



# Phenomenology Study: Description of Coping Stress Mechanism on A Mother with Down Syndrome Children

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**Abstract.** Research background of this research is a short interview result between two mothers who have children with Down syndrome. The result is both of them are experiencing various problems when have a baby with Down syndrome. This research is aimed to reveal what things are in faced by mothers with children with Down syndrome. The characteristics of subjects in this research are three mothers who have children with Down syndrome, live in Klaten, and aged between early and middle adulthood. This research is qualitative with phenomenology approach. Data collection method used in this research is interview. Data analysis technique used in this research is Interpretative Phenomenological Analysis (IPA). The result of this study was that the three subjects experienced stress in the process of self-acceptance regarding the condition of children with Down syndrome. there are three subjects who can accept and care for their children due to self-encouragement and social support from family and environmental factors as well. Social support can reduce stress when you have down syndrome children. It makes three subjects encouraged to give their best to educate their children to be independent through appropriate therapy and education.

**Keywords:** coping stress mother, down syndrome children, coping stress mechanism

## 1 Introduction

An adult woman who has found a matched partner will decide to get married. Marriage is done to build a new family, and also to have baby. It explains that one of the sources of happiness and satisfaction for a woman is when she has children. Some of women feel complete when they are pregnant and give birth to a baby after a marriage. Ibrahim and Nur stated that the pregnancy is a happy waiting period for a mother [1]. One of the functions of a woman is a mother who's naturally to have a baby [2].

Some married couples expect the presence of a child. Children are a valuable asset in a family. Children who are born perfect is a hope for parents. Parents are expecting healthy children, both of physically and mentally. However, not all children are born

and grow up normally. Some of them have limitations both in physical and psychological, that was experienced since the beginning of the development process. Children who experience developmental disorders are children with special needs.

[3] stated that children with special needs are also called a child with barriers, disabilities, and another terms becoming one of the groups that belong to the children with special needs. Somantri stated that children with special needs, one them is mental retardation (tuna grahita) who have intellectual abilities below the average and the level of abnormality is low, medium, and high, with an IQ of 70-25 [4]. One of the mentally retarded / mentally retarded children is Down syndrome. Slow development is the main of characteristics children with Down syndrome. Moreover, Down syndrome have distinctive facial features, including folds at the corners, slanted eyes that tend to point upwards, a flat nose, a face like a Mongolian, and a small mouth with a flat palate so that their tongue slightly stretched out. Children with Down syndrome usually can be easily folded and bend his body while normal child even cannot do that thing [5].

Gunarhadi (2008) stated that factor that led to a high risk of having baby with Down syndrome is the mother's age that more than 35 years. However, it does not mean that baby who was born from the mother more than 35 years old will probably suffers down syndrome. Stray [6] stated that in the fact 80% of children with Down syndrome are born from mother whose age is less than 35 years old. Gunarhadi stated that reproduction system of child with down syndrome has normal function like child in his age. It will be a particular challenge for parents to provide a better understanding of reproductive system of kids and provide special treatment in puberty [6].

Children with Down syndrome shortly are suffering barriers both of physically and mentally. It is probably difficult to the family to accept this difficult situation of children with Down syndrome. Kemis & Rosnawati (2013) stated that the presence of a child with Down syndrome causes tension in the family, so that the parents will experience feelings of guilty and disappointment with the birth [7]. Anggraini's research findings in 2013 stated that from 29 parents with children with special needs, 17 parents (58.62%) were embarrassed by the presence of children with disabilities. Meanwhile, there are 10 parents (34.48%) who feel down after knowing that their child is classified as child with special needs (ABK) and does not meet the expectation [8]. Children born with developmental disorders caused parents to reject and blame themselves for the conditions experienced with the presence of their children which does not meet to the expectations [9]. Findings from [10] showed that parents who have children with special needs are experiencing feeling of unlikely to accept the situation of their children. Rejection is not only done by other individuals around their neighborhood but also come from their own families.

Having child with special needs is one of the sources of stress and burden for parents both physically and mentally. Lestari stated that the source of stress is one of the problems of family members with special needs [11]. The burden experienced by parents with special needs children raises emotional reactions to them. Sanders & Morgan [12] stated that parents of children with Down syndrome have little hope that their children will live a normal life, and it was found that parents with Down syndrome experience more stress and self-accommodation problems. Pressure faced by mothers in caring for children will trigger stress in parenting, especially for mothers whose children

with special needs such as Down syndrome, the stress that come up will affect to the development and relationship between mother and children [13]. Research by Ricci & Hodopp [12] showed that some mothers are more stressfull than fathers.

The thing that needs to be emphasized is some parents still experience problems in accessing the right information so they don't know for sure about handling children properly. Parents are the key factor of a child's life before and after birth and are responsible for caring for and treating him as a child who was born normally [11]. Parents' acceptance of the child's condition greatly affects the development of children with special needs in the future. Lestari stated that parents are essential of helping to develop children's abilities which are a gift from God that must be maintained and cared for [11]. According to Barnard and Martell stated that some families consider the main responsibility for children and doing housework is the duty of mother [14]. Mother as one of the parents of children with Down syndrome plays an important role of knowing the development of children. Karina's research findings (2012) stated that mothers with Down syndrome children parenting them by accepting the children's condition and giving expressions of affection which have an impact on more optimal development of Down syndrome children [15]. Parents who are lack of knowledge about down syndrome will assume that her child has resistance will affected to less affection and even make them can't talk forever. [7] stated that the consequences of the problems and stress experienced by parents will lead to rejection or may even provide excessive protection, which will result in behavioral and emotional problems to children. Self-acceptance in mothers who having a child with Down syndrome is not easy, because parents, especially mothers, still think that a child who has Down syndrome becomes a deficiency or a negative side in their lives [16]. The results of Syaputra et al says that there is a significant relationship between the relationship of social support and acceptance parents of children with Down syndrome [17].

Down syndrome children who receive good care dan treatment will show progress in their development, for the example is Stepanie Handojo, a child with Down syndrome who has achievements as a world-class swimming athlete and also as a pianist who break the record of MURI by playing 22 songs in 2009 [18]. Also, Samuel Santoso is a child with Down syndrome who experts in painting, and gets a MURI record for his artwork. Samuel exhibited his paintings in 2011. Down syndrome children have the opportunity to reach achievements and get awards. Stephani and Samuel are some of the children with Down syndrome who win and award the championship. It is also influenced by self-acceptance and parenting. Self-acceptance can come from internal and external. The parenting support group is one of the external factors.

Based on interviews done to two mothers with Down syndrome children aged around 7-17 years who attend SLB-C "X", children with Down syndrome are more difficult to guide because children have difficulty in communicating to know and understand what they think and want. Based on the results of these interviews, mothers who play an active role in the development of their children with Down syndrome will accompany and train children to be able to perform basic skills. If a child with Down syndrome has been able to perform basic skills on their own, the child with Down syndrome can be classified to show a form of independence. In the process of parenting, mothers experienced various problems.

Many stories come up from mothers who have children with Down Syndrome interest researcher to observe more regarding to their experiences in Klaten region. The objective of this research is to reveal what things are faced by mothers who have children with Down syndrome.

## 2 Research Method

This research is a qualitative research with phenomenology approach. Polkinghorne defines phenomenology as a study used to provide an overview of the meaning of the experiences of several individuals regarding a particular concept [19]. Phenomenology seeks to discover the psychological meanings contained in phenomena during the investigation and analysis of living examples. The purpose of phenomenological research according to Smith is to capture information as closely as possible how the phenomenon is experienced in the context of the phenomenon [20].

Technique used to sample the subject is purposive that customized to the criteria that have been made by the researcher covering three mothers whose children is down syndrome, aged from early and middle adulthood and live in Klaten. Data collection technique used in this research is interview. The themes used in this study include themes regarding professional care, themes about Stressors due to having children with Down syndrome, themes regarding Social support and self-adaptation, and themes regarding the upbringing of children with down syndrome. Following is the interview guideline based on the theme used:

**Table 1.** Interview Guide

No.	Question items
1.	What actions done during the pregnancy?
2.	How is mother's response knowing that her baby was born with down syndrome?
3.	How is husband's response knowing that her baby was born with down syndrome?
4.	How is family's reaction regarding to the information?
5.	How is the response that coming from the environment?
6.	What are the obstacles experienced by mother?
7.	How is mother's process of self-acceptance?
8.	What factors encourage mother to love her baby's condition?
9.	What efforts done by mother during the parenting period?
10.	What is mother's expectation to her child with mental retardation?

Data analysis in this research is using Interpretative Phenomenological Analysis (IPA) method. IPA method is used to analyse and having these stages below [20]:

1. Making interview transcript from the interview
2. Repeating reading of interview transcript and giving descriptive, conceptual and linguistics comments
3. Finding the emergent theme for every answer from the subjects in the transcript. Emergent theme is a summary of researcher's interpretation based on

the answer from the subject that has been given of explorative comments for making certain theme

4. Grouping relevant emergent themes to get superordinate theme
5. Moving to the next subject in the transcript
6. Finding the main theme by associating the superordinate theme among subjects
7. Describing the main theme

### 3 Result and Discussion

Below is the conclusion table from main and superordinate theme:

**Table 2.** Main and superordinate theme

<b>Main theme</b>	<b>Superordinate theme</b>
Professional treatment	Observation of delay symptoms on children.
	Medical diagnostic
Stressor is having children with down syndrome	Family matter
	Environment matter
	Self-conflict
	Parenting's problems
Social support and self- adaptation	Family's support
	Environment's support
	Problem solving (coping stress)
Parenting of children with down syndrome	Acceptance of children's condition
	Implementation of parenting system

This research raises four main themes, covering: 1) Professional treatment as medical treatment efforts in professional way. The efforts of the subjects to get a diagnosis and medical solution regarding to the child's condition. (2) The stressor of having a child with Down syndrome is based on the process of self-acceptance regarding to the condition and medical diagnosis of the three subjects experiencing emotional changes. This is influenced by problems from family, environment, individual self, and pattern of parenting. It will trigger stress on the three subjects. (3) Social support and self-accommodation cover social support and self-accommodation, contains positive encouragement that affects to the process of self-acceptance. The social support factor itself comes from the family and the environment. The three subjects got supports from family and environment. The way of solving the problems also affects the process of self-acceptance. (4) Parenting for children with Down syndrome is about caring for children with Down syndrome which is affected by internal and external factors. The

theme of caring for children with Down syndrome includes subject's self-acceptance and the parenting to children.

### 3.1 This Research Raises Four Main Themes

1. Professional treatment as medical treatment efforts in professional way. The three subjects conducted an examination and determined a medical diagnosis regarding delays in children. Subjects WT, S, and RM received information about the health of the child, he is not having a disorder but the child is having Down syndrome. Wahyuning stated that 90-95 percent of children with Down syndrome have low intelligence (IQ), which is below 30 [6]. Medic provides solutions to the three subjects for child disorders, covering providing therapy and sending children to special schools. Special treatments were carried out by WT, S and RM in order to make children could be handled properly. Mark Slikowits stated that the interventions given to children with Down syndrome are occupational therapy, speech, physiological, and special education [6].
2. Stressor is having children with down syndrome. The stressor of having a child with Down syndrome is based on the process of self-acceptance regarding to the condition and medical diagnosis of the three subjects experiencing emotional changes. WT, S, and RM are disappointed with the results of the diagnosis that came from the experts as well as anxiety about the child's future. This includes the denial stage, [21] stated that at this stage, she began to distrust her medical diagnosis and filled with confusion. In line to [22] stated that the first reaction that comes up in parents who know their child has a disorder are surprise, rejection, anxiety, and even anger with the reality experienced by the child. The three subjects were angry about what had happened. There are often statements that blame the situation, feeling unfair why his family has experienced this. Savir (2005) stated subject experienced future phases of anger were come up sense of injustice within the state experienced. Problems appear in the family of the three subjects; the rejection from family relatives. The third condition of the child with Down syndrome is triggered from environment around. This is the third source of the subject's stressor. The findings of (Ghonyiah , 2015) that when having a child with Down syndrome, some neighbors in the neighborhood around where they live give pressure and negative responses. The three subjects experienced parenting stress because they did not understand how to handle Down syndrome children. [11]) stated that pressure or stressful situations occurred during parenting. Ghonyiah and Savira research findings also showed that mother with Down syndrome children experience various problems in life related to the parenting of children . It affects the subject's psychological condition. In line to the r[10]research Savira and Ghonyiah mother whose child with Down syndrome experience kece period n at the time of child care[10]. The three subjects experienced economic constraints, which is one of the stressors due to insufficient needs for therapy children. The third subject is not only get pressure from

themselves but also stressor from outside; family, neighborhood and the future of a child. In line to research by Ghoniyah and Savira (2015) which states that anxiety or stressors arise due to negative treatment of the environment and children's future. In addition, because of the disease suffered by the child. Economic constraints also affect the stress on the subject

3. Social support and self-accommodation cover social support and self-accommodation, contains positive encouragement that affects to the process of self-acceptance. Support that comes from family, outside the three of subjects encourages to accept the child's condition. Moreover, the three subjects also take care of children well and solve problems that comes up. The findings of Ghoniyah and Savira's research showed that social support from the family in caring for children with Down syndrome makes mothers able to overcome problems that comes up [10]. Emotional support from the husband in the form of attention and motivation also makes the subject comfortable and calm [23] stated that emotional support is support in the form of attention and empathy that appears in a person when he sees the situation of others. In line to [24] which stated that emotional support creates a sense of comfort in a person in a stress condition. The existence of support from the husband, will make the mother feel accepted with the situation she is experiencing so that the mother does not feel alone in facing very difficult circumstances [11]. Kahn & Antonoucci [25] stated that social support that comes from people who are always present throughout their lives every day such as parents, children, and husband/wife. The findings of Putri and Lestari's research (2015) stated that the process of caring for mothers, husbands also try to help raise children [11], [26]. Subject S gets instrumental support, according to instrumental support is direct and tangible support by giving or lending money [24]. S's brothers and sisters help in terms of attention and finance which aims to alleviate the subject's economic problems in caring for children so as to make the subject feel calmer. the results of research that family support greatly influences the self-acceptance of a child with Down syndrome [27]. Support from the environment was also obtained by the three subjects so that they could manage emotions to be more positive. WT and RM subjects get support from fellow mothers who have children with Down syndrome. In line to the findings of the research by [28] that fellow parents who have children with Down syndrome and exchanging opinions have a positive effect on themselves. In contrast, subject S received support from the preacher that made S accept the child's condition. The support obtained from the environment will make the subject do not feel pressure and experience stress in raising their children [29]. The findings of research stated that environmental support affects the management of positive emotions in mothers who have children with Down syndrome [30]. Furthermore, mothers who have children with Down syndrome can accept the child's condition when the family and the environment do not mind the child's condition. At this stage, the bargaining process begins on the subject, [21] stated that this stage is the stage when the process of entertaining oneself over the child's condition. The subject's accommodation begins with the

subject's way of coping with stress, which is called by emotional focused coping. [11] stated that one of the coping strategies is emotional focused coping, which is an effort made to change the emotional experience of stress by regulating emotional responses aimed of being able to adjust to situations that are considered stressful. The subject considers the problems experienced can be resolved properly. Related to the findings of Suri's research stated that parents who have children with Down syndrome consider the problems they face will make them better in dealing with problems because problems cannot be avoided and find solutions to solve them [28].

Coping stress has done to make three subjects accept their children's condition with sincerity and accommodate themselves. It is according to the findings of research done by [10] stated that gradually after the mother goes through life with a child with Down syndrome, she is able to understand and adjust to the child's condition. Moreover, the three subjects also did not feel ashamed of the condition of children who had deficiencies. All three subjects passed the stages of acceptance (reception). According to stages are stages in which parents have run to pie point of surrender and accept the children's condition and hope for the best based on the child's abilities [24].

4. Parenting for children with Down syndrome is about caring for children with Down syndrome which is affected by internal and external factors. Self-acceptance in the child's condition is shown by the three subjects in the application of parenting to children to be independent. [11] stated that child care aimed to develop or improve children's abilities based on love. In line with research by Wiryadi which states that parents play an essential role in delivering educational success to the independence of children with Down syndrome [31]. The three subjects send their children to school with the aim that children can be independent and can be useful for the surrounding environment. These skills are a way to train the independence of children with Down syndrome [6]. Mentions four roles of parents, covering parents as decision- maker, responsibility as a parent, responsibility as a teacher, and as an advisor. The three subjects performed the four roles [22]. First, take a decision of giving medical treatment. The three subjects are responsible for the presence of their children with Down syndrome so that they plan for their children's future. The subject also provides children's education that is line to the child's development and obstacles. Subject WT, S, and RM are also give advice and guidance to the child. The results of research the care that parents give to children with Down syndrome affects children's independence. When parents judge children in the eyes of parents, it is proven to be indirectly motivated by the independence of children with Down syndrome [32].



## 4 Conclusion and Recommendation

An early medical diagnosis brings up stress on the subject of the research. Another stressor also come from self-acceptance with the children's condition that does not meet the expectation. Family tends to blame the subject because giving birth a baby with Down syndrome and subject's neighborhood which gives negative responses and pressure. This is because of lack of understanding on the subject in understanding and caring for a child with Down syndrome. Therefore, it makes subject experienced rejection to baby with down syndrome.

Subjects receive emotional support from their husbands in the form of attention and support to always take good care of their children and also participate in parenting. In addition, the subject received instrumental support in the form of financial support from the voice. Subjects also get support from fellow mothers who have children with Down syndrome in their environment. These social support factors have a positive impact on the subject, so that the subject is able to cope with stress which affects the acceptance of the condition of the child with Down syndrome sincerely. Self-acceptance of the child's condition affects optimally caring for Down syndrome children, efforts are made by the subject, namely by sending children to school, providing therapy and teaching self-development.

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