Psychological Problem in Pediatric Disorder of Sex Development Patient and Relatives

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ABSTRACT

Disorder of sexual development (DSD) is one of challenging disorder that has to be done clinically and physiologically. The patients and relatives may experience various psychosocial problems that have an impact on their live. The aim of this study is to look at psychological problem in children with DSD and their relatives. A systematic search was conducted in PubMed for articles representing information on psychological problem to the patient and their relatives. Relevant data were extracted and narratively reviewed. The result of this review can be used as basic data in the development of counselling program for the patients and their relatives.

Introduction

When a mother give birth to a baby, usually we can know the baby’s gender by examining the external genitalia. However, it can be complicated when the baby has a congenital disorder called Disorders of sex Development (DSD).1 A pediatric disorder of sexual development (DSD) happens when a child is born with sex organs that did not develop properly due to a chromosomal abnormality or the production of hormones. The disorder can range from mild to serious, affecting the development of genitalia and reproductive organs at different ages. A child with DSD is often associated with stigma and kept hidden from the society especially in the developing countries. That can be happened because of the poor understanding and awareness about DSD.2 The molecular analysis which needed to diagnose DSD is limited to research center in big cities whereas the early diagnosis and treatment are so important for DSD patients.3 These limitations made the patients had not received a proper medical care and still in doubt about their gender identity.4

Individuals with DSD have several types of manifestation like genital ambiguity to phenotypes that can go unnoticed or appear normal. Genetic, hormonal and environmental factors during prenatal and postnatal development are likely the factors that responsible for DSD manifestations.5 The incidence of DSD is estimated to be 1 in every 4,500-5,500 births.6 Diagnosis and containment procedures in DSD condition as soon as possible is very important, so that it can be done to minimize the complications not just in medical, but also psychological and
Methods

This literature study was carried out by summarizing and analyzing articles related to the study questions and objectives. The search method was conducted using several electronic databases, such as Scopus, Wiley, Pubmed with the keywords psychosocial, Disorder of Sex Development, children, and quality of life. Inclusion criteria in this literature search are (1) study articles that have titles and content that are in accordance with the study objectives; (2) full text; (3) in English; (4) quantitative and qualitative study articles; (5) year of publication 2015-2021. While the exclusion criteria are (1) the article does not have a complete structure; (2) in the form of article review.

<table>
<thead>
<tr>
<th>No</th>
<th>Author, Year</th>
<th>Main Finding</th>
</tr>
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<tbody>
<tr>
<td>1</td>
<td>Fitrianingrum, 2021</td>
<td>Most Acceptance were based on the surgical stage completion in which higher in mother than father</td>
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<td>2</td>
<td>Lampalzer, 2021</td>
<td>Parent of children with DSD condition have an accessible counseling structure but lack of specific support option</td>
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<td>3</td>
<td>Listyasari, 2019</td>
<td>A strong emphasis on multidisciplinary approach and close follow up is important to ensure both physical and psychological well-being of DSD patient</td>
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<tr>
<td>4</td>
<td>Ernst, 2018</td>
<td>Psychosocial care is integral to multidisciplinary DSD care</td>
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<tr>
<td>5</td>
<td>Ediati, 2017</td>
<td>Stigmatization was stressful and related to isolation and withdrawal from social interaction for DSD patients and families</td>
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<tr>
<td>6</td>
<td>Dessens, 2017</td>
<td>Most psychosocial care is provided by parent. It is assumed that parental support is as important as acceptance to become affectionate caretaker</td>
</tr>
<tr>
<td>7</td>
<td>Listyasari, 2017</td>
<td>Comprehensive management is needed to help the patient in diagnosis, gender assignment and support to improve quality of life</td>
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<td>8</td>
<td>Selveindran, 2016</td>
<td>Children with DSD have a higher degree of psychological distress</td>
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Psychological in patients with DSD

Psychosocial and social-environmental problems and management of DSD that identified in earlier time can reemerge during childhood. The pediatric psychology and child life specialties are highly useful in case especially when urogenital surgery is done beyond infancy. But genital examination should be kept as minimum as possible due to the child will recall these experiences as traumatic or contributing to a negative body image. In comparison, to children who remain uninformed or misinformed about their condition, children with adequate education will have better opportunities to develop adaptive coping skills, including positive self-image and expectation for fulfilling their future adult life. In puberty, they may develop some anxieties. Repeated genital examinations, medical photography, repeated medical treatments, and atypical genital appearance are particularly anxiety provoking. Some will develop uncertain feeling about their masculinity or femininity, sexual adequacy, or sexual orientation. They often postpone having intimate relationship due to such insecurities and fear of rejection. All of these events can lead to behavioral problems.

Psychological in relatives

The birth of a child with mosaic sex chromosome DSD with ambiguous genitalia often creates confusion for parents. They are faced with the fact that their children are born without a “clear gender” or are born with “two genitals”. This condition will certainly be very difficult to be accepted by parents, especially when there is a lack of information about
children's disorders, so parents often show different expressions such as surprise, anger, sadness, shame and especially for mothers, feelings of guilty. Parents with DSD in their child are often isolate their selves from the community.9

Diagnosing a child with a rare disorder, such as mosaic sex chromosome DSD, is often stressful for parents and families. The level of stress and coping strategies used by parents are influenced by the time of diagnosis, type of disease, severity and cause, presence of non-invasive, invasive or surgical, mental and behavioral changes and treatment or therapy.9

Empirically, coping is a process when an individual is able to manage a problem through emotionally acceptable behavior. Coping can also be interpreted as an individual’s acceptance of demand, the ability to reduce or tolerate pressure, and management to control emotions to reduce stressful situations. Psychological support for parents must be provided continuously, and continues to extend to the whole family, in order to accept the child's condition and use appropriate coping to overcome their condition.9

There are four themes that describe parents' coping strategies, namely parents' efforts to get closer to God, social support, child protection, and decision making about surgery. Almost all parents try to find information about abnormalities that occur in children and accept children as destiny from God. Every parent has a different way approaching to God when dealing with problems related to children. Experience using coping religiosity to be able to accept children's disorders and take lessons from everything that happens to children. Support from family, neighbors, work environment and the environment around the house, even from other parents who have children with DSD is an important factor for parents who have children with DSD.9

**Conclusion**

Psychosocial care for patient and relatives that affected by a disorder of sex development is currently limited. Families struggle with some challenges such as genetic information, medical complex, anatomical differences (whether or not surgery is done), surgical complications, lack of clarity in some gonadal tumor risk, doubt about the stability of the child's gender identity, and fertility potential. Detection of a DSD patient at birth is commonly an acute problem. Some parents explain that a high level of emotional distress and cognitive confusion often occurs at that time.10 The delayed intervention may reduce the quality of life in patients, implying the significance of early detection and diagnosis.

Children diagnosed with DSD have a heavy psychological impact on them or their parents. Depression, anxiety, post-traumatic stress, and uncertainty of cure are some things that might happen to them. Another problem that will occur is that the patient will be treated for a long time. This condition is exacerbated by the culture, which is being considered taboo to talk or discuss abnormality in sexual and genitalia so the parents often keep their child's condition secret and do not look for help.9

DSD is not widely known among health practitioners. Clinicians specialized in DSD treatment are challenged with patient’s and parent’s difficulties in coping with the unusual physical development and the depreciative reactions of their atypicality. It is also limited by diagnostic and treatment facilities. Treatments necessary for survival, aims to reduce physical atypicality and to repair their sexual function. These interventions have been criticized as they impact the child's life and are often performed without the child's consent.11

**References**


