THE REFLECTION OF PARENTING IN ISLAMIC TEACHING IN ROBERT HOGE'S UGLY

THESIS



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ABSTRACT

Laudza, S.N. (2020). *The Reflection of Parenting in Islamic Teaching in Robert Hoge's Ugly*. English Department, UIN Sunan Ampel Surabaya. Advisor: Dr. Wahju Kusumajanti, M.Hum

Keywords: disability, moral value, an Islamic perspective

This study aims to discuss the parents' assertiveness, which has a child with disabilities in Ugly novel. This study then reveals several stages of model parental reaction to disability and ways to deal with it. This study focuses on two research questions; they are; (1) What are the stages of Robert's family attitudes to their disabled child portrayed in Ugly? (2) How did the family's attitude affect Robert's life in accepting his condition portrayed in Ugly?

A qualitative method was chosen to be used in this research. This study used new criticism as the tools for analysis. Another tool used is the psychological approach used is Gargiulo's model of parental reaction to a disability, which covers reactions towards it. Followed by using moral value to get the moral lesson from this story based on the Islamic perspective, the researcher finds the quotations and narratives from the novel that suitable with the characteristic of psychological approach and moral value based on the theory.

This study found characteristic of the parents that match with the theory. First, such as shock, depression, grieving reaction. The second how parents deal with guilt, embarrassment, or shame. The last, the parents started to be comfortable and accept the situation, followed by adaptation and acceptance. Other results in this study, researchers revealed the attitude of patience in facing the ordeals and accepting the reality, which has a positive effect on their disabled child. Such as, their disabled child can solve the problem wisely, confidently, and accept all the shortcomings they have.

ABSTRAK

Laudza, S.N. (2020). *Refleksi Pengasuhan Dalam Ajaran Islam pada Novel Karya Robert Hoge "Ugly"*. Program Studi Sastra Inggris, UIN Sunan Ampel Surabaya. Pembimbing: Dr. Wahju Kusumajanti, M.Hum

Kata kunci: disabilitas, pesan moral, perspektif islam.

Penelitian ini bertujuan untuk membahas usaha orang tua yang memiliki anak disabilitas pada novel "Ugly". Penelitian ini mengungkapkan beberapa model tahapan reaksi orang tua yang memiliki anak disabilitas dan bagaimana cara untuk mengatasinya. Studi ini berfokus pada dua rumusan masalah, yaitu;

(1) Apa saja tahapan – tahapan yang merefleksikan perilaku keluarga Robert terhadap anak disabilitas mereka yang tercermin dalam novel *Ugly*? (2) Bagaimanakah perilaku orang tua dapat mempengaruhi kehidupan Robert dalam menerima kondisinya yang tercermin dalam novel *Ugly*?

Metode kualitatif dipilih untuk digunakan dalam penelitian ini. Studi ini juga menggunakan teori new criticism sebagai alat untuk menganalisis data. Teori lain yang digunakan adalah pendekatan psikologis yang menggunakan model dari Gargiulou ntuk mengetahui reaksi terhadap hal tersebut. Selain itu, penelitian ini menggunakan unsur pesan moral guna mendapatkan pelajaran dari cerita tersebut yang berdasarkan perspektif Islam. Peneliti menemukan kutipan dan narasi dari novel yang sesuai dengan karakteristik pendekatan psikologis dan nilai moral berdasarkan teori.yang digunakan.

Penelitian ini membuktikan bahwa adanya tahapan reaksi orangtua seperti awal reaksi terkejut, depresi, dan berkabung. Selanjutnya tahap kedua, orang tua akan menghadapi rasa bersalah, dan malu. Tahap terakhir adalah orang tua mulai merasa nyaman dan terbiasa dengan situasi tersebut. Dilanjutkan dengan tahap adaptasi dan penerimaan sebagai tahap akhir bagi orang tua dalam menerima semua kekurangan anak mereka. Hasil lain yang ditemukan dalam penelitian ini, peneliti menemukan perilaku sabar dalam menghadapi cobaan, menerima kenyataan yang memiliki dampak positif untuk anak disabilitas. Seperti anak disabilitas mampu untuk lebih bijak dalam menangani masalah, menjadi percaya diri, dan dapat menerima semua kekurangan yang mereka miliki.

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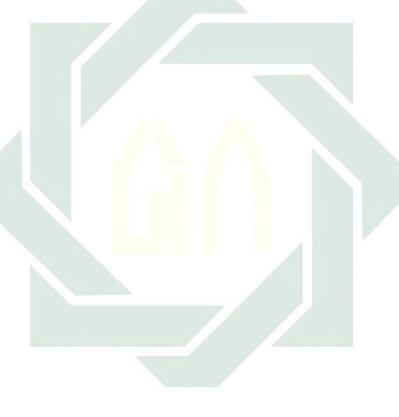
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CHAPTER I

INTRODUCTION

In this chapter, the researcher conducts an introduction consist of the background of the study, statement of the problem, objectives of the study, scope and limitation, significance of the study, research method, and definition of key terms.

1.1 Background of the Study

Quran is a way of life. It is a guide book for all life aspects of humans, no matter they believe in it or not. Surah Al-An'aam (6: 73) implies that God is all-will. He who desires all the paths of the destiny of human life and the universe. Likewise, sometimes life's destiny does not go as expected. Usually, people feel sad or disappointed when reality is not what they expected. One of the cases is when parents expect the presence of healthy and normal children in their lives. However, they must face the fact when they are blessed with a child who is far from perfect.

In Islamic teachings, Muslims know what is called patience. Patience is the foremost and emphasized moral with the most quotation in the Quran. It must be reflected through the behavior of Muslims. In verse Al-Baqarah (2: 153-157) written an appeal from God to be patient in facing the ordeal and shows that God greatly glorifies people who can face the ordeal patiently. For whoever is experiencing hardship and sadness and always includes Allah in every prayer, then Allah will always be with the steps of Muslims. Then, humans should not mourn for life when they do not get the reality that is not expected because patience leads to goodness. Maybe what people think is good, not necessarily is

good and not necessarily that people think is not good is bad. Because only Allah best for His servants.

To learn patience in daily life, one of the media that can teach people about the meaning of patience is a novel, and this statement proved after the researcher read the novel and found the moral lesson of patience. Depdikbud (2005: 788) stated that a novel is a form of life story created by fictional characters but made into a true story. True, which means that proves can be accepted logically. Logic means a relationship between one story and another in the story itself and is a tool to provide information to the reader. A novel is also interpreted as long prose that contains the story of a character's life with character around them, which can be shown through the character behavior and nature of each character.

This study discusses the reflection of patience that is found in a novel entitled Ugly. It is a novel written by Robert Hoge in 2015. Hoge was born in Brisbane, Australia, on 22 July 1972. He is a journalist, a science writer, and a speechwriter. This novel tells Robert's life journey that was born with some issues. Throughout his life, Robert had to discover ways to adapt to taking walks with prosthetic legs, dealing with bullying, and making life choices regarding his own decision.

Robert experienced many twists and turns of life when he was born as a disabled child and facing all the ordeals he gets. Pratiwi (2018: 1) states that physical changes caused by congenital disabilities will certainly cause feeling distress from both the parents, family, and the people closest, especially when

receiving bad judgment from others. It is certainly a pressure for people with disabilities and families to face the judgment of others.

The journey that Robert went through drains the emotions and energy he had. Nevertheless, he always has a patience heart to accept all the reality he gets. It cannot be done without the great influence of his parents, who always support him to become a better person who never gives up, can pass all the trials, and accepts himself as he is.

Many studies have discussed the moral value in literary work. The researcher found some studies with the same theme that is moral value. First, Abdul Hakim (2014) studied moral value in the Skripshit novel. This previous study generally focused on the main character's attitude in reflecting good and bad moral behavior in the novel. Whereas, in this study, the researcher specified one type of moral behavior, which is patience, to be able to make a further discussion about patience in the novel.

Second, Eldiana (2017) discussed the moral value in The Little Mermaid short story. This study focused on the kind of moral value based on Kinnier et al. and the Golden Rule. Meanwhile, the researcher only found several types of moral values based on theory. Different from the previous study, this research used a suitable theory based on Gargiulo in identifying the attitude of each character in the story, which makes this research more relevant to the theory used.

Third, Irma Ulfia (2019) about moral values in The Adventure of Pinocchio story, which focused on revealing the categories of moral value and describing the building children's character implied to the novel. This study uses two principles theory to analyze the data. This study used two different

approaches with two different theories. There are moral values based on Linda & Eyre and the theory of children's character building based on Lewis. However, different from this study, the researcher only used one theory that can cover many related aspects. Among other psychological approaches, moral value, and Islamic perspective that makes this study more efficient and relevant in conducting the research

The last, from Zahrotun (2017) that discussed the moral behaviors of Andreas Tangen in Knut Hamsun's Hunger novel. The study focused on the moral behavior of the main character to discuss the relation of literary work with moral norms in society. Whereas, this research analyzed three main characters in the novel related to Islamic teaching in being patient.

Based on several previous studies above, it gives an idea to the researcher to conduct the study using the psychological approach by Gargiulo's model about the stages of parental reaction to a disability, continued by the influence of parents in accepting their disabled child accompanied by moral value theory to identify the reflection of patience based on Islamic perspective. The reason the researcher used an Islamic perspective to analyze the novel because the researcher has no idea about other religions. In other words, the researcher only knows Islam religion. In Islam, Muslims are taught to be patient, and it can be found in the characters' attitude in the novel in order to give a precious lesson for the reader that may be considered as moral teaching that may be useful in life.

1.2 Statement of Problem

- 1. What are the stages of Robert's family attitudes to their disabled child portrayed in Ugly?
- 2. How did the family's attitude affect Robert's life in accepting his condition portrayed in Ugly?

1.3 The Objective of the Study

- To describe the stages of Robert's parents' attitudes to their disabled child in Ugly novel.
- 2. To describe the effect of Robert's parents' attitude towards Robert's life in accepting himself in Ugly novel.

1.4 Significance of the Study

Many benefits could be earned from Ugly novel research, especially for the literary world and specific readers both theoretically and practically.

Theoretically, this research is expected to broaden insights on the fundamental theories of literary works and characters in the novel. This research used a psychological approach that is related to moral values that explain kinds of good morals from this novel based Islamic perspective.

Practically, through research in Ugly novel, the author can provide a deeper understanding and valuable information on the moral values depicted in this novel, which can be implied in daily activities. Usually, readers consider the novel for entertainment. Furthermore, people who also experience the same thing in this novel; hopefully, it can be an inspiration and motivation for their life.

Likewise, for parents who have disabled children, this study aims to teach the positive side of dealing with a disabled child as a parent or teacher.

1.5 Scope and Limitation

In this research, the author focused on analyzing the data collected from narratives, dialogues, and conversations from Ugly novel by Robert Hoge. The data relates to Robert Hoge, Vincent Hoge as the Father, and Mary Hoge as the Mother character. Moreover, for the limitation, the author analyzed the characters' attitudes related to the moral which is patience, reflected through the attitude and behavior based on Islamic teaching.

1.6 Definition of Key Terms

Disability: A physical or mental condition that limits a person's

movements, senses, or activities. (Charlton, 1998: 6)

Islamic Perspective: The point of view based on Islam that calls for

understanding Islam in its totality related to all the

aspects of human life. (Al-Qaradawi, 1995: 220)

Patience: The ability to survive in severe conditions such as

facing trials, accepting provocation without

responding with annoyance or anger, or surviving

when under pressure, especially not complaining

when faced with difficulties. (Ibnu Qayyim al-

Jauzzy cited from Rofiq, 2019: 10)

1.7 Research Method

The methods of study consist of some major components stated below.

1.7.1 Research Design

In conducting the research, this study used qualitative methods. Based on Yin (2011: 18) stated that the qualitative method is the embodiment of the data to the evidence. Supported by Creswell (2009:175), qualitative research means the researcher will expand the description and making the analysis based on theory. Further, he explains that qualitative methods deal with the collection of multiple data such as documents or even an interview rather than only focus on one source. The purpose of this qualitative method is to give critical understanding to the reader, which considers the moral value in the Ugly to provide the best interpretation.

1.7.2 Data Source

In this research, the data were collected in the form of quotations, or utterances of the narrative. Likewise, the data were taken into two categories, primary and secondary data. The researcher used Ugly novel by Robert Hoge as the primary data source. Whereas, the researcher used secondary data sources outside of the story, such as theory books, textbooks, other thesis or journals, internet sources, et cetera.

1.7.3 Data Collection

The way of collecting the data, the researcher followed some procedures:

1. The author read the novel Ugly as a primary data source repeatedly and carefully, to get a complete and well understanding.

- 2. The author decided which quotations are relevant to the criteria of the stages of parental reaction to the disabled child that related to the moral value in the characters from the novel. The quotations are in all forms, such as dialogues, sentences, and phrases.
- The author collected the data based on the statement of the problems to answer the questions.

1.7.4 Data Analysis

The researcher analyzed the data into some steps, as follow:

- 1. After collecting the data, the author exposed the data to find the problems
- The author gave the data coding or labeled to recognize the moral value in the story
- 3. The author collected the data that has been labeled and coded according to the stages of the parental reaction to the disabled child related to the reflection of a patience attitude based on an Islamic perspective.
- 4. The author interpreted the data
- 5. The author concluded.

CHAPTER II

THEORETICAL FRAMEWORK

This chapter discussed the review of related literature, which is used by the researcher to complete this study. This researcher provides theories and some explanations about previous studies which are related to the topic of this study.

2.1 New Criticism

Tyson (2015:137) states that in new criticism, the form of textual elements is considered as data, such as plots, characters, settings, and themes. Other than that, Castle (2007: 122) states that new criticism is a method that focuses on reading.

2.1.1 Character and Characterization

Based on Nurgiyantoro (2002: 165) states that character is an individual figure who is shown in a narrative of work or drama. Which makes the reader assume that the characters are interpreted have a moral that is reflected through the words and actions taken. Same with Abrams (1985: 21) states that the character is an essential part of the literary work because the character is the person who performs the actions that make the story successful. This statement, also supported by Wahyuningtiyas (201: 3), who states that characters in the story have the function as a messenger. The aim is to deliver messages relating to morals to the reader.

Further, Schirova (2006: 22) states that characterization is used to appear as an explanation of characters. Character always related to people or things in the story, while characterization is the author's presentation and character development. While Stanton (1965: 17) states that characterization is a

description of interests, emotions, attitudes, and moral values owned by the character.

This study applied the character and characterization to get the complete description of how the characters in the literary work reflect Islamic teaching.

2.2 Psychological Approach

Wortman (1999: 4) stated that psychology is useful for explaining things in the literature to reveal phenomena in character. This statement, supported by Wellek & Warren (1997: 93), who explains that psychology will always be in the literature.

2.2.1 Stages of Parental Reaction to Disability

Gargiulo (2012: 121), in his book Special Education in Contemporary Society, states that parents' reaction to disability involves three stages; primary, secondary, and tertiary. All those stages include various kinds of feelings and reactions.

The first response that happens is shocked. Because, in this phase, parents have not been able to deal when they receive the news about their child's disability. After that, sometimes parents will give a denial reaction as an escape from their reality. In the primary phase, it is also marked by sadness, when parents grieve the loss of their "ideal child" or "perfect baby," which causes depression as a result of the grieving process.

In the secondary phase, parents deal with their guilt, which somehow they might have contributed to the inability of their son or daughter. Guilt generally follows the "if only" mindset: "If only I had not to take pills when I was pregnant," "If only we had gone to the hospital faster," "If only I had kept the

medicine cabinet locked." it is an attempt to calm the feelings of guilt parents.

Other common reactions are angry and unacceptable reactions, which are often followed by the question "Why me?". Finally, shame or embarrassment are also the consequences experienced by parents as a result of having a disabled child.

Furthermore, in the last stages, the parents begin to look for ways to deal with God, science, or anyone they believe can help their children. The next phase is adaptation because parents become more comfortable with their disabled child and begin to gain confidence in their parenting abilities. As in many other models, acceptance is the ultimate goal of parents. Acceptance is characterized as a change in mindset in which efforts are made to solve the problems. Parents also not only accepting their son or daughter but also can accept themselves in dealing with their strengths and weaknesses. Related to acceptance, is the attitude which implies positive actions for parents and their disabled child.

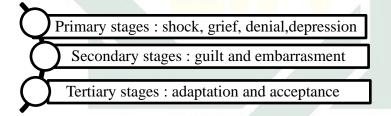


Figure 2.1 the stages of parental reaction to disability (source: Special Education in Contemporary Society, 2012)

2.3 Moral Value

Kanisius (1987: 14) states that the origin of moral teachings comes from people who have a status such as parents, teachers, community, religious leaders, or books, which contain good advice. Another statement expressed by Salam (1997: 3) morality is a value system of how we live as human beings. The value system is in the form of advice, discourse, rules, and orders, which are passed

down through generations through religion and culture about how humans should live well. Morals are part of values, so they are known as moral values. Value is one of the points that need to be explained in the literature concerning something. Another opinion was put forward by Linda and Eyre (1997: 67), who stated that moral values are the result of an assessment process to understand the life values of God and humans that will guide human creativity and knowledge.

2.4 Islamic Perspective

Abdulah (200: 49) stated that Islam is a sacred religion given by Allah SWT to guide human life spiritually and ritually as a way of life, which is determined to be a good servant. This opinion is also supported by a statement from Al-Qaradawi (1995: 220 - 227) states that the Islamic perspective is an idea, notion, viewpoint according to Islam that aims to understand Islam based on human social life and how Islam has maintained a balance between life and rules.

Islam is a way of life, including all aspects of human life. Islam presents all solutions for life problems in social life. Islam also upholds the morals and ethics that determine behavior from standards that are wrong and right always to guide human attitudes and avoid behavior outside the norms.

The Qur'an has explained the moral foundations and described how the faith of those who believe, regulates human beings to always behave well as a way of life. The Qur'an also describes the struggle of the prophets to uphold ethical values in life. Allah has ordered humans to have good morals as the word of Allah SWT.

2.4.1 Patience Based on Islamic Perspective

Mubarok (2001:73) defines patience as being steadfast without complaining in the face of trials and obstacles in a certain period to reach the goal. This statement supported by Al- Qayyim (2006: 25), who states that the word patient (ash-shabr) originally means to hold or imprison. Patience means to refrain from complaining, not mourning or grieving, and withhold anger.

2.4.2 Kinds of Patience

Kinds or levels of patience according to the Prophet Muhammad SAW, as in the hadith narrated by Ibnu Abi ad-Dunya, described in three levels, namely: 1) patience in the face of trials, 2) patience in obeying Allah's commands, and 3) patience not to do immoral behavior.

Of the three types of patience, al-Qardlawi (1989: 35-51) divides it in more detail aspects. Al-Qardlawi divides patience into six types, namely:

2.4.2.1 Patience in Receiving Life's Trials.

In this case, Allah SWT says in the Quran surah al-Baqarah (2: 155-157) Every human being will not be separated from all the trials that befall him, both the calamities related to his personality, as well as trials and disasters that befall on a group of people and nations. Against all kinds of disasters in the form of floods, hurricanes, accidents, and earthquakes that bring human victims and property, it is all a test, which must be faced with patience.

Based on the explanation above, humans are always told to remember

Allah SWT, remember His power and will that no one and anything that can
hinder Him. Everything that happens in this world, whether considered by humans
as an unfortunate destiny or disaster, or that is felt like a mercy and joyous

blessing, then it is all from Allah SWT, and the trials of life, both physical and non-physical, will befall everyone, whether in the form of hunger, thirst, pain, fear, loss of loved ones, loss of property et cetera. Such trials are natural so that no one can escape them. What is needed is to accept it with patience while returning everything to Allah SWT.

2.4.2.2 Patience from Lust

In Quran Surah Yusuf (12: 53) in has been written that humans were created by Allah SWT with lust, so that sometimes humans do according to the invitation of their passions. Lust always invites people to the path that is not good. In Surah Al-Munafiqun (63: 9) also reminds those who believe and remind humans to be patient, not to be provoked by the pleasure of life and is tempted by the splendor of the world that makes you forget yourself to forget Allah SWT.

2.4.2.3 Patience in Obedience to Allah

Allah SWT says in Surah Maryam (19: 65) that patience must also be done when obeying God, especially in carrying out worship such as praying on time, praying the midnight prayer, fasting, and dhikr and leaving all His prohibitions. And to anyone who worships but is not accompanied by patience will give less

2.4.2.4 Patience in Da'wah

Al-Quran teaches patience in da'wah as advised by Lukman al-Hakim to his son in Surah Luqman (31: 17), which contains patience when carrying out da'wah to uphold the religion of Islam sometimes must be taken with twists and turns full of various obstacles and challenges. Because that, then patience is needed in da'wah.

2.4.2.5 Patience in War

Allah SWT exclaimed in the Quran surah Al-Baqarah (2: 177), affirming that patience in battle is one of the characteristics of the obedient servant. Warfare is very much needed patience. Moreover, the enemies faced are more numerous and more durable. Patience here can also be done to set the best strategy.

2.4.2.6 Patience in Relationship

In the Quran surah An-Nisa' (4: 19) Allah SWT says humans are social creatures. Of course, it cannot be separated from the group with each other, both with his own family and with others. In groups, people often find things that are unpleasant and offensive. Because of that, in everyday relationships, patience is needed so that humans do not get angry easily and do not quickly break the relationship silaturrahim when meeting something less pleasant. Relationships between husband and wife who become one family often have problems that can crack the relationship between the two.

2.4.3 The Primacy of Patience

Praise Allah for those who are sincere in their faith, as His word in Surah Al-Baqarah (2: 177) explains that those who are patient in facing difficulties, and suffering is the true meaning of people who are reliable and whoever is patient in such conditions will be elevated by God. Surah Hud (11: 11) also explained that anyone patient, even though he is in trouble, will get forgiveness and a great reward from Allah. Furthermore, according to the Surah Al-Furqan (25: 75) anyone who can be patient, then they will get high dignity in heaven and be given the highest respect as an obedient servant. In various verses of the Quran

Al-Baqarah (2: 153 & 249), Al-Anfal (8: 46 & 66), Ali 'Imran (3: 146) Allah states that He is with those who are patient and Allah love people who are patient.

2.5 Review of Related Studies

In this research, the author provided some previous studies related to this study, which used as references by the author.

In the first previous study is conducted by Abdul Hakim (2014), in his research, the author used the Skripshit novel by Alitt Susanto. The subject used is the Skripshit novel itself, and the object of research is the moral values in the novel. This type of research uses descriptive documentary research, which means describing the subject under study and then analyzing the object as the main of the research. The conclusion from this research found there are two categories of morals in the Skripshit novel, namely good morals and bad morals. In good morals, the character found tawadhu ', ikhtiar, qonaah, ta'awun, and always grateful. While the bad morals character found is israf, revenge, lying to parents.

In the second study conducted by Eldiana Ardi (2017), the author used the famous literary works by Hans Christian Andersen, The Little Mermaid, as the subject of research. The type of research used descriptive qualitative methods to know about what kinds of moral values reflected in the novel. The data of the research used the novel itself and made the open-question questionnaire methods to get a response from the reader. The result of the research found the entire moral values based on Kinnier et al. and the Golden Rule, such as self-respect, humanity, self-discipline, and acceptance of personal responsibility and respect and caring for each other.

In the third study conducted by Irma Ulfia (2019), the author used a fairy tale novel by Carlo Collodi entitled The Adventure of Pinocchio as the subject of the research. This research used a qualitative method also used two principles theory to analyze. There are moral values by Linda & Eyre and theory based on Lewis about children's character building. The study focused on revealing the categories of moral value and describing the building of children's character related to the novel. The result of the study founds some elements of moral values, and there are love, affection, sensitiveness, honesty, bravery, self- discipline, and respect related to the novel.

In the fourth study conducted by Zahrotun (2017), the author examines the moral behaviors of the main character, Maslahah Mursalah in Knut Hansum's Hunger. The aim of the study to analyze moral behaviors portrayed by Maslahah Mursalah as the main character and the effect of the main character's action in Hunger. The result of the study proven that the main character in the novel portrayed moral behavior, which caused the advantages for the public. There is evil and good behavior such as self-conception, sense of helpfulness, sense of merciful, lying and distrust, stealing, and sense of getting offended.

Based on previous studies above, the researcher concludes that this research is different from other studies that have been carried out above; first, the novel that the researcher used was Ugly novel, and this literary work has never been examined by previous research. The other differences are the subject of the study is the main character. It is chosen so because his disability is also an additional point in this research. This study also explained the other characters' attitude and effort in a test of life with disabilities.

Based on the reason above, of course, it makes the story in this novel different from other studies. However, the journey faced by the characters is more challenging and more appealing to discuss. The researcher also uses a combination of the psychological approach to identify the stages of the reaction of parents having children with disabilities, and then followed by moral values to look for a reflection of the form of patience shown by parents and the main character in accepting reality based on the Islamic perspective approach.



CHAPTER III

PARENTING THAT REFLECTS ISLAMIC TEACHING

In this chapter, the researcher discusses the data found in the study. They are analyzed using moral value and Islamic perspective to see whether the characters reflected Islamic teaching on being patient in facing the ordeal of life.

The discussion is divided into two main topics as the research question assign. The first is unfolding the parents' attitude when they found their newborn was not healthy physically, and the second is elucidating Roberts's accepting of his disabled condition

The novel told about a family that expected a new member in 1972. The Hoges had had four children before the fifth born. Unfortunately, the youngest was not as healthy as the other four. The Hoges had to face this test of life. The mother, Mary Hoge, was unable to accept this condition and rejected her breed.

3.1 The Stages of Family's Assertiveness Toward The Newborn

Al- Hadid (57: 22-23) all disasters and disasters that hit the surface of the earth, such as earthquakes, floods, and other natural disasters as well as disasters that befall humans, such as accidents, diseases, et cetera. have been determined to occur beforehand and written in Lawh Mahfudz before God created the creatures - His. It means that nothing happens in this world that escapes the knowledge of God and is not written in Lawh Mahfudz. Determining everything that will happen is very easy for God because He knows all things, both existing and future, both large and small, visible and invisible.

It could be that Robert's presence in the lives of Mary and Hoge was not the ordeal for them; otherwise became the blessing given by God to them. As indicated by Al-Baqarah (2: 156-157) reminds of destiny that given by Allah SWT is not necessarily what they expect is right for them, and what they do not expect is not suitable for them.

Likewise, Allah says in surah Al-Baqarah (2: 286) that He never gives trials beyond the ability of His servant. We are also instructed always to be patient and believe in the decisions Allah SWT gave during the tests because, with patience and trust, all tests or trials and calamities can be passed well, bringing goodness and blessing. Allah SWT has given tests and trials in each of his servants according to their respective portions.

3.1.1 Primary Stages

At this stage arises a feeling of tragedy; parents will be sad because their child was born with disabilities. Parents easily express feelings of shock, deep sorrow, disappointment, anxiety, aggression, and an attitude of fear in parents also arises because they feel unable to take care of children with disabilities, which in the end parents show a denial attitude.

3.1.1.1 Shock

According to Gargiulo (1985) stated that the reaction of sadness and shock is the first reaction the parents will experience when they know that they have a child with a disability. It is very natural to happen because the parents did not prepare for this condition to come.

At the beginning of the story, Mary gave birth to Robert on Sunday, 23rd July 1972. However, the situation at that time did not seem enthusiastic. Everything seemed quiet that makes her felt something wrong with her child. After hearing the doctor's explanation about her baby condition (p. 5), she decided to refuse to look at her son. It was shown from the quotation, "Dad had already visited me on his own by the time he saw Mum. When he described how I looked, they both burst into tears. 'Perhaps he'll die,' Mary said to her husband." (Hoge, 2015: 5)

In the quote, "they both burst into tears" (Hoge, 2015: 5) refers to the feelings of Robert's parents. Knowing that their baby condition was born with an unperfect form, they were stuck in deep sorrow, shocked, and did not expect to get a situation like that.

3.1.1.2 Grief

At this stage, Robert's mother showed a reaction of grieving and experiencing profound sadness, including the first stage, which is very reasonable for parents knowing that they have a disabled child. It is shown in the quote, "The doctor asked my mother if she would finally like to see her baby. Mum knew there was something wrong with me. Until she saw me, though, the pain and the grief need only exist in her mind." (Hoge, 2015:8)

A mother who has not met her baby since she gives birth. Moreover, after a week, the doctor tried to persuade her to meet her child. Finally, she said to the doctor if she changes her mind and chooses to meet her child. Although she did not know what she expected to see her disabled child. The quotation illustrated that the grieving phase showed how her feelings filled with doubt and sadness that only she felt at that moment.

3.1.1.3 Denial

The next reaction is that parents begin to show a reaction of denial. The form of rejection is a way for parents to avoid the fact of knowing to have a child with a disability.

"No. 'I wished he would go away or die or something,' Mum explained later when she started writing some of her thoughts down. It gets worse when Mum has the intention to leave me in hospital. 'I just wanted to be finished with it all,' she said. 'I told the hospital staff I did not want my baby. I would not, under any circumstances, take it home." (Hoge, 2015: 7)

The condition above illustrated Robert's mother, who still cannot accept the reality that happened to her. Every time someone asked her when she would come and saw her baby, her answer was the same, she refused to meet Robert. The deep sadness makes it difficult to accept Robert's condition at the time. It was not easy for her after knowing that her son has a disability. Even she intended to leave her baby in the hospital and refuses to take her baby home with any circumstances.

"She saw my eyes too widely spread, and my splayed nostrils. She saw my disable legs and crooked toes. Mum looked at me again and decided she did not care about her son. About me. 'I didn't feel anything for this baby,' she wrote in her diary. 'I had finished it completely. I had to change my mind; I was not taking him home.' She packed her bags and left the hospital without me." (Hoge, 2015:9)

The mother's attitude shows she is not accepting the reality that had happened is also illustrated by the quote above. It showed the disappointment of having a disabled baby rather than a normal one. It is seen when she saw her baby condition with the large tumor in her baby's head, which made the eyes not in their proper position with a splayed nose, deformed legs, and incomplete toes made her want to ignore the baby even more, and was sure to leave Robert as he had never been born at the first place.

3.1.1.4 Depression

The stage of depression is a form of reasonable consequences of the grieving process that makes the occurrence of deep and drawn-out sadness. The reaction is shown in the quotation, "...She still very sad and could not bring herself to take me home. One day, after she visited me, she cried and told her sister with desperation and honesty, 'He is so ugly.' (Hoge, 2015: 11) It is illustrated by the attitude of mothers who are always crying over the condition of their children.

3.1.2 Secondary Stages

At these stages, parents feel guilty for having children disabled, because they feel unable to look after their children as best they can for nine months of pregnancy. Then, effected their child was born with a disability. Parents also feel ashamed to introduce their children to other people because their children (with disabilities) are considered "disabled" and are different from children in general. Parents tend to be closed about their disabled children. It means parents not allowing their disabled child to go outside of the house or other public spaces and do not allow them exposed to the outside world.

3.1.2.1 Guilt

At this stage, the reaction from guilt included in the secondary stage of parents' acceptance of the child's disability. Parents' guilty reactions arise because they think they also take part in causing a child's disability. This reaction is clearly shown in the quotation, "Mum kept asking other people what she should do. No

one gave her an answer. They always said with the same answer: whatever decision she chooses, and they will support her" (Hoge, 2015:11)

In the quote above, it clearly showed mother behavior who always asks what she should do to the closest, shows that she looks hesitant to make a brief decision. She feels guilty by leaving Robert, but she also feels very heavy to accept Robert as his son because of his appearance. (p.13) Another thing that made Robert's mother feel guilty because of the mistakes she made while pregnant. In the story, it is explained that the mother took some drugs while she was pregnant because she did not know that she was pregnant. The incident made her feel sad, and the drug should have made her feel better. Otherwise, Robert has a congenital disability (p.63)

3.1.2.2 Embarrassment

The next reaction is followed by the reaction of parents' shame that arises when faced with a social environment that rejects the existence of children with disabilities. Environmental attitudes can cause a decrease in self-esteem felt by mothers who think children are an essential part of her life.

"Mum was refuse to take me out. She was not ready to face the judgment of strangers when they saw her child. For a long time, the only place I went as a baby was to the hospital for various appointments. No shopping trips. No playground visits. Just appointments and Fortress Hoge." (Hoge, 2015:15)

The embarrassment of having a deformed child seen in the quotation above when Robert's mother decided never to bring Robert out even once. The only place Robert could visit was the hospital for various appointment meetings. There are no trips to public places. Only appointments and homes. Because she worries it can destroy her pride, and she was afraid by the judgment of people

when they saw her child. It shows that Robert's mother could not accept Robert's condition at that time, instead feel shame and hid Robert from the outside world.

3.1.3 Tertiary Stages

At this stage, parents realistically begin to accept the child's condition. Parents begin to seek help and medical experts or an expert in their field to help their children with disabilities. Parents also have reached the point of maturity in terms of accepting what has happened. They began to think positively, that this was a trial they had to face. They understand the condition of their children well by looking for information related to the good parenting of children with disabilities, therapy centers, et cetera, according to the needs of children.

3.1.3.1 Adaptation

At the last stage, the reaction of parents begins to be able to adapt to their disabled child's condition that makes them emotional such as sad, grief, depression, et cetera. Parents realize the situation that they face will be very difficult to go through, but this reaction is the first reaction for parents to accept their children with disabilities.

"Mum realized it wouldn't be the last tough decision she would have to make about my future. It was not going to be easy. She knew it would mean battles for her and for me, but she had made up her mind." (Hoge, 2015:13)

Although there was still a feeling of sadness, and she still terribly hard to believe this could happen to her, but she began to try to accept Robert slowly. Even though it would be difficult for her to take Robert, she had to fight with her ego and started to accept Robert with any circumstances, and she knew of the many ordeals she and Robert would face, many tough decisions would come to

her, but that did not change Robert's mother's intention to bring Robert home. The attitude of the mother illustrated the form of the adaptation to accept Robert's condition.

3.1.4 Carrying Out The Treatment

In the Islamic teaching, Allah SWT in Surah Al-Imran (3:146) reminds people when in this endeavor there is something that humans find difficult, or he considers to be detrimental, in essence, it is a temporary test which must be dealt with patiently; hold back for a moment to think about the problems faced with a clear mind and heart, find a solution, then struggle again with other ways better. Therefore, God will praise those who are patient, who never give up in undergoing any difficulties.

Same as an attitude that Robert's parents, Carrying out the treatment as the action of the parents begins to deal with the reality that God destined for them, and tried to seek help by science, or anyone they believe might be able to help their child this phase called an adjustment. It was illustrated by Mary and Vincent, who sought medical help who could help them carry out surgical procedures and facilitate Robert's development.

Robert's parents, who not only accept Robert with all his shortcomings, also tried everything to provide the best way for Robert, by carrying out various surgical procedures by surgeons experts in their respective fields. All surgeries were done to correct the deficiencies that Robert has. Hoping that Robert can be well accepted by the social without having to be distinguished because he is different from the others.

Robert's parents are families who work in farm and animal husbandry, while Robert's father also works as a laborer. With all the limitations that Robert's parents have, it never eliminates their efforts to make their child better. As long as it will be good for Robert, they will do everything possible and facilitate the best medical treatment for Robert. This subchapter describes the treatment undergone by Robert's. The doctors performed a series of surgeries and procedures before and after the surgery that Robert had to go through.

Based on the Children's Hospital of Philadelphia article of the procedures before undergoing surgery stated that the surgeon and surgical team would review the medical history, any medications are taken, and any test results. The surgeon will also give a complete physical exam to check the current health. Also, there is a consultation session to have all the questions answered about the surgery itself, also be able to answer questions about insurance coverage and how to go about getting pre-approval for a child's operation.

It will be needed immunization records, insurance card, as well as any referrals may need Guardianship papers, Consultation letters from other specialists to see Current lab results, Copies of any X-rays, CT scans or MRI scans, complete medical history, a list of all medications taking, or recently taken, including prescription and over-the-counter and a list of all allergies (especially latex allergy).

Parents and children will meet with both the advanced practice nurse (APN) and the surgeon after they examine the patient and review information and will discuss a possible option for the patient. In this session, it will complete the surgical and pre-anesthesia evaluation during appointment visits. Also will receive

preoperative preparation instructions, as well as information about the surgery itself. Moreover, this procedure will train the parents to let them know about any lab work, vaccines, or medicines that will be needed before surgery. Then, they will finally be able to schedule the date for the surgery.

(https://www.chop.edu/patients-and-visitors/guide-your-childs-surgery/your-childs-preoperative-appointment)

In this case, as a parent certainly will spend a lot of time and energy in preparing for future operations. The number of procedures that must be pass requires more energy and time to be available for check-ups, observations, and various evaluations needed. It is clear how Robert's parents are trying their best for their children to be well received in the social environment and can make it easier for Robert to get along with his peers.

1. Remove the Tumor

"Doctors had done a small operation just after I was born to remove the tumor that split the middle of my face and caused my facial deformities. It meant I was left with no nose at all – and with nostrils drilled into the flat center of my face. Plus, my eyes still sat more than twice as far apart as they should have been." (Hoge, 2015:25)

The first operation that Robert had to do at the age of five days old is to undergo treatment of tumor removal in his head. It was done to overcome more dangers that would arise if the tumor continued to exist in his forehead. Because of the tumor, was made Robert's face deformed, which makes Robert had no nose at all and an improper eye position on the side of the head.

2. Amputate the legs

In the second operation, the doctor decided to amputate one of Robert's legs. Because based on Doctor's explanation that Robert would never be able to walk with a squashed left foot. Moreover, Robert has a foot length that is not the same as his right foot.

"They decided to do was to chop off one of my legs. The doctors told my parents I would never walk on my squished left leg normally. It was just too short. That meant amputating the foot and fitting me with a prosthesis – an artificial leg." (Hoge, 2015:19)

By amputating Robert's leg, the aims are to match his leg with a prosthesis - an artificial leg, which makes it easier for Robert to walk normally. Moreover, Robert's right foot is more complicated because Robert's legs experience tilted forward like pointed ballerinas toes; it caused Robert cannot walk properly. Robert could have placed the front of his feet on the ground when he stood but not the heels. However, the operation the doctor performed on Robert's right leg to fix it failed. Furthermore, Robert is required to undergo further surgeries for his right leg.

3. Major Surgeries

"Slowly and surely, the doctors made their plans to sculpt up my cranium, move some pieces around, toss away the chunks they did not need, and put some new stuff in for good measure. They would move my eyes closer, reposition my nostrils, and rebuild a new. All that medical magic would give me a new face that was more acceptable to society. The doctors cannot be sure how long the complex surgery would take, but they were expecting it would be up to six hours. That meant lots of risks. Being put under general anesthetic for a long time will give rise to brain damage. Next up was the chance of infection, which is especially high when the bone is being cut and moved around. Any operation on the face also means lots of bleeding. Combined, the risks meant the operation could kill me. I'd had six operations since I was born, but none was anywhere near as risky as this one." (Hoge, 2015:26)

The first major operation, the doctor was to carve out the skull, move a few pieces, get rid of pieces that they do not need, and put some new items in their proper size. The doctor will also reposition Robert's eyes closer together, reposition Robert's nostrils and make a new nose crave by cartilage from the toes, besides, to complicate the surgeries, even more, the doctors wanted to amputate the right foot at the same time, and the doctors suggested I'd be better used two artificial legs rather than having just one because of the right leg more complicated. The foot on it was angled forward like a ballerina's pointed toes and cannot work properly either (p.26)

In addition to undergoing the major surgeries procedures at the same time, the entire procedure also took twice as much as expected, recording more than twelve hours, which means that it took a long time for Robert's parents to wait for the operation to proceed. Robert, who started as a boy with a right leg and deformed legs, no nose, and eyes on the side of his head. Finally, he can complete the surgical procedure with the position of the eyes already in place, the two amputated legs, and a new nose. Besides requiring a very long time in the operation process, but also requires more energy for Robert to survive during the operation. Robert has been sedated for a long time. Three times the blood has been replaced. Despite all the surgical procedures, Robert survived and was born for a second time.

Not only are the surgeries at risk, based on Celletti in her article titled The Complete Guide to Rhinoplasty (2018), there are costs that Robert's parents have to spend on the major operation that Robert undergoes. Rhinoplasties, the operation for reposition the nostrils, eyes, and nose, can range from approximately

\$6,000 to \$15,000 (8000 AUD - 21000 AUD), which is worth one year up to 2,5-year salary in Australia.

Based on Plastic and Reconstructive Surgery Global Open Journal (2017) Overall, the total cost of manufactured patient-specific implants for craniofacial reconstruction and cranioplasty (nose surgery) is estimated at around 250 USD (4000 AUD) https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5732683/

Based on The Journal of Bone and Joint Surgery America (2007), Costs for reconstruction and amputation were similar. When prosthesis-related costs added, there was a substantial difference between the two groups (\$81,000 (118,000 AUD) for patients treated with reconstruction and \$91,106 (132,000 AUD) https://www.ncbi.nlm.nih.gov/pubmed/17671005

Based on ABC News (2013, para 1-4) stated for patients treated with amputation. The cost is worth buying at least around five units houses in Sidney in 1972. The projected lifetime health-care cost for the patients who had undergone amputation was three times higher than that for those treated with reconstruction (\$509,275 and \$163,282, respectively)

https://www.hss.edu/newsroom_prosthetic-leg-cost-over-lifetime.asp

4. The Second Major Surgeries

"The team eliminate some cartilage from my ribs and partially rebuilt the shaft of my nose. They used the rest of the pieces to perfecting some other small gaps and bumps in my face and prepared them for the future operation in a few years. That would be the major one that would make me look more normal." (Hoge, 2015:138)

The doctor has planned for the next operation in a few years. It will be the second major operation for Robert. This time the operation will make Robert's face have more perfect results than the previous operation to look healthier. The

operation takes several hours. The surgeon team will remove some cartilage from Robert's ribs and partly rebuild Robert's nose bridge. They will use the remaining pieces to smooth out some small gaps and bumps on Robert's face.

5. Post-Operative Surgeries

After undergoing leg amputation, Robert also had to undergo a series of healing and rehabilitation to adapt to the prosthetic leg and adjust to using a prosthetic leg. The limb will be treated with special compression bandages or compression socks to help heal the wound quickly. It will also help prepare residual limb for a prosthesis. The team of medical health will also give some advice on how to wash and take care of the prosthetic legs.

The rehab will likely include doctors, therapists, nurses, and a prosthetics

Rehab will begin after the surgery to work on upper body strength and maintain

range of motion in the remaining limb. Overall rehab could take from a few weeks

to a few months. In this amputation surgery, Robert also spends his time and

energy. He has to do various postoperative procedures that require recovery time

and training in the use of prosthetic leg to be able to adapt using his new leg.

Then continued Robert needs a prosthetic leg to walk correctly. Based on the Amputee Coalition article (2019) The price needed for prosthetic leg is also not cheap; it requires much money to buy prosthetic limbs and replace prosthetic legs periodically every year to adjust body growth. The price of a new prosthetic leg can cost from \$5,000 to \$50,000. (7000 AUD - 80.000 AUD) it is worth to buy two motorcycles until two Range Rovers cars in Australia. Source:

https://www.amputee-coalition.org/leg-amputation-guide/

However, even the most expensive prosthetic leg is built only three to five years of wear and tear, which means Robert will need to replace throughout a lifetime, also to walk using prosthetic legs requires training. That is hard enough to be able to walk properly finally. Because Robert was still very young for using prosthetic legs, Robert's mom and dad tried everything they could, to make Robert feel comfortable while he uses his prosthetic legs, they were looking for special boots that fit Robert's feet - high heels for a two-year-old boy - but that also unsuccessful (p.19) When Robert was two years old, Robert still could not walk normally, but Robert's parents kept trying. After a year of slow and patient training, Robert's mother always patient taught Robert to walk, and finally when he at three years old, Robert got his first step (p.19)

3.1.5 Acceptance

At this stage, Robert's parents' behavior begins to accept reality as Robert's is. In Islamic teachings, Robert's parents' behavior includes patience and accepting the destiny God has set for them. As for the glory that they will receive as they are patient people, the reward is heaven. According to Islamic teaching and Quran in Al-Furqan (25: 75), An-Nahl (16: 96), Ar-Rum (30: 60), Az-Zumar (39:10), and Al-Insan (76: 24) how Muslims must be patient, which was destined by God to his servant. Destiny is a decree of God, from a great destiny to an unfortunate fate, a Muslim must accept it. He cannot protest with the destiny that Allah has ordained for him. Because every destiny that God sets, there must be a silver lining.

In the last stage is the process of parents trying to recognize, understand, and accept the conditions that occur. In this phase, parents also realize that in the

acceptance process, parents not only accept the condition of their children but also accept them as parents who have children with disabilities.

1. Dad

The form of acceptance reaction was first shown by Robert's father in the quote, "He knew I might be an ugly baby, a baby with a serious problem, but he also knew his son was a fighter. 'No chance – he is too strong and healthy,' he said." (Hoge, 2015: 5)

However, the response given by Robert's father was different. When he saw Robert's condition for the first time, he knew if the baby has various problems physically. However, he believes that his child would be healthy and will stay alive. From the quotation below, it clearly showed Robert's father is the first person that is more rational to accept the condition whatever shortcoming that Robert experienced.

"He was pretty rough-and-ready himself and had no problems taking me out in public. He mostly ignores it or told them, 'Pull your head in.' with kids, he took a less direct approach." (Hoge, 2015:17)

Another attitude from Robert's father is showed in the quote above that he accepts all conditions that his son experienced. It was seen from the way he did not hesitate to bring Robert to the public place and did not care about the opinions of others towards him and his son. It included the behavior of accepting his son as he is.

Likewise, he showed psychological support when he was responding to the judgment of people against his son. He typically tends to be more defended, and he was quite ready to deal with the situation. As in the quotation above, when he yelled, "pull your head in" to other children who are trying to mock Robert. "Pull your head in" usually as an Australian means 'you better off to stop being annoying.' In this case, Robert's father responded by tending to deal with situations aggressively, giving a fierce impression to protect Robert from the judgment of others.

"Once in a while, I would hear comments or get questions. 'Look at his legs!' 'Why do you have a squashed nose?' 'What is wrong with your face?' 'Look at his legs!' 'Why do you have a squashed nose?' 'What is wrong with your face?' Not Dad, however. He was in hearing distance when a child came to stare and ask a pointed question, he yelled, 'Oi, you! Go tell your mother she wants you.' One time when Dad yelled that at a boy who had asked me if I could smell through my nose." (Hoge, 2015:17)

Another form of psychological support that he has given to his son is when he and Robert go to the Wynnum Wading Pool, which is famous as a massive ocean pool. At that time, Robert get comments and lots of questions about Robert's appearance. When he knew about it, he gives a loud warning to them who has teased his son by yelling to the child, "Oi, you! Go tell your mother she wants you," which means 'go away; you're not welcome here; get lost.' He did look more fierce towards others who mistreated Robert. However, it shows that he supports and loves his child.

2. Robert's Siblings

The next party to accept Robert's presence as a child with a disability are Robert's siblings it is shown in the quote below

"They explained the situation, describing what I looked like and what was wrong with my legs. They talked for a long time, and when they finished, the whole family was burst into tears. Then came the big question. Mum pointed at my eldest brother, Michael, and asked, 'Should we bring Robert home?' Michael paused, silent for a few seconds while everyone watched and waited. 'Yes,' he said. 'And you?' Mum asked and pointed at Gary. 'Yes,' Gary said. Then came to Paula. 'Yes,' she said. Finally, Mum pointed at Catherine. 'Should we bring Robert home?' Mum asked. Catherine paused. 'Yes' (Hoge, 2015:12)

After Mary and Vincent telling the condition that their youngest sibling condition that was born deformed, they finally decided to involve them in the decision to bring their youngest sibling home. The decision must still be taken, because Robert is part of The Hoges, and all the children take part in deciding. Robert's parents asked the children one by one in the decision to bring Robert home, and all agreed to take Robert home to meet his other siblings. In this case, his siblings' decision to bring Robert home illustrates the form of acceptance to accept every shortcoming that their youngest sibling has in whatever form.

"None of them changed their mind to bring me home. There were concerns and curiosity on their young faces, but all of it was for me, not for themselves. My sister Paula doesn't remember the way I looked at being the main issue for my siblings when I first came home. 'You were a baby, and it was just the way you were,' she said". (Hoge, 2015:13)

The form of acceptance showed from the siblings about their youngest brother illustrated when after the whole family took the decision, the siblings met their youngest at the hospital for the first time. Their enthusiasm reflected when the whole family came to visit the newborn, and each brother and sisters had a turn holding Robert. They feel happy to welcome a new face in their family. Also, the decision to bring their brother still the same; there is no regret for them to bring him home. As well as Paula, the eldest sister, she assumed that her youngest brother's congenital disabilities were not a big problem for her and the other siblings.

"You were a baby, and it was just the way you were," she said. "The quote shows that Robert's sister sincerely accepted her youngest brother's condition because his brother's condition is not his fault, Robert was just a baby

like the others, and for them, Robert still the youngest brother they loved, just like the other younger siblings.

3. Mother

Looking at the enthusiastic response from the other children when they saw Robert and received Robert with great joy (p.13) and how Robert's father accepted Robert's shortcomings (p.5, p.17) made Robert's mother finally realized what she was doing all this time. It is shown in the quote

"Mum started to realize that she had been focusing on what other people might think of her new baby. 'My worry and my concern were more a matter of pride than anything else,' Mum said. She started thinking about how she could have reacted if my problems were on the inside rather than the outside. (Hoge, 2015: 13)

In the quotation above, Robert's mother explained her feelings that she was only afraid that her self-esteem was falling because she had a child with a congenital disability and deformed legs. She started to understand that she had been focusing on what other people might think of her new baby; instead, she had to face the problems more wisely and solve the problems, not because of other people's thoughts.

"That is my son you are discussing,' she hissed at them. The woman looked at her in surprise. 'He has not got a harelip or a cleft palate, and he is quite normal mentally,' Mum said. 'And I'll thank you not to make a diagnosis until you are more qualified.' They turned away without saying anything. (16) It might have taken her a week to come and see me for the first time and another month before she decided to bring me home, but when she did, Mum's love for me grew fast and fierce." (Hoge, 2015:16)

The attitude from the mother illustrated when she accompanies Robert, who had to attend an appointment at the hospital. In the payphone, she made a phone call, leaving Robert with his father for a while. She overheard a conversation of two women on her back while she was queuing. They turned out

to talking rudely about Robert. The mother, who realized that it was her child who was being talked about, immediately turned around and spoke to the two women and defended her son. She spoke to them tough enough to the two women until they left her in shock and left without saying anything.

At that moment, the affection that she gives for Robert is illustrated when she defends her child in front of people who are talking rudely about her child. As time goes by, her attention towards her child shows a form of acceptance in accepting all the shortcomings of his childhood experiences. In this case also clearly illustrated how she gave psychological support for their children by defending their children when there are people who were rude toward her child.

"Mum decided she was ready to take me into the big world. Like the other mums and their kids had done before, we went for a trip to the local shops. Expecting the worst possibility, she held her head high to avoid meeting the stares of other people, but no one commented, and if anyone stared at me, she would do not notice. In the future, whenever she finds people staring at her and her ugly little boy, Mum settled for staring back." (Hoge, 2015:16)

The quotation above also clearly showed psychological support for her child. The way she is responding to people's judgment, she prefers to be ignorant toward the people who were staring with a strange look to her child in a public place. She will put her head up to avoid eye contact with others. Her fierce attitude towards others makes others reluctant, and no one dares to take a risk for comment anything about her child.

Even though at first she felt ashamed of people's judgment of her and it would destroy her pride of having a child with congenital disabilities, but over time, she was no longer care about people's perception of her and her child. For her, having

a child that was different from other children was not something to hide from the world. Instead, she dared to show her deformed child to the world.

From the discussion above, the process of acceptance is conducted well by Robert's family. It starts with the father as the most responsible person for his family. Robert's father has been a good model for his family. It is easier for other members of the family to accept Robert as he is.

3.2 Process of Robert's Acceptance of His Condition

The previous discussion has revealed how the family undergoes what is necessary to show their patience in facing their family's destiny. In this subchapter, the researcher will continue analyzing Robert's attitude in accepting himself as a child with a disability. The researcher also wants to prove the influence of parents does give a significant impact on Robert's acceptance in deciding his life

3.2.1 Insecure

In this case, it is very reasonable to happen when Robert feels insecure about his environment. Because this insecure phase occurs when Robert begins to enter the school and adapt to a new environment and new people who are not familiar with the presence of Robert at school.

'Some people look at me and say, "That boy hasn't got any legs. He must have been in an accident," I said. 'You don't really care about that, do you?' Mum asked. 'Yes, I do.' 'People really aren't trying to be unkind when they say that. If you wear your shorts, they'll be able to see how clever you are and how well you can manage and all the things you can do that they can't do.' I still didn't want to, but I wore shorts." (Hoge, 2015:47)

Robert's sense of insecurity began to appear after some time he entered school. When Robert had an appointment with a doctor at the hospital, Robert's mother hurriedly told Robert to change his clothes for a hospital appointment. At that time Robert asked his mother if he could use long pants to go to the hospital because he knew that many people would pay attention and realize that Robert did not have perfect legs, and had to use prosthetic legs to help him walk, this made Robert insecure if he has to use shorts is shown in the quote 'Some people look at me and say, "That boy hasn't got any legs. He must have been in an accident,' I said."

However, the sense of insecure that Robert experienced got advice from his mother that Robert did not need to think about what other people said, Robert's mother said that not everyone intends to be mean when commenting on what Robert experienced. It would be good if Robert could be confident in showing himself, shows how smart and shows that he do something that other people may not be able to do. Although this opinion was still not accepted by Robert, he tried to obey what his mother told him.

In the quote "If you wear your shorts, they'll be able to see how clever you are and how well you can manage and all the things you can do that they can't do." illustrates the way of Robert's mother taught Robert to be confident in whatever he was, and always proud of what he had. The role of Robert's mother in dealing with Robert's self-confidence is essential for Robert to become a support system in ensuring that the people around him accept him as he is along with the shortcomings he has.

There is not upon the blind [any] constraint nor upon the lame constraint nor upon the ill constraint nor upon yourselves when you eat from your

[own] houses or the houses of your fathers or the houses of your mothers or the houses of your brothers or the houses of your sisters or the houses of your father's brothers or the houses of your mother's sisters or the houses of your mother's brothers or the houses of your mother's sisters or [from houses] whose keys you possess or [from the house] of your friend. There is no blame upon you whether you eat together or separately. But when you enter houses, give greetings of peace upon each other - a greeting from Allah, blessed and good. Thus does Allah make clear to you the verses [of ordinance] that you may understand. (An-nur (24:61)

In Islamic teaching, Allah SWT teaches people to appreciate each other as it says in surah An-Nur (24:61) Allah SWT highly glorifies people with disabilities as the argument above, teaches us to tolerate each other, not discriminating either in physical form, hair color, or skin color because human nature is all the same, nothing is better for the perfect, nothing is bad being disable. Then humans should not feel insecure with what they already have, because human nature has flaws. All the perfection only belongs to Allah SWT

"There was the kid with the harelip. There was the one with flaming red hair and pale white skin. There was a girl who was already taller than all of the boys within the class. There was this one really skinny kid and all the fat ones. Each one had something different about them. I just had different differences." (Hoge, 2015:49)

Robert has entered his first year at school. Of course, for Robert, the activity of going to school and interacting with other children at school is a new thing that he had never found in the hospital as he had been living. Robert began to realize that he was the only child who was different at school. He had an imperfect face and used a pair of prosthetic legs. He felt he found many things that made him different from other children.

Likewise, in the hospital, he found there was a child in a wheelchair; there was a child with a strange lump in his neck. There was a child with a cleft lip.

Nevertheless, the difference makes each of them have something different about

them. However, not for Robert, he felt that he was a different child, no legs, nobody height, or a wheelchair. He is just a different one.

In this case, it can conclude that Robert began to feel insecure about the conditions when he joined the school for the first time. It was felt by Robert when he started to interact with other friends at school and realized that he was not like most physical children he often finds at school. This statement is supported in the quote, "Each one had something different about them. I just had different differences." 'different differences' in this case, shown by the physical Robert who does not have legs, do not have a nose and the location of the eye that is far from their proper position, according to him it is a differentiator for Robert with other children, and the differentiator that Robert has is very different from the children other he found because there was no one like him.

"Have you ever sat on the beach and watched the tide come in? You might not notice the water rising as one wave follows another, but if you wait half an hour, the dry patch you were sitting on is in danger of being overtaken by water. That's what it was like for me at school. The change was gradual, but by the time I was seven, I had started to notice a difference in the way some of my classmates treated me. It's not far from the first gentle wave of genuine interest and curiosity to a crashing tide of teasing and meanness." (Hoge, 2015:59)

The treatment Robert received by his friends gradually made Robert more insecure about his appearance at the time. Robert realized this when he was seven years old. He felt that his friends who started of curiosity about Robert's condition now became the things he most avoided. The quote "crashing tide of teasing and meanness" described his friends began to mock Robert because of his appearance.

"One of the boys pointed me. 'Ha ha – look at the cripple,' he said. I didn't know exactly what a cripple mean, but I was pretty sure, even at that age, that I did not like it. Some of the others in the group started up too, like kookaburras at sunset. 'Cripple, cripple, cripple,' they shouted. I picked myself up off the ground and hid from them for the rest of lunch, but when

I got back to class, some of the kids were still calling me 'cripple.' (Hoge, 2015:61)

The first incident that Robert experienced is when Robert was playing with his friends the game 'brandy' at school. It is a game that throws a tennis ball to one of the other players. Robert, who at that time had the turn to throw a tennis ball running as fast as he could to get as close as possible to his friends who were targeted by his pitching. Robert, who ran across the tilted asphalt, made him slip, causing something to happen.

Robert's right leg slipped off, and he fell in a forward-falling position and his hands as his support to protect his head. When Robert fell, the group that Robert was pursuing just saw Robert fall while laughing at him. Then, one of the boys pointed at Robert and called him 'cripple.' Robert did not know what it was a flaw, but he was quite sure that it was not the right word to say. Because of that incident, some other children also began to mock Robert as 'Cripple.' It makes Robert hide from them for the rest of the lunch, but when Robert returns to class, some children still call him a 'cripple.'

"I turned to Mum. 'Mum, what does cripple mean?' 'It's someone who has legs that did not work properly,' she said. 'Like me?' I asked. Mum paused. 'Well, yes, kind of like you,' she said. 'Why? There was someone calling you names at school?' I didn't realize it at the time, but this turned into a turning point. I didn't reflect on it straight away. It just happened. I decided to hide the truth from Mum. Mum repeated her question again, and I just kind of shrugged and half-grinned to hide my embarrassment. 'No. I just heard someone say it the other day,' I said. 'That's all.' (Hoge, 2015:62)

The incident is enough to make Robert think about the events of his friends who chase him. After school, Robert asked his mother the meaning of the words given by his friend to him. Robert's mother replied that cripple is someone whose feet are not functioning correctly, realizing this immediately makes Robert

feel insecure with conditions that do not have perfect legs. However, when the mother asks if there is a child who calls Robert 'cripple', Robert chooses to hide it from her as if nothing has happened to him.

3.2.1 Indomitable Facing the Ordeal

This subchapter will describe the next stage of how Robert can finally deal with the shortcomings he has. He began to accept himself and feel comfortable with himself without caring about other people's judgment on him and respond to other people's judgments more wisely; it can be seen from the quotation below

"The operations the doctors had done on my face over the years started to give the result. I started to make new friends at school and at home. Some kids were quick to realize how different I was, but many others seemed did not notice, or at least not to care. I was not the most popular kid in school. I did not have people rushing to spend every possible second with me at lunch. But I wasn't totally eliminated and ignored either." (Hoge, 2015:71)

Facial surgery performed by doctors for years finally gave a significant change for Robert. The Doctor's goal to make Robert's face more friendly to make Robert socially acceptable was quite successful. It is proved by Robert starting to make friends at school and home. Maybe the operation did not make Robert a favored child in his school, but at least he was not eliminated or ignored by his friends.

"Like most schools, Guardian Angels had a yearly event sports carnival. The fact I had no legs did not excuse me to take the part. If God did not want me to race, he would not have given me artificial legs." (Hoge, 2015:81)

When Robert's school, Guardia Angels, held an annual sports carnival,
Robert, who likes sports, was very enthusiastic about participating in the sport that
would be held. Despite the limitations that Robert has, that is not an obstacle for
him. The optimistic attitude showed in his quote which said "if God did not want

me to race, he would not have given me artificial legs." It shows that with the limitations, he has no reason to stop trying.

Another form of support depicted in the quote above is when Robert's mother fully supported Robert's choice to take part in the sprint race competition because it was also for Robert's good. Although she knew if Robert would not be a winner in this race, at least she allowed Robert to try and teach Robert that with the limitations that Robert faced was not a reason for Robert to stop trying and just give up on the situation he was facing. The statement was also confirmed by Robert's mother's quote, saying, "I know Robert can't win,' she told Dad. 'But he can get in there and try." (p. 82)

Another form of support depicted in the quote above is Robert's mother's attempt to facilitate what Robert needs in the sprint race. Robert's mother bought race supplies such as a new white sweatshirt, green bottle shorts, one sand shoe, and one long white sock. From both attitudes is a form of support from the family for Robert in dealing with reality. A sense of optimism, confidence, and trying to find the abilities in Robert seen in the form of Robert's parents' attitude towards Robert (p.82)

Sprint race began. Robert did not expect anything from the race. Robert just wants to try something new for him and prove that Robert, with all his limitations, can also do what other people do. It is shown in the quote, "I wasn't thinking about running a record time or qualifying for the Olympics or being a spectacle. I just wanted to run. And win." (Hoge, 2015:83) Robert's decision is also due to the influence of parental support that fully supports whatever Robert chooses, such as Robert's decision to take part in the sprint race in the quotation

above. Although Robert has flaws, that does not make him ashamed and does not want to try, precisely because the full support given to Robert makes Robert more confident with his abilities

"By the time I reached the halfway point, the other kids were pass through the finishing line. Now I was racing myself, really. Racing on my own but not alone. Parents and teachers started supporting me on, and I finished the race feeling like a winner. The timekeeper at the finish line later said they had to ask the other kids in the race who'd won because everyone was watching me instead. Mum asked me if I minded, not winning. 'No, of course not,' I said. Later, Catherine ran her race and managed to come last as well. I turned to Mum and said, 'Look, Catherine came further last than I did." (Hoge, 2015:85)

The shot remarked the seconds' sprint race to begin. In the first round, Robert can still keep pace with the other children. With his limitations, Robert had to take a big step to compensate, even though Robert had absolutely no functioning knee, and most of his legs consisted of only two straight pieces of metal. Robert has to swing his legs to run. The difficulties that Robert faces is because Robert has crippled legs, and he tries hard to do everything possible to run.

About ten meters away, Robert realized that he had fallen far behind the others, but it did not discourage him. He continued to swing his legs and was full of confidence that he could still catch them. So even when Robert realized that he was the last child to be on the finish line, he just swung his legs faster and faster. However, when Robert reached about one-third of the road to the race, Robert fell forward and was unable to stop, because Robert could not control it. Robert fell right on the oval grass. There was no severe wound for him that makes him hurt.

Robert began to rise again to finish the race. Robert believed that he still had time to chase other children in front of him. He made a very significant effort

to push his arms and legs that keep swinging, panting. Until he found that other children had crossed the finish line. That did not stop Robert; for him, this was the time for Robert to race himself to drive himself forward. However, it has the full support of Robert's parents and other teachers. Even though Robert became the last participant in the finish line, that did not make him sad or disappointed.

Otherwise, he made his mind that if he is not a winner, at least he has become a winner for himself against his limitations. It is illustrated when Robert's mother asked whether Robert objected if he did not win then Robert answers "No, of course not,"

The quotation above illustrates how Robert was very optimistic about the limitations he faced. Robert was able to break the impossibility that so far, others have thought, and he did his best. Being a disability is not a reason to be a useless person. Otherwise, Robert proves that there is no difference, whether it is healthy or disability; as long as he has a strong desire and belief to be able to do, there is nothing impossible to get.

"Life outside of the classroom was changing for me too. I was getting better at facing other kids. If someone started teasing me, I tried my best to ignore it. I was also starting to understand that I could try to ignore the way I felt when people called me names. At home, I was learning how to deal with my four older siblings, learning how to argue – even while losing eighty-two percent of the arguments I had with them and almost all of the arguments I got into with my parents. I was starting to understand what was easy and comfortable, and what was more challenging. I was starting to conquer my disability and grasp my place in the small world I inhabited." (Hoge, 2015:106)

In grade four, Robert's life outside the classroom also began to change.

Robert gets better at dealing with other children. If someone starts teasing or mocking Robert, he will do his best to ignore what other children say to him.

Robert also began to understand that he had the choice to ignore or let go of his

feelings when people call him. Similar to what happened at home, Robert learned how to deal with his four brothers, learned how to argue. Robert began to understand what was easy and comfortable and what was more challenging for him to face. Robert began to be able to conquer his inability and create a comfort zone that Robert created himself.

In this case, Robert becomes used to facing the temptation or ridicule from his friends. He is no longer feels sad or insecure about the situation. Instead, he chooses how to ignore what people say about him and tries to choose what he should accept and not. It also makes him more accepting of himself with all the circumstances. This quotation also shows how the influence of the family and environment of the house affects how Robert is accustomed to solving problems wisely

"I'd only been at Iona a few weeks when a kid I'd never met before called me 'Toe-Nose'. He must have seen the media cover about my big surgeries when I was four and knew that the doctors had to create my nose out of a toe. Four weeks in, I already being called half-a-dozen other names that were not Robert – cripple, spastic, legless, and the dreaded Toe-Nose. Although some of my friends had come to the new school, like me, sometimes it felt like in the loneliest place in the world. I'd pick up a new nickname every six months or so. Some would be forgotten for a year or two.some would slowly lose their power to hurt me and would fall into disuse." (Hoge, 2015:114)

Being in Iona for a few weeks becomes a new challenge for Robert to adjust to his new school and the children at Iona College. For them, Robert had a face that was not normal enough for a child of his age at the time, so that Robert had to take back nicknames and mocks from other children. For example, when a child whom Robert had never met before called Robert as 'Toe-Nose.' The child must have seen media coverage of the big operation Robert had when he was four years old and knew that the doctor had made Robert's nose from his toe.

Four weeks at Iona College, Robert had already gotten half a dozen nicknames, such as cripple, spastic, legless, and the dreaded Toe-Nose. It makes Robert sometimes miss his old friends who think Robert is an ordinary child like other children, and also it makes Robert feels like in the loneliest place in the world. Nicknames did not stop from the beginning Robert entered Iona College, Robert will get a new nickname every six months or so. However, Robert was used to facing and choosing to ignore what other children said to him so that gradually. The mocks that children often uttered to Robert slowly would increasingly lose the power to hurt Robert and no longer be used. It made him mentally stronger in dealing with the bullies.

3.2.2 Accepting True-life

In this subchapter, the researcher would like to illustrate the attitude of Robert in making significant decisions in his life to run life with shortcomings he has, and it also shows how the significant influence of family and support from parents to make the decisions Robert took for his life. In the quotation, it is clearly illustrated when Robert has to make the decisions to carry out further operations.

"Over the next few weeks, I asked my parents a question here, a question there. Then they sat me down and said it was time to talk properly. I wasn't surprised that they wanted to hear my opinion before they made their decision. They were good like that. 'Robert,' Mum said, 'you know we've been talking about you having another operation on your face. A big one.' 'Yep.' She looked at Dad and took a deep breath. 'Well,' she said, 'this decision isn't up to us. You're fourteen, and we think you should decide whether the doctors do the operation or not.' 'It's your life, so your choice,' Dad said." (Hoge, 2015:175)

Robert knew that the time would come when the surgeon would perform another significant operation on Robert. An operation that will make everything right and Robert's parents say that day has arrived. The doctor who handled

Robert had discussed it with Robert's parents, who, in turn, raised the prospect with Robert. This operation will be as massive as Robert's first enlargement operation at four and a half years old. The bumps on Robert's head will be ironed, Robert's nose will become almost normal, and Robert's eyes will move a little closer together. Robert will look much, much better.

However, that continues to be a big question for Robert now, how it feels to look normal. Is making the nose a standard shape makes girls pay more attention to Robert. If the operation goes well, are the other children will stop teasing Robert again? Will he still be called Toe-nose or another lousy nickname? That is still a question for Robert. Known that Robert's age is already enough in making decisions, finally, Robert's parents gave the decision to Robert, would Robert agree to carry out this major operation or not. Everything has been handed over to Robert.

"I was smart enough to know I'd always far from the ordinary – no matter what the doctors did to my face, I will never go to sleep one night and wake up the next morning to found out I'd grown new legs" (Hoge, 2015:178)

The time of decision arrived. Robert's mother and father, Robert and Robert's eldest brother, Michael, were also there, talking about how they operated at the end of the school year, and hopefully, Robert will be back with his friends in January, with new faces and everything. After having had quite a lot of operations since he was a child, the process is long, painful, sad, and that everything can go wrong. Robert thinks whether undergoing all these operations is worth it to the pain Robert felt throughout his life.

"Michael, who had usually been quiet until then, suddenly speak up. What use is looking normal if he cannot even see himself?' I paused at that, and everyone turned to look at me. I still have no idea exactly how and why,

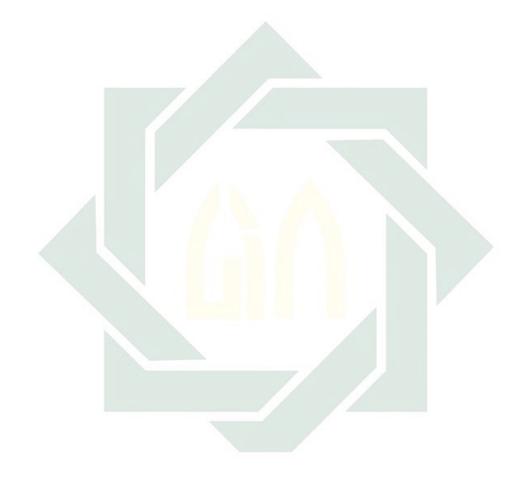
but that one question brought all of my thinking into focus. In that instant, I owned my face. I can rely on the doctors who had done so many wonderful things to get me so far. I might give them the chance to move me a bit closer to normal, risks, rewards, and all. Or I might take my chances and make my ugly way in a sometimes ugly world just the way I was. Until then, everything in my life had been controlled by what I looked like. But I had no right to have my own face. I'd to say no abut my appearance, and no one can control of what I have to choose about my face." (Hoge, 2015:181)

However, immediately, Michael's words made Robert aware of everything he had done 'What use is looking normal if he cannot even see himself?' Robert might believe everything to doctors who try hard to make Robert's face healthy so that it can be socially acceptable, but he can also take risks and make his way of life without having to follow the standards of others about his ugly face. Robert realized that almost everything in his life had been governed by what Robert would look. However, that makes Robert not having the right to himself. He is not allowed to be himself because of social judgment, and he is different from others. Until Robert realized, the only person has a right to decide on his life; it was himself not a doctor or someone else's judgment.

"I decided that I was not going to have that operation. I might never be an experimental object, but I was enough with being the doctors' clay. I knew I was ugly. But everyone is uglier than they think. We are all more beautiful too. We all have flaws only we can own. An operation to fix my face might be leaving behind this horrid, bumpy, uneven, unequal, disquieting, disfigured, scary face that made who I am now. Sometimes people would say to me that I'd managed to do quite well despite my appearance and my disability. Moreover, I started to realize that I had not become who I was despite those things. There was much chance I had become who I was because of my ugliness and my disability. 'I do not want to have any more surgeries. Ever.' It was me, my legs and my ugliness facing the world." (Hoge, 2015:18)

Finally, Robert already knew what he must do for his life. He decides that he will not have surgery again. Maybe Robert's dream of being a handsome man will never come true, but for him, it has been enough to give his life's decision to

a doctor who continually changes his face. No one can be perfect, nor can Robert. Everyone has their shortcomings, and that is not a problem. Maybe Robert is an ugly child, has no legs, but that does not mean Robert is the only ugly man. Everyone has flaws in their own way.



CHAPTER IV

CONCLUSIONS

Ugly by Robert Hoge tells about the author's life journey, who was born with some issues. Robert had a tumor on his face, and his legs did not form correctly. He experienced many twists and turns of life since he was born as a disabled child. Robert and his family had to face all the ordeals and struggled in accepting one of the family members' conditions.

The researcher conducted this study because this novel had never been studied before. Many studies examine psychological approaches or moral values to find as the leading theory. Furthermore, this study also combines psychological approach by using Gargiulo's model to find struggles of Robert's parents' experience and collaborate moral value based on perspective Islam to prove Islamic teaching also can be universal teaching in conducting research.

This study found Gargiulo's model of parental reaction to disability portrayed in Robert's parents' attitude reactions to their deformed child, starting from initial response of shock (2015: 5) disbelief to prepare for the news of their child's disability, the next reaction is denial (2015: 7, 9) as a form of escape from the reality, followed by depression (2015: 11) and of the grieving process (2015: 8) in the primary stages.

The next is secondary stages from Gargiulo's model, Robert's parents deal with guilt (2015: 11) which is the feeling that difficult to deal by parents at this stage also during this stage the feeling of embarrassment or shame (2015: 15) is one of the consequences that Robert's parents get as the result of having a child with disabilities.

The last stages are tertiary stages, which is Robert's parents started to be comfortable and get used to the situation, then started to seek help for their child, such as medical, mental, or therapist handling who are experts in their respective fields (2015: 19, 25, 26). Followed by acceptance stages as the final stages for Robert's parents accepting all of the shortcomings their child have (2015: 13, 5, 17, 12, 13, 16, 138)

Other results that can be found in this study are the behavior of patience in the face of the ordeals, patience in accepting the reality, and patience in trying to be better, such as carrying out various operations. Besides, the researcher found that parental affection for children with disabilities can be a significant influence on children's development, children can be wiser in dealing with problems, become confident, and the main goals are children can accept all the deficiencies they have.

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