WORLD JOURNAL OF ADVANCE HEALTHCARE RESEARCH

SJIF Impact Factor: 3.458

ISSN: 2457-0400
Volume: 2.
Issue: 4.
Page N. 96-101
Year: 2018

Original Article **www.wjahr.com**

PRIMARY CAREGIVER EFFORT FOR IMPROVING QUALITY OF LIFE OF FAMILY MEMBERS WITH MENTAL RETARDATION: FAMILY PERSPECTIVE

Angela A. M. Lusia Laka[1]*, Indah Winarni[2] and Setyoadi[3]

[1]Master of Nursing Student, Faculty of Medicine, Brawijaya University, Indonesia.
[2,3]Lecturer of Medicine Faculty, Brawijaya University.

Received date: 01 May 2018 **Revised date:** 22 May 2018 **Accepted date:** 12 June 2018

Corresponding Author: Angela A. M. Lusia Laka
Master of Nursing Student, Faculty of Medicine, Brawijaya University, Indonesia.

ABSTRACT

Introduction: The role of family as primary caregiver is important to help family members who have mental retardation to go through the daily activities in life. However, family is vulnerable to have psychological problem in accompanying them. Responsibility of primary caregiver in improving quality of life of family members who are treated will be hampered in the midst of primary caregiver limitation. Prolonged psychological issues can cause primary caregiver to experience difficulty in doing treatment so that the expected positive effects on family members who are treated cannot be obtained fully. Therefore, primary caregiver effort is really needed to increase the quality of life of family members who have mental retardation. Family holds a crucial role as primary caregiver in taking care of family members who suffer from mental retardation to perform daily life activities. However, caregivers are also vulnerable to psychological problems. Primary caregivers' responsibilities to improve the life quality of the mentally-retarded family members. **Objective of the Study:** This study aims to explore the meaning of family's experience as primary caregiver in treating family members with mental retardation in depth. **Participants and Method:** This study was a qualitative research which used interpretive phenomenological approach. This study involved 8 participants who were family of family members with mental retardation. The data collection was done through in depth interview by using interview guidelines. The obtained data were analyzed using Interpretative Phenomenological Analysis (IPA). **Results:** There were 2 themes obtained from this study. They are accepting the condition and acknowledging the importance of family support as primary caregiver. **Conclusion:** Family as primary caregiver try to improve quality of life of family members with mental retardation by improving themselves and accepting conditions so that they are able to carry out their responsibility as well as be aware of the importance of family support as primary caregiver by showing struggle efforts in assisting family members with mental retardation.

KEYWORDS: Effort, Primary Caregiver, Quality of Life, Mental Retardation, Phenomenological.

INTRODUCTION

Prevalence of mental retardation (RM) is estimated up to 2.3% of the total number in worldwide.[1] The estimation of the amount of children with disability in Indonesia based on data from World Health Organization(WHO)[2] is around 7-10% from the total number of the children. Data obtained from Central Statistics Body (BPS) mention that there are 8.3 million of children with disability out of the population of children which is 82,840,600 million with 30,460 children out of that population suffered from mental retardation.[3]

Someone with mental retardation has difficulty in communicating, taking care of him or herself. Moreover, he or she cannot take his or her own decision, recreation, work, health, and security.[4] Based on previous study conducted by the researchers, School for Exceptional Children (SLB) and St. Anna Mentally Disabled Institution, Tomohon, North Sulawesi were established because the founders found the fact that many of family who has family member with mental retardation felt ashamed to expose the existence of that member. They tend to hide that member from society. This makes those with mental retardation feel down and cannot develop themselves. That fact motivates those founders to give facility for family and children by giving a place to learn and nursery.

Family members have most of the time or those who meet, interact, and give care to family members as primary caregiver. The role of primary caregiver is very important especially for helping them go through their daily activities in life and for fulfilling their life needs. However, children with mental retardation are often get rejection from their family and even from their parents should act as primary caregiver, whether it is done consciously or not. A study conducted by Nagarkar *et al*[5] proved that 85% mothers whose children suffers from mental retardation got depressed due to the burden of facing their children and social stigma which trigger stress for those mothers. Stress which causes family to depressed can influence psychological state of family member with mental retardation. Karasavvidis, *et al*[6] illustrated that condition as vicious circle where children cause stress to mothers and mothers cause stress to children. Parents' stress influences treatment carried. If they cannot overcome their stress, their role as parents will be typically dysfunction.[7]

Family as primary caregiver tries out various way to fulfill the need of family members with mental retardation. Besides, it gives satisfaction and fewer burdens for those who take care of those family members with mental retardation. Family in carrying out their role as primary caregiver cannot despite the presence of variety of factors either internal or external that might support and hinder them in treating family members with mental retardation.

According to Napolion,[8] family assumes that the existence of family with mental retardation is airman and grace from God whom must be protected. Hence, family feels big responsibility to educate and nourishes them with affection despite their condition and circumstances. Family tries to improve quality of life of family members with mental retardation. Family often thinks over uncertainty of the future of family members with mental retardation whether they have the potential to be independents and whether they are capable of sustaining their life in the future especially when family who nourishes them are not present besides them any longer.[9]

Prolonged psychological issues can cause primary caregiver to have difficulties in giving treatment so that positive effect expected by family members with mental retardation will not be optimum. This will causes the possibility of primary caregiver in achieving a better life for family members with mental retardation in the midst of their limitation. Based on the phenomenon mentioned above, this study aims to give meaning for family's experiences as primary caregiver in taking care of family members with mental retardation so that the treatment given can give positive impact of the caregiver itself especially for family who suffers from mental retardation.

PARTICIPANTS AND METHOD

Study Design

This study used qualitative method with interpretive phenomenological approach. Qualitative research is a method which explains phenomenon or social object through an approach which explores, finds, describes, and explains. Phenomenological approach used in this study focused on the understanding of individual life related to reality uniqueness of life of each individual including unique and specific responds and interaction experienced with society.[10]

Study Setting and Participants

This study was conducted in Tomohon City, North Sulawesi Province Tomohon has institutions and schools for exceptional children (SLB), places where children with mental retardation. Many families sent and picked up their family members with mental retardation in SLB which made it easy for researchers to study and obtain the data either in SLB or in participants' home.

The participants or the subjects of this study were 8 family members who played role as primary caregiver. The number of sample used in this qualitative study was adapted to the surfeit or saturation achievement where from the obtained data the researchers could not find any new information.[10] Thus, the number of participants did not influence the result of this study.[11] The participants were selected by considering criteria set by the researchers which are; facing family member with mental retardation, living under the same roof with family member with mental retardation, having experience in treating family member with mental retardation at least for 5 years, are able to read and write, are willing to be participants by signing approval form for being participants (informed consent).

Data Collection

This study had obtained ethics agreement from Health Sciences Research Ethics Committee of Government General Hospital Prof. Dr. R. D. Kandou Manado number 023/EC-KEPK/II/2018. This study was conducted in 2 months, February – March 2018.

This study was conducted by the researchers themselves in three times by visiting to maintain mutual trust with participants. Researchers did the interview which was suited with participants' agreement in School for Exceptional Children (SLB) and participants' home. Technique used in collecting the data was in depth interview to obtain complete understanding on research problem in details.[12] The interview was a semi structured interview with the help of interview guide where the questions used were open ended questions focusing on individual daily life seen from individual perspective. The process of interview was around 25 – 60 minutes. Participants' statements were recorded in form of audio (MP3). Researchers guarantee the confidentiality of identity and the data obtained through the interview conducted with participants.

Data Analysis

Data analysis in this study was conducted using Interpretative Phenomenological Analysis (IPA) according to Jeong and Othman,[13] with the following steps: 1) Reading and Re-reading and Initial Noting, 2) Developing emergent themes, 3) Searching for connection across emergent themes, 4) Moving to the next cases, 5) Looking for pattern across cases.

Findings

Theme 1: Willing to accept the condition

This theme express participants' statement when the condition happened, where participants sincerely willing to accept the condition. Participants accepted the condition fatefully and stoically and got ready to face and to try lived. Participants' statements regarding this matter were as follows:

*"…well it **means that God gives me child with this condition, I have to be grateful.** Even though the child is like this, I still have to send him to school" (P4-2).*

*"…children like these are often called or known as slow, weak brain, or whatever **so be it, willy-nilly,**…" (P1-18).*

*"…but I can only stroke my chest, **so be it, let it be**" (P3-18).*

*"There is only one point, I have to pray and **resilient in facing this.** And one more point **receive him as he is, sincerely** not forced to do so" (P6-24).*

The participants acknowledged that everything that happened to hem will be tough and torture. However, the participants were grateful on what they had and believed on God. The experienced state was blessings from God with the belief that participants will always give the ability to get through it. The participants considered the suffered pain as blessing to be enjoyed and appreciated. Therefore, participants accepted the condition gratefully. Participants' statements regarding this matter were as follows:

*"I do take care of him **not as burden but as blessing**… …instead of torturing me, it is better for me **to enjoy the moment**" (P6-8,24).*

*"Now, I am **really grateful**, …this child, even if his condition is like this, but I can see that he brings **a lot of blessings**" (P8-42).*

*"…well there is no burden in taking care of this child. I am **grateful** for the fact that I geta son…" (P4-14).*

*"For me, God gave me a child like this so **God will also give me the ability** to take care of him..." (P6-18).*

Theme 2: Acknowledging the importance of family support

Participants expressed that they have role in their daily activities. Participants acknowledged that their family members had not been able to be independent and got difficulty in fulfilling their needs. That matter was stated by participants in the following citation below:

***"He has not been able to be independent** …, **I have to take him a bath, make him get dressed, and everything has to be taken care**… **He has not fully understand"** (P8-14).*

*"…may be more into willingness, **we have to set the time** to be able to fulfill his willingness. He likes to take a walk" (P1-26).*

*"…but my child has to be treated, so **I get him treated**, there he gets complete, there is doctor, everything is complete …" (P6-4).*

Participants have to help their family members in fulfilling their need with various struggles. Treatment on family members with mental retardation is different and special which has to be understood by participants. Therefore, participants have to express the struggle in the midst of limitation in treating their family members. Participants have to do their best, with visible steps to support the life of their family members. That matter was expressed in the following participants' statement:

*"…sometimes I borrow **someone's phone to browse on how to treat this child,** I said that I pay for the Internet lapsed, or I buy 1GB Internet data for me to use …" (P7-8).*

*"Instantly I told the nurse, there is a nurse who lives next door, **If my child gets angry, I call him as soon as possible to help me soothing my child**" (P3-28).*

*"Now I am sick, **I am not feeling well but I have no choice. I have to work. If not, my child will be displaced**, will starve to death, poor him" (P5-20).*

*"I was forced to say …**lend me 20 thousand, you can cut care of my sewing after it finished because I have to buy diapers**. I feel sorry for him for not able to attend the school "(P7-6).*

*"I met her and said, …**help me. I let my son to attend the school, I will keep my eyes on him.** An hour is enough. Let him plays and feels, oh actually I am not the only one who is like this" (P6-8).*

Participants expressed their anxiety during the treatment on their family members. Besides getting treatment, family members have to get special supervision so that they are safety guaranteed. Participants felt anxious with the behavior of their family members which can endanger themselves and people around them. This is also the responsibility of participants as primary caregiver. Participants' statements of their anxiety are as follows:

"The current hindrance is that after he becomes adult, ***his emotion ugh really high****... ...****he takes knife, anything, he looks for sharp things.*** *...That is the only thing* ***I am afraid of for now****" (P3-5,26).*

"Well if this child goes out, he can go into the main street. He goes straight without stopping; ***he does not want to go home anymore. That is what I am afraid of"*** *(P7-14).*

*"...if he goes to the main street, he does not know the way back home, ...****but we are afraid if he suddenly get lost****" (P8-42).*

Participants felt anxious if their family members are not able to be independent. Meanwhile, participants also realized that they did not have enough time to treat their family members. For that, participants expressed their desire to continue taking care of their family member by asking God so that they are given the opportunity to live longer to take care and accompany their family members. Participants' statement regarding this matter can be seen in the following citations:

"That is why, sometime I pray to God so that my child can understand soon, be adult soon, ***until they can understand completely, God can take me away after that****" (P2-34).*

"Hopefully I ***do not get sick, so that I can accompany him*** *until wherever I can" (P7-30).*

"I ask to God ***when accompany him so that I do not get sick.*** *Don't!" (P8-48).*

*"...so that is the main problem, a matter of time... ...****if I have my own business I believe we will have much time****, there will be much time to go anywhere, to take care of child, as if there will be much time to spare" (P1-20,28).*

"...Well we live near main street. Moreover, I have a stall,... ...so people will not stop coming to my stall,... ...so well ***at least my attention for him will not reduce if we are here****, ..." (P6-8).*

DISCUSSION

Theme 1: Willing to accept the condition

The existence of family with mental retardation was really influence family condition especially those who became primary caregiver. That condition drained energy, mind, and emotion, so as to make primary caregiver feeling distress. Unstable emotion felt by family narrowed their movement in living their life, either their role as family in general or as primary caregiver to family members with mental retardation. Hence, primary caregivers tried to look for their own happiness. This change of mind was a coping mechanism of family in handling stress. Responds done by primary caregivers were to overcome stress or to less the burden and to fix the conflict are a coping so that they are able to adapt with their environment.[14] Instead of rejecting or avoiding daily situation which full of pressure, people tend to choose to fix the problem by changing their mindset so that they are able to overcome the pressure, make it less, or even remove the situation which causes stress.[15]

Primary caregiver tried to consider suffer as blessing. The definition of blessing according to Great Dictionary of Indonesian Language (KBBI)[16] is gift from God which brings happiness for human life. Primary caregivers visualize their experience in accompanying their family members as a gift from God which has to be thanked, graced, and passed sincerely. Sincerely according to KBBI[16] is big heart or sincere. It means that primary caregivers weresincere in accepting the condition of their family members with mental retardation. Sincerely accepting the condition is a process where family acknowledges aspects and limitation of wither themselves as primary caregivers or their family members who suffer from mental retardation.

The efforts made were accompanied by act such as supporting any forms of assistance for the development of family members with mental retardation. According to Hendriani, *et al*,[17] an attitude of accepting shown by family was an equal attitude to family members with mental retardation and to other family members. Do not try to hide the condition from other people can be an attitude of accepting too. Accepting family members with mental retardation will help them develop themselves so that they can be accepted by their environment. Handayani[18] stated that an attitude of accepting is an awareness of individual characteristic, acknowledgement on strength and weaknesses without blaming them to others, and determination to use and develop the strength and weakness in daily life.

Theme 2: Acknowledging the importance of family supports especially as primary caregiver

The involvement of primary caregiver in treating family members with mental retardation is an important thing which can be manifested in form of support to individual development of family members with mental retardation. Videbeck[19] interprets family support as support given by family members when problems occur to other family members. Family members with mental retardation have problem in doing daily activities so that they depends on others to fulfill their needs.

The role of family as caregiver in treating family members with mental retardation can help their social development by applying various functions such as educational, protection, social, economic, and religious functions.[20] Responsibilities in fulfilling the needs make primary caregiver feel the burden and think of the right way to treat family members with mental retardation.

Primary caregivers were fully aware of their role so that they tried their best in treating and fulfilling the need of their family members with mental retardation. Therefore, often a concern arose when primary caregiver had no opportunity to take care of family members with mental retardation for a long period of time. A study conducted by Kermanshahi, *et al*[9] stated that family feels anxious to think the future of family members with mental retardation which is unsure, whether they have the potential to be independent and are able to survive their life in the future, get the protection and treatment in the future, have proper job, especially when family who takes care of them are not with them any longer. This makes primary caregiver continues to try hard with big hope that their family members with mental retardation will get qualified life in the midst of their limitation.

Primary caregiver*s'* awareness on the importance of special treatment for family members with mental retardation makes them doubt on their ability in playing their role, whether the treatment had been conducted right and effective. Primary caregivers who feel that they have taken wrong way, try to fix it by digging information and broadening their knowledge on treatment for their family members with mental retardation. The willingness to give the best treatment is believed to be able to give maximum result. The result of the study conducted by Merdekawati, et al[21] stated that attitudes in treating children with mental retardation will be better if the family has better knowledge.

CONCLUSION

The result of this study shows that the efforts done by family caregivers in improving quality of life of their family members with mental retardation are sincerely accept the condition so that they are able to do their responsibility without any burden and acknowledging the importance of family support as primary caregivers so that they keep on trying to give the best treatment for their family members.Therefore, family members can do their responsibility as primary caregivers with positive impacts on the development of family members with mental retardation or family members as primary caregivers themselves.

CONFLICT OF INTEREST

There is no conflict of interest.

ACKNOWLEDGEMENT

I would like to show my gratitude to School for Exceptional Children C St. Anna Tomohon who had been source of information in this study.

REFERENCES

1. Kumar D, Simh N, Scie M. Study of Burden in parents of children with mental retardation, 2016.
2. Ministry of Health RI. Rencana Strategis Kementerian Kesehatan Tahun, 2010-2014. 2010; Jakarta.
3. Infodatin. Penyandang Disabilitas Pada Anak. Pusat Data dan Informasi Kementrian Kesehatan RI., 2014.
4. Prabowo, E. Buku Ajar Keperawatan Jiwa. 2010. Edisi 6. Jakarta: EGC.
5. Nagarkar, A., Sharma, J. P., Tandon, S. K., Goutam, P. The clinical profile of mentally retarded children in India and prevalenceof depression in mothers of the mentally retarded. Indian Journal of Psychiatry, 2014; 56(2).
6. Karasavvidis, S., Avgerinou, C., Lianou, E., Priftis, D., Lianou, A., Siamaga, E. Mental Retardation and Parenting Stress. International Journal of Caring Sciences, 2011 January; 1(4).
7. Boyd, B.A. Examining the relationship between stress and lack of social support in mothers of children with autism. Focus on Autism and Other Developmental Disabilities, 2002; 17: 208–215.
8. Napolion, K. Pengalaman Keluarga Dalam Merawat Anak Tunagrahita Di Kelurahan Balumbang Jaya Kecamatan Bogor Barat Kota Bogor: Studi Fenomenologi, Tesis: Universitas Indonesia, 2010.
9. Kermanshahi, S. M., Vanaki, Z., Ahmadi, F. Kazemnejad, A. Iranian mothersperceptions of their lives with children with mental retardation: A Preliminary phenomenological investigation. Journal of Developmental Physical Disabilities, 2008; 20.
10. Afiyanti, Y. & Rachmawati, I. N. Metodologi Penelitian Kualitatif dalam Riset Keperawatan. Jakarta: PT Raja Grafindo Persada, 2014.
11. Moleong L.J. Metodologi Penelitian Kualitatif. Bandung: Remaja Rosda Karya, 2016.
12. Afifudin & Seabani. Metode Penelitian Kualitatif. Bandung: Pustaka Setia, 2009.
13. Jeong, H., & Othman, J. Using Interpretative Phenomenological Analysis from a Realist Perspective.The Qualitative Report, 2016; 21(3): 558-570.
14. McCubbin, H. I & Thompson, A. I.Family assessment inventories for researchand practice. Madison: Universityy of Wisconsin, 1983.
15. Pompeo, D.A., Carvalho, A., Olive, A. M., Souza, M. G., Galera, S.A.F. Strategies for coping with family members of patients with mental disorders. Rev. Latino-Am. Enfermagem, 2016; 24: e2799. DOI: 10.1590/1518-8345.1311.2799.
16. KBBI. Great Dictionary of Indonesian Language. Jakarta: Language Center, 2015; ISBN 987-979-689-779-1.
17. Hendriani, W., Handariyati, R., Sakti, T.M. Penerimaan Keluarga Terhadap Individu yang Mengalami Keterbelakangan Mental, 2006 Agustus; INSAN, 2(8).

18. Handayani, Eko.Anak dengan Gangguan Auitism. Jakarta: Universitas Terbuka, 2008.
19. Videbeck, S. L. Buku Ajar Keperawatan Jiwa. Jakarta: EGC, 2008.
20. Ramadhan, A. Peranan Keluarga Terhadap Perkembangan Kecerdasan Emosional Anak. Jakarta: Naskah Publikasi.
21. Merdekawati, D., Dasuki. Hubungan Pengetahuan Keluarga Dan Tingkat Retardasi Mental Dengan Kemampuan Keluarga Merawat. Journal Endurance, 2017 June; 2(2): 186-193.