Pediatric Education Discharge Support Strategies for Newly Diagnosed Children With Cancer

**KEY WORDS**
Pediatric oncology
Nursing
Nursing research
Magnet

**Background:** Discharge education practices vary among institutions and lack a standardized approach for newly diagnosed pediatric oncology patients and their parents. **Objective:** The purpose of this American Nurses Credentialing Center–supported pediatric multisite trial was to determine the feasibility and effectiveness of 2 nurse-led Parent Education Discharge Support Strategies (PEDSS) for...
families with a child who is newly diagnosed with cancer. **Interventions/Methods:** A cluster randomized clinical trial design assigned 16 Magnet-designated sites to a symptom management PEDSS intervention or parent support and coping PEDSS intervention. Outcome measures evaluated at baseline, 1, and 2 months after diagnosis include symptom experiences, parent perceptions of care, unplanned service utilization, and parent evaluation of the PEDSS interventions. **Results:** There were 283 newly diagnosed children and their parent participating in this study. Linear mixed models revealed pain differed over time by the intervention; children in the symptom management group had a greater decrease in pain. Greater nausea and appetite disturbances were experienced by older children in both groups. Fatigue and sleep disturbance showed a significant decrease over time in both groups. The symptom management group reported significantly greater satisfaction with the PEDSS intervention. **Conclusions:** This study is among the first to examine the effects of 2 different early-discharge planning strategies for families of a newly diagnosed child with cancer. The evidence supports a standardized discharge education strategy that can be successfully implemented across institutions. **Implications for Practice:** Nurses play a major role in the educational preparation and discharge of newly diagnosed pediatric cancer patients and their families.

More than 11,000 children in the United States younger than 15 years will be diagnosed with cancer in 2020. Parents of a child newly diagnosed with cancer receive extensive information before their child is discharged; however, little is known about best practices for providing this education and the effectiveness of standardized content. Parents often report difficulty with the complexity of information and are overwhelmed, particularly regarding physical care needed at home for their child. Furthermore, there is a lack of standardized educational content and approach to education delivery for newly diagnosed pediatric oncology patients and their parents across institutions. This results in considerable variability in the delivery of critical education, including symptom assessment and management content, leading to parental concerns regarding their ability to appropriately care for their child at home. A nursing qualitative study found that parents reported the fast pace and large quantity of information during the initial hospitalization as stressful; they reported that strategies such as having written information, keeping information concise on key topics, and receiving anticipatory guidance so they knew what to expect would be helpful. Parents can be overwhelmed with numerous adverse effects their child experiences at home and lack knowledge on how to appropriately manage treatment-related symptoms while coping with the new diagnosis of cancer.

While a cure for childhood cancer over the last 3 decades has increased to greater than 80%, efforts to manage cancer treatment symptoms struggle to keep pace. Symptom toxicity during pediatric cancer treatment often results in complications, treatment delays, and therapy dose reductions. Children with cancer often experience multiple symptoms from their disease and treatment. Pain, fatigue, sleep changes, nausea, appetite changes, and fever are the most frequently reported physical symptoms (prevalence >30%) during childhood cancer treatment. Children with cancer report treatment-related symptoms as the worst part of treatment, creating difficulties in completing daily activities and resulting in difficult memories long after treatment has ended.

To increase the understanding of the impact of early discharge education for parents of a child newly diagnosed with cancer, the nurse-led Parent Education Discharge Support Strategies study was developed and implemented. The PEDSS study is a cluster randomized controlled trial to assess the effectiveness and feasibility of 2 interventions, a symptom management strategy or support and coping strategy, created to educate parents prior to the child’s initial hospital discharge.

### Methods

Study sites were recruited by the American Nurses Credentialing Center, which sent out a call for Magnet-designated institutions interested in participating in the PEDSS study. Each of the 16 Magnet-designated institutions that applied was cluster randomized to 1 of the 2 PEDSS intervention groups. The first intervention arm provided symptom management strategies that included a worksheet describing the most commonly experienced treatment-related physical symptoms, strategies to reduce symptom distress, and when and how to contact the cancer team (Figure 1). The second intervention arm provided support and coping strategies accompanied by a worksheet.
Figure 1  ▪ Symposium management worksheet.

(Figure 2) with material adapted from the American Cancer Society regarding dealing and coping with a new cancer diagnosis.19 Content validity of the worksheets was established from the literature and confirmed by 4 pediatric oncology nursing experts.12,13 In both PEDSS intervention groups, nurses reviewed and discussed content with participants prior to the first hospital discharge and at study assessment visits.

Each institution participating in the study had a nurse principal investigator (PI) responsible for the study at their facility. Initial PI site training occurred virtually with the overall study PI and study coordinator and guided by standardized content based on the study protocol, including eligibility, consent procedures, intervention delivery, and data collection. Site PIs also completed a one-on-one check-off using a standardized checklist for obtaining consent and delivering the intervention through a simulation led by the study PI or designee. Site PIs, after completing formal training, were responsible for conduct of the study at the clinical site including engaging and training study nurses, enrolling subjects, obtaining consent, and supervising or coordinating data collection. A total of 98 nurses across all study sites participated in the PEDSS study; a range of 1 to 16 nurses with a median of 7 nurses per site were involved. All site nurses received formal training on how to obtain informed consent and deliver the intervention; annual return demonstrations of both the consent and intervention delivery were completed with the site PI. Details describing fidelity of the study implementation methods were recently published.19,20

The interventions were supplementary to preexisting educational practices at each site, which remained unchanged. A previous publication reported the PEDSS intervention was easily

| What to look for... | What to do... |
|---------------------|---------------|
| **FEVER**           |               |
| Fever               | * Be prepared to go to clinic or hospital |
|                     |               |
| **PAIN**            |               |
| New pain            | * Give pain medication as directed |
| Pain not getting better with usual methods | * Try relaxation or distraction |
| Irritability or restlessness |               |
|                     |               |
| **NAUSEA**          |               |
| Not able to drink fluids or not urinating | * Give nausea medications as directed |
| Not urinating/peeing | * Try relaxation or distraction |
| Not able to take oral meds | * Offer small frequent meals throughout the day |
| Upset stomach       | * Avoid foods with a strong smell |
| Feeling the need to vomit/throw up/puke | * Avoid very sweet, greasy, or spicy foods |
|                     | * Ask your child to drink small sips of fluid during the day |
|                     | * Do not force your child to eat |
|                     |               |
| **APPETITE CHANGES: WEIGHT LOSS** |               |
| Not able to drink fluids | * Offer small amounts of foods throughout the day |
| Not urinating        | * Offer high calorie drinks like milk or smoothies |
| Not wanting to eat   | * Talk to dietician for high calorie food suggestions |
| Feeling full after few bites | * Add butter, oil, cheese, peanut butter to foods |
| Taste changes or no taste with food | * Use plastic utensils if food tastes like metal |
|                     | * If food has no taste, add spices or seasoning |
|                     |               |
| **APPETITE CHANGES: WEIGHT GAIN** |               |
| Increased appetite/feeling hungry | * Allow your child to eat when hungry |
| Change in appearance (face and stomach) | * Provide healthy food choices |
| Food cravings        | * Talk to dietician for food suggestions |
|                     |               |
| **FATIGUE**         |               |
| Difficult to wake up, confusion, not responding | * Encourage daily exercise (such as walking) |
| Lethargy, feeling tired | * Drink fluids throughout the day |
| Feeling weak         | * Offer different kinds of foods |
| No energy to do things | * Make sure your child gets enough sleep at night |
| Not able to concentrate or think clearly | * Put your child to bed at the same time every night |
|                     |               |
| **DIFFICULTY SLEEPING** |               |
| Difficulty falling asleep | * Encourage quiet activities right before bedtime |
| Difficulty staying asleep | * Put your child to bed at the same time every night |
| Waking often during the night | * Prevent sleep interruptions during night |
| Not feeling rested when you wake | * Keep room dark and quiet while sleeping |
|                     | * Turn off electronics at bedtime |

* Clinic: __________

* After hours: __________
Support for Parents and Caregivers

When a child is diagnosed with cancer, the entire family is affected. This worksheet has suggestions about caring for yourself during this time. If you have concerns, please let us know and we can contact professionals to help you.

| Topic                | Other families found it helpful to...                                                                 |
|----------------------|---------------------------------------------------------------------------------------------------------|
| Expect changes       | • Talk to your other children about changes in their normal routine                                     |
|                      | • Talk to a social worker about leave of absence from work and other available resources               |
|                      | • Ask relatives and friends to help you                                                                  |
| Help from the cancer team | • Write out your questions for the doctor or nurses                                                  |
|                      | • Talk about your concerns with the members of your child’s healthcare team                            |
|                      | • Consider going to parent support groups                                                               |
| Take care of yourself | • Consider some form of exercise, such as walking                                                      |
|                      | • Make sure you are eating regularly                                                                   |
|                      | • Continue to take your medications                                                                    |
|                      | • Keep up with your scheduled doctor’s appointment                                                      |
|                      | • Participate in relaxing activities, such as meditation                                                |
| Involve your child   | • Explain the diagnosis and treatment in words your child can understand. Ask for help                 |
|                      | • Encourage your child to share his/her feelings by talking, writing, or playing                        |
|                      | • Answer questions when your child is asking for information                                             |
| Involve others       | • When you are ready, share information with others                                                    |
|                      | • Encourage family members to share their thoughts and emotions                                         |
|                      | • Ask for help                                                                                         |

Figure 2 ▪ Coping and support worksheet.

integrated into their institution’s existing work processes and nursing education practices. Sites reported the PEDSS intervention complemented current nursing education discharge practices. Site PIs expressed that the intervention provided a concise, parent-friendly document, focused on symptoms or support for the patient and family they otherwise would not receive.

Study assessments were used to assess symptom severity at the time of assessment and occurred at 3 time points: prior to hospital discharge after initial diagnosis, 1 and 2 months postdischarge. Patient pain, nausea, appetite changes, fatigue, and sleep disturbances were self- or parent-reported through web-based tools. Parents shared information regarding their comfort in providing care after discharge and the feasibility of the intervention and use in the home. Outcome measures also included unplanned service utilization and feasibility and fidelity evaluation of the worksheets.

Inclusion criteria for the study included a parent, legal guardian, or caregiver of a patient aged 3 to 17 years who was newly diagnosed with any type of malignant disease on an inpatient oncology unit. The parent and child needed to speak English, Spanish, or Arabic because of the worksheets and questionnaires being available only in those languages. Children with cognitive disabilities were not eligible to participate. All study procedures were approved by the institutional review board of the primary site or site-specific institutional review boards prior to enrollment.

Measures

Data were collected through a web-based data collection tool administered through a computer or iPad and downloaded through a secure server. Children newly diagnosed with cancer frequently
need to return to the clinic and/or the hospital for further care during their treatment protocol, making subsequent data collection time points feasible. Study personnel at each institution obtained demographic information on each participant from the medical record after consent was obtained, and information was entered into the web-based system. Additional information was obtained from the child, adolescent, or parent (if the child was <7 years old). An overview of evaluation measures is listed in Table 1. Outcome measures evaluated at baseline prior to discharge and 1 and 2 months after diagnosis included symptom experiences at the time of assessment (pain, fatigue, sleep, nausea, appetite), parent perceptions of care, and feasibility and fidelity evaluation of the worksheets.

SYMPTOM ASSESSMENT

All symptoms were measured for severity at the time of assessment at each time point: at the initial hospital discharge (time 1) and at 1 and 2 months (times 2 and 3) during clinic or hospital visits following the initial hospital discharge. Subjects 7 years or older were asked to rate their symptoms, and parent proxy was used for children younger than 7 years.

Pain was measured using the Wong-Baker Faces Scale. This tool is an extremely reliable and valid tool used for more than 30 years to evaluate pain in children as young as 4 years of age.22

Nausea was measured using a visual analog scale (VAS) in the form of a thermometer that rates the severity of nausea from 0 to 100. The VAS includes a statement at each end representing one extreme of the dimension being measured (eg, no nausea). The VAS is widely used and is noted for ease of administration.23,24 To maintain consistency with all symptom measures, a parent proxy was used for children younger than 7 years.

Appetite changes were measured with the Simplified Nutritional Appetite Questionnaire. The Simplified Nutritional Appetite Questionnaire is a 4-item scale asking subjects to select 1 of 5 answers representing the child’s appetite. Answers are tallied on a numerical scale (a = 1, b = 2, c = 3, d = 4, e = 5). Results range from 4 to 20, with higher scores indicating better appetite and a score of 14 or lower indicating severe appetite changes.21 Subjects 7 years or older were asked to answer the appetite questions, and parent proxy was used for children younger than 7 years of age. The tool has established reliability and validity.25

Fatigue was measured with the Adolescent Fatigue Scale (AFS) for adolescents 13 to 18 years of age, the Childhood Fatigue Scale (CFS) for children 7 to 12 years of age, or the Parent Fatigue Scale (PFS) to obtain proxy responses from parents of children younger than 7 years. The AFS is a 13-item self-reported scale measuring fatigue and intensity on a 4-point Likert scale. Ratings range from 0 to 52; recent work using Rasch methods identified a cutoff score of 31 for severe fatigue.24 The AFS subscales (function, energy, and mood) were used to further define the symptom. The CFS is a 10-item questionnaire assessing the experience of fatigue-related symptoms. The participants are asked to rate how much they are bothered by fatigue on a 4-point Likert scale ranging from “not at all” to “a lot.” Scores range from 0 to 40; recent work using Rasch methods identified a cutoff score of 12 for severe fatigue.26 The PFS is a 17-item scale assessing parent perception of fatigue experienced by their child. Scores range from 0 to 68, with a cutoff PFS score defining severe fatigue as 41 or greater. Three subscales of the AFS, CFS, and PFS (function, energy, and mood) were used to further define the symptom. Each scale has established validity and reliability.27–30

Sleep disturbances were measured using subscales of the Sleep-Wake Scale (SWS)–self-report for subjects 7 years or older and SWS–parent report for subjects younger than 7 years. Both instruments include 5 subscales including going to bed, falling asleep, maintaining sleep, going back to sleep, and returning to wakefulness. The SWS–self-report includes 28 items (5–6 items per subscale) and uses a 6-point Likert scale. The SWS–parent report includes 26 items (5–6 items per subscale) rated on a 6-point Likert scale.29,30 Ratings are calculated as a mean score for each subscale, ranging from 1 to 6, with higher scores indicating better sleep quality. Both scales have established reliability and validity.31–33

UTILIZATION OF HEALTHCARE SERVICES

At 1 and 2 months following diagnosis, the nurse or research assistant entered the number of unscheduled clinic visits, emergency room visits, and unplanned hospitalizations in the web-based data collection tool based on information in the medical record.

FEASIBILITY

Key indicators of successful program implementation included education on the PEDSS worksheets at discharge, use of the worksheets, and satisfaction with the worksheets. Parental use...
and satisfaction with worksheets were evaluated by self-report from parents at 2 months post-hospital discharge. Self-report feasibility questions asked parents to rate 6 statements regarding ease of use, readability, quickness of use, enjoyment, helpfulness, and program recommendation on a 5-point Likert scale. Higher scores indicate more satisfaction with the intervention. Questions were based on an acceptability tool developed for other symptom management interventions.34,35

**Statistical Analyses**

Bivariate analyses were conducted to compare the intervention group’s demographics and patient characteristics (age, gender, ethnicity/race, and patient diagnosis). To examine the effect of the interventions on childhood cancer symptoms during the first 2 months following the initial hospital discharge, linear mixed models (LMMs) were used. Because participants were randomized at the site (ie, institution) level rather than at the individual level, these models consisted of 3 levels: level 1—repeated measures; level 2—individuals; and level 3—sites. To address selection bias at the individual level that may have occurred because of site-level randomization, inverse probability of treatment weighting was implemented in LMM models.36 Inverse probability of treatment weighting is a propensity score method designed to reduce such selection bias.37–39 In LMM models, a time × intervention group interaction was used to examine whether the rate of change in the outcome over time depended on intervention group.

To examine change in parent perceptions of preparedness for care, dependent-samples t tests were used to test for change between time 1 and time 3. If this revealed significant change, linear regression models were used to regress change scores on intervention group and demographic and patient characteristics. To examine the effect of the interventions on unplanned utilization of healthcare services and preventable toxicity, we used χ² tests. In these, we tested the relationship between the intervention group and unscheduled clinic visits, emergency room visits, and unplanned hospitalizations at time 3. Differences in intervention evaluation (timing of intervention, frequency of intervention worksheet use, and where the intervention worksheet was placed) and intervention satisfaction by intervention group were tested using bivariate tests.

### Results

The 16 Magnet-designated institutions were part of the Children’s Oncology Group and were randomized based on the number of new pediatric cancer patients per year; large institutions had 35 new patients or more each year, and small institutions had fewer than 35 new patients each year. Four institutions were in each category split equally by small or large institution size and symptom or support group intervention. The 16 participating institutions were found throughout the northeast, southeast, and Midwest regions of the United States; 1 institution was in Saudi Arabia. There were 283 newly diagnosed children and their caregivers participating in this study; 120 enrolled in the support and coping groups and 155 in the symptom management group. Most children with cancer were school-age young adolescents (mean, 9.36 [SD, 4.47 years]; Table 2) and were fairly evenly distributed between males and females (44.88% female). Age and gender did not differ by intervention group (t = 1.23, P = .22; χ² = 1.71, P = 19).

Non-Hispanic White, Hispanic, and non-Hispanic Black persons constituted the majority of participants (56.54%, 19.08%, and 7.42%), although this makeup differed by intervention group (χ² = 12.59, P = .01), in that non-Hispanic White and Hispanic persons were more common in the support and coping groups (60.16% and 21.09%), and non-Hispanic Black persons were more common in the symptom management group (11.61%). Leukemia was the most common diagnosis (57.60%), along with lymphoma (18.02%) and solid tumor (20.14%), although this composition differed by group (χ² = 8.24, P = .04), in that leukemia was more common in the support and coping groups (66.41%). Using the pain assessment at time 1, 95% of children completed self-reports in English, 0.05% in Spanish, and 4.5% in Arabic. Using the parent perception survey, 94%
of parents completed questionnaires in English, 4% in Spanish, and 2% in Arabic.

There were 23 refusals (8%) to participate and 6 (0.16%) who were withdrawn from the study; 4 participants were discharged early before completing the baseline assessment and intervention, and 2 others consented then decided not to participate.

Linear mixed-models regressing symptoms over time × intervention group and patient characteristic covariates are present in Table 3. In predicting pain, the main effects for time and intervention were significant (b = 0.31, t = 1.98, P = .048; b = -0.40, t = -9.32, P < .001), indicating that pain symptoms were slightly higher at baseline in the symptom management group, and across groups, pain symptoms tended to decline over time. The interaction between intervention and time was also significant (b = -0.18, t = -2.98, P = .003), indicating that pain decreased over time more in the symptom management group. Patient characteristics were not significantly related to this outcome (age: b = 0.01, t = 0.92, P = .36; gender: b = 0.15, t = 1.38, P = .17; ethnicity/race: F = 1.59, P = .17; diagnosis: F = 1.22, P = .30).

For models of nausea, the main effects for time and intervention were not significant (b = -1.74, t = -1.44, P = .15; b = 3.23, t = 1.32, P = .19), and the interaction between these was not significant (b = 1.74, t = 1.08, P = .28). For this outcome, greater nausea was experienced by older-age children (b = 0.52, t = 2.04, P = .04); other patient characteristics were not significant (gender: b = -3.78, t = -1.57, P = .12; ethnicity/race: F = 0.37, P = .83; diagnosis: F = 0.62, P = .54).

In predicting appetite disturbance, the main effects for time and intervention and the interaction between these were not significant (b = -0.05, t = -0.32, P = .75; b = 0.59, t = 1.11, P = .27; b = -0.03, t = -0.14, P = .89). Older-age children experienced more appetite disturbance (b = -0.07, t = -2.12, P = .03). Diagnosis was associated with appetite disturbance (F = 6.10, P < .001), in that participants with leukemia reported less appetite disturbance than those with solid tumors (b = 1.36, t = -3.65, P < .001). Other patient characteristics did not significantly predict this outcome (gender: b = -0.08, t = -0.30, P = .77; ethnicity/race: F = 0.41, P = .80).

For fatigue, the main effect of time was significant (b = -3.24, t = -6.62, P < .001), indicating that fatigue symptoms decreased over time. The main effect for intervention and the interaction between time and intervention were not significant (b = -0.45, t = -0.47, P = .64; b = 0.71, t = 1.06, P = .29). Ethnicity/race was significant (F = 3.30, P < .01), in that Hispanic participants reported less fatigue than non-Hispanic White individuals (b = -3.51, t = -3.20, P < .001). Other participant characteristics were not significant (age: b = -0.09, t = -0.92, P = .36; gender: b = -0.52, t = -0.62, P = .54; diagnosis: F = 0.34, P = .80).

For sleep disturbance, the main effect of time was significant (b = -1.71, t = -4.02, P < .001), indicating that sleep disturbance decreased over time. The main effect for intervention and the interaction between time and intervention were not significant (b = -0.15, t = -0.13, P = .90; b = 0.01, t = 1.75, P = .08). Gender was significant, in that females reported less sleep disturbance than males (b = -2.21, t = -2.17, P = .03). Ethnicity/race was significant (F = 3.11, P = .01), in that Hispanic participants reported less sleep disturbance than non-Hispanic White persons (b = -3.36, t = -2.48, P = .01). Other participant characteristics were not significant (age: b = -0.08, t = -0.69, P = .49; diagnosis: F = 1.41, P = .24).

Paired t tests examining change in parent perceptions of preparedness to care revealed a significant increase in parent preparedness from discharge (time 1) to 2 months later (time 3) (mean, 31.24 [SD, 4.25] and 31.97 [SD, 4.38]; t = 2.15, P = .03). Linear regression models of time 1 to time 3 change scores regressed in the intervention group and demographic and patient characteristics revealed no differences in parent preparedness (b = 0.97, t = 1.39, P = .17). In this model, patient diagnosis was significant (F = 4.47, P = .004) in that parents whose children had lymphoma and central nervous system tumor had a greater increase in perceived preparedness relative to parents whose children had solid tumors (b = 3.62, t = 3.28, P = .001; mean, 31.24 [SD, 4.25] and 31.97 [SD, 4.38]; t = 2.15, P = .03).

### Table 3 Symptoms Regressed on Intervention by Time

|                      | Pain | Nausea | Appetite Disturbance | Fatigue | Sleep Disturbance |
|----------------------|------|--------|----------------------|---------|-------------------|
| **Time**             | -0.40| -1.74  | -0.05                | -3.24\*| -1.71\*           |
| **Intervention**     | 0.31 | 3.23   | 0.59                 | -0.45   | 0.15              |
| **Time × intervention** | -0.18| 1.74   | -0.03                | 0.71    | 1.01              |
| **Age**              | 0.01 | 0.52\* | 0.07\*              | -0.09   | -0.08             |
| **Gender: female**   | 0.15 | -3.78  | -0.08                | -0.52   | -2.21             |
| **Ethnicity/race**   |      |        |                      |         |                   |
| Hispanic             | -0.35| 1.00   | 0.42                 | -3.51 b | -3.36 b           |
| Non-Hispanic Black   | -0.24| -4.32  | 0.49                 | -3.22   | 2.90              |
| Non-Hispanic, other  | -0.12| 1.39   | 0.19                 | -0.04   | -2.78             |
| Ethnicity unknown    | -0.29| -1.67  | 0.34                 | -1.32   | 1.41              |
| **Patient diagnosis**|      |        |                      |         |                   |
| CNS                  | -0.27| 2.07   | 0.28                 | -0.11   | -5.03             |
| Leukemia             | -0.07| -3.74  | -1.36 b              | -0.30   | 1.56              |
| Lymphoma             | -0.31| -3.25  | -1.39                | -1.29   | -0.23             |

Abbreviation: CNS, central nervous system.

Unstandardized coefficients shown. Reference category for ethnicity/race: non-Hispanic White. Reference category for patient diagnosis: solid tumor.

\*P < .01.
\*\*P < .05.
Linear mixed models revealed pain as the only symptom that differed over time by the intervention. Pain was slightly higher at baseline in the symptom management group, and across both groups, pain symptoms tended to decline over time. However, pain decreased over time more in the symptom management group. The symptom management group received specific information on pain—what to look for and how to address pain concerns. Information in the symptom management group specifically focused on symptoms and provided basic information to parents on how to manage pain at home.

### Discussion

This study examined the effects of 2 different early-discharge planning strategies for families of a newly diagnosed child with cancer. The importance of this study is supported by the lack of guidelines to inform the essential informational content delivered to caregivers of newly diagnosed pediatric oncology patients. The PEDSS study was designed to address the gap by examining 2 interventions: (1) how to support and cope with a new cancer diagnosis or (2) how to manage common cancer treatment symptoms. Symptoms were measured for severity at the time of assessment at each time point: at the initial hospital discharge (time 1) and at 1 and 2 months (times 2 and 3) during clinic or hospital visits following the initial hospital discharge.

### Table 4

| All Participants (n = 260) | Support Worksheet (n = 113) | Symptom Worksheet (n = 147) | $\chi^2$ | $P$ |
|---------------------------|-----------------------------|-----------------------------|--------|----|
| Unscheduled clinic visit  |                             |                             |        |    |
| Yes                       | 35 (13.62%)                 | 9 (8.04%)                   | 5.26   | .02|
| No                        | 222 (86.38%)                | 103 (91.96%)                |        |    |
| Emergency department visit|                             |                             |        |    |
| Yes                       | 67 (25.87%)                 | 33 (29.46%)                 | 1.33   | .25|
| No                        | 192 (74.13%)                | 79 (70.54%)                 |        |    |
| Unplanned hospitalization |                             |                             |        |    |
| Yes                       | 79 (30.50%)                 | 37 (32.74%)                 | 0.48   | .49|
| No                        | 180 (69.50%)                | 76 (67.26%)                 |        |    |
| Septic event              |                             |                             |        |    |
| Yes                       | 10 (3.86%)                  | 6 (5.31%)                   |        |    |
| No                        | 249 (96.14%)                | 107 (94.69%)                |        |    |

Fisher exact test conducted for septic events.

*Number of unplanned visits.

$b = 4.19, t = 2.31, P = .02$). Parents whose children had lymphoma had a greater increase in perceived preparedness relative to parents whose children had leukemia ($b = 2.15, t = 2.28, P = .02$). Other participant characteristics were not significant (age: $b = 0.12, t = 1.56, P = .12$; gender: $b = 0.74, t = 1.10, P = .27$; race/ethnicity: $F = 1.24, P = .30$).

Results of $\chi^2$ tests examining differences in the number of unplanned utilization of healthcare services at time 3 by intervention group are presented in Table 4. These revealed the symptom management group was more likely to have unscheduled clinic visits ($\chi^2 = 5.26, P = .02$). In contrast, neither intervention group increased emergency room visits or unplanned hospitalizations ($\chi^2 = 1.33, P = .25$; $\chi^2 = 0.48, P = .49$; $\chi^2 = .34$).

Analyses examining group differences in the evaluation of the interventions and satisfaction with the worksheets are presented in Table 5. Participants in the symptom management group were more likely to place the worksheet in visible sight or a binder ($\chi^2 = 21.17, P < .001$). The evaluation of the timing of the intervention and frequency of intervention use did not differ between groups ($P = .26$; $\chi^2 = 5.43, P = .37$). All measures of satisfaction revealed greater satisfaction with the intervention among those in the symptom management group (ease of use: $t = 4.69, P < .001$; easy to read: $t = 4.77, P < .001$; quick to use: $t = 4.65, P < .001$; likeable: $t = 4.58, P < .001$; helpful: $t = 4.83, P < .001$; would recommend: $t = 4.77, P < .001$).

### Table 5

| Timing of intervention | Support Worksheet | Symptom Worksheet | $P$ |
|------------------------|-------------------|-------------------|-----|
| Too early              | 2 (1.72%)         | 6 (4.14%)         | .26*|
| About right            | 114 (98.28%)      | 137 (94.48%)      |     |
| Too late               | 0 (0.00%)         | 2 (1.38%)         |     |
| Frequency of use       |                   |                   | .37*|
| Every day              | 5 (4.35%)         | 8 (5.44%)         |     |
| 2–6 times every week   | 8 (6.96%)         | 21 (14.29%)       |     |
| Once every week        | 27 (23.48%)       | 38 (25.85%)       |     |
| Once every other week  | 20 (17.39%)       | 20 (13.61%)       |     |
| Once a month           | 27 (23.48%)       | 34 (23.13%)       |     |
| Never                  | 28 (24.35%)       | 26 (17.69%)       |     |

Where worksheet placed

| In visible sight       | 20 (17.54%)         | 64 (43.84%)        | <.001*|
| In binder              | 82 (71.93%)         | 74 (50.68%)        |     |
| Lost or do not know    | 8 (7.02%)           | 4 (2.74%)          |     |
| Other                  | 4 (3.51%)           | 4 (2.74%)          |     |

*P value for $\chi^2$ or Fisher exact test.

$^P$ value for independent-samples $t$ test.
Models examining other symptoms demonstrated no differences between the 2 interventions but did reveal important relationships over time. Greater nausea and appetite disturbance were experienced over time by children older than 7 years. This finding is consistent with evidence on the prevalence of nausea and vomiting in children with cancer. Children with leukemia reported less appetite disturbance than those with a solid tumor. This finding is supported by the type of therapy used to treat leukemia versus a solid tumor. Steroids are commonly used for leukemia treatment and cause increased appetite. Children undergoing treatment for solid tumors receive chemotherapy that is highly emetogenic over frequent cycles and may not have time for appetite recovery before starting another treatment cycle.

Fatigue and sleep disturbance showed significant changes, demonstrating decreased prevalence over time in both groups. Hispanic participants reported less fatigue and less sleep disturbance compared with other race/ethnic groups. Females reported less sleep disturbance than males.

Other studies demonstrate that over the continuum of treatment, fatigue decreases in children. Fatigue is associated with sleep disturbances, but it is difficult to determine which symptom is the result of the other or whether they occur simultaneously. Previous studies conflict in relation to the effect of race/ethnicity on symptom severity; some found no differences in Hispanic children compared with non-Hispanic groups. Further research is needed to explore the impact of ethnicity on cancer treatment symptoms over time.

Parents in both PEDSS intervention groups felt more confident in their preparedness to care for the child with cancer over time. An interesting finding revealed that parents of children with a diagnosis of lymphoma or central nervous system tumor felt more prepared after 2 months than parents who had a child with a solid tumor. This is unlikely because of the numbers of hospitalization days at initial diagnosis, given that the amount of time between diagnosis and the first phase of treatment did not differ by diagnosis ($F_1 = 1.89$, $P = .13$). Unscheduled clinic visits were more likely to occur in the symptom management group with no increase in emergency room visits or unplanned hospitalizations in either group. One potential explanation is that parents in the symptom management group were more aware of when to bring their child experiencing symptoms to the clinic, but more research is needed to support a causative relationship.

Parents in the symptom management group were more likely to place the worksheet in a visible site or in their binder. The symptom management group also reported significantly greater satisfaction in the worksheet’s ease of use, readability, quickness to use, likeability, and helpfulness, and they would recommend it to others. The symptom management worksheet revealed more tangible information with specific actions parents can use to manage a particular physical symptom. The symptom management worksheet was more concrete than the coping and support worksheet, and this could be the reason for the parents being more satisfied with this education approach. The worksheet supplements and concisely summarizes what is being taught by the healthcare providers before discharge. This finding stresses the importance of concise information on symptom management and that it can be effectively communicated through a worksheet. Findings in this study are supported by Rodgers and colleagues, who found that parents of a newly diagnosed child with cancer are often overwhelmed with the amount of education provided.

This study provides evidence that a standardized discharge strategy can be successfully implemented across multiple children’s hospitals and with participants who are non–English speaking. Although further studies to examine the effectiveness of a standardized education discharge strategy with a more diverse sample are needed, this study demonstrates early evidence supporting the potential scalability and sustainability of early discharge interventions in the pediatric oncology population. Effective and standardized interventions to support parents of children newly diagnosed with cancer are necessary to promote high-quality and equitable care.

A limitation of the study includes evaluation of the intervention with a targeted patient population. The study lasted only 2 months and provides a very short snapshot of the trajectory of cancer symptoms over time. Although symptom severity at the time of each of the assessments was identified, the study may not have fully captured symptoms occurring between visits, particularly those with persistent low to moderate levels of severity that may not have warranted accessing the healthcare system. Because only Magnet hospitals were used in the study, the results cannot be generalized to all hospitals.

Another limitation of the study includes the delivery of the PEDSS intervention worksheet only in paper format. As the availability and capabilities of electronic devices increase, electronic formats should be considered for delivery of symptom management. Future studies should evaluate the use of a tool delivered electronically, such as a phone application, to assist parents in managing their child’s symptoms. Further work continues to be needed in diverse childhood cancer populations and languages.

There are numerous strengths to this study. The inclusion of Magnet-designated institutions as study sites, which supported the implementation of nurse-led interventions, led to success in a strong enrollment, with few participants who refused (8%) or withdrew (0.16%). The cluster randomized clinical trial design represents a major strength. The feasibility and scalability of this intervention at multiple institutions, given the first hospitalization is typically short and intense, were a success as a supplement to existing education for families of a child newly diagnosed with cancer. The study was geographically diverse with pediatric cancer centers representing large, medium, and small cancer programs from across the United States and supports the feasibility of expanding and sustaining the intervention on a broader scale. Pediatric oncology patients and their parents have historically been willing to participate in research that benefits future patients and are able to provide meaningful feedback, which makes them an ideal population to evaluate interventions.

### Conclusion

When a child is diagnosed with cancer, the initial hospitalization provides an opportunity for nurses to prepare the family for caring for their child at home. Parents in both PEDSS intervention groups felt more confident in their preparedness to care for the child with cancer over time. This finding was true for parents completing the study in English, Spanish, and Arabic. Findings
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