Introduction/Background

Families of children, adolescents and young adults (AYA) newly diagnosed with cancer experience emergent hospitalizations and intense medical interventions. During this stressful time, families must absorb knowledge and skills needed to care for their ill child at home (Landier et al., 2016; Rodgers, Stegenga, Withycombe, Sachse, & Kelly, 2016). These families also face concurrent emotional, psychosocial, and physical challenges (Aburn & Gott, 2011). In addition, they have extensive learning needs. Care is not only limited to the inpatient setting alone but also incorporates outpatient clinic visits and care provided in the home. Hospitalizations have evolved into shorter lengths of stays (Flury, Caflisch, Ullmann-Bremi, & Spichiger, 2011). Parents are increasingly asked to manage medications, emergency situations, and the total care of their child (Aburn & Gott, 2014). New diagnosis education includes effects of treatment, chemotherapy side-effects, pain management, central line care, medication administration, follow-up care, and other information specific to the diagnosis. Lack of a comprehensive discharge education program affects the patients and family, the hospital organization, and inpatient and outpatient nursing staff.
Local Problem

Poor planning affects the quality of education provided and opportunity for follow-up reinforcement. Parents poorly prepared for discharge often do not have the correct medications or equipment for home. Medication errors occur because families have limited understanding and/or lack the tools that they need to ensure proper timing and doses of medications (Walsh et al., 2011). Families not clear about follow-up requirements often have trouble scheduling clinic appointments resulting in missed follow-up appointments and delay in treatment. Lack of complete discharge preparation affects patient safety (Lerret, 2009; Weiss et al., 2017). Patients not brought to the hospital in a timely fashion when symptomatic result in adverse patient outcomes. Furthermore, inadequate or ineffective teaching has resulted in unplanned readmissions.

Effective teaching and discharge planning, begun at admission, facilitates safe care following discharge. Deficiencies within our discharge process that contributed to unplanned readmissions, medication errors, and adverse patient outcomes were identified. According to families who participated in prepilot focus groups, not feeling prepared for home increased stress and was a source of dissatisfaction. A process to create and evaluate a program to better prepare families to provide care at home for their ill child following the initial hospitalization was proposed to address these deficiencies.

At the same time, lack of a cohesive discharge teaching plan was a major dissatisfaction for nurses on the unit. Teaching and preparation for home were often delayed until the last day or two before discharge. Trying to impart large amounts of information in a short period of time, often with families requiring interpreters, added to the distress of the discharging registered nurses. Without a clear approach to track or easily document what teaching had been completed, education was inconsistent and affected timeliness of discharge. Incomplete documentation of patient/family education contributed to incomplete communication between the inpatient and outpatient settings; decreasing the efficiency of the outpatient team and continuity across care settings.

A poster presentation and breakout session at the Association of Pediatric Hematology/Oncology Nurses Annual Conference addressing different aspects of discharge education stimulated continued discussion of deficiencies in our existing discharge education process and reenergized the search for a possible solution. Each member of the project team brought a unique perspective to the project. The outpatient Nurse Coordinator saw the need for improved transition to outpatient care and follow-up. The professional practice specialist realized the impact of discharge education on unplanned readmissions, medication errors, and adverse patient outcomes. All understood the frustration of the clinical nurses trying to provide effective education within a complex system that often presented barriers to communication, time, resources, and support.

The aim for the Road to Home (RTH) program was to develop interactive patient education methods to engage nurses, clinical team members, parents, and patients in the new diagnosis cancer education process. With improvements in communication, nursing resources, and discharge tools, the goal was to realize improved patient/family readiness for the transition to home and outpatient care, and ultimately improve satisfaction with the discharge education process. The PICO question developed for this performance improvement project was as follows: Compared with our current process, will a standardized interactive new diagnosis education program (RTH) improve nurse and family satisfaction with the discharge education process in families of children and AYA newly diagnosed with cancer and the nurses who provide their education?

Method

Setting and Participants

Our institution is an urban academic medical center encompassing a 32 bed Hematology/Oncology/Blood and Marrow Transplant unit (HOCU), an outpatient clinic seeing 75 to 100 patients per day, and multiple dedicated clinical care teams. The 290 newly diagnosed oncology patients a year and more than 1,500 oncology patients total represent a wide multicultural population. In light of this busy and diverse practice, the new education program needed to be both efficient and transferable across many different cultures and diagnoses.

The goal of developing a standard approach to new diagnosis education and discharge planning was one of beneficence; families across our patient population would receive the same level of quality discharge education and be empowered to have the autonomy to care for their ill children at home. Participation in family focus groups and the pilot program was optional. Only English speaking families were included in the pilot due to limited resources for translation of materials at that time. Additionally, to efficiently assess for gaps in the new process, only one oncology team (Leukemia and Lymphoma) was included in the pilot. The concept of social justice dictates equal distribution of resources, which was subsequently addressed in the program rollout to all oncology teams and in additional languages.

Developing the Road to Home (RTH)

An extensive literature search was completed targeting identified discharge education concerns and results were incorporated into the final RTH program. Current education materials and processes were reviewed by Nursing Education Committee members. Recommendations included changes in teaching methods, documentation,
availability of resources, and alignment with the Children’s Oncology Group Family Handbook©. Funding was secured to support the implementation of the RTH program.

Caregivers of five children with newly diagnosed hematologic malignancies were interviewed regarding their hospital discharge experience to elicit feedback about the current and proposed discharge teaching process. All children were past the initial induction phase of treatment. Specific questions were asked about their discharge teaching and preparedness. In addition, the Oncology Parent Advisory Council supported project development by giving constructive feedback regarding early program design development. All caregivers expressed increased stress related to not feeling prepared to care for their child at home after initial discharge. Caregivers gave feedback regarding specific concerns and discharge education needs.

The HOCU Nursing Satisfaction with Discharge Education survey was developed and validated with the direct care members of the unit-based Education Committee. The survey revealed high dissatisfaction especially regarding lack of protected time to provide effective discharge education. Post survey, nurses had the opportunity to offer feedback and an exchange of ideas and suggestions (Table 1).

The education committee collaboratively designed the RTH board with the project team leaders. Important components of the teaching process define each road on the board; with each step reflecting topics consistent with those covered in the Children’s Oncology Group Family Handbook. Scripts for nurses were created outlining the education content, resources, sample teach-back questions and tips for each section. All direct care nurses received training on the new program during staff meetings and small group sessions.

### The Road to Home! Program

**Teaching Board.** The initial concept of the RTH program was the development and implementation of a 2 ft x 3 ft magnetized wall mounted board that hangs in the patient’s room. The four roads encompass education needs from admission to discharge. “Information Highway” covers initial information given at diagnosis. “Teach Back Street” encompasses knowledge that the parents need to “teach back” to the clinician (Kornburger, Gibson, Sadowski, Maletta, & Klingbeil, 2013). “Demonstration Lane” is care requiring hands-on return demonstration. “Ready for Home Road” addresses the discharge planning arrangements that need to be in place prior to leaving the hospital. The RTH wall board is a family-centered visual aid used jointly by families and clinicians that quickly conveys to all who enter the hospital room the family’s advancement toward discharge. Progress is tracked with magnetic cars and/or dry erase markers (Figure 1).

**Education Station.** An educational delivery method was developed using the content of the Children’s Oncology Group Family Handbook, which is given to patients and their families at diagnosis. Included in each family handbook is a section individualized to the institution and specific to diagnoses and local community resources. To improve teaching efficiency, an education station was created to include a centralized location for written teaching materials, the Children’s Oncology Group Family Handbook, and other teaching tools. A portable rolling cart contains hands-on supplies and central line mannequins used for demonstration with caregivers. A binder of teaching scripts and tips for nurses that linked to the steps on the RTH and the Children’s Oncology Group Family Handbook was included.

**Tool Kit/Bags.** In an effort to address medication issues, each family was given a tool kit at discharge. Included in

### Table 1. HOCU Nursing Satisfaction with Discharge Education Process.

<table>
<thead>
<tr>
<th>Survey questions</th>
<th>Prepilot (n = 30, 42%)</th>
<th>Postpilot (n = 22, 31%)</th>
<th>1-year follow-up (n = 31, 47%)</th>
<th>3-year follow-up (n = 13, 22%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discharge education and planning is an organized process</td>
<td>2.3</td>
<td>2.8</td>
<td>3.5</td>
<td>3.6</td>
</tr>
<tr>
<td>It is easy to identify my patient/families learning needs and progress</td>
<td>2.5</td>
<td>2.9</td>
<td>3.2</td>
<td>3.3</td>
</tr>
<tr>
<td>I have the knowledge necessary to provide safe and effective discharge education</td>
<td>3.9</td>
<td>4</td>
<td>4.5</td>
<td>4.6</td>
</tr>
<tr>
<td>I have the resources necessary to provide safe and effective discharge education</td>
<td>3.3</td>
<td>3.8</td>
<td>4.6</td>
<td>4.5</td>
</tr>
<tr>
<td>I have the time and support necessary to provide safe and effective discharge education</td>
<td>2.5</td>
<td>2.8</td>
<td>3.1</td>
<td>3.3</td>
</tr>
<tr>
<td>Discharge education and planning is a multidisciplinary team effort</td>
<td>2.9</td>
<td>3.4</td>
<td>3.8</td>
<td>3.5</td>
</tr>
<tr>
<td>Patients/families are well prepared for discharge</td>
<td>2.8</td>
<td>3.2</td>
<td>3.7</td>
<td>4</td>
</tr>
<tr>
<td>Overall I am satisfied with discharge education and planning</td>
<td>2.4</td>
<td>2.9</td>
<td>3.8</td>
<td>3.5</td>
</tr>
</tbody>
</table>

Note. HOCU = Hematology/Oncology/Blood and Marrow Transplant unit. 5 = strongly agree; 4 = agree; 3 = neither agree nor disagree; 2 = disagree; 1 = strongly disagree.
the insulated tote bag are items necessary to safely care for their child in the home: a thermometer, a pill organizer, a pill cutter/crusher, oral medication syringes as needed, and business card(s) with the center’s emergency phone numbers. Medication prescriptions were filled by pharmacy and reviewed by nursing for accuracy and family understanding before discharge. Families were encouraged to bring the toolkit with all medications to each clinic visit. This practice allowed the clinician to review the correct medication administration with the caregivers and make any changes.

**RTH Pilot** The pilot began with leukemia/lymphoma patients once the boards were designed and printed and a mounting mechanism was approved. A RTH board was placed in each patient’s room after the new diagnosis meeting with the clinical team. The nurse provided an overview of the program’s goals and objectives. Teaching checklists were developed that correspond with the RTH board and the Children’s Oncology Group Family Handbook content, allowing the nurse to document the progress of the patient toward discharge.

The pilot for the program was completed over 6 months with 22 families participating.

**Results**

**Findings and Program Expansion**

Pilot evaluation included postdischarge telephone calls assessing parent satisfaction with the **RTH**. Each caregiver was asked a standard set of questions to gain insight on the new education process: 82% stated that the board helped them understand what they needed to learn; 95% could accurately teach back fever guidelines after discharge; 91% consistently brought their toolkit with medications to clinic visits. Caregivers also offered feedback regarding teaching methods and content of the toolkits. The nursing satisfaction survey completed after the pilot indicated improved nurse satisfaction with the new process across all questions. Highest gains were seen in questions related to discharge education and planning being an organized, multidisciplinary process with adequate resources available. Overall nursing satisfaction with discharge education and planning increased from 2.4 to 2.9 on a 5-point scale after the 6-month pilot period (Table 1, Column 2).

After the pilot evaluation, the **RTH** boards were modified based on feedback obtained from family members and nursing staff. The program was expanded to include all families of children and AYA with all oncology diagnoses.
Education regarding the program was presented to oncology providers, the outpatient nurse coordinators and other multidisciplinary team members. Additional boards and RTH materials were translated into Spanish and Arabic.

Despite postpilot nursing survey results showing improvements across all questions, only small gains were made regarding time and support necessary to provide safe and effective discharge education and it remained one of the lowest rated survey questions. Nurses expressed that they felt communication about discharge education needs was much improved but that they continued to struggle with finding time to teach during a busy shift.

In response, and to be more efficient with nurses’ teaching time, the education committee developed a weekly family education class called “Cookies, Counts, and Central Lines” that addresses basic discharge concerns. The facilitator assesses families’ needs, individualizes teaching, and provides participants their undivided attention. This allows direct care registered nurses to focus on teaching without having a patient care assignment. Bedside teaching then focuses on follow-up and reinforcement assuring that families are prepared before discharge and reduces the stress of last minute education. In over 100 postclass evaluations collected over 2 years, 100% of participants found the class helpful, appreciated the materials and would recommend the class to other families.

A follow-up Nursing Satisfaction Survey conducted after program expansion to the all newly diagnosed oncology families and implementation of the “Cookies, Counts, and Central Lines” class again showed significant improvements across all questions asked. Larger gains were seen in areas related to having the knowledge, resources, and time and support necessary to provide safe and effective discharge education. Overall nursing satisfaction with discharge education and planning increased from 2.4 to 3.8, a 1.4 point gain on a 5-point scale 1 year after program implementation (Table 1, Column 3).

On further evaluation, the education committee felt that the classroom setting did not meet the needs of all families. Some families were not comfortable in a class setting, had learning needs that fell outside the scope of the class, needed extra hands-on or 1:1 reinforcement, or had unique interpreter needs. Because of the local multicultural population, there was often a need for more than one interpreter per class, which was challenging in a small group setting.

The Education Committee proposed the creation of the Patient/Family Education Advocate and Resource (PEARs) role. The direct care nurses who fill this role are scheduled weekly for 8 hours on the class day. In addition to teaching class, they schedule 1:1 appointments for follow-up, hands-on reinforcement, discharge medication teaching and special needs. PEARs work with all HOCU patients and families needing education.

Providing needed support for patient/family education to direct care nurses has increased staff engagement and awareness of family education needs. Nurses routinely check in to make sure the families on their assignment are on the PEAR’s list when appropriate, communicate with the families about class time and other needs, and follow-up with education reinforcement. Other team members such as social work reach out to families who may not often be available and schedule them to be at the hospital on PEAR days for teaching. Specific concerns or areas of education that need continued reinforcement after discharge are communicated to the outpatient nurse coordinators.

**Patient Satisfaction**

Patient Satisfaction data were tracked throughout the entire RTH performance improvement process. Four questions related to education and discharge from the Press Ganey survey (2018) that measures parent or guardian reports of their family’s experience of their child’s inpatient care were evaluated.

Percentage of families responding “Very Good” increased across all questions. Percentage increases ranged from 9% for “felt ready for discharge” to 59% for “speed of discharge process.” Sustained increases were seen in “nurses inform using clear language” and “instruction for child home care” as well. These survey results encompass all patients admitted to the inpatient unit and were not specific to the oncology patient population (Figure 2).

**Development of Electronic Health Record Documentation**

Throughout the pilot, nursing input was obtained about the content and flow of the documentation checklists. Feedback was incorporated into developing an electronic version of the RTH documentation, built to match the four RTH “roads.” After roll out of the initial electronic RTH record, nursing staff reported improved satisfaction with documentation content; however, they reported difficulty with flow when multiple content areas were covered in a single education session.

With additional revisions, the RTH documentation was condensed to one electronic form updated with each teaching session, so all records are retained. Up to 10 teaching sessions can be documented within each content section, which includes time frames, learner resources, content, learner assessment, teaching method, outcome, and status. Icons built into the form allow the nurses to see which sections are completed. All multidisciplinary team members can easily see discharge education progress.

**Discussion**

Effective teaching is needed to assure safe care of a child or AYA newly diagnosed with cancer following discharge. Nurses need adequate knowledge, resources, time,
and support to provide effective teaching that will help caregivers understand therapies, side effects, and care of their child at a time when they are often overwhelmed and anxious.

The RTH program is meeting the goals for increased family and nurse satisfaction with discharge education and helps assure that families are better prepared to safely care for their child at home. Parents have expressed great appreciation and stated that the program eases transition to home. This feedback is reflected in sustained increases in patient satisfaction indicators (Press Ganey 2018) related to discharge education and planning. The final nursing satisfaction survey completed 3 years after implementation of the RTH and encompassing all aspects of the program showed sustained improvements in nursing satisfaction with the discharge education process. Per nursing comments, remaining dissatisfiers are related to the day of discharge paperwork and medication reconciliation, which are larger systems issues. Continuous performance improvement methods were used to modify the program using multiple Plan-Do-Check-Act cycles. Family and nurse satisfaction scores and stakeholder feedback were used to guide improvements to the program and ensure sustainability.

**Sustainability**

The RTH program has taken considerable resources to maintain but is worth the effort given the overwhelmingly positive response from families and nurses. Nurses new to both inpatient and outpatient oncology are taught all components of the RTH program as part of the unit-based Hematology/Oncology Essentials onboarding classes. Members of the Education Committee function as family education resources for the rest of the staff on a daily basis. During the initial development of the RTH, funding was sought to cover expenses related to developing the RTH boards, copyright, and associated teaching materials. After the initial Board of Visitors grant, funding sources were limited and fragmented; various individual donors and institutional partners have contributed to the economic viability of the program. Currently, the oncology service covers the costs of providing the customized inserts for the Children’s Oncology Group Family Handbook and the RTH tool kit bags and supplies, indicating the shared recognition of the program’s value.

An unexpected limitation to sustainability has been the management of the RTH board placement in the rooms. Over time, the mounting hooks have been removed and not replaced during room maintenance/painting. On discharge, boards are not properly returned to the central storage area. Due to the above barriers, direct care nurses are less likely to ensure timely placement of boards for their assigned patients when appropriate. Development of an ongoing board management plan is needed.

**Growth, Expansion, and Future Direction**

The RTH project was submitted to the Clinical and Translational Science Institute, a partnership between the institution and a local university, and was chosen to develop the requirements and a prototype user interface for medical software applications. A graduate student, who is also a former patient, was assigned to create a RTH application for the iPhone. The application is currently in the development phase.

There are ongoing efforts to develop the RTH program for use with other diagnoses and complex needs patients throughout the hospital system such as Neurology Service,
Blood and Marrow Transplant and Gastroenterology/Intestinal Rehab services. These patients often have lengthy hospitalizations and this education process can be developed for both families and providers to focus on extensive discharge teaching needed for these complex patients.

Conclusion

The Road To Home! program has met our aim to develop interactive patient education methods to better engage nurses, clinical team members, parents, and patients in new diagnosis cancer education processes. The improvements in communication, nursing resources, and discharge tools incorporated within the RTH program have proven to affect sustained improvements in nursing and family satisfaction with the discharge education process.

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