Children Comorbidities Associated with High Parental Self-Efficacy: A Study on Parents of Children with Down Syndrome

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Abstract: *Background*: Parental self-efficacy (PSE) in parents of children with Down syndrome (DS) refers to parents' efficacy in their capability as parents nurturing their children with DS. Therefore, this study aimed to determine factors that may influence PSE in parents of children with DS.

Methods: This cross-sectional study was carried out on 87 parents of children with DS. Self-Efficacy Parenting Task Index (SEPTI) was administered to measure PSE levels. Spearman's rank correlation and independent t-test were applied to determine factors that may influence PSE. These include gender, children's age, duration of being diagnosed with DS, comorbidities, number of children in the family, parents' age, educational level, monthly household income, place of residence, genetic counseling, and support group.

Results: The results showed that the median scores of SEPTI were 114 (101-143), and 57.5% of parents had moderate PSE levels. Significant factors affecting PSE include children with comorbidities (r = - 0.197, p = 0.033) and the place of residence (r = -0.212, p = 0.024). Parents of children with fewer comorbidities (119 (109-128), *p* =0.034), those with higher education (118 (110-132), *p* = 0.031), and those living in urban areas (115 (101-143), *p* = 0.025) demonstrated higher PSE. Additionally, multiple linear regression analysis showed children's comorbidity as the most significant predictor in PSE (PR= 0.17, 95% CI = 0.03 - 0.77, *p* = 0.020).

Conclusions: Children with comorbidities affect self-efficacy in parents of children with DS, besides the level of parent's education and the place of living identity.

Keywords: Down Syndrome, parental self-efficacy, comorbidities, level of education, place of living identity.

INTRODUCTION

Down syndrome (DS) is a common genetic condition often found in individuals with intellectual disabilities and congenital heart defects caused by the presence of an extra full or partial copy of chromosome 21 [1,2]. World Health Organization (WHO) estimated the incidence of DS to be between 1 and 10 out of 1,000 births worldwide. The prevalence is also increasing in the global population [1,3,4]. According to data from the Indonesian Basic Health Research (Riskesdas) issued in 2019, the incidence of DS cases among children aged 24 to 59 months showed a steady increase. In 2010, the incidence was recorded at 0.12%, rising to 0.13% in 2013 and 0.21% in 2018 [5].

Individuals with DS have different health conditions and life changes. Some require intensive health care from birth, while others face minimal complications. Health problems often experienced by individuals with DS include congenital heart disease, Obstructive Sleep Apnea (OSA), thyroid diseases, epilepsy, gastrointestinal diseases, hearing and vision problems, intellectual disabilities, developmental problems, immunological dysfunction, hematological and musculoskeletal problems [1].

Children with intellectual disabilities have obstacles in carrying out daily activities due to limited intelligence and ability to interact socially, which affects the psychological condition of parents [6]. The feelings of parents after being informed of children with DS diagnosis include shock, anger, sadness, despair, confusion, stress, and disappointment [7-9]. One of the factors that affects the psychological well-being of parents is parental self-efficacy (PSE) [10].

PSE is the belief in oneself as a parent who can carry out roles and duties in caring for children [11]. Pasyola *et al.* [12], in a study of mothers having children with intellectual disabilities, found that the higher the PSE, the higher the psychological well-being. Meanwhile, the lower the PSE, the lower the psychological well-being and the more susceptible to stress and depression. PSE provides benefits to the parent-child relationship, parental mental health, and children's development [13-16].

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The increase in the developmental status of DS patients is influenced by the presence of comorbidity, socioeconomic status, home environment, and parental education level [17]. Based on the results of a systematic review conducted by Harita and Chusairi [18], factors that influence PSE in parents of children with disabilities include gender, fatigue, experience of caring for children with disabilities, social support, stress, stigma, and parental participation.

Early diagnosis and intervention of DS do matter, as late diagnosis and management can lead to worse clinical conditions and comorbidities [19,20]. Providing referrals for genetic counseling of the suspect diagnosis of DS is important [21]. Genetic counseling has benefits and psychological support for parents [21,22]. However, the role of the genetic counseling process in PSE has not been evaluated in previous studies. This study hypothesized that child factors (age, gender, duration since diagnosis, comorbidities, number of children in the family) and parental factors (age, gender, level of education, household income, place of living identity, genetic counseling, support group) are factors that may affect the PSE in parents of children with DS. Therefore, this study aimed to identify factors that may influence the PSE in parents of children with DS and identify the factors that will increase PSE in parents of children with DS.

MATERIALS AND METHODS

Study Design

This observational study used a cross-sectional approach. It was conducted on parents of children with DS from July to September 2023 at Dr. Kariadi General Hospital and Diponegoro National Hospital (RSND), Semarang.

Respondents

The samples were selected using a consecutive sampling method from all parents having children clinically diagnosed with DS at Dr. Kariadi General Hospital and RSND, Semarang. During the study period, there were 87 parents with DS children who met the inclusion criteria. These include parents who have had children diagnosed with DS by a pediatrician and those caring for children with DS who were willing to sign an informed consent form stating their willingness to participate in this study. Exclusion criteria include parents of children with DS who were visiting Dr. Kariadi General Hospital and RSND for the first time and have not been diagnosed by a pediatrician. In addition, children with DS and not cared for by parents were excluded.

Instruments

The Basic Parent and Child Data Questionnaire was used to obtain children's data on age, gender, duration since diagnosis, comorbidities (congenital heart disease, thyroid diseases, hearing diseases, visual impairment, developmental delays, behavioral problems, gastrointestinal diseases, musculoskeletal problems), and the number of children in the family. The parents' data collected included age, gender, education level, income, place of residence, genetic counseling process, and attending support groups.

The genetic counseling process instrument consisted of 9 Yes and No questions based on the definition of the process according to the National Society of Genetic Counselors (NSGC) [20]. The process includes (1) Interpreting family health history and to determine the risk of disease recurrence, for example, the question, "Have you ever received an explanation from a medical professional regarding the diagnosis of your child's condition?" (2) Providing education on disease inheritance patterns, genetic testing, management, prevention, resources and studies related to the disease, for example, "Have you ever received information from medical personnel regarding the risk of having another child with the same condition?" (3) Genetic counseling to promote informed choices and adaptation to risks or conditions, for example, "Have you ever received information on support from medical personnel such as local or national support group communities?"

Self-Efficacy Parenting Tasks Index (SEPTI) is an instrument for measuring PSE. It has been used and validated in some studies in Indonesia. Rahayu and Mangunsong [24] validated the SEPTI in parents of children with special needs from various regions in Indonesia, with Cronbach α being 0.906. Pasyola *et al.* [10] validated it in mothers who had children with intellectual disabilities, with Cronbach α being 0.843. Salsabila *et al*. [25] validated it with the Cronbach α of 0.813.

This study used the SEPTI scale by Coleman and Karraker [26], which has been translated into Indonesian and validated by Kharisma [27] on 30 parents of children with ASD. The scale consists of 39 question items and has a reliability coefficient of α = 0.966. The factors assessed by the scale are emotional availability, nurturance, protection, discipline, play, teaching, and routine.

SEPTI was filled out by parents with measurements using a Likert scale from a scale of 1, "strongly disagree", to a scale of 4, "strongly agree", with a total score range of 39-156. High SEPTI scores indicate high PSE, and the total score was categorized into less able (39-78), able (79-117), and very able (118-156).

Data Collection

Parents of children with DS were interviewed using the Basic Parent and Child Data Questionnaire regarding questions on the genetic counseling process. Subsequently, parents were given the option to fill out the SEPTI scale independently or accompanied. The data collected were checked for completeness.

Data Analysis

Data were analyzed using the Jamovi 2.3.28 computer program. Spearman's rank correlation and Independent t-test were used to determine the correlation and comparison between age, gender, duration since diagnosis, comorbidity, number of children in the family, education level, income, place of residence, and support group to PSE.

Variables with 2 groups that were not normally distributed used the Mann-Whitney statistical test. Meanwhile, variables with more than 2 groups that were not normally distributed used the Kruskal-Wallis + Post Hoc Mann-Whitney statistical test. The results of the variables in the bivariate analysis with a p-value <0.25 were continued with multivariate analysis. The difference was considered statistically significant when the p-value was <0.05. Descriptive analysis was performed on genetic counseling process data.

RESULTS

This study was conducted on 87 parents of children with DS, including 12 fathers and 75 mothers. Parents aged > 35 years were 64 (73.6%) with a mean of (39.5 (6.6)), and the majority, namely 44 (50.6%), had secondary education (SMA/MA/SMK). A total of 59 (67.8%) parents had income > IDR 2,000,000, 80 (92%) lived in urban villages, and 57 people (65.5%) joined support groups. The gender of children was mostly male, with a total of 50 (57.5%), while 41 (47.1%) were mostly aged 1-3 years, with a median age of (31 (5-144) months, 58 (66.7%) have been diagnosed for 1-5 years, 75 (86.2%) had > 1 comorbidities, and 43 (49.4%) were members of a family with > 3 children (Table **1**). In total, 50 (57.5%) and 37 (42.5%) of parents had PSE in the capable and very capable category, with none in the less capable (Table **2**).

Based on Table **3**, 79 parents (90.80%) have received an explanation from medical personnel regarding the diagnosis of their children's condition. Explanations and information on physical characteristics that indicate DS were obtained by 78 parents (89.65%), while explanations regarding comorbidities or medical problems related to the diagnosis and the occurrence of DS were obtained by 88.50% and 82.75%, respectively. The recurrence risk of having a child with the same condition as DS was only obtained from 59 parents (67.82%). There were 66 parents (75.86%) who had received information regarding chromosome examination. The majority, 83 and 85 (95.40% and 97.70%), have received management or treatment related to children's condition, including evaluation of the growth system, hearing, eyes, thyroid profile, cardio, and management of referrals to other specialists when needed. Additionally, most parents, 66 people (75.86%), have received information on local and national support group communities.

Analysis of the influence between children and parents' factors on the total PSE score revealed a significant negative correlation in children with comorbidities (r = -0.197, *p* = 0.033) and place of living identity (r = -0.212, *p* = 0.024). A significant difference was obtained in child comorbidities (119 (109-128), *p* =0.034), parental education (118 (110-132), *p* = 0.031), and place of living identity (115 (101-143), *p* = 0.025) (Table **4**). Multivariate analysis was carried out on comorbidities, parents' education, and area of residence simultaneously to obtain the dominant factor that may predict parents' PSE score (Table **5**). The results showed that in children with comorbidities (PR= 0.17, 95% CI = 0.03 - 0.77), *p* = 0.020 was the dominant factor influencing PSE score. Parents of children with DS who have more comorbidities have a lower PSE than those who have children with one comorbidity.

The analysis results of children and parents' factors affecting the domains of PSE in parents of children with DS are presented in Table **6**. There are seven specific domains in PSE using SEPTI, namely emotional availability, nurturance, protection, discipline, play, teaching, and routine. The analysis results of children

Table 1: Characteristics of Parents of Children with DS

Category	Father (n=12) n (%)	Mother (n=75) n (%)	Total (n=87) n (%)
Children Factors			
Gender			
Male	8 (66.7)	42 (56)	50 (57.5)
Female	4 (33.3)	33 (44)	37 (42.5)
Age			
0 - 1 year	2 (16.7)	6 (8.0)	8 (9.2)
1 - 3 years	4 (33.3)	37 (49.3)	41 (47.1)
3 - 5 years	2 (16.7)	15 (20.0)	17 (19.5)
> 5 years	4 (33.3)	17 (22.7)	21 (24.1)
Duration since diagnosis			
< 1 year	2 (16.7)	7 (9.3)	9 (10.3)
1-5 years	6 (50)	52 (69.3)	58 (66.7)
> 5 years	4 (33.3)	16 (21.3)	20 (23)
Comorbidities			
1 Comorbidities	1 (8.3)	11 (14.7)	12 (13.8)
> 1 Comorbidities	11 (91.7)	64 (85.3)	75 (86.2)
Number of children in the family			
1	1 (8.3)	13 (17.3)	14 (16.1)
2	5 (41.7)	25 (33.3)	30 (34.5)
>3	6 (50.0)	37 (49.3)	43 (49.4)
Parents' Factors			
Age			
< 35 years	1 (8.3)	22 (29.3)	23 (26.4)
≥ 35 years	11 (91.7)	53 (70.7)	64 (73.6)
Education			
Primary education (Elementary School (SD) - Junior High School (SMP))	1 (8.3)	20 (26.7)	21 (24.1)
Secondary education (Senior High School (SMA)/Vocational High School (SMK))	9 (75)	35 (46.7)	44 (50.6)
Higher education	2 (16.7)	20 (26.7)	22 (25.3)
Income			
> IDR 2.000.000	9 (75)	50 (66.7)	59 (67.8)
< IDR 2.000.000	3 (25)	25 (33.3)	28 (32.2)
Residence			
Urban Village	11 (91.7)	69 (92)	80 (92)
Rural Village	1 (8.3)	6 (8)	7 (8)
Support Group			
Joined	4 (33.3)	53 (70.7)	57 (65.5)
Not Joined	8 (66.7)	22 (29.3)	30 (34.5)

Description: IDR = Indonesian Rupiah.

Table 2: Characteristics of Parental Self-Efficacy Levels in Parents of Children with DS

Score Category	Less Capable	Capable	Very Capable	Median (Min-Max)
Father (n=12)	0 (0%)	5 (41.7%)	7 (58.3%)	116 (101-128)
Mother (n=75)	0 (0%)	45 (60%)	30 (40%)	114 (102-143)
Total (n=87)	0 (0%)	50 (57.5%)	37 (42.5%)	114 (101-143)

Description: Less able = 39-78; Capable = 79-117; Very Capable = 118-156.

Table 3: Descriptive Data of "Yes" Responses to the Genetic Counseling Process

Description	Father (n=12)	Mother (n=75)	Parents (n=87)
	n (%)	n (%)	n (%)
Have you ever received an explanation from a medical professional regarding the diagnosis of your child's condition?	10 (83.33)	69 (92.00)	79 (90.80)
Have you ever received an explanation and provision of information explaining physical characteristics that point to DS?	9 (75.00)	69 (92.00)	78 (89.65)
Have you ever received an explanation regarding medical problems related to the diagnosis suffered by children?	10 (83.33)	67 (89.33)	77 (88.50)
Have you ever received an explanation of information from a medical professional regarding why DS occurs?	9 (75.00)	63 (84.00)	72 (82.75)
Have you ever received an explanation of the risk of having another child with the same condition as DS?	5 (41.67)	54 (72.00)	59 (67.82)
Have you ever received an explanation for chromosome examination?	5 (41.67)	61 (81.33)	66 (75.86)
Have you ever received an explanation of management/treatment related to children's condition? (example: evaluation of growth systems, hearing, eyes, thyroid profile, cardio).	12 (100)	71 (94.66)	83 (95.40)
Have you ever received an explanation referral to other specialists if needed? (example: medical rehabilitation, heart, child development)?	12 (100)	73 (97.33)	85 (97.70)
Have you ever received information on support from medical professionals such as local or national support group communities (Example: POTADS, parents' groups with children who have DS)?	6 (50.00)	60 (80.00)	66 (75.86)

Table 4: Factors Affecting Parental Self-Efficacy in Parents of Children with DS

Category	r	*p*	Median	*p*
			(Min-Max)	
Child Factors				
Gender				
Male	-0.105	0.167[b]	115 (101-143)	0.167[c]
Female			114 (105-127)	
Age				
0 - 1 year	-0.063	0.719[b]	114 (101-132)	0.833[d]
1 - 3 years			115 (102-143)	
3 - 5 years			114 (104-128)	
> 5 years			114 (106-141)	
Duration since diagnosis				
< 1 year	-0.017	0.561[b]	112 (101-132)	0.892[d]
1-5 years			115 (102-143)	
> 5 years			114(106-141)	

(Table 4). Continued.

Category	r	p	Median	p
			(Min-Max)	
Comorbidities				
1 comorbidity	-0.197	0.033[b]*	119 (109-128)	0.034[c]*
> 1 comorbidity			114 (101-143)	
Number of children in the family				
1	0.161	0.069[b]	114 (101-126)	0.189[d]
2			112 (104-141)	
>3			115 (102-143)	
Parental Factors				
Age				
< 35 years	-0.041	0.355[b]	114 (101-132)	0.355[c]
≥ 35 years			114 (102-143)	
Gender				
Male	-0.092	0.197[b]	116 (101-128)	0.197[c]
Female			114 (102-143)	
Education[a]				
Primary education (Elementary School (SD) - Junior High School (SMP))	0.156	0.075[b]	114 (105-125)	0.031[d]*
Secondary education (Senior High School (SMA)/Vocational High School (SMK))			113 (101-143)	
Higher education			118 (110-132)	
Income				
> IDR 2.000.000	-0.147	0.913[b]	115 (101-141)	0.087[c]
< IDR 2.000.000			113 (102-143)	
Residence				
Urban Village	-0.212	0.024[b]*	115 (101-143)	0.025[c]*
Rural Village			108 (102-122)	
Support Group				
Joined	-0.008	0.528[b]	114 (102-141)	0.473[c]
Not Joined			115 (101-143)	

Description: IDR = Indonesian Rupiah. [a]post-hoc analysis between education group: primary education vs. secondary education, $p = 0.579$; primary education vs. higher education, $p = 0.334$; secondary education vs. higher education, $p = 0.024$* | [b]Spearman's rank correlation | [c]Mann-Whitney | [d]Kruskal-Wallis | *significant $p < 0.05$.

factors influencing the domains of PSE obtained significant results, namely gender in the emotional availability domain (male 17 (13-20), female 16 (15-19), $p = 0.018$). Comorbidities factors in children have a significant effect on the emotional availability domain (1 comorbidity 17 (15-19), > 1 comorbidity 16 (13-20), $p = 0.019$) and the routine domain (1 comorbidity 18.5 (17-20, > 1 comorbidity 18 (15-24), $p = 0.022$). The number of children in the family also has a significant effect on the teaching domain (one number of children in the family 21 (17-24), two number of children in the family 20 (17-27), more than three number of children in the family 21 (17-28), $p = 0.031$). The gender factor of parents shows significant results in the protection domain (male 15 (11-20), female 17 (13-29), $p = <0.001$). Parents' education factor had a significant effect on the PSE nurturance domain (primary education 20 (16-23), secondary education 18.5 (15-24), higher education 20 (18-23), $p = 0.014$). Additionally, parental income has a significant effect on the routine domain (> IDR 2.000.000 18 (15-24), < IDR 2.000.000 17 (15-18), $p = 0.039$). Parents' residence factor significantly influenced nurturance (urban village 17 (13-20), rural village 16 (14-18), $p = 0.011$),

Table 5: Multivariate Analysis of Factors Affecting Parental Self-Efficacy in Parents of Children with DS

Category	PR (95%CI)	p-value
Child Factors		
Gender		
Male	0.51 (0.19-1.36)	0.18
Female		
Comorbidities		
1 Comorbidity	0.17 (0.03-0.77)	0.02*
> 1 Comorbidity		
Number of children in the family		
1		
2		
>3	1.16 (0.61-2.21)	0.64
Parents' Factors		
Gender		
Male		
Female	0.42 (0.11-1.59)	0.20
Education		
Primary education (Elementary School (SD) - Junior High School (SMP))		
Secondary education (Senior High School (SMA)/Vocational High School (SMK))		
Higher education	1.28 (0.62-2.63)	0.50
Income		
> IDR 2.000.000	0.96 (0.33-2.78)	0.95
< IDR 2.000.000		
Residence		
Urban Village	0.28 (0.03-2.65)	0.27
Rural Village		

Description: IDR = Indonesian Rupiah; PR = prevalence risk; *significant $p < 0.05$.

protection (urban village 13 (10-20), rural village 11 (10-14), $p = 0.021$), and routine domain (urban village 18 (15-24), rural village 17 (15-18), $p = 0.019$).

DISCUSSION

This study aimed to determine factors influencing PSE in parents of children with DS. The results showed that children's comorbidities, level of parent education, and place of living identity are factors that influence the level of PSE in parents of children with DS. Parents of children with one comorbidity have higher PSE in the domain of emotional availability and routine compared to those having more than one comorbidity.

Mothers of children with DS apply a more permissive parenting style, provide less routine structure, and have fewer expectations than those with typical children [28]. Parents of children with DS often show negative parenting styles related to their children's behavioral problems [29]. Children who have better general health, high levels of developmental function abilities, high social-emotional abilities, and fewer behavioral problems are associated with high PSE [24,30-33].

Comorbidities in children with DS require parents to have good health literacy and early intervention. Parents with higher educational backgrounds have higher PSE in the domain of nurturance compared to those who have lower educational backgrounds. Maternal health literacy is significant for education, PSE, and early childcare practices [34]. Parents with higher education can actively access childcare

Table 6: Factors Affecting Parental Self-Efficacy Domain in Parents of Children with DS

Category	Emotional Availability		Nurturance		Protection		Discipline		Play		Teaching		Routine	
	M *(min-max)*	*p*	*M* *(min-max)*	*p*	*M* *(min-max)*	*p*	*M* *(min-max)*	*p*	*M* *(min-max)*	*p*	*M* *(min-max)*	*p*	*M* *(min-max)*	*p*
Children Factors														
Gender		0.018^{b*}		0.125^{b}		0.441^{b}		0.819^{b}		0.209^{b}		0.094^{b}		0.201^{b}
Male	17		19		13		13.5		14		21		18	
	(13-20)		(15-24)		(10-18)		(10-17)		(12-17)		(17-28)		(15-24)	
Female	16		19		13		14		14		21		18	
	(15-19)		(16-23)		(11-20)		(10-16)		(12-17)		(17-24)		(15-21)	
Age		0.202^{c}		0.995^{c}		0.699^{c}		0.642^{c}		0.534^{c}		0.731^{c}		0.537^{c}
0 - 1 year	17		19		13		13.5		13.5		21		18	
	(13-19)		(15-23)		(12-16)		(12-15)		(12-15)		(17-23)		(15-22)	
1 - 3 years	17		19		14		14		14		21		18	
	(14-20)		(15-24)		(10-18)		(11-17)		(12-17)		(17-28)		(15-24)	
3 - 5 years	16		20		12		13		14		21		18	
	(15-19)		(17-22)		(11-18)		(10-16)		(12-16)		(18-23)		(15-20)	
> 5 years	16		19		13		14		14		20		18	
	(13-20)		(16-24)		(11-20)		(11-17)		(12-17)		(18-27)		(15-23)	
Duration since diagnosis		0.174^{c}		0.977^{c}		0.945^{c}		0.972^{c}		0.257^{c}		0.439^{c}		0.298^{c}
< 1 year	17		19		13		14		14		21		18	
	(13-19)		(15-23)		(12-16)		(12-15)		(12-15)		(17-23)		(15-22)	
1-5 years	16.5		19		13		14		14		21		18	
	(14-20)		(15-24)		(10-18)		(10-17)		(12-17)		(17-28)		(15-24)	
> 5 years	16		19		13		14		13.5		20		18.5	
	(13-20)		(16-24)		(11-20)		(11-17)		(12-17)		(18-27)		(15-23)	
Comorbidity		0.019^{b*}		0.382^{b}		0.241^{b}		0.201^{b}		0.078^{b}		0.104^{b}		0.022^{b*}
1 Comorbidity	17		19.5		13.5		14		14		21.5		18.5	
	(15-19)		(16-22)		(11-18)		(10-16)		(13-16)		(19-24)		(17-20)	
> 1 Comorbidity	16		19		13		14		14		21		18	
	(13-20)		(15-24)		(10-20)		(11-17)		(12-17)		(17-28)		(15-24)	
Number of children in the family		0.149^{c}		0.689^{c}		0.958^{c}		0.531^{c}		0.918^{c}		0.031^{c*}		0.184^{c}
1	16		19.5		13.5		13.5		13.5		21		18	
	(13-18)		(15-23)		(11-15)		(11-16)		(12-16)		(17-24)		(15-20)	
2	16		19		13		13.5		14		20		17	
	(13-20)		(16-24)		(11-20)		(11-17)		(12-17)		(17-27)		(15-23)	

>3	17		19		13		14		14		21		18	
	(15-20)		(15-24)		(10-18)		(10-17)		(12-17)		(17-28)		(15-24)	
Parental Factors														
Age		0.819[b]		0.290[b]		0.459[b]		0.706[b]		0.323[b]		0.266[b]		0.223[b]
< 35 years	16		20		13		13		14		21		18	
	(13-19)		(15-23)		(10-16)		(11-16)		(12-16)		(17-24)		(15-22)	
≥ 35 years	17		19		13		14		14		21		18	
	(13-20)		(15-24)		(10-20)		(10-17)		(12-17)		(17-28)		(15-24)	
Gender		0.688[b]		0.829[b]		<.0.001[b]*		0.595[b]		0.811[b]		0.655[b]		0.141[b]
Male	16		18.5		15		14		13.5		20.5		18	
	(13-19)		(15-21)		(11-20)		(11-15)		(13-17)		(17-26)		(15-20)	
Female	17		19		13		14		14		21		18	
	(13-20)		(15-24)		(10-16)		(10-17)		(12-17)		(17-28)		(15-24)	
Education[a]		0.149[c]		0.014[c]*		0.662[c]		0.535[c]		0.219[c]		0.070[c]		0.258[c]
Primary education (Elementary School (SD) - Junior High School (SMP))	16		20		13		14		13		21		18	
	(14-19)		(16-23)		(11-18)		(10-15)		(12-16)		(18-24)		(15-20)	
Secondary education (Senior High School (SMA)/Vocational High School (SMK))	16		18.5		13		13		14		20		17	
	(13-20)		(15-24)		(10-17)		(11-17)		(12-17)		(17-28)		(15-24)	
Higher education	17		20		13.5		14		14		21		18	
	(15-19)		(18-23)		(10-20)		(10-16)		(12-17)		(18-25)		(15-22)	
Income		0.153[b]		0.159[b]		0.104[b]		0.801[b]		0.223[b]		0.202[b]		0.039[b]*
> IDR 2.000.000	17		19		13		14		14		21		18	
	(13-20)		(15-24)		(10-20)		(10-17)		(12-17)		(17-27)		(15-23)	
< IDR 2.000.000	16		18		13		14		14		20		17	
	(15-20)		(15-24)		(10-16)		(11-17)		(12-17)		(17-28)		(15-24)	
Resident		0.074[b]		0.011[b]*		0.021[b]*		0.831[b]		0.762[b]		0.124[b]		0.019[b]*
Urban Village	17		19		13		14		14		21		18	
	(13-20)		(15-24)		(10-20)		(10-17)		(12-17)		(17-28)		(15-24)	
Rural Village	16		17		11		14		14		20		17	
	(14-18)		(15-21)		(10-14)		(11-15)		(13-17)		(17-22)		(15-18)	
Support Group		0.415[b]		0.138[b]		0.916[b]		0.668[b]		0.542[b]		0.455[b]		0.350[b]
Joined	16		19		13		14		14		21		18	
	(13-20)		(15-24)		(10-18)		(10-17)		(12-17)		(17-27)		(15-23)	
Not Joined	16.5		19		13		14		14		21		18	
	(13-20)		(15-24)		(11-20)		(10-17)		(12-17)		(17-28)		(15-24)	

Description: IDR = Indonesian Rupiah | [a]post-hoc analysis between education group: primary education vs. secondary education, *p* = 0,397; primary education vs. higher education, *p* = 0,403; secondary education vs. higher education, *p* = 0,010* |[b]Mann-Whitney | [c]Kruskal-Wallis | *significant $p < 0.05$.

knowledge and receive significant social support compared to those with low education [35]. A study conducted by Sari [36] in Indonesia stated that maternal self-confidence levels in childcare tended to be very high in the majority of respondents with a highly educated background. Children from parents with a higher education background in Indonesia have lower morbidity rates, a higher percentage of outpatient care, and a higher percentage of health insurance ownership compared to those from low parental educational backgrounds [31].

There are some differences in the fulfillment of childcare needs based on the place of living identity, which are urban villages and rural villages. Parents who live in urban villages fulfill self-esteem and self-actualization parenting better than parents who live in rural villages [38]. Parents living in urban villages have higher PSE in the domains of nurturance, protection, and routines than those who live in rural villages.

Comorbidities can affect the management of individual care with DS. The greater the number of comorbidities, the more intervention and good management are needed. The distance to facilities is one of the inhibiting factors for parents who live in rural villages. Although the cost of child health care can be covered by health insurance, transportation and accommodation expenses are not covered. Some parents who live far from health facilities have to make sacrifices to save money and time, one of which is by staying in a halfway house or using free assistance services, including free ambulances from the region.

Data from the National Socio-Economic Survey (Susesnas) in 2023 showed that the percentage of out-of-pocket (OOP) health expenditure, in which the personal expenditure borne by the community to obtain health service, was still 61.8% of total health expenditure. Urban households spend 5-10% less OOP compared to rural households, as many health facilities are concentrated in urban areas [39]. The barriers experienced by rural communities in Indonesia in accessing health services are geographical isolation, high transportation costs, and long travel times [40].

Based on the maternal and children health profile issued by BPS (Central Bureau of Statistics) 2022, the morbidity rate of Indonesian children in rural areas was higher than in urban. Data from the 2022 National Socio-Economic Survey (Susesnas) indicates that the primary reasons children in Indonesia do not receive outpatient treatment are self-medication and the perception of treatment being not necessary. This percentage is significantly higher among children living in rural areas (0.66%). The use of health insurance for outpatient care is higher in urban areas compared to rural areas [37]. Individuals in Indonesia living in cities have a better chance of being healthy (1.02%) than those living in rural areas [41].

Parents of children with DS feel very helped when the resident area has easy access to health services. The residential environment and accessibility of health services affect prevention efforts carried out in accordance with standard procedures, which can influence a person's survival [19,42]. Barriers to obtaining genetic diagnosis are geographic isolation and lack of access to health professionals trained in genetic medicine services [43].

The additional copy of chromosome 21 in each or some cells affects every organ system in the body of DS patients. Each DS patient has a different condition based on the various comorbidities. Management of care requires multidisciplinary cooperation from various medical teams, social care, and education teams [1]. Children with DS should be given regular check-ups to determine the progress of the condition. DS patients consult with various consultants such as geneticists, pediatricians, cardiologists, pediatric lung specialists, neurologists, ophthalmologists, orthopedists, child psychologists, physiotherapists, audiologists, and speech therapists [44]. Appropriate management, monitoring, and early intervention of medical problems reduce morbidity and improve children's health conditions [17]. Genetic counselors also play a role in helping to provide appropriate referrals to patients [38].

The management of DS care at Dr. Kariadi Hospital and Diponegoro National Hospital is good based on the response to the answer "yes" in the genetic counseling process regarding referrals to other specialists when needed, the explanation by medical personnel regarding a child’s diagnosis, information on the physical characteristics that indicate DS, child comorbidities in DS, and information about the cause of DS. Genetic counseling for parents was carried out by discussing the facts and children's future. This includes providing an overview of all health problems, guidelines for follow-up evaluations, and early intervention to support children development. Providing information about the diagnosis to parents even though it has not been confirmed by karyotyping and sharing insights into the physical characteristics that support the diagnosis should be carried out by genetic counselors as practice guidelines in communicating prenatal or postnatal DS diagnosis [38].

The lowest response to the genetic counseling process was obtained on questions about the risk of having another child with the same condition (recurrence risk). Genetic counselors must explain recurrence risk and screening for future pregnancies [46]. This may have been conveyed by the genetic counselor, but parents do not pay significant attention to it or forget about the delivery. Based on the interviews with parents > 35 years old and who have more than one child, none intend to know more about the recurrence risk for future pregnancies. This would be different for parents under 35 years old and whose first child has been diagnosed with DS.

Chromosome examination received a good response from parents. Parents knew about chromosome examination but selected not to comply. This is because chromosome examination in Indonesia cannot be financed by the Social Security Administering Agency (BPJS) health insurance. Parents did not need the examination because the physical characteristics often confirm the presence of DS in children. Patients are not passive in receiving health care and only comply with decisions made by health care providers. Although healthcare providers can have power over medical authority, patients only have authority over family health experience and choices for treatment [47].

Parents have received information regarding support from medical personnel, such as support groups. In general, information related to conditions and diagnoses can affect the condition of clients and families. Counselors should have knowledge of supportive resources that help families cope with the reality of the disease condition being experienced [48]. The genetic counseling process may also provide facilities for accessing information, including books, articles, or websites that offer information about special schools and guide parents to join groups of children with DS [46]. Parents who received updated, accurate, and positive information in a sensitive manner following DS diagnosis from health professionals showed positive emotional responses and were more optimistic about their children's future and well-being [20,49,50].

In a systematic review, Madlensky *et al*. [51] stated that genetic counseling can influence self-efficacy in following treatment recommendations expected to reduce morbidity and mortality. This is in line with the results of this study based on the "yes" response in the genetic counseling process. A high response was obtained in diagnosing childhood diseases and managing child care with DS. About 57.5% of parents had a capable PSE level, and 42.5% had a very capable level, but none was in the less capable category.

PSE mediates parent involvement for both mothers and fathers [52]. Society in Indonesia still adheres to the traditional division of gender roles, placing the father’s role as the breadwinner in the family [53]. In Indonesia, fathers with special needs children are quite involved in parenting, although some of their parenting roles are indirect. Fathers had low participation in direct parenting roles, such as caring for a child’s daily routine [54]. Indirect parenting by the father involves monitoring the child’s development condition through communication, especially with his wife [55].

This study provides new insights into factors that may affect the PSE in parents of children with DS, especially in Indonesia. This new insight can benefit parents by maximizing their role as parents nurturing their children with DS, optimizing their child’s development, and managing factors that contribute to weakening the PSE.

Future studies require more comprehensive studies and analyses of specific comorbidities in children with DS. In fact, informational support data should not only be obtained from the genetic counseling process but also from the intensity of social media and internet use by fellow parents of children with DS. Thus, all activities associated with better literacy may affect the PSE.

LIMITATIONS OF THE STUDY

Due to the lack of father participation, the number of samples was not balanced between fathers and mothers, which may have affected the results/conclusions.

CONCLUSION

In conclusion, parents of children with DS have capable and very capable PSE levels. The main factor influencing the level of PSE was children with comorbidities, in addition to the level of parent education and also the place of living identity. The higher the number of comorbidities, the lower the self-efficacy; however, higher parental education and living in an urban area increase self-efficacy. Information support from the genetic counseling process and good management of children with DS have an important role in the PSE of parents.

The parents who participated in this study were dominated by mothers because, in Indonesia, the mother is more responsible for daily and routine childcare than the father. The father's role is that of the leader, who is responsible for providing financially and making major decisions. For future studies, further study of fathers' participation is crucial, using a qualitative phenomenology approach to explore and deepen the understanding of the father's perspective.

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ETHICAL APPROVAL

This study has received approval in the form of ethical clearance from the Health Research Ethics Commission (KEPK) of Dr. Kariadi General Hospital No. 1494/EC/KEPK-RSDK/2023.

CONSENT

Before conducting the study, all respondents had received information and were given the freedom to decide whether to participate or not. Respondents who joined this study, voluntarily signed an informed consent form.

CONFLICTS OF INTEREST

The authors declare they have no conflict of interest.

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