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SYMPTOMS IN CHILDREN WITH ADVANCED CANCER: CHILD AND NURSE REPORTS

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Abstract

Background—Systematic studies on the specific symptom experience in children with advanced cancer are limited.

Objective—To examine common symptoms and to explore commonly occurring symptoms over time.

Methods—A prospective and longitudinal study design was used. Data were collected at 10 data points from 60 children over a 5-month period. Children ranged from 6 to 17 years old, spoke English or Spanish, were diagnosed with advanced cancer, and were receiving health care in one of four Southern California hospitals. Nurses documentation of symptoms were examined.

Results—Sample: Children 52% 6–12 years and 48% 13–17 years; 42% female, 58% male; 55% Latino and 30% Caucasian. Pain, nausea, drowsiness and energy loss were reported by children in over 50% of the interviews. Children's and nurses' reports of symptoms were similar except children reported significantly more frequency and intensity of pain.

Conclusions—Children with advanced cancer were able to report and describe their symptoms. There were few differences by gender, age, and ethnicity.

Implications for Practice—It is important that children's symptoms are clearly communicated to nurses and these study findings may be used to anticipate and manage the symptoms experienced by children with advanced cancer.

Keywords

children; advanced cancer; symptoms

Cancer remains a major cause of death in children, ranking second only to accidents in child mortality.¹ Children living with cancer experience multiple symptoms as a result of their disease and/or its treatment. Symptoms experienced by children with cancer are distressing, and multiple symptoms may share underlying mechanisms and influence the severity of the distress experienced.^{2,3} Children not responding to treatment will develop active, progressive, advanced disease and move toward end of life with the length of time varying from weeks to months.^{4,5} Challenges in understanding the complexity of children with advanced cancer and their symptom experience are common. These include differing perspectives by different agents (e.g., child, parent, provider) and the developmental stages of the child on symptom experience⁶ as well as variations in socio-cultural components.

Children experience distressing physical symptoms from the disease process and from ongoing treatment, yet knowledge about the symptoms over time as reported directly by children is limited.⁷ A meta-analysis including prospective, retrospective, and survey research designs was conducted by Hinds and colleagues about the use of patient-reported outcomes (PRO) in children and adolescents with advanced cancer. They concluded that empirically based information about this population is scarce, and nearly 85% of studies did not include PRO.⁷ Subjects' ethnicity/race was not specified.

Similar limitations were noted in a widely cited study by Wolfe and colleagues.⁸ Methodological limitations have also been noted in systematic literature reviews. The most common limitations for pediatric advanced cancer research included small sample size, single-institution research, emphasis on retrospective studies, limited information about developmental factors associated with symptoms, underrepresentation of underserved and early childhood patient groups, the exclusion of non-English speakers,⁹⁻¹² and in studies of pediatric oncology end-of-life.¹³ Linder¹⁰ conducted a literature review of 53 articles published from 1986 to 2006 in which 43 studies describe physical symptoms in children and adolescents receiving cancer treatment. According to this review, most studies included a broad age range but did not address specific developmental considerations or participant ethnicity.

The purpose of this paper is to focus on the symptoms of children with advanced cancer from the perspective of the child over time. The data are part of a larger study examining quality of life in children with advanced cancer. The specific research question was: What symptoms do children with advanced cancer report? The specific aims were to (a) examine the child-reported and nurse-reported symptoms, (b) compare symptom experience in Latino and Caucasian children by age, gender and diagnosis, and (c) examine change of symptoms over time.

Background Literature

Advanced Disease and the Symptom Experience

Pain is one of the most common symptoms in children with cancer. Several other physical symptoms are commonly reported by pediatric patients and their parents. Pritchard et al.'s study¹³ involved the English-speaking parents of 52 children who died secondary to cancer-related complications. The most concerning and commonly reported physical symptoms included **pain, weakness, fatigue, changes in appearance, dyspnea, and sleep patterns**. Results indicated there were no significant differences when controlled for gender, disease

type, and location of death. Mack and colleagues⁶ conducted a retrospective study including 144 English-speaking parents of children with advanced cancer and 52 pediatric oncologists. The sample was 93% Caucasian and 83% female. They found that children's response to physical pain and treatment varied by type and characteristic of the cancer, the child's developmental stage, and coping style.

A study by Ljungman, Gordth, Sorensen, and Kreuger¹⁴ found that 49% of children experienced cancer-related pain at diagnosis with three persistent treatment problems of mucositis, abdominal pain, and neuropathic pain in the legs. Three studies, two retrospective and one prospective, identified pain as a major distressing symptom.^{15,16,17} **Nausea and vomiting** are less common though sometimes more difficult to manage than pain.^{4,16,18,19} Kohler²⁰ found that 50% of children experienced **constipation** and **anorexia**. **Fatigue** and **sleep loss** are also frequent problems among this pediatric cohort^{4,16,21,22} as well as **dyspnea, breathlessness,**⁵ **nosebleeds, seizures** and diarrhea.^{4,19,23,24}

Symptoms experienced by children undergoing cancer treatment rarely occur in isolation and symptom prevalence is expected to increase as the cancer progresses causing eventual death.²⁵ In a widely cited study, Wolfe, Grier, Klar, Levin, Ellenbogen, Slame-Schatz, Emanule, and Weeks²⁶ found that parents of children with advanced cancer most commonly reported their child suffered from fatigue, pain, and dyspnea in the last month of life. Wolfe et al.'s study²⁶ included English-speaking parents. Ninety-one percent of the sample were Caucasian. Wolfe and colleagues conducted a retrospective follow up to their study in 2000. The study involved a chart review of 119 children whose death was associated with cancer. Parent surveys were also collected. Only English-speaking families and individuals who lived in the U.S. were included; race/ethnicity was not specified. Commonly reported physical symptoms included pain, dyspnea, and fatigue. Collins et al.¹⁶ conducted a cross-sectional study of children aged 10 to 18 years and discovered that the most common advanced cancer physical symptoms were low energy, pain, drowsiness, nausea, cough, and lack of appetite.

Both clinical reports and research data have found that symptom clusters can significantly impact a child's functioning.^{2,3,27,28} Moody, Meyer, Mancuso, Charlson and Robbins²⁹ conducted a qualitative study of 31 pediatric oncology patients ages 5 to 21 years to explore the effects of cancer on children's functioning. The sample included a diverse population consisting of 41% Caucasian, 41% Latino, 12% Asian, and 6% African American children. The data analysis yielded frequent reports of physical discomfort, particularly experiences of pain and disability, as well as decreased pleasure for food. In addition, pain experiences were a source of primary concern for these children as were difficulties with the enjoyment of typical childhood activities.

Limitations in symptom research have been reported. Baggott and colleagues² conducted a systematic review of multiple symptoms studies including pediatric oncology patients ages 0 to 22 years where the mean age of participants was 12.74. Subject race/ethnicity was not specified. They asserted that although there has been an increase in studies assessing multiple symptoms in pediatric oncology patients, research in this area is scarce and in need of improvement. Suggested areas of focus included changes in symptoms across time; better understanding of symptom trajectories; inclusion and exploration of contextual and demographic characteristics such as age, gender, and ethnicity; the relationship between symptoms; and functional outcomes such as quality of life. In addition, Gedaly-Duff, Lee, Nail, Nicholson, and Johnson³⁰ conducted a pilot study involving 9 children aged 8 to 18 years and found that sleep disturbances have a bidirectional relationship with pain and fatigue. This team highlighted the importance of examining symptoms over time, exploring

the relationships between symptoms, and investigating the impact of symptom clusters on children's outcomes in an effort to develop appropriate interventions.

In summary, while there is a body of literature about symptoms in children with cancer, there are few that involve direct reports from children. Many of the studies are retrospective rather than prospective and are derived from chart reviews or from parents following death of their child. No studies were found comparing child and nurse symptoms reports.

Theoretical Framework

The conceptualization for this study is based on the University of California San Francisco Symptom Management Model³¹ as revised.³² This model has three dimensions: the symptom experience, symptom management strategies, and symptom outcomes all of which are connected and influenced by the interrelated paradigms of person, health/illness and environment. The symptom experience includes description of symptoms, evaluation of symptoms and response to the symptoms. This manuscript focuses on the symptom experience dimension as reported by children with advanced cancer and their nurses during hospitalization, clinic visits or at home.

Methods

The study used a prospective, longitudinal design using child self-report and nurse reports. Four facilities in southern California participated, and children were identified at each site by a designated health professional. Criteria for inclusion were 6- to 17-year-olds with leukemia non-responsive to treatment or relapsed, Stage IV solid tumor that had recurred or progressed as defined by bone marrow or radiographic studies, and English or Spanish speaking. Children with known developmental level below 6 years, another chronic illness associated with pain, or a new diagnosis of cancer were excluded. Children were interviewed while in the hospital, clinic or home.

Instruments

Memorial Symptom Assessment Scale^{16,25} (MSAS)—The MSAS is used to evaluate the presence, frequency, severity (all ages), and distress (ages 10–18 yrs) for each of 30 symptoms in children age 6 to 18 years. Subscales include physical symptom subscale (PHYS), psychological symptom subscale (PSYCH), and global distress index (GDI). For each endorsed symptom, the child is asked to rate the frequency, severity, and distress. Higher scores indicate greater frequency (1="rarely," 2="occasionally," 3="frequently," 4="almost constantly"), severity (1="mild," 2="moderate," 3="severe," 4="very severe") or distress (1="not at all," 2="a little bit," 3="somewhat," 4="quite a bit," 5="very much). Each symptom score is an average of the three dimensions, and the subscales include physical (PHYS), psychological (PSYCH), Global Distress Index (GDI) as well as a total MSAS (T-MSAS) score that is the average of the symptom scores for all 32 symptoms. Cronbach alpha coefficients for internal reliability have ranged from 0.76 to 0.87. Convergent and discriminate validity were confirmed by significant correlations ($p > 0.05$) with other measures of symptoms. Construct validity was shown by a significant relationship ($p > 0.05$) with anti-emetic and analgesic administration. The Spanish translation of the MSAS has been used with adults who were hospitalized medical-surgical patients.³³ For this study, four Spanish-speaking research assistants examined the Spanish version of the MSAS to establish face validity for use with a Spanish-speaking pediatric cancer population. During completion of this measure by children in this study, the children showed no difficulty in responding.

Common Toxicity Criteria—Revised³⁴ (CTC—Revised)—The CTC—Revised is a measure of chemotherapy adverse effects, which is widely used in clinical trials, and includes 24 categories of possible chemotherapy-related adverse effects. The term “toxicity” is used for historical purposes, but the use of “adverse event” (any unfavorable symptom, sign, or disease) is recommended. The CTC, v2.0 is a means for adverse event reporting. Each adverse event item is rated from 0 to 4 with higher score indicating worsening condition (0 = none/within normal limits, 4 = life-threatening or disabling) and a rating of 5 indicating “Death related to adverse event.” According to the CTC Manual, independent researchers made an effort to report additional adverse event items identified in their studies following the development of the original version of the CTC. The Common Toxicity Criteria Review Committee subsequently created the CTC, v2.0 to improve the standardization of this measure with inclusion of relevant items. Reliability and validity information was not available from NCI at this time.

Data Collection Procedure

Approval to conduct research with human subjects was obtained from the institutional review board of each facility, consent was obtained from parents, and assent was obtained from the children. Two (2) to three (3) research assistants conducted the interviews at each of four (4) sites. Training included review of a training manual, role play with the principal investigator, and completion of a child interview with supervision. All subjects entered the study while in the hospital or clinic setting and after voluntarily agreeing to participate. Research assistants obtained demographic data from the child and from the medical record and children independently completed the MSAS questionnaire. Subjects were asked to complete 10 interviews scheduled at 2-week intervals during a 5-month period. The 5-month duration of this study was determined by talking with nurses and physicians working with this population, as there were no prior studies indicating the optimal timing. The data were collected every 2 weeks to adequately address the research question and to avoid undue subject burden. Data collection took place during pre-arranged appointments in the hospital, clinic, or home setting. Research assistants did not proceed with data collection if the child was too tired or ill at the time of each interview.

The child provided the self-report data on the MSAS, which was audio-taped. The parent(s) remained present during this interview if he/she chose. The child received a token of appreciation by the interviewer after each interview. The child’s designated nurse documented the child’s symptoms on the CTC within 24 hours.

Data Analysis

Data were entered using double data entry for accuracy. SPSS® was used to obtain descriptive statistics, exploratory factor analysis (EFA), and standard parametric inferential tests. EQS® was used for confirmatory factor analysis (CFA). HLM6® was used for all growth curve modeling. Following a descriptive report of participant characteristics, statistical procedures were used to select and consolidate symptom variables. This was necessary, not only to develop and confirm expectations of how symptom variables would group, but also to reduce the number of variables to enhance parsimony of interpretation. MSAS symptoms were first selected based on prevalence. Matching symptoms from the CTC were then identified and selected for use. Based upon *a priori* expectations, a common measurement model for both sets of corresponding symptoms was tested using CFA (see Figure 1 for illustration of model tested).

Descriptive and comparative statistics were obtained for the resulting composite symptom variables. Having established the variable set, t-tests were used to analyze differences in symptoms by gender, age groups (6–12 years and 13–17 years), ethnic groups (Latino and

Caucasian), and survival status at the end of the study (surviving or deceased). Growth curve modeling of symptoms over time was then conducted. Following the establishment of a single trajectory over time for each symptom for all participants, tests for differences in curves by gender, age, ethnicity, and survival status groups were also completed.

Results

Participant Characteristics

Sixty-nine children were approached for participation in this study and 64 consented; however, four children died before participating. Only five parents/children refused due to reluctance for long term involvement in a study and concern regarding their children's reaction to discussing their symptom experience. Each of 60 children completed between 1 and 10 interviews. Demographic characteristics and types of cancer are summarized in Table 1. Gender, age groups, and survival status categories were relatively balanced in size. Only two ethnic categories, Latino and Caucasian, contained enough subjects to enable group-based analyses. Data from the four sites showed no differences based upon gender, age groups, ethnicity, or survival status; however, differences based upon types of cancer were significant (Chi-square [12] = 24.42, $p = .018$). Half of the participants were deceased at the end of the study. All subjects diagnosed with ALL were alive at the end of their participation in this study whereas all children diagnosed with AML and brain tumors were deceased, and there was a 50% chance that children diagnosed with rhabdomyosarcoma and other less common cancers were still living at the conclusion of their participation. Full symptom prevalence data were available for 59 of the 60 participants, and the number of interviews varied by patient (range = 1 to 10 interviews, $M = 6.1$).

Symptom Variable Prevalence

The fifteen most prevalent symptoms reported on the MSAS were selected for further analyses. All other symptoms occurred in less than 25% of the sample. These symptoms are listed in the order of prevalence in Table 2. Pain, nausea, drowsiness and energy loss were reported in over 50% of the interviews. The percentages associated with each MSAS symptom represent the average percentage that each symptom was reported by each child across all interviews.

In addition, the fifteen symptoms from the CTC that corresponded with those reported in the MSAS also were selected for further evaluation. Symptom prevalence for each CTC symptom is reported beside the matching MSAS symptom in Table 2. The greatest difference between the child and nurse ranking occurred for the symptom of pain (56% prevalence on MSAS vs. 23% prevalence on CTC).

Symptom Variable Grouping

In order to confirm expected symptom factor structure, a conceptual measurement model that defined four groupings of individual symptom variables was created and tested using confirmatory factor analysis (CFA). This model was tested separately for child self-reported (MSAS) and nurse-reported (CTC) symptoms. The four latent constructs and their associated symptoms were 1) **emotional** (sad/depressed, worried/anxious, irritable), 2) **gastrointestinal** (GI) (loss of appetite, nausea, vomiting and weight loss), 3) **pain and fatigue** (pain, lack of energy/weakness, drowsiness/fatigue, sleep loss, itching, and headaches), and 4) **hair and skin** (hair loss and skin changes). Resulting standardized path coefficients of the two CFA's are reported in Figure 1. With one exception (a single cross-loading from the pain and fatigue construct to the skin changes variable for the CTC model), *a priori* models provided good fit to the data for both the MSAS and CTC data (CFI = .97 and .99, RMSEA = .07 and .07). Given that the four categories were supported by the CFA,

composite variables were created by averaging the symptoms intensity ratings in each category. Finally, though the CFA supported the combination of pain and fatigue, these two constructs were subsequently separated to enable more direct comparison with results. This separation is consistent with clinical and empirical literature. The *pain* construct was designated from the symptoms pain, itching, and headaches while the *fatigue* construct was formed from the symptoms lack of energy/weakness, drowsiness/fatigue, and sleep loss. Subsequent comparative and growth curves analyses were conducted on five rather than four constructs from each symptom inventory (MSAS and CTC).

Descriptive Statistics for Study Variables

For the purpose of preliminary screening and basic descriptive statistics, scores from all symptom variables were averaged across all interviews for each participant. Descriptive statistics for the ten categorical symptom variable groups (five from the MSAS and five from the CTC) are reported in Table 3. Distributions from all variables were visually evaluated for normality. Symptom scores tended to be slightly to moderately skewed positive. No variables exhibited truncated range, and no univariate outliers were observed.

MSAS vs. CTC

Results indicated that there were significant differences between symptoms reported by children on the MSAS as compared to the nurse report of symptoms on the CTC. Though statistical tests for differences were deemed inappropriate given that scale anchors are not identical, the anchors are conceptually similar. A graphic representation of the mean differences between MSAS and CTC symptom intensity (see Figure 2) is presented as evidence that, while all symptom intensity levels were approximately equal in four of the five constructs, children are self-reporting (MSAS) higher levels of pain compared to reports by their nurses caring for them (CTC).

Group Differences in Average Symptom Levels

Differences in symptom intensity were tested by gender, age, ethnicity, and survival status, both for self-report (MSAS) and nurse report (CTC). Results are reported in Table 4. Only a single difference was observed for gender (males self-reporting higher GI symptoms) and ethnicity (nurses reporting higher levels of pain for Caucasians). For age groups, those older (13–17) self-reported higher levels of pain and fatigue than those younger (6–12), and nurses also reported higher levels of pain for the older group. An interesting pattern was observed in reference to survival status. While the two groups self-reported similar levels of symptoms (with the exception of GI symptoms), nurses reported significantly higher symptom levels for the deceased group in four of the five symptom categories (hair and skin being the exception).

Symptoms over Time: Growth Curves Analyses

Growth curves were analyzed using HLM6® to calculate regression intercepts and slopes for each individual's symptom intensity levels across multiple interviews. Results for the level one model across all participants (β_{00} intercept and β_{10} slope) and the level two models testing group differences (β_{01} differences in intercept and β_{11} differences in slope) by gender, age, ethnicity, and survival status are reported in Table 5. Intercepts represent the starting point of each symptom trend over interviews (time) while slopes indicate the direction and magnitude of change in symptom intensity over time. Significance in intercept (β_{00}) indicates that the starting point for symptom intensity is greater than zero (zero reflecting no presence of the symptom). Significance in slope (β_{10}) indicates the symptom intensity changes significantly over time. Significant differences in intercept (β_{01}) or slope

(β_{11}) between groups suggest that the groups compared differ in either their starting points or their symptom trajectories (slopes).

As expected, all level one intercepts were significantly different from zero, demonstrating that the children and their nurses report significant symptom presence for all five symptom groups. Symptom slopes are not all significant. Based upon child self-report, emotional, GI, and hair/skin symptoms decreased significantly over time in treatment. MSAS pain and fatigue intensity did not increase or decrease significantly. Across all participants, nurse symptom reports from the CTC did not result in a significant slope, positive or negative, for any of the symptom constructs.

Level two tests of between group differences resulted in relatively few significant results. MSAS self-report differences were seen for the intercepts of emotional and fatigue symptoms between younger and older groups (with older groups starting at a higher level), the intercepts of GI symptoms between genders (males being higher), and pain intercepts between ethnic groups (with Caucasians being higher). No significant slope differences for self-reports were observed. From the nurse reports (CTC), significant differences for intercepts were observed between those surviving and those deceased by the end of the study for emotional and fatigue symptoms (with higher starting points for those deceased). Nurses also registered a difference in slope between these groups for the hair and skin symptoms (with those deceased having a higher, positive slope indicating an increase in these symptoms). CTC reports also resulted in significant differences in intercepts by ethnicity for GI symptoms (Latinos higher) and pain symptoms (Caucasians higher). Nurse reports also resulted in a significant difference in slopes by ethnicity for GI symptoms (Caucasians symptoms increasing more over time). Finally, a difference in intercept was noted between age groups for pain symptoms with the older group starting at a higher level.

Discussion

Pain, nausea, drowsiness, and energy loss were the most frequently reported symptoms by the children in this study. These symptoms are consistent with the findings of many in the literature. For example, Collins et al.¹⁶ and his colleagues discovered that low energy, pain, drowsiness, nausea, and lack of appetite were among the most common advanced cancer physical symptoms among children ages 10 to 18 while Hinds et al.²² found that fatigue was a common symptom. When the parents of children who died secondary to cancer-related causes were interviewed, Pritchard et al.¹³ found that the most concerning and commonly reported physical symptoms also included weakness, changes in appearance, and dyspnea.

While pain was identified as the most frequent and severe symptom by the children, it was ranked as much less frequent and severe by nurses. Nurses listed hair loss, drowsiness, nausea and appetite loss as the most frequently reported symptoms. This difference may be related to previous reports that parent and physician reports of a child's pain differ. It is also possible that the symptoms reported by nurses are more easily observable based on behavioral assessment whereas a child's pain could be camouflaged by a child's involvement in age-appropriate activities (e.g., watching TV, playing videogames) or sleep as a means of coping with pain.

Given the interest in symptom groupings in recent studies, an attempt was made to determine if the MSAS and CTC symptoms would collapse into similar groupings. Indeed, the data supported the presence of four symptom groupings: Emotional, Gastrointestinal, Pain and Fatigue, and Hair and Skin. While there has been an emerging interest in symptom groups/clusters, this is a fairly new area of study. Nursing science is interested in symptom

groupings because symptoms usually do not occur in isolation and can impact both symptom management and quality of life.^{29,27}

Pain and fatigue were examined independently during analyses because they are well-documented, both clinically and empirically, as separate symptoms. The possibility that a constant relationship exists between pain and fatigue merits further investigation. Gedaly-Duff and her colleagues³⁰ pilot findings, for example, point to a bidirectional relationship between sleep disturbance and both pain and fatigue. It is possible that an underlying link between these two symptoms exists thereby suggesting the importance of considering the treatment effect of one symptom on the other.

While both child and nurse reports yielded the same symptom groupings, an unexpected finding of consequence was that the children reported notably higher levels of pain severity and frequency. This disparity is consequential given that pain has been identified as a main problem in children with cancer. Further, nurses often base pain management decisions on children's report of pain. A possible explanation is a function of the study procedure. The child reported current levels of pain on the MSAS whereas nurses provided information about the child's pain based on clinical judgment on the CTC.

There were very few differences in symptom experience by gender, age, and ethnicity. Specifically, male children reported a higher frequency of gastrointestinal symptoms compared to females. Future studies may elucidate the underlying mechanism for this finding. The older children (age 13–17 years) reported higher levels of pain and fatigue than their younger counterparts (age 6–12 years), and nurses also reported higher levels of pain for the older group of children. Developmentally, older children's ability to communicate is more mature and it is possible that they communicated their symptom experience more fully. Finally, nurses reported higher levels of pain for Caucasians. This finding begs further examination of questions regarding cultural and ethnic factors that impact children's symptom experience. The inclusion of homogeneous subject populations in studies has limited research opportunities to elucidate the symptom experience of diverse groups. Fifty-five percent of children who participated in this study were Latino and thirty percent were Caucasian. Additional information about race/ethnicity and cultural considerations based on this research data will be reported in another paper.

Half of the children in this study died during the five-month course of their participation. All of the children with AML and brain tumors died while those with ALL were still alive at the end of the study. The children were within the expected trajectory of the disease, and this outcome is consistent with literature regarding prognoses associated with these diagnoses.¹

Both children and nurses reported significant symptom presence for all symptom groups over time. It appears that while the presence of symptoms may have increased over time, symptom severity, fortunately, was being managed and actually decreased over time for all children. However, it was a surprising result that the children who died during the course of this study did not report increased symptom severity. While pain and fatigue frequency and intensity remained stable for all children, they reported a significant decrease of emotional, gastrointestinal, and hair/skin symptom groupings over time. Conversely, symptom groupings remained stable over time per nurse reports. It may be that the decrease in emotional and gastrointestinal symptom intensity and frequency is the result of effective management and intervention including medications and counseling. Findings that nurses made more observations about changes in physical appearance and reported less pain prevalence as well as lower pain severity compared to the children suggest that pain management is complex. This disparity may reflect a difference in nurse beliefs about the effectiveness of a child's pain management compared to the child's perception. It is also

plausible that children may feel less concerned about their changes in physical appearance (e.g., hair) as their cancer progresses, and their focus may shift to other symptoms that are perceived as more distressing. Another hypothesis about fatigue and energy loss is that these symptoms are difficult to manage given disease progression, and these symptoms may not be as obvious to care providers due to the children's participation in sedentary activities (e.g., watching TV). It is a standard procedure for nurses to assess and manage pain. Fatigue, by contrast, is less frequently assessed, and, if identified, interventions are generally not implicated except to recommend rest. Ultimately, a deeper understanding about the difference between child and health care provider symptom assessments is needed given implications for perceived quality of care and understanding, symptom management, and patient-provider communication.

This prospective study fills a gap in describing the symptom experience of children with advanced cancer from both the child and nurse perspective over a five month period or until the child's death. Nurses are the primary care providers in the hospital, and our findings show that most nurse symptom reports were similar to the child in our sample with the exception of pain intensity and frequency. It is important that a child's symptoms are clearly communicated to nurses and that nurses directly ask children about their symptoms. Furthermore, more than half of the children were male and half were Latino, a population that is underrepresented in research.

Despite the emotional burden and stress associated with advanced disease, parents and children who were approached for inclusion in this study expressed their willingness to participate and remained in the study with few exceptions. The research assistants were careful to inquire about a child's ability to participate prior to each interview, thus providing a comfortable atmosphere within which the interview could occur. Such studies can provide a means by which underrepresented populations and improved methodologies are better understood.

This study was limited to a single component (symptom experience) of the University of California San Francisco's Symptom Management Model.³¹ Our study provided an expanded examination of this component by including both child and nurse symptom reports. Study data will be examined for the purpose of investigating the interface of symptom manage and outcomes such as quality of life with other elements of the model.

While this study extends existing knowledge of the symptom experience from both the child and the nurse perspective, several limitations to the study are acknowledged. Missing data is a common occurrence and challenge when longitudinal studies are conducted. Measurement limitations also arose due to differences in the MSAS and CTC scale anchor descriptors. The graphic representation (Figure 2) supported our assumption that most symptom categories were nearly identical in reference to intensity with pain a clear exception. In addition, our findings are limited to one geographical area within the United States, and the sample was small, primarily consisting of Latino and Caucasian populations. Further, a broad developmental range and multiple diagnoses were included. Future studies that focus on a specific developmental group and specific diagnoses (e.g., brain tumors) will aid in better understanding pediatric oncology symptoms within specific contexts, thus guiding the ongoing refinement of interventions.

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Figure 1.
Confirmatory Factor Analysis Results for MSAS and CTC Symptom Factors.

Figure 2.
Symptom category.

Table 1Characteristics of the Sample ($N = 60$)

Variable	n	%
Gender		
Female	25	41.7
Male	35	58.3
Ethnicity		
African American	1	1.7
Asian	2	3.3
Latino	33	55.0
Caucasian	18	30.0
Other	6	10.0
Age		
6 to 12	31	51.7
13 to 17	29	48.3
Cancer Type		
ALL	14	23.3
AML	8	13.3
Brain Tumor	18	30.0
Rhabdomyosarcoma	7	11.7
Other	13	21.7
Site		
A	22	36.7
B	13	21.7
C	15	25.0
D	10	16.7
Mortality Status at End of Study		
Living	30	50.0
Deceased	30	50.0

Table 2

Prevalence Across all Interviews for 15 most frequently reported symptoms

Symptom	Self-Report MSAS			Nurse-Report CTC		
	Rank	Valid	%	Rank	Valid	%
Pain	1	60	56	14	59	23
Nausea	2	60	54	3	59	51
Drowsiness	3	60	52	2	59	67
Energy Loss	4	59	51	11	59	27
Appetite Loss	5	59	39	4	59	41
Weight Loss	6	59	36	9	59	38
Irritability	7	59	35	7	59	41
Hair Loss	8	59	34	1	59	69
Itching	9	59	33	13	59	25
Sadness	10	59	31	6	59	39
Skin Changes	11	59	31	5	59	39
Headache	12	59	31	12	59	26
Sleep Loss	13	60	31	10	59	32
Worry	14	59	28	8	59	39
Vomiting	15	59	28	15	59	23

Table 3

Descriptive Statistics for Symptom Intensity Variables					
Variable	N	Mean	SD	Minimum	Maximum
MSAS					
Pain	60	0.84	0.60	0.00	2.10
Fatigue	60	0.80	0.57	0.00	3.00
Gastrointestinal	60	0.74	0.59	0.00	2.75
Hair & Skin	60	0.65	0.68	0.00	2.83
Emotional	60	0.54	0.45	0.00	1.70
CTC					
Hair & Skin	59	0.82	0.53	0.00	1.83
Fatigue	59	0.75	0.61	0.00	2.56
Gastrointestinal	59	0.59	0.56	0.00	2.75
Emotional	59	0.48	0.51	0.00	2.00
Pain	59	0.33	0.31	0.00	1.16

Table 4

Independent Samples t-Tests For Gender/Age/Ethnicity

Variable	Gender		Age		Ethnicity		Status	
	t	p	t	p	t	p	t	p
MSAS								
Emotional	0.75	.461	-1.56	.124	-0.99	.327	-0.82	.414
Gastrointestinal	2.05	.045^b	-1.40	.166	0.57	.574	-2.97	.004^a
Pain	0.79	.432	-2.64	.011^b	-1.93	.060	-0.99	.328
Fatigue	1.53	.131	-2.34	.023^b	-1.13	.264	-0.43	.663
Hair & Skin	-0.57	.573	-0.09	.930	-0.10	.922	-0.73	.468
CTC								
Emotional	-0.88	.383	-0.09	.926	-0.99	.330	-3.95	<.001^a
Gastrointestinal	1.08	.286	-0.91	.369	0.84	.403	-3.23	.002^a
Pain	-1.35	.184	-2.24	.029^b	-2.49	.016^b	-2.38	.021^b
Fatigue	-0.49	.629	-0.17	.868	-1.67	.101	-2.90	.005^b
Hair & Skin	-0.15	.881	-0.05	.962	0.42	.674	-0.80	.427

^a Significant at <.01

^b Significant at < .05

Table 5
Growth Curves Coefficients for MSAS & CTC: Overall, & by Gender, Age, Ethnicity, and Status

Variable	Overall		Group 1		Group 2 Difference	
	Intrept.	Slope	Intrept.	Slope	Intrept.	Slope
MSAS						
Emotional	0.71^a	-0.03^a				
Male to Female	0.72 ^a	-0.03 ^a	0.72 ^a	-0.03 ^a	-0.05	-0.01
Younger to Older	0.72 ^a	-0.03 ^a	0.72 ^a	-0.03 ^a	0.43 ^a	-0.05
Latino to Caucasian	0.74 ^a	-0.03 ^a	0.74 ^a	-0.03 ^a	0.12	0.01
Surviving to Deceased	0.71 ^a	-0.03	0.71 ^a	-0.03	-0.09	0.04
Gastrointestinal	0.94^a	-0.05^a				
Male to Female	0.94 ^a	-0.05 ^a	0.94 ^a	-0.05 ^a	-0.44 ^a	0.03
Younger to Older	0.94 ^a	-0.05 ^a	0.94 ^a	-0.05 ^a	0.20	-0.02
Latino to Caucasian	0.98 ^a	-0.05 ^a	0.98 ^a	-0.05 ^a	-0.38	0.05
Surviving to Deceased	0.92 ^a	-0.04 ^a	0.92 ^a	-0.04 ^a	-0.20	0.04
Pain	0.90^a	-0.02				
Male to Female	0.90 ^a	-0.02	0.90 ^a	-0.02	-0.04	-0.00
Younger to Older	0.90 ^a	-0.02	0.90 ^a	-0.02	0.28	0.02
Latino to Caucasian	0.95 ^a	-0.02	0.95 ^a	-0.02	0.43 ^a	0.02
Surviving to Deceased	0.90 ^a	-0.01	0.90 ^a	-0.01	0.05	0.01
Fatigue	0.84^a	-0.01				
Male to Female	0.84 ^a	-0.01	0.84 ^a	-0.01	-0.21	-0.01
Younger to Older	0.85 ^a	-0.01	0.85 ^a	-0.01	0.38 ^a	-0.03
Latino to Caucasian	0.90 ^a	-0.02	0.90 ^a	-0.02	0.06	0.03
Surviving to Deceased	0.83 ^a	-0.00	0.83 ^a	-0.00	-0.17	0.05
Hair & Skin	0.89^a	-0.06^a				
Male to Female	0.89 ^a	-0.06 ^a	0.89 ^a	-0.06 ^a	0.08	-0.00
Younger to Older	0.89 ^a	-0.06 ^a	0.89 ^a	-0.06 ^a	-0.09	0.02

Variable	Overall		Group 1		Group 2 Difference	
	Intcpt.	Slope	Intcpt.	Slope	Intcpt.	Slope
Latino to Caucasian			0.95 ^a	-0.06 ^a	-0.09	0.02
Surviving to Deceased			0.88 ^a	-0.05 ^a	-0.12	0.05
CTC						
Emotional	0.47^a	0.00				
Male to Female			0.46 ^a	0.00	0.05	0.01
Younger to Older			0.46 ^a	0.00	0.18	-0.03
Latino to Caucasian			0.47 ^a	-0.00	-0.06	0.04
Surviving to Deceased			0.46 ^a	0.01	0.41 ^a	0.01
Gastrointestinal	0.67^a	-0.02				
Male to Female			0.67 ^a	-0.02	-0.38	0.05
Younger to Older			0.67 ^a	-0.02	0.21	-0.02
Latino to Caucasian			0.70 ^a	-0.02	-0.52 ^a	0.07 ^a
Surviving to Deceased			0.66 ^a	-0.01	0.26	0.04
Pain	0.34^a	-0.00				
Male to Female			0.34 ^a	-0.00	0.10	0.00
Younger to Older			0.34 ^a	-0.00	0.24 ^a	-0.02
Latino to Caucasian			0.33 ^a	-0.00	0.33 ^a	-0.02
Surviving to Deceased			0.34 ^a	-0.00	0.18	-0.00
Fatigue	0.68^a	0.01				
Male to Female			0.68 ^a	0.01	0.14	-0.02
Younger to Older			0.68 ^a	0.01	-0.06	0.02
Latino to Caucasian			0.65 ^a	0.01	0.25	0.01
Surviving to Deceased			0.68 ^a	0.02	0.44 ^a	0.01
Hair & Skin	0.84^a	-0.00				
Male to Female			0.84 ^a	-0.01	0.07	-0.01

Variable	Overall		Group 1		Group 2 Difference	
	Intcpt.	Slope	Intcpt.	Slope	Intcpt.	Slope
Younger to Older			0.83 ^a	-0.00	0.17	-0.03
Latino to Caucasian			0.82 ^a	-0.00	0.04	-0.02
Surviving to Deceased			0.83 ^a	0.00	-0.18	0.07 ^a

^aSignificant at <.05