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Exploring the Relationship Between Symptom Management and Distress in Pediatric Oncology Nurses

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EXPLORING THE RELATIONSHIP BETWEEN SYMPTOM MANAGEMENT AND DISTRESS IN PEDIATRIC ONCOLGY NURSES

by

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ABSTRACT

Pediatric oncology is known to be a stressful work environment due to the difficult aspects regarding patient care. This known stress related to work and caring for pediatric oncology patients can negatively impact nurses, patients and families. The purpose of this study is to examine: relationships between patient symptom management and nurse distress; strategies used by nurses to manage symptoms in pediatric patients with cancer; nurse perceptions of effectiveness of non-pharmacologic or nursing interventions; and nurse distress related to managing symptoms in pediatric patients with cancer. Registered nurses (N=13) at a local children's hospital participated in an online survey. The survey included the Nurses' Distress and Interventions for Symptoms Survey (NDISS) and the Stressor Scale for Pediatric Oncology Nurses (SSPON). Descriptive and correlation statistics were used to analyze data. Results showed that the most commonly managed symptoms were pain (100%), nausea/vomiting (100%), hair loss (100%), fatigue (92.3%), worry (92.3%), mouth sores (84.6%), and trouble sleeping (69.2%). On average, participants reported using at least 10 strategies to manage these symptoms. The most common strategies included: active listening, encouraging family involvement, family support, and reducing sleep interruptions. Most participants felt like they managed the symptoms effectively. Overall, the most common stressors for pediatric oncology nurses were related to co-workers (71.8%) and system demands (68.9%). There was no statistically significant relationship between symptom management and nurse distress. Further research should be conducted on the relationship between nurses and significant stressors other than symptom management. Identifying these significant stressors, especially related to co-

workers and system demands, would be the first step in the development of appropriate

interventions, such as supportive programs, for decreasing nurses' stress response.

DEDICATION

This undergraduate thesis is dedicated to my amazing family, boyfriend, friends, and mentors.

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INTRODUCTION

Statement of the Problem

Cancer is the second leading cause of death in children. In 2016, approximately 10,380 children younger than 15 years old and approximately 5,000 adolescents aged 15 to 19 were diagnosed with cancer (American Cancer Society [ACS], 2016). It was estimated that 1,250 children younger than 15 years old and 600 adolescents aged 15 to 19 would die from their disease (ACS, 2016). The three most common types of childhood cancers are leukemia, brain and other central nervous system tumors, and neuroblastoma. Leukemia accounts for approximately 30% of all childhood cancers (ACS, 2016). Brain and other central nervous system tumors account for about 26% of childhood cancers (ACS, 2016). Neuroblastoma, the most common cancer in infants, accounts for about 6% of all cancers in children. Unfortunately, childhood cancer rates have slightly increased over the past few decades. However, because of major treatment advances and research in the recent years, more than 80% of children with cancer now survive 5 years or more (ACS, 2016). These numbers are significant, because they show that even though pediatric oncology is a small subspecialty, there are thousands of pediatric oncology patients needing care provided to them on a day-to-day basis.

Once a child is diagnosed, the type of treatment will vary and is based on the type and stage of the cancer. Treatment options often include chemotherapy, radiation therapy, surgery, or a combination of treatments. Children with cancer have individual needs and are treated on pediatric oncology units where staff members are trained to specialize in this type of care. Pediatric oncology patients often experience distressing symptoms due to the aggressive treatment used to cure the disease, and they will frequently live with unrelieved symptoms on a

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daily basis (Hockenberry, 2004). According to research, some of the most common symptoms that cause distress in children with cancer are treatment-related pain, fatigue, nausea, vomiting, poor appetite, hair loss, and trouble sleeping (Hedstrom et al., 2003; Collins et al., 2002; Rheingans, 2008). Additionally, pediatric oncology patients normally rate their symptoms as the most challenging aspect of treatment (Rheingans, 2008; Woodgate, Degner, & Yanofsky, 2003). Nurses often report that patients' symptom distress is a primary contributor to a highly stressful nursing environment in pediatric oncology. If patients' symptoms are not managed effectively, nurses watch their patients suffer (Barnard, Street, & Love, 2006; Bond, 1994, de Carvalho, Muller, de Carvalho, & de Souza Melo, 2005; Rheingans, 2008).

Symptoms are defined as a patient's subjective report or a sudden change in their condition (Rheingans, 2008; Anderson, Anderson, & Glanze, 1994). Typically, there are pharmacologic agents used to manage the patients' distressing symptoms (Panzarella et al., 2002; Rheingans, 2008). Nurses are able to use non-pharmacologic interventions as an adjunct to pharmacologic agents; however, the effectiveness of nursing interventions may not be clear to nurses which may impact their use and application.   For example, treatment-related pain is one of the most distressing symptoms that pediatric oncology patients experience. When treating pain, nurses typically have an underlying fear of how the child will tolerate the pain medication because of inexperience or fear of receiving them. Also, there might be times where the pharmacologic agents might not be completely effective for pain. Nursing interventions for pain can include non-pharmacologic methods such as distraction, emotional support, music therapy, and other relaxation techniques. Nurses may be hesitant to try these interventions due to lack of

knowledge related to non-pharmacologic interventions for pain and/or uncertainty related to their effectiveness.

Another challenge that pediatric oncology nurses may encounter is that a patient might not be able to give an accurate subjective report about the symptoms that they are experiencing. Not being able to manage distressing symptoms in pediatric patients may trigger distress for nurses. Research has shown that watching patients suffer is one of the most stressful work-related situations for pediatric oncology nurses (Chang, Kicis & Sangha, 2007; Bond, 1994). This may lead to long-term or negative consequences for nurses such as debilitating exhaustion, compassion fatigue, early resignation, job dissatisfaction, or even burnout (Hinds et al., 1998; Rheingans, 2008; Hecktman, 2012).

The overall specialty of pediatric oncology is considered to be a particularly susceptible and occupationally stressed profession (Hinds et al., 1998). There is a strong need to tackle work-related stressors that impact nurses within pediatric oncology, because these stressors take a toll on nurses and also have consequences for patients and their families (Mukherjee, Beresford & Tennant, 2014). Since there is a lack of published research about the relationship between symptom management and nurses' distress, especially in the subspecialty of pediatric oncology, it is critical that we examine the distress that nurses experience when symptoms are not managed optimally (Hecktman, 2012).

PURPOSE OF STUDY

The purpose of this descriptive, exploratory research study was to examine: 1) the relationships between symptom management and nurse distress; 2) strategies used by nurses to manage symptoms in pediatric patients with cancer; 3) nurse perceptions of the effectiveness of non-pharmacologic or nursing interventions; 4) nurse distress related to managing symptoms in pediatric patients with cancer. A description of nursing interventions used, including perceived effectiveness of these interventions, will allow us to have a better understanding into the nurses' experience of managing patients' symptoms (Rheingans, 2008). It is imperative that significant stressors for nurses who care for pediatric oncology patients be identified because it will ultimately lead to the development of appropriate interventions for reducing nurses' distress.

METHODS AND PROCEDURES

Design

  This research study used a descriptive, exploratory design. The survey was made available through Qualtrics® software to Registered Nurses who have provided direct patient care to pediatric oncology patients. This research was completed through the Honors in the Major program under the supervision of Dr. Victoria Loerzel.

  The setting for this research study was the in-patient Hematology and Oncology Unit at Arnold Palmer Hospital for Children. Approval was obtained from University of Central Florida's Institutional Review Board (Appendix A), Arnold Palmer's (ORMC) Human Resource Department, and Orlando Health's Nursing Research Council (Appendix B). This study had minimal risk and received a waiver of documentation of consent.

Inclusion and Exclusion Criteria

  Participants were eligible to partake in this research study if they were registered nurses, age 18 or older, and who worked with inpatient pediatric oncology patients. Participants were not eligible to partake in this research study if they were clinic or office nurses who do not directly participate in the care of pediatric oncology patients.

Procedures

  There were approximately 32 registered nurses employed on the in-patient Hematology and Oncology Unit that comprised this convenient sampling pool. After receiving permission from the unit's Nurse Manager and Learning Specialist, the Principal Investigator (PI) went to the unit two separate times and explained the survey nurses who worked on the unit. The PI arrived to the unit at 0645 to meet with both day shift and night shift nurses, and explained the

study's purpose, requirements, dates available and incentive for completing the survey. The survey was open for 2 weeks. When the survey time period opened Jennifer Penn, the Learning Specialist on the Pediatric Oncology unit who had access to employee email addresses, sent an email to the unit's nurses containing a link to the online survey. The participants were notified that they must complete the survey in one sitting. Another email was sent at the end of the first week by Ms. Penn as a reminder to complete the survey by the deadline. Each email included an informational (consent) letter (Appendix C) and the link to the Qualtrics® survey. The nurses were notified that the survey should take approximately 15-20 minutes to complete. At the end of the two-week window, the survey closed and no more data was collected. At the end of the survey, participants were asked to provide their first and last name so they could receive a $5 gift card as a "thank you" for completing the study.   Data containing personal identifiers, such as first and last names, were de-identified by the Principal Investigator and her faculty mentor prior to analysis.

Instruments

Participants were asked to complete a 78-question survey that included the Nurses' Distress and Interventions for Symptoms Survey (NDISS) and the Stressor Scale for Pediatric Oncology Nurses (SSPON). Demographic questions and open ended questions about managing symptoms were also included.

Twelve demographic questions were asked related to current work with direct patient care, age, gender, race, number of years in practice, number of years in the pediatric oncology setting, highest level of education, and any certifications or additional training.

The Stressor Scale for Pediatric Oncology Nurses (SSPON) was a 50-question survey that was created to measure role-related stress in pediatric oncology nurses. It measures stressors related to: co-workers (n=6), system demand (n=12), knowing what is ahead (n=5), limitations of care (n=12), emotional demand (n=13), and dying with grace (n=2). The PI received permission from Dr. Pamela Hinds to modify the survey from a visual analogue scale to a Likert scale for use in an online format. All 50 questions were presented using a ten point Likert scale with choices from: not stressful at all (0) to as stressful as can be (10) (Hinds et al., 1990, 1998). Total scores ranged from 0 to 500. Higher scores reflected the nurse's perception of more intense role-related stress. Scores for the subscales s were as follows: co-worker (0 to 60), system demand (0 to 120), the knowing what is ahead (0 to 50), the limitations of care (0 to 120), the emotional demand (0 to 130), and the dying with grace (0 to 20).

Previous studies have estimated the internal consistency of the total scale at .90 to .94 (Bond, 1994; Hinds et al., 1990, 1998). It has also yielded evidence of concurrent validity in distinguishing groups of nurses by years of practice (Bond, 1994; Hinds et al., 1990, 1998). The original survey was a visual analog scale with a Cronbach alpha score of 0.93. For this study, Cronbach alpha was consistent with the original visual analog scale at 0.977. See Table 1 for SSPON reliability for the total and subscale scores.

Table 1: SSPON Reliability

	Cronbach's Alpha
Previous total instrument (Visual analog scale-original study)	0.93
Present total instrument (Likert scale)	0.977
Co-worker subscale	0.738
System demands subscale	0.936
Knowing what is ahead subscale	0.915
Limitations of care subscale	0.802
Emotional demands subscale	0.919
Dying with grace subscale	0.842

The Nurses' Distress and Interventions for Symptoms Survey (NDISS) was a 28-question survey that was created to measure nurse distress and action related to 7 common symptoms (pain, nausea/vomiting, mouth sores, trouble sleeping, fatigue, worry, and hair loss). Each of the seven symptoms had 3 aspects. First, nurses reported their experience with and distress level (0 to 4 Likert scale) related to the presence of these symptoms in the past month of taking the survey. Second, nurses indicated which interventions they used to treat the symptom. Finally, nurses rated the perceived effectiveness (0 to 4 Likert scale) of the interventions that they selected (Rheingans, 2008). The content validity index (CVI) results for the NDISS was .88, which demonstrated excellent content validity for the newly developed instrument (Rheingans, 2008). A test-retest method was used for reliability. The overall average percentage of agreement was 0.83 (range 0.74-0.92) (Rheingans, 2008). The remaining questions were assessed with the test-retest correlations with an overall average of 0.57 (range 0.42-0.72) (Rheingans, 2008).

Finally, four investigator-developed open-ended questions allowed participants to share any further information about managing symptoms and any related distress. The first open-ended question invited the nurse to describe how open they are to using non-pharmacologic methods to help patients. The second open-ended question allowed the nurses to share their favorite non-pharmacological intervention to use and why. The third open-ended question gave the nurses a chance to explain some barriers and/or facilitators to non-pharmacologic methods that they might encounter. The last open-ended question allowed the nurses to share how often they suggest non-pharmacologic methods to the patient and their family and if they feel supported when they do in fact suggest them.

Data Analysis

Qualtrics® software was used to design the survey and collect data. Data was downloaded from Qualtrics® software into an Excel® Spreadsheet. The spreadsheet was then uploaded into the current version of IBM® SPSS® statistical software for further analysis. The Principal Investigator (AS) and her HIM faculty advisor (VL) conducted the analysis. All variables were explored using descriptive statistics (frequencies, means, percent's). Total and subscale scores were computed for the SSPON and aggregated for the sample. Scores from the NDISS were also computed and aggregated. A Pearson r correlation was used to examine relationships between nurse distress and symptom management.

FINDINGS

Demographics Information

All participants were registered nurses and performed direct patient care with pediatric

oncology patients (100%, n=15). The typical participant was female (100%), Caucasian (80%),

and about 31.8 years old (Range: 22 to 63 years old). The mean number of years' participants

reported practicing as a registered nurse was 6.77 (Range: 2 to 25 years). The mean number of

years reported working with the inpatient pediatric oncology population was 5.27 (Range: 1 to

21 years). Most held a bachelor's degree (86.7%, n=13). Out of the 15 surveyed nurses, 5 were a

Certified Pediatric Oncology Nurse, Pediatric Certified with ANCC, Certified Pediatric

Hematology/Oncology Nurse, or Chemotherapy Certified.

Table 2: Demographics (N=15)

Characteristic	(%)
Currently working as a registered nurse with direct patient care with pediatric oncology patients?	100%
Gender	
Female	100%
Male	0%
Race	
White/Caucasian	80%
Asian/Pacific Islanders	6.7%
Hispanic/Latino	6.7%
Black/African American	6.7%
Age	Mean: 31.8 years (range 22-63)
Years practicing with the inpatient pediatric oncology population	
Less than 2	26.6%
2-5	33.3%
6-9	26.6%
10-13	6.7%
14-17	0%

18-21	6.7%
22-25	0%
Years practicing as an RN	
Less than 2	13.3%
2-5	40%
6-9	26.6%
10-13	6.7%
14-17	0%
18-21	6.7%
22-25	6.7%
Education Level	
Associate's Degree	6.7%
Bachelor's Degree	86.7%
Master's Degree	6.7%
PhD	0%
Oncology Certifications/Training	
Certified Pediatric Oncology Nurse (CPON)	13.3%
Pediatric Certification with ANCC	6.7%
Certified Pediatric Hematology/Oncology Nurse	6.7%
(CPHON)	6.7%
Chemotherapy Certified	66.7%
None	

The Nurses' Distress and Interventions for Symptoms Survey (NDISS)

Of the 15 nurses who were surveyed, 13 completed through the NDISS portion of the survey. All nurses reported having patients with pain, nausea/vomiting, and hair loss. Twelve nurses (92.3%) had patients that experienced fatigue and worry. Eleven nurses (84.6%) had patients that experienced mouth sores. Sleep troubles were the least common symptom to be reported (n=9, 69.2%).

Majority of participants reported at some distress related to managing these symptoms. Overall, nurses' distress was greatest when patients had pain and lowest with hair loss. The most bothersome symptoms were nausea/vomiting, pain, and mouth sores. The least bothersome

symptoms were sleep troubles and hair loss. Table 3 details Nurses' Distress/Bother for each

symptom.

Table 3: Nurses' Distress/Bother (N=13)

Symptom	None (n, %)	A little bit (n, %)	Somewhat (n, %)	Quite a bit (n, %)	Very much (n, %)
Pain	1 (7.7%)	0 (0%)	4 (30.7%)	8 (61.5%)	0 (0%)
N/V	1 (7.7%)	2 (15.4%)	0 (0%)	9 (69.2%)	1 (7.7%)
Mouth sores	3 (23.1%)	1 (7.7%)	3 (23.1%)	5 (38.5%)	1 (7.7%)
Sleep troubles	6 (46.4%)	2 (15.4%)	3 (23.1%)	2 (15.4%)	0 (0%)
Fatigue	3 (23.1%)	3 (23.1%)	5 (38.5%)	2 (15.4%)	0 (0%)
Worry	1 (7.7%)	3 (23.3%)	5 (38.5%)	4 (30.7%)	0 (0%)
Hair loss	5 (38.5%)	4 (30.7%)	1 (7.7%)	2 (15.4%)	1 (7.7%)

The overall average number of nursing interventions used to treat each symptom was 9.9.

The greatest number was used to manage pain (n=15.85); the least number was used to manage

hair loss (n=5.38). A variety of interventions were used for each symptom. The most frequently

used interventions across all symptoms were active listening, encouragement of family

involvement, family support, and reduced sleep interruptions. The least frequently used

interventions were meditation, imagery, and art therapy. In Table 4, numbers indicate the

number of nurses who reported using the non-pharmacologic method for each symptom. For

instance, 10 nurses tried active listening when treating pain.

Table 4: Total Interventions Used by Symptom (N=13)

Intervention	Pain (n)	N/V (n)	Mouth Sores (n)	Sleep Troubles (n)	Fatigue (n)	Worry (n)	Hair Loss (n)	Total
Active Listening	**10**	7	4	4	3	**11**	9	**48**
Adjust nighttime sleep regimen	2	3	2	**12**	8	3	0	**30**
Anticipatory guidance (explain what is happening)	6	6	3	1	3	9	4	**32**
Anxiety-reducing medications	7	7	5	8	1	7	0	**35**
Art therapy	1	1	2	0	2	2	1	**9**
Assist with physical needs	6	5	4	1	9	4	0	**29**
Build trust	8	4	2	1	4	**11**	4	**34**
Counseling	2	2	2	0	0	7	4	**17**
Decision-making support	2	4	1	1	3	7	4	**22**
Deep breathing	5	8	2	5	3	4	0	**27**
Distraction	**11**	7	6	2	3	4	1	**34**
Emotional support	8	5	5	3	4	5	7	**37**
Encourage family involvement	9	6	5	5	5	8	6	**44**
Family support	**10**	6	4	4	4	9	6	**43**
Humor	8	4	5	2	1	3	3	**26**
Imagery	2	3	1	0	0	0	1	**7**
Meditation	2	1	0	1	0	1	0	**5**
Mouth care/hygiene	5	6	**10**	0	0	0	0	**21**
Music therapy	3	1	1	3	2	1	1	**12**
Mutual goal-setting	7	3	3	2	5	**10**	2	**32**
Nausea-reducing medications	8	**12**	4	3	0	3	0	**30**
Nutrition	2	5	5	0	3	2	0	**17**
Pain-reducing medications	**11**	6	**11**	7	2	2	0	**39**
Pet therapy	4	1	2	0	1	4	0	**12**
Play therapy	**11**	3	4	0	3	5	1	**27**
Positioning	**10**	6	1	8	6	0	0	**31**
Prayer	2	1	2	0	0	1	3	**9**
Presence	6	4	4	3	3	5	2	**27**

Psychosocial support for patient	6	4	2	5	4	8	6	**35**
Reduced sleep interruptions	**10**	8	5	9	8	4	0	**44**
Relaxation	9	7	4	9	7	3	0	**39**
Sleep-inducing medications	4	2	1	9	1	0	0	**17**
Spiritual support	2	1	2	0	0	4	2	**11**
Stress management	6	3	3	4	2	4	2	**24**
Other	1	1	0	0	0	0	1	**3**

Nurses reported pain and sleep troubles as the most effectively treated symptoms; worry and hair loss were perceived as the least effectively managed. Table 5 presents the Perceived Effectiveness of Management for each symptom.

Table 5: Perceived Effectiveness of Management for each symptom

Symptom	None	A little bit	Somewhat	Quite a bit	Very much
Pain	0 (0%)	0 (0%)	3 (23.1%)	9 (69.2%)	1 (7.7%)
N/V	0 (0%)	0 (0%)	4 (30.7%)	7 (53.8%)	2 (15.4%)
Mouth sores	0 (0%)	0 (0%)	5 (38.5%)	7 (53.8%)	1 (7.7%)
Sleep troubles	0 (0%)	0 (0%)	3 (23.1%)	5 (38.5%)	5 (38.5%)
Fatigue	0 (0%)	1 (7.7%)	5 (38.5%)	5 (38.5%)	2 (15.4%)
Worry	0 (0%)	1 (7.7%)	6 (46.2%)	3 (23.1%)	3 (23.1%)
Hair loss	0 (0%)	2 (15.4%)	4 (30.7%)	4 (30.7%)	3 (23.1%)

The Stressor Scale for Pediatric Oncology Nurses (SSPON)

The total mean score for the SSPON was 318.87 (Range: 169 to 413), which indicates a moderate intensity of role-related stress. The subscales with the highest mean item scores were co-worker (Mean=43.13, Range: 27 to 53) and system demands (Mean=82.73, Range: 32 to 110).

Table 6: SSPON Descriptive Statistics (N=13)

	Mean (s.d)	Minimum	Maximum
Co-worker Subscale (0 to 60 points)	43.13 (6.266)	27	53
System demands subscale (0 to 120 points)	82.73 (22.305)	32	110
Knowing what is ahead subscale (0 to 50 points)	27.07 (11.943)	4	40
Limitations of care subscale (0 to 120 points)	79.07 (14.553)	54	99
Emotional demands subscale (0 to 130 points)	76.07 (21.931)	33	103
Dying with grace subscale (0 to 20 points)	10.40 (5.166)	0	16
Total SSPON Score	318.87 (75.469)	169	413

The most stressful situation was watching a patient suffer and not being able to do anything about it (Mean=8.93, Range 8-10), which was a part of the limitations of care subscale. Other questions that were a part of the system demands and co-worker subscales had some of the highest means. The questions that indicated a high distress level were: when a manager doesn't arrange for adequate staffing (Mean=8.33, Range: 4-10), feeling we have waiting too long to do something that could help a patient (Mean=8.20, Range: 5-10), and a coworker not realizing how busy I am and starts making demands on me (Mean=8.13, Range: 5-10).

The question that had the lowest mean was when patients die at home rather than here at the hospital with us (Mean=2.00, Range: 0-5), which was a part of the limitations of care subscale and indicates mild distress level. Other questions that were a part of the emotional demands and knowing what is ahead subscales had some of the lowest means. The questions that indicated a moderate distress level were: feeling dissatisfied with how I personally handle the dying of a special patient (Mean=4.27, Range: 0-8), when the child screams when I'm trying to

start an I.V. (Mean=4.27, Range: 0-9), when a new patient is admitted and I think of all that is ahead for him/her (Mean=4.47, Range: 0-8), when other professionals do more than they are qualified to do (Mean=4.80, Range: 0-8), and feeling that I've gotten too close to a patient or family (Mean=4.93, Range: 1-8).

Correlations

Pearson r correlations were run to examine the relationship between nurse distress and symptom management. There was no correlation between the total SSPON score and NDISS total score. There was also no correlation between participant's age, number of years in practice or number of years working with pediatric patients and distress.

Open-Ended Questions

Answers to the first open-ended question, which invited participants to describe how open they are to using non-pharmacologic methods to help patients, were overwhelmingly positive. Most of the surveyed nurses (n=10, 76.9%) stated that they felt quite or very comfortable with using non-pharmacologic methods, and other nurses (n=3, 23.1%) stated that they felt somewhat or pretty comfortable with using non-pharmacologic methods.

Nurses were also asked what their favorite non-pharmacological intervention to use was and why. Majority of the responses collected were distraction techniques and play therapy. Nurses stated their favorite non-pharmacological intervention to use and why: "Distraction, I usually do a little tap dance for my patients", "Humor – I like making the patients laugh and putting a smile on their face", "Play therapy is the best education and distraction", "Emotional support because it allows the child to know that you are not only listening to them but also that you are there for them when they need someone", and "Deep breathing".

The third open-ended question give the nurses a chance to explain some barriers and/or facilitators to non-pharmacologic methods that they might encounter. Nurses who responded were not specific on whether their answer was a barrier or facilitator. Some of the responses that were related to barriers were: "Patient usually requests pharmacologic methods and refuse non-pharmacologic", "Time – When I have a busy assignment it's hard to carve out extra time to just hangout and build a friendlier rapport with the patient", "Patient willingness to accept treatment method", "Doesn't work as well", and a few stated "Age of patient". There were no specific answers related to facilitators to non-pharmacologic methods that they might encounter.

The last open-ended question allows the nurses to share how often they suggest non-pharmacologic methods and if they felt supported when suggesting them. Most nurses (69.2%) stated that they suggest non-pharmacologic methods often and they felt supported when they do in fact suggest them.

DISCUSSION OF FINDINGS

Nurses' Distress and Interventions for Symptoms Survey

Nurses are frequently responsible for managing multiple symptoms at one time, especially in pediatric patients with cancer. Pain, nausea/vomiting, and hair loss were among the most frequent symptoms to be reported, which is consistent with the literature (Drake et. al., 2003; Williams, Schmideskamp, Ridder, & Williams, 2006; Rheingans, 2008). Nurses were most bothered by the symptoms of pain, nausea/vomiting, and mouth sores. Most of the time these symptoms are treated by using pharmacologic interventions. It is likely that nurses found these symptoms to be the most bothersome because pharmacologic interventions are expected to work. Nurses may be distressed when they do not work since pain, nausea/vomiting, and mouth sores are physical side effects that can be very distressing to patients. When medications do not work, nurses may feel helpless and may be hesitant to introduce a non-pharmacologic intervention which could take time to figure out what works and what doesn't work. Nurses were not as bothered by the symptoms of fatigue, sleep troubles, and worry. It is possible that nurses do not find these symptoms as bothersome, because they are not considered as urgent or as serious side effects that require immediate intervention. Hair loss was the least bothersome symptom. Perhaps this is because nurses accept hair loss as a side effect and there is nothing that can be done to prevent it. Also, it is possible that patients who are in distress related to symptom management may vary based who was admitted on the unit at the time of study being conducted.

Nurses reported using an average of 9.9 nursing intervention to treat each symptom. The breadth of interventions chosen for each symptom were very interesting. Majority of nurses relied greatly on pharmacologic methods; however, there were a number of non-pharmacologic

interventions used as well. In addition to using pain-reducing medications, ten nurses used distraction and family support to treat pain. Distraction therapy aims to take the child's mind off the discomfort by concentrating on something else that is happening. Distraction techniques could include: hypnosis, reading books, drawing a picture, or listening to music (Martin, 2013). While it is uncertain which types of distraction techniques these nurses are using in practice the Oncology Nursing Society (ONS) Putting Evidence in Practice (PEP) for pain shows that hypnosis, medical clowning (humor), and music therapy are likely to be effective at reducing pain (Oncology Nursing Society [ONS], 2016a). However, there are many interventions that have not had their effectiveness established yet such as acupressure, guided imagery, and meditation which were intervention options on the survey (ONS, 2016a).

In pediatrics, patient and family centered care is based on the understanding that the family is the child's primary source of strength and support (Eichner & Johnson, 2012). It is appropriate to include the family in care and offer support. However, it is uncertain why some nurses reported using nutrition and building trust with patients with pain. Perhaps the survey was unclear or maybe these are interventions that the nurses use all of the time regardless if they are effective or not. Regardless, further research should be conducted on this.

At least 8 nurses were using adjust nighttime sleep regimen and assist with physical needs to treat fatigue. According to ONS PEP cards, some sort of exercise is recommended for practice, while energy conservation and activity management is likely to be effective (ONS, 2016b) in managing fatigue. Some of the interventions that nurses reported using for fatigue have not had effectiveness established. This includes oral nutritional interventions, guided imagery, relaxation therapy, meditation, and music therapy (ONS, 2016b).

The least frequently used non-pharmacologic interventions were art therapy, meditation, imagery, and prayer. It is possible that nurses were not using these interventions because they were either not trained in how to perform them, they would have been too time-consuming to use, or the resources were not available. This is in contrast with interventions nurses learned in the nursing program such as active listening, emotional support, and "hands on" medical interventions, such as medication administration, repositioning, and mouth care/hygiene, that were more frequently used by these participants.

Nurses reported that managed pain and sleep troubles most effectively and that worry and hair loss were perceived as the least effectively managed symptoms. Over 60% of nurses were quite a bit to very sure that their interventions helped for pain. Perhaps it is easier to assess and measure pain compared to worry. When nurses administer pain-reducing medications they are able to see the results of their intervention within a short time period, and they have something concrete to go by. It is difficult to measure and assess worry in a short time period like pain.

Stressor Scale for Pediatric Oncology Nurses

The findings from the SSPON had some similarities and differences from previous findings within the pediatric oncology nursing literature. The areas of co-workers and system demands were identified as particularly stressful in this study. In previous studies, the areas of dying with grace, limitations of care, co-workers, and emotional demands seemed to be the most stressful for nurses (Bond, 1994; Hinds, et al., 1990, 1998). The item that was rated most stressful was "watching a patient suffer and not be able to do anything about it", which correlated with previous literature (Bond, 1994). In previous research, nurses report that watching a patient suffer was a primary contributor to a highly stressful nursing environment

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(Barnard, Street, & Love, 2006; Bond, 1994, de Carvalho, Muller, de Carvalho, & de Souza Melo, 2005; Rheingans, 2008). Other highly stressful situations in this study were "when a manager doesn't arrange for adequate staffing"; "feeling we have waiting too long to do something that could help a patient"; and "a coworker not realizing how busy I am and starts making demands on me" were not reported by previous studies. It is possible that the nurse may feel helpless or overwhelmed in situations of low staffing and may feel like they can't say no to their co-worker who is asking for help which leads to increased frustration and distress. In addition, this sample was younger and newer to nursing. The mean age for the sample was 31.8 years of age and 50% of nurses have been working in the pediatric oncology setting for 5.4 years or less. Perhaps this is a transition time for these nurses and many are still trying to navigate the system or trying to organize their work with patients who have multiple issues in this population. Parent studies that used the SSPON were conducted in 1990, 1994, and 1998 (Bond, 1994; Hinds et al., 1990, 1998). In the 1990's, electronic charting did not exist on a large scale. Perhaps electronic charting causes distress for younger and newer nurses who are still trying to learn the system.

The item that was the lowest stressor and also found in previous literature was "when a patient dies at home rather than here at the hospital with us" (Bond, 1994). Perhaps nurses thought that the fact of the death occurring at home rather than in the hospital is not a stressor to them because they think there would be a better outcome for the patient and their family. Other items that were rated low and did not cause distress were "feeling dissatisfied with how I personally handle the dying of a special patient" and "when a child screams when I'm trying to start an I.V." were not consistent with previous studies (Bond, 1994; Hinds, et al., 1990, 1998).

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Perhaps nurses found these items as low stressors because patients were dying at home rather than the hospital. It is unclear why the item "when a child screams when I'm trying to start an I.V. was not distressful. Perhaps screaming during an I.V. insertion is routine, or the nurse could have used distraction methods to help ease the child's discomfort or fear.

Correlations

Even though there were no correlations or relationships between symptom management and nurses' distress, there was still an abundance of information gained from this study. This samples size was small, or perhaps the instruments that were used for this study were not appropriate. More research should be done to explore this relationship.

Open-Ended Questions

Non-pharmacologic interventions are usually determined by the nature of the case, what works for the specific patient, and the skills of the healthcare professional. These interventions are relatively noninvasive and present less risk to the patient than invasive or pharmacologic interventions do. However, non-pharmacologic interventions may take more time to perform and the nurse might not always have time. Overall, it seemed that majority of nurses were very comfortable with using non-pharmacologic interventions to help patients. Non-pharmacologic interventions can be very important adjuncts to treatment modalities for pediatric patients with cancer. Research has shown that non-pharmacologic interventions are more beneficial to patients that do not respond to pharmacologic interventions; however, it is uncertain which non-pharmacologic interventions work more effectively than others (Rheingans, 2008). When nurses where asked to report their favorite non-pharmacological intervention, most offered some form of distraction such as deep breathing, tap dancing, humor, or conversation. Perhaps nurses found

that methods of distraction helped them more when it came to helping the patient. Most of the interventions that were reported also helped the nurses establish a rapport with their patient, which is important in the pediatric oncology setting. The two most common barriers to using non-pharmacologic methods were not having enough time and the patient's age. In today's fast-paced hospital routine nurses typically have a large number of responsibilities, so perhaps nurses feel like they don't have enough time to try these interventions or rather they don't want to waste their time. If the nurse has a younger patient, they might not be able to verbalize what they need. So, nurses will go to pharmacologic interventions, since that can be measured.

Limitations

This study had several limitations. First, the sample size was small and included nurses from only one hospital in the local area. This sample may not adequately represent other pediatric oncology nurses across the nation or worldwide. Males and other ethnic groups other than Caucasian were underrepresented in this study due to the randomized convenience sample. The generalizability of this study was limited by the small convenience sample and underrepresented demographic groups. In the future, the sample size could be increased by including multiple hospital systems across the nation or by targeting nurses who are a part of the Associate of Pediatric Hematology/Oncology Nurses. By increasing the sample size, more demographic groups could be represented. Second, since the convenience sample was small, demographic variables could not be grouped for comparison. This limited the full extent of the analyses possible. Third, the survey was lengthy. Due to time constraint, some of the participants may have been unable to complete the entire survey. It is also possible that some participants who had accessed the survey told other nurses who had not taken the survey that it

was too long, deterring other potential participants. In the future, the survey could be available for a longer period of time or the PI could develop a survey that reduces the number of questions being asked. Depending on the size of the sample or availability of a grant, larger incentives could be offered as well. Personal factors that might be confounding variables and might impact the nurses' stress levels were not examined. In the future, personal factors will be added to the demographics. Lastly, the two very different constructs of stress and distress were not previously defined and were interchangeably used in this study.

Recommendations for Practice

This research study shows that pediatric oncology nurses' have distress related to co-workers and system demands. Research has shown that work-related distress can lead to compassion fatigue and burnout which are associated with poor decision making, adverse clinical events, and poor quality of care and irritability with patients and colleagues (Mukherjee, Beresford & Tennant, 2014). It is imperative that nursing implications for self-care and prevention of distress are established and made known to nurses working with the pediatric oncology population. Supportive interventions may help individual staff nurses to develop adequate stress management and coping skills to use in their practice. These include: identifying situations that are hard so that the nurse can better manage difficult situations in the future; knowing one's limits; utilizing or developing resources that are or could be available in the workplace such as Employee Assistance Programs; identifying tasks that can be delegated so the nurse is able to spend more time focusing on the patient care that requires attention; take allotted break time away from patient care; training nurses appropriate time management techniques; develop support group sessions; practice active listening; and taking time for self-care. The

identification of the work-related stressors will allow administration to establish priorities to help reduce significant areas of stressors, and to make sure that these supportive interventions are being implemented.   Although nurses may not always have direct influence over systemic stressors regarding issues such as continuity of care, the nurse can speak to their nursing or hospital administrators as advocates for appropriate resources, staffing, and workloads (Sherman, 2004). Or perhaps nurses just need a safe place to vent about these issues.

Recommendations for Education

Distress related to patient care can start as soon as one enters nursing school. Education on predictors of stress and healthy coping strategies should be taught to nursing students when they first start. Examples include: avoid caffeine, exercise regularly, meditation, get more sleep, manage time wisely, talk to someone, and keeping a stress diary (Reeve, Shumaker, Yearwood, Crowell, & Riley, 2013). As for nurses already in practice, in-service training, conferences, and continuing education programs (such as the mind, body, spirit program) about coping skills can give a necessary boost to the quality of care a nurse provides, while at the same time strengthening the interdisciplinary team.

As for symptom management, nursing programs should focus on and stress the implementation of non-pharmacologic interventions to complement pharmacologic interventions. Developing elective courses about symptom management may enhance a nursing student's education. For nurses already in practice, educational specialists should develop in-services to teach nurses about the interventions that are likely to be effective and those interventions who effectiveness has not been established yet according to the Oncology Nursing Society Putting Evidence in Practice.

Recommendations for Research

Overall, a larger research study needs to be conducted to explore what nurses already know about non-pharmacological interventions. Further research could include an educational intervention study for nurses as well as studies on appropriate non-pharmacologic interventions, such as art therapy, pet therapy, meditation, imagery, and how they affect children with cancer. Perhaps this research will provide nurses with support and will decrease nurses' distress related to symptom management. Personal and interpersonal factors, such as cultural or family influences, that may influence nurses' distress when working with this population need to be considered when conducting further research as well. It would also be interesting to see if nurses who have chronically ill children as their own are more likely to experience distress or if it is a buffer for them when they work with this population. Additional research could be conducted on whether the style of nursing, such as primary nursing or team nursing, has an effect on distress. Organizational factors such as the staffing ratio, perception of staffing, and turnover rate should be considered when looking at the causes of distress in pediatric oncology nurses. Lastly, levels of distress in relation to the cultural and social supports that each child has and whether these factors may increase or decrease the nurse's distress in managing symptoms should be considered as well.

SUMMARY

Stress is a known side effect in nurses providing care to chronically ill children.   In this study, nurses felt as if the distress was coming from the areas of co-workers and system demands. However, nurses are still experiencing distress related to symptom management as well. By providing education on how to deal with the distress and conducting further research in years to come, hopefully the rates of distress will decrease in the pediatric oncology.

APPENDIX A: UCF IRB APPROVAL LETTER

University of Central Florida Institutional Review Board
Office of Research & Commercialization
12201 Research Parkway, Suite 501
Orlando, Florida 32826-3246
Telephone: 407-823-2901 or 407-882-2276
www.research.ucf.edu/compliance/irb.html

Approval of Exempt Human Research

From: **UCF Institutional Review Board #1**
FWA00000351, IRB00001138

To: **Victoria Loerzel** and Co-PI: **Amanda Michael Wimmersberg**

Date: **November 08, 2016**

Dear Researcher:

On 11/08/2016, the IRB approved the following activity as human participant research that is exempt from regulation:

Type of Review:	Exempt Determination
Project Title:	The Exploration of the Relationship Between Symptom Management and Distress in Pediatric Oncology Nurses
Investigator:	Victoria Loerzel
IRB Number:	SBE-16-12635
Funding Agency:	UCF College of Nursing Intramural Grant(CON)
Grant Title:	College of Nursing Honors-In-The-Major (HIM) Research Grant
Research ID:	N/A

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these changes affect the exempt status of the human research, please contact the IRB. When you have completed your research, please submit a Study Closure request in iRIS so that IRB records will be accurate.

In the conduct of this research, you are responsible to follow the requirements of the Investigator Manual.

On behalf of Sophia Dziegielewski, Ph.D., L.C.S.W., UCF IRB Chair, this letter is signed by:

Signature applied by Patria Davis on 11/08/2016 10:16:17 AM EST

IRB Coordinator

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APPENDIX B: ORMC APPROVAL LETTER

October 4, 2016

Patria Davis
Chair, Institutional Review Board
University of Central Florida

Dear Patria,

I am writing to let you know that a UCF Honors in the Major Student, Amanda Wimmersberg, has submitted her proposal for a research study at Orlando Health entitled **The exploration of the Relationship between Symptom Management and Distress in Pediatric Oncology Nurses.** She has submitted this proposal along with her faculty advisor, Dr. Vicki Loerzel, to the Nursing Research Council for review. They will be submitting this to the UCF IRB per our new process with Orlando Health. They have also gained approval through the nursing manager on the units at APH and from HR to approve the survey method.

This letter indicates that The NRC has reviewed the proposal and providing support and approval to submit to the UCF IRB..

Please let us know if you have any further need for clarification or any questions.
Thank you for the privilege to review this proposal.

Sincerely,

Daleen Penoyer, PhD,RN,CCRP,FCCM

Daleen Penoyer, PhD,RN,CCRP,FCCM
Director Center for Nursing Research and
Chair, Nursing Research Council
Orlando Health

APPENDIX C: INFORMATION (CONSENT) SHEET

University of
**Central
Florida**

EXPLANATION OF RESEARCH

Title of Project: The Exploration of the Relationship Between Symptom Management and Distress in Pediatric Oncology Nurses

Principal Investigator: Dr. Victoria Loerzel, PhD, RN, OCN

Other Investigators: Amanda Wimmersberg, Nursing Student

Faculty Supervisor: N/A

You are being invited to take part in a research study. Whether you take part is up to you.

- The aims of this research study are to examine: 1) relationships between symptom management and nurse distress; 2) strategies used by nurses to manage symptoms in pediatric patients with cancer; 3) nurse perceptions of effectiveness of non-pharmacologic or nursing interventions; 4) nurse distress related to managing symptoms in pediatric patients with cancer.

- This research study will be performed on the In-Patient Hematology and Oncology Unit at Arnold Palmer Hospital for Children. You will be invited to participate in this research study through an email sent to your work accounts. The email will include the link to proceed to the Qualtrics survey should you choose to participate.

- You will be asked to complete a 78 question online survey that includes demographic questions (8 questions), the Nurses' Distress and Interventions for Symptoms Survey (28 questions), the Stressor Scale for Pediatric Oncology Nurses (50 questions), and open ended questions about managing symptoms (4 questions). The survey is expected to take 15-20 minutes to complete in one sitting.

- At the end of the survey, you will be asked to provide your name so they can receive a $5 gift card as an incentive for completing the study.

You must be 18 years of age or older to take part in this research study.

Study contact for questions about the study or to report a problem: If you have questions, concerns, or complaints contact Amanda Wimmersberg, Undergraduate Student, BSN Nursing Program, College of Nursing at (618) 698-5238 or Dr. Loerzel, Faculty Supervisor, College of Nursing at (407) 823-0762 or by email at Victoria.Loerzel@ucf.edu.

IRB contact about your rights in the study or to report a complaint: Research at the University of Central Florida involving human participants is carried out under the oversight of the Institutional Review Board (UCF IRB). This research has been reviewed and approved by the IRB. For information about the rights of people who take part in research, please contact: Institutional Review Board, University of Central Florida, Office of Research & Commercialization, 12201 Research Parkway, Suite 501, Orlando, FL 32826-3246 or by telephone at (407) 823-2901.

1 of 1

APPENDIX D: SURVEY

Demographics Survey:

1. Are you currently working as a registered nurse with direct patient care with pediatric oncology patients?
    a. Yes
    b. No

2. What is your age?

3. What is your biologically assigned sex?
    a. Female
    b. Male

4. With which racial or ethnic group(s) do you most identify? (Select all that apply)
    a. American Indian/Native American
    b. Asian/Pacific Islanders
    c. Black/African American
    d. Hispanic/Latino
    e. White/Caucasian
    f. Other (Please describe)

5. How many years have you practiced as a registered nurse?

6. How many years have you worked with the inpatient pediatric oncology population?

7. What is your highest level of education?
    a. Nursing Diploma
    b. Associate of Science
    c. Bachelor's Degree
    d. Master's Degree
    e. Doctoral Degree

8. Have you completed any certifications or training related to oncology nursing?
    a. Oncology Certified Nurse (OCN)
    b. Certified Pediatric Hematology/Oncology Nurse (CPHON)
    c. Certified Pediatric Oncology Nurse (CPON)
    d. Other

Stressor Scale for Pediatric Oncology Nurses (SSPON):

1. Feeling a coworker doesn't care enough about doing a good job.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

2. Coworker calls in sick when I know that's not true.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

3. Working with someone who tries to find something you have done wrong.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

4. Working with someone I don't think is competent.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

5. Not being able to get a prompt enough response from a doctor.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

6. Feeling we have waited too long to do something that could help a patient.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

7. Coworker not taking the initiative when there is work to be done.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

8. Watching a patient suffer and not be able to do anything about it.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

9. Coworker not realizing how busy I am and starts making demands on me.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

10. When nurses and doctors are not communicating well about patients.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

11. When there is nothing more we can do, to provide comfort for a patient

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

12. When a new patient is admitted and I think of all that is ahead for him/her.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

13. Working with infants who have a very rare form of cancer.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

14. When a newly diagnosed patient who is just beginning treatment dies right away.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

15. Working with teenagers who are used to being independent and are becoming more and more dependent.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

16. Knowing a patient has given up.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

17. Dealing with families who do not speak English.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

18. Dealing with parents who have too much hope.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

19. Seeing parents react to the diagnosis and prognosis.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

20. Watching a family suffer.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

21. When a patient who has been hospitalized a long time dies.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

22. When other professionals do more than they are qualified to do.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

23. When the child screams when I'm trying to start an I.V.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

24. When a favorite patient dies.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

25. Working with teenagers who know exactly what is happening to them.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

26. Seeing a patient relapse.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

27. Dealing with parents who don't trust me.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

28. Thinking about all that family members need to know about the disease and its treatment.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

29. Not being able to get caught up.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

30. Seeing what I believe is going beyond aggressive care for a patient and not letting the patient die.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

31. When equipment and supplies are just not available.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

32. Using equipment I'm not familiar with.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

33. When a manager doesn't arrange for adequate staffing.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

34. Making mistakes.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

35. Feeling I can't get all of my work done.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

36. Feeling that I've gotten too close to a patient or family.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

37. When patients die at home rather than here at the hospital with us.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

38. Not knowing how to help a patient have more determination to get better.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

39. Feeling dissatisfied with how I personally handle the dying of a special patient.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

40. When a nursing/medical administrator doesn't really know about what is going on with patients.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

41. Trying to meet the needs of both the patient and the family.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

42. Having to continue tests on patients who are on terminal care.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

43. Trying to teach patients and families plus getting my other work done.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

44. Not being certain of what to say to parents of a newly diagnosed child.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

45. Not feeling comfortable with my skills.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

46. When I can't answer a question about my patient.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

47. Not being certain of what to say to parents of a dying child.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

48. When a nursing/medical administrator doesn't try to make a problem situation better.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

49. Hospital services are not available around the clock, seven days a week.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

50. When staffing plans are inadequate.

Not stressful at all										Stressful as can be
0	1	2	3	4	5	6	7	8	9	10

Nurses' Distress and Interventions for Symptoms Survey (NDISS):

1. **In the past month, have any of your patients experienced PAIN?**

    ☐ No →   **SKIP to #3**

    ☐ Yes →   **2. How much did it distress or bother <u>you</u> that your patients had PAIN? (Please select one response)**
        ☐ Not At All (0)
        ☐ A Little Bit (1)
        ☐ Somewhat (2)
        ☐ Quite a Bit (3)
        ☐ Very Much (4)

3. **Which of the following do you normally use to help treat PAIN?** *Include what you personally administer and what you arrange for someone else to administer.* **(Please check all that apply)**

☐ Active listening	☐ Mouth care/hygiene
☐ Adjust nighttime sleep regimen	☐ Music therapy
☐ Anticipatory guidance (explain what is happening)	☐ Mutual goal-setting
	☐ Nausea-reducing medications
☐ Anxiety-reducing medications	☐ Nutrition
☐ Art therapy	☐ Pain-reducing medications
☐ Assist with physical needs	☐ Pet therapy
☐ Build trust	☐ Play therapy
☐ Counseling	☐ Positioning
☐ Decision-making support	☐ Prayer
☐ Deep breathing	☐ Presence
☐ Distraction	☐ Psychosocial support for patient
☐ Education	☐ Reduced sleep interruptions
☐ Emotional support	☐ Relaxation
☐ Encourage family involvement	☐ Sleep-inducing medications
☐ Family support	☐ Spiritual support
☐ Humor	☐ Stress management
☐ Imagery	☐ Other: _____
☐ Meditation	☐ Other: _____
(continued in next column)	☐ Other: _____

4. **How effective do you feel you are at managing PAIN using these interventions? (Please select one response)**
   - ☐ Not At All (0)
   - ☐ A Little Bit (1)
   - ☐ Somewhat (2)
   - ☐ Quite a Bit (3)
   - ☐ Very Much (4)

5. **In the past month, have any of your patients experienced NAUSEA/VOMITING?**

   - ☐ No → **SKIP to #7**

   - ☐ Yes → **6. How much did it distress or bother <u>you</u> that your patients had NAUSEA/VOMITING? (Please select one response)**
     - ☐ Not At All (0)
     - ☐ A Little Bit (1)
     - ☐ Somewhat (2)
     - ☐ Quite a Bit (3)
     - ☐ Very Much (4)

7. **Which of the following do you normally use to help treat NAUSEA/VOMITING?** *Include what you personally administer and what you arrange for someone else to administer.* **(Please check all that apply)**

☐ Active listening	☐ Mouth care/hygiene
☐ Adjust nighttime sleep regimen	☐ Music therapy
☐ Anticipatory guidance (explain what is happening)	☐ Mutual goal-setting
	☐ Nausea-reducing medications
☐ Anxiety-reducing medications	☐ Nutrition
☐ Art therapy	☐ Pain-reducing medications
☐ Assist with physical needs	☐ Pet therapy
☐ Build trust	☐ Play therapy
☐ Counseling	☐ Positioning
☐ Decision-making support	☐ Prayer
☐ Deep breathing	☐ Presence
☐ Distraction	☐ Psychosocial support for patient
☐ Education	☐ Reduced sleep interruptions
☐ Emotional support	☐ Relaxation
☐ Encourage family involvement	☐ Sleep-inducing medications
☐ Family support	☐ Spiritual support
☐ Humor	☐ Stress management

☐ Imagery ☐ Meditation (continued in next column)	☐ Other: _____ ☐ Other: _____ ☐ Other: _____

8. **How effective do you feel you are at managing NAUSEA/VOMITING using these interventions? (Please select one response)**
   - ☐ Not At All (0)
   - ☐ A Little Bit (1)
   - ☐ Somewhat (2)
   - ☐ Quite a Bit (3)
   - ☐ Very Much (4)

9. **In the past month, have any of your patients experienced MOUTH SORES?**

   - ☐ No →   **SKIP to #11**

   - ☐ Yes →   **10. How much did it distress or bother <u>you</u> that your patients had MOUTH SORES? (Please select one response)**
       - ☐ Not At All (0)
       - ☐ A Little Bit (1)
       - ☐ Somewhat (2)
       - ☐ Quite a Bit (3)
       - ☐ Very Much (4)

11. **Which of the following do you normally use to help treat MOUTH SORES?**
    Include what you personally administer and what you arrange for someone else to administer. **(Please check all that apply)**

☐ Active listening	☐ Mouth care/hygiene
☐ Adjust nighttime sleep regimen	☐ Music therapy
☐ Anticipatory guidance (explain what is happening)	☐ Mutual goal-setting
	☐ Nausea-reducing medications
☐ Anxiety-reducing medications	☐ Nutrition
☐ Art therapy	☐ Pain-reducing medications
☐ Assist with physical needs	☐ Pet therapy
☐ Build trust	☐ Play therapy
☐ Counseling	☐ Positioning
☐ Decision-making support	☐ Prayer
☐ Deep breathing	☐ Presence
☐ Distraction	☐ Psychosocial support for patient
☐ Education	☐ Reduced sleep interruptions

☐ Emotional support	☐ Relaxation
☐ Encourage family involvement	☐ Sleep-inducing medications
☐ Family support	☐ Spiritual support
☐ Humor	☐ Stress management
☐ Imagery	☐ Other: _____
☐ Meditation	☐ Other: _____
(continued in next column)	☐ Other: _____

12. **How effective do you feel you are at managing MOUTH SORES using these interventions? (Please select one response)**
- ☐ Not At All (0)
- ☐ A Little Bit (1)
- ☐ Somewhat (2)
- ☐ Quite a Bit (3)
- ☐ Very Much (4)

13. **In the past month, have any of your patients experienced TROUBLE SLEEPING?**

- ☐ No → **SKIP to #15**

- ☐ Yes → **14. How much did it distress or bother <u>you</u> that your patients had TROUBLE SLEEPING? (Please select one response)**
  - ☐ Not At All (0)
  - ☐ A Little Bit (1)
  - ☐ Somewhat (2)
  - ☐ Quite a Bit (3)
  - ☐ Very Much (4)

15. **Which of the following do you normally use to help treat TROUBLE SLEEPING?** *Include what you personally administer and what you arrange for someone else to administer.* **(Please check all that apply)**

☐ Active listening	☐ Mouth care/hygiene
☐ Adjust nighttime sleep regimen	☐ Music therapy
☐ Anticipatory guidance (explain what is happening)	☐ Mutual goal-setting
	☐ Nausea-reducing medications
☐ Anxiety-reducing medications	☐ Nutrition
☐ Art therapy	☐ Pain-reducing medications
☐ Assist with physical needs	☐ Pet therapy
☐ Build trust	☐ Play therapy
☐ Counseling	☐ Positioning

☐ Decision-making support	☐ Prayer
☐ Deep breathing	☐ Presence
☐ Distraction	☐ Psychosocial support for patient
☐ Education	☐ Reduced sleep interruptions
☐ Emotional support	☐ Relaxation
☐ Encourage family involvement	☐ Sleep-inducing medications
☐ Family support	☐ Spiritual support
☐ Humor	☐ Stress management
☐ Imagery	☐ Other: _____
☐ Meditation	☐ Other: _____
(continued in next column)	☐ Other: _____

16. How effective do you feel you are at managing TROUBLE SLEEPING using these interventions? (Please select one response)

☐ Not At All (0)
☐ A Little Bit (1)
☐ Somewhat (2)
☐ Quite a Bit (3)
☐ Very Much (4)

17. In the past month, have any of your patients experienced FATIGUE?

☐ No → **SKIP to #19**

☐ Yes → **18. How much did it distress or bother <u>you</u> that your patients had FATIGUE? (Please select one response)**
     ☐ Not At All (0)
     ☐ A Little Bit (1)
     ☐ Somewhat (2)
     ☐ Quite a Bit (3)
     ☐ Very Much (4)

19. Which of the following do you normally use to help treat FATIGUE? *Include what you personally administer and what you arrange for someone else to administer.* **(Please check all that apply)**

☐ Active listening	☐ Mouth care/hygiene
☐ Adjust nighttime sleep regimen	☐ Music therapy
☐ Anticipatory guidance (explain what is happening)	☐ Mutual goal-setting
	☐ Nausea-reducing medications
☐ Anxiety-reducing medications	☐ Nutrition
☐ Art therapy	☐ Pain-reducing medications

☐ Assist with physical needs	☐ Pet therapy
☐ Build trust	☐ Play therapy
☐ Counseling	☐ Positioning
☐ Decision-making support	☐ Prayer
☐ Deep breathing	☐ Presence
☐ Distraction	☐ Psychosocial support for patient
☐ Education	☐ Reduced sleep interruptions
☐ Emotional support	☐ Relaxation
☐ Encourage family involvement	☐ Sleep-inducing medications
☐ Family support	☐ Spiritual support
☐ Humor	☐ Stress management
☐ Imagery	☐ Other: _____
☐ Meditation	☐ Other: _____
(continued in next column)	☐ Other: _____

20. How effective do you feel you are at managing FATIGUE using these interventions? (Please select one response)
- ☐ Not At All (0)
- ☐ A Little Bit (1)
- ☐ Somewhat (2)
- ☐ Quite a Bit (3)
- ☐ Very Much (4)

21. In the past month, have any of your patients experienced WORRY?

- ☐ No → **SKIP to #23**

- ☐ Yes → **22. How much did it distress or bother <u>you</u> that your patients had WORRY? (Please select one response)**
  - ☐ Not At All (0)
  - ☐ A Little Bit (1)
  - ☐ Somewhat (2)
  - ☐ Quite a Bit (3)
  - ☐ Very Much (4)

23. Which of the following do you normally use to help treat WORRY? *Include what you personally administer and what you arrange for someone else to administer.* **(Please check all that apply)**

☐ Active listening	☐ Mouth care/hygiene
☐ Adjust nighttime sleep regimen	☐ Music therapy
	☐ Mutual goal-setting

☐ Anticipatory guidance (explain what is happening)	☐ Nausea-reducing medications
	☐ Nutrition
☐ Anxiety-reducing medications	☐ Pain-reducing medications
☐ Art therapy	☐ Pet therapy
☐ Assist with physical needs	☐ Play therapy
☐ Build trust	☐ Positioning
☐ Counseling	☐ Prayer
☐ Decision-making support	☐ Presence
☐ Deep breathing	☐ Psychosocial support for patient
☐ Distraction	☐ Reduced sleep interruptions
☐ Education	☐ Relaxation
☐ Emotional support	☐ Sleep-inducing medications
☐ Encourage family involvement	☐ Spiritual support
☐ Family support	☐ Stress management
☐ Humor	☐ Other: _____
☐ Imagery	☐ Other: _____
☐ Meditation	☐ Other: _____
(continued in next column)	

24. How effective do you feel you are at managing WORRY using these interventions? (Please select one response)
- ☐ Not At All (0)
- ☐ A Little Bit (1)
- ☐ Somewhat (2)
- ☐ Quite a Bit (3)
- ☐ Very Much (4)

25. In the past month, have any of your patients experienced HAIR LOSS?

☐ No → **SKIP to #27**

☐ Yes → **26. How much did it distress or bother <u>you</u> that your patients had HAIR LOSS? (Please select one response)**
- ☐ Not At All (0)
- ☐ A Little Bit (1)
- ☐ Somewhat (2)
- ☐ Quite a Bit (3)
- ☐ Very Much (4)

27. **Which of the following do you normally use to help treat HAIR LOSS?** *Include what you personally administer and what you arrange for someone else to administer.* **(Please check all that apply)**

☐ Active listening	☐ Mouth care/hygiene
☐ Adjust nighttime sleep regimen	☐ Music therapy
☐ Anticipatory guidance (explain what is happening)	☐ Mutual goal-setting
☐ Anxiety-reducing medications	☐ Nausea-reducing medications
☐ Art therapy	☐ Nutrition
☐ Assist with physical needs	☐ Pain-reducing medications
☐ Build trust	☐ Pet therapy
☐ Counseling	☐ Play therapy
☐ Decision-making support	☐ Positioning
☐ Deep breathing	☐ Prayer
☐ Distraction	☐ Presence
☐ Education	☐ Psychosocial support for patient
☐ Emotional support	☐ Reduced sleep interruptions
☐ Encourage family involvement	☐ Relaxation
☐ Family support	☐ Sleep-inducing medications
☐ Humor	☐ Spiritual support
☐ Imagery	☐ Stress management
☐ Meditation	☐ Other: _____
(continued in next column)	☐ Other: _____
	☐ Other: _____

28. **How effective do you feel you are at managing HAIR LOSS using these interventions? (Please select one response)**
   ☐ Not At All (0)
   ☐ A Little Bit (1)
   ☐ Somewhat (2)
   ☐ Quite a Bit (3)
   ☐ Very Much (4)

Open-Ended Questions:

1. How comfortable are you to using non-pharmacologic methods to help patients?

2. Overall, what is your favorite non-pharmacological intervention to use and why?

3. What are some barriers and/or facilitators to using non-pharmacologic methods that you encounter?

4. How often do you suggest non-pharmacologic methods to your patients, and do you feel supported when you do in fact suggest them?

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