how the care recipients prefers to be addressed after identification, and register this (fully legally) in their administration. A small effort from the gender team, that dignifies the identity of the care recipient.

Necessary Decentralization

The previously mentioned improvements and complaints that came out of the research, are predominantly unknown with the gender teams. The majority of the complaints are aimed at the VUmc. The VUmc does not only seem blind to expressed improvements, they seemingly don't even hear most of them. The respondents expressed a fear to out criticism (against the VUmc), because according to them, they would not be able to receive this care elsewhere. The fact that complaints are not or rarely known (at the VUmc) means that no changes can be made, even on an individual level. This is worrying and reiterates that decentralization is of great importance.

8 Informierte Zustimmung in der Trans*-Gesundheitsversorgung. Erfahrungen eines US-Amerikanischen Community Health Center. J. Eisfeld, A. Radix Z. Sexualforsch. 2014; 27; 31-43

What Does Good Transgender Health Care Look Like?



As mentioned, the respondents were extensively asked about their ideas for the ideal transgender health care, what the best possible transgender health care would look like according to them. Barely any respondents are able to think any further than direct improvement: *"I know that I was able to dream away, but if something is impossible, then it is useless to dream about it."* Strikingly, nullifying the current negative aspects, is already considered a dream.

Clearly, customized health care is very much desired, in the form of informed consent and without protest from health insurance agents, who get a slap in the face too. Based on the answers we received we can more or less portray the following ideal:

Good transgender health care is created with a good understanding of the desired care (informed consent), does not commence with a required psychological screening, yet offers the possibility for psychosocial/therapeutic/accompanying/supportive health care for those that need it, regardless of possible desires for somatic care. Hormones are essentially available through the GP and specialized care should be obtainable throughout the country (rather than needing to travel across country). All involved practitioners are not only qualified but also consider the desires of the care recipient to be fundamental. They thereby put their needs first instead of a rigid protocol. Practitioners deliver advanced and innovative health care, that is unproblematically covered by health insurance.

Medical treatment is independent of the care recipient's gender identity or expression (in appearance, mannerisms and/or clothing). Non-binary gender identities and expressions are treated equally to more common gender identities. All genders count. And all genders have equal rights and equal access to quality care.

"The patient is better at determining for themselves when a surgery or the start of hormone treatment is needed, necessary prostheses and binders and hormones are compensated because these are required. Practitioners work according to informed consent and do not obstruct the patient, clear guidelines and possibilities. Ideal care is more accessible by means of decentralization. The health care needs to be available in more places, spread throughout all of the Netherlands. Also, we need better support."

Good transgender care thus demands a smooth-running process, in careful agreement with and initiated by the care recipient. Care that is aimed at the wishes of those who need it. With state of the art process management (Lean Six Sigma, as mentioned by a respondent) and: "All people in a position that deals with many people should be well informed, at the very least GPs, doctors, psychologists [...], but also the

people that take on leadership positions after their schooling, such as managers and HR people."

Gradually, the gender team at the VUmc is expanding the current generic treatment towards a sort of à la carte care. Despite insisting that they exclusively execute the treatment that care recipients ask for, practice proves that the focus is still on the protocol's one size fits all process. Some practitioners at the gender team are more active at this than others, which results in arbitrariness for health care recipients.

Another participant pointed to the informed consent issue as follows:

"You shouldn't have to convince cis people that you are trans in order to receive health care", hitting the nail on the head. Indeed, the gender teams consist purely of cisgender people who work from a ciscentric perspective. In order to change that the team needs to be open to changing it.

"I would like to see much more emphasis on the social/emotional aspect of the transition (contrary to the physical/medical), and that this support is readily available for everyone. And not by some kind of protocol but tailored to the needs of the client." This quote is representative of how crucial psychosocial affairs are and how closely the medical-somatic health care should be tied to it. The Dutch model is clearly not in line with the needs of care recipients. Besides the desire for informed consent, the answers showed a strong need for substantial psychological or psychosocial care, rather than forced psychiatric evaluation.

Problems with health care insurance is another topic mentioned frequently. Repeatedly having to tell telephone operators that transgender health care certainly is covered in the basic health care package, is one of these problems. Care recipients expect less bureaucratic nonsense because it really just concerns basic health care.

More differentiation in health care offered ('à la carte care') can thus be easily executed. A happy coincidence is that this would make transgender health care more affordable, since needless procedures will be redundant and because health care agents are not continuously rejecting and re-accepting compensation for health care.

Good medical practice consists of addressing the care recipient with the gender they themselves indicate. In other words, interventions can be filed under the removal of tissue or correcting a shortage. For masculinisation, breast reconstruction is already being classified as gynaecomastia: undesired breast growth on males. Breast construction should be paralleled to it and should likewise be considered a correction of a shortage of female breast growth. Achieving this is partially dependent on a gender neutral provisional system. Thereby the gender marker for who receives oestrogen or testosterone, for example, would be irrelevant. Currently, a trans woman is unable to get oestrogen without approval of gender dysphoria because legally she is documented as being born in a 'man's body'. If the system were gender neutral, an agreement from the practitioner would be enough: they did after all see the person in question. Other characteristics of good health care, as brought forth in comments, were customized care and agency. Nowadays care recipients are mouthy 'care consumers',

who are well informed about medical possibilities thanks to co-trans people and the internet.

There is a great need for a care provider that takes the care recipient seriously, discusses personal options and -when needed- offers medical advice. Then, the ultimate decision lies with the care recipient.

Agency is particularly important in transgender health care because many trans people have a past during which their opinion was frequently disregarded. They were dressing too feminine or rather too masculine. They walked like a sissy or like a lumber jack or they desired a profession that didn't match their perceived sex. Thus, it is essential that particularly transgender health care recipients are heard and seen. The entire process is essentially about becoming yourself, so the care recipient should be at the wheel: only the care that you want, when you want it. Obviously within reason. It is up to care providers to regulate this.

For various reasons, some transgender care recipients seek health care abroad. They are entitled to this, according to European laws and regulations regarding health care (abroad health care and free choice of practitioner) because transgender health care is after all normal health care. In practice, however, this does not seem the case.

The last decade has finally birthed the notion that professionals from the target audience have an added value for care recipients, because this allows for the opportunity to mirror and identify themselves with their care provider. The same already goes for gay and lesbian therapists, for bicultural psychologists and for psychotherapists with a disability; only transgender professionals are yet to be taken seriously. That is direct discrimination.

This research shows a great need for substantial psychosocial guidance. This has various reasons, first of all living in a body and a gender role that do not suit you leaves scars that are not always solved with medical treatment alone. Amongst trans people it is well known that the true transition only happens after any medical treatment (if desired).

Secondly, there are vastly outlying differences in interaction and expectation of men and women, the so-called unwritten codes of conduct. A quite applicable and indicative comment to describe this is: *"The gender team gave me new swimming shorts, but no one told me how to swim"*.

Thirdly, non-binary trans people struggle with the fact that they live in a society that only knows and recognizes men and women. How can one develop a healthy self-image in a society that does not accept one's identity? These questions have a deep influence on a person's quality of life. Someone's social success and chances are dependent on this. Yet there is still no attention for this within transgender health care.

The amount of trans people with wrongful diagnosis and therefore wrong treatment is shockingly high, with all its subsequent consequences, personal as well as societal.

It is essential that all therapists, psychologists and other practitioners incorporate gender diversity and the signs of gender dysphoria in their education. This could reduce the amount of false diagnoses, and thereby wrongly prescribed treatment, to an acceptable level.

Rights Concerning Health and Health Care



All important human rights treaties and documents are very clear on one point: everyone has the right to the highest attainable standard of care. It has been clarified in the Universal Declaration of Human Rights (art. 25.1), in the Declaration of Social and Cultural Rights (art.12, General Comment 14), in the constitution of the World Health Organization (Preamble), in the Social Charter of the Council of Europe (art. 11) and the European Declaration of Human Rights (EVRM, div. loci). These encompass a central theme of health care and the absence of sickness which is a positive right. Countries are judged on whether they follow these declarations. Germany, for example, was criticized, in an ESC rights committee conclusion, for pathologizing trans people⁹. The committee regularly speaks out about access to transgender transition care and the separation of gender recognition and transition care.

The Committee Against Torture (CAT) is concerned about the agency, bodily and psychological integrity of trans people that needs to be improved “by removing harmful requirements for the legal recognition of the gender identity of trans people, such as sterilization”¹⁰. The latter has happened in the Netherlands, though it is merely an example. The treaty bodies predominantly comment on health and inadequate access to health care which is relevant here too, since a larger group is seeking health care than receiving it.

Furthermore, there are the good many care recipient’s rights that are derived from other rights. So, the right to health care in general is a patient’s right, but is strongly connected to sexual and bodily agency that lies at the heart of the CEDAW, the UN Women’s Declaration. This year too, the Netherlands was questioned extensively about health care and expert statement by the CEDAW committee.

Customised care is only delivered here and there in the case of transition care. Nevertheless, this is a basic right. According to Yogyakarta Principle 18, overtreatment and unnecessary treatment are violations of rights. In Sweden, a law is being prepared that will offer a restitution for damages to trans people that changed their sex between 1972 and 2013 because of the enforced coupling of sex reassignment surgery and legal sex change. This is in line with Yogyakarta Principle 28, the right to effective remedies and compensation. In Argentina, a woman was granted an individual reparation, after years of being denied her rights. Both forms require active lobbying and litigation in order to acquire justice for those who altered their sex indicators

under an old regime and, voluntarily or not, their bodily sex. The Netherlands has done nothing about this yet.

On the bright side, everyone -so too, trans people- has the right to customized care, to good and impartial information. The care recipient is supposed to be decisive in their own treatment.

9 E/C.12/DEU/CO/5, par. 26

10 CAT/C/CHN-HKG/CO/5, par. 29A

Conclusions and Recommendations



This report clearly indicates that there is an evident deficit in the care for trans people in the Netherlands. Participants complain about the long waiting times, lack of respect due to having to endure forced psychiatric evaluation, limited adequate psychological help, and deficient work by insurance companies. There is practically no tailored care and trans people suffer from that fact. The centralised clinical care is overwhelmed by the demand and decentralized care is scarce and being retained at the top. Apparently the KZcG is lacking the insight to implement improvement and that is where this report comes at hand.

Other care, such as psychosocial, psychological, is not readily available, whilst earlier research has also taught us that there is a desperate need for this. More and better psychiatric and social support can empower people and reduce care wishes. We conclude that although health care is available, it is insufficient.

We recognize a need for structural improvement and change in order for care recipients to get what they are entitled to: customized care. Just like everywhere else.

Based on the gathered complaints and wishes we can recommend the following:

- 100% customized care, from a set menu to à la carte.
- Involve trans professionals in health care and listen to them.
- Invest in psychosocial support for those who need this, so people can cope with life in a society that does not understand trans people.
- Improve the knowledge of other health care professionals, such as by incorporating transgender into relevant educational curricula.
- Better communication from care providers and health care insurance agents.
- Organize knowledge about and insight into non-binary genders, and listen to them.
- No gatekeeping, but an open-minded attitude

In conclusion, at the very least the Standards of Care need to be followed up more precisely and explicitly. Our research reveals that this is not the case in the Netherlands. Thus, our advice is to actually practice the Standards of Care. Implementing an informed consent model is urgently recommended. It is the only model in which the

care recipient is actually taken seriously while allowing for a nuanced and individual approach.

Discussion

In future research, we would like to further examine health care satisfaction with a breakdown of ethnicity factors. Our research is insufficiently intersectional and we would have liked to delve deeper into the effects of bad health care on enhancing socio-economic inequalities.

Appendix: List of questions in the survey

0. How old are you?

00. What are the first 4 digits of your postal code, or your city of residence?

1. What is your gender? Multiple options are possible here.

Trans*
Transwoman
Transman
Agender
Androgynous
Genderqueer
Gender non-conforming
Genderfluid
Bigendered
Female
Male
Other, namely

2. Are you out as a trans* person towards

your family?
your friends?
your colleagues?
your fellow students?
your neighbours?

not at all/everybody/not applicable (range 1-5)

3. How strong is your social support system?
range: very weak- very strong

4. What kind of intimate relationships do you have? (Multiple options are possible, but you don't need to answer this question if you don't want to)

An exclusive relationship
Multiple relationships
An open relationship
No relationship at the moment
Sexdates

5. What is your yearly income?
(You don't need to answer this question if you don't want to)

Don't have an income
Governmental financial aid (ziektewet/uitkering)
I am retired
Up to 15.000€
16.000 to 25.000€
26.000 to 50.000€
51.000€ and up

6. What is the highest educational level that you completed?

No completed education
Primary school
Secondary school
Vocational training
Bachelor
Master
PhD
Other, namely.

7. Did you ever consider or receive trans* related health care?

Yes, I considered getting trans* related health care
Yes, I received trans* related health care
No, I neither considered nor received trans* related health care

8. You indicated that you received trans* related health care. Could you tell us what you received?
OR: You indicated that you considered trans* related health care. Could you tell us what you considered?

Multiple choices are possible here.

Counselling/therapy
Hormones
Facial hair depilation
Top surgery
Bottom surgery
Facial surgery
Other, namely

9. Where did you receive trans* related health care?

VUmc
UMCG
GP/family doctor
self medication
other, namely

10. Did you have any negative experiences when you received trans* related health care?

11. Did you have any positive experiences when you received trans* related health care?

12. Do you still have unfulfilled trans* related health care needs?

Multiple choices are possible here.

Counselling/therapy
Hormones
Facial hair depilation
Top surgery
Bottom surgery
Facial surgery
Other, namely.

13. What are the reasons that keep you from asking for/receiving this type of health care?

1
4. Trans* health care of your dreams

In the upcoming part we would like to find out how ideal trans* health care looks like according to you. Imagine anything was possible and describe the trans* health care of your dreams. You can mention aspects that would improve the existing system, and/or come up with alternative ways of providing optimal health care for trans* people. There are no limits to your imagination, so please feel free to share anything with us that you dream about in terms of trans* health care.

15. In this part of the survey we would like to present suggestions that other trans* people made in order to improve trans* health care in the Dutch context.

Please indicate for each statement to what extent you agree that this aspect is important for improving trans* health care.

reducing waiting times at gender clinic
better reimbursement of medical procedures
extension of psychological support
increasing societal knowledge and acceptance towards trans* people
facilitate legal procedures to change passport and documents
improvement of chances of employment for trans* people

16. Yet other trans* people also mentioned the suggestions below in order to improve trans* health care.

Please indicate for each statement to what extent you agree this aspect is important for improving trans* health care.

decentralize treatment of trans* people in the Netherlands
teach practioners about gender diversity
remove pressure to fully present as either female or male
teach practioners to address trans* people correctly (e.g. preferred pronouns and name at all times)
improve treatment during diagnostic period
improve treatment in medical period

17. In this part of the survey we will list negative experiences that some trans* people unfortunately had to make in the past when asking for trans* related health care. We would like to ask you to share which of these negative experiences you also had to deal with.

Multiple options are possible here, but you can skip this question if you didn't experience any of this.

I had to undress my upper body in front of psychologists
I had to undress my lower body in front of psychologists
I had to undress fully in front of psychologists
Psychologists asked me invasive question that were unrelated to gender (e.g. questions about sexuality)
Practitioners were clearly unfamiliar with trans*
Practitioners were condescending to me
Practitioners asked questions about my medical history in order to educate themselves on the topic
Practitioners were clearly unfamiliar with and biased towards trans* people of colour
Practitioners addressed me with name and/or pronouns that were assigned to me at birth
Practitioners treated me as if I was mentally ill or confused

This is the end of questions about your experiences with trans* related health care.

Do you have anything to add before the survey ends?

Colophon



Principle 17:

vreer verkerke
Jochem Verdonk
Simon Huges
Adri van Diemen
Brand Berghouwer
Sabine Bastiaans

Researcher:

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Thanks to:

Fund De Trut Foundation



P

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made possible by:

