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ORIGINAL RESEARCH

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MAIN CAREGIVER'S EXPERIENCE IN MEETING SELF-CARE NEEDS AMONG ADOLESCENTS WITH ASD IN PONTIANAK MUNICIPALITY, WEST BORNEO, INDONESIA: A QUALITATIVE STUDY

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ABSTRACT

Background: Autism spectrum disorder (ASD) is a complex developmental disorder, increasing in number, faster than that of other developmental disorders in the world. This complex disorder affects a child's self-autonomy, which is important for individual self-care.

Objective : This study is to explore main caregivers' experience to meet self-care needs among adolescents with ASD in Pontianak, West Borneo, Indonesia.

Methods: Qualitative semi-structured in-depth interviews were done with 7 main caregivers that have lived together and taken care of the adolescents with ASD in Pontianak Municipality, West Borneo Province. Sampling was taken with purposive sampling (maximum variation). Source (interviews) and method (observations of self-care activities and documents like photos, learning reports and field notes) triangulations were taken on 1 participant and 7 autistic adolescents. Participants' statements were recorded by using a voice recorder, and then transcribed, coded, interpreted, and categorized in order that sub-topics and main topics could be formed.

Results: The study identified five main topics: i.e., 1) Autonomy in self-care; 2) Care effort; 3) Feelings, support, and expectations. Three findings of the study emphasize the potentials of children with autism to be autonomous in daily self-care.

Conclusions: Adolescents with ASD can potentially meet the needs of their daily care independently.

Key words: Caregiver experience, main caregiver, adolescent, ASD, self-care, basic needs

INTRODUCTION

The increasing number of children with ASD is the fastest in the world compared to other developmental disorders. Three to six children are diagnosed with ASD everyday per 1000 neonates.¹ In Indonesia, the number of children with autism can not be known exactly, but the Center for Health Statistics (*Badan Pusat Statistik*) in 2010 predicted that the increase of children with autism is 1.14% of the total population of 237.5 million people or the total reached 2.4 million people with an increase of 500 children with autism each year.² This condition encouraged the central government through the Ministry of Education and Culture of the Republic of Indonesia to develop the program of building 24 autism centers in several provinces, including in Pontianak Municipality, West Borneo Province.³ In 2014, 81 children were diagnosed to suffer ASD in Pontianak Municipality. In 2015, the number with ASD in Pontianak Municipality reached 130 people, including 61 children (<10 years old), 66 adolescents (10-19 years old), and three adults (> 19 years old). The data were based on reports from four schools of children with special needs and one of the autism centers in Pontianak Municipality, West Borneo Province.

It is believed that genetic factors causing cerebral structure disorder is one of the main underlying causes of autism among children. Consequently, children tend to suffer cognitive, affective and psychomotor disorders throughout their life. The disorder causes children with autism to be unable to meet the needs for self care autonomously. So that their parents will face challenges, the increase of stress, tension, unpreparedness, and most times will feel lost to meet the self care needs for their children whose load

increases with the increasing age and demands approaching adolescence. This delimitation exists because a child with ASD will continue to develop their sexual organs and have puberty like normal adolescents.⁴⁻¹⁰ In contrast to the above qualitative research results revealed that ASD children can not be independent from the results of quantitative research conducted by Smith *et al.* in 2012 (quantitative research) revealed interesting results concerning the capacity of children with ASD in meeting self care needs autonomously. The results showed that children with ASD can have the ability to meet self care autonomously if they were taught self care since childhood through the early period of adolescence. This quantitative study has limitations in exploring environmental factors and how parents teaches the child self-care fulfillment skills with ASD.¹¹ Based on these facts, this research aims to study about main caregiver's experiences to meet self care needs among adolescents with ASD in Pontianak Municipality, West Borneo, Indonesia.

METHODS

Study Design

The study was conducted using a qualitative method with the aim to explore main caregiver's experiences in meeting self-care needs among adolescents with autism. Several demographic data including status of relationship between caregiver and children were also collected for purposive sampling with maximum variation.

Population and Sample

The population in the study is the main caregivers that met self-care needs for adolescents with autism in Pontianak Municipality, West Borneo Province. The

researcher collected data on the number of children with autism in three schools that have accepted students with ASD diagnosis, one clinic that supports the growth and development of children with autism, and one autism center in Pontianak Municipality in order to locate sufficient and suitable samples in accordance with the criteria of the study. The study used two specific places for sampling, i.e. informal special needs schools in Pontianak.

Participants recruited in the study met the following inclusion criteria: main caregivers that have lived together and taken care of adolescents with autism aged 10-19 years old. All the adolescents were diagnosed with autism by a qualified physician or psychologist in accordance with the Diagnostic and Statistical Manual of Mental Disorders-4th Edition (DSM-4), certified with a proof of official diagnosis explanation letter, agreed with approval sheet (informed consent form), and able to tell the story about their own experiences with the Indonesian language or Pontianak Malaya language clearly. Exclusion criteria were: the main caregiver who took care of adolescents with autism aged 10-19 years old, accompanied by double handicap, and with severe conditions such as infection, surgery, and trauma.

The study was conducted for two months (March to April 2016). The total number of caregivers that met the inclusion criteria was seven people. The majority of main caregivers worked as civil servants, two caregivers were hired, and one is a housewife. Participants consisted of 2 biological mothers, 1 biological father, 1 aunt, 2 caregivers, and 1 couple (a father and foster mother).

Data Collection

The study was approved by the Medical and Health Research Ethics Committee

(MHREC) Faculty of Medicine Universitas Gadjah Mada, registration number KE/FK/94/EC/2016. Data in the study were collected by interviews to explore the main caregiver's experience in meeting self-care needs among adolescents with autism spectrum disorder in Pontianak. The topics interviewed were: main caregiver's knowledge on self treatment in adolescents with autism, main caregiver's skills in meeting self-care needs in adolescents with autism, and main caregiver's concerns in meeting self-care needs in adolescents with autism.

Interviews were done in comfortable, quiet, and safe places selected for participants' privacy. The selection of place for interviews was based on agreement between researcher and participants, i.e. in public place (cafe), personal house, workplace, mosque, and special meeting room around school area. Interviews were done by using both the local Malay language and the Indonesian language.

In-depth interviews using semi-structured questions were done with seven participants, and expanded on with field notes. Participants' statements were recorded using a recording device in Samsung Galaxy Tab 4. The results of the in-depth interviews were transcribed, coded, interpreted, and categorized, thus forming main topics and subtopics. The data collected were then analyzed using a descriptive qualitative technique.

Data analysis

Data were analyzed by content analysis model using Colaizzi's method of data analysis with the following steps: 1) Transcribing the interview result in narrative form, 2) Filtering/coding of words associated with phenomenon, 3) Formulating or interpreting meaning from the significant statements, 4) Classifying

the interpretive results of any statements that are significant for determining the appropriate sub themes/themes, 5) The findings of the study were integrated into an exhausted description of the phenomenon in this study, 6) The fundamental structure of the phenomenon was described, and 7) Validation of the findings was sought from the research participants to compare the researcher's descriptive results.^{12,13}

Trustworthiness

Triangulation method was performed by collecting data using several methods data collection (interviews and observations) on the same phenomenon, with the aim to evaluate whether the phenomenon the participants described as having a relationship and correspondence with. Member checking (returning to the participants following data analysis) or peer checking (using a panel of experts or an experienced colleague to reanalyze some of the data) were also conducted as ways of ensuring that the researcher has analyzed the data correctly.^{14,15} In this study, the issues of trustworthiness were addressed through internal member checking during the interview by the principle investigator and through the verification of participants by face-to-face

discussion. Peer-review was done by an independent person or an experienced researcher (research supervisors) to compare and contrast on the data quality and interpretations, and notes that documented all methodological issues and decisions. Bracketing was ensured by discussing among researchers about personal biases, and experiences with the research topic.

Ethics approval and consent to participate

The study conforms to the principles outlined in the Declaration of Helsinki 2008 and was approved by Medical and Health Research Ethics Committee (MHREC) Faculty of Medicine Universitas Gadjah Mada (registration number KE/FK/94/EC/2016). Written informed consent was obtained from all participants prior to any data collection.

RESULTS

The results of the study showed three main topics: 1) Autonomy in self-care; 2) Care efforts; 3) Feelings, support and expectations. Those themes are illustrated below with exemplars from the informants' stories using pseudonyms for the informants.

Table 1: Results Listing Main Topics and Sub-themes from Data Triangulation

Themes	Sub Themes	Explanations
Autonomy in self-care	The main caregivers' knowledge about the kind of self-care	<ul style="list-style-type: none"> • Elimination: defecation and urination. • Personal hygiene. • Eating and drinking. • Wearing clothes.
	Fulfillment of self-care	<ul style="list-style-type: none"> • Partial Compensatory. • Supportive educative. • Independence.
	The ways to teach self-care	<ul style="list-style-type: none"> • Seeing the child's ability and initiative. • Give an example. • Gradual, diligent and patient. • Provide busyness and responsibility. • Be firm.

Themes	Sub Themes	Explanations
		<ul style="list-style-type: none"> Shows attitude when not happy, provide explanations, and give punishment. Give rewards for success to child.
	The length of time to teach self-care	<ul style="list-style-type: none"> Elimination : urination = 2 years. Elimination : defecation = majority children are not independent for that until adolescence. 1 participant revealed it takes for 2 years and 2 months after replacing the old squat toilet closet. Personal hygiene = 4 years. Eating and drinking = 3 months – 1 years. Wearing clothes = 1-2 years.
	Factors that influence independence in self-care	<ul style="list-style-type: none"> Handling of late professional decision due to a lack knowledge. Emotional closeness. Concerns parents. The parents' perception of cognitive, motor, and sensory ability and sensitivity of child. The child's emotional state fluctuates.
Care efforts	Increase knowledge about autism.	<ul style="list-style-type: none"> Utilize the print media. Following training. Observing and understanding attitudes and behavior of children with autism, during stay over and living together. Take advantage of technology (use wifi, TV). Following the seminar. Brainstrom with friends that have the same experience.
	Utilize health services.	<ul style="list-style-type: none"> Consultation and treatment with the doctor Consultation with a psychologist. Alternative therapies.
	Implement diet.	<ul style="list-style-type: none"> Dietary resources: doctor, psychologist, seminar. The content of information on dietary submitted on diet food such as milk, chocolate, instant noodles, food from wheat flour and flavorings.
	Meet the needs of education.	<ul style="list-style-type: none"> Formal. Informal.
	Meet the needs of self-care and autonomy.	<ul style="list-style-type: none"> Elimination : defecation and urination. Personal hygiene. Eating and drinking. Wearing. Cooking. Shopping. Clean the house.
Feelings, support and expectations	Feelings of primary caregivers caring for children with ASD.	Denial, feel love, gratitude, pride, despair and resignation.
	Support and resistance to parenting with ASD.	Sources of support: Yourself, couples life, friends, and family (parents, nephew and cousin).
		Source obstacles: Family (satire about the condition of the child), environment community (verbal abuse, behavior unpleasant, and threatening acts of child abuse).
		Caregivers response to the obstacles: angry, sad, hurt,

Themes	Sub Themes	Explanations
		protective and leave warning.
	Main caregiver's hope to children with ASD.	Independent, continuing education until to college, and get married.
	Main caregiver's hope to health worker.	Providing information through health education and seminars about ASD, held a special program with services for health checks periodic health, medicine, nutritional status examination and appropriate diet nutrient supplements for children with ASD.
	Main caregiver's hope to school.	Improving the quality of human resources (Teacher should improve their competent to teach children with ASD), improve facilities and infrastructure (tool practice, a decent school buildings, extra supervision), subjects taught more emphasis on the child's independence and the corresponding interest and talents.
	Main caregiver's hope to government.	Provide financial assistance, set up better programs with special schools for students with autism, held a consistent program.

Autonomy in self-care

Results of the study revealed the potentials of children with autism to become more autonomous in meeting daily self-care needs. This autonomy can be seen from the statement of a participant that the child she cared for could do self-care activities autonomously, and two participants said that they only help by giving instruction to the children:

"...all done by himself...." (P3)

"...I do not want to help him again... I do not want to help, just drive him..." (P5)

The study showed that four participants stated that they still provide some help for children to meet daily self-care activities:

"...I think not .. yet .. he still has many shortcomings.." (P1)

The study also revealed several aspects to give special attention in terms of teaching autonomy for children, such as patience, diligence, and teaching gradually:

"...Yes (gradually) .. all have to use an example. He is newly taught. Slowly all .. very very slowly ..." (P5)

The teaching is given by providing some examples, then asking children to repeat the activities shown:

"...Slowly Taught.. Given the example first.." (P1)

Teaching also includes giving a task to make something, but it should be supervised to avoid inappropriate autistic behavior:

"...responsibilities, we should be alert about him...." (P5)

Caregiver should give some punishments if children did inappropriate behavior:

"...Sometimes I pinch her thigh movement ..." (P2)

The caregiver gives reward such as approbation if children did something good:

"...it is vital that he do good .. if we thumb, nice..." (P4)

To maximize the effort to make children autonomous, the caregiver should realize and avoid some factors that can affect children's autonomy, such as delay in recognizing any developmental disorders and appropriate decision making to examine children:

"...firstly not want to say .. a .. do not say .. then finally .. a year I did not even say wait two years .. not too..." (P3)

The caregiver sometimes gives excessive help due to emotional attachment:

"I was washing, I have to do it, probably because it was too dear.." (P1)

The caregiver sometimes is afraid about something:

"...I'm afraid if I teach this, my will was not at home, he's like cooking for himself..." (P4)

The caregiver often perceived the limitation of cognitive, affective, and psychomotor capacity of children.

"...obstacles sometimes he does not focus .. ha ah .. (P4)

"...because my son was disgusted .. " (P1)

"...motoric him, not well coordinated...(P6)

The children's emotional condition is often fluctuating: *"...moody.." (P1)*

Care efforts

Participants of the study revealed that they did six treatment activities to improve the children's quality of life, i.e. by improving knowledge on autism. The improvement of knowledge was done by participants through utilizing the printed media such as books and newspapers, learning children's behavior by observation, utilizing technology such as the Internet and TV broadcast, opinion exchange, and attending training and seminars:

"...information from the Internet only.." (P2)

" I usually just read from a book..(P4)

"...It was also obtained from newspaper..." (P7)

"...television..." (P4)

The treatment efforts can be done by utilizing health services (consultation as well as medical and alternative treatments):

"we were medical doctors consulting a doctor first time.." (P2)

"...we have to see a psychologist..." (P7)

The treatment effort can also be done by regulating diet:

"...he had to diet, and can not eat sugar, like shiitake, later he was getting hyper..." (P6)

The treatment effort can be done by meeting the needs for formal education (Kindergarten, Elementary School, Junior High School, and Senior High School) and informal education (courses in accordance with children's talent and interest):

"...When second-graders, we moved to this school, school-based specialty..." (P5)

The treatment efforts can be done by realizing the importance of social interaction for children:

"...I also often encourage all community solidarity such as Java community associations, studies show neighbors, I take it everywhere I encourage home .. friends .. the same chat friends .. I encourage him to continue..." (P6)

The treatment efforts can be further done by meeting the needs for autonomy (elimination, clothing, having foods and beverage, and self cleanliness):

"...I help sometimes, I like it (demonstrating how to clean up feces in hand rubbing buttocks)..." (P2)

"...we also take (rice)..." (P5)

Results of this study revealed a duration required by the caregiver to teach autonomy in self-treatment to children. Time required for teaching elimination was about 2 years:

"Nine years of age I was taught from the age of about ten to eleven .. (2 years).." (P3)

Participants argued that the skills that were the most difficult to teach were elimination. Five caregivers stated that children still have been unable to loosen the bowels or urinate in an autonomous manner:

"Defecate is the most difficult to teach him .. yet ..during these 13 years, I still have to wash..." (P1)

Only one participant stated that the child was able to loosen the bowls autonomously. The skill was gained after the caregiver had an initiative to replace the toilet from squatting closet to sitting closet. The sitting closet meant that the child did not see the feces. The caregiver perceived that the child will not learn the skill to loosen the bowl because of 'tingling on mushy thing' or focusing on the feces and not the process. This idea is felt to be useful. The caregiver said that the child was autonomous and only required the time of approximately 2 months to teach it to be autonomous (after the child had previous urinating skill):

"...not too long .. about two months..." (P7)

Three participants' revealed that the time required in learning to be autonomous wearing clothes was between 1-2 years:

"Probably about maybe a year (children can wear their own clothes).." (P3)

"A .. 10 .. ten .. we teach the eight nine ten is good .. he .. is good..." (P5)

The time required by children to learn eating and drinking skills was between 3 months–1 year:

"It was a year.. one year..." (P4)

"..it was about three months..." (P6)

The time required for children with ASD to learn autonomy in self cleanliness was 4 years:

"Yeah .. (ages eight and nine years began to be taught), he was also the first to use bathroom. At age 12 he was able to completely do..." (P5)

In addition, participants also revealed that there were other skills that can be done by children, i.e. cooking skills that require time of 3-6 years to be autonomous:

"nine years .. twelve years already.." (P3)

"a .. age .. ten years it appears he's good at it.." (P4)

The shopping and house cleaning skills are still learned by the child to this date:

"By himself took the trolley... l'm still paying..." (P4)

"...she can help us clean...(P5)

Feelings, support, and expectations

Results of the study revealed emotional attachment between the main caregiver and children. This attachment can be seen in the stages of grieving undergone by the care provider such as denial, hopelessness, sadness, relentlessness, gratefulness, and pride:

"...give up..." (P1)

"...Leave thankful God is like this ..." (P4)

"The pity is also with child..." (P6)

"...sad .. not like the other children..." (P7)

Participants gained some supports from themselves, couple, friends and family in going through the grieving stages:

"I still support my own heart and my wife only..." (P2)

"..friends (teachers) showed Anges attention .. I follow overwhelmed nominally.." (P3)

"...I support my younger brothers .. encouraged me.." (P4)

In addition to support, participants also got difficulty in caring for children with autism. The constraint is from the family, such as insinuation and from the surrounding community such as verbal violence, violent threat, and keeping away from children with ASD:

"Oh no .. if you like to offend the family would not be far away.." (P2)

"...a neighbor told to hit the boy. if it happened to him to deal with me and the police...." (P3)

"...This was the scene I do not bring him another nanny same people say are you crazy ya boy" (P5)

The caregivers expressed their expectation to the children with autism,

health personnel, school, and government. The highest expectation of caregiver to the children is that they were able to be autonomous in self-treatment activity, attending higher education, working, and then marrying:

"I wish that young independent, self she could take care of himself..." (P1)

"...for example he can work alone, looking for money or anything..." (P3)

"A I believe my son my son could.. God willing, I will, I'll lecture him this.." (P4)

"...so she can get married to a husband who can guide..." (P7)

The caregivers expected that health personnel hold specific health service programs (such as treatment, examination of nutrient status, and diet in accordance with the needs of children with ASD), providing the newest information about autism, through seminars and extension:

"there should be counseling, for example, why an increasing number of children with autism. why, while I was pregnant and nutritional attention...." (P4)

"...not indiscriminate diet. nutritional intake each child is different...." (P7)

The caregivers expected that school can improve human resources' quality, facilities, and try providing more subjects on children's autonomy:

"Teachers here the teachers..teachers here do not understand children with autism." (P2)

"Can there be a means and infrastructure tools props like that ... so can help teachers to teach children with ASD..." (P6)

"There should be monitoring of CCTV which also came from students already there. can not .. (unsupervised). Sometimes there are students who try to run out..." (P7)

"...we expect him to be independent. it is important that academic, independence but we need more...(P7)

The caregivers expected that the government could give funds and consistent programs for children with ASD:

"Seriously deal with this .. founded, teacher should also understand and are competent toward autism..." (P2)

"...I ask the government to pay attention to children's special needs children who have free school like other public elementary school .." (P4)

DISCUSSION

This section discusses the three main topics found in this study, i.e.: (1) Autonomy in self care, (2) Care efforts, and (3) Feelings, support and expectations. Results of the study revealed that children with ASD have potentials to be autonomous in meeting the daily needs for self-care. The results of the study were in line with those of a study by Smith et al. in 2012 that revealed that autism children can have the ability of meeting the needs for self-care autonomously if they were taught the ways to do self-care activities under 20 years old.¹¹

Autonomy in self care

The factors found to affect the autonomy of children with autism in the study were as follows: 1) The delay of main caregiver in recognizing developmental disorder and retardation and in making the decision to examine the child caused by lack of knowledge of caregiver, the input given by others, and difficulty to access distant health service; 2) excessive help given by the main caregiver to the child due to emotional attachment such affection, worry to leave the child having difficulty in doing him/herself, always want to protect, and only have one child; 3) the main caregiver's anxiety if the child did dangerous activity that harms him/ herself when the caregiver was not at home, and afraid that the child gets lost away if he/she was left to go alone; 4) The main caregiver's perception about the cognitive capacity of children with ASD, thus affecting the child to learn and do self

care; 5) the main caregiver's perception on the child's sensory sensitivity on mushy things, thus causing him/her to try not seeing, taking hold of, and expelling anything that is mushy in nature, for example, the child has 'tingling feces' when loosing the bowels; 6) caregiver's perception on the child's motor capacity that was not coordinated well; and 7) fluctuating emotional condition of child.

On the other hand, the results of the study were different from those of a study conducted by DePape and Lindsay in 2014 indicating that children with ASD were unable to meet the need for self care autonomously because of some cognitive, affective and psychomotor disorders during their life. This difference was due to differences in inclusion criteria.⁵ The present study was conducted among main caregivers living together with children with ASD (no parent or others with familial relationship with children), while the DePape and Lindsay study was conducted with parents of children with ASD (both father and/or mother).⁵ The researcher assumed that the opportunity of children with autism to be more autonomous in doing self care would be higher if they were cared for by others, and not their biological parents or relatives.

Care efforts

Results of the study revealed that the treatment efforts to improve quality of life children with ASD were done through 5 ways, i.e.:

First, improving knowledge about ASD. The caregiver tried to improve knowledge about ASD by utilizing the printed media such as reading books and newspaper that contain information about ASD, learning children's behavior when living together, utilizing technology, exchanging opinions, and attending

training and seminars. The researcher assumed that the lack of the caregiver's interest and effort to improve knowledge about autism was because of the effect of educational background, i.e. Junior High School and Senior High School. The assumption was supported by Hesse et al, 2005 indicating that one of the factors affecting the caregiver's talent and effort to seek health information is education background. The caregiver with a background of high education had higher talent and interest to seek health information.¹⁶

Second, caregivers also did are efforts by utilizing health service such as seeking any consultation about the children's health by visiting a psychologist and physician as well as doing any medical and alternative treatments. Results of the study showed the main caregiver's disaffection about treatment given to children with ASD. The caregiver stated that at the initial treatment the child was very compliant with any forms of suggestions and treatment. However, at the middle part of the treatment, the caregivers often stop the medication by their own initiative. They assessed that the treatment done to children with ASD by giving drugs was not the best way to cure the child. The drugs are assessed to cause worse impact for the child's health, such as the decrease or increase of body weight, weakness of body, and the child often slept. *Raising Children Network* in 2013 stated that the treatments done for children with autism are the ways that can reduce autism behaviors, but not cure the autism itself. Familial education and intensive behavioral direction are the efforts for health that can give better results in terms of overcoming autism behavior compared to drugs administration. If the drugs must be used for the children with ASD, it is important

for the caregiver to discuss with a physician on medical treatment, as well as the benefit and effect for the child.¹⁷

Third, regulating diet. Participants also made the treatment efforts by regulating the diet. The information about diet is obtained by the caregivers from health personnel such as a psychologist, physician, and health seminar. The result of the study showed satisfaction that was felt by participants related to diet given to the children. Foods as diet menu for children with autism that were selected by the caregiver were milk, chocolate, snack as sachet beverage and noodle, foods from wheat flour and flavoring. The selection of diet as the efforts to reduce autism symptoms is one of the appropriate options. This finding was in line with results of the study by Matthews,¹⁸ indicating that diet can help children to have the better quality of sleeping and better cognitive capacity, reduce misery and skin eruption, improving digestion, and children's behavior. Gluten and casein are the most common substance of foods to be avoided for the autistic children's consumption. Matthews in 2013 stated that the objective of diet is to be committed to the selection of the most appropriate food for children by adding or substituting certain foods.¹⁸ *Autism Research Institute* in 2016 showed that both gluten and casein-free diets help in reducing many autism symptoms among 65% children, while for the remaining 35% it did not help. This result confirmed the approach that a decision about diet to be given to children with autism cannot be generalized among all the children. The caregiver should actually consider whether or not the diet intervention is an effective intervention for specific children.¹⁹

Fourth, meeting the needs for education. The main caregivers also tried

to meet children's need for education by giving formal education (Kindergarten, Elementary School, Junior High School, and Senior High School) as well as informal school (nonscholastic courses that were appropriate with children's talent and interest). Realizing the importance of social interaction for children, the caregiver has an initiative to involve children in some social activities such as visiting friend's house, attending neighborhood events and local community meetings or leaving them to play with other children in neighbor with supervision. However, results of the study show that there are caregivers not leaving them to socialize with new social environment outside school and house, although they actually realize the children's needs for social interaction with others in the new environment. The limitation of social interaction to children with ASD had negative effects that can cause retardation in children's development and skills.²⁰

Fifth, meeting the needs for autonomy. This research reveals the need for child self-reliance can be done in three ways that is with the help of part, direction and independence. This study also finds the time span the child needs to learn independence to be completely independent. Elimination of urination: 2 years, elimination of bowel movements: the majority of children are not independent until the age of adolescence, but findings on one participant express the time required for 2 years 2 months, personal hygiene: 4 years, eat drinking: 3 months - 1 year, and dress: 1-2 years.

Feelings, support, and expectations

Results of this study found grieving felt by caregiver, i.e. denial, hopelessness, sadness, relentlessness, gratefulness and pride during treating children with ASD.

Such grieving feelings were caused by the lack of preparedness of the main caregiver for dealing with autistic children's condition and the emotional attachment felt by caregiver when living together with them. The grieving stage felt by the caregiver in this study was in line with the grieving stage as stated by Bowlby, consisting of denial (shock and distrust), sadness and relentless feeling, thinking disorder and hopefulness, and recollection of self-confidence to survive compared to the grieving stage as shown by Kubler-Ross's consisting of denial (shock and distrust), angry, hard bargain, and accepting.²¹ This study did not find the open stage such as anger and hard bargain mentioned separately as in the open stage according to Kubler-Ross. It is assumed that the stage of anger and hard bargain simultaneously occurred with a denial stage felt by the caregiver.

LIMITATION OF THE STUDY

The study had several limitations, i.e. only mentioned the underlying causes and the factors affecting the reduced intensity of autism behavior among adolescents. It is expected that further study can study more deeply the underlying causes and the factors affecting the reduced intensity of autism behavior among adolescents with ASD. Also, it is also important for further studies to explore cultural and legal aspects that affect diet compliance and the patterns of rejection by public schools to not accept any children with autism diagnosis.

It is expected that health personnel can provide more health information holistically about children with ASD in accordance with the authority owned. The provision of sufficient information can be provided such as clear explanation given when there are health consultations, treatment, seminars, extension or health

service programs for children with ASD. It is expected that the provision of information can emphasize the newest aspects of evidence-based research about autism and be in accordance with the actual needs of children with ASD.

This provision of clear information about autism can improve the knowledge of people about ASD itself. It is expected that the local government can give more attention to the development and welfare of children with ASD. The attention can be given by providing aids, both funds and facilities that support the special needs of these special children's education and welfare.

CONCLUSION

The results of the study showed that children with ASD had the potentials to be autonomous in meeting the daily needs for self-treatment activities. Such autonomy can be achieved with a main caregiver's commitment to teach skills to children with ASD. The commitment is shown in treatment efforts in accordance with the children's needs.

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