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

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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
300 native ethnicities
743 local languages
± 17,000 islands
237.5 million people
Indonesia setting

- Born with ambiguous genitalia or late onset ambiguity
- Gender assignment by midwife/parents
- DSD center Semarang
- Male
- Female
- Clinical evaluation
  - Physical examination
  - Genetic and hormonal analyses
Management of DSD in Semarang, Indonesia

The Sexual Adjustment Team

Dr Kariadi Hospital - Faculty Medicine Diponegoro University

On patient’s initial visit

- Physical examination & Ultrasound
- Hormonal analysis
- Chromosomal analysis
- Psychological evaluation

Team meeting:
- Case discussion: diagnostic findings
- Diagnose establishment
- Discuss treatment program
- Determine treatment plan

Treatment and monitoring
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

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<tr>
<th>WESTERN COUNTRIES</th>
<th>INDONESIA</th>
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<tr>
<td>• DSD is identified early at birth (newborn screening)</td>
<td>• The majority of affected individuals were referred late</td>
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<td>• Early medical treatment will be offered</td>
<td>• Many affected individuals living without medical treatment</td>
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<td>• Gender change is rare</td>
<td>• 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</td>
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<td>• Multidisciplinary team provide care that accessible &amp; affordable</td>
<td>• Social withdrawn and depression</td>
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<td>• Social stigmatization influenced self-initiated gender change</td>
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<td>• Multidisciplinary team only available in Semarang and Jakarta</td>
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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%),
Only 39% of 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

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Thank you

Arigato gozaimasu | Terimakasih | Matur nuwun

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