The TRSC-C and Childhood Leukemia in Thailand and the USA: Symptom Occurrence/Severity and Care Strategies for Symptom Relief.

Phoebe D. Williams, Ubolrat Piamjariyakul, and Jenna DeGennaro

Phoebe D. Williams, PhD, MN, MA, RN, FAAN, Professor, School of Nursing, Kansas University Medical Center, Kansas City, Kansas, USA
Ubolrat Piamjariyakul, PhD, RN, Research Associate Professor
Jenna DeGennaro, BSN (honors)), RN, School of Nursing, Kansas University Medical Center, Kansas City, Kansas, USA
pwilliam@kumc.edu;upiamjariyakul@kumc.edu;degennarojm@gmail.com

Abstract. *Background:* Treatments for Acute Lymphoblastic Leukemia (A.L.L.) cause significant side effects in children. Symptom alleviation affects treatment adherence and success.

Purposes: Examine in two countries, during cancer treatments, by parent report: (a) symptom occurrence and severity on the Therapy-Related Symptom Checklist for Children (TRSC-C); and (b) strategies to relieve symptoms reported on the Symptom Alleviation: Self-Care Methods (SASCM) tool. Both tools have good psychometric properties.

Methods: A secondary analysis of data from a larger study. Samples: **USA** 51 children, mean age 7.9 yrs; 45% male; 86% on chemotherapy; and **Thailand** 63 children, mean age 7.7 yrs; 79% male; 81% on chemotherapy. Parents rated on the 30-item TRSC-C: scale "0"None; "1" A bit; "2"Quite a bit"; "3" A lot; "4", A whole lot). On the SASCM, descriptive and content analyses were done.

Findings: **A. % Symptom occurrence:** 19 symptoms out of 30 were reported to occur in 40%-84% of the USA children; among Thais, 16 of 30 symptoms were reported to occur in 41%-92% of the children. Top 5 reported symptoms were: (USA) feeling sluggish, hair loss, nausea, appetite loss, irritable; (Thailand) hair loss, nausea, fever, weight loss, vomiting. **Symptom severities (top 5)** were: (USA) feeling sluggish, hair loss, appetite loss, irritable, nausea; (Thailand) hair loss, fever, nausea, appetite loss, irritable. **B. Top symptom alleviation categories** were: (USA) prescribed and over-the-counter medications and mind/body control (comfort measures, massage); (Thailand) mind/body control (comfort child, pray), and diet/nutrition/lifestyle change (rest, soft diet).

Conclusion: The TRSC-C facilitates identification, monitoring, and management of symptoms. Large percentages of patients report many symptoms listed on the TRSC-C. Oncology instruments that mention fewer than 10 symptoms will under-document symptom concerns of patients.

Implications: More studies on the applications of the TRSC-C and SASCM in different cultures and countries are needed. Use of electronic tools for storage and access of symptom reports by patients/parents may improve patient-clinician communications and adherence to treatment.

1 Introduction

Acute Lymphoblastic Leukemia (A.L.L.) is a cancer involving lymphoid tissue, the lymphatic system and immature cells. Approximately 80-85% of all leukemia diagnoses in children is A.L.L., with peak occurrence in children ages two to five years. This type of cancer affects twice as many white as nonwhite children and is more common in boys than girls. Chemotherapy with or without radiation to any localized site in the central nervous system is the treatment of choice [1]. Pediatric patients undergoing treatments for A.L.L. experience many side effects with significant implications for parental care giving and continuation of treatment [2].

Conceptual Framework. Information about common symptoms and monitoring the success of self-reported strategies can guide health care providers (HCPs) in optimizing help for patients during treatments for cancer and counseling parents on caregiving [2]. That is, when HCPs assist individual patients, they must be able to use (and guide patients in the use of) medically prescribed treatment measures including use of "self-care" or "parental care," in the case of pediatric patients.

Purposes. The purposes of this study were to examine in two countries during A.L.L. treatments: (a) the occurrence of symptoms associated with treatment and (b) the severity of symptoms, as reported by parents on the Therapy-Related Symptom Checklist for Children (TRSC-C); and the (c) symptom relief strategies that parents report on the Symptom Alleviation: Self-Care Methods (SA:SCM) tool.

2 Literature Review

The earliest study focused on monitoring cancer treatment-related symptoms and how parents/caregivers alleviated these symptoms was reported by Williams, Schmideskamp, Ridder, and Williams[3]. The researchers used an early version of the Therapy-Related Symptom Checklist (TRSC) with pediatric cancer inpatients in the Midwestern U.S. whose parents reported symptom occurrence and severity on the TRSC; parents also reported care strategies they and their children used to relieve symptoms. The TRSC, however, was previously developed and used with adults (See other papers SS14). This early initial study with children indicated that most frequently reported symptoms (subscales) were fatigue, nausea, eating, fever, oropharynx, pain, and hair loss. Moreover, the parental care/complementary care strategies used were largely diet/nutrition/lifestyle and mind/body control [3].

Recently a revised child-friendly, clinically useable tool, called the Therapy-Related Symptom Checklist for Children, TRSC-C [4] (See SS14 report) was calibrated and is now being used. The calibrations study was conducted with 385 children, 5-17 years, at 5 university-affiliated outpatient oncology/hematology clinics across the USA. The TRSC-C has excellent internal consistency reliability with a Cronbach's α=0.91; and concurrent validity with the PedsQL and the Lansky, instruments that measure quality of life and functional status, respectively.

Pediatric oncology research in the USA has studied single symptoms, used small samples and research designs of varying quality [5-7]. TRSC-C use and results have been reported in recent studies [2]. Riddle et al. [8] had shown significantly higher scores on the TRSC-C among acute lymphoblastic leukemia (A.L.L.) patients during the "early" and more intense phase of treatment, as compared to the "later" phase, reflecting construct validity. A TRSC-C (Spanish version) has been published [9]. Pediatric oncology studies done in non-Western countries include Taiwan and Indonesia [10,11]. In Hong Kong, high TRSC-C scores were found to correlate negatively with quality of life as measured by the Pediatric Quality of Life scale (PedsQL) [12]. Gonzalez et al. [13] reported a Cronbach's alpha of .87 using the TRSC-C (Spanish version), with 65 children/parents in Puerto Rico; symptom occurrence and severity were consistent with results earlier reported in the U.S.A. Gonzalez et al. also used the SASCM and reported an alpha coefficient of .82.

Except for the studies done using the child or adult versions of the TRSC and the SASCM, other symptom-related studies found in the literature did not use comprehensive checklists with good psychometric properties to determine what symptoms are being experienced, how severe these are, or what strategies were being used by parents to alleviate symptoms. The newly calibrated TRSC-C is a comprehensive checklist that enables uniform data collection among pediatric cancer patients. This uniformity is required to better monitor and treat symptoms experienced by patients and their families.

3 Methods

3.1 Design and Sample

The study design in this report is cross-sectional and descriptive. Study settings were children's hospitals in Bangkok, Thailand, and in the Midwestern and Southwestern USA. Inclusion criteria were: parents and their children with cancer diagnosis, who had received at least two treatments, and parental consent to participate in the study. IRB approvals were obtained at all study sites. For this paper, only patients with diagnoses of A.L.L. were included.

3.2 Instruments

The data collected in the original study used two instruments: the Therapy-Related Symptom Checklist for Children (TRSC-C) and the SASCM tool. The SASCM is used to report self-care strategies to alleviate symptoms reported on the TRSC-C. For each symptom reported, the parent is asked what methods were used to alleviate the symptom, and whether or not the method helped relieve the symptom (yes/no answer). Studies reported good internal consistency reliability of the SASCM. Higher scores indicate more frequent engagement of parents in care.

Data Analysis. Descriptive statistics were used to address study aims (a) symptom occurrence and (b) symptom severity, as reported by parents on the 30-item TRSC-C. To address aim (c), content analysis was done of parents' verbatim answers regarding symptom relief methods reported. Methods used were then classified into complementary care categories, as developed earlier for the adult TRSC.

4 Results

4.1 Sample Characteristics

The sample in Thailand consisted of 63 children whose mean age was 7.71 years, 79% male, with 81% undergoing chemotherapy only while the rest received combination therapy. There were 61 Thai parents; the mean age was 37.8 years, with 83.6% being female and 87% being married. The USA sample consisted of 51 children with A.L.L. whose mean age was 7.96 years, 45% male, and 86% undergoing chemotherapy only while the rest received combination therapy (chemotherapy and radiation therapy). There were 47 parents; the mean age was 38.6 years, with 91.5% being female and 80% being married.

4.2 Symptom Occurrence and Symptom Severity

Thailand. Regarding percent symptom occurrence: 16 of 30 symptoms were experienced by 40% or more (range of 41-92%) of the Thai children as reported by parents. The top 5 in (%) occurrence were: Hair loss (92%), nausea (75%), fever (70%), weight loss (67%), and vomiting (65%). Regarding the mean severity scores on each of the 30 symptoms: the top 5 severe symptoms (mean severity scores) were: Hair loss (2.4), fever (1.22), appetite loss (1.17), nausea (1.16), and irritable (1.13).

USA. Regarding percent symptom occurrence: 19 of 30 symptoms were experienced by 40% or more (range of 40%-84%) of the USA children as reported by parents. The top 5 in (%) occurrence were: Feeling sluggish (84%), hair loss (78%), nausea (76%), appetite loss (74%), and irritable (70%). The top 5 severe symptoms (mean severity scores) were: Hair loss (2.28), feeling sluggish (2), appetite loss (1.82), irritable (1.76), and nausea (1.6).

Importantly, the remaining symptoms listed on the 30-item TRSC-C have been reported with less frequency (range, 10%-38%) and severity by parents of children in both countries. Nevertheless, when the checklist is used during the care of individual patients, a symptom that is reported would merit attention by the health care provider. Also, it is important to note that in this study, the calculations of mean severity of the individual symptoms included "0", with this meaning no presence or concern about the symptom. If only those reporting the symptom (with scale ratings at 1 through 4) were calculated, mean severity would actually be about *one point higher.* This would raise reported severity levels to "severe" on the check-listed symptoms.

4.3 Symptom Alleviation Methods Used

Thailand. The top symptom alleviation categories: Mind/Body Control (reported 260 times; or, 28% of all symptom items and strategies used), Diet/Nutrition/Lifestyle (reported 190 times; or, 20% of all strategies used), and over-the-counter (OTC) medications (reported 177 times; or, 19% of all strategies used) The total number of strategies used by the 67 Thai parents, across all symptom alleviation categories and TRSC-C items was 927.

USA. The top symptom alleviation categories that were used in the United States included Prescribed Medications (reported 165 times– or 25% of all symptom items and strategies used) and OTC medications (reported 165 times—or, 25% of all strategies used), and Mind/Body Control (reported 125 times– or, 19% of all strategies used). The total number of strategies used by 51 U. S. parents, across all symptom alleviation categories and the seven TRSC-C subscales, was 662.

Conclusions that can be drawn from this study are that (a) similarities and differences were found in symptom occurrence and severity and the symptom control methods used by parents in two countries; (b) both Thailand and USA parents reported identical 4 out of the 5 top severe symptoms, but of the 4 identical symptoms, USA parents reported higher mean severity on 3 out of the 4; and (c) to alleviate similar symptoms on the TRSC-C, Thai parents most often reported the use of methods classified in the "Mind/Body Control" category. USA parents most often reported the use of methods in the Prescribed Medications and Over-the-Counter (OTC) medications (tied) categories.

4.4 Study Implications

Research implications underline the need for studies on the applications of the two instruments used in this study, the TRSC-C and SASCM, especially in evidence-based practice (EBP). For example, advance practice nurses used the (adult) TRSC to monitor the occurrence and severity of symptoms: these guided the intervention provided including patient education/ counseling. Improved functional status and patient satisfaction with symptom management were reported when the TRSC was used [14]. The use of the TRSC-C in health care delivery and its effects on outcomes such as functional status, quality of life, and costs also should be done, as illustrated in another study with the adult TRSC [15]. Health Care Providers (HCPs) can enhance the performance of symptom alleviation among patients thereby better retaining patients in treatment, improving adherence, and enhancing patient outcomes.

5 Conclusions

Recent studies have used the TRSC and TRSC-C with oncology patients. A systematic tracking and assessment of patient-reported symptoms during therapy is essential. Such tracking enables oncology care providers to identify and prioritize symptoms needing intervention as well as focus on patient self-care strategies to alleviate symptoms experienced at home. The TRSC was previously developed and used with adults; much of the research on the TRSC-C has been preceded by studies using the TRSC with adults (see other papers in SS 14).

References

1. ACS, American Cancer Society. Cancer Facts and Figures. Atlanta, GA: American Society. Retrieved 02/12/13 at http://www.cancer.org/Research/CancerFactsFigures/CancerFactsFigures/cancer-facts-figures- . 2013
2. Williams P D, Williams K A, Williams AR. (2014). Parental caregiving of children with cancer, family impact, economic burden: Nursing perspectives, *Issues in Comprehensive Pediatr Nurs* 2014; doi: 10.3109/01460862.2013.855843 [Online ahead of print.]
3. Williams PD, Williams AR, Kelly KP, Dobos C, Gieseking A, Connor R, . . . Del Favero D. (2012). A symptom checklist for children with cancer: The TRSC-C. *Cancer Nursing* 2012, 35(2), doi: 10.1097/NCC.0b013e31821a51f6
4. Williams PD, Schmideskamp J, Ridder L, Williams A. Symptom monitoring and dependent care during chemotherapy in children. *Cancer Nurs. 2006a;* 29(3):188-197.
5. Hooke MC, Garwick AW, Gross CR. Fatigue and physical performance in children and adolescents receiving chemotherapy. *Oncology Nursing Forum* 2011, 38(6): 649-57. doi: 10.1188/11.ONF.649-657
6. Baggott C, Dodd M, Kennedy C, et al. Changes on children's reports on symptom occurrence and severity during a course of myelosuppressive therapy. *J Pediatr Oncol Nurs* 2012*;* 27(6):305-315.
7. Meeske KA, Patel SK, Palmer SN. Factors associated with health-related quality of life in pediatric cancer survivors. *Pediatr Blood Cancer 2007; 49*(3), 298-305. doi: 10.1002/pbc.20923
8. Riddle R., Williams, P D. Treatment time variable (early vs. later) as a determinant of TRSC-C symptom severity among pediatric outpatients with A.L.L. (paper). In *Proceedings of KUMC Student Research Forum* University of Kansas Medical Center: Kansas City, KS, April 2009.
9. Williams PD, Robinson J, Williams AR. Symptom occurrence and severity on the Therapy-Related Symptom Checklist for Children (TRSC-C) Among Hispanic pediatric oncology outpatients. *Cancer Nurs* 2013a; doi: 10.1097/NCC.0b013e3182948438
10. Yeh C-H, Wang C-H, Chiang Y-C, Lin L, Chien L-C Assessment of Symptoms Reported by 10- to 18-Year-Old Cancer Patients in Taiwan. *J Pain Symptom Manage* 2009, 38(5): 738-746. doi: DOI: 10.1016/j.jpainsymman.2009.04.023

11. Sitaresmi M N, M ostert S , Purwanto I, G undy CM, V eerman S , V eerman A JP. (2009). Chemotherapy-related s ide ef fects i n c hildhood a cute l ymphoblastic l eukemia i n I ndonesia: P arental p erceptions. *Journal of Pediatric Oncology Nursing* 2009, *26*(4): 198-207. doi: 10.1177/1043454209340315
12. Li, H.C., Williams, P.D., Lopez, V., Chung, J., Chiu, S. (2013). Relationship among therapy-related symptoms, depressive symptoms, and quality of life in Chinese children hospitalized w ith c ancer: An e xploratory s tudy. *Cancer Nursing; 36*(5), 3 46-354. DOI : 10.1097/NCC.06013e31824062ec
13. Gonzalez V , W illiams P D, C araballo JN, C olon G . S ymptoms during pe diatric c ancer treatments as reported by Puerto Rican mothers on the TRSC-C (Spanish version) (poster). *Annual APHON (Association of Pediatric Hematology/Oncology Nurses) Conference.* Pittsburgh, PA. October, 2012.
14. Williams PD, Williams KA, Roling-Lafaver S, Johnson R, Williams AR. An intervention to manage patient-reported symptoms during cancer treatment. *Clinical Journal of Oncology Nursing* 2011, 15(3): 253-258.
15. Williams PD, Graham KM, Storlie DL, Pedace TM, Haeflinger KV, Williams DD, Otto D, Sloan J A, W illiams AR. Therapy-Related S ymptom Ch ecklist (T RSC) u se d uring t reatments at a cancer center. *Cancer Nurs* 2013, 36(3):245-54.