Child Rights Fulfilment of Children with Thalassemia: The case of Indonesia

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Abstract

Thalassemia is a genetical disease detected in the early lives of an individual. Blood transfusion is still the only treatment believed to be one of the means to prevent death for children with thalassemia. The blood transfusion is needed once a month, thus will prevent the children from normal interaction with their peers. Thalassemia is also influencing the physical condition of the children, because with the genetic blood disorder, the child face will have a unique feature. The physical changes are potentially disturbing the interaction between the children with thalassemia with the surrounded people which in the end will endanger the rights fulfillment of the children with thalassemia. Using quantitative and qualitative study, the research is trying to find out the fulfilment of child rights for children with thalassemia. It is found that the children with thalassemia have received their rights appropriate and in accordance with the ability of their parents. Although the children sometimes received discriminative and maltreatment from their peers and parents, but at the same time, they also received social support from their extended family and friends. The social supports serve as protective factors for the children and the parents to cherish their lives and be grateful for the lives they have.

Keywords: Child rights, Beta Thalassemia, Child Welfare
Background

Thalassemia is a genetical blood disorder which is common for people residing in the Mediterranean, East Asia, and South East Asia. For Indonesia, thalassemia occurrence mostly at Eastern Priangan. With the estimated total people with thalassemia of 7,700 individuals all over Indonesia (www.radarcirebon.com/45-penderita__thalasemia-ada-di-jawa-barat.html; retrieved at 03 October 2016, 15.15 WIB), the number is still growing despite the effort of prevention program conducted by Ministry of Health and other stakeholders is encouraged. Almost 45% of the total individuals with thalassemia resided in West Java. Thus strengthening the justification of research on Thalassemia at West Java Province. Thalassemia is a genetical disease detected in the early lives of an individual. Children with thalassemia acquired blood transfusion as well as the chelation therapy to reduce the iron in their blood as the result from the blood transfusion. Blood transfusion is still considered as the only way to reserve the red cell blood within the body of the patients. Children with thalassemia featured a unique development of the part of their body. The thalassemia major individuals appear normal when being delivered, however, at the age of 3-18 months, the anemia symptom and other symptoms such as faster heartbeat and facies cooley. Facies cooley is a unique feature of thalassemia major seen from the nose stem that being sucked inside and cheek bone that protrude as the bone marrow works extra hard in overcoming the hemoglobin deficit. In general, the thalassemia major individuals have to get blood transfusion and lifetime medication. Without a proper treatment, their lives expectancy can only be sustain around 1 – 8 years old (https://thalassemiaindonesia.blogspot.co.id/p/tentang-talasemia.html retrieved at 03 October 2016, 14.40 WIB).

Other than their distinguish facial feature, the children with thalassemia are also prone to side effect of their lifetime medication treatment. These can be seen from the bio, psycho, social and spiritual aspect of the child. With the distinguish feature, they are prone to discriminative attitude as well as misconduct behavior from their surrounding. The discriminative attitude and misconduct behavior received by the children with thalassemia is preventing them from gaining their rights as children as stated in the Child Rights Convention, which has been ratified by Indonesian Government at 1990 through President Decree No. 36 year 1990.

In Indonesia, the child rights fulfillment for healthy children themselves are challenging, moreover with their condition of thalassemia, the challenge can be twice. The same challenge goes for the parents as well. Thus the rights fulfillment for the children with thalassemia is another challenging factors either for the parents or for the government. The children and their family will need to adjust to their condition, and previous research claimed that the chronically ill children with their family will experience the problems twice compare with the healthy children (Oscar, et.al., 1994). Scholars also found that children with chronically ill showed psychological, academic, social, and family dysfunction (Oscar et.al. 1994).

The dysfunction occured due to bio, psycho, socio, and spiritual aspects. Bio aspect refer to the physical condition of the children with thalassemia shown by the unique facial features
and darkened skin due to iron overload after the blood transfusion. The psycho aspect refer to state of feelings such as, acceptance feeling, confidence, loss and grief, guilt and low self esteem. The social aspect refer to the interaction state of the children with either their peers or their surroundings. The social dysfunctioning happened because the children with thalassemia experienced less interaction with other children or people due to the lifelong medication process. The last aspect of dysfunction of the children with thalassemia is the spiritual aspect, which is refer to their beliefs. The spiritual dysfunction happened because the children and their family felt that their situation is unfair to them, and they started to disbelief in God, at an extreme point, the children and their family might questioning the existence of God, and arising question of “why me?”, “what did I do wrong?”. These dysfunctioning will potentially disrupt the welfare of the children with thalassemia and might endanger their child rights fulfilment. Research on rights fulfilment of the children with thalassemia is important to inform the practice of care for children with thalassemia with their families by multidisciplinary team (doctors, nurses, social workers).

Research on the welfare of the children with thalassemia is still limited, moreover for the publication. Thus this research on child rights fulfilment of children with thalassemia is aiming at describing the rights fulfilment of children with thalassemia in Indonesia. It is hoped that this research can stimulate more research on social interaction aspect of the children with thalassemia in their everyday’s lives.

**Beta Thalassemia, Child Welfare and Child Rights**

Thalassemia is a red blood genetic disorder affecting the production of red blood cell. The red cell blood will easily defected which then causing anemia. Thalassemia is inherited by the carrier parents to their children and is a life-threatening illness. The illness usually detected at early stage of a child, predicted from 3 months the symptomps start to appear. There has not yet found the appropriate cure for thalassemia, and the only way to keep the thalassemia children alive is through blood transfusion and iron chelation medication to reduce the iron in the blood due to the transfusion. Both medication is a lifetime treatment and currently has increased the live expectancy of the children with thalassemia. Thalassemia is being devided into two type mentioned by the UK Thalassemia Society (2008: 11) as:

- **β thalassaemia major (BTM)** in which haemoglobin production is so reduced that normal growth, development and quality of life can only be achieved by regular red cell transfusions from infancy. Death at an early age is inevitable if no transfusions are given. Where the term ‘thalassaemia’ is used without qualification, it usually refers to **β thalassaemia major**.

- **β thalassaemia intermedia (BTI)** in which a reduced amount of haemoglobin is produced, sufficient for growth and development without the absolute requirement for regular transfusions. Growth may fail, and other complications may develop, in later childhood and adulthood, requiring regular transfusions to start.

The effect of thalassemia to a child is not only endanger their lives, but also endanger their interaction and functioning as a human being. Widayanti, et.al. (2011: 484) stated that
individuals affected by beta-thalassaemia are not well integrated into society and chose to stay in their houses, and die before they reach the age of ten. The research also mentioned that many parents are not able to afford the costs of treatment due to their low socio-economic status (Widayanti, et. al. 2011: 484). Meanwhile, Baghianimoghadam, et.al. (2011) found that children with thalassemia experience a reduction in their physical, mental and social capabilities. Sananreangsak, et.al. (2012: 161) quoted Aydin, et.al (1997) and Gorree (2001) of the many issues faced by the children with thalassemia ranging from physical, psychological, socio-cultural and spiritual in accordance with their stage of development.

Children with thalassemia should receive a comprehensive care in order to achieve their welfare. The comprehensive care should include their medical treatment and their side effects as well as psychosocial intervention for them to be able to be functioning as necessary. Anemia Institute for Research and Education Canada (2009) proposed two components of comprehensive care for individual with thalassemia as a network of care and lifelong education and communication between patient and health care team (p. 11-14). The two components are a perfect combination of care covering the biopsychosociospiritual aspects of the child’s lives. Acknowledging the two components of care by the multidisciplinary team means the complete care not only for the children with thalassemia, but also for their parents and siblings.

The condition of biopsychosociospiritual of the children with thalassemia will influence the child welfare. Conceptually, all children are included into vulnerable population of being violated for their rights (Apsari, 2015), moreover for children with thalassemia. The child rights will not be fulfilled if the parents’ rights are violated. Thus, government as the duty holder need to ensure that the parents/families’ rights are fulfilled in order for them to realize their children’s rights fulfilment. This means that the rights of the children are vulnerable to be achieved due to their reduction in functionality. This added up to the child rights fulfilment especially for children with thalassemia.

Child welfare will be disturbed if the child experiences many obstacles along their development, as stated by Soetarso (2003) in Apsari (2015: 14-15). The obstacles such as malnutrition and inadequate housing; receive no care; ill and without appropriate health care; physically maltreated; maltreated and sexually exploited; do not receive a normal experience which can bring feelings of being loved, dignity and longing; emotionally disturbed due to continuous quarrel within the family, separation and mentally ill parents; and exploited, worked overtime, influenced by the unhealthy environmental and experience demoralization. The definition of child welfare itself has brought up a wide range discussion of simply referring to condition among neglected and abused children (Petr, 2003) to a condition of basic needs achievement for a healthy growth and development of a child including adequate income of the parent, housing, health issue, education and environment (Clifton & Hodgson, 1997).

The child welfare can be achieved with the fulfilment of the child rights. Child rights is an international agreement and being ratified by almost all countries in the world, including Indonesia at the year 1990 through President Decree No. 36. The countries which chose to ratify the convention obliged to report the fulfilment of the child rights within their country, to a committee of child rights which serves as the surveillance body for the implementation of the child rights in the country (Apsari, 2015). Government of a country is served as the
duty of bearer of the child rights fulfilment, as well as the civil society, including the non government organization, national and international.

The child rights based on the Convention is being devided into three large group, according to Durrant (2007:v), which are the right to survival and full development of their potential; the right to protection; and the right to participate in decision-making. These rights are comply to any children, healthy or sick. Every acts in the convention are connecting one another, as mentioned in Apsari (2015: 13) for example, the health and health care for a child will be influenced by the standard of living of the child and the availability of social security for every child, thus the child will benefit from the health care service in accordance with the child’s needs. Sometimes, in practice, the child rights fulfilment is in contrast with adult rights (parents rights), thus, as the duty bearer, the government must consider and achieved the rights of the parents first in order for the children to achieve their rights.

The child rights are rights that allowing a child to grown in accordance with their age development. With the definition of a child as a person from 0 – 18 years old, the rights of the children with thalassemia are also in accordance with their age development. The children with thalassemia targeted in this study are in the age range of 6-12 years old. At the age of 6-12 years old, according to Erikson, a child is in his/her middle childhood (Woody, 2003) and the characteristics are healthy, able to make friends and learn new things in their lives. Meanwhile, Fass & Mason (2000b) quoted by Hutchinson (2003a:205) said that the middle childhood children is considered as the education, play, leisure time and socialization as live dominating activities. Meanwhile, the children with thalassemia face challenges in some of the above activities, as quoted by Hutchinson (2003a), thus it is expected from the concept and reality that, the children with thalassemia might be in a situation where their rights are not fulfilled. This study is aiming at exploring whether the statement is in accordance with the reality.

The child rights in this study refers to the three group of right as mentioned earlier in the paper. The right to survive and full development of their potential were being broken down into the rights to the right to food, housing, education, leisure time activities and recreation as well as gaining access to information, cultural activities, information on their rights and the rights to express their views and opinions, dignity and self worth; the rights to protection consist of rights to get protection from abuse, neglect and maltreatment, the rights to get protection from exploitation, and the rights to get protection from cruelty act.

Methods

In order to get comprehensive understanding of the condition of the children with thalassemia, an indepth interview using interview guide to the children and their family is developed. The interview guide had gone pass throught the ethical committee of Medicine Faculty of University of Padjadjaran and the interview have gain the permission. The process then continued to sent the inform consent to the children and their family during their visit to the Hasan Sadikin Hospital for their routine blood transfusion. The children and their family gave the permission to the team to interview them during the transfusion. Sixty children and their parent (mother or father) were being interviewed at the hospital as the location of study. The interviewed children are at the age range of 6-12 years old and mostly are resided at Western Bandung Municipality. The children were accompanied by their
mothers and have to travel long distance to reach the hospital. The interview process was using the time of the children during their blood transfusion, which took two hours. The two hours was spent to build the relationship and explore the responds to the guidance.

The child rights in this study refers to the three group of right as mentioned earlier in the paper, however, for the interview instruments, the rights to participate in decision making were integrated to the rights to survival and full development of their potential. Thus making only two rights are included into the child rights. The right to survive and full development of their potential were being broken down into the rights to food, housing, education, leisure time activities and recreation as well as gaining access to information, cultural activities, information on their rights and the rights to express their views and opinions, dignity and self worth; the rights to protection consist of rights to get protection from abuse, neglect and maltreatment, the rights to get protection from exploitation, and the rights to get protection from cruelty act.

**Result**

The number of children with thalassemia in Indonesia is not as large as the number of children with cancer, however, their concerns are almost similar with the latter disease. The families of the children with thalassemia were not aware on their children’s illness, and the parents also said that they do not know the name of the disease. There is a thalassemia foundation called YTI (Yayasan Talasemia Indonesia) and parents of children with thalassemia organization called POPTI (Persatuan Orang Tua Penyandang Talasemia Indonesia). Both organization have assisted the children with thalassemia and their family in their child rights fulfilment. However, due to the not-so-famous illness, thalassemia patients often misunderstood, thus vulnerable to mistreated by the public. POPTI even serves as a recommendation provider for children with thalassemia to receive the social insurance or assistance, either from the government or the private sectors.

The POPTI are spread out all across Indonesia including in West Java Province, where the office is located in Bandung City. It is served as the bridge of communication between each stakeholders involved in providing care for the children with thalassemia such as hospital, government, family, school, POPTI and the children. According to POPTI, the person with thalassemia often received discrimination from school, workplace, and surrounding community. For the adult patient with thalassemia, the discrimination is experienced when they apply for work, one of the requirement is to obtain the state of the health recommendation letter, thus will prevent them for health clearance from the health care centre.

At the hospital, during the blood transfusion, the children are categorized as the age range of 6-14 years old. During the interview, the POPTI hoped that the children or adult are being put in the same room during the blood transfusion, but due to the policy of the hospital, they are being separated. This makes the data collection of the numbers of the children or patients with thalassemia difficult to gather because of the difference category based on the age range.
In this research, the Hasan Sadikin Hospital together with POPTI established a help desk for the children with thalassemia and their families whenever they have questions of queries on their illness and services that are available to them. The help desk often provides the children with thalassemia either the new comer or the old patient with recommendation or assistance with their medical needs.

The children with thalassemia interviewed mostly are boys, 31 out of 60 children. The age of the children is ranging from 6-12 years old. They were being diagnosed of thalassemia in almost similar time, which is from the age of 3 months up to 3 years old. Although some of them were diagnosed even when they were born. The maximum age of diagnosed was when the child reach the age of 8 years old and 10 years old. This means that before the children and their family aware of the illness they child experience, they were in a constant confuse and worry. There is also a similar notation on the time of diagnosed as thalassemia patient as mentioned by POPTI, that there was a case of a grown up diagnosed as suffering from thalassemia when he was already in his middle age and already have offsprings that 3 of his children was found to suffer from thalassemia in the family. This fact described the awareness of a person on an illness that he/she suffers, thus explaining the knowledge of thalassemia among people. This unawareness will lead people to discriminate and maltreated the children with thalassemia which will then prevent them from the fulfilment of their rights.

The informants in this study mostly resided at Bandung Municipality, which means that they have to spend some money to travel to the hospital, which is located in the middle of the city of Bandung and they also have to spend extra money while waiting for their children for blood transfusion. During blood transfusion, the children were accompanied mostly by their one of their parents, some of them were accompanied by their uncle and grandmother. Some of them also come together with the whole family, which then costing a lot more money to spend during their visit to the hospital,

**The rights to survival and full development of their potential**

The right to survive and full development of their potential were being broken down into the rights to food, housing, education, leisure time activities and recreation as well as gaining access to information, cultural activities, information on their rights and the rights to express their views and opinions, dignity and self worth.

The research found that the child rights to survive and full development of their potential are accomplished adequately. All of the children received the blood transfusion said that their access to food is adequate in accordance with their diet. They are aware of the diet that is prohibited for them. However, some of the children and their family sometimes violate their strict diet such as the prohibition of eating vegetables. The children sometimes cheated to eat the vegetables, and even sometimes, the parent gave them the menu with vegetable although they are aware on the consequences and understand that their children are prohibited to eat vegetables. The parents are giving pocket money to the children, and despite their illness, the children still buy foods that might not be suitable for their
condition. However, there was no report on the worse condition of a child with thalassemia because of eating food that might endanger their health.

The fulfilment of children rights for health and health care can be seen from their access to receive medical care including blood transfusions and other medication needed for their illness. Currently, the children with thalassemia received assistance for their medical expenses only from the BPJS Kesehatan (Health Insurance) provided by the government. They can receive the insurance after showing the letter of recommendation from POPTI as one of the requirement. With the health insurance, the children can gain access to maintain their health. However, their access only applied during their visit to the hospital, yet other expenses during their stay at the hospital for blood transfusion, is not covered by the insurance. Thus the parent still have to spend extra money during their visit.

For housing, the families of children with thalassemia have settled in their own houses and despite the limited space in the house, the children are happy to share room with their parents. They felt comfortable and secure because of that sharing room with their parents. Schools are fun, and all of the children have vision for their future. Some of the children are aware that they can not be exhausted, so they chose an appropriate vision for their future. The children also said that because they are aware of their live expectancy, for some older children, they are hesitate to have a dream, although for some of the younger children, they are eager at sharing their dreams when they grown up. At school they do not experience challenges in following the activities, however, some of the children felt less confidence due to their physical condition. The parents gave the children the liberty to decide whether they want to go to school or not. The schools themselves have understood the condition of the children with thalassemia thus they give permissions to the children for limited activities during sport lesson. This means that the children with thalassemia have the opportunity to be fulfilled their rights in education.

For the cultural activities, the children with thalassemia often being taken by the POPTI to cultural events, in this instance, the sundanese cultural event, such as went to Saung Angklung Ujo. At school, some of them are able to play angklung and almost all of the children are interested in joining the cultural activities. As for activities at their leisure time, all informants like enjoy to travel far away and visit a playground based on the information from their friends. The children with thalassemia are aware of the economical condition of their parents, thus make them rarely go for recreation. The only recreation they have is playing at the playground with their friends. Although the parents sometimes upset and angry at them, but the parents provide understanding to their children of why do they prevent the children from visiting a far away playground. However, for involving the children with thalassemia in decision making for their lives, the children do not achieved their rights appropriately, and this is happen because the parent thinks that their children are unable to make a proper decisions, thus the parents always take on the decision making and the children should follow the decision that has been made.
The rights to protection

The rights to protection covering the rights of protection from abuse, neglect and maltreatment, the rights to get protection from exploitation, and the rights to get protection from cruelty act. Most informants said that they experience mocking from their friends because of their unique feature and complexion. However, they also said that they have best friends and that these best friends have helped them going through rough times in their lives.

As the parent’s rights fulfillment, the majority of the parent have received the social support needed from their extended family. However, some neighbors also envy them because they received the service from BPJS although they are considered as wealthy. Some informants also mentioned that they children’s acceptance of the illness took a while because none of their family have experienced such illness. Although the majority of the children interviewed mentioned that they experienced mocking from their friends, but they still have best friend or close friends who are always supporting them.

None of the children with thalassemia who are being interviewed have experienced abuse, neglect, maltreatment, exploitation and cruelty act from other persons in their lives. This means that the child rights to protection have achieved and accomplished because the parents think that the children’s lives are endanger because of the illness.

The research found that the children and their family need shelter before and after they received the blood transfussion. Until the interviewed done, there is not yet shelter being build for the thalassemia children and their families. POPTI also have the same idea of providing shelter for the children and their families, but POPTI and the parents are still unable to find donation in fulfilling a dream of building a shelter for children with thalassemia and their families.

Conclusion and Recommendation

The child rights fulfilment for healthy and normal children are sometimes violated at some points due to a believe that children are the property of their parents. However, such situation is not the same with the children with thalassemia. The parents tried so hard to ensure their children to receive the best care because they are aware that the children’s lives are endanger because of the thalassemia. Especially, with knowing that their children can only lives by a lifelong medical treatment, which is blood transfusion and other medicines, not to mention the side effect of the blood transfusion and other illness which emerge as the side effect of the thalassemia.

With that knowledge and understanding of the dangerous of the illness, the children are ensured to receive the proper treatment, medical and social, thus enable them to make the best of their time alive. The rights to survival and full development of their potential are achieved in accordance with the ability of the parents in fulfiling them. As for the rights to protection, the parents have also accomplished them, although at some point, the children received maltreatment from their friends. The maltreatment does make the children felt
disappointed, but they are able to bounce back due to social supports from other friends and families. Thus this research have found that the rights of the children with thalassemia are accomplished. The accomplishment is supported by existing social support the children and their families received from friends, neighbours and extended families.

Because there is a need of a shelter, this study recommend that stakeholders involved in the care for the children with thalassemia to establish a fundraising event to build the shelter. Doctors, nurses and social workers need to work together to ensure the adequacy support for the children with thalassemia and their families, including fundraising for establishing a shelter. One of the way of the fundraising is through crowdfunding which have shown some success in raising money for achieving social aims.
References


