
小児がんの子どもの将来にむけての弾力性とその支援

小児がん長期生存者を中心に

(How do we enhance resilience in childhood cancer patients for
their future: Focused on survivors)

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Errata 正誤表

- 1 p4. at Line 1: Resilience seems to be related to being able to tell their diagnosis to friends and making their purpose in this study.
- 2 #7 and #8=the adolescents who had been outpatients for less than 1 year.

Table 5 Strengths in Survivors Who were the Newly Diagnosed and had Experienced Relapse

Core Categories	Stages	Subcategories	Newly Diagnosed						Relapsed			
			1	3	4	5	6	7	8	2	9	
Cognitive discomfort	Diagnoses										+	
Distraction	Early inpatient	Purposes										
		Positive attitude				+					+	
		More knowledge of life										
Cognitive comfort	Inpatient	Purposes										
Personal competence	Inpatient	Purposes			+	+▲☆	+		+		+	
		Positive attitude			+☆	+	+☆		+▲☆		+☆	
	Connecting with friends										+☆	
	Confidence											
	Near discharge	Purposes						+		+		
Positive attitude								+				
		Confidence										
	Outpatient	Purposes			+	+	+				+	+
		Positive attitude		+	+☆	+	+☆		+		+▲☆	+
		Connecting with friends			+☆	+☆	+☆		+☆		+☆	+☆
		Confidence	+△		+	+			+			+
		More knowledge of life									+☆	+

+ = experiences of the same subcategories; ▲= with mother' support; △=with father; ☆ = with friends' support; ☆ = with others' support.;

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はしがき

平成19年度～21年度の科学研究費補助金による基盤研究（C）「小児がんの子どもたちの将来にむけての弾力性とその支援：小児がん長期生存者を中心に」の研究成果報告書です。本研究は、思春期にある小児がん経験者の方とそのご家族、そして施設のスタッフのご協力を得て行われました。皆様のご理解とご協力に深く感謝を申し上げます。

研究を進めていく中で、思春期にある小児がん経験者が身体的・心理社会的にいろいろな課題を抱えながらも、入院生活、学校生活、退院後の生活で、勇気と強さをもって日々を送っておられる側面を学ぶことができました。この研究が教育・研究・実践の分野で、小児がん経験者のQOLを高める支援を考える資料の1つとなれば幸いです。

この研究は、入院患者から長期生存者の方へと継続した調査を行っているため、これまでの研究をまとめた研究「psychosocial strengths enhancing resilience in adolescents with cancer（思春期にある小児がん患者の弾力性を高める心理社会的な強さ）」を載せております。

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研究発表

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Summary

Adolescents survivors of childhood cancer experience multiple sources of stress, nevertheless some continue to function normally and / or are resilient. The purpose of this study was to explore the ways in which survivors increase their powers of resilience, including the enhancement of psychosocial strengths enabling them to create a conducive support network. To this end, the same research method as in the previous study, 'psychosocial strengths enhancing resilience in adolescents with cancer' was applied.

This case study research method was used along with semi-structured interviews. Pattern-matching logic using the 4-stage Self-Sustaining Process model developed by Hinds and Martin was applied in order to arrive at a comparative analysis. The participants were seven adolescents aged 12 to 24 years at the time of the interviews, who had been outpatients for over one year. Their mothers also involved in this study. The adolescents were interviewed in person and the interviews recorded. The simplified form of the Japanese Version of the Self-Perception Scale (SJS-PSA) and the Social Network Map (SNM) were also applied to the adolescents and their mothers. The study was conducted between 2006 and 2009. The previous study suggested that resilience was related to purpose and stages such as being newly diagnosed or suffering relapse. The newly diagnosed adolescents spent most of their time coping with therapy during their time as an inpatient, therefore, they had a purpose of going back to school and began to study at near discharge. Other research subjects in the early inpatient stage found their purpose in going back to school and

reestablishing relationships with their friends. Resilience seems to be related to being able to tell their diagnosis to friends and making their purpose. Reasons for informing friends of their diagnosis revealed a difference between survivors who were newly diagnosed and those who had relapsed. The newly diagnosed subjects gave information after their discharge in order to make friends, whereas those who had relapsed informed their closest extant friends in order to connect with them openly. There was also a difference in between survivors who informed their friends and those who did not. The informing survivors found purpose in terms of doing something to help others, while the non-informers did not.

Individual support should be given in order to improve resilience among survivors. Nurses, physicians, families, and teachers need to be aware that survivors telling friends of their diagnosis is important. We should therefore encourage survivors to be open with their friends regarding their diagnosis. Similarly, we should encourage their friends and family members to be as supportive of and receptive to this process as possible. Finally, and due to the limited number of samples involved in this study, further research to test the validity of these findings is called for.

Acknowledgments

We would like to acknowledge and express our sincere gratitude to the research participants and their parents. We would also like to acknowledge the support of Shosuke Sunami, Shouko Ishiwatari, and Naoko Satou at the Narita Red Cross Hospital.

Psychosocial Strengths Enhancing Resilience in Adolescents With Cancer

Akiko Ishibashi, Jun Okamura, Reiko Ueda, Shosuke Sunami

Introduction

Although adolescents with cancer are at the risk of developing cognitive, emotional, and behavioral problems,^{1,2} they show resilience.^{3,4} Researchers have recognized the need for studies on resilience among adolescents with cancer to improve their quality of life.^{3,5-8} Resilience comprises enhanced positive health concepts such as hope, positive coping, and social support.^{3,9} Hope relates to self-protective factor and resilience.³ A focus on not only individual protective but also on family and social protective factors may have a positive impact on the long-term outcomes in adolescents with cancer.^{10,11} However, little theoretical research has been conducted on the interventions to help such patients with their psychosocial adjustments to the cancer experience.³ In addition, longitudinal research on adolescents with cancer could contribute in determining whether certain strategies are more effective at certain stages during the treatment.¹² The objective of this study is to explore the methods of enhancing resilience in adolescents with cancer and to help them have an improved quality of life.

Background

Conceptual Framework

The Self-Sustaining Process (Fig. 1) was used as the framework. The Adolescent Resilience Model (ARM) was developed as a theoretical model to propose the process and outcomes of resilience.³ The model includes 6 factors: illness-related risk, individual risk, family protective factors, social protective factors, individual protective factors, and outcome factors. These factors are attached to an outcome factor that comprises resilience and quality of life. Family protective factors include family atmosphere, support and resources. Social integration and health care resources are the same as social protective factors. This factor refers to maintaining peers and school life, social relationships, and a normal life. Individual protective factors are consists of derived meaning and positive coping. Derived meaning includes hope and spiritual perspective. Hope is characterized by an expectation that a positive future goal is possible.

Hope and positive coping are important concepts that enhance resilience.⁹ Being hopeful and positive about their future helps the adolescents to cope with psychological stress.^{3,19-21} Hope also encourages them to face the uncertainty of the future as well as have a positive future goal.³ Moreover, hope is defined as the degree to which the adolescents believe that a positive future exists for themselves or others.^{12(p. 339)} The substantive theory (Fig. 1) helps them achieve hope and be aware of their personal competences by positive coping during their cancer experience.¹²

Self-sustaining is defined as a natural progression indicating that the adolescents with cancer “move through to comfort themselves and achieve competence in resolving health threats”^{12(p. 339)}.

The self-sustaining process includes 4 phases: cognitive discomfort, distraction, cognitive comfort, and personal competence. Each phase comprises some strategies. Cognitive discomfort occurs immediately after becoming aware of negative or disrupting thoughts. Then, the experience of negative thoughts moves to a hopeful state. This phase includes 2 strategies: thought stopping and thought reflection. Distraction is a purposeful effort to discard threatening conditions through positive thoughts or activities. Under this phase, 9 different strategies have been identified including “doing something,” “It could always be worse,” and so on. Cognitive comfort refers to the periods of comfort and lifting of spirits. This phase includes strategies such as forgetting the disease and being hopeful. Patients have a view of the future possibilities for themselves or others during the cancer experience. Hopefulness alone is not enough to sustain this, but personal competence is also needed. Personal competence of the adolescents changes and leads to a state where they view themselves as resilient, resourceful, and adaptable in the face of serious health problems. Three strategies have been identified for this phase: commitment treatment, adaptation to symptoms, and taking care of problems. The self-sustaining characteristics usually have these qualities: (1) they can occur over minutes or weeks, while some phases take

longer than others, or they may be skipped; (2) positive relationships exist among the 4 core concepts; (3) they include influences by other people such as nurses; and (4) they have an ability to bypass distraction with humor.

Literature Review

Resilience has been conceptualized as a dynamic process involving an interaction between both risk and protective factors.¹³⁻¹⁵ When people successfully cope with stress, they become mentally stronger and enhance their resilience.^{13,15} Moreover, resilience refers to the ability to cope stress successfully with strength.^{5,7,8,16} In addition, promoting factors leading to resilience has been discussed in relation to childhood and with respect to the individual, their families, and the society.^{5,13,17,18} Resilience is often enhanced by other positive health concepts such as positive coping, meaning and purpose as well as social and emotional support.³ ARM was developed as a theoretical model to propose the process and outcomes of resilience and quality of life.³ It suggests the methods of enhancing protective factors and diminishing risks.^{10,11} It consists of 6 different factors. In the outcome factor, resilience comprises a sense of confidence, self-transcendence of the cancer experience, and self-esteem.³ Confidence is the control over events in the existing environment. Characteristics of self-transcendence include a sense of being healed; purpose and meaning; and a connectedness with others, nature, and God. Self-esteem involves feeling more knowledgeable about life and having a greater sense of purpose. Based on this model,

the Resilience Enhancing Adolescent Profile (REAP) was designed as a guide for interventions in adolescents with cancer.³ REAP is used to strengthen the individual protective, family protective, and social protective factors, and to enhance resilience.³

Methods

This study uses a case study research method with semi-structured interviews. Yin²² provided the case study description. One of the approaches to link data in case studies is a pattern-matching method or relating several pieces of information from the same case to the same theoretical proposition.²² Each case study and unit of analysis should either be similar to those previously studied by others or should differ in clearly defined ways. Internal validity is supported if all patterns fit the proposition. However, if patterns do not fit, or even if one of the variables does not fit, the propositions are deemed unacceptable. Any theory must be tested through the replication of findings by subsequent cases. Empirical results may be more effective if 2 or more cases support the same theory. Based on this idea, the self-sustaining process of Hinds and Martins¹² serves as a theoretical proposition and a guide to define the case and unit of analysis.

Participants

After being approved by the institutional review board, we obtained the permission to work with adolescent groups from the administrators and chief

oncologists of three different agencies: one from the eastern part, and the other two from the western part of Japan. Physicians in the hematology/oncology clinic identified potential participants from the appointment list. Participants were included based on the criteria that they should be 12–18-year-old adolescents with cancer who had been outpatients within 2 years. In total, 10 adolescents were approached by the physicians who briefly explained the study. Nine adolescents and their mothers agreed to meet the researchers, and after a detailed description of the study, signed the written informed consent to participate. One adolescent refused to participate due to limited availability of time for his participation. The final participants comprised 5 males and 4 females. Four had been diagnosed with acute lymphoblastic leukemia, 4 with acute myelogenous leukemia, and 1 with non-Hodgkin's lymphoma (NHL). Five of them had experienced peripheral stem cell transplantations (PSCTs). Their diagnosis was between the age of 1 to 5 years; 5 had been newly diagnosed and 4 had experienced relapse. The ages of the newly diagnosed patients ranged from 12 to 18 years (2 males and 3 females), and the period of being outpatients was between 1 and 15 months. The relapse-experienced respondents were aged between 12 and 17 years (3 males and 1 female), and were outpatients for a period between 1 and 15 months. Two of them had an experience of a poor prognosis as outpatients.

Data Collection

Reliability means to minimize errors and biases in a study by using a case study protocol.²² A semi-structured interview guide for coping strategies before and

after cancer therapy²³ was used to explore the methods of enhancing resilience. It was modified into following simple questions²⁴: (1) “Would you tell me how you felt when you heard about your illness?” (2) “Would you tell me what kind of things you do and think about that help you deal with treatments and finish them more easily?” (3) “Would you tell me what kind of things you do and think about that help you deal with the side effects of the treatment and other problems?” (4) “Were things the same or different for you when you were close to discharge?” (5) “Would you tell me what kind of things you do and think about that help you deal easily with being an outpatient?” (6) “How have things changed in your life since the discharge?” Other people also influence the lives of adolescents with cancer during the self-sustaining process.¹² In this context, all participants were asked about their support providing resources such as family, friends, teachers, and health care professionals. The same researcher conducted the interviews. Nine adolescents, 7 of them in the pediatric oncology clinic and 2 of them at their home, were interviewed individually. The interviews lasted between 30 and 50 minutes while waiting for the result of a blood test. All interviews were audiotape-recorded and transcribed verbatim. Demographic and health information was obtained from the charts. Data were collected for a period from October 2005 to August 2006.

Data Analysis

Transcribed interview data were used for analysis. Each interview was coded for themes over 3 days by the investigators. Rigorous application of coding techniques

helped to maintain the reliability and validity of the analysis.²⁵ Line by line coding of the transcripts was performed to categorize data into themes through a careful and restrictive review. Common themes were grouped together to know the lived experience of the adolescents and to validate the analysis of the findings.²⁶ Data were analyzed to compare with the self-sustaining process. First, Case 1 data was separated into 3 periods: inpatient (included early inpatient), near discharge, and outpatient. Second, data in each period were grouped based on the core phases such as cognitive discomfort, distraction, cognitive comfort, and personal competence. Third, data in core phases were classified into categories of thought stopping, thought reflection, doing something, and so on. Finally, data in each category were grouped into subcategories, coded using keywords such as shock and recovery. Additionally, social support was identified into 5 areas: friends, family, healthcare professionals, teachers, and others. The grouping and coding of data were checked strictly using the same process by three researchers. These analytic processes were replicated in all cases. Data that did not fit the categories and subcategories were also identified.

Findings

This study explored the methods of enhancing resilience in adolescents with cancer. Nine adolescents with cancer were interviewed. They were aged between 12 and 18 years and had been discharged within 2 years. The participants varied in age, diagnosis, time of the onset of disease, and type of therapy. On analysis of all the

interviews, it was found that the adolescents moved through the self-sustaining process and felt themselves hopeful and competent for resolving health related threats. By comparing data from the self-sustaining process, some differences were found in the categories. Some differences were also found in the use of subcategories between the newly diagnosed and the relapse-experienced patients. A new category called psychosocial strengths was identified. It consisted of positive attitude, purpose, connection with friends, confidence, and more understanding of life. Differences were also seen in the development of psychosocial strengths between the 2 groups.

Descriptions

The descriptions for the self-sustaining process are shown below. Case 1 (newly diagnosed) and Case 2 (relapse-experienced) are presented in full, while the remaining cases are described briefly. A summary of the descriptions is shown in Table 1 for Case 1 and 2, respectively. Cases 3, 5, 7, and 9 were similar to Case 1, while Cases 4, 6, and 8 were similar to Case 2.

Newly diagnosed adolescents

Case 1

A female junior high school student had been an outpatient for 4 months. She knew about her disease before her mother informed her. In the cognitive discomfort phase, she experienced thought stopping and thought reflection. She was

shocked when she heard about the change in her blood type following peripheral stem cell transplantations (PSCTs). However, she had a positive attitude and was able to think about a good prognosis with the support of her parents and her physician during the distraction phase. She seemed to have a purpose to live and looked forward to normalcy and believed that would not succumb to her disease despite her friend's death. When she learned that she would lose her hair, she started planning to grow her hair again. She also tried to keep herself occupied by playing games with nurses and nursing students. In the cognitive comfort phase, she became hopeful. During the inpatient period, she had a purpose of recovery and hoped of friendship and studies. These hopes persisted until after discharge. She was sent a copy of lecture notes from one of her friends, which also influenced her hope for studies. As she neared discharge, her hope was to go to an art university with her friend, to have family health, and not to relapse after discharge.

In the personal competence phase, the adolescent was commitment to therapy with the hope for recovery. She said, "I should not die due to my disease despite the death of a student whom I knew." She coped with the hard time during therapy by thinking about a movie she wanted to see. A nursing student visited and helped her have a good time. She also learned how to adapt to symptoms. For example, she sometimes changed her plan for studies when she felt very weak. Her purpose was not to fall behind in classes as she neared discharge. She took care of her problems with confidence. She studied English as diligently as possible and said, "I don't want to be falling behind in my class." She consulted a teacher about study guidebooks that were

useful. Her efforts to study continued after the discharge, and she adapted to her symptoms. Because of her condition, her parents wanted her to go to a regular high school. Hence, she gave up her plan to go to a design school. After discharge, she tried to study as much as possible by adapting to her symptoms, which allowed her to gain confidence for studies and school. When she could not attend a physic class, she asked the teacher if there was anything else she could do. She said, “My teacher had told me to write a report.” She ended up getting a grade. She made plans with friends to go to a university. She took care of problems, had a positive attitude about her hair, and was supported by her friends in this regard. She explained, “When I had gone to school wearing a bandanna, people had looked at me as if I were strange, but I had gotten used to it.” Her classmates told her that her hair was beautiful and she was very glad about that. Furthermore, she never talked with her friends about her disease and experiences in the hospital because it would trouble them. Moreover, she had a better understanding about life and said, “ Just existence is the most important thing for me...I can do it in my own way.”

Case 3

A high school female student had been an outpatient for 1 year. In the first phase, after the diagnosis, she felt shocked and thought of death. However, she was relieved when her mother told her that she would recover. During the distraction phase, she developed a positive attitude and decided to undergo therapy. Her mother encouraged her to be committed to the therapy. Hence, she spent her time writing

letters and reading books but not studying. When she started losing hair, it was very hard for her. However, she did not worry because she knew her hair would grow back again. In the cognitive comfort phase, she hoped to recover as an inpatient, and go back to school and study as she neared discharge.

In the last phase, she coped with the hard time by thinking of going home at night during therapy. As discharge neared, she made a decision to shift to a school for handicapped children because the previous school did not agree with her reentry school. She had a positive thought toward studying and tried to catch up. After she neared discharge, she gained a positive attitude. She said that she was bothered by the side effects of medications and could not study enough, but she could live with the disease now because of the support from a teacher. At that time, the teacher had advised her not to study hard. Then, she connected with her friends and informed them about her disease. Her friends visited her house often. However, she did not talk to them about her cancer experience. She liked to talk to other survivors who might understand her. Also, she felt more knowledgeable about life and said that she had known a student who knew how many years he would live. She said, "I changed my mind... living is the most important thing." Despite understanding that she might die, she took care of herself and wanted to live longer.

Case 5

A male junior high school student was discharged about 13 months before. He was disappointed when informed about the diagnosis 7 months later. During the first

phase, when a doctor explained to him about his disease, he did not understand well. In the distraction phase, he had a positive attitude and thought about receiving therapy with parental support. He said, "If I don't fight, I will not get better... I will try my best." Letters from his friends and classmates also made him feel very happy. In the next phase, i.e., the near-discharge period, he hoped to recover as an inpatient and to play with friends and study in school. His hope continued after discharge, and school grades became his concern. In the personal competence phase, during therapy, he coped with the difficult situation by thinking of recovery. A physician helped him study in his room, but he had to stop studying when he felt sick. As he neared discharge, when his therapy was completed, he gained confidence. He felt that he had "done" it. His positive attitude allowed him to catch up on his studies after discharge. He also tried to take care of a problem that resulted when an older student pulled off his hat. He would go home crying, but his fellow students apologized later. Now, he did not wear a hat at school, and his friends were understanding.

Case 7

A male junior high school student was an outpatient for 9 months, and he received a poor result on a blood test. He did not talk much during the interview. In the cognitive discomfort phase, his mother persuaded him to undergo therapy. He was a bit shocked at the time of the diagnosis because of painful tests. In the distraction phase, he had a positive attitude and decided to undergo the therapy with support from his mother. When he felt well, he played games, which he had never done before.

Letters from classmates made him feel happy, and he wanted to go back to school. In the next phase, his hope as an inpatient was to play video games (Othello) with friends and not to relapse. As he neared discharge, the hope was to go back home, and then to school for playing with friends. His good attitude continued beyond discharge.

In the last phase, he had a positive attitude and said, "I just tried to think that it (the therapy) wasn't that bad." He studied in his room or in the hospital library as an inpatient. As he neared discharge, he was very happy to leave the hospital and go back to school. As an outpatient, he was careful when his friends asked him why he was wearing a hat. He talked with confidence and said, "Isn't it okay?" When he was enjoying himself at the table tennis club at school, the members made fun of him saying that he was weak. He told them to shut up. He gained a positive attitude and a purpose for the cancer. He was told that the SCT result was not a good prognosis, but he wanted to recover. His mother and he tried to contact cancer survivors who were in similar situations. He attended classes for a short time and said that he was not able to keep up with studies at all.

Case 9

A male high school student was an outpatient for 15 months. His parents had jobs and could not stay with him every day. In the first phase, when he was informed, he could not clearly understand the disease. His understanding was that he needed to spend a long time in the hospital. In the distraction phase, his mother stayed with him and had everyday conversations with him without mentioning much about the

illness. He had a positive attitude and said that when he felt too sick, he would think that the hard times would soon pass. He was able to bear it because of being with a nurse who became his friend. During the cognitive comfort phase, as an inpatient, his hope was to recover and study. As he neared discharge, he hoped to go back home and to school to meet his friends and continue his studies. He wanted to talk with his friends about his plans such as becoming a physician.

In the last phase, he was able to tolerate therapy because of a nurse who became his friend. He also tried to keep up with his studies, but sometimes he felt too sick. When he felt well, he would look after younger children. As he neared discharge, the possibility of discontinuation of friendship made him worry and he was scared of being alone at school. When he studied in the nurse's office, his friends came to see him, and this gave him a chance to keep friendships at school. After discharge, he aimed to study in the future. He put much effort into studies and wanted to take his studies to a higher level. His friends and he also talked about their futures, but not about his disease. He said, "The biggest part of the cancer experience was to spend a lot of time with and talk to adults." He gained confidence because he had been unable to talk that much before.

Relapse-experienced adolescents

Case 2

A female junior high school student had been discharged about 4 months ago. In the cognitive discomfort phase, she experienced thought stopping and thought

reflection. Apart from expressing shock, she showed other responses such as returning home without taking treatment after the diagnosis. She tried to promote positive thoughts in the distraction phase. She decided to receive the therapy and go home as soon as possible. Her mother supported her child by staying with her. Losing hair made her more positive by making her hope for normalcy. She had a better understanding of life and said, "Very short hair was the latest fashion." Her aim was to explore her musical talent in the future. She interacted with friends and had a good time playing games. She also talked about school and her purposes with friends, which created the experience of cognitive clutter. As an inpatient, in the cognitive comfort phase, she hoped of going back to school and taking dance lesson. She already had hope for discharge. During the near-discharge period, she was relieved that she would be going home soon and could forget about the cancer. Her hope was to go back to school and play with friends, which she did every day after discharge. However, she did not have hopes for recovery.

As an inpatient in the personal competence phase, she faced the cancer by committing to therapy and adapting to her symptoms. Because she felt there was nothing she could do about it, she was patient with painful procedures. She had confidence during the exhaustive phase of therapy. She took baths by herself because she wanted to. When she felt well, taking care of problems with a positive attitude made her willing to study hard to reach her purpose. Moreover, by connecting with close friends, she could talk about hospital and school life over the phone. Nearing discharge, she learned how to take care of herself by adapting to her symptoms. She

gained confidence when she was preparing to go back to school and insisted on going back to school. Her mother said that her doctor ordered her back to school 6 months later, but she negotiated with a physician to go back early. She and her friends made plans over the phone very often for her after-discharge period. She had a positive attitude and studied with purpose after discharge. She attended school and studied hard as much as possible because she did not want to miss any classes. When she felt tired in school, she rested in the health office. She also took dance lessons after school for developing her musical talent. Moreover, by connecting with friends and talking about her disease and its side effects, her friends frequently visited her to play. After the interview, she nodded when her mother said, “You can cope with any hard situation in the future, can’t you?” She had gained confidence.

Case 4

A male high school student had been an outpatient for 1 month. His prognosis became poor. In the cognitive discomfort phase, he was shocked when he heard about the relapse. In the distraction phase, he had a positive attitude and believed that he would never suffer from illnesses. He did not feel that he was in danger and said, “If I need a transplant, I will do it.” His purpose was to get out of the hospital. His mother stayed with him every day. His friends who talked to him about school through a glass window in a cream room to influenced him to go back to school. His purpose along with his friends helped him cope with cancer therapy and to have hope. In the cognitive comfort phase, as an inpatient, he hoped to never suffer from

illness, to study, and to talk with friends in school. Nearing discharge, he had the hope to graduate from high school along with his friends. After discharge, his hope was to recover completely, improve his studies, get a job, and to blend into the society.

By the personal competence phase, as an inpatient, when he felt well, he began to study with support from a counselor. He had a positive attitude and thought about his school life. He said that he had talked about so many things he could do with his junior high school friends after being an inpatient. However, he did not inform his friends. As he neared discharge, he gained confidence and said that he had slowly begun to think that he was recovering. He also said, "The therapy was difficult, but now that I look back on it... it wasn't that difficult." After discharge, he had a positive attitude and wanted to graduate from the high school with the support of his friends. His stomach hurt and his leg muscles were weak, so he practiced walking. It was difficult for him to go to school, so his friends visited him to help him with studies. Moreover, because of the poor result on his blood test, he had the purpose of receiving PSCTs again. When he signed the consent form, his mother said that she tried to think that his will was the most important factor.

Case 6

A male primary school student had been an outpatient for 1 year. In the cognitive discomfort phase, he thought hard about being in relapse. In the distraction phase, he had a positive attitude and confidence and felt no serious threat because of his previous experience when he was discharged after 7 months of therapy. Then, he said,

illness, to study, and to talk with friends in school. Nearing discharge, he had the hope to graduate from high school along with his friends. After discharge, his hope was to recover completely, improve his studies, get a job, and to blend into the society.

By the personal competence phase, as an inpatient, when he felt well, he began to study with support from a counselor. He had a positive attitude and thought about his school life. He said that he had talked about so many things he could do with his junior high school friends after being an inpatient. However, he did not inform his friends. As he neared discharge, he gained confidence and said that he had slowly begun to think that he was recovering. He also said, "The therapy was difficult, but now that I look back on it... it wasn't that difficult." After discharge, he had a positive attitude and wanted to graduate from the high school with the support of his friends. His stomach hurt and his leg muscles were weak, so he practiced walking. It was difficult for him to go to school, so his friends visited him to help him with studies. Moreover, because of the poor result on his blood test, he had the purpose of receiving PSCTs again. When he signed the consent form, his mother said that she tried to think that his will was the most important factor.

Case 6

A male primary school student had been an outpatient for 1 year. In the cognitive discomfort phase, he thought hard about being in relapse. In the distraction phase, he had a positive attitude and confidence and felt no serious threat because of his previous experience when he was discharged after 7 months of therapy. Then, he said,

“We (his mother and he) had a purpose for receiving the therapy... that we would fight until the blood test results were good.” He was faced with cancer therapy and spent time playing with a boy who was in a similar situation. In the next phase, as an inpatient, his hope was to study as much as possible and play with the boy. His hope as he neared discharge was to go home and back to school to meet classmates soon. After discharge, his hope was to study and play with friends.

In the personal competence phase, as an inpatient, his early purpose and hope led him to cope with the therapy and connect with a friend. He suffered through the radiation by thinking of playing and talking with his friends. He also studied when he felt well, but sometimes he had to give up his studies. Nearing discharge, he had a positive attitude and was happy about going back to school. He said that at first it had been difficult to be inside all the time. Therefore, he made plans to study and to play with friends all day long. Beyond discharge, his positive attitude helped him achieve hope with the support from his friends. He started attending school only in the mornings and rested in the afternoons. He also tried to connect with friends and asked them to help him with homework.

Case 8

A male junior high school student was an outpatient for 1 year. He did not talk much when he was in the hospital. In the first phase, he was shocked when informed that he could not go to school. During the distraction phase, he had a positive attitude and felt he could withstand cancer with his mother’s support. As an

illness, to study, and to talk with friends in school. Nearing discharge, he had the hope to graduate from high school along with his friends. After discharge, his hope was to recover completely, improve his studies, get a job, and to blend into the society.

By the personal competence phase, as an inpatient, when he felt well, he began to study with support from a counselor. He had a positive attitude and thought about his school life. He said that he had talked about so many things he could do with his junior high school friends after being an inpatient. However, he did not inform his friends. As he neared discharge, he gained confidence and said that he had slowly begun to think that he was recovering. He also said, “The therapy was difficult, but now that I look back on it... it wasn’t that difficult.” After discharge, he had a positive attitude and wanted to graduate from the high school with the support of his friends. His stomach hurt and his leg muscles were weak, so he practiced walking. It was difficult for him to go to school, so his friends visited him to help him with studies. Moreover, because of the poor result on his blood test, he had the purpose of receiving PSCTs again. When he signed the consent form, his mother said that she tried to think that his will was the most important factor.

Case 6

A male primary school student had been an outpatient for 1 year. In the cognitive discomfort phase, he thought hard about being in relapse. In the distraction phase, he had a positive attitude and confidence and felt no serious threat because of his previous experience when he was discharged after 7 months of therapy. Then, he said,

early impatient, his purpose was to go home for a night. During therapy, he spent time exchanging letters with friends. In the cognitive comfort phase, as an inpatient, he hoped about successful therapy and studies. Nearing discharge, he hoped to play baseball with teammates. After discharge, his hope was to play baseball with his teammates and not to relapse.

By the last phase, as an inpatient, letters and photos from classmates encouraged him to cope with therapy and study when he felt well. He also gained confidence after passing through the hard time. He said, "If I could go through this, I can go through anything." Nearing discharge, he prepared to go back to school. After discharge, he had a positive attitude and achieved his goal of playing baseball. To prepare for playing, he ran near a park every morning with all his family. He also gradually improved in his studies, and his best friends supported him. He said that when his friends would ask why he was wearing a hat, his best friend would ask them not to inquire. When asked about his disease, he answered truthfully because he wanted to be brave. He had a better understanding about life.

Differences in Categories

The findings of the above case studies suggested that the adolescents experienced the entire process from being an inpatient to an outpatient. They had hope and achieved competence in resolving health threats. By comparing data from the self-sustaining process, some differences were found in the categories. Three of the 9

illness, to study, and to talk with friends in school. Nearing discharge, he had the hope to graduate from high school along with his friends. After discharge, his hope was to recover completely, improve his studies, get a job, and to blend into the society.

By the personal competence phase, as an inpatient, when he felt well, he began to study with support from a counselor. He had a positive attitude and thought about his school life. He said that he had talked about so many things he could do with his junior high school friends after being an inpatient. However, he did not inform his friends. As he neared discharge, he gained confidence and said that he had slowly begun to think that he was recovering. He also said, "The therapy was difficult, but now that I look back on it... it wasn't that difficult." After discharge, he had a positive attitude and wanted to graduate from the high school with the support of his friends. His stomach hurt and his leg muscles were weak, so he practiced walking. It was difficult for him to go to school, so his friends visited him to help him with studies. Moreover, because of the poor result on his blood test, he had the purpose of receiving PSCTs again. When he signed the consent form, his mother said that she tried to think that his will was the most important factor.

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strategies fitted into the categories during the distraction phase . The rest of them, such as “It could always be worse,” “Made it this far,” “God will take care of me,” “Looking back,” “Knowledge of survivors,” and “Others have hope for me” did not fit in the categories. None of the patients forgot about their cancer during the cognitive comfort phase.

Differences in Subcategories

The adolescents had hope and achieved competence in resolving health threats from being an inpatient to an outpatient. There were differences in the subcategories, which are shown between the newly diagnosed and the relapse-experienced patients as they passed through the treatment process. For example, the subcategories included keywords of coping strategies such as shock, other responses, and recovery in the cognitive discomfort phase. The newly diagnosed patients hoped to recover as an inpatient, but others did not. On the other hand, the newly diagnosed patients did not use the coping strategies of school, but the relapse-experienced patients did. Compared to the relapse-experienced patients, the newly diagnosed patients did not interact with their friends in the hospital, even though they wanted to have friendships. A summary of the findings during the self-sustaining process for the newly diagnosed and the relapse-experienced patients is shown in Table 2.

Newly diagnosed adolescents

In the cognitive discomfort phase, they experienced a shock at the time of diagnosis, as they heard about their illness. Some of them thought of death and painful tests. In the distraction phase, as early inpatients, they were positive about the illness and decided to have therapy with support from their mothers, who too were positive about the illness. Two of the patients were positive about losing their hair, because it was explained that their hair would grow back. As inpatients, during the cognitive comfort phase, recovery was hopeful in all cases except for one where the patient was diagnosed with NHL and did not understand the disease clearly, and consequently became seriously ill. Not all patients had hopes of returning to school. They had hopes of studying, but the one who did not talk much was not hopeful about studies. As inpatients, they spent their time coping with the therapy and did not interact with their friends. Friends such as nurses supported them and spent time doing some activities with them. After the near discharge period, school, studies, and friends were their hope. During the personal competence phase, as an inpatient, the adolescents coped with the therapy and the side effects with a hope of recovery. They did not have the hope about going back to school, but tried to study at the hospital class; however, their studies were sometimes stopped because of the side effects. During the near discharge period, except for those who did not talk much, the patients resumed their studies in an effort to go back to school. The rest, even though they wanted to, did not interact with their friends during their hospital stay. As outpatients, the adolescents had friendships and studies as the reasons to go back to school. Their friends

supported them when they were teased about having less hair. However, some of them never interacted with their friends about their cancer and experiences in the hospital. Two of the patients attended classes for only a short period of time because of poor prognosis and the side effects.

Relapse-experienced adolescents

During the cognitive discomfort phase, the relapse-experienced patients wanted either to go home or to their school. During the distraction phase, their positive attitude allowed them to cope with the therapy and have a purpose to move out of the hospital. They had hopes of going back to school. They spent time in therapy and interacted with their best friends who encouraged them to cope with the therapy and study in order to go back to school. Their mothers also stayed with them or visited them every day. In the cognitive comfort phase, all patients except the one who did not express well, hoped to continue with their studies, school, and friends as inpatients and outpatients. The latter did not hope for school as an inpatient and for studies as an outpatient. During the near discharge period, while all hoped not to study, two expressed hope for recovery. One was given a poor prognosis and the other had hoped to play baseball with a team. Friendship was their hope as inpatients and outpatients. During the personal competence phase, patients coped with the therapy as inpatients. They studied and exchanged information about their school and hospital experience with their special friends. All of them thought about school, except the one who talked less. As they neared discharge, the adolescents were ready to go back to

school and connect with their friends. As outpatients, with support from their friends, they were hopeful of friendship, school, and studies. The patient with poor blood test results had a hard time studying as planned. Additionally, their mothers and families supported them in the hospital and after their discharge.

New Category

The new category of psychosocial strengths was identified for the period from early inpatient to outpatient. In certain circumstances, an individual may be made strong by unpleasant and potentially hazardous events.^{15,27} Resilient individuals have both strong internal and external protective factors to move forward.²⁷ “Protection may lie in the ‘steeling’ qualities”¹³ (p. 326) that are more likely to arise when people have to cope successfully with stress.^{13,15}

The psychosocial strengths consisted of positive attitude, purpose, connection with friends, confidence, and more understanding of life. Childhood survivors have high levels of self-esteem.²⁸ Self-esteem refers to the extent to which an individual has a positive or negative attitude towards himself or herself.³ Acceptance is characterized by listening to and gaining satisfaction from someone or something including others, the self, and the past and present situations. Acceptance and high self-esteem may lead to broader perspectives, activities, and purposes.²⁹ Characteristics of self-transcendence include a sense of connectedness with others, nature, and God; being healed; and having a purpose and meaning.²⁹ Adult survivors of childhood cancer tend

to express more positively and engage in close relationships.^{28,30} Confidence is a perception that one has control over events in the environment and this may help in lowering stress.^{3,31} The pediatric cancer survivors expressed themselves as more mature than their healthy peers. They felt themselves being more knowledgeable about life.^{20,30}

Differences between newly diagnosed adolescents and relapse-experienced adolescents

A difference was found between the newly diagnosed and the relapse-experienced patients during the development process of a new coping strategy. The newly diagnosed group had 3 types of patients and the relapse-experienced group revealed 2 types of patients. Compared to the newly diagnosed, the relapsed-experienced patients had their purpose during the early inpatient period and their strength of connection with friends during the inpatient period. A summary of the psychosocial strengths is shown in Table 3. Based on this, the development waves for the newly diagnosed and the relapse-experienced patients were made.

Newly diagnosed adolescents

Three types of developing psychosocial strengths were found from the distraction phase to the personal competence phase. Here, strengths developed individually as early or late and categorized as after the early inpatient period; during the inpatient period, but not nearing discharge; and in the near discharge period.

Strengths of the 5 factors developed gradually after discharge. Type 1 patient, as exemplified in Case 1, had a purpose for life in the early inpatient period. She explained, “I should not die.” It led her to have the purpose of recovery as an inpatient. In the near discharge period, the girl had a purpose of not falling behind in class and caught up with her studies with the support from a teacher. As an outpatient, this purpose led her to gain confidence and negotiate with her plans for studies, and she decided to go to a university. Getting used to losing hair was an example of her positive attitude, and she gained more understanding about life, saying, for instance, “Living was most important.”

Type 2 patients, as exemplified by Case 7, had a positive attitude towards no relapse during the early inpatient period. As an inpatient, the student had a positive attitude towards his illness and explained, “I just tried to think that it wasn’t bad.” He did not talk much about the near discharge period. When he was given a poor blood test result as an outpatient, he had a purpose of recovery. This positive attitude led him to decide to repeat the therapy. The student also gained confidence about being teased for wearing a hat. He said, “When my friends asked me why I was wearing a hat, I said ‘Isn’t it okay?’” Type 3 patients, exemplified by Cases 3, 5, and 9 had positive attitudes and coped with the therapy with the hope of recovery as an early inpatient. One of them developed the hope of recovery in the near discharge period. As they neared their discharge, they developed a positive attitude towards going back to school. They decided to go back to school and caught up with their studies. One of them gained confidence on finishing the therapy. As outpatients, each of them used a

variety of strengths: future purpose, connection with friends through visitors, and confidence in talking to adults. Living with cancer and catching up with studies were examples of a positive attitude. Additionally, one who had side effects explained, "...And I could not study enough...I can live with my disease now because of the support from my teacher." One of the patients gained more understanding of life and described that living was most important.

Relapse-experienced adolescents

After the distraction phase, two types of improving psychosocial strengths were found. The figure explains that strengths increased when the adolescents were early inpatients and continued to develop after discharge. In the distraction phase, Type 1 patients, as exemplified by Cases 2, 4, and 6, developed a positive attitude and a purpose of finishing the therapy. They thought that they would never be defeated and would recover through the therapy. One of them had a better understanding of life. She said, "Having very short hair is a fashion." They had a purpose, such as presenting their music talent, getting out of the hospital, going home, and getting a good blood test result. The younger patients showed a purpose with the support from their mothers.

The adolescents were hopeful in the personal competence phase. As inpatients, they connected with their friends by talking about their future and their illness. The friends influenced their positive attitude to cope with the therapy and to give them hopes to rejoin school. For instance, one of the patients coped with

radiation, because after finishing the therapy, he would talk and play with a friend who had a similar illness. Another patient, for example, developed confidence to face the future by playing baseball. During the near discharge period, they had a positive attitude and gained confidence. An example of a positive attitude was to make plans of going back to school all day long. Feeling good about the negotiation of plans for studies and cessation of therapy were examples of confidence. One of the patients said, "I can go through anything." As outpatients, they had a positive attitude about achieving their purposes. They began to take dance lessons after school, go to school only in the morning, run every morning near a park with their family, and ask friends for help. One of them had a new purpose of playing baseball in a club with teammates. Enjoying life and not blaming it for everything were explained by a better understanding of life. Coping with difficult situations was a cause for them to gain confidence. The one who received a poor prognosis made a new purpose of receiving PSCTs again. Type 2 patients, exemplified by Case 8, did not speak much during the interview. Therefore, as he neared discharge, no strengths were found because of limited information.

Development of psychosocial strengths

We found differences in the process of developing psychosocial strengths between the 2 groups. The development of psychosocial strengths is summarized and illustrated in Figure 2. The development process seemed to be unsteady in the newly

diagnosed adolescents. The psychosocial strengths developed individually as early or late. After an initial life-threatening period, a positive attitude gradually became important. The patients hoped for recovery through support from their mothers and spent their time coping with the therapy as inpatients. A positive attitude to cope with the therapy, a purpose, and confidence increased as inpatients, but it was difficult for them to have the hope of going back to school and they began to study as they neared discharge. Friendship was also a hope in the near discharge period, but was usually achieved as an outpatient. Even though they had friendship, some of them never spoke to their friends about their experiences in the hospital. They attended school and tried to have an adolescent's life as an outpatient.

The development of psychosocial strengths seemed to be steady in the relapse-experienced adolescents. As early inpatients, they did not feel positive about recovery, but became positive and developed the purpose of getting discharged. Their purpose helped them cope with the therapy, think about life after discharge, and study in order to go back to school. During the inpatient period, they interacted with their best friends who encouraged them to achieve their purpose. After discharge, they tried to achieve hope and purpose with their psychosocial strengths.

Discussion and Implications

This study explored the methods of enhancing resilience in adolescents with cancer. Psychosocial strengths may influence the resilience of the patients, and they

may gain strengths while experiencing the self-sustaining process. The strengths of positive attitude, purpose, connection with friends, confidence, and more understanding of life were the buffers for them to feel that they were leading quality of life.

The findings show that the development process seemed to be unsteady in the newly diagnosed patients. A positive attitude may lead them to have their hope for recovery and gain strengths in the future. On the other hand, the process appeared to be steady in the relapse-experienced patients. Purpose may be an important guide for them to connect with friends and cope with cancer, and may lead to improve their other strengths. To enhance resilience, 5 factors may be important for them at certain stages and to the individual with social support. As early inpatients, friends are important for the newly diagnosed adolescents, while emotional support is significant for the relapse-experienced adolescents. For them, their mothers and friends were considered the key persons. Additionally, a cultural variation between the US and Japan may be a cause of some of the differences in the categories.

Newly diagnosed adolescents

Positive attitude

Mothers, who had a positive attitude, may have been vital in helping their children to gain a positive attitude and hope. The mother's belief that cancer is not fatal may have been important for the development of strengths for the child. When the patients felt that their life was threatened during the initial period, they developed a

positive attitude towards the therapy with the support from their mothers. This led them to have a hope of recovery during the early phase, and helped them cope with the therapy and gain strengths to achieve hope and purpose after discharge. Mothers are the most significant source of emotional support for a child with cancer.^{19,25} Wong and Chan³³ found that Chinese parents of children with cancer initially react to the diagnosis with shock, denial, and worry. But they accept it as their fate in the short-term and develop hope for the future. This study also reported that the beliefs of Yuan, which originate from Buddhism, might help mothers in avoiding the feeling of guilt and interpersonal hostility.³³ A study showed that parents require support for coping strategies and for developing hope.³⁴ Nurses need to support mothers emotionally to help them be positive about their child's illness.

Hope of recovery

It was important for the adolescents to have a hope of recovery and return to a pre-cancer life. A positive attitude helped them cope with the therapy, have a hope of recovery, and prepare themselves to return to school and catch up with their studies during the near discharge period. Dealing with cancer forces the patients to return to their routine ways of life as quickly as possible.³⁵ In this study, most of the patients did not make plans to go back to school until they were outpatients. This may be because it was their first experience of cancer therapy, and they spent most of their time coping with the therapy. This may also have prevented them from the opportunities to interact with their friends. Adolescents with cancer are offered information regarding

their illness, treatment, and the side effects, but not regarding their future.³⁶ As early inpatients, information on the future was important for the newly diagnosed patients. Nurses need to focus on maintaining a social network of friends, emphasizing the importance of attending school, and talking about emotional concerns during the treatment of adolescents with cancer.

Friends

Peers and school are significant for normalcy of adolescents with cancer. A normal life with friends is important for their development.³⁷ In this study, friendships seemed to be an important factor helping them to have a normal life. The adolescents began to develop hopes of going back to school and to interact with their friends as the time of discharge came closer, but not enough to maintain healthy peer relationships. Even as outpatients, they tended not to express their cancer experiences openly to their friends. Friends encouraged them not only to go back to school and complete their studies but also to live a normal life. Their feeling of normalcy in school depended on their perception of how well they had kept up with their classmates and their studies and how they were being accepted by their peers.³⁸ They were affected by feelings of being different and isolated from their peers and by that of loss of interactions with the peers and their classmates.^{36,37,39,40} During cancer therapy, nurses should create such an environment, where patients can discuss their awkward situations and also the ways in which they can deal with them. Adolescents need an opportunity to discuss how

they felt about the changes in their body to help them deal with them. Encouragement for friends to contact peers with cancer as well as emotional support for mothers may be significant.

Adolescents having high levels of support from their parents tend to receive high levels of support from their friends as well.³² Parental support may enable the child to have good friendships. In this study, in some cases, the adolescents did not speak about their cancer experience to their friends in school, which may be considered as a cultural aspect. In Japan, almost two-thirds of the family members of children patients with cancer do not want the diagnosis to be discussed with the patient and the others.⁴¹ If mothers inform their children about the diagnosis, children may feel at ease to speak openly to their friends about their cancer experience. Studies on family resilience^{3,42,43} may help in encouraging mothers to disclose their child's disease.

Relapse-Experienced Adolescents

Purpose

Having a purpose seemed to be important for them to gain strengths later. Most of the adolescents had a purpose as early inpatients. The purpose may have been gained from their previous experience of cancer, which included the feeling of uncertainty and denial. A relapse of disease causes great anxiety because of negative memories; however, adolescents who have relapsed successfully cope with cancer and

have strong experiences that build strengths.¹⁵ They may have felt uncertainty about their future when informed of the relapse, and this feeling may have negatively influenced their hope, social support, quality of life, and resilience.^{7,10} Some studies have described coping strategies for uncertainty that include social support, opportunities to express feelings,⁴⁴ feeling of certainty, escape from worry about the future, and acceptance of what is not in their control.⁴⁵ Getting used to cancer with time, gaining experience, and being flexible are also some of the coping strategies that lead to a sense of normalcy.⁴⁶ However, stress with uncertainty may not always be completely negative. Certainty is decreased when the family's sense of hope is lowered and the joy of good times is taken away.⁴⁷ Researchers reported that maintaining a sense of normalcy and a balance between hope and uncertainty are important. Moreover, families feel positive if the child looks well, and is normal and happy.⁴⁸ For the adolescents and their mothers, nurses provided hopeful messages and encouraged them to believe that a cure was still possible, thus, helping them to cope with their fears and uncertainties. Open communication about the patient's hopes and fears, and the offer of social support should also be encouraged. Additionally, protective denial helps the adolescents obtain hope to balance negative illness with positive hope. Patients focus less on the seriousness of their illness and more on their health and life goals.⁴⁹ Nurses should provide emotional support to the adolescents to have a purpose by showing an understanding of their uncertainty and denial.

Special Friends

Special friends may be important to encourage them for achieving a purpose, and be a major help for them to maintain their school life. As early inpatients, the adolescents connected with their special friends and developed the hope of resuming school with their support. Guidance to studies and going back to school became the major reasons for coping with cancer therapy. During the near discharge period, having friendships seemed to be more important than to study. Social support is a protective factor that influences resilience in adolescents with cancer.^{3,7,8} Parents, relatives, and teachers are good sources of support; however, friends offer significant support for sharing their experiences.³⁶ Adolescents with cancer can maintain a normal life by having pre-cancer relationships with their friends who help them inform about their condition, deal with their different feelings, and keep up with schoolwork and activities.

Self-Sustaining Process

Adolescents gained strengths through the self-sustaining process, but some of the categories did not fit for the distraction and cognitive comfort phase. We suggest that cultural differences are observed in the strategies for removing disturbing thoughts and gaining a positive attitude between the United States and Japan. Research states that since most samples involve the adolescents who are White and non-Hispanic, the

influence of culture on resilience is unknown. Careful attention needs to be directed towards sampling.⁸ Further studies are needed to determine how culture affects resilience.

Limitations

There were several limitations to this study. The limited interview time and techniques might have affected the data. When outpatients relayed their inpatient experiences, their poor recall might have also been a cause of inaccuracy. Besides, data were collected while the subjects were waiting for a blood test result. Anxiety may have therefore affected the accuracy of the information. Moreover, teenagers often feel shy to disclose intimate information. Additionally, the self-sustaining process focuses only on adolescents with cancer; hence, family perspectives are also needed for childhood cancer care.⁶

Conclusion

This study explored the methods of enhancing resilience in adolescents with cancer using the self-sustaining process. Patients developed psychosocial strengths by achieving hope and purpose during the self-sustaining process. Equipping nurses to manage individual care for the adolescents has the potential to improve their strengths

and enhance resilience. Furthermore, emotional support from their mothers and encouragement from their friends were valuable. Further studies are still needed to determine the methods of enhancing resilience in adolescent survivors and in those with a poor prognosis of quality of life. The results of these studies will help adolescents with cancer to enhance their resilience and quality of life.

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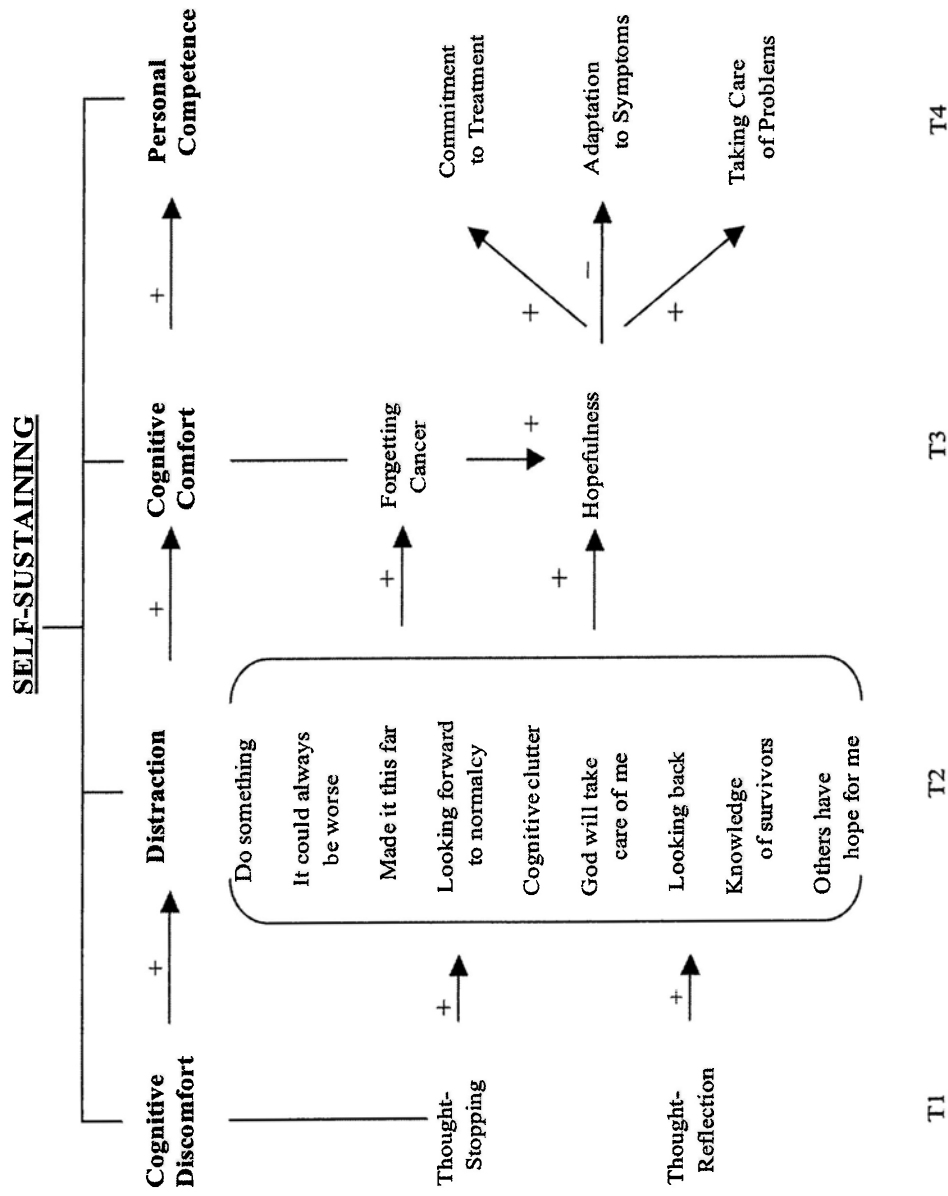
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Figure 1. The Substantive Theory: Categories, core concepts, and the central organized construct



T1, T2, T3, and T4 indicate time frames. Movement through the process and positive relationships are indicated by a plus sign. (Adapted with permission from Hinds and Martin, 1988).

Table 1. Self-Sustaining Process in Adolescents With Cancer (Case 1)

Stages	Core Categories		
	Cognitive Discomfort	Distraction	Cognitive Comfort
Inpatient	<p>I felt nothing about cancer. (2)</p> <p>A change in my blood type shocked me. (2,15)</p> <p>I worried about SCT, but I was relieved as I heard about good prognosis with it from a doctor. (2,18,28)</p>	<p>I played games with a nursing student. (3,22,27)</p> <p>When I was told about falling my hair fall, I cried and didn't want to get my therapy. Mother said that she would buy a pretty hat for me. (6,26)</p> <p>I was relieved when my hair grew again. (6,18)</p>	<p>I wanted to study. One of my friends sent her lecture notes to me. (11,21,27)</p>
Near discharge			<p>Personal Competence</p> <p>My parents told me that I should not go to a design school because of the hard programs, so I decided to go to a regular high school. (14,23,26)</p> <p>I asked a teacher what kind of study guidebooks were useful. (14,15,20,29)</p> <p>I studied English as hard as possible by myself. I didn't want to be behind in my class. (14,15,20,21)</p>
Outpatient			<p>When I went to school without the bandana, my classmates said that my hair was beautiful. (14,22,27)</p> <p>I asked a phys-ed teacher if there was something I could do. He said that I could write a report. (14,15,20,29)</p> <p>People looked at my bandanna as if I were strange, but I was getting used to it. (13,14)</p> <p>I never talked with my friends about my disease and experiences in the hospital because it would trouble them. I was glad that they didn't ask me about my disease. (14,23,27)</p> <p>After having my cancer, just existing is the most important thing for me. I don't care if I do something slower than others do. It is ok. I can do it in my way. (14,15,23,24)</p> <p>I decided to go to an university which had not hard programs. (14,21,23)</p>

Categories: 1, thought-stopping; 2, thought-reflection; 3, do something; 4, it could always be worse; 5, made it this far; 6, looking forward to normalcy; 7, cognitive clutter; 8, knowledge of survivors; 9, others have hope for me; 10, forgetting; 11, hopefulness; 12, commitment to treatment; 13, adaptation to symptoms; 14, taking care of problems; 15, shock; 16, other response; 17, recovery; 18, positive thinking; 19, purposes; 20, school; 21, studies; 22, friendships; 23, living with cancer; 24, cope with therapy; 25, psychosocial strength; 26, family; 27, friends; 28, health care professionals; 29, teachers; 30, other people.

Table 1. Continued. (Case 2)

Stages	Core Categories			
	Cognitive Discomfort	Distraction	Cognitive Comfort	Personal Competence
Inpatient	I wanted to leave the hospital as soon as possible.(2,16)	I thought about my purpose and the activities I wanted to do after discharge. It was ok because it will grow again. Very shor hair is the fashion. (6,18,19) I spent free time talking to friends and nurses, watching films, and reading cartoons. (3,11,22,27)	I had a dream in the future to be a music talent.(11) There was a school I want to go to. 11,22) I studied because I want to do it.(11,21) I wanted to talk to my friends about school by phone. (11,22,27)	I had painful procedures, but I could be patient because I could do nothing about it. (12,24,25) I took care of myself as much as I could... I went to the bathroom by myself during BMT (exhaustive phase in the therapy). My mother and aunt stayed with me during the therapy. (13,14,24,25,27) I used hats and artificial hair when I lost my hair. (14,23,26) I told about my disease to my friends. (14,23,27) I studied as I was alone to go to the school (in a single room and getting therapy),(14,20,23) I listened to music when I had a hard time (during a hard time). (13,24) I talked about school and me with friends by phone. (21,23,28)
Near discharge		I felt that my condition would be better at home (10,26) I wanted to go to school and to play soon. (11,20,21)	(Mother said) a doctor ordered my child to go back to school 6 months later, but my child negotiated with a physician to go to school early. (14,23,25,28) I often called to my friends and talked about out plan for after discharge. They will visit to my house. (13,22)	
Outpatient		I want to go to school and study every day.(11,20,21) I want to play a lot with my friends in the amusement park. (11,22,27) I want to take a private dance lesson. (11,19)	I go to school with my wig.(14,23) I don't mind if I go to the outpatient clinic, but I wish I could go there on Saturday (She did not want to miss classes). (12,23,25) My mother takes me to school by car everyday. (13,23,26) I use the health office in school when I feel tired.(13,14,23,28) I don't need to participate in physical activities in school. (14,23,29) I don't talk with my classmates about cancer experiences in the hospital. (14,23,25,27) Mother said, "you can cope with any hard situation in future, can't you" (I nodded). (14,25) I take dance lessons after school.(14,19) My friends come to my house. (13,22,27)	

1, thought-stopping; 2, thought-reflection; 3, do something; 4, it could always be worse; 5, made it this far; 6, looking forward to normalcy; 7, cognitive clutter; 8, knowledge of survivors; 9, others have hope for me; 10, forgetting; 11, hopefulness; 12, commitment to treatment; 13, adaptation to symptoms; 14, taking care of problems; 15, shock; 16, other response; 17, recovery; 18, positive thinking; 19, purposes; 20, school; 21, studies; 22, friendships; 23, living with cancer; 24, cope with therapy; 25, psychosocial strength; 26, family; 27, friends; 28, health care professionals; 29, teachers; 30, other people.

Table 2. Summary of Self-Sustaining Process in Newly Diagnosed and Relapse-Experienced Adolescents

Core Categories	Stages	Categories	Subcategories	Newly Diagnosed								Relapse-Experienced						
				1	2	3	4	5	6	7	8	9	10	11	12			
Cognitive Discomfort	Diagnosis	Thought stopping	Shock	+		+		+		+		+		+		+		+
		Thought reflection	Other responses	+		+		+		+		+		+		+		+
Distraction	Early inpatient	Do something	Recovery	+		+		+		+		+		+		+		+
		Looking forward to normalcy	Friendship	+		+		+		+		+		+		+		+
		Cognitive clutter	Losing hair	+		+		+		+		+		+		+		+
		*Psychosocial strengths	Receiving therapy	+		+		+		+		+		+		+		+
Cognitive Comfort	Inpatient	Hopefulness	Recovery	+		+		+		+		+		+		+		+
			School	+		+		+		+		+		+		+		+
Personal-Competence	Near discharge	Hopefulness	Studies	+		+		+		+		+		+		+		+
			Friendship	+		+		+		+		+		+		+		+
			Recovery	+		+		+		+		+		+		+		+
			School	+		+		+		+		+		+		+		+
Personal-Competence	Outpatient	Hopefulness	Studies	+		+		+		+		+		+		+		+
			Friendship	+		+		+		+		+		+		+		+
			Recovery	+		+		+		+		+		+		+		+
			School	+		+		+		+		+		+		+		+
Personal-Competence	Inpatient	Commitment to treatment	Friendship	+		+		+		+		+		+		+		+
		Adaptation to symptoms	School	+		+		+		+		+		+		+		+
		Taking care of problems	Studies	(+)		+		(+)		+		(+)		+		(+)		+
			Friendship	+		+		+		+		+		+		+		+
Personal-Competence	Near discharge	*Psychosocial strengths	Cope with therapy	+		+		+		+		+		+		+		+
		Adaptation to symptoms	School	+		+		+		+		+		+		+		+
		Taking care of problems	Studies	+		+		+		+		+		+		+		+
			Friendship	+		+		+		+		+		+		+		+
Personal-Competence	Outpatient	*Psychosocial strengths	Friendship	+		+		+		+		+		+		+		+
		Adaptation to symptoms	School	+		+		+		+		+		+		+		+
		Taking care of problems	Studies	+		+		+		+		+		+		+		+
			Friendship	+		+		+		+		+		+		+		+

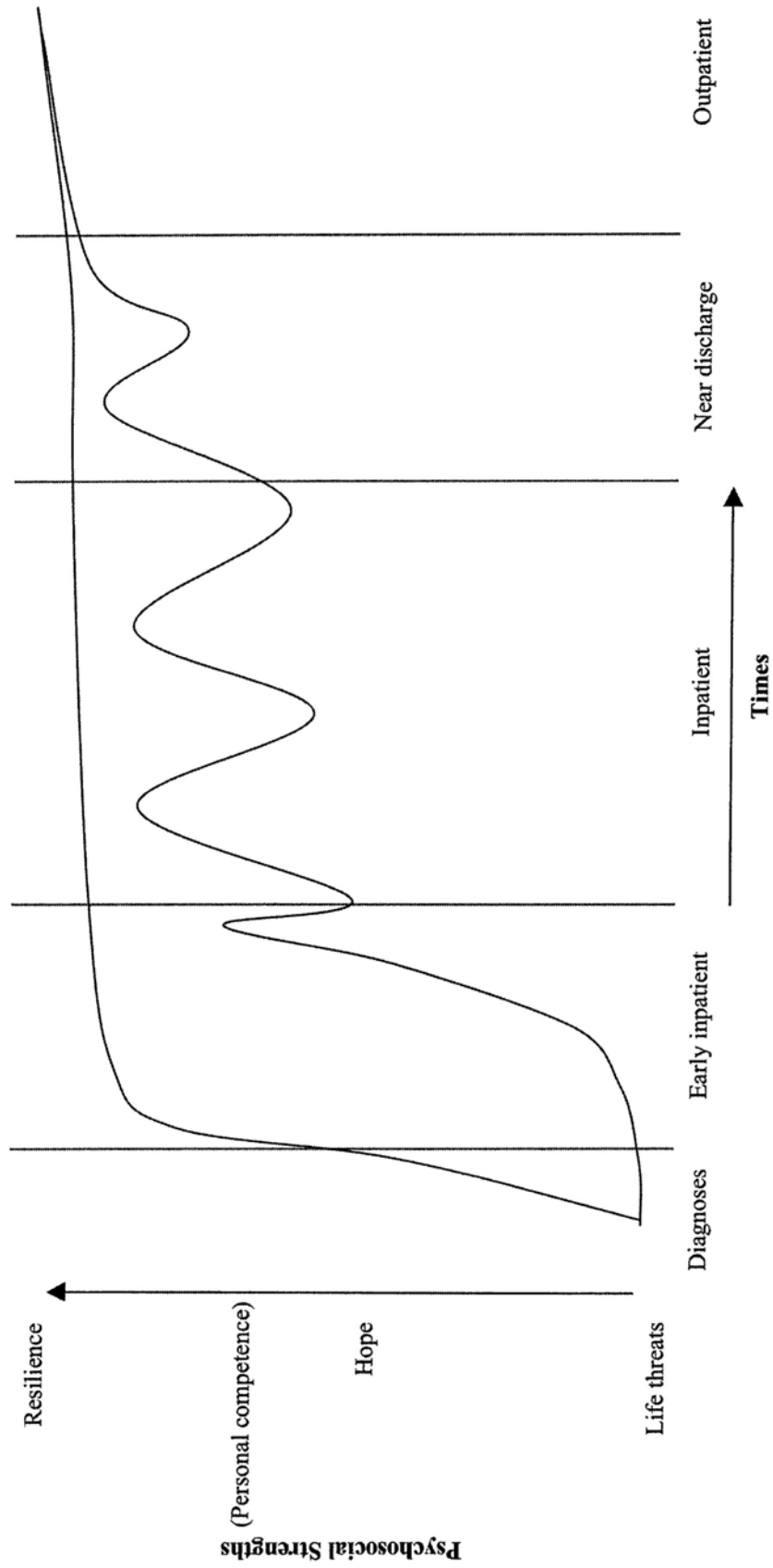
Note: Studies = The adolescents studied with their strong will; + = The adolescent had the same experiences as the key words of the subcategories; (+) = The adolescents gave up study sometimes because of side effects; {+} = The adolescents did not talk about their cancer experiences to their friends; *Psychosocial strengths = It is a new category and defined as both strong internal and external protective factors to move forward that resilience individuals have (Rutter 1985).

Table 3. Psychosocial Strengths in Newly Diagnosed and Relapse-Experienced Adolescents

Core Categories	Stages	Subcategories	Newly Diagnosed						Relapse-Experienced										
			1	3	5	7	9	2	4	6	8								
Cognitive discomfort	Early inpatient	Purposes	+																
		Positive attitude	▲+	▲+	+	▲+	☆+				+	+	▲+	▲+	▲+	▲+	▲+	+	
		More knowledge of life																	
Cognitive comfort	Inpatient	Purposes	+																
		Purposes	+																
		Positive attitude					+												
Personal competence	Near discharge	Connection with friends																	
		Confidence	+																
		Purposes	+																
Personal competence	Outpatient	Positive attitude																	
		Confidence	+																
		Purposes	+																
Personal competence	Outpatient	Positive attitude	★+	★+	+	+	+	+											
		Connection with friends																	
		Confidence	☆+	☆+															
Personal competence	Outpatient	More knowledge of life	+	★+															
		Purposes	+																
		Positive attitude	+																

Note: + = experiences of the same subcategories; ▲ = mothers; ★ = friends; ☆ = others.

Figure 4. Waves of Developing Psychosocial Strengths in Newly Diagnosed and Relapse-Experienced Adolescents



NDA = Newly Diagnosed Adolescents; REA = Relapse-Experienced Adolescents

NDA: From an initial period of life threats, the strengths gradually peak in the inpatient. However, the peak line becomes unstable from the inpatient to the near discharge. The strengths gradually develop after the discharge. REA: From life threats, the strengths rapidly increased in the early inpatient and gradually develop after the discharge.

How do we enhance resilience in childhood cancer patient for their future:

Focused on survivors

Akiko ishibashi, Masayo Uchida, Jun Okamura, Junko Ogawa

(An extension of a previous study in adolescent with cancer to explore methods of developing resilience in adolescent survivors of childhood cancer)

Introduction

Resilience in adolescents with cancer helps them to be more positive about their lives. The current 5-year survival estimates are greater than 80% for children with cancer (Rowland & Bellizzi, 2008). The Institute of Medicine Survivorship provides six recommendations for health care policy and practice (Hewitt, M., Weiner, S. L., & Simone, J.V., 2003). These include the themes: evidence-based guidelines; follow-up care; developing standards and models of care; increasing awareness of late effects and required follow-up care; improving professional education and training; improving access to care for survivors; and increasing research to prevent or manage late effects. The Adolescent Resilience Model has been developed as a guide for psychosocial interventions in adolescents with cancer (Haase, 2004). In Japan, follow-up is required to assess the late effects of cancer, such as psychosocial problems

caused by not telling others about the diagnosis (Naraya et al, 2004), and to determine how effective the social environment was for adolescents with cancer and their parents (Okuyama et al, 2009).

Literature Review

Mullan (1985) defined the survivor life as “seasons for a survivor” and divided it into acute, extended, and permanent phases. Feeling of fear and anxiety were constantly present during the acute survival phase. In the extended survival phase, the life of a survivor begins to return to normal as it was before the diagnosis of cancer. It is important to recognize that the long-term and late effects occur in the permanent survival phase. Rowland et al (2001) described that the family is seen as the secondary survivor. Nurses need to learn more about survivorship (Shepherd & Woodgate, 2010) and effective models of care are required to reduce the complexity and cost of follow-up care (Ruccione, 2009). In addition, Ruccione (2009) described that nurses need effective methods to educate survivors in order to promote behaviors that will help them sustain themselves over time. Some nursing interventions for the positive outcomes in survivors have been reported. Cantrell and Conte (2008) reported an intervention for improving hope in young female survivors of childhood cancer. A Hope Intervention Program using a Web-based design was conducted. The outcomes from a pilot study of coping skills training for adolescent and young adult survivors of childhood cancer and their parents (Santacroce et al., 2010).

Purpose

The purpose of this study was to explore how to enhance resilience in adolescent survivors of childhood cancer and to create support in helping them achieve an improved quality of life. The method used in the previous study was applied in the present study.

Methods

A case study research method was used along with semi-structured interviews. Pattern-matching logic using a 4-stage Self-Sustaining Process model of Hinds and Martin (1988) was applied to arrive at a comparative analysis. The Weekes and Kagan (1994) semi-structured interview guide was used in this study. In addition, a social network map that was modified the Five Field Map (Samuelsson, Thernlund, & Ringström, 1996) was used to analyse self-esteem and social support.

Participants

Participants were included in the study based on the criteria that they were survivors of childhood cancer, were aged between 12 and 30 years, and had been outpatients for over 1 year. Initially, nine participants and their mothers were involved. Because two adolescents had been outpatients for less than 1 year, the final number of

participants was seven. Participants included five males and two females, aged 12–24 years. The survivors' diagnoses included acute lymphoblastic leukemia (n = 5), acute myelogenous leukemia (n = 1), and non-Hodgkin's lymphoma (n = 1). The time since diagnosis ranged from 1 to 14 years. Two respondents had had a relapse since the original diagnosis, whereas five were newly diagnosed.

Data collection

After approval from the Institutional Review Board, we obtained the permission to work with adolescent groups from the administrators and chief oncologists of one agency located in the north of Japan. Physicians in the hematology/oncology clinic identified potential participants from an appointment list. Seven survivors and their mothers agreed to meet the researchers, and after a detailed description of the study, signed the written informed consent form.

Semi-structured interviews (with the guide) were used to elicit ways of enhancing resilience through the self-sustaining process. Questions were principally aimed at the outpatient period to know more about the survivors' lives. These interviews were conducted in person, audio taped by the same researcher, and then transcribed verbatim. The interviews, which lasted between 30 and 50 minutes, were conducted while the survivors were waiting for the results of a blood test. As other people also influence the lives of adolescents with cancer in the self-sustaining process (Hinds & Martin, 1988), all survivors were asked about support received from family,

friends, teachers, and healthcare professionals. Demographic and health information was obtained from medical charts. Data were collected for the period between 2007 and 2008.

Data analysis

Transcribed interview data were used for analysis. Each interview was coded for themes over five days by the investigators. Data were analyzed to compare with the self-sustaining process. First, data were separated into three periods: inpatient (including early inpatient), near discharge, and outpatient. Second, data in each period were grouped based on core phases such as cognitive discomfort, distraction, cognitive comfort, and personal competence. Third, data in the core phases were classified into categories of thought stopping, thought reflection, engaged in doing some activity, and so on. Finally, data in each category were grouped into subcategories using coded keywords, for example, shock and recovery in the early inpatient. In addition, five areas of social support were identified: friends, family, healthcare professionals, teachers, and others. The grouping and coding of data were checked closely by four researchers using the same process. These analytic processes were replicated for all cases. Data that did not fit the categories and subcategories were also identified.

Results and Discussion

By comparing data with the self-sustaining process (Table 4), the findings were found to be similar to the previous observations in terms of psychosocial strengths in the present study (Table 5). These consist of positive attitude, purpose in life, connecting with friends, confidence, and a greater understanding of life. Social support was also similar to that seen in the previous study. All the survivors received support from their mothers, friends, teachers, healthcare professionals, or volunteers from the inpatient to the outpatient periods.

The survivors' resilience seems to depend on telling the diagnosis to their friends and having a purpose in life. Some similarities and differences were found on contrasting the two themes. Survivors who were newly diagnosed and who had experienced relapse were also compared based on the criteria of the themes.

Telling others about the diagnosis

Reasons of informing friends of their diagnosis revealed a difference between survivors who were newly diagnosed and those who had relapse. Of seven participants, five informed their friends about their diagnosis. The newly diagnosed group seemed to provide the information so as to make their friends aware after discharge and to have a good school life. For example, one of the newly diagnosed survivors informed his friends when they asked him why he wore a hat.

Two participants had told their diagnoses before being asked because they did not want to be looked a stranger with no hair. Their friends and teachers supported them in their attempts to return to a normal life. One survivor, for example, was told by his friend, “You have kept up well despite this illness, haven’t you?” This kind of support gave him the confidence to continue to study. Some survivors could continue to enjoy school or play baseball with club members with adequate guidance and support from their teachers. On the other hand, the other two subjects gave information only to friends who had known about their diagnosis. They informed their closest extant friends to connect with them openly. For example, one participant maintained friendships from his last hospitalization so that he could inform his friends of his progress. The friends visited and telephoned so that he could enjoy a normal life and talked about school. They were able to share their experiences and feelings regarding cancer with their friends.

The reasons for telling others of the diagnosis in the two groups were different, but all participants seemed to have tried their best to achieve a purpose in life by disclosing the diagnosis. However, two survivors who did not inform their friends did not seem to have good friendships. For example, one of them quit club activities because of feel of weak. By continuing to conduct this study, we can determine whether these participants to develop good friendships and whether them telling their friends about the diagnosis is related to their purpose in returning to school life.

Purpose

This finding was seen as all survivors seemed to have a purpose for normalization. For example, five of the seven participants who informed their friends of their conditions had the intention of catching up their studies and returning to lead a normal healthy and social life. On the other hand, those patients who did not tell their friends expressed their intended purpose as achieving a good body condition and finding a job.

We found differences in the stated purpose between the survivors who informed their friends and those who did not (Figure 3). Of five patients, those who were newly diagnosed (one patient) and relapsed (two patients) had informed friends and had stated the purpose of doing something to help people. The ways in which they wanted to help people seemed to vary. For example, a 12-year-old, newly diagnosed survivor for 3 years said, "I want to help people (who have the same experience of cancer). I think I can understand their problems and encourage them." Of the other two, one who was 23-years-old and a survivor for 5 years, expressed that he wanted to get a job that involved doing something for people. The other patient, 24 years of age and a survivor of 11 years, wanted to be a healthcare professional to care for sick people. These patients also had good friendships and seemed to have developed psychosocial strengths. According to Parry and Chesler (2005), the experience of cancer may help

survivors to develop compassion and empathy for others. These researchers also described that a purpose in life seemed to relate to survivors' ability to find resolution with the meaning of their cancer.

Two of the three newly diagnosed patients who did not inform others of their condition did not mention helping people. They wanted their height and weight to develop properly, to get a job, and have a quality adulthood. We need to further study if a relationship between the stated purpose and the disclosure of the diagnosis, and the experience of relapse, ages of survivors, or the duration of survival exists.

The survey seemed that there is an interaction between self-esteem and social support in adolescents with cancer. Also, the mothers' self-esteem and social support seemed to have an effect on their child.

Implications

In the previous study, adolescents with cancer improved psychosocial strengths such as positive attitude, purpose of life, connecting with friends, confidence, and developed a greater understanding of life from the time of diagnosis to one year after discharge.

Differences in the development of strengths were seen between newly diagnosed adolescents and those that experienced relapse. The newly diagnosed patients hoped for recovery through support from their mothers and spent their time coping with therapy. However, it was difficult as inpatients to have the hope of going

back to school and to maintain friendships, and they began to study and connect with friends as they approached discharge. Although they had good friendship, some of them never spoke to their friends about their experiences in the hospital. The adolescents who had experienced relapse could develop the purpose that they could discharge as early inpatients. They interacted with those friends they had previously informed, and who encouraged them to achieve their purpose. Their purpose in life helped them cope with the therapy and study in order to go back to school. After discharge, they tried to achieve hope and purpose, and connected with old friends. However, they may continue to feel uncertain due to a possible recurrent relapse. During the inpatient period, friendship was needed in the newly diagnosed adolescents in order to have a good school life. Further, emotional support was also needed for the others to deal with the uncertainty.

After discharge, in this study, improving resilience seemed to depend on whether or not they informed their friends of the diagnosis. The survivors who inform about their diagnosis to friends seemed to have good friendships and a purpose in life. However, some newly diagnosed patients did not inform, in order to make friendships. Their situation seemed to persist after discharge. Encouraging survivors to tell their diagnosis to friends is important in order to have a good life, good friendship, and a good purpose in life. Healthcare professionals may be concerned that telling about diagnosis to friends is important for the survivors. A warm class environment is also needed for the survivors to encourage informing. Nurses could encourage not only the survivors to inform their friends but can also request their mothers and friends to

provide support. To enhance resilience of adolescents with cancer, mothers and friends are considered key people for emotional support and to help them live a normal life.

A portfolio, one of the interventions, may be useful as a guide about how to develop their purpose in life. With the portfolio, survivors need to set a goal and move towards the goal with purpose of resolving the problem. This can be used with individuals or groups, such as people who have the same situation, family, and so on. This may also be helpful for survivors who cannot tell others of their diagnosis to help improve friendships.

Limitations

There were several limitations to this study. Limited sample size, limited interview time, and methods used might have affected the data. When survivors relayed their inpatient experiences, their poor recall might have also been a cause of inaccuracy. Moreover, teenagers often feel shy about disclosing intimate information. In addition, the self-sustaining process focuses only on adolescents with cancer, and family perspectives are also needed for childhood cancer care.

Conclusion

This study explored ways to enhance resilience in adolescent survivors of cancer. Survivors may develop psychosocial strengths by telling friends about their diagnosis and achieving a purpose in their lives. Equipping nurses to manage individual care of survivors has the potential to improve patients' strengths and enhance resilience. Further study is needed in order to understand and support those survivors who did not tell others of their diagnosis.

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Table 4 Summary of Self-Sustaining Processes with Categories and Subcategories in Survivors

Core Categories	Stages	Categories	Subcategories	Newly Diagnosed								Relapse-Experienced		
				1	3	4	5	6	2	8				
Cognitive Discomfort	Diagnosis	Thought stopping	Shock/		+									
		Thought reflection	Other responses		+						+		+	
Distraction	Early inpatient	Recovery	Recovery											
		Do something	Friendship		+								+	
		Looking forward to normalcy	Losing hair											+
		Cognitive clutter	Receiving therapy										+	+
Cognitive Comfort	Inpatient	Strengths												
		Forgetting cancer	Recovery											+
Comfort	Discharge	Hopefulness	School											+
		Hopefulness	Studies											+
Personal-Competence	Near	Forgetting cancer	Friendship											+
		Hopefulness	Recovery											
Outpatient	Outpatient	Forgetting cancer	Recovery											+
		Hopefulness	School											
Inpatient	Inpatient	Commitment to treatment	Studies											+
		Adaptation to symptoms	Friendship											
Near	Discharge	Taking care of problems	Cope with therapy											+
		Strengths	Response to difficulties											
Outpatient	Outpatient	Commitment to treatment	School											+
		Adaptation to symptoms	Studies											
Inpatient	Inpatient	Taking care of problems	Friendship											+
		Strengths	Response to difficulties											
Outpatient	Outpatient	Commitment to treatment	School											+
		Adaptation to symptoms	Studies											
Near	Discharge	Taking care of problems	Friendship											+
		Strengths	Response to difficulties											
Outpatient	Outpatient	Commitment to treatment	School											+
		Adaptation to symptoms	Studies											
Inpatient	Inpatient	Taking care of problems	Friendship											+
		Strengths	Response to difficulties											

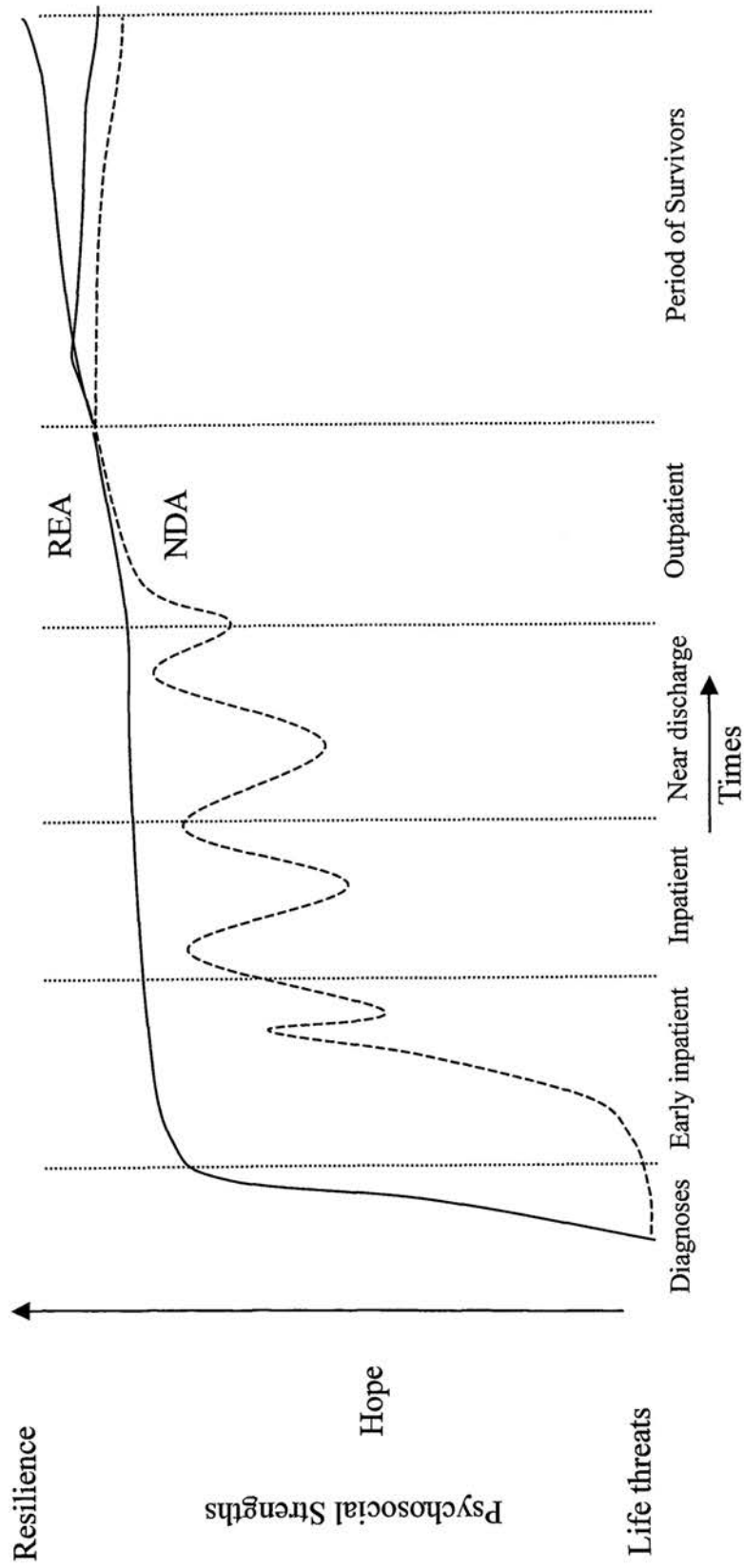
Studies = the adolescents study willingly; + = adolescent experienced the same subcategories; (+) = the adolescents gave up study sometimes because of the side effect.; {+} = adolescent did not talk about experience in the hospital to friends; Strengths and purpose were not included in the Self-Sustaining Process.

Table 5 Strengths in Survivors Who were the Newly Diagnosed and had Expeirnced Relapse

Core Categories	Stages	Subcategories	Newly Diagnosed									Relapsed			
			1	3	4	5	6	7	8	2	9				
Cognitive discomfort	Early inpatient	Purposes													
		Positive attitude				+									+
Cognitive discomfort	Inpatient	More knowledge of life													
		Purposes													
Personal competence	Inpatient	Purposes			+	+▲★	+							+	
		Positive attitude			+★	+	+★							+★	
		Connecting with friends													+★
		Confidence													+★
Near discharge		Purposes													
		Positive attitude													+
		Confidence													+
Outpatient		Purposes			+	+	+								+
		Positive attitude			+	+	+★								+▲★
		Connecting with friends			+★	+★	+★								+★
		Confidence													+★
More knowledge of life		Confidence													+
		More knowledge of life													+★

+ = experiences of the same subcategories; ▲ = with mother' support; △=with father; ★ = with friends' support; ☆ = with others' support.

Figure 3 Waves of Developing Psychosocial Strengths in Adolescent Survivors



NDA = Newly Diagnosed Adolescents; REA = Relapse-Experienced Adolescents; ID = Informed Diagnosis; No Informed Diagnosis

NDA: From an initial period of life threats, the strengths gradually peak in the inpatient. However, the peak line becomes unstable from the inpatient to the near discharge. The strengths gradually develop after the discharge. The strengths seem to gradually decrease in survivor's stage. REA: From life threats, the strengths rapidly increased in the early inpatient and gradually develop after the discharge. The strengths seem to increase and decrease in survivor's stage.

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