

Differences/Disorders of Sex Development (DSD): A World of Uncertainty

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Winnie Mandela calls on South Africa to stand behind Caster Semanya after claims the gender-row runner is a hermaphrodite

By DAILY MAIL REPORTER

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The former wife of Nelson Mandela has called on all of South Africa to stand behind gender-row athlete Caster Semanya after claims the 800m champion runner is a hermaphrodite.

Winnie Mandela spoke out as Caster's mother Dorcus reacted with fury to the report that her daughter has both male and female sex organs, but no womb or ovaries.

The Sydney Daily Telegraph published the details yesterday after reportedly speaking to a source close to the International Association of Athletics Federation (IAAF).



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Shock claims: Caster Semanya celebrates her 800m victory in Berlin last month amid an international row over whether she is a man or a woman



DSD Disorders of Sex Development

Congenital conditions in which the development of chromosomal, gonadal, or anatomical sex is atypical

DSD



a world of uncertainties

Naming
Diagnosis
Gender
Genital surgery
Disclosure
Fertility
Outcomes

INTERSEX DSD

V.S.

INTERSEX vs DSD

“I am not a disorder”

“Words can wound”

“Why not VSD (Variations of Sex Development?) Or Differences of Sex Development?”

“People are free to identify as Intersex”

INTERSEX vs DSD

Intersex is a vague term

Does one need to have ambiguous genitalia to be “intersex?”

Do men who are XX or women XY “qualify?”

What about transgender individuals identifying as “intersex?”

DSD clearly include conditions that do not necessarily appear with ambiguous genitals

Intersex has a political meaning and history;
DSD does not

Intersex could refer to a social identity and
DSD to a medical diagnosis

DSD is a diagnosis

Knowledge from all medical fields apply

Evidence-based medicine should be used for all medical/surgical decisions on patients with DSD

UNCERTAIN NAMING



Medical labeling has clinical and social consequences

Should clinicians label members of a sexual minority?

Should there be an “intersex exception” when it comes to clinical labeling?

Could “Disorders/Differences in Sex Development” be a compromise?

DIAGNOSTIC UNCERTAINTY

DSD

Questions from the real world

- Is it worth and useful to test « everything »?
- To know what exactly?
- When do we know « enough » to provide high quality patient-centered care?
- Tentative Answers:
 - We don't know what we don't know if we never capture it
 - It's been a historically growing target and will continue to grow
 - Genome sequencing has allowed to increase dramatically the amount of information at a lesser effort for patients

UNCERTAINTY

Gender Assignment

	TRADITIONAL	CHALLENGE
GID DETERMINANT	Gender of rearing	Prenatal Androgen
ROLE OF GENITALIA	Crucial to identity, adjustment	Reflects brain masculinization

ASSIGNING GENDER

Based on outcomes from medical literature

Considerations of hormones, fertility,
genetics

What about external genitalia?

CONGENITAL ADRENAL HYPERPLASIA (CAH):

Excess of Androgens masculinizes the genitals of XX fetuses.

Internal reproductive organs are female and fertile.

Typical assignment has been female mostly based on preserving fertility.

CAH WITH SEVERE MASCULINIZATION

REARED AS GIRLS

- **95% (N= 250) maintained gender identity as women**
- **5% experienced gender dysphoria** (not related to degree of genital virilization) (Dessens et al, 2005)

REARED AS BOYS

- Among those with severe masculinization; **low/variable incidence of developing gender dysphoria**
- **N=35 initially assigned male, but not reassigned female after diagnosis** (Can Cua et al, 1989; Woelfle et al., 2002, Gupta et al., 2006; Dessens et al., 2005)
- **18/35 adults**
- **4/18 dysphoria**
- **N=10 no dysphoria** (Lee, Houk & Husmann, 2010)

UNCERTAINTY

Genital Surgery

	TRADITIONAL	CHALLENGE
RATIONALE	Anatomy to match rearing	Comfort of others
CONSEQUENCES	+ gender identity + adjustment + sex. intercourse	- gender change - sex. function
DECISION-MAKER	Physician and Family	Patient (when old enough)

DECISION MAKING

Genital Surgery

Based on literature?

Little available, with no easy objective assessments

Surgical techniques change

No evidence-based answers



QUESTIONS TO ASK BEFORE GENITAL SURGERY

Would anyone desire atypical genitals?

Will surgery create normal-looking genitals?

Will surgery preserve sexual sensation?

Will there be complications?

Will surgery solve psychological issues?

CAH WITH SEVERE MASCULINIZATION

REARED AS GIRLS

- **Genital surgery**
- **Multiple surgeries**
- **Complications**
(vaginal stenosis, hairy vagina, short vagina)

- **Functional and cosmetic results** (according to physician and patient) **in general not optimal** (eg, pain during intercourse, cosmetic dissatisfaction) (Creighton et al., 2001, Gastaud et al., 2007)

REARED AS BOYS

- **Little to no surgery needed, no loss of sensitive genital tissue**

UNCERTAINTY

Disclosure

	TRADITIONAL	CHALLENGE
STRATEGY	Limit disclosure	Full disclosure
RATIONALE	Prevent GID confusion	Prevent secrecy/shame

Intersex Surgeries Are A Human Rights Violation, Says U.N. Group

But some doctors and bioethicists argue that calling intersex surgeries “torture” could end up doing more harm than good for kids born with ambiguous genitalia.

posted on Sept. 19, 2015, at 7:15 a.m.



Azeen Ghorayshi

BuzzFeed News Reporter

“These are social interventions on your genitals — if we’re going to use that language about Africa, we’re going to have to use it here,” Alice Dreger, a historian of medicine and intersex patient advocate, told BuzzFeed News.

“This completely antagonizes the medical community. This is not progress, in my opinion,” Eric Vilain, professor of human genetics and pediatrics at UCLA, told BuzzFeed News.



DSD-TRN: Improving health for people living with DSD

The DSD-Translational Research Network

grant # R01 HD068138 from the *Eunice Kennedy Shriver* NICHD (upcoming HD093450)

“Disorders of Sex Development:

Platform for Basic and Translational Research”

*For more information, please contact the DSD-TRN coordinator,
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