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Ethical dilemmas and decision-making in the healthcare for transgender minors

Vrouenraets, L.J.J.J.

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INTRODUCTION

In the last decades, in various parts of the world, the number of children and adolescents referred to gender identity clinics has increased enormously, and minors with gender incongruent experiences have increasingly become a subject of discussion (e.g. Arnoldussen et al. 2020; Arnoldussen et al., 2022b; Kaltiala et al., 2020; Pang et al., 2020; Wiepjes et al., 2018). The question how to best organize care for these children and adolescents has become very prominent and subject of public debate (e.g. The Observer, 2022). Determining what constitutes the best care inescapably involves thinking about ethical issues and dilemmas. The research described in this thesis explores ethical issues and dilemmas surrounding early medical treatment for transgender minors. This first chapter is an introduction to the topic. It describes the clinical characteristics of gender dysphoria and its treatment options, mainly focusing on treatment that includes puberty suppression (PS). Furthermore, adolescents' medical decision-making competence (MDC) regarding starting PS, the role of media attention in referral rate and care of transgender children and adolescents, and legal and moral aspects are introduced. Finally, the overall aims and research questions of the thesis are described, and an outline of the other chapters is provided.

GENDER DYSPHORIA

Children and adolescents diagnosed with gender dysphoria experience an incongruence between their birth-assigned sex and their experienced gender, which is accompanied by distress (American Psychiatric Association, 2013). Table 1 shows the criteria for a diagnosis of gender dysphoria for children according to the 5th version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). Table 2 shows the criteria for a diagnosis of gender dysphoria for adolescents and adults according to the DSM-5. Over the years and since the start of this research in 2013, terminology around gender identity related diagnoses has changed. The DSM-5 and the DSM-5-TR now use 'gender dysphoria', the 11th version of the International Statistical Classification of Diseases and Related Health Problems (ICD-11) uses 'gender incongruence', while prior to these terminologies, the term 'gender identity disorder' was used (American Psychiatric Association, 2013; American Psychiatric Association, 2022; World Health Organization, 2022). While preparing the revisions of the Diagnostic and Statistical Manual of Mental Disorders (DSM) and International Statistical Classification of Diseases and Related Health Problems (ICD), recommendations were made to replace 'gender identity disorder' by 'gender dysphoria', and 'transsexualism' by 'gender incongruence' respectively (Bedirhan Üstün, Jako, Çelik, Lewalle, & Kostanjsek, 2007; Cohen-Kettenis & Pfafflin, 2010; Drescher, Cohen-Kettenis, & Reed, 2016; Zachar, Regier, & Kendler, 2019). Reasons for these recommendations were that the condition can be

present to a lesser or greater extent, and that it may fluctuate over time. Furthermore, the authors aimed to make a move to depsychopathologization of the condition. They wanted the terminology to be non-stigmatizing and acceptable to those who fulfil the criteria (Cohen-Kettenis & Pfafflin, 2010; Rodríguez, Granda, & González, 2018). Whereas the DSM is a psychiatric classification system, in the ICD-11, the classification gender incongruence was moved from the chapter 'mental disorder' to a new chapter entitled 'conditions related to sexual health'. The reason for this was to avoid the mental health stigma of being diagnosed with a mental disorder (World Health Organization, 2022). Since the terms used to address this condition changed over time, and during the undertaking of this research, in this thesis several terms will be used alternating¹. In the general introduction, and in the general discussion the term 'transgender children/adolescents/individuals' is used as an umbrella term to refer to individuals who have gender incongruent experiences and/or present with questions about their gender identity, and to individuals diagnosed with gender dysphoria.

Until a couple of years ago, gender dysphoria was considered to occur rarely (Zucker & Lawrence, 2009). Over the past decades however, the number of minors seeking care regarding their gender incongruent experiences has increased tremendously throughout the Western world (Aitken et al., 2015; Chen, Fuqua, & Eugster, 2016; Pang et al., 2020; de Vries & Cohen-Kettenis, 2012; Wood et al., 2013; Handler et al., 2019). For example, by 2017, the annual number of referrals in Norway, the UK and Sweden had increased 12-, 14-, and 19-fold respectively compared to 2011 (Kaltiala et al., 2020). Finland is another example of a country with an immense increase of child and adolescent referrals. In Finland, the annual number of referrals in 2017 had increased six-fold compared to 2011, when the first two gender identity clinics for children and adolescents were introduced in this country (Kaltiala-Heino, Sumia, Työläjärvi, & Lindberg, 2015). Similarly, in the Netherlands, there was an immense increase in the number of adolescents assessed at gender identity clinics between 2000 and 2016 (Arnoldussen et al. 2020; Arnoldussen et al., 2022b).

1 Terms that will be used in the chapters 2 to 7 are 'transgender minors/children/adolescents/people/individuals', 'adolescents diagnosed with gender dysphoria', and 'identifying as transgender'. In some chapters terms are used that we would not use nowadays anymore; terms like 'gender dysphoric minors/adolescents/adults', and 'children/adolescents/individuals with gender dysphoria'. The reason for this is that, even though in many health care systems a diagnosis of gender dysphoria is used for giving access to state funded transgender health care, using these terms does reify the condition (Bouman et al., 2017). Furthermore, chapter 4 contains the following sentence: 'This article uses the term 'transgender adults/adolescents/children' to refer to persons diagnosed with gender dysphoria'. We would not use this sentence nowadays anymore, since the term 'transgender adults/adolescents/children' is used as an umbrella term, and may also be used for individuals who do not (yet) have a gender dysphoria diagnosis, but nevertheless have gender incongruent experiences and/or questions about their gender identity.

Table 1. Criteria for a diagnosis of gender dysphoria in children according to the DSM-5 *

Gender dysphoria in children is defined as a noticeable incongruence between one's experienced/expressed gender, and their birth-assigned gender. This incongruence should be lasting at least six months, as manifested by at least six of the following:

- An intense desire to be of the other gender, or an insistence that one is the other gender (or some alternative gender that is different from one's birth-assigned gender)
 - A strong preference for cross-dressing (wearing typical clothing from the gender opposite to the birth-assigned gender), and a strong resistance to wearing typical clothing from the birth-assigned gender
 - A strong preference cross-gender role in fantasy play or make-believe play
 - A strong preference to do activities, or play with toys and/or games that are stereotypically used or engaged in by the other gender
 - A strong preference for playmates of the other gender
 - A strong rejection of activities, tops, and activities that are stereotypically used or engaged in one's birth-assigned gender
 - A strong dislike of one's primary sex characteristics
 - An intense desire for the physical sex characteristics that match one's experienced gender
 - In order to meet the criteria for the diagnosis, the condition should also be associated with clinically significant distress, or it should significantly impair one's functioning socially, occupationally, and/or in other important areas of functioning
-

* American Psychiatric Association, 2013

Table 2. Criteria for a diagnosis of gender dysphoria in adolescents and adults according to the DSM-5 *

Gender dysphoria in adolescents and adults is defined as a noticeable incongruence between one's experienced/expressed gender, and their birth-assigned gender. This incongruence should be lasting at least six months, as manifested by at least two of the following:

- A noticeable incongruence between one's experienced/expressed gender, and one's primary and/or secondary sex characteristics (in young adolescents, the anticipated secondary sex characteristics)
 - An intense desire to get rid of one's primary and/or secondary sex characteristics because of the noticeable incongruence with one's experienced/expressed gender (in young adolescents, an intense desire to prevent the development of the anticipated secondary sex characteristics)
 - An intense desire to have the primary and/or secondary sex characteristics of the other gender
 - An intense desire to be of the other gender (or some alternative gender that is different from one's birth-assigned gender)
 - An intense desire for society to treat them as the other gender (or some alternative gender that is different from one's birth-assigned gender)
 - A strong conviction that one has the characteristic feelings and reactions of the other gender (or some alternative gender that is different from one's birth-assigned gender)
 - In order to meet the criteria for the diagnosis, the condition should also be associated with clinically significant distress, or significantly impair one's functioning socially, occupationally, and/or in other important areas of functioning
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* American Psychiatric Association, 2013

TREATMENT FOR GENDER DYSPHORIA

Not only the acceptable terminology and the number of referrals changed over the years, also the recommendations regarding the (medical) treatment for these children and adolescents have been in motion. Three broad approaches regarding treatment for *pre-pubertal children* with gender incongruent experiences have been described in the

literature. A first approach in pre-pubertal children is described as the ‘therapeutic model’ (Dreger, 2009). This approach consists of direct or indirect efforts to reduce the child’s cross-gender identification. A second approach is described as the ‘affirmative model’ (Ehrensaft, 2012). This approach considers all outcomes of gender identity to be equally desirable and valid. Furthermore, it allows children who express the desire to socially transition² to do so after careful counselling. The third approach in pre-pubertal children is described by some as ‘watchful waiting’: parents are advised to keep options open about their child’s long-term gender identity and to avoid early social transition, without direct efforts to ‘prohibit’ the gender incongruent behaviour of their child (Drescher & Byne, 2012; Turban, de Vries, Zucker, & Shadianloo, 2018b). Treatment for pre-pubertal children regarding this approach is predominantly psychological, focusing on, if any, the child’s concomitant behavioural and emotional struggles and providing parent counselling (de Vries & Cohen-Kettenis, 2012). Of these three described approaches, ‘watchful waiting’ is the most commonly advised in the Netherlands in pre-pubertal children with gender incongruent experiences.

Not all pre-pubertal children with gender incongruent experiences, will be transgender adults. Of the pre-pubertal children referred to a gender identity clinic, only a minority (2-33%) return around or after the onset of puberty with the desire to undergo gender-affirming medical treatment (GAMT) (Ristori & Steensma, 2016). In contrast to these findings of clinical follow-up, a recent convenience sample of socially transitioned children showed very few retransitions after five years (Olson, Durwood, Horton, Gallagher, & Devor, 2022). In addition, not all (young) adults referred to a gender identity clinic with the desire to undergo GAMT, have had gender incongruent experiences as a child or have expressed a desire to be of a different gender as a child. Gender diversity thus may have several developmental paths (Bungener & de Vries, 2022).

When gender dysphoria continues to exist when physical changes of puberty start (Tanner stage 2-3), medical care (next to the psychological care) is possible. In the late 1990s treatment with PS (using gonadotropin-releasing hormone analogues (GnRHa)) was introduced by clinicians in the Netherlands (Cohen-Kettenis, Delemarre-van de Waal & Gooren, 2008). Two established international transgender guidelines now recommend this treatment for adolescents who meet the diagnostic criteria for gender dysphoria, and fulfil the criteria for treatment with PS after they first exhibit physical changes of puberty

2 Social transition is the process by which individuals start living according to the gender role that matches their gender identity, for example by adopting a name, pronouns, and gender expression, such as haircuts and clothing which matches their gender identity.

(at least Tanner stage 2) (Coleman et al., 2022; Hembree et al., 2017³). Any coexisting psychological, social, and/or medical problem that could interfere with the assessment or treatment should be addressed, with the underlying idea that the adolescent's functioning and situation are stable enough to assess gender dysphoria/gender incongruence and to undergo treatment. Additionally, the adolescent should have sufficient cognitive capacity to give informed consent to treatment, after being informed about the effects and possible side effects of PS. Depending on the legislation in the respective country, the legal representative(s), which are in most cases the parent(s), should give informed consent too, or on behalf of the adolescent. In addition, the parent(s) or other caretaker(s) is/are involved in the care provided to the transgender adolescent, and are offered support if desired (de Vries & Cohen-Kettenis, 2012). Table 3 shows the diagnostic criteria for treatment with PS for adolescents.

Table 3. Diagnostic criteria for treatment with puberty suppression for adolescents *

Adolescents are eligible for treatment with puberty suppression if:

- The adolescent has demonstrated an intense and long-lasting pattern of gender dysphoria or gender non-conformity (whether expressed or suppressed)
 - The gender dysphoria emerged or worsened with the onset of puberty
 - Any concurrent psychological, social, and/or medical issues that could interfere with the treatment (for example, that may compromise compliance with the treatment) have been addressed, such that the functioning and situation of the adolescent are stable enough to start the treatment
 - The adolescent is having sufficient mental capacity to give informed consent to the treatment
 - The adolescent and/or parent(s)/other caretaker(s) (depending on the adolescent's age and local laws) has/have given informed consent after being informed about the effects of the treatment and fertility preservation options
 - The parent(s)/other caretaker(s) is/are involved and supporting the adolescent throughout the treatment process
 - A paediatric endocrinologist or other clinician with experience in the assessment of puberty agrees with the indication of the clinician to start puberty suppressing treatment
 - The adolescent's puberty has started (Tanner stage \geq G2/B2)
 - The adolescent had no medical contraindications to treatment with puberty suppression
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* Coleman et al., 2022; Hembree et al., 2017

In addition, the two established international transgender guidelines recommend the use of gender-affirming hormones (GAH; testosterone or oestrogen) after the start with treatment with PS for adolescents who still show gender dysphoria at about the age of 15-16. In the case of compelling reasons, treatment with GAH could be initiated for adolescents prior to the age of 16 years (Hembree et al., 2017). Surgery, for example

3 Very recently, Coleman et al., published a revised version of one of these guidelines, which resembles to a large extent the earlier version but also includes some significant changes regarding recommended care for transgender and gender non-conforming children and adolescents of which it is as yet not clear how they will affect clinical practice (2022). The research described in chapters 2 to 9 of this thesis is conducted at the time of the 7th version of the Standards of Care. Therefore, these chapters refer to the 7th version of these guidelines, while chapters 1 and 10 refer to the 8th version. Nevertheless, it is worth noting that the changes to the 8th version of the Standards of Care would not have changed the conclusions of the research described in chapters 2 to 9.

mastectomy, gonadectomy and/or hysterectomy, is recommended when the transgender individual and clinician(s) agree that this is medically necessary, and that it would be beneficial for the transgender individual's overall well-being and/or health (Hembree et al., 2017). The Endocrine Society clinical practice guideline and the 7th version of the Standards of Care recommend deferring surgery until the individual is at least 18 years old (Coleman et al., 2012; Hembree et al., 2017). Only with regard to mastectomy, the 7th version of the Standards of Care describes that it could be carried out before the age of 18 (Coleman et al., 2012). Therefore, the age requirement for mastectomy in some countries is below 18. For example, in the Netherlands, the minimum age has been lowered in recent years, and is now 16. The recently published 8th version of the Standards of Care does not describe any age limits for gender-affirming surgery (Coleman et al., 2022).

PUBERTY SUPPRESSION

The two established international transgender clinical guidelines outline several reasons for using PS in the early stages of puberty of transgender adolescents, which largely correspond to the reasons given in the late 1990s, when this treatment was first introduced in the Netherlands (Cohen-Kettenis et al., 2008; Coleman et al., 2022; Hembree et al., 2017). One of the reasons is that PS suppresses (further) development of secondary sex characteristics in a reversible manner (Hembree et al., 2017). It is therefore applied to extend the exploration and assessment phase. It provides the adolescents 'extra' time to make a balanced decision regarding subsequent GAMT by means of treatment with GAH, and possibly undergoing gender-affirming surgery, while creating peace of mind by relieving the adolescent's suffering caused by the development of secondary sex characteristics (Cohen-Kettenis & van Goozen, 1998). Another important reason to start PS in early puberty is that the physical outcome may be more satisfactory compared to no use or use of PS in later stages of puberty, because the masculinization or feminization of the body, which accompanies pubertal development, is suppressed (Cohen-Kettenis & van Goozen, 1997; Smith, van Goozen, Kuiper, & Cohen-Kettenis, 2005). Additionally, some surgeries such as mastectomy may not be necessary or less invasive (i.e. periareolar rather than inframammary approach) because development of secondary sex characteristics is prevented (van de Grift et al., 2020). Furthermore, PS can be used in adolescents in later stages of puberty to, among others, prevent facial hair growth in transgirls (assigned male at birth, with a female gender identity), and to stop menses in transboys (assigned female at birth, with a male gender identity) (Hembree et al., 2017). PS may therefore result in life-long advantages for adolescents (Cohen-Kettenis & van Goozen, 1997).

Little is known about how PS is perceived by the transgender adolescents themselves and their parents. More knowledge about the motivation of these stakeholders to apply for PS

will help to adequately support these adolescents in their decision-making process, and give them the information and care they need.

MEDICAL DECISION-MAKING COMPETENCE

A major issue in paediatric ethics in general is decision-making competence for medical treatments. The right balance needs to be struck between protecting minors who are not fully capable of making the decision themselves to start or refuse a medical treatment, and respecting minors' evolving autonomy (Appelbaum, 2007). According to the international transgender guidelines, an important prerequisite to start treatment with PS is that transgender adolescents are competent to give informed consent (Coleman et al., 2022; Hembree et al., 2017; see also table 3 which can be found at page 14). There is increasing public discussion whether adolescents are actually competent to make a decision regarding PS treatment, especially because the treatment has far-reaching long-term consequences (e.g. Baron & Dierckxsens, 2021; D'Abbrera, D'Angelo, Halasz, Prager, & Morris, 2020; Giordano, Garland, & Holm, 2021; Levine, 2022; Pang, Giordano, Sood, & Skinner, 2021; Siddique, 2021; Tampier, 2022). To date, little empirical research exists regarding minors' medical decision-making (MDC) competence to decide on starting PS in the transgender context. In addition, little is known about the perceptions of transgender adolescents, their parents, and clinicians on the minors' MDC to decide on starting PS. Research regarding these aspects is needed to underpin both the ethical debate and clinical practices.

MEDIA ATTENTION

In recent years, not only the number of referrals increased enormously in various parts of the world, there has also been an explosion of media attention regarding transgender children and adolescents worldwide. Actually, one of the suggested causes for the increased number of referrals, is the increased media attention regarding transgender children and adolescents (de Graaf & Carmichael, 2019). Newspapers, television programs, magazines, movies, and the internet pay increasing attention to transgender children and adolescents (Pang et al., 2020; Sadjadi, 2013; Zucker, Bradley, Owen-Anderson, Kibblewhite, & Cantor, 2008). Most portray these children and adolescents as fascinating and sometimes somehow strange, and simultaneously as ones to feel compassion for (Sadjadi, 2013). The media have an increasingly important influence on the development of adolescents' identity, especially in western communities (Alper, Katz, & Clark 2016; Henrich, Heine, & Norenzayan, 2010). One could therefore wonder if the increasing media attention has an influence on the number of children and adolescents referred to gender identity clinics. In addition, the question can be asked whether this influence is positive or negative.

One thing that can be said, is that the increase in media coverage has also led to heated discussions between people who criticize the use of early medical treatment, and the ones who support the use of it, and to polarization of the way we conceive transgender children and adolescents. Treatment strategies are no longer private conversations between minors, their parents, and their clinicians, but have become a public debate.

LEGAL ASPECTS

Besides media attention, case law also plays an increasing role in the care and rights of transgender individuals nowadays. In various countries, e.g. the United States, Canada and England, high profile federal appellate cases have addressed transgender individuals' rights regarding for example bathroom visits, and outlawing reparative or conversion therapies (e.g. Andrade & Redondo, 2022; Byne, 2016; Fleming & McFadden-Wade, 2018; GLAD GLBTQ Legal Advocates & Defenders, 2017; Stolberg, 2017; Walch, Davidge-Pitts, Safer, Lopez, Tangpricha, & Iwamoto, 2021). In addition to these cases that promote transgender individuals' rights, there are also legal cases that seek to curtail the care of transgender individuals. One of the most prominent is the case of Keira Bell. Keira Bell is a detransitioned patient of the Tavistock and Portman National Health Service (NHS) Trust and the Gender Identity Development Service (GIDS) who started treatment with PS at the age of 16, and brought her case to court. She filed a lawsuit against the NHS and the GIDS because she was, according to herself, not challenged enough before being allowed to start PS (Barbi & Tornese, 2022). In the context of this lawsuit, the High Court of Justice in London ruled in December 2020 that transgender adolescents under the age of 16 are highly unlikely to understand the long-term effects of PS, and that they therefore are not competent to decide to start this treatment (Dyer, 2020a). In response to this verdict, it was decided nationwide that transgender minors in England could no longer start treatment with PS before the age of 16, unless a court order was obtained (Dyer, 2020b). Strikingly, the verdict and subsequent treatment restrictions were carried out even though at that time there was no empirical evidence on the MDC of transgender adolescents regarding the decision to start treatment with PS. Of note, the Court of Appeal overturned this verdict and judged that 'it was for clinicians rather than the court to decide on competence to consent', referring to the current clinical situation (Dyer, 2021; Thornton, 2021). Still, decisions such as the one that was made in England are predominantly based on age standards prescribed by law, and on MDC assessments of clinicians which are likely to be influenced by their personal subjective views of what is in the adolescent's best interest, rather than on scientific data (Hein et al., 2015d; de Vries, Wit, Engberts, Kaspers, & van Leeuwen, 2010). Therefore, more research is needed to fill in this gap in knowledge so that such decisions, with profound consequences for so many transgender children and adolescents, are based on scientific data on capacity development.

ETHICAL DILEMMAS

In the Netherlands, PS is part of the treatment protocol for transgender adolescents. Elsewhere in the world, for example in some other countries in Europe and North America, it is not always standard of care due to various ethical concerns and/or financial constraints (Gridley et al., 2016; Puckett, Cleary, Rossman, Newcomb, & Mustanski, 2019; Naiingolan, 2021). These concerns include worries about the treatment's impact on physical, cognitive, and psychosocial development, and doubts about a minors' competence to make decisions with possibly far-reaching consequences (Anacker et al., 2021; Chen et al., 2020; Kreukels & Cohen-Kettenis, 2011). Treatment teams providing PS to adolescents are inherently faced with all kinds of ethical dilemmas, which have become increasingly pressing since the exponentially growing numbers of referrals and the public attention regarding transgender care (Gerritse et al., 2018). It seems that with the increasing visibility of transgender persons, and awareness of transgender health issues, a growing polarization between two 'camps' occurs; people who criticize the use of early medical treatment state that boundaries are being crossed by the use of early medical treatment, stemming from the principle to 'first do no harm', while advocates of early medical treatment believe that the current treatment is too restrictive, stemming from the principle of 'self-determination'. Although according to the people criticizing early medical treatment, PS might entail risks, refraining the adolescents from the treatment might have harmful life-long effects as well with regard to psychological, social, and/or medical well-being of the adolescent (de Vries et al., 2021). So, in order to provide transgender minors the care they need, it is necessary that the debate moves forward by elucidating these different perspectives and by pursuing depolarization. Clinical science can help resolve controversy through profound follow-up, which is not yet thoroughly developed in this area (Levine, 2018). Additional data on the treatment and its potential effects, and elucidation of the underlying moral considerations of all stakeholders are therefore essential in order to move forward the debate and bring the necessary nuance in the field.

AIMS

The Netherlands play a pioneering role in using PS in transgender adolescents. As with other controversial medical ethical issues, like euthanasia and abortion, this stance meets both international criticism and support. Since the immense increase in the number of minors seeking professional help for their gender incongruent experiences, and since more and more people express their opinions of what, according to them, is the best care for transgender minors, this has become even more pressing (e.g. Arnoldussen et al., 2020; Arnoldussen et al., 2022b; Kaltiala-Heino et al., 2015; Kaltiala et al., 2020; Shumer & Spack, 2013). Because of the controversies surrounding the use of PS, it is essential to underpin

the Dutch treatment strategy, and to keep on formulating the moral grounds for using it. People who criticize the use of PS, and those who support this treatment option seem to have different underlying ideas about, among others, adolescents' decision-making competence, decision-making authority, and the role of concurrent psychological, social, and/or medical issues, often without openly stating them (e.g. Dubin et al., 2020; Baron & Dierckxsens, 2021; Lemma, 2018). It is an essential task to elucidate these underlying considerations. More insight in the core of the ethical dilemmas surrounding PS, and more empirical data regarding these dilemmas are needed for at least four reasons. First, to ensure that treatment for transgender minors is not only clinically, but also ethically appropriate. Second, to find common ground between various clinicians around the world regarding early medical treatment. Third, to provide the stakeholders in the field direction to deal with these ethical dilemmas in clinical practice. And fourth, to allow clinicians to safely exercise the clinical judgment to undertake the course of action which is in the child's best interests, based on objective, scientific data and not (largely) on subjective opinions.

Therefore, the first overall aim of this research is to gain more insight in the core of the ethical dilemmas that play a role in the care of transgender minors, and the underlying intuitions and considerations of stakeholders in the field regarding early medical treatment. The stakeholders are transgender adolescents who proceeded with GAMT after PS, adolescents who were diagnosed with gender dysphoria but who did not proceed with GAMT after starting treatment with PS, their parents, clinicians working in gender treatment teams, and people who are critical about the use of early medical treatment for transgender minors. The second, subsequent aim is to provide empirical data regarding these ethical dilemmas in order to give clinicians direction on how to deal with these dilemmas, and to inform and guide the minors referred to the gender identity clinics regarding these ethical dilemmas.

CENTRAL RESEARCH QUESTIONS

To provide a response to the above aims, the following questions will be addressed:

Part 1. Setting the scene: perceptions of stakeholders on ethical issues

- What are the perceptions, views, and ideas of people who criticize the use of early medical treatment for gender dysphoria, and of those who support it, regarding PS in gender dysphoria, the aetiology of gender dysphoria, and the concepts sex, gender, child competence, and best interests? And do these perceptions, views, and ideas of proponents of PS differ from those of opponents, and if so, in what sense? (chapter 2);
- What are the perceptions, views, and ideas of adolescents diagnosed with gender

dysphoria regarding PS in gender dysphoria, and regarding the concepts sex, gender, child competence, and best interests? And do the perceptions, views and ideas of these adolescents differ from those of professionals, and if so, in what sense? (chapter 3);

Part 2. Medical decision-making competence

- Are transgender adolescents eligible for starting PS treatment competent to give informed consent to this treatment, and which variables are associated with adolescents' MDC regarding starting PS? (chapter 4);
- What are the perspectives on adolescents' MDC concerning PS of transgender adolescents who proceeded with GAMT after PS, adolescents who discontinued treatment with PS, their parents, and transgender clinicians? (chapter 5);

Part 3. Significance of puberty suppression and use of fertility preservation

- How do the trajectories of transgender adolescents after the initiation of treatment with PS look like? How many adolescents discontinued PS treatment, how many adolescents had extended use of the treatment, and how long after starting PS did the adolescents start treatment with gender-affirming hormones (GAH)? And which reasons were there for extended use and discontinuation of treatment with PS? (chapter 6);
- What functions does treatment with PS have for transgender adolescents who proceeded with GAMT after PS, adolescents who discontinued treatment with PS, their parents, and transgender clinicians? (chapter 7);
- How many adolescents made use of fertility preservation in a Dutch cohort of transgirls who started treatment with PS? Had information about the risk of infertility been given to the transgirls? Was discussion of the option of fertility preservation documented in their medical files? What was the given reason for declining fertility preservation if the adolescent had not made use of fertility preservation? And what other factors were associated with the use of fertility preservation? (chapter 8);

Part 4. Clinical ethics support

- In what way can moral case deliberation (MCD) as clinical ethics support help clinicians in dealing with ethical dilemmas in transgender care? (chapter 9).

OUTLINE OF THE THESIS

This thesis consists of four parts. **Part 1** sets the scene of the ethical issues regarding the use of early medical treatment for transgender children and adolescents according to the stakeholders. *Chapter 2* explicates the considerations of people who support the use of PS and those who criticize it, regarding the use of PS in gender dysphoria. Moral intuitions on early medical treatment, and ideas, assumptions and theories about the

aetiology of gender dysphoria, the boundaries of medicine, and the concepts gender, child competence, and best interests are described. It examines whether moral intuitions, ideas, and theories of people who criticize the use of PS differ from those of people who support it, and in what sense. The considerations of 36 professionals of 17 treatment teams from 10 different countries were taken into account while using individual semi-structured interviews and open-ended questionnaires.

To do justice to the adolescents' developing autonomy to make medical decisions, especially when it concerns profound treatments such as PS, serious consideration to the opinions of transgender adolescents needs to be given. Insight into the way these adolescents perceive the concepts sex and gender, and the use of PS in the context of gender dysphoria will help to adequately support these adolescents in their decision-making process regarding this treatment and give them the care they need. *Chapter 3* therefore explores the adolescents' considerations regarding the use of PS, and regarding the concepts sex and gender. Furthermore, it describes whether these considerations differ from those of clinicians working in gender treatment teams and of people who are critical about the use of PS in gender dysphoria, and if so, in what sense. To gain this insight semi-structured interviews with 13 adolescents concerning the use of PS were conducted in the Netherlands. Eight transgender adolescents who proceeded with GAMT after PS, and five adolescents who discontinued PS (aged 13-18 years) were interviewed.

Part 2 discusses the minors' medical decision-making competence (MDC) regarding starting PS treatment. Competence is an important topic in the controversies surrounding the use of PS. There is discussion whether transgender adolescents are competent to give informed consent to start this treatment. In some countries, this doubt has even led to limited access to this treatment. We therefore examine the MDC concerning PS of transgender adolescents. To assess MDC, judgements based on the reference standard (clinical assessment) and the MacArthur Competence Assessment Tool for Treatment (MacCAT-T), a validated semi-structured interview, were used. In addition, potential associated variables on MDC, such as age, intelligence, sex, and psychological functioning, were investigated. *Chapter 4* describes the cross-sectional semi-structured interview study with 74 transgender adolescents (aged 10-18 years; 16 birth-assigned boys, 58 birth-assigned girls) within two Dutch gender identity clinics we performed.

Chapter 5 explores the perceptions concerning MDC to start PS treatment for eight transgender adolescents who proceeded with GAMT after PS, six adolescents who discontinued treatment with PS, 12 of their parents, and 10 clinicians working in gender treatment teams. For this study individual semi-structured interviews and focus groups were used. Knowing what the perspectives of the adolescents, their parents, and clinicians are regarding the adolescents' MDC will increase our understanding of the decision-making process.

Part 3 describes the significance of starting treatment with PS or refraining from the treatment, and the use of fertility preservation. Treatment with PS for transgender adolescents was developed, among others, to extend the exploration and assessment phase by providing the adolescents more time to consider their gender, the diagnosis gender dysphoria, and the potential use of GAH, without the distress associated with endogenous pubertal development. *Chapter 6* describes the minors' trajectories after the initiation of treatment with PS, and reports the reasons for extended use and discontinuation of treatment with PS in order to find out whether PS is indeed being used as a phase to further explore and assess.

Chapter 7 focuses on how PS is perceived by transgender adolescents, their parents, and clinicians. Despite PS being the current first choice treatment, little research had examined the functions of PS from the perspectives of transgender adolescents, their parents, and clinicians. Knowledge about the perceived functions of PS can help to adequately support these adolescents in their decision-making process and give them the care they need. *Chapter 7* describes the outcomes of our study using individual semi-structured interviews and focus groups to obtain insight in the perspectives of eight transgender adolescents who proceeded with GAMT after PS, six adolescents who discontinued treatment with PS, 12 of their parents, and 10 clinicians regarding the functions of PS.

One major concern regarding starting treatment with PS for transgender minors entails the consequences for the minors' fertility. As far as currently known, the effects of treatment with PS on the secondary sex characteristics' development and the gonadal function are reversible when the treatment is discontinued. However, transgender minors who start treatment with PS at a young age, and subsequently start treatment with GAH and undergo gonadectomy, cannot make use of fertility preservation since they never undergo their endogenous puberty. In order to get more insight in this currently one of the most challenging topics concerning medical treatment for transgender adolescents, *chapter 8* reports the rate of fertility preservation among a cohort of Dutch transgirls who started treatment with PS. Furthermore, the reasons why these adolescents did or did not make use of fertility preservation are described.

As has become clear of the above, clinicians frequently face ethical dilemmas arising from the care they provide. **Part 4** describes the use of clinical ethics support for clinicians who are involved in (medical) care for transgender children and adolescents, in order to support these clinicians in dealing with these challenges more effectively. The research discussed in *chapter 9* describes the treatment teams' perceived value and effectiveness

of moral case deliberation (MCD), a relatively well-established form of clinical ethics support. We offered MCD to several treatment teams of Dutch gender identity clinics. This was evaluated in a mixed methods study using individual interviews, focus groups, MCD evaluation questionnaires, and reports of MCD sessions.

In *chapter 10* the studies of this thesis are summarised and discussed. Suggestions for future studies, and implications for clinical practice are given.