Lessons Learned in 10+ Years of Experience Using Puberty Blockers At VUMC Amsterdam

Peggy T. Cohen-Kettenis
Department of Medical Psychology
VU University Medical Center
Amsterdam
The Netherlands

Agnodice, Lausanne, November 25, 2016
Transgender Care for Adults 1

Hirschfeld (1868 – 1935)
• Institut für Sexualwissenschaft

Lili Elbe (1886 – 1931)
Transgender Care for Adults 2

- First hormone treatment by Christian Hamburger (Denmark)

- Christine Jorgensen “Classic treatment”
“Classical” Treatment

• Diagnostic phase
• Real life test / real life experience phase
• Cross-sex hormone treatment
• (Genital) surgery (SRS)
• Legal change

• Not before 18 (21; 23) years
Situation Transgender Care Adolescents?

- Clinicians rejecting
- Mental health institutions no experience
- No place to go
- No subculture / Internet
- Waiting...
Start Child & Adolescent Gender Identity Clinic (1987)

- Within department of child psychiatry → only mental health care
- Referrals mostly >16 years
- Follow-ups in adults: postoperative functioning better in persons, treated at younger ages
- Yet, nothing to offer but psychotherapy
Development of the “Dutch Protocol”

• Two stages
  – First stage 1987 - 2000
  – Seconds stage since 2000

• Collaboration with prof Louis Gooren at Vumc Amsterdam
First Stage

• > 16 years
• Hormonal treatment staged
  – First anti-androgens, later estrogens for trans girls
  – First progesterone, later androgens for trans boys
• Very closely monitored
Clinical Protocol According to Adult Standards of Care of WPATH

- Diagnostic phase (more extensive)
- Real life test / real life experience phase
- Staged cross-sex hormone treatment

- (Genital) surgery
- Legal change
Strict Eligibility Criteria

• Long lasting gender dysphoria
• Stability or exacerbation of GD at start puberty
• No interfering comorbidities
• Support from family / social network
• A good understanding of the effects of treatment
Follow-up Studies

• Cohen-Kettenis, van Goozen 
  J Am Ac Child Adolesc Psychiat, 1997

• Cohen-Kettenis & van Goozen 
  Eur Child Adol Psychiat, 1998

• Smith, van Goozen, Cohen-Kettenis 
  J Am Ac Child Adolesc Psychiat, 2001

• Smith, van Goozen, Kuiper 
  Psychol Med, 2005
Outcomes?

• Decrease of gender dysphoria
• Increase in body satisfaction
• Normal psychological / social functioning
Physical Appearance

• Treated in late Tanner stages (4 or 5)
  – Voice
  – Adam’s apple
  – Beard growth
  – Facial bone structure ➔

  – Breasts
Drop in Mean Age at Referral
Second Step

1st Diagnostic phase
No Medical intervention
half a year

11/12 - 15/16 years
‘Prolonged diagnostic phase’
Puberty Blocking
Completely reversible
max 4 year

15/16 to 18 years
Hormone treatment phase
Cross-Sex Hormones
Partially reversible
min 1 year

<11 years

Prof Henriette Delemare
Puberty-suppressing hormones: GnRH analogues

hypothesis

pituitary

testes

testosterone

ovaries

estrogens
GnRH analogues

• Much experience in children with precocious puberty
• Reversible
Multidisciplinary C & A Team

- Child & adolescent psychologists
- Child & adolescent psychiatrists
- Psychometrist
- Pediatric endocrinologist
- Pediatric nurse

> 18 years endocrinologists, plastic surgeons, gynecologists
Center of Expertise on Gender Dysphoria of the VU University Medical Center in Amsterdam
Child & Adolescent Services

- Latin America (Brazil)
- South-Africa
- Asia (Japan; Psychiatria et Neurologia Japonica, 2012)
- Australia
- New Zealand
- US 35 providers (Hsieh & Leininger, 2014)
- Canada
- Europe → Survey by Kaltiala-Heino (Finland)
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Total = 24 services
First Criticism

At first:

Too progressive

- “Abuse of medical science”
- “Today’s hype is tomorrow’s scandal”
- Nazi’s experimenting with children

- Data base from the start of puberty blocking
- Monitoring the adolescents clinically
- Follow-up studies
Recent Criticism

Now:

• Too conservative
  – Age limits puberty blockers
  – Age limits cross-sex hormones
  – Age limits surgery (Milrod: How young is too young? JSM 2014)

• Too much involvement of mental health practitioners
Wise decision?
Main Clinical Concerns

• Are GnRH analogues effective in transgender adolescents?

• Does a treatment starting with GnRH analogues at a young age result in good outcome?
  – Physically
  – Appearance
  – Mentally
Is Treatment Starting With Puberty Blockers Effective?
Report Schagen et al, 2016

• Gonadotropins and sex steroids were suppressed within 3 months
• Testicular volume decreased in transgirls
• Breast size reduction in some trans boys (only when in Tanner 2/3)
• No abnormalities of liver enzymes and creatinine

• Frequent routine monitoring of gonadotropins and sex steroids of liver enzymes and creatinine not necessary
Bone Mass Density (BMD)

Delemarre van de Waal et al., 2004, 2006
Klink et al, 2015
Schagen et al, submitted
Brain Effects?

• No effects on executive function (Staphorsius et al, 2015)
Summary Physical Effects

- GnRH analogues are effective
- Generally good outcome: no serious negative side effects
- Appearance in line with experienced gender
Psychological support, puberty suppression and psychological functioning (N=201)

Figure 2 Gender dysphoria adolescents’ psychosocial functioning (CGAS) at baseline, after psychological support, and after puberty suppression

(Costa et al, 2015)
Emotional and Behavioral Functioning

Measures (Achenbach):

Teacher Report Form (TRF)

Child Behavior Checklist (CBCL)

Youth Self Report (YSR)

(Steensma et al, 2013, De Vries, et al., 2016)
Emotional and Behavioral Functioning
(Achenbach, 1991)

CBCL, TRF, YSR
withdrawn
somatic complaints
anxious/depressed
social problems
thought problems
attention problems
delinquent behavior
aggressive behavior

Internalizing

Externalizing
Psychological Functioning Before and After Puberty Suppression (CBCL = parent report)
But
No Change in Gender Dysphoria
→ 2nd Follow-up after ‘gender affirming treatment’ (puberty suppression, cross-sex hormones and at least 1 year post surgery)

(de Vries et al, 2014)
GD Before And after Puberty Suppression And 1 Year Post Surgery

GD only drops after cross-sex hormones and surgery
Body Dissatisfaction Before and After Puberty Suppression and 1 Year Post Surgery (T0, T1, T2)
Post-operative follow-up

- No gender dysphoria
- Satisfaction with body improved
- Psychological functioning improved
- Subjective well-being comparable to general population of young adults

(de Vries et al, 2014)
Do Transgender Adolescents Only Need Medical Treatment?
Total problem score

- TRF
- YSR
- CBCL

[Bars showing data for Amsterdam and Toronto, with asterisks indicating significant differences]
• Peer relations were the main predictor of total problem score

• Peer relations should be addressed during counseling

(de Vries et al, 2016)
Other Types of Care

External factors
• Hostile environment → internalized transphobia; suicidality
• Binders for breasts resulting in broken ribs

Internal factors
• Co-occurring psychological problems
  – Autism Spectrum Disorders (ASD) (guidelines by Strang et al, 2016)
  – ADHD
International Guidelines 1

Standards of Care (7th), World Professional Association for Transgender Health (WPATH)
- 15 languages
- 120 pages
- Educational

(Meyer et al, 2001; http://www.wpath.org/publications_standards.cfm)
International Guidelines 2

- Clinical practice guidelines of the Endocrine Society (Hembree et al., JCEM, 2009)
  - Currently under revision
Other Recommendations and Guidelines

• Report of **American Psychiatric Association** (2012)
• **American Academy of Child and Adolescent Psychiatry** (2012)
• Report of the **American Psychological Association**’s (2009)
• Focus on Human Rights & Social Position
Resolution of the World Medical Association, 2015

• The WMA urges that every effort be made to make individualized, multi-professional, interdisciplinary and affordable transgender healthcare available to all people who experience gender incongruence in order to reduce or to prevent pronounced gender dysphoria.
Future Challenges

• Fertility issues

• Effects of legal changes

• Atypical treatment requests
Desire for Type of Treatment in 2013 (adults; N=249)

- Complete socially; complete medically: 67.9%
- Complete socially; partial medically: 28.5%
- Partial socially; partial medically: 3.6%

Beek et al, 2015
Do we know enough?

- First results look promising
What is Needed?

• More long-term research about
  – Gender development
  – Quality of life (social, psychological)
  – Physical development (growth, bones, brains)

• Preservation of fertility

• Eligibility criteria (age?)
What is Needed?
(2)

- Cross-clinic, cross-national studies
- Networks of researchers (Adolescent Gender Identity Research Group; AGIR)
- Fundamental research AND clinical research
Find The Right Balance Between Caution And Willingness To Move Forward