

# A Loss Experience of a Grandmother of a Grandchild With $\alpha$ -Thalassemia

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Received: February 2, 2017; Accepted: July 17, 2017; Published: August 21, 2017

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## Abstract

The prevalence of thalassemia in Taiwan is relative high. The main problem of thalassemia is not able to produce stable hemoglobin, so it needs treatments of regular blood transfusions, iron chelator, or d bone marrow transplantation. This can lead to a lifelong impact on the sick children and their families who may have a high risk of psychosocial issues. This paper was related to caring for a neonatal with  $\alpha$ -thalassemia who needed to be treated in an intensive care unit. The grandmother deeply experienced grief due to the loss of her healthy grandchild. Interaction and interview with the grandmother were recorded as process recording. Data analysis used content analysis. Findings included (1) experiencing life from enjoyment to tribulations; (2) repeatedly self-blame and difficulty accepting the inherited disease; (3) losing daily routines and plans; and (4) overcoming a high degree of uncertainty to face the future. For patients and their families, nurses should be with them and conduct active listening and recognizing their grief due to their losses. Also helping them to discover the meaning of the losses can enhance the transition process from grief to healing.

**Keywords:**  $\alpha$ -Thalassemia; Grandmother; Grief; Neonatal intensive care unit

## Introduction

Thalassemia is the most common single gene disorder, affecting millions of people worldwide. According to the latest statistics from the World Health Organization, approximately 7% of the world population carries the gene that causes this disorder, in which hemoprotein pathology prevents the production of stable hemoglobin [1]. The primary treatment for thalassemia is bone marrow transplantation. Prior to transplantation, blood transfusion and iron chelation therapy are basic treatment options. Thalassemia has a life-long effect on children and their families, and patients are at high risk for psychosocial issues [2, 3]. Currently, most thalassemia-related studies focus on genetic screening or prenatal diagnosis [4, 5]. A few studies have examined the experiences of providing care to the mother of a fetus with thalassemia [2] or to a patient with thalassemia [3]. However, studies of life experiences from the perspective of a grandmother whose grandchild has thalassemia are lacking. An understanding of grandmothers' experiences can serve as a reference for health care workers in formulating care strategies that satisfy health care needs and reduce stress.

## Literature Review

Thalassemia, also known as Mediterranean anemia, commonly occurs in residents of the Mediterranean coast as well as residents of China and other parts of Asia. Approximately 6% of Taiwanese are

genetic carriers of this disorder, in which abnormalities in globin chain synthesis cause decreased amounts of hemoglobin. Both  $\alpha$ -thalassemia and  $\beta$ -thalassemia are common in Taiwan. In  $\alpha$ -thalassemia, the complete absence of  $\alpha$  genes results in the inability to produce  $\alpha$  globin chains. Fetal symptoms include severe hemolysis, tissue hypoxia, ascites, pleural effusion, or systemic edema (also known as hydrops fetalis). Thalassemia may cause fetal death, premature birth, or death soon after birth. Because of the high prevalence of thalassemia in Taiwan, a screening system for pregnant women was established in 1991 to achieve the goals of genetic health and to prevent the multitude of problems associated with caring for a child with a congenital disorder.

Newborns with  $\alpha$ -thalassemia are often immediately placed in an Intensive Care Unit (ICU) for intensive medical care. The baby's illness, the premature delivery, the environment of the ICU, isolation from the baby, and the baby's physical and emotional problems create a substantial amount of stress, including anxiety, depression, or symptoms of trauma, for the parents and other family members. Mothers typically repress their emotions to retain control of the situation and to protect themselves from possible loss. They may even experience guilt or a sense of failure [6, 7]. When children have chronic health problems, their grandparents' reactions are quite similar to those of their parents: shock, anger, or sadness. Grandparents often take on many roles, including caring for the sick child or providing emotional or financial support. The support of grandparents can influence the family's cohesion and ability to cope with the situation. A family acts as a unit, and the adjustments made by family members influence each other. Although grandparents have important roles, very few studies have examined the experiences of grandparents [8]. Grandparents are particularly important in Chinese culture. Therefore, we explored the life experiences of a grandmother whose grandchild was placed in a NICU because of  $\alpha$ -thalassemia.

## Case Report Methods

### Data Collection and Analysis

The first author cared for the patient from April 18, 2014 to April 29, 2014 when taking her pediatric clinical practice. During the caring period, the interactions and conversations with the patient's grandmother were recorded to explore her experiences of having a grandchild with thalassemia. The recorded data were analyzed using content analysis. First, the records of conversation and interaction needed to be read multiple times to gain an overall understanding of her experiences.

Next, open coding was applied to mark meaningful phrases as the unit of analysis. Units with similar concepts were organized into subcategories and categories [9]. The rigorousness of the data analysis was based on the criteria of credibility, transferability, reliability, and confirms ability, as proposed by Lincoln and Guba (1999) [10].

## Background of the Patient and Grandmother

Signs of edema were discovered in the fetus during the 26th week of pregnancy. The mother was immediately transferred to the medical center hospital for further diagnosis and treatment. The physicians suspected the baby of having thalassemia. Five weeks after the transfer, at 31 weeks of gestation, a Cesarean delivery was performed because of severe edema. At birth, the infant weighed 2200 gm and exhibited difficulty breathing and severe intercostal restrictions. End tracheal intubation was performed in the operating room and the infant was admitted to the NICU. X-rays showed ascites; paracentesis to drain the fluids was performed immediately. The day after birth, the patient's bilirubin level was 17.31 mg/dl, and exchange blood transfusion was started. Two days after birth, the diagnosis of thalassemia was confirmed and the physician met with the family to discuss the patient's prognosis. After consideration, the family chose palliative care for the patient at the end of that day. However, the patient's condition began to improve and her treatment was changed with a goal to discharge from the hospital. She required a blood transfusion approximately every 3 weeks. Because of her poor oxygenation and circulation, a nasal cannula delivered oxygen at a rate of 0.1–0.5 l/min. Also she was fed through a gastric feeding tube because of her poor suckling ability. The main sources of income in the family were the patient's father and the patient's grandfather. The patient's grandmother was 52 years old at the time and frequently worked in a nearby factor making handcrafted goods to supplement the family income. To protect the patient's privacy and confidentiality, we used the pseudonym Baby Qi instead of the patient's real name.

## Results

The grandmother's experiences with her grandchild's diagnosis of  $\alpha$ -thalassemia and care in the NICU are described in greater detail below, including experiencing life from enjoyment to tribulations, repeated self-blame and difficulty accepting the inherited disease, losing life routines and plans, and overcoming a high degree of uncertainty to face the future.

### Experiencing Life from Enjoyment to the Tribulations

The grandmother eagerly anticipated the arrival of her first grandchild and looked forward to becoming a grandmother. She accompanied her daughter-in-law to prenatal checkups and saw the ultrasound images of the fetus. As a result, she became emotionally invested in the baby. She had begun to establish emotional ties to the baby and envisioned a bright future. The grandmother said:

*When my daughter-in-law was pregnant, I was the one who went with her [to prenatal checkups]. I didn't miss a single time. I even went in to see the ultrasound images. The joy—When she did the ultrasound imagining, I was so happy when I saw the baby. I looked at the screen and said 'Your grandma's here' (the grandmother demonstrated smiling and waving to say hello to the baby). That happiness—I felt that it didn't matter if it was a boy or girl, as long as the baby was healthy.*

When the grandmother was told that the fetus had ascites and needed to be transferred for a series of tests, she became aware that the baby was ill. The doubt and uncertainty she felt while waiting for a diagnosis caused her to be worried and anxious. When the physician diagnosed her grandchild with thalassemia, the grandmother felt helpless and scared because she knew nothing about the condition. She felt shock, sadness, and agony because she was deprived of a healthy grandchild. The grandmother said:

*We started at [another hospital] until about six months into the pregnancy. We transferred here because the baby had fluid in her belly.*

*The doctor thought there might be a bowel blockage and first ordered amniocentesis and a chromosome test.... Then one day the doctor told us the baby had thalassemia. We were all confused and had no idea what thalassemia was. Because no one told us about it, we didn't understand it at all.... That helplessness and pain—We went online when we got home; that's how we knew what thalassemia was.... It was like being hit over the head. This completely unexpected thing, it was just like being hit with a stick. We were just floored.*

The moment that the patient was born, the grandmother saw her grandchild's unusual physical appearance and symptoms. The reality of the patient's illness made the grandmother truly realize that she had been deprived of the healthy grandchild she had been expecting and destroyed her expectations about being a grandmother. She felt dismay and shock; her dreams had shattered. She was in pain and unsure about what the future would hold. The grandmother felt bipolarized emotions, from joyful anticipation to falling into a bottomless black hole. The grandmother said:

*The joy from seeing the ultrasound at first, to now—it's like a beautiful, full balloon that was burst by a needle.... Originally, we were all excited about greeting this new life, but now we're in pain. The doctor said she needed surgery right away. When the baby was brought out.... My tears just started falling (sobbing, shoulders twitching). Seeing her little body with that big belly, I was so sad and it hurt so much (sobbing). My heart broke into pieces.... It was too shocking.*

### Repeated Self-Blame and Difficulty Accepting the Inherited Disease

From the time the grandmother was told of the patient's condition, and throughout the patient's hospitalization, the grandmother repeatedly engaged in self-blame. Because the patient and the entire family were suffering because of the present circumstances, she could not help feeling guilty and blamed herself for not choosing the biggest hospital. The grandmother said:

*I did it for [my daughter-in-law]. I took her to a big hospital, for a more careful checkup.... If she had gone to a regular obstetrics and gynecology clinic, I would have asked why they went to such a small place. The result is the pain we feel today (choking up). I didn't want them to give birth in a small clinic; I told them to go to a bigger hospital. Even though we didn't take her to Changhua, [the other hospital] is still the largest hospital in town. That's why I'm in so much pain.*

The grandmother's expectations for prenatal checkups were that the health care professionals would ensure the health of her grandchild and eugenics. Therefore, the grandmother was unable to understand why these regrettable events happened even though they followed all of the doctor's suggestions. She was filled with powerlessness and anger about her helplessness. The grandmother said:

*We went for prenatal checkups every month. At some point, they told us that our insurance didn't cover certain tests. I think we paid for those tests. We got whatever tests they told us we needed. In the sixth month, all of a sudden they found fluid in the baby's belly.... And we didn't know the thalassemia until she was ready to be born.... We always did what the doctors told us to do.... I feel like the prenatal checkups were pointless.... There have been tests for [thalassemia] for dozens of years. Especially now, with eugenics, how can this happen? I don't know what to say about this.*

### Losing Life Routines and Plans

When the patient's family thought the pregnancy was "normal" and life was uneventful, they prepared for a new addition to the family by planning each member's career and responsibilities after the birth of the baby. However, these plans were interrupted by the patient's illness and need for long-term care. The family's focus turned to handling the immediate crisis, but the situation became chaotic because they lacked control over future plans. The grandmother said:

Before the baby was born, we all made plans about what we were going to do. But this messed up everything. If Baby Qi wasn't like this, her grandmother could help take care of her. But she can't because of her condition.... We had thought that her mom could go back to work after a month of postpartum recuperation. Now, everything's changed and all we can do is keep going. Basically, our life's been messed up, and we can't do anything about it.... It's like an assembly line and everyone is a component. Baby Qi is a component, but that component is broken, and now the entire assembly line has broken down.

Visiting the ICU became a part of their daily routine. However, the visits to the ICU were stressful and affected the grandmother's emotional and physical well-being. In addition, their routines were further disrupted by unpredictable or unexpected medical treatments or events. Their lack of control over daily life was inevitable. The grandmother said:

When Baby Qi was first hospitalized and I was in a hurry to make dinner, I came close to hurting myself a few times. I didn't want to tell them though. We used to have normal routines. Suddenly having to face something like this, everything is hectic but we don't know what we're doing.... Whenever the hospital calls, we need to take days off. It affects our daily lives, it's all messed up.... The baby's grandfather and the father both work and can't come [to the hospital] in the morning. After they get off work, they take a quick bath and come see the baby without eating dinner. Sometimes they only eat one meal a day. On the weekends when they don't work, [the father] comes both morning and night (visiting time). So does the grandfather.

Although the grandmother made daily visits to the hospital, she was not familiar with the environment, nor did the visits reduce her anxiety. Instead, she was very conflicted: on the one hand, she was happy to see the patient; on the other hand, she was worried and unsure about the ICU and the patient's condition. The grandmother said:

Baby Qi has always been in the hospital, she hasn't been home yet since her birth. I keep wondering what will happen today or tomorrow. Because of that unsettling feeling, I'm actually always reluctant to go to the hospital.... When I get up in the morning, I want to rush to see her, like a young girl in love who anticipates a phone call from her boyfriend every day. But that's happiness. What I feel when I come here is ambivalence.

### Overcoming a High Degree of Uncertainty to Face the Future

The patient currently requires regular blood transfusions. The grandmother felt anxious and uncertain because she was unfamiliar with this treatment. As a result, she began to build up her own experiences with blood transfusions to increase her control over and reduce her anxiety regarding the situation. The grandmother said:

The baby had a blood transfusion on the 12th. Now it's the 29th. I think they said it was 9.5 last time, it was less than 10. Now it's 8.6. I don't know if this decrease is considered fast or slow. I really want to understand. There was a doctor who wanted to give her a blood transfusion before, and he predicted that she would drop to around 6. They took her blood and it was about 7, so it dropped more slowly. Of course that made us feel better, that meant that she was a little better.

An improvement in the patient's condition did not necessarily mean that she was cured; she may still require a bone marrow transplant. The grandmother knew that her own efforts had no effect on the success of treatment and felt anxiety, fear, a lack of control, and uncertainty. She was also concerned that a bone marrow transplant could endanger the patient's life. The grandmother said:

They told me before that they were going to take care of baby to make sure she was in good enough condition for a [bone marrow transplant].... We were more worried about if she does get a transplant, what are the side effects? We were also worried; worried that she's so small. Now we're wondering what the chances of [the hospital] are doing the transplant.

...Really, that just made me so uneasy. It's like before, if I do something well, then I'd feel peace of mind. But this type of torture is so difficult. This is, you don't need to do anything, so it feels unsettling. I won't be at ease unless she is completely cured. Otherwise, this will just keep happening.

Hope for the success of the treatments and for the patient to grow up healthy were the greatest motivation for the grandmother to continue forward. Although the grandmother acknowledged her own unease and fear, she was able to face the responsibilities of difficult and challenging care giving with strength and courage. She tried her best and did all she could for the future of the patient. The grandmother said:

I often say that you're responsible for the child you gave birth to.... You do what you have to.... We're in our fifties; you can't really say we're old-fashioned. We do what we have to. Sometimes when things happen, we need to vent a little, cry a little. But we still need to be strong.... After we wipe away the tears, we just need to carry on. A condition like hers, all we can do is keep taking care of her and waiting for a match. I hope baby finds a match soon, and gets the transplant quickly. This is a necessary journey, and we need to do our best. When the transplant is successful and baby can grow up like an ordinary child that will finally be a load off our minds. Until then, we will be constantly uneasy. Still, we need to face reality. What we're working for is a happy ending.

The grandmother provided empathy and support to her family and led her family members in investing their efforts for the patient's health. The grandmother said:

Her mother couldn't eat. During the month of postpartum recuperation, she barely ate anything. I cooked a lot of meals every day, hoping she'd eat more.... What you're [the daughter in law] supposed to do, I will teach you.... This is my responsibility. They're young, they've never raised children before, and they don't have any experience. Although they're scared, they've tried hard to take care of her.

### Discussion

This study explored a grandmother's experiences from the joys of life to the tribulations of life. The grandmother experienced the anticipatory and acute grief when grandmother throughout the process of her grandchild's diagnosis and the possibility of losing her grandchild. Previous studies have asserted that family members feel deprived of a perfect child when a child is born with abnormalities [11]. Acute grief occurred when experiencing sudden loss. Acute grief elicits emotions such as extreme sadness, denial, and anger [12]. Anticipatory grief refers to grief experienced prior to actual loss. When parents of newborns in NICUs predict that the infant will not survive, anticipatory grief is a coping strategy that parents use to prevent being overwhelmed by the pressure and to prepare for the worst case scenario. However, anticipatory grief can form a temporary barrier to establishing the parent-child relationship [12, 13]. Nurses in NICUs should encourage and help parents and other family members to participate in the child's care and to gradually take on more care giving responsibilities. This would increase the parents' identification with the role of parents as well as their confidence and sense of control. Nurses should also accompany family members in their journey of grief to help them cope with their loss [13].

Studies have shown that when grandchildren are born with disabilities, their grandparents grieve for the experiences of their own children as well as their grandchildren [14]. The grandmother of the patient in this study repeatedly blamed herself and was unable to accept the occurrence of a disorder for which genetic testing exists. Studies have shown that when children are born with structural, functional, or metabolic disorders with genetic causes, their mothers experience various degrees of self-blame and guilt [11]. The patient's grandmother experienced a loss of life routines and plans. An initial loss causes additional loss, such as a feeling of wholeness, independence, and physical functioning. These losses not only disrupt an individual in the present time frame, but also produce far-reaching changes in an individual's outlook for the future

The patient's grandmother endured extreme uncertainty to shoulder a responsibility to fight for the future. Previous studies have found that parents of thalassemia patients are worried about the future. The disease exerts continued stress on the parents, and parents often waver between uncertainty and stress relief. Parents learn how to cope with the situation for their children. They deal with and face the situation with strength and shoulder responsibilities without question. They view care giving as an unending responsibility [15]. When an individual understands that uncertainty is a natural part of life and accepts the uncertainty, the spiritual crisis can elicit positive adjustments, such as renewal of hope, post-trauma growth, or self-organization. Even when an individual is faced with a situation involving extreme hopelessness or suffering, he or she can still discover the meaning of life, which allows the individual to exhibit courage and tolerance [16].

## Conclusion and Suggestions

Beginning with a patient's initial diagnosis of thalassemia, health care workers provide care to the patient and the patient's family members and thus develop close associations and relationships with them. Establishing supportive and facilitative relationships can help the patient and family cope with the chronic illness [17]. Because people may react to loss or grief in unexpected ways, health care workers should try to understand the experiences from the perspective of the patient or the patient's family members. Health care workers can assist parents/families in providing necessary information, such as the diagnosis and prognosis; identifying and strengthening effective coping strategies; and providing parenting skills [12, 13]. Nurses can be with patients/family members through active listening and acknowledging the pain of family members caused by loss. By helping patients and their family members to explore their experiences, health care workers can assist grieving individuals with finding meaning and promote their transitions from grief to healing [18].

## Declarations

No potential conflict of interest was reported by the authors. Also there was no funding support for this case report.

## References

- Viprakasit V, Limwongse C, Sukpanichnant S, Ruangvutilert P, Kanjanakorn C, et al. Problems in determining thalassemia carrier status in a program for prevention and control of severe thalassemia syndromes: a lesson from Thailand. *ClinChem Lab Med*. 2013;51(8):1605-1614. doi: 10.1515/cclm-2013-0098.
- Cheng MC. A pregnant thalassemia carrier's coping behaviors as she faces screening. *J Nurs*. 1999;46(5):44-54.
- Tsai SP, Cheng SC. Comprehensive nursing management improved the treatment outcome of a patient with  $\beta$ -thalassemia major. *Kaohsiung J Nurs*. 2013;30(1):96-106.
- Hafezi-Nejad N, Khosravi M, Bayat N, Kariminejad A, Hadavi V, et al. Characterizing a Cohort of  $\alpha$ -thalassemia couples collected during screening for hemoglobinopathies: 14 years of an Iranian experience. *Hemoglobin*. 2014;38(3):153-157. DOI: 10.3109/03630269.2014.909365.
- Liao C, Pan M, Han J, Yang X, Zhen L, et al. Prenatal control of Hb Bart's hydrops fetalis: a two-year experience at a mainland Chinese hospital. *J Maternal-Fetal Neonat Med*. 2015;28(4):413-415.
- Obeidat HM, Bond EA, Callister LC. The parental experience of having an infant in the newborn intensive care unit. *J Perinatal Edu*. 2009;18(3):23-29. doi: 10.1624/105812409X461199.
- Wigert H, Johansson R, Berg M, Hellstrom AL. Mothers' experiences of having their newborn child in a neonatal intensive care unit. *Scand J Caring Sci*. 2006;20:35-41. DOI:10.1111/j.1471-6712.2006.00377.x.
- Lee M, Gardner JE. Grandparents' involvement and support in families with children with disabilities. *EducGerontol*. 2010;36:467-499.
- Elo S, Kyngäs H. The qualitative content analysis process. *JAN*. 2008;62(1):107-115.
- Lincoln YS, Guba GE. Establishing trustworthiness. In: Bryman MA, Burgess R, editors. *Qualitative research volume III*. London: Sage; 1999. p. 397-444.
- Wright JA. Prenatal and postnatal diagnosis of infant disability: breaking the news to mothers. *J Perinatal Edu*. 2008;17(3):27-32.
- Drench ME, Noonan AC, Sharby N, Ventura SH. Loss and grief. In: *Psychosocial Aspects of Health Care*, 3th ed. Boston: Pearson. 2012:145-171.
- Dyer KA. Identifying, understanding, and working with grieving parents in NICU, part I: identifying and understanding loss and the grief response. *Neonatal Network*. 2005;24(3):35-46. doi: 10.1891/0730-0832.24.3.35
- Woodbridge S, Buys L, Miller E. Grand parenting a child with a disability: emotional rollercoaster. *Australas J Ageing*. 2009;28(1):37-40. doi: 10.1111/j.1741-6612.2008.00344.x
- Atkin K, Ahmad WIU. Family care-giving and chronic illness: how parents cope with a child with a sickle cell disorder or thalassaemia. *Health Social Care Community*. 2000;8(1):57-69. doi: 10.1046/j.1365-2524.2000.00211.x
- Agrimson LB, Taft LB. Spiritual crisis: a concept analysis. *J AdvNurs*. 2009;65(2):454-461. doi: 10.1111/j.1365-2648.2008.04869.x
- Tsiantis J, Dragonas Th, Richardson C, Anastasopoulos D, Masera G, Spinetta J. Psychosocial problems and adjustment of children with B-thalassemia and their families. *Eur Child AdolesPsy*. 1996;5:193-203. doi: 10.1007/BF00538846
- Duteau J. Understanding the lived experience of loss and grieving in persons with end stage renal disease: a humanbecoming approach. *Canadian Assoc Nephrology Nurses Technol J*. 2010;20(2):18-22.