

A Boy or A Girl ?

Managing Parental Anxiety

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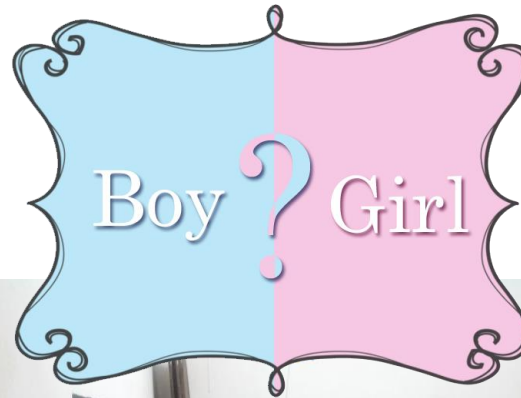


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A baby is born !

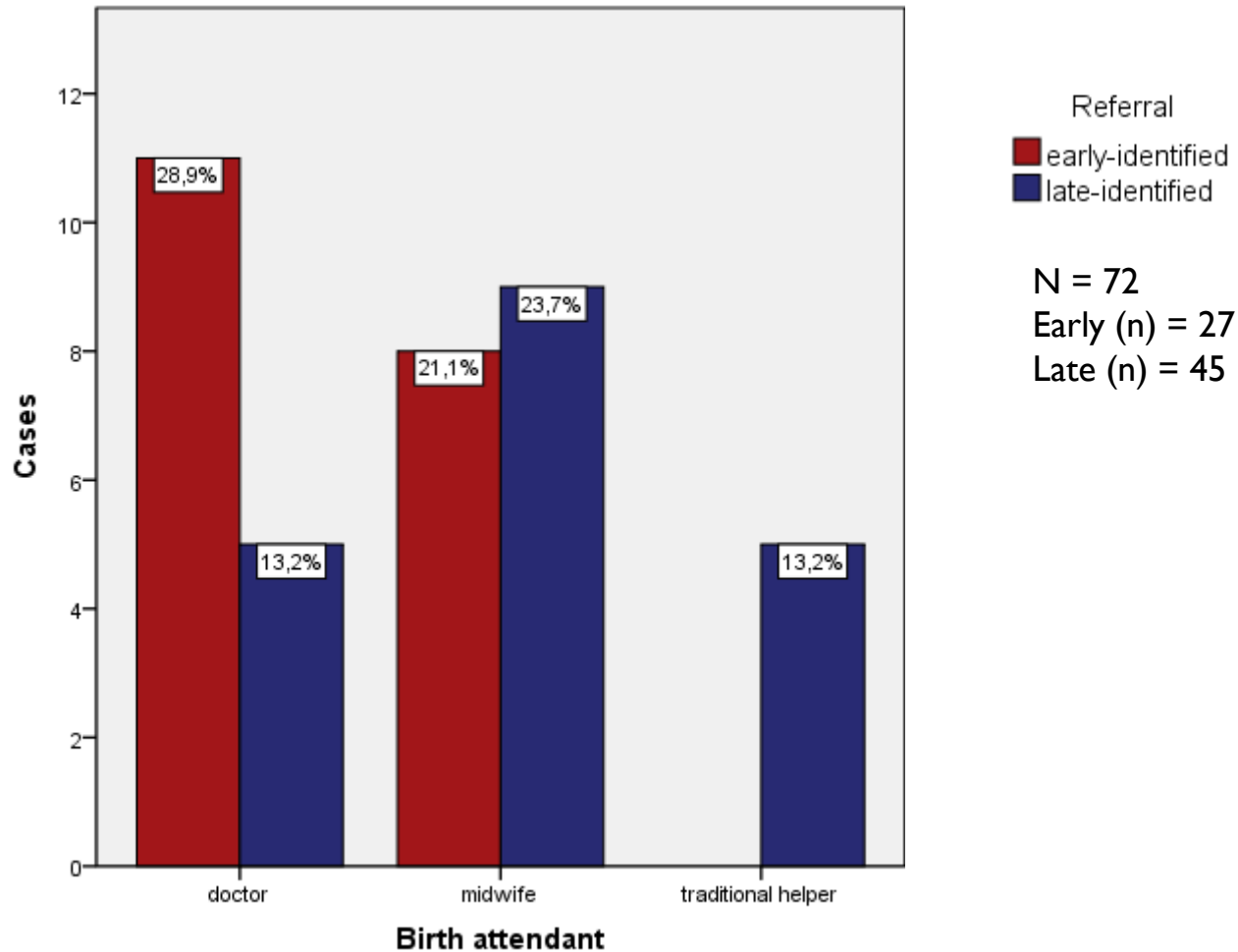
- A happy moment
- Social attention
 - extended family
 - neighbors
- Social consequence
 - Celebration
 - Cultural ceremonies
- Birth certificate



Newborn with an ambiguous genitalia

- Ambiguous genitalia is the most common form of 46,XX CAH (congenital adrenal hyperplasia) found in the newborn
- Genital ambiguity is the major reason for seeking medical care for patients with 46,XX CAH
- Gender assignment should be done based on the karyotype, hormonal evaluation, internal & external reproductive structures → takes long time
- 46,XX CAH → assign a female gender

BIRTH ATTENDANT PLAYS IMPORTANT ROLE IN EARLY REFERRAL OF BABIES WITH CAH ($P=0.02$)



A Ediati et al. Healthcare-seeking in late-identified patients with Congenital Adrenal Hyperplasia in Central Java (Unpublished data)

Attitudes towards Newborn with An Ambiguous Genitalia

MIDWIVES

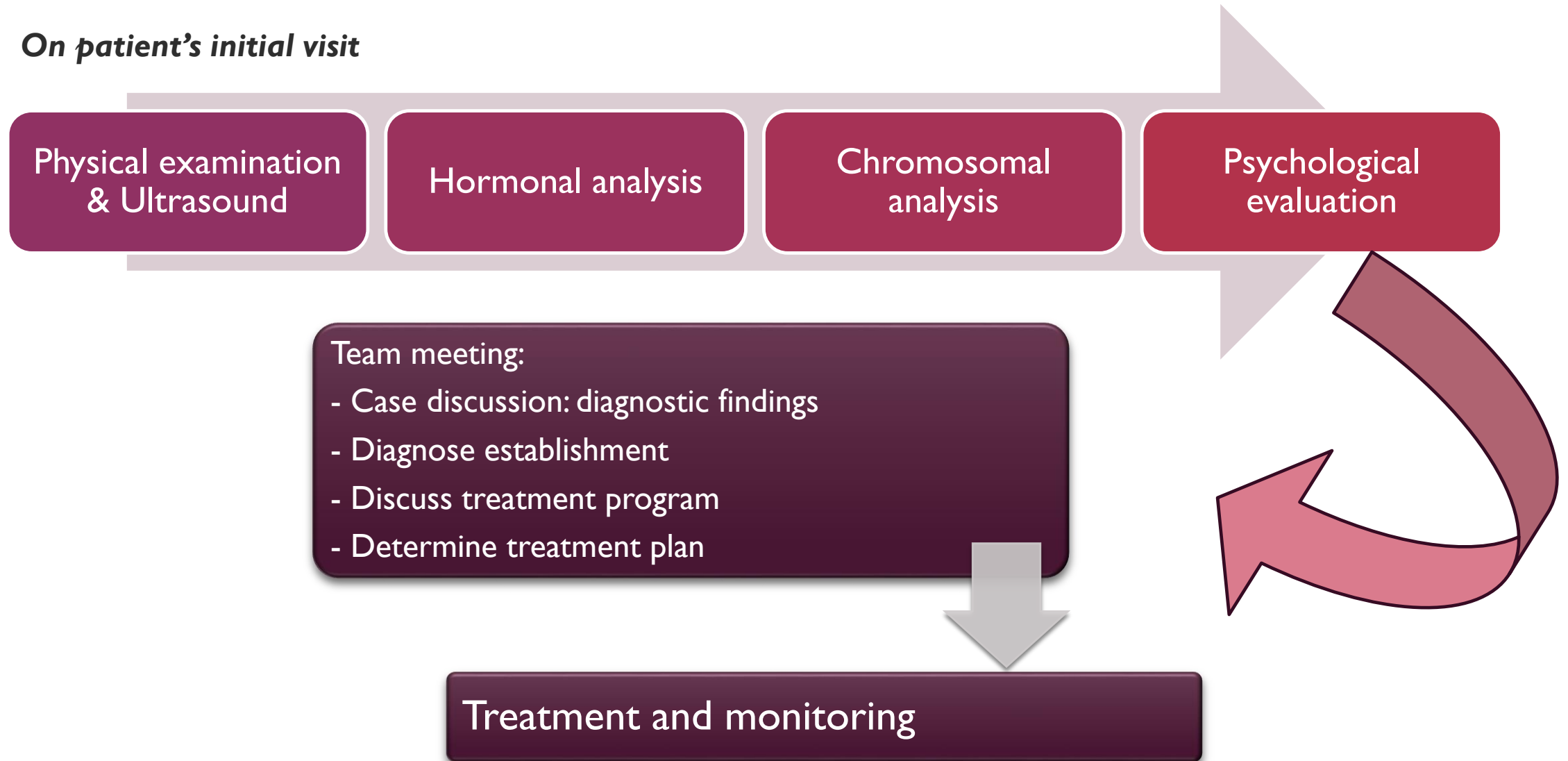
- Familiar with terms of “ambiguous genitalia”
- Aware of the psychological impact BUT do not know what to do
- Prefer to delay referral to medical doctors (3 months – unknown)
- Prefer to refer to pediatrician, pediatric urology, surgeon, hospital
- Mistakes in gender assignment

MANAGEMENT OF DSD IN SEMARANG

THE SEXUAL ADJUSTMENT TEAM

DR KARIADI HOSPITAL - FACULTY MEDICINE, DIPONEGORO UNIVERSITY

On patient's initial visit



Having a Child with Ambiguous Genitalia

PARENTS' MAJOR CONCERNS

A. Identity & parental rearing:

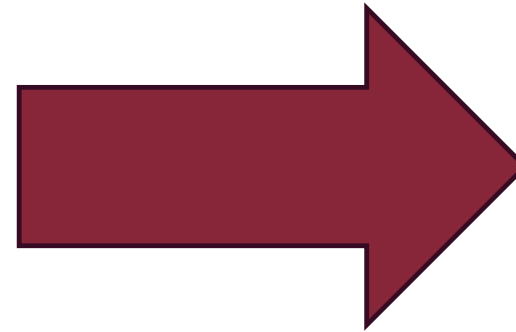
- Baby's name
- Clothing
- Child's toys
- Child's playmates
- "Tindik telinga"



MAJOR CONCERNS

B. Medical evaluation & treatment:

- Repetitive visits
- Surgeries
- Rare conditions



MAJOR CONCERNS



- Fertility
- Consequences of infertility (for affected girls):
 - Difficulties to find a partner
 - Difficulties to maintain a satisfying marriage
 - Being divorced by her husband
 - Be a lonely elderly

MAJOR CONCERNS

- Fear of:
 - Being a center of attention
 - Bullying
 - Social isolation/rejection
 - Shame

In village, people memorize across generations

REDUCING PARENTAL ANXIETY

- Listen to parental concern & worries
- Provide reliable information:
 - In a simple language
 - Reduce uncertainty
- Assure parents that they are in the good hands

It will take your time but worth for a long run

COMMON QUESTIONS FROM PARENTS

- What is an ambiguous genitalia/CAH?
- What kind of medication/medical treatment needed?
- What to do in parenting?
- How to explain this conditions to others?
- What to do during emergency?
- How to explain to the child later when she grown up?

Helps parents understand gradually

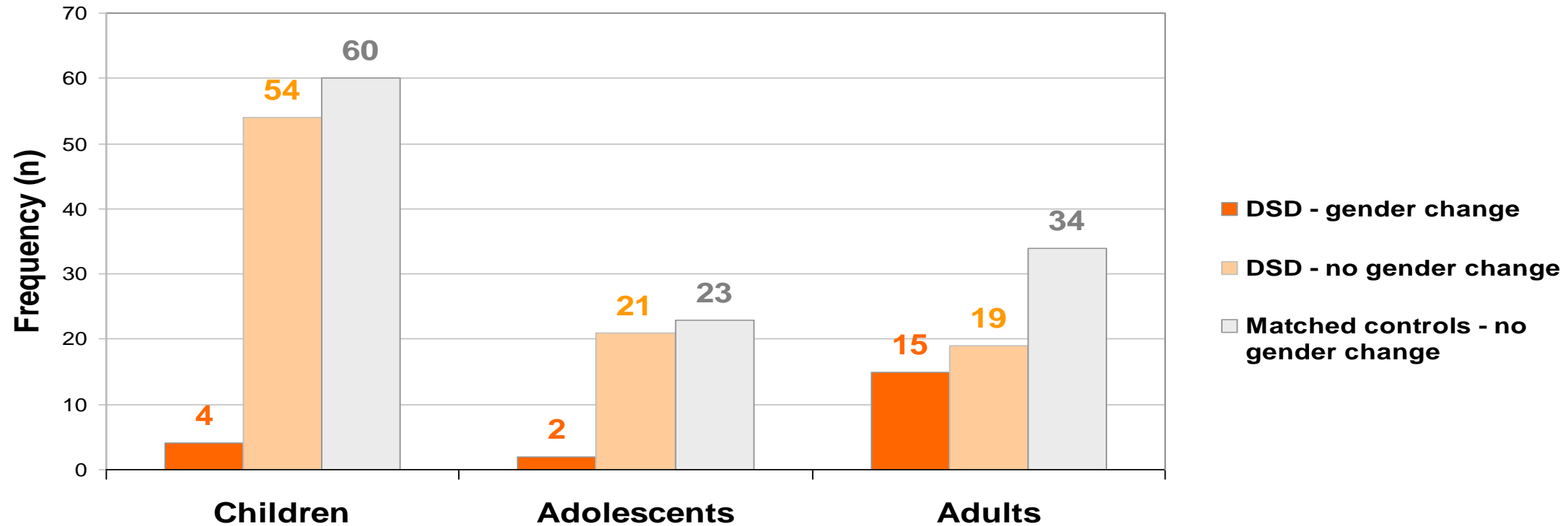
WHAT DID WE LEARN?

Semarang Experience



GENDER CHANGE: SEMARANG EXPERIENCE

Frequency of Gender change in patients with DSD



Percentage
(%)

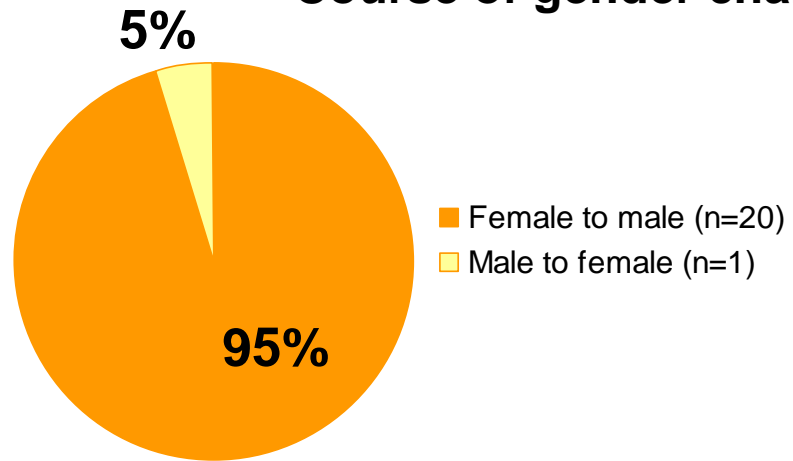
6.7

8.7

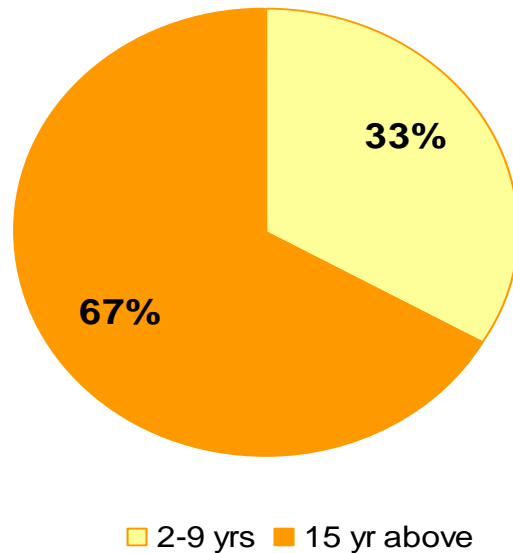
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GENDER CHANGE: SEMARANG EXPERIENCE

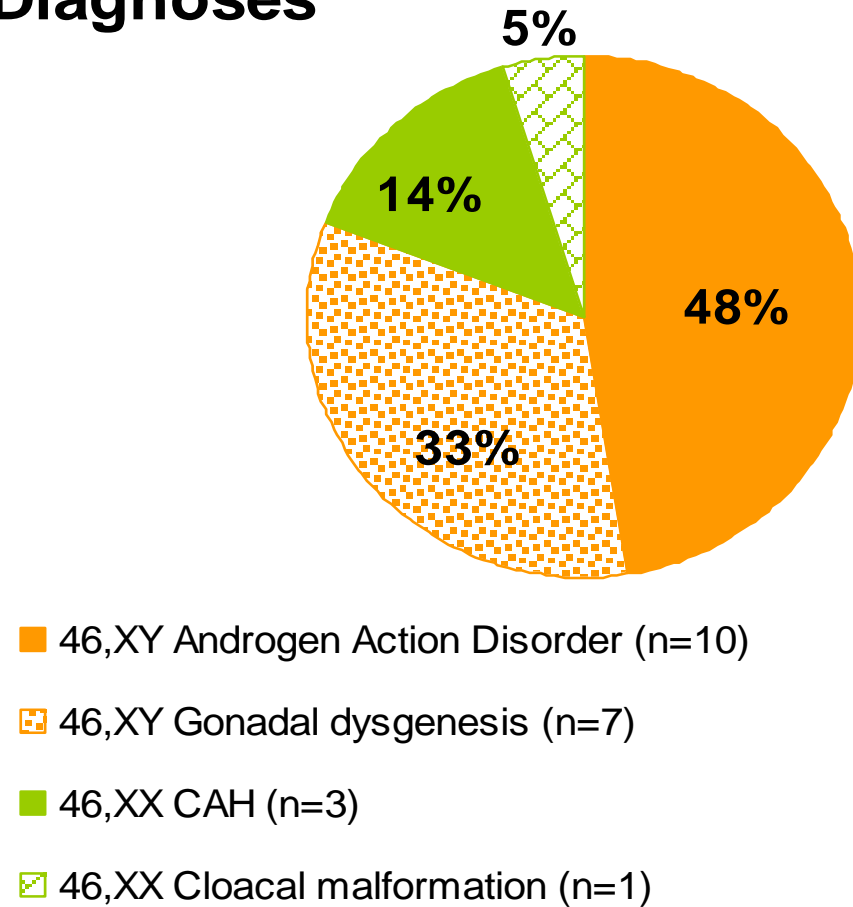
Course of gender change



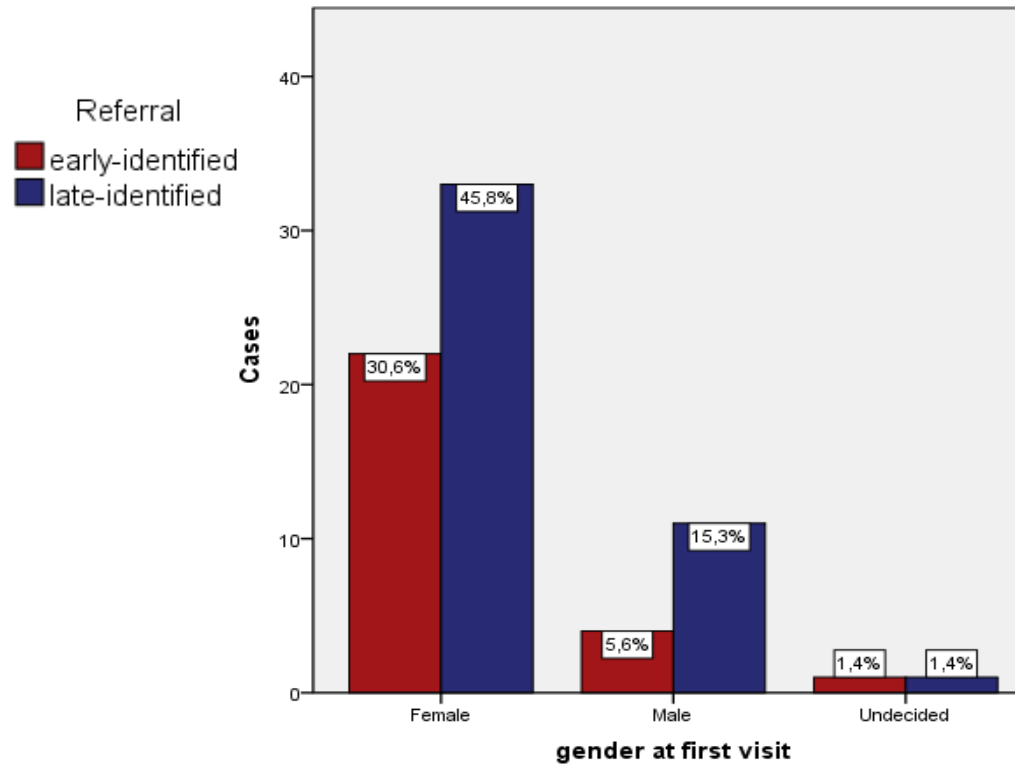
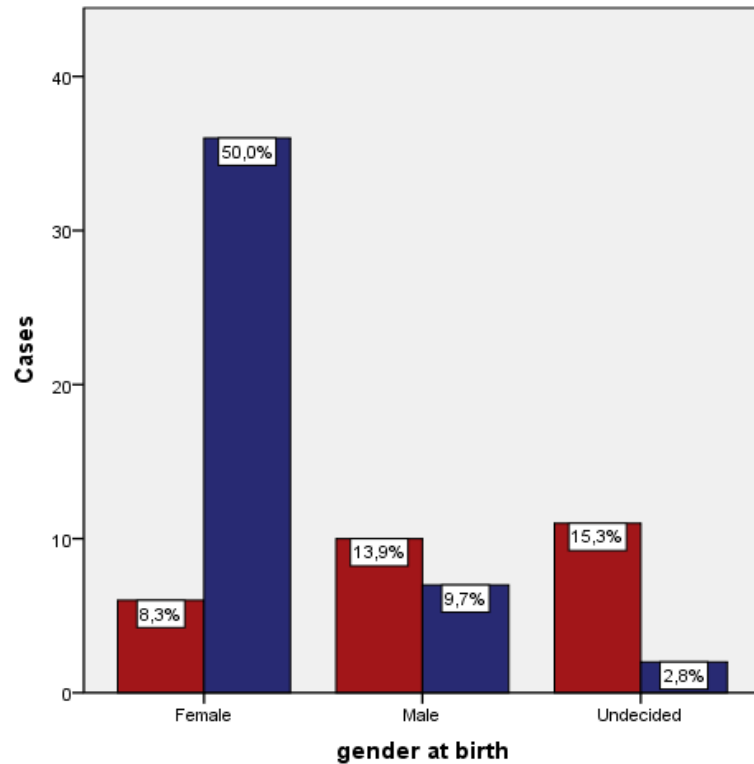
Age of gender change



Diagnoses



MORE PATIENTS WITH 46,XX-CAH WERE ASSIGNED OR REASSIGNED A FEMALE GENDER



N = 72
Early (n) = 27
Late (n) = 45

PARENTAL STRESS: STIGMA

- Higher parental stress, caused by:
 - Negative social reactions (teasing, rejection, isolation)
 - Affected girls reported more emotional problems than affected boys
- Visible ambiguity (appearance/behavior):
 - Trigger social reaction (more negative reaction than positive reaction)
 - Gender change in individuals with DSD mostly received stigmatization due to their ambiguity on appearance/behavior that are visible to others

EMOTIONAL PROBLEMS

Comparison among children, adolescents, and adults with DSDs who are scored above cut points across age groups.

Scales	Children (n = 60)	Adolescents (n = 24)	Adults (n = 34)	p-Value
Total problems	11 (18.3)	3 (12.5)	7 (20.6)	0.73
Internalizing problems	9 (15.0)	4 (16.7)	16 (47.1)	0.003*
Externalizing problems	14 (23.3)	0	5 (14.6)	0.02*
<i>Scales:</i>				
Anxious/depressed	1 (1.7)	0	10 (29.4)	<0.001**
Withdrawn/depressed	11 (18.3)	3 (12.5)	11 (32.4)	0.16
Somatic complaints	1 (1.7)	3 (12.5)	4 (11.8)	0.20
Social problems ^a	7 (11.7)	2 (8.3)	–	0.99
Thought problems	1 (1.7)	0	4 (11.8)	0.046*
Attention problems	3 (5.0)	1 (4.2)	5 (14.7)	0.24
Rule-breaking behavior	5 (8.3)	1 (4.2)	1 (2.9)	0.59
Aggressive behavior	10 (16.7)	1 (4.2)	3 (8.8)	0.26
Intrusive ^b	–	–	1 (2.9)	–

Note. Data presented in n (%). The Fisher Exact test was applied; significant at $p < 0.05$.

^a n = 84. The social problem scale was only available in the CBCL and YSR.

^b n = 34. The intrusive scale was only available in the ASR.

- Externalizing problem reported higher on children with DSD than adolescents or adults
- Aggressive behavior were found higher on young boys than girls

HIGHLIGHTS

- Parental stress and anxiety are common reactions found in parents of newborn with genital ambiguity
- Discussing sexuality still taboo; it could lead to communication problems and internalizing problems
- Parents need reliable information to better understand the child's conditions & to deal with people's reactions
- Follow-up evaluation is necessary, physically & psychologically

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