UT Southwestern Medical Center

children's health℠

The Transition Process: Key to Continued Best Transgender Endocrine Care

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Disclosures

- No conflict of interest

- Off FDA label drugs:

Histrelin, leuprolide, testosterone, estrogen, spironolactone

Transition is not Transfer

- The patient is not yet fully initiated into the "adult model" and may require assistance and support
- Successful transition leads to improved health outcomes
- More relevant for complex conditions that require multidisciplinary care
- No data on transition of care for transgender patients

Fair C. et.al. JAMA Pediatr. 2016;170 (3):205-211

Contents

1. Relevant clinical differences between the pediatric vs. the adult transgender patient

2. The transition of care process

The Pediatric Transgender Patient
Clinic Types

1. About 40 centers in the US and Canada
2. Pediatric endocrinology clinic- until age 18
3. Adolescent medicine- until age 21-25
4. Family medicine-into adulthood
5. Pediatric Gynecology - until age 21-25
6. Less common: general pediatric clinic, planned parenthood clinics

- 60% have mental health support within clinic
- Ideal setting: multidisciplinary program that includes social work, psychology and psychiatry

Resource List: Clinical Care Programs for Gender-Nonconforming Children and Adolescents. Sam Hsieh and Jennifer Leininger, PEDIATRIC ANNALS • Vol. 43, No. 6, 2014

GENECIS Program in Dallas, TX

Program Coordinator

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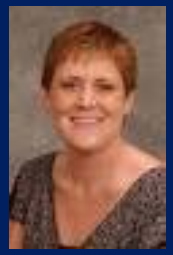

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The Pediatric Transgender Patient
Relevant Demographic Characteristics

1. Most have parental support

- Parental consent is needed for endocrine therapy
- 95% mothers and 80% fathers [1]
- Parents become strong advocates/activists

2. Educated parents

Dallas transgender program: 22% have government insurance vs. 60% in the rest of the hospital[2]

1.Young Adult Psychological Outcome After Puberty Suppression and Gender Reassignment. Pediatrics, 2014. 134(4): p. 1-9

2. GENECIS Program, Dallas TX. Data not published.

The Pediatric Transgender Patient
Relevant Demographic Characteristics

1. Possible underrepresentation of racial/ethnic minorities
Dallas transgender program: 22% non-White and 16% Hispanic vs. 60% and 50% in the rest of the hospital[2]

2. Most patients will have undergone a complete social transition when transitioning to adult care[1]
- Average age of transition: 12[2]

3. Most patients will have a legal name change and some (state dependent), also a legal gender change[2]

1.Young Adult Psychological Outcome After Puberty Suppression and Gender Reassignment. Pediatrics, 2014. 134(4): p. 1-9
2. GENECIS Program, Dallas TX. Data not published.

The Pediatric Transgender Patient Endocrine Care

"Dutch Protocol" [1]

1. Puberty suppression at the onset of (central) puberty: Tanner stage II for breast development or testicular growth

2. Cross-sex hormone therapy around age 16 (started at a younger age in most clinics)

- Guidelines by the Endocrine Soc, co-sponsored by the Pediatric Endocrine Soc[2]

1.Young Adult Psychological Outcome After Puberty Suppression and Gender Reassignment. Pediatrics, 2014. 134(4): p. 1-9

2. J Clin Endocrinol Metab. September 2009, 94 (9):3132-3154

The Pediatric Transgender Patient
Endocrine Care
Pubertal Suppression

- Prevent secondary sex characteristic/surgery
- Buy time: reversible
- Pubertal changes already developed cannot be un-done
- Eliminates menstrual periods and erections
- GnRH analogs

Histrelin (Supprelin or Vantas)
Implant every 1-2 y

Leuprolide (Lupron) 30 mg
IM every 3 m

Pubertal Suppression

Nicole Maines, 14, her twin brother, Jonas

http://archive.boston.com/lifestyle/family/articles/2011/12/11/led_by_the_child_who_simply_knew/

The Pediatric Transgender Patient Endocrine Care

Transfemale cross sex-hormone therapy regimen:

Continue GnRH agonist until gonadectomy and
oral Estrace or estrogen patch at increasing dose

- Maintenance dose reached at 2 years (2 mg Estrace)

GnRH agonists not covered:

- If puberty has not ended: Provera
- If puberty has ended: spironolactone

2J Clin Endocrinol Metab. September 2009, 94 (9):3132-3154

The Pediatric Transgender Patient Endocrine Care

Transmale cross sex-hormone therapy regimen :

Testosterone (cypionate or enanthate IM or SQ-weekly)

- Gradual increasing doses for 2 years
- Continue GnRH agonist until reaching adult testosterone levels

GnRH agonists not covered:

- If puberty has not ended: Provera
- If puberty has ended: may add Provera, Aygestin, OCP's, IUD for menstrual suppression

J Clin Endocrinol Metab. September 2009, 94 (9):3132-3154

Long-Term Effects of Puberty Suppression followed by CSH

What should the adult endocrinologist be aware of?

1. Bone mineral density
2. Fertility
3. Lack of knowledge on metabolic profile and brain development.

Long-Term Effects of Puberty Suppression followed by CSH

Bone Mineral Density Decreases Particularly in Transfemales

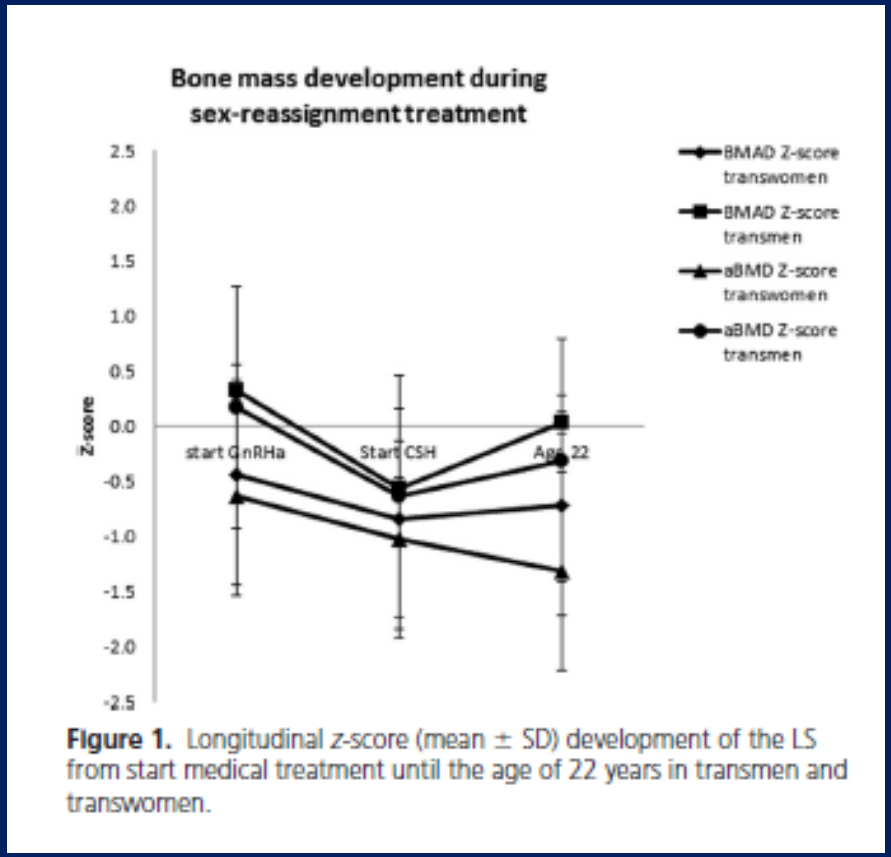


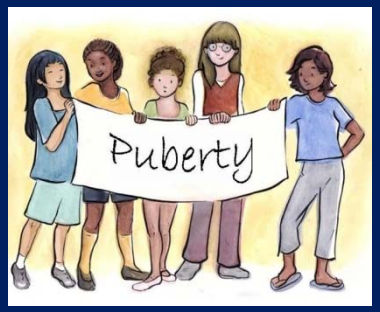
Figure 1. Longitudinal *z*-score (mean ± SD) development of the LS from start medical treatment until the age of 22 years in transmen and transwomen.

- Endocrine Soc Recommendation:

DXA until the age of 25–30 yr or until peak bone mass has been reached.

Klink D. J Clin Endocrinol Metab 100: E270–E275, 2015.
J Clin Endocrinol Metab. September 2009, 94 (9):3132-3154

Fertility: Transfemales

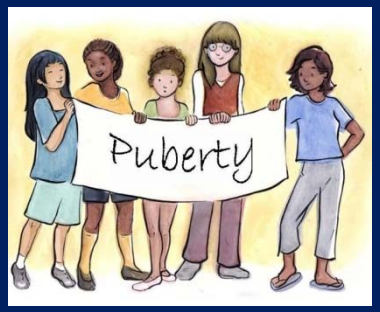


No sperm → **PUBERTY SUPPRESSION** → No sperm → **Estrogen** → Testicular damage

PUBERTY → Freeze sperm

- Puberty suppression will likely lead to infertility if puberty is not allowed to complete
- Estrogen will likely cause infertility

Fertility: Transmales



1- 2 million oocytes →

PUBERTY SUPPRESSION

300,000 oocytes →

TESTOSTERONE

<300,000 oocytes

↓

Stop testosterone

- Puberty suppression effect on infertility is unknown
- Testosterone does not cause infertility

Oocyte retrieval and freezing (ADULTS)

Pregnancy

The Pediatric Transgender Patient Fertility Implications

- Fertility preservation is currently offered only to adolescents who have completed puberty

- Utilization is low[1]:

➢ 12 % had a consultation, 4% completed sperm and 1% oocyte cryopreservation.

➢ Barriers: cost, invasiveness of procedures, and desire not to delay medical transition

1.D. Chen et al. / Journal of Adolescent Health xxx (2017) 1-4

The Pediatric Transgender Patient Surgical Care Implications

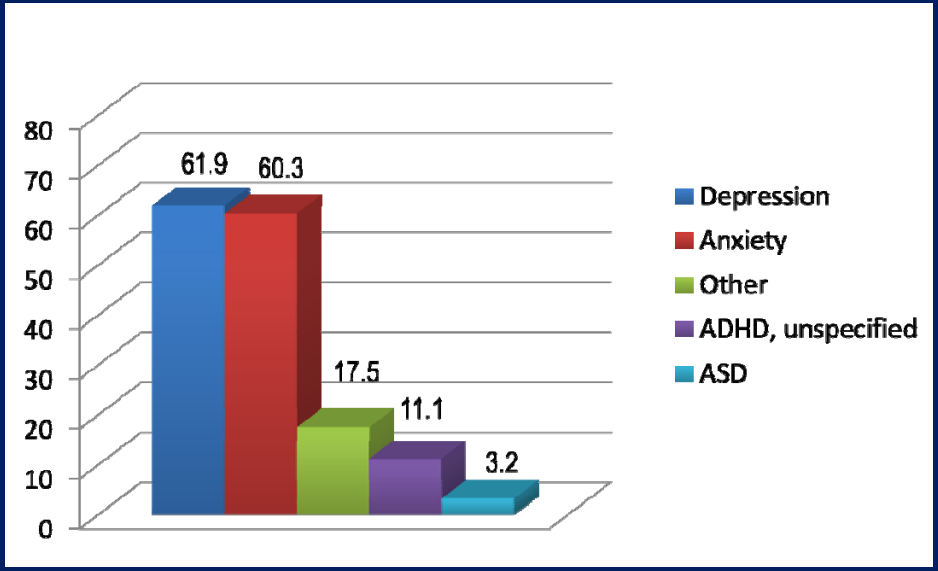
- Early puberty suppression might prevent the need for: mastectomy, breast augmentation, facial plastic surgery, traqueal shave, laser/electrolysis
- Early puberty suppression in transfemales: less scrotal and penile tissue might make vaginoplasty more challenging
- Endocrine Soc. Guidelines does not recommend surgery before age 18
- Some transmales undergo mastectomy during adolescence

J Clin Endocrinol Metab. September 2009, 94 (9):3132-3154

The Pediatric Transgender Patient Mental Health Care Implications

- Before initiating puberty suppression and/or cross-sex hormone therapy, a diagnostic assessment has to be made by a mental health provider with training in child and adolescent developmental psychopathology[1]

- Most patients have a established mental health therapist at referral[2]:

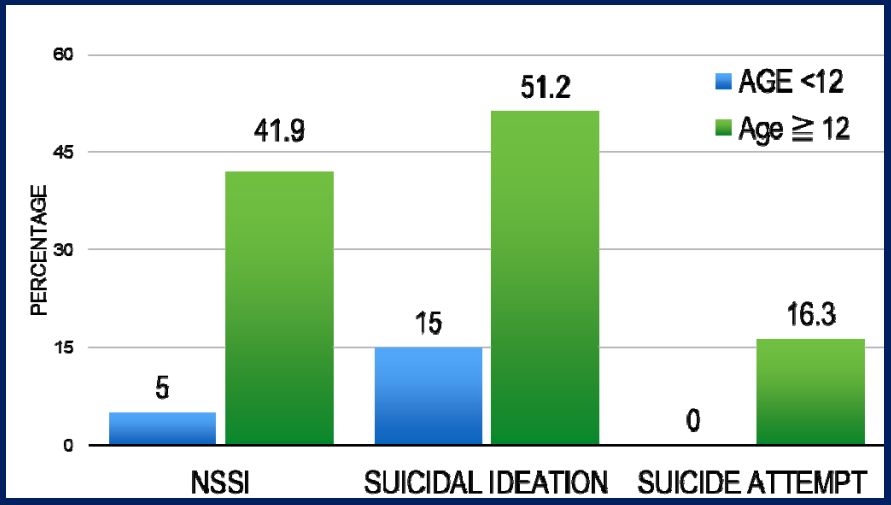


1.J Clin Endocrinol Metab. September 2009, 94 (9):3132-3154

2. Chapman M.R et.al. (AACAP) Annual Meeting, San Antonio TX, US. October 26-31, 2015.

The Pediatric Transgender Patient Mental Health Care Implications

- High risk for self harm and suicide after age 11 (at referral)[1]



- Children who have undergone a social transition before puberty have similar mental health comorbidities vs. non-transgender children[2]

1. Chapman M.R et.al. (AACAP) Annual Meeting, San Antonio TX, US. October 26-31, 2015.
2. Olson KR et.al. Pediatrics. 2016 Mar;137(3)

The Pediatric Transgender Patient Primary Care and STD's/HIV

- STD's and HIV are more prevalent[1]
- Usually not managed by the pediatric endocrinologist
- Lack of comfortable general pediatricians that will provide primary care and/or STD testing and management
- Often managed by adolescent medicine, pediatric gynecology, family practice and HIV clinic.

Reisner, S.L., et al.. AIDS Care, 2015. **27**(8): p. 1031-6.

Recommended Approach to Transition of Care to Your Adult Endocrinology Practice

Multidisciplinary Team Approach:

- Between pediatric and adult clinics
- Within the adult clinic

The Transition of Care Process

GotTransition.Org

a) 6 Core elements:

Establishing a policy, tracking progress, administering transition readiness assessments, planning for adult care, transferring.

c) Transition timeline that starts at age 12

Recommended Approach to Transition of Care to Your Adult Endocrinology Practice

Team approach between pediatric and adult clinics:

- Multidisciplinary transition team:

Minimum: Social work, mental health, endocrinology

Ideally: Surgery, ID, primary care

- Adult access to pediatric records
- Establish joint provider sessions involving members from the pediatric and adult treatment teams: transition clinic
- Use a transition/nurse coordinator

The Transition of Care Process Readiness

Physician and Care Team Assessment of Patient Skill Set

BASIC KNOWLEDGE OF YOUR MEDICAL HISTORY AND DIAGNOSES:	DATE AND INITIAL
☐ Recount what hormone deficiencies you have	_____
☐ Recount your medical history (ages and dates of any surgeries, radiation treatments, and/or other medical treatments) related to your pituitary condition	_____
☐ Recount the names and doses of the medications you are taking	_____
☐ Describe the symptoms of inadequate hormone replacement	_____
☐ Describe the need for periodic lab work to assess adequacy of hormone replacement	_____
☐ Describe the need for and recommended frequency of routine check-ups	_____

https://www.pedsendo.org/assets/patients_families/transition_toolkit/assets/GHD_Recommended_Approach.pdf

The Transition of Care Process Readiness

Physician and Care Team Assessment of Patient Skill Set

FOR PERSONS THAT REQUIRE SEX HORMONE (ESTROGEN OR TESTOSTERONE HORMONE) REPLACEMENT:

- ☐ If using transdermal (through the skin) or injections to administer medication, describe how to administer the medication _____
- ☐ Describe the possibility of skin transfer of transdermal testosterone to others, the consequences, and how to prevent transfer of medication to others _____
- ☐ Describe the importance of hormones to sexual function _____
- ☐ Describe the importance of keeping bones strong _____
- ☐ Describe the potential need for change in medical treatment when/if fertility is desired _____

https://www.pedsendo.org/assets/patients_families/transition_toolkit/assets/GHD_Recommended_Approach.pdf

The Transition of Care Process Readiness

Physician and Care Team Assessment of Patient Skill Set

BY THE ENDOCRINE SOCIETY

SHOW ABILITY TO ARRANGE FOR MEDICAL CARE:

- ☐ Be able to make an appointment _____
- ☐ Identify what insurance you have now _____
- ☐ Identify what insurance you will have when you are over 18 years of age _____
- ☐ Be able to keep track of insurance claims and co-pays _____
- ☐ Be able to know prescriptions and obtain medications/supplies before you run out _____
- ☐ Identify the name and phone number of your pediatric endocrinologist _____
- ☐ Identify the name, phone number, and office location of your internist endocrinologist _____
- ☐ Confirm contact information for urgent issues after office hours, weekends, and holidays _____

https://www.pedsendo.org/assets/patients_families/transition_toolkit/assets/GHD_Recommended_Approach.pdf

The Transition of Care Process Readiness

Physician and Care Team Assessment of Patient Skill Set

BY THE ENDOCRINE SOCIETY

DESCRIBE WHAT TO DO IN EMERGENCY SITUATIONS OR WHEN ILL:	DATE AND INITIAL
☐ Create a list with names and numbers of people who should be contacted	_____
☐ Describe how to contact your doctor's office	_____
☐ Describe when you should be calling your doctor's office	_____
☐ State what information you will need to tell the care provider	_____
☐ Identify a nearby emergency room/hospital if ever needed	_____
☐ Create an emergency plan for illness	_____

https://www.pedsendo.org/assets/patients_families/transition_toolkit/assets/GHD_Recommended_Approach.pdf

The Transition of Care Process Readiness

Physician and Care Team Assessment of Patient Skill Set

BY THE ENDOCRINE SOCIETY

NAME	INITIALS	DISCIPLINE

https://www.pedsendo.org/assets/patients_families/transition_toolkit/assets/GHD_Recommended_Approach.pdf

Recommended Approach to Transition of Care to Your Adult Endocrinology Practice

The new healthcare team should:

- Greet the patient with the awareness that s/he/they is transferring care
- Provide support and assistance with the check-in process and paperwork.
- Ask about her/his/they preferred name and pronouns
- How s/he/they prefers to be contacted (cell phone, text, or email, depending on practice situation).

https://www.pedsendo.org/assets/patients_families/transition_toolkit/assets/GHD_Recommended_Approach.pdf

Recommended Approach to Transition of Care to Your Adult Endocrinology Practice

- Parents should be allowed to attend appointments : sign form allowing the healthcare team to communicate with the parents.

- Consider a “Welcome to the Practice” guide

https://www.pedsendo.org/assets/patients_families/transition_toolkit/assets/GHD_Recommended_Approach.pdf

Recommended Approach to Transition of Care to Your Adult Endocrinology Practice

May need assistance with the following prior to the appt:

- The "unknown" of a new facility (directions, parking issues, etc.)
- Insurance issues
- Expectations for what to bring to appointment:

1. Insurance card
2. Paperwork from former pediatric endocrinologist that includes prior laboratory tests and treatment regimens.
3. Forms for the new physician (online, mailed, etc.)
4. List of medications or actual prescriptions vials/tabs

- Extra consideration in scheduling and confirming the appointment may be necessary

https://www.pedsendo.org/assets/patients_families/transition_toolkit/assets/GHD_Recommended_Approach.pdf

Recommended Approach to Transition of Care to Your Adult Endocrinology Practice

The First Encounter

- Allow Ample Time
- Review HIPAA and determine if parents/others are permitted to receive/hear information
- Review contact information during office hours and for evenings/weekends in case questions arise or for any urgent management issues.
- Review the clinical summary with the patient

https://www.pedsendo.org/assets/patients_families/transition_toolkit/assets/GHD_Recommended_Approach.pdf

Recommended Approach to Transition of Care to Your Adult Endocrinology Practice

The First Encounter: Issues to assess besides endocrine care

1. Recommend social work support available for every encounter
2. Consider having a "fact sheet" the patient can fill out

- Mental heath (anxiety and depression, suicide risk): does your patient have a mental health provider/safety plan?
- Substance abuse
- Risk for STD's
- Family and community support, bullying, discrimination, risk for physical/sexual and verbal abuse
- Plan for college/working
- Living situation/homelessness

Recommended Approach to Transition of Care to Your Adult Endocrinology Practice

The First Encounter

Discuss care plan for ongoing follow-up:

- Expectations of how an 'adult' clinic will work in the future (how the patient can get the most out of the visit).
- How to handle interim questions

– Crisis and Non-urgent (When do you want the patient to call? With whom should they speak– staff, nurse, physician? What is the best way to communicate?)

- Where to go to have lab tests performed.
- Assess need for/willingness for any additional education/resources.

Conclusions

1. Transgender youth is a vulnerable population with multiple socioemotional and mental health needs.

2. Patients cared for in a pediatric transgender program might have improved psychosocial outcomes and less need for surgical interventions.

3. Team collaboration between pediatric and adult clinics is likely to improve success of transition.

Thank you!