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ORIGINAL RESEARCH

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## CAREGIVERS' EXPERIENCE IN MEETING SELF-CARE NEEDS OF ADOLESCENTS WITH AUTISM SPECTRUM DISORDER: A QUALITATIVE STUDY

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### ABSTRACT

**Background:** Autism spectrum disorder is a complex developmental disorder, which increased rapidly than other developmental disorders in the world. This complex disorder affects a child's self-autonomy, which has become a challenge for their parents or caregivers.

**Objective:** This study is to explore main caregivers' experience to meet self-care needs of adolescents with autism spectrum disorder in Pontianak, West Borneo, Indonesia.

**Methods:** This study employed a qualitative design with semi-structured in-depth interviews. Seven main caregivers who are living together and taking care of the adolescents with autism spectrum were selected using a purposive sampling. Triangulation was conducted to ensure the trustworthiness of this study, including interviews, observations of self-care activities, documents such as photos, learning reports, and field notes. Participants' statements were recorded using a voice recorder, and then transcribed, coded, interpreted, and categorized to form main themes and sub-themes.

**Results:** The study identified three main themes: 1) autonomy in self-care, 2) care effort, 3) feelings, supports, and expectations. These findings emphasize the potentials of the children with autism to be autonomous in their daily self-care.

**Conclusions:** Adolescents with autism spectrum disorder can potentially meet the needs of their daily care independently.

**Keywords:** caregiver experience, main caregiver, adolescent, autism spectrum disorder, self-care, basic needs

## INTRODUCTION

The increasing number of children with autism spectrum disorder (ASD) is the fastest in the world compared to other developmental disorders. Three to six children are diagnosed with ASD everyday per 1000 neonates.<sup>1</sup> In Indonesia, the number of children with autism cannot be known exactly, but the Center for Health Statistics (or called *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.<sup>2</sup> 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, Indonesia.<sup>3</sup> 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 factor 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, and their parents will face challenges, increase stress, tension, unpreparedness, and most likely

will feel burden to meet the self-care needs for their children.

This dilemma exists because a child with ASD will continue to develop their sexual organs and have puberty like normal adolescents.<sup>4-10</sup> Some stated that children with ASD cannot be independent from the results of quantitative research, but Smith *et al.* in 2012 revealed that the children with ASD have capacity in meeting self-care needs autonomously if they were taught about self-care since their childhood through the early period of adolescence. However, this quantitative study might have limitations in exploring environmental factors and how parents taught and meet the self-care needs of the children with ASD.<sup>11</sup>

Given that reason, our research aims to explore main caregiver's experiences to meet the self-care needs of 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 of adolescents with ASD. 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 ASD in Pontianak Municipality, West Borneo Province, Indonesia. We collected data on the number of children with ASD in three schools that accepted students with ASD diagnosis, one clinic that supported 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.

The inclusion criteria of the sample were main caregivers who are living together and taking care of adolescents with ASD aged 10-19 years old. All the adolescents were diagnosed with ASD by a qualified physician or psychologist in accordance with the Diagnostic and Statistical Manual of Mental Disorders-4<sup>th</sup> 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. The exclusion criteria of the sample were the main caregivers who take care adolescents with ASD aged 10-19 years old with double handicap and severe conditions such as infection, surgery, and trauma.

The study was conducted for two months, from March to April 2016. The total number of the caregivers that met the inclusion criteria was seven. The majority of the main caregivers worked as civil servants, two caregivers were hired, and one was a housewife. The participants consisted of two biological mothers, one biological father, one aunt, two caregivers, and one couple (a father and a 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 this

study were collected by interviews to explore the main caregiver's experience in meeting self-care needs in adolescents with ASD. The topics for interview included main caregiver's knowledge on self-treatment in adolescents with ASD, and main caregiver's skills and concerns in meeting self-care needs in adolescents with ASD.

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

In-depth interviews using semi-structured questions and filed notes were done with seven participants. The 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 to form main topics and subtopics.

#### *Data Analysis*

Data were analyzed using Colaizzi's content analysis model 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) integrating the findings of the study into an exhausted description of the phenomenon, 6) describing the fundamental structure of the phenomenon, and 7) validating the findings by

comparing the transcripts of the research participants and the researcher's descriptive results.<sup>12,13</sup>

### *Trustworthiness*

Triangulation method was performed using several methods of data collections, such as interviews and observations on the same phenomenon with the aim to evaluate whether the phenomenon that the participants described having a relationship or correspondence with. Member checking or peer checking were also conducted as ways of ensuring that the researchers analyzed the data correctly.<sup>14,15</sup> 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 the participants by face-to-face discussion. Peer-review was done by an independent person or an experienced researcher to compare and contrast of the data quality, methodology, and interpretations. Bracketing was

ensured by discussing among researchers about personal biases, and experiences with the research topic.

### *Ethics Consideration*

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 themes: 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** Main Themes and Sub-themes from Data

Themes	Sub Themes	Explanations
Autonomy in self-care	The main caregivers' knowledge about the kind of self-care	<ul style="list-style-type: none"> <li>• Elimination: defecation and urination.</li> <li>• Personal hygiene.</li> <li>• Eating and drinking.</li> <li>• Wearing clothes.</li> </ul>
	Fulfillment of self-care	<ul style="list-style-type: none"> <li>• Partial compensatory.</li> <li>• Supportive educative.</li> <li>• Independence.</li> </ul>
	The ways to teach self-care	<ul style="list-style-type: none"> <li>• Seeing the child's ability and initiative.</li> <li>• Giving an example.</li> <li>• Gradual, diligent and patient.</li> <li>• Providing business and responsibility.</li> <li>• Be firm.</li> <li>• Showing attitude if unhappy, providing explanations, and giving punishment.</li> <li>• Giving rewards for success to child.</li> </ul>
	The length of time to teach self-care	<ul style="list-style-type: none"> <li>• Elimination: urination = 2 years.</li> <li>• Elimination: defecation = majority of the children were not independent for defecation until adolescence. One participant revealed that it took two years and two months after replacing the old squat toilet closet.</li> </ul>

Themes	Sub Themes	Explanations
		<ul style="list-style-type: none"> <li>• Personal hygiene = 4 years.</li> <li>• Eating and drinking = 3 months – 1 years.</li> <li>• Wearing clothes = 1-2 years.</li> </ul>
	Factors that influence independence in self-care	<ul style="list-style-type: none"> <li>• Handling late professional decision due to a lack knowledge.</li> <li>• Emotional closeness.</li> <li>• Concerns parents.</li> <li>• The parents' perception of cognitive, motor, and sensory ability and sensitivity of child.</li> <li>• The child's emotional state fluctuates.</li> </ul>
Care efforts	Increase knowledge about autism	<ul style="list-style-type: none"> <li>• Utilizing the print media.</li> <li>• Following training.</li> <li>• Observing and understanding attitudes and behavior of children with autism, during staying over and living together.</li> <li>• Taking advantage of technology (use Wi-Fi, TV).</li> <li>• Following the seminar.</li> <li>• Brainstorming with friends that have the same experience.</li> </ul>
	Utilize health services	<ul style="list-style-type: none"> <li>• Consultation and treatment with the doctor.</li> <li>• Consultation with a psychologist.</li> <li>• Alternative therapies.</li> </ul>
	Implement diet	<ul style="list-style-type: none"> <li>• Dietary resources: doctor, psychologist, seminar.</li> <li>• The content of information on dietary submitted on diet food such as milk, chocolate, instant noodles, food from wheat flour and flavorings.</li> </ul>
	Meet the needs of education.	<ul style="list-style-type: none"> <li>• Formal.</li> <li>• Informal.</li> </ul>
	Meet the needs of self-care and autonomy	<ul style="list-style-type: none"> <li>• Elimination: defecation and urination.</li> <li>• Personal hygiene.</li> <li>• Eating and drinking.</li> <li>• Wearing.</li> <li>• Cooking.</li> <li>• Shopping.</li> <li>• Clean the house.</li> </ul>
Feelings, support and expectations	Feelings of primary caregivers caring for children with ASD	<ul style="list-style-type: none"> <li>• Denial, feel love, gratitude, pride, despair and resignation.</li> </ul>
	Support and resistance to parenting with ASD	<ul style="list-style-type: none"> <li>• Sources of support: yourself, couples' life, friends, and family (parents, nephew and cousin).</li> </ul>
		<ul style="list-style-type: none"> <li>• Source of obstacles: family (satire about the condition of the child), and environment community (verbal abuse, behavior unpleasant, and threatening acts of child abuse).</li> </ul>
		<ul style="list-style-type: none"> <li>• Caregivers response to the obstacles: angry, sad, hurt, protective and leave warning.</li> </ul>
	Main caregiver's hope to children with ASD	<ul style="list-style-type: none"> <li>• Independent, continuing education until college, and getting married.</li> </ul>
	Main caregiver's hope to health worker	<ul style="list-style-type: none"> <li>• Providing information through health education and seminars about ASD</li> <li>• Holding a special program with services for health</li> </ul>

Themes	Sub Themes	Explanations
		checks, periodic health, medicine, nutritional status examination and appropriate diet nutrient supplements for children with ASD.
	Main caregiver's hope to school.	<ul style="list-style-type: none"> <li>Improving the quality of human resources (teacher should improve their competence to teach children with ASD).</li> <li>Improving facilities and infrastructure (tool practice, a decent school building, extra supervision), subjects taught more emphasis on the child's independence and the corresponding interest and talents.</li> </ul>
	Main caregiver's hope to government.	<ul style="list-style-type: none"> <li>Providing financial assistance, and setting up better programs with special schools for students with ASD.</li> <li>Holding a consistent program.</li> </ul>

### Autonomy in self-care

The results of the study revealed the potentials of children with ASD 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 slowly ..." (P5)*

The teaching was given by providing some examples, then asking children to repeat the activities.

*"...slowly teaching... 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)*

Caregivers should give some punishments if children did inappropriate behavior.

*"...sometimes I pinch her thigh movement ..." (P2)*

The caregivers also give 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 caregivers 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 do not want to say ... do not say ... then finally ... a year I did not even say wait two years .. not too..." (P3)*

The caregivers sometimes give excessive help due to emotional attachment.

*"I was washing, I had to do it, probably because it was too love..." (P1)*



The caregivers sometimes were afraid about something:

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

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

*"...obstacles sometimes he does not focus ... (P4)*

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

*"...his motoric responses are not well coordinated...(P6)*

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

### Care efforts

The participants of the study revealed that they did six treatment activities to improve the children's quality of life, such as by improving knowledge on ASD. The improvement of knowledge was done by the 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 could be done by utilizing health services (consultation as well as medical and alternative treatments).

*"...we consult a doctor for the first time..." (P2)*

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

The treatment effort could also be done by regulating diet.

*"...he had to diet, and couldn't eat sugar, like shiitake, later he was getting hyper..." (P6)*

The treatment effort could be done by meeting the needs for formal educations (kindergarten, elementary school, junior high school, and senior high school) and informal educations (courses in accordance with children's talent and interest):

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

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

*"...I am also often encouraged by all community solidarity such as Java community associations, neighbors, friends... chatting with friends also..." (P6)*

The treatment efforts could 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)*

The results of this study showed a duration required by the caregivers to teach autonomy in self-treatment to children. Time required for teaching elimination was about 2 years.

*"...I taught from the age of nine to eleven... (2 years)..." (P3)*

The participants argued that the most difficult skill to teach was elimination. Five caregivers stated that children were still unable to loosen the bowels or urinate in an autonomous manner.

*"Defecation 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, 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 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 a year (children can wear their own clothes)...” (P3)*

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

In addition, the participants also revealed that there were other skills that could be done by children, such as cooking skills that require time of 3-6 years to be autonomous:

*“...nine years ... twelve years already...” (P3)*

*“a .. age .. ten years old... 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 he took the trolley... I was still paying...” (P4)*

*“...she can help us clean...(P5)*

### **Feelings, support, and expectations**

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

*“...give up...” (P1)*

*“...thankful for God it is like this ...” (P4)*

*“...Poor child...” (P6)*

*“...sad .. not like the other children..” (P7)*

The 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 attention...I feel overwhelmed...” (P3)*

*“...I got the support from my younger brothers... it encouraged me...” (P4)*

In addition to support, the participants also got difficulty in caring for children with ASD. The constraint was 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 they didn't get offended, the family would not be far away...” (P2)*

*“...a neighbor told to hit the boy. If it happened to him, they would deal with me and the police...” (P3)*

*“...This was the scene I would not bring him another nanny... same people said, are you crazy? ...” (P5)*

The caregivers expressed their expectations to the children with ASD, health personnel, school, and government. The highest expectation of the caregivers to the children is that they were able to be autonomous in self-treatment activity, attending higher



education, working, and then getting married.

*"I wish that he will be independent, could take care of himself..." (P1)*

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

*".. I believe my son could... God willing, I will teach 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 ASD through seminars.

*"...there should be a counseling, for example, why there is an increasing number of children with autism? Why? Anything during I was pregnant and nutritional problem...." (P4)*

*"...How to diet. Nutritional intake each child is different...." (P7)*

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

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

*"...it can be infrastructures or tools to help teachers to teach children with ASD..." (P6)*

*"...There should be monitoring of CCTV. We cannot let students unsupervised. Sometimes there are students who try to run out..." (P7)*

*"...we expect him to be independent. It is important than academic...(P7)*

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

*"...Seriously deal with this ... funded. Teachers should also understand and are competent toward autism..." (P2)*

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

## DISCUSSION

This section discusses the three main themes found in this study: (1) autonomy in self-care, (2) care efforts, and (3) feelings, support and expectations. The results of the study revealed that the 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 could 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.<sup>11</sup>

### *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 caregivers 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 caregivers 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 caregivers' anxiety if the children did dangerous activity that harms themselves when the caregivers were not at home, and afraid that the children got lost away if they were left to go alone, 4) The main caregivers' perceptions about the cognitive capacity of children with ASD, thus affecting the children to learn and do self-care, 5) the main caregivers' perception on the children sensory sensitivity on mushy things, thus causing them to try not seeing, taking hold of, and expelling anything that is mushy in nature, for example, the child has 'tingling feces' when losing the bowels, 6) caregivers'

perception on the children motor capacity that was not coordinated well, and 7) fluctuating emotional condition of the children.

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.<sup>5</sup> 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).<sup>5</sup> The researchers 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*

The results of the study revealed that the treatment efforts to improve quality of life children with ASD were done through five ways, including:

First, improving knowledge about ASD. The caregivers 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 researchers assumed that the lack of the caregivers' interest and effort to improve knowledge about autism was because of the effect of educational background, such as 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 educational background. The caregiver with high education had higher talent and interest to seek health information.<sup>16</sup>

Second, caregivers also did efforts by utilizing health service such as seeking any consultations about the children's health by visiting a psychologist and a physician as well as doing any medical and alternative treatments. The results of the study showed the main caregivers' disaffection about treatment given to children with ASD. The caregivers 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.<sup>17</sup>

Third, regulating diet. The 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, a physician, and through health seminar. The results 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 caregivers 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,<sup>18</sup> indicated 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.<sup>18</sup> *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 children. The caregivers should actually consider whether or not the diet is an effective intervention for specific children.<sup>19</sup>

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 (non-scholastic courses that are appropriate with children's talent and interest). Realizing the importance of

social interaction for children, the caregivers have 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, the results of the study show that there were caregivers not leaving them to socialize with new social environment outside school and house, although they actually realized 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.<sup>20</sup>

Fifth, meeting the needs for autonomy. This research revealed that the need for child self-reliance can be done in three ways with the help of part, direction and independence. This study also found the time span of the child needs to be completely independent, such as elimination of urination for 2 years, elimination of bowel movements, which the majority of children were not independent until the age of adolescence, one participant expressed the required time was 2 years 2 months, personal hygiene for 4 years, eating and drinking for 3 months and 1 year, and dressing for 1 to 2 years.

#### *Feelings, support, and expectations*

The results of this study found grieving felt by the caregivers, such as denial, hopelessness, sadness, relentlessness, gratefulness and pride during the treatment of children with ASD. Such grieving feelings were caused by the lack of preparedness of the main caregivers for dealing with autistic children's condition and the emotional attachment felt by caregivers when living together with

them. The grieving stage felt by the caregivers in this study was in line with the grieving stage as stated by Bowlby, consists of denial (shock and distrust), sadness and relentlessness 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.<sup>21</sup> 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 caregivers.

#### *Limitation of the study*

The study had several limitations: first, it 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 about 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 not to accept any children with autism diagnosis.

It is expected that health personnel could provide more health information holistically about children with ASD in accordance with the authority. The provision of sufficient information could 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 could emphasize the newest aspects of evidence-based research about autism and in accordance with the actual

needs of children with ASD. This provision of clear information about autism could 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 main caregivers' commitment to teach skills to children with ASD. The commitment is shown in the treatment efforts in accordance with the children's needs.

#### Declaration of Conflict of Interest

None declared.

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#### Authorship Contribution

The authors equally contributed in this study.

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