

# Midwives' knowledge & attitudes towards disorders of sex development (DSD) and its psychological impact: A Preliminary study



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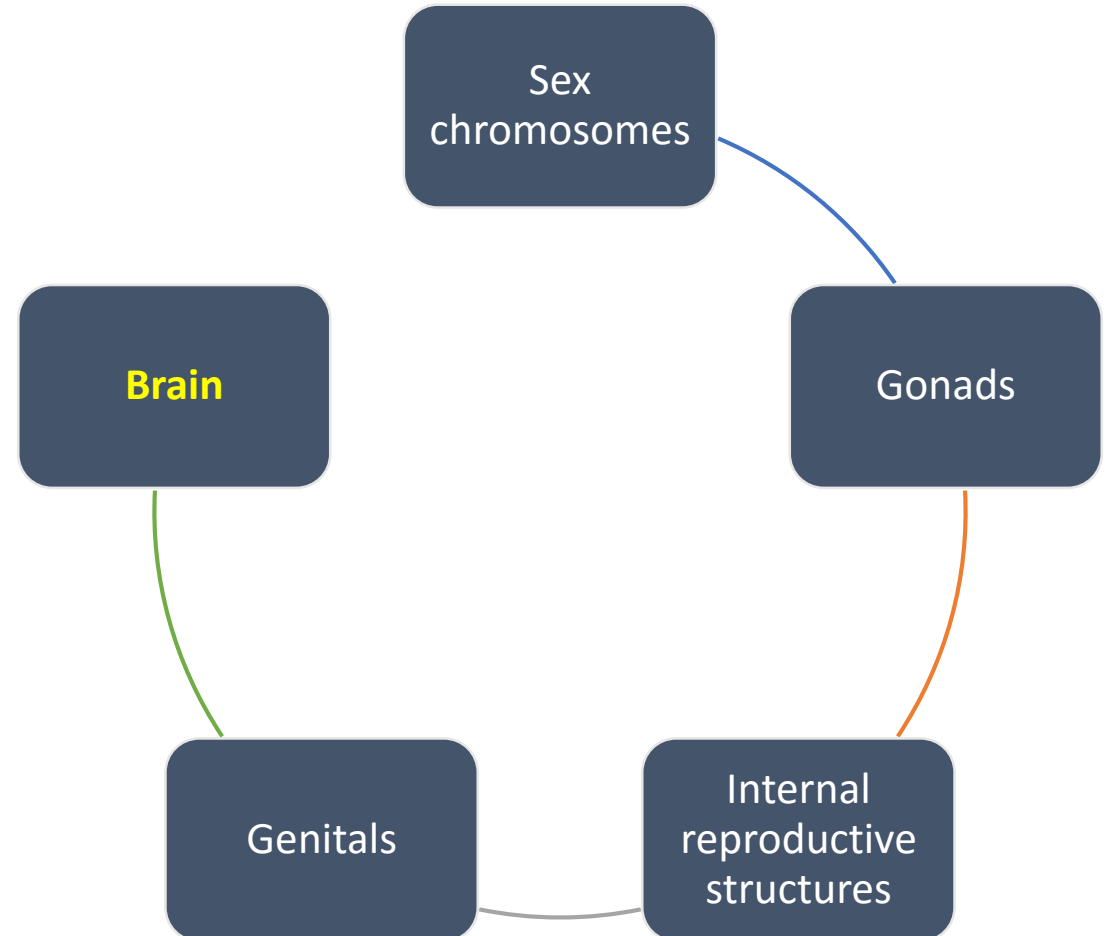


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# What is a disorder of sex development (DSD)?

**DSD is a congenital anomalies that involve atypical development of sex chromosomes and gonads, consequently atypical development of internal reproductive structures & genitals, which may also affect brain development**



- **Genital ambiguity is the major reason for seeking medical care for individuals with 46,XX DSD or 46,XY DSD**
- **Incidence of ambiguous genitalia in newborn: approx. 1 in 4500 birth**
- **Gender assignment should be done based on the karyotype, hormonal evaluation, internal & external reproductive structures, psychological evaluation → it takes long time**

# Indonesia

## Patients referral to Semarang

300 native ethnicities

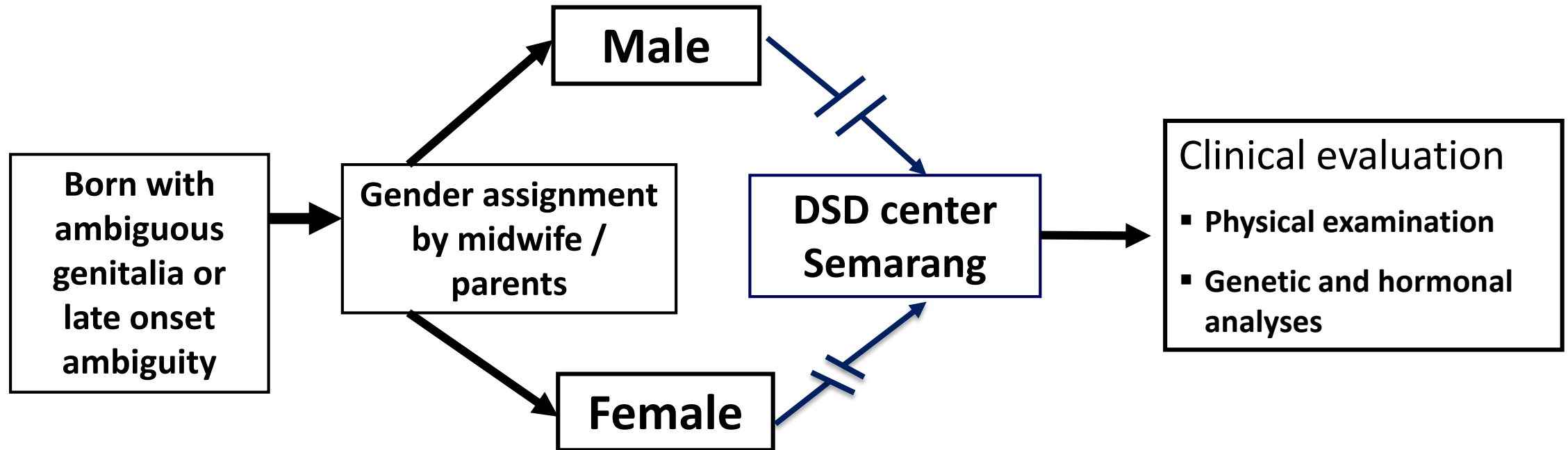
743 local languages

± 17,000 islands

237.5 million people



# Indonesia setting

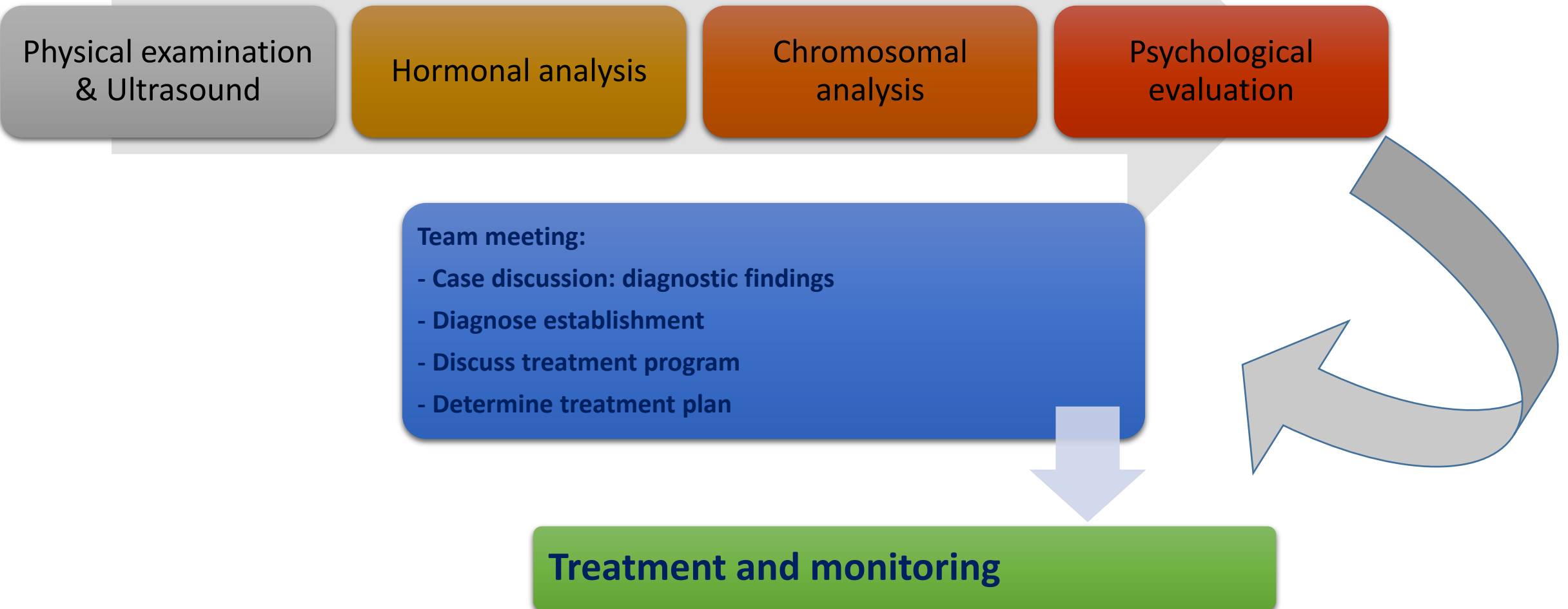


# Management of DSD in Semarang, Indonesia

*The Sexual Adjustment Team*

Dr Kariadi Hospital - Faculty Medicine Diponegoro University

## *On patient's initial visit*



## Clinical study (2004-2010)

Achmad Zulfa Juniarto et al.

Patients with DSD  
N = 286

Hormones

Molecular genetics



## Psychological study (2007-2011)

Annastasia Ediati et al.

N = 118

### *Inclusion criteria:*

- Diagnosed with DSD
- Age 6 yrs & older
- No intellectual disabilities

# *Results from previous studies*

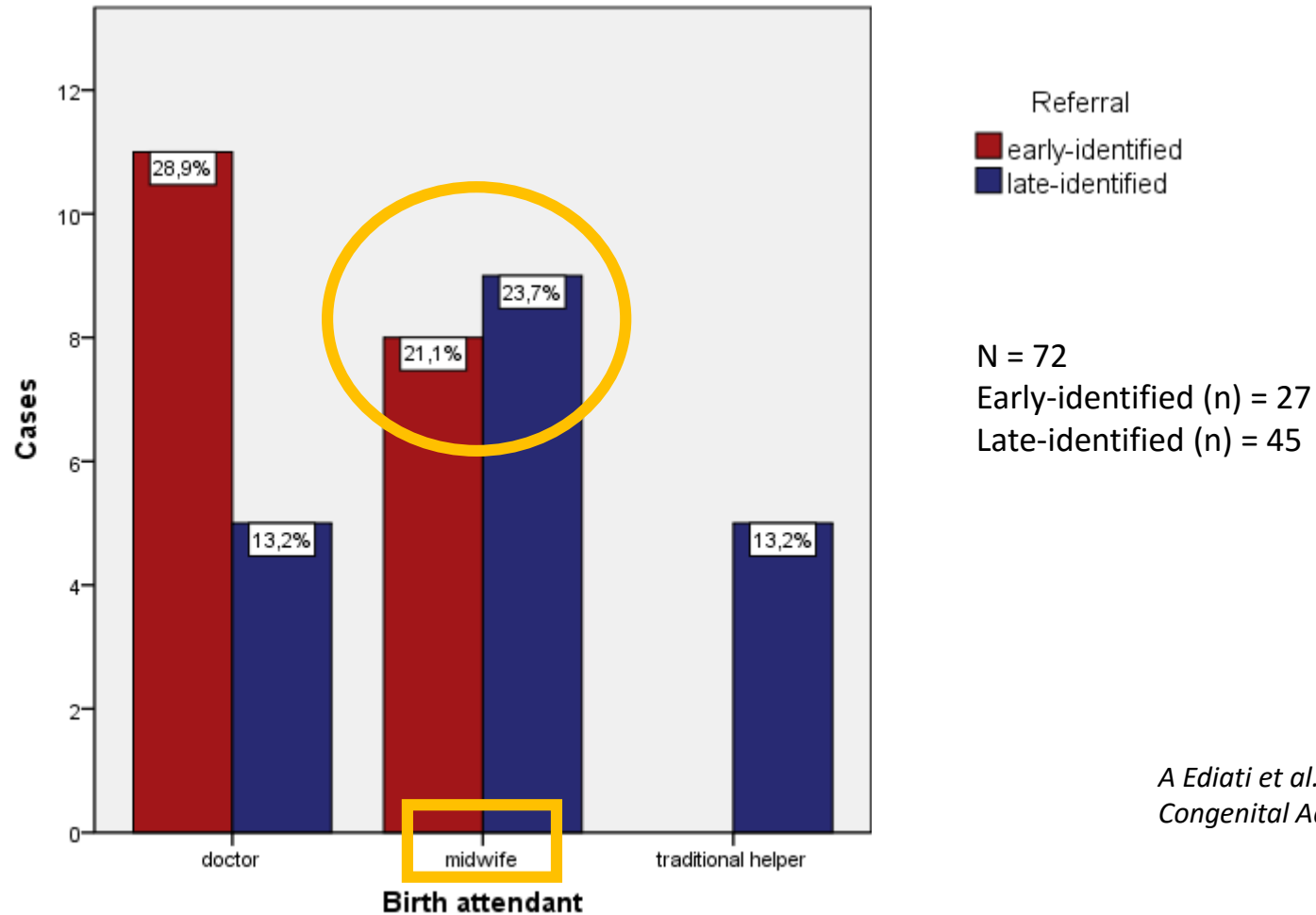
## WESTERN COUNTRIES

- DSD is identified early at birth (newborn screening)
- Early medical treatment will be offered
- Gender change is rare
- Multidisciplinary team provide care that accessible & affordable

## INDONESIA

- The majority of affected individuals were referred late
- Many affected individuals living without medical treatment
- Gender-dysphoria was prominent; a high percentage of self-initiated **MtF** gender change in **46,XY adults (44%)**; **FtM children with 46,XX Congenital Adrenal Hyperplasia**
- Social withdrawn and depression
- Social stigmatization influenced self-initiated gender change
- Multidisciplinary team only available in Semarang and Jakarta

# Birth attendant plays important role in EARLY referral of babies with 46,XX congenital adrenal hyperplasia (CAH) ( $p=0.02$ )



*A Ediati et al. (2016). Healthcare-seeking in late-identified patients with Congenital Adrenal Hyperplasia in Central Java (Unpublished data)*

# Research questions



- **Do midwives have sufficient knowledge about DSD in newborn (genital ambiguity)?**
- **What is the attitude of midwives towards a newborn with DSD that may affect their decision in gender assignment and referral to medical center?**

# Methods

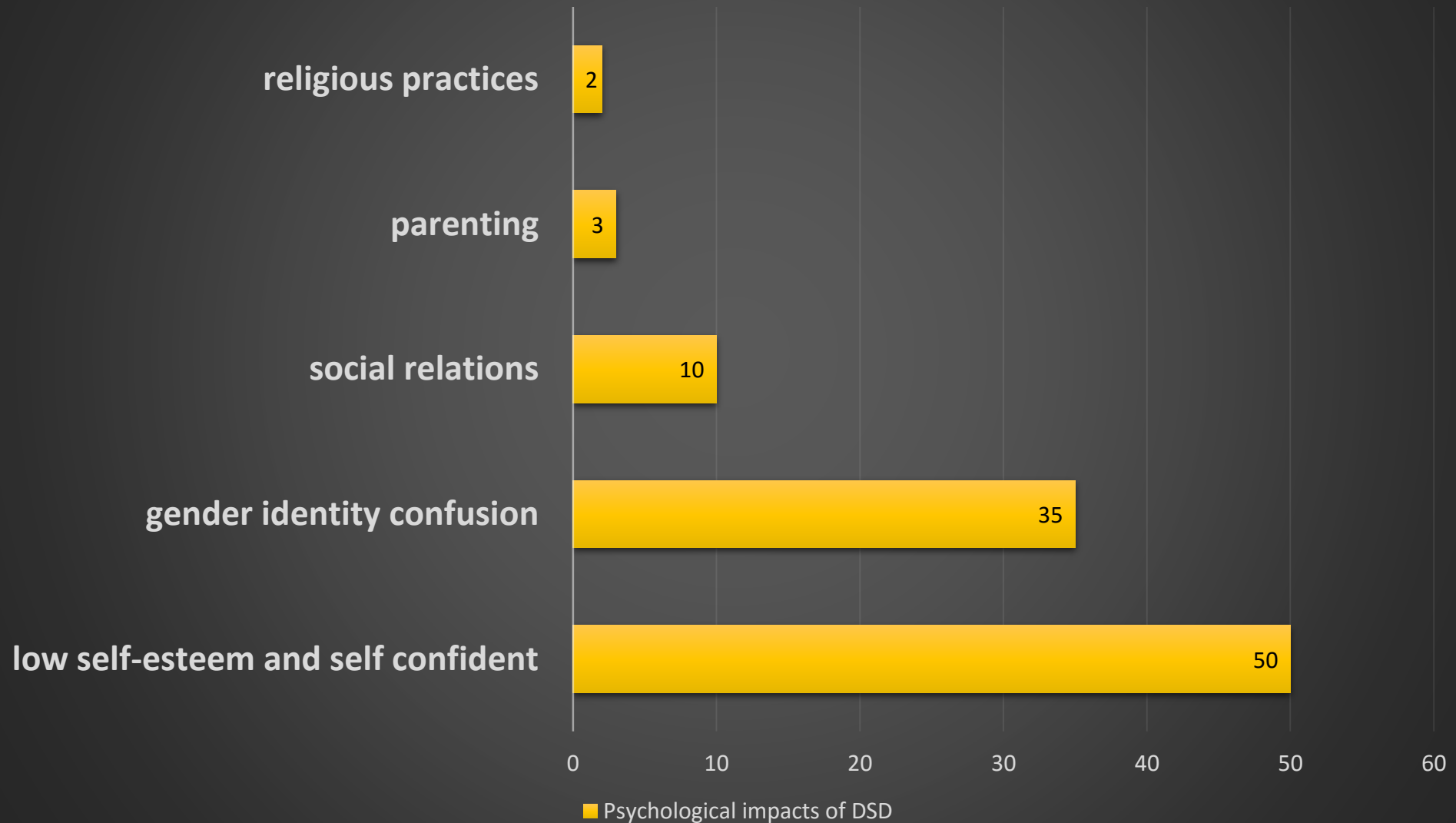


- **Participants:** 211 midwives in Semarang city, Central Java
- **Instruments:** the Midwives' Knowledge and Attitude towards DSD Questionnaire
  1. *Knowledge about DSD*
    - The terms of DSD known by midwives
    - The cause of DSD
    - The psychological impacts of DSD
  2. *Attitude towards DSD* (using 5 pictures of newborns with and without a genital ambiguity)
    - Midwives' decision on gender assignment: female, male, or undecided
    - If undecided: delay or refer (when and to whom)

# Findings: Knowledge about DSD and its psychological impacts

- The terms of “ambiguous genitalia” is more popular than intersex or DSD
- 71% midwives believed that DSD was caused by genetic-related factors
- 82% of midwives: DSD impact psychologically BUT only 39% midwives thought that psychological intervention might help
- 61% midwives: it can be cured by surgery (38%) or pills (7.5%)
- 39% midwives: no emergency condition on newborn with a genital ambiguity
- Information seeking: medical doctors (87.7%), conferences (33.6%), internet (25%), senior colleagues (10%),

## Percentage of psychological impacts of DSD: Perceived by Midwives



**Only 39%  
midwives  
thought that  
psychological  
intervention  
could help**

# Findings: Midwives' attitudes towards a newborn with DSD

- Mistakes in identification of newborn with an ambiguous genitalia → mistakes in gender assignment (44-60% midwives)
- Referral for early medical intervention:
  - Delay referral to medical doctors (3 months – unknown)
  - Refer to hospital (unspecified doctor)



# Conclusion



- **Midwives play important role in making a proper decision about gender assignment and referral for medication of newborn with a genital ambiguity**
- **Education about early identification of newborn with DSD, the psychological impact of having a DSD conditions, and the psychological intervention available for the affected individuals need to be promoted among midwives**
- **The involvement of a psychologist in raising awareness on the psychological impact of late-identification of DSD is essential**
- **Valid information about DSD for educational purposes should be made available for health practitioners in local language.**

# Acknowledgements



- The study was funded by the Ministry of Research, Technology, and Higher Education, Republic of Indonesia (Kemristekdikti)



- The presentation in the ICP2016 Yokohama was funded by the Diponegoro University & Faculty of Psychology, Diponegoro University





***Thank you***

Arigato gozaimasu | Terimakasih | Matur nuwun

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