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MATERNAL/INFANT CHARACTERISTICS AND BIRTH LOCATION IMPACT ON BREASTFEEDING INITIATION AND DURATION	2
BÖRK, L	BOTT, M J
RHETORICAL STRATEGIES IMPLEMENTED BY THE AMERICAN MEDICAL ASSOCIATION TO IDENTIFY ROLES WITHIN THE INTERPROFESSIONAL HEALTHCARE TEAM	32
EKHOLM, E M	FORD, D J
NURSE-REPORTED VS. PATIENT-REPORTED SYMPTOM OCCURRENCE, SEVERITY, AND AGREEMENT USING THE THERAPY-RELATED SYMPTOMS CHECKLIST (TRSC) IN CANCER PATIENTS	73
HEIMAN, A	WILLIAMS, P D
THE EFFECT OF NURSE CHARACTERISTICS ON SATISFACTION WITH PROFESSIONALISM IN THE WORK ENVIRONMENT	97
WRIGHT, Z	CRAMER, E

NURSE-REPORTED VS. PATIENT-REPORTED SYMPTOM
OCCURRENCE, SEVERITY, AND AGREEMENT USING THE THERAPY-
RELATED SYMPTOMS CHECKLIST (TRSC) IN CANCER PATIENTS

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ABSTRACT

Purpose: Developments in cancer treatments have resulted in increased survival of patients, but side effects/symptoms continue to be a concern. The Therapy-Related Symptoms Checklist (TRSC) has been used with adults undergoing cancer treatments. Study purposes were to examine among patients who completed the TRSC: (a) patient-reported symptom occurrence and severity; (b) nurse-reported symptom occurrence and severity; and (c) inter-rater agreement between patient-reported and nurse-reported symptoms. No study on this last question has been reported.

Theoretical Framework: Orem's Self-Care Deficit Theory focuses on individuals unable to meet their own self-care requirements. The TRSC is a tool that assists nurses in identifying these deficits, better facilitates supportive interventions to alleviate the symptoms, and promotes the patient's/caregiver's ability to enhance self-care.

Design: This is a cross-sectional study using primary data collection and analysis.

Setting: The study was conducted on patients at a single outpatient cancer center in a rural community of the Midwestern United States.

Participants: A convenience sample (N=22) of adult outpatients undergoing cancer therapy.

Methods: All patients and their nurse completed the TRSC, a 25-item checklist, with response choices ranging from "0" (none) to "4" (very severe). Descriptive statistics were used to address Purposes A and B, and a Pearson product-moment correlation analysis for Purpose C.

Results: All symptoms on the TRSC were reported in varying degrees. Regarding Purpose A, 40% or more of the patients reported 14 symptoms. Regarding Purpose B, 40% or more of nurse respondents reported 8 symptoms. In addition to higher symptom occurrence, greater symptom severity also was reported by patients compared to nurses. Regarding Purpose C, the percentage agreement between patient-reported and nurse identified symptoms was 77%, and the Pearson product-moment correlation coefficient was $r = .77$, indicating moderate agreement.

Conclusions: Use of patient self-report of symptoms is a preferred approach. A standardized tool (the TRSC) can guide nurses in providing a more complete, symptom-focused care. This may then enhance treatment compliance and improved outcomes.

INTRODUCTION

In the United States, the lifetime risk of developing cancer is 1 in 2 for men and 1 in 3 in women. However, the five-year relative survival rate for all cancers diagnosed from 2004 to 2010 was 68%, increased from a rate of 49% from 1975 to 1977 (American Cancer Society, 2015). This increased survival rate reflects improvements in both early detection and treatments; however, side effects/symptoms continue to be a concern. These symptoms may affect patients' functional status, psychological state, compliance with treatment, and quality of life.

The Therapy-Related Symptoms Checklist (TRSC) (Figure 1), a tool with good psychometric properties, has been used with adults undergoing cancer treatments in the United States, Europe, and Asia (Piamjariyakul et al., 2010; Williams, Williams, Ducey, Sears, & Tobin-Rommelhart, 1997; Williams et al., 2001). The TRSC allows a standardized, objective measurement of symptom occurrence and severity that can aid healthcare providers and nurses to individualize their care of these patients (Williams, Williams, Roling-Lafaver, Johnson, & Williams, 2011; Williams et al., 2013).

This study was guided by Orem's Self-Care Deficit Theory (Orem, 2001). This theory focuses on individuals unable to meet their own self-care requirements. Throughout cancer therapy, patients may feel their side effects are unmanageable, leading to lessened quality of life, functionality, and compliance with treatment. However, the TRSC is a tool that can assist nurses in identifying these deficits their patients are experiencing, better facilitate supportive interventions to alleviate the symptoms, and promote the patient's/caregiver's ability to enhance self-care.

Most commonly, assessments from both the patient's provider and nurse are completed and documented in the patient's medical record. However, previous studies support the use of patient self-reporting as a method of measuring each patient's experience with greater accuracy. Many clinicians believe cautious monitoring of patients through self-report may aid in the detection of early warning signs of adverse treatment effects (Williams et al., 1997). The literature is limited regarding inter-rater agreement between patient-reported and nurse-reported symptoms using a checklist; this study will explore this through using the TRSC.

REVIEW OF LITERATURE

A computer-based search was completed utilizing the CINAHL and PubMed databases to locate research related to symptom measurement and patient self-report of symptoms. The research reports were then analyzed in order to investigate both use of the TRSC and the effectiveness of patient self-report of symptoms compared to clinician report.

Nurses play a crucial role throughout the process of cancer therapy, from coping with the diagnosis to managing side effects from treatments. Youngblood, Williams, Eyles, Waring, and Runyon (1994) recognized the need for a systematic tool to aid nurses and other clinicians in reliably assessing symptoms that arise during cancer therapy. Researchers developed the 37-item Oncology Treatment Toxicity Assessment Tool (OTTAT), an early precursor to the current TRSC. Data were also collected using the 14-item Quality of Life Index (QLI) to examine the relationship between self-reported symptoms using the OTTAT and quality of life score on the QLI. A convenience sample of 91 patients aged 19-84 were included in the study. Participants were receiving outpatient care

at either a radiation oncology clinic, a bone marrow transplant clinic, or an adult medical oncology clinic, all located in the southeastern United States. All participants self-reported using the OTTAT and QLI, then returned them to the nurse researcher. Self-reported OTTAT symptoms were then compared to the nurse's progress note (in the medical record) for that patient.

Results showed the mean number of symptoms self-reported by patients on the OTTAT were 11 ± 8.0 , as compared to 1.5 ± 1.6 symptoms documented in the nurses' notes (medical record). This indicated the "usual method of assessment" (i.e. How are you feeling today?) resulted in under-documentation of the patients' symptoms and the OTTAT provided "a more comprehensive identification and self-report of toxicity symptoms than did the open-ended method assessment" (Youngblood et al., 1994, p. 123). A paired t-test was used to compare the mean number of symptoms identified on the OTTAT with those documented on the progress note using the "usual method of assessment"; the t-value was 8.7, a highly significant difference ($p = .001$). Furthermore, a Pearson product-moment coefficient analysis demonstrated a significant inverse correlation between OTTAT and QLI scores ($r = -.67$, $p = .0001$); and this finding is supported by past research as well.

A secondary purpose of that study was to explore the OTTAT symptoms reported with the highest frequency. The nine symptoms most frequently reported are consistent with previous research, and included the following: feeling sluggish, difficulty sleeping, dry mouth, taste changes, loss of appetite, depression, hair loss, skin changes, and nausea. Overall, the study concluded that the "usual method of assessment" of patients resulted in

the documentation of a significantly lower number of symptoms compared with patient self-report using a checklist, the OTTAT (Youngblood et al., 1994).

Williams et al. (1997; 2000) discussed the creation of the Therapy-Related Symptoms Checklist (TRSC). Using the Oncology Treatment Toxicity Assessment Tool (OTTAT), data were collected from 282 adult patients undergoing cancer treatments at a cancer center in the Midwestern USA. Using principal component analysis, the 37-item OTTAT was reduced to 25 items, accounting for 78.9% of the variance within the items. The TRSC and OTTAT were found to be correlated at .97. Cronbach alphas for all multiple-item subscales exceeded .70, indicating internal consistency reliability. Moreover, the TRSC and Karnofsky scores were inversely correlated, indicating construct validity. Using discriminant analysis, results also showed distinct findings between radiation therapy and chemotherapy patients, suggesting discriminant validity of the TRSC. That is, in radiation therapy patients, skin changes, constipation, bleeding, decreased interest in sex, and oropharyngeal problems were predominant. In contrast, among chemotherapy patients, hair loss, fever, bruising, nausea and vomiting, numbness of fingers and toes, and fatigue were predominant. The investigators concluded the TRSC is a clinically relevant self-report checklist for oncology patients (Williams et al., 1997; 2000).

Patient versus clinician symptom reporting was examined using the National Cancer Institute's Common Terminology Criteria for Adverse Events (CTCAE) in the study by Basch et al. (2006). Participants included 400 patients with a cancer diagnosis being treated in lung and genitourinary cancer clinics in the Memorial Sloan-Kettering Cancer Center in New York, New York. Each patient and their clinician (physicians or nurses) were

given a questionnaire with 11 common CTCAE symptoms, and results of the patients self-report were compared to the clinician reporting. In order to assess agreement of symptom reporting between clinician and patient, symptom severities were dichotomized into non-serious (grades 0–2) and serious (grades 3–4) categories. A shift in grade could make a clinically significant change in management of the patient’s care. Results using the McNemar’s exact test showed a significant difference in grading between patients and clinicians for only the symptom of fatigue. Almost all patient-clinician pairs agreed, with a higher proportion agreeing over more observable, objective symptoms rather than non-observable, subjective symptoms. Patients graded greater severity more often. In general, patients and their clinicians agreed on the symptom severity grades for 11 common CTCAE items. Differences in report were usually only one point. The researchers concluded that, in general, adverse events resulting in a change in the management of care were observable, suggesting that “patient self-reporting could improve the current procedure by notifying the clinician about objective symptoms, and alerting clinicians to patients’ perceptions of the severity of more subjective symptoms” (Basch et al., 2006, p. 907).

Fromme, Eilers, Mori, Hsieh, and Beer (2004) recognized that adverse events (AEs) in chemotherapy clinical trials have been assessed by clinicians, but the accuracy has been questioned. These researchers conducted a study which collected patient self-reporting of eight symptoms using the European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire (QLQ) C30. The study sample included 37 males with a diagnosis of prostate cancer that were enrolled onto a phase II trial of weekly calcitrol and docetaxel. Each participant completed the QLQ every four weeks throughout treatment for up to 28 weeks. Additionally, the medical oncologist providing care for the patient reported

symptoms in a designated adverse events log. A symptom was considered to be patient self-reported if there was at least a 10 point increase in a QLQ symptom score on the 0 to 100 scale, and the symptom was sustained for at least four weeks. Alternatively, a physician-reported symptom was defined as any symptom ever documented in the adverse events log. In total, 49 symptoms were detected by both the physician and the QLQ, 48 symptoms by the physician alone, and 55 symptoms by the QLQ alone. Using Cohen's kappa coefficient analysis, it was found that $\kappa=0.15$, indicating slight agreement. Overall, "The physician did not report approximately one half of the symptoms identified by the QLQ as AEs, and the QLQ did not detect approximately one half of the symptom AEs reported by the physician" (Fromme et al., 2004, p. 3488). The researchers concluded that both the patient and the physician identified important symptoms that the other did not, which suggests patient self-reporting should complement physician assessment of symptoms experienced during chemotherapy clinical trials and cancer therapy in general (Fromme et al., 2004).

In summary, the literature includes studies that describe the creation of the current TRSC as well as studies that have been conducted to investigate the value of having patients self-report their symptoms experienced during cancer therapy. The purposes of this study were to examine using the TRSC: the (a) patient-reported symptom occurrence and severity; (b) nurse-reported symptom occurrence and severity; and (c) inter-rater agreement between patient-reported and nurse-reported symptoms. These purposes will further analyze the symptoms reported by both the patient and the nurse, and will determine the inter-rater agreement among patient-reported and nurse-reported symptoms on the TRSC.

METHODS

DESIGN

This cross-sectional study used primary data from patients at a single site in a rural community of the Midwestern United States. Using convenience sampling, Subjects were included if they: (a) had a diagnosis of cancer; (b) received one or more rounds of treatment; (c) were over 18 years of age; and (d) were able to provide informed consent. Patients who received chemotherapy and/or radiation therapy were eligible.

INSTRUMENTS

The Therapy-Related Symptoms Checklist (TRSC), a 25-item tool, was used to gather information on symptom occurrence and severity experience during cancer treatment (Williams et al., 1997; 2000). Symptom severity on the TRSC was measured on a 5-point scale, "0" (none), "1" (mild), "2" (moderate), "3" (severe), and "4" (very severe). There are also four spaces at the bottom of the checklist for patients to report additional symptoms (See Figure 1). Higher total scores on the checklist indicate greater occurrence and severity of symptoms. Based on the study by Williams et al. (1997; 2000) and shown in Table 1, it is noted that 14 TRSC subscales/components/clusters resulted from a principal component analysis; the remaining are single-item subscales. For example, the Fatigue subscale has a cluster of four symptoms, namely, feeling sluggish, depression, depression, difficulty concentrating, and difficulty sleeping. The Eating subscale includes 4 items, namely, taste change, loss of appetite, weight loss, and difficulty swallowing, and so forth. The development and psychometric properties of the TRSC have been described in the literature review section above.

Study participants also completed a demographics form. The nurse data collector completed a health form that included diagnosis and stage of disease, treatment modalities and doses, and comorbidities based on the medical record. Also, the Health Form included a Karnofsky Performance/Functional Status Scale that was completed, scored, and signed by the nurse.

For purposes of a future, separate study, patients also completed the Health-Related Quality of Life- Linear Analogue Self-Assessment (HRQOL-LASA) form, as well as the Symptom Alleviation: Self-Care Methods (SA:SCM) form based on items of the TRSC. It is noted that two data collectors gathered the data, both of whom were trained by the faculty mentor. One was a registered nurse and capstone graduate student at the University of Kansas School of Nursing who initiated, applied for and obtained approval of the use of the study site; that nurse gathered data on 20 patients. The second data collector was an honors student in the BSN program at the University of Kansas who gathered data on two patients.

IRB approval was obtained from the University of Kansas Medical Center (KUMC). Both students completed the Human Subjects tutorial and the Conflict of Interest clearance.

DATA COLLECTION PROCEDURES

An informed consent form approved by the KUMC-HSC was signed by the patient prior to data collection. The nurse explained the study to the patient and answered their questions. The patient then completed the TRSC and the Demographics Form. The nurse completed the Health Form: that form included the Karnofsky Performance/Functional Status Scale, as described earlier. The patient also completed the Health-Related Quality of

Life -Linear Analogue Self-Assessment (HRQOL-LASA) form, and the Symptom Alleviation: Self-Care Methods (SA:SCM) form – these data were to be used in future, separate analyses for the study. The patient and the nurse completed the TRSC at separate locations.

Data Analysis. To address Purpose A, the TRSC self-reported by the patient was analyzed using descriptive statistics. To address Purpose B, the TRSC completed by the nurse was analyzed using descriptive statistics. To address Purpose C, the percentage agreement between the total scores on the patient-reported TRSC and the nurse-completed TRSC were analyzed; and, also a Pearson product-moment correlation analysis (Rebar, Gersch, Macnee, & McCabe, 2011).

RESULTS

SAMPLE CHARACTERISTICS

The sample of 22 adults was obtained from a single outpatient cancer clinic in a rural community of the Midwestern United States. The convenience sample included adults aged 31 to 84 years; 54.5% were female, and 45.5% were male. The mean age of participants was 56.73 years, and 86.4% were married. Cancer diagnoses included the following: 41% breast cancer, 18% colon cancer, 9% renal cell cancer, 9% esophageal cancer, and 23% other. The most prevalent cancer diagnoses in males were renal cell and colon, and in females breast cancer was the most common. In total, 54.5% of participants identified themselves as Caucasian, while 45.5% identified as Hispanic. Table 1 shows the sample characteristics.

ADDRESSING THE RESEARCH PURPOSES

Patient-Reported Symptoms. Regarding Purpose A, the occurrence of symptoms as self-reported by patients on the TRSC (Table 2) indicated that 40% or more of patients reported 14 symptoms, overall. Symptoms reported with the highest occurrence included feeling sluggish (77.3%), hair loss (72.7%), difficulty sleeping (68.2%), and nausea (63.6%). Additional measures included depression (59.1%), taste change (54.6%), loss of appetite (54.6%), numbness in fingers and/or toes (54.6%), decreased interest in sexual activity (50.0%), difficulty concentrating (45.5%), shortness of breath (45.5%), bruising (40.9%), cough (40.9%), skin changes (40.9%), sore mouth (36.4%), pain (36.4%), constipation (36.4%), weight loss (27.3%), sore throat (27.3%), and soreness in vein (where chemotherapy was given) (27.3%). Symptoms reported with the lowest occurrence included difficulty swallowing (22.7%), bleeding (22.7%), fever (18.2%), vomiting (18.2%), and jaw pain (9.1%).

Regarding the severity of symptoms as self-reported by patients on the TRSC: Table 2 shows that symptoms with the highest mean severity included hair loss (3.19), decreased interest in sexual activity (3.09), vomiting (2.75), constipation (2.63), and taste change (2.58). Additional mean symptom severities included nausea (2.43), difficulty sleeping (2.4), loss of appetite (2.25), weight loss (2.17), feeling sluggish (2.12), bruising (2.11), difficulty concentrating (2.1), difficulty swallowing (2), sore throat (2), shortness of breath (2), and skin changes (2). Symptoms with the lowest mean severity included depression (1.92), numbness in fingers and or/ toes (1.88), soreness in vein where chemotherapy was given (1.83), sore mouth (1.75), pain (1.75), bleeding (1.8), cough (1.67), jaw pain (1.5), and fever (1.5).

A few symptoms were added by patients, including diarrhea by one patient and delayed urination by one patient. One individual patient listed achy muscles, headache, blurry vision, and body shaking as additional symptoms.

Nurse-Identified Symptoms. Regarding Purpose B, regarding the occurrence of symptoms as identified by nurses on the TRSC: Table 2 shows that 40% or more of nurses reported 8 symptoms, overall. Symptoms reported with the highest occurrence included feeling sluggish (95.5%), nausea (63.6%), hair loss (63.6%), and difficulty sleeping (50.0%). Additional measures included depression (45.5%), loss of appetite (45.5%), numbness in fingers and/or toes (45.5%), taste change (40.9%), difficulty concentrating (36.4%), shortness of breath (36.4%), pain (31.8%), decreased interest in sexual activity (27.3%), bruising (22.7%), skin changes (22.7%), constipation (22.7%), soreness in vein (where chemotherapy was given) (22.7%), weight loss (18.2%), and cough (18.2%). Symptoms reported with the lowest occurrence included sore mouth (13.6%), fever (13.6%), bleeding (13.6%), difficulty swallowing (9.1%), vomiting (9.1%), and sore throat (4.6%). Jaw pain was not reported by nurses.

Regarding the severity of symptoms as self-reported by the nurse on the TRSC: Table 2 shows that symptoms with the highest mean severity included hair loss (3.64), taste change (2.22), feeling sluggish (2.19), decreased interest in sexual activity (2.17), nausea (2.07), skin changes (2), constipation (2), and soreness in vein where chemotherapy was given (2). Additional mean symptom severities included loss of appetite (1.9), difficulty sleeping (1.82), weight loss (1.75), shortness of breath (1.75), bruising (1.6), difficulty concentrating (1.5), difficulty swallowing (1.5), cough (1.5), and bleeding (1.5). Symptoms

with the lowest mean severity included pain (1.43), sore mouth (1.33), depression (1.3), numbness in fingers and/or toes (1.3), vomiting (1.25), sore throat (1), and fever (1).

A few symptoms were added by nurses, including diarrhea in one patient, GERD in one patient, and periorbital edema in one patient.

Agreement/Correlation Between Patient-Reported and Nurse Identified

Symptoms on the TRSC. The percentage agreement between patient-reported and nurse identified symptoms was 77%, and the Pearson correlation between the total scores on the TRSC (by patients, and by nurses) was $r = .77$. These findings indicate that the patients' total scores through self-report on the TRSC were moderately associated with that of the nurse report on the TRSC for each participant (Rebar et al., 2011). However, note above the differences found between patient reports and nurse reports on the TRSC specific symptom occurrence and symptom severity. These differences have implications for care provided to patients, discussed below.

DISCUSSION

Findings from this study support that adult patients experience many symptoms as a result of cancer treatment. Findings related to Purpose (A) are consistent with previous research. Williams et al. (1997; 2000) found that patient self-report on the OTTAT (a precursor of the TRSC) showed chemotherapy participants most frequently reported hair loss, fever, bruising, nausea and vomiting, numbness of fingers and toes, and fatigue. Moreover, another study by Williams et al. (2001) reported symptoms of patients receiving radiation therapy versus those receiving chemotherapy. That is, chemotherapy patients reported that feeling sluggish (79.6%), hair loss (60.4%), taste change (59.8%), loss of

appetite (57%), and nausea (54.2%) predominated. In comparison, radiation therapy patients reported that feeling sluggish (75.3%), depression (53.1%), cough (50%), pain (49%), weight loss (48.7%), and loss of appetite (48.4%) predominated (Williams et al., 2001).

In a study conducted *outside the USA* focused on symptoms reported on the TRSC by treatment type, Piamjariyakul et al. (2010) found that in adult patients receiving *combined chemotherapy and radiation therapy*, symptoms reported with the greatest occurrence were taste change (73%), loss of appetite (71%), weight loss (67%), sore throat (61%), difficulty sleeping (58%), sore mouth (56%), and nausea (50%). In comparison, in patients receiving *chemotherapy alone*, symptoms reported with the greatest occurrence were loss of appetite (73%), taste change (67%), difficulty sleeping (65%), hair loss (65%), and nausea (60%). Whereas, in patients receiving *radiation therapy alone*, symptoms reported with the greatest occurrence were loss of appetite (64%), pain (62%), taste change (55%), and constipation (47%). A nurse data collector used the TRSC during interviews conducted with patients (Piamjariyakul et al., 2010).

No study had been conducted examining the agreement between patient-reported and nurse-reported symptoms using the TRSC. However, an earlier study by Williams et al. (1994) compared the use of the “usual method of assessment” (How are you today?) to the use of a checklist (the OTTAT, a precursor of the TRSC). Other investigators have used other methods of data collection to compare patient reports and clinician reports of symptoms. Two studies that used a different checklist/“questionnaire” (Basch et al. 2006;

Fromme et al. 2004) found differences in the patient-reported symptoms and the physician-reported symptoms-- but correlations were not reported.

IMPLICATIONS AND RECOMMENDATIONS

Two studies conducted in the USA, on the clinical applications of the TRSC have been reported. The study conducted by Williams et al. (2013) at one cancer center in the upper Midwest affiliated with the Mayo Clinic, investigated the use of the TRSC by patients and the effects on outcomes (i.e., the number of symptoms self-reported by patients and documented in the medical record, managed by the clinicians, and quality of life). A cohort research design was used; patients were followed for 3 to 11 visits. First, the control group (N=55) received the standard of care including standard clinic interview and the option to meet with a RN "Cancer Guide" to create an individualized plan of care. When the first cohort was completed, the intervention group (N=58) received the standard of care and answered the TRSC immediately before each consultation (in the waiting room); the completed TRSC was then provided to the clinician for use during the clinic visit. The study found that patients in the intervention group reported on average 3.76 more symptoms than the control group (as documented in the medical record), and the number of TRSC symptoms identified decreased significantly over time. The intervention group also reported a greater quality of life on the Health-Related Quality of Life-Linear Analogue Self Assessment (HRQOL-LASA) form, as compared to the control group (Williams et al., 2013).

Williams et al. (2011) also conducted a study to evaluate the effects of a nursing intervention focused on teaching symptom management as patients undergo cancer therapy. Participants in the control group (N=10) received the usual standard of care, and

those in the intervention group (N=10) received education and counseling based on the TRSC self-reported symptoms (the intervention included face-to-face contact with the nurse, handouts, and follow-up phone calls). Patients completed the TRSC at baseline, midpoint, and endpoint of the study. The study found that at both the midpoint and endpoint, the intervention group reported lower symptom occurrence and severity on the TRSC, as compared to the control group. Also, at the endpoint, symptom occurrence and severity improved from the midpoint by 27% in the intervention group compared to 11% in the control group (Williams et al., 2011).

In this study, patients self-reported greater symptom occurrence and severity. Therefore, it is recommended that clinicians allow adult patients to self-report on the TRSC to provide more information for clinicians and nurses to use in their caregiving and alleviation of symptoms. These two studies (Williams et al., 2011; 2013) are cited here because both have used the completed the TRSC to assess patient self-report of their symptoms (occurrence and severity). In both studies, the health care providers utilized the patient self-reports as basis for care or interventions during each visit, such as in discussions and interactions with patients (including counseling and education) regarding the reported symptoms and how to alleviate and manage the symptom. During cancer therapy, use of the TSRC (a) promotes a complete and comprehensive assessment and documentation of symptoms experienced by patients, and (b) facilitates the nurses' ability to provide patient-centered education, counseling, and guidance. That is, the TRSC helps optimize oncology care to patients (adults undergoing cancer therapy) through more effective symptom monitoring and management, and improved quality of life.

Early identification of symptoms associated with cancer therapy “can foster timely symptom management through self-care or caregiver amelioration” (Williams et al., 1997, p. 85). Based on the findings of this study and previous research, it is recommended that clinicians allow adult patients undergoing cancer therapy to self-report their symptoms on the TRSC to identify symptom occurrence and symptom severity. Ultimately, this valuable information can help guide clinicians, including nurses, in providing symptom-focused care and education comprehensively, and with greater efficiency (Williams et al., 2011; Williams et al., 2013). The TRSC can help facilitate discussion of self-care alleviation methods, complementary therapies, and coping techniques that address the physical and psychosocial needs of patients undergoing cancer therapy (Piamjariyakul et al., 2010; Williams et al. 2011; 2013; Youngblood et al., 1994).

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FIGURE 1 THERAPY-RELATED SYMPTOMS CHECKLIST (TRSC)

Name: _____ ID # _____ Site/Clinic _____ Date: _____

PLEASE **CHECK** THE PROBLEMS YOU HAVE HAD IMMEDIATELY AFTER AND SINCE YOUR LAST TREATMENT. PLEASE **CIRCLE** HOW SEVERE THE PROBLEM WAS ACCORDING TO THE FOLLOWING SCALE:

0 = NONE 1 = MILD 2 = MODERATE 3 = SEVERE 4 = VERY SEVERE

CHECK ☒	EXAMPLE Pain	Degree of Severity (CIRCLE)				
		0	1	2	③	4
<input type="checkbox"/>	Taste Change	0	1	2	3	4
<input type="checkbox"/>	Loss of appetite	0	1	2	3	4
<input type="checkbox"/>	Nausea	0	1	2	3	4
<input type="checkbox"/>	Vomiting	0	1	2	3	4
<input type="checkbox"/>	Weight loss	0	1	2	3	4
<input type="checkbox"/>	Sore mouth	0	1	2	3	4
<input type="checkbox"/>	Cough	0	1	2	3	4
<input type="checkbox"/>	Sore throat	0	1	2	3	4
<input type="checkbox"/>	Difficulty swallowing	0	1	2	3	4
<input type="checkbox"/>	Jaw pain	0	1	2	3	4
<input type="checkbox"/>	Shortness of breath	0	1	2	3	4
<input type="checkbox"/>	Numbness in fingers and/or toes	0	1	2	3	4
<input type="checkbox"/>	Feeling sluggish	0	1	2	3	4
<input type="checkbox"/>	Depression	0	1	2	3	4
<input type="checkbox"/>	Difficulty concentrating	0	1	2	3	4
<input type="checkbox"/>	Fever	0	1	2	3	4
<input type="checkbox"/>	Bruising	0	1	2	3	4
<input type="checkbox"/>	Bleeding	0	1	2	3	4
<input type="checkbox"/>	Hair loss	0	1	2	3	4
<input type="checkbox"/>	Skin changes	0	1	2	3	4
<input type="checkbox"/>	Soreness in vein where chemotherapy was given	0	1	2	3	4
<input type="checkbox"/>	Difficulty sleeping	0	1	2	3	4
<input type="checkbox"/>	Pain	0	1	2	3	4
<input type="checkbox"/>	Decreased interest in sexual activity	0	1	2	3	4
<input type="checkbox"/>	Constipation	0	1	2	3	4
<input type="checkbox"/>	Other problems (please list below)					
<input type="checkbox"/>	_____	0	1	2	3	4
<input type="checkbox"/>	_____	0	1	2	3	4
<input type="checkbox"/>	_____	0	1	2	3	4
<input type="checkbox"/>	_____	0	1	2	3	4

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TABLE 1. DEMOGRAPHICS: SAMPLE CHARACTERISTICS

Variable	Category	Frequency	
Age	30-34	1 (4.5%)	Mean = 56.73 SD = 12.46 Range: 53
	35-39	1 (4.5%)	
	40-44	2 (9.1%)	
	45-49	3 (13.6%)	
	50-54	0	
	55-59	4 (18.2%)	
	60-64	6 (27.3%)	
	65-69	2 (9.1%)	
	≥70	3 (13.6%)	
Gender	Male	10 (45.5%)	
	Female	12 (54.5%)	
Marital Status	Married	19 (86.4%)	
	Single	1 (4.5%)	
	Widowed	1 (4.5%)	
	Divorced	0	
	Other	1 (4.5%)	
Number of Children	0	2 (9.1%)	Mean = 2.62 SD = 1.28 Range = 5
	1	1 (4.5%)	
	2	6 (27.3%)	
	3	7 (31.8%)	
	≥4	5 (22.7%)	
	No Response	1 (4.5%)	
Religion	Protestant	9 (40.9%)	
	Catholic	5 (22.7%)	
	Jewish	0	
	Buddhist	0	
	Other	7 (31.8%)	
	No Response	1 (4.5%)	
Ethnic Background	White	12 (54.5%)	
	African American/Black	0	
	Asian	0	
	Hispanic	10 (45.5%)	
	Native American	0	
	Other	0	
Occupation/Job	Retired	4 (18.2%)	
	Homemaker	2 (9.1%)	
	Disabled	2 (9.1%)	
	Other	10 (45.5%)	
	No Response	4 (18.2%)	
Employment Status	Part Time	0	
	Full Time	7 (31.8%)	
	Not Applicable (Retired/Homemaker/Disabled)	8 (36.4%)	
	No Response	7 (31.8%)	
Highest Education Completed	Elementary only	3 (13.6%)	
	Some high school	3 (13.6%)	
	High school diploma or equivalent (GED)	4 (18.2%)	
	Some higher education, no degree	6 (27.3%)	
	Technical or vocational school	0	
	Associate degree	4 (18.2%)	
	BS/BA	2 (9.1%)	
	Graduate degree	0	
Primary Caregiver	Self	3 (13.6%)	
	Spouse	12 (54.5%)	
	Family	2 (9.1%)	
	No Response	5 (22.7%)	
Spouse's Highest Education	Elementary only	4 (18.2%)	

Completed	Some high school	0	
	High school diploma or equivalent (GED)	7 (31.8%)	
	Some higher education, no degree	2 (9.1%)	
	Technical or vocational school	0	
	Associate degree	1 (4.6%)	
	BS/BA	2 (9.1%)	
	Graduate degree	0	
	Not Applicable	2 (9.1%)	
	No Response	2 (9.1%)	
Spouse's Age	30-34	0	Mean = 57.33 SD = 12.42 Range = 51
	35-39	1 (4.6%)	
	40-44	2 (9.1%)	
	45-49	3 (13.6%)	
	50-54	1 (4.6%)	
	55-59	0	
	60-64	5 (22.7%)	
	65-69	5 (22.7%)	
	≥70	1 (4.6%)	
	Not Applicable	2 (9.1%)	
	No Response	2 (9.1%)	

TABLE 2. SYMPTOM OCCURRENCE AND SEVERITY ON THE TRSC SUBSCALES/ITEMS, PERCENT DISTRIBUTIONS:
PATIENT-REPORTED AND NURSE-REPORTED

TRSC Symptoms/Subscales or Clusters ^c	Patient-Reported (N=22)		Nurse-Reported (N=22)	
	Percent Occurrence ^a	Mean Severity ^b	Percent Occurrence	Mean Severity
(1) Fatigue				
Feeling sluggish	77.3%	2.12	95.5%	2.19
Depression	59.1%	1.92	45.5%	1.3
Difficulty concentrating	45.5%	2.1	36.4%	1.5
Difficulty sleeping	68.2%	2.4	50.0%	1.82
(2) Eating				
Taste change	54.6%	2.58	40.9%	2.22
Loss of appetite	54.6%	2.25	45.5%	1.9
Weight loss	27.3%	2.17	18.2%	1.75
Difficulty swallowing	22.7%	2	9.1%	1.5
(3) Oropharynx				
Sore mouth	36.4%	1.75	13.6%	1.33
Sore throat	27.3%	2	4.6%	1
Jaw pain	9.1%	1.5	0.0%	0
(4) Fever				
Fever	18.2%	1.5	13.6%	1
Bruising	40.9%	2.11	22.7%	1.6
(5) Nausea				
Nausea	63.6%	2.43	63.6%	2.07
Vomiting	18.2%	2.75	9.1%	1.25
(6) Respiratory				
Cough	40.9%	1.67	18.2%	1.5
Shortness of breath	45.5%	2	36.4%	1.75
(7) Pain	36.4%	1.75	31.8%	1.43
(8) Numbness in fingers and/or toes	54.6%	1.88	45.5%	1.3
(9) Bleeding	22.7%	1.8	13.6%	1.5
(10) Hair loss	72.7%	3.19	63.6%	3.64
(11) Skin changes	40.9%	2	22.7%	2
(12) Constipation	36.4%	2.63	22.7%	2
(13) Soreness in vein (where CT is given)	27.3%	1.83	22.7%	2
(14) Decreased interest in sexual activity	50.0%	3.09	27.3%	2.17

a) Symptom occurrences are in % distributions. b) TRSC severity scale: 0=none; 1=mild; 2=moderate; 3=severe and 4=very severe. c) Fourteen subscales or clusters on the TRSC are numbered, and specific symptoms are shown beneath. Six TRSC symptoms are 'single-item subscales' (see Williams et al., 1997; 2000).