

Effects of self-help groups intervention on coping strategies of parents of children with Autism Spectrum Disorder (ASD)

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ABSTRACT

Coping strategies were significant predictors of psychosocial adaptation in parents of children with autism spectrum disorder (ASD). Self-help groups could be effective resources for parents in dealing with problems while caring for children with ASD. The purpose of this study was to analyze the effects of self-help groups on coping strategies in parents of children with ASD. This study used pre and post Quasi-experimental tests without a control group using self-help group interventions. There were thirty-three participants taken from the Malang City Autism Service Center using purposive sampling. Coping strategies based on cognitive and psychomotor abilities were measured using a questionnaire. The results showed Paired T-test in all groups, at 5% significance level, statistically significant difference between mean score before and after self-help group interventions. Coping strategies in groups that received two supervised sessions and four times independently reached higher score compared to other groups. It can be concluded that it is important to implement self-help groups for parents who care for children with special needs.

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1. INTRODUCTION

Autism spectrum disorder (ASD) is a neurological and developmental disorder that has a wide range of symptoms such as difficulties and delay in social interaction, communication and repetitive behaviors [1-3]. These deficits can be a major source of stress and frustration for parents when they raise children with ASD. The number of children diagnosed with ASD worldwide has and is still growing to 1 in 59 children in 2018 from 1 in 68 two years previous [4]. The Indonesian Autism Foundation reported an increase in the prevalence of ASD at 1 in 500 children in 2010, approximately 112,000 children with ASD within age of 5-19 years. The increase in cases of ASD also occurred in the city of Malang, reaching 847,175 children [5].

Previous study showed that parents with ASD children had destructive coping strategies instead of constructive coping strategies. These happened because parents had never received information about self-help groups to strengthening their coping strategies. Parents felt that the supporting group in the community was too formal so they felt difficulties to express feelings and share experiences [6]. Several factors which related to parents with ASD children stress were nature of situation, individual characteristics, environment, resources, perceive stress and coping responses. Therefore, it is important to build strong bonds between parents-facilitators in order to help parents of children with ASD to improve their coping skills, reduce their stress and enhance their quality of life. In addition, parents could boost their self-confidence and self-efficacy [7-9].

Self-help groups approach aimed to bringing together parents to identify their needs and gain resources to promote positive coping skills. A self-help group is a group where each member shares problems both physically and emotionally on certain issues. This group is a self-administered intervention which was designed for specific purpose. Self-help groups aim to develop empathy among fellow group members so that they provide mutual reinforcement to form new adaptive coping skills. Within the groups, it could also increase their autism awareness and facilitate access to services for ASD children. Groups can also practice to identify strengths and weaknesses in their social exchange information. Self-help groups with facilitators can help empower parents to obtain the information with regards to raising ASD children they need [10-12]. Self-help groups among parents with ASD children need to be implemented to help them deal with problems that are solved together in groups. The purpose of this study was to analyze the effects of self-help groups on coping strategies of parents of children with ASD.

2. RESEARCH METHOD

The design used in this study is Quasi experimental pre-post test without control group with self-help group interventions. The study was conducted to determine cognitive and psychomotor changes in parents with ASD children before and after having self-help group interventions. This study compared the changes of cognitive and psychomotor score within three groups as seen in research design can be seen in Table 1.

Table 1. Research design

Group	Pre-Test	Treatment	Post-Test
Group I	T1	X1	T2
Group II	T1	X2	T2
Group III	T1	X3	T2

Information:

T1= pre test

T2= post test

X1= experimental group using 6 sessions: 4 sessions with supervision, 2 independent practices

X2= experimental group using 6 sessions: 2 sessions with supervision, 4 independent practices

X3= experimental group using 6 sessions: 3 sessions with supervision, 3 independent practices

The procedures in the study are: [a] Preliminary study or pre-test was done to see the homogeneity of each class of the population. [b] The researchers gave a pre-test to see respondents' level of coping skills. [c] The researcher divided groups into three consecutive groups: X1=experimental group using 6 sessions: 4 sessions with supervision, 2 independent practice; X2=experimental group using 6 sessions: 2 sessions with supervision, 4 independent practice; X3=experimental group using 6 sessions: 3 sessions with supervision, 3 independent practice. [d] Supervision was given by the researchers and facilitators to provide comfort for the respondents. [e] Independent practice means that the respondents practicing self-help groups without supervision. [f] The researchers gave a post-test to evaluate respondents' level of coping skills.

The population in this study were all parents who cared for ASD children at the Malang City Autism Service Center. The number of ASD children at the Autism Service Center in Malang City was 47 children. The sampling technique used was purposive sampling. To minimize confounding variables, 33 parents with ASD children were chosen based on inclusion criteria: [a] children in the school age range (6 to 12 years). [b] Have taken therapy for at least 6 months. [c] Parents minimum age of 20 years. The research was located at the Malang City Autism Service Center and was conducted on March 2017.

Consent was signed after each participant had been explained about the general purpose of this study. Ethical approval was gained from the Health Polytechnic Malang, Ministry of Health of Republic of Indonesia Review Board, February 2017 (Reg.No: 386/KEPK-POLKESMA/2017). Written approval from the site was also obtained. The respondents were assessed using instrument the cognitive and psychomotor coping questionnaires pre-treatment and post-treatment. Scale used in the research was the confidence scale that the reliability coefficient alpha (α)=0.8 so it can be said that the item is quite valid and reliable.

3. RESULTS AND DISCUSSION

3.1. Characteristics of respondents

Table 2 is based on the age of the respondents. The average age of parents in group I was aged 40.3 years, group II was aged 40.5 years and group III was aged 37.2 years. Meanwhile, the average age of ASD children in group I was aged 11.5 years, group II was aged 7.2 years and group III was aged 6.8 years. ASD children in group I and group III were mostly first child in the family, while in group II were mostly the second child in family structure.

Table 2. Characteristics of respondents

Characteristics	Group I	Group II	Group III
Parents age (years)	40.3	40.5	37.2
ASD children age (years)	11.5	7.2	6.8
Birth Order	1 st child	2 nd child	1 st child

3.2. Parents coping strategies before and after self-help group interventions

The purpose of this study was to analyze the effects of self-help groups on coping strategies of parents of children with ASD. Table 3 shows the difference of coping strategies among three groups before and after self-help group interventions.

Table 3. Difference in coping strategies between pretest and posttest

Groups	Mean \pm SD	Sig. (2-tailed)
Group I (n=11)		0.000
Pre-test	60.55 \pm 3.984	
Post-test	69.64 \pm 4.178	
Group II (n=11)		0.000
Pre-test	57.64 \pm 3.171	
Post-test	71.45 \pm 3.778	
Group III (n=11)		0.000
Pre-test	62.45 \pm 4.612	
Post-test	73.91 \pm 2.809	

Table 3 shows the results of Paired T-test in all groups, at 5% significance level, all null hypotheses are rejected, thus it can be concluded that there is a statistically significant difference between mean score before and after self-help group interventions. The results also showed that groups that showed significant changes were group II who received 2 times of supervision and 4 times practice independently. The group that did not show significant changes was group I who received 4 times supervision and only 2 times practice independently.

The results showed that several factors influenced coping strategies in parents with SD children, such as social support, self motivation, and the availability of facilities and infrastructure that support child care. Most parents explained that self-help groups will provide benefits to enhance their coping strategies during care giving ASD children; however each members of the group should also give mutual reinforcement so all parents feel comfortable within the groups. Parents' motivation was the main factor that influenced problem solving skills in everyday life because it was related to the initial commitment when the child was diagnosed with ASD.

Parents' motivation influence active coping skills, self-efficacy and parents' attachment. Stress could provoke the activation of coping skills through motivation and resilience. It was considered as an internal set of processes that determines a set of behaviors. Additionally, stress could activate motivation to cope with stress. People who have higher levels of motivation tend to have positive coping skills with stressful situations. Their decisions regarding type of coping skills are influenced by the expected successful coping behaviors on their stress levels and performance [13-14]. The availability of facilities and infrastructure that support the care of ASD children also affects parents coping strategies to access information and obtain health and education services which are appropriate for children with ASD.

Raising children with ASD often brings high levels of stress and strain, compared to other parents who have children with other intellectual and developmental disabilities. They have to observe and manage their ASD children from difficult behaviors, such as running away, meltdowns, sensory overload issues and consult their growth to therapists or doctors. Thus, parents will experience financial issues because of the costs of therapies, additional teachers or facilitators at school, and other activities such as childcare and

extracurricular activities. Parents also often struggle with health services; they have to find appropriate health service providers, complete administrative paperwork to obtain subsidiary funding. These unmet service needs could exacerbate parents' stress. Complexities of ASD children behavior problems and parents as well as passive-avoidance coping could cause parents' burden. Meanwhile, the use of passive-avoidance coping had the strongest association to parents' burden. Therefore, to boost parents' self-esteem, optimism and self-efficacy while caring for ASD children, it needs support groups to promote mental well-being among parents [15-17].

The results showed a significant increase in parents' coping strategies before and after self-help group interventions. The highest difference in mean score can be seen in groups that received twice supervision. This showed that cognitive coping skills could be increased if conducted in 2 sessions. Coping strategies could be improved if each member of groups' exchanges information and knowledge about problems related to the condition of ASD children. Parents who care for children with autism will seek support, education and social policies through their participation in self-help groups. They understand that many professionals recommend parents to join self-help group as well as seek advices to professional services. Self-help groups could also promote parents' empowerment and involvement in social activities. Previous study showed that support groups could emphasize the emergence of problem-focused coping strategies to help mothers cope with situational stress in their daily life. Social support could enhance positive reinterpretation and individual growth to view something in a more positive way, and enables active coping skills. Social support given by relatives and friends, religious leaders, and health providers could be identified as coping strategies used by parents of children with special needs. It could be also identified as sources of support and active socialization. This finding is consistent with the literature as support groups serve as opportunities for information exchange, group therapy, and nonjudgmental interactions [18-20].

Self-help group was organized to enable all members of the groups to gather strength and mobilize opinion, gain opportunities for them to respond to issues concerning their livelihoods while caring for ASD children. It is an important platform to enhance parents' knowledge and awareness on ASD issues, and financial difficulties. Parents could also initiate to build generating income in several activities to help fulfilling their needs. Thus, they can contribute to the growth of the economy of families. Self-help group can come forward to form a group of the social and economic growth [21-23]. Self-help group was designed as a program that could provide assistance to the groups in both social aspects and nutritional benefits. In addition, self-help group could promote entrepreneurship using its local skills, information and assets [24-25].

Previous study investigated the benefit of self-help group that shows a short term positive effect. Self-help group of parents was based on a behavioral program and known as other therapy option for raising ASD children. This behavioral program was a therapy for parents using behavior modification techniques which were based on social learning values [26]. Self help groups provide benefits for practicing positive coping skills among parents. The benefits felt by most parents include support that was given by all members if any member encounters specific problems. Psychological stress could worsen the quality of care for children with ASD. The support provided is not only in the form of social support, but also emotional, physical and spiritual support. The self help group will gradually improve coping mechanisms of parents in caring for ASD children.

4. CONCLUSION

The coping strategy of parents with ASD children was influenced by parents' characteristics, social support, self-motivation and health facilities that support ASD children. Coping strategies in groups that received two supervised sessions and four times independent practice reached higher score compared to other groups. The Paired T-test results in Table 3 further concluded that there is a statistically significant difference between mean score pre-test and post-test since all null hypotheses are rejected at 5% significance level. It can be concluded that it is important to implement self-help group for parents who care for children with special needs. Self-help group could mobilize social resources for the improvement of social and economic status of each member and also create awareness about ASD issues and health services that should be adequately provided.

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