# 2015\_IJPE\_Ediati\_et\_al\_Espe\_D arwin.pdf

by Annastasia Ediati

Submission date: 03-Aug-2018 08:54AM (UTC+0700) Submission ID: 987176504 File name: 2015\_IJPE\_Ediati\_et\_al\_Espe\_Darwin.pdf (636.85K) Word count: 607 Character count: 3643



### ORAL PRESENTATION

**Open Access** 

## Gender change and stigmatization in late-treated Indonesian children, adolescent, and adult patients with DSD

Annastasia Ediati<sup>1,2\*</sup>, Achmad Zulfa Juniarto<sup>2</sup>, Erwin Birnie<sup>3</sup>, Jolanda Okkerse<sup>4</sup>, Anne de la Croix<sup>4</sup>, Amy Wisniewski<sup>5</sup>, Stenvert Drop<sup>4</sup>, Sultana MH Faradz<sup>2</sup>, Arianne Dessens<sup>4</sup>

From 8th APPES Biennial Scientific Meeting Darwin, Australia. 29 October – 1 November 2014

In Indonesia clinical management of Disorders of Sex Development (DSD) is challenged by limited knowledge and limited diagnostic and treatment facilities. Prior to this study, most patients remained untreated and grew up with ambiguous bodies and doubts about their gender. We investigated patients' experiences of being raised in ambiguity.

118 Indonesian patients, ages 6 - 41, with 46XX DSD (n=27), 46XY DSD (n=77) and chromosomal DSD (n=14) were compared to 118 control subjects matched for gender, age, and living area. Questionnaires for gender identity, gender role behavior and social stigmatization were translated or designed. The psychometric properties were satisfactory. For patient 3nd control group comparisons, Mann-Whitney U and Fisher's Exact tests were applied.

The results showed that 7% of the children, 8% of the adolescents and 44% of the adults changed gender, particularly non-diagnosed and non-treated patients with 46XY DSD (81%). 95% of the patients changed gender from female to male, including untreated patients with 46,XX CAH-SV. Compared to control groups, cross-gender role behavior was seen in young girls with 46XX CAH-SV (p=.047) and adolescent girls with different types of DSD (p=.01). In girls with DSD, confusion with gender identity was seen (young girls p=.004; adolescent girls p=.01). Adult men reported past cross-gender role behavior (p=.01) and past problems in gender identification (p=.01) prior to female-to-male gender change.

Children with genital ambiguity (p<.006) and cross gender behavior (p<0.001) and adults with ambiguous

bodies (p=.001) and adults who changed gender (p<0.03) suffered stigmatization. Rejection or isolation elicited depression and withdrawal from social activities in girls (p=.002), women (p=.009) and youngsters who had changed gender (p=.02).

We conclude that a high percentage of our patients changed gender. The wish for gender change was particularly seen in patients with progressive masculinization. Patients with DSD who had visible ambiguity in physical and behavioral appearance suffered stigmatization. Teasing and rejection led to strong emotional reactions. Early clinical evaluation and treatment, patient and parent education, and teaching coping strategies will improve quality of life.

#### Authors' details

<sup>1</sup>Diponegoro University, Faculty of Psychology, Semarang, Indonesia. <sup>2</sup>Diponegoro University, Faculty of Medicine, Center for Biomedical Research (CEBIOR), Semarang, Indonesia. <sup>3</sup>Erasmus University Rotterdam – Institute of Health Policy and Management, Rotterdam, the Netherlands. <sup>4</sup>Sophia <sup>4</sup>Idren's Hospital - ErasmusMC Rotterdam, Rotterdam, the Netherlands. <sup>4</sup>Oniversity of Oklahoma Health Sciences Center, Oklahoma City, Oklahoma, United States.

Published: 28 April 2015

#### doi:10.1186/1687-9856-2015-S1-O56

Cite this article as: Ediati *et al*: Gender change and stigmatization in late-t 1 ted Indonesian children, adolescent, and adult patients with DSD. *International Journal of Pediatric Endocrinology* 2015 2015(Suppl 1): 056.

<sup>1</sup>Diponegoro University, Faculty of Psychology, Semarang, Indonesia Full list of author information is available at the end of the article



© 2015 Ediati et al; licensee BioMed Central Ltd. This is an Open Access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/4.0), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited. The Creative Commons Public Domain Dedication waiver (http:// creativecommons.org/publicdomain/zero/1.0/) applies to the data made available in this article, unless otherwise stated.

## 2015\_IJPE\_Ediati\_et\_al\_Espe\_Darwin.pdf

ORIGINALITY REPORT				
10%	4%	1%	4%	
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS	
PRIMARY SOURCES				
1 preview	/-ijpeonline.biome	dcentral.com	3	
	Submitted to Sheffield Hallam University Student Paper			
	3 Submitted to University of Guelph Student Paper			
4	care.diabetesjournals.org			
<ul> <li>"Annual Meeting of the European Society of Anaesthesiology Munich, Germany, June 9–12, 2007", European Journal of Anaesthesiology, 06/2007</li> <li>Publication</li> </ul>			ine 9–12,	

Exclude quotes	On	Exclude matches	Off
Exclude bibliography	On		