

Adolescent Cancer Survivors' and their Mothers' Perceptions of Vulnerabilities, Health Status, Treatment Effects, and Roles and Health-related Behaviors

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Abstract: This qualitative descriptive study, among adolescent cancer survivors and their mothers, sought to explore the meaning of the adolescents' and their mothers': vulnerability to cancer recurrence; vulnerability to adverse late-effects of cancer treatment; views of current health status; views on treatment effects; and, roles and health-related behaviors. In-depth, open-ended interviews were conducted with 12 adolescent-mother dyads who were attending follow-up care at a tertiary oncology care setting in Bangkok, Thailand. Data were assessed using content analysis.

Within perceived vulnerability to cancer recurrence, the adolescent-mother dyads described this theme in terms of: perceived risk; cancer-related beliefs; and, signs of recurrence. The second theme, perceived vulnerability to late-effects of cancer treatment, was presented in terms of potential major organ damage and signs of late effects of cancer treatment, while views of current health status, the third theme, was defined in terms of vulnerable health, and better or good health. Views of treatment effects on health, the fourth theme, was defined by the adolescent-mother dyads as physical, psychological, and cognitive functioning. The fifth theme, roles and health-related behaviors, was the only theme described slightly different between the adolescents and their mothers. The adolescents defined roles and behaviors as: staying healthy; protecting health; dealing with facilitators and barriers to staying healthy; and, self-care. Their mothers, however, perceived roles and behaviors as promoting and protecting the adolescents' health, and their own parenting behaviors. The findings provide a better understanding of adolescent cancer survivors and their mothers' perceptions, roles, and health-related behaviors, and how they can be incorporated into nursing practice to enhance the development of interventions to protect the health of adolescent survivors of childhood cancer.

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Background

As a result of the synergetic effects of multimodality cancer treatment and subsequent damage to various organs, adolescent survivors of childhood cancer, generally, are not as healthy as other adolescents.¹ Compared to their siblings, such adolescents tend to have more functional impairment,

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adverse general and mental health, and increased vulnerability to general health problems (i.e., neurocognitive dysfunction, cardiopulmonary toxicity, endocrinopathy, and second malignancy).² When these survivors engage in risky behaviors, such as partaking of alcohol, drugs, and cigarettes, and/or engaging in unhealthy behaviors (i.e., physical inactivity), they exacerbate their vulnerability to adverse health later in life.³ However, adolescents engaged in risky behaviors often deny, or fail to recognize, their vulnerability to the negative consequences of such behaviors. Thus, it is possible that adolescent survivors of childhood cancer are most likely to demonstrate risky and unhealthy behaviors when feeling less vulnerable to the adverse late-effects of cancer treatments and recurrence.⁴

On the other hand, those who perceive vulnerability to late-effects of cancer treatments are more likely to engage in positive health behaviors, including health promoting and protective behaviors, such as demonstrated readiness to quit smoking⁵ and performing self-care.⁶ Compared to healthy adolescents, adolescent survivors have been found to report lower levels of most health-risk behaviors than older survivors, except for alcohol consumption.⁷ This may be because adolescents have difficulty making decisions that involve peer acceptance over perceived vulnerability. However, further research is needed to better understand adolescent cancer survivors' perceptions regarding their illness.

Because cancer affects the whole family, parents of cancer survivors are worried, anxious, and fearful about the late-effects of cancer treatments, as well as recurrence of their child's cancer. As a result, parents are liable to perceive that they and their adolescent survivor are vulnerable.⁸ Children who have cancer are known to be dependent on their parents, especially their mothers, as their primary caregivers. Thus, their transition to adolescence may be difficult as they seek greater independence, while having to

rely on their mothers.⁹ Even though the adolescents and their mothers often become closer, the mothers may become overprotective and precipitate increased conflict with them. Not surprisingly, adolescents and their mothers differ in terms of concerns about health, with the mothers reporting their children require restrictions and the children often presenting a more positive picture about their health.¹⁰ Some of the parent-child conflicts have been found to be attributable to the health-risk behaviors of adolescent survivors of childhood cancer, (i.e. non-adherence to protection from the sun and physical activity).^{11,12} However, empirical support for these behaviors is limited.

Despite the merit of encouraging health-related behavior, as a preventive measure, among adolescent survivors of childhood cancer, limited qualitative research has been conducted regarding such adolescents' and their mothers' perceptions of living a healthy lifestyle. One can only assume that such individuals judge their behavior by obtaining feedback from family members.¹³ Although, prior studies have revealed different perspectives about survivors' health behaviors, between childhood survivors and their parents, none have investigated, within the same study, the perspectives of both the childhood survivors and their parents. Thus, this study sought to explore, among adolescent cancer survivors and their mothers, the meaning of: vulnerability to cancer recurrence; vulnerability to adverse late-effects of cancer treatment; views of current health status; views on treatment effects; and, roles and health-related behaviors.

Method

Design: A qualitative, descriptive design was used.

Sample, Setting, and Ethical Considerations: The sample consisted of twelve adolescent-mother dyads identified from the adolescents' medical records

in the long-term “Quality of Life Program for Childhood Cancer Survivors” at the pediatric oncology clinic of a university hospital in Bangkok, Thailand. After the principle investigator’s (PI) academic institution granted approval for the study, permission to access the medical records, recruit potential subjects, and collect data, in the selected clinic, was granted by the Ethics Committee of the hospital’s Institutional Review Board.

The inclusion criteria for the adolescent survivors of childhood cancer included being: 12 to 18 years of age; in remission at least one year after completion of cancer therapy; able to communicate in Thai; and, treated at the selected pediatric oncology hospital clinic. Inclusion criteria for the mothers of the adolescent survivors of childhood cancer included: being the primary caregiver; residing in the same household as the survivor; not having a severe illness; and being fluent in Thai. Twenty adolescent survivors of childhood cancer and their mothers met the inclusion criteria and were invited to participate in the study. During this process, potential subjects were informed about: the study and what their participation would entail; confidentiality and anonymity issues; their right to refuse to participate; and, their right to withdraw, at any time, without repercussions. Twelve adolescent-mother dyads, assented and consented to participate. Eight adolescent-mother dyads declined to participate because of not having available time. The mothers were 33 to 50 years of age (mean = 42.8 years). Most (n = 11; 91.7%) of them were married.

The adolescent participants included nine girls and three boys, who: were 12 to 18 years of age (mean = 16 years); ranged in age from 4 to 15 years (mean = 8.83 years) at the time of diagnosis; and, ranged in age from 7 to 16 years (mean = 11 years) at the time of treatment completion. The largest group of the adolescents (n = 5; 41.7%) were in high school. However three (25%) were in vocational school, and three (25%) were in primary school. Only one (8.3%)

was not receiving a formal education. The adolescents’ most common diagnosis (n = 9; 75%) was leukemia (i.e. acute lymphoblastic leukemia and acute non-lymphoblastic leukemia). The other three (25%) had a tumor (i.e. osteosarcoma or brain tumor). The majority (n = 7; 58.3%) had one sibling. Four (33.3%) of the adolescents were second children, three (25%) were only children, and three (25%) were first born children.

Procedure: Data were collected, by the PI, via in-depth interviews, through use of a semi-structured interview guide, after the participants gave consent/assent. The PI-designed interview guide contained 21 open-ended questions and eight probing questions to elicit details from the adolescents and their mothers. The interviews focused on the participants’ perceptions of: vulnerability to cancer recurrence and late-effects of cancer treatment; views on current health status and treatment effects on health; and roles and health-related behavior. The questions were based on the aims of the study and the conceptual underpinnings of Symbolic Interaction Theory (SIT), specifically, identities, roles, and socialization.^{14, 15} SIT purports that human beings act toward things on the basis of the: meaning ascribed to things; and, meaning attributed to things that tends to arise out of social interactions with others. The formulated meanings are modified through an interpretive process. Symbolic interactionists view processes as important in understanding human behavior; a dynamic process in which individuals are continuously defining and interpreting each other’s acts.¹⁶

Each interview was tape-recorded and lasted 45 to 90 minutes. Each adolescence and mother was interviewed, separately, once or twice, so they could freely tell their personal stories. The interviews were conducted in the participants’ homes, or at a quiet and interruption free location of their choice (i.e. a private room in the oncology clinic). Examples of the interview questions are shown in **Table 1**.

Table 1 Example Questions for Adolescent Survivors and their Mothers

| Study Aims | Conceptual Underpinnings | Questions for Mothers | Questions for Adolescent Survivors |
|---|---|--|--|
| | <i>Identities</i> | | |
| 1. Explore the perception and meaning of vulnerability to adverse late-effects of cancer treatment | 1. Views about vulnerability to adverse late-effects of cancer treatment | (1) What are your concerns about late effects of cancer treatment on your child? Why? | (1) How does cancer treatment affect your health? |
| 2. Explore the perception and meaning of health status | 2. Views about adolescent survivors' health status | (1) What do you think about your child's health in comparison to his/her friends? | (1) How would your mother describe about your health? |
| | <i>Role</i> | | |
| 3. Describe adolescent survivors' perceptions of their roles and behaviors | 1. Identify behaviors related to staying healthy or risky | | (1) Tell me about behaviors you perform to stay healthy or that might threaten your health? |
| | 2. Views of adolescents regarding how their mothers manage for them to stay healthy | | (2) What have you observed about your mother taking care of your health? How does this affect your health? |
| | <i>Socialization</i> | | |
| 4. Describe mothers' perceptions of their roles and behaviors related to adolescent survivors' health | 1. Identify the roles of mothers in taking care of adolescent survivors | (1) What do you do to help your child stay healthy? | |
| | 2. Views of mothers about health-related behavior of adolescent survivors | (2) What kind of things (or behaviors) does your child do for his/her health? Why does your child do those things? | |
| | 3. Mothers' roles regarding nurturing and working with adolescent survivors | (1) What kind of things do you and your child do together for him/her to stay healthy? (2) How do you feel about providing care for your child? | (1) What kind of things do you and your mother do together to keep you healthy? |

Data Analysis: The process of data management and analysis consisted of: transcription and initial review of data; development of coding categories; data coding; and, review of codes and identification of themes, and linkages between and among themes. The PI transcribed, verbatim, all the interviews and notes. In order to glean a clear understanding of the content and enable development of the coding categories, initial review of data began by repeated readings of the field notes and transcription of each interview. The major categories, initially, were identified within broad topical areas of data and classified so as to narrow the information obtained into subcategories. The PI labeled each category and subcategory with a code name that was closest to the concept it described. While examining the data, the research team compared and discussed the similarities and differences of the coded categories and subcategories. Connections among the categories and subcategories were made when saturation was reached (i.e., no new themes,

categories, or subcategories emerged). The PI read and reread the interviews, in their entirety, and reflected on them as a whole.

Trustworthiness was a guiding principle for the validity of this qualitative study.¹⁷ To ensure validity, uncover patterns, and reflect on what truly were in the data, the PI reviewed the codes, throughout the data analysis process, with members of the research team who were experts in qualitative research, while reading and rereading the categorized data.

Findings

The data focused on five themes: perceived vulnerability to cancer recurrence; perceived vulnerability to late-effects of cancer treatment; views of current health status; views of treatment effects on health; and roles and health-related behaviors. Each theme and its respective categories (see **Table 2**), with supporting data, are presented below.

Table 2 Themes and their Respective Categories

| Themes | Categories | |
|---|--|---|
| | Adolescent Survivors | Mothers |
| Perceived vulnerability to cancer recurrence | Perceived risks Cancer-related beliefs Signs of recurrence | Perceived risks Cancer-related beliefs Signs of recurrence |
| Perceived vulnerability to late-effects of cancer treatment | Potential major organ damage Signs of late-effects of cancer treatment | Potential for major organ damage Signs of late-effects of cancer treatment |
| Views of current health status | Vulnerable health Better or good health | Vulnerable health Better or good health |
| Views of treatment effects on health | Physical functioning Psychological functioning Cognitive functioning | Physical functioning Psychological functioning Cognitive functioning |
| Roles and health-related behaviors | Behaviors for staying healthy | Promoting adolescent survivors' health |
| | Protecting personal health | Protecting adolescent survivors' health |
| | Facilitators for staying healthy | Parenting behaviors |
| | Barriers to staying healthy Self-care | |

Theme 1: Perceived vulnerability to cancer recurrence: The adolescents and their mothers had the same perception about the recurrence of cancer. Vulnerability to a recurrence of cancer was related to the fact that cancer was an incurable disease. As a result, three categories emerged that described the essence of perceived vulnerability to cancer recurrence: 'perceived risks;' 'cancer-related beliefs;' and, 'a sign of recurrence.'

Perceived risks: Most adolescents believed they were at increased risk of having a recurrence of cancer, compared to other adolescents. They felt this because they continued to have dormant cancer cells in their bodies, and had to deal with everyday stressful events. Two adolescents stated:

"The doctor told me not to have too much stress, but I am a stressful person. The doctor told me that too much stress could make the cancer come back."

"I felt that it remained after treatment because I need follow-up for at least 5 years."

The mothers' perceptions of a recurrence of cancer were similar to those of their children. Thinking about the cancer cells that remained in the bodies of their children caused the mothers to worry about a possible recurrence of cancer and the health risks that confronted their children. For example, two mothers indicated:

"Thinking about the cancer cells remaining in my child's body worries me, regarding where the cancer could recur again and make him more at risk than a healthy child."

"The doctor told me about the double odds of a cancer recurrence or the greater chance for a cancer recurrence in my child, compared to healthy children."

Finally, it was interesting to note that some mothers indicated there was a history of cancer in their families, although the type of cancer the family members had encountered was different from the type of cancer encountered by their children. Comments from these mothers included the following:

"In my family there were some who had cancer, but a different type. ...I had cancer of the cervix. My brother had cancer and my older sister had it."

Cancer-related beliefs: This category made reference to the participants' perceptions related to the occurrence, cause, and prognosis of cancer. It was interesting to note that the adolescents and their mothers had similar and dissimilar beliefs related to cancer. For example, they both believed that cancer could occur at any time and was the result of one's diet, especially when it came to recurrence. This could have been related to the fact that care of the adolescents, after completion of their chemotherapy, was focused on diet, especially avoidance of foods that might contribute to the occurrence of cancer (i.e. those high in preservatives). These beliefs were supported by such statements as:

"I take care of his dietary needs. Sometimes he eats fermented fish. But, I make the cooked ones for him."

"I think about the improper care of eating like a normal child. Some mothers let their children eat the wrong food or play in dirty areas. Then the disease comes back."

"The doctor said the cancer might have come from the food we eat, like soda and cheap snacks. When I was young I ate a lot of cheap snacks that were sold in front of my school."

A difference in beliefs between the adolescents and their mothers was related to unhealthy conditions. The adolescents believed, unlike their mothers, that if confronted with unhealthy physical situations (i.e., inappropriate body weight, low immunity, or health problems unrelated to cancer) they were more likely to experience a cancer recurrence. This belief was demonstrated by the following statement:

"I think that I must not play in the water with mud when I go camping. It is not worth getting cancer again, if I play in dirty water."

Another difference in beliefs, between the adolescents and their mothers, was related to the curability of cancer. Unlike the adolescents, the mothers often questioned the healthcare providers about the curability of cancer, even after their children's treatments were completed. 'Incurable cancer' was very frightening to the mothers and hearing it often led them to worry about cancer recurrence in their children. As one mother expressed:

"Sometimes I think about this [curability of cancer] and it is sad and depressive. I am afraid the cancer will come back because my family told me that this disease is incurable. Some of my relatives, such as my mother and father, said that it was useless to get the treatments. They said cancer was incurable. But, I think my child is cured. However, I still feel depressed about not knowing if and when the cancer will return."

Signs of recurrence: This category referred to adolescents and their mothers observing cancer recurrence in other children. The mothers described the signs of recurrence by way of three subcategories: 'recurrence after treatment;' 'seeing the death of others;' and, 'recurrence of cancer, but of a different type.' The adolescents, however, described this category by way of two subcategories: 'recurrence after treatment' and 'seeing the death of others.' Thus,

the only difference in descriptors for this category, between the adolescent survivors and their mothers, was the subcategory, 'recurrence of cancer, but of a different type.'

The adolescents and their mothers believed the recurrence of cancer was less likely when the adolescents had survived for at least five years after treatment completion. They had this belief because both the adolescents and their mothers indicated the physicians had provided them with information about the five-year survival rate. However, some adolescents and their mothers were aware, even after five years, cancer can reoccur. This was demonstrated by an adolescent's following statement:

"The doctor told me that after 5 years the chance of cancer recurrence is very rare. It should be all cured, but my grandfather had a cancer recurrence after 10 years. I do not know if or when cancer will come back in me."

The second subcategory, 'seeing the death of others,' was based upon both the adolescents and their mothers experiencing the death of others who had a recurrence of cancer. One mother stated that, 20 years after treatment, her father died from a cancer recurrence. This was demonstrated by the following statement:

"I feared the recurrence because my father was cured for 20 years and then had a cancer recurrence. My father had colon cancer the first time. The second time it was at the end of his colon."

An adolescent, who experienced the death of a friend from cancer recurrence, shared the following comment:

"I saw one of my cancer friends who did not take good care of himself. He ended up with cancer again. My friend, who had a cancer recurrence, could not have bone marrow transplantation, and then he died."

The last subcategory, 'recurrence of cancer, but of a different type,' was a descriptor provided by the mothers, but not by the adolescents. A number of the mothers feared, because of the type of treatment, their children would be faced with a cancer recurrence, but of a different type. This fear was reflected, by two mothers, in following statements:

"Sometimes my child complains about headaches and blurred vision. So, I think about the doctors talking about the risk of a brain tumor because of the radiation treatment my child received."

"Last year I saw a child who was a singer from the TV show who had the same cancer as my child. She died from a recurrence of another type of cancer. My daughter asked me whether she had the same disease as the singer."

Theme 2: Perceived vulnerability to late-effects of cancer treatment: The perception of vulnerability to late-effects of cancer treatment was defined, by both the adolescents and their mothers, within two categories. Those categories were: 'potential major organ damage' and 'signs of late-effects of cancer treatment.'

Potential major organ damage: This category referred to changes that could happen to the adolescents' organs, as a result of potential side effects from cancer therapies. The adolescents' physicians provided information about possible damage to major organs (i.e., brain tumors, cardiac and gastro-intestinal problems, lung nodules, and erosion of bones). The mothers' awareness of possible major organ damage was reflected in the following statements:

"I am prepared for the future because it [organ damage] will cost a lot. For some children, it will be a brain tumor, while for others it could be problems in the lungs or heart."

"My son has a mass in his lung. He still has to have an X-ray and CT scan, for follow-up, every 6 months."

Signs of late-effects of cancer treatment: This category, the second one describing this theme, referred to physical problems the adolescents could encounter as a result of cancer treatments. Both the adolescents and their mothers indicated the physicians had informed them they needed to be observant regarding symptoms related to the late-effects of radiation treatments (i.e., headaches, chest pain, bone pain, blurred vision and stomach aches). In addition, the mothers were told about the importance of having their adolescents come to see the physicians, on a regular basis, for 'healthcare check-ups.' Support for this category was reflected in the following statements by one mother and one adolescent:

"I (mother) was afraid when my child had bone pain. I was very scared that it had come back."

"The doctor checked my digestive system and my heart. He told me (adolescent) that I have a gastric ulcer that is not serious. I think the doctor was concerned that the invasive cancer cells had spread to my other organs. I had been checked 2 years ago."

Theme 3: Views of current health status: This theme was defined, by both the adolescents and their mothers, within two categories. These categories were: 'vulnerable health' and 'better or good health.'

Vulnerable health: This category referred to the adolescents' health status being compromised or 'vulnerable.' Over half the adolescents indicated their health, in general, was not as sound as other adolescents because they were weaker and had decreased endurance (i.e. fatigue). These feelings were reflected in the following statements made by two adolescents:

"I seem normal from the outside, but I am weak on the inside."

"I appear normal, but I get tired easily."

In the same respect, the mothers indicated their children got sick easily, had a low tolerance for physical activities, and had physical limitations. The mothers' thoughts about their children's current health status were reflected in such comments as:

"My child is weak on the inside."

"All my son's friends were able to grown up. They all will be in the university next year, but my son has to stay at home."

Better or good health: The second category, 'better or good health,' in this theme referred to the adolescents' and their mothers' descriptions of the adolescents' current health status compared to their health status during cancer treatment. The terms, 'better' and 'good' frequently were used during these comparative descriptions. This category was defined by way of three subcategories: 'able to do physical activity,' 'quickly recovering from a cold,' and, 'strong like other healthy children.'

'Able to do physical activity' was defined by the mothers as being able to engage in sports and attend school camp under the supervision of mothers/teachers. However, the adolescents were not allowed to engage in vigorous outdoor or sun exposure activities. This subcategory was demonstrated by the following statement from a mother:

"She went to school camp and could do everything her friends did. Last summer I let her attend school camp, but did not follow her there. I let her go by herself. I told the teacher about her limitations, such as her not being allowed to play outside, in the sun, or do vigorous activity."

'Quickly recovering from a cold' was defined by the adolescents and their mothers as staying well whenever other children got a cold. The adolescents

felt stronger than their classmates. This subcategory was demonstrated by the following statement from an adolescent:

"I felt strong when I finish the cancer treatment. Sometimes I am stronger than my friends. Most of my classmates got a cold, but I didn't."

The subcategory, 'strong like other healthy child,' was defined by the adolescents and their mothers as the adolescents being much better, at present, compared to during cancer treatment. Thus, they were seen as being healthy, like normal children. The following statements indicated how many of the adolescent felt about how their health status had improved:

"I believe that I am as strong as any other adolescent."

"Now, I feel as strong as my friends. I can run and fight with them. I'm not tired anymore and it feels good to run. Sometimes they give up when I fight with them."

Theme 4: Views of treatment effects on health:

The adolescents and their mothers described their beliefs about the adolescents' cancer treatments within this theme. They defined the theme within three categories: 'physical functioning,' 'psychological functioning,' and, 'cognitive functioning.'

Physical functioning: The essence of this category addressed the adolescents' ability to function physically, given the effects of their chemotherapeutic medications. Both the adolescents and their mothers defined this category by way of two subcategories: 'organ alterations' and 'physical limitations.'

'Organ alterations' referred to the purple color of the skin and nails, visual difficulties, headaches, and food allergies. These changes resulted from the chemotherapy the adolescents received as part of their treatment. A number of mothers indicated the cancer treatment destroyed their adolescents' skin. For example, as stated by one mother:

"My daughter's skin is now weaker than the skin of other children. This has occurred since she was discharged from the hospital. She rarely uses soap or cosmetics. If she does, her skin will crack and peel."

The second subcategory, *'physical limitations,'* was defined in terms of weaknesses in the adolescents' bones. As a result of *'weak bones,'* the adolescents tended to be unsteady when walking or running. One adolescent described her bone degradation as follows:

"My cells seemed to lose. It meant that my cells degraded sooner than other teenagers. My bones are weaker than others because I received nine courses of chemotherapy."

"It seems to me that when I exercise, I quickly feel fatigued and feel pain in my bones, if I do it vigorously. After I received chemotherapy, I could feel my bones make funny noises like they do not work well. But, that did not happen all the time. Mostly, it was my left leg."

Psychological functioning: This category alluded to the emotional changes that occurred among the adolescents. Both the adolescents and their mothers described this category by way of two subcategories: *'mood changes'* and *'habit changes.'*

'Mood changes' were seen as alterations in how the adolescents were able to contend with everyday situations. A number of adolescents talked about how easily they became *'irritable'* and *'upset.'* Several mothers described their adolescents' mood changes, especially after they ended chemotherapy, as follows:

"He/she is more aggressive, irritable, self-willed, out of control, and petulant."

"She easily becomes irritable and frustrated. She is different. My child used to be emotionally stable and funny."

In addition to mood changes that occurred, *'habit changes'* also were noted as part of the psychological functioning category. The mothers were especially aware of how their adolescents had gone from being outgoing and socially active to becoming solitary and avoiding crowds. The mothers were concerned because they saw their children becoming reclusive. The adolescents' changes in habits were reflected by the following statement from one mother:

"She changed into a quiet child. I was not certain if it was from the medication or because she was growing up. When she was younger, she seemed to be bright, cheerful, and smart."

Cognitive functioning: Cognitive functioning, the third and final category, referred to changes the adolescents experienced regarding their ability to learn and think, as well as their short-term memory loss. This category was defined through the use of three subcategories: *'learning or thinking slowly,'* *'short-term memory loss,'* and, *'decreasing intelligence.'*

'Learning and thinking slowly' was related to the adolescents' problems in dealing with their school studies. The adolescents addressed such issues as being unable to adequately follow along with other students, when content was being presented by teachers. Two adolescents described their experiences as follows:

"I wondered why I was so slow, when my friends got the answer. When I was learning to write, I wondered, since I had done it already, why the alphabet was hard to write."

"I usually speak slowly. Sometimes I forget what I am saying, because I think slowly."

'Short-term memory loss,' the second subcategory, was most disconcerting to the adolescents and their mothers, as the adolescents tried to complete activities associated with school work. As two female adolescents stated:

"I am having short-term memory loss when studying for my Japanese writing class. When I practice writing I have to write very slowly. I never had this problem before."

"I remembered everything when I was younger. Now I cannot explain some of the idioms my mom says."

"Decreasing intelligence," the third subcategory under cognitive functioning, was described as the adolescents' brains functioning slower than before cancer occurred. The mothers and adolescents believed the adolescents were forgetting things, even within a short period of time. As a result, the mothers worried that their adolescents' intelligence was decreasing and, thus, they would not be able to 'catch up' with their friends in terms of cognitive development. The mothers and adolescents felt the adolescents' changes in intelligence were a result of all of the medications the adolescents were taking. How the adolescents and their mothers described the adolescents' decreasing intelligence was reflected in such comments as:

"After my daughter received a lot of chemotherapy, I (mother) think her intelligence decreased. She may not be able to catch up with her classmates."

"I (adolescent) need to work hard to catch up with my friends. I miss class when I receive drugs and go to the hospital. Sometimes, if I am not getting enough sleep, it is not good for my brain and I think slowly."

Theme 5: Roles and health-related behaviors:

The fifth and final theme was roles and health related behaviors. Interestingly, the adolescents and their mothers identified similar, yet slightly different, categories that defined the various aspects of this theme. The adolescents' definition of roles and behaviors focused more on what they, as cancer

survivors, needed to do, while the mothers' definition of roles and health-related behaviors focused more on what they, as a parent, needed to do to support their children. Thus, the adolescents identified the following categories: *'behaviors for staying healthy,' 'protecting personal health,' 'facilitators for staying healthy,' 'barriers to staying healthy,'* and, *'self-care.'* By comparison, the mothers identified the following categories that defined roles and health-related behaviors: *'promoting adolescent survivors' health,' 'protecting adolescent survivors' health,'* and, *'parenting behaviors.'*

Behaviors for staying healthy and promoting adolescent survivors' health: Both of these categories made reference to the adolescents' and their mothers' perceptions regarding behaviors that needed to be carried out in order for the adolescent to maintain and/or facilitate his/her health and well-being (i.e. healthy eating, physical activity, healthy weight control, and obtaining information on healthy living). For example, a number of the adolescents made the following comments:

"I need to eat foods that are healthy and give me a well-balanced diet (i.e., fresh fruits, fresh vegetables, fish, chicken, and meats, but no foods with preservatives.)."

"I like swimming and know that swimming helps with my leg strength. My mother told me to swim, using plenty of energy. Both my legs are feeling better and stronger than before."

"Normally, I weigh 47-48 kilograms or up to 50. If my weight rose to 51-52, I knew I had to reduce it because my legs could not bear the extra weight. I have bad knees and they hurt when I walk."

The mothers also defined this category in terms of their adolescents: eating healthy; engaging in appropriate physical activity; maintaining a healthy

body weight; and, adapting to their illness. However, the mothers' perspectives were focused more on how they could promote their adolescents' health, such as: preparing healthy family meals; modifying their food preferences; providing dietary supplements (i.e., vitamins, Brand's essence of chicken soup, cod liver oil, and 'Nutrilite' protein powder or drink mix); encouraging safe physical activity (i.e., exercises that did not put additional strain on the knees); allowing selection of a favorite exercise; talking about the benefits of doing exercises; encouraging use of family oriented exercises; and, encouraging use of Dhamma and meditation to deal with stress. The following statements from several mothers demonstrated their commitment to promoting the health of their adolescents:

"I gave my child the supplement protein diet and checked his palms. ...If it was good, his palms would be bright red. I think it helped him to eat more."

"I told him to exercise every half hour. I told him no one can take care of you. You have to take care of yourself. If he did not walk, I could not walk for him."

"Her daddy and I wait for her at the dance class. I think that lets her do the exercise she likes best."

"My son's weight is stable. However, if I observe that his weight goes down too fast, it will be a problem."

"I taught my daughter how to use Dhamma to calm her mind when she feels upset."

Protecting personal health and protecting adolescent survivors' health: Both of these categories referred to the activities that needed to be carried out to protect the adolescent survivors' health. The

adolescents focused on what they personally needed to do, while the mothers focused on what they could do to foster their adolescents' health status. Both the adolescents and their mothers addressed prevention of: infection, cancer recurrence, and injury. Regarding prevention of infection, both the adolescents and their mothers spoke about the need for the adolescents' to avoid contaminated water and food. This is reflected in statements made by two of the adolescents:

"If a restaurant has the food covered and a clean area in which to eat, my mom will say that we can eat there."

"Before I got sick [with cancer], I drank tap water. My mother bought a water filter. Now, I drink only filtered water because my mother does not want me to drink chlorinated tap water."

Prevention of cancer recurrence involved avoidance of certain foods (i.e., foods with monosodium glutamate, and preserved or fermented fruits), as well as exposure to secondhand smoke and intense sunlight. The following statements support the adolescents' and mothers' actions related to the prevention of cancer recurrence:

"Sometimes I help my mother cook. I cook as she taught me, without MSG added, but I use seasoning powder. Sometime when I broil fish, I add galangal or ginger. I do not think the seasoning powder has any MSG."

"The sunlight affects my disease. A lot of pollution destroys the ozone, so the UV rays come down too much. Too much exposure to the sunlight makes us get cancer."

"Because of the problems these foods can cause, I rarely let my daughter eat preserved cabbage or preserved mango."

Finally, the prevention of injury was dealt with by both the adolescents and their mothers by the adolescents' avoiding such activities as: lifting heavy objects; running; jumping; and, engaging in exercise/activities that involve extensive use of the knees. Most of the mothers encouraged their children to avoid engaging in potentially risky behavior with friends. Some mothers even assisted their adolescents with the selection friends, because of a fear that certain children would be a bad influence (i.e., encourage engagement in alcohol consumption). These factors were apparent in the following statements from an adolescent and a mother.

"The doctor told me I could not totally bend my knees. I can sit on the floor with my legs tucked back to one side. If I sit for a while, it hurts my knees. The doctor told me to wear knee supports and not lift heavy things."

"He rides a motorcycle. That is the one thing he likes to do. Lately his Dad has forbid him to ride it. He told him that if he had an accident, his leg might have to be cut off. My son stopped riding."

Facilitators to staying healthy: This category was unique to the adolescents and made reference to behaviors that promote health. The adolescents defined this category in terms of five subcategories: 'personal intention to stay healthy;' 'maternal influence;' 'parental role modeling;' 'influence of past experiences with cancer;' and, 'influence of teachers' monitoring behaviors.' The first subcategory, 'personal intention to stay health,' was demonstrated by the adolescents' level of maturity they reflected in awareness of the vulnerability of their health status. Thus, they worked at staying healthy, which was reflected by such statements as:

"I try very hard to choose the right foods to eat."

"I have learned to be more adaptive and patient when dealing with problems."

The second subcategory, 'maternal influence,' appeared to be a very strong facilitator regarding actions for keeping the adolescents healthy. This was shown by way of the adolescents' comments regarding the impact their mothers had on them. As several adolescent survivors commented:

"My mother frequently reminds me about not engaging in risky physical activities, eating the right type of foods, and doing exercise on a regular basis."

"My mother has warned me about carrying out good self-care and not getting involved, with my friends, in risky activities."

"My mother often reminds me about the importance of carrying out good personal hygiene."

'Parental role modeling,' the third subcategory, made reference to the impact both parents had on the adolescents' health practices. When parents were involved with their adolescents' health practice, it appeared the adolescents were more willing to work at keeping themselves healthy. This was reflected in the following comments by one adolescent survivor:

"My father takes me to the courtyard so that we can run together. We go there three times a week..... It is fun!"

The fourth subcategory, 'influence of past experiences with cancer,' involved the effects, on adolescents, of seeing other patients who were still undergoing cancer treatment. As a result of seeing others still in therapy, they were reminded of what they went through during their own cancer treatment. This experience served as a 'wake-up' call regarding their need to continue with healthy practices. As one adolescent expressed:

"She (my mother) reminds me to think first before doing something and what it was like for me when I was in the hospital. I do not want to go back there again. I was very sick, fatigued, and lonely. I also remembered that I was all by myself."

The fifth and final subcategory was the *'influence of teachers monitoring behaviors.'* It was apparent teachers, as a result of their constant monitoring behavior, had an influence on the adolescents. The teachers' monitoring behaviors tended to focus on keeping the adolescents from engaging in vigorous physical activities. This was reflected by one adolescent's comments:

"I went to a school camp. My teacher monitored whether I should do the activity or not. My teacher didn't allow me to walk in the mud or swim. He knows I need to be careful about my hygiene."

Barriers to staying healthy: This category was unique to the adolescents and referred to the obstacles they faced in terms of engaging in healthy behavior. The category was defined by way of five subcategories: *'growing independence;'* *'inattention to self-care;'* *'unclear knowledge;'* *'peer and family negative influence;'* and, *'environmental pollutants.'*

The first subcategory, *'growing independence,'* involved the adolescents making decisions regarding how they would handle things in their lives. Thus, they did not always believe everything their mothers told them. This was shown by the following comments made by one of the adolescents:

"My mother told me not to talk on the phone too long because it would damage my hearing and affect my disease. I did not listen to her and talked on the phone for half an hour. I felt nothing."

"Inattention to self-care," the second subcategory, was in reference to the adolescents not always paying close attention to what they were doing in regards to their healthcare needs. For example, they would not: use a face mask or knee supports when required; eat healthy foods; exercise on a regular basis; or, avoid vigorous exercise. Often this behavior was related to their feelings when they were around other people. As one adolescent stated:

"I feel shame about wearing a knee support because when I do then people who see me ask me about my knee."

The third subcategory, *'unclear knowledge,'* addressed the adolescents' lack of understanding regarding the type of practices, in which to participate, to maintain health. For example, some adolescents did not always know which foods had preservatives and needed to be avoided, and whether vitamins could be used to replace fresh green vegetables. As one adolescent indicated:

"I know that I am fat. My height is only 136 centimeters. My mother wants me to be taller. She feeds me plenty of milk and wants me to reduce my weight. I do not know how tall I should be or how much I should weigh. My mother told me being overweight will cause me to be diabetic and have high cholesterol."

'Peer and family negative influence,' the fourth subcategory, dealt with the negative impact peers and family members had on the adolescents' health practices. For example, some of the adolescents' friends would encourage them to lose weight by using artificial substances or to consume alcohol for entertainment. As one adolescent indicated:

"I thought about this jelly (for weight loss) that my friend suggested, but did not buy it. I would like to know if it really helps lose"

weight. I was afraid of the side effects because it looked untrustworthy and I was afraid of cancer recurrence.”

The fifth and final subcategory, ‘*environmental pollutants*,’ referred to the ever present pollutants in the environment (i.e., contaminants in water and air). A major concern of the adolescents was the presence of smoke from cigarettes and car exhausts. These pollutants were difficult to avoid, when walking outdoors, and known to be contributors to cancer. One comment an adolescent made, regarding pollutants, was:

“I always complained to my mother that the smoke caused cancer. I encountered the smoke from cars and cigarettes a lot. I was alright with cigarette smoke, but could not tolerate the smoke from cars. It made me have headaches and get sick.”

Self-care: The fifth and final category, used exclusively by the adolescents, was self-care. To the adolescents, self-care meant them being aware of their need to engage, autonomously, in activities that supported health maintenance. This included them asking their mothers to let them care for themselves. The adolescents defined self-care by way of two subcategories: ‘*active agent*’ and ‘*shared care*.’

The subcategory of ‘*active agent*’ involved the adolescents making decisions about what they needed to do to maintain their health and monitor their symptoms. For example, some of them would prepare their own food and self-administer their prescribed medications. As indicated by one adolescent:

“I take medicine by myself. My mother lets me be responsible to eat good food at school.”

However, some of them indicated their mothers would not allow them to go, by themselves, to their personal physicians for follow-up care, until they were twenty years old. Although there was a sense of

independence among the adolescents, certain health practices were controlled by their mothers.

The second subcategory, ‘*shared care*,’ involved the adolescents and their mothers carrying out some healthcare practices together. The practices varied, but often included: cooking and eating foods that did not contribute to recurrence of cancer; engaging in certain physical activities; and, learning about food selection and preparation for cancer survivors. ‘*Shared care*’ was demonstrated by such statements as:

“I like to exercise with my mother rather than do it alone. I was over 50Kg overweight when I was on medications two years ago. Now I am not overweight and feel normal.”

“My mother told me about the benefits of eating veggies, that she read in a health book. Sometimes I remind my mother about eating veggies. We alternate reminding each other.”

Parenting behaviors: This category was unique to the mothers and referred to the strategies they used in raising and maintaining the health of their adolescents. This category was defined by way of three subcategories: ‘*being restrictive*,’ ‘*being supportive*,’ and, ‘*normalizing*.’

The first subcategory, ‘*being restrictive*,’ involved the mothers’ perceptions and actions related to the vulnerability of their adolescents’ health status. As a result, many of the mothers tended to display rigidity regarding physician appointments and supervision of their adolescents’ healthcare behavior. For example, many of the mothers were adamant about their adolescents attending all follow-up appointments with their physicians, as well as carrying out preventive self-care actions (i.e., healthy eating and avoidance of risky physical activities). This was evident, as reflected by one mother’s comments regarding being restrictive:

"He (her son) has not received any medications, since 2008. We have to check that he does not have a recurrent lung tumor. The doctor told me to follow up, because he needs to be consuming appropriate foods and checking for signs of cancer."

The second subcategory that reflected parenting behaviors, 'being supportive,' was demonstrated by the mothers as they encouraged their adolescents when they tried to walk with mobility aides (i.e., canes) or carry out good healthcare practices (i.e., eating the right type of foods and engaging in appropriate physical activity). As one mother commented:

"He (her son) said he would try for his mommy, not for himself. He did not want me to suffer with his sickness. He said this because he might have known what was on my mind or because he has grown up. He said what I had been thinking. I could feel that."

'Normalizing,' the third and final subcategory that defined parenting behaviors, dealt with mothers trying to make their adolescents' lives as normal as possible, given their circumstances. This involved such actions as allowing the adolescents to do as much for themselves, as reasonably possible, and to engage in activities in a manner they preferred (i.e., preparing foods the way they liked them and exercising as they preferred). As two mothers indicated:

"I allow him (her son) to do the exercises that he likes."

"I allow her (her daughter) to be as independent as possible."

In summary, the findings of this qualitative study noted that both the adolescents and their mothers used similar descriptors (categories) to present their perceptions of the adolescents': vulnerability to cancer recurrence; vulnerability to adverse late-effects of

cancer treatments; views of the current health status; and, views of treatment effects on health. The mothers and adolescents slightly deviated as to how they defined the theme, roles and behaviors. The adolescents focused on what they needed to do as individuals, while the mothers focused on how they could support their adolescents' efforts in trying to stay healthy.

Discussion

The adolescent survivors and their mothers defined vulnerability to cancer recurrence in terms of: perceived risks (i.e., remaining cancer cells in the body, and/or cancer in the family); cancer-related beliefs (i.e., cancer can occur at any time, and/or questionable curability of the disease); and, signs of recurrence (i.e., cancer can reoccur after treatment). The fact the adolescents and their mothers were concerned about a potential recurrence of the adolescents' cancer was similar to prior research, wherein, cancer survivors often have been found to have a sense of sadness about the uncertainty of a possible recurrence of their illness.¹⁸

The terms used, by both the adolescents and their mothers, to define perceived vulnerability to late-effects of cancer treatment included: potential major organ damage (i.e., increased sensitivity of the skin) and signs of late-effects (i.e., headaches from radiation therapy). Both the adolescents and their mothers were aware of the vulnerability of the adolescents' health status that resulted from the long-term effects of cancer treatments. For example, taking part in a variety of physical activities was no longer possible for many of the adolescents because their bones had been compromised and were not as strong as they had been prior to having cancer and receiving treatment. This finding was congruent with prior findings that revealed a number of physical performance limitations (i.e., difficulty kneeling, lifting, and carrying objects) among cancer survivors.^{2, 19}

The views of the adolescent-mother dyads, regarding the current health status of the adolescents, were revealing. The terms they used to describe this theme were: vulnerable health (i.e., weaker with less endurance and being fatigued), and better or good health (i.e., now able to do more physical activity than during treatment). The adolescents and their mothers were aware of the adolescents' vulnerable health that resulted from his/her illness and related treatments. However, they both agreed the health status of the adolescents was better after, rather than during, the cancer treatments. The fact the adolescent-mother dyads spoke about the presence of the adolescents' low endurance was similar to prior research that noted the presence of fatigue.^{20, 21}

The adolescent-mother dyads identified the impact of cancer treatments in three areas of the adolescents' functionability: physical (i.e., skin changes), psychological (i.e., mood changes) and cognitive (i.e., difficulties with memory and ability to learn). The fact that changes in physical functioning were noted, in this study, was consistent with the findings of a prior study regarding skin problems that arise as a late effect of radiation therapy and some chemotherapy agents (i.e. skin color changes, fibrosis, telangiectasia, and thinning of the skin).²² The finding addressing psychological changes also was congruent with previous findings regarding discordant feelings among cancer survivors.²³ This has been especially noted with respect to the difficulties cancer survivors experience when interacting with their family and friends. Finally, the finding addressing the mothers' awareness that mood changes have occurred in their children, since being diagnosed with cancer, was consistent with prior research that noted cancer therapies can affect cognitive function (i.e. poor quality in decision making regarding risk behaviors) among adolescents.²⁴

The adolescent-mother dyads perceptions of roles and health-related behavior focused, for the

adolescent survivors, on what they personally needed to do to maintain their health, while the mothers focused more on what they, as a parent, needed to do to adequately support their adolescents in their quest to stay healthy. The adolescents defined their roles and behaviors with such descriptors as: engaging in behaviors for staying healthy (i.e., eating healthy, controlling weight, obtaining information about healthy care of self, and being mature about potential vulnerability of health); doing things to protect their health (i.e., eating clean food and avoiding fermented foods); identifying facilitators for staying healthy (i.e., mothers' influence on, and parental involvement in, their adolescents conduct of healthy behaviors); identifying barriers to staying healthy (i.e., being inattentive to care of self, environmental pollutants, and negative influence of friends and family members); and engaging in self-care (i.e., taking part in autonomous care of self). Mothers on the other hand described their roles and behaviors in such terms as: promoting the adolescents health (i.e., preparing healthy meals, providing dietary supplements, and encouraging the use of Dhamma to deal with stress); protecting the adolescents' health (i.e., preventing consumption of fermented foods and engagement in unsafe physical activities, and accompanying the adolescents to follow-up physician appointments to assure compliance); and, parenting behaviors (i.e., providing encouragement when the adolescents demonstrated healthy behavior).

A number of these findings are similar to those of prior research. For example, the importance of keeping follow-up physician appointments was noted in two studies,^{25, 26} while the fact the adolescent survivors engaged in healthy eating behaviors was noted in one study.²⁷ Maternal involvement, with children regarding their health behaviors, was supported by prior research, wherein, similar to this study, the mother's attitude and behavior had the potential of influencing the child's dietary thoughts

and actions.²⁸ The finding that the adolescents displayed an increased sense of maturity, regarding the ever present vulnerability of their health, was similar to prior research that noted personal growth and maturation among childhood cancer survivors.^{29, 30} Finally, the fact the adolescents identified the presence of barriers to staying healthy was similar to prior studies that noted barriers, such as fatigue and low endurance,^{20, 21} can influence ones participation in healthy exercise.

Limitations and Recommendations

When applying this study's findings, the limitations of the study need to be taken into consideration. For example, the vast majority of the sample had a diagnosis of leukemia, even though efforts were made to recruit adolescent survivors of various types of cancer. Therefore, the findings may not be generalizable to adolescents with non-leukemia types of cancer. Secondly, only one pediatric oncology clinic, located in a university hospital, was used for obtaining data. Thus, the findings may not be applicable to adolescents being treated in other types of health care facilities. Finally, since the data were obtained via interview, one has to assume the adolescent-mother dyads responded truthfully. Based upon the limitations of this study, future studies need to consider: replicating the research using adolescents who have different forms of cancer; using more than one study site; using study sites that include private and non-academic institutions; and, obtaining data via multiple sources, rather than only interview.

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การรับรู้ความเปราะบางต่อผลข้างเคียงระยะยาวจากการรักษาโรคมะเร็งและ พฤติกรรมสุขภาพของวัยรุ่นผู้รอดชีวิตจากโรคมะเร็งในวัยเด็กและมารดา

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บทคัดย่อ : การวิจัยเชิงคุณภาพเชิงบรรยายในการศึกษาครั้งนี้มีวัตถุประสงค์เพื่ออธิบายการรับรู้และความหมายของความเปราะบางต่อผลข้างเคียงระยะยาวจากกระบวนการรักษาโรคมะเร็งวัยเด็กของวัยรุ่นผู้รอดชีวิตและมารดาการรับรู้สภาวะสุขภาพบทรบและพฤติกรรมที่มีต่อภาวะสุขภาพรวมทั้งการรับรู้ในบทบาทที่ต่อกันของทั้งวัยรุ่นผู้รอดชีวิตและมารดาผู้วิจัยศึกษาโดยการสัมภาษณ์เชิงลึกใช้คำถามปลายเปิด สัมภาษณ์วัยรุ่นผู้รอดชีวิตและมารดา 12 คู่ ที่มาพบแพทย์ในหน่วยของโคโลยีคลินิกโรงพยาบาลพุทธยุมิ กรุงเทพมหานคร ประเทศไทย

จากการวิเคราะห์ข้อมูลเชิงเนื้อหาพบว่า มี 3 ประเด็น ได้แก่ การรับรู้ความเปราะบาง ในเรื่องผลข้างเคียงระยะยาว การรับรู้ภาวะสุขภาพ การรับรู้บทบาทและพฤติกรรมสุขภาพ ทั้งวัยรุ่นผู้รอดชีวิตและมารดา มีการรับรู้ความเปราะบางต่อการกลับเป็นโรคมะเร็งซ้ำ และ ความเปราะบางต่อผลข้างเคียงระยะยาวของการรักษาโรคมะเร็ง วัยรุ่นผู้รอดชีวิตรับรู้เหมือนกับ มารดาในเรื่องภาวะสุขภาพที่มีความเปราะบาง หรือรับรู้การมีสุขภาพดี สำหรับการรับรู้บทบาท และพฤติกรรมสุขภาพ วัยรุ่นผู้รอดชีวิตพูดถึงพฤติกรรมสุขภาพที่ทำเพื่อการมีสุขภาพที่ดี การป้องกันสุขภาพ สิ่งที่จะช่วยเหลือ และสิ่งที่เป็อุปสรรคต่อ การมีสุขภาพดี มารดารับรู้บทบาท และพฤติกรรมในการดูแลวัยรุ่นผู้รอดชีวิต ได้แก่ การส่งเสริมสุขภาพ การป้องกันสุขภาพ และ บทบาทในการเลี้ยงดูลูก ผลการศึกษาสามารถนำไปใช้ร่วมกับการพัฒนาและปรับปรุงการให้ การพยาบาล เพื่อเป็นการป้องกันและพัฒนาให้มีสภาวะสุขภาพที่ดีในวัยรุ่นผู้รอดชีวิต จากมะเร็งวัยเด็ก

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