

THE PATIENCE DESCRIPTION OF PARENTS WITH CHILDREN WITH DISABILITIES

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ABSTRACT

Parents who have children with disabilities need coping patience. The aim of this study was to find out the description of patience of parents who have children with disabilities. There were 43 research subjects using purposive sampling technique. The data collection method used was the patience scale based on Yusuf's theory (2010). Dealing with the results of research on the level of patience of parents who have children with disabilities at Special Schools (SLB) in Harau district, the majority of parents have a level of patience in the high category, namely 58.1% or a total of 25 people. When it is viewed based on gender, age, income and type of disability, it has indicated that there is no significant difference in the category of patient level.

Keywords: *Patience, Disability, Parents of children with disabilities*

INTRODUCTION

In accordance with the United Nations Children's Fund (UNICEF), one of 20 children under the age of 14 in the world, or 93 million children, experience various disorders (UNICEF, 2013). There were 9,957,600 children with disorders out of 82,980,000 children overall, or around 12% of Indonesian children had disorders (Lestari, et al., 2018).

Regardless of their limitations, every child with disabilities such as children with disabilities has unique qualities and potential. Parents with disabilities in children must understand is to maximize their abilities and potential. In terms of child development, family or parents are the main service providers for children with disabilities. Because every child with a different level of disability has various challenges that require unique treatment, parents need to know how

to handle their child. In general, families and parents are required to have the necessary knowledge to properly care for, educate and support children with disabilities (Ministry of PPPA RI, 2013).

Family economic needs are another important consideration for planning interventions (Bailey & Simeorsson, 1988). Family acceptance of the child's impaired status is very important because it will affect the care, education, treatment, and growth of the child even though failure to do so can result in serious problems (Pistav, Mutlu, & Kayhan, 2012). Families need the same resources and assistance as their children. The needs of children with disabilities can also be met if the family's needs are met.

The family environment will be affected when having children with

special needs. The types of emotions that occur and how they behave will also differ (Hardman, et al., 2002). Along with the psychological stress experienced, parents also have to manage various external tensions. Being a parent of a child with special needs means having to deal with the reactions of society, which sometimes do not accept the existence of their child with disabilities. Children with unique needs sometimes face inappropriate or even cruel responses from society (Mangunsong, 2011).

Marettih (2017) suggested patience as a parent's coping mechanism for children with disabilities. To achieve the goals of parents with children with disabilities, they need patience. Patience according to Mubarok (2009) is the ability to maintain a calm demeanor in facing temptations and challenges for a predetermined time. Parents learn to be more patient when dealing with children who need special care. Parents must have patience when raising a child with disabilities in ordinary life.

Patience according to Yusuf (2010) is the ability to regulate, control and direct behavior, feelings and actions, as well as overcome various difficulties in a comprehensive and integrative manner. According to Jauziyah (2003), patience is the ability to stop, hold back, or hold back. Meanwhile, patience means keeping the spirit from worrying, the mouth from grumbling, and the limbs from actions that are not commendable (in Irsyad, 2012). When disaster strikes or

when you are in danger, patience can be the solution.

Subandi (2011) asserted that patience is an understanding that is interpreted from various religions, patience, namely having many forms of self-control, accepting efforts to solve problems, enduring suffering, experiencing the bitterness of life without whining, being persistent, and putting oneself in a lot of effort. Patience when viewed from the perspective of various religions, patience can have many different connotations. Some of these meanings include practicing self-control, working hard to achieve goals, and struggling to solve problems rather than avoid them. Another definition of patience is controlling emotions, deliberating carefully before acting, easily forgiving others, not holding grudges, and having high tolerance.

According to Arraiyyah (2002), patience means having self-control, never giving up, and being calm in addressing and resolving all problems that arise. The word patience has both preventive and restrictive roots. To be patient, one must refrain from grumbling, talking, shouting, slapping faces, tearing clothes, and other aggressive behavior. Morals will be able to refrain from despicable acts is the essence of patience. Therefore, practicing patience includes the need to act hastily and exercise self-control when facing and accepting situations.

Parents who have children with disabilities, they are required to have good character (morals) in educating their children. Anatassia, Milla and El-Hafiz (2015) explain the virtues of

virtue in solving the main problems are patience (32.82%), intelligence (29.74%), compassion (17.44%), wisdom (13.33). %) and obedience (6.67 %). Patience and intelligence emerge as the most important virtues needed in problem solving.

Regarding to the explanation above, patience can be the main key besides intelligence in solving the problems of parents with children with disabilities in dealing with various situations in educating their children with disabilities.

Being patient involves struggling and trying to forget energy while still having faith and enthusiasm for positive results. Patience is not an attitude or behavior that just gives up without even trying. Yusuf (2010) suggests three aspects included in the concept of patience, namely: 1). Strong determination, which means holding firmly to their stance or principles, they will not change what they have planned. 2). Be steadfast. Fortitude or steadfast is the ability of people when facing trials and various challenges in life, there are indicators of steadfastness as follows: a) Fighting power: carry out all activities to obtain good results or goals. b) Stress tolerance: the way people deal with problems and overcome them in order to achieve goals. c) Being able to learn from failure: making failure a motivation to move forward and not to retreat because there are goals to be achieved. d) Willing to accept feedback to improve themselves. 3) Diligent, namely carrying out tasks consistently so that goals can be achieved. There are indicators of persistence, namely: a) Anticipation is

being responsive to what is happening or will happen, and have a backup plan if there are difficulties in achieving goals. b) Planned is having a plan or already preparing a plan to achieve the goal. c) Direction is giving direction to the goal to be achieved.

Mayori's analysis (2022) has collected from five parents with disabilities using a qualitative approach, he concluded that each of the five informants has a different level of patience. Based on the five informants, three indicated that they would always be close to their children, while the other two preferred to avoid them rather than risk harming themselves and their children.

Aryani's research (2017) describes the difficulties faced by instructors who teach and educate mentally retarded children, including a shortage of special education teacher professions (PLB), salaries that are too low, heavy workloads, and insufficient class sizes. size, emotional requirements, adolescent behavior among students, and social interactions. This is a sign that the teacher is losing his temper and unable to control his emotions.

The educational success of children with disabilities is determined by the effectiveness of early intervention involving the role of parents. Special schools in designing therapy services for children with disabilities that involve special school teachers, but do not involve the role of parents will be less effective. This is due to limited service time at Special Schools, while children with disabilities spend more time with their parents. With the findings from this basic

research, a mapping of parents' patience with children with disabilities will be obtained which can be used in various future studies.

This research is to find out the description of patience from a psychological perspective on parents with children with disabilities in Harau District.

RESEARCH METHODS

Statistical descriptive research is to find out the value of an independent variable, either one or more variables without making comparisons, or connecting with other variables. The results obtained are in the form of a picture of patience which can be presented in graphical or percentage form. (Sugiyono, 2019). In this study using descriptive statistics with the population being parents with children with disabilities who attend special schools in Harau District, West Sumatra Province.

Table 1.
Research Population of Parents With Children With Disabilities

School Name	Total
SLB Al Munawaroh	10 Students
SLB N 1 Harau	52 Students
Total	62 Students

Purposive sampling was used in this study. Subjects selected based on the criteria of this study are:

1. Parents who have children with disabilities
2. Enroll school in SLB
3. Live in Harau District

The population of this study was 62 people, of which there were parents

who enrolled their children in SLB Harau District but did not live in Harau District, so they were not included in this study. Researchers obtained the number of research subjects as many as 43 people according to the criteria mentioned above. The patience scale used is the patience theory of Yusuf (2010). After trying out, out of 40 items, 8 items were dropped because items that had item differential power (r_{ix}) ≥ 0.3 were declared good (Azwar, 2015). Then by using Cronbach's alpha formula, the reliability value obtained with 32 items was 0.909 .

FINDING

Demographic data of parents who have children with disabilities are; the number of male subjects was 16 people (37.2%) and the number of female subjects was 27 people (62.8)%. The research subjects aged 23-25 years were 49 people or 49%, and the number of subjects aged 20-30 years was 1 person (2.3%), aged 31-40 years were 18 people (41.9%), aged 41-50 years as many as 22 people (51.2%) and aged more than 50 years as many as 2 people (4.7%). Most of the research subjects were in the income category of less than 1 million with a total of 28 people (65.1%). The most research subjects were children in the mentally retarded category with a total of 28 people (65.1%). The research subjects at SLB 1 Harau consisted of 34 people (79.1%) and SLB 1 Al-Munawaroh consisted of 9 people (20.9). These results can be seen from table 2 below:

Table 2.
Demographic Data of Parents With Children With Disabilities

Demographic Data		Frequency	Percentage (%)
Gender	Male	16	37,2%
	Female	27	62,8%
Usia	20-30 Years Old	1	2,3%
	31-40 Years Old	18	41,9%
	41-50 Years Old	22	51,2%
	> 50 Years Old	2	4,7%
Income	< IDR 1 Million	28	65,1%
	IDR 1-2 Million	9	20,9%
	IDR 2-3 Million	6	14,0%
Disability	Autism	5	11,6%
	Blind	3	7,0%
	Deaf	7	16,3%
	Mentally Disabled	28	65,1%

The categorization of parents' patience who have children with disabilities can be divided into five categories based on empirical scores

with a mean of 104, a max value of 127, a min of 92 and an SD of 8.9. The categorization in this study was obtained as follows:

Table 3.
The Score Range of Participants' Score Categorization of Parents with Children with Disabilities

Categorization	Score Range	Frequency	Percentage
Very High	$104 \leq X \leq 128$	18	41,9%
High	$88 \leq X < 104$	25	58,1%
Medium	$72 \leq X$	0	0%

	< 88		
Low	$56 \leq X < 72$	0	0%
Very Low	$32 < 56$	0	0%
Total		43	100%

Dealing with these categories, it can be asserted that parents who have children with disabilities, they experience patience are in the very high category with 18 people (41.9%), in the high category 25 people (58.1%)

and no one has patience in the medium category, low or very low.

The score for the resilience aspect of parents with children with disabilities can be seen based on table 4 below:

**Table 4.
Score Range of Participants' Score Categorization of Parents' Perseverance With Children With Disabilities**

Categorization	Score Range	Frequency	Percentage
Very High	$26 \leq 32$	20	46,50%
High	$22 \leq X < 26$	23	53,50%
Medium	$18 \leq X < 22$	0	0%
Low	$14 \leq X < 18$	0	0%
Very Low	$8 < 14$	0	0%
Total		43	100%

Based on these categories, it can be argued that parents who have children with disabilities in the aspect of resilience are in the very high category with a total of 20 people (46.5%), in the high category 23

people (53.5%) and no subject has patience in the aspect of resilience. in the medium, low or very low category.

The fortitude aspect score can be seen based on the table below:

**Table 5.
The Score Range of Score Categorization of Parents with Children with Disabilities: Endurance Aspect**

Categorization	Score Range	Frequency	Percentage
Very High	$45,5 \leq$	18	41,9%

	56		
High	$38,5 \leq X < 45,5$	25	58,1%
Medium	$31,5 \leq X < 38,5$	0	0%
Low	$24,5 \leq X < 31,5$	0	0%
Very Low	$14 < X \leq 24,5$	0	0%
Total		43	100%

Dealing with these categories, it indicated that parents who have children with disabilities in the aspect of fortitude are in the very high category with a total of 18 people (41.9%), the high category is 25 people (58.1%) and there are no

subjects who have patience in the aspect of fortitude in the medium, low or very low category.

The score of the persistence aspect of parents with children with disabilities can be seen based on table 6 below:

Table 6.
Score Range of Score Categorization of Parents with Children with Disabilities: Perseverance Aspect

Categorization	Score Range	Frequency	Percentage
Very High	$45,5 \leq X \leq 56$	14	32,6%
High	$38,5 \leq X < 45,5$	29	67,4%
Medium	$31,5 \leq X < 38,5$	0	0%
Low	$24,5 \leq X < 31,5$	0	0%
Very Low	$14 < X \leq 24,5$	0	0%
Total		43	100%

The data above explains that the aspect of persistence in parents

with children with disabilities is in the very high category with a total of 14

people (32.6%), in the high category 29 people (67.4%) and there are no subjects who have patience in the aspect of persistence in the category moderate, low or very low.

The score of aspects of parental patience with children with disabilities based on gender can be seen based on table 7 below:

Table 7.
Patience Description of Parents with Children with Disabilities Based on Gender

Categorization	Gender		Total
	Male	Female	
Very High	4	14	18
High	12	13	25
Medium	0	0	0
Low	0	0	0
Very Low	0	0	0
Total			43

Patience with male parents with children with disabilities in special schools (SLB) in the Harau sub-district is in the high category. Meanwhile, the level of patience of female parents who have children with disabilities in

special schools (SLB) in the Harau sub-district is in the very high category.

The score for aspects of parental patience with children with disabilities based on age can be seen based on table 8 below:

Table 8.
Patience Description of Parents with Children with Disabilities Based on Age

Categorization	Age				Total
	21-30 ^{yo}	31-40 ^{yo}	41-50 ^{yo}	> 50 ^{yo}	
Very High	0	10	8	0	18
High	1	8	14	2	25
Medium	0	0	0	0	0
Low	0	0	0	0	0
Very Low	0	0	0	0	0
Total	1	18	22	2	43

Dealing with the results of the table analysis above, it can be concluded that the majority of parents

with children with disabilities in special schools (SLB) in Harau sub-district who are aged 31-40 years have a very

high level of patience and are aged 21-30 years, 41-50 years and >50 years. years are in the high category.

The score for aspects of parental patience with children with disabilities based on parental income can be seen based on table 9 below:

Table. 9
Patience Description of Parents with Children with Disabilities Based on Income

Categorization	Income			Total
	< IDR 1 Million	IDR 1-2 Million	IDR 2-3 Million	
Very High	11	4	3	18
High	17	5	3	25
Medium	0	0	0	0
Low	0	0	0	0
Very Low	0	0	0	0
Total	28	9	6	43

Parents with children with disabilities in special schools (SLB) in Harau sub-district with the majority of income <1 million to 3 million have a level of patience in the high category.

The score for the patience aspect of parents with children with disabilities based on the categorization of the types of child disabilities can be seen based on table 10 below:

Table 10.
Patience Category of Parents with Children with Disabilities

Categorization	Disabilities				Total
	Blind	Deaf	Mentally Disabled	Autism	
Very High	1	4	11	2	18
High	2	3	17	3	25
Medium	0	0	0	0	0
Low	0	0	0	0	0
Very Low	0	0	0	0	0
Total	3	7	28	5	43

Parents with children with disabilities in special schools (SLB) in Harau district with the majority of children with visual impairments, mental retardation and autism have a level of patience in the high category

while the deaf are in the very high category.

DISCUSSION

Based on the results of research on the level of patience of parents with

children with disabilities at SLB Harau district, the majority of parents have a level of patience in the high category, namely 58.1% or a total of 25 people and the level of patience in the very high category, namely 41.9% or 18 people, but found that there is no level of patience in the medium, low and very low categories. This means that most parents with children with disabilities in SLB in Harau sub-district have a high level of patience when viewed from categorization.

Based on the data above, it turns out that even though they are parents who have problems with children with disabilities in SLB Harau sub-district, basically they still have a level of patience that can support them in accepting the realities of life in educating their children who have various physical and intellectual limitations.

This is in line with the research of Zainal, K., Zakaria, S. M., and Aun, N. S. M. (2021), Autism spectrum disorders present challenges, stress, and burdens for caregivers. To ensure the quality of life especially the welfare of caregivers, they need the necessary support. Financial, emotional, physical and social life challenges are all domains that contribute to the burden of parenting. Financial problems are reported to be the most important challenges in parenting. This is due to the high costs incurred for the management of treatment and therapy, as well as food costs and daily expenses. Acceptance and spiritual aspects are positive coping mechanisms in managing and caring for autistic children. In conclusion,

caregivers also need emotional and practical support from family members. The government and non-governmental organizations must pay more attention to the needs and constraints faced by caregivers, especially financial constraints. positive coping in the management and parenting of children in this study is patience.

This study uses the patience theory expressed by Yusuf (2010) which consists of aspects of fortitude, firmness and perseverance. Parents who have a level of patience in the high and very high categories always provide strong support for their children, provide good rules for their children and are always patient in teaching their children about discipline, this is patience in the aspect of persistence. Parents who have children with disabilities also try to provide treatment or therapy for their children's recovery, teach children to stay enthusiastic, try to stay calm and have faith in the path that Allah SWT has given, this is patience in the aspect of fortitude. In addition, parents of children with disabilities also provide direction to their children and convince their children to make their dreams come true, which is patience in terms of perseverance.

The results of the study illustrate that the level of patience is based on gender, namely male parents who have children with disabilities in special schools (SLB) in Harau District are in the high category while female parents are in the very high category. Female parents have patience which is in the very high category. When

viewed by age, parents who have children with disabilities in special schools (SLB) in Harau District who are aged 31-40 years have a very high level of patience. When viewed from the perspective of income, parents who have children with disabilities in special schools (SLB) in Harau District with an income of <1 million to 3 million have a level of patience in the high category. When viewed from the type of disability, parents who have deaf children, they have patience in the very high category.

The results of Mayori's research (2022) based on information from the five research informants concluded that each of these informants had a different level of patience in dealing with these children with special needs. Of the five, three indicated that they would always be close to their children, while the other two preferred to avoid them rather than risk harming themselves and their children. The five informants in this study had characteristics in common with this study, namely being patient in accepting their children from the start, not grumbling when dealing with them, being firm in their own behavior and that of their children, firm in their hopes for the future and capable.

Marettih and Wahdani (2017) stated that patience is one of the coping methods for parents who have children with disabilities where children really need special care, attention, education, and training not only for a short period of time, but throughout their lives.

Individual patience can also increase if the social or family environment supports it well.

According to Sarason (in Maisyarah & Matulesy, 2015) there are three protective factors to increase individual patience, namely family factors, individual factors and community factors.

The results of the study based on gender chi-square analysis showed that the result of the asymptotic significance value was 0.084 ($p > 0.05$). This indicates that there is no significant difference in the level of patience between male and female parents. These results are in line with Indriani's research (2015) that there is no difference in the level of patience between men and women.

The results of the study based on the age of the chi-square analysis showed that the result of the asymptotic significance value was 0.282 ($p > 0.05$). This means that there is no significant difference in the frequency of the level of patience of parents based on age.

The results of the study on the description of patience in parents who have children with disabilities in special schools (SLB) in Harau district based on income chi-square analysis show that the results of the asymptotic significance value are 0.876 ($p > 0.05$). This means that it is known that there is no significant difference in the frequency of parents' patience levels based on income.

The mapping results above are even more interesting when it is linked to Islamic psychology, bearing in mind that the majority of parents who have children with disabilities in West Sumatra are Muslim and usually associate their patience with God's commands to be patient and God's

prohibition not to be patient. This research will be more meaningful if the theory used uses an Islamic approach.

This research still has limitations due to it reduces patience merely in accordance with patience from the perspective of psychological theory.

CONCLUSION

The majority of parents who have children with disabilities in special schools in the Harau district, they have a level of patience in the high category, namely 58.1% or a total of 25 people. Whereas, if it is viewed based on gender, age, income and disability, it has indicated that there is no significant difference in the category of patience level. For the following researchers, they can use patient theory from an Islamic psychological perspective on Muslim parents who have children with disabilities in Indonesia.

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