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UNIVERSITY OF SAN DIEGO
Hahn School of Nursing and Health Science
DOCTOR OF PHILOSOPHY IN NURSING

RESILIENCE AND QUALITY OF LIFE IN TAIWANESE SURVIVORS OF
CHILDHOOD CANCER

by

Li-Na Chou, MSN, RN

A dissertation presented to the
FACULTY OF THE HAHN SCHOOL OF NURSING AND HEALTH SCIENCE
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In partial fulfillment of the
requirements for the degree
DOCTOR OF PHILOSOPHY IN NURSING

May 2006

Dissertation Committee

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ABSTRACT

Resilience and Quality of Life in Taiwanese Survivors of Childhood Cancer

Survivors of childhood cancer are at risk to develop physiologic-psychosocial complications that affect their quality of life. This study explored how the independent variables of illness-related risk (ILLRK), individual risks (IRK), protective factors (PF) and resilience (RS) affected the dependent variable - quality of life (QOL) -- in Taiwanese survivors of childhood cancer.

Triangulated research methodology was employed to 1) identify the statistical relationships between the variables and (2) explore qualitatively what these variables meant to the subjects and how their perceptions further explained the statistical results. Haase's (2004) Adolescent Resilience Model was used as the theoretical framework.

Ninety-eight Taiwanese adolescent cancer survivors, diagnosed with brain tumors or leukemia before the age of 16 years, surviving at least 5 years after diagnosis, were recruited. From this sample, 12 were selected for the interview segment. Four valid and reliable Likert-scale instruments were used to assess the variables, while a semi-structured interview format was used for the qualitative component. Descriptive statistics, ANOVA, and multiple regressions were used to describe the sample, and analyze the data. Analysis of the interview data looked for recurring themes.

Quantitative findings: 1) statistical significance ($p < .001$) between the QOL in survivors of brain tumor and leukemia; 2) statistically positive relationships ($p < .001$) between PF, RS, and QOL; 3) statistically negative relationships ($p < .001$) between ILLRK, IRK and QOL. The significant predictors affecting QOL were ILLRK, IRK, RS and cancer types.

Qualitative findings: 1) theme of loss of self explained IRK; 2) chronic fear explained ILLRK; 3) good sense of self explained PF; 4) rebounding even using less than optimal coping strategies explained RS; 5) control of one's life explained QOL. Culture influenced ones sense of self and control.

Resilience is critical to achieving optimal quality of life. Protective factors can predict type of resilience and quality of life. Interventions to enhance protective factors are critical. Cancer type also contributes to lower QOL. Different interventions for brain tumors or leukemia survivors must be considered. Cultural beliefs and practices can influence how survivors interpret risks, resilience, and quality of life. These results can support nursing efforts to effect changes in health policy, nursing education, and nursing practice in Taiwan.

DEDICATION

I would like to dedicate this dissertation to:

The memory of my father

My dear mother and family

ACKNOWLEDGEMENTS

I would like to thank the participants in this study, the dissertation committee, my friends and my family. I would not have finished this study without their help, support and everlasting encouragement.

First, I want to appreciate the adolescents who participated in this study. Because of their enthusiasm, this study was finished smoothly. Their experiences truly have contributed my teaching knowledge and give me direction for future study.

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CHAPTER 1

INTRODUCTION

Background and Significance of the Problem

Childhood cancer cure rates have increased dramatically over the past few decades with 5-year survival rates increasing from less than 30% in the early 1960s to nearly 80% in the late 1990s, with the 10 year survival approaching 70% (Ries, Eisner, Kosary, Hankey, Miller, & Clegg., 2003; Smith & Hare, 2004). In the United States, the 5-year survival rate is now about 78% and the number of childhood cancer survivors alive today is estimated to be at least 270,000 (Reis et al., 2003). A study by Brenner (2003) investigated 18,100 who were diagnosed with cancer below age 15 years between 1975 and 1999. The results demonstrated that the increase in 10-year survival rate between children diagnosed in 1975-1979 and children diagnosed in 1985-1989 was particularly strong for patients with leukemia (up 18.9%). By 1995-1999, the estimated rate of 10-year survival for all ages and all forms of childhood cancer combined was 75.2%; 8.7% higher than the 10-year survival rate for the 1985-1989 cohort. The American Cancer Society (2003) estimated that by the year 2010, one in 250 young adults would be a long-term childhood cancer survivor.

Internationally, such success in pediatric cancer survival is also evident. Steliarova-Foucher, Stiller, Kaatsch, Berrino, Coebergh, Lacour and Parkin (2004) surveyed 63 European population-based cancer registers that documented over 120,000 tumors in children and adolescents in 1970-1999. The findings showed the overall 5-year survival for children in the 1990s was 70% and was much the same in adolescents. There is similar childhood cancer survival rates reported in Canada (Population and Public Health Branch, Health Canada, 2003). This success reaches to Taiwan where the Taiwan childhood cancer statistics reflect that

approximately 70% to 80% of the 550-600 Taiwanese children and adolescent who are diagnosed with cancer every year will survive the disease (Republic of China, Childhood Cancer Foundation, 2002).

The Impact of Surviving Childhood Cancer on the Child and Family

The successful treatment of pediatric malignancy by multimodality therapy has improved the outcome for children with cancer; however, during the cancer treatment, survivors experience residual physical, behavioral, or psychosocial sequelae associated with the disease or its treatment (Bhatia & Landier, 2005; Meyer & Fuemmeler, 2005). Even though aggressive treatment plans may be successful, severe side effects are common. A body of evidence supports the presence of adverse late effects (e.g., neurocognitive problems, premature menopause, cardiac dysfunction, sexual development, second malignancies) among survivors of childhood cancer (Bhatia & Landier, 2005; Smith & Hare, 2004). There may also be changes in alteration of body image, low self-esteem, and interpersonal relationships resulting from diseases, treatment programs, and their side effects (Bessell, 2001; Zebrack, Gurney, Oeffinger, Whitton, Packer, Mertens, et al., 2005). Children face uncertain physical, emotional, and social outcomes, and experience a guilt-relief dyad in their survivorship (Parry, 2003). However, it may be difficult for children to verbalize these experiences because children may not have achieved linguistic, cognitive, or experiential maturity.

The sizeable population of survivors present many important questions related to patients' treatment decision-making, quality of care, physical health after cancer treatment, and quality of life. Research focused on the late effects of cancer survivorship within the physical realm uncovered secondary neoplasm, cardiovascular, pulmonary, musculoskeletal, gastrointestinal, and reproductive system dysfunctions (Bhatia & Landier, 2005; Hudson,

Mertens, Yasui, Hobbie, Chen, Gurney, et al., 2003). Studies of psychosocial functioning of adolescent and young adult survivors of childhood cancer have found that approximately 10% to 20% of individuals showed signs of psychosocial maladjustment (e.g., emotional disturbances, behavioral problems, somatic distress, and impaired occupations, etc) (Zebrack, Zeltzer, Whitton, Mertens, Robison, Odom & Borton, 2002; Zeltzer, Chen, Weiss, Guo, Robison, Meadows, et al., 1997).

Investigations of the psychosocial consequences among childhood cancer survivors presented mixed findings. For example, a number of studies suggested that many survivors of childhood cancer were at increased risk for maladaptive psychosocial sequelae and emotional difficulties, including depression (Essen, Enskar, Kreuger, Larsson, & Sjoden, 2000) and symptoms of posttraumatic stress (Hobbie, Stuber, Meeske, Wissler, Rourke, Ruccione et al., 2000). Other researches found behavioral adjustment problems and preoccupation with somatic concerns (Shankar, Robison, Jenney, Rockwood, Wu, Feusner, et al., 2005), negative self-esteem and body image perceptions (Essen et al., 2000; Zebrack & Chesler, 2001).

In sharp contrast, some researchers found healthy levels of psychosocial adjustment and physical functioning among long-term survivors (Newby, Brown, Pawletko, Gold, & Whitt, 2000; Shankar et al., 2005). Some reported that a significant portion of the childhood cancer survivors seemed to be better adjusted than their peers, better adjusted in optimism and hope, had strong bonds to and deeper love for family and friends, a self-increased capacity for empathy, a desire to help others, and to live a life to the fullest more so than before their cancers were diagnosed (Karian, Jankowski, & Beal, 1998; Parry & Chesler, 2005). Several studies identified that promoting optimism, valuing life, and being resilient resulted in achieving a more positive outcome for the patient (Karian, et al., 1998; Parry & Chesler, 2005).

A child diagnosed with cancer disrupts family interactions and places stress on all members (Woznick & Goodheart, 2002). Parents of children with cancer experience a series of stressful life events such as financial stress and persistent physical and emotional strain that causes uncertainty and anxiety (Lahteenmaki, Sjoblom, Korhonen, & Salmi, 2004). Studies in both Western and Asian culture have shown that the parents of children with cancer felt a sense of helplessness, loss of control, guilt and self blame for the child's cancer, and uncertainty about the child's and the family's future (Lahteenmaki, et al., 2004; Ow, 2003). The impact on the siblings of childhood cancer patients is also profound as these siblings demonstrated impaired cognitive, motor, and emotional function compared to the reference group and a lower quality of life than peers (Houtzager, Grootenhuis, Hoekstra-Weebers, & Last, 2005).

In Taiwan, Chien, Lo, Chen, C. J., Chen, Y. C., Chiang, & Chao (2003) studied 30 families of children with brain tumors and found that the caregivers had lower scores in the physical health and psychological domains of quality of life than the normative reference group. In Chao, Chen, Wang, Wu, & Yeh's (2003) study, the parents of patients with cancer became more protective (i.e., more cautious about the patient's diet and daily care) and more lenient and demanding toward the child (i.e., lower expectation on academic performance and household chore responsibility). A surprising finding in the study contradicted other findings regarding effect on siblings. This study indicated there were positive changes in siblings' behaviors such as assuming more responsibility, achieving more independence, and developing a greater closeness to the patient.

Survivors of childhood cancer not only contend with the physiological cancer processes and potential disease and treatment sequelae but must also contend with the disruptive psychosocial and family processes. It is known that cancer patients face many challenges as

survivors. Unfortunately, there is disproportionate research in this area to the increasing number of childhood cancer survivors. Questions about the impact of childhood cancer and its treatments have been raised by these survivors as they look at the quality of their life and their future in relation to physical and cognitive development, marriage and family, vocational potentials, and future health problems. The ultimate goal of cancer survivorship research should be to answer these questions.

This shortage of research on the survivorship of childhood cancer makes it difficult for health care professionals to provide appropriate, comprehensive interventions and follow-up care. According to the Index of Chinese Periodical Literatures, research articles related to survivorship, resilience, or quality of life in Taiwanese children with cancer are rare. Most of the literature in Taiwan has been translated from textbooks and research articles of Western cultures. Therefore, health care providers in Taiwan acquire their knowledge of survivorship of childhood cancer from the Western culture. The problem is that culture affects many aspects of psychosocial functioning of childhood cancer survivors and their families. Though the physiology of childhood cancer survivors may be similar across cultures, the lived experience and meaning of childhood cancer survivors can be different across cultures. Cultural differences can influence how childhood cancer survivors perceive, behave, and manage their life. Cultural beliefs and values help explain how coping strategies, resilience, and quality of life are viewed in the management of a childhood cancer survivor's psychosocial health. In order to understand how Taiwanese childhood cancer survivors describe their experiences and how resilient the childhood cancer survivors are, more relevant research is needed.

Survivorship and Resilience

Children need hope, love, support, and a trusting environment to achieve their developmental goals. These can help them develop the inner strength and resilience necessary to successfully overcome the adversities that may and often occur in their life. Children with the experience of life-threatening illnesses such as cancer face the greatest adversity and are more vulnerable physically and psychosocially. This vulnerability may affect the development of optimal resilience. Miller (2003) found that the most important threats to the development of children are those adversities that damage the basic human ability to develop psychologically. Woznick & Goodheart (2002) suggested that cancer impacted a child's development at each age level. Evidence has shown that adolescents with cancer often feel exhausted and physically incapable; they have a higher potential for vulnerability in accomplishing normal development tasks than their healthy peers (Varni, Katz, Seid, Quiggins, Friedman-Bender & Castro, 1998; Woodgate, 1999).

In the 1950s and 1960s, when the survival rate of childhood cancer was low, a cancer diagnosis meant almost certain death and, therefore, most research on childhood cancer rarely focused on the child, but rather on the reactions of the caregivers or the families. However, in the 1970s and 1980s, with the increase in survival, there was a shift from *dying* to *living* with cancer (Eiser, 1994). The field was expanded to include the experiences of children. From the 1990s on, researchers and clinicians recognized the need not only to understand the maladaptive behavior caused by the adversities but also to focus on how individuals dealt successfully with stress and adversity. It was a paradigm shift from pessimistic to optimistic perspectives that concentrated on coping, competence, adjustment, and adaptation, as well as on long-term cancer survivors.

This new point of view support the importance of understanding the experiences of childhood cancer survivors with a “resilience-centered” approach (Eiser, 1994; Woodgate, 1999).

Resilience has been defined as the ability to withstand stress and destructive life challenges or positions after being changed by outer forces with a return to normal (Garmezy, 1991). It included interactions between risks and assets, a dynamic processes fostering positive adaptation with significant adversities (Luthar, Cicchetti, & Becker, 2000). Over the last 3 decades, many skilled researchers have attempted to improve the understanding of survivorship and resilience, and identify factors that affect resilience in children and youth who have survived under these adverse conditions. Researchers have found some children with experiences of previous traumas might have become blocked in their development and growth or trapped in a victim position (Woodgate, 1999). On the contrary, resilient children with similar experiences could adapt well, overcome them, and go on to live a better life (Parry & Chesler, 2005).

What is resilience in adolescents? According to Olsson, Bond, Burns, Vella-Brodrick, & Sawyer (2003),one explanation for adolescent resilience in the face of risks was their use of competent behaviors or effective functioning combined with family and social support to modify the impact of the risk. This supported the child’s achievement of good mental, functional capacity and social competence. Hunter (2001b), furthering the research begun by Hunter and Chandler (1999) discussed resilience as a phenomenon that exists along a continuum moving between optimum, self-protective or survival resilience depending on the stressors, support systems, internal and external environment, and the adolescent’s coping behaviors.

It appears that various perceptions of resilience exist and all are important to consider when working with children who survive major crises in their lives. All the conclusions indicate

that resilience is practiced in many ways, some healthful and some not. The child's quality of life, internal and external environment, and life choices often reflect that child's resilience position.

Conceptual Framework

The development of the conceptual framework in this study is based on the Adolescent Resilience Model (ARM) developed by Haase (2004a). The ARM is based on both deductive and inductive research methods and describes the resilience processes and outcomes experienced by patients with cancer and other chronic illnesses (Haase, 1987; Haase, Britt, Coward, Leidy & Penn, 1992; Haase & Rostad, 1994). It was one of the first theoretical models to propose a comprehensive, integrative representation of the resilience and quality of life process and outcomes in adolescents with cancer. Haase (2004) recognized that resilience was a complex and multidimensional. It is a positive health concept and the positive outcomes of resilience enhance one's quality of life (Haase, Heiney, Ruccione & Stutzer, 1999).

The ARM focused on two philosophical perspectives: life-span development and meaning-based models. The first philosophical perspective, life-span development, was developed from Weekes' (1991) study. The life-span perspective assumes that developmental changes are affected by biological, psychological and maturational aspects of an individual. Development is also affected by the adolescent's response to health and illness, as well as history and environment. The second philosophical perspective was derived from the work of Costain, Hewison & Howes (1993). It is a "meaning-based model" that focuses on the perception of the child /adolescent about their health and illness. Children/ adolescents' perceptions, beliefs, actions, and relationships with others can affect the meaning of illness and impact their quality of life (Haase, 2004a).

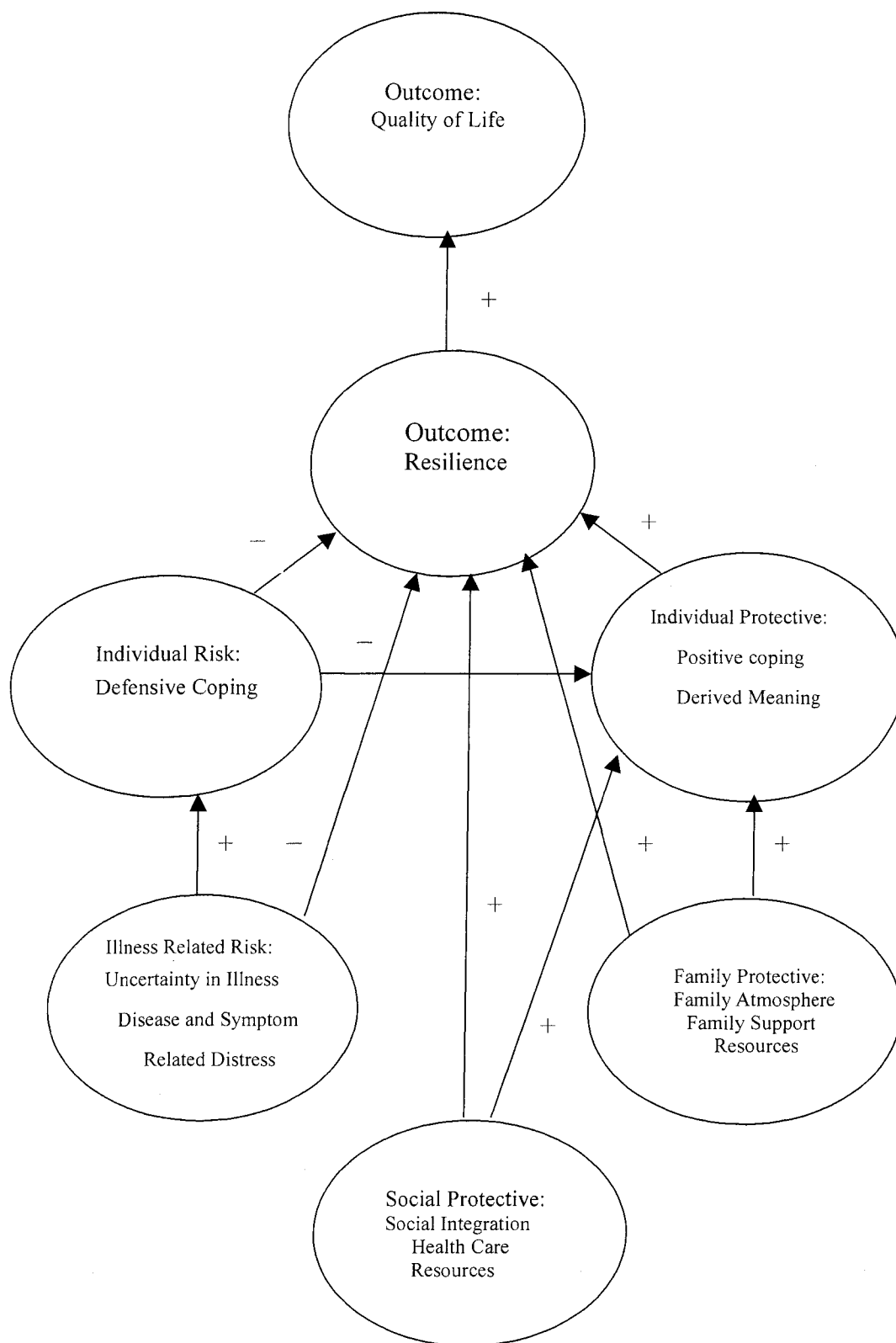
Haase considered that quality of life was a concept of well-being (Haase & Braden, 2003). This multidimensional construct consists of such dimensions as physical problems (physical, toxicity, body image, and mobility), psychological, social, and spiritual factors (psychological, interpersonal, happiness, spiritual, and financial), and other dimensions that included the individual, culture, politics, philosophy, and time. Each variable can affect quality of life (Haase & Braden, 2003).

Haase (2004a) further delineated the ARM concepts and related components collapsing them into the dimensions of illness-related risk (e.g., uncertainty in illness, disease, and symptom-related distress), individual risk (e.g., defensive coping, evasive, fatalistic, and emotive coping), individual protective factors (e.g., positive coping through optimism, sense of mastery, confidence, self-esteem; increased social support and knowledge about cancer and its treatment), family protective factors (e.g., family atmosphere, family support and resources), social protective factors (e.g., social integration, health care resources), and the outcome (e.g., resilience and quality of life) (see Figure 1). Haase (2004a) considered that physical functioning and symptom distress could fluctuate during the course of cancer therapy, and might affect quality of life in adolescent with cancer.

Research has shown that childhood cancer survivors are surrounded by illness-related risks such as uncertainty in illness (Parry, 2003), and individual risks factors such as defensive coping (Stam, Grootenhuis, Caron & Last, 2005), /protective factors such as family (Orbuch, Parry, Chesler & Repetto, 2005), social support (Madan-Swain, Brown, Foster, Vega, Rodenberger, et al., 2000), hope, sense of mastery, and self-esteem, all assisting the survivors to positively cope with life's challenges. In this study, the ARM model lays the foundation for understanding the relationships among protective factors/risk factors, resilience, and quality of

Figure 1

Adolescent Resilience Model (Haase, 2004)



life in childhood cancer survivors. The value of this model for this proposed research study is it serves as the guide to explain how illness-related stressors, family/individual support, and resilience findings from the data affect quality of life. It may help the nurse or other health care providers identify ways to effectively intervene.

Purpose

Health care providers working with children with cancer can help these children be survivors of cancer and live quality lives if they understand the variables necessary for these children to achieve these goals. What does a child need to be resilient in a way that helps them overcome the potentially negative physical and psychosocial outcomes of cancer? This knowledge could help pediatric oncology nurses develop appropriate interventions for children and adolescents during the cancer experience and as cancer survivors, help prevent the development of conditions that hinder their quality of life.

The purpose of this study is to identify the relationships between illness-related risks, individual risks, protective factors, resilience, and quality of life in Taiwanese survivors of childhood cancer. As more children with cancer around the world are exposed to medical methodologies that help them survive, it becomes critical that research on this subject be conducted in the international arena. Taiwan is achieving great strides in cancer therapy but little relevant research has been done on this subject in this country. This study intends to conduct an exploration into the relationships among the aforementioned variables in Taiwanese childhood cancer survivors, and help identify why some children survive more successfully than others.

A triangulated research design was utilized to explore the phenomena of survivorship of childhood cancer in Taiwan. A quantitative design was used to explore the relationships between demographics, illness-related risks, individual risks, protective factors, resilience, and quality of

life in Taiwanese childhood cancer survivors; while a qualitative component was incorporated to help further explain the quantitative findings and contribute to the validity of the instruments used with a non-Euro population.

Key Variables and Definitions

The following are definitions used to operationalize the variables in this study.

Dependent Variable

Quality of Life. Quality of life is an individual's perceptions of his or her position in life, including his or her physical health, psychological status, level of independence, and social relationships within the context of the culture and value system in which they live and in relation to their goals, expectations, standards, and concerns (The WHOQOL, 1995). In this study, quality of life includes five domains: physical functioning, social functioning, psychological functioning, cognitive functioning, and outlook on life. Quality of life was measured by the Minneapolis-Manchester Quality of Life's instrument (MMQL) (Bhatia, Jenney, Bogue, Rockwood, Feusner, Friedman, et al., 2002). This instrument is valid and reliable with a reliability coefficient of 0.92.

Independent Variables

Resilience. Haase (2003) considers resilience is a sense of confidence/mastery and self-esteem, a positive adjustment in the face of adversity or managing stressors. Resilience includes internal and external factors (Mandleco & Peery, 2000). The internal factors are cognitive and personality characteristics (e.g., self-esteem, locus of control, optimism). External factors include general health, family protective factors, social protective factors, and culture. Resilience will be measured using the Resiliency Attitudes and Skills Profile (Hunter & Hurtes, 2001). This instrument is valid and reliable with a reliability coefficient of 0.91.

Protective Factors. Protective factors include individual, family and social protective that enhance the resilience in adolescents with cancer (Haase, 2004). Protective factors affect the degree to which the adolescent is able to maintain family, peer, and school relationships and to expand social relationships such as health care providers and colleagues etc. Protective factors were measured by the subscales – Insight, Independence, Relationships, and Value Orientation in the Resiliency Attitudes and Skills Profile tool.

Illness-Related Risks. Disease and symptom-related distress were identified as important components of illness-related risks in adolescents with cancer (Haase, 2004a). These factors negatively influence resilience and quality of life (Haase, 2004a). Illness-related risks associated with childhood cancer survivors are caused by the disease and its treatments. In this study, these risks were classified as disease entities and treatment entities. They were measured by a researcher-developed Risk Assessment Questionnaire. Section I of this instrument, specific to the risks, had been reviewed by experts for validity and its reliability was assessed during this research study.

Individual Risks. It is found that coping strategies could influence how people respond to stressful events. The study of Haase et al (1992) found the most frequently used coping strategies by adolescents to deal with cancer and its treatments were defensive behaviors. Defensive coping strategies consist of a belief in predestination, evading or denying the disease, and emotional responses that negatively affected the resilience and quality of life outcomes (Haase et al., 1992). When childhood cancer survivor's protective factors are positively reinforced, the individual's risks factors decrease. Individual risks were measured from Section II of the researcher-developed Risk Assessment Questionnaire. Experts for validity had reviewed Section II of this instrument and its reliability was assessed during this research study.

Cancer Types. The type of cancer influences quality of life. Cancer types assessed in this study were those with brain tumors and those with leukemia. These two types of cancer were chosen because research has shown these types have the worst and best outcomes respectively. The type of cancer was requested on the demographic questionnaire.

Demographics. Age, gender, and socioeconomic status have been identified as potential risk factors to the individual experiencing cancer. These variables were included on the demographic questionnaire.

Research Questions

The following research questions are being explored in this study:

1. Is there a difference in the quality of life between Taiwanese childhood survivors of brain tumor and leukemia?
2. What is the relationship between quality of life and resilience in the Taiwanese childhood survivors of brain tumor and leukemia?
3. How do the following variables affect quality of life -- type of cancer, resilience, protective factors, illness-related risks, individual risks, and demographics -- in Taiwanese childhood survivors of brain tumors or leukemia?
4. What does quality of life, resilience, protective factors, illness-related risks, and individual risks mean to Taiwanese childhood survivors of brain tumors or leukemia?

Summary

Impact on childhood cancer and numerous long-term effects of childhood cancer have been discussed. The result of advances in the treatment of childhood cancer has increased the number of survivors reaching adulthood. Childhood cancer survivors remain a neglected population in the area of physiological, psychosocial, and occupational services. There is little

theoretical research conducted on the experience of these survivors or on interventions developed that might help them positively adjust to the surviving experiences. The purpose of this study is to explore the phenomenon of survivorship of childhood cancer in Taiwan and its implications for clinical practice. In this study, the ARM serves as the theoretical framework. This study will be one of the first investigations using triangulated methodologies to explore the relationship between the variables in a Taiwanese population. A thorough discussion of the literature is presented in Chapter 2.

CHAPTER 2

REVIEW OF THE LITERATURE

This review of the literature addresses the following: (a) surviving childhood cancer, (b) illness-related and individual risks, (c) protective and resilience factors related to childhood cancer survivors, (d) quality of life on childhood cancer survivors, and (e) critique and gaps in the literature.

Surviving Childhood Cancer

As more children survive cancer rather than die from it, there are increased burdens placed upon the health care system, the family, and the community. Cancers and its treatment can have life-altering late effects on the childhood cancer survivors. As survival rates keep increasing and length of life following cancer has been extended, it is becoming more obvious that childhood cancer survivors are paying a price for their survival. Research indicates that surviving cancer is tough for adult patients (Dow, 2003); however for childhood cancer patients, surviving cancer has profound effects physically, mentally, and socially, exacerbating the challenges inherent in normal developmental processes (Schulmeister, 2004). According to the suggestions by the American Cancer Society (Haase, Mauer & Reaman, 1998), long-term quality of life assessment is a critical issue in childhood cancer survivors because it assesses the influence of cancer diagnosis and its treatment on children, their development, families, peers, and social institutions across their life.

The treatment for childhood cancer and the survival rate of the patients of children cancer in Taiwan is similar as that in the U. S., but the attention paid to the patients and the survivors in Taiwan is far less than that in Western countries. For example, the U.S. has founded institutes such as the Children's Cancer Group (CCG) and the Pediatric Oncology Group (POG), etc., that

can support the epidemiological studies, sponsor workshops related to childhood cancer, and encourage clinical research in pediatric oncology. Such institutes do not exist in Taiwan. Though there is health insurance for all citizens in Taiwan, health disparities among vulnerable population such as childhood cancer survivors still exists. At present, there is no official organization in Taiwan to research and support pediatric cancer control, issues of childhood cancer survivorship, late effects of treatment, psychosocial outcomes, and long-term care. This investigator hopes the results of this study can inspire Taiwan medical personnel to better understand and care for childhood cancer survivors; as well as influence the Taiwan government to better support this vulnerable population.

Illness-Related Risks in Childhood Cancer Survivors

Life-threatening illnesses (e.g., cancer) bring hardship and terror to children, both physically and psychosocially (Woznick & Goodheart, 2002). The intensive treatment leads to frequent and sometimes long hospitalizations, with distressing, repeated, invasive, and painful procedures, radical changes in physical appearance, and numerous physical side effects. Clinicians have found that survivors of childhood cancer are at an increased risk for death related to therapeutic interventions and secondary cancers, substance abuse, uncertainty, vulnerability to future health problem, powerlessness and isolation (Woznick & Goodheart, 2002). In addition, there are physical and psychosocial developmental adversities compromised by the cancer itself, coping difficulties with the cancer diagnoses and the survivorship, rejection or alienation from peers or others, disruptions at home, and school difficulties related to the numerous days missed (Woznick & Goodheart, 2002). The illness-related and individual risks for childhood cancer survivors are dependent on the original disease and location, the survivorship potential for the cancer type, the type and intensity of treatment modalities, the child's age, gender and

developmental stage at diagnosis, their temperament and personality characteristics, and family and other support systems (Woznick & Goodheart, 2002).

Second neoplasm. Excluding the original cancer, the second neoplasm was a significant leading cause of death in survivors of childhood cancer (Mertens, Yasui, Neglia, Potter, Nesbit, Ruccione et al., 2001). Being a patient with cancer, particularly a pediatric or adolescent survivor, significantly increased the risks of second neoplasm at other body sites.

Mertens et al. (2001) demonstrated that in 5-year survivors of childhood and adolescent cancer, they had a 10.8-fold excess in overall mortality ($CI_{95} = 10.3, 11.3$). There were significantly higher mortality in female survivors ($M = 18.2$) and survivors with an initial diagnosis of leukemia ($M = 15.5$) or CNS tumor ($M = 15.7$). Moreover, other reports showed that the chance of contracting a second malignant neoplasm in survivors of childhood cancers were six to 10 times higher than in the general population diagnosed with a first cancer (Vega-Stromberg, 2004).

Cardiac dysfunction. Radiation (Lackner, Benesch, Schagerl, Kerbl, Schwinger & Urban., 2000) and chemotherapy agents, including anthracyclines (Lackner et al. 2000) or dexrazoxane (Lipshultz, Rifai, Dalton, Levy, Silverman, Lipsitz, et al 2004), used for childhood cancers, have been linked to decreased heart function in childhood cancer survivors. Lackner et al. (2000) observed that anthracyclines and irradiation decreased left ventricular ejection fraction to below 50% in survivors of childhood cancer. More than 50% of long-term childhood cancer survivors of ALL were treated with anthracyclines or doxorubicin (Lipshultz, et al 2004), many of them had long-term cardiac problems, including late congestive heart failure (Kremer, van Dalen, Offringa, Ottenkamp, & Voute, 2001).

Respiratory problems. Childhood cancer survivors of leukemia who received radiation therapy to the chest wall, certain chemotherapy drugs such as bleomycin (Thrall & Scalise, 1995) or cancers that spread to the lung from other primary sites were vulnerable to pulmonary problems such as decreased lung volume, fibrosis, and an inflammation of the lung tissue (Lackner et al., 2000). Pulmonary fibrosis was the most common respiratory late effect and could occur months or even years after treatment and all of the pulmonary side effects could cause difficulty in breathing, coughing, and difficulty with exercise in survivors of childhood cancer (Bottomley & Kassner, 2003).

Neurological deficits. Many long-term childhood cancer survivors who received CNS irradiation, intrathecal chemotherapy (e.g., MTX) or brain surgery suffer from neurological late effects (Bottomley & Kassner, 2003). For example, long-term survivors of leukemia treated during a younger age or who were female might be at risk for neurocognitive sequela (Leung, Hudson, Strickland, Phipps, Srivastava, Riberio, et al., 2000). Anderson, Godber, Smibert, Weiskop & Ekert (2000) documented that high-dose chemotherapy, radiotherapy (> 18 Gy), or chemotherapy plus radiotherapy delivered to the CNS was associated with learning disabilities (cognitive impairments) in survivors of childhood ALL who were 5 years-old or less at time of diagnosis. Lackner et al (2000) found that, at the end of cancer therapy, the nervous system was the most frequently affected organ system compared to the endocrine system or the other systems and that the brain tumors caused a higher proportion of severe neurological deficits (>80%) when compared to leukemia.

Renal side effects. Renal damage (e.g., tubulopathy, asymptomatic urinary electrolyte wasting, glomerular dysfunction) may be associated with irradiation doses and chemotherapy agents with high cumulative doses (Rossi, Godde, Kleinebrand, Boos, Ritter & Jurgens, 1994;

Skinner, R., Pearson, English, Price, Wyllie, Coulthard, M. G., et al., 1996). The Lackner et al. (2000) study found 39 of the 223 (17%) survivors of childhood malignancies of the kidneys were affected by single chemotherapeutic agents (e.g., cisplatin at a median cumulative dosage [MCD] of 545 mg/m^2 , ifosfamide [MCD 15 g/m^2], or combined agents such as cisplatin [MCD 400 g/m^2] and ifosfamide [MCD 18 g/m^2], or abdominal irradiation with a median irradiation dosage of 33.9Gy).

Abnormal endocrine function and growth. Endocrine dysfunctions were also significant consequences of childhood cancers and their treatment modalities documented in 20% - 50% of childhood cancer survivors (Sklar, 2001). The risk of developing these adverse events was related to the cancers and/or its treatment with chemotherapy and radiation therapy (Cohen, 2003). Endocrine late effects include hypothalamic-pituitary, thyroid, and gonadal dysfunction and these disorders could cause abnormal growth and infertility (Cohen, 2003; Siebler, Shalet, & Robson, 2002).

Orthopedic late effects. Radiation therapy and chemotherapy could have serious adverse effects on bone metabolism and skeletal growth (Lackner et al., 2000; Siebler et al., 2002). The risk factors of survivors of childhood ALL with skeleton problems included the original cancer invading the bones (Cohen, 2003); the chemotherapeutic agent, glucocorticoid, inhibiting the absorption of the vitamin D in bone; or a cranial radiation therapy dose of 24 Gy (Kaste, Jones-Wallace, Rose, Boyett, Lustig, Rivera, et al 2001). Osteoporosis was the most significant late effect at all phases of ALL usually becoming evident 20 years after therapies (Cohen, 2003). Partial or complete amputation of an extremity caused by cancer or its treatment results in muscle group imbalance or loss of limb function due to little use of the amputated extremity (Bottomley & Kassner, 2003), further decreasing survivors' physical activities.

Sexual development and reproduction. The development of healthy sexuality was dependent on such factors as having healthy physical, psychological, and interpersonal skills. A cancer diagnosis and its treatment had the potential to disrupt the healthy development of any one of these factors. A number of studies highlighted the devastating effects that childhood cancer treatment had on sexual self-concept, body image, and identity formation in generally well-adjusted survivors (Madan-Swain, et al., 2000; Olivo & Woolverton, 2001; Puukko, Hirvonen, Aalberg, Hovi, Rautonen, & Siimes, 1997). The use of more aggressive treatments could increase the number of people at risk for reproductive failure. Female cancer survivors who received chemotherapeutic agents (e.g., cyclophosphamide) were vulnerable to both infertility and loss of sex steroid hormone production (Cohen, 2003). Male cancer survivors who received chemotherapy (i.e., alkylating agents) and radiation therapy caused both testicular damage and abnormalities of gonadal function (Bhatia & Landier, 2005).

Hepatic dysfunction. Abdominal radiation, chemotherapy, and blood transfusion could cause hepatic problems and led to the development of fibrosis, cirrhosis (Bottomley & Kassner, 2003), and transfusion-mediated hepatitis B or hepatitis C (Strickland, Riely, Patrick, Jones-Wallace, Boyett, Waters, et al., 2000). Lackner et al (2000) studied 223 survivors of childhood cancer who were off cancer treatment for over 9 years and found that 12 % of survivors had liver problems (e.g., hepatitis viral infection, elevated liver enzymes) and 8 % of survivors demonstrated chronic HBV, HCV infection, asymptomatic HBs- Ag carrier, and cirrhosis cause by concomitant HBV and HCV.

Hearing and vision damage. Hearing and visual loss could result from tumor involvement in that area, chemotherapeutic agents, radiation therapy, or prolonged use of antibiotics (Bottomley & Kassner, 2003). Frequently, radiation therapy given to the brain or near

the ear area following tumor resection or chemotherapeutic agents (e.g., cisplatin) induced hearing losses in childhood cancer survivors (Lackner et al., 2000). Vision might be affected from cancer, particularly if the tumor was on or near the eye, and cancer treatment with radiation and chemical therapy could be toxic to the eye leading to such complications as cataract formation, dry eye, blurred vision (Lackner et al., 2000; Nahum, Gdal-On, Kuten, Hertzl, Horovitz, & Vey Ben Arush, 2001).

Health status. The health status, complications, and development of childhood cancer have been investigated in recent years as the survival rate for children and adolescents with cancer has improved. According to Humple, Fritsche, Bartels, & Gutjahr (2001), 124 survivors of childhood cancer were followed for more than 20 years. The findings showed that 33% of the survivors had one or more serious therapy-related health problems, only 65% of the survivors achieved an adequate intellectual and mental development, and 26% of the survivors with tumors of the CNS had late effects of reduction of vision, including blindness. Hudson, et al. (2003) assessed the health of 9,535 adult survivors of childhood cancer with siblings as a comparison group. The results showed that 44% of survivors reported at least one adversely affected health domain and demonstrated poorer general health, more activity limitations, functioning impairment, and mental illness than their siblings experienced.

Individual Risks in Childhood Cancer Survivors

Developmental risks. Increased survivorship has raised issues about the impact of cancer on development processes of adolescent. According to Erikson's development theory, adolescence is a crucial stage to establish the roles and perceptions of themselves such as self-esteem, self-image, and self-confidence, build relationships with other people, develop the task of independence, and achieve physical and mental maturity for adulthood (Sigelman, 1999).

Piaget's theory of cognitive development states adolescence is the stage of formal operation in which adolescents can have the abilities to think about and use abstract ideas (Sigelman, 1999). Adolescents with a chronic illness experience such as cancer are at high risk for developing physical (Smith & Hare, 2004), cognitive (Winqvist, Vainionpaa, Kokkonen & Laning, 2002), emotional (Seitzman, Glover, Meadows, Mills, Nicholson, Robison et al, 2004), and behavioral problems (Langeveld, Ubbink, Last, Grootenhuis, Voute & De Haan, 2004) that can interfere with achieving normal development milestones.

Psychosocial risks. Due to the frequency of chronic medical complications, at-risk status, and the psychological trauma of earlier experiences, one might expect that all survivors of childhood cancer would experience a higher rate of psychosocial maladjustment than their healthy peers. Survivors might engage in more at-risk behaviors, experience academic achievement challenges and job discrimination, and have a multitude of emotions. However, the research on psychosocial outcomes of those survivors has shown equivocal and contradictory findings.

Researchers reported that adolescent survivors of childhood cancer were engaged in such risk-taking behaviors as smoking (Butterfield, Park, Puleo, Mertens, Gritz, Li, et al., 2004) and drinking problems. In contrast are the studies that have shown that pediatric cancer survivors were more resilient and more competent in their decision-making about risk participation and their use of cigarettes and illegal drugs was less (Verrill, Schafer, Vannatta, & Noll, 2000) than the general population (Emmons, Li, Whitton, Mertens, Hutchinson, Diller., et al., 2002). Other researchers also found less cigarette smoking ($p = 0.027$), lower levels of alcohol consumption ($p = 0.005$), and lower levels of recreational drug use ($p = 0.001$) than the control groups (Larcombe, Mott, & Hunt, 2002).

Cognitive risks. Cancer types, such as brain tumors and leukemias, or cancer treatment might cause physical or mental impairments that would make it more difficult to learn and would contributed to the poor academic achievement and difficulties in reading, language, and arithmetic for childhood cancer survivors (Bhatia & Landier, 2005; Winqvist et al., 2002). Recently, researchers were engaged in determining the relationships between a child's age, gender, diagnosis, and doses of cancer therapy, cognitive deficits, and academic performance. Cranial radiation therapy (CRT) caused female cancer survivors and survivors of childhood ALL to perform more poorly academically than survivors without radiation (Brown, Sawyer, Antoniou, Toogood, Rice, Thompson, et al., 1996). Childhood leukemia patients with 1800c Gy/s CRT had poorer overall performance in sensory selection, attention capacity, and sustained attention than the non-irradiated group (Lockwood, Bell, & Colegrove, 1999). Children with brain tumor who received neurosurgery and radiotherapy doses > 20 Gy were cognitively impaired (Poggi, Liscio, Galbiati, Adduci, Maimino, Gandola, et al., 2005). Children treated with cranial radiation therapy plus chemotherapy showed cumulative deficits in non-verbal and information processing skills (Anderson et al., 2000). Long-term survivors of childhood ALL treated with CRT in combination with MTX chemotherapy demonstrated deficits in attention, concentration, and the ability of sequencing and processing, but the doses of radiation and MTX were not associated with these deficits (Langer, Martus, Ottensmeier, Hertzberg, Beck, & Meier, 2001).

In Taiwan, academic performance was the most important criterion for evaluating children and adolescents' abilities of having a successful future; unfortunately, all-therapeutic modalities (i.e., chemotherapy, radiation therapy, or surgery) can cause abnormalities in physical and cognitive development. Despite this effect, research by Yeh (2002) and Yeh and Wang,

(2004) found that Taiwanese adolescents with cancer had significantly higher school competence and few attention problems when compared with the findings from the Western studies. The authors believe the Taiwanese adolescents' success were attributed to their cultural beliefs and practices that foster social success.

Occupational and vocational risks. Significantly more cancer survivors are unemployed. Unemployed survivors felt they faced job discrimination because of their cancer history (Forsbach & Thompson, 2003). More studies found that adult survivors of childhood cancer felt they had experienced discrepancies when trying to gain employment (Eiser, Greco, Vance, Horne, & Glaser, 2004; Langeveld, et al, 2003). In a comparison study, male survivors were less likely to be employed fulltime than female survivors (85% versus 92% respectively, $p < 0.02$) (Langeveld, et al 2003), and survivors of leukemia who were irradiated had higher unemployment rates than the general population (Pui, Cheng, Leung, Rai, Rivera, Sandlund, et al, 2003). In addition, there were correlations between employment status and self-perception. Unemployed survivors reported significantly higher mood disturbances than their unemployed siblings (Zeltzer, et al., 1997). One plausible explanation was that the mood disturbance in cancer survivors made it difficult to find or maintain a job. Also, Seitzman, et al (2004) found that unemployment increased the odds for negative self-concept among survivors of childhood ALL who received combinations of CNS irradiation and intrathecal MTX therapy.

Psychological risks. Many researchers have devoted their investigations to identifying the relationships of cancer disease and treatment to psychological outcomes. For example, a study by Glover, Byrne, Mills, Robison, Nicholson, Meadows, et al. (2003) found that 24% of childhood leukemia survivors reported they experienced mood disturbance, and survivors treated with high-dose CRT and MTX had higher risk of mood disturbance than those treated with no or low dose

CRT and MTX. Psychological problems have been found in adolescents with brain tumor as they internalize problems (48.4%), withdraw (22.6%), and have social interaction problems (22.6%) (Poggi, et al., 2005).

Cancer and its treatment could have a negative impact on a child's sense of self. Self-esteem is one's beliefs about oneself, the world, and the future. Several studies reported that self-esteem was rated less positively in childhood cancer survivors because of the effects of cancer on the developing self (Seitzman, et al., 2004; Varni, Katz, Colegrove, & Dolgin, 1994). Others have shown that self-esteem ratings of survivors were within normal range (Langeveld et al., 2004; Pendley, Dahlquist, & Dreyer, 1997). Survivors of pediatric cancer have reported lower self-esteem in the dimension of physical appearance (Essen, et al., 2000) and their low body-image led to difficulties in establishing relationships with siblings or others (Forsbach & Thompson, 2003). Some researchers demonstrated that survivors of the childhood cancer had lower self-esteem than their peers and, thus, were more prone to engage the risky behavior such as smoking (Emmons, Butterfield, Puleo, Park, Mertens, Gritz, et al., 2003).

Both positive and negative psychological impacts have influenced the worldview of children with cancer. Zebrack and Cheslers' study (2002) illustrated that survivors rated themselves high on happiness, feeling useful, life satisfaction, and their ability to recover from cancer and its treatment. Childhood cancer survivors with higher optimism were more competent overall and, under stressful situations, exhibited greater psychosocial adjustment as validated by greater social engagement with their peers and in their classrooms (Karian et al., 1998).

Influencing this worldview is the degree of uncertainty that pervades the child's reality. Uncertainty, defined as the unknown, the unknowable, a condition of not knowing indisputably; being unreliable, changeable, or erratic can lead to pain, anxiety, unpredictability, and potentially

negative outcomes (Bottorff, Ratner, Johnson, Lovato, & Joab, 1998; Parry, 2003). When uncertainty is high, it negatively affects the psychosocial adjustment of survivors (e.g., psychospiritual well-being and hope) (Parry, 2003; Zebrack, B. J., & Chesler, 2002). The most common and stressful sources of uncertainty for the childhood cancer survivors were: (a) health status (Park, Emmons, Malloy & Seifer, 2002), (b) infertility (Parry, 2003), (c) developing secondary neoplasm (Parry, 2003), and (d) fear of cancer developing in their next generation (Parry, 2003; Zebrack, B. J., & Chesler, 2001).

Survivors of pediatric cancer are at risk for developing psychological problems, such as depression and anxiety. Several studies described depression and anxiety as potential long-term consequences in survivors of childhood cancer (Essen, et al., 2000; Meeske, Ruccione, Globe, & Stuber, 2001). Zebrack, Zelter, Whitton, Mertens, Robison, Odom et al (2002) studied 5,736 survivors of childhood cancer and found that lower household incomes, lower education, unemployment, exposure to intensive chemotherapy, and gender (females > males) were more likely to indicate symptoms of depression in the survivors.

Posttraumatic stress disorders have also been identified in this population. Posttraumatic stress can follow the exposure to an extreme traumatic experience such as serious injury, near-death experiences, witness of events involving death, injury, or a threat to the physical integrity of another person (American Psychological Association, 1996). Cancer is a traumatic diagnosis that evokes feelings of fear, hopelessness, and terror. Treatments included many painful, invasive procedures leaving the patient with a fear of an unknown future. Once treatment is completed, infertility, growth problems, and cognitive changes became reminders of the previous traumatic event. All these factors could precipitate a full cluster of PTSD symptoms (e.g., re-experiencing the traumatic event, feeling psychologically numb, avoiding reminders of the event, and

reporting physiologic arousal). Several research studies have assessed the incidence of PTSD among survivors. Alter, Pelcovitz, Axelrod, Goldenberg, Harris Meyers, et al. (1996) and Meeske et al (2001) indicated that 22% of pediatric cancer survivors had associated symptoms of PTSD, psychological distress, and low quality of life (SF36) score. Hobbie et al (2000) found that of 78 young adults who had been treated for childhood cancer, 20.5% survivors met the American Psychological Association, Diagnostic and Statistical Manual criteria for PTSD. The study of Stuber, Kazak, Meeske, Barakat, Guthrie, Garnier, et al (1997) noted that female survivors of childhood cancer reported more symptoms of PTSD irrespective of completion of therapy.

Resilience and Protective Factors in Childhood Cancer Survivors

Resilience implies both internal and external adaptation despite illness-related risks or individual risks factors and is fostered by protective factors. Protective factors derived from inner strengths may be encouraged by circumstances or people who allow or help children deal with difficult problems and situations in a positive way. The presence of protective factors can help reduce the impact of these risks. As often reflected in the literature, resilience and protective factors contain the internal and external factors, discussed below:

Nature-nurture. Why do some children face adversities optimistically while others sink into despair and depression? No one knows for sure why some children conquer their problem while others do not. Do they have this ability to overcome the difficulties congenitally, somehow programmed by DNA or acquire the ability by training and learning during their development? Kim-Cohen, Moffit, Caspi, and Taylor (2004) believe resilience is an interaction between nature and nurture. Some researchers believe resilience is innate and that resilient children are invincible to stress (Curtis & Citthetti, 2003). Some have stated that resilience can be fostered

through appropriate interventions. For example, Hardin, S., Weinrich, S., Weinrich, M., Garrison, Addy, & Hardin, T, (2002) designed a longitudinal study to test 1,230 adolescents who had been exposed to Hurricane Hugo, and the results have been shown that adolescents who had received nursing intervention programs designed to enhance their self-efficacy had less mental distress and higher resilience than the control adolescents.

Cognitive. Research has examined the contribution of cognitive functioning to resilient outcomes (Curtis, 2000). It has been stated that cognitive impairments have been evident in survivors of childhood cancer (Langer et al., 2001; Lockwood et al., 1999). Because of the actual or potential late effects of cancer treatment on cognition, Hollen, Hobbie, Finley, & Hiebert, (2001) examined the relationship between risk behaviors, decision making and resilience of cancer-surviving adolescents and found resilient adolescent survivors with cancer appear to have more quality problem-solving and decision-making skills than those who were not resilient.

Personality. Resilient children's personality characteristics include positive self-esteem, optimism, sense of humor, being empathic, and an internal locus of control (Hunter, 2001a, 2001b; Hunter & Chandler, 1999). The results of research have identified particular personality factors that help distinguish resilient children. They are: a) problem solving in an active, evocative way, that enable them to overcome emotionally hazardous experiences, b) sense of humor, c) optimism even under disturbing circumstances, d) good self-esteem, e) hope and having a positive attitude, and f) creativity (Brooks & Goldstein, 2001; Mandleco & Peery, 2000; Rak & Patterson, 1996).

Self-esteem includes feeling and beliefs that one is capable of taking challenges, learning how to overcome difficulties from experiences, and respect for others and oneself. A positive sense of self-esteem was believed to contribute to resilience in face of adversity and can

influence social and emotional health (Hunter, 2001a, 2001b; Hunter & Chandler, 1999). Self-esteem in facilitating adjustment and active-positive coping during adolescence has been proposed by many researchers (Compas, Hinden, & Gerhardt, 1995; Steinberg & Morris, 2000). Being able to understand self, holding positive self-esteem, and strengthening oneself when in stress all play protective roles in at-risk young people. The positive self-esteem is reflected by effective coping skills and feeling of confidence or faith that everything is going to be all right (Davey, Eaker, & Walters, 2003; Rak & Patterson, 1996). Self-esteem helps at-risk children become more resilient. It appears that when stressful events do not overwhelm the ability to cope, the victory over misfortune will enhance the sense of accomplishment (Niiya, Crocker, & Bartmess, 2004). Evidence has demonstrated that positive self-esteem, self-efficacy, and confidence play a significant role in resilience (Compas et al., 1995; Davey et al., 2003).

Locus of control is the belief that one has the capacity to effectively resolve or control what is occurring in one's life. Individuals who believe that they can control events will be less affected by a degrading environment than those who do not believe that they can overcome obstacles or prevent environmental degradation (Van Haaften, Yu, & Van de Vijver, 2004). Research demonstrated that high level of control-loss such as worries about loss of friends, abilities, confidence, or body parts are evident among adolescents with cancer (Kameny & Bearison, 2002). It is necessary to investigate whether or not this holds true for childhood cancer survivors.

Optimism. Stubblefield (1995) defined optimism as expecting a positive result, putting emphasis on the present and the future, holding control, and being competent. A person with a positive outlook could reduce risk, overcome difficulties, cope with stress, and maximize the chance of success (Brooks & Goldstein, 2001). Several studies illustrated that optimistic

viewpoints helped maintain hope in dealing with misfortune, something life-threatening, or mental illness (Herman-Stahl & Petersen, 1996; Karian et al., 1998). Having hope when facing life-threatening diseases could serve as a protective function in survivors of childhood cancer by protecting the survivors from experiencing severe despair and helping them tolerate situations in which some or all of their needs were not met (Karian et al., 1998). Is resilience linked to a sense of optimism? Many survivors do overcome cancers with optimism and are ready to take challenges in life. Researches show that some of cancer survivors thought the disease brought them maturity, new strength, optimism, and found a balance in the new life (Karian et al., 1998; Persoon & Hallberg, 2004). In contrast, Gotay, Isaacs, and Pagano (2004) found that cancer survivors exhibit higher level of resilience, but not optimism, than control populations. Future research could help to find out what makes some resilient survivors maintain physical and mental wholeness during fighting with cancers.

Hopefulness. Hinds (2004) defined the meaning of adolescent hopefulness as the degree to which young people have their own philosophy of life, insist on their own ideals and hope for their future life. Hopefulness is an essential factor for adolescents who are coping with a diagnosis of cancer and survive cancer (Hinds, Quargnenti, Fairclough, Bush, Betcher, Rissmiller, et al, 1999; Hinds, 2004). Hopefulness can improve self-esteem and self-competence in the face of life-threatening events. It plays a protective function in children, prevents the experience of overwhelming despair, and tolerates the crisis situation (Ritchie, 2001).

Sense of humor. A sense of humor is an emotional release that enables one to relax tension, makes one feel good, and promotes health and well-being in children with cancer (Dowling, Hockenberry, & Gregory, 2003; Woznick & Goodheart, 2002). Humor may help a child increase immune function, lower the incidence of infection (Dowling et al., 2003), reduce

their fears of illness (Dowling, 2002), and cope with the stressors of repeated hospitalizations (Boyd & Hunsberger, 1998). Research has identified that humor may enable children and adolescents with cancer to view a stressful event from an alternative perspective, reappraise stressors as less threatening and more of an opportunity (McDonald, 2001). It can also help children cope with pain, loss, fear, anger, and uncertainty imposed by cancer and its treatment (Frankenfield, 1996), and promote psychological adjustment among children with cancer experiences (Dowling et al., 2003). A sense of humor has been described as the effective way to face this disease and “a big stress reducer” (Keene, Hobbie, & Ruccione, 2000) by childhood cancer survivors.

Creativity. Creativity is seen as a sign of mental health and emotional well-being. It involves cognitive processing and intelligence (Simonton, 2000). Research on creativity confirms that creativity can promote psychological adjustment and growth (Maranan, 2003; Simonton, 2000), and provide survivors with cancer to navigate the uncertainty and find meaning in their illness (Ferris & Stein, 2002). Investigators have demonstrated that children and adolescents have possession of creative potential (Simonton, 2000) and the creative process can help trauma survivors cope with stress (Amir & Lev-Wisei, 2001). Resilience research has shown that children with particular talents, such as creativity, have succeeded in spite of stressful and traumatic environment (Lev-Wisei & Amir, 2003).

General health. Resilient children have few childhood illnesses, they are physically strong, emotionally healthy (Cummins, Ireland, Resnick, & Blum, 1999), and positive perceptions of general health and well-being (Wagnild & Young, 1993). Resilience has been studied in relation to mental health and prevention of psychopathologies, but the phenomenon of resilience has received little attention in relation to the physical health condition. Given the

consistent association between physical health and resilience, Cummins, et al.,(1999), examined 13,454 at -risk Native American adolescents. The findings showed that over 70% of the males and females felt a sense of satisfaction with physical self; physical health was positively associated with emotional health and resilience. In contrast, survivors with physical disabilities experienced maladjustment of the mind as well as the body that presents extreme challenges to childhood resilience (Blakeney, Rhonda, & Meyer, 1998). Further, the results of cancer and its treatment-related late effects, those who were survivors of brain tumor most likely to report more performance limitations and restricted abilities to do routine activities than survivors of others childhood cancer (Ness, Mertens, Hudson, Wall, Leisenring, Oeffinger, et al., 2005).

Support systems. Family has a pivotal role in contributing to children's resilience. Family bonding and caring relations not only facilitate the development of positive expectations in life but positively influence a child's development (Hunter, 2001a; Hunter & Chandler, 1999; Spring, Wright, & McCall, 1997). Research has revealed that either children with cancer or adolescent survivors of cancer who report healthy adjustment and adaptation perceive their families to have strong cohesiveness (Newby et al., 2000; Novakovic, Fears, Wexler, McClure, Wilson, McCalla, et al., 1996). Parental participation in care is perceived as the most important factor to facilitate coping in children with cancer (Eiser, 2003; K. Enskar & von Essen, 2000). In the study by Orbuch, Parry, Chesler, Fritz, and Repetto (2005), childhood cancer survivors who report better relationships with their mothers and fathers consistently report a higher resilience ability and quality of life, especially in the psychological domain. This is of particular importance in cultures where family is the mainstay of social function such as in the Taiwanese's culture. The role of family support enhancing adjustment of child with cancer are found in several Taiwan studies (Chao, et al., 2003; Yeh, 2001a).

Positive peer relation is another significant support variable, critical for establishing intimacy, trust, and support relationships, especially in adolescence (Criss, Pettit, Bates, Godge, & Lapp, 2002; Hartup, 1996). Peers are mentioned as important protective factors for resilient adolescents facing difficult and arduous situations (Mackrell & Lavender, 2004). It has been identified that children with cancer have disruptions in peer relations because of frequent hospitalization and physical appearance changes. Friends, school peers, and friends with the same illness are important and offer support to help adolescents deal with the cancer experience (Novakovic et al., 1996; Yeh, 2002). In Bessell's (2001) triangulated study, it was reported that 47% of the adolescent cancer survivors appreciated the acceptance and understanding they received from their peers and described their peers as those who can "always be counted on no matter how their parents try to get them to stay away because they think that cancer is contagious" (p.354).

Social support might reduce the effects of stress. It can enhance the adolescents' feeling of hopefulness, self-esteem and well-being (Yarcheski, A., Mahon, & Yarcheski, T, 2001), and thus control over the difficult situations. Social support is particularly promising in enhancing disease adjustment and adaptation. Children and adolescents who have cancer or who survive cancer express the need of social support to promote their self-esteem and cope with cancer, which may, in turn influence psychosocial health (Akiko, 2001; Madan-Swain, et al., 2000).

Children require the presence of at least one caring person who can provide support for healthy development, engender trust and love, and convey passion, empathy, and respect (Hunter, 2001a; Laursen & Birmingham, 2003). A strong contributor to resilience is a long-term relationship with someone who displays a consistent, unconditional positive and faith in the child's ability to overcome adversity. Caring relationships may offer the at-risk child friendships

that help promote high self-esteem, encourage social and scholastic success and give the child a sense of high expectations. Research found that adults such as loving foster parents, relatives, helpful teachers, good neighbors, or someone meaningful to the child during or after major stress are the most critical and consistent protective factor (Hunter, 2001a; Werner & Johnson, 2004).

Culture. Coping is strongly affected by the overall culture attitudes and social values. Resilience in cancer survivors may be highly associated with the positive or negative attitudes the whole society take toward the survivor. In Taiwan, despite advances in medical technology, cancer is still perceived as a deadly illness (Yeh, Lin, Tsai, Lai, & Ku, 1999). The family's respect for Western medicine contributes to their acceptance of the cancer diagnosis, but they will search for alternative modalities -religious beliefs and practices to find a possible explanation of cancer. Yeh, Tsai, Lin, W., Lin, C., Li, & Yang, (2000) found that Taiwanese parents of children with cancer, regardless of socioeconomic status or educational level, have been using a variety of alternative therapies relieve the side effects of cancer treatment, improve the child's ability to cope with unpleasant cancer experiences, increase the child's internal strength, and maintain the child's hope. Also, in Yeh's (2001b) study it was reported that 40% of Taiwanese families consulted with diviners regarding their or their child's health status. Diviners explain that the cause of a child's illness is because of a conflict between a child's birth date and a Chinese character in his/her name. Certain rituals are then performed to diminish the harmful influence that cause the child's illness such as: changing a child's name or taking "Fu" water (Yeh, 2001b). Some studies have shown that Taiwanese parents of children with cancer tended to attribute their children's illness to his or her wrongdoing in the past life (Yeh, 2001b, 2004). Such explanations of illness or rituals may result in a punitive judgment on the parents and

patients, thus affecting psychosocial adjustment among childhood cancer survivors or children with cancer (Chao et al., 2003).

Communication. Providers have often believed that it is vital that cancer survivors receive the appropriate information about their disease, the late effects from treatment, and the need for long-term follow-up. One's study found that deficits of knowledge about their diagnosis and treatment in adult survivors of childhood cancer and impaired the survivors' ability to seek appropriate long-term follow-up care (Kadan-Lottick, Robison, Gurney, Neglia, Yasui, Hayashi, et al., 2002). Studies have documented that sharing information can reduce adolescent risk-taking behaviors (Cox, McLaughlin, Steen, & Hudson, 2006), lower uncertainty (Decker, Phillips, & Haase, 2004), and promote psychology well-being (B. J Zebrack & M. A. Chesler, 2002) in survivors of pediatric cancer. In Taiwan, cancer still carries a stigma of "death" (Yeh et al., 1999). Death is the most serious taboo event in the life of the family and individuals in Taiwanese culture. Parents want to use the word "sick" instead of "cancer" when talking with their children. People avoid discussing cancer to keep from feeling uncomfortable. Parents requested that health care providers join in a conspiracy of silence to "protect" patients from a full understanding of cancer diagnosis (Yeh, 2001a, 2002).

Quality of Life on Childhood Cancer Survivors

As survival rates increase, issues concerning the quality of life of children with cancer become increasingly relevant. J. E. Haase's and her colleagues have focused on quality of life of adolescents with cancer or chronic illness on several studies. The qualitative study of Haase & Rostad (1994) indicated that positive family atmosphere and keeping relationships with friends might enhance quality of life for adolescents with cancer. The triangulated research of Haase, Heiney, Ruccione & Stutzer (1999) found that family (parent-specific) and social support

directly influenced the adolescents' response to their illness experiences. This study also identified that the resilience of adolescent with cancer ($n = 130$) and adolescent with chronic illness ($n = 73$) directly influenced the participants' quality of life (the greater resilience, the greater quality of life of the adolescents).

Langeveld et al (2004) revealed that female gender, unemployment, severe late effects/ health problems and a low self-esteem were predictors of worse quality of life in survivors. Few studies have been found to describe quality of life in childhood cancer survivors. Different ages of survivors, sample size, measurements, and methodologies resulted in different findings among these studies. For example, Zebrack & Chesler (2002) used the Quality of Life- Cancer Survivors questionnaire in 493 subjects 16 to 18- year-old survivors of childhood cancer, who rated themselves high on happiness, feeling useful, life satisfaction and their ability to cope with cancers and its treatment; however their hopefulness was tempered by uncertainty about their future. Eiser, Vance, Horne, Glaser & Galvin (2003) applied the Peds QLTM to test quality of life in 68 survivors of acute lymphoblastic leukemia and brain tumors; those who were > 8-year-old, female and male survivors, viewed themselves to have better physical health than psychosocial health. In the study of Shankar et al (2005) the Minneapolis- Manchester Quality of Life-Youth form was used with 8- to 12-year-old children. Ninety children with remission ≥ 1 year, 72 children with actively cancer treatment, and 481 healthy children without a history of cancer or other chronic disease comprised the sample. It was found that survivors reported a better psychological functioning ($p = .01$) and overall quality of life ($p = .04$) than either children undergoing therapy or the health control group, especially in the male survivors ($p = .02$). It was unclear why these children scored higher. All of these studies found that survivors of CNS

tumors had significantly lower overall quality of life scores as survivors than other cancer diagnoses such as leukemia or nonneurologic solid tumors.

The assessment of quality of life is dependent on the subjective explanation of that quality of life by the individual; therefore, it would be inappropriate to assess quality of life without consider one's cultural value and belief. The findings from quality of life studies on western children may not be applicable to Taiwanese children with cancer or childhood cancer survivors due to the culture differences. Currently, only Yeh, Chao, & Hung (2004) have studied this phenomenon with Taiwanese children with cancer and found that understanding of the illness and communication with parents or health care providers may have positive relations with quality of life. Relevant research still needs to be explored and developed in Taiwan.

Is there a relationship between resilience and quality of life? There is little if any research on this subject in current literature. Lawford & Eiser (2001) suggested that it is necessary to explore explicitly the relationship between these two related psychological concepts - resilience and quality of life and establish how well resilience can help explain individual variation in quality of life in young children.

Critique and Gaps in Current Literature

The literature review critically examined the studies that are related to children/ adolescents with cancer or childhood cancer survivors and indicated that there are strengths and limitations in all of the literature studies. Core conceptual and methodological concerns related to the studies and gaps in current literature will be discussed. Among the concerns and gaps are the following:

Limitations

After the review of the literature, it is evident there is a consistent absence of theoretical frameworks grounding the studies. Woodgate and McClement (1997) reviewed sense of self in children with cancer and in childhood cancer survivors from developmental constructs and socio-cultural perspectives; however, the majority demonstrate theoretical shortcoming resulting in a tendency to measure multiple variables and processes without a clear theoretical understanding of their relationships to survivors of childhood cancer.

There is evidence of limited research methodologies to study this complex phenomenon and this narrow perspective can result in a narrow understanding of the childhood cancer survivors. Designs to consider may be: 1) Cross-sectional design exploring all variables at one point in time and recognize the complex relationships between them, 2) longitudinal research to understand the complex processes between the survivors and its determinants, 3) qualitative research to understand the “lived experience” of survivors of childhood cancer. As Eiser, Hill, & Vance (2000) indicated, standardized measures may show few difference, however “interview data can highlight problems not include on questionnaire measures”(p.456). Triangulated research methodologies may enrich the findings identified from any single methodology and account for the lack of valid and reliable standardized pediatric instruments (Mitchell, 1986).

There are limitations related to sample and sampling size. Most research on this subject has involved adults. What are missing are the voice of the adolescent and younger adults and the voice of the family members of these cancer survivors. Heterogeneity of the sample with a particular cancer diagnoses is important when planning the research design; however, more variety in the types of cancer survivors have experienced would be important to explore whether there are trends either across the larger category of cancer or trends across the age group of the

survivors irrespective of the cancer diagnosis. Instrumentation adjustments to account for age, reading, and comprehension differences across samples could help assess the age-related effects of cancer and survivorship.

Though ethnicity was identified as a variable affecting the quality of life, resilience and risk factors of survivorship, there were only a few studies that included non-Western perspectives on this phenomenon. Therefore, one cannot assume that the results of these studies can successfully be generalized to other cultural groups. Phillips & Weekes (2002) identified several studies with multicultural focus, but only a few were related to cancer survivorship in culturally diverse groups. Last, Grootenhuis, and Eiser (2005) suggested that future studies should be established and based on collaborative research partnerships with culturally different population and with minimal racial and ethnic differences in order to expand the current body of oncology nursing research, survivorship for example. Moreover, Hunter (2001a) suggested that limitations in resilience research with adolescents from non-Western population might suggest a cultural bias.

Several studies have investigated illness-related risks, resilience, and quality of life among survivors of childhood cancer. However, the current studies should be interpreted in light of several methodology issues. For example, Shankar et al (2005) cross-sectional descriptive design about quality of life had valid and reliable instruments, patients and family members, and an excellent sample size; however is was limited by the theoretical deficiency, lack of a qualitative component to truly understand the child's perspective on quality of life, lack of ethnic diversity as all the participants were Caucasian, leading to the conclusion that the results can not be generalized to a more racially and ethnically diverse population.

Other studies provide potentially biased or inaccurate findings since they have small sample sizes (Bessell, 2001; Essen et al., 2000; Newby et al., 2000), lack of standardized instruments (Stuber et al., 1997; Zebrack & Chesler, 2001) and comparison groups (Meeske et al., 2001; Zebrack et al., 2002), or use a single methodological approach (Park et al., 2002; Parry, 2003) to predict psychosocial functioning and its correlation to adjustment or quality of life among childhood cancer survivors.

Gaps

The gaps in the literature relate to lack of theoretical underpinnings for the studies, lack of varied research methodologies to examine the phenomenon more completely, inadequate representation in the research samples, inattention to the effect of culture on survivorship, and limited reliable and valid instruments to measure the construct of resilience. Further research needs to be conducted to address these gaps as well as to identify if there is a common denominator transcending the phenomenon of survivorship, such as resilience? Are there cultural differences in the survivor rate, quality of life, or psychosocial adjustments in childhood cancer survivors? Are there differences in ones' experience of survivorship based on age of onset, gender, family system, culture, and therapeutic regime? Answering such questions is congruent with nursing philosophy regarding the integration of the physical, psychosocial, developmental, spiritual, and cognitive domains of personhood to traumatic life events. In western research, little attention has been given to understand cancer treatment-related factors that affect resilience and quality of life in adolescent survivors of childhood cancer and provide effective interventions to assist adolescent cancer survivors in dealing with illness-related stressors.

Furthermore, there is even less research about this phenomenon in the international arena. What are the "lived experience", the illness-related stressors, resilience, and quality of life

associated with adolescent cancer survivors in Taiwan? What does survivorship mean for Taiwanese survivors of childhood cancer? How do they define resilience? Are there differences when compared with the Olsson, Bond, Burns, Vella-Brodrick, & Sawyer (2003) and the Hunter and Chandler (1999) explanations of resilience? Does the cultural difference have a direct influence on the meaning of survivorship and resilience? What are the interactions among survivorship, resilience, and quality of life in Taiwanese childhood cancer survivors? Why some children survive more successfully than others? As a researcher, it is paramount to understand the phenomenon of Taiwanese adolescent cancer survivors and investigate the relationships between illness-related risk factors, resilience, and quality of life in Taiwanese adolescent cancer survivors. It may provide high quality of nursing care and facilitate efficacious interventions to enhance Taiwanese childhood cancer survivors' well-being.

Summary

It is important for researchers who are deeply concerned about pediatric cancer survivors to identify the individual risks factors, illness-related stressors, protective factors, resilience, quality of life, and the interactions among these three variables in childhood cancer survivors in the US and around the world. Given the phenomenal lack of such understanding in the international arena, a durable study in an international arena, specifically in Taiwan, would provide useful information for pediatric nurses to help childhood cancer survivors dealing with the challenges of survivorships and promote their well being. Therefore, an adequate sample size, reliable and valid instruments, and a triangulated research design should be considered in this study.

CHAPTER 3

METHODOLOGY

As has been presented in Chapter 1 and 2, surviving cancer is a unique experience. Using the ARM conceptual framework this study intends to explore the relationships of the variables of demographics, illness-related risks, individual risks, protective factors, resilience, and quality of life. The findings hope to explain why some childhood cancer survivors are more successful than others in experiencing quality of life and to assess whether the type of resilience the survivor practices influences that quality of life. This chapter discusses the research design, setting, sample and variables. Protection of participants in this study is delineated. Information concerning data collection and data analysis for this study is discussed.

Research Design

A triangulated research design was used to answer the following research questions. Among Taiwanese childhood cancer survivors: 1) Is there a difference in the quality of life between Taiwanese childhood survivors of brain tumor and leukemia? 2) What is the relationship between quality of life and resilience in the Taiwanese childhood survivors of brain tumor and leukemia? 3) How do the following variables affect quality of life -- type of cancer, resilience, protective factors, illness-related risks, individual risks, and demographics -- in Taiwanese childhood survivors of brain tumors or leukemia? and 4) What does quality of life, resilience, protective factors, illness-related risks, and individual risks mean to Taiwanese childhood survivors of brain tumors or leukemia?

The quantitative component was comprised of the following: three Likert Scale questionnaires measuring the six independent variables of resilience, protective factors, illness-related risks, individual risks, demographics, and the type of cancer; one Likert scale

questionnaire measuring the dependent variable of quality of life; and one demographic sheet. The qualitative component was comprised of a structured interview with invited individuals willing to participate, who had completed the quantitative measures. The structural interview formats included individual sessions and focus group. The questions asked were designed to further explore the quantitative variables. Examples of these questions are: “What does quality of life mean to you? ”, “What does resilience mean to you? ”, “What does protective factors mean to you? ”, “What does illness-related risks mean to you? ”, and “What does individual risks mean to you? ”. The qualitative component was expected to further explain the quantitative findings and could add to the reliability and validity of the instruments, especially when working with children in the international arena.

Instrumentation

The instruments to be used to assess the independent and dependent variables were the following:

Demographic Questionnaire. The information gathered was related to the participant’s age, gender, diagnosis, and socioeconomic status.

The Risk Assessment Questionnaire. On the basis of literature review, Hunter (2000), and Hunter & Hurtes (2001), the investigator designed a self-report questionnaire to explore the experience of illness-related risks and individual risks in childhood cancer survivors. There were 2 sections in this questionnaire. Section I- Illness-Related Risks questionnaire was designed from literature review, and Section II- Individual Risks questionnaire was subsumed from the subscales of the *Resiliency Attitudes and Skills Profile* and the *Adolescent Resilience Screening Instrument* (Hunter, 2000). Item numbers 2, 7, 17, 22, 23, 26, and 34 of the *Resiliency Attitudes and Skills Profile* and item numbers 6, 7, 8, 21, and 22 of the *Adolescent Resilience Screening*

Instrument were selected to measure individual risks. Higher scores reflected a higher degree of illness-related risks and individual risks.

The Protective Factors Assessment. The factors were subsumed from the subscales of the *Resiliency Attitudes and Skills Profile*: relationships, insight, independence, and value orientation. Higher scores reflected a higher degree of protective factor on childhood cancer survivors.

The Resiliency Attitudes and Skills Profile. The tool was developed by Hunter & Hurtes (2001) and contained 34 items. The items constituted the subscales: creativity, humor, independence, initiative, insight, values orientation, self-esteem, self-efficacy, and relationships with family, peers, and others. The nine subscales were evaluated with a 3-point rating scale: from 0, “strongly disagree”, to 3, “strongly agree”. The sum of items provided a score for each subscale. Higher scores reflected a higher positive resilience on childhood cancer survivors. In the study, 464 participants who were 12-19 years old came from different ethnic backgrounds such as Caucasian, Haitian descent, and African- American. The Cronbach’s alpha coefficients ranged from 0.92 to 0.96 (overall alpha = 0.91) (Hunter & Hurtes, 2001).

The Minneapolis-Manchester Quality of Life (MMQL). The tool was specifically designed for adolescent survivors of childhood cancer. To validate the instrument, the MMQL Form was administered to 397 adolescents. The seven scales of MMQL Form consisted of the following: physical functioning, psychological functioning, social functioning, cognitive functioning, body image, intimate relations, and outlook on life. Scoring ranged from 0 to 4. Higher MMQL scores indicated minimal negative effect and thus greater quality of life. Instrument reliability and validity including discriminate validity, content validity, and construct validity of the MMQL had been reported (Bhatia et al., 2002). Internal consistency reliability for all items ranged from 0.67 to 0.89 (overall alpha = 0.92).

Qualitative assessment asked the participants to write down or discuss open-ended questions about their perceptions of what did quality of life, resilience, protective factors, illness-related risks, and individual risks mean to them.

Procedures

Sample and Sampling

Chang Gung Children Hospital is a medical center in Taiwan. This hospital provides treatment, outpatient consultation, and research services for childhood cancer. From the hospital records database, a purposive sample of childhood cancer survivors who met the inclusion criteria were selected. Given the nature of the subject who accepted the invitation to participate in this research study, there was the potential for sample homogeneity; however the effect of homogeneity was tempered by the final sample size calculated by power analysis and the findings from the qualitative component of the study.

To achieve statistical significance the sample size was calculated according to Cohen's (1987) formula: at a power of 0.80, an alpha level of 0.05, a moderate effect as an R^2 of 0.13, and for 6 variables, the value of L is 13.62.

$$N = \frac{13.62(1 - 0.13)}{0.13} + 6 + 1 = 98$$

N = total sample size

L = effect size index

u = number of independent variables

The final sample size was 98 subjects. From the final sample, 3 brain tumor survivors with high scores, 3 brain tumor survivors with low scores, 3 leukemia survivors with high scores and 3 leukemia survivors with low scores on quality of life were recruited to answer the open-

ended questions. These cancer types were chosen because of the research findings that discussed these two types as having the worst and best quality of life outcomes respectively.

Inclusion criteria included:

1. Between the ages of 18 to 21
2. Diagnosed with brain tumor or leukemia < 16 years of age
3. Off cancer therapy ≥ 5 years
4. Cognitively able to understand and verbally answer the investigator's questions
5. Possess the ability to read and understand Chinese well enough to answer the questionnaire
6. No formal DSM – IV psychiatric diagnoses

Data Collection

After IRB approval from USD and Chang Gung Children Hospital in Taiwan, potential subjects were contacted about their willingness to participate in this study and all consent forms were signed. Eligible subjects were asked to complete the four questionnaires. Data were collected from these subjects that were selected from Chang Gung Children Hospital records database and at the outpatient clinics. Data had been collected between September 2005 and January 2006. Each subject had been informed about the study and been asked to sign the Consent to Participate form. The investigator had provided instructions on completing the questionnaire and to answer any questions for subjects about the questionnaires. The subjects who could not finish the questionnaires in the clinic were given a self-stamped envelope so that they could send it back to the researcher after they finished them.

From the pool of subjects who had completed the questionnaires, the investigator had recruited 3 brain tumor survivors with high scores, 3 brain tumor survivors with low scores, 3 leukemia survivors with high scores and 3 leukemia survivors with low scores on quality of life

and willing to answer open-ended questions about what did they think quality of life really is, what did resilience mean to them, what were their perceptions of protective factors in their lives, and their perception of illness-related and individual risks. The interviews included 9 individual interviews and one focus group.

The investigator and a research assistant had conducted all the interviews. During the discussions, tape-recording was used. Each interview lasted 45 minutes to one hour. The investigator examined the subjects' writings and the transcribed tapes to identify the words/phrases frequently repeated. Each of the subjects' documents had been retained and labeled with a corresponding number. A small stipend was given to each subject in the study.

Protection of Human Subjects

Approval for this study was acquired from the Human Subjects Committee, University of San Diego, as well as any Institutional Review Boards associated with the various facilities in Taiwan. Subjects were selected from those willing to participate in this study based on the eligibility criteria and had the right to withdraw from this study at any time. It was explained this study would entail minimal risks to subjects such as fatigue, embarrassment or feeling uncomfortable by answering or responding to the questions. Each of the subjects was given a copy of an informed consent. After a signed consent was obtained, the subjects were asked to complete the questionnaires. Confidentiality was assured by coding each subject with a corresponding number. No names were used on any of the data sets and any subject identification were removed immediately upon completion of analysis and all materials were locked in the investigator's study with access only by the investigator and the investigator's advisor. All data will be kept a minimum of five years before being destroyed.

Data Analysis

Quantitative data were carried out with the SPSS 11.0 software program. Descriptive statistics and inferential statistics were used in data analysis. Descriptive statistics (e.g. means, standard deviations, percentages) were used to illustrate the demographic characteristics of participants. For continuous variables, t-test was used to compare for scores of quality of life, resilience, protective factors, and risks assessment between types of cancer. Discrete variables were compared for differences between types of cancer by using Chi-square test and Fisher's exact test. Pearson and Spearman correlations were conducted to determine whether relationships exist among the quality of life, resilience, protective factors, individual risks, illness-related risks, and demographic. A simultaneous multiple regression analysis was used to examine the effect of all significant correlations-- resilience, protective factors, individual risks, illness-related risks, government assistance, and cancer types-- on quality of life. A second regression analysis using backward method was conducted using the following variables to determine the best regression equation: resilience, protective factors, individual risks, illness-related risks, age, employment, government assistance, gender, and type of cancer. All tests were conducted when the statistical test yielded a two-tailed probability of 5% (the significance level). Qualitative analysis included the process of reviewing interview and written works of the subjects for recurring themes that might help explain the quantitative results.

CHAPTER 4

PRESTATION OF FINDINGS

Based on the review of literature, in the present field of nursing in Taiwan, there is lack of researches about resilience and quality of life in survivors of childhood cancer. Such knowledge deficient may affect the quality of care to the survivors of childhood cancer. The purpose of this study was to identify the relationships between type of cancer, demographics, illness-related risks, individual risks, protective factors, resilience, and quality of life. Findings from this study may improve the quality of care to the childhood cancer survivors. A triangulated research design was utilized to explore the phenomenon of resilience and quality of life in Taiwanese childhood cancer survivors. The quantitative component was used to explore the relationships between type of cancer, demographics, illness-related risks, individual risks, protective factors, resilience, and quality of life in Taiwanese childhood cancer survivors; while a qualitative component was incorporated to help explain the quantitative findings and add to the validity of the instrument findings. There were six independent variables: cancer types, demographics, illness-related risks, individual risks, protective factors and resilience, and one dependent variable: quality of life in this study.

The following research questions were:

1. Is there a difference in the quality of life between Taiwanese childhood survivors of brain tumor and leukemia?
2. What is the relationship between quality of life and resilience in the Taiwanese childhood survivors of brain tumor and leukemia?

3. How do the following variables affect quality of life -- type of cancer, resilience, protective factors, illness-related risks, individual risks, and demographics --in Taiwanese childhood survivors of brain tumors or leukemia?
4. What does quality of life, resilience, protective factors, illness-related risks, and individual risks mean to Taiwanese childhood survivors of brain tumors or leukemia?

The description of the sample, discussion of instruments, and discussion of the quantitative results and the correlating qualitative validity findings of the study are presented in chapter 4.

Description of the Sample

The demographic portion of the survey (see Appendix A) was used to collect personal data from the subjects and was designed to seek information from which a profile of the sample could be developed. The following data were collected: gender, age, cancer types, years of cancer treatment completed, living styles, financially destitute, work status, and government assistance. Information for the selected control variables, chronological age, gender, and type of cancer was also obtained from survey.

The sample consisted of a purposive sample of 98 cancer survivors recruited from Chang Gung Children's Hospital in Taiwan from September 2005 to January 2006. The youth ranged in age from 18 to 21 years, the mean age was 19.85 years. The sample was evenly distributed with brain tumor survivors ($n = 49$) and leukemia survivors ($n = 49$). Sixty-one (62.2%) Ss identified their gender as male and 37 (37.8%) Ss identified their gender as female. The average year of time since diagnosis in all Ss was 6.38 ($SD=1.21$). The majority of Ss (84.7%) lived with parents, grandparents, or spouses. Thirty-eight (38.8%) Ss were financially destitute. Forty-six Ss (46.9%) employed and 24 (52.2%) Ss worked full-time. Forty one percent of Ss had incomes below

\$18,000 New Taiwanese Dollars per month. Nine (9.2%) Ss received government assistance.

The collected data are summarized in Table 1.

Table 1

Description of the Sample

Characteristic	n	%
Male	61	62.2
Female	37	37.8
Age (Mean, S.D.)	(19.85, 1.10)	
Years Since Diagnosis (Mean, S.D.)	(6.38, 1.21)	
5	28	28.6
6	30	30.6
7	21	21.4
8	14	14.3
9	4	4.1
10	1	1.0
Live with		
Live alone	15	15.3
Mother	69	70.4
Father	73	74.5
Grandparents	8	8.2
Spouse	6	6.1
Employment - No	52	53.1
Yes	46	46.9
Full time	24	52.2
Part time	22	47.8
Income		
≤ 18,000/month	19	41.3
18,001~30,000/month	14	30.4
> 30,000/month	13	28.3

Table 2 shows the proportions for each diagnostic group and the value of the Chi-square or *t*-test. As can be seen, there were significant differences in the demographic variables of living style between survivors of brain tumor and leukemia. In addition, significant differences were seen between survivors of brain cancer and leukemia that were financially destitute. There were more leukemia survivors (22.5%) who lived alone when compared to brain tumor survivors (8.2%) and more brain tumor survivors (16.3%) who received government financial assistance when compared to leukemia survivors (2.0%).

Table 2

Description of the Sample by Cancer Survivors Diagnostic Group: ^a Chi-square Test; ^b T Test; ^c Fisher's Exact Test; * $p \leq .05$

Characteristic	Brain Tumor (n=49)		Leukemia (n=49)		χ^2	t
	n	%	n	%		
Male	34	69.4	27	55.1	2.128	
Female	15	30.6	22	44.9		
Age ^b (Mean, S.D.)	(20.02, 1.01)		(19.67, 1.18)			1.564
18 ^a	4	8.2	10	20.4	4.272	
19	12	24.5	14	28.6		
20	12	24.5	7	14.3		
21	21	42.9	18	36.7		
Time since diagnosis ^b (Mean, S.D.)	(6.53, 1.37)		(6.22, 1.03)			1.251
5 ^a	15	30.6	13	26.5	5.467	
6	11	22.5	19	38.8		
7	10	20.4	11	22.5		
8	9	18.4	5	10.2		
9	3	6.1	1	2.0		
10	1	2.0	0	0.0		
Live with						
Live alone ^a	4	8.2	11	22.5	3.857*	
Mother ^a	38	77.6	31	63.3	2.400	
Father ^a	39	79.6	34	69.4	1.342	
Grandparents ^c	3	6.1	5	10.2	0.544	
Spouse ^c	3	6.1	3	6.1	0.000	
Financially destitute ^c						
No	5	23.8	3	12.0	1.108	
Yes	16	76.2	22	88.0		
Employment ^a						
No	28	57.1	24	49.0	0.656	
Yes	21	42.9	25	51.0		
Full time	10	47.6	14	56.0	0.321	
Part time	11	52.4	11	44.0		
Income						
$\leq 18,000/\text{month}$	9	42.9	10	40.0	4.652	
18,001~30,000/month	9	42.9	5	20.0		
$> 30,000/\text{month}$	3	14.3	10	40.0		
Government assistance ^c						
No	41	83.7	48	98.0	5.995*	
Yes	8	16.3	1	2.0		

Descriptive Findings

Youth participating in the study returned the self-administered survey instruments; the Minneapolis-Manchester Quality of Life (MMQL; Bhatia, et al., 2002), the Resiliency Attitudes and Skills Profile (RASP; Hunter & Hurtes, 2001), the Protective Factors Assessment, and the Risk Assessment Questionnaire (researcher-developed instrument). Reliability coefficients were computed for the overall scales and subscales. Cronbach's alpha was used to measure scale reliability for each instrument based on the sample in this study (See Table 3 and Table 4).

Measurements

Minneapolis-Manchester Quality of Life (MMQL; Bhatia, et al., 2002), a 47-item survey, was designed to measure physical functioning, psychological functioning, social functioning, cognitive functioning, body image, intimate relations, and outlook on life. This instrument has demonstrated good psychometric properties and has a reliability coefficient of 0.92 (Bhatia et al., 2002). This instrument had not previously been used as a measurement tool in Taiwanese populations; however, in this study, internal consistency reliability for all items was 0.94 (overall alpha = 0.94).

The Resiliency Attitudes and Skills Profile [RASP] (Hunter & Hurtes, 2001) a 34-item survey, was designed to measure creativity, humor, independence, initiative, insight, values orientation, self-esteem, self-efficacy, and relationships with family, peers, and others. This instrument has demonstrated validity and reliability with a reported reliability coefficient of 0.91 (Hunter & Hurtes, 2001). This instrument had not previously been used as a measurement tool in Taiwanese populations; however in this study, internal consistency reliability for all items ranged from 0.90 to 0.91 (overall alpha = 0.91).

The Protective Factors Assessment, a 24-item measurement, was subsumed from the following subscales of the RASP: relationships, insight, independence, and value orientation. In this study, the internal consistency reliability for all items ranged from 0.84 to 0.85 (overall alpha = 0.86).

The Risk Assessment Questionnaire, a 38-item questionnaire with two sections, was a researcher-designed instrument with the Individual Risks component subsumed from the RASP instrument and the Adolescent Resilience Screening Instrument (Hunter, 2000). It was developed to explore the experience of illness-related risks and individual risks in childhood cancer survivors. Section I of the Risk Assessment Questionnaire is the researcher-developed Illness-Related Risks component. Section II, the Individual Risks questionnaire includes items 2, 7, 17, 22, 23, 26, and 34 subsumed from the RASP and items 6, 7, 8, 21, and 22 subsumed from the Adolescent Resilience Screening Instrument. Content experts reviewed the content validity of Section I and II. Content validity was evaluated through three nurse experts and two adolescents. Analysis by these experts and adolescents indicated that the Risk Assessment Questionnaire accurately and adequately represented the conceptual domain of risk factors in childhood cancer survivors. In this study, internal consistency reliability for all items ranged from 0.75 to 0.79 (overall alpha = 0.78) with a reliability of 0.74 for Section I and 0.69 for Section II.

Table 3

Reliability Coefficients for Overall Scale of Quality of Life, Resilience, Protective Factors and Risks Assessment

Scale	<i>M</i>	<i>SD</i>	Cronbach's alpha
Quality of Life	111.09	26.98	0.94
Resilience	74.54	11.59	0.91
Protective Factors	53.04	7.87	0.86
Risks Assessment	14.14	6.63	0.78

Table 4

*Reliability Coefficients for Subscales of Quality of Life, Resilience, Protective Factors and Risks**Assessment*

Scale	<i>M</i>	<i>SD</i>	Cronbach's alpha
Quality of Life			
Physical	15.57	7.25	0.87
Psychological	27.93	5.58	0.75
Social	22.34	6.02	0.86
Cognitive	22.43	7.14	0.89
Body image	10.44	4.52	0.79
Intimate relations	4.05	2.02	0.68
Outlook on life	8.34	2.76	0.90
Resilience			
Insight	15.05	3.07	0.75
Independence	9.73	2.57	0.63
Creativity	8.78	2.09	0.75
Humor	6.50	1.59	0.56
Initiative	6.12	1.52	0.52
Relationships	14.23	2.21	0.64
Values	14.02	1.99	0.55
Protective factors			
Insight	15.05	3.07	0.75
Independence	9.73	2.57	0.63
Relationships	14.23	2.21	0.64
Values	14.02	1.99	0.55
Risks assessment			
Individual risks	9.28	4.88	0.69
Illness-Related risks	4.79	2.81	0.74

Quality Of Life (Dependent Variable) in Leukemia versus Brain Tumor Survivors

Quality of Life Scores. To examine differences in quality of life (dependent variable) for leukemia versus brain tumor survivors, 2-sample *t*-tests were run. The group means, standard deviations, and *t*-test results are shown in Table 5 below. Subjects who survived leukemia scored significantly higher on all quality of life scales when compared to those who survived a brain tumor (the higher the QOL score the better the quality of life). These findings were further elucidated by the qualitative validity component of the study

Table 5

T Test for Mean Difference in Quality Of Life Between Leukemia and Brain Tumor Survivors

	Brain Tumor		Leukemia		<i>t</i>
	<i>n</i> = 49		<i>n</i> = 49		
	Mean	S.D.	Mean	S.D.	
Quality of Life	96.00	24.86	126.18	19.70	-6.66***
Physical Functioning	11.67	6.36	19.47	5.90	-6.29***
Psychological Functioning	25.55	4.99	30.31	5.16	-4.64***
Body Image	8.29	4.15	12.59	3.82	-5.34***
Social Functioning	19.76	6.18	24.92	4.64	-4.68***
Cognitive Functioning	19.59	7.38	25.27	5.67	-4.27***
Intimate Relations	3.63	2.08	4.47	1.88	-2.09*
Outlook on Life	7.51	3.05	9.16	2.17	-3.09**

* $p < .05$, ** $p < .01$, *** $p < .001$.

Resilience in Leukemia versus Brain Tumor Survivors

Resilience Scores. As shown in Table 6, there was no significant difference on the overall Resilience score between survivors of brain tumors and survivors of leukemia. On the subscale, Values Orientation, survivors of brain tumors scored significantly higher than did survivors of leukemia (the higher the score the better resilience). Though no statistical significance between two groups, there are trends evident in the results: survivors of leukemia demonstrated higher scores across all factors except relationships and values orientation. These trends are further explained by the qualitative validity component of the study.

Table 6

T Test for Mean Difference in Resilience Between Leukemia and Brain Tumor Survivors

	Brain Tumor		Leukemia		<i>t</i>
	n = 49		n = 49		
	Mean	S.D.	Mean	S.D.	
Resilience	74.12	13.17	74.96	9.88	-0.36
Insight	14.96	3.44	15.14	2.69	-0.29
Independence	9.41	2.87	10.06	2.21	-1.26
Creativity	8.59	2.25	8.98	1.91	-0.92
Humor	6.22	1.65	6.78	1.50	-1.73
Initiative	6.02	1.61	6.41	1.41	-1.27
Relationships	14.39	2.33	14.08	2.09	0.68
Values Orientation	14.53	2.01	13.51	1.86	2.61*

* $p < .05$

Protective Factors in Leukemia versus Brain Tumor Survivors

Protective Factors Scores. As indicated in Table 7, there was no significant difference on the overall Protective Factors score between survivors of brain tumors and survivors of leukemia. For the subscale, “Values Orientation”, survivors of brain tumors scored significantly higher in means score than survivors of leukemia.

Table 7

T Test for Mean Difference in Protective Factors Between Leukemia and Brain Tumor Survivors

	Brain Tumor		Leukemia		<i>t</i>
	n = 49		n = 49		
	Mean	S.D.	Mean	S.D.	
Protective Factors	53.29	9.06	52.80	6.56	0.31
Insight	14.96	3.44	15.14	2.69	-0.29
Independence	9.41	2.87	10.06	2.21	-1.26
Relationships	14.39	2.33	14.08	2.09	0.68
Values Orientation	14.53	2.01	13.51	1.86	2.61*

* $p < .05$

Though there is no significant difference in protective factors between leukemia and brain tumor survivors, there are trends evident in the results: survivors of leukemia demonstrated higher scores on two (e.g., relationship and values orientation) of the four factors. These trends are further explained by the qualitative validity component of the study.

Illness-Related Risks in Leukemia versus Brain Tumor Survivors

Illness-Related Risks Scores. As shown in Table 8, there was a significant difference on the overall Illness-Related Risks score between leukemia and brain tumor survivors. For the Physical Complications subscale and Cancer-Related subscale, survivors of brain tumors scored significantly higher than survivors of leukemia. These findings were further elucidated by the qualitative validity component of the study.

Table 8

T Test for Mean Difference in Illness-Related Risks Between Leukemia and Brain Tumor Survivors

	Brain Tumor		Leukemia		<i>t</i>
	n = 49		n = 49		
	Mean	S.D.	Mean	S.D.	
Illness-Related risks	5.94	2.62	3.65	2.55	4.38***
Physical complications	0.76	0.43	0.45	0.50	3.23**
Psychological problems	0.24	0.43	0.24	0.43	0.00
Behavioral problems	0.08	0.28	0.12	0.33	-0.66
Cancer-Related concern	4.86	2.27	2.84	2.42	4.26***

* $p < .05$, ** $p < .01$, *** $p < .001$.

Individual Risks in Leukemia versus Brain Tumor Survivors

Individual Risks Scores. As shown in Table 9, there was a significant difference on the overall Individual Risks score between survivors of brain tumors and survivors of leukemia. For the Life satisfaction subscale (i.e., I believe I have very little fun in my life, too much pressure places on me by my family and friends, and too many problems in my life), survivors of brain tumors scored significantly higher than survivors of leukemia did. These findings were further elucidated by the qualitative validity component of the study.

Table 9

T Test for Mean Difference in Individual Risks Between Leukemia and Brain Tumor Survivors

	Brain Tumor		Leukemia		<i>t</i>
	<i>n</i> = 49		<i>n</i> = 49		
	Mean	S.D.	Mean	S.D.	
Individual Risks	10.76	5.23	7.59	3.85	3.19**
Family	0.45	0.89	0.19	0.67	1.63
Neighbors	0.04	0.21	0.10	0.38	-0.85
Life satisfaction	1.90	2.02	1.08	1.98	2.02*
Locus of Control	8.22	4.32	6.84	2.93	1.86

* $p < .05$, ** $p < .01$

Correlations Between the Independent and Dependent Variables

A correlation matrix was computed to examine the relationships between the independent variables, resilience, protective factors, individual risks, illness-related, age, employment, government assistance, gender and cancer types and the dependent variable, quality of life. As indicated in Table 10, significant positive correlations were found between quality of life and resilience and protective factors. Significant negative correlations were found between quality of life and government assistance, individual risks and illness-related risks. In addition, a significant correlation was found between cancer types and quality of life, as evidenced in the *t*-test. These findings were further elucidated by the qualitative component of the study.

Table 10

Correlations Between Quality of Life and Resilience, Protective Factors, Illness-Related Risks, Individual Risks, Age, Employment, Government Assistance, Gender and Cancer Types

Quality of Life and:	n	r
Resilience ^e	98	.51***
Protective Factors ^e	98	.42***
Illness-Related Risks ^e	98	-.57***
Individual Risks ^e	84	-.67***
Age ^e	98	-.05
Employment ^f	98	.07
Government Assistance ^f	98	-.27**
Gender ^f	98	.03
Cancer Types ^f	98	.56***

^e Pearson Correlation Coefficients. ^f Spearman Correlation Coefficients

* $p < .05$, ** $p < .01$, *** $p < .001$.

Multiple Regression Analysis with Significant Correlational Variables

Before multiple regression analysis was conducted, there was a test for multicollinearity. The resulting correlation matrix is shown in Table 11. Upon review there were multicollinearity between the independent variable (IV) of protective factors and resilience (.98), between the IV of individual risks and resilience (.77), between the IV of protective factors and individual risks (.74), and between the IV of individual risks and the DV of quality of life (.67). Though resilience and protective factors were highly correlated at .98, they are reported as two different variables in this study because of the findings relevant to them uncovered during the qualitative interview component of this study. There was evidence that resilience and protective factors had different meanings for the subjects.

Table 11

Correlations Between Quality of Life and Resilience, Protective Factors, Illness-Related Risks, Individual Risks, Government Assistance and Cancer Types

	Quality of Life	Resilience	Protective Factors	Illness- Related Risks	Individual Risks	Government Assistance
Quality of Life	1.00					
Resilience	.524***	1.00				
Protective Factors	.458***	.978***	1.00			
Illness- Related Risks	-.556***	-.380***	-.350***	1.00		
Individual Risks	-.674***	-.771***	-.735***	.429***	1.00	
Government Assistance	-.269**	.121	.081	-.321***	-.179	1.00
Type of Cancer	.562***	.102	.014	-.280***	-.326***	.145*

* $p < .05$, ** $p < .01$, *** $p < .001$.

A simultaneous multiple regression analysis was used to examine the effect of all significant correlations-- resilience, protective factors, individual risks, illness-related risks, government assistance, and cancer types-- on quality of life. As shown in Table 12, the regression results indicate an overall model of six predictors that significantly explain a change in the quality of life for cancer survivors ($r = .808$, adj. $r^2 = .626$, $p < .001$).

Table 12

Model Summary Coefficients for Multiple Regression Analysis

Model	Unstandardized Coefficients		
	B	Std. Error	t
(Constant)	109.825	29.039	3.782***
Resilience	.961	.848	1.133
Protective Factors	-.990	1.215	-.814
Illness-Related Risks	-2.090	.780	-2.608**
Individual Risks	-2.087	.702	-2.971**
Government Assistance	1.793	6.699	-.268
Type of Cancer	19.708	4.739	4.158***

* $p < .05$, ** $p < .01$, *** $p < .001$.

Multiple Regression Analysis Using Backward Method

A second regression analysis was conducted using the following variables to determine the best regression equation: resilience, protective factors, individual risks, illness-related risks, age, employment, government assistance, gender, and type of cancer. Employing the backward method in SPSS, the regression equation yielding the highest coefficient of determination (r^2) was computed ($r = .806$, $\text{adj. } r^2 = .631$, $p < .001$). Table 13 summarizes the model for this multiple regression.

Table 13

Model Summary Coefficients Using the Backward Multiple Regression Method

Model	Unstandardized Coefficients		
	B	Std. Error	t
(Constant)	108.736	25.744	4.224***
Resilience	.287	.256	1.124
Illness-Related Risks	-2.067	.772	-2.676**
Individual Risks	-2.134	.665	-3.208**
Type of Cancer	21.311	4.163	4.916***

* $p < .05$, ** $p < .01$, *** $p < .001$.

The advantages of the regression model using the backward method included a slightly higher adjusted r^2 (.631 instead of .626) and the use of two fewer variables. The variables eliminated from the second regression model were protective factors and government assistance because these two variables were not significant predictors. In other words, by using these variables, the r square was less predictable.

The results of the data analysis to each research question are presented as following:

Research question 1: There was significant difference in the quality of life between Taiwanese brain tumor and leukemia survivors of childhood cancer.

Research question 2: The relationship between quality of life and resilience in the Taiwanese childhood survivors of brain tumor and leukemia revealed a significant moderate positive correlation.

Research question 3: There were four predictive variables: resilience, illness-related risks, individual related risks and cancer types that have an effect on quality of life in the Taiwanese childhood survivors of brain tumor or leukemia. All of these findings had supported the three research questions.

Findings from the Semi-Structure Interviews

From the pool of participants who had completed the questionnaires, 3 brain tumor survivors with high scores on quality of life, 3 brain tumor survivors with low scores on quality of life, 3 Leukemia with high scores on quality of life, 3 Leukemia survivors with low scores on quality of life and who were willing to answer open-ended questions, were selected.

Each interview lasted approximately 45 minutes to one hour and revealed some important findings from the detailed analysis of the interview record that further explained the results from the quantitative analysis. The findings, as follows, address the four predictor variables identified by multiple regression for QOL:

Illness-Related Risk Factors

The prevailing theme for these survivors is one of *Chronic Fear*. The number of fears presented and the severity of those fears appeared to be the constant whether or not the cancer survivor scored well on QOL. This was irrespective of the type of cancer, gender, being a recipient of government assistance, and time since diagnosis. The types of fears discussed are uncovered below:

Recurrence. The fear their cancer would reoccur. The participants said: “Sometimes I am lost in worry of disease recurrence and thus feel depression”. “I still feel worried if the disease comes back again”. “I am afraid to go to see a doctor because I am afraid that he would tell me that the disease reoccurred”. “I don’t want to have recurrence of my disease”. “I always worry about the recurrence of the disease”.

Disability. The fear they were going to be disabled as a result of their cancer. For example, the participants said: “The disease damaged my right hand and my brain, it was really a big strike to me”. “I have less physical strength than others. I often ask for a sick leave, so I don’t

have a steady job”. “There are many complications of my diseases, memory disorders, impaired hearing and seeing ability etc; these complications make me have to depend on my parents”. “I cannot coordinate my body motions well, I have a different appearance, and sometimes I may have a seizure attack, some of my friends thought it was contagious, therefore they left me”. “The impairment of the memory due to the disease has severely damaged my impetus to seek my goals and dreams”.

Unable to fulfill role expectations. The fear their cancer made them non-functional as a man or woman. For examples: “I am the only son in my family. It is unfilial if I could not have a son to carry my family name”. “I [am] worry I can’t get pregnant because of my irregular menstruation”. “I am afraid that I may be “infertile” [infertility], I can’t accept the truth”. “I want to enjoy being a mother, however I had radiation therapy, I wonder this may effect my ability to carry a child” “I am concerned that infertility would decrease my chance of marriage”.

Individual Risk Factors

In this factor, the prevailing theme for these survivors was one of *Loss of Self*. This was irrespective of the type of cancer, gender, being a recipient of government assistance, and time since diagnosis. The types of losses discussed are uncovered below

Loss of self-efficacy. The loss of their sense of mastery over their lives. Some participants said: “I am fragile and easily beaten by frustration. I worry about my ability and lack confidence”. “I’m unable to devote myself to job requiring much strength”. “At work, I have less self-confidence. I think I cannot compete with my colleagues”. “I believe in fate. I think everyone has his own destiny and that it cannot be changed”. “I do not make lots of plans for my future because I can not control my life”. “My academic achievement was severely damaged due to memory disorders. And teachers scolded me for my poor scores. This made me lose my self-

confidence and thus I suspended my schooling”. “Being unable to bear the frustration, lacking confidence and courage to face the difficulties”. “I cannot express myself well linguistically, I feel myself inferior”.

Loss of self-esteem. The loss of their sense of self worth. The participants said: “My family thinks that I may be rejected and discriminated, therefore, they don’t support my marriage, I hate my family’s opinion”. “I don’t want others’ pity”. “I don’t want to be treated as a patient or be over-protected by others”. “I don’t tell my friends my disease because I fear that I will be discriminated against or be given more care”. “I do not want to be treated differently”. “I feel much better when they don’t discriminate against me”. “I don’t like my life now because my parents interfere with my life style a lot due to worry about my disease”. “My best friend in school thought cancer was contagious and left me. The bad experience of being discriminated hurt me a lot”.

Loss of future. The loss of a possible future. There were many statements reflecting these sentiments: “I feel I have bad luck to have the disease”. “I feel pessimistic when it comes to marriage”. “I still have many negative thoughts about my future, e.g. I may die in young age, my children may have cancer, etc ”. “I start to have a negative thought to everything after I had the disease”. “I feel my life is over”. “Nobody wants to fall in love with or marry a person who suffered from cancer before”.

Protective Factors

Though this variable was not identified as a predictor variable by the backward regression technique, it had been an important variable in the original regression model and the findings are helpful to care providers when they are designing appropriate interventions to

promote better quality of life for cancer survivors. The prevailing protective theme for these survivors was having a *Sense of Self*. The participants talked about:

Hope. Maintaining hope was important to overcome the individual and illness-related risks, being resilient, and having a good quality of life. For examples: “When I face the difficulties, I think everything is going to be OK some day”. “I don’t fear or worry about anything. When I face the difficulties, I think everything is going to be OK some day”. “I always have an optimistic view of my life”. “I face everything with optimism. I don’t want to ask for trouble myself”. “I can face my disease more positively. When I see someone with the disease die, I always tell myself that I can survive and I can make it”.

Self-esteem and self-efficacy. Feeling good about one’s self and believing each could control their life was important in overcome the risks variables being resilient, and having a good quality of life. For examples: “I am confident, optimistic, and cute. I believe I can get along with others easily”. “I can rebuild my confidence, doesn’t matter what is going to happen”. “I can be confident, don’t withdraw when facing difficulty”. “I can control my fate”. “I am a capable and independent person”. “I am confident of myself. I believe I can overcome the disease and I don’t regard myself as a sick person”.

Autonomy. Being self-sufficient and having the right to choose were important to overcoming the risk variables, being resilient, and having a good quality of life. Some participants said: “I have an independent personality. I can face the difficulty by myself”. “I try my best now to learn more skills in order to be independent of others”. “I don’t want to be a burden to others; I want to have my own life”. “I am very independent. I can take care of myself as long as I can”.

Being loved and valued. Believing one was important to others was important to overcoming the risk variables, being resilient, and having a good quality of life. The participants said: “My family and teachers encouraged me a lot”. “My parents encouraged me to be optimistic and not to escape the reality thus giving me the power to defeat the disease”. “Having the will to live can be reinforced by the encouragement of family and medical personnel”. “Once I tried to give up, but my mother did not allow this option, and she begged me to live. When I saw her tears, I felt I had more will to live”. “A nurse whose care and support helped me to survive the disease”.

Perseverance. The ability to weather the storm and not give up were important to overcoming the risk variables, being resilient, and having a good quality of life. Examples: “I have a strong will and that made me overcome the pain and discomfort”. “I have personality that I can tolerate anything as much as possible”. “I have philosophy that everything is going to be OK if I can tolerate it for a moment”. “Having the will to live”. “I can tolerate lots of pain caused by the disease or the treatment”. “I have strong ability to tolerate and strong will to live, this personality gives me the power to defeat the disease”.

Self-control. Having control over the information given or not given about the disease was important to overcoming the risk variables, being resilient, and having a good quality of life. For examples: “Understanding clearly the disease would have some influence on my will to live”. “My parents did not tell me everything about my disease, I think it was a correct decision, it would give me more hope and make me more optimistic”. “I don’t want to know everything of my disease because knowing everything will make me lose my confidence”. “I don’t want to be explained a lot about the disease because this will result in lots of fear and terrors to me”.

Adaptability. Being adaptable and flexible in the face of adversity was important to

overcoming the risk variables, being resilient, and having a good quality of life. For examples: “I have the ability to adapt, and this makes me accept my physical complications”. “Due to my physical limitations, I can modify my hope for the future”. “I did my best to adapt the complications”. “I am able to adapt myself to different circumstances”.

Resilience

The ability to overcome adversity is highly correlated with one’s quality of life. The overriding theme evident from the interviews was the participants’ perception that resilience was the *Ability to Rebound*. Such themes as those below support this notion.

Acceptance. Being able to accept and move forward rather than be defeated by the adversity is important being resilient. For examples: “I face the fact that I had cancer”. “I understand that it is impossible to recover thoroughly, so I gradually accept my present physical status”. “I can accept the physical limitation brought by the disease”. “I accept and face the disease, I finish my job with my limited ability, and I do not compete with others”. “Even at worst environment, I always tell myself that do not escape the problems”.

Positive attitude. Having a positive worldview is critical to overcoming adversity regardless of the coping strategy employed. Examples: “I try my best to turn the unhappy thoughts into happy ones to make myself happier”. “Now I think I have to cherish everyday, to make myself happier, and not to think of disturbing or unhappy things”. “Although I can’t be a swimmer anymore, I still can be a volunteer to help the children in the orphanage”. “When I know someone with the same disease die, I feel that I am very lucky and that I cherish my life much more”. “I read lots of biography. I encourage myself to turn negative ideas to positive ones”.

Self-efficacy. Having control and mastery is essential to overcome adversity. Examples: “I try to live my life as others do”. “I want to live a normal life as others do”. “I can have my dreams for the future like others”. “I try to live my life as others do”. “I can have the same ability and strength as others do”.

Denying reality. For some, denying and evading the reality worked for them in overcoming the adversity. Though not an optimal coping strategy, it is one used by many children and young adults to cope. The participants said: “I do not go outside frequently in order not to face difficulties and frustrations”. “I don’t want to face or think of my future”. “I try not to think of or face the disease or anything like that in order not to feel depressed”. “I don’t want to talk about or discuss anything of the disease and its possible outcomes”. “I stay in the house, avoid having contact with outside world, and having no contact with my friends so that I don’t have to compete with my peers. This will relieve my sadness, stress and the sense of loss”.

Surviving. For some, resilience means surviving, getting through it the best way they can. One is rebounding even if the strategies used are not optimal. For examples: “In order to carry on my own life, I must confront others’ different view about my appearance”. “I have to bear more invasive examinations and treatments in order to survive”. “Sometimes daydreaming is the only support of my courage to carry on my life”. “As long as I don’t compare the health status with that of my peer or that of past, I feel to be alive is a blessing”. “To survive is to live every day no matter if life is meaningful”.

Quality of Life

Understanding the participants’ perception of Quality of Life is important to determining the validity of the dependent variable results and the QOL instrument. The participants believed quality of life was the *Ability to Control One’s Life*. This is reflected by such themes as:

Controlling one's life to be successful. Being in control and able to make one's decisions. For examples: "Go to a school of a higher grade and to be skilled in some kind of work, I believe skills and knowledge can improve my quality of life". "I can drive by myself. Driving makes me feel independent of my parents and responsible for myself. This is very important to promote quality of life". "I do my best to learn as much as possible. I believe knowledge can help me to see things clearly and enrich my life". "I try to learn and enrich myself, so that I can feel my life is valuable and vigorous".

Self-sufficient. Being self-sufficient and able to stand on one's own two feet was important to having a better quality of life. Examples: "A work can give hopes, joys, creativity, finance independent, and goals to my life". "Have a steady job and earn enough money to make my family happier". "I can have a steady job and acceptable income. This affects my quality of life a lot". "Have a steady job because I don't want to be a burden of others". "A steady job is a guarantee to a steady life, so I am skilled in repairing cars, so that I can have a steady income to take care of myself". "Have a steady job and earn money to improve the financial condition of my family". "Work makes me independent and happy. It also helps me to show my ability and self-value and gives me a sense of achievement".

Future. Believing one could have a future was important to a better quality of life. Some participants said: "A healthy body that is capable to do whatever I want, and then it make me happy". "Living a simple and happy life with healthy body and mind". "Living a life without fear of disease, treatment, disease recurrence, or death". "Living a life without fear or worry about the sequelae of the disease". "Recover from the disease, my physical status is healthy, and always have a happy mood". "Looking forward to the future and abandon the past unhappy experience of the disease".

Relationships. Knowing one had support systems and could enjoy personal relationships contributed significantly to a better quality of life. Some participants said: “Having close friends to share my life with”. “Living a life with lots of friends and sharing my feeling with”. “Keeping good relationship with my friends and sharing my experiences with”. “Having a close relationship with my family and sharing suffers and joys with”. “I get along well with my friends and colleagues, and I share my dreams and thoughts with them”. “Having a boy friend and falling in love with him ”.

Hope. Maintaining hope throughout the worst of times was important to having a better quality of life. Examples: “I want to have my own company. This gives me the power to keep fighting”. “I hope for miracles. I hope there will be newer technology that can relieve me of the disease and its side effects. I think the anticipation for miracles is the support of my life”. “I have a dream that I want to keep studying and chasing my goals”. “I want to set up a website selling dolls. This website may sell my best works to persons who like collecting dolls”. “I wish I could devote my special skills, love and patience to the children who require special education”. “Having the same ability and strength to seek my interest and follow the fashion as my peers”.

Summary of Findings

Quantitative results. A demographic profile revealed the sample’s gender, mean age, cancer diagnosis, years since diagnosis, living styles and socioeconomic status. Cross-tabulation was used to determine significant ($p < 0.05$) effects of demographic variables. There were more leukemia survivors who lived alone when compared to brain tumor survivors and more brain tumor survivors who received government financial assistance when compared to leukemia survivors.

The Chronbach's alpha for the overall of the Minneapolis-Manchester Quality of Life, the Resiliency Attitudes and Skills Profile, the Protective Factors Assessment and the Risk Assessment Questionnaire satisfied the criteria of coefficient alpha $> .70$ (Nunnally & Bernstein, 1994), which indicated the consistency of responses across the items within each of the instruments.

In relation to each study variable, descriptive statistics were calculated using means and standard deviations and t-tests were run to reveal the differences between types of cancer. Type of cancer was a significant finding with quality of life, individual risks and illness-related risks. Findings revealed leukemia survivors had better quality of life than brain tumor survivors and lower individual risks and illness-related risks than brain tumor survivors.

A correlation matrix was computed to examine the relationships between the various independent variables and the dependent variable, quality of life. Findings revealed that the survivors who reported lower risk factors and higher protective factors tend to be more resilient and the survivors who were resilient tend to have better quality of life. In addition, there was a positive correlation between individual risks and illness-related risks (the more illness-related risks the more individual risks).

Multiple regression analysis using the backward method was utilized to determine the predictive strength of each independent variable in relation to quality of life. Findings revealed four significant independent variables: resilience, individual risks, illness-related risks and type of cancer significantly affect the quality of life in childhood cancer survivors.

Qualitative results. The qualitative analysis showed that illness-related risk related factors had an overriding theme of chronic fear: fear of recurrence, disability and inability to fulfill role expectations. Individual risk factors meant a loss of self: loss of self-efficacy, loss of

self-esteem and loss of future. The protective factors were having a sense of self: hope, self-esteem and self-efficacy, autonomy, being loved and valued, perseverance, self-control and adaptability. Being resilient meant having the ability to rebound: either by accepting or denying, having a positive attitude, being self-efficacious, or surviving. Quality of life meant the ability to control one's life: being self-efficacious, believing in a future, having relationships and maintaining hope. Ascertaining the perceptions of the Taiwanese survivors of childhood cancer about the concepts measured quantitatively when using instruments developed for a Euro ethnic population was important to better understand the quantitative findings.

These findings showed that there was positive correlation between individual risks (e.g., loss of locus of control) and illness-related risks (e.g., cancer and treatment-related late effects) and these two risks factors had negative correlations on resilience and quality of life. Also, the relationships between protective factors (e.g., self-esteem, self-efficacy, etc) and resilience, and resilience and quality of life, had positive significant correlations. Haase's (2004) Adolescent Resilience Model indicated the risks factors included individual risks (e.g., defensive coping) and illness-related risks (e.g., disease and symptom-related distress) and had negative influences on resilience and quality of life, and the protective factors contained individual protective factors (e.g., self-esteem, self-confidence, etc), family and social support and enhanced the development of resilience, and a resilience outcome can promote life quality. Findings from this study supported Haase's conclusions. Elaborations of these conclusions are presented in Chapter 5.

CHAPTER 5

DISCUSSION

The nursing significance of this study is that with increased understanding on individual risks, illness-related risks, protective factors, resilience and quality of life in Taiwanese survivors of childhood cancer, care can be delivered appropriately, effectively and sensitively to the at-risk adolescents/young adults. In addition, the findings clearly demonstrate the impact of culture and social-ecology affect resilience and quality of life and make a contribution to the cross-cultural data about survivors of childhood cancer. This chapter will discuss the limitations of this study, the research conclusions, the implication of findings for health policy, nursing practice, nursing education, and recommendations for future research.

Discussion of Findings

Limitations in resilience and quality of life research in Taiwanese survivors of childhood cancer may affect the pediatric nurses' knowledge and abilities to take care of this vulnerable population. The purpose of this study was to examine the relationships between type of cancer, demographic, illness-related risks, individual risks, protective factors, resilience, and quality of life. Specifically, the study used a triangulated research design to explore the phenomena of resilience and quality of life in Taiwanese childhood cancer survivors. This study attempted to answer the following research questions: (a) Is there a difference in the quality of life between Taiwanese childhood survivors of brain tumor and leukemia? (b) What is the relationship between quality of life and resilience in the Taiwanese childhood survivors of brain tumor and leukemia? (c) How do the following variables affect quality of life does type of cancer, resilience, protective factors, illness-related risks, individual risks, and demographics in Taiwanese childhood survivors of brain tumors or leukemia? (d) What does quality of life, resilience,

protective factors, illness-related risks, and individual risks mean to Taiwanese childhood survivors of brain tumors or leukemia?

The conclusions of the study indicated that: 1). There is a significant difference in the quality of life between Taiwanese brain tumor and leukemia survivors of childhood cancer; 2). The relationship between quality of life and resilience in Taiwanese childhood survivors of brain tumors or leukemia revealed a significant moderate positive correlation; 3). The relationship between quality of life and protective factors in Taiwanese childhood survivors of brain tumors or leukemia revealed a significant positive correlation; 4). The relationship between resilience and protective factors in Taiwanese childhood survivors of brain tumors or leukemia revealed a significant highly positive correlation; 5). The relationships between resilience and individual risks and illness-related risks revealed significant moderate negative correlations; 6). The relationships between quality of life and individual risks and illness-related risks revealed significant moderate negative correlations; 7). Four predictive variables affected quality of life in Taiwanese childhood survivors of brain tumors or leukemia: resilience, individual risks, illness-related risks and cancer types. The more resilient the better quality of life; individual risks and illness-related risks negatively affect resilience and quality of life outcomes; and Taiwanese childhood survivors of brain tumors or leukemia expressed the meanings of quality of life, resilience, individual risks, and illness-related risks from their own perceptions. With regard to the findings of the first three research questions, it has been concluded these hypotheses were confirmed. The finding of the research question 1 in this study is consistent with the research on quality of life in survivors of childhood cancer (Eiser, Greco, Vance, Glaser, Galvin, Horne, et al., 2005) and the findings of research question 2 and research question 3 are consistent with resilience and quality of life in adolescent with cancer or chronic illness ((Haase, 2004).

Quality of Life

Haase (2003) clarified that dimensions of quality of life were related to physical problems, psychological, social, and spiritual factors, and other factors such as culture. Dimensions of quality of life in the present study were physical, psychological, social and cognitive functioning, and outlook on life. All of these five dimensions significantly affect quality of life in Taiwanese survivors of childhood cancer.

Research has demonstrated that health status also is related to quality of life in survivors of childhood cancer. The health status among survivors of brain tumors in this study found them to have significantly poorer physical, psychological, and cognitive functioning than survivors of leukemia, contributing to the negative affect on quality of life in survivors of brain tumors. This finding is consistent with the research of Eiser's and colleagues' research (2005) who found survivors with poorer health status, such as brain tumor survivors, had the worst quality of life.

Adolescents' concerns about one's physical appearance are well known. Individuals at this life stage are preoccupied with the way they appear to other people, especially, those of the opposite sex. Literature has indicated that body image impacts the psychosocial functioning of adolescents and found that physical appearance was a significant factor affecting quality of life in those adolescents. As the result of cancer-related treatment, survivors of brain tumors seem particularly vulnerable to having physical disabilities and concomitant negative body image. Survivors of brain tumors in the present study reported less positive feelings about body image than survivors of leukemia. This might impact on their social behaviors and ability to form intimate relationships. The sense of low self-esteem has a high potential to negatively influence quality of life in survivors of brain tumor. This finding is consistent with Abd-el-Gawad, Abrahamsson, Hellstrom, Hjalmas, and Hanson's work (2002) that found positive body image

related to positive sexual aspects and that a positive body image positively affects quality of life in adolescents with physical complications.

The major themes of quality of life identified by survivors of childhood cancer in this study included: controlling one's life to be successful and envisioning the future. Research has shown that hope for future could serve as a protective function in survivors of childhood cancer. However, these survivors of childhood cancer have to continually face uncertain futures with greater dependence on families because they are more physically and cognitively impaired than their healthy peers. Given this conflict between childhood cancer survivors' expectations and the realities of their health status, how does the adolescent cancer survivors respond and adapt to their future? The interviews uncovered the common uncertainty of future included health status, next generation health, and future goals. Compared with survivor of leukemia, survivors of brain tumor felt more hopeless in their future and this sense of hopeless had negatively affected their life quality.

Type of cancer affects the degree of adversity of individual risks and illness-related risks. These factors had significant negative effect on quality of life in Taiwanese childhood cancer survivors. Those with brain tumors had more physical complications and more serious complications (i.e., seizures, hearing/vision impairments, and hemiplegia) than survivors of leukemia. They perceived themselves as having less psychological, social and cognitive functioning, poorer body images, less potential for intimate relations, and a more negative outlook on life than leukemia survivors. They talked about how the disease "messed up their life and goals;" and how their physical complications made them "unable to study and learn the skills necessary to be independent." Brain tumor survivors did not feel they fit in anywhere, with anyone, and felt they were inferior to others in every way. Despite the fact that these survivors of

brain tumors received more government financial assistance than survivors of leukemia, they were less able to live alone than their leukemia counterparts. Brain tumor survivors reported a worse quality of life when compared to leukemia survivors. The finding related to quality of life between survivors of brain tumor and leukemia is consistent with the related works of Eiser, et al., (2005).

Haase's study (2004) found illness-related stress, individual risk, individual protective, family protective, and social protective factors affect resilience and that resilience directly influenced quality of life (the greater the adolescent's resilience, the greater the quality of life) in adolescents with cancer or chronic illness. The findings from this study showed that illness-related risks, individual risks, and protective factors significantly affect resilience and those who scored higher on the resilience index scored higher on the quality of life indexes. Therefore this study supports Haase's and colleagues' (2003) conclusions.

Resilience

Haase (2004) identified that individual positive psychological concepts (i.e., self-efficacy, confidence, and perceived health, etc), family and social supports enhance resilience processes and positive outcomes in the face of adversity. Being able to rebound was the major concept in resilience of survivors of childhood cancer in this study. This study found that there were no statistical differences in resilience between cancer types, but there were trends evident in the results: survivors of leukemia demonstrated higher scores across all factors except "relationships" and "values orientation."

Being diagnosed with cancer is a crisis but some crises can turn into an opportunity for the whole family. A new perception about what is important in life, an ability to develop a more realistic assessment of individual and family relationships, and an opportunity to develop a new

perspective on family relations often occurs. The interviews disclosed this very phenomenon: a positive change in the relationship of the survivor with their parents and siblings since diagnosis of cancer. Not only did their parents become more protective and lenient but also their siblings grew closer. This was especially true in survivors of brain tumor who had more physical impairments than survivors of leukemia and needed more assistance from family, friends, or others. The sense of dependence helped survivors of brain tumor to recognize the importance of family, friends, and caring adults and thus develop closer relationship with these individuals than survivors of leukemia.

Of interest were the interview findings that suggested either the concepts of quality of life and resilience or the items in the instruments may have meant something different to the participants. The quality of life and resilience scores did not match the interview outcomes. Interviewees talked about being resilient even though they scored low on the quality of life instrument; or they talked about a good quality of life but did not possess the qualities necessary to be optimally resilient. Some demonstrated more insight and reflection since their diagnosis. Some talked about how they evaded or denied their problem while others talked about shutting others out or themselves in so as to protect themselves from interpersonal or personal pain. They believed they could survive cancer because they either ignored or insulated themselves against the disease and its side effects. Some talked about just making it through a day because the potential for a future was limited. Some developed new life goals and priorities because of recognition of their personal vulnerability. The experiences of cancer affected survivors differently, either helping them to develop new strengths to cope with subsequent illness or supporting the continuation of such negative coping strategies as denial, emotional insulation, and survival attitudes. Some of the discussions by the participants about resilience were

consistent with the research of Parry and Chesler (2005) who found that the survivors of childhood cancer had developed new values and strengths, more psychological growth and maturity, and had closer relationships with family than their peers.

The phenomenon of resilience requires attention to a range of possible psychological outcomes and should not just be accepted as a 'positive' adaptive state. It is important to remember that not all the survivors of childhood cancer in this study showed evidence of resilience in its positive connotation. Some of the survivors defined the concept of resilience as denying reality; it was the ways to reduce impacts of adversities on individual and a kind of "resilience" to Taiwanese adolescent survivors of childhood cancer. This finding does not support Haase's work (2004a) who determined that evasive, fatalistic, and emotive coping were associated with negative outcomes, such as depression and poorer survival in adolescents with cancer, and negatively affected resilience and quality of life outcomes. However, of interest is the pervasive perception, as identified by some of these young adults, that resilience can encompass the constructs of survival, less than optimal coping, self-sufficiency, and distancing from others. This phenomenon also was shown in research by Hunter and Chandler (1999), Hunter (2001a), and Luthar (1991), who all found that despite being an at-risk youth they had positive adaptive behaviors in the presence of adversity, many apparently at-risk youth did not seem to be emotionally healthy. Resilience may mean optimal adjustment and rebounding, it may mean insulation, or survival depending on the degree of adversity the individual is encountering. One's resilience position is not fixed but fluid and can move from survival to optimal modes depending on risks, real and perceived adversities, protective factors, world view, coping strategies, and support systems.

Resilience and Quality of Life

Resilience was found to be highly correlated with quality of life. Adolescent survivors of childhood cancer in this study defined the concept of resilience as the ability to rebound from the disease and to live. One's overall satisfaction with life was defined by these participants as being "healthy" and independent, having relationships, being married, being able to work and earn an income, maintaining hope, and having a future.

The theory of human development suggests that the stage of adolescence is a critical period to develop individual independence. Compared with healthy peers, survivors of childhood cancer were more likely to report performance limitations and restricted abilities to perform personal care. Research has documented that performance limitations and restricted abilities of self-care impact on the ability for independence and lower self-esteem, self-efficacy, and resilience ability in survivors of childhood cancer. Findings from this study indicated that limitations on physical performance and daily activities among long-term survivors of brain tumor were at high risk for low locus of control, self-esteem, and self-confidence, less resilience ability and poorer quality of life.

In Taiwan, the condition for the survivors of childhood cancer to receive government assistance is that they must have multiple physical impairment and those physical complications restrict opportunities to find steady jobs and take care of themselves. Work provides a means of strength and ability, a source of financial independence, social contacts, and friendships. These aspects maintain hope and indicate a future is possible. Survivors of childhood cancer in this study identified both resilience and quality of life as having a steady work. These findings are consistent with Haase (2004a) who recognized resilience as a positive health concept, such as hope, positive self-esteem, and self-confidence, etc and the work by Kahn and Juster, (2002) who

indicated that the meaning of a person's overall satisfaction with life requires the most major life role--work and income.

Protective Factors

Haase (2004) identified these factors as individual, family, and social protective factors to enhance resilience ability in adolescents with cancer. Protective factors are essential to protect the individual from adversities. They counter risk factors and adversity, support the potential for optimal resilience, and quality of life. These factors encompass such constructs as coping, values orientation and self-appraisal, family support, peer support, and information support.

Relationships. Family support derived from good relationships with family members is a central important protective factor in promoting resilience. Such systems promote the feeling that one is loved and valued, one is a productive member of society, and one has help to do anything they want. These survivors said that without their parents' care and support, they would never have conquered the disease and overcome the pain during the treatment. Findings from the interviews indicated that caring and loving adults, such as parents, are the main support power to the survivors to face the difficulties. Such supporting systems are important to resilience and quality of life. These findings are consistent with the findings in the research by Hunter and Chandler (1999), Hunter (2001a), Luthar (2004), and Ungar, (2004) who found high risk adolescents seek close relationships with significant adults in order to establish powerful self-constructions and foster resilience ability. It also supports the work of Haase (2004); who indicated that family support could help adolescents with cancer to cope with and explore the meaning of their cancer-related experiences, thus strengthening resilience and increasing life quality in those adolescents.

Peer support was one of the major support system in survivors of childhood cancer in this study. The survivors of childhood cancer expressed that the support and encouragement they received from friends were the significant contributive factors to their survival. Haase (2004a) showed that maintaining relationships with peers were part of the social protective needs of adolescents with cancer.

Value orientation. Findings from this study indicated that brain tumor survivors believe they were more honest, just, willing to help others, able to handle difficulties, and had more positive value orientation than leukemia survivors. Literature indicated brain surgeries or radiotherapies might influence the cognitive development of brain tumor survivors. A possible interpretation is that an impairment of cognition may cause lack of sense and insight of their own limited ability in the brain tumor survivors and might result in the use of denial, setting unrealistic anticipation and unrealistic goals for themselves. Although this reflects less than optimal ways managing adversity, this coping strategy could help them avoid unhappy or painful experiences and able to survive from the damage. This unrealistic expectation is a type of “protective factor” to the Taiwanese brain tumor survivors. Haase (2004a) labeled unrealistic expectation was one way of defensive coping strategies but could be changed to positive coping if the adolescents or young adults had enough time to develop other protective factors to decrease their painful experience of cancer and its treatment-related late effects.

Sense of self. Positive self-appraisal is a critical protective factor and is necessary for successful adaptation. The interviews uncovered those survivors’ definitions of sense of self as hope, self-esteem, self-efficacy, self-perception, and self-confidence and all of this positive self-appraisal contributed to individual protective factors. At-risk adolescents who are self-confident are more resilient and can set and achieve higher expectations. The subjects in this study

believed in themselves and found their strong personalities influenced their quality of life. Some thought their strong character was genetic while others thought it was self-developed. Those who were optimistic and confident in the face of difficulties adapted better with less health consequences. These findings are consistent with the research by Aronowitz, (2005) who found at-risk youth felt competent, self-confident, and set higher expectations for themselves and could become resilient. It also supports the work by Haase (2004); who believes individual protective factors are composed of hope and positive self-appraisal. Specifically hope which is the energy to face difficult conditions and uncertainty and expect a successful future.

Autonomy. The importance of maintaining autonomy promotes an adolescent's physical and psychological resiliency. As a result of cancer and its treatment-related effects, survivors of childhood cancer may feel fragmented and hesitant in becoming self-directive. Some survivors in this study emphasized they were more independent and confident than peers. They believed a person should maintain his or her highest level of autonomy and affect his or her environment positively. The survivors defined autonomy as being involved in own treatment-related decisions, getting active in social activities, and minimizing dependence on others and those personal characters were part of protective factors. This finding is consistent with the research by Devereux, Bullock, Bargmann-Losche, and Kyriakou (2005); who found autonomy was being outgoing, going out in public more, and less dependent on others in people with physical disability.

Information support. Literature suggests survivors of childhood cancer who receive adequate information about their diagnosis and late effects from treatment have less psychological problems, such as anxiety and depression, and it enhances the well-being of those adolescents. For some, having just enough information or no information contributes to one's

quality of life. It is hypothesized that people who have more knowledge, have more choices, and a sense of more personal control; however, in this study, it was found that having minimum or no information about the disease, the treatment, the potential outcomes helped these survivors adapt better and not lose hope. This finding does not support the work of Haase (2004); who showed information needs of adolescents with cancer were part of the social protective and suggested those adolescents should receive appropriate information about their disease and treatment-related late effects throughout the cancer experience, from diagnosis continuing into survivorship. This may be a cultural-related response but it deserves more investigation.

Individual Risk Factors

Impacting resilience and quality of life are the individual and illness-related risk factors. To be optimally resilient one needs self-esteem, self-efficacy, and hope. Loss of self-confidence and life dissatisfaction increases the individual's risk, which negatively affects resilience in childhood cancer survivors. Haase (2004a) uncovered that individual risk were defensive coping strategies that negatively affect resilience and quality of life outcomes. As stated before about less information and the use of denial, the findings from this study found that less than optimal coping still contributed to higher resilience scores. Other risk findings were that childhood cancer survivors with higher individual risks were less resilient. The interviews uncovered that survivors with physical complications had less confidence in scholastic and work competencies. They were victims of the long-term consequences of the disease and the cure. There was too much peer pressure and family pressures to 'be normal,' resulting in fewer loci of control, self-efficacy and self-esteem. These experiences or perceptions affected the motives and courage of the survivors to compete with the outside world and to achieve their life goals. The finding is consistent with the work by Holmbeck, Westhoven, Phillips, Bowers, Gruse, Nikolopoulos, and

Wienke Totura (2003); who found adolescents with physical disabilities were less likely to make independent decisions and have less global self-worth and competence. It supports the work of Haase (2004a); who showed family ameliorates risk factors if family contributes to the development of the individual's attitudes, self-esteem, and coping behaviors.

Illness-Related Risk Factors

This study identified that illness-related risk factors were related to physical, psychological, behavioral problems and cancer-related concerns. Survivors of brain tumor had more physical complications (72%) related to the disease and treatment than survivors of leukemia (46%).

Because of the sequelae of the disease, the survivors with physical problems expressed that they had to face more problems in life than the survivors with normal physical functioning, and thus needed more help from family or others. This sense of dependence negatively influenced one's resilience, and the findings are consistent with the research by Holmbeck, etc., (2003).

Chronic fear was the pervading theme in the cancer-related concerns of adolescent survivors of this study. These survivors indicated they were not confident of their health status and worried about the recurrence of the disease. Literatures indicate that childhood cancer survivors may have multiple long-term complications, some of which are life-threatening, due to the disease or its treatments. Because of the sense of uncertainty about their health, they were afraid of making plans for the future. Such fear and its effect on hope or future potential negatively affect one's resilience and quality of life.

Erikson (Sigelman, 1999) discussed that adolescence/young adult stage of development to develop one's identity and develop lasting relationships. Issues of infertility, low self-esteem

and self-efficacy, dependence, and poor health negatively affect the adolescents/ young adult's potential to achieve this developmental milestone. This is especially significant in the Chinese culture in which daughter-in-laws have the responsibility and duty to have children to carry his/her husbands' family name. Both female and male survivors of this study who had received radiotherapies or brain surgeries were significantly stressed by their potential for not fulfilling this role responsibility. The senses of uncertainty about their health state, fertility status, work potential, and financial independence created tension and adverse feelings about intimate relations. These findings are consistent with the work by Zebrack, Casillas, Nohr, Adams, and Zeltzer (2004); who found survivors of childhood cancer were uncertain about their fertility status and the feeling of uncertainty impact on their intimate relationships. These findings also support the work of Haase (2004a); who defined illness-related as uncertainty in illness and disease and symptom-related distress. These factors were uncertainty in treatment-related events and physical discomforts related to disease and its late effects and had negative influences on resilience and quality of life.

Limitations

Several limitations to the interpretation and generalizability of these findings need to be mentioned as following:

Sampling. Taiwanese culture makes those who suffer from cancer, especially the childhood cancers, afraid that they may be unable to fulfill their role expectations for employment and marriage because of the fear of rejection. Cancer, in this population, is "a disease about which people don't want others to know." Obtaining subjects who will agree to participate may be difficult because of this societal perception.

Secondly then, survivors who were willing to participate might exhibit a stronger character than other survivors because their fear of societal rejection may not be as important. Such characteristics might also make them more optimistic and open-minded than other survivors. According to the literature, internal personality characteristics are important factors that contribute to one's resilience position (optimal versus survival) and quality of life. Therefore, the personality characteristics of the subjects in this study might influence the results of this study.

Culture. Different cultures have different belief systems and worldviews that affect thinking processes and decision-making abilities. In the Taiwanese culture, children are not allowed to criticize the behaviors of their parents. This factor might affect the subjects' attitudes when answering the questions in Section II - Individual Risks specific to "I grew up in a family where a parent/guardian was an alcoholic, drug user, or abusive". This could explain why all the subjects' answers reflected "a good parent/guardian." It is unknown then whether any of the subjects' home environments played a part in their individual risks, resilience, or quality of life responses.

Methodology. First, this study was based on self-reports with all responses influenced by the subjective perception of the subject. Such subjectivity can skew the results to be different than what one might find using a more objective data collection methodology.

Second, the psychospiritual dimension has been identified as an important factor affecting the quality of life in brain tumor patients (Strang, S., & Strang, P., 2001). This concept has an effect on the development of one's resilience. It was not explored in this study. In future research it would be important to conduct a longitudinal study, include items related to spiritual

thoughts/faiths in the questionnaire of quality of life, and include items related to knowledge base in the scale of protective factor assessment.

Research Conclusions

The six independent variables (type of cancer, demographics, illness-related risks, individual risks, protective factors, and resilience) and one dependent variable (quality of life) had not been included in prior research with adolescent cancer survivors. The relationships between independent and dependent variables discovered in this study add to the knowledge of how these independent variables can affect quality of life in survivors of childhood cancer and what predictive variables may be significant in working with these survivors.

These findings add new knowledge regarding survivorship of childhood cancer and support the Adolescent Resilience Model of Haase (2004a) but further embellishes that model (see Figure 2). The more expanded model is described as follows:

Type-of Cancer: The cancer types affect quality of life in Taiwanese survivors of childhood cancer. Cancer types assessed in this study were those with brain tumors and those with leukemia.

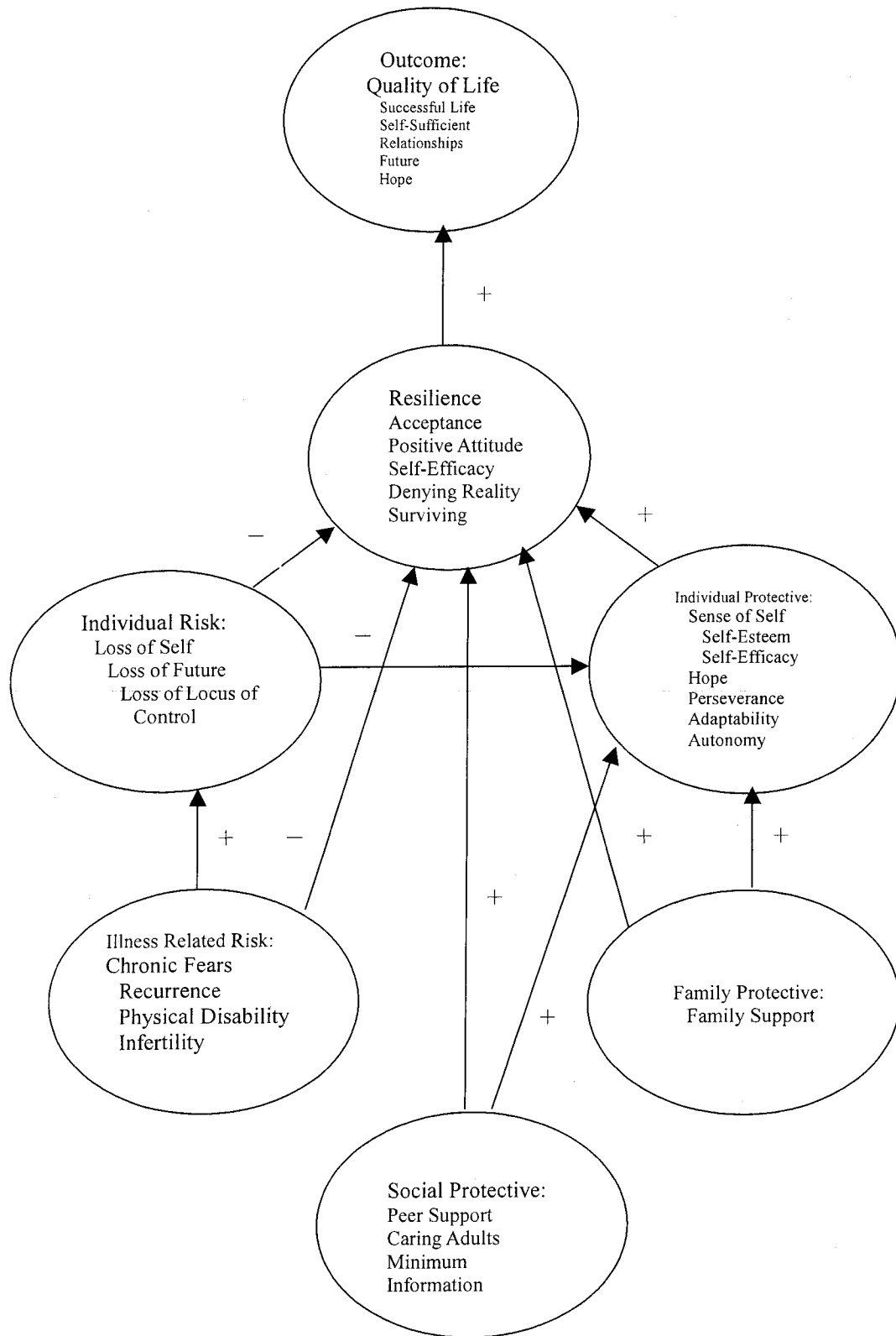
Illness-Related Risk: This factor is now composed of chronic fears: recurrence, physical disability, and infertility. These factors negatively affect resilience and quality of life and positively strengthen individual risk.

Individual Risk: This factor is now composed of loss of sense, loss of future, and loss of locus of control and has negative influences on resilience and quality of life.

Protective Factors: These refer to the extent of individual protective, family protective and social protective factors that positively influence resilience. Individual protective is now composed of sense of self (i.e., self-esteem and self-efficacy), autonomy, hope, perseverance,

Figure 2

Modification of the Adolescent Resilience Model (Haase, 2004)



and adaptability. Social support is now composed of peer and caring adults support and minimum information. Family and social support are components of protection found within and outside the family and contribute to individual protective.

Resilience: This factor is now expand to include acceptance, positive attitude, self-efficacy, as well as denying reality and surviving. All can positively influence quality of life.

Quality of Life: This factor refers to a global sense of well-being and is the outcome variable in the model. This outcome is now composed of controlling one's life to be successful, self-sufficiency, relationships, future, and hope.

The findings from this study supports the findings from other studies about survivors of cancer specifically relationships between brain tumor and leukemia survivors on quality of life (Eiser, etc., 2005), and relationships between protective factors, resilience and quality of life (Orbuch, etc., 2005).

The following conclusions drawn from this study are:

1. Illness-related risks, individual risks, illness-related risks, and cancer types are important predictive factors of quality of life in survivors of childhood cancer.
2. Illness-related risks and individual risks weaken resilience ability in survivors of childhood cancer and secondarily affect their quality of life.
3. Protective factors need to be fostered since they are found to be statistically significant to resilience and secondarily to the quality of life experienced by survivors of childhood cancer.
4. Survivors of childhood cancer with higher resilience scores tend to have better quality of life.

5. Cancer types are important to consider when planning intervention strategies to reduce risk factors and promote quality of life.

Implication for Health Policy, Nursing Practice, and Nursing Education

Health Policy

Adolescence and young adulthood are critical periods for identity formation, relationship building, growth, physical, behavioral, and cognitive development. Healthy development in body and mind in this period is closely to the development of optimum resilience and a better quality of life. This study showed that higher illness-related risks, e.g., the recurrence of the disease, the sequelae of the disease, and physical disabilities had a negative effect on resilience and quality of life. Survivors of childhood cancer need ongoing physical and mental health services so as to abate the potential resilience and quality of life problems. Physical services are necessary for assessing, intervening and preventing cancer-related physical problems and thus promoting a survivors' health status. Mental health clinics are needed to identify survivors at high risk for long-term cancer-related psychosocial problems and provide interventions to individual. Establishing survivors of childhood cancer health clinics is a potential health policy that could be enacted. Davis, Cook, and Cohen, (2005) suggested that building client-centered, high-quality clinics with accessible transportation and age/developmentally appropriate services could help in reducing disparities in health in this underserved population. Taiwanese survivors of childhood cancer in this study stated there were no such clinics. The uneven distribution of the health resources and the incomplete recognition of the health risks by the doctors and clinic specialists make the survivors of the childhood cancer unable to maintain long-term follow-up and treatment. From the suggestions of Davis, etc., (2005) and reflections of the childhood cancer survivors, the Health Insurance Administration in Taiwan could help hospitals develop health-

related counseling clinics and long-term follow-up departments designed to meet the developmental needs and cancer-specific concerns of the survivors. Currently they are treated as adult patients; though chronologically an adult, many are still emotionally children with immature coping skills and inadequate personal resources to be successful.

Nursing Practice

Nurses are the leaders and pioneers of health promotion for people, especially for adolescents or young adults who are at-risks in their homes, schools, and the community. Nurses who are knowledgeable about the life course of survivors of childhood cancer would be able to develop the interventions necessary to foster the development of protective factors, ameliorate individual risk factors, lessen illness-related risk factors, promote the development of optimum resilience, and promote the best quality of life possible. It is critical to reduce the early and late effects of childhood cancer survivorship. Nurses in Taiwan who work with cancer survivors could encourage parents of survivors of childhood cancer to be involved with their child's interventions, which could motivate protective factors of childhood cancer survivors, and thus to enhance resilience ability and promote quality of life in the survivors of childhood cancer. Nurses could facilitate the survivor's involvement in health-promoting lifestyle practices i.e., attending rehabilitation exercises or physical activities to strengthen their self-perceptions (Wright, Galea, & Barr, 2003). They could offer supportive and empowering environments where activities are designed to build the survivor's protective factors; such as skills training to promote their competencies. Nurses could also initiate community action plans to promote quality of life, such as convenient residential settings for shopping, leisure, and social activities.

Nursing Education

The nursing education in Taiwan has been criticized for its lack of attention to meeting the health-related concerns of the clients. Since this is an integral part of nursing practice and is a critical element for successful recovery from illness or prevention of health problems, nursing educators should design curricula that not only teach new nurses this skill and prepares them to practice from an evidence-based approach so as to satisfy the health-related concerns of clients but promote human well being. Critical to the curricula then is content specific to survivors of cancer and the unique challenges of assessing risk factors, promote protective factors, and develop interventions to promote the survivors' resilience and quality of life.

Future Research

An important dimension of this study was the triangulated methodology employed to assess the validity of the instruments and to better understand the answers provided on those instruments. It becomes essential to use this methodology when conducting research in a non-Euro population using instruments tested for reliability in a Euro population. Comments by the participants indicated that they preferred answering the interview questions because it allowed them to really talk about what they were feeling; something not possible in the reliable measures used. The information acquired from the interview sessions was used to further evolve the Hasse model of quality of life and resilience in survivors of childhood cancer.

As discussed before, it is also imperative that questions on standardized instruments include items critical to uncovering the full spectrum of concepts inherent in constructs such as the concepts of psychospiritual and alternative therapy in quality of life and the concepts of emotional insulation and survival in the continuum of resilience. Therefore developing reliable and valid instruments that actually assess all-important concepts in constructs is important.

In the review of the literature it is evident there is limited nursing research concerning the phenomenon of survivorship of childhood cancer. Given the increasing number of cancer survivors, nurses should conduct research across all age groups, ethnicities, and culture to identify the unique challenges these patients face; develop culturally safe interventions to address those needs; and develop reliable instruments to assess the efficacy of those interventions. A first step would be to replicate this study with a larger sample of adolescents including survivors with different cancer types, ethnic groups, and geographic regions. The results could more effectively generalize to adolescent survivors of childhood cancer.

Summary

In conclusion, this research study has furthered nursing science about survivors of childhood cancer in a non-Euro population. Of interest is the finding that despite cultural and ethnic differences, the experiences of cancer survivors are similar. One's personal characteristics, support systems, type of cancer, life and disease-related adversities, and resilience impact one's quality of life. Knowing this, nurses can begin to effect change at the local, national, and international level to improve the potential for more optimal outcomes for these survivors.

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Appendix A
Demographic Questionnaire

Demographic Questionnaire

1. I am: female _____ male _____
2. My age is: 18 ____ 19 ____ 20 ____ 21 ____
3. I had a brain tumor ____; leukemia ____
4. My cancer treatments were completed: _____ (year/ date)
5. I live: By myself _____
 With at least one parents _____
 With grandparents _____
 Other _____
6. I work: Yes _____ No _____
 Part time _____
 Full time _____
 Income _____ / year
7. I am a student: Yes _____ No _____
 Part time _____
 Full time _____
8. I am receiving government assistance for living: Yes ____ No ____
9. I am financially destitute: Yes ____ No ____

Appendix B

The Resiliency Attitudes and Skills Profile

June 9, 2005

Li-Na Chou
5702 Linda Vista Rd Apt 24
San Diego, CA92110

Dear Li-Na Chou

I am pleased to give my approval for using the instrument “the Resiliency Attitudes and Skills Profile” in your research project.

Sincerely,

Anita Hunter, PhD, RN, CPNP
Director MEPN and RN-BS Programs
School of Nursing
University of San Diego
5998 Alcalá Park
San Diego, CA 92110

The Resiliency Attitudes and Skills Profile
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For the following statements, please circle the number that best describes you and your feelings:

	Strongly Disagree			Strongly Agree
1. When my work is criticized, I try harder the next time.	1	2	3	4
2. I can deal with whatever comes in the future.				
3. Once I set a goal for myself, I don't let anything stop me from reaching it.				
4. I learn from my mistakes.				
5. I notice small changes in facial expression.				
6. I can imagine the consequences of my actions.				
7. I know when I am good at something.				
8. I am prepared to deal with the consequences of my actions.				
9. I say "no" to things I don't want to do.				
10. I can change my behavior to match the situation.				
11. My sense of humor makes it easier to deal with tough situations..				
12. My friends know they can count on me.				
13. I can change my surroundings.				
14. My family is there for me when I need them.				
15. When something goes wrong, I can tell if was my fault.				
16. It's OK if I don't see things the way other people do.				
17. Lying is unacceptable.				
18. I avoid people who could get me into trouble.				
19. It's OK if some people do not like me.				
20. I am comfortable making my own decisions.				
21. I can sense when someone is not telling the truth.				
22. When I am faced with a tough situation, I come up with new ways to handle it.				
23. I can come up with different ways to let out my feelings.				
24. I choice my friends carefully.				
25. I look for the "lighter side" of tough situations.				
26. I control my own life.				
27. I can tell what mood someone is in just by looking at him/her.				
28. I try to help others.				
29. I stand up for what I believe is right.				

30. I try to figure out things I do not understand.				
31. I am good at keeping friendships going.				
32. I have friends that will back me up.				
33. Laughter helps me deal with stress.				
34. I avoid situations where I could get into trouble.				

Appendix C

Minneapolis-Manchester Quality of Life Survey of Health



NATIONAL MEDICAL CENTER AND
BECKMAN RESEARCH INSTITUTE

Where the Power of Knowledge Saves LivesSM

Epidemiology and Outcomes Research
Smita Bhatia, M.D.
Director

May 24, 2005

Epidemiology and Outcomes Research
Division of Pediatrics
City of Hope Comprehensive Cancer Center
1500 E Duarte Rd
Duarte, CA 91010-3000

Dear Dr. Bhatia

I am writing to request a written permission to use the instrument-Minneapolis-Manchester Quality of Life in my dissertation research.

My dissertation is being supervised by my advisor, Anita Hunter, Associate Professor, Hahn School of Nursing and Health Science, University of San Diego, San Diego, CA 92110.

If this request meets your approval, please sign, date and return this letter to me.

Thank you for your help and prompt attention.

Sincerely

Li-Na Chou
5702 Linda Vista Rd Apt 24
San Diego, CA 92110

I agree to the above request.

Smita Bhatia, MD, MPH

5/25/05

Date

1500 East Duarte Road, Duarte, CA 91010-3000
Tel 626/359-8111
www.cityofhope.org

A National Cancer Institute-designated Comprehensive Cancer Center

University of Minnesota
Minneapolis-Manchester
QOL Survey of Health

SECTION A

1. Are you able to walk?

Yes No

2. How much of the time can you keep up with others of your age when taking part in sports or games, running soccer, baseball, biking, etc.?

Never, I can't keep up with them Sometimes I can Often I can Usually I can Always I can Does not apply, never do them

SECTION B

1. I have a lot of energy

Very true Somewhat true Not true or untrue Somewhat untrue Very untrue

2. I need time out to rest during the day

Very true Somewhat true Not true or untrue Somewhat untrue Very untrue

3. I have a lot of energy for running or sports

Very true Somewhat true Not true or untrue Somewhat untrue Very untrue

4. I cannot do many activities because of my health

Very true Somewhat true Not true or untrue Somewhat untrue Very untrue

5. I cannot do many activities because of my arms or legs

Very true Somewhat true Not true or untrue Somewhat untrue Very untrue

6. In games and sports, I like to watch rather than take part

Very true Somewhat true Not true or untrue Somewhat untrue Very untrue

SECTION C

1. Sad

Never Occasionally Some of the time Most of the time All of the time

2. Angry

Never Occasionally Some of the time Most of the time All of the time

3. Tired during the day

Never Occasionally Some of the time Most of the time All of the time

4. Lonely

Never Occasionally Some of the time Most of the time All of the time

5. Frightened

Never Occasionally Some of the time Most of the time All of the time

6. Anxious or nervous

Never Occasionally Some of the time Most of the time All of the time

7. Strong and healthy

Never Occasionally Some of the time Most of the time All of the time

8. Worried about dying

Never Occasionally Some of the time Most of the time All of the time

9. Worried about my health

Never Occasionally Some of the time Most of the time All of the time

10. Worried about things in general

Never Occasionally Some of the time Most of the time All of the time

11. Not as good as most people (inferior to them)

Never Occasionally Some of the time Most of the time All of the time

SECTION D

1. How satisfied are you with your weight?

Extremely satisfied Somewhat satisfied Somewhat dissatisfied Extremely dissatisfied

2. How happy are you with the way you look?

Extremely satisfied Somewhat satisfied Somewhat dissatisfied Extremely dissatisfied

3. How do you feel about your body development right now?

Extremely satisfied Somewhat satisfied Somewhat dissatisfied Extremely dissatisfied

4. I like my body the way it is.

Very true of me Somewhat true of me Not true or false of me Not very true of me Not at all true of me

5. When others look at me they think that I am poorly developed

Very true of me Somewhat true of me Not true or false of me Not very true of me Not at all true of me

6. I am uncomfortable with the way my body is developing

Very true of me Somewhat true of me Not true or false of me Not very true of me Not at all true of me

SECTION E

1. I find it difficult to make friends

Very true of me Somewhat true of me Not true or false of me Not very true of me Not at all true of me

2. I feel left out in groups of people my own age

Very true of me Somewhat true of me Not true or false of me Not very true of me Not at all true of me

3. People like to be with me

Very true of me Somewhat true of me Not true or false of me Not very true of me Not at all true of me

4. I have a lot in common with my friends

Very true of me Somewhat true of me Not true or false of me Not very true of me Not at all true of me

5. I get along well with people my own age

Very true of me Somewhat true of me Not true or false of me Not very true of me Not at all true of me

6. I have many close friends

Very true of me Somewhat true of me Not true or false of me Not very true of me Not at all true of me

7. I have similar hobbies and interests to those of people my own age

Very true of me Somewhat true of me Not true or false of me Not very true of me Not at all true of me

8. Being together with other people gives me a good feeling

Very true of me Somewhat true of me Not true or false of me Not very true of me Not at all true of me

SECTION F

1. Do you have difficulty concentrating at school?

All the time Most of the time Sometimes Occasionally Never

2. Do you have difficulty concentrating at other times (e.g., playing cards, computer games or reading)?

All the time Most of the time Sometimes Occasionally Never

3. How often is homework or study hard for you?

All the time Most of the time Sometimes Occasionally Never

4. How often do you need more help with schoolwork than others in your class?

A whole lot Quite a lot Some A little None

5. How much difficulty do you have remembering things at school/college or work?

A whole lot Quite a lot Some A little None

6. How much difficulty do you have concentrating at work or school?

A whole lot Quite a lot Some A little None

7. How much difficulty do you have with reading and writing?

A whole lot Quite a lot Some A little None

8. How much difficulty do you have with math and calculations?

A whole lot Quite a lot Some A little None

9. How much difficulty do you have with your schoolwork, compared to others in your class?

A whole lot Quite a lot Some A little None

SECTION G

1. I find it easy to have an intimate relationship

Very true of me Somewhat true of me Not true or false of me Not very true of me Not at all true of me

2. I am confident when I am with people of the opposite sex

Very true of me Somewhat true of me Not true or false of me Not very true of me Not at all true of me

SECTION H

1. I am happy with the way things are

Strongly agree Somewhat agree Do not agree or disagree Somewhat disagree Strongly disagree

2. I am happy with life in general

Strongly agree Somewhat agree Do not agree or disagree Somewhat disagree Strongly disagree

3. In general, I am satisfied with my current life situation

Strongly agree Somewhat agree Do not agree or disagree Somewhat disagree Strongly disagree

Appendix D

The Risk Assessment Questionnaire

The Risk Assessment Questionnaire

Please tell me which of these events you have experienced. Rank them in order of severity of problems the stress caused you with #1 being the stress causing the most problems. Rate the stress on a scale from 1-4 with 4 being severe stress and 1 being minimal stress

Section I: Illness-Related Risks

1. Have you had any physical complications as a result of your cancer or its treatment?
 Yes _____ No _____ If yes, what: _____

2. Have you had any psychological problems as a result of your cancer or its treatment?
 Yes _____ No _____ If yes, what: _____

3. Have you had any behavioral problems as a result of your cancer or its treatment?
 Yes _____ No _____ If yes, what? _____

Concerned Event	Minimal Stress		Severe Stress	
(). Having a relapse	1	2	3	4
(). Developing another cancer	1	2	3	4
(). Getting more invasive treatments	1	2	3	4
(). Guilt about having cancers	1	2	3	4
(). Infertility	1	2	3	4
(). Uncertainty in health status	1	2	3	4
(). My children will get cancer	1	2	3	4
(). Perceiving be discriminated	1	2	3	4
(). Others, for examples:				

Section II: Individual Risks

1. I grew up in a family where a parent/guardian was:
 - alcoholic _____
 - drug user _____
 - abusive (physically, emotionally, sexually) _____
 - unemployed _____
 - in poor health physically or mentally _____
 - none of the above _____
 - anything not listed _____
 - a good parent/guardian _____

2. I live in a neighborhood that:
 is surrounded by violence (guns, knives, abuse) _____
 is poor _____
 has gangs _____
 has poor schools _____
 is treated badly by the police and others _____
 is good, kind, and happy _____
 anything not list _____

3. I believe I have:
 too much pressure placed on me by my family _____
 too much pressure placed on me by my friends _____
 too many problems in my life _____
 very little fun in my life _____
 a very happy life _____
 anything not listed _____

Statement	Respond			
	strongly disagree	disagree	agree	strongly agree
	1	2	3	4
4. I use prayer to get me through the difficulties in my life	1	2	3	4
5. I respond to the difficulties in my life by doing such things like eating too much, sleeping too little, using drugs, smoking, drinking, closing off my feelings.	1	2	3	4

Appendix E
The Interview Guide

The Interview Guide

1. What does illness-related risks mean to you?
2. What does individual risks mean to you?
3. What does protective factors mean to you?
4. What does resilience mean to you?
5. What does quality of life mean to you?

Appendix G

Permission for Conducting Research in Chang Gung Memorial Hospital

July 7, 2005

Li-Na Chou
5702 Linda Vista Rd Apt 24
San Diego, CA 92110

Dear Miss Chou:

I am pleased to inform you that your dissertation study entitled "Survivorship of Childhood Cancer in Taiwan" has been accepted by the research committee in Chang Gung Memorial Hospital. As the Director of Nursing Department in the hospital, I grant you permission to conduct your dissertation study in Chang Gung Memorial Hospital and look forward to your findings contributing to the Taiwanese childhood cancer survivors and benefiting the nursing professionals.

Sincerely,

Director of Nursing Department
Chang Gung Memorial Hospital
Telephone: 011886-3-328-1200

Appendix H

Human Subjects Consent Form (English)

CONSENT TO BE A PARTICIPANT IN A RESEARCH STUDY

A. Purpose and Background:

Li-Na Chou, RN, a doctoral student at the University of San Diego, USA is conducting a study about surviving childhood cancer and the quality of life you now lead. By participating in this research, you will be adding to the body of nursing knowledge regarding surviving childhood cancer but more importantly about the Taiwanese child's experience in surviving childhood cancer.

B. Procedure:

You have received a packet containing several documents: two copies of the consent form, and four questionnaires related to identifying some specifics about you and your diagnosis, the risks encountered during your bout with cancer, your ability to overcome those risks, and the quality of life you now lead. These instruments are the *Demographic Questionnaire*, the *Risk Assessment Questionnaire*, the *Resiliency Attitude and Skill Profile*, and the *Minneapolis-Manchester Quality of Life* questionnaire. It is estimated that the whole process will take you approximately 1 hour. About 1 month after you complete the questionnaires, you might be contacted by mail to participate in small group discussion on the same subject. These discussions will last approximately 90 to 120 minutes and take place in a conference room at Chang-Gung Outpatient Clinic. These discussions will be audio-recorded. Your real name will not be used during the discussions. You will be identified by a code number only.

If you agree to participate, you are requested to do the following:

1. Read and sign this form and keep a copy for yourself.
2. Complete the four questionnaires.

3. A small number of people in the study (12) will be contacted by mail to take part in a group discussion approximately one month after completing the questionnaires.

C. Risks and Benefits:

1. Please keep a copy of this consent form and return a signed copy of the consent form to the research.
2. Participation in this study is completely voluntary. You may decide to cease answering the questionnaires or to decline to answer certain questions at any time without any penalty.
3. The major risk to you is the potential of feeling tired when you try to answer these questionnaires. Completing these questionnaires at your own speed can prevent this, you may also ask for time to rest and can complete the questionnaires at another time. If at any time you feel negative feelings (embarrassment or anxiety for example,) you may call the Taipei Mental Health Hotline number at 02-2502-5858.
4. The potential benefits include adding to the knowledge of surviving childhood cancer, especially surviving cancer in Taiwan. Such knowledge can help health care providers make surviving cancer a more optimal experience for children and this may improve their quality of life.

D. Confidentiality:

All data will be coded by the numbers of the questionnaire, not by the names. Your name will not appear on any of the collection tools. The consent forms will be stored at different secure area from the data and the questionnaires. If you do participate in the discussion groups, your name will not be used on the audiotapes.

All data, including the audiotapes, will be kept in a locked file cabinet in the researcher's -- Li-Na Chou, office with access only by the researcher and the researcher's advisor, Dr. Anita Hunter. All data will be kept a minimum of five years before being destroyed. Although the overall results may be reported at professional meetings or in professional journals, all individual data will remain confidential.

E. Questions:

If you have any questions, you may contact the research, Li-Na Chou, or her faculty advisor, Dr. Anita, Hunter at the telephone number or e-mails below.

Li-Na Chou, RN: linachou-07@san Diego.edu Telephone: 02-2966-4578

Dr. Anita Hunter: ahunter@san Diego.edu Telephone (USA): 619-260-7609

I have read and understood this form and consent to the research is described to me.

Your signature

Print your name

Date

Thank you very much for your time in reading and filling out this form.

Li-Na Chou, RN, Principal Investigator

Date

Appendix I

Human Subjects Consent Form (Chinese)

台灣兒童癌症存活者之復原能力及生活品質之探討
參與研究同意書 (問卷調查)

參與者姓名：_____ 日期：_____ 編號：_____

您好! 敝人(周利娜) 目前為美國聖地牙哥大學護理學院之博士候選人以及本研究之主研究員。在 Anita Hunter 副教授的指導下進行本研究。本研究目的為：了解您的復原能力與生活品質。我們非常需要您提供您的寶貴資料。本訪談將協助研究者了解您的復原能力及生活品質，進而協助研究者了解與探討影響您復原能力與生活品質的相關因素，以期促進台灣兒童癌症患者的相關服務與照護。

研究者將分別邀請 98 名已完成癌症治療者參與本研究之問卷調查。本研究預計完成的時間為六個月(民國九十四年九月至民國九十五年二月)。參與本研究，誠屬自願，且無直接的傷害或益處。您需完成填寫四份問卷。本問卷所收集的資料將協助研究者建構照護本土兒童癌症患者護理措施之依據。填寫此問卷時，某些問題可能會讓您覺得不自在，但不致於造成任何傷害。填寫本問卷的指引已詳列於問卷中，您可以在任何時間參與或是退出此研究計畫。您在填寫問卷時，若對問卷內容有任何疑問，均可隨時向研究員提出，研究員將一一詳細為您說明。您的參與將有益於提高大眾對此問題的重視與使用良好的預防措施，並協助提昇兒童癌症患者之照護品質。

任何從您得到的消息，將會保持隱密，只有編號會被使用來評估研究結果。除了主研究員，沒有任何人可拿到資料，也沒有任何人的名字會被使用。

參與本研究，您不需要繳交任何費用，為了感謝您的協助與參與，研究者將致贈您一份禮物。問卷調查前，您就會收到此份禮物。您不需要簽訂任何收據。依照本研究計畫，您與主研究員的接觸僅只一次。但日後主研究員若對您提供與本研究相關資料有關的問題，需要您的澄清時，可能會與您做電話的訪談。

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參與者簽名

參與者姓名

日期

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台灣兒童癌症存活性之復原能力及生活品質之探討

參與研究同意書 (個人訪談)

參與者姓名： _____ 日期： _____ 編號： _____

您好! 敝人(周利娜) 目前為美國聖地牙哥大學護理學院之博士候選人以及本研究之主研究員。在 Anita Hunter 副教授的指導下進行本研究。本研究目的為：了解您的復原能力與生活品質。我們非常需要您提供您的寶貴資料。本訪談將協助研究者了解您的復原能力及生活品質，進而協助研究者了解與探討影響您復原能力與生活品質的相關因素，以期促進台灣兒童癌症患者的相關服務與照護。

研究者將分別邀請 12 名已完成癌症治療者參與本研究之個人面對面訪談。本研究預計完成的時間為六個月(民國九十四年九月至民國九十五年二月)。參與本研究，誠屬自願，且無直接的傷害或益處。個人訪談所收集的資料將協助研究者建構照護本土兒童癌症患者護理措施之依據。在個人 45~60 分鐘訪談時，在訪談中將訪問您有關生理及心理相關因素的問題，某些問題可能會讓您覺得不自在，但不致於造成任何傷害。您可以在任何時間參與或是退出此研究計畫。您的參與將有益於提高大眾對此問題的重視與使用良好的預防措施，並協助提昇兒童癌症患者之照護品質。

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