Measurement Instruments for the Stimulation of Children with Autism Spectrum Disorder based on Family Care

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Abstract

Families as a primary place of growth of children with Autism Spectrum Disorder (ASD) are expected to stimulate the development and ability of children with ASD. However, the ability of families in Indonesia to offer stimulation cannot be measured regularly and continuously because there are no standard measurements. This research aims to develop the ability of family-based instruments using aself-care system. The method is divided into two stages:discussion with parents of a child with ASD and manager of anautism center; instrument development (questionnaire). Data analysis usesLisrel 5.30. The results illustrate that statements in the questionnaire can be used as a measuring instrument in 81.8% of 66 points with validity values from 0.75-0.98, reliability values from0.666-0.911, and composite reliability of each variable from0.780-0.932. This study concluded that this questionnaire is appropriate for basic reference measuring the development of autistic children based on family care.

Key words:*Autism, family ability, instrument development, self-care*

Background

Families are the primary place for autistic children to communicate and interact. Communication for autistic children means informing of the developmental capabilities that have been achieved and the individual needs for the tasks of growth and development. Interacting with an autistic child means connecting with parents and family members continuously every day[1].

Child development tasks are grouped into four categories, namely rude motoric, fine motoric, language, and socialization. Autistic children have growth and developmental tasks according to their age[2]. The rudimentary motoric skills can be identified from the lack of motion. The language skills are known from the use of phrases and expressions to the people around them. Fine motoric and socializationskills should be learned in order to be able to perform and work according to the development stage.

The role of families who have autistic children is to recognizeproblems that occur in autistic children, make decisions to take appropriate action, care for the child at home, modify the environment for the development of autistic children, and utilizehealthcare facilities according to the needs of children with autism. Improvement and empowerment of the family role should be supported by others and help can be provided by professionals or the autism center[3].

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Efforts to improve the socializationand fine motor skills of autistic children can be stimulated through the family's role at home and community support as informal education and the autism center'srole as an exclusive education for autistic children. Integrated and programmatic stimulation can improve the development of rude motoric, fine motoric, language, and socializationskills, as an indicator that autistic children can adapt to the environment. The Autism Centre of Blitar city has a parenting education programmed, the purpose of which is to provide information about autistic children's development ability and to teach families to take action with the help of child skills consultation books.

The Self-Care Deficit Nursing Theory, also known as the Orem Model of Nursing, developed by Dorothea Orem[4], is the practice of individual activities to sustain life, health, and wellbeing. Individual activity practices are grouped into minimum, partial, and total aid. The purpose of applying the Orem nursing theory to families who have autistic children is so that families can stimulate the development of rude motoric, fine motoric, language, and socializationskills. The stimulation of development by the family can be grouped into minimum, partial, and total aid.

Stimulation of development by families of children with Autism Spectrum Disorder (ASD) who received services in the Autism Centreof Blitar city is based on studies but an instrument for measuring the ability of the family to offerthe stimulation does not exist. Instruments should be able to measure the family's ability and the development of autistic children. Based on the description above, it requires the development of family ability instruments to stimulate the development of children with ASD based on self-care theory.

Objectives

This research aims to develop the ability of family-based instruments using aself-care system.

Material and Methods

The research design was descriptively aimed at the instrument's development and consisted of two stages. The first stage was the identification of the family's ability to stimulate and the autistic children's development based on the perception of the caregiver at the Autism Centre, professionals (psychologist, occupational therapist, speech therapist, and the teacher), and the parents of children with ASD at the Autism Centre of Blitar city. The second stage was to arrange and test the instruments to be used to measure the family's ability to stimulate the development of children with ASD based on self-care. The second stage involved a population of40families who have children with ASD and have received services in the Autism Centre of Blitar city. The first stage sample selection method was purposive sampling and the second stage sample selection method was the total population, with the criterion of not being outside Blitar from July - September 2017. The first stage sample was made up of three managers of the Autism Centre of Blitar city, four professionals, and three parents of children with ASD, and the second stage sample was made up of40 families. The intervention was done three times each week (August 2017) at the Autism Centre of Blitar city using Fostering Autistic Children Activities at Home (Parent's Guide) (*Bina Aktivitas Anak Autis di Rumah: Panduan BagiOrang Tua)*.

The research variables were (1) Autism Centresupport involves a parenting education program for parents of children with ASD observed using a consultation book and verified by interview; (2) social support is a form of family activity, including (a) emotional support

which is empathy given by family members in the home and which includes giving comfort, caring, and confidence to children with ASD, (b) informational support which is a family's effort to provide information, seek knowledge, advice, and provide feedback on the situation and condition for children with ASD while at home, and (c) instrumental support which is a family's effort to provide financing, developmental stimulation tools, and food according to the condition of children with ASD while at home; (3) the family's ability to stimulate development is the act of stimulating after training; and (4) the development of children with ASD lies in the ability to show fine motoric and socializationskills, and communication.

The research framework to develop a family ability assessment tool to stimulate the development of autistic children based on self-care is as below (Figure 1).

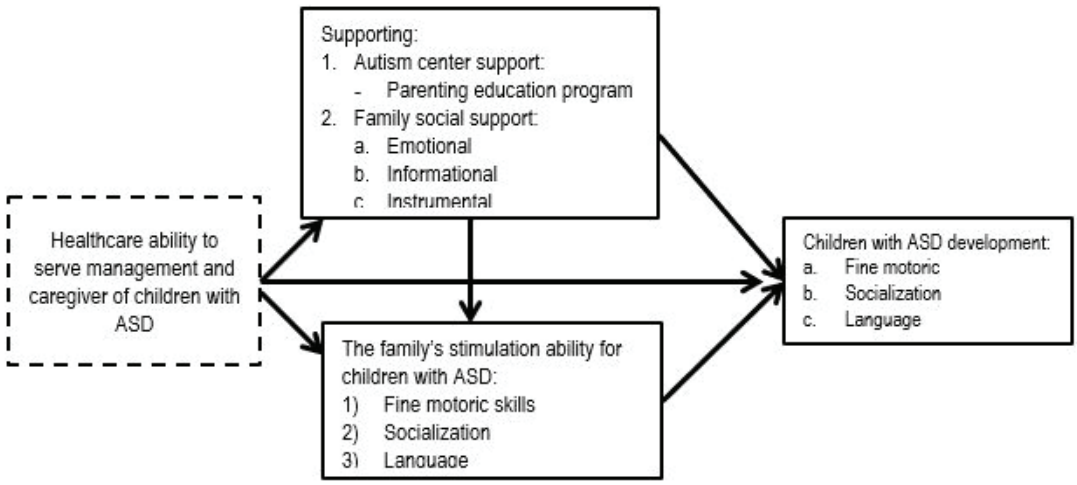

Figure 1. A framework of the instrument's development to support family ability and the development of children with ASD based on self-care nursing theory.

The data collection tool was a questionnaire prepared based on the results of group discussions and of the book *Fostering Autistic Children Activities at Home*. The data collection period was July – September 2017, at the Autism Centre of Blitar city, by the research team. The collected data for the first stage method was a focus group discussion and the second stage involvedthe family filling out a questionnaire. Data analysis used confirmatory factor analysis and structural equations to assess reliability, validity, and construct reliability.

The analysis used Lisrel (Linear Structural Relation) software. Confirmatory factor analysis was stopped if the t-test value in the validity and reliability test was higher than 1.96 (at alpha 0.05) to obtain the highest GFI.

Findings

The results of focus group discussions for this study can be seen in Table 1.

Table 1.The focus group discussion results

No.	Focus group discussion materials	The focus group discussions results agreed
1	a. Materials used to measure the family's stimulation ability and the autistic children's ability. b. Method of measuring the family's stimulation ability and the autistic children's ability. c. Editing of data collection tools based on focus group discussion results. d. Data collection executor using questionnaires to measure the family's stimulation ability and the autistic children's ability.	Fostering Autistic Children Activities at Home Parent's Guidebook Scale in the range 1 - 4 Formulated by the researcher. Researchers, research teams, and assisted professionals in the Autism Center of Blitar city.
2	a. Statement of support by the Autism Center of Blitar city b. Statement of family support c. Statement of the family ability to stimulate the developmentof autistic children d. Statement of autistic children's development	6 statements (1 - 4 scale that is Never, Ever, Frequently, and Very Frequently). Every family support (emotional, informational, and instrumental) each with 6 statements (1 - 4 scale that is Never, Ever, Frequently, and Very Frequently). Family ability to stimulate each development (fine motoric, socialization, and language) each with 8 statements (scale 1 - 4 that is Cannot, Need Help, Can, and Proficient). Each development of autistic children's skills (fine motoric, socialization, and language) each with 6 statements (1 - 3 scale that is Not Able, Need Help, and Able).
3	Data collection time	According to the visiting schedule of children and families (parents) in the Autism Center of Blitar city.
4	Development of the statement	Based on the basic questions that have been prepared.

Table 2. Characteristics of parents (mothers and fathers) and autisticchildren receiving services at the Autism Centre of Blitar city (n = 40)

No.	Characteristics	Minimum	Maximum	Average	SD
1	Father's age (years)	23	63	40.6	7.9
2	Mother's age (years)	20	51	35.9	6.8
3	Parent's income (IDR)	Not filled	6,500,000	--	--
4	Autistic children's age (years)	2	15	6.8	5.4
5	Birth order	1	3	--	--
6	Duration of autism (years)	1	7	3.7	2.7

The validity value of variables or sub-variables is less than 0.90, in line with the family income of up to 6,500,000 IDR (Table 2), even the family did not fill in the questionnaire, and supported by the parents were working in the non-formal sector (Table 3).Table 3 illustrates that the highest level of family education (around 60 - 70%) was senior school.

Table 3. Parents' characteristics (education and occupation) forautistic children receiving services at the Autism Centre of Blitar city (n=40)

No.	Characteristics	Fathers		Mothers	
		f	%	f	%
1	Education:				
	- Primary school	3	7.50	4	10.00
	- Junior high school	1	2.50	5	12.50
	- Senior high school	21	52.50	20	50.00
	- Diploma	2	5.00	2	5.00
	- Bachelor / Postgraduate	13	32.50	9	22.50
2	Occupation:				
	- Does not work	3	7.50	26	65.00
	- Laborer	4	10.00	--	--
	- Farmer	3	7.50	2	5.00
	- Private	11	27.50	5	12.50
	- Entrepreneur	8	20.00	2	5.00
	- Honorary	2	5.00	--	--
	- Professional	--	--	3	7.50
	- Government	8	20.00	2	5.00
	- Pension	1	2.50	--	--

Theconfirmatory factoranalysisresultsforvariables and sub-variables are listed in Table 4. Further analysis results from composite reliability between statements and sub-variables' influence onvariables are given in Table 4 and Table 5.This research has 10 parameters (Table 4) so it needs a minimum of 50 samples, but the maximum service capacity of the Autism Centre of Blitar city is 40 children with ASD.

Table 4. The validity and composite reliability between statements

No.	Total of valid statement	Variable / Sub-variable	Validity	Composite reliability	Alpha Cronbach
1	4 statements	AutismCentre of Blitar city support	0.98	0.827	0.740
2	5 statements	The family emotional support	0.92	0.780	0.650
3	6 statements	The family informational support	0.96	0.880	0.834

Cont... **Table 4. The validity and composite reliability between statements**

4	6 statements	The family instrumental support	0.88	0.932	0.911
5	4 statements	The parent stimulation of fine motoric ability for children with ASD	0.96	0.788	0.666
6	4 statements	The parent stimulation of socialization ability for children with ASD	0.94	0.806	0.681
7	8 statements	The parent stimulation of language ability for children with ASD	0.75	0.913	0.887
8	5 statements	The fine motoric ability of children with ASD	0.96	0.814	0.720
9	6 statements	The socialization ability of children with ASD	0.86	0.846	0.778
10	6 statements	The language ability of children with ASD	0.85	0.867	0.814

Table 5. The coefficient valuesfor sub-variables to variables and between variables

No.	Name of sub-variable and variable	Coefficient value
1	AutismCentre of Blitar city support → The family social support	0.327
2	AutismCentre of Blitar city support → The parents' stimulation ability	0.323
3	AutismCentre of Blitar city support → The children with ASD's ability	- 0.174
4	The family's social support → The parents' stimulation ability	- 0.058
5	The family's social support → The children with ASD's ability	0.169
6	The parents' stimulation ability → The children with ASD ability	0.792
7	The family's emotional support → The family social support	0.744
8	The family's informational support → The family social support	0.917
9	The family's instrumental support → The family social support	0.872
10	The fine motoric ability of children with ASD → The children with ASD's ability	0.794
11	The socialization ability of children with ASD → The children with ASD's ability	0.863
12	The language ability of children with ASD → The children with ASD's ability	0.827
13	The fine motoric ability stimulation → The parents' stimulation ability	0.817
14	The socialization ability stimulation → The parents' stimulation ability	0.781
15	The language ability stimulation → The parents' stimulation ability	0.849
16	AutismCentre of Blitar city support → The children with ASD's ability (indirect influence)	0.296

Discussion

Confirmatory factor analysis (CFA) is a powerful statistical technique for the development of measurement instruments. CFA is based on developing an instrument that begins withcomposing a written question, determiningthe scale, trialingthe instrument, collecting the data, and finally performinganalysis using CFA. CFA identifies the structure of the instrument or what the researcher thinks. CFA allows researchers to test the hypothesizedrelationship between observed indicators and construct latent variables. The researcher uses theoretical knowledge, postulates the a priori relationship pattern, and then tests the hypothesis between the indicator and the latent variable statistically[5,6].

The use of CFAs may be affected by (1) the research hypothesis being tested, (2) sufficient sample size requirements (e.g., 5-20 cases per approximate parameter), (3) measurement instruments developed, (4) multivariate normality, (5) identification of parameters, (6) outliers, (6) missing data, and (7) model fit interpretation according to the model. The approaches taken in CFA are (1) reviewing relevant theory and literature for the instrument development,(2) determining indicators and latent variables for testing, (3) determining parameters, (4) conducting preliminary descriptive statistical analysis, (5) estimating parameters in the model, and (6) assessing the fitness of the model[6,7].

Assessment of CFA conformity used GFI. GFI statistics were created by Jöreskog and Sorbom as an alternative to the Chi-Square test and calculate the proportion of variance recorded by population covariant estimates. The variance and covariance recorded by the model show how closely the model replicates the observed covariance matrix. The CFA model from Lisrel notes that the model focuses only on the relationship between observed variables and their underlying factors. The CFA model is only related to the way observed measurements are mapped to a particular factor, and not causal relationships between factors;this model is called the measurement model[7]. CFA was stopped if, after re-analysis, reducing the indicator/question indicator resulted in a t-test value foreach validity and reliability value of more than 1.96, but if conformity of the GFI decreased, then the value before the retest was done wasused. GFI is based on the ratio of the number of quadratic differences to the observed variance (for the smallest common squares). The GFI ranges between 0 and 1, with values greater than 0.9 indicating a good match withthe data. GFI is analogous to multiple quadratic correlations because it shows the observed covariance proportions described by the covariance model[8].

Composite Reliability (CR) is also referred to as the McDonald's coefficient, obtained by combining all actual variance scores and covariance in a combination of indicator variables related to construction;then, this number is divided by the total variant on the composite. Composite reliability refers to the accuracy with a scale or instrument that assesses a dimension. Reliability is defined as the proportion of variance in observed test scores associated with actual scores. Reliability is shown by double-scale management. Measurements taken twice cannot expect to get the same score but the closer the firstscore corresponds to the second score, the higher the reliability. Thus, reliability refers to the reproducibility of scores from measuring devices. Based on the classical test theory of three sources of variance: (a) the variance of the true score, (b) the variance of error (or measurement error), and (c) the total scale variance (which is the actual

number of scores and the variance error) this can be used as a result forreliability[9].

The sample size in this research is 40 samples and is categorizedas a saturated sample because the observation involved all members of the population, namelyfamiliesand children with ASD who received services at the Autism Centreof Blitar city. The sample size to estimate the parameters is between 5: 1 and 10: 1. The number of samples can be easily calculated using the formula $Sample\ size = \frac{v\ (v+1)}{2}$ where v is the many variables observed[10].

The validity values forthe variables or sub-variables measured in this research are low (less than 0.90): family instrumental support at0.88; family ability to stimulate the language at0.75;socializationability of the children with ASD at0.86, and the language ability of children with ASD at0.85. However, the value of the validity forPLA support, family emotional support, the family's informational support, the family's ability to do fine motor stimulation, the family's ability to stimulate socialization, and the fine motor abilities of children with ASD have a value greater than 0.90. This factor enables the family to not meet the children's instrumental needs for supporting the development of the children with ASD. Hurlockwrites that the development of children is a factor that should receive attention and the improvement of the child's ability needs to be stimulated by the use of tools[11]. Another factor that causes a low validity value (less than 0.90) is education. According to the experts, the higher the education the more easilybehavioral change occurs[12]. This opinion assumes that one's education facilitates the logic process to digest information provided by the Autism Centreof Blitar city into knowledge, attitude, and actions that need to be taken.

The highest validity value is for the Autism Centresupport variable. The value is very reasonable because the Autism Centre of Blitar city, as a service provider forautistic children, has sufficient resources supported by the Government of Blitar City and the Ministry of Education and Culture of the Republic of Indonesia (RI). The form of Blitar City Government support is the provision of a building and routine operational financing. The form of support from the Ministry of Education and Culture of RI is the provision of means forthe development of stimulation equipment forchildren with ASD and professional instructors to train regularly three times a year. Human resources owned by the Autism Centreof Blitar city are professionals in the field of educators, speech therapists, occupational therapists, water therapists, behavioural therapists, and psychologists. These professionals have academic skills and are equipped with training related to educating children with ASD. Also, the Autism Centreof Blitar city has a standard built into the service, so it is not influenced by the input of parents and children with ASD. The early stage of the service forchildren with ASD always assesses the ability of the children. Periodically, every three months, a parenting education programmed about the behaviour of parents or family is offered for children with ASD[13,14].

Family social support includes emotional, informational, and instrumental support[3,15] but these cannot work alone because the three things are interrelated to meet the development of children with ASD. Avalidity value forthe family's emotional and informational support over 0.90 illustrates that the family givesgood emotional support to children with ASD in the family and seeks to find appropriate information to meet the needs of the children. Suprajitno[16]writes that the

family has five tasks in health care, namely to recognizethe changes in the child's health, decide to choose appropriate efforts, care for the child while at home, modify the safety of the home environment for the child, and use appropriate health care facilities for the child. Emotional and informational support forchildren with ASD is consistent with family tasks because families must meet the needs of children, not just growth needs, but also developmental. Another reason is that children are part of the family and, according to Mugianti[17], caring for family members who have health problems includes sincerity, love, and finding the appropriate healthcare facilities.

The validity values forthe parents' ability to stimulate fine motor and socializationskills for children with ASD and motor skills of children with autism have values of more than 0.90. This factor illustrates that the family can provide and stimulate the child at home. Orem's nursing care is best used to make families nursing care agents[4] for children with ASD because the children's needs, including development, are unlikely to be met by healthcare facilities at any time in the long term. The principle of nursing care is to establish a family (as a target) so as not to depend on nurses or professionals for the development of children with ASD. The theory reveals that the fulfillment of the most favorable developmental stimulation is done by the family at home [3], and family is the first and the main place inthe child's life[18,19]. Families have more time to meet with children and meet the needs of children with ASD. Independent stimulation must be done by parents because the family playsan important role in the child's life.

According to Cohen et al.[20] measuring and assessing social support is unique because there is a unique relationship between giving and receiving support (for parents and children with ASD). Support received from the Autism Centreof Blitar City serves to help parents cope with the needs of children with ASD. The form of support from the Autism Centreof Blitar city is a monthly parenting education programmed and consultation about how the development of children with ASD can be identified by parents.

Conclusion

Indicators of variables found are: (1) the Autism Centreof Blitar City support includes parent education programmed, information on children's educational activities in the coming week, children's most recent abilities, and child development; (2) family social support relates to child protection, information forother families, encouragement, educational programmed, information on how to stimulatea child, a comfortable environment, sourcebooks, stimulation tools, information on use of tools, storage of tools, and repair of tools; (3) the family's ability tostimulate a childin terms of upper and lower limbs, facial movement, sharing toys with other children, reading, arithmetic, writing, singing, imitating, and concentration; and (4) the development of children with ASD goes hand in hand with that of other children such as in relation to following orders, helping other children, namingfriends and usingsentences.

Overall, the statements in questionnaires that were valid and reliable and can be used as a measuring instrument totaled 54 (81.8%) from 66 statements with a validity value rangingfrom 0.75 to 0.98, a reliability value rangingfrom 0.666 to 0.911, and composite reliability of each variable ranging from 0.780 to 0.932.The indirect effect of PLA support on the abilitiesof autistic children is 0.296 and the direct influence of each variable on other variables is from-0.058 to 0.917.

Suggestion

Questionnaires can be used to measure the ability of parents to stimulate the development of children with autism as a basis for efforts to improve the ability of the family to support their child.

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