# Living with the Differences: Thai Adolescents' Experiences of Living with Transfusion-dependent Thalassemia

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**Abstract:** Although transfusion-dependent thalassemia causes physical and psychosocial impacts, little is known about adolescents' experience in living with the disease. The knowledge of how adolescents live with their illness is expected to benefit patient focused nursing interventions to promote adolescents' well-being. The purpose of this study was to understand and explain Thai adolescents' experience of living with transfusion-dependent thalassemia.

Grounded theory methodology was employed to generate a substantive theory to capture that experience. Data were gathered from thirteen Thai adolescents through in-depth interviews and analyzed concurrently through constant comparative analysis to generate a substantive theory. The adolescents were recruited by purposive and theoretical sampling. Theoretical saturation was a criterion to finish data collection. *Living with the differences* emerged as a core category of the substantive theory, and consists of four related categories: illness understanding; a sense of differences; emotional experiences; and, managing the differences.

The findings provide better understanding of the experiences of Thai adolescents attempting to meet social expectations of normalcy in living with transfusion-dependent thalassemia. This understanding adds to prior knowledge of the disease and other chronic illnesses, and contributes to the development of nursing interventions to support adolescents to achieve well-being as they navigate life.

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**Key words:** adolescents, chronic illness, grounded theory, differences, thalassemia

## Introduction

Thalassemia is a chronic inherited disease caused by impaired synthesis of polypeptide-globin chains in Hemoglobin A.[1] Transfusion-dependent thalassemia (TDT), including beta-thalassemia major and severe beta thalassemia/Hb E, is the most common form of thalassemia that adolescents can survive with adequate blood

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transfusions.[2] Weakness, malaise, and activity intolerance are major clinical manifestations.[2, 3] Growth retardation, delayed puberty, poor musculature, thalassemic face and dirty gray-brown skin color are typical manifestations of the disease, with recurrent infection a common complication after a splenectomy.[2, 3] When curative treatment is impossible, adolescents receive blood transfusions, usually every 4 to 6 weeks, to maintain normal physical function and prevent cardiac dysfunction.[4] However, frequent blood transfusions lead to iron overload that may cause cardiac failure, if not managed through chelation[1,5] Certainly, TDT and its treatments have major physical and psychosocial impacts on adolescents who are at a stage in which developmental tasks can be impeded by chronic illness.[6]

According to the Thalassemia National Plan of Thailand, primary goals of health care services for adolescents living with TDT include enhancing the medical treatment of the disease and improving the patients' well-being.[7] To attain the goal of well-being, nursing professionals needs to gain a better understanding of adolescents' subjectivity of living, since little is known about Thai adolescents' experience. The knowledge is expected to explain adolescents' perspectives and behavioral responses to their illness in living with TDT.

## Review of Literature

Prior studies of Thai children and adolescents with TDT primarily have been quantitative. Their findings reveal that key stressors for these young people include anemia, weakness, fatigue, inability to play sports or engage in other vigorous activities, having a large abdomen, thalassemic face, dark skin color, missing school due to medical treatment, limited social life and social interactions, and parental overprotection.[8] Social maturity has been found to be related to illness severity among this group.[9] A previous study explained adolescents' feeling of being different and dependent, and their difficulties in developing adult social roles, especially the ability to assume occupational and family roles.[10] Similar findings have been reported in studies, which have been conducted in England and Turkey, of young people with TDT.[11, 12, 13]

There remains a gap in knowledge about Thai adolescents' experiences of living with TDT. Previous research has found that adolescents living with TDT in England value achievement in school activities and employment, and being accepted by peers. They reportedly focus on how to forget their illness, preserve some sense of being normal and compare themselves with others with more severe forms of the illness.[12] These experiences are similar to the experiences of adolescents living with cancer, attention deficit hyperactive disorder, diabetes, asthma and cystic fibrosis.[14, 15, 16, 17, 18, 19]

In Thailand, the behaviors of adolescents living with TDT have been explained by health care providers' views of their health behaviors, especially in regards to their adherence to medical treatments. [20] Social interactions, which may be rooted in Buddhism, gender identity, gratitude and self-training to cope with life situations, have not been explained in relation to adolescent Thai's behaviors.[21, 22] In addition, the most severe clinical manifestations and medical dependency regarding TDT have yet to be clearly discussed. Thus, the goal of this study was to begin to fill this knowledge gap, using a research method particularly suited to discovery.

## Method

The purpose of this study was to understand and explain Thai adolescents' experiences of living with TDT, using grounded theory methodology to generate a substantive theory to capture that

experience. The methodology was selected because of its underlying philosophy that people make meaning of their experiences and develop their sense of self through social interactions with others.[23] The classical grounded theory qualitative method was employed to reveal the adolescents' perceptions and daily behaviors as they lived with the illness.[24] The informants' experiences were captured through their own words as they explained their experiences. The researchers' preconceived ideas about the experience were identified and put aside before going into the field to prevent biasing or forcing the data, and to allow full discovery of the adolescents' experiences.[24, 25, 26]

The study was first approved by the human research ethics committee of the Faculty of Nursing, Chiang Mai University; Buddhachinaraj Hospital, Phitsanuloke; and, Uttaradit Hospital. The study was conducted in two provinces of Phitsanuloke and Uttaradit, Thailand. Potential informants were approached, by way of a letter of invitation, in the pediatric departments of Buddhachinaraj Hospital and Uttaradit Hospital. After explaining the research procedure and informants' rights, the primary researcher asked the volunteer informants and their parents to sign assent and consent forms. With the parents' permission, the primary researcher scheduled an appointment for an in-depth interview, with the adolescents, at a time and place of the adolescents' choosing.

Data were collected from May 2006 through June 2007. Each interview lasted 60 to 90 minutes and each informant was interviewed 3 to 4 times. All interviews were audiotape recorded. Informants were given the opportunity to stop the interviews at any time to rest or terminate the interviews. In conducting the interviews, the primary researcher assumed the role of learner with an open mind and high sensitive to learning about the phenomenon from the informants. The initial broad question, "What can you tell me about your experiences in living with TDT?" opened each initial interview. To facilitate the storytelling of their experiences with the illness, informants also were shown a 'My life timeline,' a line with diagnosis marked at one end, now marked in the center and future marked at the other end. Each informant's story guided follow-up questions. Each interview was transcribed verbatim. Personal data and history of the illness were recorded from the interviews and, with the informants' permission, medical records from the hospitals. The informants' behaviors during the interviews, and social contexts of the interviews, were written into the note taking. Developing hypotheses were documented in memos to capture emerging categories and their properties.

Data were analyzed by the constant comparative method, which involved concurrently collecting, analyzing, verifying and developing theoretical explanations from the data. The informants' words or phases were constantly compared within and across transcripts, for substantive coding, that included open-coding and selective-coding.[26] After interviewing the first six informants, *living with the differences* emerged as the core category. Then, with theoretical sampling, selective coding that focused on information related to the core category and open coding continued.[25] Open codes and selective codes were grouped and re-grouped according to similarities and differences to form categories and their properties. Theoretical coding was employed to generate and integrate these categories, properties and their interrelationships in a set of conceptual explanations or substantive theory.[24] Data were analyzed with the researchers' theoretical sensitivity in developmental science, psychosocial science, medical science and nursing science. Data collection and analysis stopped when theoretical saturation was achieved, no new data that explained the core category emerged.[24]

Trustworthiness was assured through the use of strategies suggested by Lincoln and Guba based on concepts of fit, workability, relevance and modifiability of a grounded theory.[24] Memos were written to assure confirmability of the inquiry process. Transcripts were reviewed mutually among the researchers to achieve agreement on coding to ensure dependability.[27] Credibility was assured through peer debriefing, member checking and triangulation of data.[27] Two nurse instructors, who were experts in qualitative methodology and grounded theory, reviewed theoretical explanations and emerging data for peer debriefing.[27] Informants were asked to review initial and final drafts of the substantive theory to determine whether the theory captured their experience.[27] Data were triangulated by crosschecking interviews, medical records and note taking. The strategies for confirmability, dependability and credibility supported the fit, workability and relevance of the substantive theory. Rich information of the substantive theory and quotations were presented to ensure transferability or modifiability of the theory.[24, 27]

To protect their confidentiality, each informant was identified by a numerical code, and the link between the two was kept in a separate locked place, accessible only to the primary researcher. The link was destroyed upon completion of the study. All audiotape recordings and transcripts were identified only by code numbers and were kept in a locked place.

## Results

Thirteen Thai adolescents with TDT, 13 to 17 years of age, participated in this study. Eleven (84.62%). were in their early to middle adolescence. Seven (53.85%) were female and six (46.15%) were male. Eight (61.54%) were studying in secondary schools or college. Five (38.46%) were studying in primary schools. All informants were Buddhist. Ten (76.92%) lived with their parents in rural areas of Phitsanuloke and Uttaradit. Three (23.08%) lived in an urban area. Their primary caregivers tended to be their mother (84.62%). However, two (15.38%) had a grandmother as their primary caregiver. The family incomes ranged from 3,000 to 20,000 baht per month, with nine (69.23%) families stating that their income was not sufficient to cover the illness expenses on top of the costs of daily life. Seven (53.85%) were diagnosed with beta-thalassemia major and six (46.15%) with beta-thalassemia / Hb E that required blood transfusions every 4 to 6 weeks. All informants had undergone a splenectomy and required iron chelating.

As shown in **Figure 1**, theoretical explanation of the phenomenon was generated in a set of four categories, based on emerging data. The core category, *living with the differences*, captured these Thai adolescents' experiences of living with TDT. The core category consists of four categories: illness understanding; a sense of difference; emotional experiences; and, managing the differences. In living with TDT, the adolescents developed an understanding of their illness. They came to understand they had a small amount of blood and body immunity, as well as a large amount of body iron and bone fragility. They perceived themselves to be different from their peers due to having TDT. They were unable to engage in strenuous activities, vulnerable to illnesses and different in appearance, resulting in them having an altered body image. These perceived differences lead to feelings of sadness, shame, envy, anger and worry. They attempted to manage these differences in order to gain a sense of normalcy through: preserving normal blood amount, decreasing body iron, strengthening bones, preventing colds, performing activities as much as possible, managing emotional experiences and mobilizing supports. Despite their efforts,

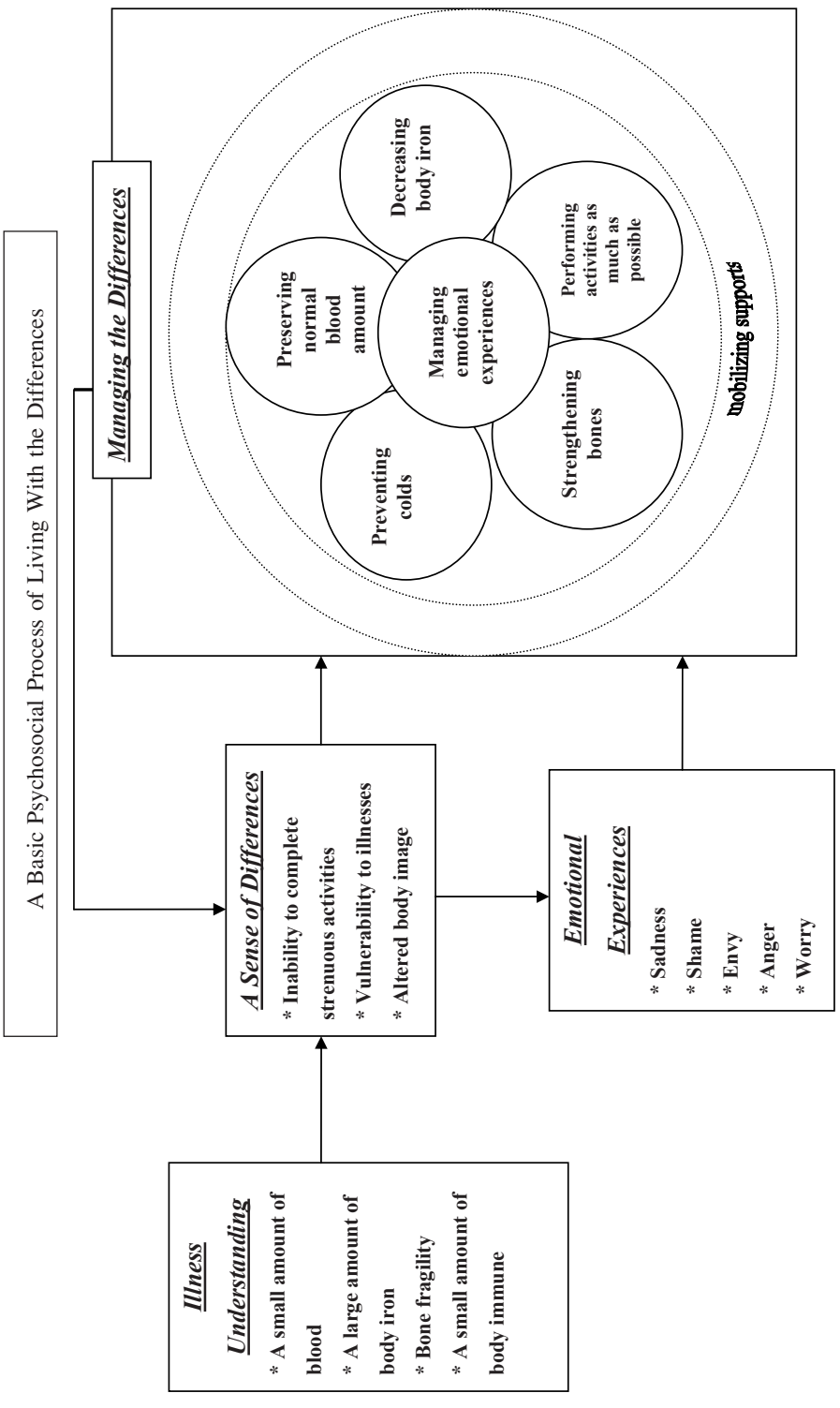


**Figure 1** A diagram illustrating the process of living with the differences in Thai adolescents with TDT

normalcy seldom was regained because of the severity and heredity of their illness, but they continued to live with their differences.

As shown in **Figure 1**, living with their differences was an ongoing daily process for these young people. Illness understanding was an antecedence of the process that induced a sense of differences and, subsequently, emotional experiences. Ongoing behaviors, that consequently appeared when the adolescents realized their differences, were labeled as managing the differences. Direction of the arrows represents an iteration of the process due to permanence of the differences. Further explanation of each of the four categories follows.

## Illness understanding

The adolescents came to understand their illness through their experiences of everyday life. They noticed they became very tired or unable to tolerate strenuous activities. Every 4 to 6 weeks they were taken to the hospital, and typically received blood transfusions. Some of them overheard a physician talking to their parents about their illness, while others directly asked their parents about what was going on. Based on their daily experiences of tiredness, blood transfusions and the information provided, the adolescents realized they were sick. They had an illness in which the ***blood volume was decreased*** and the red blood cells were destroyed by the white blood cells. The illness required them to replenish blood in their body every 4 to 6 weeks. They called their illness "Roke Lued (blood disease)," "Roke Lued Jang (a dilute blood disease)," or "thalassemia." Most of the adolescents said things such as, *"I have Roke Lued Jang. I heard the doctor talk to the nurse... It is the disease that my red blood is not enough. The red blood is decreased."* Loss of blood was compared with the crippling loss of limbs, by a 15-year-old girl with severe beta thalassemia/ hemoglobin E, as reflected in her remark, *"My arms, legs and brain are not crippled, but my blood is. Having thalassemia is being a cripple since I lose my blood."*

Their blood disease further was explained in terms of a ***large amount of body iron, a small amount of body immunity and bone fragility.*** The adolescents understood the high levels of iron in their body were caused by the frequent blood transfusions and high iron foods. They commented that iron clung to their body organs, darkened their skin color and increased their vulnerability to heart disease. Bone fragility and impaired immune system functioning were understood to be results of TDT, but were explained simplistically and rarely in scientific ways.

## A sense of differences

The adolescents perceived themselves as different from healthy people, especially peers. They were unable to complete strenuous activities, were vulnerable to illnesses and had altered body images. Their differences were explained according to their understanding of their illness and were confirmed by negative social reactions, including peers' ridicule and others' criticisms.

***Inability to complete strenuous activity*** explained the adolescents' concern about failure to tolerate vigorous activities. The adolescents stated they didn't have the energy to complete activities because of decreased blood, and were concerned about the impact of these limitations on their daily living activities, school activities and ability to secure jobs in the future. Daily activities characterized by spending energy, such as walking up three flights of stairs, and lifting heavy objects, exhausted them. They lacked the strength and endurance to play football or volleyball, or to dig holes in agricultural classes at school. Moreover, their differences were emphasized when teachers or

parents prohibited them from participating in school activities, such as sport athletics and scout camping, because they worried about serious illness possibility resulting from their exhaustion and thalassemia. A sense of differences was expressed when a 17-year-old girl described herself:

> I'm different from my friends. I can't do activities, whereas my friends do... I can't play sports in the athletic meeting or walk for social campaigns. I have to stay at home while my friends have fun with these activities.

The male adolescents often expressed their differences, especially when comparing themselves with the females:

> I differ from my friends. I can't help my friends to plant because I feel tired...You know! Even if I'm a man, I can't dig holes for planting, whereas those girls can.

Furthermore, the adolescents talked about having limited employment opportunities because of their activity intolerance. A 15-year-old girl was concerned about unemployment in the future that would prevent her from earning money for her family:

> Normal people can earn money to support their family but I can't. This is because I can't work as my friends do... I wish I would be normal, could work for money for my family, and didn't have to worry about jobs when I grow up.

***Vulnerability to illnesses*** was the adolescents' concern about being more susceptible to bone fractures, colds and heart disease than healthy people. They explained that their bones were spongy and easily broken due to having TDT. Germs could invade their bodies more easily because of their reduced body immunity. Iron overload in their bodies could lead to them developing heart disease. Their illnesses usually were severe enough for them to need hospitalization. The adolescents described their vulnerabilities as:

> The illness is related to my bones. Normal people are not like me. My arms will be broken if I fall on the ground or my arms bump against my knees... Because of thalassemia,... germs can easily invade me because my body can't resist them... The heart can't work when there is so much iron in the body. The heart gradually stops working.

***Altered body image*** presented the adolescents' perception of their appearance. They experienced differences in their general appearance and pubertal changes, which were observable to others. The adolescents were dissatisfied with their appearance, including their shorter stature, darker skin color, flatter nose and typical thalassemic face. The absence of the pubertal changes of a deepening voice, penile erections, breast enlargement and menstruation further reinforced their differences. These characteristics were perceived as symbols of their illness. For instance, the adolescents always described their typical skin color and stature:

> Ordinary people are different from us (people who have thalassemia). Their skin color is like gold. But, ours is dark. Particularly, the skin will be darker in people who replenish their blood like me or who eat too much high iron food.

> I am different from [my friends]... in appearance and stature... They have robust bodies. But, mine isn't like theirs.

## Emotional experience

The adolescents' perceptions of being different had a psychological impact and evoked negative emotions, including ***sadness, shame, envy, anger and worry.*** They were ashamed of their physical limitations and thalassemic appearance; envied their peers for being healthy; worried about being susceptible to colds, fractures, heart disease and death; and, angry at those who ridiculed or criticized them. Negative responses, particularly from peers, usually evoked negative emotions.

> I'm sad that I was born without good-looking appearance... I felt sad when my friends called me *"I-Roke-Lued"* (a man with blood disease). They said *"I-Roke-Lued"* couldn't do whatever he wanted when I refused to play football with them.

> I often get angry and realize my differences when my friends call me *"Dracula"*... because I take blood from others to stay alive.

## Managing the differences

The adolescents attempted to manage their differences for the sake of being normal. They wanted to be like their peers: strong, healthy and normal looking. Managing behaviors were based on their understanding of their illness and encompassed: preserving normal blood amount; decreasing body iron; strengthening bones; preventing colds; performing activities as much as possible; managing emotional experiences; and, mobilizing supports.

***Preserving normal blood amount*** involved three strategies to increase blood in their body. Receiving blood transfusions was a major strategy, since the adolescents believed blood was a source of power. With more blood, energy and opportunities to complete activity increased. They also took medications and consumed particular foods to enhance their blood to minimize suffering in pain during the transfusions. Their medications included two tablets of multivitamins and folic acid. Their foods included pumpkins, milk or yogurt, and Thai herbs. These strategies were based on the adolescents' past experiences, and the recommendations of their physicians or parents.

> Receiving blood makes me become normal. I can walk and do whatever I wish with my best.

***Decreasing body iron,*** primarily through their physicians' mandated time consuming and uncomfortable infusion process of chelation, was undertaken to prevent heart disease and skin darkening. Though the adolescents understood the importance of reducing body iron, it was difficult for them to maintain dietary restrictions and undergo chelation. For some, the lightening of their skin color was a visible benefit of their efforts.

> I think the chelating is good for me. I wish my skin color would be whiten shortly... I wish I could have beautiful skin like others.

***Strengthening bones*** was a strategy to minimize vulnerability to bone fractures. Avoiding accidents, drinking milk and taking calcium tablets were strategies to increase bone strength recommended by their physicians. The adolescents shared that they grew bored drinking so much milk and longed to drink soft drinks or other beverages. Despite following the prescribed regime, they still experienced fractures.

***Preventing colds*** was one of the strategies they used to manage their vulnerability to other

illnesses. Thus, they avoided those who had a cold, as well as staying in a hot or cold area for long periods. They understood that germs that caused colds could invade their bodies more easily because they had limited immunity. Colds often made them sicker than usual, with recovery requiring more time than usual.

***Performing activities as much as possible*** was a strategy the adolescents employed to gain a sense of normalcy within their limitations. They selected and modified patterns of activities to fit their tolerance. Unnecessary strenuous or physical contact activities were avoided to prevent tiredness and bone fractures. A 13 year old boy recalled his memory of playing football.

> I don't play football with my friends at school because I'm too tired. I have to run after the ball and that decreases my blood. Moreover, my friends commonly snatch the ball and hit each other with the ball violently... Instead of playing at school, I play with my close friend at home by taking turns to kick a ball. After playing for ten minutes, we usually stop playing since we get a little bit tired.

Moreover, the adolescents increased the frequency of some activities or substituted other activities for the ones they could not complete. A 16 year old boy recalled his memory of scout camping at school. He decided to look for firewood instead of going trekking.

> I was finding firewood for cooking when my friends were trekking outside the camp... Then, they could cook as soon as they arrived at the camp... I felt like I could help them complete the teacher's assignment.

***Managing emotional experiences*** was an attempt to minimize negative emotions resulting from their differences and boredom in managing daily strategies. Though try as they might, the adolescents still required regular blood transfusions and iron chelating, and could not engage in the activities of their normal peers. They maintained the irreversible physical characteristics of TDT, an ever present reminder of the disease. Their emotional well-being was improved by positive thinking, distraction, hiding and letting go. Positive thinking included focusing on the advantages of being different, appreciating their actual capabilities and hoping for normalcy. Hiding and letting go were employed when they felt hopeless about ever achieving normalcy. It also was used, by the adolescents, for keeping secret the absence of menstruation and penile erection. Some even lied to prevent other's criticisms. For instance, a 17 year old girl thought positively about her illness and differences.

> It's good to have the illness (thalassemia)... I know when there's something wrong with my body and how to take care of myself. I have no chance of being robbed, hurt or crashed by cars as others do since I don't go out at night... I don't want to have menstruation... I think it is annoying because I may have to go to the toilet frequently... Certainly, I have to receive blood earlier than usual if I had menstruation... And, I'm better than that girl (the girl who cannot walk because of thalassemia and osteoporosis). I can go to school and apply for some jobs.

The informants had given up on having a normal appearance and let go of their differences. When asked about their appearances, they said:

> I have to let it go since I can do nothing.... I have to bear with how I differ from others. There is no way to have a good-looking appearance or the robust body like them... I was born with the face that no one can have except a person who has thalassemia.

Interestingly, the concepts of karma and meditation, grounded in Buddhism, helped the adolescents to cope with their differences. A 17 year old girl, who was annoyed by the criticisms of others regarding her limitations to earn a better life, shared her experiences.

> I might do something badly in the previous life. So, in this life, I have to repay for what I had done... I Wai-Pra (pray for Buddha) and sometimes meditate to forget things related to the differences. The meditation makes me calm down so I can concentrate on my studying, which is the most important thing for now to benefit getting jobs in the future.

***Mobilizing supports*** were part of all of the managing strategies. Supports encompassed support from family, peers, school personnel, health care providers and people in society. The adolescents utilized and sought physical assistance from parents and peers to complete strenuous activities. They sought health related support from parents and health care providers to complete medical treatments to prevent illness complications. Information related to optimizing health, treating the disease and preventing complications was supported by their parents, health care providers and parents of other children with TDT. Psychological support from parents and peers helped these adolescents cope with the permanence of their differences. The following statements of a 17 year old girl with beta thalassemia major, illustrates peer support:

> I'm glad to have my friends. They give me a big help when I can't complete strenuous activities. I think it's because they understand my illness. They ask me about the illness history, the symptoms and how I take care of myself.

In addition, the adolescents sought psychological support from people in society. They wished others would understand their illness and differences, and treat them normally. One adolescent called for understanding, from others, regarding her unusual appearance.

> People often stare at me when I go to the market. They spoke quietly with the others after they saw me. It might be bad words about my appearance... They should have talked to me if they wonder about my appearance. I was willing to tell them whatever they wanted to know.

## Discussion

Living with the differences is the basic psychosocial process of Thai adolescents living with TDT. The process represents significant relationships between the illness, social interactions, social expectations and adolescents' self. The unique social context of the Thai culture appears to have influenced the adolescents' experience. The four categories the process accounts for added depth to the findings of previous studies.

A sense of differences presents the adolescents' self in which TDT and social expectations of normalcy are involved. Based on illness understanding and negative social reactions, the adolescents defined differences as the limited

capabilities, vulnerability to illnesses and unusual appearances. The differences were explained in relation to chronic hemolytic anemia, extramedullary erythropoiesis in bones, serum iron overload and body immune dysfunction of TDT.[3, 28, 29] The adolescents' self probably was formed according to their own expectations and the social expectations of normalcy that likely were to be driven by Thai social values of gender identity and gratitude. The male adolescents, in particular, often realized their differences when comparing themselves with healthy females. They never felt they were *"Chai-Cha-Tri"* (a strong man) because of their tiredness, short stature and poor musculature. In addition, opportunity for them to show their parents gratitude was limited, since the adolescents felt insecure about getting a job in the future.[30, 31]

Living with the differences presented the adolescents' behaviors of self which were aimed at meeting the social expectations of normalcy of independence in completing activities, achievement in social activities and attractive appearances. Preserving normal blood amount, strengthening bones and preventing colds aimed to increase independence in completing strenuous activities and achievement in participating in social activities with peers. Decreasing body iron was to minimize the risk of heart disease that could impede social participation and improve appearance. In other words, the adolescents managed their differences since they valued independence, a sense of achievement and peer acceptance as normalcy. These managing behaviors theoretically further were supported by developmental science.[32, 33]

A process of living with the differences of Thai adolescents with TDT adds depth of knowledge of adolescents' experiences in living with chronic illnesses. The results of this study revealed that the adolescents' sense of differences was influenced by the severity and heredity of the TDT. Congenital diseases, such as TDT and cystic fibrosis, that have visible signs or symptoms usually cause permanence of differences among those so afflicted. Severity of the illnesses, depending upon medical treatments or the possibility of disability, has been found to increase differences.[19, 34, 35] In contrast, a sense of differences has been revealed to appear only when there are episodes of symptoms in those with asthma, diabetes and attention deficit hyperactivity disorder.[16, 17, 18, 36]

Interestingly, social belief and values were involved in the adolescents' experiences of living with TDT. Thai's belief of karma and rebirth reflect the Thai adolescents' perspectives of living with the differences. Being born with TDT was described as a rebirth to repay for having done badly in the past (karma). The Thai social value of self-training to be patient in life situations appears to have shaped the adolescents' coping strategies, which were aimed at managing their differences rather than managing the social environment.[22] The experiences of the Thai adolescents, in this study, were inconsistent with a previous study, in England, wherein adolescents with beta thalassemia major were found to separate their illness from their self and focus on the here and now to live normally.[12]

## Limitations

This study has its limitation according to the social contexts of the informants. Thus, the findings should not automatically be generalized to adolescents with other chronic illnesses, or to different social circumstances. For instance, social interactions in the school setting were a daily experience for the informants in this study. Twelve of them had positive family relationships. All participants believed in Buddhism, which provided the foundation for their family living patterns and child rearing practices.

## Conclusions and Recommendations

TDT is a chronic hereditary disease that robs Thai youth of a sense of normalcy, and tends to interfere with developmental tasks. The adolescents lived with their differences since their illness was severe and caused irreversible changes in their appearance. Thai social beliefs and values, rooted in Buddhism, were found to influence the adolescents' experiences. The findings provide a better understanding of the experiences of Thai adolescents living with TDT, and add to prior knowledge of TDT and other chronic illnesses. The results are important contributions towards the development of nursing interventions to help adolescents with TDT achieve their highest psychosocial well-being as they navigate life. A sense of their differences should be recognized and integrated into nursing interventions, and preserving normalcy should be a goal of caring.

Future research is needed to further this understanding, perhaps through additional theoretical sampling or quantitative methods to assess whether the theory holds across large and diverse samples of the target population. The eventual goal should be to develop medical and nursing interventions to minimize the negative effects of TDT, and maximize functionality, quality of life, movement through developmental tasks and achievement of adult roles and responsibilities.

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# การดำรงชีวิตอยู่กับความแตกต่าง : ประสบการณ์ของเด็กวัยรุ่นไทยในการดำรงชีวิตอยู่กับโรคธาลัสซีเมียชนิดที่ต้องพึ่งการให้เลือด

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**บทคัดย่อ:** ถึงแม้โรคธาลัสซีเมียชนิดที่ต้องพึ่งการให้เลือดทำให้เกิดผลกระทบทั้งทางด้านร่างกายและจิตสังคม แต่ความรู้เกี่ยวกับประสบการณ์ชีวิตของผู้ป่วยเด็กวัยรุ่นในการดำรงชีวิตอยู่กับโรคธาลัสซีเมียชนิดที่ต้องพึ่งการให้เลือดนั้นยังมีน้อย ซึ่งความรู้เกี่ยวกับการที่ผู้ป่วยเด็กวัยรุ่นดำรงชีวิตอยู่กับความเจ็บป่วยของพวกเขาอย่างไรนั้นเป็นสิ่งที่คาดว่าจะมีประโยชน์ต่อกิจกรรมการพยาบาลที่เน้นผู้ป่วยเป็นสำคัญเพื่อส่งเสริมความผาสุกของผู้ป่วยเด็ก จุดประสงค์ของการศึกษาครั้งนี้คือ เพื่อทำความเข้าใจและอธิบายประสบการณ์ชีวิตของผู้ป่วยเด็กวัยรุ่นไทยในการดำรงชีวิตอยู่กับโรคธาลัสซีเมียชนิดที่ต้องพึ่งการให้เลือด ระเบียบวิธีวิจัยแบบการสร้างทฤษฎีเชิงอุปมานจากข้อมูลพื้นฐานได้ถูกนำมาใช้เพื่อสร้างทฤษฎีพื้นฐานที่อธิบายประสบการณ์ดังกล่าว โดยใช้การสัมภาษณ์เชิงลึกเก็บรวบรวมข้อมูลจากผู้ป่วยเด็กวัยรุ่นไทยจำนวน 13 คน ทั้งนี้การวิเคราะห์ข้อมูลได้กระทำไปพร้อมกับการเก็บรวบรวมข้อมูลโดยกระบวนการเปรียบเทียบต่อเนื่องเพื่อสร้างทฤษฎีพื้นฐาน ซึ่งผู้ป่วยเด็กได้รับการคัดเลือกเข้ามาในการวิจัยโดยการเลือกแบบเฉพาะเจาะจงและการเลือกแบบเชิงทฤษฎีตามลำดับความอิ่มตัวเชิงทฤษฎีของข้อมูลเป็นเกณฑ์กำหนดการยุติการเก็บและรวบรวมข้อมูล การดำรงชีวิตอยู่กับความแตกต่างปรากฏเป็นหมวดหมู่หลักของทฤษฎีพื้นฐาน โดยหมวดหมู่หลักนี้ประกอบด้วยสี่หมวดหมู่ที่สัมพันธ์กันคือ การเข้าใจความเจ็บป่วย ความรู้สึกแตกต่าง ประสบการณ์ด้านอารมณ์ และการจัดการความแตกต่าง ซึ่งผลการวิจัยครั้งนี้ ทำให้เกิดความเข้าใจที่ลึกซึ้งขึ้นเกี่ยวกับประสบการณ์ชีวิตของผู้ป่วยเด็กวัยรุ่นไทยในการพยายามที่จะดำเนินชีวิตตามปกติดังที่สังคมคาดหวังในขณะที่ดำรงชีวิตอยู่กับโรคธาลัสซีเมียชนิดที่ต้องพึ่งการให้เลือด ซึ่งความเข้าใจนี้ได้เพิ่มเติมองค์ความรู้เดิมที่เกี่ยวกับโรคนี้และโรคเรื้อรังอื่นๆ อีกทั้งยังเป็นประโยชน์ต่อการพัฒนากิจกรรมการพยาบาลเพื่อช่วยให้ผู้ป่วยเด็กเหล่านี้พบกับความผาสุกในการดำรงชีวิต

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