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The effect of peer support group (PSG) on stress levels of parents with mental retardation children in Bogor

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Abstract---Raising a child with mental retardation is an extraordinary and very emotional experience for parents and can affect the functioning of the family as a whole. The study shows that parents of children with mental retardation experience higher levels of stress and are at risk of mental health problems compared to parents of normal children. One of the efforts to reduce stress is by peer support group (PSG). Peer support group is a gathering of similar groups that carry out activities with the aim of improving coping, providing social support, sharing experiences, reducing fear and worry. This research aims to obtain an overview of the effect of PSG on stress levels in parents of mentally retarded children in Bogor City. This research is a quantitative study with a quasi-experimental pre test–post test control group design method to compare the intervention results of two groups: the intervention group (parents who received PSG and the control group (parents who did not receive PSG). Results showed that there was a significant effect on stress levels after PSG was carried out with P value of 0.000 at α 0.005. Based on this, it can be concluded that PSG can be used as an alternative intervention for parents with high levels of stress in caring for children with mental retardation.

Keywords---stress level, peer support group therapy, parents, mental retardation.

Introduction

The birth of a child for parents is a long-awaited moment. Children who are born perfect as expected are a source of happiness and pride for parents. All parents have plans and hopes for their children in the future, therefore a child's success is the parent's achievement. When a child is born with a disability, all the parents' hopes are lost and turned into a source of disappointment. They are required to adapt to the situation that occurs and change all hopes and plans that have been prepared previously by making new plans according to the situation experienced (Kandel, I and Merrick, J (2007).

One form of disability that occurs in children is mental retardation or developmental delays. The Centers for Disease Control and Prevention (CDC, 2015) in its report states that around 1 in every 33 babies is born with a disability and around 1 in 6 children is born with a developmental disability/mental retardation.

Mental retardation according to the World Health Organization (WHO, 2001) is a state of halted or incomplete mental development which is mainly characterized by the occurrence of skills impairment during development. The obstacles experienced affect the overall intelligence/intellectual level, namely cognitive, language, motor and social abilities. Impairment is a condition that causes abnormalities or loss of psychological, physiological or anatomical function in an individual (WHO, 2001). In addition, according to the American Association of Mental Retardation (AAMR), intellectual limitations refer to the results of an Intelligence Quotient (IQ) examination that is 2 Standard Deviations (SD) below the population average (100), <70 as well as limitations in adaptive function based on in the presence of impairment in at least two of the ten skill areas (Armatas, 2009). The ten skill areas are communication, self-care, daily activities, social/interpersonal skills, use of resources in society, self-direction, functional academic skills, work, fun, health and security/safety (Ball & Bindler, 2003).

A parent's first reaction when they find out that their child has mental retardation is denial or rejection. This rejection is usually accompanied by anger as a result of a lack of information about the child's condition, lack of communication between family members and feelings of grief. Another response is feelings of fear, especially about the care and uncertain future of the child. Feelings of guilt for causing their child to be born with a disability and tending to blame themselves are other responses that appear besides other responses such as helplessness, disappointment and rejection from the environment (Smith, 2010).

Caring for child with mental retardation brings many challenges to parents such as the additional financial burden of caring for their child's condition, dealing with the child's problematic behavior and the social stigma associated with the child's condition (Baker & Heller, 1996; Lecavalier, Leone, & Wiltz, 2006 in Hwa HA, 2011). As a result, parents often experience more physical health symptoms, negative affect and worse psychological status than parents of normal children (Ha, Hong, Seltzer, & Greenberg, 2008; Seltzer, Greenberg, Floyd, & Hong, 2004; Singer, 2006 in Hwa Ha, 2011).

Trute, Hiebert-Murphy, & Levine, (2007 in Laufer 2017) stated that raising child with mental retardation is an extraordinary and very emotional experience and can cause many difficulties for parents. Long-term care, perhaps even a lifetime, will impact life domains (e.g. marriage, career, relationships) which can cause stress and often affect overall family functioning. In addition, research results have shown that parents of children with mental retardation experience higher levels of stress and are at risk of mental health problems compared to parents of normal children.

Kumar, (2018) added that parents of children with mental retardation tend to experience common psychiatric problems such as depression, anxiety and high levels of stress. This is related to the intensity of various psychological problems faced by parents in raising children with mental retardation. Children's dependence in carrying out daily activities or looking for opportunities for children to make friends or organizing activities to participate more in social activities, financial pressure and emotional pressure such as feelings of shame or guilt are some of the things that become stressors for parents. High levels of stress will create many problems that affect the quality of life of children and family members. Families with children with disabilities have higher levels of stress, disruption of routines, poor social interactions and more mental health problems compared to families of normal children.

Support from the surrounding environment is believed to strengthen parents and reduce stress in caring for children with mental retardation. One of support is with peer support through peer support group (Tehrani, 2011). Peer support group (PSG) is a gathering of similar groups that carry out activities with the aim of improving coping, providing social support, sharing experiences, reducing fear and worry. Activities focus on the ability to solve problems by sharing experiences, knowledge and counseling among similar groups. The aim of this activity is how to improve individual function in their social environment by building mutually beneficial relationships and how individuals can change for the better. So the essence of peer support group therapy is to build relationships and reciprocity that in the end the expected result is the discovery of new skills, developing a community where each person has different roles and relationships (Mead, 2015).

The efforts made by nurses through PSG intervention can strengthen the role of nurses as educators and motivators. With this role, nurses are expected to be able to reduce parental stress and increase confidence in caring for children with mental retardation so they can adapt better and improve their quality of life.

Method

This research is a quantitative research using a quasi-experimental method with a pre test - post test control group design approach. The design was used to compare the intervention results of two groups, the intervention group (parents of children with mental retardation who received Peer Support Group and the control group (parents of children with mental retardation who did not receive Peer Support Group).

The population in this study were all parents who had children with mild and moderate mental retardation who studied at a special need school in Bogor City, totaling 276 people. The sampling method uses purposive sampling, consisted of 84 parents (42 parents as intervention group and 42 parents as control group). The data collected is primary and secondary data. Primary data was obtained from respondents by filling out a questionnaire about parental characteristics: age, education, occupation and stress level. Secondary data was obtained from reliable sources that support research.

The next step is selecting places for the intervention group and control group. To avoid contact between the intervention and control groups, the research was conducted in two different special need schools. The researcher determined that the intervention group would be carried out at SLB Tunas Kasih 2 Bogor and for the control group it would be carried out at SLB Sejahtera Bogor. After determining the group, the next step is to arrange research permits from the school. Respondents who met the inclusion criteria signed an informed consent form,

Before the intervention was carried out, all selected respondents were given an introduction (pre-conditions) about PSG and the rules that had to be implemented by respondents while participating in the research. This pre-condition implementation is carried out face to face by strictly following health protocols, wearing masks, washing hands and maintaining distance. To avoid crowds of people, the implementation time was divided into 2 sessions with different days for each group. Maximum meeting time is 1 hour.

Furthermore, the intervention group received PSG at least 2x a week for 8 times. Considering that the PSG states that the division of support groups should be ≤ 10 people, in its implementation, researchers divided intervention respondents into 6 groups with a maximum of 7 parent in each group. The intervention was carried out online using internet-based applications (whatsapp group, video call and zoom meeting). The control group was given reading material in the form of stress management through leaflets.

After 8 interventions, parents' stress levels were measured again for each group and the results were compared. This second measurement was carried out face to face by strictly following health protocols, wearing a mask, washing hands and maintaining distance. To avoid crowds of people, the implementation time was divided into 2 sessions with different days for each group. Maximum meeting time is 1 hour.

Data analysis using univariate and bivariate. For numerical data, by calculating the mean, median, standard deviation, minimum and maximum values. Meanwhile, categorical data is done by calculating frequencies and percentages. The presentation of each variable is used using tables and interpreted based on the results obtained. Univariate analysis in this study explains or describes the characteristics of respondents which include age, education, occupation and stress level.

Bivariate analysis was carried out to determine the effect of PSG on stress levels of parents of children with mental retardation. Statistical tests for all analyzes were carried out with a significance level of 95% (alpha 0.05). If the data is normally distributed, the statistical tests used the Dependent Sample T Test (Paired-Samples T-Test) and the Independent-Samples T Test. The Paired-Samples T Test was used to determine the differences in stress levels before and after the intervention between each intervention and control group, while the Independent-Samples T Test was used to determine the differences in stress level scores between the intervention group and the control group.

Result

The research results are explained in the following table:

a. Respondent Characteristics

Table 1
Distribution of Respondents Based on Respondent Characteristics (n=84)

Characteristics	Sub characteristics	n	%
Age	1. \leq 40	37	44
	2. $>$ 40	47	56
Level of education	1. High	64	76.2
	2. Low	20	23.8
Occupation	1. Working	17	20.2
	2. Non-working	67	79.8

Based on the data, it can be seen that the age distribution of respondents is more than half old, 47 people (56%). The distribution of educational levels of respondents was mostly highly educated, 64 people (76.2%). Meanwhile, the majority of respondents' job distribution was non-working, 67 people (79.8%).

b. Parental stress level before PSG

Table 2
Distribution of Parental Stress Levels Before PSG in the Intervention and Control Groups (n=84)

Variables	Group	Mean	SD	Min-Max	95% CI
Parental Stress Level before PSG	Intervention	37.81	2.830	33-43	36.93-38.69
	Control	36.98	2.424	32-42	36.22-37.73

Based on the data, it was found that the mean level of parental stress before PSG in the intervention group was 37.81 (95% CI: 36.93-38.69), with a standard deviation of 2,830. The lowest stress level is 33 and the highest is 43.

Meanwhile in the control group the mean level of parental stress before PSG was 36.98 (95% CI: 36.22-37.73), with a standard deviation of 2.424. The lowest stress level is 32 and the highest is 42.

c. Parental stress level after PSG

Table 3
Distribution of Parental Stress Levels After PSG
in the Intervention and Control Groups (n=84)

Variable	Group	Mean	SD	Min-Max	95% CI
Parental stress level after PSG	Intervention	69.36	5.839	52-77	67.54-71.18
	Control	37.31	3.064	32-47	36.35-38.26

Based on the data, it was found that the mean level of parental stress after PSG in the intervention group was 69.36 (95% CI: 67.54-71.18), with a standard deviation of 5.839. The lowest stress level is 52 and the highest is 77. Meanwhile in the control group the average level of parental stress in the second measurement was 37.31 (95% CI: 36.35-38.26), with a standard deviation of 3.064. The lowest stress level is 32 and the highest is 47.

d. The Effect of PSG on Stress Levels of Parents with Mentally Retarded Children

Table 4
Distribution of Stress Levels of Parents with Mentally Retarded Children Before and After PSG (N=84)

Variable	Group		Mean	SD	SE	P value	n
Parental stress level	Intervention	Before	37.81	2.830	0.437	0.000	84
		After	69.36	5.839	0.901		
	Control	Before	36.98	2.424	0.374	0.142	84
		After	37.31	3.064	0.473		

The results of the analysis showed that the mean stress level of parents with mentally retarded children in the intervention group before PSG was 37.81 with a standard deviation of 2,830. At the end of the intervention, the mean stress level of parents increased to 69.36 with a standard deviation of 5839. The results of statistical tests obtained P value = 0.000, $\alpha = 0.05$, thus it can be concluded that there is a significant difference between the stress levels of parents with Mentally Retarded Children before and after PSG.

Meanwhile, in the control group, the results of the analysis showed that the mean stress level of parents with mentally retarded children before PSG was 36.98 with a standard deviation of 2,424. In the second measurement, the mean parental stress level was 37.31 with a standard deviation of 3.064. The statistical test results obtained P-value = 0.142, $\alpha = 0.05$, thus it can be concluded that there is no significant difference between the stress levels of parents with Mentally Retarded Children before and after giving the leaflets

- e. Differences in Parental Stress Levels after PSG in the intervention and control groups

Table 5
Distribution of Parental Stress Levels After PSG Between Intervention and Control Groups (N=84)

Variable	Group	Mean	SD	SE	P value	n
PSG	Intervention	69.36	5.839	0.901	0.000	84
Non-PSG (leaflet)	Control	37.31	3.064	0.473		

The results of the analysis showed that the mean stress level of parents in the intervention group after PSG was carried out was 69.36 with a standard deviation of 5.839. Meanwhile, the mean stress level of parents in the control group was 37.31 with a standard deviation of 3,064. The statistical test results obtained a p value = 0.000, meaning that at alpha 0.05 it can be concluded that there is a significant difference in the average level of parental stress between the intervention group and the control group.

Discussion

Respondent characteristics

The results of the analysis can be seen that the age distribution of respondents shows that more than half are over 40 years old, namely 47 people (56%). Based on several studies, not much has been found to link parents' age and their stress level in caring for children with mental retardation. However, according to Nurpratiwi (2010), a person's age is related to emotional maturity. Emotional maturity is a condition where a person has reached a mature level of emotional development so that he can control, use and channel his emotions into useful things. Emotional maturity can be assessed through aspects that include independence, the ability to accept reality, the ability to adapt, the ability to respond appropriately to other people's feelings, feeling safe or balanced, the ability to empathize, and the ability to control anger. The older a person is, the more mature his emotions will be.

Based on education level, the results of the analysis show that the majority of parents' education levels are highly educated. The level of education is related to the information obtained by parents and curiosity in obtaining information. The higher the level of education, the greater the parents' curiosity about their child's condition. Parents with a higher educational background may have lower stress levels because they have knowledge of effective coping strategies so that they can help overcome stress in dealing with their child's behavioral problems (Khamis, 2007).

The results of the analysis based on the respondents' occupation, the majority were unemployed. Mothers who do not work tend to have more time to care for their children than working mothers, including regarding their children's health. According to Kurniati (2008), a mother's employment status can influence the

opportunities and time used to increase knowledge and attention to her children. Mothers who work as housewives have a lot of free time with their children, this means these mothers can focus more on caring for and paying attention to their children.

Stress levels before and after PSG

Based on the results of the analysis, it was found that the mean stress level of parents before and after PSG in the intervention group experienced a significant change, while in the control group the change was relatively small and not significant.

Raising a child with mental retardation is an overwhelming and very emotional experience and can cause many difficulties for parents. Long-term care, perhaps even a lifetime, will impact life domains (e.g. marriage, career, relationships) which can cause stress and often affect overall family functioning. In addition, research results have shown that parents of children with mental retardation experience higher levels of stress and are at risk of experiencing mental health problems compared to parents of normal children (Trute, Hiebert-Murphy, & Levine, 2007 in Laufer, 2017) .

Farzaekia (1985) in Aldosari and Pupaff (2014) said that for parents, raising children with mental retardation can be a burden, stressful, frustrating and feel alienating. The stress experienced can affect the physical, cognitive and emotional condition of all family members. Parents also become more alert and sensitive to responses shown by other people such as neighbors, friends and strangers. Negative responses can add stress to the family (Boss, 1988, Aldosari and Pupaff 2014).

Khamis, (2007) states that parental stress can come from several factors: child characteristics, parents' sociodemographics and family environment. In more detail, Aldosari and Pufpaff (2014) explained that the more severe the child's level of mental retardation, the higher the parent's stress level. Apart from that, the child's age, gender and child behavior are also trigger factors that can increase parental stress. Another factor that contributes to parents' stress levels is parents' socio-demographics such as parents' age, marital status and education level. Parents who are older or younger are at high risk of experiencing stress. Single parents who raise mentally retarded children alone are more stressed than intact parents, especially in terms of care, emotional, social and financial status. The level of education also greatly influences how parents with mentally retarded children manage their stress. Parents with a higher educational background may have lower stress levels because they have knowledge of effective coping strategies that can help them deal with their child's behavioral problems. The good economic status of parents also allows them to provide quality care and education for their children with special needs. Another factor that influences the stress level of parents with mentally retarded children is the family environment. Families that are religious, independent, oriented towards education and have time for recreation tend to have low stress levels. Based on this, it is clear that the source of stress for parents of children with mental retardation is very complex, caused by many and interconnected factors (Khamis, 2007).

Prolonged stress conditions experienced by parents can develop into chronic psychological distress which can risk disrupting marital relationships, family dysfunction and suffering from various physical and mental health disorders (McConnel & Savage, 2015).

Several studies state that high stress from parents is associated with high levels of substance abuse, low coping, anger, avoidant behavior and lack of social support (Brown & Pacini, 1989; Mash & Johnston, 1983; Pelham et al., 1998 in Cooke, 2010). Families with children with mental retardation have fewer social relationships than families with children with normal networks (Kazak & Wilcox, 1984 in Cooke, 2010). Parents tend to limit themselves because of shame and feelings of guilt (Valentine, 1993).

Social support such as attention, appreciation or assistance that parents feel from other people or groups can help reduce stress and increase adaptation. Support from similar groups such as support groups where parents are included is one of the efforts that can be made to reduce stress in dealing with children with mental retardation. Support Groups bring together people who are going through or have gone through similar experiences such as cancer, chronic medical conditions, addiction, loss or parenting issues. Support groups provide an opportunity for individuals to share personal experiences and feelings, problem-solving strategies or information directly related to the disease or treatment (Mayo Clinic, 2020).

Puspitasari (2017) in his research on parents who have children with mental retardation stated that parents who receive more support from their environment tend to be more accepting of their children who are physically and mentally retarded. The results of this research are also in line with research conducted by Yuliana & Hartati (2017) that mothers who have children with mental retardation experience reduced parenting stress with social support from the family and environment.

The Effect of PSG on Stress Levels of Parents with Mentally Retarded Children

Families raising children with mental retardation cannot avoid crisis situations, stress and pathology, but over time they can adapt and have various ways of dealing with the situations they face. So far there is no most appropriate way to help parents overcome crisis situations in dealing with children with mental retardation. However, several efforts and strategies have been carried out, one of which is the Peer Support Group Therapy (PSG) intervention.

PSG is a support group consisting of people who are in similar mental health or emotional situations, such as grief, substance abuse (own or a loved one), depression, and so on. This group usually meets regularly and in a structured manner, once a week for 6 – 8 weeks. Each group is led by a therapist/mental health expert who leads each meeting session. The focus of support groups centers on mental health issues faced by members such as depression or sadness.

The strategies used in support groups can vary, such as face-to-face, teleconference or online community. Group members who share experiences can become group leaders. But groups can also be led by professional facilitators such as nurses, social workers or psychologists. Common experiences among support group members are worries, daily problems, treatment decisions or similar treatment side effects. Participating in groups provides an opportunity to jointly determine the same goals and understand each other.

The benefits gained from support groups include:

1. parents feel like they have friends so they are less lonely, isolated, or judged.
2. Reduces stress, depression, anxiety, or fatigue.
3. Can express feelings openly and honestly
4. Improve skills to face challenges
5. Stay motivated to manage the conditions faced
6. Gaining a sense of empowerment, control or hope
7. Increase understanding of perceived conditions
8. Get practical feedback on alternative problem-solving options
9. Learn about health, economic or social resources

Apart from advantages, support groups also have disadvantages. Therefore, the role of the facilitator is very important to help avoid this problem. Disadvantages of support groups include:

1. Disruptive group members
2. Discussions are dominated by complaints
3. Lack of confidentiality
4. Emotional attachment, group tension or interpersonal conflict
5. Inappropriate medical advice

Several studies conducted show that support groups as part of social support have a significant influence in reducing parents' stress levels. Research conducted by Kurnia, et al, (2019) states that there is a significant relationship between social support and stress experienced by parents of children with mental retardation. Parents who receive high levels of social support have low levels of stress. The results of this study show the importance of social support in reducing parenting stress.

This research is supported by Pandey & Dubey (2019) which states that support groups can significantly and consistently reduce stress for parents, especially mothers who have children with mental retardation. Other research conducted by Abedin & Molaie, (2010) on parents of mentally retarded children in Iran stated that support groups are an effective way to reduce the pressure and stress of parents with retarded children.

Differences in stress levels of parents of mentally retarded children after PSG in the intervention and control groups

The study results prove that peer support group can reduce parents' anxiety and stress levels. This is as done by Dewi, Hamid, Mustikasari (2012) who stated that supportive group therapy can reduce anxiety levels in families with mentally retarded children. Family anxiety can decrease because supportive group therapy provides the family with the opportunity to share knowledge, feelings and experiences while caring for a child with mental retardation, so that it can act as an internal and external support system, and ultimately the family is able to manage psychosocial problems that arise during caring mentally retarded children.

Families who are at the stage of accepting a child with mental retardation are in a balanced condition. They recognize the child's limitations and try to compensate for these limitations while continuing to try to maintain communication between family members. There are four characteristics that the family has reached the acceptance stage:

1. Positive parental perception by accepting the child's weaknesses and limitations and exploring the child's skills and abilities.
2. A realistic view of children. Parents are aware of their children's limitations, and are not overwhelmed by feelings of self-pity and guilt.
3. Parents search for possible services and do not look for shortcuts.
4. Accepting parents can give love to their children without feelings of rejection or overprotection. Apart from that, parents must also remain aware that attention to children with disabilities does not come at the expense of attention provided to other family members.

Conclusion

Based on the research results, it can be concluded that most of the respondents were over 40 years old with mostly high levels of education. The results of this research also show that peer support groups have a significant effect on reducing stress levels, thus the PSG intervention for parents of children with mental retardation has a positive influence so it needs to be implemented continuously and in a structured manner. Institutions need to facilitate PSG activities and be directly involved in these activities. Each teacher at special need school can join the group and act as a facilitator. This activity can also function as a communication tool between the school and parents. The PSG implementation strategy can be implemented face-to-face and online.

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