

Through the Needle's Eye: A Qualitative Study of the  
Experiences of Adolescents with Gender Incongruence and  
their Families Seeking Gender Affirming Healthcare in  
Norway.

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### Abstract

At the time of writing, the system of gender affirming healthcare (GAH) in Norway is in a state of flux. Recent controversies have arisen around the monopoly on care held by the publicly funded gender clinic (*Nasjonalt behandlingstjeneste for transseksualisme*, NBTS) and the emergence of private providers outside of NBTS. The current situation presents an interesting context for the research behind this thesis, which had the aim of gaining a deeper understanding of the experiences gender variant youth and their parents have while seeking GAH in Norway.

The thesis uses several qualitative methods. Semi-structured interviews were conducted with gender variant youth ages 12-22 and parents with experiences seeking GAH. Interviews were also conducted with key informant healthcare providers and activists to provide deeper context. Related grey materials and media were analyzed, and community engagement provided further depth to contextual understandings.

Findings are divided into two chapters. The first examines the experiences that lead families to seek interventions like puberty blockers and hormone replacement therapy (HRT) and the meanings they place on these treatments. This study explores how study participants experience puberty as a 'crisis' warranting swift preventative action and how these experiences inform conceptualizations of gender affirming care as 'lifesaving' treatment. I present a three-fold mechanism of social, embodied and psychological suffering to understand some of the experiences that motivate study participants to seek care. The second chapter of findings looks at the families' care seeking experiences. Study participants described experiences that led to the erosion of trust in the system of gender affirming care. Drawing on several established theories of trust in healthcare, a variety of scenarios that may contribute to the development of distrust in clinicians throughout the care seeking process are explored in the context of recent controversies in GAH.

This study contributes to a deeper understanding of the experiences, values and beliefs that motivate families to seek GAH. It also provides important insights into processes of trust development and its erosion in healthcare. The findings suggest a desire for more transparency and information in the care seeking process, a system that caters more to individual needs, and greater partnership in treatment decision-making.

**Keywords:** Gender affirming care, gender variant youth, trans-specific healthcare, trust in healthcare, puberty blockers, stigma, embodied suffering, social suffering

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## Definitions and Abbreviations

**Adam's Apple Surgery** - Surgical procedures to reduce the Adam's Apple.

**ADHD** - Attention Deficit Disorder

**ASD** - Autism Spectrum Disorders (including Asperger syndrome).

**Binder** – Colloquial term for a compression vest used to flatten the chest (see binding).

**Binding** - Colloquial term for techniques used to flatten the chest.

**Breast Augmentation** - Surgical enlargement of the breasts, sometimes desired by women assigned male at birth.

**Cisgender** – An adjective indicating one who identifies with their gender assigned at birth.

**Cisnormative/Cisnormativity** - Societal assumption that all people are cisgender.

**HRT** - Hormone replacement therapy, also known as 'cross-hormone treatment' when used in gender affirming contexts.

**Early Interventions** - Gender affirming care like puberty blockers and cross-hormones provided before age 18.

**EPATH** - European Professional Association of Transgender Health

**Facial Feminization Surgery** - Plastic Surgery like reduction of the jaw bone and brow ridge to create a more feminine appearance.

**FRI** - The Organization FRI<sup>1</sup>, for LGBTQIA people in Norway, formerly LLH<sup>2</sup>

**FTPN** - The Organization for Trans People in Norway<sup>3</sup>

**Gender affirming care**: An array of healthcare options available to gender variant people including pubertal suppression, hormones, and surgeries.

**Gender dysphoria** - Discomfort associated with living in a body that does not reflect one's gender identity, or with being misgendered in social interactions. Also, the diagnosis required for gender affirming care according to the DSM-V.

**Gender incongruence** - An experience of gender that is not aligned with that assigned at birth, also the new IDC-11 diagnosis.

**Gender non-conforming** -Term used to describe those whose gender expression does not follow gender norms expected of their gender category. Some gender non-conforming people do identify with the gender they were assigned at birth, while others do not.

**Gender variant/variance** - Persons with a gender experience transcending that assigned at birth. Also called transgender, gender diverse, gender expansive, trans talented.

**GID-clinic**<sup>4</sup> - An (older) previous incarnation of NBTS.

**HBRS** - Harry Benjamin Resource Center<sup>5</sup>, patient organization for NBTS care-seekers.

**Heteronormativity** - Societal assumptions that all persons identify as heterosexual.

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<sup>1</sup> Foreningen FRI.

<sup>2</sup> For Landsforeningen for lesbiske, homofile, bifile, og transpersoner.

<sup>3</sup> Foreningen for transpersoner i Norge.

<sup>4</sup> GID-klinikken.

<sup>5</sup> Harry Benjamin Ressurssenter.

**HKS** - Health Center for Gender and Sexuality<sup>6</sup>

**HRT** – Hormone replacement therapy.

**KID-team**<sup>7</sup> - The clinic under NBTS which serves young people up to 18 years.

**Misgendering** - Referring to a person with gendered language that does not reflect the person's experienced gender.

**NBTS** - National Treatment Center for Transsexualism<sup>8</sup>, the state funded gender clinic

**Neuroatypical** – Less pathologizing term used to describe people with ASD, ADHD, etc.

**Neurotypical** - Persons not presenting with neurological variations like ADHD or ASD.

**Nonbinary** – An umbrella term encompassing transgender identities that transcend the gender binary, meaning they may not identify as exclusively male or female, may identify somewhere in-between on the gender spectrum, may experience periodic fluctuations in gender, or in some cases may not want to be ascribed a gender identity (agender).

**Phalloplasty** - Surgical intervention to create a neophallus for men assigned female at birth. Testicular implants and vaginectomy (removal of the vagina) may also be performed.

**PKI** - Patient Organization for Gender Incongruence<sup>9</sup>

**Puberty Blockers** - GnRH agonists prescribed to suppress puberty.

**Rikshospitalet/Oslo University Hospital (OUS)** - The hospital where the state funded gender clinic is located.

**Section for Transsexualism**<sup>10</sup> - NBTS' previous incarnation.

**SOC** - Standards of Care for the treatment of gender incongruence, issued by WPATH.

**Transgender** – An umbrella term encompassing a broad range of gender identities, the commonality being that they do not identify with the gender they were assigned at birth.

**Transsexual** – A person who has an experience of gender different from that they were ascribed at birth, but which is still experienced as male or female (see nonbinary).

**Transitioning** - The act of moving toward a gender role and appearance in alignment with one's experienced gender. May involve social transitioning where changes are made regarding gender expression and pronoun/name, or medical transition with gender affirming care.

**Top Surgery** - Used in this thesis to refer to mastectomy in males assigned female at birth.

**Tucking** - Techniques used by females assigned male at birth to conceal genitalia.

**Vaginoplasty** - Surgical intervention to create a neovagina for women assigned male at birth. Other surgical procedures for women assigned male at birth include penectomy, orchiectomy, clitoroplasty, and vulvoplasty.

**WPATH** - World Professional Association of Transgender Health

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<sup>6</sup> *Helsestasjonen for kjønn og seksualitet.*

<sup>7</sup> *KID-teamet.*

<sup>8</sup> *Nasjonal behandlingstjeneste for transseksualisme.*

<sup>9</sup> *Pasientorganisasjonen for kjønnsinkongruens.*

<sup>10</sup> *Seksjon for transseksualisme.*

## CHAPTER ONE: Introduction and Background

### 1.0 Introduction

The journey toward this master thesis began long before its inception. In fact, it began with my bachelor thesis in social anthropology. Although I ended up focusing only upon the experiences of transgender parents, my original idea was to include the parents of gender variant children. Although I was forced to narrow my topic, the stories of the people I talked to over the course of data gathering for that project stayed with me, especially one of the key informants of that project, a nurse who works with young people in the field of sexual health, many of whom are gender variant. I find that this nurse's exuberance regarding research in the field of gender affirming healthcare in Norway is the result of a marked lack of *any* research at all in the field. Thus, I sought them out while determining exactly what my focus might be for a health-related master, mind open and eager to contribute.

Over coffee in their Oslo office, I asked, "How can I help? What kind of research is needed?"

"*Everything!*" they laughed, eyes lit with their usual glow of enthusiasm.

Until recently, very little research on gender variant communities has been performed in Norway. There was specifically a lack of social sciences research on youth with gender incongruence. Although the amount of international literature on gender variant individuals has grown substantially in the past few years (in fact, keeping myself updated while conducting this research was quite the task), qualitative exploration of young people's gender affirming healthcare experiences remains limited (Katz-Wise et al., 2017). Considering recent controversies and political struggles in the field of gender affirming healthcare in Norway, especially as that care pertains to adolescents and teens (e.g. Fonn, 2018a & 2018b; Offerdal & Tønseth, T.M, 2018; Wæhre & KA Tønseth, 2018), it is clear more research is needed. Because of recent developments in this field of healthcare in Norway, along with some key societal and healthcare systems differences, it is at times difficult to apply the findings of studies performed in other countries to the Norwegian context. The study behind this master thesis sought to fill this gap in the literature by exploring the gender affirming care experiences of gender variant youth and their parents in Norway.

Here in the introduction, I discuss the language used in this thesis, as understanding the language as thoughtfully considered gives further context to the reader. Next, I outline some of the current research on topics in the field of gender affirming care most relevant to this thesis. In Chapter Two, I present the methods and ethical considerations surrounding this



study. In Chapter Three, I explore the experiences that lead families to seek early gender affirming care interventions like puberty blockers, and the meanings they place upon treatment. Over the course of the chapter, I also discuss how cultural norms and biomedical discourses interact with these experiences and beliefs. Based on study participants' experiences and views, as well as the literature base, I introduce a new framework for looking at suffering discourses as they pertain to the use of gender affirming care interventions.

In Chapter Four, I look at issues of trust in gender affirming care by sharing experiences study participants have had while seeking care in Norway, specifically at the publicly funded gender clinic at Oslo University Hospital<sup>11</sup> (OUS) *Rikshospitalet*. By examining these experiences through a lens of theories of trust, I hope to provide some understanding of why careseekers may feel the need to seek help with “private” care providers. I additionally explore how the public gender clinic's policies toward the use of these providers are perceived by study participants. Lastly, in the conclusion, I discuss implications of the study's findings. I additionally share some of the suggestions study participants believed could improve the experience of seeking gender affirming care in Norway, as well as some of my own.

## 1.2 About the Language of This Thesis

I acknowledge that my work is on a topic which pertains to the health and wellbeing of a group that has often been spoken of in degrading ways, even in academia. Knowing their different understandings of terminology, which terms they deem offensive or empowering, and how they themselves employ language, was crucial to the formation of the language base that I use for this thesis. Language within the gender variant community is in a near constant state of flux, and this language shift has spilled over into medicine and academia (Bouman et al., 2017). Several authors discuss how medical and psychiatric texts about gender variance have tended toward pathologizing, cisnormative language (Lev, 2013; Bouman et al., 2017; Ekins, 2005; Ansara & Hegarty, 2012; Dewey & Gesbeck, 2017). Bouman and his colleagues (2017) argue that language has been used to normalize stigma and discrimination against gender variant people.

In much of the world, the umbrella term *transgender* has come to encompass all who transcend gender norms, from transsexuals to nonbinary people who do not identify as

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<sup>11</sup> Oslo universitetssykehus.

exclusively male or female<sup>12</sup>, to cross-dressers (C Williams, 2014). But some dispute its usage in application to their own circumstances (Stryker & Currah, 2014). Cisgender is a term for those whose gender aligns with that they were assigned at birth, whereas a transgender person's gender would not match that assigned at birth (Aultman, 2014). I was admittedly slow to pick up on cultural differences in the use of terminology in Norway, where the use of umbrella terms is somewhat different than in my native U.S. As in the U.S., *transsexual* (*transseksuell* in Norwegian) indicates those who identify with and wish to fully transition to the “opposite”<sup>13</sup> gender. The term *transgender* (*transkjønnet* in Norwegian) along with its counterpart trans person (*transperson*) were understood by most participants of this study as encompassing only those who transcend the gender binary. Thus, the majority did not feel this term described them. In my initial information sheets for the study, I used the terminology ‘transgender youth’ and ‘trans-specific healthcare’. However, one organization requested I change the language to ‘youth with gender incongruence’ before distribution, reflecting the new ICD-11 diagnosis. Some families used the colloquial ‘born in the wrong body’ (*født i feil kropp*) as a descriptor of their situation, while others rejected this conceptualization. One parent scoffed at the term, saying “*Wrong body?* There is nothing wrong with *my* child!” She felt using such terminology gave the wrong message to gender variant children and those around them. I therefore only use the term when study participants do.

Other authors have found that terms used in the literature did not always match how participants describe themselves (Dewey, 2008; Ansara & Hegarty, 2012). I took care to ask study participants how they would like me to write about them. Some had no problem with terminology like trans<sup>14</sup> or trans boy/trans girl. Others did not like the word trans because they felt it was used as a derogatory term (*skjellsord*), much like ‘*jævla homo*’ which means ‘damn homo’ in English. Thus, I do not use the term transgender to describe them. All indicated that they were girls and boys like their peers, and I refer to them throughout the thesis as such. In contexts that could lead to confusion, I use the terms ‘assigned female at birth’ or ‘assigned male at birth’ for clarification. This terminology is preferred because it indicates a mistake

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<sup>12</sup> More specifically: Nonbinary is another umbrella term for people do not necessarily identify as male or female. They may feel their gender identity fluctuates (genderfluid) or understand themselves to be a mixture of male and female (genderqueer) or have no gender identity at all (agender). They may still identify as transgender, because transgender is often used as an umbrella term for all who do not identify with the gender they were assigned at birth.

<sup>13</sup> Here I use the term “opposite” in the way it was used in the ICD-10’s diagnosis of transsexualism, with the full acknowledgement that the possibilities when it comes to gender well exceed two.

<sup>14</sup> Shortened version of the word transgender.

which was made by society, and not that biological sex overrules identity (Bouman et al., 2017). Sociologist Tey Meadow (2014) asks, “If what an assigned male child tells you is that she *is* a girl, does the term transgender truly represent her personal identity?” I struggled to land upon an umbrella term for speaking of the young people of this study more generally. I therefore work with the terms ‘gender variant youth’, ‘youth with gender incongruence’, or ‘gender diverse youth’ as these terms are affirmative (Bouman et al., 2017).

I use the term ‘gender affirming care’ to describe treatment options that can help a person bring their body in closer alignment with their gender, rather than gender reassignment, as that term seems to indicate that only medical personnel can assign gender. I work under the premise that people have the right to *self-identify* and healthcare helps to *affirm* that identity. I often use the term “careseekers” rather than “patients” to emphasize the agency of families seeking help.

There are also several terms selected to describe care providers. The National Treatment Center for Transsexualism (NBTS)<sup>15</sup>, is located at Oslo University Hospital (OUS) or *Rikshospitalet* as it is often called. The gender clinic has changed names multiple times over the course of some study participants’ care trajectory. Additionally, the clinic was recently split in two, with one clinic for adults and one for youth, the latter of which took on the name NBTS KID-team<sup>16</sup>. Due to this multiplicity of monikers for the clinic, I chose to follow study participants’ lead. They call the clinic simply ‘*Rikshospitalet*’ or ‘*Riksen*’. I therefore use *Rikshospitalet* interchanged with NBTS or KID-team when the need for specificity arises. Additionally, study participants call providers offering care outside of NBTS ‘private’ (*privat*) i.e. “We had to go private.” However, a number of these providers operate under the public health system. One key informant theorized that they may all be perceived as private because careseekers must pay out of pocket for gender affirming care received outside NBTS. To denote that these providers are not part of the publicly funded clinic NBTS, but include a mixture of public and private options, I use ‘private’ when appropriate, but most often use the term ‘providers outside NBTS’. Additionally because healthcare providers at NBTS and BUP can come from a number of professional backgrounds, ranging from social workers to psychologists to endocrinologists, I most often use the term ‘clinician’ when speaking of a study participants’ specific care provider.

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<sup>15</sup> *Nasjonalt behandlingstjeneste for transseksualisme.*

<sup>16</sup> *NBTS KID-teamet.*

## Background and Literature Review

### 1.3. Gender Variant Youth

Globally, an increasing number of young people are coming out as gender variant, a trend which began in the late 1980s (Zucker, Bradley, Owen-Anderson, Kibblewhite & Cantor, 2008). As a result, clinics serving gender variant youth worldwide have experienced a rise in requests for early biomedical interventions (Zucker et al., 2008; Möller, Schreier, Li & Romer, 2009; Edwards-Leeper & Spack, 2012; De Vries & Cohen-Kettenis, 2012; Bonifacio & Rosenthal, 2015). More research is needed to determine what has caused this increase, but experts theorize that it may correlate with the rising awareness and acceptance of gender variant people in some societies (Zucker et al., 2008). This trend is also seen in Norway, and NBTS specifically reports a growth in the number of boys assigned female at birth presenting at the clinic (Wæhre & KA Tønseth, 2018; Fonn, 2018b).

The size of the population of gender variant people in most countries is unknown (Winter et al., 2016), and this is also true in Norway (Helsedirektoratet, 2015; Bufdir, 2011; van der Ros, 2016). This is because many studies to date have only counted persons presenting at clinics, so they tend to underestimate the population (Winter et al., 2016). Some gender variant people do not desire medical help, or they may obtain hormones off the black market or the internet (Bonifacio & Rosenthal, 2015; Winter et al., 2016). Some may be unable to access care at clinics (Roberts & Fantz, 2014; Winter et al., 2016). Population-based studies have come with estimates of 0.5% to 1.3% for women assigned male at birth and 0.4%-1.2% for men assigned female at birth (Winters et al., 2016). Extrapolating just the lower estimate of 0.5% to a world population of 5.1 billion people, Winter and colleagues (2016) argue that there could be some 25 million gender variant people globally.

Early social transition is becoming more common for gender variant children (Cohen-Kettenis & Klink, 2015; Durwood, McLaughlin & KR Olson, 2017). Most of this study's participants transitioned long before they ever sought medical help. Although prepubertal social transition is considered controversial (Steensma & Cohen-Kettenis, 2011; De Vries & Cohen-Kettenis, 2012; Pyne, 2017; Turban, 2017), young children may socially transition unambiguously with a change of name, pronouns and clothing in supportive environments. The reason prepubertal transition is controversial among clinicians is that some studies claim most children with atypical gender expressions in childhood "desist", i.e. come to identify more closely with their birth gender, prior to or at the onset of puberty (Menvielle, 2009; Steensma, McGuire, Kreukels, Beckman & Cohen-Kettenis, 2013). Some experts are concerned about the psychological stress a second transition could present (Steensma &

Cohen-Kettenis, 2011). Recent research shows that gender variant children who are supported in social transition experience improvement or preservation of mental health on par with matched cisgender controls (Durwood et al., 2017; KR Olson, Durwood, & McLaughlin, 2016).

Gender variant youth have been shown to present with higher rates of internalizing mental health struggles such as depression, anxiety, self-harm, eating disorders and suicidality, which are thought to be due in part to effects of undesired pubertal development (J Olson, Schragger, Belzer, Simons & Clark, 2015; Cohen-Kettenis et al., 2008; Grossman & D’Augelli, 2007; McGuire, Doty, Catalpa & Ola, 2016; Connolly, Zervoz, Barone, Johnson & Joseph, 2016) but may also be the result of minority stress and stigma (Grossman & D’Augelli, 2006, 2007; Robles et al., 2016; Hughto, Reisner & Pachankis, 2015). Many also express higher levels of stress and dissatisfaction pertaining to body image, but social acceptance may play a mitigating role (McGuire et al., 2016). Research shows gender non-conforming youth are more likely to be victims of bullying, which can impact mental health (Toomey, Ryan, Diaz, Card & Russell, 2010). A U.S. study found that gender variant children supported by their families had better mental health outcomes and quality of life than those without that support (Simons, Schragger, Clark, Belzer & J Olson, 2013). The young people that participated in this study enjoyed strong familial support. Most experienced support within their schools and local communities as well, however a few were subjected to bullying by their peers.

## **1.4 Interventions for Youth with Gender Incongruence**

### **1.4.1 *Pubertal Suppression***

The World Professional Association for Transgender Health (WPATH) Standards of Care (SOC) and The Endocrine Society Guidelines (2009) were the first to establish treatment guidelines for the medical care of adolescents with gender dysphoria (Nahata, Chelvakumar & Leibowitz, 2017). Both guidelines are based on the expert consensus of those who provide such care, clinical experience, and consideration of the latest scientific evidence (Coleman, 2009; Matte, Devor & Vladicka, 2009; Hembree et al., 2009). Experts in the Netherlands have published literature since the late-90s on what is called “The Dutch Protocol”, which first introduced the application of pubertal suppression to the treatment of gender variant youth (De Vries & Cohen-Kettenis, 2012). Some clinics also have their own protocols (e.g. Edwards-Leeper & Spack, 2012). Most literature on the treatment of adolescents with gender incongruence is based on clinical experience, and studies that have been performed are

underpowered (Mahfouda, Moore, Siafarikas, Zepf & Lin, 2017).

Gonadotropin-releasing hormone (GnRH) agonists or “puberty blockers” as they are called colloquially, are recommended in the above protocols for gender variant youth to suppress puberty. GnRH agonists desensitize GnRH pituitary gland receptors and stop the release of puberty inducing hormones (Bonifacio & Rosenthal, 2015). According to The Endocrine Society guidelines, treatment may begin once a child reaches pubertal development Tanner stages<sup>17</sup> 2 to 3, when gonadal and breast development is still minimal and may even be partially reversible (Bonifacio & Rosenthal, 2015; Hembree et al., 2017). Recent guidelines do not place limits on the chronological age of the young person (Hembree et al., 2017). The rationale for beginning at Tanner 2 is because allowing the child to experience the first stages of puberty can prove diagnostically informative for the clinician, and despite a lack of studies, papers based on clinical experience claim adolescents rarely express gender fluidity past this point in development (De Vries & Cohen-Kettenis, 2012; Cohen-Kettenis & Klink, 2015). Additionally, not observing natural pubertal development timing could lead clinicians to overlook conditions related to delayed puberty (Nahata et al., 2017). Young people in later stages of puberty may also benefit from pubertal suppression to prevent further development (Bonifacio & Rosenthal, 2015).

GnRH agonists were developed to treat precocious puberty and have been safely used for decades (Spack, 2009; Cohen-Kettenis & Klink, 2015). There are some concerns about the impact such treatment has on bone growth and cognitive development (Delemarre-van de Waal, 2014; Cohen-Kettenis & Klink, 2015; Mahfouda et al. 2017). The first follow-up study of a young adult treated in the late 90s showed no adverse effects (Cohen-Kettenis et al., 2011) and clinical monitoring of the first group of Dutch adolescents to receive treatment shows bone mass accrual normalizes after the introduction of hormone replacement therapy (HRT) (Schagen et al. in Cohen-Kettenis & Klink, 2015). A study of executive functioning<sup>18</sup> in treated adolescents showed similar performance compared to controls (Staphorsius et al., in Mahfouda et al., 2017).

Autism spectrum disorders (ASD), including Asperger Syndrome, may be more common in gender variant the population than in the general population for reasons yet

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<sup>17</sup> The Tanner stages of puberty (also known as the Sexual Maturity Rating) were developed to describe the changes seen in normal pubertal development. The rating system is divided into a series of five stages, Tanner 1-5 (Emmanuel & Bokor, 2019).

<sup>18</sup> Executive functioning refers to a collection of cognitive tasks that helps one plan, control and coordinate behavior.

unknown (Strang et al., 2016; Jacobs, Rachlin, Erickson-Schroth, & Janssen, 2014). Some experts are concerned that treatment with puberty blockers during adolescence, when the brain is in the process of reorganization, may have adverse effects on this group, as well as those with ADHD and Tourette's Syndrome (Nahata et al., 2017). Current guidelines for this subgroup advise that treatment with puberty blockers should not be denied solely based on the co-occurrence of ASD (Strang et al., 2016). Research is needed to clarify what developmental effects this treatment has on both neurotypical and neuroatypical youth.

Several benefits are associated with pubertal suppression. First, it is regarded as safe and reversible should the child wish to return to the gender assigned at birth (Cohen-Kettenis et al., 2011; Delemarre-van de Waal, 2014; Bonifacio & Rosenthal, 2015). It arrests the development of irreversible secondary sex characteristics like deepening of the voice, Adam's apple and facial hair growth in girls assigned male at birth and breast development in boys assigned female at birth. For boys assigned female at birth, puberty blockers can result in a height that is closer to that of male peers. For the girls, puberty blockers can help to achieve better breast development when paired with HRT (Spack, 2009; De Vries & Cohen-Kettenis, 2012; Edwards-Leeper & Spack, 2012; Delemarre-van de Waal, 2014).

Pubertal suppression also provides more assessment time to the diagnostic process (Delemarre-van de Waal, 2014). The extra time allows the child to explore their identity without the stress associated with pubertal development (Bonifacio & Rosenthal, 2015). Young care-seekers can also better engage in decision making about whether to introduce treatment with more permanent effects, like HRT and surgery, as they reach the age of consent for medical care (De Vries & Cohen-Kettenis, 2012; Edwards-Leeper & Spack, 2012). The age of consent for medical care is 16 years in Norway (Patient and User Rights Law<sup>19</sup>, 1999, § 4-4). According to clinical experience, few who have been treated with blockers change their minds about their desire for further treatment (De Vries & Cohen-Kettenis, 2012; Spack, 2009), but no studies exist on the topic (Mahfouda et al., 2017).

The onset of puberty may be understood as posing a threat to mental health and social functioning for gender variant youth (Cohen-Kettenis et al., 2008; Spack, 2009; Kreukels & Cohen-Kettenis, 2011). Pubertal suppression for this population began as an off-label usage of GnRH agonists. For many parents, the reasoning behind seeking puberty blockers for precocious puberty is to prevent mental health problems associated with early pubertal onset (Roberts, 2014, 2016). As discussed, this is also a part of the rationale behind offering the

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<sup>19</sup> In Norwegian, *Pasient- og brukerrettighetsloven*.

same treatment to gender variant youth. A Dutch study seemed to support this rationale, demonstrating that 55 gender variant adults treated with puberty blockers at age 12 and HRT at 16, had mental health outcomes similar to the cisgender population (De Vries et al., 2014).

#### **1.4.2 *Hormone Replacement Therapy (HRT)***

From age 16, it is possible to initiate HRT, so the young person can experience a puberty in accordance with their gender identity (Cohen-Kettenis & Klink, 2015). The most recent versions of the Endocrine Society's guidelines and the SOC Version 7 mention that some flexibility with age limits can be desired, for example when a young person began puberty early, and has been on puberty blockers for several years, which may impact bone health (Hembree et al., 2017; WPATH, 2011). In Norway, the age is set at 16 for the introduction of cross-hormones (NBTS, 2018). Testosterone for males assigned female at birth and estrogen for females assigned male at birth are introduced at intervals to mimic a natural puberty (Hembree et al., 2017). Androgen blockers may be prescribed for those assigned males at birth who are not already on puberty blockers (WPATH, 2011). The long-term effect of HRT also lacks lengthy longitudinal studies, but existing studies suggest therapy is safe (Wierckx et al., 2014; Weinland & Safer, 2015).

#### **1.4.3 *Surgery***

Surgical interventions that may be beneficial to gender variant careseekers. These include genital surgeries like vaginoplasty, penectomy, orchiectomy, clitoroplasty, and vulvoplasty for women assigned male at birth and phalloplasty for men assigned female at birth to create genitalia more in alignment with the careseeker's gender identity (WPATH, 2011:57). Women assigned male at birth may seek surgeries like Adam's apple reduction, facial feminization, vocal cord surgery, and breast augmentation to supplement breast growth achieved with estrogen therapy (ibid). Most surgeries offered to the gender variant community are not available to those below the age of 18 (ibid; NBTS, 2018), and so I do not go into detail on them here. The exception is chest reconstruction for boys assigned female at birth, which may be provided from 16 years of age, following a year of testosterone therapy and after a period of social transition (NBTS, 2018). However, according to the Endocrine Society guidelines, testosterone is not a prerequisite to surgery (Hembree et al., 2017) and the SOC state that some flexibility could be warranted in terms of the testosterone recommendation (WPATH, 2011). Chest reconstruction is often referred to colloquially as "top surgery" in the gender variant community. Current research shows that for young males assigned female at birth, this surgery can be one of the most important to their transition process, and youth and



parents in a youth clinic sample reported an improvement in mental health and subjective wellbeing following the intervention (Marinkovik & Newfield, 2017).

#### 1.4.4 *Ethical Concerns*

Irving Zola argues that at times medical experts may be guided more by values than their medical knowledge (1976). It is then potentially important to address ethical concerns experts have about treatment. One concern is whether young people *should* be treated, another is if they can be capable of making care decisions that have a major impact on their life at a young age (Vrouenraets et al., 2015). Although studies show regret rates among gender variant adults are low (Phäfflin, 1992; Dhenje et al., 2014), healthcare providers sometimes fear that young people may regret their care decisions later in life, considering high desistance rates among children (Vrouenraets et al., 2015; Nahata et al., 2017). Some experts theorize that puberty is when gender is “consolidated” and thus ask if the disappearance of dysphoria with puberty suppression may lead to misdiagnosis (Vrouenraets et al., 2015; Steensma, Wensing-Kruger & Klink, 2017).

Many raise concerns about the potential sterilizing effects of treatment (Wæhre & KA Tønseth, 2018; Sadjadi, 2013; Nataha et al., 2017; Jeffreys, 2012; Cretella, 2016). Gametes may not fully mature when pubertal suppression is followed by cross-hormone treatment. This prevents some young people from having the option of preserving fertility unless willing to go off puberty blockers for a period, but more research is needed (Nahata et al, 2017). Additionally, pubertal suppression followed by HRT does not permit penile tissue to sufficiently grow in girls assigned male at birth, limiting their options for vaginoplasty should they later desire it (ibid).

Others argue that the risks involved in treatment are outweighed by those of inaction in terms of poor mental health and treatment outcomes, along with the discrimination and stigma faced by gender variant people (Wren, 2000; Cohen-Kettenis et al., 2008; Vrouenraets et al., 2015; Kreukels & Cohen-Kettenis, 2011; Giordano, 2008). Cohen-Kettenis et al. (2008) argue that youth not provided care may instead purchase medications through non-medical sources or learn to avoid healthcare altogether. Bernadette Wren points out that ethical objections are rarely raised when children who face precocious puberty are provided puberty blockers to prevent psychological harms (2000).

To receive treatment in Norway, one must obtain the ICD-10 diagnosis F64.0 Transsexualism for adults or F64.2 Gender Identity Disorder of Childhood. These diagnoses are placed in the psychiatric chapter of the ICD-10, and some have argued whether children

should be diagnosed with a potentially stigmatizing mental illness (Drescher, Cohen-Kettenis & Reed, 2016). Indeed, Sweden removed the childhood diagnosis from their ICD-10 in 2009 (ibid). As of 2017, Denmark no longer requires any diagnosis to obtain gender affirming care and instead uses the ICD's Z-codes<sup>20</sup> to mark the need for care (Rischel & Rasmussen, personal communication, 24.05.2018). The new ICD-11, released May 2018, moves diagnoses related to gender affirming care into a sexual health chapter, renaming the diagnosis "Gender incongruence" to reduce stigma (Reed et al., 2016). However, it may take some time for WHO member states to introduce the changes it includes, as they have impacts on digital health registries and clinicians must be properly trained (*ICD-11 er lansert!*, 2018). Some clinicians argue against providing medical treatment to gender variant people at all since it has long been classified as a mental illness (Cretella, 2016; Vrouenraets et al., 2015), and may see interventions as a "narcissistic demand" rather than necessary care (Wren, 2000).

Some practitioners have concerns about treating gender variant youth because a cause of gender variance is not known (Cretella, 2016; Vrouenraets et al. 2015). Much current evidence from neuroscience (Kreukels & Guillamon, 2016), twin studies (e.g. Coolidge, Thede & Young, 2002; Diamond, 2013), and genetic studies may point toward a biological origin, for example, related to genes that code for hormone receptors (e.g. Hare et al. 2009; Foreman et al., 2018) or gestational exposure to hormones (Winter et al., 2016). Physicians may also resist providing care because they do not feel trained to meet the needs of gender variant people (Vance, Halpern-Felscher & Rosenthal, 2015; Bauer et al., 2009; Poteat, German & Kerrigan, 2013).

## 1.5 Existing Research on Gender Variance and Care-seeking Experiences

### 1.5.1 *Gender Variant Adults*

Very little research has been conducted on gender variant youth and their parents' experiences seeking healthcare, and therefore I found it necessary to look at the experiences of gender variant adults who seek treatment to get an understanding of what challenges might also be faced by young people. Qualitative research on gender variant adult experiences has been conducted in the U.S., Canada, Sweden and Norway, and show similar findings across cultures. Several studies found structural barriers to care imbedded in healthcare systems, and that providers lack information about gender variant people and their care (Bauer et al., 2009; Roller et al, 2015; Poteat et al., 2013; Linander, Alm, Hammerström & Harryson, 2017a; van

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<sup>20</sup> Z-Codes are used in the ICD to indicate conditions which can have an impact on health, but which are not considered medical conditions (ICD10data.com, 2018).

der Ros, 2013; Dewey, 2008). Several studies found that providers, including those in gender clinics, exhibited degrading, invasive, and abusive behavior toward care-seekers (Poteat et al., 2013; Bauer et al., 2009; Linander et al., 2016a; van der Ros, 2013; Nadal, Skolnik & Wong, 2012; von Vogelsang et al., 2016; Kosenko, Rintamaki, Raney & Maness, 2013; Lindroth, Zeluf, Mannheimer & Deogan, 2017; Wagner, Kunkel & Asbury, 2016). A Swedish study found that care-seekers were forced to conform to strict gender norms to obtain care (Linander, Alm, Goicolea, & Harryson, 2017b).

In their review of the literature, Safer et al. found very little in terms of quantitative studies on the healthcare experiences of gender variant adults (2016). One of the largest survey studies to date, The National Transgender Discrimination Survey in the U.S., presents similar findings to the qualitative studies above, but also found that gender variant careseekers had experiences of being denied even basic healthcare, and had suffered both physical and sexual abuse in healthcare settings (Grant et al., 2011). Transgender people of color were found to be at the highest risk of negative encounters (ibid). A similar large survey study in Sweden found that although most respondents had good experiences in the healthcare system, a relatively large number reported avoiding healthcare due to previous poor experiences and having to educate care providers on their needs (Folkhälsomyndigheten, 2015: 44).

### ***1.5.2 Youth and Family-Related Studies***

When it came to studies on the healthcare seeking experiences of young people with gender incongruence and their families, just as with adults, little quantitative research was available to draw from. Most studies that do exist are qualitative and conducted in the U.S. Europe, and Australia and so I focus on these findings out of necessity.

#### ***United States***

The majority of studies of the care seeking needs and experiences of the families of young people with gender incongruence have been performed in the U.S. A U.S. study of care providers found that they perceived navigating the medical system as difficult for young people, especially because they are dependent on parental consent and transportation (Torres et al, 2015). The same study also found education of healthcare staff was lacking (ibid). In a study of the attitudes toward fertility of gender variant youth with and without ASD, most learned of fertility issues associated with treatment through online sources (Strang et al., 2018). Few voiced a desire to have biological children, although some wondered if they may later change their minds (ibid). Grossman and D'Augelli found gender variant youth feared negative attitudes and rejection from healthcare providers (2006).

Other studies from the U.S. found that finding knowledgeable doctors willing to provide care, and staff not using correct names and pronouns, or making patients feel ‘abnormal’ were challenges experienced by young people (Breland et al., 2016; Guss et al. 2017; Turban, Ferraiolo, Martin & Oleski, 2017). Barriers to healthcare access and experiences of adultism in medicine, i.e. the belief that young people cannot know who they are or participate in informed decision making, were described by Singh, Meng & Hansen as threats to resilience (2014). Turban and colleagues also found that young people found talking to strangers about delicate matters involved in gender affirming care difficult. They also found that puberty blockers and HRT were seen as lifesaving treatment, and that gender variant youth felt care providers failed to see how anxiety and depression they struggled with were tied to social experiences such as a lack of support and discrimination (2017).

In a U.S. study of youth and parents’ perceptions of the future, caregivers expressed fear, sadness and being overwhelmed about their child’s medical treatment (Katz-Wise et al., 2017). One prospective study from a gender clinic in the U.S. found that chest reconstructive surgery had positive effects on quality of life and mental health for young males assigned female at birth (Marinkovic & Newfield, 2017). A study of records at a gender clinic in the U.S. found an average of 8 years passed between discovery of a child’s identity and care seeking, and that young people often did not have the words to define their gender diverse identities until later in life (Greenberg, Handelman & Alongi, 2017).

### *Europe and Australia*

In a Dutch qualitative study, Vrouenraets et al. (2016) found that gender variant youth participants were concerned about the lack of research on their care, but that this did not prevent them from wanting access to puberty blockers and hormones. They also found that participants expressed more concern about the lowering of age limits for puberty blockers than some clinicians, and that binary gender norms created the assumption all gender variant care-seekers would want hysterectomy or genital surgery. Some informants only wanted such a surgery if required to change legal gender (ibid). A U.K. study found that gender variant youth felt misunderstood by healthcare providers, and that the wrong pronouns were used in communication (Zeeman, Aranda, Sherriff & Cocking, 2016). Another U.K. study found that sexual health workers confused homosexuality with gender variance, perceived young gender variant people as too young to know their identity or the kind of care they need, and saw gender variant youth as unstable and misguided (Lefkowitz & Mannell, 2017). An Australian internet survey study asked healthcare professionals about their views on the needs of families

with gender variant children they serve. Professional support, correct diagnosis, and access to puberty blockers were cited as crucial for these families (Riley, Sitharthan, Clemson & Diamond, 2011).

## 1.6 Gender Affirming Care in a Norwegian Context

### 1.6.1 *A Historic View*

The Scandinavian countries are known for their lengthy history regarding the medical treatment of transsexualism. The world's first gender affirming surgery was performed on Lili Elbe in Denmark in 1929 (Hertoft & Sørensen, 1978). It was also in Denmark that Christine Jorgensen received her treatment in 1950 and became a sensation in the press (Sandal, 2017:25). In 1972, Sweden was the first country to establish a law to provide for the legal change of gender (Frøjd, 2016).

In 1953, the Norwegian Justice Department determined that hormone treatment for gender affirming care was legal, while surgery was not, as it constituted bodily harm (Sandal, 2017: 38). An informal treatment offer was provided at *Rikshospitalet* in the 1950s but was difficult to access due to a lack of information in the public sphere (Lilleslått, 2018). In 1955 Norway's first expert group on gender affirming care was formed with the task of investigating the implications of surgical treatment. The three psychiatric experts appointed could not reach consensus on whether patients could be cured via psychiatric care, or if hormone and surgical interventions were the best treatment (Sørli, 2013:46-47; Sandal, 2017: 11, 38). In 1962, the first gender affirming surgery took place in Norway (Hansen, 2001).

Already in 1956, the Minister of Health saw a need to create a law regarding gender affirming care, but this was not followed up (Frøjd, 2016). There remains no law or national guidelines pertaining to healthcare for gender variant people in Norway (Hansen, 2001). In 1979 the forerunner to today's gender clinic was created (Lilleslått, 2018). That same year, an amendment was made to the law permitting persons to change their national identification number (*personnummer*), which contains gender markers, if their gender/sex status had been changed (Frøjd, 2016). There was no language in the law designating that the change must include sterilization (Sørli, 2014; Prop.74L, 2015-2016, §4.1), but until 2016 an attestation from *Rikshospitalet* stating that full gender conversion, including castration, had been completed was required (Sørli, 2016; Van der Ros, 2016). Those who had received surgery abroad had to obtain an attest from *Rikshospitalet* following a gynecological exam (Van der Ros, 2016). In a written question (*skriftlig spørsmål*) presented in parliament to then finance minister Sigbjørn Johnsen, representative Arve Kambe argues that considering when a person

seeks gender affirming surgery abroad because they have been denied care at *Rikshospitalet*, forcing the person to then return to *Rikshospitalet* to obtain such an attestation was an unfair demand (Dokument.nr.15:947, 2012-2013). *Rikshospitalet* later began to refuse to issue attestations to those seeking surgery abroad (van der Ros, 2016), thereby denying legal change of gender to those refused care by their clinic.

In 2000, the gender clinic was closed for a period, as due to the retirement of the lead psychiatry expert and the loss of the team's surgeon, the capacity to serve patients was diminished (Helsedirektoratet, 2012). This meant all diagnostic work and follow up of those already on hormones ceased, and surgery was unavailable in Norway (van der Ros, 2013: 59-60; Hansen. 2001; Helsedirektoratet, 2012). It was also during this year that the forerunner to the Harry Benjamin Resource Center (HBRS) was established (Helsedirektoratet, 2015), which was the only patient organization for gender incongruence in Norway until 2018 when the *Pasientorganisasjon for kjønnsinkongruens*<sup>21</sup>(PKI) was formed.

In 2001 the gender clinic re-opened under the name the *GID-klinikken*<sup>22</sup> (GID or Gender Identity Disorder) (Helsedirektoratet, 2012). It is unclear when *Rikshospitalet* took up responsibility for the care of young people with gender incongruence (Helsedirektoratet, 2015: 39), but a portion of this study's families began care under the GID-clinic name. Also, in 2001, the law was amended to permit people with gender incongruence to change their name in accordance with their experienced gender (ibid). In 2008 the government's action plan *Better Living Conditions for Lesbian, Gay, Bisexual and Trans people*<sup>23</sup> was released (Eggebo, Almlie & Bye, 2015). The initiative was criticized in its final period for not doing enough to help the transgender community (Bufdir, 2011). In 2010, the Directorate of Health was given the task of investigating the healthcare offer for this group (Dokument nr. 15:1263, 2009-2010).

The clinic for gender affirming care at *Rikshospitalet* was later renamed *Seksjonen for transseksualisme* (StF)<sup>24</sup> (van der Ros, 2013), which some of the participants in this study were also treated under. The current name, *Nasjonal behandlingstjeneste for transseksualisme*<sup>25</sup> (NBTS), is then fairly new at the time of this writing. One parent

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<sup>21</sup> Patient Organization for Gender Incongruence.

<sup>22</sup> GID-clinic.

<sup>23</sup> *Bedre levekår for lesbiske, homofile, bifile og transpersoner 2009-2012.*

<sup>24</sup> The Section for Transsexualism.

<sup>25</sup> National Treatment Service for Transsexualism.

participant remarked that although they had witnessed three different name changes to the clinic, no changes were apparent with each reincarnation, and the clinic remained under the same leadership with each change.

### 1.6.2 *The Current Situation in Norway*

In 2013 an expert group was assembled by the Directorate of Health to examine potential changes to the legal gender law and suggest changes to the gender affirming care offer (Offerdal & TM Tønseth, 2018). The subsequent report released in 2015, called *The Right to the Right Gender, Health to All Genders*<sup>26</sup>, called an overhaul of both the law and the healthcare situation. The report recommended decentralization of the gender affirming care offer. It also suggested the law should be changed so that persons could freely change their legal gender without medical treatment (Helsedirektoratet, 2015), as Sweden and Denmark had already done (Sørli, 2016; Prop 74L, 2015-2016, §5.1-5.3). In Spring 2016, a law permitting self-declared legal gender was passed (Sørli, 2016) with provisions for young people over 16 years of age to change their legal gender and name independent of parental support (Frøjd, 2016). Those between 7 and 16 years may change their legal gender with the approval of both parents, with additional provisions in place for those who do not fit this scenario (ibid). Of the families that participated in this study, 11 of 13 had taken advantage of this change at the time of interview.

The number of young people seeking treatment in Norway has more than doubled since 2012, with nearly 200 new referrals to NBTS each year (Haraldsen, 2014; A. Wæhre, personal communication, 24.05.2018). In 2015, a recommendation was made for splitting NBTS into two clinics, one for adults over 18 and one for young persons from 0-18 years (Wæhre, 2015). Previously, the clinic had reported a lack of capacity to handle youth referred to them (Haraldsen, 2011, 2012 & 2013). Due to a steady increase in the number of young people seeking help, the clinic's sole child psychiatric specialist was sometimes supplemented with an adult psychiatric team without competence for working with youth (ibid). If the children's psychiatric specialist was on sick leave, young people were sometimes left without any treatment option (Wæhre, 2015). Additionally, turnover of child specialists was high (ibid). Instances of understaffing due to high turnover rates and sick leave at NBTS have been reported up to recent years (Bordvik, 2017; Lohne, 2017).

In May 2017 reorganization became reality, with the introduction of a KID-team run out of the Women and Children's Clinic at *Rikshospitalet* under the leadership of the

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<sup>26</sup> *Rett til rett kjønn, helse til alle kjønn.*

recommendation author (NBTS, 2018). Previously at NBTS, the number of patients prescribed puberty blockers was as few as 0-3 patients yearly (Helsedirektoratet, 2015: 37). However, at a recent conference, the KID-team's leader reported that 70 percent of patients under age 15 are now being treated with puberty blockers (A. Wæhre, personal communication, 24.05.2018).

NBTS in its various forms has operated as the only clinic (*landsfunksjon*) in Norway with responsibility for treating gender incongruence under the specialist healthcare services code. NBTS interprets its mandate thus that the only group provided treatment are those that obtain the ICD-10 diagnosis F64.0 Transsexualism (Helsedirektoratet, 2012), or in the case of youth, F64.2 Gender Identity Disorder of Childhood (NBTS, 2018). The clinic is criticized for having an overly strict interpretation of which patients meet the criteria for the F64.0 diagnosis (Benestad, Thesen, Aars & Olsen, 2017). In one study involving clinics in four countries, including the Netherlands, Germany, Belgium, and Norway, *Rikshospitalet's* team was indicated to have the highest threshold for giving the diagnosis (Paap, Kreukels, Cohen-Kettenis, Richter-Appelt, de Cuypere & Haraldsen, 2010). In that study only 44% of evaluated care-seekers received the diagnosis in comparison to between 83.3%-97.6% at the other clinics, but the authors caution that due to procedural issues, the study cannot be used as a definitive measure of "strictness" (ibid). Another study conducted at *Rikshospitalet* found that compared to controls and persons with personality disorders, transsexuals had normal range psychiatric testing scores (Haraldsen & Dahl, 2000)<sup>27</sup>. However, the authors admit the findings could be due to strict selection criteria for gender affirmation treatment in Norway, which results in those with some dual mental health diagnoses being denied care (ibid). It is estimated that one half to three-fourths of all seeking gender affirming care at NBTS are denied treatment (Helsedirektoratet, 2015; van der Ros, 2016).

Those not diagnosed with F64.0 are without a public treatment offer to turn to, other than psychiatric help (Helsedirektoratet, 2012; Helsedirektoratet, 2015). The SOC7 no longer differentiates between diagnoses and stresses that all with gender dysphoria and gender incongruence – regardless of whether they fit the F64.0 diagnosis – may be eligible for treatment, and recommends catering care to individual goals (WPATH, 2011). In their 2016 yearly report NBTS claims to follow the SOC (Haraldsen, 2016). They do not specify what version of the SOC they follow. The practice of only offering treatment to those with an F64.0

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<sup>27</sup> The authors chose to compare transsexual patients to a group with personality disorders because some theories attribute transsexual traits to borderline personality disorder as a potential cause (Haraldsen & Dahl, 2000).



diagnosis has been criticized nationally and internationally (Andreas, 2018; van der Ros, 2016; Eisfeld, 2014). Law scholar Anniken Sørli shows that complaints about discriminatory practices at *Rikshospitalet* are met with an assumption that those who fail to obtain the diagnosis F64.0 are not in *need* of medical help (2018b). Many who are denied help at *Rikshospitalet* are forced to pay out of pocket to seek care through alternative providers or to travel for care abroad (ibid; van der Ros, 2016; Sørli, 2018a).

Calls for dissolving *Rikshospitalet's* monopoly on gender affirming treatment have been voiced (Bufdir, 2011; Helsedirektoratet, 2015). Despite multiple evaluations of the clinic over the years, health authorities have been criticized for not responding appropriately to complaints against the clinic (Benestad, 2015; van der Ros, 2016). A lack of transparency at the clinic about their practices has an ongoing concern (ibid; Helsedirektoratet 2015). Key informant participants of this study expressed concern that no national guidelines exist for care and that the production of these guidelines has been a slow process.

A “profession war” (*profesjonskamp*), as one key informant called it, has been waged for many years over who has the authority to treat those that *Rikshospitalet* denies treatment (Benestad, 2015; van der Ros, 2016). On one side is *Rikshospitalet* and the interest group representing their patients, HBRS, who believe that only *Rikshospitalet* should be permitted to provide gender affirming care in Norway. On the other, alternative providers, most of them with a specialization in sexology (Benestad, Thesen, Aars, Olsen & Bjørkman, 2017) and several interest groups representing a broad spectrum of gender identities, who want to see a decentralization of services, opening up the field to low-threshold treatment options, for example, through a careseeker’s general practitioner (GP) (Helsedirektoratet, 2015). This dichotomy is visible in the *Right to the Right Gender* report, where the dissenting minority to most recommendations consisted of *Rikshospitalet's* and HBRS’ representatives (Helsedirektoratet, 2015). One doctor key informant that I interviewed expressed: “It is sad that there has been so much disagreement and conflict within what is essentially a quite small community [of treatment providers].”

Some healthcare providers I interviewed believed that the *Right to the Right Gender* report’s strong recommendation for decentralization gave a green light for providers outside NBTS to offer gender affirming care. As I discuss in this thesis, not only those who are denied care by NBTS are seeking out gender affirming care providers outside the clinic, but also those in the process of seeking help at *Rikshospitalet*, and those who receive the F64.0 diagnosis do so as well. Two key informants explained that their practices have seen a steep increase in the number of gender variant people, especially youth, seeking help.

*Rikshospitalet* has a history of reporting those who provide treatment to gender variant persons to the Board of Health (*Helsetilsynet*) (Benestad, 2015; van der Ros, 2016). Because of this, key informants providing care to gender variant people took extra precautions to ensure they were safe in providing care. One doctor I interviewed explained that they had checked with the Directorate of Health and the Norwegian Medical Association (*Den norske legeforening*) to see if providing hormones to patients was legal, and if they were taking any risks pertaining to their career in offering treatment to care-seekers. They told me how they were informed that if they are providing “responsible treatment” (*ansvarlig behandling*) it was not illegal. What is meant by this is unclear. Nevertheless when, over the course of this study, *Rikshospitalet* began to report providers outside NBTS again, this doctor informed me via email follow-up that they had ceased accepting new patients until further notice.

One argument *Rikshospitalet* makes is that assessments for gender affirming care must be carried out by a multidisciplinary team. However, some key informants of this study informed me that they too had assembled an informal multidisciplinary advisory group of fellow private providers with experience in the field with whom they could confer. Key informant treatment providers said they had made attempts to cooperate with *Rikshospitalet* but found *Rikshospitalet* unwilling to work with them. Recently *Rikshospitalet* has become more vocal about their views of private providers. The NBTS 2017 annual report took up the issue of those who come to the clinic already having begun hormone treatment. In the report they state:

There is no scientific documentation that hormone treatment and/or surgery should be given to trans people where transsexualism is not the issue. NBTS is quite worried over the fact that this is done anyway by private actors and health centers (*helsestasjon*) for people that NBTS believes should not have this type of treatment<sup>28</sup> (K Tønseth, 2017).

In March 2018 an opinion piece (*kronikk*) written by the leader of the KID-team and NBTS’ lead surgeon was published in *Aftenposten* accusing sexologists of “lining up” to dole out testosterone to “the nation’s daughters” (Wæhre & KA Tønseth, 2018). Only a short time later, NBTS published a new policy on their website stating that those who begin treatment outside of the clinic while under assessment for diagnosis will face discontinued assessment,

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<sup>28</sup> Author’s translation. Original text: «Det er heller ikke vitenskapelig dokumentasjon for at hormonbehandling og/eller kirurgi skal gis til transpersoner hvor det ikke er snakk om transseksualisme. NBTS er svært bekymret over at dette likevel gjøres av private aktører/helsestasjon hos personer som NBTS mener ikke skal ha denne type behandling.»

and referrals to the clinic where the care-seeker has already begun care will be rejected. The policy was removed less than a week later (Sae-Khow, 2018).

After the release of the expert group's report (Helsedirektoratet, 2015), two processes to reform the gender affirming healthcare option were set into motion. *Helse Sør-Øst*, which has responsibility for the clinic under the specialist healthcare service, was given the mandate to follow up the expert group's recommendations to determine the structure for delivery of care moving forward. To this end, a working group was established and submitted their report on March 6, 2018 (Helse Sør Øst, 2018). The Directorate of Health was tasked with creating national guidelines for (Dokument nr. 15:1092, 2017-2018). This work is still underway.

The working group was controversial among this study's key informants, many of whom felt that the group was not diverse enough, excluded some of Norway's experts with experience in the field like Esben Esther Pirelli Benestad or the *Helsestasjonen for kjønn og seksualitet (HKS)*<sup>29</sup>. Following the release of the working group's report to public hearing, several group members voiced dissent, stating that the agenda seemed to be set before the group began their work and that the report was composed time was provided to discuss topics addressed in the report (Offerdal & TM Tønseth, 2018). The report was criticized for *Rikshospitalet's* overrepresentation in the group, and for not following up with the expert group's report's recommendations for decentralization of gender affirming care (ibid; Espseth, 2018) The report also contains no plan on how changes in the ICD-11 will impact future care in Norway (Helse Sør Øst, 2018).

So, it is at this chaotic time in the field of gender affirming care that this study was conducted. The study is unique in that it captures some of the experiences of families of young seekers of gender affirming care in this time of flux.

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<sup>29</sup> Health Center for Gender and Sexuality.

## CHAPTER TWO: Methods

### 2.1 Rationale

At the time I embarked on this research project, I had very little qualitative research to draw from that was focused on young people's experiences seeking gender affirming care. In fact, during the time this project was carried out in 2017, few qualitative studies had been conducted focusing on gender variant people in Norway. To the best of my knowledge at the time, the only published studies involving the experiences of young people with gender incongruence in Norway were based upon a human rights framework, addressing the legal gender law (Sørli, 2013; Sørli, 2015), and a focus group-based quality of life study of gender variant people in Norway. This latter study had limited focus on healthcare experiences, relied on retrospective reporting, and had few young participants (van der Ros, 2013). Additionally, a retrospective study of the experiences of LGBT people in rural areas captured some of the social aspects of being a gender variant young person in rural Norway but had no focus on healthcare and concerned a now older population (Eggebo et al., 2015). Thus, their childhoods took place during a period in which gender diversity was less accepted than it is today.

My main goal with this study was to contribute toward filling at least some of the gaps in the literature that I discovered. However, the good news is that the tide is turning. By the time my research was completed, there had been an explosion in the number of projects either in progress or completed at Norwegian universities.

While conducting this study, I learned that the entire landscape of gender affirming care has changed in recent years and become increasingly complicated (Aaserud & Wik, 2017; Haus, 2018). Norwegian authorities are currently undergoing the process of writing new guidelines for gender confirming care and the next configuration of such care remains up in the air the time of this writing (Dokument.nr. 15:1092, 2017-2018). This study offers a unique view into the personal experiences of the people involved in this fluctuating system and can help to inform future policy for gender affirming healthcare in Norway.

### 2.2 Research Questions and Objectives

Because of the lack of academic literature pertaining specifically to the healthcare seeking experiences of Norwegian gender variant youth and their families, I met with several scholars from Norwegian institutions who *had* written on gender variant populations while I was designing the study. I was seeking advice pertaining to study design, suggestions of

theoretical literature that might prove helpful, and to get a feel for issues specific to the Norwegian gender affirming healthcare context that might not be immediately apparent from my previous readings. Thanks to these scholars, I was able to develop the study with a firmer grasp on what the process of seeking treatment looks like in Norway and learn more about current controversies in the field of gender affirming care. This guidance proved invaluable as I considered my research questions and when I later developed my interview guides.

This study's overall research objective was to examine how youth with gender incongruence and their families experience seeking gender affirming care in Norway. The initial research questions were:

- What experiences lead families to seek medical interventions?
- What meanings do they place on these interventions?
- Why do some families opt to seek care with providers outside NBTS?
- What are the qualities of their care seeking encounters?
- Do care-seekers feel supported in the process of care seeking?
- Do experiences of rural-dwelling families differ from those who reside closer to Oslo in terms of traveling to care-providers?
- How do careseekers strategize, prepare for appointments, and 'argue their case'?

One of the strengths of qualitative research is the flexibility to mold one's approach based on what one discovers the study needs underway (Stewart, 1998: 3). In this type of research, fieldwork and interpretation occur in tandem. One can test and challenge accounts one formulates, while also determining what directions demand further exploration (Wolcott, 1987). As I learned, researchers can also determine what directions might prove fruitless despite one's initial expectations. As I conducted the interviews, some topics of interest proved more relevant to participant experiences and their evaluations of importance than others. For example, I discovered that families prepared very little for appointments and did not actively consider what narratives may work best to argue their child's case like some of the literature on adult careseekers suggests (van der Ros, 2013; Dewey & Gesbeck, 2017). Additionally, traveling long distances for care proved only mildly inconvenient to most study participants who had to do so, except in instances of appointments cancelled last-minute. Thus, these topics were only lightly touched on in the analysis.

Of course, while I was in the field, topics also arose that I *hadn't* considered, such as fertility, evaluations of risk, and participant experiences of the age limits placed on certain forms of gender affirming care. However, while the data gathered in qualitative research can

be very broad, the handling of empirical data in an all-encompassing manner when one sits down to write is another matter (Stewart, 1998). Because of this, there are topics I intend to approach in other academic writing that I could not possibly cover thoroughly in this work alone. As for this thesis, I chose to focus on the first five topics of interest. Thus, the research questions this thesis aims to explore are:

- What experiences lead families to seek medical interventions?
- What meanings do they place on these interventions?
- What are the qualities of their care seeking encounters?
- Why do some families opt to seek care with providers outside NBTS?
- Do care-seekers feel supported in the process of care seeking?

### 2.3 Recruitment

Most participants were recruited through purposeful sampling, in which one seeks out cases which can provide rich information related to the topics the research aims to explore (Palinkas et al., 2015). In qualitative studies, sampling efforts tend to focus on obtaining a diverse group of participants with heterogenous backgrounds and experiences. Maximizing variation can provide nuance to analysis and provide opportunities to challenge analysis and theories as they emerge (Moen & Middelthon, 2015: 334; Maxwell, 2012: 235). Because of this, efforts were made to recruit parents and adolescent care-seekers under 25 years of age, at different stages in their care seeking process, with a broad range of experiences, opinions, and in locations around Norway, to capture the widest breadth of experiences possible.

Youth and their parents were recruited in several ways. I requested help from local interest groups and community health entities serving gender variant youth to spread information about my study by distributing flyers or sending out information via email. I chose to ask a variety of institutions with different stances on the delivery of gender affirming care to help with this process. The rationale behind this was that families with different experiences might be likely to be members of certain interest groups (for example those with more conservative views on treatment of gender incongruence vs. those with more progressive views) or use certain services (in example, I wondered if perhaps those who use private providers would primarily belong to a higher income bracket because of the cost of utilizing these options). Info was additionally shared via relevant Facebook groups.

One participant mother was recruited via private contact after posting on a topic of relevance in a Facebook group that indicated that she knew someone who had been to NBTS

since the recent restructuring. Up until that point, I had not yet succeeded in recruiting participants who had had experiences under the new structure. When I informed her of my study to ask her to pass on information to her friend, I discovered only *then* that she herself was a mother of a gender variant child. She then expressed a desire to contribute. That participant then went on to assist me with “snowball recruitment”, or when a participant informs friends or acquaintances of the study. This participant was educated in the social sciences and made efforts to also put me in contact with people she disagreed with and she too understood the importance of encouraging people with a broad range of experiences and views to participate. This participant also took a special concern in the gender balance in the study, attempting to help achieve diversity, which as I will later describe, proved difficult at first. The effort was deeply appreciated.

In all, participants were recruited via an even mixture of the above-mentioned recruitment sources. Given that I received a wide range of participants in terms of locality, the fact that the organizations that aided in recruitment were based in Oslo seemed to have had only a minor impact. Attempts were also made to draw in gender variant youth with immigrant backgrounds, to explore how their experiences may differ. Unfortunately, the one participant matching this description withdrew before their interview. Additionally, some who made contact expressing an interest in participation were over the age of 25, and so participation was declined, as they did not meet inclusion criteria of seeking gender affirming interventions in adolescence.

Key informants for the study were participants who either work in the field of gender affirming care as care providers or who were professionals working for interest groups that deal with topics of gender affirming healthcare. Through the media and public events, I became aware of some of the key players in gender affirming care. I made contact to invite these key informants directly via email.

## 2.4 The Participants

### 2.4.1 *Key informants*

The study included one interview each with eight key informants. Of them, four were female, two were male, and two were nonbinary. Half of the key informants identified as transgender or transsexual, meaning that have an experience of gender different from the gender they were assigned at birth. The other half were cisgender. Key informants included three professional activists working within interest groups, three doctors, and two nurses. Four of the key informants had a specialization in sexology. All had a history of working in some capacity

with youth with gender incongruence, as care providers, or by arranging events such as summer camps or support groups for young people and their families. Follow up occurred as needed via email.

**Table 1: Key Informants by occupation**

Doctor	3
Nurse	2
Interest group employee	3

**Table 2: Key informants by gender identity**

Cisgender female	Cisgender male	Trans* woman	Trans* man	Trans* nonbinary
3	1	1	1	2

\*Trans with an asterisk after it is often used to indicate that a person could identify as transgender or transsexual, with the shared trait that their gender identity is different from that assigned at birth.

### 2.4.2 Youth & Parents

The main participants consisted of ten young people, and ten parents which made up 12 “cases”. I considered one “case” to involve the journey of one youth with gender incongruence, even when participating by proxy through their parent. The cases included the stories of four girls and eight boys. Three youth participated without their parents, two parents participated without their child, and seven young people participated with at least one parent. Parents included eight mothers and two fathers. All parents identified as the gender they were assigned at birth, but three actively explored their own gender nonconformity in the interview.

All of the parents whose voices are included in the study were supportive of their children’s identities and instrumental in assisting their child in obtaining medical interventions. The two youth whose parents were not interviewed said that their parents were also generally supportive. Youth participants ranged from 12-22 years of age, with a mean age of 16.6 years. One female participant had completed all gender confirming care offered within the Norwegian system (hormones, breast augmentation and genital surgery) and one of the young men was unsure if he would pursue phalloplasty and hysterectomy or consider his journey complete. Three of the youth participants were being treated only with puberty blockers at the time of interview, whereas six were being treated with cross hormones. One had not yet received access to any medical interventions at the time of interview.

All participants had experiences of seeking care at *Rikshospitalet*. Four families had only received somatic interventions such as puberty blockers and HRT via *Rikshospitalet*. Two of those four families went through the system during a period when few private gender



affirming care providers were available, however, they had sought other providers for counseling. One family had received all care through *Rikshospitalet* thus far but was actively seeking out private providers for hormones and surgery. Two female participants were denied further care from the public gender clinic and sought help through providers outside NBTS. Most cases (n = 10 of 12) had experiences involving both *Rikshospitalet*, and providers outside *Rikshospitalet*, with 8 having received medical interventions (puberty blockers or HRT) through outside providers. All but one study participant had received all their gender affirming care in Norway, although most participants considered traveling abroad to seek care (usually surgery) in the future. No youth involved in this study had obtained their hormones illicitly by buying them over the internet or via a dealer (for an overview of the cases see Table 3<sup>30</sup>).

The rationale for including parents was to obtain a deeper understanding of family decision making and strategizing practices involved in pursuing these interventions. As most of the young people involved in this study are minors, I felt it important to interview parents because they were by necessity part of the informed consent process when gaining access to puberty blockers. This treatment begins just after the onset of puberty, when most children are under the age of 16 (the age to consent to medical treatment in Norway). Additionally, parents may have intimate knowledge about their child's day to day life, as well as their responses to care. These viewpoints can contribute additional depth to the study. My hunch was that in most cases parents would be highly active in coordinating care details, such as finding providers, arranging transportation, and providing information in the care encounter itself.

As gender affirming careseekers must regularly travel to Oslo to obtain care, I sought to draw in participants from as many regions of Norway as possible to explore how they experience the need to travel for care. This was achieved, although no participants came from localities further north than Møre og Romsdal. Main participants came from 7 different counties (*fylker*) within Norway. Additionally, families had a diverse range of income levels, with most clustered around the middle-class range.<sup>31</sup>

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<sup>30</sup> In the table, all names and some of the ages have been changed to protect the participants' identity.

<sup>31</sup> Most parents provided a rough estimate of yearly income for the family, which was compared to the median household income in Norway for 2017, obtained from the State's Statistical Central Bureau (*Statens statistiske sentralbyrå, SSB*) website. Youth interviewed alone did not know the family income level. One family's sole provider was unemployed, and another parent sole-provider was a partially employed student. Median income was approximately 633,000 Norwegian kroner (higher than the median yearly household income, but that number was skewed by the fact that one family made substantially more than all others. Most were also one-parent households due to divorce or the death of a parent.

Four cases received care under previous incarnations of the clinic before it became NBTS<sup>32</sup>, but one parent expressed that she witnessed no significant change in experiences under each incarnation. Seven cases had experiences of the transition between when youth were treated at the same clinic as adults at NBTS to the creation of the new youth clinic (KID-team). This provided not only a window into how participants view the changes, but an opportunity to explore how their experiences may be affected by this change.

**Table 3: Main participant case overview**

Case*	Age	ID**	Rikshospitalet	'Private'***
Stefan	16	Male	Under assessment	Puberty blockers HRT Counseling
Lasse Arnt Ina	13 N/A N/A	Male Father Mother	Puberty blockers	Counseling
Mari (Sofie)	N/A 17	Mother Female	Puberty blockers HRT	Counseling
Sigrid (Nathan)	N/A 15	Mother Male	Puberty blockers	HRT Chest surgery Counseling
Magne Marthe	12 N/A	Male Mother	Puberty blockers	N/A
Karl Siv	14 N/A	Female Mother	Puberty Blockers	N/A
Henrik Harald	16 N/A	Male Father	Under assessment	HRT Counseling
Pål	17	Male	Under assessment	HRT Chest surgery
Madelen Åse	16 N/A	Female Mother	Puberty blockers No longer a patient	Puberty blockers HRT Counseling
Annika Benedicte	17 N/A	Female N/A	No longer a patient	HRT Counseling
Natalie Karin	20 N/A	Female Mother	HRT Breast augmentation Vaginoplasty	Counseling
Jens	22	Male	HRT	HRT Chest surgery

\* All participants for each case are included in the same row. If a parent participated without their child, the child's pseudonym is given in parentheses, and information on treatment pertains to them.

\*\*Identity as it pertains to the study. Youth participants are identified by gender identity, parents are identified by parental role.

\*\*\* Here I use 'Private' as shorthand for treatment received outside of OUS Rikshospitalet.

Lastly, it is documented that persons with an additional diagnosis on the autism

<sup>32</sup> As mentioned in the background section, the previous names were *GID-klinikken* and *Seksjon for transseksualisme*.

spectrum (ASD) are overrepresented within the gender diverse population, while gender diversity is also common among the population diagnosed with ASD (Jacobs et al., 2014; Strang et al., 2018). This study included two participants on the autism spectrum, as well as one whose diagnosis was contested.

## 2.5 Methods Overview

Qualitative methods explore the experiences of individuals as embedded in their ‘life worlds’, and as related to their positionality in social contexts (Marecek, 2003). They seek to examine lived experiences by understanding participants as “reflexive, meaning-making, and intentional actors” (ibid: 49). Some of the insights that qualitative studies are well-suited to produce include helping us to understand the meanings participants place on experiences, as well as the context in which these experiences occur (Maxwell, 2012). They can help identify unexpected phenomena that can lead to the generation of new theories or introduce new applications of existent theories. Qualitative research may also help us to understand the processes that may lead to certain outcomes (ibid).

Such research does not claim to offer generalizability in the ways that quantitative methods may (Marecek, 2003: 63; Moen & Middelthon, 2015: 375) but instead facilitates the connection of findings discovered in particular sociocultural environments to their wider contexts (Moen & Middelthon, 2015: 333). More important than offering generalizability is the insights provided by qualitative research (Moen & Middelthon, 2015: 374; Stewart 1998). In fact, anthropologist Alex Stewart argues that rather than applying quantitative research concepts like validity and generalizability as indicators of whether a *qualitative* study has merit, the concept of ‘perspicacity’ should instead be applied (1998). Perspicacity is the extent to which a study succeeds in providing insight into the phenomena it explores (ibid).

That’s not to say that findings may not be applicable to other settings. As a part of the insights it generates, qualitative research may help in the development of new theoretical concepts or frameworks that may be applicable elsewhere, or may challenge existing concepts (Moen & Middelthon, 2015: 368-370; Stewart, 1998). And although qualitative research focuses on a particular group of participants’ experiences in specific contexts, the insights generated may also provide nuance and deepen current understandings of how broader social phenomena are experienced (Moen & Middelthon, 2015: 368; Malterud, 2001). For example, findings from this study may be applicable to other gender variant populations in similar sociocultural contexts. They may be used to provide a greater understanding of how families with gender variant children conceptualize early interventions or how young gender variant

adolescents experience puberty. They may also contribute to current understandings of how gatekeeping in healthcare encounters is experienced or how encounters in medicine may sow seeds of trust or distrust in careseekers.

Moen and Middelthon argue that good qualitative research should present diverse perspectives, record deep information about interactions, involve member validation by offering participants a chance to comment on analysis and descriptions, include reflection on the role the researcher plays, and bring “relevant outsiders” into the discussion (2015: 374). To add as much rich information and contextualization as possible, the study was conducted using a variety of qualitative methods, namely; interviews, community engagement and text-analysis. Qualitative interviews were conducted with parents and youth who have experiences seeking gender affirming care in Norway (main participants), as well as a variety of healthcare providers and activists (key informants). Key informant participants were included to provide a deeper contextual background as to the current situation of gender confirming healthcare for young people, and to provide triangulation to the study. Triangulation involves amassing information from a wide range of people and material sources, as well as using a variety of methods to access a broad spectrum of viewpoints (Malterud, 2001; Stewart 1998). In qualitative research it may operate as a kind of “validity test” (ibid) but may also contribute to a study’s “objectivity” by helping to limit the effect of bias (Stewart, 1998). Triangulation can help a researcher question their own findings (Malterud, 2001) by providing further points of reference to challenge the accounts and theories one is building about their fieldwork experiences (Stewart, 1998; Maxwell, 2013).

### 2.5.1 *Interviews*

The study’s main method of gathering data was qualitative interviews. Interviews with participants used a semi-structured format, in which certain themes were deemed important to address, but no precise questionnaire was maintained. Semi-structured interviews have the purpose of obtaining deep descriptions of a participant’s subjective views on a topic of interest (Kvale, 1996). This type of interview suits this study, given that my primary goal was to examine a diverse range of personal experiences of gender affirming care. Such interviews allow participants to express the nuances of their experiences in their own words. This style of interviewing also lends itself well to several forms of analysis (Willig, 2013:29), providing a “construction site for knowledge” as knowledge is *produced* through a conversation (Kvale, 1996:144). Semi-structured interviews are also preferred when there will only be one opportunity to interview a participant (Bernard, 1988), and since I was unsure if time would

allow for follow up interviews, I felt this method would ensure that I would get the most out of my first opportunity to speak to a family, should it become the only one.

The openness of semi-structured interviewing can lead one to perspectives the researcher may have been unable to anticipate in advance of the study (K. Moen, personal communication, 24.04.2017). There is a risk that certain details can be missed with interviews too structured by the researcher to permit their emergence (Willig, 2013: 29-31). While still being guided by what the researcher wishes to learn (Kvale, 1996), there is an opportunity for the participant to also contribute to and guide the interview's focus (K. Moen, personal communication, 25.10.2018). Indeed, in qualitative research, participants may be viewed as "co-producers of knowledge" (Moen & Middelthon, 2015: 333).

I constructed three separate interview guides for key informants, parents and youth<sup>33</sup>. These were intended as living documents that could be expanded as new themes arose over the study. Because of their flexibility, they could easily be adapted to special circumstances, such as adjusting content based on profession in the case of key informants or making changes to the language based on a participant's age or special considerations (such as in the case of participants with ASD).

### **Key Informant Interviews**

Interviews with key informants mostly involved probes into the nature of their work, thoughts on recent developments in gender affirming care, common concerns about offering treatment to young people, as well as what they like best about their work. Diversions from the interview guide occurred when a key informant's positionality could lend deeper context on gender affirming care and the current political climate around providing such care (for example, if a key informant had contributed to a recent media debate). All but one was held within the key informant's workplace; the exception was conducted on public transport per the participant's wishes due to time constraints. Interviews lasted anywhere from 30 minutes to just over an hour. Six were conducted in Norwegian, while two key informants chose to do the interview in English with occasional Norwegian supplementation.

At the beginning of the process, I opted to write field notes alone in these encounters. In these cases, I asked the participant if they would like to review the field notes to ensure that my recollection of the encounter was precise. However, as I began to realize the intricacies of the material I was getting from these key participants, I began to record them so that I could have a precise document of the exact wording of their statements, as well as ensure that no

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<sup>33</sup> See appendix F for interview guides.

nuances were lost.

### **Main Participant Interviews**

When it comes to the interviewing main participants, namely youth and parents, settings were diverse. I conducted the interviews at the locale of the participant's choice. This was sometimes their home, a local library, or on campus at University of Oslo in a private room in the case of participants who, for reasons of convenience, were interviewed directly after appointments with care providers in Oslo. Interviews generally lasted between 40 minutes to an hour and a half.

All interviews with parents and youth were conducted in Norwegian and recorded digitally. They were then transcribed as closely to the original dialect as could be achieved, considering my status as a non-native speaker. All quotes presented are translated into English by me, with the Norwegian wording included for context as needed.

When possible, parents and children were interviewed separately to provide an opportunity for discretion and authenticity. Youth could feel free to share information they may not want their parents to be privy to, while parents were free to share feelings and experiences that they might otherwise shield their children from. When such information is presented in the thesis, I use neutral terminology like 'one parent said' or 'one young participant said'. This was important, for example, when a parent reported going through an initial process of grieving over the loss of the child they thought they had. Such narratives, while common among parents of gender variant children (Katz-Wise et al., 2017; Wren 2002), could be hurtful if the child is unaware of the process their parents went through to accept their identity. In two cases parent and child were interviewed together. One such interview was due to time constraints, and the other was because the young participant, on the autism spectrum, felt more comfortable with their mother present to help supplement the account, as oral communication can prove challenging for them.

I first constructed a timeline with participants, not only to help jog their memory of the order of events in their care-seeking experience, but to allow them to get comfortable with myself as the interviewer. Opening the conversation with basic information first provides time for participants to ease into comfort with myself as a researcher, rather than diving directly into information of a more personal nature. Since gender affirming care narratives are quite often of a temporal quality (Pyne, 2017), constructing timelines was a helpful tool to get the conversation flowing and helped assure clarity. After constructing the timeline, I prompted with questions to add depth to the experiences sketched out initially.

As the study progressed, I discovered that sometimes the parent or youth spoke so freely during timeline construction that I thought it best to allow for a more loose format, and used “silent probing” where one remains inobtrusive, nodding or injecting engaged listening cues while waiting for participants to continue (Bernard, 1988:211). I then followed such moments with questions to clarify and further explore what was shared (Kvale, 1996:136). These were some of the best interviews, as they opened a window onto these participants’ subjective worlds and allowed them to be candid with me about their opinions, experiences and emotions (Holstein & Gubrium, 2003). I also engaged in “phased assertion” in which experiences and perspectives garnered from other interviews is shared to get participants talking (Bernard, 1988:215). In some cases, just asserting that I had heard others make similar statements was enough to encourage participants to continue elaborating on a point.

All parties were interviewed once, although I met with two parent participants twice. One I met first to establish rapport prior to joining the study, and the other parent graciously hosted me in her home on two occasions while interviewing. This mother often provided information not captured in the interview that are reflected instead in field notes. Field notes were written after interviews and events to capture impressions and conversations had “off the cuff”. Additionally, I recorded two parent participants’ spontaneous discussion of their experiences of care-seeking and parenting a gender variant child with their permission.

### ***2.5.2 Text Analysis***

Study participants also sometimes sent me additional materials of their own initiative, for example, letters to political and governmental entities, internal documents, personal commentary and links to press articles on developments in the gender confirming healthcare debate. These supplements to the interview data proved invaluable, for example, by letting me know how they interpret controversies in gender affirming care and how they approach these controversies as political actors. They also helped me gain access to documents I may have had difficulty locating in the public record. I was touched by the dedication of participants to ensuring that I got a more complete understanding of their experiences. Having access to these additional documents further contributed to triangulation of the study.

To provide further triangulation to the study, a diverse body of materials including relevant segments in the media, Norwegian medical journals, official reports, political documents and law texts were also amassed and analyzed. As there had recently been a significant focus on gender variant people’s healthcare experiences in the media and politics, these added materials helped me interpret patterns that I was seeing in my own data, like

providing background information on changes that were going on at *Rikshospitalet* at certain periods of time. Piecing together the legal and political history of gender affirming care in Norway also proved enlightening background information that gave me, an immigrant to Norway, a bit more of an insider's perspective.

### ***2.5.2 Community Engagement***

Lastly, owing to my training in social anthropology, a good deal of background information and triangulation lent to the study was gathered through community engagement. Over the course of this study, I attended multiple conferences, lectures and debates on gender studies and gender affirming healthcare and consulted with several of Norway's leading academics in this field of research. I participated in Pride events, was present at a protest of statements made by NBTS outside the Norwegian parliament and attended the opening statements in a pivotal court case pertaining to prior sterilization requirements for the change of legal gender in Norway. I visited participant's homes around Norway, and in one case was invited to dinner with the local gender diverse community. I had the pleasure of briefly meeting activists, care providers, and family members outside of the study participant group.

Although a large amount of this "deep hanging out" as Clifford Geertz called it, may have seemed irrelevant to the topic on the surface, it gave me invaluable insights into the struggles this community still faces. I gained knowledge of the politics and motivations behind different interest groups within the gender diverse community and developed a more natural understanding of language usage and meanings attached to language. All these experiences contributed to the formation of this study and proved helpful when it came time to engage in its analysis.

One problem arose for me which is common for academics conducting qualitative fieldwork "at home". I place "at home" in parentheses because, although I have lived in Norway for six years, I am still an outsider in some regards, having spent a good 34 years of my life living in my native United States. Nevertheless, the first challenge was defining "the field". Typically, in anthropology, the field has been marked by its 'spatial separation' from home and the field site is seen as "purer" the more "not home" it is (Gupta & Ferguson, 1997:12-13). So, when I interview a participant in Oslo, fifteen minutes from home, does the concept of the field then become diluted? Gupta and Ferguson argue that in any anthropological study, the field does not exist per se, but rather is actively constructed by the researcher (1997: 5).

As one might surmise from the broad range of activities I participated in, it was often



not until after an event that I realized how integral an experience was to my understanding of the topic of study. If, for example, when a sexologist at a local LGBT organization gives me counseling on my own gendered experiences, and it unexpectedly provides insight into how valuable such counseling can be for young people in the process of identity exploration, am I then ‘in the field’? The line can become quite blurred in this type of research. So many experiences can prove useful, not just in getting the facts straight, but by building “coherent connections (and disconnections)” (Talle, 2010:118) or in developing new interview themes.

## 2.6 Analysis

I chose to take an interpretive phenomenological approach to analysis. Phenomenological approaches have the key aim of describing the subjective experiences of human actors in “particular contexts and particular times” as they are presented to the researcher (Willig, 2013:84). The approach recognizes that an actor’s previous experiences, opinions, goals, desires and positionality influence how events are perceived, and that different people perceive the same events in very different ways (ibid). This approach is particularly suited to use with gender variant participants, as such approaches describe embodied experiences without questioning the legitimacy of subjective knowledge or negating individual agency as other methods may (Rubin, 1998). They enable the researcher to approach gender variant people’s stories with an “ethic of listening” (Rooke, 2016). Past studies of gender variant persons (as well as, I would argue, the diagnostic process) have all too often questioned their subjective narratives, agency and autonomy (Rubin, 1998).

*Interpretive* phenomenological methods seek to understand subjective experiences in their wider context. Attempts are made to examine their cultural, psychological and social undercurrents while providing theoretical bases with which to gain a fuller understanding of how norms, politics, social structuring and history inform subjective accounts (Willig, 2013). As I have a background in psychology and anthropology, I apply analytical lenses common to both fields, while also engaging with the wealth of knowledge I have acquired through the study of global and community health over the course of this master’s degree program.

In terms of the techniques, I performed thematic analysis of interview transcripts, field notes, and supplementary text materials (including grey literature, media articles, and items sent by participants). This process involves uncovering themes and their relationships in the materials. It has been argued that analysis often begins before one enters the field, and continues throughout the project (Bernard, 1988: 319). For example, I had themes in mind when I began relating to power-relations in healthcare encounters, navigating the system and

the construction of narratives to argue one's case. These were based on previous research with gender affirming care-seekers and are reflected in my research questions. Unexpected themes emerged over the course of interviews in observation of emerging patterns and lead to their introduction into interviews, such as questions related to waiting, where others fell to the wayside, like the narrative construction theme I had anticipated.

While transcribing interviews, I became intimately acquainted with the material within them. With grey materials, I did initial read-throughs prior to diving into analysis. In this early phase, I took preliminary notes about potential themes and connections revealed in the data. I then did line by line readings of the material, casting a broad net as I coded sections in the qualitative data analysis program NVivo. Codes denote basic "units of meaning" within a portion of text, and a single portion may be assigned multiple codes (Willig, 2013). At first, I coded sections freely and narrowly, with many of these early codes mostly focused on descriptive codes for segments. These could be experiences, treatment topics, or even emotions, for example 'anger', 'fear', 'puberty', 'bullying' or 'puberty blockers'. Stewart calls these codes "first order indexes" as they are based on early observations before connections are drawn (1998).

This mode of coding can result in a bit of a chaotic system at the beginning, but these organizational codes can function as indexes for finding pieces of data later during the process of decontextualization (Stewart, 1998; Maxwell, 2012). The goal is essentially to "fracture" the data to categorize and draw comparisons within and between codes (Maxwell, 2012). With computer programs like NVivo, one can easily remove fragments from their original context and compare them to other similar pieces of data to discover connections between experiences, cases, and materials (Stewart, 1998; Maxwell 2012). By comparing cases based on insights that arise throughout the process of decontextualization, one can discover, not only connections, but also inconsistencies that might challenge initial ideas (Stewart, 1998).

As this process progressed, it became apparent that certain narrow codes fit under broader themes called second order indexes (Stewart, 1998). that could be descriptive of a larger phenomenon, for example, under the code 'identity' are several lower level codes like 'early memories', 'coming out' and 'terminology', i.e. how the person refers to their identity or that of their child, and how they came to this understanding. Themes are developed based on what is deemed important in the data, and researchers often use the research questions as a guide in this process (Willig, 2013). Next, I organized and visualized connections between codes as they relate to emerging themes, writing memos on these initial insights. Moving back and forth between decontextualizing and recontextualizing the data by reading the full

accounts again in some cases, and comparing them to other sources like media articles, higher order constructs related to these other thematic nexuses began to emerge. For an example of one such construct, I discovered how suffering is tied to crises of identity and fears about one's future life chances that are exacerbated by the onset of puberty. These crises then act as a catalyst for seeking care.

As I began the process of writing up, I gave a good deal of thought to the themes that the participants of this study would find most important to shed light upon and used these insights as a guide for selection of the topics presented in this thesis. With this consideration in mind, major themes that were deemed imperative to include were trust, power, suffering, uncertainty, identity/gender, stigma, waiting, psychiatry, autonomy, and gatekeeping.

### ***2.6.1 Follow-up and member checking***

I maintained follow-up contact with study participants using the method of their choice when necessary to inform them of issues related to the study, or to clarify when there was confusion in the analysis phase. When contacted, they would often respond unprompted with updates on their situation. Member checking, or respondent validation as it is also called, was performed by offering study participants opportunities to read drafts of the chapters concerning findings to comment on the analysis and to correct any inaccuracies. This was done in waves. Chapters were first provided to those whose accounts were more heavily represented in the text. Once feedback was received from these study participants, an opportunity was then offered to all study participants to read and comment on the drafts. Study participants may see things quite differently than researchers, and an opportunity to have discrepancies pointed out can indicate a need for further examination (Stewart, 1998). Member checking can also be a way of identifying biases (Maxwell, 2012). Although some study participants did not want to read (with one stating that they simply trusted my judgement), the feedback I received from the parents and young participants that generously gave their time to the task indicated that they were pleased with the result, adding commentary that strengthened my security in the analysis and insights presented.

## **2.7 Ethics**

Working with communities that may experience vulnerability requires special consideration on its own, but when some of those participants are minors, the importance of those considerations is magnified. However, due to predefined conceptions of what constitutes a vulnerable group, some persons have been exempted from participation in research, and this is particularly true of children (Strandbu & Thørnblad, 2010). Thus, much research on young

people has been performed through an adult(ist) lens instead of paying attention to the issues young people find important (James, 1999). In recent years in Norway greater emphasis has been placed upon listening to the voices of children when their interests are at stake (Larsen, 2013). I believe that we cannot truly understand the experiences of gender variant youth without including their voices in research on matters that affect them.

In prior experiences with the gender variant community, I encountered a sense of duty to participate in research. Because so few studies had been conducted on their experiences, participants were eager to contribute positively to the knowledge base in hopes of increasing understanding of their situation. Many of the parents and youth I spoke to in this study expressed similar motivations. Many expressed hopes that such research might result in changes to policies and practices regarding the system of gender affirming healthcare. Several felt very few people had knowledge of their experiences or were willing to listen, and some expressed that they felt silenced in their grievances by the patient groups that were supposed to support them. And so, participating in research was a means of empowerment.

Some question whether participation can really be considered voluntary when one feels a moral obligation to participate. Wertheimer argues that according to the legal approach to voluntary consent "...a decision is not regarded as involuntary if it is driven by the agent's own values and preference or the agent's *circumstance* [emphasis original] (2012:231)." The will to participate as an effort to help one's community can thus be deemed a voluntary act. It is important, however to prevent participation by coercion, which could be as simple as participating due to pressure from a healthcare provider (Wertheimer, 2012). This was taken into consideration when information on this study was spread by various care providers or friends of participants.

To avoid coercion, participants were given information and encouraged to make contact if interested but were free to decline<sup>34</sup>. Had I been given information to contact prospective participants directly, they may have felt more pressure to say yes to the invitation. I considered that by going the extra step of initiating contact, participants were demonstrating a willingness to participate already. It was at this point that I provided more concise information on the study. If any potential participant suddenly ceased contact, one additional attempt was made to check in and then no further attempts were made, to avoid any semblance of pressure to participate. Several prospective participants who were initially provided with information sheets declined to participate for various reasons, and so it seems

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<sup>34</sup> The one exception being the aforementioned mother.

those who felt that participation was not for them felt free to decline.

Unlike main participants, I made direct contact with key informants via email, inviting them to participate. As the power relationship here is often balanced or even skewed in their favor, direct contact was not deemed problematic.

Additionally, at the time of interview I again went through steps to ensure that all participants were participating of their free will and were aware of the unconditional right to withdraw consent. This was especially important when it comes to the youth involved in the study. Although in the half of all cases, the young person was the one to make contact and demonstrate willingness to participate, sometimes it was the parent who made initial contact. In those cases, I tried to feel out how willing the child seemed to participate, in addition to assuring them that they could choose not to. My concern was that if parents press their children to participate, they may feel they have no choice but to say yes. I was not however, given the impression that any of the youth involved had anything other than a desire to participate. When I told participants about the right to withdraw from the study, the most common response was “Oh, I’m not going to do *that!*”

In the original research protocol, the inclusion criteria were such that both the child and the parent had to participate. This was due to concerns of consent, to ensure that both the parent consented to the child’s participation and the child consented to the parent’s participation. This would also deepen the perspective of each individual case. However, it was soon discovered that in some cases a child desired to participate but the parents did not, or vice versa. Permission to permit youth to participate without parental participation and parents to participate without their child was granted by NSD (see appendix D).

In the cases of parents that did not want to participate, one can speculate that it may have been due to a lack of time, but may also have been due to residual ambivalence regarding their child’s care, or that they felt the child could best speak for their experiences. Reasons parents gave for participating without their children were telling in terms of the topic of research. The two parents who participated without their child both made clear that they were shielding their child from further intrusion into their personal lives. They felt it was important that their stories be told, however they desired to spare the young person having to tell yet another stranger the intimate details of their gender journeys. Considering the numerous professionals they have had to confide in to receive care, this is understandable. In these cases, the child gave written consent for the parent to participate in the study.

The threat of retraumatization looms large in studies where the topic may include traumatic experiences, but there is also the opportunity for healing (Strandbu & Thørnblad,

2010). Most participants expressed gratitude that someone was listening to their story. More than one parent expressed relief after sharing their experience; as one parent exclaimed at the end of our interview: “Thank you, I never thought I’d get that out! Because it deserves to come out, actually.” At times the interviews were emotional, dealing with difficult subject matter, but some viewed the interview process as giving a purpose to their struggle. Benedicte said “We understand that our situation, that you can’t do anything about it. But you have the possibility to do something in relation to those who come after us. It’s very nice that there’s someone who’s researching it. And talks to us, so we are heard too!” Several parent participants expressed that information sharing was viewed as a tool for coping and resilience.

It is crucial to ensure that participants identities are kept anonymous. Not only was this promised to participants, but also a condition of ethical clearance at NSD. LGBT youth may be at a high risk of victimization such as harassment and bullying (Toomey et al., 2010; Eggebø et al., 2015) and parents of gender variant children have reported harassment for “bad parenting” (Green, 2015). Being identified as participants in such a study could theoretically provoke harassment. Additionally, some participants in this study expressed beliefs that those who speak out against *Rikshospitalet* may be in danger of retribution from the clinic itself.

Anonymization can prove challenging when dealing with a small community where people tend to know each other. This includes those who live at a distance, thanks to the internet and special events held for these families, such as HBRS’ summer camp (*sommertreff*). Over the course of the study it became apparent that participants were intimately acquainted with the stories of other families and thus it stands within reason that they may be identified by each other in the text based on this shared knowledge.

Key informants are also at some degree of risk from exposure if identifiable. NBTS has a history of reporting those who violate its monopoly on the care of gender incongruent persons to the authorities and has continued this practice even recently. Since there are few healthcare providers with a history of providing care to gender variant persons (Benestad, 2015; Offerdal & TM Tønseth, 2018), the possibility of identification in a such a small community may be even greater.

Saunders, Kitzinger & Kitzinger faced a similar problem in their study of the family members of persons with disorders of consciousness. Because the community is small and so few care providers exist, there was a threat that both community members and healthcare personnel may identify participants. Also like my study, several the cases present in Saunders and colleagues had also been presented in the media, and special precautions had to be taken to limit the ability to tie participant experiences to those reported in the public sphere (2015).

This thesis benefited greatly from their experience and guidance.

Names of the participants have been changed in all cases, and I have not included their geographic locations, as these were not often of relevance and could be used to narrow down identities. Occasionally participant details and narratives were mixed together to split a narrative or the gender of a child was changed when it would not impact the data. Where great effort is required to protect the identities of participants, it often necessitates finding creative ways of adapting the data without diluting its impact (Saunders et al., 2015). I consulted directly with parent and youth study participants during the member checking process to determine if they themselves felt their accounts would be identifiable. In the end, these participants approved of the final versions and expressed that they felt appropriate measures had been taken to protect their identities.

Key informants are not named but are simply referred to as ‘one key informant nurse’ or ‘one key informant that is a doctor’. Additionally, all key informants are addressed using gender-neutral pronouns. This is because the nonbinary key informants may be identifiable based on the use of gender-neutral pronouns attached to their accounts. Therefore, all key informants are addressed in the same way, with reference only to their occupational status.

Researcher engagement with the community also poses several ethical considerations. In qualitative research comments made in random encounters or overheard in public settings may prove crucial and be recorded in field notes. Questions of whose informed consent is required are always a challenge in such situations (Marecek, 2003). As the events I attended such as debates, lectures and activist events were public, it was not possible or practical to obtain informed consent from all participants. Since no direct accounts from these experiences are included in this thesis<sup>35</sup>, but were rather used to provide context, I feel that the interests of those present are nevertheless protected.

Researchers have an obligation to do everything in their power to protect their participants from undue harm (Willig, 2013). Despite the best of intentions, there is also a risk that a researcher’s work may be misused to the detriment of their participants (Bourgois, 1990). Continual and constant ethical attention must be actively drawn to situations as they arise, as well as how best to sensitively remedy them (Detamore, 2010). Ethical considerations become then an unending, precarious dance for the qualitative researcher.

The study’s research protocol and other materials were submitted to REK, however REK deemed the project to not fall under its jurisdiction. The protocol and materials were

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<sup>35</sup> The exception is statements made by experts at conferences.

then submitted and approved by NSD<sup>36</sup>. Following approval, arrangements for storage in University of Oslo's secure data service, TSD, were made. All data was stored in the TSD server until deidentified and anonymized, to protect participants involved. Recordings were deleted to protect participants from being identified by voice, while timelines were scanned, uploaded to the secure server, and the paper copy destroyed.

## 2.8 Limitations and Strengths

It is important to note that all youth study participants came from families that were at least supportive enough to allow them to seek care. Parents that are accepting of their child's gender incongruence tend to be overrepresented in the literature, as they tend to be those that present at clinics. Since parental consent was a requirement, this may also have influenced the number of young people who came from supportive households. There is a possibility that those with negative views of their child's identity and health care needs would withhold consent to participate.

One potential shortcoming is that most cases concern the experiences of boys assigned female at birth. Recruiting girls assigned male at birth proved difficult. Some parents reflected on why this might be. One mother speculated that this may be because gender variant girls have both a harder time in society due to harsher enforcement of gender norms on those perceived as 'feminine boys', and a more difficult time navigating the healthcare system:

It's a sign that the girls are more traumatized than the boys. It's a sign that they – especially the introverted ones, they can't manage it because they have it so bad. Because it's them who have the hardest time getting help, and it's them that have the hardest time expressing themselves, so they don't sign up for these kinds of interviews.

Indeed, the girls' stories included in this thesis tend to involve the most traumatic experiences.

Another observation is that parental participation was dominated by mothers. This over-emphasis on mothers may be because it may be common that mothers are more involved in the healthcare needs of youth with gender incongruence due to the "confiding" relationships they have with their child (Wren, 2002). I also failed to recruit nonbinary youth participants (although nonbinary voices are included in the key informant group). This may have been due to the criteria for joining the study: that the young person has a history of trying to obtain access to puberty blockers or cross hormones or both. Although no studies

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<sup>36</sup> The NSD project number is 55159 for reference. See appendices A through D for documentation of the ethical approval process.



have been performed on the topic, it can be theorized that because nonbinary people are not eligible for care through NBTS (K Tønseth, 2017) the number of nonbinary people who have received gender affirming care may be lower than those who have a binary gender identity. So, the probability of recruiting nonbinary youth was possibly diminished by this.

All participants were of Norwegian ethnicity, although young participant had a parent of immigrant background. Attempts were made to recruit youth of ethnic minority backgrounds, but as stated in the recruitment section, the one potential participant fitting this category declined to participate in the end. It is perhaps noteworthy that this young person declined after being informed that their parents would need to consent to participation. As two key informants told me, some of the youth they see with immigrant backgrounds struggle to gain acceptance from their families. The requirement of parental consent could have in theory impacted their willingness or ability to participate.

One consideration that is also a strength is that the oldest three youth participants (aged 19-22) may have very different experiences from the younger ones. This is because they sought care under several incarnations of the gender clinic at *Rikshospitalet*, in a period when few private options for seeking care were available and transitioned at a time when early transition was not as common as it is today. This was a conscious decision reflecting a change made in recruitment age while the study was underway. Because of a desire to gain a more encompassing view and include the voices of participants who voiced a desire to participate but fell outside of the original age range, the participation range was changed from 12 to 19 years, to 12 to 25 years.

I additionally changed the criteria to include not only those who sought puberty blockers, but also those seeking cross hormone and other treatments. This was because when recruitment was going slowly, it was suggested by other study participants that this may be because up until recently few people had received blockers in Norway. Widening the criteria for participation to include a broader age range and those seeking cross hormones turned out to be a positive, as a broader range of experiences were captured in the data. These changes were also approved by NSD.

Additionally, one participant completed his entire process from the age of 18 onward, and thus his experiences may differ from those who began to receive affirmative care earlier in life. Therefore, only the data where it seems appropriate to combine his accounts was used. Lastly, I had originally had the desire to complete discourse analysis on certain narratives. However, this is a lengthy process and due to time constraints and recruitment delays, this plan was dropped. Also, due to time constraints, I did not have the opportunity to perform

repeat interviews or include focus groups in the study. This was left open as a possibility but not a necessity.

## 2.9 Reflexivity

In qualitative research one must be transparent and open about the impact the researcher has on a study. In fact, Malterud states that such reflexivity is of equal importance to validity in quantitative studies (2001). The researcher's past, identity, personal interests, academic background and values not only shape to the work of collecting data and interacting with participants, but also play a role in choices made in the field, the theoretical framework that is applied and what is deemed important (Marecek, 2003). It is crucial that researchers are clear about their past associations with the subject matter, their motives, and the stake they themselves may have in the research (Willig, 2013). Additionally, qualities about the researcher such as education, race, age, ethnic background, gender identity, and even sexual orientation may provoke different reactions from participants, called 'response effects' (Bernard, 1988). Just the power behind the researcher role can impact a study. As Allison Rooke says, "...the self-explanations offered to the ethnographer are offered on the basis of the informants' understanding of the *kind of person* [author emphasis] the ethnographer is (2010:33)."

I am a forty-year-old queer, nonbinary American. I hold bachelor's degrees in social anthropology and psychology. I come from a lower middle-class family. Additionally, I have a history spanning over two decades of working with persons with developmental disabilities; mostly autism and cerebral palsy. I have engaged in LGBT activism since my teenage years. I confess that there remains quite a bit of activist in me, mostly present now in my organization of queer safe spaces and participation in small-scale activism like turning up for political demonstrations. Because of this background, I have a strong belief that academics working with disenfranchised groups should have a core motivation of bettering the situation of the people they study, rather than simply elevating their careers.

Over the course of my studies in anthropology, I took a focus in the Nordic region, gender, kinship, and medical anthropology. I wrote a bachelor thesis in anthropology on the experiences of transgender parents in Norway, which originally also focused on experiences of raising a gender variant child. This experience introduced me to the Norwegian trans\* community and gave me a good base in the literature. I also did a project for my psychology bachelor degree that involved interviewing a friend about their experiences seeking gender affirming healthcare, involving a timeline much like that applied in this study.

As an immigrant to Norway, when I learned that the national healthcare scheme covers gender affirming care, my initial view of this fact was positive. After all, I come from a country where healthcare is mostly privatized and gender affirming care is expensive, frequently not covered by health insurance, and out of reach for many of the people who need it. However, while conducting research for my bachelor thesis in anthropology, I became aware of the concerns of the gender variant community regarding access to gender affirming care in Norway and the politics surrounding this issue. The fact that so little research has been done, and is so needed, drove me to choose this topic. As I consulted with professionals who happened to work with gender variant youth and children in the development phase, the immediate needs of young people were drawn to my attention.

I am aware that due to my positionality, I may hold certain biases and preconceptions. The fact is that *everyone* holds biases based on their positionality. Cisgender scholars have (often unwittingly) neglected to acknowledge their unconscious biases about gender variance, thereby failing to realize the harm their pathologizing and delegitimizing discourses have caused through the years. Still nobody asks whether their cisgender identity creates bias. Therefore, it is crucial for all scholars to acknowledge and engage with their assumptions and potential biases throughout the research process, and to be open and honest about them with the reader.

To remedy any potential bias on my part, I conferred frequently with my supervisors and other collaborators. I consulted early on with academics in the field with varying theoretical stances. I was careful to include a variety of voices in the study to gain a more complete view of the situation at hand. I intentionally selected healthcare personnel and activists whose views included conservative as well as progressive viewpoints. I made certain to interview families with varying degrees of satisfaction or dissatisfaction with the healthcare they have received, and attempts were made to recruit via actors that attract careseekers with different views and experiences. The inclusion of a variety of grey materials, including those critical of gender affirming care were integrated into my research to combat potential biases.

It could be that those who perceived me as an ingroup member were quicker to open up to me or share more than they otherwise would be comfortable with. While not necessarily a bad thing, I do not believe this to be the case. At the start of this study, I was not highly visible in the queer community. My gender identity is not immediately apparent, and in most cases I was open about my transgender identity where it was natural to do so in the interview encounter. I did inform some who assisted in recruiting of my gender identity, as a means of assuring interest groups that may be protective of their members that my intentions are good.

Whether they in turn informed potential participants is unknown to me.

Anthropology has an unfortunate history of exoticizing its participants, in fact the field was founded on this practice. One way that anthropologists working in non-traditional settings have attempted to legitimize their work was by “othering” the people they study, often by studying “the powerless”, and placing clear boundaries between the participant and observer while failing to acknowledge the power imbalance this entails (Abu-Lughod, 1991). Those who choose to work within their own communities have little reason to exoticize their participants, but these studies are all too often devalued in academia, for being too close to home in the literal sense (Gupta & Ferguson, 1997). The belief is that a researcher may fail to be objective while studying their own community (ibid; Abu-Lughod, 1991). However, too often research about gender variant subjects has dehumanized them and stripped them of their agency, and I believe this may be avoided when researchers are members of gender variant communities themselves, such as I am.

I consider my embodied knowledge of how living with gender dysphoria feels, personal experiences of microaggressions and paternalism from healthcare personnel, and my understanding of how gendered language and misgendering can hurt as an asset to this research. Where gender diverse voices once were stifled and excluded from academia, a new era of trans\* scholarship is bringing renewed theoretical frameworks and depathologizing discourses to the table (Suess, Espineira & Walters, 2014). My goal is to contribute to this latter body of work and not the former.

## CHAPTER THREE: “It’s about lifesaving, plain and simple”: Early Interventions and the Promise of Preventing Suffering

### 3.1 Introduction

In Western society, the media, clinicians, academics and activists alike often term medical interventions for gender variant people as “life-saving” (Sadjadi, 2013; Giordano, 2008; Turban, 2017). Norway is no exception (*livreddende* and *livsviktig* are the words used in Norwegian). For example, in a debate piece in *Aftenposten* on why young people seek gender affirming care outside NBTS, legal scholar Anniken Sørli (2018b) writes:

For children that are rejected by NBTS, or that can no longer manage an everyday experience where life for an indeterminate time is put on hold in waiting for gender-confirming treatment, health-related help from sexologists or The Health Center for Gender and Sexuality is central. For some it is *lifesaving* (emphasis my own)<sup>37</sup>.

This lifesaving motif was not foreign to the participants I interviewed. A fragment of the title of this chapter comes from a key informant nurse, who me told how they see more and more doctors emerging from the woodworks, willing to help gender variant youth:

And that’s great, that there are other general practitioners (*fastleger*) that now are beginning to be open to seeing that it’s not so much hocus-pocus. It’s about *lifesaving*, plain and simple. To be able to be the person one is.

In their account, they too employ lifesaving as a means of portraying just how important early access to gender affirming care can be for the young people they encounter in their work.

Sigrid, mother of a boy assigned female at birth, described gaining access to gender affirming interventions for her son Nathan as “a lifesaving response” (*redningsaksjon*). Access to blockers was seen as not only giving him back the life (and body) that he once had, but as *saving* a life. By calling it literally, a rescue mission (*redningsaksjon*) she uses the same language employed in life-saving procedures like saving a person from drowning. Here we see how parents adopt concepts of life-saving to express their understanding of the necessity of timely medical intervention for their children with gender incongruence. Sigrid’s views were typical of parents interviewed, who saw gender affirming care as lifesaving interventions, with the potential to prevent their children from becoming, as Sigrid put

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<sup>37</sup> Author’s own translation. Original: «For barn som blir avvist av NBTS, eller som ikke lenger makter en hverdag der livet på ubestemt tid er satt på vent i påvente av kjønnsbekreftende behandling, er helsehjelp fra sexologer eller Helsestasjonen for kjønn og seksualitet avgjørende. For noen er den livreddende (Sørli, 2018).

it, “totally destroyed” (*helt ødelagt*).

A simple Google search of the terms ‘*livreddende behandling*’ or ‘*livsviktig behandling*’ demonstrates that the same type of terminology is used to describe the treatment of potentially life-threatening diseases like cancer or asthma. In comparison to these health conditions, making the case that gender affirming care also has the potential to spare lives may be a stretch for some. But for the participants of this study, the importance of early interventions amounts to the impact they have on a life: whether that life is a livable one in which a young person can thrive, or if it becomes unbearable, indeed *unlivable*. For many of this study’s participants, untreated gender incongruence does present an existential threat to a young person’s life.

My aim with this chapter is to introduce the reader to the experiences and influences that lead families to seek medical help for their gender variant child. In the process, I explore what about these experiences make study participants view early interventions (especially puberty blockers, but also HRT) as a lifesaving response. But ultimately, this chapter is about suffering, and how seeking early interventions is one way that families attempt to cope with and counteract suffering.

### 3.2 A Child Who Needs Saving

Where to begin the timelines? I pondered this for some time. Since the primary research question focused on experiences of seeking gender affirming care, I could have easily begun at the onset of a care seeking journey, that first attempt to reach out for guidance from professionals with the young person’s gender identity concerns. However, I opted to start “easy”, from what I thought to be the “true beginning”, as a means of getting participants to open up to me. Parents especially love to talk about their children’s early years, after all. But so too did the young participants, I found. They were often amused at the antics their younger selves concocted in asserting their subjective experiences of gender.

Indeed, participants informed me that this is often where the gender clinic’s diagnostic interview begins. It has historically been the task of clinicians to ensure that those seeking gender affirming care have a long and unchanging history of gender incongruence (Green & Money in Pyne, 2017; Butler, 2004: 70-71). Canadian gender studies scholar Jake Pyne argues that constructing the ‘correct’ chronology is crucial to acquiring a diagnosis that will unlock access to treatment, as “much is at stake in the story of the past, intended as it is, to activate the future” (2017: 102). Additionally, I theorized that these narratives could help to understand what brings a family to pursue treatment in the first place. If these early gender

affirming interventions are about saving a life, whose life is it that needs saving and from what? Why are these interventions seen as so crucial?

I begin the task of illustrating the kinds of experiences that may drive a family to seek early transition and gender affirming care by introducing you to Åse, whose daughter Madelen, was assigned male at birth. I interviewed Åse in her home, family photos in a row behind her, her two daughters prominently displayed. The photos span from infancy to recent, teenage years. I wondered when she first considered that perhaps the gender Madelen was assigned at birth might not be correct. “Right from when she was a baby!” Åse exclaimed. She explained how Madelen was always running around, Barbie dolls in hand, and dressing up in whatever she could, even when that meant “borrowing” her mother’s clothes. “I bought myself some new, pretty shoes, with a bit of a heel on them [...] They didn’t have many days in the house before that little – then a boy – was clomping around in the garden and up to play in the sandbox with these here on then!” she laughed. Being one of the few reference points she had to understand her child’s gravitation toward the feminine, Åse had thought Madelen would grow up to be a gay man, like those she’d seen on the TV show *Queer Eye for the Straight Guy*. “I thought, ‘Society can handle that!’” she said.

When Madelen was five years of age, she began to approach Åse with difficult questions. “She had a lot of questions like ‘Who decides if you’re a boy or a girl?’, ‘Can God make a mistake?’ Or things like that. [...] What should I actually answer to that? That wasn’t so easy to answer.” Åse struggled to come up with a proper response, especially when the origin of her daughter’s curiosity was yet unknown to her. Not long after, Madelen ‘came out’ loud and clear on the playground as her mother looked on. “She was looking for something in the sandbox. And suddenly stood – looked at me and she said, ‘I am actually a girl, you know. I was just made wrong’ And then she continued with what she was doing.”

Åse could thus far be trusted to allow Madelen to be creative with her gender expression, without scorn or limitations that some parents might have imposed. In retrospect, Åse sees that Madelen was seeking guidance in exploring her identity with her barrage of difficult questions. Asserting her gender in the way she does, Madelen seems unaware that her revelation is beyond the ordinary. She simply says what she needs to say and then continues playing as if nothing monumental had happened. But for Åse, this was a defining moment in her relationship to her child.

Whether their child transitioned young, or only developed an understanding of their identity later, the parents I interviewed all shared similar stories of identifying early signs in their child that they were only able to make sense of in retrospect, once the child revealed that

the gender they were assigned at birth was incorrect. Splicing together signs and signals from the past can be an important part of the sense-making process for gender variant people and their loved ones. Obviously, Åse didn't really believe her boy might really be a girl from the time she was a baby. What she means is that in retrospect, the signs emerged very early and now she has reassigned meaning to those early clues in her child's behavior. The construction of an "orderly and predictable" life narrative (Halberstam, 2016) can facilitate the "un-doing" and "re-doing" of gender (Whitley, 2013) and may be key to acceptance by family members (Bergström, 2007: 145). Organizing these memories into a cohesive narrative may also foster coming to terms with the change in one's relationship to their family member, which some parents even called a "mourning process", helping them move from, as in Åse's case, the mother of a son, to the mother of daughter (Whitley, 2013).

Soon after Madelen's revelation, Åse began to search online for resources and found the organization for patients of *Rikshospitalet's* gender clinic, HBRIS. She signed up, and along with Madelen, attended their summer camp for families for the first time that year. Seeing other young girls like Madelen was life changing for mother and daughter, both in terms of gaining peer support and learning that an early social transition was possible. "It was like looking into heaven!" Åse said. Both parents and youth I interviewed stressed how deeply important meeting others "in the same situation" was to them at this early stage. Meeting others offered not only a break from the isolation they felt, but also a chance to learn from experiences of others, and through informational workshops provided at the summer camp, discover what medical interventions were available for their children in the future.

Åse told how she and her then husband struggled to find the way forward. They ended up seeking the guidance of a sexologist with experience in the field. At first Madelen was permitted to dress up as a girl at home as a kind of "hobby" and dress androgynously in public. But it was not enough to simply have her identity honored in the privacy of her home. For Madelen, hovering in the liminal space between male and female represented an intolerable ambiguity in which one's true identity is not mirrored back by those around them. This forced hovering outside social norms that dictate legibility of gender ultimately became unlivable (Butler, 2004: 39). As Butler maintains, "In the same way that a life for which no categories of recognition exist is not a livable life, so a life for which those categories constitute unlivable constraint is not an acceptable option" (Butler, 2004: 8).

One night the two parents were discussing whether Madelen, now 7 years old, should be permitted to transition socially and live her life as a girl. Unaware she was listening at the top of the stairs, suddenly a voice piped up "It's *my* life!" Madelen here seems to be



informing her parents that she is not content with sitting idly by and allowing the adults in her life to make the decisions without her voice being heard. It is not unheard of for parents of gender variant youth to speak of being “child-taught parents” (Hill & Menvielle, 2009). Sigrid told of conversations she has had with others about parenting a gender variant child: “We feel that our kids put a leash around our neck and pull (*en løkke rundt halsen vår og drar*),” she said, making a choking sound for effect. “And we come along by the neck!” Parents may feel like they have no choice but to follow their child’s lead, when the will to live in their experienced gender is so strong and enduring.

For parents I interviewed, their children’s identities are experienced as natural, stable and beyond outside influence, indeed *unchangeable*. They had in effect already tried to impose the “wrong gender” upon their child, something that made no difference and was observed to make their child miserable. “We know it very well because we remember the last time we forced our kids to – to wear the wrong clothing. We remember that birthday or 17th of May<sup>38</sup>, or wedding or whatever,” Sigrid said. Such experiences, frequently shared by parents, were described as ones of struggle, resulting in unhappy, frustrated children.

Eventually, Åse took Madelen shopping and let her buy whatever she wanted, namely girl clothes. Åse describes: “And I took pictures of her. Wonderful! Poor thing! Oh, oi oi oi, it was so moving, you know?” Once they got home Madelen couldn’t wait to show the world:

And she stood out on the steps [of the family home] in the new clothes and then she said, ‘I really wish that someone I know would come by, so they can – see my lovely self (*se mitt nydelig jeg*).’ [She] ran around in the street and cried out ‘I was made wrong! I might be allowed to be a girl! I’m going to be called Madelen!’ Went around and told people, completely overjoyed. Completely overjoyed (*helt frelst*).

The first ecstatic shopping trip was a major turning point in the stories of families I interviewed with girls assigned male at birth. For boys assigned female at birth, that turning point often took the form of a trip to buy their first suit, or to the barber to cut their hair short. Some boys assigned female at birth described wearing boy’s clothes while keeping their female social roles, while the opposite was not possible for the girls assigned male at birth, due to stricter gender norm enforcement against those perceived to be feminine boys. This made the turning point excursion even more memorable for these girls and their parents. The

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<sup>38</sup> The 17<sup>th</sup> of May is Norwegian Constitution Day. On Norwegian Constitution Day, children march in a parade, dressed in national costume. These national costumes, called *bunader*, are highly gendered. Thus, being dressed in the wrong *bunad*, could evoke strong responses in young participants.

shopping or barber trip marks the moment in this journey at which the child is liberated from the former gender role and all its expectations, finally permitted to live as their “true self”. These tales were frequently told by parents as precious moments of unadulterated joy for their children, in which they witnessed their child bloom before their very eyes.

As mentioned in the literature review, permitting a child to transition as early as Åse’s daughter Madelen did remains controversial (Steensma & Cohen-Kettenis, 2011; De Vries & Cohen-Kettenis, 2012; Turban, 2017). Despite the controversy, parents that I interviewed who had permitted prepubertal social transition related that they regret efforts to redirect or limit their child’s gender expression and even saw their efforts as more damaging to the child than a potential second transition. Parents told how they assured their child that the way back to their old gender role remains open, and that if in the future the transition felt wrong, “there’s no shame in turning back”, as one father put it. Parent study participants often told how they saw their child go from sad and withdrawn, or even exhibiting fits of uncontrolled rage when forced into the wrong gender role, to happy and well-adjusted once permitted to transition socially. Once transitioned, episodes of frustration and rage were described as having resolved completely. Social transition was believed to be necessary to preserve their child’s wellbeing, mental health and self-esteem.

One father of a boy assigned female at birth, while strongly supportive in helping his son transition and seek care, struggled to understand how his son could be so certain of his identity when he first came out as a boy at age 14, after first coming out as a lesbian. The signs had been there all along: taking on the role of father in role-playing games, an aversion to dresses. Still, this father had his fears about whether transitioning would turn out to be the right thing. “I think it’s difficult – to understand how [my son] can be so sure – at 14, 15, 16 years of age. How he can be so one hundred percent sure (*bombesikker*) of his gender identity, when he has so little experience with life? Or with – sexuality for that matter? I think that’s a big challenge.” He also recognized that his son would likely have been worse off without transitioning and stressed that he understood that this was best for his son’s wellbeing in the here and now. His main concern was if his son understood how difficult it could be to turn back if transitioning didn’t turn out to be what was best in the long run, many years down the road. “It’s just to cross all fingers and toes and hope that this here goes well. That it’s right.” He would have to trust that they were doing right by his son, but this was clearly a challenge.

I want to briefly return to Åse’s account of her daughter’s pivotal moment in her transition, specifically how she describes how Madelen “went around and told people, completely overjoyed (*helt frelst*)”. It is interesting that Åse employs the phrase “*helt frelst*”.

The correct reading in this context would be as I chose to translate it: ‘completely overjoyed’, however, the literal translation is “completely *saved*”, in the Biblical sense. Sure, it is a figure of speech, but in a way, it is fitting, as allowing a child to transition may be seen as the *first* instance of saving their child’s life. By effectively freeing their spirit, this may be a parent’s ultimate act of faith; an act of radical acceptance and unconditional love. The next natural step then, would be protecting that child’s hard-won wellbeing. For the parents I interviewed, that often meant seeking medical interventions to stave off the unwanted effects of puberty.

### 3.3 To Save a Child from Suffering

One mother I interviewed said when her child, assigned male at birth, asserted that she was, in fact, a girl, she envisioned only a future wrought with “tragedy” for her: “I just saw a terrible life ahead. So, I thought ‘Okay, I have to do something for her. Because I don’t want that she ends up in one of these—worst statistics.’” The notion of her child’s gender variance evoked an assessment that her daughter’s prospects were grim without outside help. She felt she had to intervene in some way to save her daughter from a lifetime of suffering. Why was this her immediate assumption?

In the past, parents like this mother might have tried reparative psychoanalytic or behavioral therapies to curtail cross gender behavior in an attempt to change the child’s experience of gender, with the goal of saving them from the perceived “misery” of a transgender existence (Hill & Menvielle, 2009; Pyne, 2017). Rather than trying to change her daughter’s behavior and identity, this mother’s imagined grim future acted as a catalyst for seeking medical interventions. As Pyne puts it, the medical practice of today “now facilitates rather than forecloses trans life (2017:102).” Given that reparative therapies are now considered ineffective and unethical by the medical community (Möller et al., 2009; WPATH, 2011), transitioning has come to be seen by the medical community as reparative in itself, with puberty blockers as an option to curtail certain forms of misery.

According to Nahata, Chelvakumar and Leibowitz (2017), based out of an Ohio clinic in the U.S., many families who permit their child to transition early arrive at clinics well-informed and with their minds already made up in terms of their wish for puberty blockers. Spack (2009) says that care-seekers frequently arrive at his Boston-based clinic with the *expectation* that their need for blockers will be met. Similarly, participants in this study described having arrived at the gender clinic specifically in pursuit of puberty blockers.

In some cases, puberty blockers may be seen as the only viable option. Abstaining from treatment with puberty blockers is also a choice, but is one that is more and more

understood as destructive to a child suffering gender dysphoria tied to an unwanted puberty (De Vries & Cohen-Kettenis, 2012; Kreukels & Cohen-Kettenis, 2011; Giordano, 2008). Some well-respected proponents go as far as to call denying access to such care akin to “psychological torture” (Kreukels & Cohen-Kettenis, 2011). Instead of enduring a traumatic puberty, puberty blockers provide the means to avoid it entirely (Roberts, 2014). Some parents may buy into a narrative of the “scientific fix”, which may foster the belief that humans, equipped with the technology, have a duty to fix the wrongs of nature (Lindemann, 2006). In other words, given the promise of intervention, how could you, as a loving parent, deny your child access to technology that makes reducing the risk of “psychological torture” possible? For the parents I interviewed whose children were aware of their identity prior to puberty, choosing to simply let their child endure puberty was unthinkable. Given the opportunity, puberty was believed to be something one absolutely *should* do something about.

Gender studies scholar Jessica Cadwallader maintains that most biomedical interventions involving bodily modifications are justified with claims to their alleviation of suffering (2007). I contend that there are in fact three forms of suffering that the literature, media and to some degree participant accounts claim gender affirming biomedical interventions address. However, in much of the literature there is a failure to parse out the different aspects. In many regards this makes sense, as they tend to feed into each other. I contend that these three forms of suffering are to some extent separate, but interrelated phenomena. As such, not all of them may be present under certain conditions (and I will present an example of this later in the thesis). This makes separating them worthwhile. I argue that the suffering early interventions are meant to alleviate or prevent entail aspects of social, psychological, and embodied suffering. In the subsections below, I give each their own consideration to understand why they may be viewed as an existential threat.

### 3.3.1 *Social Suffering*

To understand the context within which a parent can only envision a “terrible life” for their gender variant child, it must be remembered that until quite recently the majority of depictions of gender variant people in Western popular culture hardly painted a positive picture. Films and television have frequently showed gender variant people as something to be reviled or laughed at, and even more sensitive films tended to depict characters as subject to abuse, or murder victims (Lester, 2015: 148-150). It wasn’t until *All About My Father* (*Alt om min far*) in 2002 and *The Girls of Toten* (*Jentene på Toten*) in 2010 that trans people came to the forefront of Norwegian culture. Previously, with very few positive representations of gender

variant lives available, it may have been difficult to imagine a future where a gender variant child can thrive. Today, many positive depictions of successful gender variant young people, such as the American reality show *I am Jazz*, focus on those who “pass” with ease, often because they had access to puberty blockers.

Cultural representations are important because they may assist in the formation of master narratives. Master narratives are “plot templates and character types” that inform a person’s understanding of how to live in the world (Delgado in Lindemann, 2006). These devices inform our expectations of the social. Philosopher and bioethicist Hilde Lindemann also utilizes film clichés to explain master narratives and their potentially negative effects, namely that of African American males commonly portrayed as drug dealers. She argues that the frequency of these portrayals fuels beliefs that African American men are more likely to be engaged in criminal behavior (2006:179-180). Likewise, media tropes about gender variant people leading miserable lives or losing their lives to murder and suicide permeate beliefs of what can be expected of a gender variant person’s life chances. These master narratives are absorbed unconsciously and can be impervious to factual evidence (Lindemann, 2006: 179).

Goffman (1990) posits that similar mechanisms of appraisals based upon normative expectations of how a person should be in the world lie at the core of stigmatization processes. If evidence arises that a person has ‘attributes’ incongruent with the features associated with the category of persons that is available to them (say a girl bearing an Adam’s apple or a boy with breasts), these differences devalue them as undesirable and flawed, potentially marking them as members of a stigmatized group (Goffman, 1990: 12). Furthermore, the stigmatized share the same culture as their appraisers. Thus, the person is often aware that they do not live up to the social standard of the group to which they aspire to belong. This self-stigma may have painful impacts on the individual’s concept of self, leading to shame (Goffman, 1990:18).

Butler argues additionally that norms are crucial to our understandings of personhood and what constitutes a “livable life” (Butler, 2004: 2). Livable lives conform to the normative boundaries society sets upon what can be considered a plausible, human life (Butler, 2004). Philosopher Eva Feder Kittay emphasizes that norms determine a person’s value, stating, “To be normal is to be included within the scope of what is of value and hence what is desirable and desired” (2006: 99). Those whose lives are “unlivable” become implausible, less than human others, denied the same level of personhood as those who conform to societal norms (Butler, 2004); they are effectively stripped of their intrinsic human value (Kittay, 2006). According to Butler, the human rights struggle of sexual minorities has primarily been a

struggle to be conceived of as persons (2004:32-33). This is arguably also true of gender minorities. Once an individual's claims to personhood are rejected, it becomes easier to subject the dehumanized individual to inhumane acts (Krállová, 2015).

Bourdieu's concept of social suffering sheds light on the commonplace, lived experiences of daily injustice or "small misery" (*la petite misère*) among those ranked lowly in the social order (1999:4), such as stigmatized groups. It is the pain of *positional* suffering, of being acutely aware of your reduced place in the larger society (ibid). Human difference can be experienced as impediments to lifetime functioning because of the devaluation of difference by society and the stigma associated with that difference (Kittay, 2006). Essentially, being of low status reduces your life chances.

Social stigma may operate as a very real threat to safety (ibid). As a group historically stigmatized for transgression of gender norms, the broadest ever systematic review of studies conducted worldwide finds gender variant people face higher rates of violence as well as discrimination in employment, healthcare and housing across cultures (Reisner et al., 2016). Some would argue that surely things are better for LGBT people in the Nordics, and comparatively speaking, that may be the case. But it is also important to note that even referring to a group as marginalized can be considered derogatory in Nordic countries and given that sameness and equality are highly prized cultural ideals in Norway, power and prestige disparities may be downplayed to maintain the notion of sameness and equality (Gullestad, 2001: 40). This may mask still-existent inequalities.

It is difficult to get an accurate presentation of the incidence of hate speech, harassment and violence against gender variant people in Norway because gender identity is not covered under the hate crime laws (Transgender Europe [TGEU] & The European Commission Against Racism and Intolerance [ECRI], 2014). Incidents often go unreported for this reason (ibid). A recent study found LGBT people in Norway were exposed to far more degrading comments and speech they experienced as hateful than the general population, which lead to feelings of reduced safety (Fladmoe, Nadim & Birkvad, 2019). A much higher number of LGBT respondents were also subject to concrete threats than the general public (ibid). A study on the quality of life of gender variant people in Norway found that a general ignorance of gender variance resulted in an atmosphere of intolerance, discrimination and exclusion, as well as harassment at work and school for that study's participants (Van der Ros, 2016). We can also look to neighboring Sweden, which bears a cultural resemblance, where a large national survey of gender variant persons found that half of respondents had been subjected to abusive treatment in the past three months, while over one third reported

recently being verbally assaulted in public (Folkhälsomyndigheten, 2015). Only one in five could attest to never being subjected to gender-based violence and 65% of respondents had avoided social situations in fear of discrimination or violence (ibid).

For many gender non-conforming youth, bullying, discrimination and ostracization at school are the first exposure they face to the kind of discrimination and harassment they may face in society as adults. Parent participants of this study often told how, prior to asking for accommodations for their gender variant child, they had worried that their child's schools would refuse to accommodate the child's needs. Several parents went into these scenarios prepared for a fight, expecting discrimination and judgment, but in most cases that fear was quickly laid to rest. One participant experienced a school unwilling to recognize her affirmed gender. She was forced to change schools.

Even though her daughter Sofie was accepted and included in their community, her mother Mari continues to deal with a certain base level of fear as to how her daughter will be received by those outside their inner circle:

I have gone around the whole time with my heart in my throat. But that's my problem. I am also scared for them [Sofie and her friends] and who they might meet. But her girlfriends have, she says they have defended her through the years. If someone has said something, then her girlfriends defended her.

Mari told me that she considered themselves fortunate that Sofie had always been treated well by the community. She was aware that there was a potential that things could have been different. For her, trusting that things would go well for her daughter has been difficult, even though her fears have been unfounded thus far.

Bullying and social exclusion were concerns for both parents and young participants of this study. Young participants who told that they had experienced bullying shared that incidents of bullying occurred more often prior to coming out, when the transgression of norms for their gender category made them an easy target for ridicule. For example, prior to transitioning, one boy named Magne told of how kids mocked him by calling him "lady man" (*damemann*). Prior to the announcement that he was indeed a boy, he was discredited in his role as a girl for his lack of femininity. Magne told how incidences of bullying resolved after he transitioned and educational presentations on gender diversity were given at his school. Once a new categorical lens was applied to perceptions of the him, he experienced support from their school and community members.

Lasse had suffered from bullying which lead him to seek help from a therapist for a

period of time. His mother Ina explained, “He wasn’t doing well – because of bullying. He was bullied at school.” I asked if the bullying had continued after Lasse came out at school. “More that, he, he’s been shut out (*utestengt*), I think. [...] Maybe they’re not directly mean, but he doesn’t get to – they’ve distanced themselves from him, then.” Arnt, Lasse’s father, continued that thought: “Yeah, it’s because if they get caught bullying, they get a written warning. And so they shut him out. But that’s fine!” Arnt added, indicating Lasse was better off being left alone. Trading direct harassment for ostracization may not be a good trade off, as Arnt implies, however. Like bullying, ostracization may also have devastating effects on mental health in the long term. Some sociologists have called ostracization a social death resulting in thoughts of death (Steele, Kidd & Castano, 2014), contributing to depression, suicidal thoughts and attempts (ibid; KD Williams & Nida, 2011).

For participants, however, the threat of social suffering was not often openly stated as a primary driver for seeking care. But, as I will discuss a bit later, it does emerge as an underlying factor in discussions about the benefits of early interventions, something I take up later in the chapter. Instead participants told how relieving *embodied* suffering was the most pressing motive behind their seeking early interventions. The onset of puberty, and with it, embodied suffering, was viewed as a ‘crisis’ requiring swift action.

### 3.3.2 *Embodied Suffering*

In the clinical literature, going through the ‘wrong’ puberty is often described as a deeply traumatic event in a gender variant young person’s life (Delemaare-van de Waal, 2013; Hembree et al. 2009). The first version of the Endocrine Society’s guidelines for treatment go as far as to make the claim that trauma resulting from a lack of action at the onset of puberty may result in arrestation of social, emotional, and even intellectual development (Hembree et al., 2009).

Discomfort, or ‘gender dysphoria’, experienced in relation to the disjuncture between gender identity and the body may only intensify with pubertal development. One key informant doctor told me that their patients dread puberty and described seeing in care-seekers “a very strong desire one can almost see on their body.” Indeed, in the DSM-V diagnostic entry for gender dysphoria the phrase ‘strong desire’ appears seven times in the relatively short text (Zucker, 2015). However, rather than a *desire*, study participants described pubertal development through discourses of discomfort and fear, as something they struggled to endure, and in some cases could not bear.

Henrik, now 16, recalled the sensation he experienced as puberty set in and his body



began to change. Although he did not yet possess a framework with which to understand his internal conflict, having not learned of gender variant identities until he was nearly done with puberty, he recalls feeling that something was very wrong. “I wasn’t doing well!” he chuckled. “Very like – *uncomfortable*. Very not okay (*ikke greit*) in a way. [...] Just such a feeling of discomfort—*all the time*...and it was – yeah – a bit stressful.” Henrik’s remembers puberty as constant discomfort, a disharmony which he could not reconcile or yet give name to. His claim that it was ‘a bit stressful’ is an attempt to downplay the situation; his tone suggested a hint of irony behind his choice of wording.

Natalie and her mother, Karin, discussed how going through puberty impacted her mental and *physical* health. Natalie was very fearful for the development of masculine facial features, and the loss of her voice. “I was scared for my appearance. I was a bit – scared to get a deep [voice]. That I would have to use a deep voice – that sounds masculine. [...] I was scared my Adam’s apple would show,” Natalie said. Natalie’s fear made her construct jewelry to hide her Adam’s apple that she wore so tightly it cut into her skin. Karin told how distress around her genital development resulted in Natalie being unable to bear to look to wash herself and that she stood in the shower with her legs crossed to cope with bathing. This made maintaining proper hygiene difficult.

Other participants also described physical health concerns that arose from attempts to cope with gender dysphoria. Pål described how he sometimes wore multiple binders, or compression vests to conceal his chest, at a time. This impacted his ability to breathe properly. Similarly, Sigrid explained that her son had developed skin breakdown from prolonged use of his binder. Åse told how her daughter, Madelen, injured her genitalia due to the unsafe tucking<sup>39</sup> techniques she used to conceal them. Shame around her genitalia caused her to evade mentioning the injury to her mother until medical attention was inevitable. “She was scared she would have to go to the doctor and she was scared she’d have to show her genitals. Just getting undressed was a very painful experience,” Åse explained. In this way, practices arising from fear and embodied suffering may inadvertently lead to very tangible manifestations of gender dysphoria in the form of *physical* health issues.

In the above accounts we see how pain and fear associated with development that is out of alignment with one’s gendered self can work not only to the detriment of the psyche, but to the body as well. Medical anthropologist Rebecca Seligman conceptualizes the self as

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<sup>39</sup> ‘Tucking’ is a term used in referring to techniques used to conceal the genitalia in a way that gives a more feminine appearance (see Dornheim, 2017).

emerging at the junction of mind and body, comprised of the interaction of cognitive and embodied processes that interact to create and maintain the individual's self-concept. Suffering, she says, can pose a threat to the integrity of self by working on both "discursive cognition" and the body itself (2010). Addressing suffering as an embodied process, she says:

Suffering has the potential to undermine the coherence of lived selves and create the experience of internal conflict, disjuncture, or fragmentation. Moreover, discontinuities in the experience of self may themselves be a source of suffering, especially when they are unexpected, unsanctioned, and resist attribution. (ibid: 297)

The experience of internal conflict and fragmentation is likely all the more pronounced when paired with a disconnect between subjective self and the physical body. For youth with gender incongruence, a discontinuity of subjective experience is paired with the invalidation of the gendered self that both pubertal changes and societal expectations invoke. According to Seligman's model, this disjuncture may make maintenance of the self into a painful struggle which not only undermines the experience of lived self but gives rise to more suffering. This suffering in turn serves as a further threat to the "coherence of self" in a kind of toxic feedback loop (2010).

Additionally, when one is forced, by illness, disability, or in this case gender dysphoria, to focus on bodily processes that are normally left in the background of cognition, what Seligman calls "hyperembodiment" emerges (2010). This hyperembodiment can further distance the sufferer from their own bodies, resulting in alienation from the corporeal aspects of their existence, an 'othering' of one's own form (ibid), which I argue may be the source of the experience some participants have of being "born in the wrong body".

For youth like Henrik who lack attribution for the discomfort and loss they are experiencing, according to Seligman's model, the experience of puberty may be an even more painful experience. However, in Natalie and Madelen's cases, even having a name for their experience at the time, society around them may have lacked an understanding of their troubling experience, as their experiences as girls with emerging masculine traits was very "unexpected and unsanctioned" at the time they transitioned. They may have experienced this fracture of self as a deep suffering without a shared context when so few around them can truly understand their experience. This may exacerbate the trauma of puberty. A loss of the self with no opportunity to work through its grief creates a suffering that becomes further embodied (Frost & Hoggett, 2008).

As sociologist Celia Roberts puts it, for gender variant youth "pubertal processes

(re)materialize a rupture between self-identity and their bodily appearance and processes (2014:333).” Using Seligman’s (2010) conceptualization of self, we can understand how this widening rupture between cognitive concepts of self, increased attention to bodily processes, and alienation from the emerging gendered body work together as a threat to the self and a source of deep suffering. Families of this study hoped to gain access to treatment early enough to alleviate suffering and prevent this rupture of self and body from becoming a chasm more difficult to bridge.

### 3.3.3 *Psychological Suffering*

Winter et al. describe health inequities in gender variant populations, especially mental health, as a “slope leading from stigma to sickness” (2016). As stated previously, internationally studies find that gender variant young persons may be more likely to struggle with depression, suicidal ideology, anxiety, eating disorders, and self-harm compared to cisgender peers (Grossman & D’Augelli, 2007; Grossman, D’Augelli & Frank, 2011; J Olson et al., 2015; Connolly et al., 2016). A recent study conducted in Norway found that 80 percent of gender variant respondents had had thoughts of suicide, with 30 percent having made a suicide attempt at some point in their lives (Benestad, Almås, Bolstad & Karlsen, 2018).

In the previous subsection, I showed how embodied suffering can pose a threat to mental health and evoke its own potent stressors. However, recent research attributes much of the disparities in mental health that remain after transition and/or gender affirming care to the stigma gender variant people face over the course of their lifetime (Robles et al., 2016). Stigma and social suffering may then be factors that create conditions for psychological suffering to emerge. Social and embodied suffering can work together to create a “perfect storm” of trauma that results in psychological suffering. This sometimes results in the emergence of damaging coping mechanisms which may create what Frost and Hoggett (2008) term “double suffering”. Double suffering is when coping mechanisms like self-injurious behaviors, eating disorders or substance abuse also cause suffering to those around the person in question (ibid).

Behind the fears verbalized by some parents could be the underlying possibility that without help, a child’s life may eventually become unlivable, unsustainable, indeed, *unsurvivable*. Treatment may therefore feasibly be thought of as preventing not only psychological harm, but potential death by overdose, starvation or suicide. Thus, treatment can be conceptualized as preventing death in the literal sense.

One mother, Benedicte, was acutely aware of the threat to the maintenance of life this

type of psychological suffering can carry. Her daughter Annika had already previously struggled with an eating disorder and self-injurious behaviors. Annika had only recently returned to school after dropping out due to her mental health struggles and had confessed to considering suicide. Telling of a recent visit to NBTS' KID-team, she expressed her daughter's urgent need for care through a framework of an unlivable daily life. "So, I said that you have to do something now, [...] you have to stop, help and stop her facial hair growth – her erections, everything there that she wakes up to every morning. [...] It's difficult to get up every day. Mmmhmm. To experience what she experiences, with herself. As if she shouldn't even *be* there. Like – I can't even imagine."

Benedicte feared that the small, every day injustices of waking to a body that doesn't match her identity would have a cumulative effect of creating an unlivable situation for her daughter, where Annika wouldn't want to exist in that body, or "be there" anymore and would try to take her own life. Without help to bring that body into alignment with her identity, Benedicte feared the worst. Benedicte believes that treatment with testosterone blockers and estrogen is the only path to creating a livable, survivable future for Annika.

In this section, I have identified three types of suffering that can emerge as the result of an atypical experience of gender that breaks with the norm. Social suffering due to the stigma often associated with gender variance, embodied suffering emerging from the fracture between the body and the cognitive self at puberty, and psychological suffering, sometimes borne of the first two forms of suffering, resulting in an increased risk of depression, anxiety, and self-harm, or even death by one's own hand. For participants, seeking gender affirming interventions are a path to preventing or reducing these forms of suffering, but specifically, they had to be obtained within a very limited developmental time frame. This rush to obtain treatment may be experienced as a state of emergency, as the family rushes to avert a crisis, and it is this that I wish to address in the next section.

### 3.4 A State of Emergency

Pubertal timing is often experienced as something that, although expected to occur at some point, was still described by some study participants as coming quickly, seemingly out of the blue. The onset of puberty differs from person to person and cannot be planned (Brooks-Gunn & Matthews, 1979). Some parents described that prior to pubertal onset, all one could do is sit back and wait as, apart from a social transition, nothing more can be done. But, once puberty begins, so too begins a sense of emergency and a race against the clock (Sadjadi, 2013).

Medical anthropologist Sahar Sadjadi points out that discourses in the clinical

literature used to support the provision of puberty blockers to youth with gender incongruence often describe puberty as “a ‘natural disaster’ that ravages the child’s body and its (gendered) integrity from within. It is an emergency, a disaster that is predictable; hence the intervention gains a preemptive feature” (2013:257). She theorizes that crisis discourses in both the clinical literature and media may instill fear in the parents of gender variant children, creating a sense of obligation to act quickly to obtain ‘timely’ help for them (Sadjadi, 2013). She asks if parents adopt these discourses, supposedly born of medical experts, as a framework for viewing their situation, and as a result perceive the situation as more desperate and pressing than it is (ibid). To that, I say we must ponder what came first. One must ask if parents adopt the narratives used by clinicians in the literature, or if the clinicians responsible for that literature describe the specter of approaching puberty in this way as a reflection of what the families they serve tell them about their experiences?

Siv is the mother of Karl, a boy assigned female at birth who will soon turn 14. Like many of the parents I interviewed, Siv had initially learned about the potential benefits offered by puberty blockers, not through clinical literature, or the media, but by networking with other parents in Facebook groups for parents of children with gender incongruence. She explained:

When I came in contact with other parents, then I understood how important it was with puberty blockers. I didn’t know they existed. I knew nothing. But I understood, because I knew that he was suffering, right? And everyone said that – that it helps with the puberty blockers. It is that that is – the solution in a way is very important. So, it was something with getting them as quickly as possible.

Siv’s contacts with other parents had informed her initial understanding of the necessity of obtaining puberty blockers early in Karl’s development to alleviate suffering. The narrative of puberty blockers saving a child from suffering and the urgency of obtaining them was described as spreading among parents of gender variant children through social networks, be it through Facebook groups, workshops and contacts with other parents made through patient groups like HBRS. Siv learned that she needn’t simply sit by and help Karl to endure the suffering brought on by puberty. Knowing that medical help was available, like any parent with a child facing a potentially serious medical condition, she felt it was her responsibility to get him the best help available. And specifically, she would have to act *quickly*.

Åse described her panic when puberty hit her daughter Madelen “sudden and hard”, its effects described as rapidly progressing. As her voice began to change, Madelen stopped talking altogether, Åse told me. “And I said, ‘Now we can’t wait any longer, we can’t just

continue to wait and see, because now it's started. And this here isn't going to go well. We have to get a hold of these blockers, quick!" Åse here expresses a sudden speeding up of time as the reality of Madelen's situation unfolded and developed into a crisis that must be met with a rapid response. As Åse observed the impact puberty had on her daughter, it became clear that she had no choice but to act.

Madelen herself explains, "I was very depressed, also. Because I didn't get much help from *Riksen*. So, I--I didn't go to the last years of junior high (*ungdomsskolen*)." For a period, both Madelen's wellbeing and her education were in jeopardy, ultimately tied to her changing body and what she and her mother saw as inaction from clinicians at *Rikshospitalet* whom Åse says did *not* see their situation as a crisis like she did. Having received blockers too late to preserve her feminine voice, and heavily targeted by bullies at school, Madelen became further socially withdrawn. She began to miss school, realizing Åse's fears that things would not go well for her.

Castañeda draws to attention discourses in the clinical literature that reveal a focus on a "developmentalism", or views that the bodies of young people with gender incongruence are "more malleable, less completed bodies than their adult counterparts", and thus more easily molded into a form that matches their internal sense of self (2010: 264). This way of thinking is also clearly reflected in some of the above accounts. This period of malleability is viewed by the participants as a steadily closing window, thus the race to avert disaster, the life-saving response, or *redningsaksjon*. Once that window closes, the damage, in their eyes, is then is done. At that point only a kind of damage control (or perhaps we should say disaster relief) through invasive surgeries can help. That the benefits of puberty blockers are so time-contingent only heightens the sense of urgency careseekers may feel.

But importantly, in Åse's account, and others, lies another implication. Åse knows her daughter well enough to anticipate her suffering. She knew this day would eventually come but was not prepared for the speed with which puberty advanced upon her daughter. This evokes a sense of panic in her as well, as to what the future holds. As her fears become realized, watching her daughter suffer proves very painful for her as well. Sitting idly by is simply not an option for her, not once puberty begins. As a mother, she understandably feels she must do something to alleviate her daughter's pain and seeking care that she understands to do just that may be one way she copes with the ordeal as well.

I have now addressed the suffering that may be experienced by those who go through puberty without the possibility of curtailing it, as well as the feeling of a developing crisis that families can experience and how this leads them to call for care "as quickly as possible" to

avoid or alleviate suffering. In the final portion of this chapter, I explore the advantages participants associate with receiving access to early interventions. In particular, I want to unpack ‘passing’ as a perceived benefit of obtaining gender affirming care at an early stage in development, and what that means to this study’s participants in a Norwegian context.

### 3.5 The Advantages of Putting Off Puberty

As discussed in the background section, one of the oft cited benefits of puberty blockers in the literature is halting the development of undesired secondary sex characteristics. Later, with HRT, the development of the secondary sex characteristics associated with the young person’s gender identity can be induced. Early interventions provide superior results and a better likelihood of being able to ‘pass’, without having to resort to more invasive procedures like chest surgery for men assigned female at birth and breast augmentation and facial feminization for women assigned male at birth (Spack, 2009).

As we sat side by side in the family living room, Sigrid told me how her son Nathan eventually made the connection that one day he would develop female secondary sex traits. The realization that he would potentially develop breasts like a woman’s was met with a dread bordering on terror that materialized well in advance of puberty. She explained, “The boys have been able to be actual boys – before puberty. But then comes this chest and voice and just – it doesn’t work. It overwhelms them (*det tar dem totalt*).” When he finally received blockers, albeit too late to avoid a future top surgery, his body reverted to its previous form and became “like a child again.” This was described as a great relief.

Puberty is not only biological, but social, marking a change of status as the child moves toward adulthood (Brooks-Gunn & Matthews, 1979). But for the families I interviewed, puberty is a looming *threat* to the child’s social status, or to *passing* as Garfinkle (2006) defines it, as: “the work of achieving and making secure their rights to live in the elected sex status”. Achieving a new social role and passing inconspicuously among peers of the same gender is work that the child has already successfully done. Puberty threatens to erase that work by spoiling their identity, effectively discrediting their acquired gender role by way of emerging traits incongruent with society’s normative expectations (Goffman, 1990: 13). As Sigrid told me, a boy, “developing an hourglass figure any girl would envy” while simultaneously failing to develop a deepened, masculine voice “doesn’t work.” Likewise, a girl who begins to sprout facial hair, develop an Adam’s apple and with it, a deep voice, has her opportunities to be unequivocally received as a young woman by society spoiled. In this way, the social can amplify embodied suffering and overwhelm the sufferer.

Puberty also threatens an undoing of what work may have been done thus far to cope with the incongruent traits of the young person's *body*, which up until puberty are private and not readily apparent affairs. Up until that point, clothing, pronouns, patterns of social grouping and play are the main markers of gender identity. These are fairly easily adopted. Puberty amplifies sex traits, making them public and hard to conceal or ignore, betraying their sense of self and evoking an *embodied* suffering. Indeed, "it overwhelms them."

A key component of the alleviation of suffering achieved by gender affirming care is ultimately social. For relief via gender affirmation to be successful, one's perception of their own identity must also be congruent with the way others perceive them (Nuttbrock, Rosenblum, & Blumenstein in Jäggi et al., 2018). A basic human need is to have one's personhood legitimized and accepted by the other party in social encounters (Gullestad :1992: 70). As anthropologist Marianne Gullestad puts it, "Social identities have no possibility of being accepted if the persons cannot anchor their desired identities in something which their social partners see as realities" (1992: 187). For those that know and accept them, this recognition may be achievable, but this still leaves a large portion of one's social existence vulnerable, as one must still relate to strangers on a day to day basis. These encounters may leave a person vulnerable to daily social stressors, misunderstandings and seemingly small transgressions that are cumulative in their effects on the psyche.

Puberty blockers provide a better chance of eliminating this catalyst for social suffering, by ensuring a more congruent appearance indistinguishable from peers of the same gender. According to communications professor Paul Martin Lester, "Passing as a concept became necessary when persons considered as 'others' wanted to participate in the benefits afforded those of the dominant culture without detection" (2015: 144). The ability to pass inconspicuously as a member of one's gender can be a survival skill, as witnessed by the victimization that may befall the visibly gender variant, those lacking what is called "passing privilege" in the gender variant community. Adolescents receiving early interventions achieve bodies that will not be "marked" by secondary gender characteristics (Castañeda, 2014), and are able to transition in "new and more complete ways" than physically mature adults transitioning can (Roberts & Cronshaw, 2017). Without the visible markers of stigma, they can go undetected in society if they desire to, with all the potential advantages that entails.

Lasse, one of the youngest participants in this study, said he feels lucky that that he was able to get access to puberty blockers early enough in his development to make a difference: "Because there's—there's a lot I don't have to go through now (*får slippe*), that I maybe would have had to go through a few months later. [...] There are things that maybe



others struggle with that I would have struggled with too. I like that I don't have to." Lasse here is speaking of the embodied suffering brought on by the development of breasts and feminine fat redistribution that he may have endured had he not been provided puberty blockers. He has been spared this suffering entirely, unlike others with gender incongruence that he knows. His father, Arnt, however, focused on a different set of benefits early interventions represented for his son:

Yeah, because we hope that he will be able to avoid having to have extra operations and – and he should be able to have, to the degree that it's possible, anonymity. To be able to go without a compression vest and all of that.

Arnt went on to mention how blockers allow Lasse the simple pleasure of being able to go bare-chested in summer at the beach that others take for granted. In this, we see not only a parent's desire for a typical childhood for his son, but the hope is that in the future Lasse can pass without the discomfort, potential injury and limitations imposed by long term binding of his chest with a compression vest to conceal breast development. Only with puberty blockers will he be spared the need to undergo procedures like top surgery which enable passing but are painful and invasive. He can also preserve his anonymity and the freedom to decide who knows his gender history, a luxury not afforded all gender variant people.

Having the liberty to go undetected may be especially important for the girls of this study. Males assigned female at birth tend to pass relatively easily after HRT and top surgery in comparison to their female counterparts who have undergone a masculinizing puberty (Edwards-Leeper & Spack, 2012). Girls assigned male at birth who go through a masculinizing puberty face development of secondary sex characteristics that are largely irreversible without highly invasive procedures such as facial feminization surgery, surgical shaving of the Adam's apple, painful electrolysis or laser treatments for hair removal and vocal cord surgeries that produce limited results (Spack, 2009). Mari explains of her daughter:

She'd rather pass. Yes, that's...it's important for many. To pass. She passes. We were at [HBRS] summer camp last summer [...]and she passes a lot better than many others. [...]That's what these hormone blockers do. There was a girl that was 190 [cm] with an Adam's apple and a deep voice—no matter how you do your makeup or dress when you have that— that deep voice— like mine is now, but I'll soon be 50. But that, that's not okay when you're 18, 19 years old. So, it means everything, actually.

Passing, Mari explains, is very important to her daughter, Sofie. Described as a private

person, she will, like Lasse, have the choice when and to whom to disclose her gender history. Sofie's history will not be given away against her will by her voice and her height, as Mari emphasizes here. This may also shield her from the discrimination and stigma that more visible individuals sharing her gender history may face (Hughto, Reisner & Pachankis, 2015) and help her to develop a more positive self-image than some with gender incongruence that gain access to medical transition past puberty achieve (van de Grift et al., 2016).

As Mari does above, other parents in this study spoke of their own children relative to the outcomes of others in their social sphere to describe the benefits of obtaining early interventions for their child. Those they made comparisons to were family friends and acquaintances whom had not received treatment, suffered through puberty, and were "traumatized" as a result. Comparison to others may help families envision possible futures for their children (Katz-Wise et al., 2017), often in terms of desirable or undesirable outcomes, or livable and unlivable lives. Such comparisons are described by study participants as a driving the desire to seek early interventions.

A number of academics have questioned the discourse of passing as it pertains to the treatment of gender variant adolescents. Claudia Castañeda argues that the discourses employed in clinical literature and the media around hormone interventions for gender incongruent adolescents are fueled by societal definitions of developmental "success" and create assumptions that the only successful development for children is a gender normative one in which gender is unambiguous (2015), i.e. where one passes. Sadjadi contends that these discourses may unintentionally cause harm to the people they are meant to help, by encouraging a sense of fatalism and supporting existing stereotypes of gender incongruent people who do not receive treatment in adolescence as "inherently damaged", destined to a life of discrimination, misery and in the worst case, suicide or murder (2013). Indeed, we see this in the master narratives about gender variance that some parent participants of this study are influenced by. Roberts and Cronshaw challenge proponents to consider how arguments in favor of puberty blockers might be voiced in a way that doesn't threaten to reinforce the stereotypes and limitations and foreclose on possibilities of a life without them (2017). I too struggle with how sensitively honor the lived realities of how families experience and cope with suffering without perpetuating notions of inevitable ruin without them.

Transgender studies scholar Susan Stryker acknowledges that one can have a deep longing for normalcy, calling it understandable considering the stigma gender variant people face. She instead places the harm in judging the value of gender diverse lives on their adherence to gender norms (2013). The desire for normalcy may be particularly strong in

Norway, where homogeneity and normativity are underlying assumptions in a society that also places a high value on equality. As Gullestad puts it, living within this “myth of homogeneity”, the homogenous is seen as the normal (2002:67). When equality (*likhet, likestilling*) is based on a culture of “imagined sameness”, you cannot be equal until you are the same (ibid, 2002: 82-87). Gullestad (2001) also points out that because of this, even bullying among children can take on a different role than outside the Nordic countries. This, she argues, is because for the maintenance of imagined sameness to be achieved, an outsider must be created. Differences must be found and given a significance, often based upon cultural traditions and norms, to reinforce the sense of belonging of others (Gullestad, 2001: 39-40). Difference poses a threat to homogeneity. Puberty blockers (used along with other gender affirming interventions) lend the possibility of sameness, and therefore, equality, to youth with gender incongruence by circumventing the marks of stigma associated with transitioning post-puberty.

Sadjadi and Castañeda are sympathetic to the suffering of young people with gender incongruence and clearly argue for the inherent *worth* of all gender variant people. However, they seem to believe that the brunt of the gender dysphoria and fear at the onset of puberty that adolescents experience is based entirely on societal reactions to gender variance, i.e. social suffering. Thus, an extreme reading of these views might be “change society and then we won’t have to fret over gender incongruent bodies.” Castañeda even notes in her analysis that she realizes that the parties involved are trying to help in the here and now, not in the context of some future ideal (2015).

I agree with the core message, but I contend that these kinds of critiques acknowledge social suffering while failing to address, and thus minimizing the *embodied suffering* experienced by these youth as their body progressively mirrors their experience of self less and less. They may indeed be correct that gender norms and the fear of stigma are major drivers behind treatment narratives. Seligman, however, asserts that healing practices best suited to the alleviation of suffering related to threats to the self must be directed at both the cognitive-discursive *and* embodied aspects of the self (2010). Gender role adjustment, social acceptance and the reconstruction of discursive elements of understandings of the self may play a key role in alleviating suffering. But without also addressing the embodied aspects of suffering, healing may be incomplete. Above all else, alleviating or preventing embodied suffering is the *most* pressing motivation parents cited for their quest for help, as it was experienced as the most devastating part of the puzzle, with the most potential to damage mental health.

Judith Butler reminds us:

Critiques of gender norms must be situated within the context of lives as they are lived and must be guided by the question of what maximizes the possibilities for a livable life, what minimizes the possibility of unbearable life, or, indeed, social or literal death (2004:8).

For the families I met over the course of this study, early interventions were believed to minimize the possibilities of future unbearable lives, and maximize the potential for a positive future, a life in which one not only survives, but thrives.

In this chapter, I have examined the meanings participant families attach to early interventions, how they are believed to not only improve quality of life, but are also credited with saving lives. I have also presented some of the experiences that lead families to seek care, as well as their perceptions of the benefits of receiving treatment with puberty blockers. I also briefly touched on their experiences of meeting resistance while seeking that care. In the next chapter, I take a closer look at some of the experiences study participants shared of seeking gender affirming care in the Norwegian health care system and explore how it is that these experiences led some study participants to distrust the clinic tasked with providing their care.

## CHAPTER FOUR: “I got a feeling of that they don’t trust you, you know?”: Trust and Distrust in Gender Affirming Care-Seeking Encounters

### 4.1 Introduction

In March 2018, an opinion piece (*kronikk*) addressed to Norwegian Minister of Health Bent Høie was published in the *Aftenposten* newspaper, written by the leader of the newly created NBTS KID-team and the lead surgeon at NBTS’ adult clinic. It calls attention to an increase in the referral of teenagers assigned female at birth seeking treatment post-puberty at the clinic. It stresses the fact that many of these teenagers begin hormone treatment with providers outside NBTS prior to seeking or while seeking treatment at NBTS. The piece all but accuses these providers of preying upon vulnerable youth, claiming that “Eager private practitioners stand in line to give masculinizing hormones to teenage girls with a desire to change their gender” (Wæhre & Tønseth, 2018). The piece makes out these providers as naive, saying that they are engaged in a misguided freedom fight and a “profession war” (*professjonskamp*) with potentially dire consequences, not just for the youth involved, but for society as a whole (*ibid*). The authors call upon Høie to reign in these private (and public) healthcare providers who offer gender affirming treatment, imploring Høie to “...hold the treatment-eager sexologists back, they offer hair growth and deep voices to the nation’s daughters, and in return we get lost fertility and an insecure future” (*ibid*).

Some study participants were offended by the article and reached out to ensure I had seen it. Those who made contact were angered by the strong emphasis placed on the mental health challenges faced by some young people with gender incongruence. They felt this was degrading and painted their children in a bad light while failing to recognize that these challenges can be attributed to both social factors and a lack of treatment for gender incongruence. The language used throughout the article was also seen as disrespectful. This was because the youth the authors refer to identify as boys but are repeatedly referred to as “the nation’s daughters” and “teenage girls” in the piece (*ibid*). One parent study participant felt this demonstrated a lack of understanding, respect and empathy for their patients, and was an affront to a young person’s right to self-define. Another parent called the piece a “power struggle (*maktkamp*)” to protect NBTS’ monopoly and shut down the providers outside NBTS who many rely upon for various aspects of care.

At the time I embarked upon fieldwork, NBTS had only recently reorganized under two clinics, one for adults, and the KID-team, for careseekers under 18 years of age. The reorganization was so new that many participants had not yet had an appointment since the

change. The change was met with cautious optimism, and some study participants praised the new leadership and direction of the KID-team as a welcome sign of change. One parent, whose son had experiences under the new structure, expressed that they had seen a positive improvement in services, but was surprised and disappointed by both the wording and the opinions set forth in the article, as they did not expect clinicians to “behave like that”.

The piece spurred a wave of public debate and political mobilization around the growing trend of careseekers obtaining gender affirming care through providers outside of NBTS, and whether this should be permitted to continue (e.g. Fonn, 2018a; Fonn, 2018b; Berglund, 2018). A good portion of the debate focused on negative experiences at NBTS as a driving force behind the trend (e.g. Hafskor, 2018a; Hafskor, 2018b; Wegling, 2018; Sae-Khow, 2018; Corneliussen, Brune & Nitzschner, 2018). Åse, as a mother who is moderately politically active with issues pertaining to gender affirming care, felt that the statements made in the opinion piece could prove harmful. She wrote:

Never have I experienced so many that are scared to be referred there [to NBTS] and get bad treatment than now, and that would rather suffer through their daily life without getting help. It’s both adults and young people that I’m hearing feel that way.

Åse tells of the fears she has encountered expressed by members of the gender variant community in the aftermath of the opinion piece. Fear of bad treatment, she says, is resulting in an avoidance of the clinic which contributes to suffering by delaying access to needed treatment. By bad treatment, she means careseekers fear that attempting to seek treatment there is a futile exercise, because they may be denied care anyway.

But these fears are not new; they are not merely generated by one opinion piece. Indeed, they date back to long before the KID-team’s existence, before the gender clinic at *Rikshospitalet* was operating under the moniker NBTS. For example, Mari told me how the first time she and her daughter attended the HBRS summer camp, over a decade ago when Sofie was just six years old, people told “horror stories” (*skrekkehistorier*) about a particular clinician at *Rikshospitalet*. “Everyone was scared,” she said. But why would careseekers fear the clinic mandated to provide care to their patient group? And why would they feel the need to seek help elsewhere, often at a personal cost?

Based on the experiences shared in the interviews I conducted, I believe the opinion piece by Wæhre and Tønseth represents just another incident in a history of growing distrust between the clinic and careseekers. It also highlights many of the key controversies that arose in interviews with families and key informants: the psychiatric focus of assessment and

treatment in the public system, the length of time the process takes, issues of identity and who determines which identities are deemed authentic, and the usages of private practitioners in gender affirming care. As such, I refer to it throughout the chapter as I explore how these particular study participants' experiences at the gender clinic, which span from 2005 to the present, have ended up creating an atmosphere of distrust that can lead to the practice the piece problematizes: seeking treatment outside NBTS.

Per Fugelli once said that trust is the basic element (*grunnstoff*) of medicine (2005). He called it the God particle, borrowing a term from physics for the elementary particle which, according to popular science, is responsible for "holding the Universe together" (ibid). But one thing Fugelli didn't mention was that the Higgs Boson (for which "the God particle" is a colloquial term) is highly unstable and can easily decay (Hu, 2013). As I move the discussion away from the meaning study participants place on gender affirming interventions and the experiences that lead them to seek them, I move on to an exploration of their experiences seeking treatment. One binding, yet unspoken thread woven throughout their accounts is that of trust, or more accurately, a breakdown of trust in "the system" that was intended to help them.

It bears mentioning that the small group of careseekers interviewed for this study cannot be taken as representative of the gender variant community in Norway as a whole. But when it comes to this group of participants, I observed that nearly all had experiences damaging to trust at some point in their care seeking journey. It became clear to me this was a group of careseekers had not only lost their trust, but over the course of seeking gender affirming care, had come to feel distrusted themselves. The rest of this thesis examines what happens when what Fugelli calls the critical element that holds the practice of medicine together comes under threat of disintegration.

#### **4.2 A Brief Exploration: Trust in Encounters with Health Care Professionals**

In the accounts of this study's participants, issues of trust, risk and power were highly problematized. It is essential to see trust, risk and power as interwoven inevitabilities in medicine, or as Norwegian philosopher Harald Grimen refers to it, a "nexus of trust, risk and power" present in all interactions between professionals and laypersons (2009:18). In the following I provide a brief overview of how these three concepts interact in healthcare encounters before moving onward to participant experiences.

Academics have presented a variety of definitions and theoretical frameworks of trust, based upon a range of societal issues from politics to interpersonal relations to healthcare (e.g.

Luhmann, 1979; Giddens, 1990; Meyer, Ward, Coveney, & Rogers, 2008; Hall, Dugan, Zheng & Mishra, 2001; Grimen, 2013). Indeed, trust has become a popular topic in the study of public health (Meyer et al., 2008; Cohn, 2015), however, I have yet to find one theory satisfactory to the analysis of encounters in gender affirming care. This may be because most theories and studies of trust in medicine pertain to general patient populations, and do not take into account the perspectives of minorities and how their experiences may differ (Hall et al., 2001; Meyer et al., 2008). Because of this, I have chosen a working definition of trust and framework for its mechanisms that is an amalgam of several scholars' ideas.

According to Fugelli (2011), "Trust is a person's sense that others' goodness, honesty and capabilities can be relied upon." It is the general sense of security that others will not betray you by acting against your interests. Luhmann sees trust as a mechanism for dealing with the risk inherent in complex societies where we often must act without complete knowledge, which necessitates reliance on our expectations of how persons or institutions should behave (1979). Giddens defines trust as a "confidence in the reliability of a person or system, regarding a given set of outcomes or events", and in healthcare scenarios, this entails faith in clinicians' expertise and the technical knowledge behind it (1990: 34). Additionally, trust is "future-facing" in that we make predictions of how others will act in the future, based on prior experiences and normative expectations (Luhmann, 1979; Giddens & Pierson, 1998; Barbalet, 2008; Grimen, 2013). But, just as the narratives study participants share of a child's gender history are revised to reflect present understandings of their identity, trust and distrust can also "extend backwards", with experiences of trust-affirmation or betrayal leading us to see past encounters in a different light (Cohn, 2015).

According to Grimen, issues of trust and power go hand in hand, and this is especially true in the context of medical encounters (2009). Trust in medicine places the trust giver in an amplified position of vulnerability, not only because they are dealing with a medical condition, but because the doctor-patient power relationship is always unequal (Grimen, 2013). Doctors not only have specialized knowledge careseekers do not, but they also function as gatekeepers to the care they need, putting them in a position of dependence (Grimen, 2009). Careseekers may be forced to trust a clinician because their options are limited, which further compounds issues of power and dependency already present (Grimen, 2001). This is most certainly the case for those seeking care at NBTS. Should they desire publicly funded gender affirming care, they become dependent upon NBTS, because seeking care at NBTS is the only way to achieve this end in Norway.

But careseekers are not completely stripped of power. Indeed, in a Foucauldian sense,



power is diffuse and relational here, reliant on the willingness of others to heed to that power (in Farsethås, 2009). Although a thorough exploration of this phenomenon is beyond the scope of this thesis, I found study participants exerted their power by becoming informed of the latest research in the field of gender confirming care. They accessed academic journals, accessed social networks, watched documentaries on social media, and attending conferences. They used this knowledge to question the authority of clinicians. They may also reclaim power by choosing to seek help outside NBTS.

According to Hall and colleagues, we expect that doctors will operate according to several key dimensions of trust including fidelity, (i.e. acting in patient's best interests without conflicts of interest or exploiting their vulnerable position); competence (which includes not only technical knowledge, but communication skills); honesty (which I argue includes transparency); and confidentiality (protection of sensitive information) (2001). Hall and his coworkers also add to this list a final component called "global trust" (ibid). I find this concept rather vague as they present it, as the "soul of trust". It essentially functions as a receptacle for any phenomena that fall outside of their other dimensions (ibid). Instead I propose, based on Grimen's (2001) work, that global trust be replaced with *reliability* (that a clinician will follow through with what he says he will do, and that their behavior and decision making is consistent over time).

Remarkably, only once was trust or distrust mentioned directly in the interviews I conducted, yet they are implicit in nearly every account. In sections to follow, I explore how not just one distinct scenario, but a series of sometimes momentous, sometimes small acts can contribute to attitudes of distrust. My aim is also to examine a series of past care seeking experiences to shed light on how careseekers might come to a point where they choose to seek care outside NBTS.

#### 4.3 "Why should they have to go through psychiatry when there's nothing wrong?":

##### Experiences with BUP Seeking Gender Affirming Care

Imagine that you're presenting at the doctor's office with a child whose health needs are urgent. This is a *crisis*. Time is running out, for you know that the longer your child waits for help, the less likely they are to benefit from the lifesaving treatment they require. You trust that the doctor will recognize your child's need for the rapid upstart of biomedical interventions and act accordingly. But instead of being referred directly to the clinic that can provide expert care for their condition, you're referred to a psychologist for a months-long evaluation process to rule out the risk that your child is suffering from a mental illness too

severe to permit treatment of their medical condition. To make matters worse, the psychologist has never encountered a young person with your child's condition before and isn't entirely sure how to proceed. Meanwhile, the clock is ticking.

I want the reader to keep this analogy of care seeking with a sick child in mind, to foster understanding of where families I interviewed stand on gender affirming care and their experience of the process they must navigate to obtain the help they feel their child needs. In Norway, families seeking gender affirming care typically begin their journey at the first tier of the healthcare system with primary care physicians (*fastleger*), school nurses, local youth healthcare centers (*helsestasjoner*) or NGOs specializing in sexual health and LGBT issues. From here, the path the majority of careseekers take is via referral to the local Children and Youth Psychiatric Clinic (*Barne- og ungdomspsykiatrisk poliklinikk*; hereafter referred to as BUP). BUP is a specialist psychiatric healthcare entity providing outpatient psychiatric services for youth under 18 years of age and their families. From BUP, a referral to NBTS is sent, following a battery of psychological tests required by NBTS prior to referral. According to study participants, they are also obliged to undergo continuous follow up with BUP for the duration of their care seeking experience, whether the family feels there is a present need for psychiatric care or not. Gender incongruence is the only medical condition in Norway that requires psychiatric care as a precondition for access to somatic interventions (Bolstad, 2019).

Mari, who we met in the previous chapter, felt the psychiatric model of gender affirming care was problematic. Banging on the table as if to emphasize her point, she argued:

Why should they have to go through psychiatry when there's nothing wrong? [...] There's nothing wrong with their mind, there's nothing wrong with – with their psyche? *Quite the opposite!* They're actually very healthy and bright (*oppvakne*).

Mari challenged the classification of gender variance as a mental disorder, seeing it as not only wrong, but contrary to her own experiences. Although study participants generally tended to subscribe to the notion of suffering as explored in the previous chapter, they saw this suffering as a natural response to the myriad challenges gender variant youth face. One parent study participant felt that due to the high prevalence of mental health challenges, psychiatric evaluation was warranted. For others, the fact that gender affirming care occurs under the purveyance of psychiatry represented a fundamental misinterpretation of the experiences, gifts, and needs of gender variant people.

Wæhre and Tønseth (2018) see it differently, saying that careseekers frequently present with serious psychiatric conditions, and that “2 of 3 are struggling with serious

depression, anxiety, self-harm, trauma, autism spectrum disorders, hallucinations or thoughts of taking their own lives.” This, they say, necessitates added caution in the provision of care to these young people (Ibid). Assuming these statistics are correct, the problem study participants had with these statements was that the authors fail to contextualize them.

Without discussing the roles that stigma (Robles et al., 2016; Winter et al., 2016) and the disconnect between subjective experience of gender and the body can play in the development of these mental health challenges (Saketopoulou, 2013), such statements might give some the impression that mental illness is inherent in this population. They may even add stigma to an already stigmatized group (Winter et al 2016; Reed et al 2016), or importantly, cause health professionals to doubt careseekers can be trusted to make sound treatment decisions (Winter et al., 2016). In a hearing response to the plans for restructuring of the gender affirming care system in Norway, members of the Norwegian Association of Psychologists make the argument that what *should* be concerning is requiring those who suffer anxiety or depression due to minority stress to seek psychiatric help for a ‘condition’ with societal causes (Bolstad, Jessen, Kvam, & Ohnstad, 2018).

Another common concern among families was BUP’s readiness to meet NBTS’ requirements for referral and continued care. Participants described how when clinicians lacked awareness of how to help gender variant youth, they experienced stress and frustration. Over the course of this section, I will explore how experiences with a second-tier psychiatric entity which has elsewhere been described as unprepared to meet the needs of gender variant people (van der Ros, 2013:21; Bufdir, 2011:30) can contribute to distrust of the system intended to help them.

Mari described how her daughter Sofie’s BUP clinician came off to the family as insensitive at their first meeting:

Good lord, the first time Sofie came, the clinician had said ‘You know, my son, he wants to wear a dress, but then I say ‘No, you can’t wear a dress! Because you’re a boy!’ So that was like [...] Sofie had to teach *her*. It was completely meaningless.

Sofie’s clinician shared a story about correcting their own son’s gender atypical desires, which Mari and Sofie interpreted as sending a gender normative message. This led Mari to believe the clinician saw Sofie’s subjective experience as silly and misguided, as something to be corrected. To Mari, this also demonstrated a lack of understanding of how to interact with gender variant youth in a validating way, which for her rendered the appointment “meaningless”. Sofie was then tasked with educating the professional. Meanwhile, an

opportunity may have been missed to help Sofie cope with the hyper-gendered social stressors of adolescence and stigma related to her identity (Vanderburgh, 2009), or with accepting the body as a ‘work in progress’ prior to gender affirming care (Saketopoulou, 2014; Langer, 2014). Mari and Sofie’s trust in the competency of her BUP clinician was negatively impacted by this encounter. For Mari, requiring her daughter to see a professional who did not seem to understand her was a waste of time, adding insult to injury.

A BUP clinician’s lack of experience with gender variant youth may also result in significant delays in referral to NBTS. Pål, 16, had already dealt with parents that didn’t believe him when he first came out as male, so he was disheartened when the BUP clinician he sought a referral from also didn’t believe him. Pål believed that the clinician’s response stemmed from a lack of awareness of gender diversity. “Her, the first clinician I had – I don’t believe she had so much knowledge about it [gender variance]. So, I think that’s why she didn’t believe me. But then I got a new clinician after that; she helped me come in at *Riksen*,” he explained. When the clinician went on maternity leave, he found support in her replacement, who completed his referral to NBTS. To him, this period of trying to convince his first clinician of his identity represents precious time he could have spent progressing toward a referral to NBTS.

Because training about gender incongruence is minimal in medical and clinical psychology training in Norway, people with gender incongruence may be met by professionals that lack understanding of their needs, including where to refer them onward for gender affirming care (LGBT-senteret, 2011: 23; Eggebø, Almi & Bye, 2015; van der Ros, 2015). The population of gender variant people may be comparatively small, and because some persons *not* specifically seeking gender affirming care may not disclose to avoid stigma, clinicians may go years without encountering one in their practice. This hinders the accumulation of experience (Bauer et al., 2009; Dewey, 2008). As a result, careseekers may find themselves educating clinicians (Rentmeester & Sallans, 2015; Dewey, 2008; Bauer et al., 2009; Wagner et al., 2016). This can be stressful for the careseeker, as it upsets the balance of power in the clinical encounter (Dewey 2008; Rentmeester & Sallans, 2015).

Although some clinicians may respond to careseekers’ attempts to advocate for their needs with curiosity and openness, others may experience this as a challenge to their expertise and respond with hostility (Dewey, 2008; Rentmeester & Sallans, 2015). I wonder if the perceived threat to one’s expertise might be even greater when the careseeker-educator is a child. I also wonder if some young careseekers may be reluctant to advocate for themselves due to additional power imbalances attributed to age. Depending on the clinician’s attitude,

openness and curiosity, or hostility, trust in that clinician's expertise and good will may either grow or erode (Dewey, 2008). One assertion made by interviewees, both parents and youth, was that "BUP doesn't know anything." When families got the impression that clinicians lacked knowledge about gender variance, this led to feelings of frustration and an erosion of trust in the clinician's ability to contribute meaningfully to their child's care.

Additionally, when health professionals are confronted with symptoms they find unusual, and with which they have little familiarity, they may have difficulty trusting the careseeker who presents with them (Rogers, 2002). Pål felt that his BUP clinician did not believe him and attributed this to their lack of knowledge about gender variance. Assuming Pål is correct, one might speculate that they may have found his norm-defying assertion that he is actually a boy unusual. Distrust in the subjective experience of a careseeker's symptoms (in this case, symptoms of gender dysphoria) could in theory lead a clinician to dismiss them as not warranting concrete action (Rogers, 2001). This may delay progression toward referral. I argue that careseekers like Pål could then come to distrust the clinician for failing to act.

Some participants describe BUP clinicians as well-meaning, respectful, and skilled with other aspects of care, such as dealing with anxiety. And indeed, with these types of challenges, psychiatric support may be viewed as a part of gender affirming care. Arnt, Ina and their son Lasse told how once clinicians at their local BUP *had* received specialized training on gender diversity through programs offered by various interest organizations, there was a discernable difference in how they were received. However, it was still care few families I interviewed felt was needed, and yet was required of all careseekers uniformly if one wishes to access somatic interventions.

As careseekers, we may not always have a long history of interactions with the healthcare providers designated to care for us. We must then rely upon normative expectations that professionals are competent to meet our needs (Luhmann, 1979; Hall et al., 2001; Grimen, 2009). These encounters represent what Giddens calls "access points", which are "places of tension between lay skepticism and professional expertise" (1990:91). Negative experiences (such as uncovering weaknesses in a professional's expertise) at these initial access points can contribute to "lay skepticism" and create wariness toward the system as a whole (ibid). A clinician's unfamiliarity with gender variance at this point in the care seeking experience may impact the interpretation of further snags in the process, should they emerge. This may bias careseekers to assume that all professionals tasked with their care are incompetent and seek confirmation of this, outside conscious awareness (Hall et al., 2001).

Some theorists of trust argue that trust is always unidirectional. I tend to agree with

Giddens's line of thinking, that for trust to function, it must be mutual (Giddens & Pierson, 1998). For example, as we see in Pål's case, doctors must trust that careseekers are telling them the truth (Rogers, 2002). They must also trust that careseekers do not have ulterior motives for seeking care and that they are competent enough to make sound decisions if they are to involve them in shared decision making (ibid). The system of gender affirming care demands the trust of careseekers, while simultaneously demonstrating a distrust of careseekers themselves, namely that they know who they are, and can make sound autonomous decisions about their futures. I will return to this point later in the chapter, as this aspect of distrust has a strong impact on the clinical encounter (ibid). Meeting clinicians whose approach they interpret as enforcing gender norms or whom they sense do not believe them can be damaging to the young person's ability to establish the trust necessary for a successful therapeutic encounter. A breach in trust so early in the care seeking journey may taint further experiences, creating a scenario where careseekers lose confidence that the healthcare providers they depend upon will understand and validate their experiences.

#### **4.4 "You have to be willing to hunker down": Fighting for Gender Affirming Care**

"You have to be prepared to fight tooth and nail, that's what we were told," Arnt explained as we enjoyed sweet buns over coffee at the family dining table. Ina, his wife, nodded. "That's exactly what we were told," she said. They were speaking of advice they received from another community member when they experienced that their son Lasse was initially denied access to puberty blockers after having been given the impression that he was a good candidate for the treatment. Episodes described as "fighting for care" often became the capstone of study participants' care seeking narratives. I found that these episodes shared a feature: they were highly related to issues of trust. In this section I will share Mari's story of fighting for care for her daughter to examine how breaches of trust can create a scenario where families feel they must fight for treatment, and how having to fight for treatment can further fuel distrust.

Mari, unlike the parents I introduced in the previous chapter, did not see puberty as an emergency, at least not initially. She had acted early to get Sofie into the system at *Rikshospitalet*, long before any actual treatment was necessary. She explained that she wanted her daughter, who is prone to shyness, to become familiar with clinicians, developing trust over time so she would feel comfortable with them. Discussing the often-intimate topics in diagnostic interviews at gender clinics with strangers can prove stressful for young careseekers (Turban et al., 2017) and Mari was hoping to ease this stress for her daughter. She

also hoped that clinicians would come to know Sofie well enough that when the time came that she finally did need help, she would be given the best possible care.

Mari remembers that Sofie was promised treatment from those very first encounters. She says they were assured by her clinician that she would never have to worry about getting a deep voice or developing facial hair and an Adam's apple, because when puberty arrived, they would give her puberty blockers to stop its progression. Sofie grew up assured that she would be spared the changes she dreaded. So, when puberty arrived, it was not viewed as a crisis. The family were calm, expecting Sofie to receive the medication she had been promised years before. Instead they were told Sofie was functioning too well to justify prescribing puberty blockers. This came as a blow to Mari:

Jeez, what a shock! [...] They are very concerned with suffering (*lidelsestrykket*). [...] If you don't have a large enough degree of suffering then – you're not enough of a patient? And so, she was denied after going in there and talking with them, because she was positive and not down in the dumps (*ned i kjelleren*). So, they want to have you down in the dumps, *but* if you are too far down in the dumps, then you don't get help because you – then you have to get back up and show that you can tolerate being in this situation (*at du tåler å stå i dette her*). Those that are too down don't get help either. Because then you're too unstable. [But] you mustn't be too psychologically healthy, because then you're not suffering enough.

Mari illustrates here a 'Catch 22' paradox often brought up in interviews: treatment was believed to relieve suffering and improve or preserve mental health. But if you are suffering too badly, you can't access gender affirming care until your mental health improves. Additionally, if you aren't suffering enough, Mari maintains, then that also can make you ineligible for treatment. Mari sees successful bids for care as the result of maintaining an equilibrium: you must suffer just the right amount, not too little, not too much. Mari's purpose for seeking out treatment for her daughter was to prevent her ever having to suffer in the first place, but never having suffered, Mari says Sofie was denied access to puberty blockers.

As mentioned in the previous chapter regarding the three types of suffering gender early interventions are meant to alleviate; in certain situations, some or even all of these types of suffering may not be present. Sofie's case is one such example. Youth like Sofie, who are promised blockers, may only rarely exhibit distress at puberty because they have been assured that there's nothing to fear (J. Olson-Kennedy, personal communication, 08.11.2017; Drescher, Cohen-Kettenis & Winter, 2012). Additionally, those who grow up in an accepting

home environment may also be less susceptible to suffering (Drescher et al., 2012) and resultant mental health struggles (KR Olson et al., 2016). One could theorize that those like Sofie, who also experience a supportive school and community environment would be far less likely to be exposed to stigma-related social suffering. Sofie may have thus far lacked markers of suffering because she had thrived under excellent developmental conditions. Additionally, she knew that treatment to halt unwanted bodily changes was available.

Mari recalled that the appointment the family had expected to end with a prescription for puberty blockers instead left her usually resilient daughter despondent. “So, then we got denied [treatment] right before we left. Yeah. Very brutal! Get denied care, now you can go home,” she said. Mari described how Sofie began to develop thoughts of death in the aftermath, indicating that she would rather die than live with the changes she would have to endure. She who was not suffering enough to warrant treatment according to clinicians, began to suffer once her hopes for treatment were dashed. Mari felt it was unconscionable to not help a careseeker to process and deal psychologically with rejection for treatment. This led Mari to question their empathy. This, paired with the shock of having been denied care they were promised, fomented distrust and feelings of betrayal.

As she watched suffering take hold of her daughter, Mari questioned, and then challenged the clinic’s decision. She says she worked over several months to change clinicians’ minds, making various attempts at communication, but without receiving a response. She felt clinicians refused to see or hear her during this time. She describes this feeling of abandonment as traumatic for Sofie:

Poor thing came home every day from school: ‘Have you heard anything? Have you gotten an answer? Have you heard anything?’ You have to just be willing to hunker down, too. Think! Poor thing! And ‘My voice!’ and ‘Do you hear? It’s gotten deeper. It’s gotten deeper...’ It was completely *traumatic*.

Sofie’s voice began to betray her sense of gendered self, seemingly more so with each passing day. According to Mari, fear of its progression toward a masculine pitch consumed her thoughts, leading her to constantly check in with her mother to see if the clinicians had reconsidered. What was not a crisis to begin with, had become one.

The language Mari employs here is also telling. Mari describes the experience in terms that evoke the act of awaiting a natural disaster: “You have to just be willing to hunker down”. Making it through is then to weather the storm, and wait helplessly in uncertainty, in the hands of fate. I argue this language is indicative of a perceived unpredictability of decision



making at the clinic, also evident in Mari's reaction of shock when expectations of promised treatment were not realized. Without predictability upon which to base the evaluations it relies upon, trust becomes difficult to build, let alone maintain (Luhmann, 1979:39).

What has happened in the above encounter is that the trust Mari's family had developed in clinicians at the gender clinic rapidly deteriorated. Trust can be eroded when a doctor is found unreliable (Grimen, 2001), breaks their promises, lacks transparency in decision making (Hall et al., 2001; Grimen, 2013:91), or when the imbalance of power is believed to be unjust (Grimen, 2013: 91). When the clinic was experienced as going back on a promise, Mari lost faith that clinicians could be relied upon.

In my interview with her, she also speculated on the decision-making process, still in a bit of disbelief as to how the clinician the family had trusted could be behind such a decision, saying "It just doesn't fit the picture I have of [them]." What she saw as a lack of transparency in the decision-making process lead her to reflect on previous encounters with the clinician, reevaluating her previous experiences, now in a new light. But she also wondered if someone higher up the chain of command made the decision instead. This caused her to question power relationships at the clinic as well. Experiences of a lack of reliability and transparency in decision making were often catalysts for families that led them to "fight tooth and nail" for treatment, as Arnt and Ina put it. Mari felt she had to fight back against the clinician's judgment, which she no longer trusted as serving her daughter's best interests.

When Mari was additionally unable to rely upon contact with clinicians in what she saw as a time of need, this further fueled her mistrust, and resulted in feelings of powerlessness. At the time, private providers of gender affirming care were not available as they are at the time of writing, and because the clinic at *Rikshospitalet* holds a monopoly on gender affirming care, the family had few other options. As Grimen argues, trust is forced when careseekers have only extreme alternatives such as forgoing care entirely (2001), or as some families considered, seeking treatment abroad. When these are not an option, the only tactic parents had left to instill some sense of power was to fight back.

Professor Tove Giske argues that healthcare personnel have a moral obligation to make patients feel followed-up and supported, which can foster a sense of security and trust (2010). Mari experienced that her family was left on their own without support, which intensified feelings of insecurity and betrayal. According to Giske, efforts careseekers make to move their case forward when they do not feel followed-up and supported may be interpreted by clinicians as exhibiting distrust, which may provoke negative responses (ibid). For this reason, some careseekers may be afraid to speak up, even when they feel mistreated

(ibid). Similarly, Mari described a feeling of apprehension, describing how she was careful not to push too hard, and create a worse situation for her daughter. “You can’t demand anything, it’s them who decides,” she said. This balancing act placed still more stress on her shoulders as a parent.

Arnt and Ina, whose voices are presented in the beginning of this section, theorized that some of the difficulties they experienced establishing communication with NBTS were structural in nature. Arnt mentioned that to their understanding, most clinicians employed at NBTS only worked at the clinic in part time positions (*prosentstillinger*), which made them difficult to reach by phone or email. “And to get in touch with people there, it has an effect on that,” he explained. Ina felt that having to “follow up constantly” to get papers they needed was difficult. “If we hadn’t nagged, we wouldn’t have gotten anything at all,” she said. Arnt and Ina suggest that having clinicians that are specifically dedicated to the realm of gender affirming care to rely on would have been beneficial, but they also understood that because the patient group is small, this could be difficult to achieve.

This discussion would not be complete without addressing the emotional aspect of trust and its erosion. Sofie’s descent into suffering was a painful, even traumatizing, experience for Mari as well, and she remembers it as having been “a nightmare” to go through. Fighting for care was the only way she knew of coping with the situation she found herself in. At this point in the interview, Mari seemed furious at the way her daughter had been treated by a clinic they had thus far trusted. The initial shock Mari says she felt upon betrayal of trust has since turned to anger. That she had to fight so hard to obtain treatment she felt her daughter was entitled to was considered an injustice. It led her to question the healthcare system as a whole, saying she “never thought something like this could happen in the Norwegian system.” For Mari, this was not simply rejection, but betrayal on an interpersonal and systemic level. Experiences of having to fight for care tended to evoke strong emotional responses from parent study participants. Eventually Mari’s hard work paid off. Sofie was provided with puberty blockers. As Mari put it, “We were saved.”

All who trust are vulnerable to some degree (Luhmann, 1979), but in crisis situations that impinge on one’s sense of self (Grimen, 2013:68), careseekers are placed in a particularly vulnerable situation, given their dependence on healthcare professionals (Hall et al., 2001; Giske, 2010). Breaches of trust that occur in this context can be especially hurtful (Grimen, 2013: 68). Because of this vulnerability, trust is a deeply emotional endeavor (Grimen, 2013: 68; Barbalet, 2008; Rogers, 2002), its violation inciting resentment and indignation (Baier, 1986; Lagenspetz & Akademi, 1992; Rogers, 2002). Lastly, it can be said that the more

important the relationship, the stronger the emotional response that can arise from violations of trust (Grimen, 2013: 68). And few relationships are more important than that of a parent and child, or that of patient and healthcare provider.

#### 4.5 A Life Put on Hold: Time and Uncertainty in the Diagnostic Process

Waiting for care was a major theme to emerge in interviews, along with resultant experiences of frustration and stagnation. This was particularly true of young interviewees, who often expressed that the length of time the process takes from initial referral to BUP to referral to NBTS to diagnosis and treatment was experienced as negatively impacting mental health. One related element that made waiting difficult was the dual stress of dealing with uncertainty in the diagnostic process. In this subsection, I explore how these two aspects, waiting and uncertainty are interrelated and the effect they have on trust in the clinical encounter.

One of the major points of contention between NBTS and those providing gender affirming care outside NBTS is the amount of time the process should take (Eide, 2017; Fonn, 2018b). This was also true of the families I interviewed, who believed that the process takes too much time. In their opinion piece, Wæhre and Tønseth accuse providers of hormones and surgery outside NBTS of rushing to provide treatment, but also acknowledge that some careseekers should have more rapid access to treatment (2018). But because all must go through the same process of referral to the clinic via the psychiatric system, study participants felt that determining who requires additional care was occurring at the expense of careseekers that likely should have had quicker access to it.

16-year-old Henrik had already experienced delays in his process. His first referral to NBTS was rejected because it was not sent by BUP. He then had to repeat the process there. “I had to wait to come in at BUP, and then I had to wait for that there. It took – everything took a long time,” he said. According to Henrik, the process took six months, but one thing that made matters worse was that his BUP clinician had neglected to send in the referral after completion. This had cost Henrik an extra month. Three months after the referral was finally sent in, he had his first appointment at NBTS. He felt three months was an acceptable period of time to wait, but because of all of the other delays in his referral, Henrik had already begun to grow weary by the time he arrived at NBTS.

Henrik explained that he had tried to remain patient and keep an open mind about NBTS, despite having heard bad things beforehand. “I tried the whole time, not to have like a really—to not have a bad opinion of *Rikshospitalet* because – that’s all anyone hears is the bad stuff, right? And I tried to have the position that maybe it’s not so bad.” But as he waited

in the clinic lobby at his first appointment, his optimism began to fade. Once 45 minutes had passed, he learned that due to interoffice miscommunication, clinicians believed that Henrik's appointment had been cancelled. This led him to consider that perhaps the rumors about the clinic were true. Having already experienced multiple delays, he described this as the instance when anticipation turned to disappointment and dissatisfaction.

Those who enter the clinic aware of its reputation may fall prey to a "self-fulfilling prophecy" where events gain special significance as justification for distrust (Luhmann, 1979: 74). This, paired with his previous delays, may have led Henrik to have a stronger reflexive response to a bureaucratic blunder than otherwise might have been the case, despite attempts at open-mindedness. Such events may then influence the interpretation of future events (ibid).

Henrik found waiting for care deeply stressful. For him, the hardest part about waiting was when clinicians could not provide a clear indication of what the process would entail or how many diagnostic appointments could be expected. This was experienced as discouraging, especially when he learned that he could expect two to three months between each assessment. Additionally, clinicians asked what he perceived to be the same questions over and over, something he ascribed to having seen a different clinician at nearly every visit. He described how every time he had a new clinician, he felt like he had to start all over. He found this frustrating.

Continuity of care and familiarity with clinicians may help foster trusting attitudes (Giske, 2010), but lacking this, Henrik's trust in the clinic also began to fade. With a contact person who provides a sense of continuity, follow up and security, careseekers can find additional strength to carry them through the uncertain process of diagnostic assessment. Without that sense of support and familiarity, careseekers may face an extra burden (ibid). A clinician's behavior can also be impacted by familiarity with careseekers. As the care provider-careseeker relationship matures over time, clinicians tend to provide more complete information to careseekers (Waitzkin, 1985).

Henrik's resolve to stay positive began to crumble over time. By his fourth appointment, with still no end in sight, Henrik had reached a breaking point:

She [the clinician] tried to be nice, the one I was talking to. And I was—I was about to cry, the whole time. And when—when we were going to go, then she was like 'Yes, I see you're not—you're not doing so well. Do you want to talk about it?' And like 'No, I can't—I don't want to talk about it.' And then I began to cry, so it was like—too late and I had to talk with her.

Coping with waiting and uncertainty in the diagnostic process has been described as a “balance between hope and despair” (Giske, 2010). The amount and quality of information provided by professionals can tip the balance either way (ibid), and Henrik, described by his father Harald as balanced and resilient, had reached the tipping point into despair.

In that moment of vulnerability, he told how the clinician attempted to console him: “And it was like ‘Yes, yes, I understand your life has been put on hold (*livet har blitt satt på vente*)’ and just like when you read all of these articles.” Although the clinician was clearly trying to demonstrate empathy toward Henrik, he doesn’t seem to trust the authenticity of their gesture, or trust sharing his emotions with the clinician. He instead attempts to get out of it, but it was “too late.” Dr. W.A. Rogers says “Trust is like a lens that colours our vision; if we trust a person, we interpret their actions favorably in light of that trust. [...] Conversely, lack of trust may prevent us from ever seeing proof of trustworthiness” (2001). From a position of distrust, Henrik interprets the clinician’s attempt to empathize as simply repeating a line he’s heard in the media. He is reluctant to confide in the clinician, possibly because, regardless of their intention, he may see them as the source of his stress.

Luhmann (1979) speaks of the process of trust turning to mistrust as a matter of thresholds, that one can remain indifferent, or even hopeful despite a series of small unfortunate events, up to a certain point. At some point, a threshold is crossed into mistrust. The offending actions can be proportionately small, akin to tiny fractures in a dam. No one major event has led Henrik to mistrust NBTS clinicians; no one experience was even particularly negative. Instead a cascade of events has chiseled away at his will to remain positive and hope eventually becomes despair as trust erodes and the proverbial dam breaks. Trust is more easily broken than it is repaired (Luhmann, 1979: 89; Grimen, 2013: 91). Once eroded, even attempts to be trustworthy, like that made by Henrik’s clinician, can be misinterpreted as inauthentic (Grimen, 2013: 94).

In a review of the literature on waiting in healthcare, Fogarty and Cronin (2007) find that key features of waiting were:

- 1 [A] Period of measured time.
- 2 Subjective interpretation of its perceived significance.
- 3 Feeling uncertain and powerless.
- 4 Anticipation of a response to the healthcare need (467).

Careseekers at the gender clinic may feel that time is immeasurable when they feel kept in the dark about diagnostic procedures or are not provided estimations of how long that process

may take to complete before treatment is provided. They place a particular significance on the time as it passes, because as the clinician in Henrik's case does acknowledge, it feels like his entire life is on hold. For him, the future is dependent upon clinicians' decisions. As we see in Mari's case, careseekers can feel that each passing day represents a potential worsening of outcomes, as well. As discussed in the previous chapter, families tended to see intervening early as resulting in not only better treatment results, but in better mental health, and happier childhoods. A sense of uncertainty and powerlessness in the process contributed not only to the stress of waiting, but to the stress of their daily lives as experienced without treatment.

A major source of vulnerability in the waiting process is the uncertainty of what one's future life will look like (Giske, 2010). Karin experienced that her daughter's mental health deteriorated while waiting for decisions on her care at the gender clinic. This was, she felt, largely due to uncertainty. "Because you wait in the unknown; one doesn't wait for anything good that's coming that you know about. You wait for— *I don't know*. Right? Maybe I never get help and maybe I'm just going to die." According to her, there is no sense of anticipation of something good that's coming, and as we see in Henrik's case, careseekers may feel there is also no end in sight to the waiting. A sense of powerlessness and vulnerability can be heightened by a lack of information, insecurity, feeling unsupported in the process, and prolonged waiting when one is dependent upon healthcare providers who act as powerful gatekeepers (Giske, 2010). The stress of waiting may also worsen symptoms and lower tolerance of the diagnostic processes themselves (Irvin in Fogarty & Cronin, 2007).

Lastly, waiting is a very subjective experience. In times perceived as a health emergency, such as that experienced by study participants at the onset of puberty, time waiting for care can be perceived as going painfully slowly, something healthcare providers may fail to recognize (Atkinson, 2016). Young people may also experience durations of time as comparatively longer than adults (Yates, 2016). These aspects can heighten the experience of waiting for young careseekers.

Research suggests clinicians tend to underestimate the amount of information careseekers desire (Waitzkin, 1985). Rogers argues that trust in careseekers ability to participate in decision-making may also play a role in how much information is given (Rogers, 2002). This may in part explain why clinicians may fail to meet the communication wishes of young careseekers. While I cannot pretend to know if clinicians at the gender clinic trust their patients, I do know that study participants often indicated that they did not *feel* trusted by them. When clinicians do not trust in the competence and autonomy of careseekers, they may withhold information and neglect to involve them in treatment decisions, which can

contribute to feelings of disempowerment (ibid).

Participants had several suggestions as to how information might be better provided to careseekers. 22-year-old Jens suggested that basic information about how the process ‘looks’, in the form of an overview or a timeline would have been helpful for him. “I know it’s a bit difficult to make because it can vary from person to person. But one could make – a general thing then,” he said. Jens understands that the process may be difficult to describe in detail due to individual considerations, but he felt that even a guideline based on the average could prove useful in providing some degree of foreseeability.

Åse, whose daughter Madelen has a mild learning disability, suggested that providing structured information to young careseekers in advance of appointments could even improve the quality of diagnostic interviews. This is because children like hers require additional processing time:

They could prepare the child a bit better, I think. ‘Today we will talk about this, and [before] next time we need you to think a bit about this because that’s what we’re going to talk about.’ For my child’ it’s that she needs a bit of time to think. [Otherwise] she doesn’t manage to answer.

Some neuroatypical young people face challenges expressing their internal experiences and thought processes without additional support (Jacobs et al., 2014). Preparing young people in this way for the diagnostic appointments could be helpful for careseekers who do not have additional processing and communication difficulties as well. It could help eliminate uncertainty about the encounter to come and enable adolescents to better provide responses when they have had time to consider their experiences and feelings. Providing such information in a letter, for example sent out when the next appointment is given, could function in a similar way to help engage the careseekers in self-reflection and diminish insecurity (Jelley & Walker, 2003).

Madelen herself felt that information about treatment and potential side effects could also have been provided in a different manner. “I think they could have had a little info sheet that one could like, have gone over themselves.” Only receiving verbal information was difficult for her, and she felt information would be better retained if she could review it at home on her own. 16-year-old Stefan noted that such information could be tailored to different age groups. “So then younger people maybe understand it too. And a bit more relevant for young people,” he suggested.

Some I interviewed were inclined to perceive uncertainty in the process as intentional.

For example, one parent compared the information-giving practices at the gender clinic to her own experiences in the healthcare profession:

I have to say, I work in healthcare, and I have never experienced such – neglect of patients. Like, if I go to a new patient in home nursing, I have to explain that: what we can do for them; define, what are your health needs? That’s how you go in. But that’s not how they [clinicians at the gender clinic] do it. They go in with very – sparse information and – misinformation. Very unclear, almost as a technique of domination (*hersketeknikk*).

Howard Waitzkin says that “one person’s ignorance is often the basis of another’s power” and the control of information can be a source of power imbalances in the clinical relationship (1985: 82). The participant quoted above believed that by withholding information, clinicians at the gender clinic abuse their power. Trust in clinicians can make periods of uncertainty manageable (Grime 2013: 61), but maintenance of trust may be difficult if one perceives that clinicians intentionally subject them to uncertainty.

Bourdieu argues that those who have unlimited power have the power to make others wait, but they also can use this power to drive patients to anxiety and feelings of powerlessness: “Absolute power is the power to make oneself unpredictable and deny other people any reasonable anticipation, to place them in total uncertainty by offering no scope to their capacity to predict” (Bourdieu, 2000: 228). But this has an additional effect: preventing the opportunity to build trust in care providers, because, as Luhmann says, “you cannot trust chaos” (1979:39). Without the ability to generalize and predict the actions of others, trust becomes an impossibility (*ibid*).

Not long after the incident described above, Henrik discovered that he could start testosterone outside of NBTS with a provider he was already seeing regularly for additional gender counseling. He told how relieved he was that he wouldn’t have to wait any longer: “And right then I cried – for joy! It was the best thing that could have happened!” Having lost a degree of faith in the process at NBTS, and struggling with long periods of waiting and insecurity, participants like Henrik described turning to other avenues of care out of desperation. Still he does not blame the clinicians at NBTS, seeing the problem as a systemic one: “It’s the system that’s wrong – maybe not the specific people that work there.”

NBTS retains its monopoly on gender affirming care in Norway, and forced into dependency as careseekers previously were, for lack of other options, they had no choice but to endure waiting and uncertainty. Now that other routes to treatment have arisen, careseekers



like Henrik make choices to turn elsewhere for care to buffer what they experience as the psychological costs of waiting, or as a safety net when outcomes at NBTS seem uncertain. In doing so, they are reclaiming control over the process, and their future lives. But one does not make backup plans if one feels others can be relied upon (Holton, 1992:72; Grimen, 2013:57). This would not have been as likely to happen without at least some degree of distrust.

#### **4.5 “You Feel Like They Like, Look at You As—Mentally Incompetent”: Negative Experiences and Gender Policing**

Norwegian doctor, sexology professor and trans person Esben Esther Pirelli Benestad once proposed a thought experiment to help the cisgender public understand how it feels to go through a diagnostic process in which one must prove their identity to clinicians who ultimately decide if they are right:

Each of us with a sense of their own gender can try a thought experiment of how it would be if someone claiming scientific insight and the power that entails, said that you are wrong; ‘We in our department have come to another conclusion’ (2008).

Benestad’s thought experiment draws attention to the subjective nature of gender, something cisgender people rarely must defend, much less against powerful gatekeepers, upon whom unlocking access, not only to treatment, but to one’s future self depends.

The notion that only clinicians can determine who the person truly is was experienced as “arrogance” by one mother, who felt that doubt was even cast upon her subjective experience of raising a son by clinicians. In this way, not only the subjective reality of the individual seeking treatment, but that of loved ones can be brought into question. For some study participants, this contributed to an atmosphere of feeling judged throughout the clinical encounter, rather than being regarded as experts on their own experiences. In addition to a feeling judged, participants also shared accounts of clinicians whom exhibited rude and unprofessional behavior that resulted in unpleasant clinical experiences. In this section, I look at how experiences of behavior unexpected of healthcare providers and feelings of that one’s subjective experience is judged can contribute to the development of distrustful attitudes toward clinicians.

Annika and her mother Benedicte shared one such experience. After a long referral process, Annika and Benedicte sat in the waiting room at NBTS for Annika’s first consultation, feeling they were finally on their way. Then came the clinician. She left a strong initial impression on the both of them. Annika described those first moments:

She came out and called out my name. So – em – I said hello, with my other name. Because I hadn't yet switched. And the first thing she said is 'Is that how you— *present yourself?*' And I was like, 'Yeeeah.' Eh—a little bit of a bad first impression. I think it was very uncomfortable.”

Annika indicated by the tone of her voice and her mannerisms that the clinician's reaction to her continued usage of her (masculine) birthname was perceived as derogatory. She additionally perceived this initial reaction as a covert attempt to dismiss her claim to a female identity. Immediately uncomfortable with the situation, Annika told how this exchange left her feeling judged. The clinician's demeanor was perceived by Annika as saying, “I don't believe you; I don't take you seriously as a young woman.”

Some readers may wonder how a simple statement could make such a strong and clearly lasting impression on Annika, asking if perhaps the clinician wasn't just asking if that was truly the name she prefers. There may be good reasons for the impact this seemingly small exchange made. Careseekers just entering diagnostic processes may be in a particularly vulnerable position (Giske, 2010; Roller et al., 2015). Because of this, they may exhibit increased sensitivity to the tone and gestures of clinicians (Giske, 2010). Studies conducted in the U.S. suggest that gender variant careseekers may be even more sensitive to subtle signals from professionals, as they may enter healthcare scenarios expecting clinicians to treat them in ways that signal their stigmatized status, based on experiences of stigma in society at large (Dewey, 2008; Kosenko et al., 2013). The way they are treated at this stage in their gender affirming care seeking experience may then have a larger impact than it might later in their transition (Roller et al., 2015). Just starting her journey, Annika may have been highly attuned to signs she read as disapproval or rejection from the clinician, and they were likely given far more significance that they might be at a later point in her transition.

Benedicte described how she too was taken aback by the clinicians' demeanor in those initial moments. “She didn't shake my hand or say hello to me. [...] And I just was like 'I'm— Annika's mother!'— and – she completely ignored me! And I just noticed her composure,” Benedicte sighed. “I knew right away that there's no chemistry between my daughter and that lady. I thought that this isn't going to go well, this.” Benedicte found it bizarre that the clinician said neither hello to her nor acknowledged her presence, despite attempts to greet her and signal her involvement as the mother of a minor seeking care. She interprets this as a sign that the clinical encounter will go badly, and senses that the clinician will be unable to establish rapport with her daughter.

When professionals behave in a manner unexpected of them, the ability to make calls based on social norms and a sense of predictability necessary for establishing trust is absent. Luhmann states that the “basic rule” of trust is based upon social norms and what we expect of one’s behavior in a given scenario:

Whoever presents himself from the outset as unapproachable – and this can be done in many different ways: by a snub, by walking past really quickly, by offending against customary demeanor or behaviour in a way which shows that one places no value in it – whoever distances himself in this way is in no position to acquire trust, because he offers no opportunities for learning and testing. (1979: 62).

What Luhmann means is that those who present themselves immediately in a hostile manner cannot be approached in a way that fosters trust building. The careseeker cannot test out their trustworthiness gradually over time, because they have already proven themselves “unapproachable” (1979). We expect doctors to be personable, or at least professionally engaged. Both Annika and Benedicte described a sense of shock over the way they were met in this initial encounter, so unexpected was the interaction.

Faced with a clinician she perceived as hostile, Annika was reluctant to share the intimate mental health details they were attempting coax out of her. The clinician’s specific focus was on details about her past struggles with anorexia, a period when Annika was at her most vulnerable. The clinician persisted in their requests for information, despite Annika’s attempts to decline immediate disclosure, something Annika experienced as “nagging”. The clinical relationship may have benefitted from stepping back from such a sensitive subject and allowing trust to build over time, facilitating disclosure. According to Benedicte, Annika has built positive clinical relationships with other care providers, but these relationships took time to develop.

The clinician seemed to Annika to lack empathy and understanding, demonstrated by her attempts to force Annika to trust her with her most intimate details. This caused Annika to shut down, which hindered the clinician’s ability to obtain a proper medical history. Annika says the clinician then dismissed her, because she “wasn’t giving her much to go on.” She didn’t hear from the clinic for a period, and later learned her case had been terminated.

Professionals must be able convince careseekers to share intimate information about themselves, and trust is crucial to this (Meyer et al., 2008). Clinicians themselves bear the burden of establishing this trust (Giske, 2010). They cannot assume trust is a given, but rather, must prove themselves trustworthy through their actions over time (Harrison & Innes, 2003).

Trust may be particularly important to care when it pertains to stigmatized groups dealing with problems that break with social norms (Rogers, 2002). Care providers who do not present themselves in a way that evidences their trustworthiness may find these patients reluctant to disclose the information demanded of their clinical work (ibid). In this way, clinicians depend on building and maintaining trust to perform their job.

Studies show that a physician's demeanor and behavior have even more to say for whether a careseeker trusts them than the length of the relationship, and so first impressions can be vitally important (Hall et al., 2001). Bedside manner, as well as their ability to solicit detailed and correct medical histories are also important factors in how we gauge the competence of clinicians (ibid). Distrust may then develop rather quickly, based on a poor first impression. As distrust often functions as a feedback loop, it can also quickly strengthen and spiral out of control (Hall et al., 2001; Luhmann, 1979). Thus, what began as a small slight in Annika's case quickly developed into a fully dysfunctional encounter. An inability to establish rapport on the part of the clinician lead to an unwillingness to disclose the kind of sensitive information necessary to her evaluation.

Luhmann additionally maintains that in situations where one distrusts another, the person who is distrusted tends to reflexively place fault on the one who distrusts (1979:74). They may fail to understand how their own actions have created a scenario where distrust has arisen, and seek revenge by responding with hostility, or by acting against the person's interests with the person's distrustful attitude as justification (ibid). In this way, distrust, like trust, can "endorse and reinforce itself" (ibid). If a clinician senses that a careseeker doesn't trust them, they may then fault the careseeker. But this spiral could just as easily work the other way; when a careseeker senses that the clinician does not trust *them*.

Playing the devil's advocate for a minute, let's consider that perhaps the clinician herself was unaware of how her behavior may have been interpreted as threatening and invalidating. One can even ask if displays of insensitive behavior by clinicians described by study participants might reflect the situation behind the scenes at the clinic. In recent years, attention has been called to a history of work environment issues at the clinic, resulting in periods of high turnover, sick leaves, and difficulty recruiting staff (Lohne, 2017; Bordvik, 2017). A culture of internal distrust in clinical work environments can lead to staff burnout (Fugelli, 2005) and burned out clinicians may inflict "vicarious trauma", by failing to exhibit empathy due to stress (Shapiro, 2018). Clinicians who themselves feel dehumanized, perhaps by colleagues as well as careseekers, may come to dehumanize careseekers, seeing them as mere problems to be studied and solved, while losing sight of the fact that they are people

with vulnerabilities and emotions (Etchells, 2003). Additionally, with high staff turnover, clinicians may have little opportunity to get to know careseekers, which can perpetuate cycles of dehumanization (ibid).

Annika and Benedicte later learned that the NBTS clinician had made comments in her journal that implied she wasn't feminine enough. The two found this not only offensive, but indicative of the clinician's outdated views of gender expression. Annika dons a more androgynous, metal girl style, preferring band t-shirts and leggings like other girls in her class. Benedicte thought the clinician's comments were also inappropriate, considering the nature of the clinic. "But she had at any rate gotten the message that you are wearing boys' clothes and you look like a boy. So that here is not okay." she paused to laugh. "That's—but the problem *is* that Annika looks like a boy! Right?"

Benedicte saw this as a problem that the clinic was supposed to help Annika with, not something for which she should be condemned, especially so early in the process. Both mother and daughter interpreted the journal entry as indicative of a dichotomy between how Annika's cisgender peers are permitted to perform femininity in their own way without question, while she feels expected to perform her gender to a higher feminine standard. The implication that she should conform to gender norms others are no longer required to in order to convince clinicians she is a good candidate for treatment was felt to be unfair.

Surveillance, in this case in the form of the clinical gaze, applies normalizing sanctions to maintain and strengthen social disciplinary orders (Foucault in Farsethås, 2009). Some clinicians may see efforts to conform to gender norms as a sign of dedication to transitioning, as well as an indicator of mental stability (Dewey & Gesbeck, 2017). In this way gender norms may be used in a disciplinary manner, rewarding with treatment those who bend to pressures to conform and rejecting those who do not (Dewey & Gesbeck, 2017; Linander et al., 2017b). But Annika and Benedicte refuse to accept what they see as a double standard, rejecting normalizing sanctions. Benedicte deflects the power of the clinical gaze by rebuking the notion that her daughter be expected to pass as a girl so early in her process, or to conform to outdated gender norms.

In the interviews with mother and daughter it was clear that the comments made in her journal were experienced by both Annika and Benedicte as hurtful and angering. Benedicte additionally seems to lose a degree of trust in the clinician's expertise: their apparent lack of understanding of the challenges a girl like Annika faces is signified to her by what she sees as unreasonable expectations of Annika's ability to pass, considering where she is in her transition process. To Benedicte, this demonstrates a fundamental lack of understanding of

why they are seeking care, and of the clinic's own role in the process of bringing her body into better alignment with her female identity. The experience also may have further solidified Annika's sense that clinicians are only there to judge her and may continue to color her views of the diagnostic process going forward.

As previously mentioned, one reason some study participants were upset by the opinion piece by Wæhre and Tønseth (2018) was their choice to call boys assigned female at birth "teenage girls" and "the nation's daughters." This was interpreted as misgendering the youth in question. This was an issue that study participants also found important to address as they had experienced it in the clinical context.

Marthe and her son Magne, interviewed together, described how misgendering impacted their initial appointment with the gender clinic. Magne was called "Lise" and female pronouns were used throughout the appointment. This made Magne visibly distraught. Marthe explained, "He was upset because he was poorly treated at *Riksen*, that they called him by the wrong name and wrong pronoun, right?"

Magne nodded to this, adding, "I was also afraid to not get help." When Marthe demanded the clinician to stop, the clinician brushed it off as being what was in the paperwork, and thus what they use in the clinic. Magne, however, interpreted the use of his former name and the female pronouns as signs that clinicians didn't believe that he is who he says he is and would likely not provide care. As a result, the trust required for communication broke down. Magne, afraid for his future, began to cry. Marthe says that the clinician interpreted Magne's emotional response as indicating that he was too anxious to receive further assessment, seemingly failing to understand how their language had contributed to her emotional response. In a discussion after their interview, Marthe called that first experience traumatizing.

The clinician in Marthe and Magne's case explained that calling a child by what is listed in their paperwork and categorizing them accordingly in that gender is just common procedure at the clinic. Ansara and Hegarty call attention to how a history of misgendering children in clinical psychology literature may set the tone for clinicians who read these papers to do the same in their practice (2012). It is then possible that they genuinely fail to realize that this causes distress to careseekers (ibid). I also wonder if responses to misgendering might be thought to be informative to the diagnostic process by some professionals. In that regard, a strong response like Magne's would indicate a strong presence of gender dysphoria.

Sigrid, however, concludes based on her own experiences with her son, that misgendering at the clinic is indicative of a lack of respect for careseekers' subjective

experience. “You come in and you introduce yourself with a name, and then they use the other name. That is harassment. There is zero respect,” she said. She here indicates a belief that clinicians are aware of the pain misgendering can cause, which is why she sees the practice as tantamount to harassment. She has come to so strongly distrust clinicians’ intentions, that she believes they would deliberately inflict pain on young careseekers.

Her experiences also led her to question her son’s clinician’s expertise in working with gender variant children. Sigrid explained that children with gender incongruence have an intuitive sense for who believes them and who does not, and a reflexive distrust for those who do not. “It’s no use meeting the kids with a neutral view and not use – [their correct] name or pronoun. Then they close off again and you get nothing out of them.” Sigrid maintains that when gender variant youth meet people who appear to cast doubt on their identities, this can cause them to distrust that person and as a result, disengage. This may prove particularly damaging in a clinical context where engaging careseekers in soliciting thorough information is key. This is evident in both Annika and Magne’s unsuccessful first attempts to gain access to care. A breakdown of trust, and thus communication, ensued when they interpreted clinician behavior as reflecting judgement or a lack of belief in their identities. An atmosphere of judgment and suspicion may be particularly harmful in a clinic designed to meet the needs of people with gender incongruence, because the perception that someone doubts their authenticity is also tied to an understanding that as gatekeepers, clinicians have power over access to treatment that careseekers see as determinate of their entire future.

I return to Annika who has had the opportunity to return to NBTS post-reorganization. She and Benedicte acknowledge that they had a significantly better encounter. Benedicte was pleased with the clinician they met. But Annika continues to feel that the diagnostic process has been primarily a fight to prove her identity against clinical paradigms that would disprove her subjective experience. Based on her experiences with NBTS, she feels that only one type of narrative is legitimized, one which she finds a difficult fit:

[There’s] one specific criteria by which they evaluate you as what you are. Because if you weren’t feminine in childhood and didn’t want to wear those clothes – so it begins to be like – they don’t believe you then. [...] My impression is that they want to get as much information as possible, so they can judge you [...] because they think, ‘Do you really need that [treatment] or not?’

By her observations, determinations as to whether a careseeker has a legitimate need for care are based upon a specific narrative that may not ring true for all gender variant people. This

particular narrative being the only one suitable to unlock access to the diagnosis F64.0 and thus treatment, may have been cemented over time by adult gender affirming careseekers of the past. Historically, care seeking adults have known by reading the clinical literature that this is the “correct” narrative to deliver, and that any deviation can result in failure (Ekins, 2005; Dewey, 2008; van der Ros, 2013).

That the subjective accounts of gender variant careseekers cannot be fully trusted may stem back to the original WPATH Standards of Care, which made claims to the “unreliability” of careseeker narratives (in Cavanaugh, Hopwood & Lambert, 2016). This method of determining who is a legitimate careseeker can result in an erasure of those like Annika, whose subjective experience differs (Roen, 2011).

Benedicte told how she sees a gatekeeping system as stripping her daughter of her right to self-determination. This was described as harmful to Annika’s mental health:

So, I have seen that she has collapsed a bit again (*hun har bretta litt sammen igjen*).  
 ::sharp inhale:: And I feel that in a way she—is becoming a bit scared that she’s never going to get there if all the other people get to decide if she’s a girl or—boy. She isn’t allowed to decide herself. She has said many times: It’s my body! [...] So, I think that she’s 17 years old! She understands what you [healthcare providers] say. She understands the risk of what she’s doing. [...] You feel like they like, look at you as—mentally incompetent (*lite begavet*), in a way.

Both Benedicte and Annika feel that at her age, nearly the age of majority, she should be trusted to know who she is, and have the right to decide over her own body. Instead, Benedicte feels her daughter has been treated as if she is not able to truly know the essence of her experience, and that only a mental health professional can determine if she needs the treatment she desires in order to move forward with her life.

Annika says, “I find it almost offensive thinking about that someone decides if you get treatment or not. And like, judges you through the whole discussion. I think it’s—very exhausting.” As Luhmann (1979) puts it, ‘strategies of distrust’ *are* exhausting (72). What Annika appears to find most tiresome is having to prove her identity against a paradigm that seems not to trust the judgement and self-knowledge of people like her. An atmosphere of distrust drains energy and becomes a burdensome affair for careseekers, but likely also for clinicians (Luhmann, 1979:72). As a result of their experiences, Annika and her mother told me that they have decided to seek treatment options outside NBTS, where they say Annika feels her identity can be explored without her feeling that it is challenged in the way she felt it



was at NBTS. They also indicated that they feel they have had a greater opportunity to engage in shared decision making with her private care provider.

Similarly, Siv said she hoped to be “received by *Rikshospitalet* in a different way” that would include helping careseekers feel that clinicians were taking their viewpoints, concerns and goals into account. “Because you feel like – you aren’t listened to. And you feel like they don’t understand. If they could be a bit more willing to work with you and try to be a bit more willing to find solutions that are best [for careseekers].” Siv felt that her family’s values and experiences could have been better included in evaluations of treatment options. Information sharing and involving the careseeker in decision making can foster trust between clinicians and careseekers (Jelley & Walker, 2003; Spencer, 2003).

In modern medicine, patients expect to be involved in decision making and few find paternalism, where a doctor makes the calls, acceptable (Irvine, 1999; Coulter, 1999). Careseekers often benefit from a partnership where clinicians work together with them (Coulter, 1999; Towle & Godolphin, 1999; Spencer 2003), and they want to feel like they are taken seriously as the experts of their own experiences (Towle & Godolphin, 1999; Jelley & Walker, 2003). Partnership requires good communication (Taylor, 2003) and trust in patient autonomy (Towle & Godolphin, 1999). Siv indicates that she does not feel that she and her son have been heard in the process of care seeking and expresses a desire for establishing a partnership with her son’s clinicians where the family can feel included in decision-making related to his care.

According to Rogers (2002), believing the careseeker is competent and respecting their autonomy is an important component of trust in healthcare. Again, the point here is not if clinicians actually trust careseekers, but that careseekers like Annika and her mother do not *feel* trusted, or that their autonomy is respected. Rogers argues that there is a moral aspect of trust that makes it worthwhile for clinicians to incorporate trust of the patient into their practice. Clinicians who trust them see careseekers as experts on their own experience and involve them in decision-making (ibid). Careseekers may experience displays of trust from their care providers as the kind of morale support that can bolster treatment outcomes (ibid). But trusting the careseeker also puts the clinician in a vulnerable position: if it emerges that they have treated someone whose account they trusted, and who later comes to regret treatment, their competence can be called into question (ibid). But trust never occurs without some risk (Luhmann, 1979). Rogers’ argument is that trust is worth a risk in terms of improved treatment outcomes and patient empowerment (2002).

#### 4.6 The Threat of Private Providers

Thus far in this chapter I have explored mechanisms of trust and distrust in the careseeker and provider relationship from the careseeker's side of the equation. However, healthcare personnel are also reliant on trust, and they too become vulnerable when trust breaks down (Grimen, 2013: 60-61; Fugelli, 2005). As stated previously, trust is forced in healthcare when careseekers have few or no other viable options. Once other options emerge, this forced relationship is in jeopardy from the professional's side (Grimen, 2001). At the time some of the families I interviewed sought care, very few options were available to them other than to continue at the publicly-operated gender clinic and, as previously explored, fight for care when they felt the need to. However, given a choice, few continue to seek care from healthcare providers they deem unreliable, untrustworthy, or whose expertise they question (Grimen, 2013: 91). Once the field of gender affirming care opened up in Norway, and both private and communal actors began to offer access to hormone therapy and even surgery, the freedom to choose where (and when) one seeks gender affirming care became a possibility.

It was interesting to me that so many study participants were using outside sources of gender affirming care while simultaneously seeking a diagnosis from NBTS. I wondered why that would be. Unfortunately, an in-depth discussion of the many reasons study participants gave for seeking care outside NBTS, and the experiences these careseekers had with providers outside NBTS is beyond the scope of this thesis, and I hope to address this in other writing. However, the narratives I have shared over the course of this chapter, suggest that in some cases, the reasons for seeking these providers may be related to trust. Participants who, like Mari, had experiences that lead them to view clinicians at NBTS as unreliable, they sometimes sought care elsewhere. When Henrik began to lose faith in NBTS due to uncertainty in the process and what experienced as excessive waiting, he obtained hormones through another provider. And when Annika had negative experiences that led her to feel judged and invalidated, she too found her way to a provider outside the clinic.

According to key informants, at the time I began conducting interviews for the study this thesis is based upon, NBTS' practice was to advise families that obtaining care from alternative providers could jeopardize their ability to receive care at NBTS. The official NBTS stance is that when careseekers have already received treatment and gender dysphoria is no longer present, they can be harder to diagnose, potentially leading to misdiagnosis (K Tønseth, 2017). However, as the study progressed, their stance became progressively harder, from issuing warnings, to taking preventative action, first in the media (Wæhre & KA

Tønseth, 2018; Fonn, 2018a), and then through clinic policy (Sae-Khow, 2018).

Study participants expressed strong feelings about NBTS' policies toward other gender affirming care providers. Harald, father of Henrik, who, as stated previously, began hormone treatment outside NBTS while waiting for his final assessments, was angered by what he saw as efforts by NBTS to reign in their patients:

They say that if someone starts treatment before they are approved with them, then all juridical responsibility is relinquished, for relevant consequences. Right? That's like, so *violent*...you know? That, I think—I almost get nauseous, too. And I don't believe it's true either. That's the worst, isn't it? I don't actually think that it's *right*—that they *can* do that! Because it's not such that---Norwegian citizens lose the right to treatment—because you do something with your body! Begin to take hormones, for example. You don't lose the right to treatment even if you have taken some hormones, that's a joke! So that's really ugly of them, plain and simple.

The clinic's policy sparked a “moral outrage” in Harald, who felt that the policy was an attempt to threaten careseekers into submission and punish those who, like his son, had come to rely on an alternative provider for interim treatment while waiting on a diagnosis from NBTS. Harald also doubted that their policy was legal. For him, their actions are a violation of their rights as Norwegian citizens, whom he points out have the right to make decisions in league with private providers in any other circumstance without losing the right to publicly funded treatment. The policy lead Harald to distrust the intentions of clinicians at NBTS, who he saw as exerting their power in an unfair way, goes as far as to call it “violent”. This violation of trust was experienced as betrayal, with its powerful emotionally reactive elements of anger and indignation.

In the past, NBTS has demonstrated a pattern of reporting the most visible private gender affirming care providers to regulatory authorities (Benestad, 2015). According to key informants, this practice had halted for a period after the Directorate of Health's expert group report was released (Helsedirektoratet, 2015). However, while this study was ongoing, word began to spread through the gender variant community that NBTS had begun to report providers again. This caused anxiety for those relying on them as their only option after care was terminated at *Rikshospitalet*. Siv had strong views about the development:

What's happening now, and what's happened before, that – *Rikshospitalet* has begun to report people; doctors and psychologists that help private. That's entirely wrong! It's completely horrible. There was someone who has said that maybe one of five

comes through the eye of the needle (*gjennom nåløyet*) at *Rikshospitalet*. And that they should then not get help at all? That's what they're trying to do now.

Siv invokes the “eye of the needle” narrative here, which several parent participants used to indicate beliefs that NBTS' criteria are too strict. She believes those who are denied treatment at NBTS should have alternatives. Additionally, she, like Benedicte and Annika earlier, feels that their practices show a paternalistic view that gender variant people cannot be trusted to know what treatment would be in their best interest, and that only those at NBTS can make this distinction. Siv goes on:

Because I think it says a lot about—about them, then. It shouldn't be happening that people are refused help. And we're talking about adults. That can—clearly not make their own choice then. [...] *Rikshospitalet*, if they are going to continue to be—a national specialist center then – they have to treat people in a different way and talk in another way, think in another way.

Siv feels that the clinic does not respect the autonomy of even adult careseekers, and that this is demonstrated by their attempts to shut down other providers of gender affirming care. Her understanding is that if NBTS decides a person is not eligible for care with them, their view is that the careseeker should not be able to obtain help anywhere. Based on interviews with key informants, this is a major area of contention in the field of gender affirming care in Norway.

Siv also alludes to what was discussed at the beginning of this subsection: the fact that healthcare professionals depend upon the trust of their patients to continue to function in their professional capacity. Siv believes that if NBTS is to retain its monopoly on gender affirming care, it must take a different approach to careseekers. As stated in the introduction, there have been calls over the years to dissolve the monopoly that exists at *Rikshospitalet* and decentralize care. There have also been arguments against this from both *Rikshospitalet* itself and the patient group HBRS. For example, in a letter to then Minister of Health Jonas Gahr Støre, HBRS leadership writes:

This means in in practice the closure (*nedleggelse*) of the specialized clinic (*landsfunksjonen*). We see this continual campaign as an attack on a rather small and vulnerable patient group. This has also led to both patients and family feeling both insecurity and despair and contacting HBRS for information on what will happen with treatment at *Rikshospitalet* (HBRS, 04.12.2012).

Much in the same way, one parent, Åse, described the fear and uncertainty she and her

daughter have felt when *Rikshospitalet* reports private providers that they rely on to the Board of Health. Since her daughter's bid for care was terminated, she has relied solely upon private providers for her treatment. At the time of interview, she was preparing her daughter Madelen "just in case" their provider was reported by getting all over her blood work for her hormone levels in order and refilling prescriptions. She explained how they too live with fears that the care they have relied upon will be taken from them. Åse experiences this threat as stressful. Experts point out that once hormone treatment has begun, cessation of such treatment is often a traumatic experience (Wylie et al., 2016).

Some weeks after the opinion piece was published, changes were suddenly made to the NBTS website announcing a new policy to be enforced from April 1<sup>st</sup>, 2018 stating that the cases of all careseekers currently undergoing assessment that had sought care outside of NBTS before the final diagnostic meeting would be terminated, and any future referrals of care-seekers that had already received treatment elsewhere would be rejected (Sae-Khow, 2018). The policy text was withdrawn from the NBTS website within the week, after Helse Sør Øst requested time to discuss new guidelines prior to the policy being put into place (ibid). Upon follow-up, none of the study participants that began private treatment while also seeking care at NBTS had been impacted by the policy.

As I have tried to demonstrate over the course of this chapter, study participants had sometimes had years of negative experiences at the clinic. These experiences caused them to distrust the clinic. They also describe how distrust has spread within the community of would-be careseekers and far beyond those who have ever entered its doors. This has created a situation where careseekers may arrive at the clinic already suspicious, and because they are expecting the worst, they will likely find the worst. Even well-meant gestures may be interpreted as hollow, or small, perhaps unintentional slights may be assigned larger meaning than they otherwise might be. And now, the clinic was seen by study participants as cruelly cracking down, attempting to protect its power by keeping its patient group in line.

Study participants have actively sought gender affirming care outside NBTS. "Treatment-eager sexologists" were not, as Wæhre and Tønseth's (2018) opinion piece depicts it, "standing in line" to help them. Careseekers may choose to avoid clinics that they do not trust once other options emerge (Grimen, 2001). I argue that the same may apply when they feel a clinic does not trust them as well. I end this chapter with another analogy, this one from philosopher Richard Holton (1994):

I can rely on a rope that I doubt to be secure because I have no alternative; but the

disposition that I exhibit in so doing is different to that which I would exhibit if I believed it were secure. If I no longer need to rely on the rope, if I were offered an alternative I believed to be secure, I would abandon my reliance on the rope and take the alternative. If I were confident in the rope I would not (68).

Let's say that rope is a bid for treatment, and if successful, you'll swing to the other side, toward treatment and presenting as the gender you experience yourself to truly be. If one has no other options, then one is forced to trust the only means available, regardless of whether one feels secure about it. They may be more cautious and behave differently than if they believed those means to be secure, but they will have no choice but to trust. Perhaps things will have gone fine with a frayed rope, or perhaps trust will have been misplaced and a swing to the other side ends in failure.

Most people would most undoubtedly rather try the swing with a safety net if it became available. For some study participants, providers outside of NBTS served this function, as a contingency plan to catch them should they fall. They were still willing to trust the rope, but not as completely as they may have had it seemed reliable to them. Should an alternative arise that allows one to avoid using the rope one deems insecure entirely, say a bridge spanning the gap, surely some many would opt to avoid the risk altogether, rather than dealing with the stress distrust can invoke. For them, it would perhaps be unusual *not* to choose the alternative they deem safer, more secure, and more certain to carry them across the divide they so badly wish to breach.

## CHAPTER FIVE: Implications and Recommendations

Much literature has focused on clinical experiences of providing gender affirming care to gender variant adolescents. Theoretical debates about the implications of these treatments have also been heavily covered in the literature. Very little research has presented the actual views and experiences of the families utilizing these treatments. The aim of this thesis was to explore some of the kinds of experiences that led these families of adolescents with gender incongruence to seek gender affirming care, as well as the meanings they themselves place upon these interventions. I also sought to facilitate a greater understanding of how seeking treatment may be experienced in a Norwegian context. I take the final pages of this thesis to recap and consider the implications of this study.

### 5.1 Main Analytical Contributions

In Chapter Three, I have examined how study participants embraced the narrative of gender affirming care as a lifesaving intervention. To give the reader a starting point on where this narrative arises from, I first a mother's experiences of raising a young girl assigned male at birth, following her story from her child's early years through to her transition to garner an understanding of how families come to terms with navigating the way forward. I argue that allowing a child to transition socially may be conceptualized as the first instance of "saving" them. Then, the interest becomes preserving the wellbeing established through permitting the child free and open expression of their gender identities. As the families of this study understand their children's gender identities as unwavering and uncompromising, I tried to provide an understanding of how they may come to see altering the body to fit normative expectations of gendered subjectivities as the best way of preventing suffering.

Based on study participants' accounts and several established theories, I introduced a novel mechanism to help foster understanding of the suffering some gender variant youth experience. I argue that three types of suffering: social, embodied, and psychological, can emerge as separate, yet interconnected phenomena. Utilizing the theories of Irving Goffman (1990), Judith Butler (2004), Pierre Bourdieu (1999), and others, I have discussed how those whose ways of being in the world conflict with social norms may be subject to stigma, devaluation, bullying and violence, which leads to social suffering. I also show how, even when the conditions required for social suffering to arise are not present, parents may still retain fears that lead to a desire to protect their child from being subjected to social suffering.

By sharing young study participants' experiences of going through the wrong puberty, I help the reader understand how the development of secondary sex characteristics out of sync

with one's subjective experience of self can result in the emergence of embodied suffering. Here I adopt Seligman's (2010) theories that address the role of the self in embodied suffering, conceptualized as a feedback loop, to offer insight into the processes that can create very tangible anguish for some gender variant youth.

Further, I argue that the combination of both social and embodied suffering can form a "toxic cocktail", creating the conditions for psychological suffering to arise. Several authors have discussed the embodied distress gender variant adolescents may experience because of the physical changes that occur at the onset of puberty (e.g. Cohen-Kettenis et al., 2008; Edwards-Leeper & Spack, 2012) The high prevalence of mental health concerns among gender variant youth has been much covered in the literature (e.g. Cohen-Kettenis et al., 2008; Grossman & D'Augelli, 2007), and in recent years, some authors have found that symptoms of psychological suffering that remain after treatment to be primarily the result of stigma and minority stress (Robles et al., 2016).

Few discuss explicitly, as I do, how embodied distress and social stigma can play into each other in untreated gender incongruence to create conditions for psychological suffering to arise. However, I stress that this mechanism is not a given; I do not intend to imply that suffering is inherent in gender variant people. I instead argue that given the right circumstances, some, or even all of these forms of suffering may not be present.

In Chapter Three I have also discussed how families struggling with the looming threat of an unwanted puberty may come to understand their situation as a crisis warranting swift, *lifesaving* action. Other authors have approached this narrative as it exists in the literature (Sadjadi, 2013, Pyne, 2017), but to my knowledge few if any have explored this narrative using empirical data co-created with those who utilize these treatments.

I have also unpacked the concept of "passing" as it occurs in study participant narratives. In doing so, I show how significant importance may be placed on passing because passing is believed to be integral to the avoidance of social, embodied and psychological suffering. Utilizing Marianne Gullestad's concept of "imagined sameness," I argue that in the Norwegian context, where equality is achieved through homogeneity, desires to conform to may be highly compelling. I have also considered the views of scholars who have problematized the concept of passing and argued that a flaw in these arguments is that these authors fail to fully account for the potent effects of embodied aspects of suffering.

In Chapter Four, I explored how themes of trust and distrust play a complex role in study participants' gender affirming care experiences. Guided by the theories of Harald Grimen (2001, 2009, 2013), Per Fugelli (2005), Niklas Luhmann (1979), Anthony Giddens



(1990) and others, I examine experiences that impacted study participants' trust in clinicians at both BUP and NBTS. First, I reveal how when study participants had experiences that led them to believe their BUP clinicians lacked experience with gender variant populations, may cause them to lose trust in their expertise and question the utility of being forced into psychiatric care. In sharing Mari's experience with her daughter, I illustrated how when careseekers perceive their care providers to be unreliable, this may set into motion the erosion of trust. Here I explore how when trust is damaged in healthcare, strong emotions related to a sense of betrayal can emerge. As I show, when careseekers feel unsupported by clinicians, a sense of helplessness may also ensue. Fighting for treatment, I argue, may be triggered by a loss of confidence in clinicians when care believed vitally important for a child's well-being and even survival is denied. I propose fighting for care may be a way parents of gender variant youth cope with a "traumatic" experience where one is dealing with the suffering of a child, but also feels unsupported in the resolution of this suffering.

Henrik's story illuminates how a young person may experience the process of referral to NBTS and diagnostic processes thereafter as burdensome and frustrating. Through this narrative, I examine how thresholds of distrust can be breached through small but cumulative acts, in where no one encounter is to blame. Here I also share how uncertainty in the diagnostic process can have the unintended result of fomenting distrust and impacting mental health. I show how some may perceive a scarcity of information provided to careseekers as deliberate, and in extreme cases even interpret the situation as an abuse of power.

I have also unpacked how initial negative encounters with clinicians at the gender clinic can deter trust from forming, and how this can have a detrimental effect on the clinical encounter. Through Luhmann's (1979) theories, I discussed how trust and distrust, like the process of embodied suffering, function as a feedback loop, with actions building upon and reinforcing each other. When participants perceived signs that clinicians were skeptical of their identities, felt judged, became fearful that they would not receive help or they disengaged, which had disastrous effects on the quality of the encounter. I additionally delved into how families interpreted scenarios where they felt unheard in decision-making processes. This again, in my view, functions a feedback loop where careseekers feel they are not trusted to know who they are and to be engaged in the decision-making process, and as a result, trust in the clinician erodes.

Throughout the chapter, I engage with a controversy surrounding a controversial opinion piece, to explore how a clinic's reputation can influence careseeker's perceptions of clinical encounters. I ask if careseekers may not enter the care seeking process predisposed to

interpret even seemingly minor, unintentional transgressions as confirmation that the rumors they have heard about the clinic are true. In line with the thinking of Harald Grimen (2001, 2013), I argue that clinicians at NBTS are also vulnerable to the development of distrust, showing how when trust in clinicians erodes, careseekers may rationalize seeking care elsewhere as a backup plan. I also maintain that careseekers may seek to reclaim power over the care seeking process by choosing to “go private” and begin HRT with an outside provider.

It is worth noting that I have found next to no literature on gender affirming care which deals directly with issues of trust in these encounters. This thesis points toward an important and previously missing theoretical approach to looking at gender affirming care encounters. Importantly, the literature on trust in healthcare may also lend ideas on how to improve those experiences for careseekers moving forward.

## **5.2 Suggestions for Further Research**

In this study I have proposed a trifold mechanism of social, embodied and psychological suffering. I argue that desires to alleviate or prevent these three forms of suffering contribute to the decision families make to seek gender affirming treatment interventions. More research would be needed to see how this theory stands up, for example in a quantitative study, or in other contexts. The youth interviewed for the study had gender identities at either end of the gender continuum (strictly male or female). More research is needed to explore the meanings nonbinary young people and their families place on treatment and to understand what their desires for treatment might be. For those who have sought interventions, it would be interesting to know more about the nature of those experiences, and if they differ from those of other gender variant youth.

This study concerned only a small number of families (a total of 12 cases), and I caution that it is not possible to draw conclusions about the extent to which their experiences are representative of seekers of gender affirming care more generally in Norway. More research is needed to explore just how widespread distrust is among gender affirming careseekers. Another interesting focus of research would be to explore the nature of trust from the clinician’s standpoint. One might also examine if beliefs about careseekers’ trustworthiness impact the degree to which they involve careseekers in decision-making.

## **5.3 Participant Suggestions for Improving Careseeker Experiences**

As discussed in the methods section of this thesis, one reason study participants provided for volunteering for research was a desire to see change in the system of gender affirming care

and contribute to bettering the experiences of those who come after them. Given that study participants sometimes claimed that they did not feel heard in the care seeking process, I'd like to give them as much of a platform to be heard now as possible. They may have felt like they have not been treated as experts of their own experiences, but I refuse to see them as anything but. I specifically asked study participants what would have made their lives easier during the process of seeking gender affirming care and they were eager to express their thoughts, which I have shared throughout the analysis. I would like to re-state them now, while offering a few of my own observations and suggestions that are related to their own.

#### Catering the Length and Content of the Care Seeking Process to Individual Needs

Study participants indicated that they experienced the length of the process they were required to go through as stressful and frustrating. They wished that the length of the process could be better tailored to the individual's distinct needs, rather than a standardized procedure, like that in place now. They also wanted to see a process less fettered to the psychiatric care system, where those who might need additional mental health supports can receive that support in tandem with assessment at NBTS, if desired.

I suggest that we might look to the changes our neighboring countries have put in place in their systems. For example, in Sweden, young care-seekers are no longer required to undergo psychological diagnostic work and are only referred to such interventions as needed (H. Bergman, personal communication, 24.05.2018). Some experts argue that basic psychological screening can be performed by gender clinics, and if needed and *desired*, psychiatric help can be offered (Wylie et al., 2016). I wonder if these supports were offered, rather than obligatory, and if they then coincided with assessment for treatment, if they might be better received and utilized.

Grimen argues that attention to the institutional structures of care seeking and gatekeeping are important. According to him, they “shape the nexus of trust, risk and power in health care, because they determine how and to what extent patients become dependent on professionals” (2009:25). He suggests that allowing careseekers to directly seek access to specialist services, rather than having to rely on gatekeepers, could be empowering and have positive impacts on trust (ibid). In some medical contexts this may not be desirable, such as in instances where a careseeker's understanding of what is wrong could be incorrect (K. Moen, personal communication, 03.05.2019). For example, a family member of mine was once suffering from what he thought was backpain due to sciatica, but which turned out to be ulcerative colitis, a painful inflammatory disorder of the intestines. In a case like this, if one

had first gone to a specialist in back pain, he would have lost precious time that could have been spent treating the intestinal disorder (and indeed this is what happened). The Norwegian healthcare system is built upon this premise to ensure mistakes like this are rare (ibid). However, given that gender dysphoria and gender incongruence are diagnoses based upon subjective experiences, rather than physical pathology, I wonder if treatment could be at least in part be provided on a lower tier of the healthcare system or involve a more direct approach to referral. I will note that I am hardly alone in this thinking (WPATH, 2011; Helsedirektoratet, 2015; Wylie et al., 2016; TGEU & ECRI, 2014; Haus, 2018; Benestad et al., 2017; Aaserud & Wik, 2017).

This study also suggests that when careseekers had experiences that led them to feel that BUP clinicians are not well-informed on issues related to gender diversity, trust in their ability to contribute meaningfully to their care was impacted. Numerous experts have pointed out that training on gender variance in medical school and clinical psychology education is rare, and as a result, clinicians enter the field unprepared to meet the unique needs of gender variant careseekers (Bauer et al., 2009; Kosenko et al., 2013; Hughto et al. 2015; Dean, Victor, & Grimes, 2016; Reed et al., 2016; Winter et al., 2016). Increased training on gender diversity in the educational system and for those already active as clinicians could positively impact clinical encounters, promote resilience (Torres et al., 2014) and foster trust.

Involving mental health professionals as gatekeepers may also come in the way of other valuable types of help they could be providing (Drescher et al., 2012; Wylie et al., 2016; Reed et al., 2016). Other authors have addressed multiple ways that healthcare providers can play a beneficial role in the lives of those exploring their gender and considering medical transition. These include teaching about gender diversity and what social support or medical help is available (Singh et al., 2014; Wylie et al., 2016; Vanderburgh, 2009), providing support in adapting to new gender roles and coming out to others (Möller et al., 2009; Riggle, Rostosky, McCants & Pascale-Hague, 2011). They may help the child to cope with their gender dysphoria (Saketopoulou, 2013; Langer, 2014) and teach resilience (Grossman, D'Augelli & Frank, 2011), in addition to helping them overcome mental health challenges related to minority stress (Wylie et al., 2016;).

#### Transparency and Clearer Information Tailored to Young Careseekers' Needs

Study participants expressed a desire for clear information on how long the process might take, and what diagnostic assessment would entail. That information about treatment could have been better tailored to careseekers' needs was also mentioned. Participants suggested

that providing an overview of what an average assessment and treatment process looks like would be helpful. I add that a better overview of what to expect might help young careseekers to better tolerate the uncertainty inherently involved in diagnostic processes, by eliminating uncertainty about the process itself.

It was suggested that all young careseekers, but especially those with additional challenges like ASD or learning disabilities, might benefit from the provision of information about the topics that would be discussed at their next appointment. This could come in the form of a list of topics or direct questions to consider beforehand. This, one mother rationalized, may facilitate better communication and possibly even improve the content of diagnostic interviews. Some participants also mentioned that receiving written information about anticipated effects and potential side effects of treatment catered to younger audiences would help them to understand and retain information better than when only verbal information is provided during appointments.

#### Greater Involvement in Care-Oriented Decision-Making

Participants indicated that they would like to be “met in a different way” that would make them feel that their opinions, values, needs and goals were heard in the decision-making process. They would like to see a greater emphasis on patient centered care, where care is catered to individual needs, power is shared, and families are involved in a partnership with clinicians to determine the best way forward.

Involving youth in shared decision making may require special considerations. Literature on informed consent and shared decision making suggests that the development of “treatment decision aids” with special adaptations that allow information to be more easily absorbed by young careseekers may be useful (Stigglebout et al., 2012; Coyne & Harder, 2011; Jelley & Walker, 2003). Special informational tools could be developed to help young persons with additional challenges like ASD contribute to decision-making (Hembree et al., 2017; Strang et al., 2016). For example, neuroatypical careseekers may prefer receiving information in diagram form (Jelley & Walker, 2003). Of course, creating these tools also takes time and significant resources.

#### Public Subsidization of Prescriptions Obtained Outside NBTS

Young participants voiced a desire for HRT and puberty blockers prescribed by providers outside of NBTS to be eligible for provision as “blue prescriptions” (*blå resept*). These are publicly subsidized, and therefore more affordable. Some young participants who saw the need to seek care outside NBTS shared concerns that they might struggle to pay for care if

their parents had not had the means to fund it. They wondered if they would be able to bear the burden of those costs as they entered adulthood.

It has been said that trust can create possibilities (Barbalet, 2008), but so too can distrust (Grimen 2013: 92). Study participants who had negative experiences that impacted trust sometimes used these experiences to rationalize turning to options outside NBTS to meet their needs. In other research, this was achieved through illicit sources without healthcare training, or by buying hormones on the internet without medical supervision, at great risk to their health (Winter et al., 2016; Drescher et al., 2012; Drescher et al, 2016; Robles et al., 2016). Study participants have been lucky enough to have qualified health professionals to rely on when they felt the need to seek help outside of NBTS. If these options were made inaccessible, care might be sought through more dangerous routes. I believe that ensuring that providers outside NBTS that provide care in a responsible manner remain able to do just that may prevent significant harm to health. Sociologist David Mechanic also argues that when careseekers have freedom to choose their own providers, they tend to trust them more than when they are reliant on those who are assigned to them (Mechanic, 2004).

#### 5.4 Further Suggestions and Implications

Lastly, I also have discussed how the reputation of the gender clinic at OUS *Rikshospitalet* lead some study participants to enter care seeking encounters with a degree of skepticism. This may create a greater potential for interactions to be seen in a bad light and for distrust to emerge. Reputation and trust are highly related and shape perception of how we estimate people will act (Newton, 2003). According to Fugelli, both trust and distrust can prove “contagious” (2005). Study participants’ accounts indicated that stories about bad patient experiences have spread throughout the community for many years. They feared that even with a change of leadership, former leaders’ attitudes toward the treatment of gender variant people still linger and influence practice. Recent statements made in the press by NBTS representatives exacerbated this fear. This study suggests that even with leadership changes, some families may continue to enter the system with expectations of having to fight for care, a lack of trust that the system is fair, and fears associated with being judged, and denied help.

President of the American Board of Internal Medicine, Dr. Richard Baron says, “Any time the health care system has failed to be reliable for someone, every subsequent clinician who encounters that patient will need to address that and re-earn that trust” (in Lynch, 2018:2). For those whose trust in the gender affirming care system has worn thin, clinicians who meet them must work even harder to prove themselves trustworthy. But how can this be

done?

It will likely take an acknowledgement of those whose experiences were less than ideal, and a commitment to change (Harrison, 2003; Taylor, 2003; Dekker, 2017). Change can be difficult and requires not only recognition of the need for it, but the development of alternatives, support for those who are involved, and the willingness to learn new skills and adapt to the change (Taylor, 2003). Addressing the systemic issues that create situations of distrust must also be part of the process (Dekker, 2017:18). It might take talking to careseekers in earnest, as I did, and determining what went wrong and what is needed to regain trust, from their point of view (Dekker, 2017). In the interviews I conducted, families told how they felt unheard in the care seeking process. Making an active effort to draw in those who have damaged trust, listening to their stories, learning from them, and enacting the necessary changes while being transparent in these efforts, can go a long way to rebuilding trust (Dekker, 2017). A dialogue can be helpful, so careseekers can also understand the thinking of clinicians (Dekker, 2017).

When clinicians themselves are not gender variant, even the most well-meaning clinicians, who have had significant training on gender diversity may still have “blind spots” due to implicit bias (A. Olson-Kennedy, personal communication, 08.11.2017; 2011; Nadal et al., 2012; Wagner et al., 2015; Dean et al., 2016). These biases can come in the way of effective listening and responding with empathy (Riggle et al., 2011). Clinicians may not recognize that some practices, like misgendering, can be harmful to the clinical encounter and trust building. If they feel they already have positive views of gender diversity, they may also take offense at and be less willing to accept recommendations of how they might improve their practices (Dean et al., 2016). Showing a willingness to get involved with the gender variant community in meaningful ways and listening to activists’ concerns is one way those working in the field of gender affirming care can become more informed on where gaps in their knowledge might be informing their practices (Alpert, CichoskyKelly, & Fox, 2017). Healthcare providers are also in a unique position to witness how social determinants of health can impact different groups and contribute to societal understanding of how “social diseases” like those arising from minority stress emerge (Fugelli, 2005). Showing one stands in solidarity with careseekers, especially when they are members of a stigmatized group, can foment trust (ibid). Ultimately, careseekers want to know care providers are their ally (Turban et al. 2017; Mechanic, 2004).

But also, careseekers might need to be willing to forgive. Philosopher Anne Baier argues that if the person whose trust was violated is unwilling to forgive and the other party is

unable to accept criticism without reactive responses, rebuilding trust after it is broken can prove an impossible task (1986). The willingness to forgive and be forgiven is crucial to repairing trust (ibid). While forgiveness can also not be forced, or even asked for in some circumstances, work can be done to demonstrate a commitment to change that fosters forgiveness in time, and with effort, a reemergence of trust (Dekker, 2017: 19-21).

### 5.5 Concluding Summary

In this thesis, I have provided a glimpse into the gender affirming care seeking experiences of adolescents and their families. Through their stories, I have explored some of the experiences that can bring families to seek care, as well as their conceptualizations of gender affirming care as vitally important, lifesaving treatment. In exploring the reasoning behind the belief that this is lifesaving care, I presented a new framework for understanding how three types of suffering: social, embodied and psychological, may emerge and interact. By seeking treatment like puberty blockers and HRT, families attempt to avoid or mitigate these forms of suffering. I showed how puberty is experienced by families as a crisis and I suggested they may cope with their child's distress by acting to secure care.

Using recent controversies in gender affirming care in Norway as a guide, I have explored a series of experiences of seeking such care and examined how they had effects on the establishment and maintenance of trust or distrust in clinicians. I described how these experiences may be understood as catalysts for seeking care outside of NBTS, and how responses to this phenomenon by the gender clinic further contributed to the erosion of trust as well as feelings of betrayal and anger for some study participants. Explorations of gender affirming care seeking experiences have rarely (if ever) been approached using theories and frameworks for mechanisms of trust and distrust. This thesis offers a new approach to the study of these experiences. Lastly, I have presented some of the study participants' ideas of how the care seeking experience could be improved. With them, I have offered suggestions of my own for how families' needs might be better met, and how trust might be repaired and restored.



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## APPENDIX A: Letter from the Internal Ethics Committee.

To: Natasha Lynn Desianto (natashadesianto@yahoo.com); Natasha Lynn Desianto;

Dear Eve,

The response from the internal committee:

Hello;

In our meeting today, Christoph and I agreed with the student's own evaluation that the protocol should be submitted to REK. We consider that the project is to be regarded as "helseforskning" in the sense that it most likely will produce new knowledge concerning health and illness.

Sincerely,

Merita Emini

Higher Executive Officer  
Master in International Community Health University of Oslo  
Kirkeveien 166  
Fredrik Holsts hus  
0450 Oslo  
Tel.: +47 2285 0611

Note: Author's name has been legally changed since ethical clearance application from Natasha "Eve" Lynn Desianto to Elian Eve Jentoft.

## APPENDIX B: REK Decision Letter



<b>Region:</b> REK sør-øst	<b>Saksbehandler:</b> Leena Heinonen	<b>Telefon:</b> 22845598	<b>Vår dato:</b> 27.06.2017	<b>Vår referanse:</b> 2017/987 REK sør-øst D
			<b>Deres dato:</b> 09.05.2017	<b>Deres referanse:</b>

Vår referanse må oppgis ved alle henvendelser

Kåre Moen  
Universitetet i Oslo

### 2017/987 Pubertetsstopp: Opplevelser fra ungdommer som søker utsettelse av pubertet, og familiene deres

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK sør-øst D) i møtet 07.06.2017. Vurderingen er gjort med hjemmel i helseforskningsloven § 10.

**Forskningsansvarlig:** Universitetet i Oslo

**Prosjektleder:** Kåre Moen

#### Prosjektleders prosjektbeskrivelse

*Veldig lite forskning eksisterer som omhandler hvordan unge transpersoner og deres foreldre opplever helsevesenet. Studien vil bidra til økt kunnskap om de erfaringene og utfordringene transkjønnede ungdommer og deres familier har når de søker pubertetsutsettende behandling i Norge. Studien vil gi kunnskap om hvordan denne gruppen navigerer helsevesenet, hva som kjennetegner deres samtaler innen familien og med helsepersonell, og hvilke typer erfaringer og hendelser som bidrar til deres ønske om å få en slik behandling. Studien spør også hvordan foreldrenes oppfatning av kjønn påvirkes av å ha et transkjønnede barn. Det vil benyttes kvalitative intervjuer (med ungdommer og foreldre), nøkkelinformantintervjuer (med eksperter, helsepersonell, aktivister og støttegruppeledere) samt fokusgruppeintervjuer (i forbindelse med "member checking").*

#### Vurdering

Denne kvalitative masterstudien omhandler hvordan unge transpersoner og deres foreldre opplever helsevesenet. Studien skal bidra til økt kunnskap om de erfaringene og utfordringene transkjønnede ungdommer og deres familier har, når de søker pubertetsutsettende behandling i Norge.

Basert på opplysningene som gis i søknad og protokoll, oppfatter komiteen prosjektet som helsetjenesteforskning, siden det fokuseres på hvordan transpersoner og deres foreldre opplever helsevesenet. Etter komiteens syn vil ikke prosjektet frembringe ny kunnskap om helse og sykdom som sådan. Prosjektet faller derfor utenfor REKs mandat etter helseforskningsloven, som forutsetter at formålet med prosjektet er å skaffe til veie "ny kunnskap om helse og sykdom", se lovens § 2 og § 4 bokstav a).

Det kreves ikke godkjenning fra REK for å gjennomføre prosjektet. Det er institusjonens ansvar å sørge for at prosjektet gjennomføres på en forsvarlig måte med hensyn til for eksempel regler for taushetsplikt og personvern samt innhenting av stedlige godkjenninger.

#### Vedtak

Prosjektet faller utenfor helseforskningslovens virkeområde, jf. § 2 og § 4 bokstav a). Det kreves ikke godkjenning fra REK for å gjennomføre prosjektet.

**Besøksadresse:**  
Gullhaugveien 1-3, 0484 Oslo

**Telefon:** 22845511  
**E-post:** post@helseforskning.etikkom.no  
**Web:** http://helseforskning.etikkom.no/

All post og e-post som inngår i saksbehandlingen, bes adressert til REK sør-øst og ikke til enkelte personer

Kindly address all mail and e-mails to the Regional Ethics Committee, REK sør-øst, not to individual staff

Komiteens avgjørelse var enstemmig.

Klageadgang

REKs vedtak kan påklages, jf. forvaltningslovens § 28 flg. Klagen sendes til REK sør-øst D. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK sør-øst D, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Vi ber om at alle henvendelser sendes inn med korrekt skjema via vår saksportal:

<http://helseforskning.etikkom.no>. Dersom det ikke finnes passende skjema kan henvendelsen rettes på e-post til: [post@helseforskning.etikkom.no](mailto:post@helseforskning.etikkom.no).

Vennligst oppgi vårt referansenummer i korrespondansen.

Med vennlig hilsen

Finn Wisløff  
Professor em. dr. med.  
Leder

Leena Heinonen  
rådgiver

**Kopi til:** [n.k.vollestad@medisin.uio.no](mailto:n.k.vollestad@medisin.uio.no); [a.l.o.middelthon@medisin.uio.no](mailto:a.l.o.middelthon@medisin.uio.no)

Universitetet i Oslo ved øverste administrative ledelse: [universitetsdirektor@uio.no](mailto:universitetsdirektor@uio.no)

Universitetet i Oslo, medisinsk fakultet ved øverste administrative ledelse: [postmottak@medisin.uio.no](mailto:postmottak@medisin.uio.no)

## APPENDIX C: NSD Ethical Clearance



Kåre Moen  
 Postboks 1130 Blindern  
 0318 OSLO

Vår dato: 25.08.2017

Vår ref: 55159 /3 /AGL

Deres dato:

Deres ref:

## Tilbakemelding på melding om behandling av personopplysninger

Vi viser til melding om behandling av personopplysninger, mottatt 19.07.2017.

Meldingen gjelder prosjektet:

55159	<i>Putting Off Puberty: A Qualitative Study of the Experiences of Transgende Adolescents and Their Families Seeking Puberty Blockers in Norway</i>
Behandlingsansvarlig	Universitetet i Oslo, ved institusjonens øverste leder
Daglig ansvarlig	Kåre Moen
Student	Natasha Desianto

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget [skjema](#). Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en [offentlig database](#).

Personvernombudet vil ved prosjektets avslutning, 31.12.2018, rette en henvendelse angående status for behandlingen av personopplysninger.

Dersom noe er uklart ta gjerne kontakt over telefon.

Vennlig hilsen

*Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.*

Marianne Høgetveit Myhren

Audun Løvlie

Kontaktperson: Audun Løvlie tlf: 55 58 23 07 / [audun.lovlie@nsd.no](mailto:audun.lovlie@nsd.no)

Vedlegg: Prosjektvurdering

Kopi: Natasha Desianto, [n.l.desianto@studmed.uio.no](mailto:n.l.desianto@studmed.uio.no)



## Personvernombudet for forskning



### Prosjektvurdering - Kommentar

Prosjektnr: 55159

Formålet er undersøke familier til transpersoner og transkjønnete ungdommers erfaringer med pubertetsunderstrykkelse i Norge.

Utvalget informeres skriftlig og muntlig om prosjektet og samtykker til deltakelse. Informasjonsskriv og samtykkeerklæring er noe mangelfullt utformet. Vi ber derfor om at følgende endres/tilføyes:

- Dato for prosjektslutt og anonymisering av datamaterialet
- Fjerne informasjon om REK godkjenning.
- Det må komme tydeligere og tidligere fram at Universitetet i Oslo er behandlingsansvarlig institusjon
- Kontaktinformasjon til veileder må tilføyes

Revidert informasjonsskriv skal sendes til personvernombudet@nsd.no før utvalget kontaktes.

Merk at når barn skal delta aktivt, er deltagelsen alltid frivillig for barnet, selv om de foresatte samtykker. Barnet bør få alderstilpasset informasjon om prosjektet, og det må sørges for at de forstår at deltakelse er frivillig og at de når som helst kan trekke seg dersom de ønsker det.

Det behandles sensitive personopplysninger om etnisk bakgrunn, politisk/filosofisk/religiøs oppfatning, og helseforhold.

Det behandles enkelte opplysninger om tredjeperson. Det skal kun registreres opplysninger som er nødvendig for formålet med prosjektet. Opplysningene skal være av mindre omfang og ikke sensitive, og skal anonymiseres i publikasjon. Så fremt personvernulempen for tredjeperson reduseres på denne måten, kan prosjektleder unntas fra informasjonsplikten overfor tredjeperson, fordi det anses uforholdsmessig vanskelig å informere.

Personvernombudet legger til grunn at forsker etterfølger Universitetet i Oslo sine interne rutiner for datasikkerhet. Dersom personopplysninger skal sendes elektronisk, bør opplysningene krypteres tilstrekkelig.

Forventet prosjektslutt er 31.12.2018. Ifølge prosjektmeldingen skal innsamlede opplysninger da anonymiseres. Anonymisering innebærer å bearbeide datamaterialet slik at ingen enkeltpersoner kan gjenkjennes. Det gjøres ved å:

- slette direkte personopplysninger (som navn/koblingsnøkkel)
- slette/omskrive indirekte personopplysninger (identifiserende sammenstilling av bakgrunnsopplysninger som f.eks. bosted/arbeidssted, alder og kjønn)
- slette eventuelle lydopptak

## APPENDIX D: Changes registered and NSD confirmation of changes to the study.

1

# Endringsskjema

for endringer i forsknings- og studentprosjekt som medfører meldeplikt eller konsesjonsplikt

(jf. personopplysningsloven og helseregisterloven med forskrifter)

Endringsskjema sendes per e-post til: [personvernombudet@nsd.no](mailto:personvernombudet@nsd.no)

1. PROSJEKT	
Navn på daglig ansvarlig: Kåre Moen	Prosjektnummer:
Evt. navn på student: Natasha Lynn Desianto	55159

2. BESKRIV ENDRING(ENE)	
Endring av daglig ansvarlig/veileder:	<i>Ved bytte av daglig ansvarlig må bekreftelse fra tidligere og ny daglig ansvarlig vedlegges. Dersom vedkommende har sluttet ved institusjonen, må bekreftelse fra representant på minimum instituttnivå vedlegges.</i>
Endring av dato for anonymisering av datamaterialet:	<i>Ved forlengelse på mer enn ett år utover det deltakerne er informert om, skal det fortrinnsvis gis ny informasjon til deltakerne.</i>
Gis det ny informasjon til utvalget? Ja: ____ Nei: ____ Hvis nei, begrunn:	
Endring av metode(r):	<i>Angi hvilke nye metoder som skal benyttes, f.eks. intervju, spørreskjema, observasjon, registerdata, osv.</i>
Endring av utvalg: Vi ønsker å gjøre følgende endringer: <ol style="list-style-type: none"> <li>1. Studiens opprinnelige utvalg var unge transpersoner mellom 12 og 18 år, sammen med minst én forelder/foresatt. Vi ønsker nå å utvide aldersgruppen til de unge deltakerne slik at personer mellom 12 og 25 år kan delta i studien. Dette er fordi vi erfarer at personer inntil 25 år kan ha verdifulle erfaringer å tilføre studien.</li> <li>2. Opprinnelig forutsatte vi at både en ungdom og minst én av hans/hennes foreldre/foresatte måtte være villige til å delta i studien. Selv om deltakelse fra foreldre/foresatte fortsatt er ønskelig, ønsker vi å tillate at ungdommer kan delta selv om foreldrene/foresatte ikke gjør det, så lenge foreldrene gir samtykke til ungdommens deltakelse. (Som tidligere vil ikke foreldre bedt om å delta dersom barnet ikke ønsker å delta.)</li> </ol>	<i>Dersom det er snakk om små endringer i antall deltakere er endringsmelding som regel ikke nødvendig. Ta kontakt på telefon før du sender inn skjema dersom du er i tvil.</i>
Annet:	

3. TILLEGGSOPPLYSNINGER

**4. ANTALL VEDLEGG**

*Legg ved eventuelle nye vedlegg  
(informasjonsskriv, intervjuguide, spørreskjema,  
tillatelser, og liknende.)*



Pernille Ekornrud Grøndal <pernille.grondal@nsd.no>

Mon 2017-10-30 13:13

Inbox

Mark as unread

To: Natasha Lynn Desianto;

Cc: Kåre Moen;

Hei,

Viser til innsendt endringskjema for prosjekt 55159.

Personvernombudet vurderer at endringene dere viser til ikke krever ny saksbehandling fra oss, men vi har til orientering registrert henvendelsen. Lykke til videre med prosjektet.

Vennlig hilsen,

Pernille Ekornrud Grøndal

rådgiver | Adviser

Seksjon for personverntjenester | Data Protection Services

T: (+47) 55 58 36 41

NSD – Norsk senter for forskningsdata AS | NSD – Norwegian Centre for Research Data

Harald Hårfagres gate 29, NO-5007 Bergen

T: (+47) 55 58 21 17

[postmottak@nsd.no](mailto:postmottak@nsd.no) [www.nsd.no](http://www.nsd.no)

# Endringsskjema

for endringer i forsknings- og studentprosjekt som medfører meldeplikt eller konsesjonsplikt

(jf. personopplysningsloven og helseregisterloven med forskrifter)

Endringsskjema sendes per e-post til: [personvernombudet@nsd.no](mailto:personvernombudet@nsd.no)

1. PROSJEKT	
Navn på daglig ansvarlig: Kåre Moen	Prosjektnummer:
Evt. navn på student: Natasha Lynn Desianto	55159

2. BESKRIV ENDRING(ENE)	
<p>Endring av daglig ansvarlig/veileder: Vi legger til medveileder Ingvild Lunde (doktorgrad stipendiat) Kåre Moen skal forbli hovedveileder</p>	<p>Ved bytte av daglig ansvarlig må bekreftelse fra tidligere og ny daglig ansvarlig vedlegges. Dersom vedkommende har sluttet ved institusjonen, må bekreftelse fra representant på minimum instituttnivå vedlegges.</p>
<p>Endring av dato for anonymisering av datamaterialet:</p>	<p>Ved forlengelse på mer enn ett år utover det deltakerne er informert om, skal det fortrinnsvis gis ny informasjon til deltakerne.</p>
<p>Gis det ny informasjon til utvalget? Ja: <input type="checkbox"/> Nei: <input type="checkbox"/> Hvis nei, begrunn:</p>	
<p>Endring av metode(r):</p>	<p>Angi hvilke nye metoder som skal benyttes, f.eks. intervju, spørreskjema, observasjon, registerdata, osv.</p>
<p>Endring av utvalg: Vi ønsker å gjøre følgende endringer:</p> <ol style="list-style-type: none"> <li>Vi ønsker å gjøre to endringer i denne studien: Endring 1 Utvalget for denne studien har tidligere vært definert som unge transpersoner mellom 12 og 25 år, enten alene eller sammen med sine foreldre/foresatte. Vi ønsker nå å justere dette ved å tillate at foreldre/foresatte til unge transpersoner mellom 12 og 25 år kan delta i studien selv om barnet ikke ønsker å delta selv. Grunnen til at vi gjør denne endringen er at vi erfarer at noen barn ikke er komfortable med å bli intervjuet (for eksempel fordi de har hatt traumatiske opplevelser knyttet til interaksjon med helsevesenet), men gjerne vil at foreldrene deltar i studien. Vi erfarer også at noen av foreldrene dette gjelder gjerne vil delta. Denne endringen medfører at noen foreldre/foresatte kan komme til å bidra med opplysninger om eget barn som tredjeperson. Som en forutsetning for å inkludere foreldre i situasjoner der barnet ikke selv deltar, vil vi derfor be om barnets godkjenning av foreldrenes deltakelse. Dersom barnet er over 15 år, vil vi be om samtykke, og dersom barnet er under 15 år, vil vi høre og respektere barnets mening om foreldrenes/de foresattes deltakelse. Endring 2 Vi har tidligere definert at utvalget skal bestå av unge transpersoner som har</li> </ol>	<p>Dersom det er snakk om små endringer i antall deltakere er endringsmelding som regel ikke nødvendig. Ta kontakt på telefon før du sender inn skjema dersom du er i tvil.</p>

<p>søkt eller søker behandling med pubertetsblokkere. Vi ønsker nå å utvide utvalget slik at unge transpersoner som ikke har søkt behandling med pubertetsblokkere også kan delta. Bakgrunnen for dette er at enkelte ungdommer ikke har kommet i kontakt med helsevesenet tidlig nok til at behandling med pubertetsblokkere er aktuelt (etter pubertet er det i de fleste tilfellene bare aktuelt å gi behandling med hormoner), mens andre aktivt kan ha valgt å ikke ville bruke pubertetsblokkere. Disse ungdommer har også viktige erfaringer som kan utvide studiens omfang og verdi.</p> <p><b>Endring 3</b></p> <p>2. For å reflektere disse endringene endrer vi tittelen på studien fra "Putting Off Puberty: A Qualitative Study of the Experiences of Transgender Adolescents and Their Families Seeking Puberty Blockers in Norway" til "Dealing With Puberty: A Qualitative Study of the Experiences of Transgender Adolescents and Their Families Seeking Trans-specific Healthcare in Norway".</p>	
<p>Annet:</p>	

### 3. TILLEGGSOPPLYSNINGER

--

### 4. ANTALL VEDLEGG

	<p><i>Legg ved eventuelle nye vedlegg (informasjonsskriv, intervjuguide, spørreskjema, tillatelser, og liknende.)</i></p>
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#### BEKREFTELSE PÅ ENDRING

Hei, viser til endringsskjema registrert hos personvernombudet 06.11.17.

Vi har nå registrert følgende endringer:

- Endring av utvalg til også å omfatte foresatte til transpersoner, under den forutsetningen at barnet samtykker dersom barnet er over 15 år, eventuelt med foreldrenes samtykke (og at barnet får informasjon og at dets mening blir hørt) dersom barnet er under 15 år.
- At dere utvider utvalget til også å omfatte transpersoner som ikke har fått behandling med pubertetsblokkere.
- Endring av tittel (krever ikke endringsmelding)

Personvernombudet forutsetter at prosjektopplegget for øvrig gjennomføres i tråd med det som tidligere er innmeldt, og personvernombudets tilbakemeldinger. Vi vil ta ny kontakt ved prosjektslutt.

Vennlig hilsen,

Pernille Ekornrud Grøndal  
 rådgiver | Adviser  
 Seksjon for personverntjenester | Data Protection Services  
 T: (+47) 55 58 36 41

NSD – Norsk senter for forskningsdata AS | NSD – Norwegian Centre for Research Data  
 Harald Hårfagres gate 29, NO-5007 Bergen  
 T: (+47) 55 58 21 17  
[postmottak@nsd.no](mailto:postmottak@nsd.no) [www.nsd.no](http://www.nsd.no)

## BEKREFTELSE PÅ ENDRING

Hei, viser til endringsmelding registrert hos personvernombudet 12.9.2018.

Vi har nå registrert at ny dato for prosjektslutt er 30.6.2019.

Personvernombudet forutsetter at prosjektopplegget for øvrig gjennomføres i tråd med det som tidligere er innmeldt, og personvernombudets tilbakemeldinger. Vi vil ta ny kontakt ved prosjektslutt.

-----

Pernille Ekornrud Grøndal  
rådgiver | Adviser  
Seksjon for personverntjenester | Data Protection Services  
T: (+47) 55 58 36 41

NSD – Norsk senter for forskningsdata AS | NSD – Norwegian Centre for Research Data  
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T: (+47) 55 58 21 17  
[postmottak@nsd.no](mailto:postmottak@nsd.no) [www.nsd.no](http://www.nsd.no)

## BEKREFTELSE PÅ ENDRING

Hei, viser til endringsmelding registrert hos NSD 22.02.2019.

Vi har nå registrert at ny dato for prosjektslutt er 30.09.2019 (tidligere 30.06.2019).

NSD forutsetter at prosjektopplegget for øvrig gjennomføres i tråd med det som tidligere er innmeldt, og våre tilbakemeldinger.

Vi vil ta ny kontakt ved prosjektslutt.

Med vennlig hilsen,

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Eva J. B. Payne  
Rådgiver | Adviser  
Personverntjenester | Data Protection Services for Research  
T: (+47) 55 58 27 97

NSD – Norsk senter for forskningsdata AS | NSD – Norwegian Centre for Research Data AS  
Harald Hårfagres gate 29, NO-5007 Bergen  
T: (+47) 55 58 21 17  
[postmottak@nsd.no](mailto:postmottak@nsd.no) [www.nsd.no](http://www.nsd.no)

Note: Author's name has been legally changed since the original ethical clearance application from Natasha Lynn Desianto to Elian Eve Jentoft. NSD and the University of Oslo faculty were made aware of, and registered the name change.



## APPENDIX Consent forms and information provided to potential study participants

Note: Researcher has changed name legally since the consent forms were in use. Study participants have been informed of the name change, as well as a change of email address. The prior email contact is still active.

### Informasjonsskriv til ungdom 12-25 år



**UiO : Universitetet i Oslo**

## Dealing With Puberty: A Qualitative Study of the Experiences of Gender-Incongruent Adolescents and Their Families Seeking Gender-Confirming Healthcare in Norway

### BAKGRUNN OG HENSIKT

Unge personer med kjønnsinkongruens mellom 12 og -25 år søkes til deltakelse i et forskningsprosjekt som handler om hvordan de og familiene deres opplever å søke pubertetsutsettende eller/og hormonell behandling i Norge. Forskningsprosjektet er del av en masteroppgave ved Universitetet i Oslo. Vi vil gjerne vite mer om hvorfor og hvordan familiene velger å søke behandling. Intervjuene blir lagt opp som en samtale om ditt liv før og mens du søkte behandling. Vi vil også gjerne vite mer om hvordan det går når man kommer i kontakt med helsepersonell for å få tilgang til behandlingen. I tillegg ønsker vi å vite mer om hvordan familier beskriver sin situasjon til helsepersonell, og hvordan folk skaffer seg informasjon om behandlingstilbudene. Studien ønsker å rekruttere både de som har fått behandlingstilbud og de som har fått avslag enten det var fra Rikshospitalet (Oslo universitetssykehus) eller andre steder. Forskeren håper at studien kan gi viktige opplysninger om hva slags behandling unge personer med kjønnsinkongruens ønsker seg, og hvordan behandlingstilbudene i Norge kan forbedres i framtida.

### HVA INNEBÆRER STUDIEN?

Dersom du velger å delta i forskningsprosjektet, vil du bli intervjuet én eller eventuelt flere (maksimum tre) ganger. Intervjuene tar cirka 1-1.5 timer. Forskeren ønsker også å intervju dine foreldre/foresatte dersom det er i orden for deg. Ønsket er at du og dine foresatt/foreldrene intervjues hver for dere hvis det er mulig.

### MULIGE FORDELER OG ULEMPER

Å delta i undersøkelsen gir deg kanskje ingen personlige fordeler (selv om det for noen kan være en god opplevelse å snakke om personlige opplevelser med en interessert forsker). Forskeren håper imidlertid at studien kan bidra til kunnskap om hva unge personer med kjønnsinkongruens ønsker seg som behandling og hva de erfarer når de søker den, og til at andre unge personer med kjønnsinkongruens får et bedre behandlingstilbud i framtida. Deltakelse i studien vil ikke på noen måte påvirke framtidig søknader om behandling i noen retning. Av mulige ulemper ved deltakelsen må det nevnes at samtalene tar litt av din tid, og vi er oppmerksomme på at det noen ganger kan være en belastning å snakke om opplevelser knyttet til personlige forhold og helsebehandling.

#### HVA SKJER MED INFORMASJONEN OM DEG?

Lyddopptak av intervjuene vil bli lagret i et kryptert datasystem med høy sikkerhet på Universitet i Oslo. Bare forskeren vil ha tilgang til dem. Etter intervjuet vil samtalens innhold bli skrevet ned og lydfilen bli deretter slettet. Alt du forteller vil bli anonymisert, slik at det ikke skal være risiko for at informasjon kan spores tilbake til deg. Intervjuene skal brukes i samband med en masteroppgave i Internasjonal samfunnshelse ved Universitetet i Oslo. Deler av studien kan også bli brukt i artikler i akademiske publikasjoner og presentert på konferanser. Informasjonen i oppgaven kan også bli delt med helsemyndighetene, organisasjoner og stiftelser som kan ha interesse i saken, fortsatt i anonymisert form. Prosjektets sluttdato er 31.12.2018. Etter den datoen, vil navnelisten bli slettet, og indirekte personopplysninger slettes eller omskrives.

#### DELTAELSE

Det er helt frivillig å delta i prosjektet og du kan når som helst og uten å oppgi noen grunn trekke deg fra deltakelse uten at dette får behandlingsmessige eller andre konsekvenser for deg. Du kan ta kontakt med forskeren når som helst under studien med spørsmål eller for å trekke deg ved å skrive til eller ringe "Elian" Natasha Desianto [n.l.desianto@studmed.uio.no](mailto:n.l.desianto@studmed.uio.no) eller (47) 40052747. Du kan også ta kontakt med studiens veileder Kåre Moen ved å skrive [kare.moen@medisin.uio.no](mailto:kare.moen@medisin.uio.no) eller du kan ringe (47) 22850599. Deltakelsen av dine foreldre/foresatte er avhengig av ditt ønske om å delta. Dersom du ikke vil delta i prosjektet, blir ikke dine foreldre/foresatte bedt om å delta. Det er lov å delta uten dine foreldre/foresatte, men de må signere samtykkeskjemaet dersom du er under 18 år.



## Informasjonsskriv til voksne og samtykkeskjema



# UiO : Universitetet i Oslo

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET

## DEALING WITH PUBERTY: A QUALITATIVE STUDY OF THE EXPERIENCES OF GENDER-INCONGRUENT ADOLESCENTS AND THEIR FAMILIES SEEKING GENDER-CONFIRMING HEALTHCARE IN NORWAY

Dette er en forespørsel til deg om å delta i et forskningsprosjekt for å forstå hvordan ungdom og deres foreldre/foresatte opplever det å søke pubertetsutsettende og/eller cross-hormoner behandling i Norge. Forskningsprosjektet er del av en masteroppgave i International Community Health ved Universitetet i Oslo. Vi vil gjerne vite mer om hvorfor og hvordan familiene velger å søke behandling. Intervjuene blir lagt opp som en samtale om deres liv opptil og mens ungdommen søkte behandling, samt hvorvidt foreldrenes tenkning rundt kjønnsstatistikken endrer seg gjennom det å ha et transkjønnede barn. Vi vil også vite hvordan det går når unge personer med kjønnsinkongruens og deres familier kommer i kontakt med helsepersonell. I tillegg ønsker vi å få vite mer om hvordan familier argumenterer for barnets case til helsepersonell, og hvordan folk skaffer seg informasjon om behandlingstilbudene. Studien ønsker å rekruttere både de som har fått behandlingstilbud og de som har fått avslag, enten det er fra Rikshospitalet eller andre steder. Forskeren håper at studien kan gi viktige opplysninger om hva slags behandling unge personer med kjønnsinkongruens ønsker, og hvordan behandlingstilbudene i Norge kan forbedres i framtida.

### HVA INNEBÆRER PROSJEKTET?

Dersom du og ditt barn velger å delta i forskningsprosjektet, vil du og barnet bli intervjuet én eller eventuelt flere (maksimalt tre) ganger. Intervjuene tar cirka 1-1.5 timer. Forskeren ønsker at intervjuene med ungdommen og de foresatte/foreldrene skjer hver for seg hvis det er mulig.

### MULIGE FORDELER OG ULEMPER

Å delta i undersøkelsen gir deg kanskje ingen personlige fordeler (selv om det for noen kan være en god opplevelse å snakke om personlige opplevelser med en interessert forsker). Forskeren håper imidlertid at studien kan bidra til kunnskap om hva unge personer med kjønnsinkongruens og deres familier ønsker seg som behandling og hva de erfarer når de søker den, og til at andre unge personer med kjønnsinkongruens får et bedre behandlingstilbud i framtida. Deltakelse i studien vil ikke på noen måte påvirke framtidige søknader om barnets behandling i noen retning. Av ulemper ved deltakelse må det nevnes at samtalen tar litt av din tid, og vi er oppmerksomme på at det noen ganger kan være en belastning å snakke om opplevelser knyttet til personlige forhold og helsebehandling.

**FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE**

Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, ber vi deg undertegne samtykkeerklæringen på siste side. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke uten konsekvenser. Dersom du trekker deg fra prosjektet, kan du kreve å få slettet innsamlede intervjuer og opplysninger, med mindre opplysningene allerede har inngått i analyser eller er brukt i vitenskapelige publikasjoner. Dersom barnet ikke ønsker å delta på et senere tidspunkt, vil informasjon om hele familien bli trukket. Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte "Elian" Natasha L. Desianto med epost [n.l.desianto@studmed.uio.no](mailto:n.l.desianto@studmed.uio.no) eller telefon: (47)40052747. Du kan også ta kontakt med studiens veileder ved å skrive eller ringe Kåre Moen på [kare.moen@medisin.uio.no](mailto:kare.moen@medisin.uio.no) eller (47) 22850599.

**HVA SKJER MED INFORMASJONEN OM DEG?**

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Du har rett til innsyn i hvilke opplysninger som er registrert om deg og til å få korrigert eventuelle feil i de opplysningene som er registrert.

Lyddoptak av intervjuene skal bevares på et kryptert datasystem med høy sikkerhet på Universitetet i Oslo og det er bare forskeren som har tilgang til dem. Etter intervjuet vil samtalens innhold bli skrevet ned og lydfilen slettet. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte personidentifiserende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Alt du forteller vil bli anonymisert, slik at det ikke skal være risiko for at det kan spores tilbake til deg og familien din. Prosjektets forventet sluttdato er 31.12.2018. Etter den datoen, vil navnelisten slettes, og indirekte personopplysninger slettes eller omskrives.

Intervjuene skal brukes i samband med en masteroppgave i Internasjonal samfunnshelse ved Universitetet i Oslo. Deler av studien kan også bli brukt i artikler i akademiske publikasjoner og presentert på konferanser. Informasjonen i oppgaven kan også bli delt med helsemyndighetene, organisasjoner, og stiftelser som kan ha interesse i saken, fortsatt i anonymisert form.

Prosjektleder har ansvar for den daglige driften av forskningsprosjektet og at opplysninger om deg blir behandlet på en sikker måte.

**GODKJENNING**

Prosjektet er godkjent av Personvernombudet for forskning, saksnr. 55159.



# UiO : Universitetet i Oslo

**SAMTYKKE TIL DELTAKELSE I PROSJEKTET "Dealing With Puberty: A Qualitative Study of the Experiences of Gender-Incongruent Adolescents and Their Families Seeking Gender-Confirming Healthcare in Norway"**

JEG ER VILLIG TIL Å DELTA I PROSJEKTET

-----  
Sted og dato

-----  
Deltakers signatur

-----  
Deltakers navn med blokkbokstaver

Hvis et prosjekt inkluderer barn og ungdom under 16 år, skal i utgangspunktet begge foresatte undertegne.

Som foresatte til \_\_\_\_\_ (Fullt navn) samtykker vi til at hun/han/hen kan delta i prosjektet.

-----  
Sted og dato

-----  
Foresattes signatur

-----  
Foresattes navn med blokkbokstaver

-----  
Sted og dato

-----  
Foresattes signatur

-----  
Foresattes navn med trykte bokstaver



# UiO : Universitetet i Oslo

**SAMTYKKE TIL DELTAKELSE I PROSJEKTET "Dealing With Puberty: A Qualitative Study of the Experiences of Gender-Incongruent Adolescents and Their Families Seeking Gender-Confirming Healthcare in Norway"**

JEG ER VILLIG TIL Å DELTA I PROSJEKTET

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Sted og dato

-----  
Deltakers signatur

-----  
Deltakers navn med blokkbokstaver

-----  
Sted og dato

-----  
Deltakers signatur

-----  
Deltakers navn med blokkbokstaver

Hvis et prosjekt inkluderer foreldre uten at barnet skal delta, skal i utgangspunktet barnet undertegne (dersom barnet er 15 år eller eldre) .

Som barn til \_\_\_\_\_ (Fullt navn) samtykker jeg til foreldrene mine kan delta i prosjektet.

-----  
Sted og dato

-----  
Barnets signatur

-----  
Barnets navn med blokkbokstaver

Forespørsel om deltakelse i forskningsprosjektet

**“Dealing With Puberty: A Qualitative Study of the Experiences of Gender-Incongruent Adolescents and Their Families Seeking Gender-Confirming Healthcare in Norway”**

**Formål**

**Studien vil undersøke hvordan ungdom og deres foreldre/foresatte opplever det å søke pubertetsutsettende eller/og cross-hormoner behandling i Norge. Vi vil gjerne vite mer om hvorfor og hvordan familiene velger å søke behandling, samt hvorvidt foreldrenes tenkning rundt kjønnsstatistikk endrer seg gjennom det å ha et barn med kjønnsinkongruens. Vi vil også vite hvordan det går når unge personer med kjønnsinkongruens og deres familier kommer i kontakt med helsepersonell. I tillegg ønsker vi å få vite mer om hvordan familier argumenterer for barnets case til helsepersonell, og hvordan folk skaffer seg informasjon om behandlingstilbudene.**

**Prosjektet er en masteroppgave i Internasjonal samfunnshelse som gjennomføres på Institutt for helse og samfunn (HELSAM) ved Universitetet i Oslo.**

**Hva innebærer deltakelse i studien?**

**Dersom du velger å delta i forskningsprosjektet, vil du bli intervjuet én eller eventuelt flere (maksimum tre) ganger. Intervjuene tar cirka 1-1.5 timer. Forskeren ønsker å intervju unge personer med kjønnsinkongruens mellom 12 og 25 år, og deres foreldre/foresatte. Ønsket er at ungdommen og foresatt/foreldrene intervjues hver for seg hvis det er mulig.**

**Kontakt**

**Dersom du ønsker å delta eller har spørsmål, ta kontakt med Elian Desianto med e-post [n.l.desianto@studmed.uio.no](mailto:n.l.desianto@studmed.uio.no) eller på telefonnummer 40052747.**

## APPENDIX F: Interview Guides

### Intervjuguide nøkkelinformanter

- Foretrukne pronomer på engelsk
  - Din historie om å gi behandling
  - Rikshospitalets reaksjon
  - Situasjon nå
  - Risikoer
  - Følelser rundt det å kunne gi behandling
- 
- Stilling
  - Antall pasienter i pubertets-alderen
  - Økning i antall som søker behandling
  - Antall som tar pubertetsblokkere (PB)
  - Kriteriet for PB
  - Hvorfor familiene sier de vi ha PB
  - Ditt ståsted
  - Risiko/antall år på PB/umodenhet
  - Forskning med ungdom på PB hos NBTS
  - Frykten for å feilbehandle
  - Nye endringer hos NBTS
  - Kritikk om NBTS
  - Måte å få second opinion?
  - Mening om privatbehandling
  - Nye diagnostiske retningslinjer
  - Hvordan er det å jobbe med ungdommer
  - Kliniske erfaringer med ungdommer (forståelse, hvordan se dem?)
  - utfordringer
  - Gleder

**Intervjuguide for forelder :****Demografisk informasjon:**

- Sivilstatus til foreldre/foresatte
- Barnets alder
- Barnets nåværende utdanningsnivå
- Har barnet fått diagnose GID eller annet?
- Søsken og deres kjønnsidentitet
- Yrke til foreldre/foresatte
- Utdanningsnivå til foreldre/foresatte
- Familiens inntektsnivå
- Etnisitet
- Religion
- Politisk tilhørighet
- Region i Norge (generelt)

**Tidslinjeskaping:**

- Tidlig barndom
- Viktige hendelser/erfaringer
- Hendelser/følelser/bekymringer da barnet nærmet seg puberteten
- Kommunikasjon om kjønnsidentitet
- Kommunikasjon med barnets skole
  - Fastleger?
  - BUP?
  - Privat psykolog eller psykiater?
  - Stiftelser?
  - Støttegrupper?
- Prosesser og timeavtaler
- Tiden etter pubertetsblokkere (hvis aktuelt)
- Juridisk kjønnsendring
- Framtidsønsker

**Detaljerte spørsmål etter tidslinjeskapingen**

- Erfaringer rundt det å ha et barn med kjønnsinkongruens
- Ang. kommunikasjon med barnet om kjønnsidentitet:
  - Førsteinntrykk?
  - Familiens samtaler?

- Opplevelser av kommunikasjon med andre

**Planlegging/forberedelser før timeavtaler:**

- Informasjonsinnhenting
- hva var viktig å vite på forhånd?
- hvor søkte dere informasjon?
- **Sosialnettverk/sosialstøtte**
  - Bruk av støttegrupper?
    - Sosialnettverk på nettet (Facebook, blogger, nettsider osv.)?
    - Venner med lignende erfaringer?
  - Samtaler og informasjonsdeling, deling av andres erfaringer?
  - Hva var viktig å ha som støtte?
  - Hva slags hjelp/støtte ønsker du hadde vært tilgjengelig?
- **Barnets case:** beskrivelser av situasjonen/barnets behov som ble diskutert med ekspertene/legene, overbevisningsprosessen
  - syntes dere at det var noe ekspertene vil høre, noe som funker best til overbevisning?
  - Var det informasjon dere valgte å utelate?
- **Hvorfor pubertetsblokkere?**
  - Egne meninger?
  - Diskusjoner med familien
  - Hva overbeviste familien at dette var den beste veien fremover?
- Meninger rundt mulige ukjente risikoer

- **Barnets evne til å gi samtykke:**
  - risiko, mulige bivirkninger, videre behandling, osv?
  - Fra hvilken alder syns du barn burde kunne velge selv å få pubertetsutsettende behandling?
  - Hvordan var det som forelder å gi samtykke for barnet?
- **Spesifikke opplevelser/samtaler med**
  - fastleger,
  - psykologer,
  - endokrinolog,
  - BUP,
  - stiftelser,
  - NBTS,
  - osv.
- **Fastlege:**
  - reaksjon
  - legens kunnskap om kjønnsstatistikk + hvordan henvise barnet
- **BUP:**
  - Oppfatninger rundt det å måtte få en psykiatrisk diagnose?
  - Samtaler med BUP-personell
- **Oppfatninger rundt kjønnsidentitet? Endringer?**
- **Meninger om den diagnostiske prosessen:**
- ble barnet trodd? støttet gjennom prosessen?
- Følelser etter diagnosesetting/avslag?
- noe som var spesielt utfordrende? f.eks. :
  - det å informere og møte andre
  - lengden og prosessen man må gjennomgå for å få behandling
- behandling
- reiser for å få behandling
- det å ha transkjønnede barn?
- **Hvis avvist:**
  - opplevelsen av å hjelpe et barn som måtte gjennomgå et uønsket pubertet,
  - barnets motstandsdyktighet/mestring.
- **Gleder?**
  - (ang. Opplevelser med barnet,
  - det å gjennomgå prosessen sammen?)



## Intervjuguide for ungdom

### Basis informasjon:

Alder, skole, interesser, kjønnsidentitet i egne ord, foretrukne pronomer

### Tidslinjeskaffing:

- Tidlige minner
- Skole
- Opplevelser om det å diskutere kjønnsidentitet med familiemedlemmer, venner, medelever, osv.
- Støttegrupper/kontakter
- Hvordan/når/hvor skaffe seg informasjon om behandling?
- Opplevelser av timeavtaler
- Framtidige ønsker

### Intervju:

- Syn/oppfatninger rundt **kjønn**
- Hva skjedde når du diskuterte kjønnsidentiteten din med
  - familien,
  - venner,
  - skolen,
  - osv?
- **Sosialovergangen**
  - prosessen,
  - hjelp fra familien, skole, osv.
- **Informasjonsinnhentning**
  - kjønnsidentitet,
  - sosialovergangen,
  - støttegrupper,
  - behandling,
  - Hvordan og hvor?
  - Hva var mest nyttig?
  - Var informasjonen forståelig?
  - Er det noe som kunne forbedres?
- **Opplevelse av pubertetens første faser før behandling-**
- **Forberedelse før timeavtaler -**
- **Utdypning: timeavtalenes opplevelser, dvs.**

- ventetid,
- reiser til behandling,
- samtaler med
  - Leger
  - Psykolog
  - Andre eksperter.
- Hva ble diskutert?
- Synes du at legen/psykologen/osv var stolte på/støttet deg?

- **Følelser/opplevelser etter å ha fått bekreftet/avslått behandling.**
- Hvis avvist:
  - opplevelsen av å måtte gjennomgå pubertet,
  - motstandsdyktighet/mestring.
  - Har du blitt fulgt opp?
- **Risiko og behandling, meninger & følelser om:**
  - det å gjennomgå livslang behandling,
  - hvordan diskutere risiko og behandling/ønsker med familien?
- **Mening: pasientens alder og informert samtykke**
- **Utdypning: framtidige ønsker, planer, drømmer**
- **Glede: Opplevelser rundt sosialovergangen, dvs.**
- **Utfordringer:**
  - Hva var det vanskeligste med prosessen om å søke behandling?
  - utfordringer i sosialovergangsprosessen?
  - Med behandling?