# Complementary Therapy to Relieve Pediatric Cancer Therapy-Related Symptoms in the USA

Annemarie Slaven, BSN Honors Student
Faculty Mentors: Phoebe D. Williams, PhD, RN, FAAN
Ubolrat Piamjariyakul, PhD, RN
University of Kansas School of Nursing

#### Abstract

Children undergoing treatment for cancer often receive chemotherapy or radiation therapy and may experience many symptoms linked to these treatments. This study examined complementary therapies and self-care or dependent-care methods used by pediatric patients and parents to alleviate symptoms during cancer treatments. The specific purposes of this study were to assess symptoms and the complementary therapies and self-care or dependent-care methods used by pediatric patients and parents during cancer treatments. Orem's self-care/dependent-care concept was used to guide the analysis of the care pediatric patients received. Secondary analysis was done on data collected from a cross-sectional, multi-site study in the Midwestern and Southwestern USA. The sample included 92 parents of children ages 1-17 years old; 52% were females; 16 were less than 5 years old; 53 were 5-11 years old, and 23 were 12-17 years old. Of the cancer diagnoses reported, 56% had leukemia and 44% had other cancer types. The 30-item Therapy-Related Symptom Checklist for Children (TRSC-C) was used to record patients' symptom occurrence and severity on a 5-pt scale (0, no symptom; 4, "A whole lot"). The Symptom Alleviation: Self-Care Methods (SA:SCM) tool was used to identify methods parents used to alleviate therapyrelated symptoms. To address the study purposes, descriptive data and content analyses were conducted. Symptom occurrences of 19 symptoms were reported by 40% or more of the patients and had a mean severity of "2" or "Quite a bit." The top five symptoms included nausea, feeling sluggish, hair loss, loss of appetite and vomiting. Of the six categories of self-care or dependent-care methods and complementary therapies, four were found useful; herbal treatments were not mentioned. The two categories most utilized were Prescribed Medications and Mind Body Control. Assessing patient-reported and parent-reported symptoms and the use of self-care and dependentcare methods and complementary therapies help parents cope and help their children.

#### Introduction

According to the American Cancer Society (ACS, 2011), cancer is the leading cause of disease-related death in children aged 0-14 years. In fact, about 11,210 children in the United States under the age of 15 will be diagnosed with cancer in 2011 (ACS, 2011). Childhood cancer rates have been rising slightly for the past few decades (ACS, 2011). However, with improved efficacy of cancer treatment, the 5-year survival rate for childhood cancers has increased to 80% overall (ACS, 2011). More types of cancers are being treated with chemotherapy and radiation at high or sustained dosages. The research program of Dr. Phoebe D. Williams deals with the increased

concerns about symptoms during treatment and patients' reactions. The initial (pilot) and subsequent studies examined symptom occurrence and severity as monitored and reported by parents and caregivers of children and adolescents during chemotherapy and radiation therapy. The pilot study also focused on ways parents helped to alleviate symptoms through self-care or dependent care. Williams' research findings showed that systematic assessment through patient/parent self-reports of symptoms during treatment cycles allows care providers to more effectively manage early conditions that threaten successful therapy (Williams et al., 2006). In 2012, a calibrated instrument, the Therapy-Related Symptom Checklist for Children (TRSC-C) was developed for use by patients/parents to "self-report" the occurrence and severity of symptoms during pediatric cancer treatments (Williams et al., 2012).

# **Purpose**

The purpose of this research was to examine during pediatric cancer treatments: (a) what parents of children in the USA report they do to help alleviate symptoms during cancer therapy; (b) what complementary (dependent) care categories are reported.

## **Conceptual Framework**

The concept of self-care by Orem (1995) was used to guide the data collection and analysis. Self-care is defined as the "voluntary regulation of human functioning and development that is necessary for individuals to maintain life, health, and well-being" (p. 95). Parents or caregivers care for their children and monitor their self-care needs because many children cannot always care for themselves, which Orem refers to as dependent care (Williams et al., 2006). Parents and caregivers implement dependent care strategies with their child during cancer treatments.

Complementary care is a term used to describe the methods parents and caregivers use to alleviate the symptoms caused by cancer therapy. Complementary Care and Therapies, as used in this study: are "care modalities or self-care used as adjuncts to mainstream medical care, as provided in a cancer clinic" including chemotherapy (Williams et al., 2006; 2010, p. 38) and are also called "integrative therapies" (Wesa et al., 2008). Various methods are used are classified into six different categories by Williams et al. and co-investigators (2006; 2010, Piamjariyakul et al., 2010).

# Literature Review

An Internet database search using CINAHL and PubMed helped the student locate pediatric oncology treatment research from the past 15 years. The research supports the theory that parents play a crucial and an integral part of their child's treatment process during cancer therapy. When a child is diagnosed with cancer, often parents become overwhelmed with new stressors and do not

feel as though they are adequately caring for their child and themselves. The focus of the literature review was directed towards: (a) parental coping and dependent care methods utilized by parents of children with cancer, and (b) symptom monitoring and management during pediatric cancer treatments.

# Parental Care during Pediatric Cancer Treatments

A study participant in the Flury et al. (2011) qualitative study explained, "caring for a medically fragile child at home is equal to a full time job" (p.2). Parents have to keep children under surveillance 24 hours a day for severe side effects and it takes a toll. Parents in this study were interviewed about their experiences of taking home their sick child for the first time after the diagnosis and what new tasks they were facing 4 to 7 weeks later. Hospital stays, reduced to a minimum (due to the ability to place central intravenous lines and give chemotherapy at home and have specialized home care services) force parents to abruptly come to terms with their child's lifethreatening illness and begin taking on an overwhelming amount of new duties involved in caring for a sick child.

According to the study by Flury et al. (2011), parents of children with cancer need information about treatment and condition as well as contact with the medical staff on a regular basis. They need training and support for home health work. When parents first learn of their child's diagnosis, they are confronted with a lot of information both written and oral. The first weeks at home are the most challenging. They are given instruction for many new considerations and dependent care and complementary care methods including administration of medication and symptom management. Health care professionals can provide better discharge teaching for parents of newly diagnosed children with cancer about potential problems and solutions.

Findings in the study by James, Keegan-Wells, Hinds et al. (2002) done in the USA showed parental caregiving of ill children led to negative physical and emotional health of parents. This was a descriptive, exploratory study of 151 parents who were actively involved in the care of their sick child. They answered 6 open-ended questions on the *Care of My Child with Cancer* survey. Content analysis of 1,280 responses showed two types of actual assistance were found to be most helpful by parental caregivers: timely education about their child's health status from Health Care Providers and emotional support from family members, friends and others. Findings provided ideas for future interventions to ease the workload of parents of children with cancer. Examples of helpful topics included ways of monitoring the patient's medical status, and maintaining other roles and activities outside the home.

Symptom Monitoring and Management during Pediatric Cancer Treatments

Rheingans (2008) conducted a study using surveys from 509 pediatric oncology nurses in the United States, focused on the most distressing symptoms experienced and reported by pediatric patients. The survey was used to assess nurses' views on patient symptoms experienced, the distress symptoms caused, and what interventions were used to treat patient symptoms. Pain was the most commonly reported symptom and trouble sleeping was the least common. Nurses' distress was greatest with trouble sleeping and the least with hair loss. The study found nurses use an average of 12.7 interventions including emotional support, art therapy, deep breathing, distraction, humor, massage, music therapy and acupuncture. Symptom management is typically led by the administration of pharmacologic agents, but this study emphasizes the importance of non-pharmacologic agents and providing a more holistic approach through other interventions.

In the study by Baggott et al. (2004), a questionnaire was mailed to 1,000 pediatric oncology nurses asking about their practices for advising patients and their families about self-care measures and reporting of adverse symptoms. The survey had three domains: advice about symptoms for which it is appropriate to initiate self-care prior to calling for professional advice, consensus self-care interventions recommended for common symptoms, and advice on when to call immediately for professional assistance. An analysis of 135 valid responses showed consensus that nurses were recommending similar self-care interventions for eight common adverse symptoms (constipation, weight loss, fatigue, pain, infection, nausea, mouth sores and bleeding) and advice for when patients should promptly report to health care providers.

The study by Berg et al. (2009) used semi-structured interviews with 25 cancer survivors (8 to 18 years of age) to investigate the late effects of childhood cancer on participation and quality of life. It concluded many survivors experience lower quality of life scores, as measured by the Pediatric Cancer Quality of Life Inventory, and are less likely to participate in vigorous leisure activities due to late effects of the disease or effects of the chemotherapy and radiation therapy. These included lower extremity pain and numbness, memory and attention deficits, fatigue and depression. These patients needed to be offered self-management and self-care strategies to cope with ongoing symptoms.

In the pilot study by Williams et al. (2006) the Therapy-Related Symptom Checklist (TRSC-C) child version was given to parents/caregivers of 11 children and adolescents (12 to 18 years). Findings showed that the most common symptoms were feeling sluggish (fatigue), pain, hair loss, sore mouth, vomiting, loss of appetite, weight loss, fever, constipation-- and nausea which was reported by all children. In this study, Williams and co-investigators suggested that healthcare

providers need to assist patients and family members to cope with the side effects of therapy; moreover, systematic assessment through a caregiver-report (or a child self-report) checklist could help with both identification and prioritization of symptoms needing intervention. The TRSC-C assists parents and healthcare providers in monitoring the symptoms experienced by pediatric oncology patients.

The study found that symptoms were physiological, psychological and social in nature. Pediatric oncology nurses should be knowledgeable about child development and be able to identify their patients' symptoms and treat them adequately to improve their quality of life. Ignored side effects can lead to anxiety toward treatment and create unsuccessful outcomes. Pediatric oncology nurses need tools to help parents gauge their child's symptom occurrence and severity, and methods to alleviate them.

In the instrument development study by Williams et al. (2012), data were collected from 385 children 5-17 years old with cancer at 5 university-affiliated oncology clinics across the USA (central, western, eastern, southeastern). Parents used the TRSC-C to report symptom occurrence and severity during chemotherapy, radiation therapy and combined CT/RT. The study calibrated the 30-item TRSC-C; "kid-friendly" terms (shown in Figure 1) were used to monitor symptom occurrence and severity during chemotherapy, radiation therapy, or combined CT/RT. The study showed the TRSC-C, with psychometric properties of excellent reliability and validity, improves communications among patients, parents, clinicians and others. It allows self-report of symptoms and shared decision-making and is a quality tool to improve quality of life of pediatric oncology patients.

#### Methods

# Design

The larger study was a cross-sectional, descriptive study by Dr. P.D. Williams conducted in the USA and in Thailand; IRB approvals were obtained at all sites. Secondary analysis of data collected in the Midwestern and Southwestern USA was done for this report to address the research purposes. In order for the honors student to participate in this research, she had to obtain *KUMC-IRB approval* as well as a *Conflict of Interest* clearance.

#### **Instruments**

The Therapy-Related Symptom Checklist-Child, TRSC-C (Williams et al., 2012), a patient/parent self-report tool, was used to gather information on symptom occurrence and

severity experienced during cancer treatment. Parents used the 30-item TRSC-C to record patients' symptom occurrence/severity on a 5-pt scale: "0" (no symptom), "1" (a bit), "2" (quite a bit), "3" (a lot), and "4" (a whole lot). Scores of "2" or more indicate symptoms were more severe. The TRSC-C also had a space at the bottom of the checklist for parents and/or patients to report additional symptoms (not listed on the TRSC-C) they might be experiencing. A Cronbach's alpha coefficient of .91 (indicating good internal consistency reliability), and good content and construct validity have been reported on the TRSC-C (Williams et al., 2012).

Another tool used in the study was the Symptom Alleviation: Self-Care Methods (SA:SCM) tool. Self-Care Methods, in this study, may include complementary care and therapies to relieve symptoms. The SA:SCM was used to identify methods parents used to alleviate therapy-related symptoms as reported on the TRSC-C. The tool also measured whether the method was found useful or not in alleviating symptoms. It measured how often methods or strategies were used, as well. A "0" indicated "not done" and a "4" indicated "done very often." Williams et al. (2012b) have reported a Cronbach's alpha coefficient of .72 on the SA:SCM.

Parents also completed the Demographic form. The Health and Other Data form was completed by the Nurse Clinician; she also rated the child's condition and activity (functional status) using either the Lansky scale (5-15 years) or the Karnofsky scale (16-17 years).

#### Data analysis

To address the study purposes, data on parents' dependent care methods were content analyzed by this student. The researcher, on each of the 25 symptoms made a tally in tabular format of all the reported parental alleviation methods-- or their complementary care responses to the Symptom Alleviation: Self-Care Methods (SA: SCM) tool. These responses were classified into six categories (Williams et al, 2006; 2010), namely: (a) Diet, Nutrition, and Life-style change; (b) Mind Body Control; (c) Biologic Treatment; (d) Herbal Treatment; (e) Other methods; and (f) Taking Prescribed Medications. The categories were clear for most of the methods used; only a few responses needed clarification by the Mentor. Symptom alleviation methods used for each symptom reported were finally counted and reported in Table 2.

#### Results

## **Sample Characteristics**

The parents of 92 pediatric oncology patients were included in the sample. The ages of their children ranged between 1 and 17 years old; 52% were females. Sixteen were less than 5 years old,

53 were between the ages of 5-11 years old, and 23 were between the ages of 12-17 years old. Of the 92 children, 56% had diagnoses of leukemia and 44% had Other cancer types including nervous system tumors, Wilm's tumor, rhabdomyosarcoma, retinoblastoma, lymphoma, and cancers of the liver, ovary and kidney.

# **Symptom Occurrence and Severity Reported**

The occurrence and severity of symptoms reported on the TRSC-C are shown in Table 1. The table consists of 30 items clustered into the 7 TRSC-C subscales (Willams et al., 2012a). Overall 40% or more of the sample reported 19 symptoms [nausea (80%), feeling sluggish (80%), hair loss (80%), loss of appetite (74%), vomiting (72%), irritable (69%), pain (61%), weight loss (58%), headache (52%), agitation (47%), depression (46%), constipation (45%), bruising (42%), fever (41%), afraid (41%), tripping and falling (40%), skin changes (40%), sweating (40%) and difficulty sleeping (40%)]. The typical mean severity of the symptom was "2" or "Quite a bit." It is noted also that the larger study (Williams et al. 2012b) found that the TRSC-C scores were significantly related to patients' functional status, as rated on the Lansky-Karnofsky scale.

### **Complementary or Dependent Care Method Reported**

The six categories of complementary or dependent-care methods that parents/caregivers reported on the SA:SCM tool are shown in Table 2. The six categories are: A. Diet, nutrition, and life-style changes; B. mind body control; C. biologic treatment; D. herbal treatment; E. other methods; and F. taking prescribed medications. Each of the 30 TRSC-C symptoms is listed in the first column of Table 2 and the number of times each complementary therapy method was used to alleviate each symptom was listed under the categories A, B, C, D, E, or F. For example, the symptom "Feeling sluggish" occurred commonly—47 parents reported using B. Mind-Body Control, while 1 parent reported using F. Prescribed Medications. It should be noted that parents/ caregivers had the option of reporting "Do Nothing" (E), if that was in fact how they marked their response on that symptom. Of the six categories of self-care or dependent-care methods or complementary therapies, four were found useful; herbal treatments were not mentioned.

The two most common categories were (a) taking prescribed medications and (b) mind/body control. Findings in prescribed medications category included taking anti-emetics such as Zofran for nausea, laxatives for constipation, Xylocaine for a sore mouth, and pain relievers such as Tylenol or Oxycodone. Examples of parental (dependent) care methods in the mind/body control category included providing reassurance, rewards; holding, hugging and saying "I love you"; playing

and talking with mom; sleeping; and using a heating pad. The most common findings in the Other category included nutritionist consult; mouth care, ice chips, magic mouthwash, and throat spray.

#### Discussion

The study findings showed that the TRSC-C is a tool that health care professionals can use to help all parents, but especially those with newly diagnosed children, to observe and report the occurrence and severity of their child's symptoms -- and relay the information to health care providers during treatments. By also gathering the information on the SA: SCM, a list of ways to relieve symptoms were found, and these can be shared with parents in their efforts to relieve symptoms during their child's chemotherapy or radiation therapy. When parents first learn of their child's diagnosis, they are confronted with much information, both written and oral (Flury et al., 2011). Moreover, the findings in the James et al. (2002) study showed that parental caregiving of ill children led to negative physical and emotional health of parents. However, timely education from Health Care Providers about their child's health status and ways to monitor it was of the greatest assistance to them.

The study by Baggott et al. (2004) showed that nurses recommended to parents similar self-care interventions for 8 common adverse symptoms (constipation, weight loss, fatigue, pain, infection, nausea, mouth sores, and bleeding), and advised that they should promptly report these to health care providers. The study by Berg et al. (2009) found cancer patients needed to be offered self-management and self-care strategies to cope with ongoing symptoms from the late effects of the treatments for childhood cancer. This is information that can be documented with the TRSC-C and the SA: SCM tools, as shown in this study.

The Williams et al. (2006) pilot study of parents of 11 children and adolescents with cancer showed the TRSC-C is a tool that improves communications among patients, parents, clinicians and others by allowing for self-report of symptoms and shared decision-making to relieve symptoms. The checklist uses terms that a child would use to express discomfort and this allowed for more accurate reporting of symptoms, as shown in this study.

As mentioned, the TRSC-C was an effective tool for parents and caregivers to report symptoms their child experienced, and the SA: SCM was an effective way to help them identify dependent-care methods and complementary therapies used to alleviate symptoms. The five most reported symptoms were nausea, feeling sluggish, hair loss, loss of appetite and vomiting; the first 3 were most reported by the children, each at 80%. Another children's study confirmed the most

common symptoms included hair loss, nausea, vomiting, and loss of appetite (Williams et al., 2012b).

Parents and caregivers used dependent-care strategies and complementary therapies to alleviate many of the symptoms children exhibited. Using prescribed medications and mind/body control were the most effective categories. A study completed on Thai pediatric cancer patients indicated that the complementary therapy category Diet, Nutrition, and Lifestyle" was most common, followed by the category Mind Body Control (Shanberg & Williams, 2010). Common methods in the first category as used by Thai parents included adding flavoring to food items, changing the variety of foods, providing small frequent meals, and offering soft or liquid diets. Examples of specific methods used in the Mind/body control included massage, sponge baths, providing words of encouragement, allowing more periods of rest, and varying activities (Shanberg, Williams & Piamjariyakul, 2011). Comparing the results from studies done in Thailand and the United States suggests that international collaboration is feasible to study symptom monitoring and ways to manage symptoms during chemotherapy and radiation therapy. The patients experienced similar symptoms, yet cope differently.

According to Rheingans (2008), symptom management by nurses was typically done through the administration of pharmacologic agents. The study also emphasized the importance of using non-pharmacologic agents and providing a more holistic care. It discussed the use of interventions such as emotional support, art therapy, deep breathing, distraction, humor, massage and music therapy, which are all classified in the B. Mind/body category on the SA:SCM tool (Williams et al., 2006; 2012b).

In conclusion, the study found that dependent (parental) care helped manage symptoms. Moreover, assessing patient/ parent-reported symptoms and parents' use of dependent care methods or complementary therapies during pediatric cancer treatments also helped parents cope when they knew that they were helping their children.

#### **Implications for Nursing**

Nurses and other care providers can enhance care during treatments through assessments with a symptoms checklist. They also can advise parents on ways to alleviate their children's symptoms. Pediatric oncology nurses should be knowledgeable about child development and be able to identify their patients' symptoms and treat them adequately to improve their quality of life. Ignored side effects can lead to anxiety toward treatment and create unsuccessful outcomes.

# Acknowledgements

Funding for the poster presentation of this report was awarded to this student by Sigma Theta Tau—Delta Chapter. The poster was presented at the annual *Mind & Heart Research Symposium* at the Stowers Institute in Kansas City, MO in November 2011 and the 34<sup>th</sup> Annual *Student Research Forum* at the University of Kansas Medical Center in March 2012. Partial funding for the data collection was awarded to Honors mentor, Phoebe D. Williams, PhD, RN, FAAN, by the *Alex Lemonade Stand Foundation*.

Figure 1 Therapy-Related Symptom Checklist-Children (Williams et.al, 2012)

# THERAPY-RELATED SYMPTOM CHECKLIST-CHILDREN (TRSC-C)

Name:	ID#		Date:	
Age:	Gender: Male	Female	_	
DI EVCE II	DENTIFY below THE P	PORTEMS VOITH	VE HAD IMME	DIATELV
	D SINCE YOUR LAST			
THE PROB	LEM WAS ACCORDIN	G TO THE FOLLO	WING SCALE:	
0=NO SYMPTOM	1 = A LITTLE BIT	2 = QUITE A BIT	3 = ALOT	4 = A WHOLE LOT

CIRCLE HOW SEVERE   Pain	EXAMPLE		CIRCI	E HO	W SEV	FRE
Nausea [Feel like throwing up; Upset stomach; Stomach hurts]		<u>0 I </u>	1	•		•
Nausea [Feel like throwing up; Upset stomach; Stomach hurts]	Loss of Appetite [Not feeling hungry; Eat less; Not feel like eating]	4 9	1	2	3	4
Vomiting [Throwing up]		1440	1	2	3	4
Weight Loss [Losing weight; Feel skinnier]		<b>10.</b>		2	3	4
Sore Mouth [Mouth hurts; Hurts to eat]   0   1   24   3   4   3   4   4   3   4   4   3   4   4		0	1	2	3	4
Difficulty Swallowing [Hard to swallow; Hurts to swallow]	Sore Mouth [Mouth hurts; Hurts to eat]			2/L	3	4
Sore Throat [Throat hurts]	Difficulty Swallowing [Hard to swallow; Hurts to swallow]	. 0	4	4	3	4
Jaw Pain [Jaw hurts; Hurts to chew or yawn]		0	1	1.2	3	4
Cough [Coughing much]	Jaw Pain [Jaw hurts; Hurts to chew or yawn]	T A	4	_	3	4
Shortness of Breath [Hard to breath; Breathe fast   1		0		2	3	4
Depression [Feel sad a lot; Cry more]	Shortness of Breath [Hard to breath; Breathe faster to the state of th		1	2	3	4
Difficulty Concentrating [Hard to think Hard to pay abundants   0	Feeling Sluggish [Feel very tired; Feel lazy]		1	2	3	4
Difficulty Sleeping [Hard to go to sleep [Rard to stay aslesh]	Depression [Feel sad a lot; Cry more]	0	1	2	3	4
Difficulty Sleeping [Hard to go to sleep [Rard to stay aslesh]	Difficulty Concentrating [Hard to think Hard to pay attention ]		1	2	3	4
Fever [Feel very hot; High temperature]   The Bruising [Dark spots on skins Exprise easily]	Difficulty Sleeping [Hard to go to sleep Plant to stay aslesp]	0	1	2	3	4
Bleeding [Bloody nose; Bleet   Start from cuts, starthes, or with brushing teeth]   Constitution out; Losin mair   Constitution out   Constitution   Con	Fever (Feel very hot: High temperature)	0	1	2	3	4
Hair Loss [Hair falking out; Losin hair]	Bruising [Dark spots on skin Amise easily]	0	1	_	-	4
Hair Loss [Hair falking out; Losin hair]	Bleeding [Bloody nose; Bleed 1997] from cuts, schurches, or which brushing teeth]	0	1	2	3	4
Pain [It hurts]	Hair Loss [Hair falling out, Losing hair]	0	1	2	3	4
Numbness in Filences and Topic [The ling fingers/ toes; fingers/ toes]   0	Skin Changes [Man feels dry or red Skin Bels driftent]	0	1	2	3	4
Numbness in Filence and Topic [The ing fingers/ toes; fingers/ toes]	Pain [It hurts]	0	1	2	3	4
Constipation [Hard to "poop"]       0       1       2       3       4         Sweating       0       1       2       3       4         Itching [Want to scratch skin]       0       1       2       3       4         Hard to urinate [Hard to "pee"]       0       1       2       3       4         Afraid [Feel nervous; worried]       0       1       2       3       4         Headache [Head hurts]       0       1       2       3       4         Irritable [Feel upset easily; get mad easily]       0       1       2       3       4         Agitation [Feel restless; can not stay still]       0       1       2       3       4         Tripping or Falling       0       1       2       3       4         Other (List)       0       1       2       3       4         Other (List)       0       1       2       3       4	Numbness in Fire and Tops (Tineing fingers/ toes; fingers/ toes  "falling asleep"; Fingers to save Cont	0	1	2	3	4
Sweating		0	1	2	3	4
Hard to urinate [Hard to "pee"]       0       1       2       3       4         Afraid [Feel nervous; worried]       0       1       2       3       4         Headache [Head hurts]       0       1       2       3       4         Irritable [Feel upset easily; get mad easily]       0       1       2       3       4         Agitation [Feel restless; can not stay still]       0       1       2       3       4         Tripping or Falling       0       1       2       3       4         Other (List)       0       1       2       3       4         Other (List)       0       1       2       3       4         Other (List)       0       1       2       3       4		0	1	2	3	4
Afraid [Feel nervous; worried]       0       1       2       3       4         Headache [Head hurts]       0       1       2       3       4         Irritable [Feel upset easily; get mad easily]       0       1       2       3       4         Agitation [Feel restless; can not stay still]       0       1       2       3       4         Tripping or Falling       0       1       2       3       4         Other (List)       0       1       2       3       4         Other (List)       0       1       2       3       4         Other (List)       0       1       2       3       4	Itching [Want to scratch skin]	0	1	2	3	4
Headache [Head hurts]	Hard to urinate [Hard to "pee"]	0	1	_	3	4
Irritable [Feel upset easily; get mad easily]		0	1		3	4
Agitation [Feel restless; can not stay still]       0       1       2       3       4         Tripping or Falling       0       1       2       3       4         Other (List)       0       1       2       3       4         Other (List)       0       1       2       3       4         Other (List)       0       1       2       3       4		0	1		_	4
Tripping or Falling       0       1       2       3       4         Other (List)       0       1       2       3       4         Other (List)       0       1       2       3       4         Other (List)       0       1       2       3       4		•	1			
Other (List)       0       1       2       3       4         Other (List)       0       1       2       3       4         Other (List)       0       1       2       3       4	Agitation [Feel restless; can not stay still]	0	1		_	4
Other (List)         0         1         2         3         4           Other (List)         0         1         2         3         4		_	-			
Other (List) 0 1 2 3 4	• • • • • • • • • • • • • • • • • • • •	•	1	_	_	
out (Eddy	Other (List)	_	1	2	3	4
					3	4

Copyright©2010 Phoebe D. Williams, PhD, and Arthur R. Williams, PhD

Table 1 Distribution of Symptoms and Severity on the TRSC-C (N=92)

TRSC-C Symptoms and Factors	0	1	2	3	4	Mean (SD)	% Occurrence
Nutrition-related							
Loss of appetite	24	13	21	21	12	1.82 (1.395)	74
Nausea	18	25		10		1.81 (1.382)	80
Vomiting	26	33	13	10		1.37 (1.279)	72
Weight loss	39	28	10	8		1.05 (1.223)	58
Feeling sluggish	18	17	19	17		2.04 (1.437)	80
Hair loss	18	7		17		2.51 (1.552)	80
2. Psychosocial/CNS							
Depression	50	18	7	9	7	0.96 (1.316)	46
Difficulty concentrating	60	17	4	3		0.68 (1.201)	35
Pain	36	16	15	11		1.44 (1.470)	61
Irritable	29	16	13	16		1.74 (1.526)	69
Agitation	49	14	7	9		1.13 (1.485)	47
Headache	44	17	12	12		1.11 (1.320)	52
Afraid	54	10	13	6		0.95 (1.345)	41
3. Oropharyngeal						,	
Sore mouth	56	14	7	9	5	0.82 (1.252)	39
Difficulty swallowing	74	9	3	3		0.35 (0.874)	20
Sore throat	74	7	7	2		0.34 (0.806)	20
Jaw pain	62	15	9	2		0.56 (0.991)	33
4. Bone marrow toxicity/neuropathy						, , , , ,	
Fever	54	11	10	13	3	0.90 (1.257)	41
Bruising	53	13	9	10		0.93 (1.315)	42
Bleeding	66	15	5	5		0.44 (0.833)	28
Numbness of fingers/toes	67	8	4	8		0.62 (1.181)	27
Tripping/falling	55	19	11	2		0.69 (1.061)	40
5. Skin toxicities							
Skin changes	55	8	16	6	6	0.90 (1.283)	40
Itching	65	11	9	3		0.55 (1.025)	29
Sweating	55	17	8	6		0.78 (1.191)	40
Cough	62	17	4	5		0.57 (1.034)	33
6. Shortness of Breath, Other							
Shortness of Breath	77	6	4	1	3	0.32 (0.880)	16
Difficulty sleeping	55	15	9	5		0.84 (1.267)	40
7. GI, GU-Other							
Constipation	51	15	9	9	7	0.97 (1.329)	45
Hard to urinate	79	5	5	1		0.24 (0.705)	14

TRSC-C scale severity 0-4: 0 = None, 1 = A bit, 2 = Quite a bit, 3 = A lot, 4 = A whole lot % Occurrence = % reported of presence of symptom

Table 2 Symptoms Reported on the TRSC-C and Self-Care Methods Used

Symptoms reported	Α	В	С	D	E	F
Taste change	34	0	0	0	0	1
Loss of appetite	14	1	4	0	1	21
Nausea	4	4	0	0	0	62
Vomiting	4	2	0	0	1	49
Weight loss	6	2	4	0	1	15
Sore mouth	0	0	0	0	10	16
Cough	1	3	0	0	5	5
Sore throat	2	1	0	0	5	4
Difficulty swallowing	0	0	0	0	7	1
Jaw pain	0	1	0	0	1	15
Shortness of breath	0	5	0	0	0	1
Numbness fingers/ toes	0	2	0	0	0	6
Depression	0	17	0	0	6	3
Difficulty concentrating	0	7	0	0	0	1
Fever	0	3	0	0	3	26
Bruising	0	13	0	0	15	0
Bleeding	0	4	0	0	8	1
Hair loss	0	9	0	0	0	0
Skin changes	0	17	0	0	0	0
Afraid	0	34	0	0	0	1
Difficulty sleeping	0	6	0	0	1	10
Pain	0	8	0	0	0	44
Constipation	4	0	0	0	0	31
Hard to urinate	0	0	0	0	0	1
Tripping/falling	0	19	0	0	0	3
Sweating	0	14	0	0	0	0
Itching	0	15	0	0	0	15
Irritable	0	27	0	0	0	5
Agitation	0	14	0	0	0	3
Feeling sluggish	1	47	0	0	8	1
Other:						
Dizzy	0	10	0	0	3	0
Diarrhea	6	0	1	0	0	5
Dry mouth	9	5	0	0	0	7
Headache	3	10	0	0	0	35
Totals	88	300	9	0	75	388

Self care methods, by complementary care categories: A = Diet, Nutrition, and Life-style, B = Mind Body Control, C = Biological Treatment, D = Herbal Treatment, E = Other, F = Prescribed Medications (Williams et al. 2006).

## References

- ACS, American Cancer Society: childhood cancer. Available at <a href="http://www.cancer.org/cancer/cancer">http://www.cancer.org/cancer/cancer</a> in children. Accessed October 27, 2011.
- Baggott, C., Dodd, M., & Kato, P. (2004). A survey of self-care and dependent-care advice given by pediatric oncology nurses. *Journal of Pediatric Oncology Nursing*, 21(4), 214-222.
- Berg, C., Neufeld, P., Harvey, J., Downes, A., & Hayashi, R.J. (2009). Late effects of childhood cancer, participation, and quality of life of adolescents. *OTJR: Occupation, Participation, and Health*, 29(3), 116-124.
- Flury, M., Caflisch, U., Ullman-Bremi, A., & Spichiger A. (2011). Experiences of parents with caring for their child after a cancer diagnosis. *Journal of Pediatric Oncology Nursing*, published online 13 April 2011, DOI:10.1177/1043454210378015.
- James K, Keegan-Wells, D., Hinds, P.S., Kelly, K.P., Bond, D., Hall, B., Mahan, R., Moore, I.M., Roll, L., & Spekhart, B. (2002). The care of my child with cancer: Parents' perceptions of caregiving demands. *Journal of Pediatric Oncology Nursing*, 19(6), 218-228.
- Rheingans, J. (2008). Pediatric oncology nurses' management of patients' symptoms. Journal of Pediatric Oncology Nursing. *25*(6), 303-311.
- Shanberg, R., & Williams, P.D., (2010): Complementary therapy to relieve pediatric cancer therapyrelated symptoms in Thailand. Poster presented at *Mind and Heart Honors Conference*, Kansas City, KS, Nov.
- Shanberg, R., Williams, P.D., & Piamjariyakul, U. (2011). Complementary therapy and care to relieve pediatric cancer therapy-related symptoms in Thailand. *The Journal of BSN Honors Research*, 4(1). http://archie.kumc.edu/handle/2271/987.
- Wesa, K., Gubili, J., Cassileth, B. (2008). Integrative oncology: complementary therapies for cancer survivors. *Hematology Oncology Clinics of North America*, 22(2), 343-353.
- Williams, P.D., Schmideskamp, J., Ridder, E.L., Williams, A.R. (2006). Symptom monitoring and dependent care during cancer treatment in children: pilot study. *Cancer Nursing*. 29(3):188-197.
- Willams, P.D., Lopez, V., & Chair, S. et al. (2010). Symptom monitoring and self-care practices among oncology adults in China. *Cancer Nursing*, *33*(3):184-193.
- Williams, P.D., Williams, A.R., Kelly, K.P., et al. (2012): A symptom checklist for children with cancer: Therapy-Related Symptom Checklist-Children (TRSC-C). *Cancer Nursing*, *35*(2):89-98.

Williams, P.D., Dobos, C., Piamjariyakul, U., Slaven, A., Geiseking, A., Connor, R., & Williams, A.R. (2012). Symptom monitoring and dependent care during cancer treatments of children and adolescents (poster). *Western Institute of Nursing Research Conference*, Portland, OR, April.