RETURNING TO NORMALITY AMONG ADOLESCENTS WITH LEUKEMIA RECEIVING CHEMOTHERAPY

Mr. Surasak Treenai

A Dissertation Submitted in Partial Fulfillment of the Requirements
for the Degree of Doctor of Philosophy Program in Nursing Science
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การกลับคืนสู่ความเป็นปกติในวัยรุ่นโรคลิวคีเมียที่ได้รับเคมีบำบัด

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สุรศักดิ์ ตรีนัย : การกลับคืนสู่ความเป็นปกติในวัยรุ่นโรคลิวคีเมียที่ได้รับเคมีบำบัด. (RETURNING TO NORMALITY AMONG ADOLESCENTS WITH LEUKEMIA RECEIVING CHEMOTHERAPY) อ.ที่ปรึกษาวิทยานิพนธ์หลัก: รศ. ดร. วราภรณ์ ชัยวัฒน์, อ.ที่ปรึกษาวิทยานิพนธ์ร่วม: รศ. ดร. จินตนา ยูนิพันธุ์, 140 หน้า.

การได้รับการรักษาด้วยเคมีบำบัดได้เพิ่มความยากลำบาก และความทุกข์ทรมานให้กับชีวิตของวัยรุ่นโรคลิวคีเมีย จากการต้องมารับการรักษาที่คลินิกและการเข้าพักรักษาตัวในโรงพยาบาลมากมายหลายครั้ง และจากผลข้างเคียงที่หลากหลายของเคมีบำบัด การช่วยเหลือวัยรุ่นกลุ่มนี้ให้ดำรงชีวิตกับการได้รับเคมีบำบัดอย่างประสบความสำเร็จ ต้องอาศัยความเข้าใจในประสบการณ์ของวัยรุ่นเหล่านี้อย่างแท้จริง ซึ่งสิ่งนี้ไม่สามารถได้มาด้วยการศึกษาผ่านมุมมองของคนนอก การศึกษานี้เป็นการวิจัยแบบสร้างทฤษฎีจากข้อมูลตามวิธีการของ Glaser โดยมีเป้าหมายเพื่อศึกษาว่าวัยรุ่นโรคลิวคีเมียมีชีวิตกับการได้รับเคมีบำบัดอย่างไร ผู้ร่วมวิจัยคือวัยรุ่นโรคลิวคีเมียซึ่งมีอายุระหว่าง 12- 19 ปี จำนวน 20 ราย เก็บข้อมูลโดยการสัมภาษณ์แบบเจาะลึก วิเคราะห์ข้อมูลโดยการเปรียบเทียบข้อมูลที่เกิดขึ้นตลอดเวลา “การกลับคืนสู่ความเป็นปกติ” ถูกค้นพบว่าเป็นกระบวนการพื้นฐานทางสังคม ซึ่งวัยรุ่นโรคลิวคีเมียใช้ในการมีชีวิตอยู่กับการได้รับเคมีบำบัด กระบวนการพื้นฐานทางสังคมนี้มี 4 ขั้น คือ การตระหนักว่าเป็นผู้ป่วยมะเร็งเม็ดเลือดขาว การยอมรับว่าการรักษาด้วยเคมีบำบัดเป็นกุญแจสำคัญของการที่จะมีชีวิตตามปกติ การเรียนรู้การดูแลตนเองที่เกี่ยวกับการได้รับเคมีบำบัด และการทำการดูแลตนเองอย่างดีที่สุด วัยรุ่นโรคลิวคีเมียต้องผ่านขั้นตอนแรกคือ “การตระหนักว่าเป็นผู้ป่วยมะเร็งเม็ดเลือดขาว” ก่อนจะก้าวไปสู่ขั้นตอนอื่นๆ การคาดหวังอนาคตที่สดใสกว่าปัจจุบัน ถูกค้นพบว่าเป็นแรงผลักให้วัยรุ่นโรคลิวคีเมีย ใช้ทรัพยากรและความพยายามของพวกเขาที่จะผ่านขั้นตอน 3 ขั้นสุดท้ายเพื่อกลับคืนสู่ความปกติตามที่เขาได้กำหนดไว้

ความรู้เกี่ยวกับการดำรงชีวิตกับการได้รับเคมีบำบัดจากมุมมองของวัยรุ่นโรคลิวคีเมียสามารถใช้เป็นแนวทางในการพัฒนาการปฏิบัติการพยาบาลสำหรับวัยรุ่นโรคลิวคีเมียที่ได้รับเคมีบำบัดได้ต่อไปในอนาคต

สาขาวิชา พยาบาลศาสตร์

ปีการศึกษา 2556

ลายมือชื่อนิสิต ....

ลายมือชื่อ อ.ที่ปรึกษาวิทยานิพนธ์หลัก ....

ลายมือชื่อ อ.ที่ปรึกษาวิทยานิพนธ์ร่วม ....

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KEYWORDS: LEUKEMIA / ADOLESCENT / CHEMOTHERAPY / GROUNDED THEORY

SURASAK TREENAI: RETURNING TO NORMALITY AMONG ADOLESCENTS WITH LEUKEMIA RECEIVING CHEMOTHERAPY. ADVISOR: ASSOC. PROF. WARAPORN CHAIYAWAT, D.N.S., CO-ADVISOR: ASSOC. PROF. JINTANA YUNIBHAND, Ph.D.,140 pp.

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Field of Study: Nursing Science
Academic Year: 2013

Student's Signature ....
Advisor's Signature ....
Co-Advisor's Signature ....

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CHAPTER I
INTRODUCTION

Background and significance of the study

Acute lymphoblastic leukemia (ALL), a malignant disorder of lymphoid hematopoiesis, is the most common malignancy of adolescents. Now, although leukemia remains the leading cause of disease-related death among adolescents (ages 12 to 19 years) in Thailand, advanced in chemotherapy have changed leukemia survival rates in adolescents. Before the use of advanced chemotherapy in 1990, the adolescent patients with leukemia survived for 4 – 6 month. Today, more than 75% of adolescents diagnosed with ALL survive for at a least 5 years and overall cure rate greater than 70% (Kamsa-ard et al., 2006; Laosombat, Wongchanchailert, Sattayasevana, Wiriyasateinkul, & Watana-Arepornchai, 2002; Sriamporn et al., 1996).

Under the current treatment protocols, adolescents with leukemia need to go through several phases of chemotherapy: remission induction, consolidation or intensification, and maintenance or continuation therapy, with CNS sanctuary therapy generally provided in each stage (Colby-Graham & Chordas, 2003). This means that they need to be continually in the hospital to receive multiple cytotoxic drugs at high dose for 2-3 years (Haase & Rostad, 1994; Weeker & Kegan, 1994; Altman & Reaman, 2008). Thus, nurses must help the adolescents with leukemia to live with chemotherapy.

In Thailand, adolescents with leukemia were frequently admitted in hospital. The range of stay for chemotherapy was 7- 14 days depended on the prognosis and the side effects of chemotherapy. During chemotherapy adolescents with leukemia need to encounter several painful procedures, such as several venipuncture, and bone marrow aspirations. Painful procedures were reported as the continuous source of stress for adolescents with leukemia (Bossert, Van Cleve, Adlard, & Savedra, 2002). Many adolescents with leukemia reported that chemotherapy disrupted their relationship with parents and siblings because they were isolated from them. The social support from family members for adolescents with leukemia during hospitalization for chemotherapy is not enough (Eiser, Eiser & Greoce, 2002).

Furthermore, when the adolescents with leukemia stay in the hospital for chemotherapy, their lifestyle will be changed by hospital's regulation and procedure (Hinds, Scholes, Gattuso, Riggins, & Heffner, 1990). Moreover, receiving chemotherapy in the hospital was experienced as isolating, restricting and long lasting for adolescents with leukemia (Calaminus, Weinspach, Teske, & Gobel, 2000; Kupst & Schulman, 1988). Hockenberry-Eaton (1998), founded that the environment in the hospital may affect the adolescents' experiences which increase isolating. Thus, not only are adolescent separated from their own life, but they must reside in a new place that may often be disruptive to their rest. The time to stay in hospital for receiving chemotherapy is hard for those adolescents. The adolescents with leukemia showed a strong desire to return to their original life, and they missed family and friends while facing an unfamiliar hospital environment (Woodgate & Deger, 2002).

In addition, most of adolescents with leukemia confront the side effect of cytotoxic drugs after two times of treatment. Several studies founded that the side effect of chemotherapy made the adolescent become highly psychologically distressed and may perceive a low quality of life (Haase & Rostad, 1994; Weekes & Kagan, 1994; Hockenberry-Eaton & et al, 1998; Kameny & Bearison, 2002; Eiser, 2004).

Nausea and vomiting are the common side effect of chemotherapy that happen in hour after receiving chemotherapy (Docherty, Sandelowski, & Preisser, 2006). The adolescents with leukemia will take antiemetic to treat nausea and vomiting, often following chemotherapy, but the indescribable discomfort from a feeling of nausea cannot relieve (Decker, 2006; Hockenbery, 2004). The antiemetic is not enough to help adolescents with leukemia and they need special nursing care.

Fatigue are the another issue that affected to adolescent with leukemia during chemotherapy (Hedström, Ljungman, & von Essen, 2005). Fatigue were frequently report from adolescents with leukemia that fatigue is not only a common symptom but that it is highly disruptive and distressing (Hockenberry-Eaton & Hinds, 2000). It can hamper individuals' capacity for self-care (Kestler & LoBiondo-Wood, 2012). Moreover, adolescents with leukemia reported that fatigue interfered their daily living. The feeling of "no power" made them mood and self-care activities were limit. The patient's response by fatigue are sleeping, and cancelling activities (Dodd & Mishel, 1988; Hockenberry-Eaton et al., 1998).

Adolescent's hair falls after receiving chemotherapy in eight hours and completely hair loss in a week. This is other factors which make life more difficult for adolescents. Moreover, systematic review founded that the changes in body image from chemotherapy such as hair loss, pallor, and look ill were worse than the disease and more difficult to cope (Fotchman, 2006; Altman & Reaman, 2008). The adolescents with leukemia who have body image disturbance prefer to stay at home and do not go out. The chemotherapy treatment physically separated the children from their peers, as they were not able to attend school or be involved in usual. For adolescents with leukemia, obvious changes in appearance due to chemotherapy was difficult to live with, especially for teen girls (Ferrel, 1996; Sheng-Yu & Eiser, 2009).

In order to be able to live day by day with the uncomfort cause by various side effects of chemotherapy and to live with chemotherapy, the adolescents with information for applying to (Aldridge & Roesch, 2007; Decker, 2006; Kyngäs et al., 2001; Wu, Chin, Haase, & Chen, 2009).

The majority of adolescents with leukemia follow the treatments protocol, even though nobody knows what their future will be. Whether to live or death, most adolescents with leukemia accept the chemotherapy as a part of their lives and try to have optimal lives (Stam, Grootenhuis, & Last, 2001). They want to go back to normal life, especially going to school because school is an essential component of teenager's world (Dahlberg & Love, 2007; Deatrick & Knafl, 1990; Deatrick, Knafl, & Walsh, 1988; Van Staa, Jedeloo, Latour, & Trappenburg, 2008; Roberta Lynn Woodgate & Degner, 2003). However, adolescents with leukemia frequently absent from school because of hospital visit and chemotherapy side effects. In addition, the adolescents with leukemia may fear to meet their peers because the change in body image and they are now "different from their peers". Relationship with peer group, thus, very difficult (Ferrell, 1996; Fotchman, 2006; Haase & Rostad, 1994; Weekes & Kagan 1994). As result, the adolescents with leukemia feel more isolated.

More stressors that adolescents with leukemia need to cope with include disruption of life routine from numerous clinic visits and hospitalizations, the prognosis, chemotherapy and its side effects, interaction with family and peers, and "dealing with two worlds that of health and illness as well as of specialness and normalcy" (Chesler & Barbarin, 1987). There is increasing recognition of the special needs and problems of adolescents with leukemia who face invasive, onerous, and lengthy treatment at a time of major developmental changes.

However, helping these adolescents to go successfully through the above difficulties require truly understanding of their experiences, which cannot be obtained through studies with ethic viewpoint which is the mainstream literature. Research in the topics of coping with cancer have focused on coping strategies used by child and adolescents with cancer such as include distraction, seeking social support and problem-solving (Sorgen & Manne, 2002; Decker, 2006; Aldridge & Roesch ,2007). Unfortunately, these coping strategies were derived from the broad theoretical dimensions of problem-solving and emotion-focused coping vs. avoidance coping; these categories were inadequate for capturing the actual experiences of adolescents coping with chemotherapy. Successful coping during chemotherapy requires the adolescents with leukemia to effectively manage their emotions and behavior, interact with the social and teenager’s life.

Adolescents with leukemia tend to be included as a part of childhood cancer group and many studies focused on parents’ perceptions in an attempt to understand the effect of chemotherapy instead of the adolescents’ perception (Bashore, 2004; E. A. Earle, Clarke, Eiser, & Sheppard, 2007; Gibson, Aldiss, Horstman, Kumpunen, & Richardson, 2010; Kathleen A Knafl & Deatrick, 2002; Novakovic et al., 1996; Robinson, 1993). In order to get the real essence of how Thai adolescents with leukemia live with chemotherapy, the emic viewpoint was explored.

This study only provides an empirical basis for generating an explanation of how Thai adolescents live with treatments regimens, but also adds insight and understanding of the context and consequence of adolescents’ decision and.

The finding that emerges from the action of adolescents with leukemia when they solving the problem in their life during chemotherapy can summarize as the grounded theory.

The researcher employed the glaserian grounded theory method to guiding this study. The knowledge emerged in this study could provide insight for nurse and help them find the most appropriate way to promote the health and well-being of adolescents with leukemia in relation to chemotherapy

Research Question

How do adolescents with leukemia live with chemotherapy?

Research Objective

To discover how adolescents with leukemia live with chemotherapy.

Scope of the study

This study focus on how adolescents with leukemia live with chemotherapy. Data were collected by in-depth interview with adolescents who were diagnosed of leukemia and treated by chemotherapy at least two times.

Initial Operational definitions

The term “living process” of adolescents with leukemia receiving chemotherapy represented how adolescents with leukemia lived day by day during chemotherapy, particularly how they solve the problems caused by chemotherapy in order to meet their needs.

This definition was used only at the starting point to guide the interview. The true meaning of living process was emerged after the analysis.

Expected benefits

The research finding can help nurses and other health professionals to gain more understanding of the experience of adolescents with leukemia during chemotherapy.

The finding of this study which is the process of living with chemotherapy in the perspective of these themselves can use as a substantive theory to guide nurses in providing care for adolescents with leukemia who are treated by chemotherapy.

CHAPTER II
LITERATURE REVIEW

This chapter presents a brief overview of literature in a board substantive area of the living with chemotherapy of adolescents with leukemia was first done, which was then narrowed to the health problem of adolescents with leukemia. The next step was to look for literature on nursing care for adolescents with leukemia during chemotherapy. A review of literature revealed what questions had been addressed among adolescents with leukemia and confirmed the paucity of research on the perspective of adolescents with leukemia related with how they live with chemotherapy. The literature on grounded theory methodology was the review in the third part to use as a framework for researcher in this study.

The review literature was focuses on three major topics

1) Living with chemotherapy of adolescents with leukemia.

2) The nursing role to caring for adolescent with leukemia during chemotherapy.

3) Grounded theory methodology.

In grounded theory study it is important to study with no preconceive idea about the phenomena of interest. The literature review of this study will be helping the researcher to identify the scope of the study and the gap of knowledge that the finding of the study can fulfill.

Living with chemotherapy of adolescents with leukemia

The term leukemia, from the Greek “white blood,” refers to cancers of the blood-forming or hematopoietic tissues. The three major classifications of childhood leukemia are acute lymphocytic leukemia (ALL), accounting for 75% to 80% of pediatrics leukemia; acute myelogenous leukemia (AML), accounting for 20% to 25% of pediatrics leukemia; and chronic myelogenous leukemia, accounting for less than 5% of pediatrics leukemia. Chronic lymphocytic leukemia rarely is reported in pediatric population.

For adolescents acute lymphoblastic leukemia (ALL) is the most common. In Thailand the incident rate of leukemia was 27.6 per million, 340 news case of childhood leukemia were reported in every year and 38.5% were adolescents (Kamsa-ard et al., 2006). Approximately 13 new cases of adolescents with leukemia per one million populations are diagnosed each year in Thailand (Sriamporn et al., 1996).

Under the current treatment protocols, adolescents with leukemia need to go through several phases of chemotherapy: remission induction, consolidation or intensification, and maintenance or continuation therapy, with CNS sanctuary therapy generally provided in each stage (Colby-Graham & Chordas, 2003). This means that they need to be continually in the hospital to receive multiple cytotoxic drugs at high dose for 2-3 years (Haase & Rostad, 1994; Weeker & Kegan, 1994; Altman & Reaman, 2008). In Thai, the first hospitalization period for adolescents with leukemia needs to be 2 to 3 months to achieve induced remission and for the first (and even second) course of treatment to be consolidated. During the remission stage, adolescents with leukemia need to be in the hospital for about half a month every course according to their treatment scheme. In addition, adolescent with leukemia must be receiving chemotherapy as soon as possible to cure the leukemia.

The problem that adolescent with leukemia encountered are even more complicated, especially at the time of chemotherapy. Helping the adolescents with leukemia to find appropriate methods to maintaining their life during chemotherapy is important and nurses need to intervene. The problems that adolescents with leukemia are confront during chemotherapy come from four sources.

First, the symptom of leukemia that affected adolescent's daily living. The most common symptoms are anemia, bleeding, weakness, bone and joint pain, and repetitive infections were suffering. Adolescents with leukemia need help from parents to care when they have the symptom of the disease but it is inappropriate with the need of adolescent to be independent to caring themselves. The conflict of parents and adolescents was founded in several studies (Clarke, Davies, Jenney, Glaser, & Eiser, 2005; DeJong & Fombonne, 2006; McGrath, 2001). Moreover, the symptom of leukemia is complicated and adolescent describe the minimal of symptoms that they are actually experienced (Hinds et al., 1990; Roberta Lynn Woodgate, Degner, & Yanofsky, 2003). This put adolescents with leukemia under stress and the adapting ability with illness was decreases (Aldridge & Roesch, 2007). In addition, the aggressive of leukemic symptoms leading the adolescents with leukemia accepted chemotherapy as a choice to be cured. The decision process for chemotherapy is very short. Lack of preparation for essential information about chemotherapy was reported in several studies (Bashore, 2004; Docherty et al., 2006; Landier et al., 2011). Adolescents with leukemia self-care ability during chemotherapy was decreased (Golchin, Sharifi, Ziaee, & Taheri, 2011).

Second, the side effect of chemotherapy such as nausea, vomit, and fatigue (Hedström et al., 2005) are the another issue that affected to adolescent health. Most of adolescents with leukemia confront the side effect of chemotherapy after two time of treatments because the duration around 1 month between the first and the second treatments was much more for side effect presents that reported in some study (Docherty et al., 2006). Nausea and vomiting are the common side effect of chemotherapy that happen in hour after receiving chemotherapy (Docherty et al., 2006). The adolescents with leukemia will take antiemetic to treat nausea and vomiting, often following chemotherapy, but the indescribable discomfort from a feeling of nausea cannot relieve (Decker, 2006; Hockenbery, 2004). The antiemetic is not enough to help adolescents with leukemia and they need special nursing care. Fatigue are the another issue that affected to adolescent with leukemia during chemotherapy (Hedström et al., 2005). Fatigue were frequently report from adolescents with leukemia that fatigue is not only a common symptom but that it is highly disruptive and distressing (Hockenberry-Eaton & Hinds, 2000). It can hamper individuals’ capacity for self-care (Kestler & LoBiondo-Wood, 2012). Moreover, adolescents with leukemia reported that fatigue interfered their daily living. The feeling of “no power” made them mood and self-care activities were limit. The patient’s response by fatigue are sleeping, and cancelling activities (Dodd & Mishel, 1988; Hockenberry-Eaton et al., 1998). Adolescent’s hair falls after receiving chemotherapy in eight hours and completely hair loss in a week. This is other factors which make life more difficult for adolescents. In systematic review founded that the changes in body image such as hair loss, pallor, and look ill were worse than the disease and more difficult to cope (Kyngäs et al., 2001; Whitsett, Gudmundsdottir, Davies, McCarthy, &

Friedman, 2008). Adolescents with leukemia who have body image disturbance prefer to stay at home and not going out. The feeling of isolation was founded in some study (Hockenberry-Eaton, Kemp, & Dilorio, 1994) . The method to help adolescents cope with the change of body image is need. Some study founded social support from parents and friend was related to coping with the body image disturbance but the relation of social support with coping and adaptation are not clear (Kupst et al., 1984; Ritchie, 2001).The chemotherapy treatment physically separated the children from their peers, as they were not able to attend school or be involved in usual. For adolescents with leukemia, obvious changes in appearance due to chemotherapy was difficult to live with, especially for teen girls (Ferrel, 1996; Sheng-Yu & Eiser**,** 2009).

The side effect of chemotherapy has also been related to noncompliance during the course of treatment (Hedström, Skolin, & von Essen, 2004; Williams et al., 2010). The rate of noncompliance in adolescent who has side effect of chemotherapy was 59% (Langeveld, Ubbink, & Smets, 2000). Adolescents with leukemia need to help to adaptation with side effect of chemotherapy especially during the induction chemotherapy that use the high dose of cytotoxic drug (Docherty et al., 2006).

Third, the diagnosed of leukemia. To diagnose as leukemia for adolescents is symbolize as a slow and painful death rather than a potential curable disease (Desandes, 2007). Because adolescent has a cognitive to understand the word “cancer” is a cause of death. Adolescents will be living with the fear of death all the time until the cancer is curing. Bearison (1991) found that many children showed more problems with social and adaptive skills than healthy children, especially in adolescents with leukemia because they were stress and depress more often than did their peers. The particular keyword to describe the response of adolescents when they perceive of death that comes together with leukemia was: uncertainty, shock, disbelief, depression and aggression (Emily Anne Earle & Eiser, 2007; Roberta Lynn Woodgate et al., 2003). Adolescents with leukemia need to talk about the fear of death with someone but it cannot happen. Because talking about death is unlucky and uncomfortable for Thai people. Adolescents with leukemia were fall in to severe emotional stress because they cannot take out the meaning of death from leukemia in their mind and the illness will be worse (Eiser, 2004).

Finally, Adolescents need to receive chemotherapy for relieve and curing the leukemia in the hospital. During the remission stage, children need to be in the hospital for about half a month every course according to their treatment scheme. One caregiver is allowed to stay with patients. The caregiver will be presence in day time because no area for sleep and caregiver cannot stay in long period because the caregiver has to work or take care another family member. In addition, when the adolescents with leukemia stay in the hospital the teenage clothes will replace by the patient dress. They life stay will be replace by hospital regulation and procedure. Having leukemia in the hospital was experienced as isolating, restricting and long lasting. Hockenberry-Eaton et al. (1994), found that the environment in the hospital may affect the adolescents' experiences which increase isolating. Thus, not only are adolescent separated from their own life, but they must reside in a new place that may often be disruptive to their rest. The time to stay in hospital to receive chemotherapy is the hard time for adolescents. Adolescents showed a strong desire to return to their original life, and they missed family and friends while facing an unfamiliar hospital environment.

In addition, the literature review in several qualitative studies in adolescents with leukemia describes the major themes were as follows: (a) I am normal but may do things differently, and (b) chemotherapy and leukemia hurts me in many ways.

I am normal but may do things differently. Researchers concerned with the impact of leukemia on adolescents have, until recently, directed their attention mainly toward identifying the degree of psychopathology or psychosocial maladjustment in pediatric with cancer. Some study focused in adolescents with leukemia in psychosocial adjustment. (Aldridge & Roesch, 2007; Grootenhuis & Last, 2001; R. Woodgate, 2000; Roberta Lynn Woodgate & Degner, 2002). Most of this work has been framed within the quantitative paradigm, with researchers relying on the use of standardized instruments that measure various psychosocial constructs such as a sense of self. Overall, the findings from this line of research inquiry suggest that although having cancer does not always lead to maladjustment, it nonetheless puts child and adolescents with cancer were at greater risk (Bessell, 2001) Although findings from quantitative research have increased the knowledge base in certain areas, such as factors associated with maladjustment in children and adolescents with cancer and children's long-term adjustment to cancer (Hockenberry-Eaton et al., 1994), there are limitations in this work. First, the use of standardized instruments may not be applicable given that many of the measures were originally developed in healthy children. Certain questions may not only be inappropriate to ill children's experiences, but may also preclude children from telling their whole story. This deficiency can lead to limited insight into a child's perception of his or her personal experiences with cancer during cancer treatment (Hockenberry-Eaton & Minick, 1994). Another limitation of quantitative work is that the analysis is not concerned with understanding health as it unfolds but with predicting and comparing how ill children’s perspectives deviate from the “norm” or from those healthy children (Baumann, 1996). The perceptions of children with cancer may be viewed as atypical or abnormal instead of being just different when compared with their healthy peers. Bearison (1991) noted that, although there is an impressive array of experimental data and psychological theories regarding normal childhood development, it may be difficult to apply this knowledge to children with cancer, because very little is known about what constitutes an adequate range of adjustment reactions among children experiencing stress and trauma from a disease such as cancer. In effect, a comprehensive understanding of what is normal for children with cancer has not been promoted by quantitative research. Existing work has reinforced the assumption that there is only one kind of “normal” for children. Accepting the latter would be appropriate if all children developed within the same contextual background. But children with cancer experience phenomena that are not experienced by their healthy peers and hence may experience a different type of normal.

Chemotherapy and leukemia hurts me in many ways. Another way that qualitative research has added to quantitative research findings is in relation to understanding how hurt is perceived and experienced by children and adolescents with cancer. To date, quantitative research has tended to focus on the study of “hurtful” events that are a direct result of physical pain. Most notably is the examination of the degree of pain and distress experienced by children who undergo medical procedures during chemotherapy (e.g., bone marrow aspirations) (Roberta L Woodgate, 1999; Roberta Lynn Woodgate & Degner, 2003)

However, recent qualitative research in the study of cancer-related procedures and treatment has resulted in a beginning knowledge base in understanding the hurt experienced by pediatric cancer patients (Madan-Swain et al., 2000). In addition to providing valuable information about pediatric patients'coping responses, this work, unlike quantitative research, underscored how the symptom pain was interpreted in the larger context of the illness. Not only was treatment pain perceived to be the worst thing about having cancer (Weekes & Kagan, 1994) , but, in fact, childhood cancer survivors equated the diagnosis of cancer with pain.

The themes review reinforces the assumption that children's experiences with cancer are complex and context bound. Accordingly, more research from a qualitative perspective is warranted, because this paradigm affords researchers the ability to access detailed accounts of complex phenomena (Strauss & Corbin, 1998). Although there are many areas that need to be studied from a qualitative perspective, a first step may be to further explore the two themes that emerged from this review to confirm and/or expand on them. Additionally, researchers need to explore certain phenomena from different qualitative or interpretative perspectives.

Several studies of children with cancer have focus on coping strategies used by adolescents with cancer include distraction, seeking social support and information, problem-solving, cognitive restructuring, blaming others, self-criticism, positive thinking, acceptance, wishful thinking and emotional regulation (Sorgen & Manne, 2002). Unfortunately, these coping strategies were derived from the broad theoretical dimensions of problem- and emotion-focused coping vs. avoidance coping; these categories are inadequate for capturing the actual experiences of adolescents coping with illness and treatments. In addition, these categories of coping strategies are based on models of coping in adults and lack input from the adolescents themselves.

Some researchers conducted qualitative research in child and adolescents. The finding descried the in-depth knowledge to understanding the feeling of child and adolescents with cancer (Rechner, 1990; Hinds, 1990; Hasse & Rostad, 1996). Moving to the understanding of how adolescents with leukemia live with chemotherapy are important for full fill the knowledge of nursing to caring adolescents with leukemia because adolescents with leukemia must be follow the treatments protocol without any choice and nobody knows what the future will be. Whether to live or death, most adolescents with leukemia were accepted the chemotherapy as a part of their lives and tried to have optimal lives (Stam et al., 2001). There is increasing recognition of the special needs and problems of adolescents with leukemia who face invasive, onerous, and lengthy treatment at a time of major developmental changes. Stressors for adolescents with leukemia include disruption of life routine from numerous clinic visits and hospitalizations, understanding the prognosis, and treatment; adapting to the treatment, and related side effects; interacting with family and peers; and “dealing with two worlds, that of health and illness, of specialness and normalcy”(Chesler & Barbarin, 1987).

The dual challenges of normal adolescent development and the stressors inherent in chemotherapy, the treatment of leukemia, may be overwhelming for many adolescents due to their limited experience dealing with stressors of this magnitude. Successful adaptation during chemotherapy requires adolescents with leukemia to effectively manage their emotions and behavior, interact with the social and teenager’s life, and think in new ways in their attempt to alter or decrease sources of stress. These are all processes linked to how adolescents with leukemia live with chemotherapy.

This is the process of living with chemotherapy in the real situation from the experience of adolescents with leukemia. Understanding this experience is knowing how to assist those who are in trouble with chemotherapy. Yet, despite of the vast amount of literature adolescents with leukemia, little research has been conducted from the real situation of how adolescents living with chemotherapy. The nurses need to understand chemotherapy and leukemia as the response to live, seeking as a source of information, in the case of study, the adolescents with leukemia.

The nursing role to caring for adolescent with leukemia during chemotherapy.

Most of adolescence with diagnosed by leukemia has a problem to adaptive with live during chemotherapy because leukemia challenges the adolescent's sense of self-esteem, leading to feelings of loss of control at a time of life when self-image is pivotal to normal development (Adler & Page, 2008; Eden, Barr, Bleyer, & Whiteson, 2008; Kupst et al., 1984). Periods of hospitalization for chemotherapy may contribute to increased dependence on parents, who quite naturally feel protective and want to take over care. Peer contact will decrease at a time when peer group acceptance is crucial. Reliance on family for financial support and on health care professionals for treatment contributes to a feeling of lack of independence.

Chemotherapy is the major treatment for leukemia in adolescents and this treatment changes the life style of teenagers (Hokkanen, Eriksson, Ahonen, & Salantera, 2004). Education can be disrupted, future occupational plans may be changed, either out of necessity because of disease progression or because of the perceived threat of leukemia to life. Questions arise about competence or appropriateness of obtaining employment, insurance, a mortgage and even a partner. These factors maybe more important to adolescents than the prospect of dying.

In addition, adolescents are living with, not dying of leukemia, and we must direct our efforts towards helping adolescents to live with their disease and maintain the chemotherapy with the teenager's life. Helping the adolescents to find appropriate methods to living with chemotherapy is important. Nurses need to intervene.

The goals of caring for the adolescents with leukemia during chemotherapy can be defined as adolescent can maintain the optimum health or dying with dignity if the disease cannot success curing. Nurse and health professional are attention in coping and adaptation in adolescent with leukemia.

Nursing care for adolescents with leukemic during chemotherapy

The important point for caring adolescent with leukemia during chemotherapy are focus on several coping strategies that used by adolescents with leumemia such as, distraction, seeking social support and information (Decker, 2006; Sorgen & Manne, 2002). Moreover, these coping strategies were derived from the broad theoretical dimensions of problem- and emotion-focused coping vs. avoidance coping; these categories are inadequate for capturing the actual experiences of adolescents coping with illness and treatments. In addition, these categories of coping strategies are based on models of coping in adults and lack input from the adolescents themselves (Ellis, 1991; Parry & Chesler, 2005).

The findings of the study in field of coping in pediatric cancer improve nurses' understanding of the coping strategies. It is vital to increase awareness among nurses and other healthcare professionals who work with children with cancer to recognize the in-depth knowledge of coping strategies because it is important to provide holistic care, especially for adolescents with leukemia who has the uniqueness of developmental task and the difficult to living with leukemia.

Nursing care to promote adaptation in adolescent with leukemia

Most of adolescence with diagnosed by leukemia has a problem to adaptive with live, and their living are suffer and difficult. Because adolescence is a time of crisis developmental change and conflict. The symptoms of leukemia such as anemia, bleeding, weakness, bone and joint pain, and repetitive infections will made adolescent are more difficult to cope. Because the symptoms affected adolescent's daily living. The closely care by parents and others is need for adolescent who has leukemic symptoms but it is conflicting with the need of adolescent to be independent. The conflict of parents and adolescents was founded in several studies (Clarke et al., 2005; McGrath, 2001). This put adolescent patients with leukemia under stress and the adapting ability with illness was decreases (Alridge & Roesch, 2007). Nursing attention need to be directed to the adaptation as a goal of caring for adolescents who are face the leukemia. The goals of adaptation of adolescents with leukemia can be defined as adolescent can maintain the optimum health or dying with dignity if the disease cannot success curing. Nursing care that aims to achieve adaptation as a goal for adolescents with leukemia is very complexes because the nursing care will compose by an intentional, interacting, active, dynamic, individual, and motivating process experience by both the nurse and patient. In addition, Extra adaptation is requiring when adolescents were diagnosed as having leukemia because they will be in crisis by the impact of leukemia.

Adaptation is the most central concern when pediatric nurses provide care to adolescent patients with leukemia. Nursing care that aims to achieve adaptation as a goal for adolescents with leukemia is very complexes because the nursing care will compose by an intentional, interacting, active, dynamic, individual, and motivating process experience by both the nurse and patient.

When focusing on the research in the field in adaptation of adolescents with leukemia. Several studies of children with cancer have focus on the process and situational aspects of adaptation and coping with cancer in children and found that children and families showed a variety of coping strategies, each depending on situational. Whereas may of coping studies focus on coping during active treatment, in longitudinal studies of Kupst and colleagues (Kupst et al., 1995; Kupst et al., 1984; Patenaude & Kupst, 2005), which followed children and families from diagnosis thought long-term survival, focus on coping during specific phase of treatment and beyond and assess coping strategy and adequacy of coping. These studies found a wide variety of individual difference in the use of coping strategies in children and parent and no consistently significant predictors of adaptation. A recent study (Grootenhuis & Last, 2001) asked whether coping strategies differed depending on the status of the child’s cancer (remission vs. relapse or second malignancy). Comparing 84 children with differing survival expectation, they found that disease status did not predict children’s defensiveness or use of cognitive control strategies.

A most recent trend in adaptation research involves less orientation toward classification of survivors’ strategies and more interest in finding correlates or predictors of adaptation and adjustment. Several researchers have posited a regressive adaptive style to explain the common findings that children with cancer typically show lower level of distress on self-report measurement. Similar findings of low distress and indications of repressive adaptive style have been suggested in studies of long-term survivors (Elkin, Phipps, Mulhern, & Fairclough, 1997). Results of earlier work indicated that avoidance and even denial, for example, maybe adaptive in some situations but not in others (Phipps, 2007; Phipps & Steele, 2002). More work need to be done to determine the appropriateness of these coping style and strategies under a variety of circumstance.

Research in Outcomes of adaptation is a focus for nursing practice. This study is an analysis of experiences reported during adolescents' adaptation to cancer and is based on the concepts of adaptation described in the Roy Adaptation Model (RAM). Yeh (2001) reported that positive adaptive approaches are definable only by the individual with cancer. Haase (2004) identified the need for research priorities that emphasize positive psychosocial adjustments in adolescents with cancer. In another study, Perrett (2007) suggested that the research be geared toward meaning-based models and qualitative studies that can form a basis for interventions.

When focusing on nursing care for improve adaptation of adolescent with leukemia. Nurse researchers founded adolescents with leukemia face many stresses that challenge their ability to cope (Adler & Page, 2008; Eiser, 2004). Furthermore, adolescents with leukemia need an assessment of multiple distresses symptom that they have limited to describe (R. L. Woodgate, 2006). Ramini, Brown & Buckner (2008) use Roy Adaptation Model to examine adaptive strategies of adolescents with cancer. They founded that the model need to be clarify, especially the cognator and regulator mechanisms. The nursing intervention to help the adolescent patient with leukemia cannot be set up until nurse gain more knowledge specific to adaptation of this patients group.

Appropriate nursing care for adolescents with leukemia, especially in Thai context.

Nursing care that aims to achieve the goal is very complexes because the nursing care will compose by an intentional, interacting, active, dynamic, individual, and motivating process experience by both the nurse and patient. In addition, the responses of adolescents when they having diagnosed as leukemia is comprised of the adolescent's live with the following situations: the cancer diagnosis, the beginning to the ending of treatment and the follow up period. Nurse need the data from adolescent's perspective, especially the experience of dealing with chemotherapy that adolescents acting out.

In addition, special care for adolescent with leukemia is need. Leukemia is the life life-threatening illness. To diagnose as cancer for adolescents is symbolize as a slow and painful death rather than a potential curable disease (Beisser, 1999). Because adolescent has a cognitive to understand the word "leukemia" is a cancer that was a cause of death. Adolescents will be living with the fear of death all the time until the leukemia is curing. Adolescent with leukemia need to talk about the fear of death with someone but it cannot happen. Because talking about death is unlucky and uncomfortable for Thai people. Adolescents with leukemia were fall in to severe emotional stress because they cannot take out the meaning of death from leukemia in their mind and the illness will be worse (Eiser, 2004; Decker, 2006; Treenai & Chiyawat, 2006).

Adolescents with leukemia must be follow the treatments protocol without any choice and nobody knows what the future will be. Whether to live or death, most adolescents with leukemia were accepted the chemotherapy as a part of their lives and tried to have optimal lives (Stam et al., 2001). Most of adolescents with leukemia need to go back to normal living, especially going to school because school is an essential component of teenager's world (Woodgate & Degner, 2003; Dahlberg & Love, 2008).

Stressors for adolescents with leukemia include disruption of life routine from numerous clinic visits and hospitalizations, understanding the prognosis, and treatment; adapting to the treatment, and related side effects; interacting with family and peers; and "dealing with two worlds, that of health and illness, of specialness and normalcy"(Chesler & Barbarin, 1987).

The dual challenges of normal adolescent development and the stressors inherent in chemotherapy, the treatment of leukemia, may be overwhelming for many adolescents due to their limited experience dealing with stressors of this magnitude. Successful adaptation during chemotherapy requires adolescents with leukemia to effectively manage their emotions and behavior, interact with the social and teenager's life, and think in new ways in their attempt to alter or decrease sources of stress. These are all processes linked to how adolescents with leukemia live with chemotherapy.

The emic view of adolescents with leukemia during chemotherapy become important and should be considered, since they are the principal experts in their needs relating to wellbeing and human values. In this sense, nurses need to understand chemotherapy and leukemia as the response to live, seeking as a source of information, in the case of study, the adolescents with leukemia.

Grounded theory methodology

This study aims to generate the grounded theory of adolescents living with chemotherapy. The grounded theory method was developed by Glaser and Strauss during the 1960s. It was first described by them in their 1967 book, The Discovery of Grounded Theory, and was further explicated by Glaser in his 1978 book Theoretical Sensitivity.

Grounded theory is a qualitative research method that was developed for the purpose of studying social phenomena from the perspective of symbolic interactionism (Charmaz, 2006). Grounded theory uses a systematic set of data collection and analysis procedures to develop an inductively derived theory from the data. Field research and interviews are the usual methods for gathering data (Artinian, Giske, & Cone, 2009). The generation of the theory occurs during actual research (Glaser, 1978), and is based on comparative analyses between or among groups of persons within a particular area of interest.

This comparative analysis is a central feature of grounded theory and is often referred to as the constant comparative method. Therefore, the grounded theory method, along with its technique of constant comparison, allows a researcher to identify patterns and relationships between these patterns (Glaser, 1978; Morse, Stern, & Corbin, 2008).

Grounded theorists emphasize the importance of theoretical sampling in the context of constructing theory from data. This is purposive sampling that often occurs after initial data have been collected and preliminarily analyzed. The purpose of theoretical sampling is to strategically increase the diversity of one's sample with the idea that this diversity will provide new information that will help one better appreciate and define the constructs and propositions that are evolving. The motivation behind theoretical sampling is not to obtain representativeness, but rather to seek out new information that provides perspectives on the boundaries and nature of concepts and relationships between them (Charmaz, 2006).

The process of generating grounded theory is: both hierarchical and recursive because researchers must systematically categorize data and limit theorizing until patterns in the data emerge from the categorizing operation. This method requires data collecting, open categorizing, writing memos, determining a core category, recycling earlier steps in terms of the core category, sorting memos, and writing up the theory (Glaser 1978).

The primary purpose of grounded theory, then, is to generate explanatory models of human social processes that are grounded in the data (Artinian, Grike & Cone, 2009). A second purpose of grounded theory is to elaborate on and modify existing theories (Strauss & Corbin, 1998). According to Strauss and Corbin (1998), the major distinguishing factor between grounded theory and other qualitative research methods is its emphasis on theory development, either substantive or formal. A substantive theory is grounded in research on one specific content area such as patient care. Hence, substantive theory evolves from the study of a phenomenon situated in one particular situational context.

In contrast, formal theory pertains to a conceptual area such as pain or violence (Glaser, 2006)Therefore, a formal theory emerges from a study of a phenomenon examined under several different types of situations (Strauss & Corbin 1998).

Basic assumptions of grounded theory

Assumptions of the grounded theory method Although Glaser and Strauss never state explicitly the assumptions (or label certain criteria as assumptions) underlying the GT method, these assumptions are inherent in their and others' writings. The major assumptions of grounded theory methodology can be summarized as follows (Artinian et al., 2009; Charmaz, 2006; Glaser, 1998):

1) Inquiry is structured by discovery of social and social psychological processes. Data collection and analysis phases of research proceed simultaneously.

2) Both the processes and products of research are shaped from the data rather than from preconceived logically deduced theoretical frameworks. The data for grounded theory come from the research participants that having the directed experience in the topic of research. The researcher can explore the data by interviewing research participants and observation the phenomena in the research filed for the intuition of the nature of participants.

3) Analytic processes prompt discovery and theory development rather than verification of pre-existing theories. In the development of grounded theory, constant comparative analysis is the central approach to data analysis. The approach occurs when data collection and data analysis take place simultaneously. Following are the four stages in constant comparative method : 1) comparing incidents applicable to each categories, 2) integrating categories and their properties, 3) delimiting the theory, and 4) writing theory.

4) Coding and categorizing data were the process aim to generate a theoretical description from given pattern of behavior in study phenomena. The first step of data analysis is developing qualitative codes to characterize the data. Coding is the process by which researchers simultaneously categorized and summarize many pieces of data to determine and establish a short name for the segments of data. Data coding activities include open coding, selective code and theoretical code (x).

Open code was the vital first step. The researcher gave the code for label the data line by line from the interview transcripts. Several strategies are offered for code building. These include staying close to data, choosing words to reflect data, creating short codes, remaining open to building new codes, comparing data with other data, and moving quickly though data (x). Sometime open coding can use in vivo codes whereby codes are named using the participants' exact word. Researchers benefit from using in vivo codes by protecting themselves from using preconceived notion to establish code.

Selective code is the process is the process of integrating and refining the theory. The goal is to identify a central category and to establish links among categories. Researchers employ inductive and deductive perspective during constant comparative analysis to set and test hypotheses or create hunches about the central or core categories and its relationship.

Theoretical code is the final coding process to generate grounded theory. Theoretical codes were the code that conceptualize how selective codes may relate to each other. Glaser points out that theoretical code have to earn their way in the analysis, like any other code, as pattern start to emerge substantively. This narrows down the options for relation selective codes. These code can be inspired by existing theories, as with some Glaser's coding families.

5) Research writing memos and use for writing up the ideas about selective code and their theoretically coded relationships. Memos will occur during the process of data analysis. In additions, researchers use memo for captured the idea that appear during collecting data and writing some hypothesis about data analysis. They may rise questions in memo during data collection and analysis. A record in memos helps remind the researcher of important information because when writing a memo, the researcher use both inductive and deductive reasoning.

6) Theoretical sampling refines, elaborates, and exhausts conceptual categories. Based on their own decisions and before collecting data, researcher determine the inclusion criteria for the participants, along with the setting and methods. These process are known as purposive sampling. As soon as the first collected data are in hand and analyzed, the researcher make other decision and have new direction to obtain data from selecting new participant from whom they believe to gain relevant experience. Furthermore, they may change a setting or adjust the data collection method. All adapted procedures are called theoretical sampling (Schreiber, 2001)

In grounded theory study, recommended sample sizes are varied and depend upon the characteristic of a domain of inquiry. A narrow domain requires interviews with fewer participants than does a board domain of inquiry. More important is the assurance that theoretical saturation is reached. Saturations refers to the practice by which researcher continue data collection until no new data found. Moreover, researchers must be able to explain variations in categories or subcategories and be sure that the relation among categories, subcategories, and concepts are clearly explicated and validated. In theoretical saturation, the quality of data is considered more important than data that are found frequently in the interview (Becker, 1993).

7) Grounded theory methodology is not only aimed at studying processes, but also assumes that making theoretical sense of social life is itself a process.

8) The systematic application of grounded theory analytical techniques leads progressively to more abstract analytic levels.

Another important distinction Glaser makes is the twofold principle of (a) entering into the study of a phenomenon with no preconceived ideas of what data should be there and (b) remaining true to the data that are found. There can be no predetermined hypotheses or coding schemes to guide the analysis of data. A third distinction in using Glaser's approach is the need to stay long enough in the setting to allow the researcher to identify the major concern of the participants so that the core category or process that depicts their answer to the problem is allowed to emerge. Glaser insists that the theory must respect and reveal the perspective of the subjects and not that of the researcher (Glaser, 1998).

The basic method of grounded theory, constant comparative analysis, is based on theoretical sampling: the concurrent collection, coding, and analysis of data, which is used to direct further data collection appropriate for developing the emerging theory. Grounded theory is developed by constant comparison of incident with incident. The comparisons are recorded in theoretical memos, which are the "theorizing write up of ideas about codes and their relationships as they strike the analyst while coding" (Glaser, 1998). By recording the comparisons in memos using theoretical codes, the researcher develops categories and hypothesizes relationships among categories. These relationships are then tested through theoretical sampling until categories are saturated and a core category emerges that describes the behavior used by the subjects to resolve their main concern. The goal of grounded theory is to discover the core category. This goal is aided by theoretical sorting of the memos, which makes possible the integration of connections among the categories and leads to a rich, multivariate theory.

Types of Data Analysis

Data analysis is based on a three-level conceptual perspective analysis. Glaser (1998) outlines these three levels as follows:

1) The first level is the data.

2) The second level perspective is the conceptualization of the data into categories and their properties. There are sublevels that exist within this level.

3) The third level is the overall integration of data into a theory through data sorting.

4) A fourth level perspective is the formalization of a substantive theory to a more general conceptual level by constantly comparing substantive theory articles writing theoretical statements

After formal analysis of data, memos, and field notes, the researcher sets about the task of describing theory. Scientists have different ways of doing so. Some grounded theory researchers describe the relevant variables within the theory and the relationships between them, developing the logic and past empirical support for those relationships. These scientists might use path diagrams to help them present their theories. Other grounded theory researchers present the theory in the form of propositions, conclusions, or theses, and then weave a set of arguments in support of those statements. The arguments are logically derived from empirical data from research. Emergent theorists tend to frame their theories using propositions and then develop supporting arguments. Given such an orientation, it is useful to consider perspectives from the field note and memo. The focus here is on building effective argument structures in support of propositions.

Treatment of Reliability and Validity in Grounded Theory

Initially Glaser specified the criteria for judging the quality of a grounded theory as “fit, work, relevance, and modifiability”. In an analysis of these criteria using a realist interpretation, Lomborg and Kirkevold (2003) conclude that fit “is a matter of correspondence to facts in social reality” and that work, relevance, and modifiability “are argued to support the fitness of a theory and to be useful in the broader evaluation of the quality of grounded theories”.

More recently, Glaser (1992; 1998) has addressed the issues of reliability and validity and concludes that grounded theory does well in meeting the established criteria:

1) Credibility: A grounded theory is abstract of time, place, and people. Because the categories are constantly compared to vary them for application and to develop new properties, he states that when a theory is generalizable, fits, works, is relevant, and is highly modifiable, this method produces a product that is credible.

2) Transferability: Because a grounded theory transcends experience it moves from description of what is happening in a particular situation to an understanding of the process by which it happens. Since it is abstract of time, place, and people it can be more readily applied to a new situation with emergent fit.

3) External validity: The concept of fit means that the theory both fits the situation from which it was generated and can be generalized to other situations by constant comparison.

4) Dependability: All categories and properties are constantly verified during the process of generating theory. New data or changing conditions just require modification as categories vary and these modifications are worked into the theory.

5) Conformability: The problems of reproducibility, replication, and objectivity are not pertinent to the grounded theory method because conceptualization is the goal, not description. The conceptual patterns, once discovered, stand on their own and new data will only extend or modify the theory.

This study employed grounded theory to developed knowledge with the purpose to discover how Thai adolescents live with cancer. Grounded theory was appropriate method of this study for several reasons. First, grounded theory explores social process and this is helpful when the goal is developing theory that explains human behaviors during their interactions with other people in society (Morse et al., 2008). Second, adolescents with leukemia were in transition, from adolescents who have a healthy life to as leukemic patients. In addition, they living with illness and treatment regimen. Nursing research has shown that grounded theory is suitable for the study of individual behavior related to developmental transition and challenging situation (Wuest, 2012). Finally, grounded theory is beneficial when less is known about the area of study, as is the cased for adolescents with leukemia. “The goal of grounded theory is to generate a theory that accounts for a pattern of behavior which is relevant and problematic for those involved” (Glaser, 1998).

Participants were encouraged to share experiences, view their situation, and build relationship with researcher. During interview, the researcher and participants had interaction with each other and data analysis were partially created through this social process. A reflexive process was used during the interactions with in order to enhance the rigor of the study. The researcher's prior roles, experiences, values, and beliefs could influence the process of data collection and analysis. Reflexive processes provided a way to help the researcher critically examine his personal interface with the data. As a result of using the grounded theory approach, a researcher could arrive at a very solid useful theory. Especially, the study generated a theoretical framework to help health care provider better understand adolescents with leukemia who receiving chemotherapy with Thai context and potentially develop interventions to assist adolescents with leukemia.

CHAPTER III
METHODOLOGY

This chapter covers the overview of research design including the research setting, research participants, research instruments, data collection method procedure, data analysis, and trustworthiness of data analysis was presents.

Research setting

Two tertiary general hospitals in Bangkok were the settings of this research. Both hospitals have a cancer unit that provides care for child and adolescents with leukemia. Treatment protocols for leukemia and hospitalization policies in both settings were similar. Adolescents with leukemia had to admit to a cancer unit chemotherapy continually to receive place with in both multiple drugs at high doses. Only one caregiver was allowed to stay with the patients in the hospital.

Research participants

Participants in this study were adolescents with leukemia receiving chemotherapy at Thammasat university hospital, and Queen Sirikit National Institute of Child Health. Inclusion criteria were as follows:

1) Thai boys and girls aged 12-19 year olds with the diagnosis of leukemia and were treated with chemotherapy.

2) These adolescent knew their diagnosis and received chemotherapy at least two times. Side effects of chemotherapy such as, nausea, vomiting, fatigue, and body

image disturbance tend to occur after the second course of chemotherapy. In addition, these adolescents had experience on hospital admission and discharge.

3) All participants were full of conscious and be able to understand the interviewing.

Five adolescents who met the inclusion criteria were purposively recruited. Data from each case were analyzed. Tentative code were developed and use to guide the researcher in term of what data would be collected next, and where to find the next participants. This theoretical sampling method was used for recruiting following participants until the data were saturated.

During the theoretical sampling the inclusion criteria were still used as a means of selecting new participants. Fifteen participants were recruited in the phase of theoretical sampling. The data were saturated by twenty participants.

The age of participants ranged from 12 to 19 years old. Four participants (20%) were in the early adolescents phase, 14 year olds . Ten (50%) were in the middle adolescents phase, 15-17 years old, and six (30%) were in late adolescents phase, 18-19 years old. All of them were Thai and Buddhists. The majority finished junior high school (60%, N=12); two finished elementary school (10%), two were studying in vocational study programs; and three were studying at bachelor level. Ten participants dropped out of school because of illness, but all of them have a plan to go back to study. Three participants was die in February 2014.

Ten participants were diagnosed at the age of 13 years old, and the remain ten participants diagnosed at the age of 10 – 12 years old. Seven participants were in the induction and consolidation phase, three participants were in the re-intensification phase, and seven participants were in the maintenance phase.

Nine participants in this study lived in Bangkok and eleven participants lived in Patumthani.

Protection of human subjects

Prior to data collection, the proposal, interview guide, and subject consent form were review and approve by The Ethics Review Committee for Research Involving Human Research Subjects of the research filed.

After the approval, the researcher gave the informed potential participants and their parents about the research. When the parents agreed and signed the consent form, the adolescents and their parents were explained they could withdraw from study any time. The adolescents were asked about their decision to join the study. Those who expressed their intension to participate in the study were asked to sign the consent form.

Research instruments

The important instrument of the study was the researcher because the researcher took a major role in the process of inquiry. The amount and quality of data and the depth of the analysis depended upon the ability of the researcher. Therefore, the researcher’s qualification was presented here.

The researcher had master’s degree in pediatric nursing and had experience in providing care for children and adolescents in a pediatric oncology nursing more than 5 years. In addition, the researcher had conducted a qualitative research in pediatric nursing. During the doctoral education, the researcher took a grounded theory research course for 2 credits in Faculty of Nursing, Chulalongkorn University. In this course the researcher had a chance to interview and analyzing data. The researcher was mentored by the advisor who had experience in supervise in grounded theory research.

The assisting tools consisted of a demographic data form, and an initial set of interview questions (see in APPENDIX A) that were used to collect data from the first 2 participants. The opening questions were quite broad. After data from these participants were analyzed, new interview questions were developed and used in order to get more focused information.

Data collection procedure and data analysis

Data collection procedure

Data collection began in October, 2012 and finished in March 2014 by researcher. Data were collected by electronic-recorded interview using an interview guide.

To gain the cooperation with the cancer unit, the researcher asked the head nurse to introduce the researcher to nursing staff. After nursing staff suggested potential participants, researcher introduced himself to the participants

When the participants expressed their intention to join the study, an appointment was made by the researcher to meet the participants for the in-depth interview. The participants were selected the date, time and place for the interview after they listened to the information statement and sign the consent form. The chosen place for interview was also selected on mutual agreement between the researcher and the participants in order to assure the participants' confidentiality and to protect the researcher's safety.

The in-depth Interviews were approximately 40-60 minute in length. All interviews were recorded by digital device. The interview questions were open-ended. The main interview questions for the interview was *“Could you describe to me, or tell me, what happen when you received chemotherapy?”*

The researcher obtained spontaneous descriptive information from adolescents with leukemia by allowed the adolescents to pick the pieces of their own experience to share and active listening. The researcher took notes of issues that had been raised during the interviews as a way of remembering the data that emerged.

Data analysis

Data analysis was the steps of code and made the conceptualized with data. The researcher was analyzed the data that get from the interviewing. In this study, the data analysis procedure began after the first interview was transcribed verbatim and lasted until the writing of data was complete.

The constant comparison method was employed to analyze the data. It was use in each line, sentence, and paragraph from the transcript to look for concepts emerging from data. Each code was compared to all codes to look for similarities, difference, and general patterns.

During data analysis the memos were written while coding, collecting, and analyzing the data. The memos were wrote the idea about substantive codes and their theoretical code relationship. Something the researcher wrote any words, phrase, or sentence that suggested an idea for researcher to analyze the data, such as “the next interview should ask and deeply explore about how adolescents with leukemia caring themselves when they have chemotherapy side effect,” “The participants talking about they read the medical book about leukemia. How they get the book? What they understand after reading the text book about leukemia?" Thus, the memos in this study captured the meaning of conceptualizing perspectives of the researcher and helped the researcher to integrate codes and to generate a substantive theory and model.

The data analysis was not a linear process, but one that took the researcher back and forth between levels of understanding across the course of interviews. In this study, the researcher consulted his advisers in all process of data analysis.

The steps of data analyzed was presented as follows;

1. As a first step, recorded interview data were transcribed in full (all voices Included). The researcher completed the first two transcripts, a process important to immersing researcher again in the stories, and attuning researcher to how the researcher was asking questions and responding, and enabling the early process of theoretical sampling.

The interview and transcript were conducted in Thai language. The format documents were made to make the analysis process be easy. The researcher made the documents with two columns, the left column will be brank for put the coding during data analysis. The right column was inserted by the interview transcript line by line. The interview transcripts were read carefully with the researcher's concentration.

2. The open coding was start, line-by-line coding. The codes were wrote at the left column beside the transcript on the right column. The researchers were moved quickly for coding the interview transcript.

All coding were coded in English. The gerunds, loosely defined end in ‘ing” was used as the codes. Some ‘in vivo,” the participants’ word could use as the codes in this process.

Sometime the researcher could not find the appropriate code in English. The researcher used Thai word as the beginning codes. The researcher was supervised by his adviser during open coding process to avoid analyzing data with preconceived notions.

2. The subcategories will be identified. Subcategories are characteristics and properties of categories along a continuum or dimensional range. The researcher used the memos to make the linkages among subcategories, to allow for some conceptual order to be placed on the data. This was done by asking questions about relationships in the data (constant comparison) or by testing hunches against the data.

Initial codes were shorten and compared. Similar codes were grouped together under a more abstract code. New similar codes were then grouped together to create a cluster. Then cluster were reduced into meta-cluster with label. The label of data was grouping together to became concept. This was the stage of selective code.

4. Researcher worked to compare concepts with concepts. By began to detail these at various levels of abstraction, with lower-level concepts (e.g. having pain, being fatigue) forming a foundation for those at a higher level (e.g. Facing sickness). As these higher-level concepts, or categories, served as collections of codes sharing some manner of association, researcher continued to use a constant comparative process to explore their properties (e.g. intensity, timing) and property dimensions (e.g. severe, late) to further define the category . The similar concepts were grouped together to develop categories

These abstract codes, was defined by their richness and ability to capture broader concepts, became the provisional theoretical categories. Notably, this process is recognized as one of the most challenging stages in grounded theory analyses and researcher experienced it as such. Accepting this, researcher attempted to stay with the complexity, consulting with advisor to read and look the categories that was created.

5. The core category was identified and it was the central of the finding, around which all the other sub-categories could be subsumed. The memos was used to write the detail of the core category and sub-categories.

6. The final stage of data analysis consisted of comparing the finding of this study with related or relevant existing theories. This approach was minimized to use the preconceived idea on the data analysis.

Additionally, in conducted this study, a high proportion of direct quotes form research participants were included to provide “the thick descriptions.” The main advantage of using participant’s quotes was that it provided particular participants with a voice which had not been altered by researcher bias. Therefore, the word used by the participants were not changed. (The example of some interview transcript with coding and some memos were in APPENDIX E)

The codes that was emerged became more and more specific to the understanding how adolescents with leukemia live with chemotherapy. Data saturation was reached with 20 participants. The data analysis process was stopped.

Trustworthiness of data analysis

Evaluating of Reliability and Validity in Grounded Theory

The researcher used several method to establish trustworthiness on this study as describe below.

1) Credibility

In this study, credibility was evaluated through the vividness and faithfulness of description of phenomena. The grounded theory method was adopted and established the rigorous of research methodology by the adoption of constant comparison method for analyzing the data, theoretical sensitivity was applied in the research process, and theoretical sampling was used to meet the criteria of the sampling for grounded theory.

In order to increase the credibility of this study, the researcher was selected the appropriate participants by using rigorous the inclusion criteria. The prolonged engagement in field of research was considered and attempted through this research process.

The researcher attempted to establish a good relationship with the participants in order to build trust and rapport in the data collecting process. All participants in this study expressed the feeling of willingness to join this study. Following the interviews many participants expressed a number of positive feelings about being involved in the interview process. Some participants thanked me for allowing them to be involved and many remarked at how they had not talked about their experiences during chemotherapy to that degree with anyone before.

The data collecting methods were used various source, such as in-depth interviews, observations and field note, to increase the credibility.

2) Transferability and external validity

The researcher described the data of this study based on the participants' information. Theoretical sampling employed for recruit participants that had direct experience in living with chemotherapy. Fittingness is an interchangeable term of transferability or generalization. It refers to the application of a set of findings to another setting. Fitting ness in this study based on a "thick description" about time, place, people, and the context of finding that was provided by the researcher. This means that the findings of the study will be strengthened by provide rich, thick slices of finding data to make transferable judgments. In addition, a test of fittingness werebe passed when the finding reflect the phenomena being studied. Moreover, if the readers of the explanation of the theory derived from the data find them meaningful in term of their own or other familiar contexts, this reflects the fittingness.

3) Dependability and Conformability

Dependability and conformability constitute the stability of finding. The evaluation of conformability based on the characteristics of data. The data of this study was verified during the process of generating theory by the "audit," which is a major technique of establishing the stability of data. In this study, the thesis advisors were audited the data of the study. The dissertation advisors were discuss with the researcher and talked about coding process. The coding concepts and the preliminary categories were compared and discussed for agreement between the researcher and the advisors.

CHAPTER IV
RESULTS

In this chapter results of the analysis were reported. The discovered basic social process and it categories were described. Quotes were also provided to enrich the information. “Returning to normality” was discovered as the basic social process of living with chemotherapy in adolescents with leukemia. This process is composed of four major stages: realizing being a leukemic patient, accepting chemotherapy as a key to normal life, learning self-care related to chemotherapy, and pursuing the best self-care.

Adolescents with leukemia needed to go through the first stage, "Realizing being a leukemia patient" before stepping through other stages. In addition, these adolescents with leukemia were driven by their "looking for brighter future". The model in figure 1 illustrated this process. Its detail description was followed.

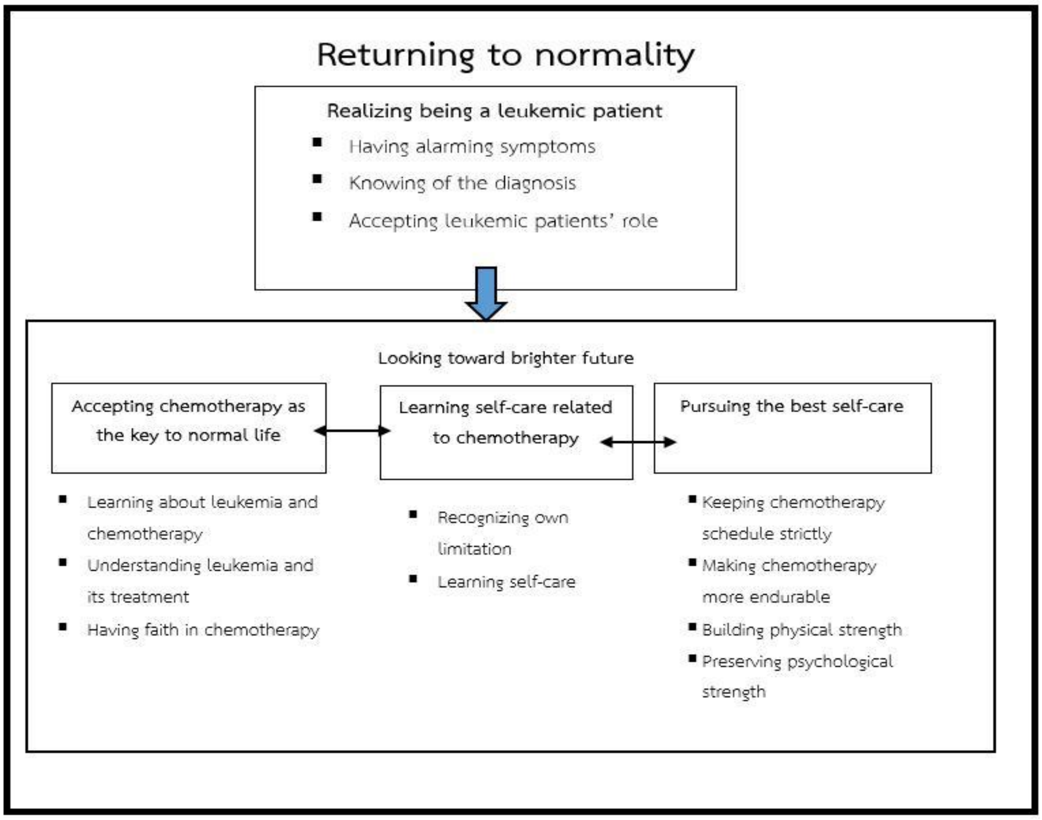

Figure 1: The basic social process: Returning to normality

The basic social process: Returning to normality

“Returning to normality” was the basic social process that adolescents with leukemia, use in day-to-day that they live with chemotherapy. This basic social process use the effort of adolescent’s cognitive developments because adolescents with leukemia made it with the decision to do the action that could help to returning to the normality.

Adolescents with leukemia defined “normality” their own way, not the same meaning that healthy adolescents or general people may define. They recognized that they were not as strong as they use to be and could not do everything that their peer could do. With that recognition, they define “normality” as something that they could perform like healthy adolescents with their limitation health.

The normality was the action that adolescents with leukemia could be a part of the activity with peers, or family. This activity was not the active participated such as, the adolescents only sit for watch their friend play basketball, or they join the family’s trip to the beach but not swing in the sea.

The usual living is the harmony to live by maintaining the normality of a teenager’s life. Many adolescents with leukemia go back to study, and playing with friends in the same way before getting leukemia. The optimum outcome in leading the normal living is that they preserving of the normality by house care, gardening and cooking.

For adolescents with leukemia “normality” that they return was simple and related with the causal and happy living. When adolescents with leukemia recognized that they were not as strong as they used to be and could not do everything that their peer could do. With that recognition, they define “normality” as something that they with their limited health could perform like regular adolescents, e.g. being able to eat their favorite food or vegetables and fruits, or going out on a long trip. This was the indicators of the success to return to normality.

The reasons that adolescent with leukemia defined the normality in this way because they want to be a part of the group; friend, and family. In addition, adolescents with leukemia could detected the strength of their body by the experience that they have during chemotherapy, and detected the risk of their health. Then, the adolescents with leukemia, use their effort to reduce the barrier to be “normality” as they should be.

Adolescents with leukemia felt that it was important for day-to-day lives to continue as normal as possible in order to facilitate adjustment to the chemotherapy and reintegration with friends during the treatment period. As 16 years old, adolescents with leukemia said; “I have what the calls a normal life, going out to meet and join the activity with my friends.”

Some adolescents with leukemia who receiving chemotherapy and the leukemia not cured .They can having the normality by asking parents to change their cloth to school uniform and take them back home after death. At this point of, archiving of the normality could happen in adolescents with leukemia even though at the end of life.

For all adolescents with leukemia in this study, “returning to normality” were that they could return to the possible life. The possible life was the simple living that could happen in the reality of their situation, not in the dreaming.

Returning to normality in the perspective of adolescents with leukemia were not a static concept, but a staged and transient process. “I get used to the highs and lows and the ups and downs to go back to my daily life.”

Adolescents with leukemia needed to go through the first stage, "realizing being a leukemia patient" before stepping through other stages; “accepting chemotherapy as a key to normal life”, “learning self-care related to chemotherapy”, and “pursuing the best self-care”. The other three stages models that emerged could happen in the forward and backward.

In addition, these adolescents with leukemia were driven by their "looking for brighter future". The other aspects of the bright future of adolescents with leukemia included thinking about the batter day in the future, believing about the good life, keep walking for another day, not having any weaknesses, and thinking that they “having the future.” Most of adolescents with leukemia have never experienced a major illness, much less a life-threatening one. They typically have a sense of invincibility, and a cancer diagnosis immediately forces them to consider their mortality.

Adolescents with leukemia returning to normality at the time that they were readiness. It was not an urgent but it can wait for readiness to returning to normality. The adolescents with leukemia in this study were presented to “returning to normality” such as, going back to study, and keep in touch with friends. Adolescents with leukemia was “returning to normality” by doing something with their limited health like regular adolescents, e.g. being able to eat their favorite food or vegetables and fruits, or going out on a long trip. This was the indicators of the success to return to normality.

For adolescents with leukemia were recognized that they were not as strong as they used to be and could not do everything that their peer could do. Adolescents with leukemia was manifested in the form of action strategies to reducing the barrier for being a normal teenager as they should be. The simple strategy that adolescents with leukemia was used for returning to normality was *“listen to the voice within.”*

Listen to the voice within was developed in adolescents with leukemia. This strategy as the method to make a question with themselves about “health status” and make a conclusion by the sense. In addition, adolescents with leukemia was confront the side effects of chemotherapy that occur over and over again. They were detected the strength of their body by the experience that they have. The adolescents with leukemia “not” go back to the normality by ignoring the risk of their health because they know the risk could disturb the normality that they need in future. As one 13 years old boy said; *“I’m listen to the voice within to get back to live as normal. I know the risk of infection, but my body will let me know when the infection was battered and I can going out for travel to the beach with family.”* Some adolescents with leukemia discussed how they felt insecurities about going back to normal living during chemotherapy: “I’m hoping that when I finished chemotherapy, then pretty soon I should get back to normal, but you just don't know do you?" Again, the sense of the health status that adolescents with leukemia were assessed was the answer. Adolescents with leukemia will wait until they were ready for returning to the normality. As 14 years old girl said; *"I have fever and weakness after chemotherapy. I know by myself that my body not ready to go out. I stay in my house until everything was ok. It's look like I talk with my body and know what I need to do."* In addition, the strategy to detecting the health status in adolescents with leukemia, that called *"listen to the voice within"* can help the adolescents with leukemia living with the normal life as it possible.

For adolescents with leukemia who receiving chemotherapy and coming to the end of illness. They preserved the normality by fulfill they need to returning to normality by asking parents to change the hospital cloth to school uniform and take them back home after death. The adolescent with leukemia who were die was in this group because these adolescents can archive to returning to normality. It's important to say that, returning to the normal life as much as possible by returning to normality was the importance engine for turning on the attitude to living for adolescents with leukemia during chemotherapy.

Stage 1: Realizing being a leukemic patients

"Realization being a leukemic patient", was the first stage that reflected how adolescents becoming leukemic patients and living with chemotherapy. The three subcategories consisted of having alarming symptoms, knowing the diagnosis, and accepting leukemic patients' role were founded as the subcategories that supported in this stage.

The adolescents began life as a healthy child, and they became leukemic patients by realizing they had an illness after the aggressive symptoms of leukemia affected their routine life. Additionally, the adolescents questioned their life because of the severe symptoms, which led them to stop a normal routine. They believed that the symptoms of leukemia could be relieved by going to see the doctor. This belief reflected that adolescents participated in the decision process and chose the best way to solve the illness.

The realization of being a leukemic patient was important to establish and highlight a substantial step forward in the adolescents' understanding of how their health was changed by illness.

The need to return to normal living as a teenager forced adolescents with leukemia to receive chemotherapy. Moreover, physicians told patients that chemotherapy was the best way to treat leukemia. The three subcategories of this realization process are described in the following.

Having alarming symptoms

The adolescent's symptoms of leukemia varied over time, and they experienced differing degrees of concern about these changes. However, each adolescent observed changes in his or her physical performance. As the adolescents described how they came to sense something had changed in their body, their stories highlighted visible and acute signs or symptoms, including extreme pain, tiredness, bleeding, excessive sweating, and high fever.

The symptoms had usually happened before, but they were *'unfamiliar and unrelenting'*. At the first time that symptoms show up, the adolescents just only think, "The symptoms will be better soon," or "It is the normal sickness" because some symptoms can happen in normal sickness such as, fever, bruising and weakness. Every adolescent were alert for the threat of illness when the symptom come worse. The symptoms become "aggressive" and "severe" that make the adolescents can be conceptualized about the symptoms that happen was unfamiliar and unrelenting. For example, one adolescent shared how he recognized the extreme pain in legs as a sign, and he was tempted to stay home from school when it briefly subsided:

"I usually feel pain in my legs after I play basketball. At night the pain was severe, it was like a bone pain, pain in the bone. I could not move my leg and could not walk. I let my parents know. I stopped going to school on that day." (12 years old girl)

When the adolescents had symptoms, they asked their parents for help and tried to alleviate the symptoms by themselves. The basic home medication was used, but often, the medicine did not help. The Adolescents became aware that the symptoms were not normal because every symptom was '*unresolved by the regular treatment'*. Adolescents were apprehensive that something has changed in their body by the symptoms that not healing when the time was passing by. The symptoms that happen not normal anymore the basic treatment that they have at home cannot relieve the symptoms. The symptoms are worse when the time was passed. Adolescents reported that routing life are stopping by severe symptoms. Finally, the adolescents realized that their symptoms were serious if the commonly used pain medication did not improve their symptoms. As 16 year old boy said:

“I take paracetamol and cold pack to relieve my fever, but my body seemed like I have a fire inside. My parents gave me the traditional herb to drink but it did not help. The simple medication can help.”

Beyond these signs of concern, the adolescents were particularly attentive to changes that persisted, interfered with their normal living, and were perceived as *‘severe and progressive.’* All symptoms lacked a clear explanation because they occurred suddenly and were severe and progressive. Some adolescents, for example, became concerned when they began to notice a “trend” of worsening symptoms, such as severe tiredness after exercise and powerlessness the next day. Another adolescent explained his growing concern about the persistent pain he felt. He believed that the symptoms were progressive in a bad way.

The adolescents realized quickly that they had an unfamiliar sickness. Every adolescent that participated in this study could not maintain their normal routine. They could not do basic activities, such as walking, because of the severe pain. Some adolescents could not eat because they had severe fatigue and high fever. The symptoms transformed the illness to a severe sickness, and it affected the adolescents’ routine life. All basic activities stopped, and a social life outside the family did not exist. The adolescents were alarmed by the symptoms of their illness.

Knowing the diagnosis

When adolescents had particular symptoms, such as bleeding, excessive sweating, and high fever, they were unable to continue routine life. They could not resolve the illness by themselves. Every adolescents going to hospital. The adolescents will meet the physician and having the investigation. Some adolescents going to see the physician several time before they knowing what happen.

'*Having a series of investigations*" was mentioned as the approach to explain the adolescents' symptoms. Moreover, this method was used to find the appropriate treatments that were specific to the sickness. The adolescents saw several physicians for physical exams and received appropriate medication. The initial tests at the first hospital visit included complete blood count, chest x-ray, blood chemistry, and urinalysis. The adolescents felt like patients because their health was being evaluated. Additionally, some adolescents who had severe symptoms were admitted to the hospital for observation. After abnormal results were found from the initial evaluation, another physician explained that a specific test would be needed. An adolescent recalled the special test very clearly: *"The doctor tells me that he will give me a special test. Bone marrow aspiration was the procedure."*

The adolescents who underwent bone marrow aspirations had a variety of emotions, including fear, frustration, and anxiety. An adolescent said: *"I am really anxious and a little afraid because this is a special procedure. I have no idea about the result."* Full evaluation took two or three days. Some adolescents had to go to the hospital more than once.

'Guessing of having cancer' was emerged as the point at which they transitioned from a normal adolescent to a leukemic patient. A series of abnormal results were found, and the parents of the adolescents were the first person to know the diagnosis of leukemia. All the adolescents were excluded from the discussion that occurred between the physician and parents. The adolescents noticed other people's

strange expressions as the cues that something was wrong. The parents' responses after hearing that their child had leukemia were not concealed from the teenagers. An adolescent explained: "My parents had a discussion with the doctor without me. After they discussed, I saw my mom crying. I knew I had a severe illness."

Some parents tried to calm down and avoid talking to their children about the diagnosis that they just discovered. However, the adolescents observed strange signs from their parents, such as cool hands, different tone of speaking, and facial expressions. The signs confirmed that "something bad happened", but the parents tried to calm down and avoided telling the adolescent about the diagnosis. A girl with 18 year olds described the experience in the following way: *"My father held my hand. I felt his hands were cool. He looked so sad, I had a severe illness. He smiled with the red eyes and he tried to not cry. I knew something bad happened."*

In informing the adolescents about medication treatment, physicians used the word "chemotherapy". Adolescents knew this word and an adolescent explained that he though *"I guess that I have cancer because cancer patients receive chemotherapy."* Additionally, when adolescents heard the term "blood disease", they were doubtful and tried to ask the doctor for more details. The doctor explained some details, such as "your white blood cells are more productive and not under control. It makes you sick." The adolescents were suspicious, and one adolescent had guessed: *"The illness is not only a blood disease. I think it is severe, maybe it is cancer in my blood."*

'Being informed by parents or by physician'

The adolescents received information about their illness and learned of the leukemia diagnosis by their parents or physician. The information that the adolescents received was consistent with their suspicion of having cancer. After hearing their diagnosis, the adolescents did not panic, and they used the information they received about leukemia to decide to receive chemotherapy treatment. However, they asked for clarification about chemotherapy because they needed more information. One adolescent described: *"I need to know more about chemotherapy. Does it help me to get rid of leukemia?"* Physicians and parents gave more information about chemotherapy, but the adolescents asked for more details and directly asked the physician about the chemotherapy, using questions such as *"Can you tell me more about chemotherapy?"* The doctor then explained the treatment more directly. The adolescents focused most on the possibility that chemotherapy could cure their leukemia. Many adolescents stated: *"Chemotherapy is the choice of treatment. I was bright in my mind."* All the adolescents with leukemia in this study desired to have chemotherapy because of the chance of being cured.

Adolescents with leukemia were to summarize their information and knew the truth of the illness happening with their life. The conclusion in mind that they had leukemia and became the real. "Leukemia was a logical conclusion" as 14 year olds adolescents with leukemia, shared:

"The doctor told me the diagnosis of my illness. Everything was concluded that I was diagnosed with blood cancer. It was a truth and real. I became a patient having leukemia"

In learning of their disease, the first lesson for the adolescents was to becoming leukemic patient. Deliberations was over the meaning of symptoms, the medical diagnosis, and the completed conclusion of every cue. Every teenager felt "numb," and "hot flush on face," on the time that they completely knew the diagnosis.

Accepting leukemic patients' role

After the adolescents realized their diagnosis, treatment began as soon as possible. The adolescents with leukemia 'accepted chemotherapy as a treatment'. This was the step towards realizing their role as a leukemic patient. The time they spent in the hospital for chemotherapy allowed the adolescents to learn more about leukemia and chemotherapy because they could ask for more information from the physicians and nurses that spent time with them. Information, such as the cause of leukemia and the chance to be cured, showed that leukemia was different from other types of cancer. This belief process was a strategy that adolescents with leukemia used to reflect on the opportunity to live. It was the starting point for adolescents with leukemia to think "What should I do after having leukemia?"

"Leukemia is a cancer of white blood cells. It's a cancer but I know it has a chance to be cured by chemotherapy. Because nowadays, many children with leukemia are cured. This is a different form of cancer. Maybe my leukemia can be cured and I know what I can do when I have leukemia. I will take care of myself." (15 years old boy)

Adolescents with leukemia referred to themselves as a "leukemic patient" when they spoke with health professionals. Additionally, they described that they merged their understanding of the illness with the realization of being a leukemic patient. They demonstrated their understanding of the cause of leukemia and accepted that staying in the hospital was an important part of treatment. An adolescent said:

"I'm a leukemic patient. I know that leukemia is the cancer of the white blood cells. My white blood cells are too high and the white blood cells make me sick. Every leukemic patient must understand this topic because it is the basic information for going on with treatment for decreasing the white blood cells." (19 years old girl)

Moreover, the adolescents had to tell the significant people in their life about the illness. This task was not complicated but needed to be done at the right time. For adolescents with leukemia, the significant people they had to tell about their leukemia were close friends. Most of the adolescents with leukemia in this study called their close friends to share this information.

Stage 2: Accepting chemotherapy as the key for normal life

After adolescents with leukemia having alarming by leukemic symptoms, getting to know the diagnosis, and accepting leukemic patients' role. The chemotherapy was individualized treatments. Adolescents with leukemia accept chemotherapy as a treatment not only following the rules to be cured, but also the big steps to formation to learn about leukemia and chemotherapy. In addition, being treated by chemotherapy was the most important task of adolescents with leukemia.

Learning about leukemia and chemotherapy

Adolescents with leukemia *"being told"* about chemotherapy, the essential and the choice for relief leukemic symptoms. The physician will tell the adolescents with leukemia about the chance to cure by receiving chemotherapy together with the need to start chemotherapy as soon as possible.

Chemotherapy, sometimes referred to as “chemo,” is a term used to describe a group of medicines that have the potential to destroy the leukemic cell. “Chemo” was the term that adolescents with leukemia know, they perceive these treatments are very common, and they were likely to encounter them as part of their treatments regimen.

“The doctor said, chemo is the drug for treat leukemia. I can be better or be cured by receiving chemotherapy” (15 years old girl)

Eventually the adolescents with leukemia have the information about chemotherapy from a physician. Most felt the information only receiving. Leukemic adolescent do more action to find information about chemotherapy. The strategies that called *“seeking for more information”* were founded.

Adolescents with leukemia go in seek for more information on chemotherapy by self-directed. They start to seek by *“asking physicians”*, directly. The major question was “Can you tell me more about chemotherapy?” Every patient had a physician who answered questions that they had. The physician will explain more about chemotherapy directly to adolescents with leukemia. The next question for seeking information by “asking about the prognosis or the chance to cure” of leukemic were asked directly to the doctor .The question such as, “How long that I have chemotherapy?” “When leukemia was gone and when I get better?”, as adolescents with leukemia shared:

“The doctor tells me more about leukemia when I ask him about the detail of chemotherapy. Leukemia is the problem of my white blood cell…Leukemia

can be better in moths after I receive chemotherapy ,but it depended on how the severity of leukemia. The doctor said some people getting better, but some are not. Chemotherapy is appropriate for leukemia, some patients can be better." (14 years old girl)

Many adolescents with leukemia not only seeking the information about illness and chemotherapy by asking questions to the doctor but also seeking information by themselves. Because adolescents with leukemia have ability to explore the information, *"reading"* the medical book about leukemia and chemotherapy was explained. Adolescents with leukemia will find the source of medical book by themselves. For example, some leukemic adolescent finding the resource of medical text book by asking for help from friends who have brother study in medicine to borrow a medical book, specifically in cancer and chemotherapy. When adolescents with leukemia reads the medical book, they merge the information that they receive from a doctor with the information that they read. The understanding of chemotherapy is important for adolescents with leukemia and it will become more than the understanding. Because chemotherapy was an essential part to cure and every patient must rely on chemotherapy. Chemotherapy will be an important task for adolescents with leukemia.

"I called to my friend who have brother study of medicine. I ask him for borrowing a book about cancer and chemotherapy from his brother. I know from the book about the importance of chemotherapy. It can cure leukemia, especially in childhood. Chemotherapy is important that why the doctor told me to admit of having chemo on hospital"

"Chemo is important for cancer patients. Chemo can cure cancer in children. I founded in the book. It is important to receiving chemotherapy. I realized came to be a new task of every leukemic patient... " (18 years old boy)

"Getting information from internet" about chemotherapy was another way for seeking information by some adolescents with leukemia. Because all of them was easy to access the information from the internet. The searching key words were "chemotherapy and leukemia" and adolescents with leukemia could find the essential information. The ability to search the information about leukemia and chemotherapy from internet was the same as the ability to gain the data from reading medical books. Adolescents with leukemia, use the data as a truth for realizing that chemotherapy was important for them and chemotherapy was explained as a new task for adolescents with leukemia.

"I am searching on the internet about leukemia and chemotherapy. I found many websites that provide the information. Chemotherapy is the way to cure leukemia. Some child gets better after chemotherapy. The sickness will be better after receiving chemotherapy and some patients can go back to studying. I think chemotherapy is important if I am not taking it the illness not better." (19 years old boy)

Benefit of chemotherapy was focused by adolescents with leukemia after they have more information about chemotherapy. The potentiality in curing leukemia was perceived by patients. It was important information that adolescents with leukemia learn and they are willing to undergo treatments. Adolescents with leukemia didn't commented about hope to be cured. They only described the information that they receive, as adolescents with leukemia said:

"The doctor told me that my illness will better if I receiving chemotherapy as soon as possible. Chemotherapy can help." (18 years old boy)

The information about side effects of chemotherapy was explained to adolescents with leukemia by physician. They know that general side effects such as, nausea, vomiting, feeling fatigued, and hair loss will happen in the most of the patients who receiving chemotherapy. Adolescents with leukemia also described the information about the treatment to relieve some side effect, especially the anti-emetic drugs that they will have before starting chemotherapy. Adolescents with leukemia responded that chemotherapy began soon after diagnosis was confirmed. The parents and physician made the decision about chemotherapy.

"Timing" to learning while receiving chemotherapy was started when the adolescents with leukemia admission in cancer unit. During chemotherapy was the time to readjust the normal routine. Adolescents with leukemia stop all activity in their life. The first chemotherapy treatment was the time to "learning," even though adolescents with leukemia had been given information and explanations about the chemotherapy and side effects. Experiential learning had the greatest impact on reducing their anxiety about the unknown.

"Before I start chemotherapy. I was nervous because it's the first time of chemo. I don't know what's going on. When the time has come. It's ok, I feel better. I have anti-emetic drug before start the treatment. It's not bad." (19 years old boy)

This learning strategy was just learning to know the side effects. Because the effects of chemotherapy to physiological and psychological not happen too much at the first the time of treatment. Adolescents with leukemia explained only the feeling of "discomfort", and "boring" because they only sit and sleep in bed.

Understanding leukemia and its treatment

Adolescents with leukemia *"understanding leukemia and its treatment."* They have been able to explain about leukemia correctly. They showed the understanding of the cause of leukemia and accept as the important part of staying in hospital for treatment. The cause of leukemia and the chance for curing showed that leukemia was different from another kind of cancer. This was a strategy which adolescents with leukemia engage, and reflect to the opportunity to live when receiving chemotherapy. As adolescents with leukemia, said:

"I'm a leukemic patient. I know that leukemia is the cancer of white blood. My white blood cell is too much and the white blood cell makes me sick." I need a treatment in hospital. Chemotherapy can decrease the white blood cell. If the white blood level returns to normal. I will get better. " (16 years old boy)

"Recognizing the important of self-care" was developed in adolescents with leukemia' mind. Because the information such as, the cause of leukemia and the chance for curing showed that leukemia was different from another kind of cancer. This was a strategy which adolescents with leukemia know the meaning of information and reflect to the uniqueness of living with leukemia. The uniqueness of leukemia that adolescents with leukemia perceived was the start point for adolescents with leukemia to thinking "What should I do after I have received chemotherapy?...I need to take care of myself" The opportunity to cure by chemotherapy that adolescents with leukemia know become the trigger to see the way of self-care. Adolescents with leukemia reflected during the conversation as follows:

"When I have chemotherapy I must caring myself. Only chemotherapy cannot help. I must help myself." (16 years old boy)

"Leukemia is the cancer of white blood. Its cancer, but I know it's have a chance to cure by chemotherapy. Because now a day, many children with leukemia were cured. This is the different form another kind of cancer. Maybe my leukemia can be cured and I know what I can do when I have leukemia. I will take care myself" (16 years old girl)

Having faith in chemotherapy

"Having faith in chemotherapy" was the perspective on the chemotherapy of adolescents with leukemia. Some adolescents with leukemia, they said; "my life was hanging on chemotherapy because it's the way to cure my disease." The feeling that they say not sadness, but it was the feeling of great confidence that chemotherapy can help them. In addition, they have enough information about chemotherapy the knowing that chemotherapy can cure or make them better was developed. This knowledge of chemotherapy and the faith in chemotherapy were used to support the adolescents with leukemia for moving on with chemotherapy.

The faith in chemotherapy that adolescents with leukemia have was consistent with the need of their parents. The adolescents with leukemia' parents need to encourage the adolescents with leukemia to start chemotherapy treatments for as soon as possible because parents are the first person who knowing the diagnosis of leukemia in adolescents. They have already discussed with the doctor about chemotherapy and making decision to admission adolescents with leukemia in the hospital for chemotherapy. When adolescents with leukemia willing to receive chemotherapy. The encouraging by patents for chemotherapy treatment was easy to follow. Adolescents with leukemia also emphasized on the accepted of decision making for chemotherapy by parents, and *"following their parents' decision."* The information about chemotherapy was explained by parents. In addition, some parents ask the physician to give the explanation about chemotherapy before leukemic adolescent's admission in hospital. Adolescents with leukemia transformed the decision making by parents to the decision of themselves.

"My parents told me, they want me to admit in hospital and treat by chemotherapy. They explained about the plan for me to receiving chemotherapy in hospital. It's like my parents already decision for chemotherapy. It makes me easy to decide to accept the chemotherapy. I follow my parents' decision because they see what is good for me... It's very easy for me to stay in hospital for chemotherapy."

Most of adolescents with leukemia who were interviewed had a similar understanding of leukemia can be cured by chemotherapy. Adolescents with leukemia were "knowing that chemotherapy was the best way to cure," and "wanting to start treatment as soon as possible."

Adolescents with leukemia wanting badly to be cured. This is the cause that made chemotherapy were common and adolescents with leukemia were likely to accept the treatment for curing leukemia. Here were what several of the adolescents with leukemia had to say regarding their own accepting chemotherapy stories:

"I choose to receive chemotherapy because I want so badly to be cured. I have more knowledge about chemotherapy. If I wait, I think my symptom will become worse. I want to be cured."

"Chemotherapy is common for cancer patient because every patient receiving this treatment. My symptom was bad. I cannot wait and spend too much time waiting. I want to get rid of cancer. I can stay in the hospital today and have chemotherapy."

Stage 3: Learning self-care related to chemotherapy

Leukemic adolescent staying with illness and chemotherapy for the chance of curd. Learning self-care related to chemotherapy was initial skill to take care of themselves in adolescents with leukemia. Adolescents with leukemia described a mixed experience of receiving helpful information about learning self-care.

Two strategies to learning for self-care started with the first skill "Recognizing own limitation", and second skill "learning self-care". Both skills were related to chemotherapy

Recognizing own limitation

Adolescents with leukemia started to learn self-care by assessing overview of health status that call "recognizing own limitation". Adolescents with leukemia compared previously health before illness with the health during chemotherapy. They founded that they did not healthy anymore and they are learning the limit of physical that never happen before.

"Being sick easily" was the physical limitation that adolescents with leukemia recognize. Adolescents with leukemia may have to deal with physical limitation as a result of their treatment regimens. Leukemic adolescent described that they have some sickness when the weather was changing. *"I couldn't breathe when* *the weather was cold*." Some adolescents with leukemia have the symptoms such as, severe running nose, have a fever, and feeling lethargic. All symptoms was happening without any cause of infection, but it happens in daily living when everything seems to be normal for adolescents with leukemia

Some physical limitations are usually temporary, they can still be troublesome. Adolescents with leukemia found that they fatigue did not subside with a few weeks of completing a chemotherapy, and this was very disappointing to them. Adolescents with leukemia realize that their condition will improve with time. They try to rest more and precaution for doing hard work, but fatigue was not improved. One adolescents with leukemia stated:

"I thought that my body was going to feel better, like I did before I receiving chemotherapy, but it's been upsetting because I still don't feel 100% yet. I still feel fatigue in the morning and every time when I do some activity such as walk to second floor"

"I still have fatigue. It's not better. Maybe it will be better soon for a month. I rest more, doing exercise, not doing a hard work, but the fatigue was the same"

Another limitation to live that adolescents with leukemia had to learn for self-care and it was related to chemotherapy was "cognitive." Every adolescent with leukemia had a previous life in school. They have ability to learn with the attention. After receiving chemotherapy adolescents with leukemia needed to go back to school, but they found some limitation in ability to learn.

Adolescents with leukemia have difficulties doing work related to study and require more time to complete homework. They can also have problems in such areas as handwriting, slowing in mathematic. As adolescents with leukemia described:

"I do mathematic slowly after I was in chemotherapy. I thought it's the side effect. At the end of my treatment schedule, I have radiation, it makes me slowly to calculate. I used to be good in match, before all treatment regimen"

Response to physical limitation and the change of ability to learn were expressed in both positive and negative emotions. All of adolescents with leukemia reported more positive feeling than negative ones. Because they still having life and carry on the treatments.

"I can't change and I can't choose and it seems like I lose something. I'm not happy but not sad. Any why I can smile and try to live and have to treat the leukemia"

The "direct experience from trying to be back to the same life style" made the adolescents with leukemia knowing their health status, and recognizing own limitation. Adolescents with leukemia testing the limitation, especially the physical performance by be back to the same life style. Because they need to know "what can I do?" The outcomes were that they are learning how to caring themselves and how to go back to live as usual together with the limitation.

Adolescents with leukemia interpreted the things that they see in cancer unit from other patients. They perceived the benefit of self-care and they adopt all self-care action and use in daily life.

"I need to know what happen if I have the exercise as usual. Because I play football before I have leukemia and treat with chemotherapy. Two days later,

after I go back home from hospital. I play football as usual. Just only 1 hour. I feel very exhausted. My heart was beating like a drum. The next day I feel tired and have a fever. Next time after chemotherapy. I stay at home to rest in 2 weeks. Start some exercise then I can go back to play football. I can play only the day that the weather not too hot. If having rain, I will stay only at home, not go out."

"The fatigue is very bad. If the patients want to relief from fatigue they must have appropriate time to sleep at night. I use to stay until midnight for watching the T.V. program. Going to bed around 2 am. The next day I feel very fatigued. The fatigue was better in 2 days. By now I know that after chemotherapy, at home, you must sleep. I go to bed around 9 p.m. Sleep all night."

Learning self-care

Leukemic adolescent have to "Learning self-care" for living not surrender. The information from a health care provider was the source for adolescents with leukemia to start to learn to care. In additional, leukemic adolescent looking for the direct information from their experience and observe another leukemic patient in the cancer unit. Learning to manage side effect, health promotion and disease prevention were leading by the purpose to receiving chemotherapy with the expectation for a change to be cured.

Physical performance limitations are one of the potential long-term consequences of chemotherapy. Adolescents with leukemia not surrender and let the limitation interrupt the need to live. They have to learn self-care. To live with illness and chemotherapy adolescents with a leukemia move to the third stage for maintaining to live as it possible.

"Learning with side effect and management" of chemotherapy was the first strategy to be learned for self-care. Because adolescents with leukemia who receiving chemotherapy after only one or two days they will have the side effect symptoms.

Nausea and vomiting were the most common symptoms. Adolescents with leukemia did not ask for anti-emetic every time because they know the period and the severity of the nausea. They will ask for pill before the vomiting happened. In addition, they learn to drink a little warm water, eat small meals, and try to relax during chemotherapy.

Tiredness was another side effect from chemotherapy. Adolescents with leukemia monitoring this symptom by themselves and they think tiredness helps them sleep easy, but they know that tiredness will be worse if they not eat. When adolescents with leukemia feel much tried they will ask for help from the nurse. Intravenous and liquid diet will provide for leukemic adolescent.

All adolescents with leukemia had lost their hair as a result of chemotherapy. Most adolescents with leukemia dealt with the process of losing their hair by monitoring the number of fallen hair. Cutting hair very short was done by parents before losing all hair. Some boy shaving hair off when having hair fall during shampooing.

Adolescents with leukemia learned to monitor and manage side effect by themselves with help from parents and the using of the information that they have. The example that leukemic described as follows:

"I feel tiredness after chemotherapy. I felt easy to sleep, sleep in a long time. Next day, I still tiredness because I did not eat anything. Next time of

chemotherapy, I know how to rest. I have a nap at noon and assess how I feel. If I did not tire too much, I will eat some food and rest in bed. If I was very tired. I will tell the nurse for help. She will make some special drink for me. I will be better.”

“My hair was falling after chemotherapy. I saw many hair on my pillow. When I walk hair was falling. When I shower and shampooing, the hair become broken and fallen...a lot then I had shaving hair off. In one or two weeks my hair grows back again. The hair is soft and growing so fast”

Some leukemic adolescent complained about the alteration of taste sensation. It makes a problem when they eat. The favorite food was not delicious anymore, with this problem the pattern of food that they eat was changed. Adolescents with leukemia try to not add a salt in their food, clear soup or natural food was a choice.

“When I am going back home after chemotherapy. All food is terrible taste. I love to eat curry, but the tongue was changed. The taste was not the same. I don’t know why. I add some sauce, some chili, but the taste not better. I change to eat a soup and the vegetable because it's delicious as it be”

After adolescents with leukemia learn with side effect of chemotherapy and had experienced side effect symptoms. This skill start when adolescents with leukemia “monitoring the side effect by themselves" and "learning to manage side effects of chemotherapy." Adolescents with leukemia knowing the severity of side effect of having side effect in several times.

“Learning health promotion and disease prevention” was the second skill that shows on learning self-care in adolescents with leukemia. Adolescents with leukemia integrated the learning side effect and the learning of side effect manage

together. However, learning health promotion and prevention were directly to the problem of leukemia that affect the daily living. For preventing health, adolescents with leukemia had learned what the risk to get infected. Moreover, they know that immune was damaged. Leukemic adolescent know that they will have sickness easily more than healthy children.

"I'm worried about infection that will happen easily because my white blood cell not work. Chemotherapy also destroyed my immune. I try to stay at home after chemotherapy, 1 or 2 weeks. Then going to check up again. If my white blood level was ok, I can go out or go to school. It was very important for leukemic patient and must be learned"

For promoting health, Adolescents with leukemia have learned the benefit to eat a good food and the outcomes of sufficient sleep. They described the good feeling in daily life, even if the illness not cured.

"The food that I eat was very important. I say to myself every time when I want to eat. The uncooked food was a precaution for eating. Some fruit if I want to eat must be clean. The water must be boiled or clean, bottle water is appropriate. I was learning that I must have a good sleep, 8-10 hr. Will be fine. The good sleep helps me a lot to refresh myself. The late night TV program is precaution to watch if you want to have a good sleep."

Most of adolescents with leukemia expressed the view that they were expected to "pick up information and learn with it" As these leukemic adolescent noted:

"It's not a case of guesswork or asking. It is an information that all leukemic patients like me must be learned. The nurses give me advice about side effect and it's appropriate to learn."

"I received information about side effect of chemotherapy from the nurse again, when the treatment was started. 'What is the side effect?'... I am learning with an information"

"Receiving advices from nurses" was important for adolescents with leukemia in learning self-care. When the time to receive chemotherapy and confronting the side effect on the cancer unit, nursing staff play the important role to give the information about side effect of chemotherapy. Nursing staff will inform the essential data related to "side effect" that will happen at the first time and inform about another side effect that come up next. Nurses always inform the information about some guidance for care during chemotherapy, adolescents with leukemia described the way that they are learning as follows:

"At the first time of chemotherapy. The nurses ask me about what I know about chemotherapy. I tell her about the information about any side effect that the doctor gives me. The nurse let me know about the side effect that will happen first, such as nausea, discomfort in stomach and weakness. She told me more about how she helps to decrease the nausea and vomit by giving me some pills. She gives me a cool water and some sweet drink. She tells me to eat more food such as eggs, pork and milk before stat chemotherapy. I learn with every information. I know what to do to make me feel ok."

"After I received chemotherapy for 1 day. The nurse asks me about what I know about side effects of chemotherapy. I said I will have a weakness and

my hair will fall. She said I know is true. She told me more about the hair fall and her giving me an advice about to cut hair short. She asks me about the pain in my mouth and she gives me a guidance of mouth care to prevent the pain and ulceration. The nurse told me how to care my mouth, I should avoid irritating foods such as spicy, and hot food. I should use a soft bristle toothbrush and brush your teeth after eating... I do it as nurse advice and learning with it"

Adopting the advice from the nurse and use it was an easy and useful for adolescents with leukemia. The perspective of "Doing thing easy" was the booster to follow the good self-care advice that adolescents with leukemia have to perceive. As one adolescents with leukemia, said;

"When I have chemotherapy. The nurse ware the hygienic mask when she gave nursing care. I ask her about why she wears it. She said she the hygienic mask can reduce the spread of germ to me. Because during chemotherapy my immune was suppressed. The nurse will ask everyone who sicks and want to visit me in hospital to wear hygienic mask too. It's not comfortable to wear masks, but I understanding how to prevent infection. I wear ask my cousin, my friend, to wear hygienic mask when they come to visit me in hospital. Sometimes I wear it too for preventing to get infected."

"Learning from direct experience." was important for adolescents with leukemia to apply with self-care activity. Both my observations and adolescents with leukemia' accounts suggested that the nurse gave essential information and it was useful for learning self-care. Because every side effect from chemotherapy that nurses mention were "occurred." All leukemic adolescent experiences about the effect from chemotherapy with their body. The experience of fatigue becomes more than weakness. The experience of having hair fall become to be the baldness. Some late side effect of chemotherapy that happen to adolescents with leukemia and no one never discuss before, such as being infertile and growth retard was happening. Learning from direct experience look like the lesson for leukemic adolescent when they receive chemotherapy in a long time, as they said:

"As I know my hair will fall after chemotherapy. My hair starts to fall after chemotherapy in 6 or 7 days. My hair falls a lot..... I become a baldness 3 days. It happens so quickly. No one knows what it was. This experience teaches me to prepare my hair before chemotherapy"

"I know it's not normal. Because I'm 13 years old, but I don't have a period. I think it happens because I receiving chemotherapy. I think I stopped growing up because my height was stopped... I'm very short when I compare with friends. I will ask my doctor or nurse in someday. I think it happens because chemotherapy. All I do was try to eat after receiving chemotherapy. Maybe it's not permanent because when my hair fall it can grow up back again."

"Observing other patients" in cancer unit when adolescents with leukemia stay in hospital was important because this action was the strategy to learn and adapt as self-care activity. In this learning strategy adolescents with leukemia were learning when they meet other leukemic patients. Many adolescents with leukemia did not have the experience to meet up leukemic patients or cancer patients in real with closely. In cancer unit, especially at the time of admission for chemotherapy was the time to meet up other patients. The pale face, the small body and some patient who baldness were seen by adolescents with leukemia. They were realized that side effect happened to all of leukemic patients and they will become one of patients who have side effect in the future. The anxiety or fear when leukemic adolescent see other patients have side effect from chemotherapy not present in the conversation with me. All adolescents with leukemia describe that they learn from other patients. They didn't ask questions or talking with other patients about side effect they just observing only. One adolescents with leukemia explained this:

"I meet other patients in hospital. Most of them are paler and look small. Someone has baldness. I look at them and thinking about myself. The information that I know from the doctor was I will have a side effect from chemotherapy. I will be baldness in soon. On the first day in cancer unit I just stay in bed look other patients. They not good, but not too bad. I know chemotherapy effect the patient, but if everyone can have chemotherapy, I can have it like another patient."

Leukemic adolescent have to "Learning self-care" for living not surrender. The information from the nurses was the source for adolescents with leukemia to start to learn to care. In additional, leukemic adolescent recognizing own limitation, looking for the direct information from their experience, and observe another leukemic patient in the cancer unit. Learning side effect of chemotherapy and manage side effect, health promotion and disease prevention were leading by the purpose to receiving chemotherapy with the expectation for a change to be cured. Physical performance limitations are one of the potential long-term consequences of chemotherapy. Adolescents with leukemia not surrender and let the limitation interrupt the need to live. They use the psychical limitation as the director as a part of learning self-care. To live with disease and chemotherapy.

Stage 4: Pursuing the best self-care

At this stage Leukemic adolescent took action regarding self-care that they are learning and *"pursuing the best self-care."* A variety of self-care perform were practiced and modify for the goodness of fit with chemotherapy. Adolescents with leukemia show the cognitive ability to be care of himself. Four strategies were used for pursuing the best self-care with effectiveness outcome to live with chemotherapy. The first strategy was "keeping a chemotherapy schedule strictly", second strategies "making chemotherapy more endurable", the third strategy "building physical strength", and forth a strategy "psychological strength". All strategies were an action to achieve a major aim that was adjusting life to fit into new role as being leukemic patients with the force to returning to normality.

Keeping chemotherapy schedule strictly

"Keeping chemotherapy schedule strictly" was the first strategy to maintain self-care with the aim to do for the best. Adolescents with leukemia doing three actions when they move from home to stay in hospital. All actions implied the purpose of leukemic adolescent keeping chemotherapy schedule strictly because they don't want to script the schedule. In addition, staying in hospital was a big change from living a normal teenage life to patients with leukemia. *"Preparing for each treatment"* was the action that leukemic adolescent use for *Keeping chemotherapy schedule strictly*. Because the period to stay in the hospital were 6 to 10 days or more. Adolescents with leukemia not only wait to admission in hospital.

In addition, they prepare many things before going to stay in hospital for chemotherapy. The preparation of adolescents with leukemia focused on each appointment of chemotherapy.

"Reminding themselves about the appointment," was the technique for preparing that adolescents with a leukemia use for keeping every treatment schedule. Adolescents with leukemia are the teenager who being sick and they know chemotherapy is the choice for a cure. They have chemotherapy as a piece of work to be done. Adolescents with leukemia were recorded the schedule of chemotherapy in their own way, such as put the number of chemotherapy appointment in the calendar, draw the time tables of chemotherapy in notebook and marking the period of chemotherapy on the pocket calendar. All leukemic adolescent can remember the time to go to hospital for receiving chemotherapy and never forget.

"I went to the hospital for chemotherapy constantly. I never missed the appointment. When I get a schedule of chemotherapy, I record in my little calendar and put it in my pocket. Three days before chemotherapy I will mark on the calendar to remind me… it important for me to go on a date. I don't want to miss"

"At the first time of my chemotherapy, I stay in hospital for 10 days and go home for the rest 2 days then go to hospital again. It's like a cycle. I came to the hospital on time of appointment because I follow the chemotherapy schedule and I remind the schedule I put the number in my calendar at home. It the schedule was tight, such as stay in hospital for 4 days, go home 3 days then go back to hospital again. I will make a note in my notebook for that… I think I can continue treatment by my own record."

Chemotherapy was a long continuing treatment. Adolescents with leukemia assenting to chemotherapy schedule. This was the tactic to help adolescents with leukemia for carrying the schedule of treatment and preparing before the treatments begin. The feeling of assent helped leukemic adolescent think positive with the schedule to admission in hospital and receiving chemotherapy. Adolescents with leukemia were aware of chemotherapy schedule and it was meaningful to them. In this point, adolescents with leukemia described as follows.

"I was agreeing with chemotherapy schedule. I feel ok… All I do is go on with a schedule, it must be. I have the feeling like this because I know the time of chemotherapy that I will have and I can make a plan for that, make my plan to do something before receiving chemotherapy. It helps me a lot and was meaningful for me to know treatment schedule."

"Finding support," was the next preparation to stay in hospital for adolescents with leukemia at the time of chemotherapy. They find the support for themselves; parents' presence, personal materials, and things to do while being hospitalized were the support.

"Parents' presence" was the important support for adolescents with leukemia. All of them start to prepare for mind safety by "asking parents to be with." Most of the parents were alternately present with adolescents with leukemia. If they couldn't stay they will go back home in the morning and stay with adolescents in the evening. Feeling safety and receiving support was described by adolescents with leukemia. Parents' presence made adolescents with leukemia be safe and decreasing their stress. Moreover, parents can help adolescents, and they are the person that knowing the specific need for adolescents with leukemia. As adolescents with leukemia, said:

“I need my parent come to stay with me in hospital during my chemotherapy schedule. It’s good that they are able with me in almost of the day. I feel good and they make me secure because they can help if I ask”

Leukemic adolescent *“collecting the personal material”* for using in hospitals. It was another support for adolescents with leukemia to stay in hospital. The personal stuff is not only a towel, glasses, toothbrush, but also a comic book, little radio with headset and some toys. All personal stuff made adolescents with leukemia maintaining the feeling of control because going to stay in hospital is the situation that adolescents with leukemia must follow, not under their control. The personal material can use as the recreation activity in the hospital, such as comic books, and little radio. This is the personal support that matches with the need of adolescents with leukemia. Adolescents with leukemia explained as follows:

“I am collecting my glass, small radio with headset, my towel, T-shirt to wear when I go back home, the comic cooks and some toy go. All that I bring is for me to stay in hospital. I must stay for a week or month in hospital. I can control what I want by bring some favorite item come with me to the hospital. I will use it everyday”

However, adolescents with leukemia “*getting help from friends and teacher,”* for keeping a chemotherapy schedule. Adolescents with leukemia telling close friends to know about the illness that happen. The teacher is another significant person that adolescents with leukemia telling by phone about the diagnosis of leukemia. Because close friends and teachers were the significant person related to school life of a teenager. They can help adolescents with leukemia to manage the schooling and giving support. Adolescents with leukemia were decision and choose to pause school life that obstruct chemotherapy, but they desire to go back to study again when the disease was better.

"I let my friend know what happen to me. I need her help in arranging my class and help me about any job in school. Absolutely, she always supports me. It was very important to be leukmic patient like me."

"I am calling my teacher and let him know what happen. I told him that I have leukemia and need to absent from school. I sent the letter from doctor to school. I feel like I pave the way to telling what happen to me in the future. Maybe I can go back to study or not, it depended on my illness. It's true and I am telling to my teacher about my life of leukemic patients in hospital. He came to visit me at home sometime when I go out from hospital. It was a good support."

Making chemotherapy more endurable

Chemotherapy was hard and difficult. Adolescents with leukemia trying with the best for taking the treatment. When adolescents with leukemia already to go to hospital for chemotherapy. The time to stay in hospital was the time to do something for pursuing the best self-care.

Adolescents with leukemia *"making hospitalization more comfortable,"* because they need to be comfortable to support the normal life that they need to be returned. Adolescents with leukemia "making some change" to substitute the things that they pause and loose when they stay in hospital. The change might seem like a little thing, but the "the change" were helped leukemic adolescent to be successful in adjusting routine activity.

Adolescents with leukemia were making beds, and setting appropriate environment. In my observation every adolescent with leukemia make the hospital bed that they stay as a personal zone. They put some personal photo near the bed, place the small model of cartoon hero over cabinet near the bed, and use their own cartoon cup that they bring from the house. Some adolescents with leukemia place the small, colorful clock near the pillow in bed. When I ask them about the things that they made, they said:

“I stay in hospital for 3 weeks for chemotherapy. I ask my mom to bring my photo, my clock and my mug when I stay 2 days in hospital; I put them on the bedside cabinet. The nurse tells me that it's my area and it's good to change the hospital environment.

“*Helping with chores”* was another tactic that adolescents with a leukemia, use for making the time of hospitalization more comfortable. Leukemic adolescent assist some hospital activity such as, making gauze bandage, helping a younger patients for toilet, and helping need to refill drinking water for other patients. The helping hand with chores of adolescents with leukemia made the connection with the hospital, the place that stay for chemotherapy. This tactic made adolescents with leukemia spent the time in hospital during chemotherapy in the effective way. The helping with chores was an activity that substitute the normal activity in life.

“After I spent 5 nights in the hospital, I can help some hospital job such as, chat with the new patient, let them know how to care the I.V. line when they going to toilet. I think it a little help for hospital that I can do. I feel like all made me can stay in hospital without thinking about the normal activity that I stop... It cannot replace but it a substitute for the things that I stop when I am in hospital”

"Making friends with other patients" was essential to make the chemotherapy period more endurable. Having new friends that being the same can occur only the time to stay in hospital. Adolescents with leukemia having new friend, making new relationship and being friendly with leukemic patient friends. Adolescents with leukemia, use two tactics for making friends with other leukemic patients. The first tactics was being connected with another leukemic patients.

In summary, the word "connected" represents the using of "chatting" and "sharing" as the tactic for being connected to the new friend that they have leukemia. Adolescents with leukemia chatting with another leukemic patients when they meet up in hospital, especially at the time to stay in bed for chemotherapy. Adolescents with leukemia chatting about school, symptom of leukemia and chemotherapy schedule each other. When they chat it not only hearing the stories form leukemic friend who are in the same boat but also "sharing" the same feeling and shared understandings. Adolescents with leukemia also sharing something with leukemic friend such as comic book, magazine and toys. To "chatting and sharing" not depended on the difference of age or gender but it was depended on the opportunity to meet leukemic friend who comes to the hospital at the same time for chemotherapy. The example of the explained from adolescents with leukemia is as follows:

"When I stay in hospital for chemotherapy. I meet new friends, she was leukemic patients, but older than me. We smile to each other and chatting about leukemia. She told me about her symptom and her schedule for chemotherapy. It seems like we are sharing with the same feeling and understand each other. Because

we the same. She gave me some book to read during chemotherapy. I meet her when the schedule in the same day. She is my new leukemic friend."

"I have two friends in the hospital, they have leukemia. I think we are connected by chatting about our symptom. I shared the cartoon book with him. It's good to have a friend who is in the same situation. We can share our understanding of illness together."

Building physical strength

Adolescents with leukemia understand the importance to receive chemotherapy, and they do more by building physical strength to make chemotherapy more endurable. A number of activities have been conducted using in everyday life of adolescents with leukemia. Eating enough healthy food, taking vitamins, modifying resting and activity pattern, preventing from infection, and relieving symptoms and discomfort.

Building physical strength was paramount as the tactics to working with practice and modify "activity" by adolescents with leukemia' knowledge. Because adolescents with leukemia knowing the reason of illness, the importance of treatment regimens, and they have experience of the side effect condition. The outcomes of the previous stage "learning self-care" were integrated. All activity was used in hospital during chemotherapy and using at home after discharge. Building physical strength activity was similar with to having a good health behavior. Because the activity that adolescents with leukemia perform were supporting health and alleviate chemotherapy side effect. The outcomes of activity proving by the direct experience of adolescents with leukemia. Adolescents with leukemia keep continuing all activity.

In addition, they can adapt the activity follow the changing of symptom and side effects condition when they need.

The action of Building physical strength, focus to improve physiological aspects because adolescents with leukemia knowing that the body have an illness and chemotherapy made the body become weak. Adolescents with leukemia change to "eating enough health food", eggs and milk were the choices one. Adolescents with leukemia adding some "nutrient" in their food and they never eat anything like that before. This is the good behavior about eating because adolescents with leukemia, eating healthy food, even though not liking them.

"I'm adding liver to diet. My mom will cook liver with green vegetable every 2 days of my meal. I don't like to eat liver and vegetable, but I change for good health."

"I don't like to eat vegetable, especially green vegetable because the smell. But I change to eat a lot of green vegetables. Eat more vegetable was a good source of vitamin."

During chemotherapy adolescents with leukemia "finding strategies to encourage themselves to eat" because the nausea, and the feeling of discomfort in stomach decreased the food intake. Adolescents with leukemia adapt their meal by separate 3 meals to little 5 meals with a liquid diet at early night. By this activity, adolescents with leukemia can eat more food and the physical recovering and strength. In addition, chemotherapy altered tastes. Some adolescents with leukemia tastes the food like metallic. When they eat small meals with natural tastes it can help to eat more food. Every leukemic patient eats some supplementary food, vitamin and mineral was eat frequently. They think it can help during chemotherapy. Some patients feel refreshed and can eat a lot of meals after taking the vitamins. The parents provide the vitamin for adolescents. Sometime they ask the doctor to order the vitamin when staying in hospital.

"I cannot finish my meal because I have a discomfort in the stomach. Someday day I only eat 5 spoons. Some food was tasted as metallic. I ask my mom to make a small meal for me. I eat a little disk and separate to 5 meals per days. I can eat by that way and eat it all. The clear soup, boil vegetable and some fried rice are my menu"

"Modifying resting and activities pattern" is the activity with building physical strength continuing from eating enough healthy food. Because leukemic symptom lead them for changing this behavior. The weakness symptom of leukemia will be severed at the time of chemotherapy. Someone being tiredness and sleep pattern has changed. Leukemia adolescents rest more in the daytime during chemotherapy. They will take a nap and wake up at noon until evening. The long sleep was at night. Adolescents with leukemia did every activity quick and fast when they were healthy. Leukemia symptom and chemotherapy were the cause of powerlessness, but adolescents with leukemia not stop all activity. They love to walk to the hospital balcony, keep play sport and game, and keep exercising. Leukemic adolescent still having all activity, but modify all activity for appropriateness. The hard exercise activity such as running was changing to walk or ride the bicycle. To do everything by modifying rest patterns and activity made adolescents with leukemia keeping their life and keep a connection with another. Because they don't stay only in bed or being at home, even if they having sickness.

"The leukemia symptom and side effect of chemotherapy was disturbing my sleep pattern. Sometime I feel very tired to wake up and chemotherapy will make me more tired. I try to have some nap at noon and wake up in the evening. I can have a nice sleep at night. I change my sleep cycle and it became a good habit when I can do it in every time that I have chemotherapy."

"At my village when I go out for running I will meet some friend. When I have leukemia and chemotherapy it change because I can't run it a cause of powerlessness. I ride my bicycle around my village and this was substituted for running. I can meet my friend by doing this"

Chemotherapy pushed adolescents with leukemia to stay in hospital. They feel like every activity was disturbed, especially sleep and wake pattern in the first time to stay in hospital. As one adolescents with leukemia, said;

"I wake up at 4 a.m. Or 5 a.m. because the staff wake me up for medication or blood check. At night I cannot sleep because I sleep all day in bed. I have change my sleep pattern."

Adolescents with leukemia thinking about changing sleep pattern of staying in hospital. This action becomes the tactic for building physical strength.They found waking up in the early morning was a good habit. Because they had defecated in every morning. This activity represented better control of bowel incontinence pattern and related to previous tactic named "eating enough healthy food" because both tactic can prevent the constipation that was the side effect of chemotherapy. Leukemic adolescent was modify the time to go to bed. They go to bed early, stop to watch late night series and stop to play game computer at night when they stay at home after discharge. Because they knowing the benefit of appropriate sleep time. Adolescents with leukemia explained:

"I am changing my sleep-wake time after discharge from hospital. I was waking up around 5 am. Every day and goes to bed around 10 p.m. I stop to play game computer at night because it distracts me. It was good to wake up early in the morning because I didn't have the constipation anymore. By now it was a good new habit of mine."

Preventing from exhaustion was the last tactic to "building physical strength". This tactic used as the activity for decreased the feeling of exhaustion during daytime. Adolescents with leukemia warning themselves by this word "slowing down" when doing something that using their energy. Because adolescents with leukemia knowing that their physical is not well as healthy adolescents. At the time of recovery after chemotherapy was the time that adolescents with leukemia concerning about exhausting. "Being precaution for hard exercise" was done for preventing the physical exhaustion by adolescents with leukemia. One leukemic adolescent describe:

"I know my body was not the same because I feel exhausted very easily. After chemotherapy, during two weeks was the time to warning myself about doing everything slow down. I walk not run to preventing exhaustion and not did do some hard work that uses hard energy. It's difficult at the first time, but if I want to get better I must do"

"Preventing from getting infection" was the last tactic related to building physical strength. Adolescents with leukemia having frequent sickness by contact sick people. From these experience adolescents with leukemia learn to prevent to get infected by "restrict to visit people" especially, the sick people. They choose to stay at home as much as possible after chemotherapy and will go out when they know the result of checkup that the level of white blood cell were normal. It was not the usual social life of adolescents to stay at home and limiting to meet people, but adolescents decision to do this self-care activity. They can "wait' until their body was strong enough to meet their friend. Adolescents with leukemia explained:

"I know that I was sick easily, especially after chemotherapy. The doctor said I will have a minimal risk after having chemotherapy in 1 or 2 weeks and I must visit the doctor for a checkup. I only stay at home when I go back home for preventing from infection. I'm not meeting friends or any visitor during I stay home after chemotherapy because I will get infected. I will wait for a checkup. My parents will tell everyone who wants to meet me to wait until I didn't have a risk for infection."

To prevent from infection, this activity showed the role of parents in knowing the risk of infection of leukemic adolescent. All parents supported by the understanding. As one parent of adolescents with leukemia told me. "I know my son not healthy. He gets an infection easier and he knows that. I told his friend to visit him when he gets better."

"Relieving symptoms and discomfort" was the last tactic of adolescents with leukemia to caring the physical domain to be a strength. Leukemic was the acute illness at the beginning and it became chronic illness that adolescents had to live with it. Leukemic adolescent have to relieve some leukemic symptoms and side effect of the treatment regimen in daily living. They consistency with supportive treatment that they receive from the doctor, such as take multivitamin, folic and other pill. If they have some abnormal condition when they stay at home and consult the doctor or nursing staff by making phone calls. "Hot bathing" was the way to relieve the discomfort symptom, such as body pain, having more sweat, and feeling drowsy. “Massaging” was chosen as one of self-care activity to alleviate the discomfort symptom. Someone having massaging on both legs by themselves. Someone ask their parents to do massaging. Someone uses a message machine at home. All adolescents with leukemia, use massaging as a relaxation activity, but they don't massage when they have a fever. This is important point that confirmation the best manner of self-care activity of adolescents with leukemia.

“I have multivitamin tablets every in the morning. When I have some illness symptoms I will call to a cancer unit for a consult. When I stay at home, I shower by hot water because it can decrease my body pain and make me refresh, but if I have a fever I did not do this activity.”

“I have been massaging by myself and sometimes I use a massage pillow. It's good for relieving body strain. If I have severe pain on my body I will consult the doctor or nurse at the cancer unit before using analgesic."

Preserving psychological strength

"Preserving psychological strength" was the second paramount strategies for pursing the best-care in daily life during chemotherapy. This strategy was important because the strength of physical could not happen if the psychological aspect not be strong.

However, leukemic adolescent was living dependent on “chemotherapy” because chemotherapy as an essential treatment regimen to make a remission in leukemia. Chemotherapy was important for adolescents with leukemia. In the conversation with me all of adolescents with leukemia, said something like they *"keep hanging on with chemotherapy"* and not showing suffer feeling. In the other hand, they show that they *"preserving psychological strength*" in their living process.

"I can not to stop chemotherapy. It demeaned my body, but it helped me to get better from leukemia. I cannot stop to take it. I keep hanging on with chemotherapy"

To preserve psychological strength adolescents with leukemia have three tactics in daily life. The first tactic "keeping contact with friends" while doing in the early date after adolescents with leukemia pursuing the school life. Leukemic adolescent took a school book to the hospital and ask friend about homework by phone. This action was started after they passed the first chemotherapy and still living in hospital. All adolescents with leukemia reading school book during hospital. Some adolescents with leukemia asking their friend to bring the homework to do in hospital. This was the action to keeping to study in hospital because school life was the important part of psychological wellness. In addition, adolescents with leukemia not only keeping to study, but also "keeping contact with friends." Their friendship with teenage friends was the strengthening of the psychological aspect. Adolescents with leukemia describe in this way:

"I bring the school book with me during a stay in hospital. I receiving chemotherapy and the side effect is not bad. I ask my friend to bring the homework for me. My friend come and it makes me good. We laugh and they come to see me every time when I call. Friendship is very important and make me strong inside "

It was clearly difficult for the adolescents with leukemia to foster friendships when they were receiving treatment. "How are you feeling?" was the friend responds when adolescents with leukemia make a phone call to their close friends.

By this question they "receiving support from a friend". Adolescents with leukemia and friend chatting about the friendship that they will maintain although they are separate. This is the start point to *"continuing to have activities with friends"*. When leukemic adolescent and friends have to meet. They can continue the regular activity together. In addition, their friend treats adolescents with leukemia as normal. It was a good activity to preserving psychological strength. As adolescent with leukemia, said:

"Friend was important. I have two special friends. I make a phone call to let her knew that I have leukemia. They ask me 'How do I feel', listen to me and support me. I meet them when I go back home. We play and talking as usual. It's important to be like I don't have illness."

Adolescents with leukemia and family have a good activity together, such as going to beach, cooking at home and go out for a picnic. All good activity that adolescents with leukemia do with family referred to the appreciating and welcome for a good time, it involved finding and experiencing some joy in life. This action was "maintaining positive attitude" to live during chemotherapy.

"I was sick, but I still have a good time with my family. Last month we going to picnic at Lumpini Park. We have to cook some food together. It was a good time and happy moment. This activity keep me happy with my life."

Adolescents with leukemia had the difficult moment in illness and treatment journey. Adolescents with leukemia still "maintaining positive attitude" by laughing with other" and "making difficult situation more fun" were the activity that adolescents with leukemia use, they described as follows:

"Sometime I cannot run away from a bad situation. I just thinking in the funny way and making some joke. The nursing staff laugh with me when I make

a joke, such as the time to have chemotherapy. 'It a little bottle, I need more' something like that and I can laughing with the moment."

"Having blood check was not easy. Blood check many, many, many time. I said to myself 'If I have 1,000 time of blood check maybe I get reward form hospital.' I told my mom and we are laughing."

"Clinging to religious belief" was the last activity of preserving psychological strength. Clinging to religious belief reflect the psychological strategy because leukemic adolescent could be calm down, having peaceful, and having good emotion. Because religious belief was doing good things as mentioned in religious doctrine. Thais' ways of life is so familiar with making merit when adolescents with leukemia staying in hospital in someday the monk will come to the cancer unit and adolescents with leukemia can make a pray. When leukemic adolescent go back home, they pray before going to bed, and making merit in the morning by putting food in the bowl of monks. They make merit again at a temple on the day of birth. Adolescents with leukemia develop the religious belief would bring happiness, peaceful life and other good things.

Some adolescents with leukemia never make a pray before. They start to pray and it was a new action to make psychological strength. Adolescents with a leukemia start to make a prayer during they were in hospital. Nursing staff informed about making pray before going to bed. Some cancer unit gave the pray book to adolescents with leukemia if they need. Adolescents with leukemia start to make a pray and doing every night. The pray can made adolescents with leukemia sleep with the mindfulness and having a good consciousness.

"It good to making a pray every day. I wake up in the morning and making merit by putting food in the bowl of monks. I have the good feeling, and peaceful. My life will bring. My family was happy"

"I never pray. I did some but not consistently. When I become leukemic patients praying was good. I pray before going to bed. The nurse in the cancer unit gave me a prayer book. I can concentrate, alert and knowing what I do. It's like you have to concentrate with your mind. Praying can help me to have a mindful."

Looking toward brighter future: the force that drive to returning to normality

Looking toward a brighter future was intrinsic force of adolescents with leukemia that made them be able to go through the long process of chemotherapy. These adolescents always thought about the completion of chemotherapy and they recovered from the illness. Then they could go on with their regular life and achieve what they had dreamt to work as pilot, teacher or engineer.

Moreover, for most of adolescents with leukemia they were realizing to do the good things and planning to return to the new study in the future. As one of adolescents with 14 years old said; "I have a plan to go to studying again. Vocational study is appropriate for me because it's not a long course and I can study with receiving chemotherapy. When I finish the course I can do something good for my life and my parents in future."

Some the brighter future was closer. For example, when they were hospitalized for chemotherapy or bone marrow aspiration, they would look forward to the day of their discharge with was brighter day of them

Every adolescent with leukemia thinking about the future when they were stopped the chemotherapy treatment. The time to discharge from cancer unit and stay at home was the time to thinking about the normal life that was the brighter future. This idea can help adolescents with leukemia to keep continuing with chemotherapy treatment.

Every adolescent with leukemia thinking about the future when they were stopped the chemotherapy treatment. The time to discharge from cancer unit and stay at home was the time to thinking about the normal life that was the brighter future. This idea can help adolescents with leukemia to keep continuing with chemotherapy treatment.

In addition, adolescents with leukemia felt better from leukemic symptoms or felt good because some aggressive leukemic symptoms such as, bleeding was relief after they were received chemotherapy. Adolescents with leukemia were happy when they had time to stop his or her chemotherapy. A normal life was returning back for the adolescents with leukemia and they enjoyed to do the normal things and join family activities. The child experienced life as being easier and freer since they found an increase in physical strength.

“Felling stronger” were the changes of the outlook of adolescents with leukemia after they had chemotherapy. Some of them are remission and some the symptom of leukemia get better. Moreover, Adolescents with leukemia felt stronger because they had been diagnosed with leukemia they were stronger, not physically, but emotionally. They often spoke about physical impairment and exhaustion so they did not necessarily feel stronger physically. The adolescents with leukemia felt that they could stand up for themselves better after chemotherapy, and that this was as a result of receiving chemotherapy.

The experience of receiving chemotherapy as an adolescent led to them appreciating their living. It was almost as if their treatments gave an opportunity to live a life longer from the day that they having alarming symptoms. Leukemic adolescent faced the aggressive symptoms, and as a result are no longer taking their live for granted. They had a different experience form their peers and they now find that they appreciate being alive.

Adolescents with leukemia used the various strategies in the four stage models that emerged in this basic social process, “returning to normality,” consisting of realizing being a leukemic patient, accepting chemotherapy as a key to normal life, learning self-care related to chemotherapy, and pursuing the best self-care. Adolescents with leukemia, use the four stage model to come to terms with the leukemia diagnosis, management of the illness, its treatment, and treatment consequence. The need for all of the adolescents with leukemia was to return to a level of “normality” after they had chemotherapy.

“Looking toward brighter future” was the connection of all stage models and work as the life expectancy for adolescents with leukemia. The future in adolescents with leukemia’ eyes was the needs to live. Even though they have a disease, and taking chemotherapy.

“I have leukemic. I must receiving chemotherapy. My life was changing, but my future is stable. Because I am the same person. I think about the future and living with everything from the same father.”

Returning to normality was manifested in the form of action strategies to reducing the barrier for healthy and being normal teenager as they should be. *“Looking toward brighter future”* was defined as the driving force that adolescents with leukemia, use as the key to accepting the illness and treatment regimen and ignite the bright future.

The other aspects of the bright future of adolescents with leukemia included thinking about the batter day in the future, believing about the good life, keep walking for another day, not having any weaknesses, and thinking that they “having the future.” Most of adolescents with leukemia have never experienced a major illness, much less a life-threatening one. They typically have a sense of healthy teenage, and the chemotherapy forces them to consider their mortality.

CHAPTER V
DISCUSSION

In this final chapter, findings are discussed in relationship to research questions, selected knowledge, and previous research. The Implications of this research are addressed in the subsequent section. This chapter finishes with research conclusion.

Summary of research results

Summary

"Returning to normality" as a basic social process for keeping the normality for living with chemotherapy in adolescents with leukemia. Returning to normality was manifested in the form of action strategies to reducing the barrier for healthy and being normal teenager as they should be.

Looking toward a brighter future was defined as the force drive for adolescents with leukemia to use their effort to keep the future that leukemic adolescents wanted to be. In addition, looking toward brighter future could help the adolescents with leukemia continuing with chemotherapy.

The four stage models that emerged in this basic social process, "returning to normality," consisting of realizing being a leukemic patient, accepting chemotherapy as the key to normal life, learning self-care related to chemotherapy, and pursuing the best self-care. Each stage has to support each other, has specific boundaries, and characterization of response.

This basic social process began when adolescents "realized that they were leukemic patients" without retaliating being leukemia patients, they could not move on to the following stages. There was no fix order for the last 3 stages; accepting chemotherapy as the key to normal life, learning self-care related to chemotherapy, and pursuing the best self-care. Any stage could occur prior to the other. In addition, the adolescents had gone back and forth among these 3 stage.

The conclusion to become leukemic patients was clear and they “accepting chemotherapy as the key to normal life.” to living with leukemia as the leukemic patients and receiving chemotherapy. This was the new task for adolescents with leukemia to carry on. The choice to be cured appeared in leukemic adolescent's mind. They have faith in chemotherapy.

Adolescent with leukemia must me Learn to caring themself. Everything that they learn was related to the living with chemotherapy. Adolescents with leukemia had to “Learning self-care related to chemotherapy” as a third process for living with chemotherapy and maintain their life. They are learning to manage side effects, learning health promotion and disease prevention. Physical limitations are one of the potential long-term consequences of chemotherapy. Adolescents with leukemia were let the limitation interrupt the need to living. They are recognizing own limitation and have to learn according to the limitation as a part of learning self-care.

In this last process leukemic adolescent took action regarding self-care that they are learning and “pursuing the best self-care.” A variety of action was practiced and modify for the goodness of fit with daily living. Adolescents with leukemia show the cognitive ability to be care of himself. The strategies of self-care were an action for adjusting life to fit into a new identity as being leukemic patients with the force to get back to normal living as normal adolescents. Doing a self - care activity was similar with to having a good health behavior. Adolescents with leukemia learning self-care related to chemotherapy, and pursuing the best self-care with the need to live as normal adolescent. The help of parents, friend, nurses and doctor were important to maintaining self-care activity.

Finally, adolescents with leukemia can live with illness and treatment regimen. They are reducing the barrier to being healthy and being a normal teenager as they should be. Chemotherapy was the new task for adolescents with leukemia to carry on until the illness cured or dying with maturity.

Discussion

In this study, the finding have addresses the study question of “How do Thai adolescents live with chemotherapy?”

“Returning to normality,” was the basic social processes in this study. These adolescents defined normality their own way, not the same meaning that healthy adolescents or general people may define. They recognized that they were not as strong as they use to be and could not do everything that their peer could do. With that recognition, they define “normality” as something that they with their limitation health could perform like healthy adolescents.

For all adolescents with leukemia in this study, the normality that they return was the simple life meant being able to being with friends, which was now possible as their health improves after receiving chemotherapy.

In addition, adolescents with leukemia was confront the side effects of chemotherapy that occur over and over again. They were detected the strength of their body by the experience that they have and detected the risk of their health.

Then, the adolescents with leukemia, use their effort to reduce the barrier to being a normal teenager as they should be.

The adolescents with leukemia in this study were presented to “returning to normality” by detecting and preserving of normality. They are trying to go back to study, and keep in touch with friends. This is the strategies for adolescents with leukemia to maintain to be normal living as they can achieve. For leukemic adolescent who receiving chemotherapy and coming to the end of life. They preserved the normality by asking parents to change their cloth to school uniform and take them back home after death. Schooling and the sense of going back to school were the important issue of preserving the normality for leukemia patients. This issue was similarly with some previous research that founded school life was the important emotional support for children with cancer (Bessell, 2001; Glasson, 1995).

During the past 30 years, research and firsthand accounts of family response to childhood chronic conditions have drawn on the concept of normalization to convey the way in which many families in response to childhood chronic illness and disability (Deatrick, 1999; Earle, 2007). The numerous of studies the concept of normalization has emerged as the result of addressing how families response to child with chronic illness (Deatrick, Knafl, & Murphy-Moore, 1999; E. A. Earle et al., 2007; Kathleen A. Knafl & Deatrick, 1986).

Although, health professional consider the psychological effects of chemotherapy in the negative effect. The results of this study showed the positive effect that adolescents with leukemia can living with chemotherapy and maintaining their life day-by-day by returning to normality.

In this study the adolescents with leukemia were perceived “the normality” that they return was simple and related with the causal and happy living. Moreover, returning to normality in the perspective of adolescents with leukemia were not a static concept, but a staged and transient process. Adolescents with leukemia were archived the normality after they received chemotherapy and they were known by themselves about the time that they were prompted to returning to normality.

The results in this study had similarities and differences in the study in the field of adolescents with cancer by Van Staa et al. (2008) and Rechner (1990). They observed that adolescents with chronic disorders, living with illness was “normal.” By comparing themselves with healthy peers, they recurrently stress their own normality. Adolescents with cancer in both studies strongly agreed with the statement, “I am like everyone else, my illness is something extra.” The adolescents responded to cancer by experiencing the illness and determining that they were normal. They developed a philosophy of being positive and redefined their social world in order to get on with life.

In the results of this study showed that adolescents with leukemia felt that it was important for day-to-day lives to continue as normal as possible in order to facilitate adjustment to the chemotherapy. This was the process that adolescents with leukemia push themselves to live with chemotherapy by “looking toward brighter future.” This reinforces adolescents with leukemia to live because looking toward brighter future was the “force that drive” for adolescents with leukemia to use their effort to keep the future that leukemic adolescents wanted to be and living with chemotherapy by returning to normality.

In addition, adolescents are a time of change and conflict as the individual seeks to find his identity and establish his independence, identity (Fochtman, 2006; Hollis & Morgan, 2001).

The “Realization of being a leukemic patient” was consistent with the formation of identity in the adolescents’ development. The identity of the adolescents with leukemia was to remain rooted in reality while the illness happened. The chemotherapy was a new experience for the adolescents. They established a new identity by accepting their role as a leukemic patient and did not deny the illness.

Having been diagnosed as leukemia was the crisis events, interrupting of the normal process of identity formation and disrupting the normal life. The adolescents with leukemia were developing a new identity to living with chemotherapy. The self-identified formation was influenced by leukemic symptoms and the start of chemotherapy. Being leukemic patients was substituted for the identity of healthy adolescents. In the other hand, Madan-Swain et al. (2000) stated that a chronic illness may negatively influence identity formation in adolescents and they identified as having fewer achievements compared to healthy adolescents. The future study to explore the perception of adolescent with the identity of leukemic patient is needed.

However, the findings from this study came from 20 adolescents with leukemia that were not compared to healthy adolescents. The study showed that the leukemia symptoms may affect the adolescents in both negative and positive ways. The adolescents suffered, especially if the symptoms were severe and unresolved by regular treatment. However, the symptoms were warning signs that alarmed the adolescents to consider their health. It was important to highlight how the adolescents perceived their health had been changed by illness. This finding can be used to encourage a positive perception of symptoms in adolescents with leukemia to establish self-care interventions for adolescents with leukemia in the future.

This research determined that the adolescents with leukemia “accepting chemotherapy as a key to normal life” because chemotherapy as the only curing method. Adolescents with leukemia sought and received chemotherapy information by asking physicians, and seeking information by themselves, which indicated they gained knowledge about leukemia and its treatments. This knowledge of leukemia was used to support their journey during chemotherapy treatment. Most of the adolescents with leukemia who were interviewed had a similar understanding that leukemia can be cured by chemotherapy. They “wanted to get rid of cancer” and “wanted to start treatment as soon as possible.” Chemotherapy was the primary treatment for the adolescents with leukemia. They had to accept and endure their new identity as a leukemic patient.

The findings of this study show that adolescents can accept chemotherapy and realize the chance to be cured. In this study adolescent with leukemia was seek the information about chemotherapy by themselves. It may be the evidence to show that adolescents with leukemia need the information of treatment at the time when they know the diagnosis. Several studies were supported this finding that adolescents with cancer need to know the information about leukemia and chemotherapy at the time of diagnosis (Boman & BodegåRrd, 2000; Grootenhuis & Last, 2001). It is important that the health professional, consider the type and format of information that adolescents with leukemia need. In this study, we found that a direct explanation with appropriate timing was important. Additionally, the adolescents with leukemia need to ask about their health care. However, the appropriate format to give information about leukemia and chemotherapy needs further study.

Learning was the form of strategies to solve the problems for adolescents with leukemia in this research. Because adolescents with leukemia have ability to seek the illness information, and they brave to asking the question about illness to physician. In addition, they summarize the information of chemotherapy that they receiving from physician and nurse. They judgment about what should they do by the information.

This study shows some point about Thai culture on child discipline. Because adolescents with leukemia only follow the parent's decision on treatment without the involvement of decision. Adolescents with leukemia transform the decision making by parents to the decision by themselves. Because parents always choosing the best way, especially in the time of crisis. Adolescents with leukemia can moving on with chemotherapy by the easy to be accepting the treatment, not to deny.

Adolescents with leukemia receiving social support from family and friends. Close friend at school was an important resource for support started at the time of adolescents with leukemia knowing the diagnosis. When adolescents with leukemia admission to hospital for chemotherapy another leukemic patient where the new source of support. Roberta L Woodgate (1999) founded adolescents with cancer can find and use social support by themselves and positive social relations are considered to improve the quality of life of individuals in general and to help protect or buffer them from stressful life events, such as cancer.

Adolescents with leukemia in this study were confronting with chemotherapy and its side effects. But they are leaning with side effect. “Pick up information and learn with it” was expressed by adolescents with leukemia in this study. Nursing staff will inform the essential data related to “side effect” that will happen at the first time and inform about another side effect that come up next. Nurses always inform the information about some guidance for care during chemotherapy. However, Adolescents with leukemia showed the experienced in confronting the progressive of side effect of chemotherapy and Some late side effect of chemotherapy that happen to adolescents with leukemia and no one never discuss before, such as being infertile and growth retard.

“Learning self-care related to chemotherapy”, and “pursuing the best self-care” were found in this research. Adolescents with leukemia started to learn by assessing overall health status. They found that they did not healthy anymore and they learning the limit of physical that never happen before. But the most difficult to created self-care activity was the physical limitation are usually “temporary”. This is consistent with the study of Ness et al. (2008) and Golchin et al. (2011) which found that physical limitation is difficult to cured and adolescents with cancer need a rehabilitation with the self-care training program for creating self-care activity. In this study, many adolescents with leukemia found that they fatigue did not subside with a few weeks of completing chemotherapy. Some leukemic adolescent complained about the alteration of taste sensation. It make a problem with nutrition intake. Response to physical limitation and the change of ability to learn were expressed in both positive and negative emotions. All of adolescents with leukemia reported more positive feeling than negative ones. Because they still having life and carry on the treatments.

Adolescents with leukemia pursuing the best self-care with effective outcome to live with illness and treatment. The perspective of “Doing thing easy” was the booster to follow the good self-care behavior that adolescents with leukemia have to see and perceive from nursing staff on cancer unit. This issue reflected the way to learn self-care in adolescents when they perceive the self-care activity was easy to adopt (Anderson et al., 2002; Baggott, Beale, Dodd, & Kato, 2004). Moreover, adolescents with leukemia applying advice for caring themselves. The act of self-care not only use in hospital during chemotherapy, but also use at home when adolescents with leukemia discharge and they can adapted self-care action follow the changing of symptom and side effects condition when they need, such as altering the timing of meals, and modifying nutrition.

However, leukemic adolescent was living dependent on “chemotherapy” because chemotherapy as an essential treatment regimen to make a remission in leukemia. In the conversation with me all of adolescents with leukemia, said something like they “keep hanging on with chemotherapy” and not showing suffer feeling. In the other hand, they show "psychological strength" in their living process. Hokkanen et al. (2004) supported this finding that adolescents with cancer were focused with here and now. They use resources recognized in self to make life easier and maintain a positive attitude during illness.

Strengths and limitation

The strengths of this study required the researcher to presents the research process to display its reliability and completeness. Therefore, the participants and the researcher had interactions and built relationships with each other. The participants cooperated in the study and data analysis were practically created through this social process. The researcher used a reflexive process to provide a way to critically examine his personal interface with the participants and data. Hence, a solid and useful theory was generated from the study. In this study, the researcher collecting data through various technique, including in-depth interview, observation, and filed notes, which took place in the cancer unit and participant home that provide the essential data. The researcher developed concepts that emerged under the supervision of the dissertation adviser. Heterogeneous sampling were performed to seek variation in the information in order to increase the application of the study. Heterogeneous sampling were carried out by searching for personal information about the participants and their experience in living with illness and chemotherapy of adolescents with leukemia.

The researcher make no claim about the generalization of the finding, but the findings of this study provide the living process of Thai adolescents with leukemia that can be guide the work of pediatric nursing with adolescents with leukemia. Sample selection was limited by the homogeneity of participant who attended the cancer care unit at two tertiary hospital in Bangkok. Most participants lived in Bangkok and Patumthani, central region of Bangkok. All of them had parents to take care during illness. Therefore, the finding may not be applicable and transferable beyond this group. In addition, the researcher interviewed the participants two time at least. The participant had more opportunities to voice their need and to express their feeling compare to those who did not participate in this study. These interactions might provide additional support the restoring the normality. As a result, it might have impact on the experiences of these young people.

Implications of this research

The goal of grounded theory is to generate a substantive theory. The findings can provide powerful implications for policy, nursing practices, and future research.

Implication for nursing practice

This study provides several directions for nursing and health care provider. It provides special lenses to gain better understanding of the participants' experience of being adolescents with leukemia and receiving chemotherapy. Without understanding the adolescents with leukemia' experience, nursing staff will lunch program or caring that are ineffective. Nursing staff can provide nursing intervention to meet the needs of adolescents with leukemia as follows;

Nurse and health care provider might be change the lenses to look at the adolescents with leukemia as the person who have severe illness, the person who has life threatening, or the person who have less hope for the adolescents who need to go back to the normality. The need assessments must have the direction to assess "the perspective of returning to normality" as the important aspect for adolescents with leukemia who receiving chemotherapy. If the adolescents with leukemia showed that they have a need to keep the normality, it is the way to promote health in this group. In addition, nurse need to assessing the parents who taking care for adolescents with leukemia about what should they perceive about the health of adolescents with leukemia. Especially, when the parents and adolescents with leukemia has a different viewpoint of the health.

Additionally, nurse and healthcare provider should concern about the identity development in adolescents with leukemia. "Realization being a leukemic patient", was the first stage for returning to normality for adolescents with leukemia. This was that reflected of how adolescents becoming leukemic patients and living with chemotherapy. When their realization of being leukemic patient, they can accept chemotherapy as the treatments in the easiest way with the effective coping strategies for living with side effects of chemotherapy. Nursing assessment about how adolescents with leukemia perceive themselves and the knowing of the leukemic patient's role that adding from the teenager role should be assessed.

The adolescents with leukemia have ability to learn about the illness and treatments by themselves. To provide information to adolescents with leukemia, nurses should consider their preferred sources. For example, some adolescents with leukemia prefer the detail (medical knowledge) about leukemia. The information on this point need to explain clearly with simple words and can access online.

Parents and close friends are the source of social support for adolescents. Leukemic friend is another support during chemotherapy. Group activity for leukemic adolescent in cancer unit may appropriate for the easy connect and share understanding with the feeling of togetherness. Parents are another group that nurse should be careful. The nurse might be chatting with parents about their emotion when adolescents have leukemia, including assessing the need helping them cope.

Nursing intervention with the objective to encourage adolescents with leukemia to learning self-care with the advice from a nurse is appropriated. Nurses need to detect the physical limitation together with adolescents with leukemia and nurses must open to learn from adolescents with leukemia' experience. In addition, adolescents with leukemia was observed the health behavior form nursing staff in cancer unit and observing another leukemic patients' self-care behavior. The effective self-care program might be including this issue by allowing the leukemic patients to lean in group method. The poster of self-care activity for leukemic patients can put in the area of cancer unit to motivating self-care practice.

Implication for nursing research

The findings from this study provide basic knowledge of the living process of Thai adolescents with leukemia receiving chemotherapy. The next step should be theory testing. The developed theory can be used as an explanatory model for an intervention study. These is need to develop a program for adolescents with leukemia who receiving chemotherapy. Such program will contribute to the adolescents with leukemia, and family. The program for promoting the learning of self-care, the program to maintain the chemotherapy with the adjusting daily activity of adolescents with leukemia were the example.

Additional research is needed to follow these adolescents with leukemia in term of mental health and development process. The funding can be used to understand the development process and mental health of adolescents with leukemia in the long run and bright about nursing interventions that correspond to these issues effectively.

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APPENDICES

APPENDIX A: Interview Guide

The interview guide is focusing on "How Thai adolescents live with chemotherapy?" This interview guide is using the semi-structure question technique that mean the researcher can be adapt the question with the context of .interview but the stem of question must be keep

The interview questions

1. Opening phase

The researcher will be introduced the objective for interview and telling the research participants about the length of time of interview.

2. Interview Phase

Main interview questions.

"Could you describe to me, or tell me, what happen when you have chemotherapy?"

Probing question

"What did that happen?" "What did you notice then?"

"Can you tell me more about........?"

In addition, the researcher can create the new question that can be used to help the research participants give more detail about the experience of live with illness. This type of question will be create in the time of interview and it depend on the story that the participants expressing.

3. The closing phase

"Is there anything you would like to tell me?"

"Is there anything else you think I should know?"

ภาคผนวก ก: แนวทางการสัมภาษณ์

แนวการการสัมภาษณ์มุ่งเป้าหมายไปที่การดำเนินชีวิตของวัยรุ่นกับการป่วยเป็นมะเร็งเม็ดเลือดขาว โดยผู้วิจัยใช้แนวการสัมภาษณ์แบบกึ่งโครงสร้าง ซึ่งหมายความว่าผู้วิจัยสามารถปรับเปลี่ยนคำถามเพื่อการสัมภาษณ์ได้เพื่อให้เข้ากับบริบทของการสัมภาษณ์ โดยยังคงไว้ซึ่งเป้าหมายหลักของการสัมภาษณ์

ขั้นการสัมภาษณ์

1.ขั้นเปิดการสัมภาษณ์

ผู้วิจัยจะทำการอธิบายเป้าหมายการสัมภาษณ์ และบอกระยะเวลาในการสัมภาษณ์ให้ผู้เข้าร่วมวิจัยทราบอีกครั้งเพื่อให้เกิดความเข้าใจที่ตรงกันในการสัมภาษณ์ครั้งนี้

2.ขั้นการสัมภาษณ์

คำถามหลัก

“คุณช่วยอธิบาย หรือเล่าให้ฉันฟัง ว่าเกิดอะไรขึ้นบ้างเมื่อคุณได้รับเคมีบำบัด”

คำถามที่ใช้ขณะการสัมภาษณ์ เพื่อช่วยให้วัยรุ่นโรคมะเร็งเล่ารายละเอียดเพิ่มเติม

“คุณมีอะไรจะบอกฉันเพิ่มเติมอีกมั๊ย เกี่ยวกับ” “คุณหมายความอย่างไรเมื่อคุณพูดถึง”

3.ขั้นปิดการสัมภาษณ์

“มีอะไรที่คุณอย่างเล่าให้ฉันฟังอีกไหม”

“มีอะไรที่คุณคิดว่าฉันควรรู้อีกหรือไม่”

APPENDIX B: Participant recorded

Participant code ....

[ ] Boy [ ] Girl Age..............

The level of education ....

The place of interview ....

Researcher note

....

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....

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....

ภาคผนวก ข: แบบบันทึกข้อมูลผู้เข้าร่วมวิจัย

รหัสของผู้เข้าร่วมวิจัย ....

[ ] ชาย [ ] หญิง อายุ.............

ระดับการศึกษา ....

สถานที่ให้สัมภาษณ์ ....

บันทึกของผู้วิจัย

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APPENDIX C: Information Sheet and Consent Form

ข้อมูลและคำแนะนำสำหรับผู้ป่วยหรืออาสาสมัคร(Information Sheet)

ชื่อโครงการวิจัย กระบวนการดำเนินชีวิตในวัยรุ่นไทยโรคมะเร็งเม็ดเลือดขาวที่ได้รับเคมีบำบัด
ชื่อหัวหน้าโครงการวิจัย นายสุรศักดิ์ ตรีนัย นิสิตหลักสูตรพยาบาลศาสตรดุษฎีบัณฑิต
คณะพยาบาลศาสตร์ จุฬาลงกรณ์มหาวิทยาลัย
สถานที่วิจัย แผนกผู้ป่วยนอกกุมารเวชกรรม และหอผู้ป่วยเด็ก
โรงพยาบาลธรรมศาสสตร์เฉลิมพระเกียรติ

สถานที่ทำงานและหมายเลขโทรศัพท์ของหัวหน้าโครงการวิจัยที่ติดต่อได้ทั้งในและนอกเวลาราชการ

ที่อยู่ปัจจุบัน 208/44 (The Link condo 3) ซอยสุขุมวิท 50 ถนนสุขุมวิท พระโขนง คลองเคย กรุงเทพฯ

โทรศัพท์มือถือ 08-1910-7077 E-mail address: streenai@hotmail.com

ที่ทำงาน คณะพยาบาลศาสตร์ จุฬาลงกรณ์มหาวิทยาลัย

อาคารบรมราชชนนีศรีศตพรรษ ชั้น 12 ถนนพระราม 1 แขวงวังใหม่ เขตปทุมวัน กรุงเทพฯ 10330 โทรศัพท์ 0-2218-1157 โทรสาร 0-2218-1130

สถานที่ปฏิบัติงาน : คณะพยาบาลศาสตร์ จุฬาลงกรณ์มหาวิทยาลัย (อาจารย์)
ที่อยู่ปัจจุบัน : 208/44 (The Link condo 3) ซอยสุขุมวิท 50 ถนนสุขุมวิท
พระโขนง คลองเตย กรุงเทพฯ 10110
โทรศัพท์เคลื่อนที่: 081-910-7077
E-mail: streenai@hotmail.com

ผู้สนับสนุนทุนวิจัย ศูนย์สร้างสุขภาวะผู้มีปัญหาสุขภาพเรื้อรัง คณะพยาบาลศาสตร์
จุฬาลงกรณ์มหาวิทยาลัย

ระยะเวลาในการวิจัย ณ โรงพยาบาลธรรมศาสสตร์เฉลิมพระเกียรติ ประมาณเดือนมกราคม 2556 – เมษายน 2557

ที่มาของโครงการวิจัย

การวิจัยนี้เป็นการศึกษาที่เกี่ยวกับการดำเนินชีวิตกับโรคมะเร็งเม็ดเลือดขาวในวัยรุ่นไทย เพื่อที่จะหาทางช่วยเหลือวัยรุ่นที่ป่วยเป็นโรคมะเร็งเม็ดเลือดขาวให้เขาดำเนินชีวิตได้อย่างดีที่สุด ไม่ว่าจะหายจากโรคหรือชีวิต นอกจากนั้นผลการศึกษาวิจัยนี้ยังสามารถช่วยให้พยาบาลและบุคลกรสุขภาพอื่นๆ มีความรู้เข้าใจที่ดียิ่งขึ้นเกี่ยวกับการดำเนินชีวิตในสถานการณ์ต่างๆที่เกิดขึ้นจากการป่วยด้วยโรคมะเร็งเม็ดเลือดขาวของวัยรุ่น และสามารถใช้เป็นข้อมูลในการพัฒนาการปฏิบัติทางการพยาบาลเพื่อช่วยเหลือวัยรุ่นโรคมะเร็งเม็ดเลือดขาวได้

วัตถุประสงค์ของโครงการวิจัย

เพื่อศึกษาการว่าผู้ป่วยวัยรุ่นโรคมะเร็งเม็ดเลือดขาวดำเนินชีวิตอยู่กับโรคมะเร็งเม็ดเลือดขาวอย่างไร

ท่านได้รับเชิญให้เข้าร่วมการวิจัยนี้เนื่องจาก ท่านเป็นวัยรุ่นที่มีอายุระหว่าง 12 – 19 ปี และได้รับการวินิจฉัยจากแพทย์ว่าป่วยเป็นโรคมะเร็งเม็ดเลือดขาว รวมทั้งได้รับการรักษาด้วยเคมีบำบัดมาแล้วอย่างน้อย 2 ครั้ว ซึ่งเป็นกลุ่มผู้ให้ข้อมูลหลักในการศึกษาครั้งนี้

จะมีผู้ร่วมวิจัย/อาสาสมัครนี้ ประมาณ 30 คนเป็นผู้ป่วยที่โรงพยาบาลธรรมศาสตร์เฉลิมพระเกียรติ

หากท่านตัดสินใจเข้าร่วมการวิจัยแล้ว สิ่งที่จะขอให้ท่านปฏิบัติคือ

ให้สัมภาษณ์เกี่ยวกับการป่วยเป็นมะเร็งเม็ดเลือดขาว การรับการรักษาด้วยยาเคมีบำบัด โดยมีระยะเวลาการสัมภาษณ์ประมาณ 45 -60 นาที จำนวน 1 ถึง 2 ครั้ง

ความเสี่ยงที่อาจจะเกิดขึ้นเมื่อเข้าร่วมการวิจัย เนื่องจากการศึกษาครั้งนี้เป็นการให้สัมภาษณ์ จึงไม่มีความเสี่ยงหรือผลข้างเคียงใดๆ ที่จะกระทบด้านร่างกาย แต่บางคำถามอาจกระทบความรู้สึกของท่าน ท่านจึงมีสิทธิ์ที่จะปฏิเสธการให้สัมภาษณ์ หรือสามารถที่จะถอนตัวจากการศึกษาครั้งนี้ได้ทุกเวลาที่ต้องการ

อย่างไรก็ตาม การให้สัมภาษณ์อาจทำให้ท่านรู้สึกไม่สะดวกสบาย หรือเสียเวลา ดังนั้น ในการขอให้ท่านเลือกเลือกช่วงเวลาที่ไม่ให้รบกวนการตรวจรักษา อาจเป็นช่วงที่ท่านตรวจรักษาเสร็จ หรือทำการนัดเวลาสัมภาษณ์ได้ตามที่ท่านสะดวก และเห็นสมควร ท่านไม่ต้องเร่งรีบให้สัมภาษณ์และสามารถพักระหว่างการสัมภาษณ์ได้

หากท่านไม่เข้าร่วมในโครงการวิจัยนี้ ท่านก็จะได้รับการตรวจเพื่อการวินิจฉัยและรักษาโรคของท่านตามวิธีการที่เป็นมาตรฐาน

หากมีข้อสงสัยที่จะสอบถามเกี่ยวข้องกับการวิจัย หรือหากเกิดผลข้างเคียงที่ไม่พึงประสงค์จากการวิจัย ท่านสามารถติดต่อ นายสุรศักดิ์ ตรีนัย โทรศัพท์หมายเลข 081-910-7077ได้ตลอดเวลา 24 ชั่วโมง

ท่านจะได้รับการช่วยเหลือหรือดูแลรักษาการบาดเจ็บ/เจ็บป่วยอันเนื่องมาจากการวิจัยตามมาตรฐานทางการแพทย์ โดยผู้รับผิดชอบค่าใช้จ่ายในการรักษาคือ คณะพยาบาลศาสตร์ จุฬาลงกรณ์มหาวิทยาลัย

ประโยชน์ที่คิดว่าจะได้รับจากการวิจัย ท่านจะไม่ได้รับประโยชน์ใดๆ จากการเข้าร่วมในการศึกษาครั้งนี้โดยตรง แต่อย่างไรก็ตามผลการวิจัยจะแสดงให้เห็นถึงข้อมูลสำคัญที่สามารถใช้พัฒนาการพัฒนาการปฏิบัติทางการพยาบาลเพื่อส่งเสริมการดำเนินชีวิตกับโรคมะเร็งเม็ดเลือดขาวสำหรับวัยรุ่นไทย นอกจากนั้นผลการวิจัยยังให้แนวทางในการวิจัยเกี่ยวกับตัวแปรอื่นที่เกี่ยวข้องกับการจัดการกับโรคมะเร็งเม็ดเลือดขาวในวัยรุ่น

ค่าตอบแทนที่ผู้ร่วมวิจัย/อาสาสมัครจะได้รับ ท่านจะไม่ได้รับค่าตอบแทนจากการวิจัยนี้

ค่าใช้จ่ายที่ผู้ร่วมวิจัย/อาสาสมัครจะต้องรับผิดชอบเอง ไม่มี

หากมีข้อมูลเพิ่มเติมทั้งด้านประโยชน์และโทษที่เกี่ยวข้องกับการวิจัยนี้ ผู้วิจัยจะแจ้งให้ทราบโดยรวดเร็วและไม่ปิดบัง

ข้อมูลส่วนตัวของผู้ร่วมวิจัย/อาสาสมัคร จะถูกเก็บรักษาไว้เป็นความลับและจะไม่เปิดเผยต่อสาธารณะเป็นรายบุคคล แต่จะรายงานผลการวิจัยเป็นข้อมูลส่วนรวมโดยไม่สามารถระบุข้อมูลรายบุคคลได้ ข้อมูลของผู้ร่วมวิจัย/อาสาสมัครเป็นรายบุคคลอาจมีคณะบุคคลบางกลุ่มเข้ามาตรวจสอบได้ เช่น ผู้ให้ทุนวิจัย ผู้กำกับดูแลการวิจัย สถาบันหรือองค์กรของรัฐที่มีหน้าที่ตรวจสอบรวมถึงคณะกรรมการจริยธรรมการวิจัยในคน เป็นต้น โดยไม่ละเมิดสิทธิของผู้ร่วมวิจัย/อาสาสมัครในการรักษาความลับเกินขอบเขตที่กฎหมายอนุญาตไว้

ผู้ร่วมวิจัย/อาสาสมัครมีสิทธิ์ถอนตัวออกจากโครงการวิจัยเมื่อใดก็ได้ โดยไม่ต้องแจ้งให้ทราบล่วงหน้า และการไม่เข้าร่วมการวิจัยหรือถอนตัวออกจากโครงการวิจัยนี้ จะไม่มีผลกระทบต่อการบริการและการรักษาที่สมควรจะได้รับตามมาตรฐานแต่ประการใด

หากท่านได้รับการปฏิบัติที่ไม่ตรงตามที่ได้ระบุไว้ในเอกสารชี้แจงนี้ ท่านสามารถร้องเรียนไปยัง สำนักงานคณะอนุกรรมการจริยธรรมการวิจัยในคน มหาวิทยาลัยธรรมศาสตร์ ชุดที่ 1 คณะแพทยศาสตร์ โทรศัพท์/โทรสาร 02-926-9704

ลงชื่อ.. ผู้ร่วมวิจัย/อาสาสมัคร
(..)
วันที่......................................

หนังสือแสดงเจตนายินยอมเข้าร่วมการวิจัย
(Consent Form)

โครงการวิจัยเรื่อง กระบวนการดำเนินชีวิตในผู้ป่วยวัยรุ่นไทยโรคมะเร็งเม็ดเลือดขาวที่ได้รับเคมีบำบัด
วันที่ให้คำยินยอม วันที่ ....เดือน ....พ.ศ..............................

ก่อนที่จะลงนามในใบยินยอมให้ทำการวิจัยนี้ ข้าพเจ้าได้รับการอธิบายจากผู้วิจัยถึงวัตถุประสงค์ของการวิจัย วิธีการวิจัย อันตรายหรืออาการที่อาจเกิดขึ้นจากการวิจัยหรือจากยาที่ใช้ รวมทั้งประโยชน์ที่จะเกิดขึ้นจากการวิจัยอย่างละเอียด และมีความเข้าใจดีแล้ว ซึ่งผู้วิจัยได้ตอบคำถามต่างๆ ที่ข้าพเจ้าสงสัยด้วยความเต็มใจ ไม่ปิดบัง ซ่อนเร้น จนข้าพเจ้าพอใจ และเข้าร่วมโครงการนี้โดยสมัครใจ

ข้าพเจ้ามีสิทธิ์ที่จะบอกเลิกการเข้าร่วมการวิจัยนี้เมื่อใดก็ได้ ถ้าข้าพเจ้าปรารถนาโดยไม่เสียสิทธิในการรักษาพยาบาลที่จะเกิดขึ้นตามมาในโอกาสต่อไป

ผู้วิจัยรับรองว่าจะเก็บข้อมูล เฉพาะเกี่ยวกับตัวข้าพเจ้าเป็นความลับและจะเปิดเผยได้เฉพาะในรูปแบบที่เป็นสรุปผลการวิจัย

การเปิดเผยข้อมูลเกี่ยวกับตัวข้าพเจ้าต่อหน่วยงานต่างๆ ที่เกี่ยวข้องกระทำได้เฉพาะกรณีจำเป็นด้วยเหตุผลทางวิชาการเท่านั้นและจะต้องได้รับคำยินยอมจากข้าพเจ้าเป็นลายลักษณ์อักษร

ผู้วิจัยรับรองว่าหากเกิดภาวะแทรกซ้อนใดๆ ที่มีสาเหตุจากการวิจัยดังกล่าว ข้าพเจ้าจะได้รับการรักษาพยาบาลโดยไม่คิดค่าใช้จ่าย และหรือจะมีการชดเชยค่าตอบแทน ตลอดจนเงินทดแทนความพิการที่อาจเกิดขึ้นตามความเหมาะสม

ข้าพเจ้ายินยอมให้ผู้กำกับดูแลการวิจัย ผู้ตรวจสอบ คณะกรรมการจริยธรรมการวิจัยในคน และคณะกรรมการที่เกี่ยวข้องกับการควบคุมยา สามารถเข้าไปตรวจสอบบันทึกข้อมูลทางการแพทย์ของข้าพเจ้า เพื่อเป็นการยืนยันถึงขั้นตอนโครงการวิจัยทางคลินิก โดยไม่ล่วงละเมิดเอกสิทธิ์ ในการปิดบังข้อมูลของการสมัครตามกรอบที่กฎหมายและกฎระเบียบได้อนุญาตไว้

ข้าพเจ้าได้อ่านข้อความข้างต้นแล้ว และมีความเข้าใจดีทุกประการ และได้ลงนามในใบยินยอมนี้ด้วยความเต็มใจ

ในกรณีที่ข้าพเจ้าไม่สามารถอ่านหนังสือได้ ผู้วิจัยได้อ่านข้อความในใบยินยอมนี้ให้ข้าพเจ้าฟังจนเข้าใจดีแล้ว ข้าพเจ้าจึงลงนามในใบยินยอมนี้ด้วยความเต็มใจ

ข้าพเจ้าสามารถติดต่อผู้วิจัยซึ่งเป็นผู้รับผิดชอบเรื่องนี้คือ นายสุรศักดิ์ ตรีนัย ได้ตลอดเวลา 24 ชั่วโมง ที่อยู่ปัจจุบัน 208/44 (The Link condo 3) ซอยสุขุมวิท 50 ถนนสุขุมวิท พระโขนง คลองเคย กรุงเทพฯ

โทรศัพท์มือถือ 08-1910-7077 E-mail address: streenai@hotmail.com

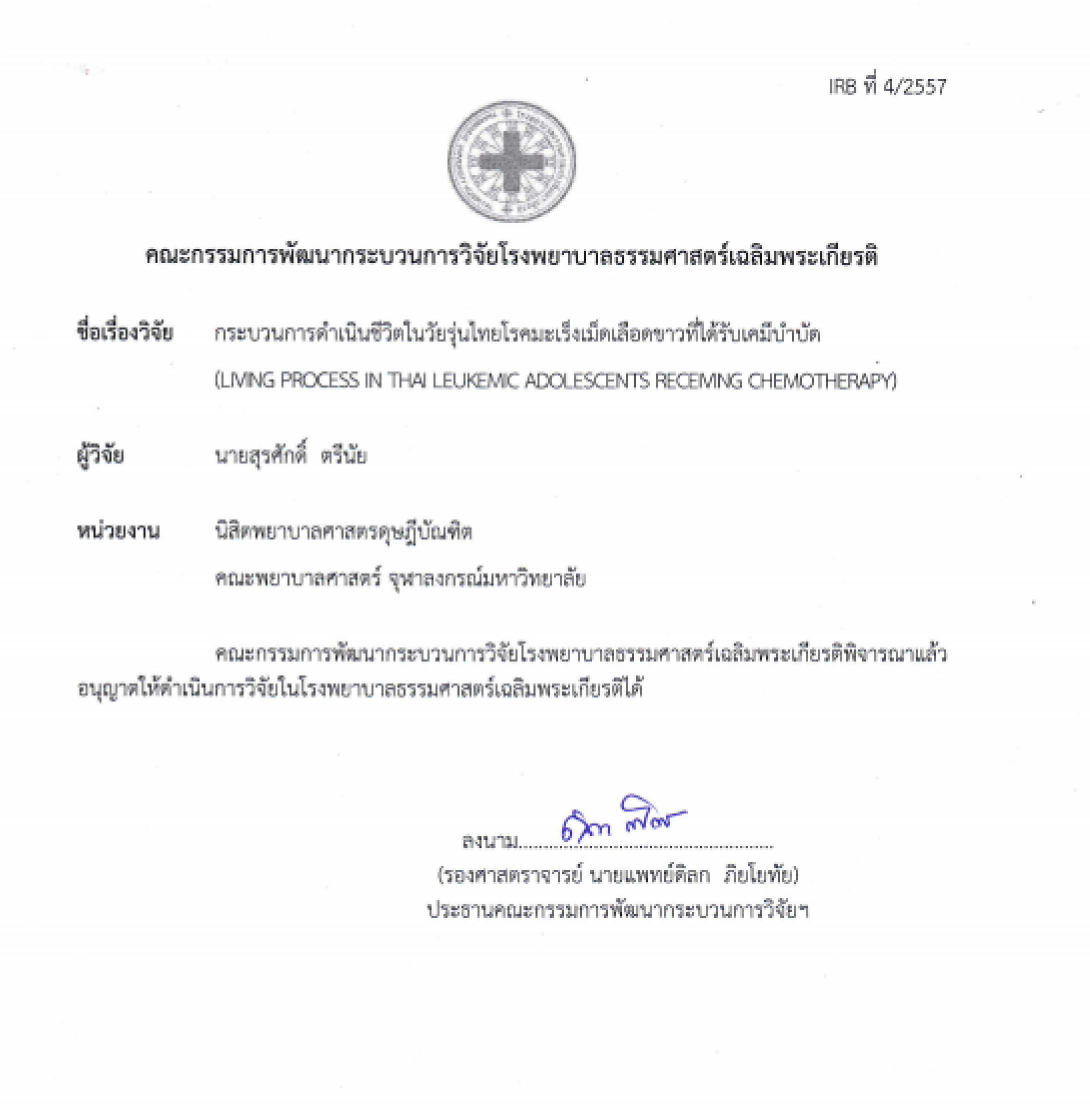
ลงนาม.......................................ผู้ยินยอม
(...)
ลงนาม.......................................พยาน
(...)
ลงนาม.......................................พยาน
(..)

ในกรณีที่การศึกษาวิจัยครั้งนี้ มีความจำเป็นอย่างยิ่งที่จะต้องให้ผู้เยาว์และหรือบุคคลไร้ความสามารถมีส่วนร่วมในการวิจัย ข้าพเจ้าได้อ่านข้อความข้างต้นแล้ว มีความเข้าใจในสิทธิและหน้าที่ของผู้เข้าร่วมโครงการวิจัยทุกประการและยินยอมให้ผู้เยาว์ และหรือ บุคคลไร้ความสามารถเข้าร่วมการวิจัยได้ จึงลงลายมือชื่อไว้เป็นหลักฐาน

ลงนาม.......................................
(...)
ผู้ปกครอง ผู้แทนโดยชอบธรรม หรือ ผู้มีอำนาจกระทำการแทน

ลงนาม.......................................พยาน
(...)
ลงนาม.......................................พยาน
(..)

APPENDIX D: The approval document for IRB



IRB ที่ 4/2557

คณะกรรมการพัฒนากระบวนการวิจัยโรงพยาบาลธรรมศาสตร์เฉลิมพระเกียรติ

ชื่อเรื่องวิจัย กระบวนการดำเนินชีวิตในวัยรุ่นไทยโรคมะเร็งเม็ดเลือดขาวที่ได้รับเคมีบำบัด
(LIVING PROCESS IN THAI LEUKEMIC ADOLESCENTS RECEIVING CHEMOTHERAPY)

ผู้วิจัย นายสุรศักดิ์ ตรีนัย

หน่วยงาน นิสิตพยาบาลศาสตรดุษฎีบัณฑิต
คณะพยาบาลศาสตร์ จุฬาลงกรณ์มหาวิทยาลัย

คณะกรรมการพัฒนากระบวนการวิจัยโรงพยาบาลธรรมศาสตร์เฉลิมพระเกียรติพิจารณาแล้ว อนุญาตให้ดำเนินการวิจัยในโรงพยาบาลธรรมศาสตร์เฉลิมพระเกียรติได้

ลงนาม..
(รองศาสตราจารย์ นายแพทย์ดิลก ภิยโยทัย)
ประธานคณะกรรมการพัฒนากระบวนการวิจัยฯ

APPENDIX E: The example of some interview transcript with coding and some memos

The interview transcript with coding

1	Participant no 8 / Interview 1	
2		**อยากให้เล่าถึงการป่วยเป็นโรคมะเร็งเม็ดเลือดขาวหน่อยครับ ค่อยๆเล่า**
3	Never think before I am strong, being a basketball player Being strong before sick Having symptom suddenly Training for sport day that will come on July. Training as usual and didn't know what happen. Feeling exhausted Exhausting not usual, "it abnormal"	เล่าตั้งแต่แรกๆ เลยนะคะ *ที่เริ่มแรก ไม่เคยคิดมาก่อนมาจะเป็นอะไร* หนูเป็นคนแข็งแรง เป็นนักกีฬาบาสเก็ตบอลของโรงเรียน อาการที่เริ่มตอนนั้นตรงกับช่วงที่กำลังจะมีแข่งกีฬาสี ตอนนั้นซ้อมกีฬาเยอะมาก เวลาเล่นก้ต้องมีวิ่ง มีล้ม มีกระแทก มีชนกันกับเพื่อนๆ ตอนนั้นจำได้ว่าเป็นช่วงต้นๆ เทอม ประมาณเดือนกรกฎาคม ก็ซ้อมบาสเป็นปรกติ พอเล่นเสร็จรู้สึกเพลียมาก เพลียผิดปรกติ

Memo 1 / participant no 8 interview 1

Leukemic symptom was suddenly happen during the normal living, What they do when the symptom happen? How they take care themselves?

Memo 2 / participant no 8 interview 1

Exhausting not usual, "it abnormal".

The abnormal that the participant explained mean? Need to explore more.

1	Participant no 8 / Interview 1	
2		เห็นบอกว่าจะไม่ใส่วิกผม แม้ว่าผมจะร่วงเหรอครับ
3	Waiting to see her face when having a baldness will look weir when having ball baldness Having a ball head after chemotherapy Having hair fall Having seen another patient have a shot hair cut Planning to have a haircut before taking chemotherapy Knowing the schedule of chemotherapy Staying at home when having a ball head	อยากรอดูก่อนว่าเวลาหัวโล้นยังไง หัวโล้นก็ไม่ต้องออกจากบ้านเลย คงดูแปลกๆไปไหนมาไหนคงจะแปลกๆ คงจะร้อนมาก มาคราวก่อนเห็นมีคนไข้แบบเด็กตัวเล็กที่ผมร่วงหัวโล้นหมด คนอื่นๆคนไข้อื่นผมจะสั้นๆ ดูสั้นๆ อาจจะไม่จำเป็นต้องทำอะไรก็ได้ เพราะว่าหนูให้ยาติดกัน 2 อาทิตย์หมอเขาบอกว่าตัดผมสั้นมาก่อนก็ได้ ผมจะค่อยๆร่วงตอนที่อยู่บ้าน แล้วเว้นอีก 4 วัน มาให้ยาครั้งหน้าค่อยดูว่าเป็นไง ร่วงมากมั๊ย คอยดูไปก่อน แต่ก็ไม่อยากใส่วิก ดูแปลกๆ น่ากลัว เหมือนผมไม่เป็นธรรมชาติ ใส่หมวกน่าจะดีกว่า ร่วงก็ต้องร่วง ต้องยอม แม่บอกแล้วแต่จะเอาวิกที่ธนาคารเขาไปใส่ก้ได้

Memo 1 / participant no 9 interview 2

The 16 years old girl, preparing to wear cap when losing hair. She said “Wearing a wig is weir and looking not natural.”

How adolescents prepare before they have a hair fall was need to explore?

This participant use the word “preparing”, how about the another participants

VITA

I am Mr.Surasak Treenai, I was born in on November, 1978 in Chai Nat. I graduated from bachelor degree in nursing science at Faculty of Nursing, Thammasat University. After graduated I work as a register nurse at intensive care unit, Thammasat university hospital for 5 years. During, 2000-2003, I studied for a master of nursing science at Faculty of nursing, Chulalongkorn University. I moved to work as a lecturer at Faculty of Nursing, Thammasat University. During 2010 -2014, I studied for Doctor of Philosophy Program in Nursing Science (Ph.D.), at Faculty of nursing, Chulalongkorn University.

Now, I work as a lecture at Faculty of nursing, Chulalongkorn. If you want to contact me, please contact via e-mail: streenai@hotmail.com