"Paradigm Shift in Intersex: Psychiatry's Role"

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Traditional Approach: Concealment-Centered

(John Money, Lawson Wilkins, Johns Hopkins)

"Surgical Reconstruction of Ambiguous Genitalia in Female Children"

(video, 1990)

Goals of Concealment-Centered Approach:

- Happy, healthy patient with stable gender identity (heterosexual)
- Happy, healthy parents with gender-stable child

Principles of Concealment-Centered Approach

- 1. Gender identity is formed via <u>nurture</u>, not nature.
- 2. Genitals must be unambiguous for social nurturing to form a psycho-socially unambiguous gender identity.
- 3. Intersex is a shameful social problem; avoid discussion whenever possible.
- (This is an anatomically strict, psychosocial theory of gender-identity development.)

Concealment-Centered Approach

 Early cosmetic surgery is used to make genitals appear unambiguous
 (Concealment of physical ambiguity)

So about 90% of intersexed children are made into girls.

"You can poke a hole, but you can't build a pole."

-- a prominent Boston surgeon

Concealment-Centered Approach

- 2. Parents and child are shielded from discussion of intersex.
 - (Concealment of knowledge of intersex)
- Shielded from details of diagnosis, anatomy, genetics
- Shielded from medical texts (including, often, patient records)
- Shielded from support groups & patientadvocacy groups

Concealment-Centered Approach

- 3. Follow-up surgeries and hormone treatments(continued concealment of intersex physically)
- 4. Patient and parents are continually reassured all is fine.
- Reassured about gender assignment
- Not referred to support groups (continued concealment of intersex socially)

Why Doesn't Concealment Work?

"Hermaphrodites Speak!"

(video, 1995)

Mani Mitchell

Angela Moreno

Concealment: Psychosocial Problems

- 1. Surgeries do not eliminate parents' feelings of confusion, shame, grief, guilt.
- 2. Surgeries may amplify or cement feelings of confusion, shame, grief, guilt.
- 3. Concealment is always incomplete. Aura of secrecy signals shame, doubt.
- 4. Patients come to see doctors as adversaries, avoid medical care.

Concealment: Biological Problems

- 5. A significant number of intersexed children wind up transitioning to the gender not assigned. Many have same sex orientation.
- 6. Outcomes of early surgeries are poor cosmetically and functionally.

Concealment: Historical Problems

- 1. Intersex people born before medical management and cosmetic surgeries survived psychologically and socially.
- 2. As adults, intersexed people sometimes sought surgeries to improve function, appearance.
- 3. Many intersexed people did not seek "repairs" or "normal" genitals. They sought only explanations.

Concealment: Ethical Problems

- 1. Essentially experimental without adequate follow-up
 - Lack of evidence that this works
 - Evidence that it doesn't work
 - Evidence that it isn't necessary
- 2. Violates principles of informed consent

Concealment: Ethical Problems

- 3. Violates patient autonomy
 - Risks sensation, appearance, fertility w/o medical justification
 - Secrecy forecloses patient future choices w.r.t.
 gender, sexuality, personal presentation:
 Prevents finding peer support and information

Concealment: Ethical Problems

- 4. Treats boys and girls asymmetrically (sexist)
 - For boys, sexual function (penis size) is paramount
 - For girls, reproduction is paramount
- 5. Treats intersexed children and parents by a different standard than others. Assumes they need paternalistic care rather than autonomy and informed consent.

Concealment: Legal Problems

- 1. Physicians are legally vulnerable
 - Concealment of medical status, risks from parents
 - Interventions w/o informed consent
- 2. Risk of violent retribution by former patients.

Intersex eludes simple definitions and simple solutions

- 1. The concern about determining a single, clear sex, and prohibiting change, is long-standing in Western history.
- 2. Peer support saves lives and families.
- 3. Public discussion about intersex leads to greater understanding and acceptance (including self-acceptance).

Reform: A Patient-Centered Approach

- 1. Distinguish between medical and social issues.
 - Be honest about social challenges; they can be ameliorated but not eliminated.
- 2. Put patient's welfare before needs of parents, society, teaching institutions.
- 3. Assign a legal/social sex as boy or girl, relying on the most likely outcome given etiology/presentation and recognizing the chance of gender transition.

Patient-Centered Approach Doesn't Dismiss Mental Health

- 4. Team approach, but let each specialist handle his/her specialty:
 - Endocrinologist treats endocrine risks/problems.
 - Surgeon treats anatomical risks/problems.
 - Psychiatrist, psychologist, or social worker treats social risks/problems.

Patient-Centered Approach

- 5. Don't treat parents' emotional distress by surgery on child.
- Provide parents immediate and follow-up support (professional and peer).
- Distinguish between what parents want and what patient needs.
- 6. Consistently provide honest, complete, comprehensible information.
- 7. Provide access to peer support.

Patient-Centered Approach: Psychiatrists Needed

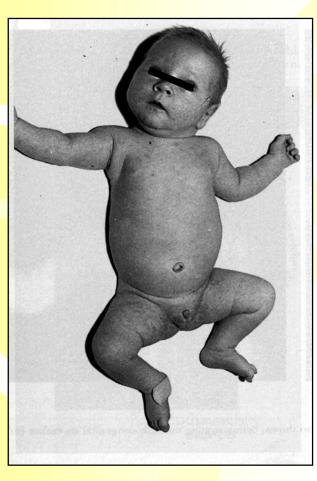
- Some centers already implementing
- Endos, surgeons: "We need psychiatrists!"

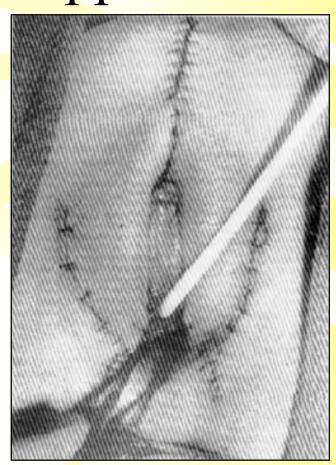
Patient-Centered Approach: Psychiatrists Needed

- New protocols needed
 - Counsel parents, intersex children
 - Counsel families who have been lied to
 - Counsel pts exploring sexuality/gender id/considering transition
 - Counsel pts considering surgery
- Update medical school curricula

What do Intersex People Look Like?

Concealment Approach





What do Intersex People Look Like?

Patient-Centered Approach



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Lynnell Stephani Long



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