

# A Study on the Self-Concept of Adolescent With Down Syndrome Siblings in Special Needs State School in Jakarta

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## ABSTRACT

**Background:** Down Syndrome is a type of genetic disease caused by abnormalities on chromosome 21 which causes the patients to experience delays in physical and mental development. As a result, this has an impact on the family, including siblings. The purpose of this study was to figure out the image of self-concept on adolescent who has down syndrome siblings in Special Needs State School in Jakarta. **Methods:** The study used descriptive analytic with cross sectional design with a total sample of 31 respondents. The univariate analysis used frequency and proportion as well as average distribution. **Result:** A total of 19 respondents (61.3%) have a high self-concept while 12 respondents (38.7%) have a low self-concept. **Conclusion:** Self Concepts of adolescents can be influenced by how they accept their sibling condition. Therefore, adolescents are expected to adjust their sibling condition who has down syndrome in order to form a good self-concept.

**Keywords:** *Adolescent, Down Syndrome, Self-Concept, Sibling*

## 1. INTRODUCTION

Down syndrome is caused by an abnormality in chromosome 21, out of a total of 23 human chromosomes. Normally, all the chromosomes are paired so that the total is 46. Whereas in people with Down syndrome, there are three chromosomes, or it is called trisomy, so that the number that should be 46 becomes 47. This is what causes the metabolic system in cells to go awry, which causes Down syndrome [1]. The presence of an extra or abnormal chromosome causes people with Down syndrome to experience retardation both physically and mentally [2].

The incidence of Down syndrome in Indonesia, according to the records of the Indonesian Center for Biodiversity and Biotechnology (ICBD) Bogor, is estimated that there are more than three hundred thousand children with Down syndrome [3]. Society often underestimates or even discriminates against children with Down syndrome or other children with special needs. The presence of a child with a certain disability in the family not only affects the lives of the child's parents, but also the entire family [4].

The result of research conducted by Naibaho et al. (2017) found that 50% of adolescents felt obliged to help and care for their siblings with special needs by teaching proper eat, watching, and bathing them. Meanwhile, half of them think that they don't have to

play a role in helping to look after their siblings because they think about their activities outside which is quite a lot [5]. Adolescent siblings of children with special needs have certain strong feelings that may occur because they are driven by shame, and there will likely be negative feelings. There may also be a feeling that family and social life are being constrained and disturbed [6].

Having siblings with special needs, even though it leads to stress, but does not always cause negative things. This can help creative problem solving and personal growth. Children who have siblings with disabilities can appreciate the different things and become more understand and respect of differences between people [7]. However, sometimes siblings of children with disabilities have a worse view of their own adjustment of behavior, physical appearance, and popularity regarding self-concept [8]. The self-concept is formed based on a person's life experiences, relationships and patterns of interaction with other people or the environment [9].

Adolescence is a major period to form self-concept. All adolescents would want to have normal siblings, because in that age range it takes people who are close to them to exchange and share stories. Siblings have an important role in this, because they will spend more time together. Meanwhile, adolescents who have siblings with special needs such as Down syndrome will

have obstacles in communicating with their siblings, so that making them become a more closed person [10].

Nurses can deal with the impact that occurs due to denial reactions from adolescents who have siblings with Down syndrome. The rejection that occurs can lead to a lack of self-confidence as a result of the shame of having a sibling with Down syndrome. This will later affect the self-concept of adolescents. Therefore, nurses can act as a counselor who help adolescents to integrate the facts and express their feelings as well as an educator in helping to form the self-concept of adolescents who have siblings with Down syndrome.

**2. METHODS**

The design of this study was carried out quantitatively with a descriptive analytic type. This study design used a cross sectional approach. The population which was taken was adolescents who have Down syndrome siblings in Special Needs State School in Jakarta, with a total population of 31 people. In this study, because the number of respondents was only a few, the entire population was used as the research sample (31 people). The inclusion criteria in this study were: 1.) Down syndrome siblings in SLB Negeri Jakarta, which are included in the adolescent category, 2.) Cooperative, able to work well together, 3.) Willing to fill out informed consent. While the exclusion criteria include: 1.) Down syndrome siblings who are still children or

adult, 2.) Respondents who were not present at the time of filling out the questionnaire.

The research location was SLB Negeri in Jakarta, including SLB Negeri 01 Jakarta, SLB Negeri 02 Jakarta and SLB Negeri 07 Jakarta. The data collection process for research began in April-June 2019 by distributing questionnaires to respondents. There are two questionnaires used and the two questionnaires are standardized and can be used to measure the results of acceptance of adolescents with Down syndrome siblings and their self-concept.

The first questionnaire is the Sibling Inventory of Behavior questionnaire (Schaefer & Edgerton, 1979). This questionnaire includes aspects such as empathy, kindness, involvement, acceptance, anger, teasing, avoiding and embarrassment. This questionnaire contains 28 statements to determine the acceptance of siblings and uses a Likert scale with 5 answer choices. The second questionnaire is the Adolescent Self-Concept Short Scale: A Version of PHSCS (Veiga & Leite, 2016). Includes aspects such as anxiety, physical appearance, behavior, popularity, happiness, and intellectual. This questionnaire contains 30 statements to determine adolescent self-concept. The method of measurement uses a Likert scale, which contains 6 answer choices [11].

This study was approved by The Health Research Ethics Committee University of Pembangunan Nasional Veteran Jakarta with a letter-number B/1913/5/2019/KEPK.

**3. RESULT**

**Table 1. Characteristics of Respondents by Gender (n=31)**

Characteristics	Sub Characteristic	Frequency	Percentage (%)
<b>Gender</b>	Male	15	48,4
	Female	16	51,6
<b>Total</b>		<b>31</b>	<b>100,0</b>

Based on table 1, the characteristics of respondents by gender category found that male respondents are 15 people (48,4%) while female respondents are 16 people (51,6%). So, in this study, the majority of adolescent

respondents with down syndrome siblings in Special Needs State School in Jakarta were female.

**Table 2. Characteristics of Respondents by Age (n=31)**

Characteristics	Mean	Median	SD	Min-Max	95% CI
<b>Age</b>	15,29	16	2,912	11-20	14,22-16,36

The average age of the adolescents as shown in table 2 is 15,29 with a standard deviation of 2,912 and median value 16. The youngest age is 11 years old and the

oldest is 20 years old. The result of the analysis can be concluded that 95% believe that the average age of adolescents is between 14,22 until 16,36 years old.

**Table 3. Results of Sibling Inventory of Behaviour Questionnaire (n=31)**

Statement	Never	Seldom	Sometimes	Often	Always
I'm pleased by the progress he/she makes	0	0	1	18	12
I show/tell him/her interesting thing	0	2	4	16	9
I tease/annoys him/her	7	5	13	6	0
I help him/her in any way possible	0	0	2	17	12
I get angry with him/her	3	6	19	3	0
I accept him/her as a playmate	0	0	2	13	16
I'm embarrassed with him/her in public	23	5	2	1	0
I want him/her to succeed	0	0	0	16	15
I stay away from him/her if possible	21	4	5	1	0
I get ideas for things we can do together	0	2	8	14	7
I do things to please him/her	0	1	0	15	15
I fuss/argue with him/her	11	7	10	1	2
I have fun at home with him/her	0	0	1	16	14
I act ashamed of him/her	24	5	2	0	0
I show sympathy when things are hard for him/her	0	1	2	16	12
I frown/pout when I have to spend time with him/her	17	12	2	0	0
I teach him/her new skills	1	1	7	14	8
I say unkind things to him/her	16	14	1	0	0
I help him/her adjust to new situations	1	2	2	14	12
I treat him/her as a good friends	0	0	1	8	22
I try to avoid being seen with him/her	25	5	0	0	1
I'm concerned for his/her welfare/happiness	0	0	0	14	17
I would rather be alone than with him/her	24	6	1	0	0
I make plans that include him/her	0	1	9	14	7
I hurt his/her feelings	17	13	0	0	1
I try to comfort him/her when he/she is upset	1	0	5	11	14
I complain about the trouble that he/she makes	14	9	6	2	0
I'm glad to have him/her in the family	0	0	0	8	23

In the table above, it can be seen the number of respondents who answered the choice of never, seldom,

sometimes, often, and always for each question in the questionnaire

**Table 4. Analysis of Adolescent Acceptance with Down Syndrome Siblings in Special Needs State School in Jakarta (n=31)**

Characteristics	Mean	Median	SD	Min-Max	95% CI
Adolescent Acceptance with Down Syndrome Siblings	119,84	120	9,557	90-134	116,33-123,34

The average of the acceptance score of adolescent with down syndrome siblings is 119,84 with a standard deviation of 9,557 and a median value 120. The largest of the total score is 134, while the smallest score is 90 based on the maximum total score on the questionnaire is 140 and the smallest is 28. The result of the analysis

can be concluded that it is 95% believed the average of the total acceptance score of adolescents with down syndrome siblings ranges from 116,33 to 123,34. The higher the total score obtained, the better respondent's acceptance.

**Table 5. Results of Adolescent Self-Concept Short Scale Questionnaire (n=31)**

Statement	Total Dis-agreement	Dis-agreement	More Dis-agreement Than Agreement	More Agreement Than Dis-agreement	Agreement	Total Agreement
I'm often afraid	1	18	0	8	3	1
I'm good-looking	0	2	2	10	14	3
I often get into trouble	1	19	4	4	2	1
I feel left out of thinks	3	17	7	2	2	0
I'm a happy person	0	0	0	4	17	10
I'm good in my schoolwork	0	1	1	10	17	2
I cry easily	5	9	5	6	6	0
I have a pleasant face	0	0	2	9	18	2
I get into a lot of fights	13	11	6	1	0	0
I'm among the last to be chosen for games	3	12	9	3	3	1
I'm unhappy	13	11	5	0	0	2
My classmates in school think I have a good ideas	0	1	0	14	13	3
I'm nervous	5	11	7	3	4	1
I have nice hair	1	2	0	6	17	5
In school I'm a dreamer	6	15	7	2	1	0
My classmates make fun of me	9	15	5	2	0	0
I'm cheerful	0	1	2	9	13	6
I can give a good report in front of the class	0	0	1	12	15	3
I get nervous when the teacher calls on me	4	10	8	4	3	2
My looks bother me	9	15	5	1	0	1
I do many bad things	12	12	6	0	0	1
It is hard for me to make friends	9	15	7	0	0	0
I'm lucky	10	16	5	0	0	0
I'm an important member of my class	0	1	2	12	12	4
I'm shy	3	12	7	5	4	0
I'm strong	0	2	4	7	12	6
I behave badly at home	12	13	4	1	0	1
In games and sports, I watch instead of playing	5	8	5	8	2	3
I'm often sad	7	14	7	2	1	0
I forget what I learn	6	10	10	4	0	1

Table 5 shows the number of respondents who answered the choice of total disagreement, disagreement, more disagreement than agreement, more agreement than

disagreement, agreement, and total agreement for each question in the questionnaire.

**Table 6. Analysis of Adolescent Self-Concept with Down Syndrome Siblings in Special Needs State School in Jakarta (n=31)**

Characteristics	Mean	Median	SD	Min-Max	95% CI
Adolescent Self-Concept with Down Syndrome Siblings	138,68	140	11,232	116-164	134,56-142,80

The average of the self-concept score of adolescent with down syndrome siblings is 138,68 with a standard deviation of 11,232 and a median value 140. The largest of the total score is 134, while the smallest score is 90 based on the maximum total score on the questionnaire is 180 and the smallest is 30. The result of the analysis can be concluded that it is 95% believed the average of the total self-concept score of adolescents with down syndrome siblings ranges from 134,56 to 142,80. The higher the total score obtained, the better self-concept of the respondent.

#### 4. DISCUSSION

This study divides adolescent acceptance and self-concept into two categories, high and low based on the mean value. According to this, 20 respondents (64.5%) have a high acceptance, while the remaining 11 respondents (35.5%) have low acceptance. For the self-concept, 19 respondents (61.3%) have a high self-concept and 12 respondents (38.7%) have a low self-concept.

The stages of acceptance begin with the denial (rejection) phase and culminate in the acceptance phase [12]. The acceptance phase is the last phase which is the target of all conditions for the incident experienced by a person. The other four phases are negative statements that must be abandoned in a positive direction. What is meant in this phase is that someone can accept reality, face it, and choose to do what they can in it [13]. Acceptance is an ongoing process and never constant. Acceptance is an open attitude taken from life and this attitude needs to be lived from time to time [14].

Cindy & Sudarji's research states that adolescents who have reached the acceptance stage have a positive view from within themselves towards their siblings with disabilities, communication within the family, understanding, and knowledge about the condition of their siblings with disabilities. Meanwhile, respondents who have not yet reached the acceptance stage have negative perceptions of the condition of their siblings and lack of communication within the family [15].

In adolescence, self-concept is easily distracted. Adolescent's behavior will reflect the self-concept they have. Various kinds of situations and conditions that occur in adolescent life will form personality patterns through their influence on self-concept, for example the psychological and physical changes that occur at this time [16]. Self-concept is very important in terms of understanding someone and their behavior. This self-concept is formed from someone's internal experiences, relationships with other people, and their interactions with the outside world. Interactions have a strong influence on human behavior [9]

The components of self-concept are identity, body image, self-esteem, and role performance. Someone's response to her/his self-concept fluctuates throughout the range of self-concept responses, from adaptive to

maladaptive [17]. Branje et al (2014) in their research explain that high self-concept can be related to various kinds of adjustments that exist and is supported by open communication with parents. Meanwhile, the problem of developing one's self-concept can increase internal disorders such as symptoms of depression and anxiety.[18].

Santoso and Handayani (2018) in their research entitled "psychological adjustment effectivity in elder siblings of children with down syndrome" describes the factors that affect the adjustment of siblings of children with down syndrome are the involvement of parents and relationships with siblings. The presence of siblings can provide several functions that cannot be replaced by parents, such as being always ready and available to accompany siblings in various ways [19].

Sibling relation is important to adolescents, in this case forming adolescents to be more responsible. They think that they have duties and obligations as brothers/sisters to do, but in certain cases they and their younger siblings can joke and discuss like friends. Effective communication can occur when adolescents know how to convey messages using language that is easily understood by their siblings [20].

#### 5. CONCLUSION

The analysis of 31 adolescents with down syndrome siblings obtained 20 respondents (64.5%) have a high acceptance, while the remaining 11 respondents (35.5%) have low acceptance. For the self-concept, 19 respondents (61.3%) have a high self-concept and 12 respondents (38.7%) have a low self-concept.

With this research, adolescents are expected to increase their acceptance of their siblings with Down syndrome in order to form a better self-concept. Furthermore, parents can become role models or good examples for their children. Nursing institutions, especially psychiatric nurses, must provide preventive, promotive and can be a counselor for adolescents to express their hearts and minds. The next researchers can examine about the denial that occurs in adolescents with children with special needs, how the community stigma about families with these children, make better measuring instruments, and try research using qualitative methods.

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