

COPING STRESS ON MOTHERS OF AUTISTIC CHILD

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ABSTRACT--- *The previous research mentioned that mother with autistic child has higher stress level compared to mother with normal child development. Stress that is not handled well can cause impact on the mother who has autistic child. This scoping review used Arksey and O'Malley framework which consisted of 5 stages such as identifying research question, identifying relevant articles, selecting the articles, making data chart and arrange them, summarizing and reporting the research result. Using web confidence application for selecting 111 relevant articles until 11 articles left to be reviewed. The review results mapped some themes such as coping form, initial response, and factor which influence coping stress on mother with autistic child. Literature gap found was that coping stress of mother with autistic child is not mostly done yet in developed countries with low income. Mixed method design was rarely used to investigate coping stress and guideline and special service for coping with stress on mother with autistic child are not available yet.*

Keywords--- *Coping Stress Mother, Autistic Child, ASD.*

I. INTRODUCTION

According to World Health Organization (2013), Autism Spectrum Disorder (ASD) refers to a sequence of condition signed by some degrees of social behavior disorder, communication and language, and various interest and little and unique activities for individual to do repeatedly. It is estimated that 1 out of 160 experiences ASD. During the last 50 years, ASD occurrence increases globally [1].

The research results reveal that parents of ASD child experience higher care stress compared to parents with child who suffers other disability [2]. The mother who has ASD child shows bigger heart beat and cortisol response towards acute psychosocial stress [3]. Parenting stress relates to the symptoms and behavior problem of ASD child [4]. Nurturing child with ASD can become a stressful experience for parents. When it is left unmanaged, high stress will lead to depression symptom development, until it is necessary to highlight the support for coping stress [5].

Coping is a behavior response and thought towards stress with the usage of available resource in oneself or surrounding environment. Coping strategy aims to overcome the situation and pressures that is felt pressing, challenging, burdening, and exceeding the resources owned [6].

The mental health of a mother who has ASD child must obtain special attention. Therefore, it is necessary to do article review in order to know how far is the research about coping stress on the mother who has ASD child.

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II. METHODOLOGY

This scoping review used Arksey and O'Malley framework. Scoping review has requirement to identify all relevant literatures apart from the research design used [7]. The framework consists of five steps: (1) identifying research questions, (2) identifying relevant articles, (3) study selection, (4) data charting, (5) summarizing and reporting the result.

Step 1: Identifying Research Questions

Based on the problems elaborated in the background, then the research questions of this scoping review are (1) How do mothers owning autistic child cope with stress? (2) How is the initial responses of mothers towards ASD diagnose on her child? (3) What are the factors that influence the way how mothers owning autistic child in coping with stress?

Step 2: Identifying of Relevant Articles

The ways conducted to identify the suitable articles are by determining the inclusion and exclusion criteria, determining the database and grey literature that will be used and determining the suitable keywords with the topic wanted.

The inclusion criteria in this scoping review are (1) the articles published in 2000-2019, (2) the articles are published in English language or Indonesian language, (3) the articles that discuss about the mother who has autistic child and coping with stress, (4) primary research or articles published in journals that had been through peer-reviewed, and (5) documents, reports, policy manuscript or WHO guidelines or other formal organization.

Literature search used 3 databases such as Pubmed, EBSCO, WILEY. The researcher also used grey literature in the form of google scholar search engine, documents coming from specific website such as WHO. Literature search in various databases by using specific keyword, boolean operator, and usage of "OR" and "AND".

Step 3: Study Selection

Article selection used covidence which is a web application which eases article selection from various databases. The selection process runs in two stages such as abstract screening and full text screening. The results of article selection was made into the flowchart called as prism flowchart as follow:

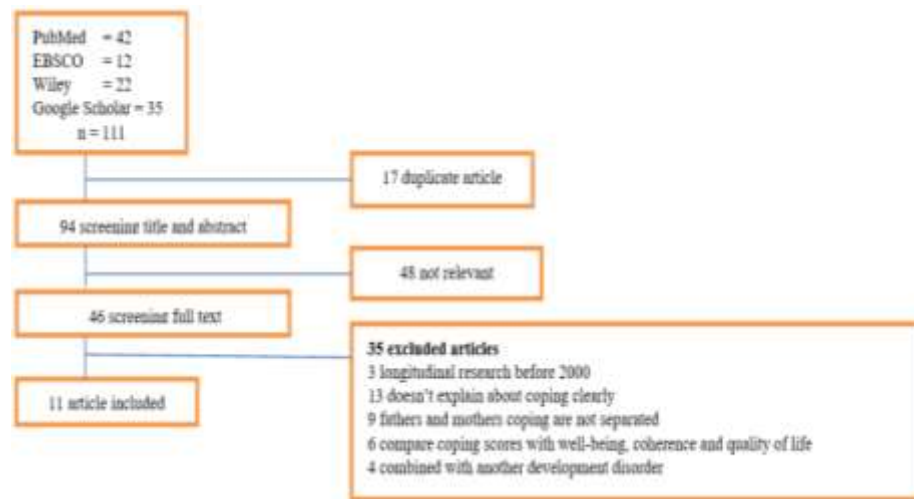


Figure 1: Prism flowchart

Step 4: Data Charting

All collected articles then were reviewed and put into the table containing information about the title, author name, publication year, purpose, research design, data collection techniques, result, comment, and result score of article assessment. All reviewed articles were also criticized to know the quality of selected articles. The critical assessment tool used was Mixed Methods Appraisal Tools (MMAT) 2018 version. The included articles had average score 36/42.

Step 5: Summarizing and Reporting the Result

Last step is summarizing/taking conclusion and reporting the result of reviewed article. The researcher categorized the result of article review into 2 category; first based on the article characteristics and the second based on content in the article in the form of coping done by the mother who has autistic child which then will result some themes.

Table 1: Charting the Data of Article

No	Author /Year/ Country	Title	Research Design	Participants/Sample Sizes	Results
1	Kuhaneck, et al. (2010) USA	A Qualitative Study of Coping in Mothers of Children with an Autism Spectrum Disorder	Qualitative Phenomenology	11 mothers of autistic children	Based on data analysis then concluded into 6 themes of mothers' coping, such as: "Me Time", making plan, share burden, knowledge, Lifting the restraints of Labels, and recognizing joy [8].
2	Gray (2003)	Gender and coping: The parents of	Qualitative	32 mothers and 21 fathers of	Mothers and fathers have different coping strategy. Mothers' coping strategies are pressing the emotion

	Australia	children with high functioning autism		autistic children (asperger syndrom)	and wreaking the sadness, supports from surrounding, making the plan, and religion/belief approach [9].
3.	Koydemir (2009) Turkey	Impact of autistic children on the lives of mothers	Consensual Qualitative Research	10 mothers of autistic children	The themes appeared after data analysis are: Mothers' experiences, reaction towards child's disability, stress sources. The coping strategies used are support from the family, loving her child, asking for professional assistance, support from close friends, and assistance from school teacher and counselor, the involvement with child education, and evaluation of special education center [10].
4	Lutz (2012) USA	Coping with autism: A journey toward adaptation	Narrative Research	15 mothers of male autistic children and 1 mother of female autistic child	The main responses of mothers towards autism stressor are sadness and anger, tense, not comfort and relationship, feeling of guilty and doubt, disappointment and sacrifice. Forms of mothers' coping are: Finding the answer, support, socialization, spirituality, respecting and redefining life and various roles and revising the dream and future plan [11].
5	Marshall (2010) Canada	Coping Processes as Revealed in the Stories of Mothers of Children With Autism	Qualitative with narrative approach	5 mothers of autistic children age 6-11 years old	The research results were categorized into 2 themes such as coping strategy expressed through participants' life story and coping strategy expressed from the full episode of stress [12].
6	Safe (2012) Australia	The experiences of mothers of children with autism: Managing multiple roles	Qualitative Phenomenology	7 mothers of autistic children age 6-12 years old	4 themes were obtained from the interview with mothers of autistic children such as paradox, frustration, finding the right support, the mother as the therapist and something (sacrifice) that must be given [13].

7.	Smith (2008) USA	A Comparative Analysis of Well-Being and Coping among Mothers of Toddlers and Mothers of Adolescents with ASD	Mixed method	151 mothers of autistic toddlers and 201 mothers with autistic adolescents	There is significant difference on coping with behavior release in which mothers of adolescent autistic child is higher than mothers with autistic toddlers [14].
8.	Wang (2013) China	Parenting stress in chinese mothers of children with ASD	Quantitative	150 mothers with autistic children that ever gained treatment.	Coping strategies (active coping, negative coping, and so on) significantly related to the stress of mothers' parenting. The statistic results of coping strategies and informal support towards stress experienced by the mother are as follows: Active coping (-0.205 / $p < 0.05$), negative coping (0.176), family support (0.134), friend support (0.157), other support (0.131) and formal social support (0.237/ $p < 0.01$) [15].
9.	Zablotsky (2013) USA	The association between mental health, stress and coping supports in mothers of children with ASD	Quantitative	507.000 mothers of autistic children	Mothers of ASD child with strong coping perception and get emotional social support and social support from neighbor have smaller risk of experiencing mental health disorder and high risk of stress [5].
10.	Ang (2019) Singapore	Mental Health and Coping in Parents of Children with Autism Spectrum Disorder (ASD) in Singapore: An Examination of Gender Role in Caring	Quantitative	106 mothers and 97 fathers of autistic children	Significant interaction observed between stress and active avoidance coping for father and mother. The item of active avoidance in Brief COPE involved the strategies such as giving up in coping, blaming and criticizing themselves, and expressing negative feeling. Positive coping does not appear as significant moderator in the correlation between stress and depression in this research [16].

11.	Lin (2015) Taiwan	Coping strategies, caregiving burden, and depressive symptoms of Taiwanese mothers of adolescents with autism spectrum disorder	Quantitative	60 mothers of autistic children age 10-19 years old	Fewer depression symptoms if using fewer coping strategies which focuses on emotion (such as mental release and behavior release). Coping variable which focuses on the problem (active coping, plan, re-interpreting, and positive growth, and the oppression of competitive activities) predicting depression symptoms [17].
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III. RESULTS AND DISCUSSION

The first grouping is based on the level of country economy, research year, and the design used and it is found out that: (1) there were few coping stress research on mothers of autistic children at countries with low and medium income, (2) there are many coping stress research on mothers of autistic children in the last 10 years which reveal that the awareness and care towards the psychology of autistic child parenting increases, and (3) the mixed method design is still rarely used in investigating coping stress on mothers of autistic children.

Thematic reviews found three themes such as coping ways, mother responses, and the factors that influence mothers' coping ways.

1) Coping Ways (n=10)

Coping stress is differentiated into 2 such as positive and negative.

Coping positive

Coping positive covers spiritual approach, making plan, accepting autism, share burden together with the spouse and "me time" [P1, P4-P6, P8, P11].

The mother handles her stress by searching for peace in the religion, for instance by becoming more religious and increase her attention towards spiritual aspect [P2] one of the way is by coming frequently to the church [P]. Some mothers also believe that her kid's autism is the plan prepared by God for her and believe that God will help them to get through any difficulty they pass [P5]. Religion approach as coping stress is in line with another research which states that coping religious is certain individual way using their belief in managing stress and the problems in life [18]. Through praying, ritual, and religious belief it can assist someone in coping when facing stress in life because there are expectation and comfort [19].

The next form of positive coping is plan. In general plan is divided into 2 such as long term plan and short term one. Long term plan is done by mothers by choosing the education and care which is considered precise for autistic child and replan her life for instance the job and residence which can accept autism [P4-P7]. Short term plan in the form of anticipation towards the difficulty that might emerge caused of unpredicted trait and autism

behavior disorder. The example of short term plan is managing the routine activities well and setting the routine for the child for the transition from one activity to another one [P].

Another form of positive coping is loving and enjoying the kid's parenting process [P6, P7]. Parenting the kid with autism needs intense concentration emotionally and physically, until mothers also need diversion such as owning "me time" [P1].

Negative Coping

The forms of negative coping are rejection attitude, self isolation, no self confidence, and making comparison [P2, P5-P7, P10]. Mothers who have autistic children feel isolated because they are avoided by other mothers who have normal kids because there is different development [P6]. Mothers make comparison between autism diagnose and the occurrence that is felt worse. This makes them think that they are more lucky compared to other people until it decreases the stress that they feel [P5].

2) Responses Towards Child Condition (n=2)

There are some forms of mothers' responses at the beginning of autism diagnose of her child such as rejection, anger, sad, until frustration. When the mother rejected the fact that her child owns autism and not believe in the diagnose, then this is followed by the feeling of anger, desperate, and sad [P6]. Sometimes the mother keep her feeling first until she feels unable anymore and then wrecking it through sadness for example by crying [P2].

3) Factors Which Influences Forms of Mothers' Coping Stress (n=7)

Supports

The supports from the people around the mother such as husband/spouse, family, close friend, until neighbors. The supports for the mother can be in the form of sharing stories and discussion, become the good listener towards the complaint, until the spouse helps the household jobs and share responsibilities in parenting and watching autism child [P1-P3, P5].

The form of another support is group support. One of ways mothers cope with her stress is by building a community, so that they can share experiences and knowledge to each other as a mother of autistic child [P5].

Child Age

The age of autistic child parented influences the coping form used by mothers. On mothers with adolescent in general focuses on the emotion such as anger compared to mothers with toddler autistic child [P7].

Knowledge and Information

Good knowledge and information about autism ease mothers in taking decision to choose the parenting, care, and suitable education to her child condition. The process of obtaining knowledge and information about autism can be through various ways such as asking the professional, teachers, and counselors [P1, P3-P5].

The mother has the role as advocate [P1] and therapist for her autistic kid and the role as an educator about autism for the people around her until she really needs good knowledge and information [P5, P6].

Stress Sources

Stress sources of mothers of autistic child are worries about the future, care cost, behavior socialization disorder on autistic child. The worry about the future of autistic child is because of their various limitation which makes them difficult to be independent and take decision independently even in adult age [P3, P4, P6].

Environment

Environment has big effect towards mothers' way of coping. Some mothers choose the job related to autism for instance by becoming the consultant or educator of autistic child [P4]. Some other mothers choose the residence environment which can accept autism. Meanwhile some others choose to only be friends with people who can accept and respect her autistic child [P4, P5].

Some mothers choose to support her child to socialize with child who has normal development. This is as one of the effort to decrease the autism labelling on her child [P1].

IV. CONCLUSION

Many research about coping stress of mothers of autistic child start to be conducted in the last 10 years however it is still rarely conducted at developed countries and low income countries. Mixed method design is also rarely used and there is still no guideline of special treatment to handle the stress of mothers of autistic child.

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