A Comprehensive Survey of Institutional Patient/Family Educational Practices for Newly Diagnosed Pediatric Oncology Patients: A Report From the Children's Oncology Group

Janice S. Withycombe, PhD, RN, MN, CCRP1, Rachel Andam-Mejia, MSN, RN2,3, Annie Dwyer, RN (PG Paediatric Oncology)4, Abigail Slaven, RN, CPHON®5, Katherine Windt, BSN, RN, CPHON®6, and Wendy Landier, PhD, RN, CPNP, CPON®7

1Emory University, Atlanta, GA, USA
2Children's Hospital of The King's Daughters, Norfolk, VA, USA
3College of Health Sciences, Old Dominion University, Norfolk, VA, USA
4The Children's Hospital at Westmead, Westmead, New South Wales, Australia
5Steven & Alexandra Cohen Children's Medical Center of New York, New Hyde Park, NY, USA
6Rady Children's Hospital–San Diego, San Diego, CA, USA
7University of Alabama at Birmingham, Birmingham, AL, USA

Abstract

Patient/family education is an important component of nursing practice and is essential to the care of children newly diagnosed with cancer. Practices regarding patient/family education in Children’s Oncology Group (COG) treatment centers have not been well described. We used an Internet-based survey to determine current patient/family educational practices at COG institutions; participation rate was 90.5% (201/222). Patient/family education was delivered primarily by an individual (rather than a team) at 43% of institutions. Advanced practice nurses had primary responsibility for providing education at 32% of institutions. “Fever” was the most frequently reported topic considered mandatory for inclusion in education for newly diagnosed patients. More than half of institutions reported using checklists and/or end-of-shift reports to facilitate health care team communication regarding patient/family education, and 77% reported using the “teach-back” method of assessing readiness for discharge. Thirty-seven percent of institutions reported delays in hospital discharge secondary to the need for additional teaching. An understanding of current practices related to patient/family education is the first step in...
establishing effective interventions to improve and standardize educational practices in pediatric oncology.

Keywords
childhood cancer; patient/family education; teaching; new diagnosis

Introduction
Each year, an estimated 10,380 children between the ages of 1 and 14 years (Siegel, Miller, & Jemal, 2015) and 5330 adolescents between the ages of 15 and 19 years (Ward, DeSantis, Robbins, Kohler, & Jemal, 2014) are diagnosed with cancer in the United States. Up to 90% of these children are cared for at health care centers that are members of the Children's Oncology Group (COG; O'Leary, Krailo, Anderson, & Reaman, 2008). These institutions provide specialized treatment and services needed to care for children with cancer. One of these services, patient and family education, has long been recognized as an important component of pediatric oncology nursing practice (Nelson & Guelcher, 2014). Appropriate education lays the foundation for care that is provided at home after a new cancer diagnosis and can potentially influence patient outcomes. In recognition of this, the COG Nursing Discipline has identified understanding the effective delivery of patient and family education at COG institutions as a priority for research (Landier, Leonard, & Ruccione, 2013).

Currently, limited evidence exists on which to base best nursing practices for providing patient/family education in pediatric oncology settings (Aburn & Gott, 2011; Rodgers et al., in press). Additionally, there is a paucity of information available regarding institutional practices pertaining to the provision of specialized education for families in order to prepare them to safely and appropriately care for a newly diagnosed child with cancer. The purpose of this study was to conduct a comprehensive survey of COG institutions aimed at determining the current state of practice regarding the delivery of patient/family education to parents/caregivers of newly diagnosed pediatric oncology patients prior to the child's initial discharge home after receiving chemotherapy in the inpatient setting.

Methods
This study was deemed exempt from review by the institutional review boards at Palmetto Health, Columbia, South Carolina and Emory University, Atlanta, Georgia; and by the institutional review boards at each of the coinvestigators’ institutions.

The research team was selected from the COG Nursing Discipline membership by a competitive application process based on knowledge, experience, and interest in pediatric oncology patient/family education. Team members included Registered Nurses (RNs) and Advanced Practice Nurses (APNs) in a variety of roles who were employed in clinical, administrative, and academic positions from institutions representing the range of size and geographic diversity within the COG. Prior to development of the initial survey instrument, the research team reviewed relevant literature related to patient/family education (Aburn & Gott, 2011; Kelly & Porock, 2005) and best practices for survey methodology (Braithwaite,
Emery, de Lusignan, & Sutton, 2003; Cook, Heath, & Thompson, 2000; Kittleson, 1997; Schleyer & Forrest, 2000; Villar, Callegaro, & Yang, 2013). A multidisciplinary panel of pediatric oncology experts, which included representation from medicine, nursing, psychology and patient advocacy, reviewed the initial survey instrument. Modifications to the survey content were made based on the expert panel review. Last, the developed survey was entered into a SurveyMonkey® platform. The major content areas of the survey included demographic characteristics (of both the respondent and the COG site), specific topics commonly taught to families of newly diagnosed patients, health care team member(s) responsible for providing the education, methods used to deliver the educational content, communication by health care team members regarding provision of family education, educational materials used to assist with/supplement educational content, methods used to assess learning, and perceived delays in hospital discharges related to noncompletion of essential education. A full copy of the survey tool is available online.

By design, only one response per institution was allowed; therefore, in order to collect the most accurate information from each site, strict criteria were set for study participation. To be eligible, the survey respondent was required to be a RN or APN who was actively engaged (defined as knowledgeable and involved) in providing education to newly diagnosed pediatric oncology patients in the inpatient setting. The inpatient setting was specified, because of concerns that there may be different educational needs or practices within an outpatient environment.

In order to identify the most appropriate nurse to represent each institution in the survey, the study team first contacted the COG Responsible Investigator (RI) Nurse (the nurse responsible for COG-related nursing communication) at each site. An introductory e-mail was sent to the RIs detailing the study and requesting the name and contact information of a nurse within their institution who met the study eligibility criteria. A survey link, along with an introductory e-mail describing the study, was then sent to the identified nurse for each site. Nonresponding RIs and/or eligible nurses were sent up to 2 additional reminder e-mails, at 2-week intervals. If no response was received after the e-mails, then the study team initiated personal phone calls for follow-up.

Pilot testing of the survey was conducted from September to October 2014, at 10 selected COG sites that included varied geographical locations and institutional sizes. The pilot sites were asked to report the length of time that it took to complete the survey and any content or technical issues encountered with the online survey system. Feedback received from the pilot testing resulted in only slight wording modifications to a small number of items to improve readability of the survey; these changes did not alter the content of the items.

Group-wide survey administration, to all remaining COG sites, occurred between November 2014 and April 2015.

Basic demographic information, for both the respondent and their institution, was reported by the survey respondent. Additional demographic characteristics of each COG institution were abstracted from COG registration and enrollment data (based on a 3-year average), and from the American Nurses Credentialing Center (ANCC) website, to determine which sites
held ANCC Magnet® designation, a measure of institutional nursing quality (Morgan, Lahman, & Hagstrom, 2006).

Statistical Analysis

Descriptive statistics were used to summarize the survey data. A multivariate logistic regression model was developed to examine predictors related to discharge delay secondary to incomplete education; variables included in the model were hospital unit type, ANCC Magnet® status, nurse to patient ratio, nurse responsible for education, use of a patient/family education protocol, clarity of health care team communication, proportion of non- or limited-English-speaking patients, and annual COG registrations/enrollments.

Results

Survey Population

In October 2014, there were 224 COG member institutions. Two sites were ineligible for survey participation; one site did not treat newly diagnosed patients and another site reported that only physicians provided patient/family education at their institution. Of the 222 remaining sites, 201 completed the survey, yielding a participation rate of 90.5% (Figure 1).

Characteristics of Survey Respondents—Of the survey respondents, 99% were female, 36.5% were between the ages of 20 and 39 years, while 63.5% were 40 years or older. The educational preparation of survey respondents included 47.5% holding a master’s degree or higher and 52.5% holding a bachelor’s or diploma degree in nursing. Survey respondents also reported their role as APN (35%), bedside nurse (17%), nurse coordinator (17%), educator (15%), or other (16%).

Characteristics of COG Institutions—Eighty-seven percent of COG institutions are located within the United States, and 39% hold current ANCC Magnet® accreditation (Table 1). The average number of COG registrations per year ranged from less than 20, 21 to 40, and greater than 40 at 31%, 37%, and 32% of institutions, respectively; 56% of sites reported that their newly diagnosed pediatric oncology patients are generally treated on a specialized pediatric oncology unit, whereas 44% reported that newly diagnosed patients are typically treated on a general pediatric unit; 34% of institutions reported at least 25% of patients to be from non- or limited-English speaking families. The majority of institutions (62%) reported RN to patient staffing ratio during day shift (on the unit where pediatric oncology patients were cared for) as 1 RN to 3 or 3.5 patients.

Provision of Education

APNs were identified as having primary responsibility for providing education to newly diagnosed patients in the inpatient setting at 32% of the sites, followed by bedside RNs (25%), patient/family educators (18%), coordinators (13%), clinic nurses (6%), and others (6%). The large majority of sites (90%) reported that their institution provided some type of training to prepare nurses to provide patient/family education, with the most common method of training consisting of a formal class or workshop, identified by 67% of sites. Other reported training methods included provision of information during orientation for
newly hired nurses, training through self-learning modules, “on the job training,” or yearly competencies. In contrast, 10% of the institutions reported that they had no current training programs to prepare nurses to provide education to patients and families.

Delivery of patient family education was reported to involve primarily one individual (or individuals sharing a common role) at 43% of sites, while a team approach was utilized by 24% of sites, and 33% of sites reported using a combination of team and individual delivery of patient/family education. Seventy percent of sites reported using a clearly delineated protocol or established process for providing patient/family education, while 30% of sites stated that the use of a clearly established process occurred less than half of the time.

**Essential Educational Content**

Sites were asked to rate which educational topics their institution considered necessary in order to safely discharge a patient home for the first time after a newly diagnosed child had received their initial chemotherapy. The following 6 topics were reported by at least 90% of institutions as essential for inclusion in teaching “all of the time” prior to discharge: Fever (99% of sites), signs and symptoms of infection (97%), how and when to call the health care team (97%), home medications (96%), explanation of diagnosis (94%), and chemotherapy side effects (90%). The proportion of sites indicating that specific educational topics were necessary for inclusion in initial education is shown in Figure 2.

Sites also reported that a variety of disciplines contributed to the provision of education for parents/caregivers of newly diagnosed patients. Individual disciplines were identified as having the primary responsibility for teaching specific topics (Figure 3), including pediatric oncologists (responsible for education regarding diagnosis and clinical trials at 98% and 91% of institutions, respectively), nurses (responsible for education regarding central line care, prevention of infection, temperature taking, signs and symptoms of infection, how and when to call the health care team, and fever at over 90% of institutions), psychosocial professionals (responsible for education regarding coping/psychosocial adjustment at 63% of institutions), and dietitians (responsible for education regarding nutrition at 50% of institutions). Additionally, 23 institutions (10%) indicated that they were unable to select a primary discipline for several topics, as education regarding those topics is a collaborative effort between disciplines at their institutions.

**Communication Methods**

Sites reported using a variety of communication methods among health care team members to share what educational topics had been taught to patients/families and what topics remained to be covered. These communication methods, and the proportion of sites reporting their use, included the following: checklist, form, or discharge plan (67%); end of shift report (56%); informal notes, such as “sticky notes” or worksheets (26%); and white boards or similar devices in patient rooms (18%). Sites were allowed to select more than one communication method if multiple methods were used at their institution. Interestingly, 34% of sites reported that a single individual (such as an educator) was entirely responsible for education and therefore did not need to consult with the team regarding what had been
taught and what needed to be taught, and 6% of sites reported that no team communication methods were currently in use related to tracking patient/family education.

**Assessment of Learning**

Institutions also reported how they assessed parents/caregivers of newly diagnosed patients to determine whether sufficient learning had occurred, in preparation for a safe discharge home. Sites reported a variety of assessment methods, with some reporting use of more than one method, including “teach-back” (Kornburger, Gibson, Sadowski, Maletta, & Klingbeil, 2013), a method that involves the family “teaching” or demonstrating to the health care team what they have learned (77%); evaluation by the multidisciplinary team (70%), bedside RN (52%) or educator (40%); and use of a test or quiz (18%). Seven percent of sites reported that they currently had no method for assessing discharge readiness.

**Discharge Delays**

Institutions were also asked to report how often the discharge of a medically stable, newly diagnosed patient was delayed due to the need for additional teaching. Thirty-seven percent of sites reported that delays in discharge occurred “some,” “most,” or “all the time,” while 63% of the sites reported that delays in discharge “rarely if ever” occurred secondary to the need for additional teaching. To explore predictors of delayed discharge due to noncompletion of teaching, a multivariate logistic regression module was developed, controlling for unit type, nurse-to-patient-ratio, nurse responsible for education, site ANCC Magnet® status, and the use of an established protocol for providing patient/family education. Institutions that reported a lack of clear team communication were more than twice as likely to report delayed patient discharges (odds ratio [OR], 2.32; 95% confidence interval [CI], 1.10-4.88; \( P = .026 \)). Likewise, institutions with ≥25% limited- or non-English speaking patients were 2.6 times more likely to report delayed patient discharges (OR, 2.56; 95% CI, 1.28-5.13; \( P = .008 \)), and very large institutions (those with more than 75 COG registrations per year) were 3.1 times more likely to report delayed discharges (OR, 3.14; 95% CI, 1.20-8.19; \( P = .019 \)).

**Limitations**

The primary limitation of this study is that each institution was represented by a single individual, and it is possible that this individual could have provided inaccurate or biased information. We addressed this limitation by asking each RI nurse to recommend a nurse for survey participation who was thoroughly familiar with and involved in the institution’s efforts to educate newly diagnosed pediatric oncology patients and their families. As such, the reported data is believed to reflect the institutional practices to the best of the survey respondents’ knowledge. Additionally, some of the outcome data (ie, discharge delays) were self-reported, since objective measurement of these data was beyond the scope of this study. It is also possible that the nonparticipating COG sites (\( n = 21 \)) have different educational practices that are not represented within this study. Despite these limitations, this study has many strengths, including the >90% participation rate, the large and geographically diverse sample of COG institutions, and the fact that this is the first comprehensive report of institutional patient/family educational practices for newly diagnosed pediatric oncology patients.
Discussion

To our knowledge, this study is the first to comprehensively describe patient/family educational practices across over 200 COG institutions. As such, it addresses an important gap in the literature. Major findings from this study include significant variability in practices relating to the delivery of patient/family education for newly diagnosed pediatric oncology patients across the large and diverse network of COG institutions. While we found that multiple disciplines are often instrumental in providing education, and specific educational content may be taught by pediatric oncologists, dietitians, and behavioral scientists, the responsibility for patient/family education of newly diagnosed pediatric oncology patients is primarily associated with the discipline of nursing. The findings of this study therefore have significant implications for nursing practice.

The results from this survey indicate that not all COG institutions employ standard protocols or established processes for teaching families. Inconsistencies in communication also exist among staff regarding what has been taught and what still needs to be taught to newly diagnosed patients and their families. Substandard communication among health care team members and incomplete documentation of health related information are 2 issues that can lead to decreased quality of care around the discharge timeframe (Berry et al., 2014). Checklists have been successfully employed in the surgical setting to assist with improving the quality of patient care (Treadwell, Lucas, & Tsou, 2014; Walker, Reshamwalla, & Wilson, 2012) and may also prove useful for documenting and communicating patient/family educational needs. In this study, 67% of institutions reported using a checklist, form, or discharge plan related to patient/family education. It is unknown to what extent these checklists and other communication tools are evidence-based and to what degree they assist with improving patient care and outcomes.

Regarding content of educational information, there was reported variability across institutions regarding the topics that were considered essential for inclusion in teaching prior to discharge. “Fever” was the most frequently reported topic that was considered mandatory for teaching prior to a patient’s first discharge home from the hospital. The importance of teaching this topic is supported by the fact that fever, and fever with neutropenia, are the 2 most common conditions associated with use of emergency departments by pediatric cancer patients (Mueller et al., 2015). Inclusion of other topics to ensure a safe transition to the home setting are not as clearly established in the current literature, but may become evident through the work underway within the evidence-based practice initiatives of the COG Nursing Discipline and the Association of Pediatric Hematology/Oncology Nurses.

While nurses are intricately involved in providing patient/family education, not all are fully knowledgeable about the teaching process (Carpenter & Bell, 2002; Kelo, Martikainen, & Eriksson, 2013). It is encouraging that 90% of the COG sites represented in this study reported that their institution provided training to prepare nurses to provide patient/family education. The quality and effectiveness of these training programs are unknown, but literature supports the concept of teaching nurses how to provide patient/family education. Nursing training programs related to the teach-back method for delivering patient/family education have proven to be beneficial (Fidyk, Ventura, & Green, 2014; Peter et al., 2015).
Additionally, training programs to enhance nursing knowledge related to providing discharge education to patients and families have been developed and successfully implemented for use within other pediatric subspecialties, such as cardiology (Staveski et al., 2015). The ability of nurses to provide education is of high importance, as effective delivery of education is a strong indicator of a parent's readiness for discharge home (Weiss et al., 2008).

Our findings indicate that there is variation in the techniques used within institutions to assess learning and discharge readiness of patients and families. It is unknown which of these assessment methods is most effective, but there is evidence to support the effectiveness of the “teach-back” method (Kornburger et al., 2013). We also found that discharge delays due to incomplete education in medically stable patients were not uncommon, and that significant predictors of discharge delays included lack of clear team communication, having at least 25% of families who were limited- or non-English-speaking, and very large institutional size. These factors may represent the increased complexity of providing care for large and diverse populations, which may contribute to discharge delays. Interestingly, to our knowledge there are no studies that have evaluated the association of discharge delays and patient/family education in pediatric oncology. Examining discharge readiness indicators and reasons for discharge delays in medically stable pediatric oncology patients represents a potential area of focus for future research.

**Conclusion**

Our findings suggest that there is significant variability in the delivery of patient/family education across COG institutions, including variability in the methods of delivery, content considered essential, health care team members involved, and assessment of learning. Understanding current practices related to patient/family education is the first step in establishing effective interventions to improve and standardize educational practices in pediatric oncology. Findings from this study will be used, in conjunction with other research, to inform the development of standardized methods for effective delivery of education to parents/caregivers of newly diagnosed pediatric oncology patients.

**Acknowledgments**

The authors would like to thank each of the survey participants who graciously and thoughtfully responded to this survey. We would also like to acknowledge Yanjun Chen, MS, for providing statistical review; Dr Withycombe’s prior institution, Palmetto Health in Columbia, South Carolina, and Dr Lundier’s prior institution, City of Hope in Duarte, California, for their support during development of this study, and Dr Peter Adamson, Chair, Children’s Oncology Group (COG), for his support in allowing access to the COG data used in this study.

**Funding**

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study was supported by a Children’s Oncology Group Nursing Fellowship in Patient/Family Education awarded to Janice Withycombe and funded through the National Cancer Institute/National Clinical Trials Network Group Operations Grant (U10CA180886; Principal Investigator: Adamson), and by Alex’s Lemonade Stand Foundation.
**Biography**

**Janice S. Withycombe** is an Assistant Professor at Emory University within the Nell Hodgson Woodruff School of Nursing and a researcher with Children’s Healthcare of Atlanta in Georgia.

**Rachel Andam-Mejia** is a Clinical Practice & Education Specialist for inpatient medical-surgical nursing at the Children's Hospital of The King's Daughters. She is also adjunct faculty at Old Dominion University within the College of Health Sciences, School of Nursing.

**Annie Dwyer** is a Clinical Nurse Specialist on the inpatient Oncology/BMT unit at the Cancer Centre for Children, The Children's Hospital at Westmead, NSW, Australia.

**Abigail Slaven** is an Assistant Nurse Manager of the inpatient Hematology/Oncology/Bone Marrow Transplant Unit at Cohen Children's Medical Center of New York within the Northwell Health System.

**Katherine Windt** is a nurse in the Peckham Center for Cancer and Blood Disorders, Hematology/Oncology/Bone Marrow Transplant unit, at Rady Children's Hospital - San Diego.

**Wendy Landier** is an Associate Professor in the Division of Pediatric Hematology/Oncology and in the School of Nursing, and a member of the Institute for Cancer Outcomes and Survivorship, at the University of Alabama at Birmingham in Birmingham, Alabama. She also serves as Chair of the Children's Oncology Group Nursing Discipline.

**References**


Figure 1.
Study participation.
Figure 2.
Educational topics considered necessary by institutions for a safe discharge home.
Figure 3.
Disciplines reported to have primary responsibility for education of newly diagnosed patients, by topic.
Table 1
Characteristics of COG Institutions.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Geographic location&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>United States</td>
<td>192</td>
<td>86.5</td>
</tr>
<tr>
<td>Canada</td>
<td>15</td>
<td>6.8</td>
</tr>
<tr>
<td>Australia</td>
<td>8</td>
<td>3.6</td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
<td>3.1</td>
</tr>
<tr>
<td>Unit type (caring for newly diagnosed patients)&lt;sup&gt;b&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>General pediatric</td>
<td>88</td>
<td>43.8</td>
</tr>
<tr>
<td>Specialized pediatric oncology</td>
<td>113</td>
<td>56.2</td>
</tr>
<tr>
<td>ANCC Magnet® Accreditation&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>87</td>
<td>39.2</td>
</tr>
<tr>
<td>No</td>
<td>135</td>
<td>60.8</td>
</tr>
<tr>
<td>Proportion of non- or limited-English speaking families&lt;sup&gt;b&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≥25%</td>
<td>66</td>
<td>34.0</td>
</tr>
<tr>
<td>&lt;25%</td>
<td>128</td>
<td>66.0</td>
</tr>
<tr>
<td>RN to patient ratio in pediatric oncology (day shift)&lt;sup&gt;b&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 RN to ≤2.5 patients</td>
<td>26</td>
<td>13.4</td>
</tr>
<tr>
<td>1 RN to 3-3.5 patients</td>
<td>121</td>
<td>62.4</td>
</tr>
<tr>
<td>1 RN to 4-4.5 patients</td>
<td>40</td>
<td>20.6</td>
</tr>
<tr>
<td>1 RN to ≥5 patients</td>
<td>7</td>
<td>3.6</td>
</tr>
<tr>
<td>Size of COG institution, based on annual registrations&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Small (&lt;20)</td>
<td>68</td>
<td>30.8</td>
</tr>
<tr>
<td>Medium (21-40)</td>
<td>81</td>
<td>36.7</td>
</tr>
<tr>
<td>Large (41-75)</td>
<td>39</td>
<td>17.6</td>
</tr>
<tr>
<td>Very large (&gt;75)</td>
<td>33</td>
<td>14.9</td>
</tr>
</tbody>
</table>

Abbreviations: ANCC, American Nurses Credentialing Center; COG, Children's Oncology Group; RN, registered nurse.

<sup>a</sup>Reported numbers include all eligible COG sites with available data.

<sup>b</sup>Reported numbers include all COG sites responding to survey item.