

INTERSEX/DISORDERS OF SEXUAL DEVELOPMENT (DSD), GENDER DYSPHORIA (GD), SOGIESC CULTURE AND THEIR CONTROVERSY IN INDONESIA

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ABSTRAK

Androgen Insensitivity Syndrome (AIS) dan Disorders of Sexual Development (DSD) merupakan kelainan bawaan yang mempengaruhi perkembangan anatomi organ reproduksi. Pengobatan AIS seringkali menimbulkan tantangan medis dan sosial, terutama yang berkaitan dengan konstruksi gender. Operasi rekonstruksi gender pada usia dini masih kontroversial karena risiko trauma psikologis dan ketidakpuasan di kemudian hari. Disforia gender (GD), yang terjadi pada 8,5–20% individu dengan DSD, mencerminkan ketidaksesuaian antara identitas gender dan jenis kelamin yang ditetapkan saat lahir, dan dipengaruhi oleh faktor biologis, psikologis, dan sosial. Di Indonesia, wacana Orientasi Seksual, Identitas dan Ekspresi Gender, dan Karakteristik Seks (SOGIESC) masih menghadapi resistensi yang kuat karena norma budaya dan agama yang konservatif. Akibatnya, individu dengan perbedaan SOGIESC rentan mengalami diskriminasi fisik, psikis, dan seksual. Dalam konteks kebudayaan Indonesia, terdapat sejarah pengakuan gender non-biner seperti yang terjadi pada masyarakat Bugis, namun norma tersebut terkikis oleh dominasi nilai-nilai agama sejak era kolonialisme. Penelitian ini menyoroti pentingnya pendekatan berbasis hak asasi manusia dalam pengelolaan AIS dan GD, termasuk menghormati keputusan individu terkait identitas gendernya. Kesadaran pemerintah dan pengakuan hukum diperlukan untuk mengatasi stigma dan diskriminasi, serta mendorong masyarakat untuk menerima keberagaman gender sebagai bagian integral dari hak asasi manusia.

Kata kunci : dukungan keluarga, kesadaran diri, penularan tuberkulosis paru

ABSTRACT

Androgen Insensitivity Syndrome (AIS) and Disorders of Sexual Development (DSD) are congenital disorders that affect the anatomical development of the reproductive organs. Treatment of AIS often poses medical and social challenges, especially in relation to gender constructs. Gender reconstruction surgery at an early age remains controversial due to the risk of psychological trauma and dissatisfaction later in life. Gender dysphoria (GD), which occurs in 8.5–20% of individuals with DSD, reflects a mismatch between gender identity and the sex assigned at birth, and is influenced by biological, psychological, and social factors. In Indonesia, the discourse on Sexual Orientation, Gender Identity and Expression, and Sex Characteristics (SOGIESC) still faces strong resistance due to conservative cultural and religious norms. As a result, individuals with SOGIESC differences are vulnerable to experiencing physical, psychological and sexual discrimination. In the context of Indonesian culture, there is a history of non-binary gender recognition such as in the Bugis community, but this norm has been eroded by the dominance of religious values since the era of colonialism. This research highlights the importance of a human rights-based approach in the management of AIS and GD, including respecting individuals' decisions regarding their gender identity. Government awareness and legal recognition are needed to overcome stigma and discrimination, and encourage society to accept gender diversity as an integral part of human rights.

Keywords : family support, self awareness, transmission of pulmonary tuberculosis

INTRODUCTION

DSD is defined as a condition of sexual disorder that can occur as a result of a congenital condition, either due to genetic (development of atypical sex chromosomes), gonadal or

hormonal factors that determine the development of the anatomy of external reproductive organs. Androgen insensitivity syndrome (AIS) is a common etiology of disorders of sexual development (DSD). The prevalence of DSD in the global population is around 0.1-2%, and 8.5-20% of them have gender dysphoria (Furtado et al, 2012).

Therapy for AIS is very complicated as it can cause psychological distress in later days. One of the therapeutic options, sex reassignment with surgery for gender construction, is often done as soon as possible by surgeons and family doctors. This is done on the grounds of achieving better results because gender construction is still flexible if done before the second year of life. Premature intervention can be controversial, i.e. performing unnecessary surgery on people with DSD, giving hormonal therapy, and other procedures that are performed solely with the aim of adapting a person's gender to the construction and social expectations. Thus, giving such therapy often causes a feeling of disappointment and betrayal, especially if an irreversible surgery has been performed. Gender construction is influenced by social factors, norms, expectations and behavior that correspond to their gender.

This recent times has the idea that the act of 'normalization' is unnecessary and prefers to leave themselves as they are. As time passes, people with AIS may feel that they are not in line with a defined gender, known as gender dysphoria. According to the American Psychiatric Association (APA) and the DSM V, gender dysphoria is a psychological disorder that occurs as a result of an inconsistency between the sex assigned to a person at birth and their gender identity. Gender dysphoria has several causes, both biologically, psychologically and socially. the impact of gender-related dysphoria leads people who experience it often to social discrimination because of their different anatomy (Maliano, 2016). Gender identity is a major problem in both AIS and other DSD conditions. Gender dysphoria is also closely linked to Sexual Orientation, Gender Identity and Expression, Sex Characteristics (SOGIESC), which is still taboo in many countries, including Indonesia. Concepts in a society that is still highly boxed up behavior and roles based on one's gender make people with different SOGIESCs highly vulnerable to discrimination (psychologically, physically, and sexually).

METHOD

This research uses a descriptive qualitative approach to analyze the phenomena of Disorders of Sexual Development (DSD), Androgen Insensitivity Syndrome (AIS), and Gender Dysphoria (GD) in social, cultural and medical contexts in Indonesia. Data was collected through literature reviews from various scientific sources, such as medical journals, reports from human rights organizations, as well as cultural documents related to SOGIESC. The analysis was conducted critically on biological, psychological, and sociocultural aspects, with a focus on the impact of early medical intervention and the challenges of discrimination faced by individuals with DSD and AIS. This research also considers historical and contemporary perspectives on gender diversity in Indonesian culture, as well as its relevance to current medical policy and practice.

RESULT AND DISCUSSION

What is Androgen Insensitivity Syndrome?

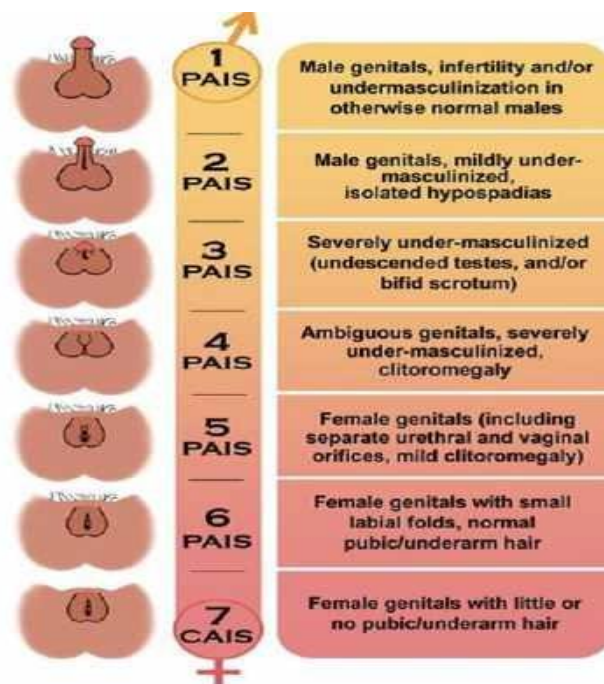
Androgen insensitivity syndrome (AIS) is a common etiology of disorders of sexual development (DSD) (Singh et al, 2021). DSD is defined as a condition of sexual disorder that can occur as a result of a congenital condition, either due to genetic (development of atypical sex chromosomes), gonadal or hormonal factors that determine the development of the anatomy of external reproductive organs. AIS occurs due to the presence of genetic alteration of the XY chromosome so that the body can not respond to testosterone either fully

or partially. This condition is characterized by the presence of feminization (undermasculinization) of the external genitals, both at birth and during puberty, i.e. marked by impaired secondary sexual development (Rajuddin et al, 2018).

Why AIS Therapy is Controversial?

The treatment for AIS is complex and can cause psychological distress in later days. One option is sex reassignment with surgery for gender construction, often performed before the second year of life to achieve better results. However, premature intervention can be controversial, leading to unnecessary surgery, giving hormonal therapy, and other procedures that are performed solely with the aim of adapting a person's gender to the construction and social expectations. Thus, giving such therapy often causes a feeling of disappointment and betrayal, especially if an irreversible surgery has been performed. Surgery can also cause chronic pain, nerve damage and scarring. Surgery like gonadectomy can cause a person to become sterile and have to undergo hormone therapy for the rest of his life. Gender construction is influenced by social factors, norms, expectations. But this adult has the idea that the act of 'normalization' is unnecessary and prefers to leave them as themselves.

DSD therapy remains controversial due to the lack of clear and ethical guidelines. Until 40 years ago, patients typically underwent gender reassignment surgery before the second year of life. In the 1990s, a full consent policy was introduced, allowing feminization or masculinization before adulthood only if it was obligatory for a medical condition. The medical community still uses surgical techniques like clitoral reduction or vaginoplasty in neonates and infants. The Consensus Statement on Management of Intersex Disorders in 2006 emphasized the importance of focusing on gender identity and quality of life over biological indicators. Legal recognition and government awareness of individual rights are needed.



Source: Thangaraj K, Rajender S. Androgen Insensitivity Syndrome. Encyclopedia of Molecular Mechanisms of Disease. Berlin, Heidelberg: Springer; 2009

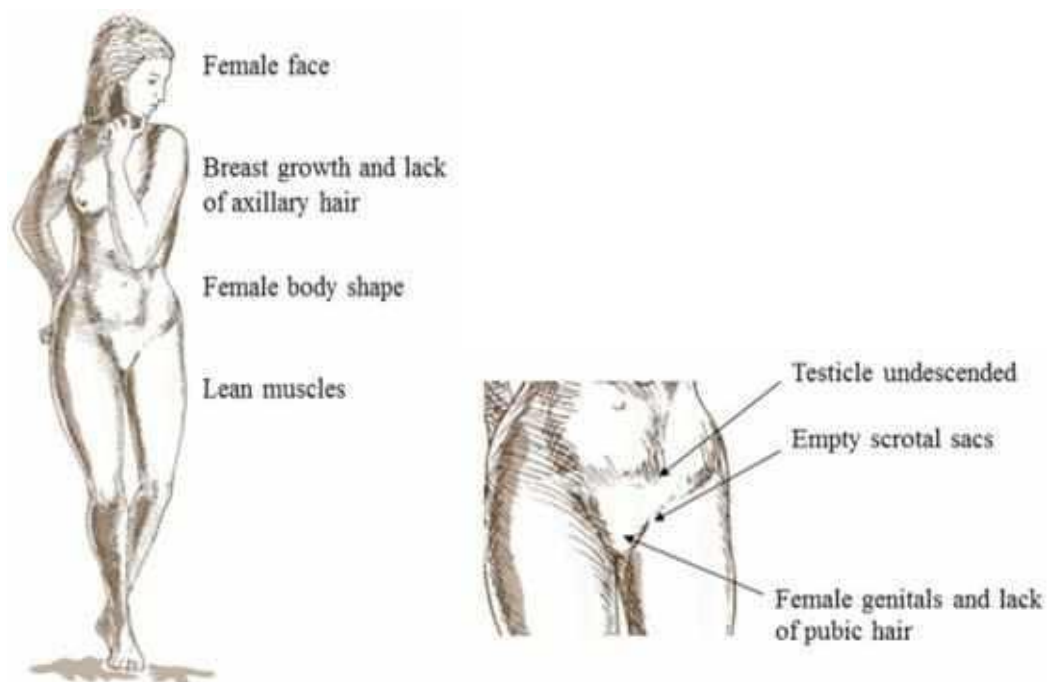
What are AIS Degrees?

AIS has varying degrees, including Complete AIS (CAIS), Partial AIS, and Mild AIS (Furtado et al, 2012).

Complete androgen insensitivity syndrome

(CAS) is characterized by normal female external genitalia in individuals 46-XY with normal testicular development but undescended testicles due to inability of cells to respond to androgen. CAIS is closely related to a deleterious mutation of the AR gene, which interrupts receptor function, preventing target cells from responding to testosterone or DHT. This results in estrogen taking over, leading to the development of female external genitalia.

The primordial testicles produce an anti-Müllerian hormone that suppresses internal genitalia growth, but the external organ forms shorter and shows a 'blind ending' (Furtado et al, 2012).



Picture 2. Complete Androgen Insensitivity Syndrome

Partial Androgen Insensitivity Syndrome (PAIS)

PAIS occurs due to the inability of cells to respond to androgen partially. This condition is caused by the occurrence of missense mutations in the androgen receptor gene. (AR). Individuals with PAIS have ambiguous external genitalia at birth such as enlarged clitoris, gynecomastia, and high-pitched voice.

Mild Androgen Insensitivity Syndrome (MAIS)

MAIS is a condition where individuals have normal male external genitalia but mild testosterone insensitivity. People with MAIS are usually fertile or can become fertile with the help of hormonal testosterone therapy. The concentrations of LH and testosterone can be used as an MAIS probability index in infertile males to screen for an androgen receptor gene mutation (AR). Female offspring of individuals with MAIS can lower the mutated AR gene to become carriers.

How Hard AIS is Diagnosed?

AIS diagnosis is sometimes difficult to determine. In individuals, CAIS is generally not

detected until puberty with primary amenorrhea occurrence and reaches the puberty phase longer than usual. The hypothalamus and the pituitary gland still stimulate the testicles to produce testosterone that will be converted to estradiol. The presence of estradiol will lead to the formation of characteristics typical of women such as normal breast formation, reshaping of the pelvis, body fat distribution. Individual CAIS is usually higher than average due to the Y chromosome that affects growth. There is also a short vagina, no uterus or there are also residue of Mullerian or Wolffian ductus. Testicular undecensus can be found on the descent pathway, ranging from the abdomen to the labia or scrotum. The testicles are most often found in the inguinal canal. CAIS individuals are usually diagnosed with laboratory as well as clinical findings and confirmed by detection of defects in the AR gene. PAIS individual diagnosis, if patients come with ambiguous external genital anatomy at birth usually caryotype analysis and can also be performed hormonal analysis. Hormonal profiles in individuals CAIS and PAIS have similarities, that is, at birth levels of testosterone and luteal hormone (LH) higher than normal boundaries men (Rajuddin et al, 2018) (Batista et al, 2018) (Hughes et al, 2012).

Gender Dysphoria, AIS and Discrimination

As time passes, people with AIS may feel that they are not in line with a defined gender, known as gender dysphoria. According to the American Psychiatric Association (APA) and the DSM V, gender dysphoria is a psychological disorder that occurs as a result of an inconsistency between the sex assigned to a person at birth and their gender identity. Gender dysphoria has several causes, both biologically, psychologically and socially. AIS is a rare disorder, with an incidence of 1:20,000, but the impact of gender-related dysphoria leads people who experience it often to social discrimination because of their different anatomy. Gender identity is a major problem in both AIS and other DSD conditions. Gender dysphoria is also closely linked to Sexual Orientation, Gender Identity and Expression, Sex Characteristics (SOGIESC), which is still taboo in many countries, including Indonesia. Concepts in a society that is still highly boxed up behavior and roles based on one's gender make people with different SOGIESCs highly vulnerable to discrimination.

Correlation Between AIS and GD

Gender dysphoria (GD) is a prevalent condition in the global population, with 8.5-20% of DSD individuals experiencing it (Furtado et al, 2012). Endocrinological research by Foreman et al. in 2018 reinforced this statement, indicating an increased prevalence of GD in individuals experiencing androgen exposure disorder during gestation (Foreman et al, 2019). AIS individuals have significant hormonal instability when the fetus is caused by the AR gene mutation, especially in PAIS individuals with partial responsiveness to testosterone. There is a correlation between a mother's testosterone levels at the time of pregnancy and the behavior of her child, with a child of a mother with a high testosterone level showing less feminine behavior and a son of a woman with a low testosterone level showing more feminine conduct.

Gender identity is a complex thing that encompasses biological, psychological, and sociocultural factors, making it difficult to predict the psycho-sexual characteristics of a person in the future (Furtado et al, 2012) (Barista et al, 2018) (Foreman et al, 2019). Biologically, there is evidence of the importance of androgen hormones in the development of the brain in the fetus related to their gender identity and sexual orientation. Neuroimaging examinations showed that a person's brain with an assigned male gender with a female gender identity is more similar to the gender brain they believe. If this happens in the brain that is still developing, it can cause the individual to develop gender dysphoria (18,20,24).

Post-mortem research in MRI study found that women tended to have more grey matter substance, whereas men had more white matter and CSF substance. At the beginning of research on

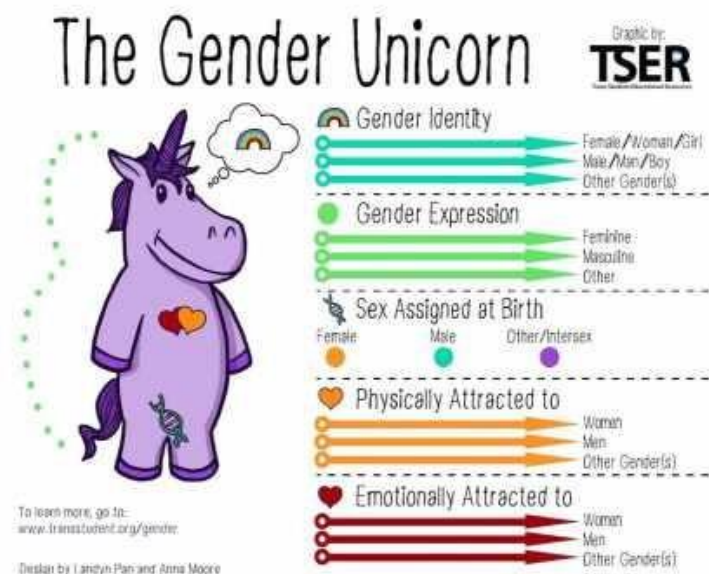
DSD in 1950, it was believed that biological factors had a greater role to play in determining gender development and that androgen exposure in the fetus was not only related to determining sexual differentiation but also the nature of their future behavior. However, Furtado et al. research suggests that androgen is a minor influence of gender dysphoria, and cultural and psychological factors contribute to the occurrence of GD (Furtado et al, 2012).

Social environmental factors and pressure from parents influence a person's gender development. Psychologically, part of a person's gender identity development occurs when they label themselves as the gender they believe in and start imitating their same-sex models. In most studies, it is said that children reach gender consistency before puberty. Starting with gender labelling, gender stability and finally gender consistency. However, in some individuals, especially individuals with AIS, this gender consistency is often late. It's said that it's not just biologically related, that is, not directly caused by their atypical sex organs, because GD can occur in individuals who have undergone surgical therapy, i.e. gender identity can develop without the presence of external genitals.

Therefore, it is difficult to determine whether the factors that play a greater role in the occurrence of GD but surely the accumulation of biological, psychological and sociocultural factors that cause the onset of the dysphoric feelings. 17. Sociocultural pressures, such as SOGIESC, are still a taboo topic in Indonesia, affecting people's behavior and roles based on their gender. People with different SOGIESC are still vulnerable to discrimination in various contexts, psychologically, physically, and sexually.

SOGIESC

Sexual Orientation, Gender Identity and Expression, Sex Characteristics (SOGIESC) is an understanding of sexual orientation and gender that is designed to open up the minds of the wider public, and is shaken by the many human rights violations that occur in societies that refuse to accept diversity. SOGIESCs are vulnerable to discrimination, injustice due to their gender identity, problems in the conduct of intersex individuals (Park, 2019).



Picture 3. The Gender Unicorn

Sexual orientation is the physical, emotional or sexual attraction to a particular individual. Some common sexual orientations are heterosexual (interest in different sexes), homosexuals (interests in the same sex), bisexual (interest in the sexes of male and female), pansexuals (interests in a person regardless of gender or Gender identity is how a person expresses himself, Some common gender identity are masculine, feminine, androgyny (expressing themselves in a masculine and feminine way), gender fluid (a person who is adaptable to gender identity and expression, embracing one, multiple, or no gender). Sexual characteristics, i.e. related to a person's biological chromosomes, gonads and related to intersex individuals.

In this recent times, there is a classification aimed at non-male and non- female individuals namely gender queer or non-binary and there is an increased awareness that a person's gender identity, gender expression and sexual orientation are very diverse and constitute a spectrum. A non-binary gender identity is an individual who feels to be in or out of the binary category of gender (Park, 2019) (Elliott, 2017).

SOGIESC Culture in Indonesia and Their Controversy

Some cultures in the world have already acknowledged that not all genders can be categorized into binary gender categories like Hijras in South Asia, 2 spirits in Native American, Muxes of Indigenous in Mexican culture. Most people in Indonesia think that this culture comes from Western countries that doctriante their liberal views on sexuality and gender identity. But if seen more broadly long before the colonialism era, Indonesia itself had a culture of gender diversity for a long time. In Indonesia, one example is the Bugis culture which is a tribe in South Sulawesi that believes that there are 5 different gender identities such as oroane (male), makkunrai (female), calabai (feminine male), calalai (masculine female), bissu that have mixed characteristics between male and female. However, since colonialism and independence, Indonesia

has been under fundamentally Islamic regimes, the Bishu has been persecuted and banned for being associated with transgender and homosexual identities. Apart from the Bugis culture there is also the Toraja culture that believes that the important leaders are the burrake tattiku (woman) and the burake tambolang (man dressed as a woman) (Elliott, 2017) (Tumanan, 2020).



Picture 4. Illustration

Later homosexuality was also found in eastern Java culture, namely Reog Ponorogo which shows a relationship between two characters (warok and gemblak) both male. Another Indonesian culture is the longer dance of Banyumas Central Java, a dance performed by men dressed like women.



Picture 5. Illustration



Picture 6. Illustration

However, Indonesia is now very closed to the presence of such a culture of diversity. One example is an Indonesian film entitled “Memories of my Body” or “*Kucumbu Tubuh Indahku*” which shows the culture of Central Java “*Lengger*” who won several nominations to represent Indonesia at the world film competition. The film demonstrates diversity of gender identity and sexual orientation, but the film has been controversial in Indonesia until it has been banned from theaters in some cities.

CONCLUSION

Androgen insensitivity syndrome (AIS) is a common disorder affecting 0.1- 2% of the global population. It is a psychological disorder resulting from inconsistencies between a person's sex assigned at birth and their gender identity. Gender identity is closely linked to Sexual Orientation, Gender Identity and Expression, Sex Characteristics (SOGIESC), which is still taboo in many countries, including Indonesia. Treatment for AIS is complex and can cause psychological distress in later life. Gender development is influenced by social environmental factors and parental pressure. In Indonesia, SOGIESC is still taboo, affecting behavior and roles based on gender. This has led to discrimination, injustice, and problems in intersex conduct. Legal recognition and government awareness of individual rights are needed to address this issue.

ACKNOWLEDGMENT

The researcher would like to express his gratitude for the support, inspiration and assistance to all parties in helping the researcher complete this research, including the participants who were willing to participate in the research until it was completed.

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