



Experimental Research

Effect of parental skills-based psychoeducation intervention on parental stress index and severity of children with autism spectrum disorders: A pilot study

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ARTICLE INFO

Keywords:

Autism spectrum disorder
Parental stress
Psychoeducation
Severity scale
Child well-being

ABSTRACT

Objective: Analyzing the effect of psychoeducation on parental stress index and the severity of children with autism spectrum disorders.

Methods: Participants in the study consisted of autism spectrum disorder children and their parents who were divided into 2 groups (treatment = 15 and control group = 20). Participants were given psychoeducation as many as 6 sessions for 14 weeks (7 weeks for each group). Participants were measured for the value of the childhood autism rating scale (CARS) and autism parenting stress index (APSI) pre-post psychoeducation.

Results: There were significant differences in the treatment group in terms of total CARS values (40.73 ± 7.17 vs -7.67 ± 4.91 ; $p < 0.001$), communications (5.60 ± 1.45 vs -4.73 ± 1.49 ; $p = 0.001$), social interactions (10.20 ± 2.18 vs 8.93 ± 2.66 ; $p = 0.011$), and psychomotor (18.33 ± 3.96 vs 14.27 ± 3.90 ; $p < 0.001$) before and after psychoeducation, whereas there were no significant differences in the control group ($p > 0.05$). In the treatment group, there were significant differences in total APSI values (17.33 ± 9.99 vs 12.20 ± 4.02 ; $p = 0.001$), social difficulties (8.73 ± 4.60 vs 6.00 ± 4.02 ; $p = 0.002$), and physical (4.13 ± 3.54 vs 2.27 ± 2.99 ; $p = 0.013$) before and after psychoeducation, while there were no significant differences in behavior ($p = 0.443$). There were no significant differences in the control group ($p > 0.05$). There was a significant influence between psychoeducation on parental stress index ($p = 0.003$) and the severity of children with autism spectrum disorders ($p < 0.001$).

Conclusion: There is a decrease in parental stress index and severity of children with autism spectrum disorders after parental psychoeducation intervention.

1. Introduction

The incidence of autism spectrum disorders always increases [1]. An increase in the number of children with autism spectrum disorders in 2011–2013 was reported as much as 3.22% [2] and the latest study in 2017 stated that it was estimated that as many as 7% of children in the world had autism [3]. The Centers for Disease Control and Prevention in 2014 reported that autism spectrum disorders occurred approximately 1 in every 68 births in the United States [4]. Parents who have children with autism spectrum disorders experience greater stress than parents who have children with mental retardation and Down syndrome [5]. Caring for children with autism spectrum disorders also often leads to

depression, anxiety, and somatic complaints that lead to problematic family situations and symptoms of fatigue (burn out) in parents [6,7]. This causes decreased efficacy of parenting or confidence in the competence of parents in caring for their children. Thus, parents of children with autism spectrum disorders require greater support than can be provided by the community, family, and friends [8].

The handling of autism recommends 3 things related to family or caregiver aspects, such as 1) the need for active involvement from parents/caregivers as part of the intervention, 2) evaluating family-related factors, and 3) considering socio-cultural aspects and economic capabilities. Active family involvement, both as a co-therapist that is well supervised as part of an intervention, including setting goals and

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<https://doi.org/10.1016/j.amsu.2021.102873>

Received 19 August 2021; Received in revised form 16 September 2021; Accepted 16 September 2021

Available online 20 September 2021

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priorities for therapy, can have a positive impact, both in terms of development programs and behavioral programs [9]. The involvement of parents/family activities in the care of children with autism can be maximized through psychoeducation on parents. Psychoeducation of parents that provides accurate information and introduces parents to effective therapeutic approaches shows increased adaptation and family acceptance as well as improves symptoms, educational aspects, and social aspects in individuals with autism spectrum disorders. When a child with autism spectrum disorder exhibits problematic behavior, fear, or stereotypical behavior, parents need to evaluate whether any of their behaviors as parents contribute to causing problems for the child and if the parents can change their behavior, then this too can reduce the stress experienced by children [10–12].

Psychoeducation is more focused on aspects of parental knowledge about a disorder, and children who experience the disorder will benefit indirectly from the knowledge obtained by their parents. A study comparing parental education with parental training found that psychoeducation to parents resulted in a strong engagement and satisfaction with parents, where if knowledge was given more deeply to parents, it would most likely be an indirect pathway to correct the disruptive behavior of children with autism spectrum disorders [12,13].

In Indonesia, there were 13 children with autism spectrum disorders per 10,000 population in 2016 [14]. In Surabaya, it was also reported that there was an increase in the number of children with autism spectrum disorders in 2014 and 2015 as many as 25 children [14,15], while in 2019 it was reported that there were 105 children [16]. This study investigated the effect of a parental skills-based psychoeducation intervention, via the parental stress index and severity scale, for children with autism spectrum disorders.

2. Methods

2.1. Participants

There were two groups in this study, namely parents with autism spectrum disorder children and autism spectrum disorder children. The criteria for participant inclusion (parents with autism spectrum disorder children) included biological mothers who are primary caregivers, have lived with children >6 months, have a minimum of primary school education, can speak Indonesian properly and correctly (oral and written (reading and writing)). Participant's inclusion criteria (children with autism spectrum disorders) included children diagnosed with autism spectrum disorders [17], children aged 2–12 years, and have received standard therapy [18] ≥1 month. Participant's exclusion criteria (parents with children with autism spectrum disorders) were parents who become primary caregivers suffering from psychotic disorders or major depressive disorders [17]. Whereas, participant's exclusion criteria (children with autism spectrum disorder) included children having epilepsy or global developmental delay disorders or childhood autism rating scale (CARS) < 30 at the pre-test conducted by a psychiatrist. Participants first received an explanation of the objectives, benefits, rights, and obligations in the research process. Informed consent was obtained from all participants.

2.2. Study design

This Pilot study was experimental research involving pretest and posttest with control group design. The study was carried out for 14 weeks (7-week intervention for each group) in which participants were assessed before and after the intervention (psychoeducation). Participants were recruited in Child and Adolescent Psychiatry Day Care Clinic, Dr. Soetomo General Academic Hospital, Surabaya, Indonesia. The study was conducted from January to June 2019, with the first control group being evaluated for 7 weeks followed by the treatment group. Interventions given to participant's parents in the form of psychoeducation were given once a week with additional notes of skills that

parents should conduct while at home. Participants were divided into 2 groups: the treatment group (n = 15) and the control group (n = 20; Fig. 1). Participants were measured for parents' stress index and severity of children with autism spectrum disorders before and after psychoeducation.

Psychoeducation provided to parents was divided into 6 sessions (Table 1). Session 1 explained the definition and causes of autism spectrum disorders, diagnosis of autism spectrum disorders, and management of autism spectrum disorders; Session 2 explained the complete concept of holistic management of autism spectrum disorders; Session 3 explained the non-medication skills guide for autism spectrum disorders for parents to overcome social difficulties and overcome behavioral problems; Session 4 explained the non-medication skills guide for autism spectrum disorders for parents to deal with physical problems; Session 5 explained the guidelines for the treatment/medication of autism spectrum disorders for parents; Session 6 involved parents to make future planning for children with autism spectrum disorders [19].

2.3. Autism parenting stress index

Autism Parenting Stress Index (APSI) is used to measure the level of stress of parents with autism spectrum children. This tool consists of 13 items, namely (1) child's social development; (2) child's ability to communicate; (3) tantrum/meltdown; (4) aggressive behavior towards siblings or peers; (5) self-injurious behavior; (6) difficulty in making transitions from one activity to another; (7) sleep problems; (8) child's diet; (9) bowel problems (diarrhea, constipation); (10) potty training; (11) not feeling close to a child; (12) concern for the future of child being accepted by others; and (13) concern for the future of child living independently. These 13 items are grouped into 3, such as social difficulties (items 1, 2, 11, 12, and 13), behavior (items 3, 4, 5, and 6), and physical (items 7, 8, 9, and 10). APSI is declared valid and reliable by Cronbach's alpha = 0.827 [20–23]. APSI used to measure the level of stress of parents with autism spectrum children was the Indonesian version of APSI.

2.4. Childhood autism rating scale

Childhood Autism Rating Scale (CARS) is used to measure the severity of autism spectrum children aged ≥2 years. The CARS consist of 15 scales, and each is rated according to a division of 4 points. The 15 scales are: (1) relationship to people; (2) imitation; (3) emotional responses; (4) body; (5) object use; (6) adaptation to changes; (7) visual response; (8) listening response; (9) taste-smell-touch response and use; (10) fear or anxiety; (11) verbal communication; (12) non-verbal communication; (13) activity level; (14) level and consistency of intellectual responses; and (15) general impression [24]. The CARS is divided into 5 categories, namely communication (items 9 and 12), social interactions (items 1, 3, 6, and 10), psychomotor (items 2, 4, 5, 7, 8, 9, and 13), intellectual response (item 14), and general impression (item 15). The CARS used was the Indonesian version of CARS which is declared valid with a Cronbach's alpha = 0.91 (n = 606); 0.90 in children aged 2 years (n = 376); 0.93 in children aged 4 years (n = 230) [25].

2.5. Statistical analysis

The results of measurement data were tested for normality before choosing an appropriate statistical test. The statistical test used to analyze differences in the control group and the treatment group was paired *t*-test or the Wilcoxon test. Both tests were also used to analyze the comparison of measurement results before and after psychoeducation interventions. Meanwhile, an independent *t*-test or Mann Whitney was conducted to analyze the effect of psychoeducation on parental stress index and the severity of children with autism spectrum disorders. Statistical tests were significant if $p < 0.05$ with 95% CI. Measurement data were analyzed using IBM SPSS Statistics software

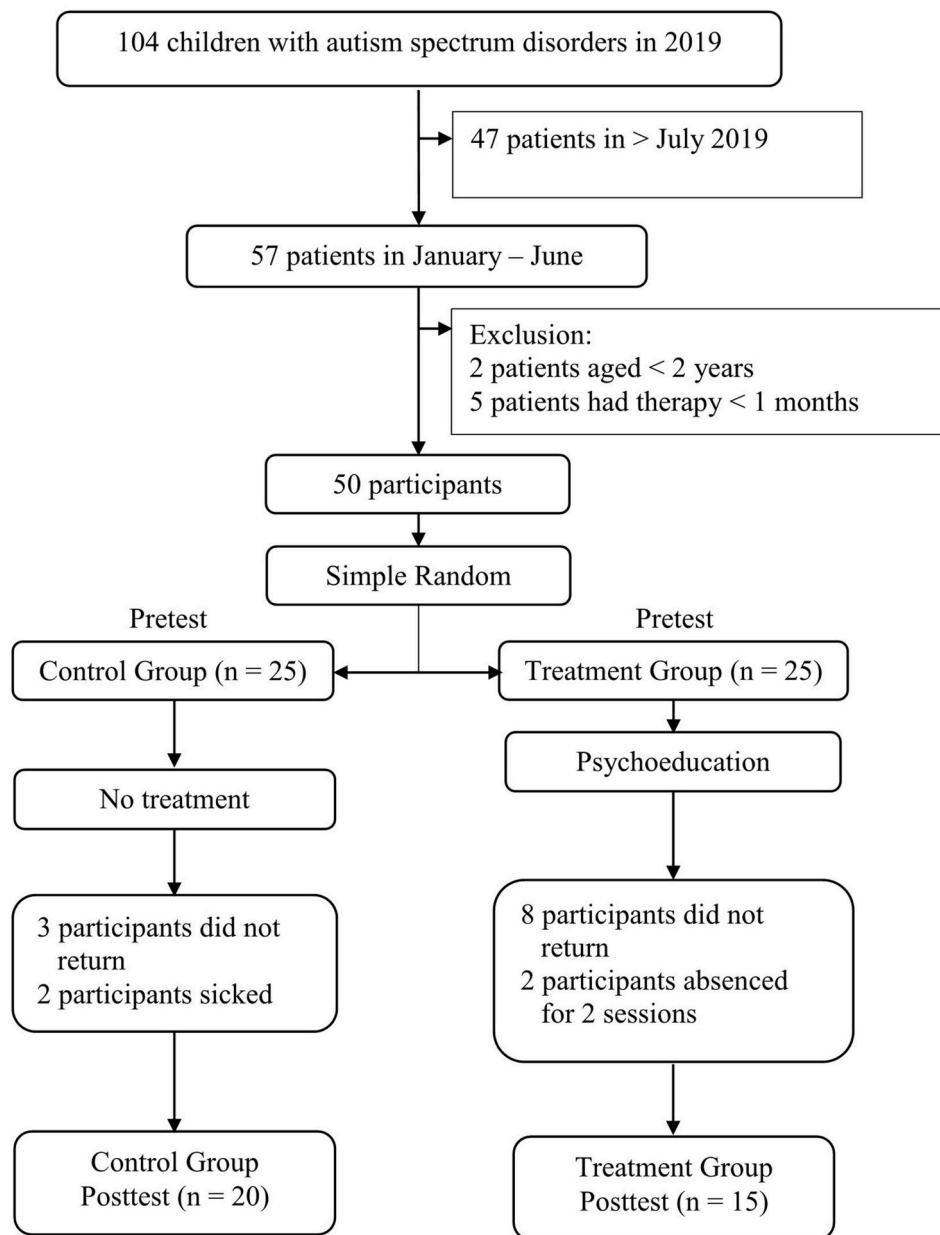


Fig. 1. Flowchart identification of participant numbers.

version 23.0 (IBM Corp., Armonk, NY, USA).

3. Results

3.1. Characteristics of participants

The characteristics of participants in the study are described in Tables 2 and 3. All participants in the control group (children) were boys (100%), while the treatment group consisted of 13 boys (86.70%) and 2 girls (13.30%). Most participants (parents) had high school education (control group = 65%, treatment group = 73.30%). The duration of the intervention in the control and treatment groups were 2.58 ± 2.95 years and 2.93 ± 3.67 years, respectively. In the control and treatment group, most participants used health financing facilities from Healthcare and Social Security Agency (control group = 65.00%, treatment group = 66.67%). Other participant's medical funding came from personal financing as much as 30.00% (control group) and 33.33% (treatment group), while the rest used other insurance (5.00%). All participants

(children) did not have other accompanying diseases, as they only experienced autism spectrum disorders. Most of the caregivers of children other than mothers when at home were the father (control group = 60.00%, treatment group = 80.00%), followed by grandparents of 20.00% each.

3.2. Effects of psychoeducation on the severity of children with autism spectrum disorders

The total CARS value of psychoeducation effect on parents with children with autism spectrum disorders before the intervention was $p = 0.678$, and after the intervention was $p = 0.011$. The difference in total CARS values before and after the intervention (psychoeducation) in the control and treatment groups was 0.20 ± 4.72 and -7.67 ± 4.91 , respectively ($p < 0.001$). In the communication subscale, the difference between the CARS values before and after psychoeducation in the control and treatment groups was 0.05 ± 1.00 and -0.87 ± 0.83 , respectively ($p = 0.007$). In the social interaction subscale, the difference

Table 1
Flow of psychoeducation for parent.

Sessions	Topics
Session 1 (30 min)	<ul style="list-style-type: none"> • APSI evaluation • Psychoeducation contract • The definition and causes of autism spectrum disorders, • diagnosis of autism spectrum disorders, • management of autism spectrum disorders.
Session 2 (30 min)	The complete concept of holistic management of autism spectrum disorders.
Session 3 (30 min)	The non-medication skills guide for autism spectrum disorders for parents to overcome social difficulties and behavioural problems.
Session 4 (30 min)	The non-medication skills guide for autism spectrum disorders for parents to deal with physical problems.
Session 5 (30 min)	The guidelines for the treatment/medication of autism spectrum disorders for parents.
Session 6 (30 min)	Involved parents doing future planning for children with autism spectrum disorders
Session 7 (30 min)	APSI evaluation

Table 2
Average characteristics of participants.

Characteristics	Mean \pm SD	
	Control (n = 20)	Treatment (n = 15)
Mother's age (year)	35.55 \pm 7.34	36.40 \pm 7.13
Child's age (year)	5.81 \pm 2.38	6.56 \pm 2.86
Duration of mother staying with child (year)	5.70 \pm 2.59	6.69 \pm 5.88
Duration of hospital treatment (year)	2.58 \pm 2.95	2.93 \pm 3.67

between CARS values in the control and treatment groups was -0.35 ± 1.60 and -1.27 ± 2.18 , respectively ($p = 0.109$). In the psychomotor subscale, the difference between CARS values in the control and treatment groups was 0.65 ± 2.50 and -4.07 ± 3.01 , respectively ($p < 0.001$; Table 4). This study found a difference in the CARS values between the control and treatment groups before ($p = 0.678$) and after ($p = 0.011$) psychoeducation.

In terms of intellectual response, the CARS value in the control group before psychoeducation showed that most participants (children) had an abnormal intellectual response in the moderate category (55.00%). After psychoeducation, the children were improved as 50.00% of them had an abnormal intellectual response in the moderate category ($p = 0.885$). Whereas, in terms of general impression, the CARS value in the control group before psychoeducation showed that most participants had a condition of abnormal general impression in the moderate category (65.00%), and they got improved after psychoeducation (55.00%; $p = 0.527$).

This study found a significant difference in CARS values of intellectual response and general impression in the treatment group before and after psychoeducation. Before psychoeducation, 40.00% of children had a severely abnormal intellectual response, and after psychoeducation, as much as 6.70% were in the category of severely abnormal ($p = 0.004$). A similar condition was also found in general impressions as many as 60.00% of participants with moderate general abnormality and 33.33% of participants who behaved severely abnormal. After psychoeducation, 40.00% of participants behaved moderately abnormal, and 6.70% of participants behaved severely abnormal ($p = 0.001$).

3.3. Effect of psychoeducation on stress index of parents with children with autism spectrum disorders

Effect of psychoeducation on parents with children with autism spectrum disorders on the total APSI value before the intervention was $p = 0.338$, and after the intervention was $p = 0.399$. The difference in the

Table 3
Demographic characteristics.

Demographic Data	Control (n = 20)	Treatment (n = 15)
Religion	19 (95.00)	12 (80.00)
Islam	1 (5.00)	2 (13.33)
Christian	0 (0.00)	1 (6.67)
Catholic		
Race	19 (95.00)	13 (86.67)
Java	1 (5.00)	1 (6.67)
Chinese	0 (0.00)	1 (6.67)
Arabs		
Occupation	14 (70.00)	13 (86.67)
Housewife	3 (15.00)	2 (13.33)
Entrepreneur	3 (15.00)	0 (0.00)
Other		
Mother's Level of Education	0 (0.00)	0 (0.00)
Elementary School	3 (15.00)	3 (20.00)
Junior High School	13 (65.00)	11 (73.33)
Senior High School	2 (10.00)	0 (0.00)
Diploma	2 (10.00)	1 (6.67)
Bachelor		
Mother's Health Status	19 (95.00)	12 (80.00)
Doctor visit 0–3 x/year	0 (0.00)	1 (6.67)
Doctor visit 4–6 x/year	1 (5.00)	2 (13.33)
Doctor visit >6 x/year		
Marital Status	18 (90.00)	15 (100.00)
Married	2 (10.00)	0 (0.00)
Widow		
Income	17 (85.00)	12 (80.00)
<5 million/month	3 (15.00)	3 (20.00)
5–10 million/month		
Child's Sex	20 (100.00)	13 (86.67)
Male	0 (0.00)	2 (13.33)
Female		
Child's Education	3 (15.00)	2 (13.33)
None	7 (35.00)	3 (20.00)
Early Childhood Education and Development	5 (25.00)	2 (13.33)
Kindegarten/Inclusive Kindegarten	5 (25.00)	8 (53.33)
Elementary School/Inclusive Elementary School		

total APSI value before and after psychoeducation in the control and treatment groups was 0.05 ± 4.817 and -5.13 ± 4.58 , respectively ($p = 0.003$). In the social difficulty subscale, the difference between the APSI values before and after psychoeducation in the control and treatment groups was -0.05 ± 1.67 and -2.73 ± 2.79 , respectively ($p = 0.003$). In the behavior subscale, the difference in APSI values in the control and treatment groups was 0.30 ± 2.66 and -0.53 ± 2.62 , respectively ($p = 0.362$). In the physical subscale, the difference between the control and treatment groups was -0.20 ± 1.70 and -1.87 ± 2.53 , respectively ($p = 0.026$; Table 4).

The APSI measurement results in each item showed a child's social development in the control and treatment group ($p = 0.748$; $p = 0.180$, respectively), children's ability to communicate in the control and treatment group ($p = 0.527$; $p = 0.016$, respectively), tantrums (control $p = 0.888$; treatment $p = 1.000$), aggressive behavior towards siblings or peers (control $p = 0.739$; treatment $p = 1.000$), self-injurious behavior (control $p = 0.107$; treatment $p = 1.000$), difficulty in making transitions from one activity to another (control $p = 0.564$; treatment $p = 0.066$), sleep problems (control $p = 0.655$; treatment $p = 0.084$), diet problems (control $p = 0.851$; treatment $p = 0.028$), bowel problems (control $p = 0.705$; treatment $p = 0.655$), potty training (control $p = 0.603$; treatment $p = 0.059$), not feeling close to child (control $p = 0.527$; treatment $p = 0.024$); concern for the future of child being accepted by others (control $p = 0.248$; treatment $p = 0.167$); concern for the future of child living independently (control $p = 0.748$; treatment $p = 0.041$).

This study found no significant differences in the control group, whereas, in the treatment group, there were significant differences in the pre and post-test in terms of children's ability to communicate, diet

Table 4

Effects of psychoeducation on parental stress index and severity of children with autism spectrum disorders.

Variable		Pretest	Posttest	Comparison	Effect
CARS	Total value	39.70 ± 7.26	39.90 ± 6.84	0.852	0.000**
	Control	7.26	6.84	0.000**	
	Treatment	40.73 ± 7.17	33.07 ± 8.24		
	Communication	5.70 ± 1.72	5.75 ± 1.52	0.825	0.007*
	Control	1.72	1.52	0.001*	
	Treatment	5.60 ± 1.45	4.73 ± 1.49		
	Social Interaction	10.85 ± 2.13	10.50 ± 2.01	0.340	0.109
	Control	2.13	2.01	0.011*	
	Treatment	10.20 ± 2.18	8.93 ± 2.66		
	Psychomotor	17.35 ± 4.07	18.00 ± 3.46	0.259	0.000**
	Control	4.07	3.46	0.000**	
	Treatment	18.33 ± 3.96	14.27 ± 3.90		
APSI	Total value	14.50 ± 5.84	14.55 ± 6.71	0.963	0.003*
	Control	5.84	6.71	0.001*	
	Treatment	17.33 ± 9.99	12.20 ± 9.57		
	Social problems	7.45 ± 3.75	7.40 ± 3.70	0.895	0.003*
	Control	3.75	3.70	0.002*	
	Treatment	8.73 ± 4.60	6.00 ± 4.02		
	Behaviour problems	4.00 ± 3.10	4.30 ± 3.87	0.619	0.362
	Control	4.47 ± 3.25	3.93 ± 4.13	0.443	
	Treatment	3.25	4.13		
	Physical problems	3.05 ± 2.04	2.85 ± 1.35	0.606	0.026*
	Control	2.04	1.35	0.013*	
	Treatment	4.13 ± 3.54	2.27 ± 2.99		

Note: * significant <0.05; ** significant <0.001.

problems, not feeling close to children, and concern about children's independence in the future.

4. Discussions

This study focused on the APSI designed by Silva and Schalock to be used in identifying which areas are needed to improve parental skills and assessing the effects of interventions on parental stress [22,23]. After psychoeducation interventions to parents, this study found differences between pre and post-test in the treatment group in terms of the total APSI score, aspects of the social problem group, and physical problems.

It takes a special way of interaction between parents - children with autism spectrum disorders which communication used is different from children with growth and development disorders. Parents who have children with autism spectrum disorders must be sensitive to their child's characteristics to avoid excessive stimulation. Through psychoeducation, parents gain a lot of understanding and also non-medication skills regarding the characteristics of the problems - social and physical difficulties that occur specifically in children [7]. This study found significant differences in the pre and post-test in terms of children's ability to communicate, diet problems, not feeling close to children, and concern about children's independence in the future.

The lack of difference in the statistical test between the control and treatment groups in terms of aspects of the child's behavior is possibly due to several factors. In this study, participants in both groups went through an intervention period that exceeded two years. Generally, educational interventions focus on behavioral problems, and within 2 years after the diagnosis of children with autism spectrum disorders, parents have adjusted to the needs and challenges of care [26,27]. However, parents also need to be taught about the basic cognitive experiences of children that affect their behavior. Through this

understanding, it is expected to have a positive influence on parents in viewing behaviors that are often difficult to overcome. Parents will also learn to understand the function or meaning behind their child's behavior [28]. Therefore, in parental psychoeducation, the cognitive analysis of behavior should not be optional but becomes a mandatory material that needs to be educated.

Parents' initial perception of their child, which precedes the diagnosis, contributes to the condition of stress in parents beyond the severity of symptoms [8]. In this study, there were differences in the CARS values between the control and treatment groups. The proposed intervention model from various recent studies for parents who have children with autism spectrum disorders is a psychoeducational intervention model that focuses on emotional evaluation and understanding and its impact on parents' social intelligence. This approach is coupled with programs to stabilize the emotional condition of parents. The duration of the psychoeducation session for 6 sessions also becomes an evaluation of its role in overcoming various dynamics of stress in parents. A personal approach to each parent in the process of psychoeducation can be a special program to deal with stress [29] which will affect the parenting process to cope with symptoms in children.

Another important psychoeducation material that is often a source of concern from assessing the degree of stress of parents is about the child's future and acceptance of the social environment in the future. Determination of coping strategies used by parents in overcoming problems encountered in achieving a good quality of life for children is another very important factor. Coping strategies chosen by parents often fluctuate, which shows a dynamic process over time in accepting the child's condition with a diagnosis of autism spectrum disorders. Although there has not been a single successful strategy in the stress dynamic process of parents with children with autism spectrum disorders, psychoeducation can be one of the preferred strategies to overcome this problem. Psychoeducation for parents needs to explain this aspect including participation programs such as IFSP (Individualized Family Service Planning), IEP (Individualized Educational Planning) processes, family-centered services, including communication with family, responsive listening, and functional support arrangements for family [7,30,31]. Benchmarks for the success of psychoeducation as a strategy of choice are ongoing assessments in each session regarding parental interest to participate, priorities of parental involvement in children's intervention, availability of time and energy to participate, willingness to provide long-term commitment, and the participation and support of other family members and other close friends, including the communication process in the family and parenting models [30].

Parental psychoeducation that provides an understanding of the social aspects and future planning of children will improve family belief systems that affect the adaptation and resilience of individuals [28].

5. Conclusions

Family is the most important environment for children. Interaction of children with autism spectrum disorders and parents greatly affect each other, both the condition of parental stress and the development of symptoms of childhood disorders. Providing psychoeducation for 6 sessions in 7 weeks is expected to maximize all interventions in children with autism spectrum disorders. There are significant differences in terms of CARS and APSI values between the control and treatment groups before and after parents' psychoeducation. The next areas of studies suggested by this study are dynamic coping strategies used by parents, parents' social intelligence, and dynamic behavior of children with an autism spectrum disorder.

Ethical Approval

We have conducted an ethical approval base on Declaration of Helsinki at Ethical Committee in Dr. Soetomo General Academic Hospital, Surabaya, Indonesia.

Ethics statement

All procedures performed in studies involving human participants were by the ethical standards of the Health Research Ethics Committee.

Funding

None.

Authors' contributions

All authors contributed toward data analysis, drafting, and revising the paper, gave final approval of the version to be published, and agree to be accountable for all aspects of the work.

Consent

We have requested the patient's consent to publish this case report for educational purposes.

Registration of Research Studies

Name of the registry: Health Research Ethics Committee in the Dr. Soetomo General Academic Hospital, Surabaya, Indonesia

Unique Identifying number or registration ID: 0899/KEPK/I/2019.

Hyperlink to your specific registration (must be publicly accessible and will be checked): -

Guarantor

Royke Tony Kalalo.

Data availability

The dataset used and/or analyzed during the current study is available from the corresponding author on reasonable request.

Declaration of competing interest

The authors declare that they have no conflict of interest.

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