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ORIGINAL RESEARCH

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EFFECT OF FAMILY EMPOWERMENT IN ENHANCING THE CAPABILITIES OF CHILDREN WITH AUTISM

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ABSTRACT

Background: Children with autism as individuals have a right to receive developmental needs obtained from parent/caregiver during their stay in the family. The family ability can be improved through empowerment training to provide stimulation for the development of children with autism.

Objective: This study aims examine the effect of family empowerment in enhancing the capabilities of children with autism.

Methods: The research design used a two-stage quasi-experiment. The first stage was a training for parent/caregiver of children with autism using modules. Training was done three times in the Autism Service Center (PLA) of Blitar City Indonesia. The second stage was the parent/caregiver provided stimulation to their children at home. There were 33 children selected using total sampling in the PLA of Blitar City on April – August, 2016. Data were analyzed using descriptive statistics and paired t-test.

Results: The family ability to stimulate the capability of children with autism in the sense of hearing, vision, motoric, and inviting to play obtained average changes of 61.99%, with average items increased from 18.52 to 30.00. While the increase capabilities of children with autism were categorized into five classification: communication, fulfilling of activity daily living, language-numbers-tactile, psychology, and understanding commands.

Conclusion: There was a significant effect of family empowerment in enhancing the capabilities of children with autism. Thus, training to improve the ability of parent/caregiver in caring children with autism needs to be implemented in a planned and gradually manner.

Keywords: autism, children, family empowerment

INTRODUCTION

Children with special needs have visible symptoms of developmental disorders of social interaction, mutual interaction, and behavior. Autism is a persistent neurological disorder.¹ Although neurological disorders cannot be treated, symptoms can be eliminated or reduced so that it can no longer be distinguished between autistic and non-autistic children. Children with autism are just like other children and need the affection of parent. The form of family affection is able to accept and understand the condition of autistic children including meeting psychosocial needs.^{2,3}

Every day, children with autism with the various condition still live in the family environment because the family is the first and primary place for them. The role of families with autistic children is to know, decide, treat, modify the environment, and utilize of service facilities.⁴ Families are demanded to meet the needs of children, as well as their treatment both in health facilities and at home.

Sensory integration is a basic need or requirement for autistic children in order to absorb any information through motoric, cognitive, and social learning in everyday life. The sensory integration could be implemented by family through sensory stimulation to learn, regulate and adjust, which leads to a good habituation and automatic adaptive response.⁵ In addition, the purpose of fulfillment of sensory integration is to increase body awareness, reduce behavior that is contrary to normal conditions, increase alertness and interaction with environmental changes, improve eye and hand coordination, improve interaction skills, foster speech and communication,

affect responses and the child development through the response of vision, smell, groping; improve the ability of the child's perception, provide stimulation, and help reduce restlessness. The ultimate goal of fulfilling the sensory integration is to improve the child's personal skills including dressing, writing, shodding, eating, and routine activities.

However, the family role to fulfillment the needs of sensory integration cannot be done directly if the family have a lack of knowledge and experience to do with autistic children. Thus, efforts to increase the family's ability to enhance capabilities or fulfill the sensory integration of children with autism is needed. The aim of this study was to examine the effect of family empowerment in enhancing the capabilities or sensory integration in children with autism.

METHODS

Study design

This was a quasi-experimental study with two stages. The first stage was to give a training to parent/caregiver of children using modules. The second stage was that the parent/caregiver provided stimulation to their children at home. The parent/caregiver with autism is a person who has a blood relation or not who daily deals with children with autism at home, supplies their needs, and sends them to the therapy or activities performed by the autism service center (Pusat Layanan Autis / PLA) of Blitar City.

Setting

This study was conducted in the Autism Service Center (Pusat Layanan Autis /

PLA) at Blitar City on April – August 2016.

Sample

Total sampling was employed in this study, and there were 33 samples involved in the Autism Service Center (Pusat Layanan Autis / PLA).

Intervention

The training given to the parents or caregivers was done three times in the Autism Service Center on the 11th, 18th, and 25th of August 2016. Another intervention at home was done twice per week for 6 weeks under supervision of nurses.

Instruments

Family ability refers to the response of parent (father or mother)/caregiver who has children with autism regarding the action to fulfill the sensory integration needs of the children, as measured by checklist scale developed by the researchers based on the purpose of sensory integration and the guidebooks. The measurement was done before and after the family empowerment by calculating the check mark “Yes” (if a child performs the activity) and “No” (if no performing or failed to perform) in the ratio scale. While the individual ability of the children with autism refers to the ability to dress, write, shoe, eat, store the

goods used, communication for help, and personal hygiene of children who have been diagnosed with autism and received services in the autism service center (Pusat Layanan Autis / PLA) expressed orally or in writing by the parent/caregiver. Validity and reliability of the instruments have been performed.

Data analysis

Descriptive statistics was performed to describe the mean. For comparison of data between the two groups, paired *t*-test was used, respectively. In addition, to explore more information, qualitative methods during data collection was performed. Perceptions of parent/caregiver about the capability of autistic children were written freely and qualitatively and then themes grouped by content analysis.

Ethical clearance

Ethical clearance was approved by the Health Research Ethics Commission of Poltekkes Kemenkes Malang with Registration Number 185 / KEPK-POLKESMA / 2016.

RESULTS

Characteristics of autistic children and their parents who received services at PLA Blitar City shown in Tables 1 and 2.

Table 1 Characteristics of children with autism who received services at PLA Blitar City

Characteristic	f	%
The children age (years old):		
Under 5	1	3.0
Preschool (< 7)	10	30.4
School (≤ 12)	18	54.5
Teenagers (> 12 – 18)	4	12.1
Minimum: 4 years old; Maximum: 14 years old; Average = 7.8; SD = 2.6		
The child is the child		
First	12	36.4
Second	17	51.5

Third	2	6.1
More than the third	2	6.1
Gestational age when an autistic child was born:		
Less than 9 months	4	12.1
Enough (9 months)	29	87.9
Educational background of the children:		
No education	11	33.3
Kindergarten (Public kindergarten)	10	30.3
Elementary school (Special school)	12	36.4
Institution who first diagnosed as an autistic child:		
Other autistic centers	10	30.3
PLA (Autism Service Center) Blitar City	8	24.2
Hospitals (Blitar and another city)	15	45.5
Length of diagnosis with autism:		
Did not know	6	18.2
1 – 3 years	16	48.4
4 – 6 years	11	33.4

Table 2 Characteristics parents of autistic children who received services at PLA Blitar City

Characteristic	Father		Mother	
	f	%	f	%
Parent's age (year)				
No information	2	6.1	2	6.1
20 – 30	2	6.1	-	0.0
31 – 40	12	36.4	6	18.2
41 – 50	9	27.3	12	36.4
51 – 60	6	18.2	11	33.3
> 60	2	6.1	2	6.1
Parent education:				
No information	2	6.1	-	0.0
No education	2	6.1	2	6.1
Elementary school / same level	4	12.1	2	6.1
Junior school / same level	8	24.2	10	30.3
Senior school / same level	9	27.3	9	27.3
Higher education	8	24.2	10	30.3
Parent occupation:				
No information	2	6.1	-	0.0
Government employees	4	12.1	6	18.2
Entrepreneurs	13	39.4	2	6.1
Private employees	8	24.2	2	6.1
Worker	4	12.1	-	-
Merchant	2	6.1	2	6.1
Housewife			21	63.3
Parent income (IDR):				
No information	16	48,5	23	69.7
< 1.5 million per month	6	18,2	4	12.1
1.5 – 3.0 million per month	11	33,3	4	12.1
> 3.0 million per month	-	0.0	2	6.1

Table 3 The ability of parent/caregiver to stimulate sensory integration for autistic children using Paired t-test

Sensory stimulation of parents	The number of items measured	Number of items done during observation									p-value
		Min		Max		Mean			SD		
		Before	After	Before	After	Before	After	Mean difference	Before	After	
Vision	15	2	6	13	14	6.73	10.42	54.83%	3.07	2.42	0.000
Hearing	11	1	4	6	10	3.85	6.27	62.86%	1.95	1.82	0.000
Motoric	10	0	1	8	7	3.09	4.24	37.22%	2.57	1.95	0.000
Invite to play	14	0	5	9	13	4.85	9.06	86.80%	2.91	2.29	0.000
Total	50	-	-	-	-	18.52	30.00	61.99%	8.30	6.42	-

Perceptions of parent/caregiver about the capability of autistic children were written freely and qualitatively. The themes were grouped into five capabilities: (1) Communication: the children could do two-way communication but articulation is not clear (began to respond); (2) Fulfilling the needs of daily living: children sometimes self-feeding, self-taken of his/her drinking water, and sometimes open and wear his/her own clothes, and asking for daily toileting needs; (3) Language, numbers, and tactile: children can memorize the letters A-F, identify the numbers 1-20, write their own names, give color to the book coloring the image, and can go home alone; (4) Psychology: children tend to hyperactivity, intelligence, has no own initiative; and (5) Understanding commands: they were willing to work, taking out garbage, drying clothes, imitating a few words, and being able to follow simple commands.

DISCUSSION

Training for parent/caregiver aimed to keep families continuously able to train their children. Parent/caregiver in the study stated, "... if from the beginning we are trained, we can also train children at home according to ability ...", "... may be taught to families who have children diagnosed with autism first here ...", and

"Why just now?". According to Buckley, training is a planned and systematic effort to transform or develop knowledge/skills/attitudes through learning experiences, to achieve effective performance in one or many activities.⁶ The training purpose is enabling individuals to acquire the ability to perform tasks or activities that are given and realize the potential.

Training for parent/caregiver of autistic children must be done because children are always at home every day and at all times to communicate verbally and non-verbally. The family is the primary and foremost place for the child.⁴ This condition is supported that nearly two-thirds (63.3%) of parent who at all times contact with children with autism are as housewives (Table 2). It is indicated that the trained family will give a therapeutic effort for their children all the time.

Training can also be used as an effort to empower and increase family responsibilities⁷ to educate of children with autism. These efforts are consistent with family duties in health. Bailon and Maglaya describes five family duties, namely: (1) identifying family members with health problems, (2) deciding to seek health care, (3) caring for family members with health problems, 4) modifying the home environment for family members who have health problems, and (5)

utilizing health care facilities as a reference for family members.⁴ Family tasks, if given training, will be able to do effectively and efficiently.⁴

Based on Table 2, the training has the benefit as a multifarious effort because about 50% of parent/caregiver (father and mother) of autistic children have senior and higher education. The level of education has a role in an educational process.⁸ Those who have higher education will be easier to understand and receive information. This situation is supported by a mother's statement, "What can I do at home to my child?". The statement supports that parent have the responsibility and effort to educate for their children, as they stay with the parent in almost all the time.

The ability of parent/caregiver is to stimulate vision, hearing, motoric, and invite to play of children. But before training, there were some children who have not been stimulated in motoric and not been invited to play (Table 3). There was only a small change after the training on motoric stimulation. It could be because the parent/caregiver did not understand the motoric stimulation for their children before training. However, after the training, the parent/caregiver understood the motoric stimulation but might feel afraid to use the equipment because the children might play or hang in the equipment.

Stimulation of vision, hearing, and invite to play is very easy to learn and do because according to the parent/caregiver, indicated that children with autism have done three activities inadvertently every day. After being trained, the parent/caregiver states/tell, "... it turns out that this is the purpose of stimulation for

autistic children ..." and "... I do at home frequently...". The module training improves the ability of parent/caregiver to understand the roles and actions that need to be done for children with autism. The intervention can turn family functions into service providers to sick family members.⁹ that is consistent with that five family duties in the health.⁴

Parents or caregivers were telling qualitatively about the ability of children with autism after the training. The qualitative results can be grouped into five capabilities: *communication, ability to fulfill daily life, language - numbers - tactile, psychology, and understanding the command*. The autistic child's ability to speak is not solely due to training interventions gained during the research, but the autistic child from the service has been trained to meet his or her own needs with minimal assistance by the parent/caregiver at home. The success of the children that can be proud is the ability to understand the command, because children with autism before getting therapy in the autism center of Blitar City did not want to be ordered and did anything for what they wanted (tantrums). But after training, the children were willing to accept and perform simple commands, this ability makes autistic children behave actively if parent/caregiver do similar activities that need help. For instance, in the waste disposal activities, the children offer to dispose of garbage when the parent/caregiver (mother) finished doing the cooking activities.

The ability of parent/caregiver to increase their children ability deserves an award. In this study, the parents were able to change the daily needs of the children who focused on one thing to explore the

environment close to the children. It could be said that the role of parents is very important for children with autism. The situation is synchronized that family members who have health problems in order to receive care sincerely, affection, and use of health care facilities.¹⁰

The ability of children with autism was described by parent/caregiver qualitatively in line with the explanation,^{11,12} that aspects of child development include physical, intelligence, emotion, language, social, personality, moral, and religious awareness. Based on Table 1, two-thirds (66%) of autistic children were in school and adolescence, so the ability of autistic children has been in accordance with the task of development. The task of child development at school age is learning to acquire physical skills to perform the game, learning to form a healthy attitude towards oneself as a living creature, learning to associate with peers, learning to play roles as gender, learning basic skills for reading - writing - arithmetic, learning to concepts develop every day, developing conscience, learning to gain personal freedom, and developing positive attitudes toward social groups and institutions.¹¹ Autistic children as individuals have the same developmental tasks with healthy children, so the ability to help his/her developmental task be passed and get the attention from parent/caregiver so child development tasks are met.

The development task of an autistic child is guaranteed to be fulfilled by everyone. The Act of Republic of Indonesia about Child Protection in article 9, paragraph 1, states that every child has the right to receive education and teaching in the context of his personal development and his level of intelligence according to

interests and talents.¹³ This means that every autistic child must also be fulfilled of the development task. The family as a home for autistic children should also meet the needs of the development.¹⁴ The Act of Republic of Indonesia about Population Development and Family Development, especially article 1 point 7, is written that family development is an effort to realize quality families who live in a healthy environment. Furthermore, it is explained that quality family is a family formed based on legal marriage and is characterized by well-being, healthy, go forward, be autonomy, has an ideal number of children, forward-looking, responsible, harmonious, and devoted to God.¹⁵

CONCLUSION

The empowerment of parent/caregiver has a great impact on the capabilities of children with autism with the following results: (1) The ability of parent/caregiver was increased after attending training to stimulate the sense of hearing, vision, motoric, and invite to play of the children, and (2) Parent/caregiver expressed qualitatively regarding the increased ability of their children in communication skills, fulfilling daily life, language - numbers - tactile, psychological, and understanding commands. Thus, the ability of parent/caregiver stimulation should still be gradually evaluated by professional and enhanced in a planned manner.

Declaration of Conflicting Interest

None declared.

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Author Contribution

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