



RESEARCH ARTICLE

The Correlation Between Sense of Community Towards Parents Who Had Down Syndrome Children

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Abstract

Every parent wants to have the child they want. Parents want to have children who are perfect physically, mentally, and spiritually. But in reality not all parents have this opportunity, in some cases, there are some of them who have children who experience mental retardation such as Down syndrome. One of the factors that influence the caregiver's burden is social support, where social support can be provided by a community. This research is correlational quantitative research. This objective of the study was to determine whether there is a correlation between a sense of community and the burden of caregivers on parents who have children with Down syndrome. The population in this study were parents who had children with Down syndrome. The sample in this study amounted to 142. The sampling technique in this study was carried out by purposive sampling technique. The instrument used in this study was a caregiver burden scale consisting of 38 items (31 valid items and 7 invalid items) with a reliability coefficient of 0.873 and a sense of community scale consisting of 34 items (30 valid items and 4 invalid items). Reliability coefficient was 0.915. The results of calculations with data processing software, obtained a sense of community is in the high category and caregiver burden is in the low category. Hypothesis testing was carried out using the Spearman correlation formula resulting in a rho value of -0.473 with a significance value of 0.000. Thus, the hypothesis which reads that there is a negative correlation between sense of community and caregiver burden on parents who have children with Down syndrome is accepted. The higher the sense of community, the lower the caregiver's burden. Vice versa, the lower the sense of togetherness, the higher the caregiver's burden.

Keywords: caregiver's burden; sense of community; parents; down syndrome

Abstract

Setiap orang tua pasti mendambakan memiliki anak yang sesuai dengan yang mereka idam-idamkan. Para orang tua ingin memiliki anak yang sempurna baik secara fisik, mental, maupun rohani. Namun pada kenyataannya tidak semua orang tua memiliki kesempatan tersebut, pada beberapa kasus, ada sebagian dari mereka ditakdirkan memiliki anak yang mengalami retardasi mental seperti *down syndrome*. Salah satu faktor yang mempengaruhi *caregiver burden* adalah dukungan sosial, dimana dukungan sosial dapat diberikan oleh suatu komunitas. Penelitian ini merupakan penelitian kuantitatif korelasional. Penelitian ini bertujuan untuk mengetahui apakah ada hubungan antara *sense of community* dengan *caregiver burden* pada orang tua yang memiliki anak *down syndrome*. Populasi dalam penelitian ini adalah orang tua yang memiliki anak *down syndrome*. Sampel dalam penelitian ini berjumlah 142. Teknik pengambilan sampel dalam penelitian ini dilakukan dengan teknik *purposive sampling*. Instrumen yang digunakan dalam penelitian ini berupa skala *caregiver burden* yang terdiri dari 38 aitem (31 aitem valid dan 7 aitem tidak valid) dengan koefisien reliabilitas sebesar 0,873 dan skala *sense of community* yang terdiri dari 34 aitem (30 aitem valid dan 4 aitem tidak valid) dengan koefisien reliabilitas sebesar 0,915. Hasil perhitungan dibantu dengan *software* pengolah data, diperoleh *sense of community* berada pada kategori tinggi dan *caregiver burden* berada pada kategori rendah. Uji hipotesis dilakukan dengan formula korelasi *Spearman* menghasilkan nilai *rho* sebesar -0,473 dengan nilai signifikansi 0,000. Dengan demikian hipotesis yang berbunyi ada hubungan negatif antara antara *sense of community* dengan *caregiver burden* pada orang tua yang memiliki anak *down syndrome* diterima. Semakin tinggi *sense of community*, maka semakin rendah *caregiver burden*. Begitu juga sebaliknya, Semakin rendah *sense of community*, maka semakin tinggi *caregiver burden*.

Keywords: *caregiver burden*; *sense of community*; orang tua; *down syndrome*

INTRODUCTION

Parents are period of transition from individual responsibility to adult responsibility. Status as a parent is defined as a period of crisis because it requires a lot of changes in behavior, values, and roles (Hurlock, 1980 :294). For some adults, being a parent is an award as well as a challenge, this is because when they become parents, they will face demands related to the parenting role (Hurlock, 1980 :295).

Every parent wants to have the child they want. Parents want to have perfect children physically, mentally, and spiritually (Amira, 2015). But in reality not all parents have this opportunity, in some cases, there are some of them destined to have children who experience developmental delays.

One of the developmental barriers experienced by a child is mental retardation or intellectual disability (intellectual development disorder). The term mental retardation refers to the limitations of real function, cognitive and adaptive functions. According to Wijayani & Budi (2011) mental retardation is a term used to refer to children who have intellectual abilities below average. In DSM V it is explained that mental retardation or intellectual disability (intellectual development disorder) is a disorder during the developmental period that includes intellectual and adaptive function deficits in the conceptual, social, and practical realms. There are several types of mental retardation, one of which is Down syndrome (Sularyo & Kadim, 2000).

According to Pratiwi (2014) Down syndrome is a physical condition caused by gene mutations when the child is still in the womb. Down syndrome itself occurs due to chromosomal abnormalities caused by the formation of chromosome 21. These chromosomes are formed due to the failure of a pair of chromosomes to separate from each other during division. This disorder has an impact on retardation of physical and mental growth (Dewi & Wibowo, 2015).

Down syndrome can also occur due to drug intake factors or intake errors during pregnancy, exposure to radiation and because the mother's age is above the age of 30 years (Rahma & Indrawati, 2017). We can recognize children with Down syndrome physically, namely a flat face shape such as a Mongolian race, slightly crossed eyes, a small mouth, a small head, a short neck, and relatively short hands and feet (Martin, 2009 in Renawati, Darwis). & Wibowo, 2017).

Based on estimates from the World Health Organization (WHO), there is one of the case of Down syndrome per 1.000 births to 1 event per 1.100 births worldwide. Every year, about 3.000 up to 5.000 children are born with Down syndrome. WHO estimates that there are 8 million people with Down syndrome worldwide. In Indonesia, the tendency of Down syndrome in children 25-59 months is increasing. Based on the results of the Ministry of Health's Basic Health Research in 2010, the prevalence of Down syndrome was 0.12%. However, this value increased to 0.13% in 2013 and became the 3rd most disability in children in Indonesia (based on the daily news

tirto.co accessed on January 17, 2019).

The existence of biological factors and psychological factors that are different between normal children in general and children with Down syndrome, makes children with Down syndrome require special attention from parents. The role of parents is very important because the development of children with Down syndrome is slow and different. This is because parents are caregivers, namely someone who provides assistance to people who have disabilities and need assistance because of their limitations (Retnaningsih & Dini, 2016).

In fact, caring for a child with Down syndrome brings its own problems for the family, especially the parents. Children born with developmental disorders cause parents to reject and blame themselves for the conditions experienced, namely the presence of their children who are not in line with expectations. It is not easy for parents to accept immediately.

Based on an article written by Viana, et al (2013) showing that family burdens are related to mental and physical disorders in the world, the results of the WHO World Mental Health (WMH) survey show that respondents in high, middle, and low income countries having a family with a fairly serious health is reported to experience a burden (burden) of 39.00–39.6%. The burdens they feel include the burden of having limited time of 22.9–31.1%, financial burden of 23.3–27.21%, psychological pressure and feelings of shame of 6.0–17.2%. The existence of physical disabilities and mental disorders is related to the increasing burden felt by the caregiver.

Given, Given, & Kozachik (2001:215) reveal that the caregiver's difficulty or pressure in caring for family members is called the caregiver burden. Caregiver's burden are mental pressures or burdens that arise on people who care for the elderly, chronic illnesses, family members or other people who are physically or mentally disabled (Retnaningsih & Dini, 2016). The caregivers in this study are parents as informal caregivers.

Soraya (2009) in Pratiwi (2014) revealed that the burdens experienced by parents include physical burdens, psychological burdens, problems in childcare, financial burdens and social burdens. The physical burden that appears on the family caregiver in the form of sleep disturbances, fatigue and pain (Fletcher et al, 2008). The psychological burden felt by the family is that they experience shock, stress, overflowing emotions, feelings of guilt, and even some families experience depression (Estes, Munson, Dawson, Koehler, Zhou, & Abbott, 2009). The financial burden felt by the family occurs because most children with Down syndrome have chronic diseases and are more than 3 times more likely to undergo examinations, besides that they usually do therapy, this makes them require quite a lot of additional costs (McGrath, Stransky, Cooley, Moeschler, 2011). The social burden felt by the family is the existence of negative comments, cynical gazes, as material for ridicule, and even rejection from the community (Dewi & Wibowo, 2015).

The results of interviews conducted by researchers with parents who have children with Down syndrome have the following results:

"After the doctor verdict my child to be a child with Down syndrome at the age of 6 months, it was very shocked, when I came home the body was like numb. It felt like I couldn't believe what the doctor said. At first I felt like crying when I saw a child, the air was sad, I just couldn't believe it. Even at that time I was also in a bad mood, my husband also blamed me for this situation. So at first maybe because I didn't expect it, so at that

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time my husband was annoyed when he saw me, it also made me even more depressed. The atmosphere in the family, which is usually busy, has become quiet.” (W1/RD/19-01-2019)

In addition, based on data obtained from the Association of *Parents of Children with Down Syndrome* or commonly abbreviated as POTADS (Anggredi & Valentina, 2015) that the reactions shown by parents with Down syndrome children initially experience feelings of surprise, inner shock, cannot accept condition of their children, blame themselves, and avoid the reality that befell their children. The next response in parents with children with Down syndrome they feel sad, disappointed, and angry when they know what they will face and experience.

Ghoniya & Savira (2015) in their research also revealed that parents who had Down syndrome children at the beginning of their birth felt very deep disappointment, feelings of shame, and anxiety about the abnormal condition of their children. Interviews conducted by Lestari & Mariyati (2015) found that parents of children with Down syndrome initially experienced stress, refused to accept the child's presence, felt sorry for themselves, were ambivalent, and felt guilty for giving birth to a different child.

Retnaningsih & Dini (2016) conducted a study on the burden of parents in caring for children with disabilities at the Special School level in Semarang. The result is that the burden of parents in caring for children with disabilities in the burdened category is 68 people or as much as 54.8%. The burden on parents based on the questionnaire generally feels angry because their children are different from children in general, feels tired of caring for and caring for children with disabilities, feels depressed, fears for their children's future, lacks money for caring for disabled children, feels guilty, and it is also stressed.

Research conducted by Yusri & Fitria (2016) about caregiver burden on families of children with special needs at Special School in Banda Aceh has the result that the burden on families with mild mental retardation shows a heavy burden that is felt by 66.7 percent. The burden of families with moderately mentally retarded children (53.6%) is 15 people, most of the burdens on families with autistic children show a heavy burden of (60%) as many as 3 people, most families with deaf children show a burden weight of (61.1%) as many as 11 people, all families with children with physical disabilities showed a heavy burden of (100%) as many as 4 people, all families with children with visual impairment showed a light burden of (100%) as many as 2 people. So that the total family burden according to the category with the child's condition is a heavy burden of 39 people (59.1%).

Based on the data above, it can be concluded that the pressures experienced by parents who have children with Down syndrome are more felt when new parents find out about their child's different conditions. The pressures that are often felt by parents are more psychological, in this case the parents experience distrust, feelings of disappointment, sadness, anger, shame about the child's condition and also anxiety about the child's future.

In addition, in Indonesia itself, a lot of negative treatment is still given by parents or the public who have not been able to accept the existence of children with mental retardation, especially Down syndrome. Many negative treatments are embraced by the community with the belief that the abnormality that occurs in children with Down syndrome is a curse that occurs in a family. This belief is also a burden for parents who have children with Down syndrome.

Burden experienced by parents is recognized to be able to interfere with family relationships, family life, and life plans for the child (Datta, Russell, Gopalakrishna, 2015). If this burden continues to be felt by parents, then their attitude towards the child will also have an effect, both in terms of how to take care of their child and how to meet the needs of the child, both physically and psychologically (Dewi & Wibowo, 2015). In addition, the consequences of the obstacles and burdens experienced by parents will lead to rejection or may even provide excessive protection, which will result in behavioral and emotional problems in children. On the other hand, because of the burden experienced, parents do not treat their children properly and even leave the child.

As reported by Suara.co, a six-month-old baby boy named Gammy in Australia was abandoned by his biological parents due to suffering from Down syndrome. His parents refused to take care of him and chose to leave him at his brother's house. In addition to having Down syndrome, this baby boy also has a heart disorder. This creates new problems for people who care for them because they do not have the money for treatment (based on news daily Suara.com accessed on January 17, 2019).

The existence of various types of burden felt by parents who have children with Down syndrome is influenced by various factors. One of the influencing factors is the existence of social support (Bull, 1990). Social support is defined as a series of exchanges that provide material, physical, social contact and emotional support. Several studies on social support to caregivers have shown that the presence of social support can reduce the burden (Bull 1990). Social support can be provided by the family or the environment or community.

Interaction that takes place in a community will form a bond. In addition, by joining individuals in a community, individuals can feel the benefits and also have a feeling that the community can fulfill their needs which can only be obtained when individuals join the community. The existence of positive benefits and also the fulfillment of needs, can make individuals increasingly feel that the community is important to themselves. Community members can also have an influence on the emergence of behavioral changes that show that community has deep meaning for individuals (Amin, 2015 in Maryam, 2017). This is what is called a sense of community.

Sense of community is a feeling of mutual connectedness, interdependence between members in which there is enthusiasm, trust, shared expectations, shared values and goals, and there is an overlapping history among members (Rovai, 2002). One of the things that can be obtained through integration in the community according to Weiss (1994) in Maslihah (2011) is that there is emotional support from people who have similar experiences in their lives, this will provide reinforcement for parents with children with Down syndrome so that they can reduce the burden. that is felt.

Like interviews that researchers have done with parents who are members of the Down syndrome child community. The following are the results of interviews that have been conducted by researchers.

“When I first entered the community, which contained parents with children with Down syndrome, they welcomed me very warmly, apart from that, they received a lot of information. So in this community we share stories and conditions of our children, we strengthen each other and share information. I feel that it's not just me like this, I have a new family. It makes my heart more relieved, because the information I get is no longer confused about the care of my child, in the

end what are you sad about, because we think that we are special parents because we were given a special care.” (W1/RD/19-01-2019)

“I have been in this community for a long time, Ms., here I really get support from the members. As a parent, I was initially devastated and sad when I found out that my child had Down syndrome. Moreover, it turns out that my son also has a heart disorders, this makes me even more devastated. I was confused at the time, ma'am, but thank God, I got information or advice from friends about treatment, even though I had to go back and forth outside the city, madam, it was very expensive, hehe but it didn't matter for the sake of the child's recovery. What makes me feel lucky and grateful again is that there are many children with Down syndrome whose conditions are worse than mine. Yes, the existence of this community makes me know many things, so that makes me happy.” (W2/BY/20-01-2019)

Based on interviews or preliminary studies above, parents with children with Down syndrome who participate in the community have a feeling of belonging, a feeling that members mean each other to other members and to the group, and a belief that the needs of members will be met through the commitment of members to be together. Research conducted by Afifah (2018) on the effect of sense of community on resilience in adolescents with disabilities due to accidents shows that sense of community can increase resilience. This means that the sense of community contributes to the resilience of youth with disabilities due to accidents. The interest and influence of a person on a group or a person has an influence on what the group is doing and the feeling that the needs of members will be met from sources received through group membership are factors that can increase the resilience of adolescents with disabilities due to accidents.

Research conducted by Lukito, Lidiawati, & Matahari (2018) on sense of community and self-efficacy in students who participate in the arts community has a positive relationship. Where individuals who have a high sense of community, the individual has high self-efficacy, and vice versa. This happens because the community provides expectations that must be achieved by other group members. In addition, the correlation that occur in the community can increase the individual's confidence in achieving the expectations given by the group.

Based on previous research, no one has examined the relationship between sense of community and caregiver burden on parents who have children with Down syndrome. In fact, as a parent who has a child with Down syndrome has its own burden. This research is considered very important because it can provide a new picture and enthusiasm for parents who have children with Down syndrome. Therefore, researchers want to examine the correlation between Sense of community and caregiver burden in parents who have down syndrome children.

The researcher proposes a hypothesis that will be tested for truth, namely there is a negative correlation between sense of community and caregiver burden in parents who have down syndrome children. This means that the higher the sense of community for parents with Down syndrome children, the lower the caregiver burden. Vice versa, the lower the sense of community for parents with Down syndrome children, the higher the caregiver burden.

RESEARCH METHODS

This study uses a quantitative approach, the research design used is correlational research. According to Sumanto (2014:14) correlational study was to determine whether there is a correlation, and how far a correlation exists between two (measurable) variables or more. The dependent variable in this study is the caregiver's burden and the independent variable in this study is the sense of community.

The population in this study were parents who had children with Down syndrome as many as 240 people. The sampling technique used is purposive sampling by determining special characteristics that are in accordance with the research objectives so that they can answer the research problem as many as 142 respondents of parents who have children with Down syndrome.

This research was conducted in the POTADS community (the association of parents of children with Down syndrome) having its address at Griya Patria Jl. West Pejanten No. 16E Pejanten Minggu Market, South Jakarta. The research was carried out from one up to three July 2019 by distributing the Google website address for the sense of community scale and caregiver burden scale on one of the social media applications. The scale that has been filled in by the respondent goes through the scoring or scoring stage. The scoring steps are carried out by assigning a score to each answer that has been filled in by the respondent with a vulnerable score of one to five if the statement is favorable (supportive) and vulnerable to a score of five to one if the statement is unfavorable (not supportive) on the sense of community scale and sense of community scale which will then be tabulated. The tabulation of the sense of community and caregiver burden data is separated, this is done to facilitate the processing of research data with the help of data processing software.

The data collection in this study used the caregiver burden scale and the sense of community scale. The caregiver burden scale is based on several indicators of caregiver burden expressed by Dillehay & Shandy (1990) namely physical burden, psychological burden, social burden, and also economic burden. The results of the validity test showed that there were 31 items. The results of the reliability test on the caregiver burden scale obtained a reliability coefficient of 0.873 in the high category. The sense of community scale is based on indicators derived from the sense of community aspects proposed by McMillan & Chavis (1986) consisting of Membership, Influence, Integration Fulfillment of needs, and Shared Emotional Connection and broken down into 30 items. The reliability test on the sense of community scale obtained a reliability coefficient of 0.915 which was included in the high category. Data analysis used is Spearman correlation analysis technique with the help of data processing software.

RESULTS

The research study was to obtain an overview of the caregiver burden and sense of community for parents who have children with Down syndrome. In addition, to find out whether there is a correlation between sense of community for parents who have children with Down syndrome.

Table 1.
Overview of Caregiver Burden

Interval	Criteria	Caregiver Burden	
		Σ Subject	(%)
113,33 \leq X	High	0	0
71,68 \leq X<113,33	Medium	22	15,49
X<71,68	low	120	84,51
TOTAL		142	100

Table 1 shows that there is no caregiver burden with a high category for parents who have children with Down syndrome. Meanwhile, in the medium category it was

15.49% (22 people), and the low category was 84.51% (120 people).

Table 2.
Overview of Sense Of Community

Interval	Criteria	Sense Of Community	
		Σ Subject	(%)
110 \leq X	High	136	95,77
70 \leq X<110	Medium	6	4,23
X<70	Low	0	0
TOTAL		142	100

The conclusion based on table 2 can be seen that the sense of community in parents who have children with Down syndrome is in the high category, namely 95.77%

(136 people), the medium category is 4.23% (6 people), and 0% low.

Table 3.
Spearman Correlation Test Results

		Correlations		
			Sense Of Community	Caregiver Burden
Spearman's rho	Sense Of Community	Correlation Coefficient	1,000	-,473**
		Sig. (2-tailed)	.	,000
		N	142	142
	Caregiver Burden	Correlation Coefficient	-,473**	1,000
		Sig. (2-tailed)	,000	.
		N	142	142

** . Correlation is significant at the 0.01 level (2-tailed).

Based on table 3, it can be seen that the correlation coefficient between sense of community and caregiver burden is -0.473. The significance value in this study is 0.000. The significance value is 0.000 <0.05, which means that there is a significant relationship between sense of community and caregiver burden. A negative coefficient value indicates the opposite relationship or the direction of the correlation is not in the same direction, which means that there is a negative relationship between sense of community and caregiver burden on parents who have children with Down syndrome. This means that the higher the sense of community, the lower the caregiver burden felt by parents with children with Down syndrome.

The results of this calculation show that the working hypothesis which reads "there is a negative correlation between sense of community and caregiver burden on parents with children with Down syndrome" is accepted.

DISCUSSION

Caregiver Burden Parents Who Had Down Syndrome Children

According to Thara (in Afrieni & Sartana, 2016) caregiver burden can be defined as the presence of

problems, difficulties, or adverse effects that affect the lives of patients such as family members. In addition, based on the opinion of Bainbridge, et al (in Werdani, 2018) caregiver burden can also be interpreted as a multidimensional reaction as a result of an imbalance in care for personal time and social roles, physical and emotional conditions, financial resources, and social resources that will affect welfare. caregivers as a whole.

The caregiver burden felt by parents who have children with Down syndrome often causes problems in their daily lives. Problems that are commonly felt by parents, such as family problems in treating children, financial problems that are needed more, worries about the child's future. This is also conveyed by Mangunsong, 2011 (in Ghoniyah, 2015) that worries often arise because of several problems such as finances and children's opportunities to face future realities. In addition, Mangunsong, 2011 (in Ghoniyah, 2015) also states that generally the source of the burden or burden on parents comes from the negative treatment of normal people towards people with disabilities. Even when parents have a child with Down syndrome, they often get a negative view or ridicule from society regarding the limitations that the child has. If so, it can make parents stressed and experience feelings of guilt. Kemis and Rosnawati, 2013 (in Rahma & Indrawati, 2017) revealed that the presence of a child with Down syndrome creates

tension in the family, so that parents experience feelings of guilt and disappointment with their birth.

In this study, caregiver burden was measured using the caregiver burden scale, the higher the total score obtained, the higher the caregiver burden. On the other hand, the lower the total score obtained, the lower the caregiver burden. In general, the caregiver burden for parents who have children with Down syndrome is in a low condition with the percentage reaching 84.51% (120 people). In accordance with the characteristics that compose it and based on these results, it can be interpreted that the caregiver burden of parents with children with Down syndrome is relatively low. This means that parents who have children with Down syndrome accept that their children are different from normal children in general and are not so burdened both physically, psychologically, socially, and economically. In this case, parents consider the problems experienced can be resolved properly.

The opinion above is supported by research conducted by Suri, 2012 (in Rachmawati & Masykur, 2016) which states that parents who have children with Down syndrome have a little burden, this is because they consider the problems they face will make them better in dealing with problems because they problems cannot be avoided and are more concerned with the best solution to solve them.

The results of research conducted by Zahro & Mustikasari (2014) also have the result that parents with children with disabilities have low stress levels which can be characterized by being able to develop the right job, find appropriate coping behaviors, be able to understand their own needs and the needs of the child. This is supported by research conducted by Purba (2018) which reveals that caregivers do not feel a heavy burden in caring for children with mental retardation because caregivers have accepted the presence of the child, caregivers always take care of their health, and caregivers try to meet the needs of children, one of which is providing the best education.

There are four indicators of caregiver burden which are taken from the definition of caregiver burden from Dillehay & Shandy (1990). The four indicators are (1) feeling the negative impact on the physical side of caring for sick people, (2) feeling the negative psychological impact on caring for sick people, (3) feeling the negative social impact of caring for sick people, (4) feel the negative economic impact of caring for sick people. Based on the descriptive analysis, it can be seen that the four indicators are in the low category.

The first indicator is to feel the negative impact on the physical side of caring for sick people. The results showed that feelings as a negative impact on the physical condition of parents who had children with Down syndrome were in the low category, namely 85.21% (121 people). The low feeling of negative impact on the physical aspect illustrates that parent in caring for children with Down syndrome have sufficient sleep time, are enthusiastic in taking care of children, have sufficient rest time, do not feel tired in taking care of children, and always think positively so that the body feels good. Staying fit in taking care of children with Down syndrome and household matters.

The second indicator is feeling the negative impact on the psychological side of caring for sick people. The results showed that feelings as a negative impact on the psychological aspects of parents who have children with Down syndrome are in the low category, with a percentage of 75.36% (107 people). The low feeling of negative impact on this psychological aspect indicates that parents are not disappointed when they find out the child is a person with Down syndrome, worries about the child's future are low,

remain enthusiastic about having children who are different from other normal children, accept the child's condition, remain strong in having a child with Down syndrome. syndrome. patient with the child's behavior.

The third indicator is feeling the negative social impact of caring for sick people. The results showed that feelings as a negative impact on the social aspect of parents who had children with Down syndrome were included in the low category, with a percentage of 90.14% (128 people). The low feeling of negative impact on the social aspect of parents who have children with Down syndrome indicates that parents remain comfortable when neighbors and relatives know the condition of the child, happy to see children playing with the outside world and being accepted by society, happy to spend time with children, happy because they are always get support from the family, believe that the community will accept the condition of the child, always be confident when bringing the child to a crowded place, and parents feel increasingly strong in living life.

The fourth indicator is feeling the negative economic impact of caring for sick people. The results showed that feelings as a negative impact on the economy of parents who have children with Down syndrome are included in the low category with a percentage of 73.24% (104 people). The low level of negative impact on the economy of parents who have children with Down syndrome illustrates that parents are enthusiastic about making a living to support their child's growth and development, parents do not regret spending a lot of money on child therapy, and the family's economic condition is stable.

Based on the description above, it can be concluded that the caregiver burden felt by parents who have children with Down syndrome in order from the lowest is the negative impact on the social, physical, psychological, and economic aspects. Parents with Down syndrome children who have negative feelings in social terms are 128 people, in second place, namely in terms of physical, 121 people, third in psychological terms, 107 people, and last in economic terms, 104 people. However, in terms of indicators in terms of physical, psychological, and financial aspects, there are some people who have a high caregiver burden, this can be caused by several factors.

Research conducted by Putri (2013) found other factors that affect the caregiver burden, these factors are (1) work status is related to the income received by a person, if someone has sufficient income, the perceived burden can also be minimized. (2) Relationships in the family, family relationships here are said if the caregiver has a close relationship with the sick person, the perceived burden will decrease, and vice versa. (3) Memory and behavior, in this study memory and behavior problems are the most dominant factors related to caregiver burden. Caregivers who experience memory and behavior problems tend to be unable to control themselves and their emotions in the face of behavioral changes that occur in sick people, so that it will have an impact on their attitudes and behavior. (4) Satisfaction with care, satisfaction with caring is influenced by how a person accepts and carries out his role as a caregiver and the form of the relationship between children and parents. The more positive experiences that are felt in caring for sick people, the lower the burden experienced.

Based on the calculation of the empirical mean, from the four indicators, the comparison value for feeling the negative impact on the physical aspect of caring for sick people is 12.8380; feel the negative impact on the psychological side of caring for sick people by 13.9296; feel the negative impact on the economy as a result of caring

for sick people of 17.6408; and feel the negative impact on the economy as a result of caring for sick people by 14.4930.

Sense Of Community Parents Who Have Down Syndrome Children

McMillan & Chavis (1986) revealed that sense of community is a feeling where members mean each other to each other and the group, and there is a belief that needs will be met through their commitment to always be together. Sense of community is also closely related to the feeling of being cared for, treated well, and valued as an individual and accepted as part of the community and social life. Sense of community in this study was measured using a sense of community scale. The higher the score obtained, the higher the level of sense of community in the community, and vice versa, the lower the total score obtained by the subject, the lower the level of sense of community.

Based on the results of the descriptive analysis, it is known that in general the sense of community of parents who have children with Down syndrome is in the high category, with a percentage of 95.77%. From these results, it can be seen that most parents who have children with Down syndrome have a close, reciprocal emotional relationship with other community members and are comfortable with joining the community.

Supported by research conducted by Prayoga & Herdiyanto (2014) where in his research the sense of community felt by subak administrators was in the very high category of 58.6%. These results show a feeling of belonging, the existence of togetherness among community members increases the commitments that have been formed previously. This commitment is very beneficial to community members and also the sustainability of the community in the future.

Research conducted by Maryam (2017) also states that the sense of community owned by UMSIDA administrative employees is in the high category at 20% and moderate at 59%. This states that most employees feel they have a feeling of attachment, feel meaningful to other members and also to their own community, and believe that their needs can be met through shared commitment in their community.

In addition, Amin, 2015 (in Maryam 2017) also states that the higher the level of sense of community a person has, the more likely that person is to maintain membership in the community. Luhman, 1995 (in Rahmawati, 2017) also revealed that someone who has a high sense of community tends to have a deeper sense of security and participates in many activities held by the community.

The above statement is supported by research conducted by Lukito, Lidiawati, and Matahari (2018), the sense of community owned by students who participate in the arts community is in the high category. This proves that individuals who have a high sense of community will feel more like they are part of their group. This happens because individuals do not only think that the community is only a place to gather and share experiences, but there is a responsibility that must be achieved together.

The sense of community scale in this study uses four aspects, namely membership, influence, integration fulfillment of needs, shared emotional connection. The first aspect, membership, is a feeling of belonging or being part of a personal connection and a feeling of being part of a group. In this aspect, parents who have children with Down syndrome have a high category with a percentage reaching 91.55% (130 people). This shows that parents who

have children with Down syndrome are comfortable when communicating in the community, being a member of the community is an identity and pride, trusting members in the community, and feeling that joining the community is important.

The second aspect, influence, is interest in the group and also has an influence on what the group does. In this aspect, parents who have children with Down syndrome have a high category with a percentage of 90.85% (129 people). This shows that parents of children with Down syndrome are happy when they know there is a special community for parents with Down syndrome, feel that their presence can provide benefits, are very enthusiastic about being part of the community, know the importance of joining the community, and feel that they get many benefits in the community.

The third aspect, integration fulfillment of needs, is a feeling where the needs of its members can be met from sources received through group membership. In this aspect, parents who have children with Down syndrome have a high category with a percentage of 90.85% (129 people). This shows that parents who have children with Down syndrome get support from community members, have common goals with community members, provide solutions to each other, and share important information related to Down syndrome.

The last or fourth aspect, shared emotional connection is a commitment to time, history, and experience. In this aspect, parents who have children with Down syndrome have a very high category with a percentage of 92.96% (132 people). This shows that parents who have children with Down syndrome care about each other, share experiences that can motivate each other, and tell each other about their child's growth and development.

Based on the description above, it can be concluded that the aspects of sense of community that are felt the most by parents with Down syndrome children are in order from the highest to the integration aspect of fulfillment of needs, which is as many as 132 people. In second place is membership as many as 130 people. The order of the three aspects is influence as many as 129 people and shared emotional connection as many as 129 people. Based on the calculation of the empirical mean of the four aspects, the comparison value for the membership aspect is 33.8521; the influence aspect is 25.6972; aspects of integration fulfillment of needs of 21.2887; and for the shared emotional connection aspect of 29.6972.

Sense Of Community with Caregiver Burden on Parents Who Have Down Syndrome Children

Based on the results of the research correlation test using the Spearman correlation technique, it is known that the coefficient of sense of community towards caregiver burden is -473. The significance value in the study was 0.000. The significance value is 0.000 < 0.05, which means that there is a relationship between sense of community and caregiver burden for parents who have children with Down syndrome. The correlation between sense of community and caregiver burden shows that both have a negative relationship. Correlation that has a negative relationship indicates the relationship is in the opposite direction. This can be interpreted as the higher the sense of community, the lower the caregiver burden, conversely the lower the sense of community, the higher the perceived caregiver burden.

The results of this study support the research conducted by Purwantika, Setyawan, Ariati (2013) that students who have a sense of community have a

comfortable feeling in developing relationships with other students so that they can be responsible, develop themselves, and benefit from each interaction carried out with other members, so as to reduce academic procrastination.

This means that the sense of community contributes to the caregiver burden felt by parents who have children with Down syndrome. The existence of parental interest in joining the community and the benefits derived from membership in the community make the members' needs feel fulfilled, so that membership in the group becomes a factor that can reduce the caregiver burden.

This is in line with the opinion of Goodwin, 2009 (in Lukito, Lidiawati, Matahari, 2018) which states that when individuals join a community, individuals can feel the benefits and also have a feeling that the community can fulfill their needs which can only be obtained when individuals join the community. In addition, the existence of a community can create new enthusiasm for parents, they can support each other or provide mutual support to each other in their community. Parents who get support from people who have something in common, make them have positive thoughts. The existence of support from people who are in this community can alleviate the problems faced, which will affect the process of treating children with Down syndrome.

Supported by the opinion expressed by Cohen, Wills, Davis & Swan (in Karademas, 2006) support from others, especially those obtained in the community, seems to have an influence on health both directly and indirectly. The arrival of other people in the lives of parents who have children with Down syndrome makes them have positive attitudes and thoughts, so as to reduce the perceived caregiver burden.

It's just that the decline in the caregiver burden on parents who have children with Down syndrome is also influenced by other factors. Other factors that influence individuals to reduce the caregiver burden according to Anggraeni & Valentina (2015) are (1) the point of view of the problem, parents who understand the meaning of the existence of a child with Down syndrome are grateful for realizing that children are gifts from God and are considered as things which strengthens the family. (2) A good coping strategy, in this case the parents of children with Down syndrome overcome the problem by finding out and learning about Down syndrome, besides that they overcome problems by meeting the daily needs of the child, as well as providing facilities that can help the child's development and develop children's abilities to the fullest.

In line with the opinion of Mangunsong, 2011 (in Zahro & Mustikasari, 2014) which states that parents who can accept children with Down syndrome will find out the condition of their children through various media, both online, newspapers, consulting with health workers, and through books. which is read.

Sari, Sukarlan, and Pohan (2013) in their research also revealed that one of the factors that influence the caregiver's burden is the caregiver's motivation. When someone has a strong motivation to achieve a goal, then this person will be more likely to want to take the action and more likely to persist when facing obstacles (Bandura, 1997 in Sari, Sukarlan, and Pohan, 2013). In addition, strong motivation is related to self-efficacy, self-efficacy determines how an individual feels, thinks, behaves, and how they motivate themselves.

Based on the explanation above, the caregiver burden felt by a person is also influenced by various factors, namely the point of view of the problem, good coping strategies, work status, family relationships, memory and

behavior, satisfaction in caring for and also the motivation of the caregiver. In this study, the emphasis is on the caregiver burden on parents who have children with Down syndrome, because parents with children with Down syndrome feel some negative feelings as a result of caring for children with Down syndrome. The caregiver burden referred to by the researcher is a condition that is felt by individuals as a result of caring for other individuals to meet their needs, thereby causing negative feelings both physically, emotionally, socially, and financially, especially in parents who have children with Down syndrome.

Sense of community in this study is defined as a feeling where members have a sense of belonging, a feeling that members mean each other to others and to the group, and a belief that members' needs will be met through a commitment to be together.

The correlation between sense of community and caregiver burden on parents has a significant correlation. These results indicate that there is a correlation between sense of community and caregiver burden on parents who have children with Down syndrome. This is in line with research conducted by Jatisari & Dewi (2013) which states that sense of community has a relationship with the individual self, where individuals will behave in a more positive direction. The sense of belonging that can be felt in the community and the feeling of being part of a community provide an evaluation of the process of acceptance and respect for oneself.

Davidson (1991) also argues that people who have a high sense of community towards a group, they can have a feeling of ownership, they believe that they can exercise control over the group and are also influenced by the group, they believe that their needs can and are met. because of the collective ability within the group, and lastly because of the history of togetherness that can create a very strong emotional bond.

The results of the descriptive analysis on two variables stated that the level of sense of community for parents with children with Down syndrome was in the high category, while the caregiver burden variable was in the low category. In this study, the research subject was reviewed from these aspects so that it affected the research results.

RESEARCH LIMITATIONS

There is still a limited theoretical basis regarding the caregiver burden variable in the context of parents who have children with Down syndrome, most of which are discussed are caregiver burdens for people who have severe mental disorders and chronic diseases.

Collecting data using google forms, research subjects may judge that the answers given are correct or incorrect answers, because in this case the researcher cannot explain directly that the answers to be given are not judged right or wrong, but all answers are acceptable if they do the work seriously and in accordance with the circumstances of the respondent.

Specifications of research respondents who did not specify the gender of the parents, namely mother or father. So there is no relevant data related to the perceived burden between mothers and fathers.

CONCLUSION AND SUGGESTION

The research hypothesis "There is a negative correlation between sense of community and caregiver burden on parents who have children with Down syndrome" is accepted. This means that the higher the perceived sense of community, the lower the caregiver burden felt. On the other hand, the lower the perceived sense of community, the higher the caregiver burden. Descriptive statistical results found that the lowest burden is felt sequentially by parents who have children with Down syndrome in terms of social, physical, psychological, and economic aspects. The aspect that most influences the level of sense of community is the integration of fulfillment of needs.

Based on the results of data analysis, discussion and conclusions, the researchers put forward several suggestions, namely for research subjects it is expected to keep the spirit in living life, because having a child with Down syndrome is a privilege. In addition, parents who have children with Down syndrome are expected to take full advantage of the existing community, for example as a place for sharing to express problems so as to reduce stress.

The community is expected to continue to strengthen each other, always increase support both materially and psychologically, and also hold activities that can increase the enthusiasm of parents of children with Down syndrome and also activities that can develop the abilities of children with Down syndrome.

Future research is expected to be more able to observe or observe the subject when the subject fills out the psychological scale, thereby reducing the subject in providing faking good answers and providing a sense of security and comfort for the subject in providing answers that have been given by researchers on a psychological scale.

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