Our Trans[ition] Journey
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Disclosure
We have nothing to disclose other than we are family.

Purpose and Objectives
Purpose:
Discuss the lived experience of gender transition for a post pubertal young adult— the process, challenges, and lessons learned.
Objectives:
1. Describe at least three communication challenges faced during transition
2. Identify four or more ways patients are impacted while accessing healthcare
3. Elucidate five or more proactive actions to minimize trauma to transgender patients and their families
Data

- US Transgender Survey (2016)
  - Summer of 2015
  - Online, anonymous
  - 18 years and older (42% were age 18-24 years)
  - N ~28,000
  - 302 page report

Lived Experiences

- Discrimination and stigma are experienced in:
  - Housing
  - Education
  - Employment
  - Health care
  - Poverty
  - Violence
Lived Experiences

- 39% experienced serious psychological distress in month prior to survey compared to 5% of US population
- 40% have attempted suicide in their lifetime, nearly nine times the rate of US population (4.6%)
- 7% attempted suicide in the past year, nearly twelve times the rate of US population (0.6%)
- Androgynous youth may be more vulnerable

Communication Challenges

- **Misgendering**
  - Wrong name
  - Wrong pronouns
  - Scheduling, the advice nurse, or billing
  - From check in to check out
  - If people caught themselves it turned into a huge deal

- **Paperwork**
  - Visit summaries
  - EHR
  - Medical records (physical copies)
  - Prescriptions
  - Labs
  - Mail correspondence
Communication Challenges

• **Electronic Communication**
  - Emails to and from providers
  - Surveys
  - Stored information/databases
  - Texts
  - Automated calls
  - Reminder calls
  - Preventative care reminders

• **Lack of adequate language**
  - Providers
  - Nurses
  - Front office staff
  - Back office staff

Impact on the Patient

• **Establishing care with trans competent providers**
  - Primary care doctor dropped me after I came out
  - She had no idea who to refer me to
  - She had no information to give me
  - No “directory” for trans care
Impact on the Patient

• Difficulty identifying qualified, knowledgeable, open minded providers with availability
  – The one PCP who was the specialist wasn’t accepting any new patients.
  – Primary care doctor was selected because he stated he worked with patients of “all” genders. Not because he was a specialist.
  – No one in network was qualified or knowledgeable as a counselor
  – Having to walk a QMHP through writing me a letter

Impact on the Patient

• Confusion about appropriate care
  – I’ve been asked about my prostate
  – Not had people talk to me about reproductive health
  – Had providers very confused about safe sex practices
  – General confusion about my anatomy

Impact on the Patient

• Processes for hormones (6 months)
  – Meet with my PCP
    • Received information on the effects of hormones, side effects, health risks
  – Get referred to a QMHP for my letter for hormones
    • Find an out of network QMHP because no one in network is “qualified”
    • Pay a couple hundred dollars out of pocket for the minimum three sessions
    • Get my letter stating that I am of sound mind
  – Meet with my PCP
    • Sign informed consent paperwork
    • Get prescribed hormones!
Impact on the Patient

• Processes for top surgery (about a year)
  – Insurance
    • Work with an insurance representative to make sure that I am not denied coverage for surgery
    • Must be insured for 6 consecutive months (additional student loans to cover cost)
    • Lots of paperwork (pre-determination paperwork from surgeon and QHMP)
  – Receive a second letter from QMHP
    • Stating I am of sound mind, and also have “persistent gender identity disorder”
  – Find a surgeon who is trans friendly
    • Schedule several months out
    • Make sure they have submitted all of the proper codes and paperwork to insurance
    • Get surgery!

Impact on the Patient

• Processes for hysterectomy (about 9 months)
  – Two letters from separate QHMP’s 1 in network, 1 out
    • One QMHP was in network, had never written a letter, walked him through it
    • One in network but not in house QMHP with extensive questionnaire
  – Referral from PCP for surgery
    • This took several messages and phone calls to get started
    • Was told to consult with OB/GYN about options
  – Meet with an OB-GYN
    • Find out PCP should have gone over my options prior to a referral
    • Few more meetings and exams, then schedule surgery
    • Get surgery!

Impact on the Patient

• Communication
  – Misgendering
  – Microaggressions
  – Reminders of system failure
  – Difficult to engage with reminders
Impact on the Patient

• Care avoidance due to fear of being treated differently
  – Dreaded going to the doctor for routine visits, and would put
    them off, or avoid them all together
  – Urgent care was extremely daunting
  – Put off routine lab work

Impact on Patient

• What does being treated “differently” mean?
  – 70%* of transgender patients reported at least one of these health experiences, based on transgender status:
    • Being blamed for their health condition
    • Refusal to touch or excessive precautions
    • Harsh language
    • Physical roughness

*Numbers were much higher for racial/ethnic minorities and low-income transgender people

Impact on the Patient

• Gatekeeping
  – Five appointments with two providers to get on hormones
  – At least seven appointments with four providers for my hysterectomy
  – Four letters over five years proving that I am of sound mind
  – Every single person involved in these appointments and processes was cisgender
Action

- Prioritize EHR information with correct name and pronouns
- Correct all databases
  - Visit summary
  - Labs
  - Appointment reminder texts/calls
  - Surveys
  - Internal messages
  - Emails
  - Scheduling
  - Medical record
  - Labels
  - Mail
  - Billing
  - Research
  - ID bands
Action

- **Labels and language**
  - Mr/Mrs/Miss/Ms, ma’am/sir
  - ‘women’s’ health care - PAPs and birth control
  - ‘men’s’ health care - prostate exam

- **Don’t make a big deal out of misgendering**
  - Acknowledge
  - Apologize
  - Move on

Action

- **Education for staff**
  - Send staff to education opportunities outside of the organization
  - Bring speakers/educators to the organization
  - Have a series of learning modules all staff can access

Action

- **Educate staff specifically to their roles**
  - **Clinical staff**
    - Providers
    - Nursing staff
    - Medical assistants
    - X-Ray technicians
    - Lab staff
    - Advice nurse
    - Pharmacy staff
  - **Administrative staff**
    - Schedulers
    - Call centers
    - Office personnel
    - Receptionists
    - Billing staff
    - Referral coordinators
Action

• Hire staff who are knowledgeable about transgender healthcare
  – Make receiving quality care accessible
  – Ensure there are enough providers
  – Patient advocates

Action

• Ask ALL patients about gender identity and pronouns
  – Sex and gender of past/present/future partners
  – Normalize all mental health, relationships, taking care of bodies, and unplanned pregnancies
• Staff that know about
  – HIV risks
  – Safer sex practices
  – Non-invasive STI testing

Action

• Transgender advisory committee
  – To develop policy, process, and procedures
  – Receive feedback from patients
  – Provide education
  – advocate for patients
    • Establish leadership support
    • Form the committee
    • Ensure their voices are heard within the organization
    • Spread word about the resource
    • Make it accessible
Resources/References

National Center for Transgender Equality
A social justice advocacy organization for transgender people
www.transequality.org

National LGBT Health Education Center
Educational programs, activities, and consultations with the goal of optimizing health care for lesbian, gay, bisexual, and transgender people
www.lgbthealtheducation.org

Transgender Law Center
Civil rights organization advocating for transgender communities
www.transgenderlawcenter.org

World Professional Association for Transgender Health
Education, training, and evidence-based care, education, research, advocacy, public policy, and support in transgender health
www.wpath.org

The Joint Commission
Urges U.S. hospitals to create a more welcoming, safe and inclusive environment that contributes to improved health care quality for lesbian, gay, bisexual, and transgender (LGBT) patients and their families.
https://www.jointcommission.org/lgbt/

Institute of Medicine

GLMA: Health Professionals Advancing LGBT Equality
Mission of ensuring the health and well-being of LGBT individuals and families.
www.glma.org

Movement Advancement Project
Independent think tank that provides rigorous research, insight and analysis that help speed equality for lesbian, gay, bisexual and transgender (LGBT) people.
www.lgbtmap.org

Recommended Readings


Debate is Growing About How to Meet the Urgent Needs of Transgender Kids. Scientific American Mind (2016), Jan/Feb, 26-35.

Of what am I afraid? JAMA. 2012; 307(4) 371-372

Transgender and Gender Identity Issues, NASW policy statement

Transgender-Competent Health Care
http://socialworktoday.com/archive/exc_060614.shtml
Recommended Readings

The Third Gender by Jesse Bering
The Transgender Child by Stephanie Brill and Rachel Pepper
Helping Your Transgender Teen: A Guide for Parents by Irwin Krieger
Trans Bodies, Trans Selves Edited by Laura Erickson-Schroth
Transgender Explained for those who are not by Joanne Herman
I AM: Trans People Speak http://www.transpeoplespeak.org
Social Services with Transgender Youth, Edited by Gerald P. Mallon

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Thank you!