

THE RELATIONSHIP BETWEEN COPING STRATEGY AND SOCIAL SUPPORT WITH CAREGIVER BURDEN

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Abstract:

The goal of this study was to analyze the relationship between coping strategies and social support with caregiver burden in parents/caregivers Down syndrome in Surabaya. Method: The method used is the design of observational analytical research, cross sectional, against parents or caregivers of Down syndrome in Surabaya. Ways of Coping Questionnaire (WCQ) instrument to measure coping strategies, The Multidimensional Scale of Perceived Social Support (MSPSS) for measuring social support, and Caregiver Burden Assessment (CBA) to measure caregiver burden. Statistical analysis uses correlation tests. Results: The study sample was 37 parents / caregivers of children with Down syndrome in Surabaya. The results obtained by parents / caregivers Down syndrome dominantly using coping focused on emotions (89.4%). High levels of social support were felt by parents/caregivers (51.4%) and the total burden of parents/caregivers was low and very low (64.8%). The results of the analysis between coping strategy with caregiver burden, and social support analysis with caregiver burden, did not get a meaningful relationship ($p>0.05$). Research found a meaningful relationship between parents/caregivers who have severe problems and the level of independence ana k Down syndrome with caregiver burden ($p<0.05$). Discussion: From the above results it can be concluded that there is no meaningful relationship between coping strategy and social support with caregiver burden in parents / caregivers of Down syndrome. Caregiver burden is more related to the condition of parents who have severe problems in the last 6 months and the level of independence of children Down syndrome.

Keywords: coping strategy, social support, caregiver burden

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INTRODUCTION

The number of children with Down syndrome in Indonesia is showing an increase. Based on the Basic Health Research (Riskesdas) results in 2010, children aged 24 months - 59 months who experienced Down syndrome by 0.12%, while in 2013 to 0.13% and in 2018 increased again to 0.21%. Data from the Indonesian Down Syndrome Association, states that cases of Down syndrome are almost 300,000 cases (Riskesdas, 2013; Ariani et al., 2017). Down syndrome is the most common genetic disorder of intellectual disability and one of the neurodevelopmental disorders caused by the addition of the 21st chromosome (trisomy 21) in children (Davis, 2008). Children with Down Syndrome experience delays in motor development, language, specific deficits in verbal memory and extensive cognitive deficits and are at high risk of health problems such as congenital heart disease, respiratory distress, gastrointestinal disorders, hypothyroidism, vision problems and hearing problems (Alexander and Walendzik, 2016). Risk factors for Down

Syndrome are old age during pregnancy related to biological aging of the ovaries, having a history of giving birth to children with trisomy 21 before and environmental factors such as alcohol & nicotine, drugs (oral contraceptives, hormone therapy, radiation therapy and fertility drugs), exposure to toxic waste and having infections (Stephanie L. Sherman, *Emily G. Allen, Lora H. Bean, 2007).

Slow development in children Down syndrome causes children with Down syndrome to need more care and attention (Alexander and Walendzik, 2016). Stimulation is an important factor that affects the physical and mental development of children with Down syndrome, so parents/caregivers must play an active role in daily life activities related to self-care and the health problems of children with Down syndrome. Chronic health problems in children with Down syndrome affect various aspects of parent/caregiver life and can lead to fatigue, social isolation, stress and caregiver burden (Bourke et al., 2009). In addition, it causes parents/caregivers with Down syndrome must change daily habits and experience emotional, physical, financial, limited burdens in doing social and/or recreational activities, and face the social consequences of community stigma (Alexander and Walendzik, 2016).

Parents/caregivers make time to care for a Down syndrome child for an average of 40 hours/week, ranging from basic activities to medical support (Adelman et al., 2015). Caregiver burden is the strain or burden of parenting that occurs in someone who cares for a child with a disability. Hoenig and Hamilton (1996) explained that burdens are divided into two, namely objective burdens and subjective burdens. Objective load refers to the periwtiwa and activities associated with the negative addressing of caregivers. Subjective burden refers to caregivers' feelings that arise when fulfilling functions as caregivers. Zarit, Reever, & Bach-Peterson (1980) clarify the concept of parenting burden by defining burden as the extent to which caregivers perceive physical health, emotional health, social life, and financial status resulting from parenting with disabilities (Oh and Lee, 2009). Unfortunately, parents/caregivers of Down syndrome do not get enough social support from the community and do not like to admit that they have children with Down syndrome for fear of criticism from the community, causing high rates of caregiver burden in parents/caregivers with Children Syndrome Down (Alexander and Walendzik, 2016). Social support can be interpreted as caring, values, and guidance given to individuals by family, friends, and other important people in their lives to provide physical comfort and emptiness (Mahanta and Aggarwal, 2013).

According to Schaefer, Coyne, and Lazarus (1981), social support is divided into five forms, namely, emotional support, award support, instrumental support, information support, and networking support. Social support provided to parents /caregivers of Down syndrome can affect adaptation and coping strategies and reduce the stress experienced to give positive results (Cohen, S., & Wills, T. A., 1985). Coping is a process-oriented way that can change over time and depends on how coping selection can differ according to the situation. In general, coping is divided into reactive coping (reactions following stressors) and proactive coping (aiming to neutralize the causes of future stress) (Schoenmakers, Tilburg & Fokkema, 2015). According to Lazarus and Folkman, coping is divided into problems-focused coping (PFC) and emotion-focused coping (EFC). Bawaslah's research (2016) conducted in Jordan suggests conducting research with local locations and cultures and more in analyzing the coping strategies used by parents/caregivers of children with disabilities. Recognizing coping strategies will help professionals and service providers find appropriate ways for parents /caregivers to adapt to children with disabilities. In addition to coping strategies, more research is needed for social support needs in parents/caregivers that affect caregiver burdens. The high number of caregiver burdens in parents who have children with mental disabilities makes researchers interested in finding out caregiver burden and its relationship with coping strategies and social support in parents/caregivers Down syndrome so that the results of the study can be used to improve services in hospitals and help the parents of the child Down syndrome.

METHODS

This study was conducted in the Community of Parents of Children with Down Syndrome Surabaya (POTADS Surabaya). The sample in this study was a parent or caregiver of a Down syndrome child who is a member of the Association of Parents of Children with Down Syndrome Surabaya who meets the criteria of inclusion and exclusion (research requirements). The inclusion criteria in this study are parents/caregivers aged 20 - 60 years with a biological child Down Syndrome, have been informed and willing to follow the research, live at home and care for Down Syndrome children aged 2 - 17 years, can speak Indonesian properly and correctly, orally or in writing and do not suffer from severe mental disorders. The exclusion criteria of this study are parents/caregivers who experience severe physical disorders (chronic diseases) that can affect the ability to care for children. Sampling techniques and information for consent are done online using a google form that has previously been explained through the zoom application regarding the questionnaire filling mechanism. The study was conducted in June 2021 and August 2021. The study design used observational, cross-sectional analytics using the Ways of Coping Questionnaire (WCQ) instrument to measure coping strategies, The Multidimensional Scale of Perceived Social Support (MSPSS) to measure social support, and the Caregiver Burden Assessment (CBA) to measure caregiver burden. Statistical analysis uses the Kruskal Wallis correlation test to determine the relationship between coping strategies and caregiver burdens, and Spearman correlation tests to determine the relationship between social support and caregiver burden. This research has received an ethics certificate from the Health Research Ethics Committee of the Faculty of Medicine, Universitas Airlangga Surabaya, Indonesia, with the number 96/EC/ KEPK/FKUA/2021.

RESULT AND DISCUSSION

Respondents who met the criteria for inclusion, exclusion and have filled out questionnaires provided through google form are 37 parents/caregivers of Down syndrome in Surabaya. Table 1 shows the characteristics of parents/caregivers with Down syndrome in Surabaya dominated by the ages of 30-39 years (43.2%), Muslims (86.5%), Last Education College (48.6%), married (91.9%), not working (48.6%), and sufficient economic status (83.8%). In addition, families are predominantly two children (45.9%), do not live with large families (67.6%), and no family helps with Down syndrome childcare (51.4%). In addition, 9 parents/caregivers experienced severe problems in the last 6 months, such as family economic problems, work, completeness of medicines at home, or mothers and fathers are in different cities.

Table 2 shows the characteristics of Down Syndrome children in POTADS Surabaya dominated by the ages of 2 - 6 years (37.8%), have the privilege (first child/single / youngest / only boy/child who is highly expected to be born (64.9%). Children diagnosed with Down syndrome average less than 6 months (62.2%) and are the first child (37.8%). Despite experiencing Down syndrome, almost half (51.4%) of children can do activities independently, and parents/caregivers do not ask for help from others in caring. The most widely used strategy by parents/caregivers of Down syndrome in Table 3 is Emotion-focused coping (EFC) (89.4%), with positive reappraisal coping strategy is the most widely used type of coping (54.1%).

In the study shown in Table 4, social support was obtained by moderate special people as many as 19 people (51.4%), high family support which was 22 people (59.5%), moderate friend support as many as 22 people (59.5%) and the total social support obtained as high as many as 19 people (51.4%).

Based on Table 5, the total caregiver burden is low, which is 16 parents/caregivers (43.2%). Table 6 shows the results of the Kruskal Wallis test; there is no meaningful relationship between caregiver burden with age, religion, education, marital status, employment, economic status, and the number of children in subjective burden or objective burden ($p > 0.05$). Mann Whitney's test results showed there was no caregiver burden relationship between living with a large family or not, and there was a help or not good on the subjective burden or objective burden ($p > 0.05$). But it

shows a meaningful relationship between parents/caregivers who have severe problems with caregiver burden, both subjective and objective ($p < 0.05$).

Kruskal Wallis and Mann Whitney's test results in Table 7 showed no meaningful association for caregiver burden based on child characteristics ($p > 0.05$). But it was found that the relationship of caregiver burden (objective burden) with the level of child independence ($p < 0.05$).

Table 8 shows Kruskal Wallis test results show no meaningful relationship between coping strategy with subjective burden, objective burden, and total caregiver burden ($p > 0.05$). Furthermore, the results of cross-tabulation between coping strategy with subjective burden, objective burden and total caregiver burden, namely parents/caregivers who use coping self-control and positive reappraisal, show low and very low-level results.

Table 9 shows the results of Spearman's correlation are as follows:

1. Special social support of subjective burden, objective burden and total burden indicates no meaningful relationship ($p > 0.05$).
2. Family social support for subjective burden, objective burden and total burden indicates no meaningful relationship ($p > 0.05$).
3. Friends' social support of subjective burden, objective burden and total burden indicates no meaningful relationship ($p > 0.05$).

Table 1. Characteristics of parents/caregivers of Down syndrome in Surabaya

Characteristic	n (%)	Average Raw inequality
Age (years)		42,14 9,034
21-30	3 (8,1%)	
31-40	16 (43,2%)	
41-50	11 (29,7%)	
51-60	7 (18,9%)	
Religion		
Islam	32 (86,5%)	
Catholic	4 (10,8%)	
Christian	1 (2,7%)	
Education		
Elementary school graduate	2 (5,4%)	
JHS - SHS graduate	17 (45,9%)	
University graduate	18 (48,6%)	
Marital status		
Unmarried	1 (2,7%)	
Married	34 (91,9%)	
Widow/Widower	2 (5,4%)	
Employment		
Not working	15 (40,5%)	
Working	22 (59,4%)	
Economic status		
Desperately poor	1 (2,7%)	
Lower middle class	3 (8,1%)	
Upper middle class	31 (83,8%)	
Rich	2 (5,4%)	
Number of children		
1 child	7 (18,9%)	

2 children	17 (45,9%)
>2 children	13 (35,1%)
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Availability of people who help	
Father/mother in child care	
Exist	18 (48,6%)
None	19 (51,4%)
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Father/mother lives with	
Extended family	
Yes	12 (32,4%)
Not	25 (67,6%)
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Severe problems experienced	
in the last 6 months	
Exist	9 (24,3%)
None	28 (75,7%)
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Table 2. Characteristics of Down syndrome in Surabaya

Characteristic	n (%)	Average Raw inequality
Age (years)		9.11 5,087
2 - 6	14 (37.8 %)	
7 - 11	10 (27%)	
> 11	13 (35.1%)	
Status of children who have Down syndrome There		
are privileges	24 (64.9%)	
No privileges	13 (35.1%)	
Order of children who have Down syndrome		
First	14 (37.8%)	
Second	13 (35.1%)	
Third	6 (16.2%)	
Fourth	4 (10.8%)	
Lengthy from the time a child is diagnosed with		
Down syndrome		
< 6 months	23 (62.2%)	
6 months - 1 year	3 (8.1%)	
1 - 2 years	3 (8.1%)	
> 2 years	8 (21.6%)	
Lengthy from the time the child begins to receive		
therapy.		
< 6 months	13 (35.1%)	
6 months - 1 year	5 (16.2%)	
1 - 2 years	5 (16.2%)	
> 2 years	12 (32.4%)	
Number of other children		
< 6 months	9 (24.3%)	
6 - 12 years	19 (51.3%)	
>12 years	18 (48.6%)	
The child gets regular therapy/treatment.		
Yes	23 (62.2%)	
No	14 (37.8%)	
The child's progress after therapy		
None	1 (2.7%)	
Less Good	2 (5.4%)	
Excellent	19 (51.4%)	

	15 (40.5%)
The level of independence	
Needs help.	12 (32.4%)
Needs supervision	6 (16.2%)
Independent	19 (51.4%)

Table 3. Use of the dominant coping strategy of parents/caregivers Down syndrome

Coping Strategy	(n)	(%)
Problem-focused coping (PFC)	4	10,8
Planful problem solving	0	0
Confronting	2	5,4
Seeking social support	2	5,4
Emotion-focused coping (EFC)	33	89,4
Distancing Self-control	1	2,7
Positive reappraisal	10	27
Positive reappraisal	20	54,1
Distancing and positive reappraisal	1	2,7
Escape avoidance and positive reappraisal	1	2,7

Table 4. Description of parents/caregivers social support Down syndrome

Social Support	N	%
Special Person		
Low	1	2,7
Moderate	19	51,4
High	17	45,9
Family		
Low	1	2,7
Moderate	14	37,8
High	22	59,5
Friend		
Low	2	5,4
Moderate	22	59,5
High	13	35,1
Total		
Low	1	2,7
Moderate	17	45,9
High	19	51,4

Table 5. Description of caregiver burden parents/caregivers Down syndrome

Caregiver burden	N	%
Subjective burden		
Very low	7	18,9
Low	16	43,2
Moderate	9	24,3

High	4	10,8
Very high	1	2,7
Objective burden		
Very low	10	27
Low	18	48,6
Moderate	5	13,5
High	3	8,1
Very high	1	2,7
Total Caregiver Burden		
Very low	8	21,6
Low	16	43,2
Moderate	6	16,2
High	6	16,2
Very high	1	2,7

Table 6. Analysis of the relationship between parents/caregivers characteristics of Down syndrome and caregiver burden

Characteristic	n	Subjective Burden	p-value	
			Objective burden	Caregiver burden
Age	37	0,338	0,463	0,520
Religion	37	0,646	0,466	0,688
Education	37	0,434	0,508	0,596
Marital Status	37	0,391	0,643	0,464
Empoyment	37	0,194	0,209	0,155
Economic Status	37	0,370	0,308	0,301
Living with extended family	37	0,719	0,958	0,811
Someone else helped	37	0,860	0,870	0,860
Number of children	37	0,577	0,174	0,313
Severe problems experienced In the last 6 months	37	0,003 *	<00,001	0,002

Table 7. Analysis of the relationship between the characteristics of a Down syndrome child and caregiver burden parents/caregivers Down syndrome

Characteristic	n	Subjective Burden	p-value	
			Objective burden	Caregiver burden
Age of the child	37	0,958	0,915	0,772
Status of a Child With Down Syndrome	37	0,430	0,392	0,987
Order of Down syndrome children	37	0,259	0,162	0,478
Lengthy a child is diagnosed with Down syndrome	37	0,667	0,723	0,737
Lengthy the child gets therapy	37	0,946	0,979	0,934
Number of other children aged < 6 years	37	0,385	0,991	0,638
Number of other children aged 6-12 years	37	0,474	0,551	0,446
Number of other children aged > 12 years	37	0,298	0,198	0,112
Children get regular therapy / treatment at the hospital	37	0,519	0,522	0,767
The child's progress after therapy	37	0,810	0,644	0,799
Child's level of independence	37	0,682	0,049	0,763

Table 8. The relationship between coping strategy with subjective burden, objective burden and total caregiver burden parents/caregivers Down Syndrome

		<u>Subjective burden</u>					<u>p-value</u>
<u>Coping Strategy</u>							
Problem-focused coping							
-	Positive reappraisal						
-	Confronting						
-	Seeking social support						
Emotion-focused coping (EFC)							
-	Distancing						
-	Self-control						
-	Planful problem solving						
-	Distancing and positive reappraisal						
-	Escape avoidance and						
<u>Coping Strategy</u>		<u>Very low</u>	<u>Low</u>	<u>Moderate</u>	<u>High</u>	<u>Very high</u>	
Problem-focused coping (PFC)							
-	Positive reappraisal						
-	Confronting		1 (50%)			1 (50%)	
-	Seeking social support	1 (50%)	1 (50%)				
Emotion-focused coping (EFC)							
-	Distancing					1 (100%)	
-	Self-control		6 (60%)	3 (30%)	1 (10%)		0,913
-	Positive reappraisal	6 (30%)	7 (35%)	5 (25%)	2 (10%)		
-	Distancing and positive reappraisal		1 (100%)				
-	Escape avoidance and			1 (100%)			
<u>Coping Strategy</u>		<u>Very low</u>	<u>Low</u>	<u>Total caregiver burden</u>		<u>Very high</u>	<u>p-value</u>
				<u>Moderate</u>	<u>High</u>		
Problem-focused coping(PFC)							
-	Positive reappraisal						
-	Confronting		1 (50%)			1 (50%)	
-	Seeking social support	2 (100%)					
Emotion-focused coping (EFC)							
-	Distancing				1 (100%)		0,734
-	Self-control		6 (60%)	2 (20%)	2 (20%)		
-	Positive reappraisal	6 (30%)	8 (40%)	3 (15%)	3 (15%)		
-	Distancing and positive reappraisal		1 (100%)				
-	Escape avoidance and			1 (100%)			

Table 9. The relationship between social support and caregiver burden in parents/ caregivers of Down syndrome

<u>Relationship</u>		<u>n</u>	<u>rs</u>	<u>p-value</u>
Special person social support	Subjective burden	37	0,102	0,548
	Objective burden	37	0,126	0,458
	Caregiver burden	37	0,008	0,963
Family social support	Subjective burden	37	0,035	0,835
	Objective burden	37	-0,026	0,878
	Caregiver burden	37	-0,099	0,559
Friends social support	Subjective burden	37	-0,126	0,458

Total social support	Objective burden	37	-0,170	0,313
	Caregiver burden	37	-0,210	0,212
	Subjective burden	37	-0,062	0,717
	Objective burden	37	-0,028	0,872
	Caregiver burden	37	-0,201	0,232

The results showed that 62.2% of parents knew that their child had Down syndrome for less than 6 months. Research conducted by Lam and Mackenzie shows that emotion-based coping strategies are applied when parents experience the early stages of accepting their child's condition. Parents tend to think more negatively about the causes of their child's illness and seek information from various sources. Parents avoid other people because they have Down syndrome children, do not ask outsiders for help, are afraid to cry in front of others, and feel that everything is normal. The next stage is the second stage, where parents begin to realize their responsibility to care for children with disabilities, where problem-based coping strategies are more often used. In the final stages, parents begin to realize that their child's limitations are not as bad as they imagined. The coping strategy used in the third phase is mixed (Lam and Mackenzie, 2002). Emotion-based coping strategies may seem like a maladaptive reaction, but when parents find answers to their problems, they manage their initial psychological state and care for their children over time and help maintain responsibility. The results showed that total social support, each type of support, such as support from friends, family, & special people, was at moderate & high levels. It is in line with the CY's research. Hsiao, that informal social support (support from relatives, friends and non-professional sources of help) provides the most dominant assistance to families raising Down syndrome children in Taiwan & Western families. Many parents believe giving the attention and understanding they feel from relatives and friends helps to validate roles, values and helps to cope well with challenges. According to family/close relatives, informal social support is specifically beneficial because it helps in social-emotional support (CY.Hsiao, 2014).

The study results found that many parents were still married (91.9%); this was following the study of Caicedo & Zajicek Farber, which found that most caregivers were married. It has the potential for strengthening & support in caring for a child with Down's syndrome with a partner. Strong support from partners, siblings and grandparents will improve psychological health. This study's total caregiver burden, subjective burden, and objective burden were at very low and low levels (around 65%). It is in line with the research results conducted in March 2019 – March 2020 in Egypt. This study of 457 primary caregivers of Down's syndrome children showed that 51.9% had no burden or had a low burden, 40.7% had a low to moderate burden, and 7.4% had a moderate to high burden (Alam El-Deen et al. al., 2021). This low or very low carrier burden is consistent with the Down syndrome benefit theory, which is the parent's perception of Down's syndrome. Several things show the differences in the experiences of parents of children with Sindowma Down and parents with other children with disabilities are a group of parents of Down's syndrome children who provide support. First, down's syndrome is the most common intellectual disability, so that in association groups, parents become more familiar. The risk factor for Down syndrome children is pregnancy at an old age. It results in Down's syndrome children being born to older and more mature mothers and having a higher socioeconomic status. Moreover, children with Down syndrome are quite stable and have fewer behavioral problems than other children with disabilities.

The results showed that the total caregiver burden was high in 6 (six) parents/caregivers (16.2%). The parents/caregivers have experienced problems in the last six months in the form of work problems and economic problems (husband was laid off). The test results showed that there was a relationship between parents/caregivers with severe problems with the caregiver burden ($p < 0.05$). Research conducted by Liu, Heffernan and Tan in 2020 explained that parents/caregivers of Down's syndrome children are prone to emotional exhaustion, and the influencing factors are insufficient financial resources, conflict of responsibilities, and lack of social activity (Liu et al.,

2020). The results of cross-tabulation between coping strategy and total caregiver burden found that parents who used positive reappraisal and self-controlling coping strategies found low and very low caregiver burdens, but the statistical test results showed that there was no significant relationship between the use of coping strategies and caregiver burdens on parents/caregivers Down's Syndrome children.

Some parents have certain coping strategies in dealing with stressful situations. Some coping strategies are more successful in some situations than others. Research conducted on mothers of children with Down's Syndrome in Malaysia in 2008 showed that most mothers used religious coping as a coping strategy and acceptance coping. Parents accept their children with Down's Syndrome as part of their destiny. In the process of parents in the acceptance stage, they seek help from others and through communication with others, mothers realize that their child's condition is not the worst so that they can accept the fact that their child was born with Down Syndrome (Norizan and Shamsuddin, 2010). Coping strategies such as spiritual beliefs, hopes, family and community support can give life meaning and purpose and help parents to adapt to their new lives. Most parents, i.e., 95% of mothers, emphasize spiritual beliefs in dealing with children with intellectual disabilities. Spiritual beliefs make parents interpret why God gave them children and leave everything to God through prayer. Faith in God strengthens parents, especially for many mothers. A qualitative study on family perceptions of caring for children with disabilities among 14 families in Moshi, Tanzania, McNally and Mannan in 2013 found that participants emphasized belief in God and His power to deal with their experiences of raising children with disabilities (Oti-Boadi , 2017). The results showed that there was no significant relationship between social support and caregiver burden. Research by Koichiro Shiba, Naoki Kondo, and Katsunori Kondo in 2016 reported that there was no relationship between the number of sources of social support and the level of caregiver burden, namely that informal social support was associated with a lower caregiver burden, while formal social support was not associated with the caregiver burden. . A significantly lower caregiver burden was observed among caregivers with informal social support from a caregiver's family living with relatives, while among sources of formal social support, only support from a family doctor was significantly associated with a lower caregiver burden. This study found that the dominant parent/caregiver did not live with a large family, thus enabling social support not to affect the caregiver burden on the parent/caregiver.

The results of this study indicate that there is no relationship between social support and caregiver burden, which can be explained for several reasons, namely:

1. Social support is only useful for someone who is suffering from difficulties in stressful conditions (Cohen, 2004)
2. Social support can be received or felt when it is given several times in times of need rather than the total amount of support (del-Pino-Casado et al., 2018)
3. The existence of other sources of social support, namely supports from groups or communities.

CONCLUSION

Research with 37 respondents regarding the relationship between coping strategies and social support with caregiver burden on parents/caregivers of Down's syndrome children in Surabaya shows that the most widely used coping strategy by parents/caregivers is emotion-based coping strategies. Social support received by parents/caregivers is moderate and has high levels of support. The description of the total caregiver burden on parents/caregivers is more dominant at very low and low levels. There is no relationship between coping strategy and caregiver burden and no relationship between social support and caregiver burden.

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