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

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Summary

Chapter 1

In the last decades, in various parts of the world, the number of minors seeking care regarding their gender incongruent experiences has increased tremendously throughout the Western world, and transgender minors have increasingly become a subject of discussion (e.g. Aitken et al., 2015; Arnoldussen et al. 2020; Arnoldussen et al., 2022b; Chen et al., 2016; Handler et al., 2019; Kaltiala et al., 2020; Pang et al., 2020; Wood et al., 2013; Wiepjes et al., 2018). Additionally, over the years, the term used to address this condition changed, there has been an increase of media attention regarding transgender children and adolescents worldwide, and case law also plays an increasing role in the care and rights of transgender individuals nowadays (e.g. Dyer, 2020a; Pang et al., 2020; Stolberg, 2017; GLAD LGBTQ Legal Advocates & Defenders, 2017; Walch et al., 2021). Herewith, the question of how to best organize care for these children and adolescents has become very prominent. However, determining what constitutes the best care for these transgender minors brings ethical issues and dilemmas along.

The recommendations regarding the (medical) treatment for these children and adolescents have been in development as well. Over the last few decades, the possibility of treatment with puberty suppression (PS) has generated a relatively new, but controversial dimension to the clinical management of transgender adolescents. Even though the use of PS in the care of these minors was adopted by a rapidly increasing number of gender identity clinics, and two established international transgender guidelines included this treatment option, many clinicians working with transgender minors remain critical (Coleman et al., 2022; Hembree et al., 2017; Rew et al., 2021; Vrouenraets et al., 2015).

Another issue in the care of transgender adolescents about which there is no consensus is the minors' MDC when starting PS. According to two established 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). However, 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 et al., 2020; Giordano et al., 2021; Levine, 2022; Pang et al., 2021; Siddique, 2021; Tampier, 2022). To date, little empirical research exists regarding minors' MDC to decide on starting PS, and little is known about the perceptions of the 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.

Debate about care for transgender minors moves between extremes, and discussions are at times emotion-laden. People claiming the risks of the use of early medical treatment, and the ones who stress its benefits seem to have different underlying ideas about,

among others, minors' MDC, 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). What was missing in the discussions is an elucidation of the underlying ideas and theories. Additionally, insight into the considerations and ideas of transgender adolescents themselves, their parents, and experienced professionals remains limited.

The overall aims of this study were therefore twofold. First, we aimed 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 second, subsequent aim was to provide empirical data regarding these ethical dilemmas that play a role in the care of transgender minors. Herewith to make sure 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.

Chapter 2

Chapter 2 explicates the considerations, underlying ideas, assumptions, and theories of those who criticize and those who support the use of early medical treatment regarding treatment with PS for transgender minors. Our goal was to get a clearer picture of the similarities and differences between their viewpoints in order to move forward the ethical debate. In total, 36 professionals, working in 17 different treatment teams in 10 different countries from around Europe and North-America, participated in this interview and open-ended questionnaire study.

The results show that the considerations of people claiming the risks of the use of early medical treatment, and people supporting it touch on fundamental ethical concepts in paediatrics; concepts such as best interest, autonomy, and the role of the social context. From the literature, interviews, and questionnaires, seven themes emerged which gave rise to different, and sometimes even opposing, views on early medical treatment for transgender adolescents. The first theme is the availability or nonavailability of an explanatory model for gender dysphoria (GD). Even though most informants agree that a combination of factors, such as genetic, hormonal, neurodevelopmental, and psychosocial factors play a role, opinions differ as to whether, and if so, which factor(s) prevail in the aetiology (De Vries & Cohen-Kettenis, 2012; Meyer-Bahlburg, 2010). The second theme regards the nature of GD; most informants find it difficult to articulate their thoughts

about this aspect. Many see GD as neither a medical disease nor a social construct, but as a normal, but less frequent variation of gender expression. However, some state that the need for medical treatment in itself, to relieve the suffering, implies that GD is not merely a normal variation, and that that is what defines GD as a disorder. The role of physiological puberty in developing a consistent gender identity is the third theme that emerged. Most informants agreed on the fact that treatment with PS indeed may change the way adolescents think about themselves. However, most of them did not think that PS inhibits the spontaneous formation of a gender identity that is congruent with the assigned gender after many years of having an incongruent gender identity. Additionally, several endocrinologists mentioned that PS has been used for many years in precocious puberty, and no cases of GD have been described in that context, as far as they know. Also, most emphasized that they deliberately start PS only when the adolescents have reached Tanner stage 2 or 3, in order to give them at least some kind of 'feeling' with puberty before starting to suppress puberty. The fourth theme is the role of comorbidity. The prevalence of co-occurring psychiatric problems in transgender minors is high (de Vries et al., 2011; Meyenburg, 2014; Wallien, Swaab, & Cohen-Kettenis, 2007). The precise mechanisms that link GD and coexisting psychopathology are unknown. Most informants state that it differs between individuals, and depends on the comorbid problem whether GD and the co-occurring problem(s) are merely coexisting or interrelated. Some professionals stress the importance of addressing treatment of severe coexisting psychopathology before addressing GD-related medical interventions, while others state that it depends on the individual and specific comorbid problem. The fifth theme regards the possible physical or psychological harmful effects of early medical interventions for transgender minors, and of refraining from interventions. Although (the sparse) research until now mostly shows no negative, and even positive results regarding the consequences of PS, advocates of the treatment remain cautious and people criticizing the treatment sceptical because of the fact that (long-term) risks and benefits of available treatments have not been fully established. Possible harmful effects of refraining from interventions are mentioned too. The sixth theme regards medical decision-making competence (MDC) and the decision-making authority, which is an important point of disagreement in the discussion regarding early medical treatment for transgender minors. Most informants agreed on the thought that adolescents' competence should be determined on an individual case by case basis. They did not agree on how to actually do this, for example regarding who should have final authority to make decisions regarding early medical treatment; the adolescents themselves, and/or the parent(s) and/or treatment team were mentioned. The last theme regards the role of the social context in the way gender dysphoria is perceived. Some think that the way gender incongruent behaviour of minors is perceived in a specific culture, largely influences whether it is pathologized or not. Furthermore, some speculate that the increasing attention in the media might lead to medicalization of gender incongruent behaviour.

The discussion regarding the use of PS is in full swing. Some consider the established international transgender guidelines too liberal, while others find them too conservative. Additionally, more and more treatment teams embrace the Dutch protocol, but still retain a feeling of unease. Discussion of the diverse themes needs to continue based on research data as an addition to merely opinions. Otherwise ideas, assumptions and theories on GD treatment will diverge even more, which might lead to (even more) inconsistencies between approaches recommended by clinicians across different sites/countries. Moreover, participation in the study encouraged several clinicians in thinking more explicitly about the various themes and to discuss the ethical issues in their teams.

Chapter 3

In chapter 2 we described the considerations regarding early medical treatment of 36 professionals from 17 treatment teams worldwide. Nevertheless, little is known about the way transgender adolescents themselves think about early medical treatment. The third chapter therefore describes a study on the considerations and opinions of transgender adolescents concerning the concepts of 'sex' and 'gender', and the use of PS in GD. Furthermore, we compared the considerations on the use of PS of the adolescents with those of professionals, using the data collected in chapter 2.

Informants were 13 adolescents, between the ages of 13 and 18, diagnosed with GD recruited from the gender identity clinic in Leiden, the Netherlands. All adolescents, except for one, were treated with PS. The adolescent who was not treated with PS immediately started treatment with gender-affirming hormones (GAH) because she was above the age of 18 when treatment was indicated, which is in line with the Dutch protocol. The mean age at which the participating adolescents started PS was 15 years and 10 months. Individual semi-structured interviews, containing general topics and no close-ended questions, were conducted (30-40 minutes). After no new content was found in the interviews, subject enrolment was stopped, this is called data saturation (Guest et al., 2006).

Three themes emerged from the interviews; the first theme regards the difficulty of determining what is an appropriate lower age limit for starting PS. Most adolescents found it difficult to define an appropriate age limit and saw it as a dilemma. The adolescents seemed to be more cautious than some professionals, for example regarding the minors' MDC in this context; most adolescents had doubts about whether minors are capable of making decisions regarding medical treatment at the age of 12 or younger, while some treatment teams are exploring the possibility of lowering the current age limit for PS. The second theme regards the lack of data on the long-term effects of PS; this lack is not a reason to not start PS in most adolescents. However, this was a big issue for the professionals. The third theme, the role of the social context, consisted of two subthemes: the first one was the increased media-attention, on television and on the internet, the

second one was an imposed stereotype. Both adolescents and professionals had diverging viewpoints regarding the increasing media-attention; some thought positively about this, while others raised doubts.

Comparing the interviews of the adolescents with those of the professionals reveals that the adolescents and professionals do not agree about all topics. It is striking that, compared to the professionals, adolescents were often more cautious in their treatment views. It is important to give voice to the transgender adolescents themselves in order to prevent professionals acting upon (possibly incorrect) assumptions about the adolescents' views instead of the adolescents' actual considerations and opinions. Gathering more qualitative research data from transgender adolescents in other sites/countries is encouraged.

Chapter 4

Chapter 4 reports on the examination of transgender adolescents' medical decision-making competence (MDC) to give informed consent for starting treatment with PS. Transgender adolescents' competence to give informed consent is an important prerequisite for PS (Coleman et al., 2012; Hembree et al., 2017). However, in society, there is doubt whether they are capable of this, which in some countries has even led to limited access to this intervention. There is no empirical evidence on transgender adolescents' MDC to decide on PS. Therefore we assessed in a structured, replicable way, the MDC of Dutch transgender adolescents who were assessed eligible to start PS. The participants were 74 adolescents between the ages of 10 and 18. All attended the gender identity clinic in Amsterdam or Leiden, the Netherlands. All participants underwent the usual diagnostic trajectory, including a psycho-diagnostic assessment and several monthly sessions with a mental health provider over a longer period of time (usually about six months), before being assessed eligible for PS. The MacArthur Competence Assessment Tool for Treatment (MacCAT-T) was used. This is a quantitative semi-structured interview used to assess the four criteria a person needs to fulfil in order to reach MDC, being: understanding the information relevant to one's condition and the proposed treatment, appreciation of the nature of one's circumstances, reasoning about benefits and potential risks of the options, and being able to express a choice (Appelbaum & Grisso, 1988). The study aimed not only to assess the adolescents' MDC, but also to investigate potential associated variables (e.g. full scale IQ, sex, age, behavioural and emotional difficulties). The parent-reported Child Behaviour Checklist (CBCL) was used to assess behavioural and emotional difficulties (Achenbach & Rescorla, 2001; Verhulst & van der Ende, 2013).

The diagnostic trajectory concludes with a session for signing an informed consent (IC) statement by the adolescent and parents. This standard IC session was videotaped and used to establish the reference standard for MDC. After the IC session, the MacCAT-T interview was administered, which was also videotaped, to provide the MacCAT-T based

judgements of MDC. A panel of 12 experts - including child psychiatrists and psychologists, paediatric endocrinologists, and master thesis medical students - was trained in judging MDC. The adolescent's MDC in each IC video was judged by two expert and the clinician involved in the adolescent's diagnostic trajectory. The MDC in each MacCAT-T video was judged by three experts.

We found that 93.2% and 89.2% of the transgender adolescents who were about to start PS and were participating in this study, were assessed competent to give IC on the basis of the standard clinical assessment and when using the MacCAT-T interview, respectively. The intermethod agreement was 87.8%. The interrater agreements of the reference standard and MacCAT-T-based judgements were 89.2%, and 86.5%, respectively. Furthermore, full scale IQ-score and sex were both significantly related to MacCAT-T total score; birth-assigned girls showed a higher total MacCAT-T score, as did adolescents with a higher full scale IQ-score. Age at the IC session, level of emotional and behavioural challenges, and the duration of the diagnostic trajectory were not significant related to the MacCAT-T total score.

It is reassuring that the majority of the transgender adolescents participating in this study seem to have thoroughly thought about PS, understand what PS involves, and are deemed competent to decide. However, this might not be similar for all other contexts, particularly because our study cohort had extensive and thorough diagnostic evaluation before the MDC assessment, as opposed to adolescents without this support. Additionally, the study results indicate feasibility and validity of the MacCAT-T in clinical practice. However, these results do not answer questions on how to respect the developing autonomy of incompetent adolescents ethically. We conclude that as long as there are only limited data on transgender adolescents' MDC regarding starting PS, an individualized approach is highly important for this group.

Chapter 5

Chapter 5 reports on the perceptions on medical decision-making competence (MDC) to start PS of transgender adolescents who proceeded with gender-affirming medical treatment (GAMT) after PS, adolescents who discontinued treatment with PS, their parents, and clinicians. According to international transgender guidelines, one of the prerequisites for PS is that adolescents have MDC (Coleman et al., 2012; Hembree et al., 2017). As described earlier, chapter 4 describes an assessment of 74 transgender adolescents' MDC regarding starting PS, showing that the vast majority (about 89%) of these adolescents is competent to consent to this treatment. Nevertheless, little is known about the considerations and ideas of transgender adolescents themselves, their parents, and clinicians regarding adolescents' MDC to start PS.

In order to obtain insight into these considerations and ideas, semi-structured interviews were conducted with eight transgender adolescents (10-15 years old) who proceeded with GAMT after PS ('continuers'), six adolescents (10-17 years old) who discontinued treatment with PS ('discontinuers'), and 12 of their parents. In addition, two focus groups with in total 10 clinicians from the gender identity clinics in Amsterdam and Leiden, the Netherlands, were held.

The four criteria one needs to fulfil in order to have MDC - understanding, appreciating, reasoning, communicating a choice - were all, to a greater or lesser extent, mentioned by most participants, just as the relatedness to a specific decision and context (Appelbaum & Grisso, 1988). Most adolescents, parents, and clinicians find understanding and appreciating PS and its impact important for MDC. Most informants, including most adolescents themselves, stated that they thought that they themselves/ the adolescents did not fully understand and appreciate the treatment and its consequences. However, most of them estimated that they/the adolescents were nonetheless able to decide about the treatment. Most adolescents, parents, and clinicians stated that not being able to understand and appreciate the impact of certain consequences of PS is inherent to the adolescents' age and/or developmental stage. Parents' support was considered essential in the decision-making process. The fact that PS has effects that are largely medical reversible was a reassuring idea for some adolescents and parents, while other adolescents did not take this aspect into account when deciding about PS. Certain consequences of PS and uncertainty about long-term effects (e.g. potential loss of fertility when proceeding to GAH and gonadectomy) causes doubts for some. Most clinicians encounter difficulties defining MDC. Some mentioned that they assess MDC differently depending on the adolescents' developmental age. Some adolescents, parents, and clinicians mentioned the role of age, intelligence, and mental health problems as possible variables associated with MDC. Some clinicians pondered whether too much importance is placed on the adolescents' MDC. Although some stakeholders have in mind that there is an association between having MDC and not having regrets about a decision later in life, this is not endorsed by literature (Pang et al., 2021).

We concluded that clinicians find it difficult to assess adolescents' MDC regarding starting PS, and to put into practice in a uniform way. Dissemination of knowledge and support concerning assessment of MDC and encountered ethical dilemmas about transgender adolescents' MDC is desirable in order for clinicians to adequately support adolescents and parents in the decision-making process.

Chapter 6

Treatment with PS aims to give the transgender minors the opportunity to explore their gender identity, and time to consider if they wish to pursue GAMT while development of

unwanted secondary sex characteristics is suppressed in order to reduce distress. Even though the effects of PS on pubertal development are reversible, the treatment may bring short-term adverse effects along. Additionally, few clinical research data are available on long-term adverse effects. Furthermore, opinions about the use of PS vary. To gain more insight into the use of PS in transgender adolescents, chapter 6 documents adolescents' trajectories after the initiation of treatment with PS. The chapter reports on discontinuation of treatment with PS, prolonged use of PS, and initiation of GAH in order to investigate the duration of treatment with PS. Additionally, it explores reasons for extended use and discontinuation of PS in a retrospective way.

The study population consisted of 143 (67%) of the 214 adolescents registered at the Curium-Leiden University Medical Centre gender identity clinic in Leiden, the Netherlands, who were eligible for treatment with PS by virtue of their age/pubertal status, and all started treatment with PS. The adolescents were between the ages of 11 and 18, and 38 of them were transgirls, and 105 were transboys. Of these adolescents who started treatment with PS, treatment status was reviewed. If they had used PS monotherapy for more than three months longer than minimally required before the start of GAH according to the local protocol, the reason for this was noted. Adolescents who had started treatment with PS and had stopped this treatment were included in a detailed review. Baseline characteristics such as age and gender, and data on the start, duration, and discontinuation of treatment were recorded from the medical files, as well as reasons given for the discontinuation of the treatment with PS and the adolescents' and parents' views on the treatment.

According to the local protocol, before the start of treatment with PS, all adolescents had a diagnostic evaluation by a paediatric endocrinologist and mental health professional to confirm the diagnosis of gender dysphoria according to the DSM-5 criteria, to assess the presence of any medical, psychiatric, or psychosocial problems that might interfere with treatment, to assess if the adolescent was able to give informed consent for the treatment, and to confirm that puberty had started, as recommended by current established international transgender guidelines.

We found that after a median duration of 0.8 years (0.3-3.8) on PS, 125 (87%) adolescents started GAH. Nine (6%) adolescents discontinued treatment with PS, five of whom no longer wished GAMT. Several reasons were given for the discontinuation of PS, being among others, the experience of falling in love, the feeling of being either male or female, experiencing side effects of the treatment, and experiencing of concurrent psychosocial problems interfering with the exploration of gender identity. Thirteen adolescents had used PS for longer than required by protocol for reasons other than logistics and regularly met with a mental health professional during this time. This supports the idea that the time on PS is used as an extended diagnostic phase where adolescents can further explore

their gender identity and treatment wishes, and work on issues that might interfere with successful treatment.

In conclusion, the vast majority of adolescents who started treatment with PS proceeded to GAH, possibly due to eligibility criteria that select those highly likely to pursue further GAMT. A small number of adolescents discontinued treatment with PS because they no longer wished GAMT. This indicates that not all adolescents and parents assume that the outcome of identification as transgender is the only possible outcome and shows that gender identity can still fluctuate when using PS, at least in some adolescents. However, gender dysphoria subsided in a small number of adolescents and it is uncertain if this would have been different without treatment with PS. Due to the observational character of the study, it is not possible to say if treatment with PS itself influenced the outcome. Some adolescents used PS for a prolonged period before starting GAH while regularly meeting with a mental health professional which is consistent with the use of treatment with PS as an extended diagnostic phase. The great majority who had started treatment with PS continued with GAH. It is important to take this into account when counselling adolescents who consider this treatment and their parents.

Chapter 7

Chapter 7 describes the perceptions of transgender adolescents, their parents, and clinicians on the function of treatment with PS for transgender adolescents. It is not known whether the functions of PS as described in established international transgender guidelines correspond to the perceived functions of PS according to the aforementioned stakeholders (Coleman et al., 2012; Hembree et al., 2017). For this study the same sample and method as described in chapter 5 were used.

The results show that the continuers, discontinuers, their parents, and clinicians do not all have the same views on the functions of PS. Primarily, all informants considered inhibition of (further) development of secondary sex characteristics an important, and for some the most important, function of PS. Some discontinuers did experience PS as an expanded diagnostic phase, providing them 'extra' time before deciding on GAMT, while most continuers saw PS as the first step of GAMT. Nevertheless, some continuers and some of their parents were glad that the effects of PS were reversible even if they did not expect to change their minds. One continuer and several parents used the time (their child was) on PS, to get used to (their child) living in the affirmed gender role. Some clinicians considered it important that adolescents mature a little further during the years they receive PS, and that, while they experience less distress due to the undesired development of their bodies, they may be better able to decide on whether or not to proceed with GAMT and carefully consider the consequences of their decision. One of the discontinuers mentioned this

function as well. Some clinicians mentioned that the extra time provided them time for additional assessment.

Although international transgender guidelines emphasize providing time for exploration of gender identity as an important reason for PS, many adolescents nowadays seem to have clear ideas about their gender identity and treatment wishes, and experience PS as the first step of GAMT (Coleman et al., 2012; Hembree et al., 2017). For some discontinuers however, PS offered a valued period of exploration. The extra time served a function for some parents and clinicians in some cases as well. Guidelines could be modified to provide more customized care, taking adolescents', parents', and clinicians' ideas about the functions of PS into account.

Chapter 8

Whereas the effects of PS are reversible, long-term use of gender-affirming sex steroids may affect fertility, and if gonadectomy is performed, the transgender person will definitely be infertile. Infertility may have a major impact on the lives of transgender minors, and previous studies suggest that fertility preservation can influence quality of life in transgender adolescents. Nowadays, the World Professional Association for Transgender Health (WPATH) and Endocrine Society recommend counselling regarding fertility preservation options before initiating treatment with PS. However, two recent studies from the United States indicate that transgender minors rarely use fertility preservation. In order to get insight into the use of fertility preservation among Dutch transgirls, chapter 8 describes how many adolescents made use of fertility preservation in a Dutch cohort of transgirls who started treatment with PS. In addition, we assessed if information about the risk of infertility had been given, if discussion of the option of fertility preservation was documented in the medical file, and what the given reason for declining fertility preservation was if the adolescent had not made use of fertility preservation. Furthermore, we explored what factors were associated with the use of fertility preservation.

The study was a retrospective review of medical records of 35 transgirls who started treatment with PS between 2011 and 2017 at the Curium-Leiden University Medical Centre gender identity clinic in Leiden, the Netherlands. Extracted data from the medical files were age, intelligence quotient (IQ), Tanner stage, testicular volume, ethnicity, sexual orientation, psychiatric comorbidity, family situation, and information about the desire to have children.

All adolescents had been informed on the risk of infertility, and 32 (91%) of them were counselled about the option of fertility preservation. Thirteen (41%) of the counselled transgirls were referred for sperm cryopreservation, and twelve (38%) of them had actually

been to the fertility clinic to try to cryopreserve sperm. One transgirl who had been referred had not been to the fertility clinic and had not started treatment with PS yet at the time of the analysis because of psychosocial issues. Nine (75%) of the transgirls who had been to the fertility clinic to try to cryopreserve sperm, were able to cryopreserve sperm suitable for intrauterine insemination ((IUI) or intracytoplasmic sperm injection (ICSI).

Given reasons for not wanting to be referred for fertility preservation were (some of the transgirls gave more than one reason) not wanting to have children (17%, $n = 4$), wanting to adopt (13%, $n = 3$), feeling uncomfortable with masturbation or having an aversion of their penis (17%, $n = 4$), and feeling uncomfortable with the idea of being the biological father of the child (4%, $n = 1$). No specific reason for declining fertility preservation was known in eight (33%) adolescents, and eight (33%) of the adolescents were not referred for fertility preservation because they were in early puberty and were not able to produce a semen sample through masturbation.

The mean age at the start of treatment with PS in the group of transgirls who attempted fertility preservation was significantly higher than in the group that did not attempt fertility preservation. Tanner stage, testicular volume, and mean IQ in the group who attempted fertility preservation was not significantly different from that in the group who did not. Neither were family situation and psychiatric comorbidity (depression, anxiety disorder, posttraumatic stress disorder, or autism spectrum disorder). Furthermore, fewer Caucasian transgirls (20%) attempted fertility preservation than transgirls (70%) with other ethnicities including Asian, African, and South American.

In conclusion, one third of the transgirls attempted fertility preservation, and most were able to store sperm suitable for future intrauterine insemination (IUI) or intracytoplasmic sperm injection (ICSI). This stresses the need to discuss this topic before the start of treatment with PS. Making different sperm extraction options available such as testicular sperm extraction or electroejaculation stimulation may make fertility preservation more accessible for transgirls for whom masturbation is a barrier. Fertility preservation is currently not available for early pubertal adolescents, but research in this area might open up fertility preservation options for this group too. With future options on the way, an ethical and legal debate is essential, taking into account the right to equality and non-discrimination and the right to procreate of transgender people.

Chapter 9

Chapter 9 describes the evaluation of the usefulness of moral case deliberation (MCD) in dealing with moral challenges and dilemmas in the care for transgender minors. MCD is a facilitator-led, collective moral inquiry based on a real case (Dauwerse et al., 2014; Molewijk et al., 2008a; Stolper et al., 2016). It is a relatively well-established form of clinical

ethics support. MCD sessions were introduced in two Dutch treatment teams of gender identity clinics where specialists in child and adolescents psychiatry and psychology, and (paediatric) endocrinology worked in multidisciplinary teams. Between October 2013 and January 2015 the two teams participated in a total of 17 MCD sessions. The treatment team members evaluated the use of MCD. Data was collected using six individual interviews, two focus groups with in total 15 clinicians, a cross-sectional survey using an MCD evaluation questionnaire at two moments (T0, $n = 34$; T1, $n = 22$), and audiotapes of six MCD sessions.

The clinicians rated MCD as highly valuable in situations when confronted with moral challenges. They reported that MCD helped them to more effectively deal with moral challenges, and that it contributed to improved mutual understanding and open communication among team members. Additionally, according to them, it made them pay closer attention to their own arguments and contextual factors, rather than blindly following the clinical protocol. Furthermore, it strengthened their ability to make decisions and take action when managing ethically difficult circumstances. However, the clinicians also made critical remarks about MCD: some felt that the amount of time spent discussing an individual case was excessive, that MCD should lead to more practical and concrete results, and that MCD and the insights gained during the MCD sessions needed better integration and follow-up in the regular work process.

Especially in the care for transgender minors, treatment decisions are often surrounded by complex moral controversies and uncertainties. During MCD sessions, the professionals' reasoning and knowledge are included, yet MCD makes (possible conflicts of) underlying norms and values explicit and gives suggestions how to handle the uncertainty or disagreement within a team. As such, MCD can be seen as an additional tool that can be used in complex cases. More research focusing on the actual contribution of MCD to the improvement of care quality (including its determining factors), the involvement of transgender people in MCD sessions, and on how to integrate clinical ethics support more into daily work processes, is needed.

Chapter 10

Ethical challenges and dilemmas are inextricably linked to transgender care, especially regarding the care of children and adolescents, and the possible life-long consequences of providing them with or refraining from early medical treatment. This is because it is a relatively new field, in which developments are rapid, there is still relatively little empirical data available on long-term outcomes, and it is a subject of a polarized debate. The challenges and dilemmas regarding early medical treatment for transgender minors, which were already expressed by clinicians about a decade ago, as described in our first article from 2015, only seem to have been enlarged and sharpened since then (Vrouenraets et al., 2015). Initially, these dilemmas seemed to be an issue only for those directly involved

in this care. However, today, a much broader group of people is expressing their opinions and thoughts regarding this subject. Additionally, the role of the media and case law are increasing. With this, the debate seems to have become only harsher. Additionally, the controversy seems to have become greater, and people claiming the risks of early medical treatment, and the ones claiming its benefits appear to be driven apart even further (e.g. Lament, 2014; Osserman & Wallerstein, 2022). Currently there hardly seems to be much little room for a 'nuanced middle-ground' anymore (e.g. Bazelon, 2022).

More insight in the core of the ethical dilemmas that play a role in the care of transgender minors, and more empirical data that could give direction in some of the ethical dilemmas are needed in order to give clinicians direction to deal with these issues, and to inform and guide minors referred to the gender identity clinic. Therefore, the first overall aim of this research was 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.

The starting point of this thesis was a broad interview study we conducted which gave insight into the ethical dilemmas that play a role in the use of early medical treatment for transgender minors according to the stakeholders (Vrouenraets et al., 2015; Vrouenraets et al., 2016). In this context, we interviewed clinicians working with transgender minors, and people criticizing the use of early medical treatment for transgender minors from around Europe and North-America, transgender minors themselves, and their parents. Multiple themes, described in chapter 2 and 3, emerged which gave rise to different, and sometimes even opposing, views on the treatment for transgender minors. In subsequent chapters, we examined several of these themes to gain deeper understanding of the controversies and possible solutions. In the general discussion we reflect on the meaning of our study outcomes to the broader context of the political and public discussions. We will do this by means of five themes that consistently emerged in these discussions: the minors' medical decision-making competence (MDC), considerations regarding starting or refraining from PS, co-occurring psychosocial challenges, the social context, and clinical ethics support. One by one, these themes are discussed. For each theme, it is described how the considerations, ideas and newly obtained scientific data, when applicable, have changed and developed over the years.

The field of the care of transgender children and adolescents has been, and still is, in motion, and the associated ethical challenges and dilemmas, require the clinician to take an adjusted role with regard to (medical) treatment for transgender minors. They can be seen as balance artists; initially they had to balance between the treatment wishes, demands, and voices from predominantly the transgender minors, their parents, and their own (M. de Vries, 2020). Nowadays, the voices of other influences, such as professional associations, the media, and case law seem to have become louder. Therefore, clinicians need to find an adequate balance in the force fields between these different 'layers', of which some are relatively 'new', and of which all are continuously in motion concerning their perspective on the ethical dilemmas that play an important role in early medical treatment for transgender minors, as outlined in this thesis, into account (M. de Vries, 2020).

Although PS is not a risk-free medication and additional (worldwide) multicentre long-term quantitative and qualitative data are called for to better understand the possible adverse reactions and benefits of the treatment, treatment with PS still seems promising for transgender minors when given in a context of sufficient psychological support (e.g. Rafferty et al., 2018; Ramos et al., 2021; Turban & Ehrensaft, 2018). However, despite the promising current state of science regarding the medical and psychological aspects of care for transgender minors, an ethical justification for the treatment seems to be required in addition. Therefore, data is needed from an ethical perspective to fill in this gap in this ongoing debate regarding the use of early medical treatment for transgender minors. The findings outlined in this thesis seem to justify the use of early medical treatment for transgender minors from this ethical point of view, as proposed in the two established international transgender guidelines (Coleman et al., 2022; Hembree et al., 2017). Despite this justification, various concerns as described in this thesis still need to be weighed with each individual minor. The results of this thesis show that, among others, the minors' MDC, the possible physical and/or psychological harmful effects of early medical interventions and of refraining from interventions, the consequences for fertility, the co-occurring psychosocial challenges, physiological puberty in developing a consistent gender identity, and the social context play an important role regarding early medical treatment and therefore should be taken into account when determining the most appropriate care for the minor in question.

Additionally, dissemination of knowledge and support concerning the assessment of MDC and encountered ethical dilemmas is desirable in order for clinicians to adequately support minors and their parents in the decision-making process regarding early medical treatment. A good step to do so has been taken by some Dutch researchers; they have,

largely based on the findings gained in several of the studies included in this thesis, developed an ethics support tool, the so called 'Competence Consultant' (De Snoo-Trimp et al., 2022a). This tool provides clinicians with information and direction on how to deal with minors' MDC (De Snoo-Trimp et al., 2022a). It would be very helpful if such an ethics support tool could be made available to clinicians in other countries as well. However, despite the grip these developments offer, ethical challenges and complex cases will be indistinguishably linked to care for transgender minors (Vrouenraets et al., 2021). The use of moral case deliberation (MCD), a relatively well-established form of clinical ethics support, shows to help clinicians to more effectively deal with these ethical challenges and complex cases (Dauwerse et al., 2014; Molewijk et al., 2008a; Vrouenraets et al., 2020).

This thesis shows that care for transgender children and adolescents inherently involves ethical dilemmas, even if more clinical research data will be provided to underpin the evidence-base. Evidence alone will likely not be able to provide answers to all raised uncertainties concerning adolescent gender-affirming medical care. Ethical dilemmas will therefore probably remain part of this sensitive field of care. This thesis illuminates some of these ethical dilemmas and proposes ways of dealing with them in clinical practice.

