

The Relationship between Sense of Coherence and Parenting Stress in Mothers of Children with Autism Spectrum Disorder

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Abstract: Taking care of children with autism spectrum disorder is different from taking care of children in general. This phenomenon often leads the mothers to experience parenting stress. This study aims to find out the relationship between sense of coherence and parenting stress in mothers of children with autism spectrum disorder. Data collection in this study is using a technique of survey and involving 32 mothers. Mothers of children with autism spectrum disorder in ages between 5-13 years old, and they come from many different schools and therapy center in Surabaya, Sidoarjo, Gresik, and Tangerang. The result of data analysis shows that there is a negative and significant relationship between sense of coherence and parenting stress.

1 INTRODUCTION

Autism spectrum disorder is a developmental disorder in case of speaking and communicating, social interaction, playing and imagining, as well as there are restricted interest and repeating behavior (American Psychiatric Association, 2013). The total amount of patients who suffered from autism spectrum disorder in every country continues to increase every year. The data from KK Women's and Children Hospital and National University Hospital have mentioned that one out of 150 children in Singapore has suffered this kind of disorder. This number is higher compared with the prevalence of autism spectrum disorder by WHO, in which one out of 160 children in the world (Goy and Tai, 2016). The total amount of patients who suffered from autism spectrum disorder and following health treatment in RSUD Dr. Soetomo Surabaya are also arising. In 2009 there are 92 patients, in 2010 there are 100 patients, and in 2011 becomes 125 patients (Anna, 2012). Those data simply show that there are more parents of children with autism spectrum disorder.

The treatment for children with autism spectrum disorder is different and need more efforts compared to the normal one. Aggressive behavior and the appeared tantrum as a response towards children's environment changing, makes the mothers have to adapt with children's condition. The symptoms of

autism spectrum disorder that appear on children make parenting become such a burden as well as a hard process to be followed by parents (Ooi, et al., 2016). Mothers who taking care of children with autism spectrum disorder will also be facing with some challenges and difficulties. The challenges in taking care of children with autism spectrum disorder will affect on the physical condition and emotion of the parents. That condition makes the parents tend to experience parenting stress (Ludlow, Skelly and Rohleder, 2011). Parenting stress is a process which appearing philological reaction and negative psychology in case of fulfilling the role as parents. Commonly, that negative reaction is in a form of feeling as well as a negative thought towards themselves and children in which it related with the role as parents (Deater-Deckard, 2004).

Some research towards parents of children with autism spectrum disorder have mentioned that mothers are experiencing more critical and higher level of parenting stress than fathers (Pisula, 2011). The tendency of mothers who tend to experience parenting stress is due to the mothers' intensity that is often spending time with children. The condition of children with autism spectrum disorder is needed more attention, support, and direction that are much higher and long terms compared to normal children. That condition then asks the mothers to give most of their time and energy to take care of their children (Kuhaneck, et al., 2010).

The level of parenting stress towards mothers of children with autism spectrum disorder is influenced by many factors. Some of the factors are related with children's condition such as the severity level of autism (Pastor-Cerezuela, et al., 2016), children ages (McStay, et al., 2014), problematic behavior that arises, obstacle in self-regulation, and the cognitive development in children tend to significantly influence the level of parenting stress in mothers (Pisula, 2011). Parenting stress towards mothers of children with autism spectrum disorder is also related with the cognitive development on children, the needs of children to be observed (dependent), with the problematic behavior that arises (Bouma and Schweitzer, 1990). The other factors such as the acceptance of mothers towards children's diagnosis, lack of professional and social supports as well as the family acceptance towards the children condition also influence the level of parenting stress in mothers (Pisula, 2011). The supports and social acceptance that are being given will mean nothing if the mothers valued themselves as receiving no support at all. Therefore, the individual factor is factors that influence mothers in valuing the supports and social acceptance as well as the cause to influence the stress.

One of the individual factors that influence parenting stress towards mothers is that their perspective on the problem that are experienced (Pisula, 2011). The mothers' perspective or orientation related to parenting that has been done will influence their level of parenting stress and psychological health (Olsson, Larsman and Hwang, 2008). The intended perspective here is the sense of coherence.

Sense of coherence (SoC) is a point of view or individual's orientation about his/her life, in which one individual sees his/her life in general structured, can be controlled, and meaningful. SoC reflects a person's perspective towards his/her life and capacity in responding the situation that causing stress, people with the high level of SoC is capable of recognizing themselves and using what they have to improve their own welfare (Eriksson and Lindström, 2006). Individuals with a high level of SoC tend to feel the stimulus of the environment in a structured way that allows them to anticipate all possibilities and be able to manage the existing resources in order to fulfil the demands as challenges that need to be faced and not as a threat or stressor (Antonovsky, 1987).

According to Antonovsky (1987), SoC is the source of a person's healthiness and welfare, therefore SoC is associated with the effort to

decrease the stress level or individual's depression. One of the researches that have been conducted by Mak, Ho, and Law (2007) found that mothers of children with autism spectrum disorder in Hongkong with a high level of SoC are having more low level of parenting stress, even though that autism spectrum disorder is considered as a severe autistic disorder. The existence of high level of SoC is marked with a good development of stress and the ability to control the environment become a meaningful action, this condition makes mothers for having positive perception towards parenting, whereas parenting is a clear process, manageable, and give them meaning. Therefore, it can minimize the level of parenting stress that is experienced by mothers.

Sense of coherence (SoC) to mother and its relation with the level of parenting stress that experienced by mothers of children with autism spectrum disorder are the aspect that is going to be examined in this research. The writer is interested in examining there is a relation or not between sense of coherence with parenting stress that experiences by mothers of children with autism spectrum disorder.

Based on the previous research, the writer also hypothesized that there is a negative and significant relationship between SoC and parenting stress in mothers of children with autism spectrum disorder.

2 METHOD

2.1 Type and Variable

The type of research that used in this study is quantitative research with a technique of survey. The variable that used in this study consists of sense of coherence as an independent variable and parenting stress as a dependent variable.

2.2 Subject

The determining subject of this research has been done by using a technique of purposive sampling, whereas the writer uses assessment to choose the cases with specified criteria (Neuman, 2007). The subject in this research is married women; live with her husband and children in ages between 5-13 years old that diagnosed with autism spectrum disorder. There are 32 respondents that are suitable with those criteria and they are coming from many different schools and children therapy center for special needs in Surabaya, Sidoarjo, Gresik, and Tangerang.

2.3 Data Collection

The data collection is using a questionnaire that's spread via online and offline to several schools and children therapy center for special needs that is located in Surabaya and Sidoarjo. The spreading process of this questionnaire is done by sharing a link via online to social media and giving it via offline through teachers in school and therapists.

The questionnaire that's used to measure sense of coherence in this research is *Sense of Coherence Scale* (SOCS, $\alpha = 0.92$) which arranged by Antonovsky (1987). This questionnaire has 29 aitem and unidimensional, also has one dimension which is *sense of coherence* and there are three indicators such as *comprehensibility*, *manageability*, and *meaningfulness*. Sample items of the scale are: 'Do you have very mixed up feelings and ideas?' (comprehensibility), 'How often do you have feelings that you're not sure you can keep under control?' (manageability), and 'How often do you have the feeling that there's little meaning in the things you do in your daily life?' (meaningfulness).

The questionnaire in order to evaluate parenting stress in this research is the *Parenting Stress Index-Short Form* (PSI-SF, $\alpha = 0.87$). This questionnaire is arranged by Abidin (1995). This questionnaire has 36 aitem and consisted of three dimensions such as *parent distress*, *difficult child*, and *parent-child relationship*. Sample questions consisted of the following: "There are quite a few things that bother me about my life," "My child gets upset easily over the smallest thing," "My child smiles at me much less than I expected."

2.4 Technique of Analysis

This research is a test relation or correlation; therefore, it used the correlation technique of *Pearson Product Moment*. It is because the data in this research fulfil the parametric statistic assumption test.

3 RESULTS

The subjects are domiciled in Surabaya, Sidoarjo, Gresik, and Tangerang. The subject age range is in between 28 years old until 49 years old. The majority of the subject lives in Surabaya. The subject's last education is starting from Junior High School graduate until bachelor degree. The subject consisted of housewives, teachers, and employees.

Based on table 1, it is known that the highest score aspect in the variable of parenting stress is the aspect of parent-child relationship with average score 31.41. While the highest score aspect in variable of sense of coherence is the aspect of manageability with average score 51.16.

Table 1: Descriptive Statistical Analysis

Dimension	N	Min	Max	Mean	SD
Parenting Stress – Parent Distress	32	12	43	23.78	7.25
Parenting Stress – Parent-Child Relationship	32	14	49	31.41	7.04
Parenting Stress – Difficult Child	32	14	44	31.22	7.81
SoC – Comprehensibility	32	25	76	50.41	10.79
SoC – Manageability	32	31	69	51.16	8.58
SoC – Meaningful	32	26	56	42.22	8.94

Correlation test of *Pearson Product Moment* between sense of coherence and parenting stress are basically showing that there is a negative and significant relationship between those two variables ($r = -0.73, p < .01$).

Based on the above correlation test, it can be concluded that there is a high and significant correlation between those two variables. The negative tendency relation shows that there is an inverse relationship between sense of coherence and parenting stress.

4 DISCUSSION

The result of this research agrees with the hypothesis that proposed as well as matched with the previous research that has been conducted by Mak, Ho, and Law (2007), in which there is a negative and significant relationship between sense of coherence and parenting stress in mothers of children with autism spectrum disorder. Based on Mak, Ho and Law's research (2007) sense of coherence is one of the protective factors towards parenting stress in mothers of children with autism spectrum disorder. The level of parenting stress tends to become low when mothers have a high level in sense of coherence.

Autism spectrum disorder is a developmental disorder that tends to persist and difficult to restore or heal the sufferers to be "normal". The development aspects that are constrained are also important aspects of one's life, such as communication, social interaction, and behaviour. The treatment of children with autism spectrum disorder need a long time, long terms, as well as need more cost (Mak, Ho and Law, 2007). Low level of supports and social acceptance has also become pressure for mothers (Sharpley, Bitsika and Efremidis, 1997). All of those things are not only affected the patient's life, but the various aspect of parents' life who taking care of the children as well. These can lead to the emergence of pressure that led to the emergence of parenting stress (Mak, Ho and Law, 2007). The experience of children parenting with autism spectrum disorder is understood as a burden to the parents' (Williamson, et al., 2013).

Abidin (1995) stated that there are three aspects of parenting stress (*parent distress, difficult child, parent-child relationship*) and they are influencing each other in the increasing of parenting stress that is experienced by parents who took care of their children. Parent's distress results after parent's personal factors necessary to functioning in the role of a parent and subsequent execution of parenting tasks are utilized. The perception of a difficult child is arising from the appraisal that this child's characteristics make him or her hard to parent. The parent-child relationship is about the parent's perception that the child does not meet expectations, and that their reciprocal interactions do not reward the role of the parent (Abidin, 1995).

The dominant aspect is the dominant stress sources that felt by the parents. In this research, the relation between parents and children (parent-child relationship) is a dominant aspect in parenting stress variable. This aspect focused on the expectation level of the parents towards the children (Abidin, 1995). This aspect is also about how far parents feel the characteristics of children in accordance with the expectations of parents and how far the parents feel close to the children. Based on that explanation, there is an indication that mothers who become the subject in this research are having hope and or certain expectation about their children who suffered from autism spectrum disorder, but unfortunately, that kind of hope and or expectation is not fulfilled. This case is related with Hayes and Watson's statement (2013) that said parenting stress is started to appear when parents are forcing an ideal or general thought to be applied while taking care of

children with specified characteristic, such as autism spectrum disorder.

For Indonesian society that tends to follow the eastern culture, they still considered that the task of parenting, treatment, and responsibility towards children are given specifically to mothers. This case is certainly improving the tendency of high level in parenting stress to mothers, whereas in fact, mothers who more intensely interact with children in daily activities. This is supported by data that shows most mothers in this research are the housewives, whereas they play a greater role in providing daily needs, nurturing, and interacting with children. This parenting stress that is experienced by mothers will later become such a manifestation in emotional condition, the negative way of thinking and or belief, bad relationship with spouse, and also parenting behaviour that has a negative tendency (Montgomery and Whiddon, 2010).

Having children with autism spectrum disorder is also can be assumed as a life phenomenon that is traumatic for mothers (Oelofsen and Richardson, 2006). An occurrence can be perceived as a traumatic event certainly involves one's cognitive aspect. Cognitive activity is a key element in valuing that traumatic event as a stressor or not. Because of that, having and taking care of children with autism spectrum disorder will not always be related to the increasing of parenting stress because it depends on the cognitive activity of the mothers. An event can be valued as the cause of parenting stress if the experienced attribute did not give a positive meaning towards mothers.

Sense of coherence is one of the cognitive activities that making mothers can value their experience in parenting their children who suffered from autism spectrum disorder as an experience that is not causing parenting stress. Evolving the sense of coherence becomes such a needed thing to be considered in developing a successful adaptation (Antonovsky and Sourani, 1988).

The dominant aspect of sense of coherence in this research is the aspect of manageability. The aspect of manageability is about how mothers can flexibly manage the challenges in their life. This aspect emphasized the importance of programs that accessible to mothers, whereas discussing about how to develop their ability in problem-solving, time management, assertive, and relaxation (Oelofsen and Richardson, 2006).

Aspects that tend to be less dominant is the thing that mothers need in order to support them to take care of the children in an optimal way. The aspect of comprehensibility about how far an event is

perceived as an event that is able to be understood. This aspect wants to emphasise on the importance of the clarity of information that the mothers understand regarding with the disorder condition that experience by the children, a provided and needed service or treatment for children, as well as the mothers' experience of parenting in a direct way. The aspect of meaningfulness is about how far mothers realized that life makes sense and that at least some of the problems and demands posed by living are worth the investment of energy. This aspect emphasized on the importance of giving support to mothers to have perception and positive reaction towards the challenges that they are facing. This aspect is also about how to cope with helplessness, hopelessness by exploring all caregivers' experiences and give an understanding that all of them are meaningful towards the mothers. Through this way of thinking, it can be known a specific need that must be developed in mothers, since each family and parents are having different kinds of required treatments (Oelofsen and Richardson, 2006).

Mothers with a high sense of coherence can manage their way of thinking towards their own children, their role as parents, and the family role in case of taking care. Those mothers are able to keep thinking rationally in the middle of all life demands, they have self-confidence and enough resource to face all of the demands, and also having the motivation to keep going through that challenges and believe that kind of experience will give a meaning or lesson to mothers. (Oelofsen and Richardson, 2006). Positive adaptation process that is experienced by mothers can be in form of perspective (worldview) changing, particularly about life and developmental disorder that experienced by children as well as the consciousness of a positive contribution by the presence of children to mothers, family, and society in general. The experience of taking care children with autism spectrum disorder becomes the event that has positive meaning towards mothers if mothers can have hope and always see the available chances. This shows that having an appropriate value and perspective are the important factors in facing the demand of life, in this case, taking care of children with autism spectrum disorder (King, et al., 2006).

This research has some limitations in sampling, in which the writer did not use the technique of random sampling; therefore, the result could not be generalized. Another factor that could be related to parenting stress, such as the severe level of autism

and the total of siblings, can not be analyzed due to incomplete data that had been gained.

5 CONCLUSION

The result of this study shows that there is a tendency to a negative and significant relation between sense of coherence and parenting stress in mothers of children with autism spectrum disorder. Mothers who have a high level in sense of coherence will experience a low level in parenting stress. On the other hand, mothers who have a low level in sense of coherence will experience a high level in parenting stress.

Based on the research that has been conducted, the writer suggests to mothers of children with autism spectrum disorder to consult their problem related with children's disorder condition with the help of professionals in order to make mothers can understand what can be done to make the children keep growing optimally based on their own condition. Besides, mothers can also involve in many events that are held by foundations in which specifically engaged in the ministry of children with special needs in order to obtain new perspective in parenting as well as can give positive supports to each mother. By following those positive activities with children, mothers can understand more of their children and their needs.

REFERENCES

- Abidin, R.R., 1995. *Parenting stress index: professional manual*. 3rd ed. Odessa, FL: Psychological Assessment Resources, Inc.
- American Psychiatric Association, 2013. *Diagnostic and statistical manual of mental disorders*. 5th ed. Arlington, VA: American Psychiatric Association.
- Anna, L.K., 2012. *Logam berat dapat picu autisme*. [online] Available at: <<http://health.kompas.com/read/2012/11/01/09055083/Logam.Berat.Dapat.Picu.Autisme>> [Accessed 1 February 2018].
- Antonovsky, A., 1987. *Unravelling the mystery of health: how people manage stress and stay well*. San Francisco, CA: Jossey-Bass.
- Antonovsky, A. and Sourani, T., 1988. Family sense of coherence and family adaptation. *Journal of Marriage and the Family*, 50(1), pp.79-92.

- Bouma, R. and Schweitzer, R., 1990. The impact of chronic childhood illness on family stress: a comparative study between autism and cystic fibrosis. *Journal of Clinical Psychology*, 46(6), pp.722-730.
- Deater-Deckard, K., 2004. *Parenting stress*. New Haven: Yale University Press.
- Eriksson, M. and Lindström, B., 2006. Antonovsky's sense of coherence scale and the relation with health: a systematic review. *Journal of Epidemiology and Community Health*, 60(5), pp.376-381.
- Goy, P. and Tai, J., 2016. *1 in 150 children in Singapore has autism*. [online] Available at: <<http://www.straitstimes.com/singapore/health/1-in-150-children-in-singapore-has-autism>> [Accessed 1 February 2018].
- Hayes, S.A. and Watson, S.L., 2013. The impact of parenting stress: a meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 43(3), pp.629-642.
- Johnston, C., Hessel, D., Blasey, C., Eliez, S., Erba, H., Dyer-Friedman, J., Glaser, B. and Reiss, A.L., 2003. Factors associated with parenting stress in mothers of children with fragile X syndrome. *Journal of Developmental and Behavioral Pediatrics*, 24(4), pp.267-275.
- King, G.A., Zwaigenbaum, L., King, S., Baxter, D., Rosenbaum, P. and Bates, A., 2006. A qualitative investigation of changes in the belief systems of families of children with autism or Down syndrome. *Child Care Health Development*, 32(3), pp.353-369.
- Kuhaneck, H.M., Burroughs, T., Wright, J., Lemanczyk, T. and Darragh, A., 2010. A qualitative study of coping in mothers of children with an autism spectrum disorder. *Physical dan Occupational Therapy In Pediatrics*, 30(4), pp.340-350.
- Ludlow, A., Skelly, C. and Rohleder, P., 2011. Challenges faced by parents of children diagnosed with autism spectrum disorder. *Journal of Health Psychology*, 17(5), pp.702-711.
- Mak, W.W.S., Ho, A.H.Y. and Law, R.W., 2007. Sense of coherence, parenting attitudes and stress among mothers of children with autism in Hong Kong. *Journal of Applied Research in Intellectual Disabilities*, 20(2), pp.157-167.
- McStay, R.L., Dissanayake, C., Scheeren, A., Koot, H.M. and Begeer, S., 2014. Parenting stress and autism: the role of age, autism severity, quality of life and problem behaviour of children and adolescents with autism. *Autism*, 18(5), pp.502-510.
- Montgomery, M.J. and Whiddon, M.A., 2010. *Developmental assessment and feedback relieves parenting stress*. [pdf] Available at: <http://counselingoutfitters.com/vistas/vistas10/Article_16.pdf> [Accessed 1 February 2018].
- Neuman, W.L., 2007. *Basic of social research: qualitative and quantitative research*. 2nd ed. Boston: Pearson Education, Inc.
- Oelofsen, N. and Richardson, P., 2006. Sense of coherence and parenting stress in mothers and fathers of preschool children with developmental disability. *Journal of Intellectual and Developmental Disability*, 31(1), pp.1-12.
- Olsson, M.B., Larsman, P. and Hwang, P.C., 2008. Relationships among risk, sense of coherence, and well-being in parents of children with and without intellectual disabilities. *Journal of Policy & Practice in Intellectual Disabilities*, 5(4), pp.227-236.
- Ooi, K.L., Ong, Y.S., Jacob, S.A. and Khan, T.M., 2016. A meta-synthesis on parenting a child with autism. *Neuropsychiatric Disease and Treatment*, 12, pp.745-762.
- Pastor-Cerezuela, G., Fernandez-Andres, M.I., Tarraga-Minguez, R. and Navarro-Pena, J.M., 2016. Parental stress and ASD: relationship with autism symptom severity, IQ, and resilience. *Focus on Autism and Other Developmental Disabilities*, 31(4), pp.300-311.
- Pisula, E., 2011. Parenting stress in mothers and fathers of children with autism spectrum disorders. In: M.-R. Mohammadi, ed. 2011. *A comprehensive book on autism spectrum disorders*. Croatia: InTech. Ch.5.
- Sharpley, C.F., Bitsika, V. and Efremidis, B., 1997. Influence of gender, parental health, and perceived expertise of assistance upon stress, anxiety, and depression among parents of children with autism. *Journal of Intellectual and Developmental Disability*, 22(1), pp.19-28.
- Williamson, J.A., McCabe, J.E., O'Hara, M., Hart, K., LaPlante, D.P. and King, S., 2013. Parenting stress in early motherhood: stress spillover and social support. *Comprehensive Psychology*, 2(11), pp.1-14.