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Resilience in adolescents with cancer

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Children and adolescents with cancer experience multiple stressors, nevertheless some function well or are “resilient.” Focusing on resilience in childhood cancer patients and understanding why and how resilience develops during the cancer experience is of great value. This knowledge may provide information to health care professionals to facilitate intervention for promoting resilience and improving quality of life in adolescents with cancer. The purpose of this article is to review the literature and to develop conceptual understanding related to resilience in adolescents with cancer. The literature review includes the history of resilience in childhood cancer patients, resilience as defined by Rutter, and a resilience model of adolescents with cancer. Also, coping strategies for hospitalization, coping strategies for cancer, and the self-sustaining process in adolescents with cancer are presented. The results of the literature review suggest that Hinds and Martin's the self-sustaining process is an useful model for understanding why and how adolescents with cancer develop their resilience. This model should also be focused on not only the developmental stages but also the cultural differences such as telling the name of disease and the length of hospitalization.

Key words : Children, Adolescents, Cancer, Hospitalization, Stressors, Resilience, Protective Processes, Coping Strategies, Self-Sustaining Process, Quality of Life

I Introduction

With improvements in cancer therapy, over 70% of childhood cancer patients survive for 5 years after diagnosis (Tsukimoto 2002). Research has increased regarding the cancer experience and it's potential to put adolescents with cancer at risk for developing cognitive, emotional, and behavior problems (Zevon et al., 1987). Many children and adolescents may develop psychological problems from such life stresses, but others function well or are “resilient” (Luthar and Zigler 1991). Researchers have spoken about the need for studies related to resilience of cancer patients during childhood. Such studies may develop information about passive interventions for improving resilience and lead to promotion of quality of life in children and adolescents with cancer (Haase 1997; Woodgate 1999b).

The purpose of this article is to review the literature associated with the study of resilience in childhood and to address what is meant by resilience in childhood cancer patients. These include: (a) the history of resilience in childhood cancer patients; (b) the concept of resilience as defined by Rutter; (c) a resilience model for adolescents with cancer; (d) coping in children and adolescents with cancer. Recommendations and

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implication for research and practice are discussed.

II History of Resilience in Childhood Cancer Patients

During the past two decades, resilience in children and adolescents has been studied in the areas of poverty, behavioral problems, and substance abuse in the United States (Stewart et al., 1997). In 1950s and 1960s survival rates of adolescents with cancer were low. Researchers studied about the care of the dying child, negative responses to cancer, and maladjustment behavior (Eiser 1994). Because of development of better treatment methods, survival rates of childhood cancer patients increased in the 1970s and 1980s, and research focused on cognitive developmental tasks and revealing the diagnosis of cancer. The disease interferes with the normal stage of cognitive development. However, some studies found that self-esteem and self-efficacy in childhood cancer patients were high (Eiser 1994). Also, when children were not told about their illness, they picked up hints from adult conversations and imagined that their situation was hopeless (Bluebond-Langner 1978). Because of their condition being kept secret, children with cancer felt isolated and withdrawn from their families (Deasey-Spinetta and Spinetta 1980). These findings contributed to a shift in theoretical emphasis from negative side effects to the positive side of coping and adjustment.

Since 1990s, studies about living with cancer have come of age. Resilience has been studied in childhood cancer patients in the 1990s. Research on coping, adjustment, and adaptation in childhood cancer and cancer survivors has been conducted (Enskar et al., 1997; Novakovic et al. 1996; Nichols 1995; Weeks and Kagan 1994; Glasson 1995; Enskar et al., 1997; Hockenberry-Eaton and Minick 1994; Hinds et al., 1999; Boy and Hunsbeger 1998). Also, research on adolescents with cancer showed that revealing the diagnosis and giving information were involved in the planning and decision-making about treatment and gave realistic hope (Dunsmore and Quine 1995). Children and adolescents with cancer were normal children who were forced to cope with extraordinary circumstances. This idea led to attention on concepts such as "resilience" and "coping" (Eiser 1994).

However, these concepts were difficult to use practically because they could not be placed in a meaningful theory. In order to put empirical findings to work usefully, adequate theoretical models were needed to organize them. A model for resilience of children, fortunately, was recently developed by Rutter (Woodgate 1999a).

III Resilience as Defined by Rutter

According to Rutter (1987; 1990), people who develop disorders have frequently suffered from greater risks experienced over a long period of time. However, Rutter has found that the experience does not seem to be the whole story, but has been turned into resilience.

1. Clarification of Protective Factors

Rutter (1985) reports that researchers have tried to make a list of protective factors. Based on this, Rutter began to clarify factors that may be involved as possible mechanisms.

His model has seven key points. First, a person's response to any stressor will be influenced by his situation and by his capacity to incorporate stressors into his or her belief system. Age also influences the response to stressors because of level of understanding. Second, dealing with life stressors, people may not use particular coping strategy so much, but they do act-not simply

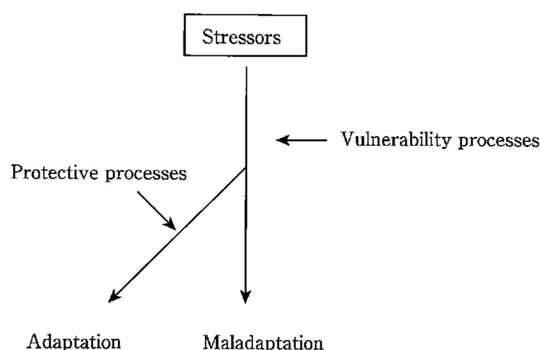

Figure 1 Conceptual Orientation for Protective and Vulnerability Processes of Rutter

react. Next, people's ability to act positively is related to their self-esteem, self-efficacy, and problem solving skills. Fourth, self-esteem and self-efficacy may be fostered by stable and affectional relationships, by success, achievement, and positive experiences, as well as by temperamental attributes. Fifth, such personal qualities may operate through their interactions with and in their responses to and from other people. Moreover, coping with stressful situations can be strengthened through their life. Successfully facing stress and increasing social competence through control and suitable responsibility promote resilience. Last, all the evidence shows the importance of developmental links. According to Rutter (1985), protection does not primarily lie in the protection of supportive factors or operation at one point in time or over a prolonged time period. Rather, protection, the quality of resilience, settles in how people deal with changes of life and what they do about their situations. Protection is also influenced by experiences in early life, during later childhood and adolescence, and by circumstances in adult life.

2. Vulnerability and Protective Mechanisms

The concepts of vulnerability and protective processes are more specific definitions than that of resilience. The essential feature of the processes is an adaptation of the person's response to the risk situation. Initially, the processes require vulnerability or protection to react to a factor that leads to a maladaptive outcome. It must be in some sense "catalytic" so that it changes the effect of another variable, instead of changing the effect of its own. In this reasoning vulnerability and protection are the negative and positive poles of the same concept. This interactive mechanism is used for both vulnerability and protective processes. Protective processes are preferred over vulnerability processes when a negative direction is changed into on adaptive one, but vulnerability processes occur when an adaptive direction is turned into a negative one (Rutter 1990) (Figure 1).

3. Protective Processes

Rutter (1987; 1990) has not defined vulnerability processes clearly. Immunization does not involve positive physical health directly. Vulnerability factors are like lack of immunization and lack of preparation. Also, vulnerability processes, as opposed to protective processes, are reported to occur when a previously adaptive trajectory

is turned into a negative outcome. Rutter (1993) has discussed the influence of protective processes. Protective processes may include three features. First of all, the protective processes reduce the impact of the risk by characteristic or through alteration or involvement in the risk. The processes reduce the chance of negative chain reactions that come from the risk, as well. Also, through secure and supportive personal relationships or success in task achievement, self-esteem and self-efficacy are promoted. Moreover, the protective processes come to be viewed as opportunities of a positive kind. Protection lies in how people deal with changes in life and what they do about their stressful or disadvantageous circumstances. In that connection, the mechanisms as developmental processes need to be emphasized to cope effectively with future stress and to overcome past psychosocial risks. This includes the psychological operations related to mechanisms of turning points in people's lives when a risk may be redirected to a more adaptive direction. At turning points it appears helpful to use the protective process.

4. The Origins of Resilience

Resilience could lie in both preceding and succeeding circumstances. According to Rutter (1993), resilience is suggested by five key concepts. First, potential turning points in people's lives are important in connection with the preceding and succeeding circumstances. People who seemed set on a maladaptive life are able to turn it to a more adaptive direction. The turning points enhance resilience in adult life. Next, success in one arena gives people positive feelings of self-esteem and self-efficacy to have the confidence to deal with life's challenges. The experience of pleasurable success is helpful to enhance the self-concept that promotes resilience. Moreover, there are individual variations in vulnerability to adverse experiences that come from accepting or steeling experiences to the risk at early age. Resilience usually settles in the struggle with stressors for a time, but not in the escape from risk experiences, or only in positive health features or good experiences, rather it si the case that unpleasant events may in fact strengthen people. When people have coped successfully with stressful experiences, steeling effects are more likely to come. Fourth, individual differences in vulnerability may derive from personal characteristics. Two key features may be mentioned. Personal features are influenced by environment. They are also influenced by how people respond to particular stressors. In other words, the interaction between people and their environments may lead to a positive direction. Lastly, how people assess their circumstances is important. The same event is viewed quite differentially by different people. It is important to access life's challenges with a positive mind, with confidence to deal with risky situations, and with the capacity to adapt it to one's own personal style.

5. Invulnerability

In consideration of the phenomenon of resilience, Rutter (1993) has described why the concept of invulnerability instead of resilience is unhelpful. Four reasons are suggested. First, invulnerability seems to express a perfect resistance to damage. However, even individuals who are more resistant than others have their limits. Second, it seems to focus on all risk situations. There is but a range of mechanisms where risk factors are operate and are changed into resilience. Third, the term sounds like a fixed feature of the individual. Yet, resilience may settle in the interaction between social environment

and the individual. Finally, invulnerability seems to deal with an unchanging characteristic. That is notrealistic because there are developmental changes that will influence resilience.

6. A Consideration of the Study on Resilience

In addition to defining the concept of resilience, Rutter (1993) has advised studying resilience. To begin with, avoiding thought of some single answer to problems of life, researchers should use several different sources of measurement and indication over time. Also, people may suffer in a range of different ways. Resilience is not in terms of the chemistry of the moment either. Therefore, it is necessary to take a much longer time span to view within a developmental framework. Moreover, how the processes influence to increase resilience should be focused upon because of the little existing understanding about protective processes.

IV Resilience Model of Adolescents with Cancer

Considering the gains in survival rates for childhood cancer, an understanding of resilience in adolescents with cancer is essential. Also, interventions that may increase resilience in childhood cancer patients need to be studied. Garmezy (1991) has described protective factors and categorized them including: personality features, family cohesion, and support systems. Based on work of Rutter (1985; 1987) and Garmezy (1991; 1993; 1994), Woodgate (1999a) recently developed a resiliency model for conceptual understanding of resilience in adolescents with cancer in order to help them to increase resilience. The components of the model are stressors of risk situations, protective and vulnerability factors or processes, and outcomes. Woodgate has described relationships between the model's components.

Adolescents with cancer may experience both basic developmental tasks and the stress associated with cancer at the same time. How the adolescent responds to the stressors depends on the presence of vulnerability and protective factors or processes. If the adolescents can deal with a stressful event, their sense of self and social competence will increase. Then, the adolescents may also have more success in dealing with future stressful events. As a result, increased self-esteem and social competence skills, as protective factors, may serve the adolescents to move toward adaptation. Outcomes of resilience are possible in adolescents with cancer. All the components act interdependently. On the other hand, the process will become a vulnerability process when an adaptive trajectory is turned into a negative one (Woodgate 1999a).

Woodgate has remarked that adapting this model should guide primary prevention programs such as social skills training programs in adolescents who are newly diagnosed with cancer. Moreover, care providers need to be aware that potential dangers exist, such as cultural beliefs. Although adolescents with cancer may show social competence, they may have emotional problems. For instance, if a culture believes the idea that good patients are cured and bad ones are not, then it might believe that all children and adolescents can beat cancer when they try hard enough.

V Coping in Children and Adolescents with Cancer

Rutter (1993) has described that when people successfully cope with stress, steeling effects come in protective processes and promote resilience. Also, coping strategies including being positive and having hope for the future help ado-

Coping Strategies for Hospitalization
Maintaining relationships with friends
Support from their family
Setting relationships with others
Coping Strategies for Cancer
Positive thinking for painful procedure
Hope for the future
Try to lead a normal life (i.e., creasing daily activities)
Focus on getting back to a normal life (i.e., school reentry)
Spiritual support (i.e., church)
The Self-Sustaining Processes for hopefulness
Cognitive discomfort (i.e., thought-stopping)
Distraction (i.e., do something)
Cognitive comfort (i.e., forgetting cancer)
Personal competence (i.e., commitment to treatment)

Figure 2 Coping in Children and Adolescents with Cancer

lescents to deal with their cancer experience (Enskar et al., 1997; Hinds and Martin 1988; Novakovic et al., 1996; Rechner 1990; Weekes and Kagan 1994). With these ideas, the research about coping strategies and the self-sustaining process in childhood cancer patients is reviewed (Figure 2) .

1. Coping Strategies for Hospitalization

According to Foley et al (1993), childhood cancer patients have experienced limitations in normal life because of hospital admissions. In particular, separation from important people, such as peers and family, and school activities may lead to losses in self-identity, self-esteem, academic achievements, and interpersonal relationships. Using a quantitative method, Nichols (1995) conducted a study to assessed social support networks and coping mechanisms. As a result of change in friendships of adolescents with cancer because of hospitalization, they may tend to have small and more specific social networks and less contact with others. In addition, Desy Spinetta (1981) identified school-related behaviors of childhood cancer patients by their teachers who filled out questionnaires on the subject. According to this researcher, physical change, the loss of friends, trouble keeping up with school work, and separation anxiety may disrupt the return to school and could cause trouble in school activities and peer relationships.

In dealing with hospitalization, the maintenance of relationships with friends and classmates has been identified as an important protective factor for adolescents with cancer (Rechner 1990; Enskar et al., 1997; Fowler-Kerry 1990; Glasson 1995; Lozowski 1993; Nichols 1995; Novakovic et al., 1996; Nichols 1995). Psychosocial support from other peers diagnosed with cancer was also valued through the sharing of experiences with others in similar situations (Lozowski 1993; Novakovic et al., 1996; Hockenberry-Eaton and Minick 1994; Weekes and Kagan 1994) .

The family has also been recognized as a sup-

portive factor to help children and adolescents to cope with the stressors of cancer both physically and psychosocially (Enskar et al., 1997; Fowler-Kerry 1990; Smith et al., 1991; Weekes and Savedra 1988; Blotcky and Cohen 1985). Unfortunately, relationships with parents were altered by increased dependence on their parents and decreased control for adolescent cancer patients during illness (Foley et al., 1993). The adolescents with cancer may also struggle between dependence and independence with support of parents and medical and nursing staff. The adolescents may feel parents are overprotective. This overprotectiveness continued even when their children could be more autonomous. These findings were supported by a study to assess the psychosocial needs of adolescents with cancer. Nine adolescents participated in a three-month support group discussed in group sessions (Orr et al., 1984). This issue aside, however, adolescents with cancer received their greatest support from their parents during painful and difficult situations (Enskar et al., 1997). Through survey with Harter's Self-Perception Profile for Adolescents and Sawin and Marshall's Future Orientation Scale, Overbaugh and Sawin (1992) stated that their children showed higher levels of perceived self-esteem when parents had higher expectations about their children's future success. Moreover, using a phenomenological study, the establishment of relationships with people such as nurses, school teachers, and other parents has been identified as important as well (Rechner 1990).

In addition, based on quantitative methods, Boyd and Hunsberger (1998) have described the importance of minimizing distress during hospitalization. Thirty nine school age children and adolescents with cancer in remission participated in the study about their life stressors and coping strategies. Familiarity with the hospital environment may be an important factor. The children believed that knowing the nurses and knowing what to expect made it easier for them to repeat hospitalization. The hospital environment also helped the children to promote their coping strategies during hospitalization. Even though the hospital environment could cause stress, recreational activities such as TVs, telephones, and playroom assisted the coping strategies such as distraction and reduced isolation. The ability to see outside from their hospital bed supported the strategy of distraction.

2. Coping Strategies for Cancer

Researchers have found that the childhood cancer experience is stressful. Uncertainty is the greatest source of psychosocial stress for cancer patients as well as childhood (Koocher 1985). Also, childhood cancer patients showed lower self-esteem scores related to school and academic performance than those of healthy children (Mullis et al. 1992)

In dealing with cancer, adolescents with cancer use a variety of coping strategies. Adolescents use coping strategies with physical pain during treatment events. For example, thinking positively, thinking about good things, having as optimistic view, making jokes, and holding hand by a parent, nurse or others during painful treatment procedures were identified (Fowler-Kerry 1990; Weekes and Kagan 1994; Weekes and Savedra 1988; Weekes et al., 1993). Other studies have stated that coping strategies such as being positive and having hope for the future help adolescents with cancer deal with psychological stresses (Enskar et al., 1997; Hinds and Martin 1988; Novakovic et al., 1996; Rechner 1990; Weekes and Kagan 1994).

Using a grounded theory approach, Bull and

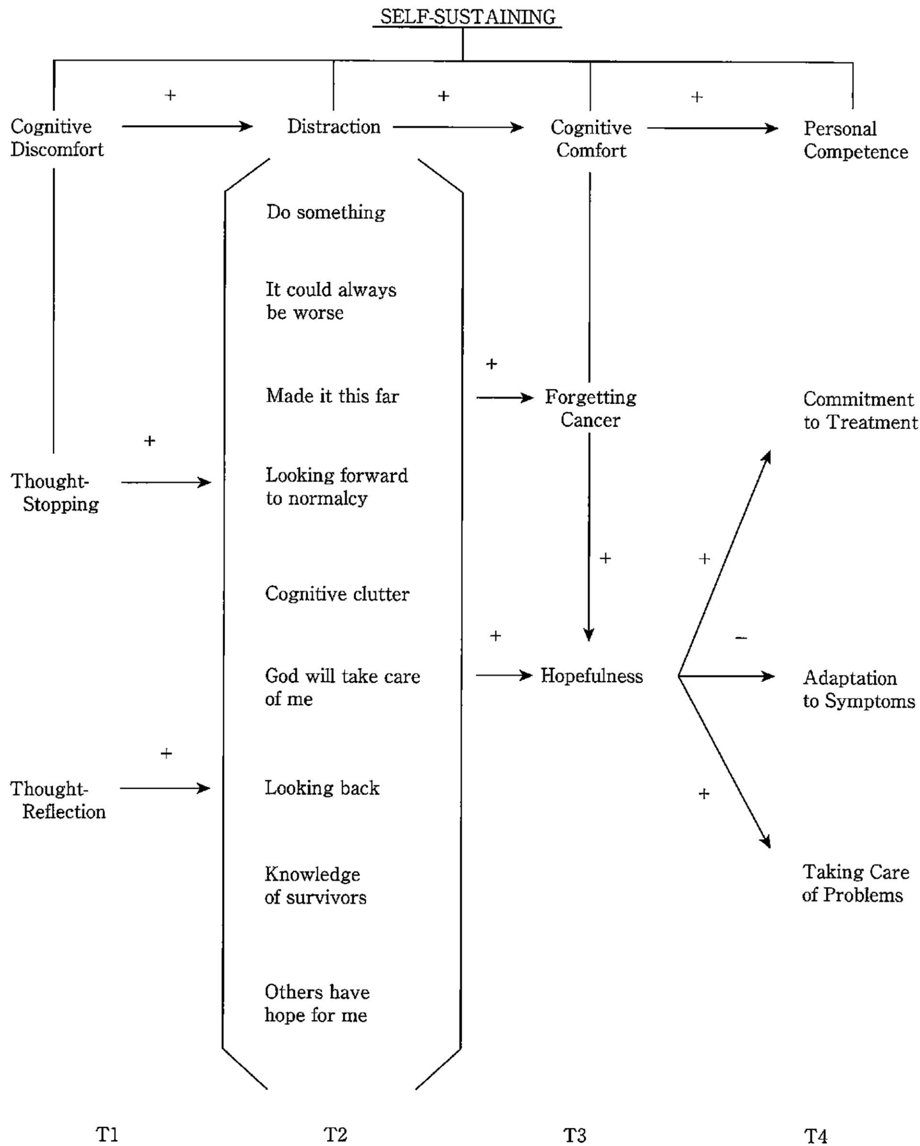

Figure 3 The Substantive Theory: Categories, core concepts, and the central organized construct (T1-T4 indicate time frames)
(Adapted with permission from Hinds and Martin, 1988)

Drotar (1991) have described the differences in the use of coping strategies with cancer experiences in school-age children and adolescents with cancer. The study found that adolescents used emotional-management coping strategies, but younger children used problem-solving strategies. The authors have thought that the adolescents with cognitive maturity may understand the ineffectiveness of problem-solving strategies for stressors. For example, children

with cancer cannot stop their hair from falling out and have little choice about receiving treatment for cancer or its side effects.

Weekes and Kagan (1994) conducted qualitative research focused on cancer experiences and coping strategies before and after completing therapy. Thirteen adolescents who mixed cancer diagnoses aged 11 to 18 years were interviewed at 4 points in time 3 to 6 months prior to completion of treatment, at time of completion, 3 and 6 months after completion. The adolescents revealed different coping strategies before and after completion of treatment. Before completing therapy, most of the adolescent cancer patients described themselves as different from their peers and their lives as not being normal. However, they tried to lead a normal life. The adolescents used five coping strategies. These included positive thinking, not thinking about treatments, busyness, like the focus on interesting activities, reinterpretation, such as growing closer to family or reducing risky behaviors, and philosophical stance, such as meeting specific time-limited goals.

After completion of cancer therapy, the adolescents used three coping strategies: negotiation, cognitive reliving, and selective forgetting, to focus on getting back to a normal life. Negotiation involved activities of daily living. Cognitive reliving was a way that imagined the cancer experience again to consider a hint for present and future behavior. Similar to this study, Glasson (1995) has found that a coping strategy of adolescents with cancer in outpatient clinics was to participate in a normal way of living with their peer group. For example, adolescents with cancer became powerful for catching up with school-work before school re-entry. Also, adolescents with cancer believed that they were not changed psychologically and still the same person and accepted it through their social support networks (Rechne 1990; Overbaugh and Sawin 1992).

Some studies found that adolescents with cancer felt helpless and sought spiritual support while being initially diagnosed. Therefore, help from prayer and church was important in order to find relief, comfort, and answers (Fowler-Kerry 1990; Hinds and Martin 1988; Nichols 1995).

3. The Self-Sustaining Process in Adolescents with Cancer

Hinds and Martin (1988) have conceptualized the self-sustaining process (Figure 3) that helps adolescents with cancer meet hopefulness during their cancer experience. This study explored how adolescents cope with and moved through dilemma to achieve hopefulness and competence in resolving health threats. Participants were 58 adolescent cancer patients with varying diagnoses and different stages of treatment. Stage of treatment varied with 7 in induction, 27 in maintenance, 18 off therapy, and 6 in relapse. They were between the age of 12 and 18. The study method used a grounded theory approach and data were collected through interviews, observations, and health records.

The self-sustaining processes include four phases: cognitive discomfort, distraction, cognitive comfort, and personal competence. The first phase occurs immediately after the adolescents became aware of negative or disrupting thoughts about their illness. Cognitive discomfort includes two strategies: thought stopping and thought reflection. Next, distraction is one of purposeful effort to do away with threatening conditions through more positive thoughts or activities. Both the physical and cognitive strategies help to remove the disturbing thoughts.

Nine strategies are constructed in this phase: "do something", "I could always be worse", "made it this far", "looking forward to normalcy", "cognitive clutter", "God will take care of me", "looking back", "knowledge of survivors", and "others have hope for me". The adolescents do not depend on one of the nine strategies. Rather, they shift their strategies because of the immediate situation. Younger adolescents use a few strategies such as "I could always be worse". Also, cognitive comfort refers to the periods of comfort and lifting of spirits that the adolescents with cancer experience during the course of their illness. They have a view of future possibilities for themselves or others during the cancer experience. This phase includes two strategies: forgetting cancer, and hopefulness. Finally, personal competence changes into a state where the adolescents view themselves as resilient, resourceful, and adaptable in the face of serious health problems. Personal competence includes three strategies. These are "commitment to treatment", "adaptation to symptoms", and "taking care of problems". The adaptation to symptoms was defined as the degree to which the adolescent feels discomfort from side effects of disease or therapy. The adolescent shared a displeasure for the loss of hair, nausea, and vomiting, but became more tolerable by a kind o f adaptation to the symptoms. The adaptational outcomes of the adolescent are self-focused and not environment-focused. Therefore, personal control of the disease does not exist.

Hinds and Martin have concluded that the self-sustaining process is changeable and it can occur in minutes or weeks. Also, some phases take longer than others or may be skipped. Moreover, the improvement of the adolescent through the process can be influenced by behaviors and attitudes of others.

VI Discussion

This section briefly reviews the literature review and recommendations for strategies to develop the study of resilience in adolescents with cancer. Rutter developed the concept of resilience in children and adolescents. Woodgate adapted this study and further developed the resilience model for adolescents with cancer. This model describes how their resilience develops using stressors, protective and vulnerability factors or processes and outcomes. However, the model appears weak in its description of processes. Rutter has expressed the view that knowing about protective processes and the influence of these processes rather than just focusing upon protective factors was important in order to promote resilience. Hinds and Martin studied about how adolescents with cancer achieved hopefulness. The adolescents revealed that they experienced hopefulness in moving through the self-sustaining process such as cognitive discomfort, distraction, cognitive comfort, and personal competence. They used various coping strategies in the processes. Other studies showed that psychosocial support from people and the hospital environment were valuable for adolescents with cancer in order to cope with their experience of hospitalization. Adolescents who experience cancer have also used different coping strategies in different developmental stages and in alternative phases of cancer therapy.

The authors believe that the self-sustaining process may be useful for understanding how adolescents with cancer develop their resilience. That is because the self-sustaining process is a study for the protective processes that Rutter has mentioned. There are two important objects in use for the model. Research should focus on people who support the adolescents in order to

promote resilience. This model should also be aimed at adolescents who are at different developmental stages. Also, the authors propose that building a knowledge base for expanding on cultural differences should be investigated. Rutter pointed out that research on resilience had to focus on the specific processes that operate in particular circumstances for particular outcomes. Researchers should be concerned with two cultural differences. The first is in regarding revealing the diagnosis of cancer or not. The second concerns is differences in length of average stay in the hospital. Based on the history of resilience in childhood cancer patients, research reviewed in this study may have been conducted in the situation that most adolescents with cancer were told of their diagnosis. However, this is not always the norm in other cultures. The length of hospitalization also appears to be different in different countries (US Bureau of the Census 1991; Japan Statistics and Information Department Minister's Secretarial 1999). This approach will improve the understanding of resilience on certain patients in certain cultures and help adolescents to cope with cancer.

Understanding about resilience may be vital to the study of adolescent cancer patients. Such knowledge is also extremely valuable for the conceptual framework to support adolescents with cancer and improve their resilience. Furthermore, it is important for health care professionals to be aware of resilience during their day to day clinical practice (Morse and Field 1995; Hasse and Rostad 1994). Reporting research outcome may provide information for teachers to teach, for researchers to further delve into their area of speciality, and for health care professionals to facilitate patient care. Through these efforts adolescents with cancer will have greater opportunity to enrich their lives and promote their quality of life as a result of learning to successfully cope with the cancer experience.

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