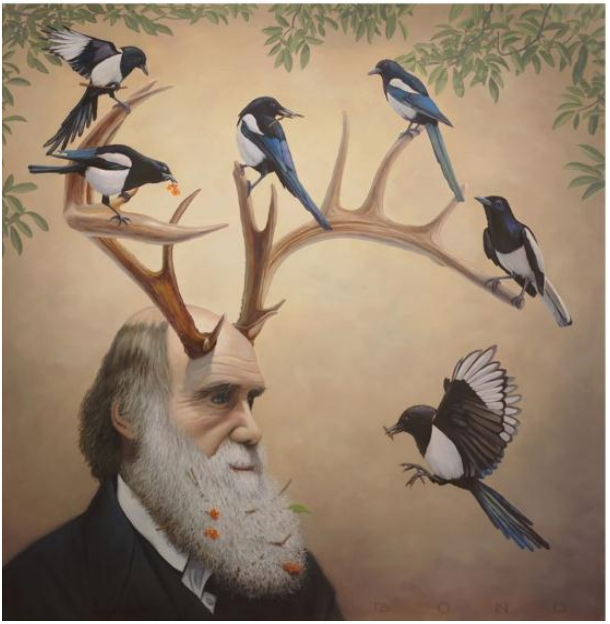
opción

Revista de Antropología, Ciencias de la Comunicación y de la Información, Filosofía, Lingüística y Semiótica, Problemas del Desarrollo, la Ciencia y la Tecnología

Año 35, 2019, Especial N° 22

Revista de Ciencias Humanas y Sociales
ISSN 1012-1587/ ISSNe: 2477-9385
Depósito Legal pp 198402ZU45



Universidad del Zulia
Facultad Experimental de Ciencias
Departamento de Ciencias Humanas
Maracaibo - Venezuela

Opcion, Año 35, Nº Especial 22 (2019):*2899-2921*
ISSN 1012-1587/ISSNe: 2477-9385

Experience Of Mothers With Chronically Disabled Children In Remote Areas

Erna Setijaningrum[1*], Siti Mas'udah[2]

[1]Department of Public Administration, Faculty of Social and Political Sciences, Universitas Airlangga, Surabaya, Indonesia.
***erna.setijaningrum@fisip.unair.ac.id**
[2]Department of Sociology, Faculty of Social and Political Sciences, Universitas Airlangga, Surabaya, Indonesia.; siti.masudah@fisip.unair.ac.id

Abstract
This study aimed to find out how the experience of the mothers with chronically disabled children in remote areas finding ways to overcome their problems. This study employed a qualitative method. The results of this study showed that mothers with chronically disabled children felt stressed, were considered a family disgrace, and experienced discrimination from the community. They tried to find a way to solve their problems by actively participating in the routine activities carried out by their communities. They received a lot of benefits from the activities. They felt more confident, received a lot of information regarding the care of children with chronic disabilities, were optimistic, empowered, patient and accepted the situation.

Keywords: experience of mothers, children, disabilities, remote areas, overcoming problems.

Experiencia de madres con niños con discapacidad crónica en áreas remotas.

Este estudio tuvo como objetivo descubrir cómo la experiencia de las madres con niños con discapacidad crónica en áreas remotas encuentra maneras de superar sus problemas. Este estudio empleó un método cualitativo. Los resultados de este estudio mostraron que las madres con niños con discapacidad crónica se sentían estresadas, se las consideraba una desgracia familiar y sufrían discriminación por parte de la comunidad. Intentaron encontrar una manera de resolver sus problemas participando activamente en las actividades rutinarias que realizan sus comunidades. Recibieron muchos beneficios de las actividades. Se sintieron más seguros, recibieron mucha información sobre el cuidado de niños con discapacidades crónicas, fueron optimistas, capacitados, pacientes y aceptaron la situación.

Palabras clave: experiencia de madres, niños, discapacidades, áreas remotas, superación de problemas.

1. INTRODUCTION

In the village community, most people live in poverty and in remote rural places. According to the study by SYAHZA and SUARMAN (2013), it is suggested that household vulnerability indicates low economic development in all levels of the community, resulting a vulnerable and poor region. Previous studies have shown that a low level of health leads to high mortality in both adults and children, since there is a lack of access to health services. CHASANAH (2015) stated that maternal mortality is caused by two factors. Firstly is late childbirth delivery and secondly, there is teenage and advanced maternal age, the number of children, and a short pregnancy interval.

A lack of medication due to cost causes the poor, such as farmers and fishermen, to prefer traditional over modern medication (TRIRATNAWATI, 2010). Inadequate health information provided to the parents affects their child's health quality. KARINA and WARSITO's study (2012) revealed that this information is closely linked to education level and comprehension ability, particularly for the mother, when concerning the vaccination schedule as well as their refusal to vaccinate their baby. Moreover, people

in remote locations that are far from health access tend to use native healers for giving birth, resulting in a late birth delivery (ANGGORODI, 2009).

Various attempts have been undertaken by the patients, from modern medicine through to alternative medication. Traditional treatment is preferable, for example therapy, due to the frustration and anxiety experienced as a response to more expensive medical treatments (GINTING, 2014). These attempts sometimes meet failure concerning the following factors: the higher cost of medication, inaccessible health facilities, and the side effects of the previous medication that had a bad impact on the child (HANDIAN, WIDJAJANTO, & SUMARNI, 2017). Similar to this, ADAMS, LEE, PRITCHARD, & WHITE (2009) examined that the problems faced by the poor could possibly come from healthcare workers such as doctor who does not give them a sufficient explanation of their diagnosis or who refuse to see the patient outright. One of the factors is because the patients have had a disability since childhood. The poor families in the village with chronic illness also deal with treatment failures. They avoid outpatient facilities and unreasonable medical specialists, in addition to delays in the hospital services. They look for local treatments and even medicate by themselves which can lead to complications in their condition (SURYAWATI, 2005).

Disability occurs due to a lack of information on health and child development held by the parents. In nurturing a child, the parents tend to have no awareness and responsibility when facilitating baby from the stage of pregnancy onwards (Ministry of Women Empowerment and Child Protection of Indonesia, 2013). According to EINFELD et al. (2012), the parents' knowledge highly determines the growth and development of children with disabilities. They need training to enhance their children's growth and development as well as the frequency of their family interactions.

There are studies suggesting that children are more vulnerable than adults to disease because they more easily get infected by bacteria (PASALLI, POEKOEL, NAJOAN, 2016). Consistent with this result, LEE, HAN, DAN LEE (2007) revealed that children under 5 years old are highly vulnerable to getting infected by viruses, especially those who are genetically vulnerable as well.

Children tend to have more intimacy with their mothers than with their

fathers. Children often tell information about themselves to their mothers because they perceive it as a positive behaviour to communicate by respecting their child's self-esteem (NORA & WIDURI, 2011). In fact, if the children are disabled, then they will experience more tension with their mother. The mothers are perceived as having more of a role as a caregiver that the fathers because of their ability to provide an adaptive environment that is stimulating, and nurturing for their children (FAHMY, 2017).

It was determined that the closeness of the mother to their disabled child would eventually lead the mother to stress when dealing with their physical illness, isolation, and the insufficient time available to other tasks. GIBSON (1995) suggested that mothers always give their best for their children and they try to perceive the positive aspects of a child's illness. The mothers of disabled children may deal with several burdens, such as depressive symptoms (MILLER GORDON, DANIELE, & DILLER, 1992), depression (EITHAN, AMAN, ROBERT, 2010), a higher depression level than the fathers (OLSSON & WANG, 2008), sadness, anger, loneliness, being accused by their family (ERGUN & ERTEM, 2012), further anxiety and depression resulting a poor life quality for the mother (BUMIN, GUNAN, & TUKEL, 2008), more emotions (GRIFFITH, HASTINGS, PETALAS, & LLOYD, 2014), anxiety (DDYKENS, FISHER, TAYLOR, LAMBERT & MIODRAG, 2014), pressure (DUMAS, WOLF, FISMAN, & CULLIGAN, 2015), feeling mentally broken (MCCONKEY et al., 2006), stress (MCCONKEY et al., 2006; LUKSIC et.al., 2000), psychological pressure (BRESLAU, STARUCH, & MORTIMER, 1982), being incapable of achieving personal fulfilment because they have to give their spare time to caring for their children (WALLANDER & VENTER, 1995), being worried (MONSEN, 1999), sleep disorders and having a higher stress level than those who do not have disabled children (PORTER & LOVELAND, 2018).

In terms of overcoming these problems, the mothers of disabled children will seek to find solutions. The mothers with disabled children who lived in Klang Lembah Malaysia tried to accept the condition, were proactive in their thinking, and were closer to God, hoping that He would solve their problems (ILIAS et al., 2016). In Boston America, a mother of disabled children who lived in a village exerted all of the resources that they had access to in order to overcome their problems (SOUSA, 2011).

The research concerning the efforts of the mother of disabled children in remote areas is limited, particularly in children with chronic disabilities. Thus, the writers were interested in examining how mothers with disabled children find a solution.

2. RESEARCH METHODS

This study employed the qualitative descriptive method. This study was conducted in Sawahan, Nganjuk district, East Java, Indonesia. Geographically and economically, Sawahan is a remote region where people living below the poverty line. This sub-district has 16 children with disabilities, encompassing the 7 villages of Bareng, Duren, Margopatut, Ngliman, Sawahan, Sidorejo, and Kebon Agung. Interestingly, all of the disabled children had a chronic disability, thus they were very dependable on another person, especially their mother.

This study examined 16 mothers of children with chronic disabilities using in-depth interviews. The process of the interview was carried out between June and August 2019 in Javanese. To obtain accurate data, the writer attended regular activities hosted by the mothers. Furthermore, the writer visited their homes to hone the data by conducting in-depth interviews and a direct observation of the children's condition.

3. RESULTS AND DISCUSSION

3.1. Disabilities in a Remote Place

According to Statistics Indonesia (BPS) of Nganjuk (2017), geographically, Sawahan has mountainous contours that lead to a lack of access to transportation connections from one region to another. The asphalt road is about 86.75 km in length and the rocky road runs for 56 km. Most of the region in Sawahan is dominated by forest (68%), dry land (13%), paddy rice fields (10%), and compounds (9%). Given these geographical conditions and a lack of transportation, it is considered to be a remote place.

The following picture shows the condition of Sawahan road leading to the location where the mothers of the children with chronic disabilities lived. The problems found in Sawahan are caused by the limited health access as well as the service and geographical factor (isolated area), resulting in dif-

ficulty accessing quality health services (LIU, HSIAO, & EGGLESTON, 1999). JAFFAR et al. (1997) suggested that the condition of being a remote place in Indonesia leads to obstacles related to delivering health programs as well as a lack of medical equipment which is only provided by and to bigger local health centres. Access to health services among the poor indicates low quality health services. The low literacy possessed by the village community is marked by an unhealthy lifestyle, poor environment, as well as inaccessible roads (SUHARMIATI, LAKSONO, & ASTUTI, 2013). Similar to this, JUTTING (2014) explained that low health access is found among developing countries. This occurs due to a lack of financial support that leads to low health services and uneven health facilities.

Figure 1. Road condition of Sawahan district

The livelihood of the Sawahan residents is mostly labourers as farmers (76%), civil servants, military, police and related services (5%), traders (10%), and others (9%). Sawahan residents still live on the poverty line, as seen from their simple houses, which are made of walls (51%), wooden boards (27%), and bamboo (22%) as shown in the following photographs.

Figure 2: House Condition in Sawahan

SRINATH REDDY'S study (2005) conducted in poor rural India found that the chronic diseases experienced by poor people are the result of a high consumption of tobacco, a lack of nutrients, the slum's environmental impact, and a lack of public awareness of disease risks. In the USA (HEITZMAN, BUZHARDT, RUSINKO, & MILLER, 2013), a mother with a disabled child had the problem of being unable to access information technology because she was in a rural and remote area. In New South Wales (NSW) Australia, a mother in a rural and remote area had difficulty accessing various community-based therapy services (DEW et al., 2012). Mothers with disabled children who live in rural Africa experience barriers to accessing information that requires certain advocacy methods based on gender, race, and class (STANLEY, 2015). One mother had difficulty getting access to health and social services because she lived in a rural and remote area in South Western Ontario, London (ELFORD, 2015).

Chamber (in SUYANTO, 2001) revealed that the essence of poverty lies in a deprivation trap. In detail, a deprivation trap consists of five elements; 1). Poverty, 2). Physical weakness, 3). Alienation or a degree of isolation, 4). Vulnerability and 5). Helplessness. These five elements are usually interrelated and they become dangerous opportunities for poor people and their families. Chamber explained that the poverty trap is one of the reasons why individuals and families remain in the cycle of poverty.

Living in poverty is not only about a lack of money and economic resources, but it also includes various things such as health, low education, unfair treatment in the law, vulnerability to the threat of criminal action, powerlessness when facing a greater power, and powerlessness in determining one's own life. The five elements of poverty proposed by Chamber illustrate how poor people tend to be weak, isolated, vulnerable, and powerless, which becomes a deadly factor against poor families when it comes to living well.

The informants in this study were mothers with disabled children. Its characteristics can be seen from their age, the number of children,

education, employment, deciles (grouping of poverty) and the percentage of total income concerning the cost of caring for a disabled child. Most of the mothers were aged 40 years and over, had more than two children, almost all of the mothers worked as farm labourers or did odd-job and they belonged to a very poor families. The following is a table of the characteristics of the mothers in this study.

This study found that the mothers had a low education graduate and almost of them spent more than fifty percent of their income on the cost of caring for their disabled child. In addition, the mothers with a low level of education could not understand the provided information, either from the health care workers directly or from health books, so they could not improve their understanding regarding the children's health information (SISTIARANI, GAMELIA, & SARI, 2014).

Almost all of the disabled children in this study were not the first child, and they were under 17 years old. Most of them were female, while a few of them were male. Both poor and very poor mothers had children with chronic disabilities. All of the mothers in this study had a chronically disabled child. The following are pictures of the chronically disabled children.

Figure 3: Chronic Disabled Children

This study found that both groups of poor and very poor mothers had disabled children with similar physical and mental conditions. The availability of health access also affected the child's nutrition, with the increasing number of child patients indicating the stakeholder's failure to control the service quality and disproportionate distribution of health facilities (FRANKENBERG, 1995). In terms of their physical condition, all of the disabled children in this study had smaller, crooked, stiff and immovable leg and hand bones. They also could not speak. In addition, most of them had a crooked spine and cervical bones. In terms of their mental condition, most of them did not respond to outer stimulus, and only a few could respond to the stimulus by moving their eyeballs, turning their head or moaning. From the disability's chronology, all of the children from both groups have had chronic disabilities since they were born. This condition was revealed by the following two mothers:

This is their condition since birth. Small, crooked, and stiff leg and hand bones. Cannot talk, just groaning (Wwk)

Yes, since birth. A small, crooked and stiff leg and hand bones. They are difficult to move. The spine is also crooked, the cervical too. Does not respond when called. (Is)

Besides having a chronic disability, the children are prone to fever and diarrhoea due to having a poor immune system. This study found that their poor immune system was caused by a lack of nutritious food intake, as they only ate porridge and inadequate protein sources. Only one mother claimed that she sometimes gave additional milk and cereal to improve her child's nutrition. The following were statements regarding feeding:

I give porridge and soup. S/he cannot swallow vegetables, so only the soup. I add fish sometimes, only if s/he wants. (Rom)

Only eat porridge. S/he does not want others. I usually give vegetable soup, but only the soup. The protein sources are usually mashed

tempeh and tofu mixed with the porridge. (Mar)

I give milk sometimes. I feed him/her with soft rice. Sometimes I buy baby cereal too. (Wwk)

3.2. Treatment for Chronically Disabled Children in Remote Areas

The study found there to be differences in terms of the treatment efforts made by the poor mothers and very poor mothers. The group of poor mothers tried to treat their children in hospitals and health centres. In addition, they did reflexology, treatment by the shamans, and herbal medicine. There were many efforts made by the mothers in this group to seek the healing of their children, both medical and non-medical. Some of the efforts undertaken by the mothers included preparing costs, seeking a certificate of being a poor family, undergoing medical, alternative, and herbal treatments, and seeking information (HANIFAH, MEDIANI, & NURHIDAYAH, 2018). The following were statements made by three mothers regarding to treatment:

I went to Dr. Soetomo Hospital, mam, the biggest hospital in Surabaya. I treated my children for two years. Performing therapy in the hospital. Two years I rented a boarding house near to the hospital. Because there was no progress, I decided not to continue. (Srt)

I went to Nganjuk Hospital. But I cannot continue since I have to go back and forth. I was exhausted and had no time. (Tum)

I went everywhere, starting with the health centre and hospital through to other treatments. Alternative medicine was in terms of reflexology, shamans and traditional herbal medicine. (Ksn)

On the other hand, mothers with a very poor condition never treated their children in hospital but some of them went to a health centre. All of the mothers in this category treated their children with reflex-

ology, shamans and herbal medicine. The following were the statements made by three mothers:

I never went to hospital. But I have taken my child to the health centre. My children's routine treatment includes reflexology, visiting shamans, and herbal medicine. (War)

I once went to a shaman. He said that my child was subject to witchcraft, black magic and others. So, what he meant was to get rid of bad luck. But my child's condition remains the same. (Kas)

I never treated my child in hospital or at a health centre. Only alternative treatment like visiting a shaman and herbal medicine. (Tin)

3.3. Mother's Problem: Difficulties Seeking a Way Out

The problems faced by the mothers in this study can be classified into four groups, namely personal problems, family problems, problems with society, and problems with the government. The group of poor mothers had fewer problems than the group of very poor mothers as seen in Table 1.

Table 1. Problems Faced by the Mothers Due to Having Chronically Disabled Children

Scope of Problem	Poor	Very Poor
Personal problems	- Stress. - Feeling ashamed and depressed. - Does not have friends.	- Stress - Having a heavy life burden. - Confused and not knowing what to do. - Does not have support. - Does not have friends.
Family problems	- Being considered a disgrace to the family.	- Being considered a disgrace to their family. - Exclusion by their family. - Being blamed by their family. - Often quipped by their family. - Being considered the party that is responsible for the child's disability.
Problems with/in the community.	Being excluded by their neighbours as they think that disabled children are bad karma, an infectious disease, a hereditary disease and a public disgrace.	Being excluded by their neighbours as they think that disabled children are bad karma. They think that they are an infectious disease or a hereditary disease and they are seen of as a public disgrace.
Problems with the government.	- Difficulties accessing the health services. - Lack of attention from the government.	- Difficulties accessing the health services. - Insufficient financial assistance. - Lack of attention from the government.

Sources: Research Results, 2019

Even though the mothers in the poor group had fewer problems than those in the very poor group, the mothers in both groups were equally stressed regarding personal problems. HOFFMAN et al. (2009) found that mothers with disabled children have a higher level of stress. Mothers care more for disabled children than their other family members. Caring for a disabled child often makes the mothers feel difficult, particularly during the transition to school, which results in depression. Therefore the mothers need special support from their family (MEGASARI & KRISTIANA, 2016). The following were statements made by mothers from both groups:

It's stressful. I feel confused, heavy, and do not have friends.(Was)

It's stressful having a child like this. I am confused about what to do. It feels like life is hard. Moreover, my family gives me no support. Similar with others, I also feel that I do not have the same friends, so it increases my stresses. (Sum)

Yes, it's indescribable. Stress, shame. I am depressed. (Tum)

Regarding family problems, the mothers in both groups felt that having a disabled child was shameful disgrace for their family. The following were statements made by two of the mothers:

My family said that I was a family disgrace because they feel shame. (Srt)

I am an embarrassment to my family, because having a disabled child is a disgrace. (Marn)

Mothers in both groups were equally discriminated against by the community. The following is a statement made by one of the participants:

People do not want to accept us. They exclude me, because having

a disabled child is like an infectious disease, hereditary disease, and even a public disgrace. (Is)

3.4. Efforts Made by the Mothers to Overcome the Problem

The mothers in this study had made some efforts to overcome the problem of having disabled children. There were many challenges faced by the mothers in their efforts to find healing for their children. For instance, the mothers had difficulties when dealing with children who were difficult to calm (MARETTIH & WAHDANI, 2017). This study found that one of the efforts made by the mothers was by forming a community among them. This community has an agenda where the mothers share information and strengthen one another. Their routine meeting is held every month. The community was formed seven years ago, starting from the concerns of two mothers (Ksm and Srt) who wanted to find a way out. They then contacted several other mothers with disabled children. The community then gathered five mothers together to make activities to strengthen one another. They finally agreed to hold regular meetings every month, every Minggu legi (Javanese calendar). The community has now reached 16 people. The meeting location is held every month at a member's house. The monthly activities include arisan by as much as Rp 20,000 and their contribution fund is as much as Rp 5,000.

A study conducted by GIBSON et al. (2011) found that sometimes the mothers are exhausted when facing the obstacles and challenges involved in caring for their disabled children, such as obstacles in school, health care and due to a lack of funds from the government. Therefore, mothers who have children with chronic disabilities are very interesting to examine. This study is important as an effort to improve the health of the poor in society and to offer solutions to the problems faced by poor families, especially the mothers who have children with chronic disabilities. The routine meetings held by the mothers have been running for about seven years. Many benefits have been felt by the mothers as they now have friends, confidence, information related to the care of chronically disabled children, opti-

mism and empowerment. They become patient and accepting of the situation.

The mothers now feel that they have friends in their community which makes them confident. Therefore they are no longer stressed, embarrassed, and confused. This was stated by the following two mothers:
Now it feels like I already have friends. Yes, in this community. Yes, because we have a similar fate, so now I don't feel stressed anymore. I can tell my problems and stories to the members of this community. (Wwk)

I feel confident now. Yes, no more stress. In the past, I was embarrassed and confused. Now I have a community like this. There is a friend in the same boat. There are friends ... whom I can talk to. (Ksm)

The mothers also get a lot of information related to alternative medicine in the form of reflexology, financial assistance from the government, the development of the child's condition, diet, and traditional herbal medicine. From all of the information obtained, the mothers are optimistic and empowered to overcome the problem. This was stated by the following two mothers.

"Yes, after joining this community, I get many benefits. One of them is reflexology treatment, government assistance, herbal medicine, and also learning what food suitable for my child. Now, I know that if there is a problem, I immediately know the solution. I am more optimistic now. (Tin)

"There is a lot of information. Now I know alternative medicine, reflexology. Then, there is help from the government, and a food menu. Then the developing condition of my child. Also, there are traditional herbs for my child's stamina. Now I feel more optimistic and can overcome my own problems ". (Rom)

In addition, the current benefit obtained by the mothers is awareness of being able to accept the situation. This awareness increases after they strengthen or motivate each other. One form of mutual encouragement and motivation is visiting each other when there is one mother whose child is sick. This was revealed in the statements of the following two mothers:

The most perceived benefit is that now all of the mothers are able to accept the situation. Indeed, children with disabilities like this should be treated well. We motivate each other to be strong. If there is a child who is sick, then all members will visit (Srt)

Now, I have accepted my fate. I have to do this. Having a disabled child must be well received. Anyway, the mothers here often strengthen each other. One form of mutual encouragement is when there is a child who is sick. They will visit to see the situation. We motivate each other to sincerely accept our condition. (Jmn)

After conducting more in-depth interviews, this study found in the data that currently there are still problems of community discrimination felt by the mothers in both poor and very poor groups. Many neighbours do not want to receive food from them. It should be noted that people in Sawahan have a tradition of exchanging food between neighbours at an event known as Weton and Suro. Weton is usually held to celebrate a person's birth based on the Javanese calendar. In the Weton event, a family makes a prayer, followed by sending food to their neighbours. As an illustration, if there are five family members, then the Weton event is held five times a year. On the other hand, the Suro event is carried out every Javanese New Year in the form of a ritual cleansing of the sacred weapons (Javanese people call keris) followed by sending food to their neighbours.

Based on the testimony of the mothers from the very poor group, their neighbours did not want to receive food from them because they felt disgusted. Academics recognise religiosity, spirituality, and social support as factors that influence a patient's ability to deal with

chronic illness. SOHAIL et al. (2019) found that aspects of religiosity, spirituality, and social support are needed when overcoming chronic diseases. They consider that the mothers caring for children with chronic disabilities have unhygienic hands. This was stated by the following mothers:

Until now, there are still many neighbours who do not want to receive food from me. The neighbours think that I have a handicapped child. So yeah, they think that I have dirty hands. They think that my food is dirty. (KS)

Until now, the neighbours do not want to receive the food I give to them. They look disgusted. Yes, they think that my hands are dirty, not clean, because of treating disabled children. They think that my hands are dirty, and they are disgusted with my cooking . (Rom)

My current problem is with the neighbours. If I give them food, most of them refuse. It looks like they are disgusted because they think that my hands are not clean from the traces of handicapped children. So yes, my cooking is considered unclean. Almost all of them feel disgusted. (Is)

4. CONCLUSION

The condition of poverty and remote areas that are geographically difficult to reach do not discourage mothers who have children with chronic disabilities when it comes to finding a way to overcome their problems. The efforts made by the very poor mothers to overcome their problems were far more severe than those of the poor mothers. Both groups benefit from the formation of this community, which is to have a friend to share things with and to strengthen one another. However, no matter how strong the efforts of the mothers to fix of their problems, they were unable to eliminate the negative image from society. This negative image has become a major burden for the mothers when they are living their lives because of the discriminatory treatment from the community.

5. ACKNOWLEDGMENTS

We would like to thank Mr. Harsono, a field officer from the Social Service Department who took the researchers to the research sites that were very difficult to reach. To Mr. Sudarmantono, the Head of Vulnerable Communities from the Social Service Department who had provided the initial information to the researchers to raise this theme for potential research, I also give my thanks.

REFERENCES

ADAMS, E. F., LEE, A. J., PRITCHARD, C. W., & WHITE, R. J. 2009. "What Stop Us from Healing the Healers: A Survey of Help-Seeking Behaviour, Stigmatisation and Depression within the Medical Profession". International Journal of Social Psychiatry. Vol. 56, No 4: 359-370.

ANGGORODI, R. 2009. "Dukun Bayi dalam Persalinan oleh Masyarakat Indonesia". Makara. Vol. 13, No 1: 9-14.

BUMIN, G., GÜNAL, A., & TÜKEL, S. 2008. "Anxiety, depression and quality of life in mothers of disabled children". S.D.Ü. Týp Fakultesi Dergisi. Vol. 15, No 1: 6-11.

BRESLAU, N., STARUCH, K., & MORTIMER, E. A. 1982. "Psychological Distress in Mothers of Disabled Children". Am J Dis Child. Vol. 136, No 8: 682-686.

CHASANAH, S. U. 2015. "Peran Petugas Kesehatan Masyarakat dalam Upaya Penurunan Angka Kematian Ibu Pasca MDGs 2015". Jurnal Kesehatan Masyarakat Andalas. Vol. 9, No 2: 73-79.

DDYKENS, E. M., FISHER, M. H., TAYLOR, J. L., LAMBERT, W., & MIODRAG, N. 2014. "Reducing distress in Mother of Children with autism and other disabilities: A randomized trial". Pediatrics. Vol. 134, No 2: 454-463.

DEW, A., BULKELEY, K., VEITCH, C., BUNDY, A., GALLEGO, G., LINCOLN, M., BRENTNALL, J., & GRIFFITHS, S. 2012. "Addressing the barriers to accessing therapy services in rural and terpencil areas". Disability and Rehabilitation. Vol. 35, No 18: 1564–1570.

DUMAS, J. E., WOLF, L. C., FISMAN, S. N., & CULLIGAN, A. 2015. "Parenting Stress, Child Behavior Problems, and Dysphoria in Parents of Children with Autism, Down Syndrome, Behavior Disorders, and Normal Development. Exceptionality". A Special Education Journal. Vol. 22, No 2: 97-110.

EINFELD, S.L., STANCLIFFE, R.J., GRAY, K.M., SOFRONOFF, K., RICE, L., EMERSON, E., & YASAMY, M.T. 2012. "Interventions Provided by Parents for Children with Intellectual Disabilities in Low and Middle Income Countries". Journal of Applied Research in Intellectual Disabilities. Vol. 25, No 2: 135-142.

EITHAN, M.H., AMAN, H., & ROBERT, A. 2010. Mood Problems of Mothers with disabled childern in Saudi Arabia: A Preliminary Prospective Study. Saudi Medical Journal. Vol. 31, No 10: 1161-1165.

ELFORD, L. M. 2015. "Mothers' Lived Experience of Parenting an Infant/Young Child with Special Needs in a Rural Context". Electronic Thesis and Dissertation Repository. https://ir.lib.uwo.ca/etd/2688

ERGUN, S., & ERTEM, G. 2012. "Difficulties of mothers living with mentally disabled children". Journal of the Pakistan Mediacal Association. Vol. 62, No 8: 776-780.

FAHMY, M.I. 2017. "Hubungan antara Parenting Self Efficacy dengan Psychological Well Being Ibu yang Memiliki Anak dengan Disabilitas Intelektual". Thesis: Universitas Muhammadiyah Malang. Indonesia.

FRANKENBERG, E. 1995. "The Effects of Access to Health Care on Infant Mortality in Indonesia". Health Transition Review. Vol. 5, No 2: 143-163.

GIBSON, C.H. 1995. "The Process of Empowerment in Mothers of Chronically Ill Children". Journal of Advanced Nursing. Vol. 21, No 6: 1201-1210.

GIBSON, B.E., TEACHMAN, G., WRIGHT, V., FEHLINGS, D., YOUNG, N.L., & MCKEEVER, P. 2011. "Children's and Parent's Belief regarding the Value of Walking: Rehabilitation Implications for Children with Cerebral Palsy". Child: Care, Health, and Development. Vol. 38, No 1: 61-69.

GINTING, F. 2014. "Perepsi Pasien Kanker Payudara terhadap Pengobatan Alternatif". Thesis: Universitas Gadjah Mada.Yogjakarta.

Indonesia.
GRIFFITH, G. M., HASTINGS, R.P., PETALAS, M.A., & LLOYD, T.J. 2014. "Mothers' expressed emotion towards children with autism spectrum disorder and their siblings". Journal of Intellectual Disability Research. Vol. 59, No 6: 580-587.
HANDIAN, F.I., WIDJAJANTO, P.H., & SUMARNI. (2017). "Motivasi, Hambatan dan Strategi Orangtua Keluarga Miskin dalam Merawat Anak dengan Leukemia Limfoblastik Akut (LLA)". Jurnal Care. Vol. 5, No 1: 77-91.
HEITZMAN-POWELL, L.S., BUZHARDt, J., RUSINKO, L.C., & MILLER, T.M. 2013. "Formative Evaluation of an ABA Outreach Training Program for Parents of Children With Autism in Terpencil Areas". Focus on Autism and Other Developmental Disabilities. Vol. 29, No 1: 23-38.
HOFFMAN, C.D., SWEENEY, D.P., HODGE, D., LOPEZ-WAGNER, M.C., & LOONEY, L. 2009. "Parenting Stress and Closeness: Mothers of Typically Developing Children and Mothers of Children with Autism". Focus on Autism and Other Developmental Disabilities. Vol. 24, No 3: 178-187.
ILIAS, K., LIAW, J.H.J., CORNISH, K., PARK, M.S.A., & GOLDEN, K.J. 2016. "Wellbeing of mothers of children with "A-U-T-I-S-M" in Malaysia: An interpretative phenomenological analysis study." Journal of Intellectual & Developmental Disability. Vol. 42, No 1: 74–89.
JAFFAR, S., Leach, A., Greenwood, A.M., Jepson, A., Muller, O., Ota, M.O.C., Bojang, K., Obaro, S., & Greenwood, B.M. 1997. "Changes in Pattern of Infant and Childhood Mortality in Upper River Division, The Gambia, from 1989 to 1993". Tropical Medicine and International Health. Vol. 2, No 1: 28-37.
JUTTING, J.P. (2014). "Do Community-based Health Insurance Schemes Improve Poor People's Access to Health Care? Evidence from Rural Senegal". World Development. Vol. 32, No 2: 273-288.
KARINA, A.N. & WARSITO, B.E. 2012. "Pengetahuan Ibu tentang Imunisasi Dasar Balita". Jurnal Nursing Studies. Vol. 1, No 1: 30-35.
LEE, K.Y., HAN, J.W., & LEE, J.S. 2007. "Kawasaki Disease May Be A Hyperimunne Reaction of Genetically Susceptible Children to Variants of Normal Environmental Flora". Medical Hypotheses. Vol. 69,

No 3: 642-651.
LIU, Y., HSIAO, W.C., & EGGLESTON, K. 1999. "Equity in Health and Health Care: The Chinese Experience". Social Science and Medicine. Vol. 49, No 1: 1349-1356.
LUKSIC, M., JAVORNISKY, G., DIMARIO, F. J., & MD, J. 2000. "Assessment of Stress in Mothers of Children With Severe Breath-Holding Spells". Pediatrics. Vol. 106, No 1: 1–5.
MARETTIH, A.K.E. & WAHDANI, S.R. 2017. "Melatih Kesabaran dan Wujud Rasa Syukur sebagai Makna Coping bagi Orangtua yang Memiliki Anak Autis". Marwah: Jurnal Perempuan, Agama, dan Jender. Vol. 16, No 1: 13-31.
MCCONKEY, R. TUESDALE-KENNEDY, M., CHANG, M.Y., JARRAH, S., & SHUKRI, R. 2006. "The Impact on Mothers of Bringing up a Child with Intellectual Disabilities: A Cross-Cultural Study." Internatinal Journal Nurse Studi. Vol. 45, No 1: 65-74.
MEGASARI, I., & KRISTIANA, I.F. 2016. "Hubungan antara Dukungan Sosial Suami dengan Penerimaan Diri pada Ibu yang Memiliki Anak Down Syndrom di Semarang". Jurnal Empati. Vol. 5, No 4: 653-659.
MILLER, A. C., GORDON, R. M., DANIELE, R. J., & DILLER, L. 1992. "Stress, Appraisal, and Coping in Mothers of Disabled and Nondisabled Children". Journal of Pediatric Psychology. Vol. 17, No 5: 587–605.
MONSEN, R. B. 1999. "Mothers' experiences of living worried when parenting children with spina bifida". Journal of Pediatric Nursing. Vol. 14, No 3: 157–163.
NORA, A.C. & WIDURI, E.L. 2011. "Komunikasi pada Ibu dan Anak dengan Depresi pada Remaja". Humanitas. Vol. 8, No 1: 45-61.
OLSSON, M. B., & WANG, P. H. 2008. "Depression in mothers and fathers of children with intellectual disability". Journal of Intellectual Disability Research. Vol. 45, No 6: 535-543.
PASALLI, C.R., POEKOEL, V.C., & NAJOAN, X. 2016. "Sistem Pakar Diagnosa Penyakit Anak Menggunakan Metode Forward Chaining Berbasis Model". E-Journal Teknik Informatika. Vol. 17, No 1: 1-6.
PORTER, N., & LOVELAND, K.A. 2018. "An Integrative Review of Parenting Stress in Mothers of Children with Autism in Japan". In-

ternational Journal of Disability, Development and Education. Vol. 66, No 3: 249-272.
SISTIARANI, C., GAMELIA, E., & SARI, D.U.P. 2014. "Fungsi Pemanfaatan Buku KIA terhadap Pengetahuan Kesehatan Ibu dan Anak pada Ibu". Jurnal Kesehatan Masyarakat Nasional. Vol. 8, No 8: 353-358.
SOHAIL, M.M., MAHMOOD, Q.K., SHER, F., SAUD, M., MAS'UDAH, S., & IDA, R. 2019. "Coping through Religiosity, Spirituality, and Social Support among Muslim Chronic Hepatitis Patient". Journal of Religion and Health. DOI: 10.1007/s10943-019-00909-4
SOUSA, A. C. 2011. "From Refrigerator Mothers to Warrior-Heroes: The Cultural Identity Transformation of Mothers Raising Children with Intellectual Disabilities". Symbolic Interaction. Vol. 34, No 2: 220–243.
SRINATH REDDY, K., SHAH, B., VARGHESE, C., & RAMADOSS, A. 2005. "Responding to the Threat of Chronic Disease in India". Lancet. Vol. 366, No 9498: 1744-1749.
STANLEY, S.L.G. 2015. "The Advocacy Efforts of African American Mothers of Children with Disabilities in Rural Special Education: Considerations for School Professionals". Rural Special Education Quarterly. Vol. 34, No 4: 3–17.
SUHARMIATI, LAKSONO, A.G., & ASTUTI, W.D. 2013. "Review Kebijakan tentang Pelayanan Kesehatan Puskesmas di Daerah Terpencil Perbatasan". Buletin Penelitian Sistem Kesehatan. Vol. 16, No 2: 109-116.
SURYAWATI, C. 2005. "Memahami Kemiskinan secara Multidimensional". Jurnal Managemen Pelayanan Kesehatan. Vol. 8, No 3: 121-129.
SUYANTO, B. 2001."Kemiskinan dan Pemberdayaan Masyarakat Miskin". Masyarakat, Kebudayaan, dan Politik. Vol. 14, No 4: 25-42.
SYAHZA, A., & SUARMAN. 2013. "Strategi Pengembangan Daerah Tertinggal dalam Upaya Percepatan Pembangunan Ekonomi Pedesaan". Jurnal Ekonomi Pembangunan. Vol. 14, No 1: 126-139.
TRIRATNAWATI, A. 2010. "Pengobatan Tradisional, Upaya Memaksimalkan Biaya Kesehatan Masyarakat Desa di Jawa". Jurnal Manajemen Pelayanan Kesehatan. Vol. 13, No 2: 69-73.

WALLANDER, J. L., & VENTERS, T. L. 1995. Perceived Role Restriction and Adjustment of Mothers of Children with Chronic Physical Disability. Journal of Pediatric Psychology. Vol. 20, No 5: 619-632.

UNIVERSIDAD DEL ZULIA

opción

Revista de Ciencias Humanas y Sociales

Año 35, Especial No. 22 (2019)

Esta revista fue editada en formato digital por el personal de la Oficina de Publicaciones Científicas de la Facultad Experimental de Ciencias, Universidad del Zulia.
Maracaibo - Venezuela

www.luz.edu.ve

www.serbi.luz.edu.ve

produccioncientifica.luz.edu.ve