



## **Sample Poster/Paper Presentation Abstracts**

### **Paper Presentation: Engaging Children and Healthcare Providers in the Co-Design of a Mobile Technology-Based Symptom Assessment App**

#### **Author(s)**

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#### **Basis of inquiry**

Mobile technology supports child-centric approaches to symptom reporting by incorporating game-based features to support children in reporting symptoms. Engaging child and clinician users as co-designers facilitates the potential success of these technologies.

#### **Purpose/Objectives**

We describe the development of a child-centric symptom assessment app using school-age children (6-12 years) receiving treatment for cancer and pediatric oncology healthcare providers as co-designers.

#### **Methods**

This two-phase project was guided by the cooperative inquiry framework which engages children as technology co-designers. Phase 1 was an exploratory phase followed by programming during Phase 2.

Phase 1 participants were 27 children (14 males; median 9 years) receiving treatment for cancer and 22 healthcare providers (21 female; 15 nurses; median 30-34 years). Children participated in “draw and tell interviews” describing their symptoms. They were also asked about their preferences for an app and its design. They also described games and apps they liked, including desirable features. Healthcare providers participated in focus group sessions in which they related their perceptions of children’s symptoms, approaches for symptom assessment, challenges encountered when assessing symptoms, and their ideas and preferences for a symptom assessment app. Patient and provider responses were recorded and analyzed using qualitative content analysis. Data were shared with the game design team to guide initial app development with consideration to the technology, aesthetics, audience, and the underlying play/question/theory.

Phase 2 participants were 29 children (20 male; median 10 years) and 18 healthcare providers (16 female; 10 nurses; median 30-34 years). Children and healthcare providers interacted with prototypes of the app as part of its preliminary usability evaluation and to provide additional input into the app’s content and features. Data were shared with the programming team to support iterative refinements to the app.

#### **Findings or Outcomes**



Phase 1: Both children and healthcare providers identified nausea, fatigue, pain, and sadness as most frequently occurring symptoms. Children’s drawings also depicted the consequences of symptoms on children’s daily lives. Healthcare providers reported primarily relying on observation to assess symptoms and related challenges in discerning and interpreting children’s behaviors. They also expressed a desire to understand specific characteristics of symptoms to guide interventions.

Both children and healthcare providers emphasized the capacity for personalization and creativity within the app. Children related that the app should facilitate interactions with the healthcare provider, support the child’s preferred method of communication, and avoid unnecessary talking. Healthcare providers related that the app should emphasize patient/provider interaction and have the capacity for data storage and retrieval to support trending of symptoms.

Phase 2: Children and providers offered suggestions regarding phrasing of text-based items and interactions with the app’s features that were addressed in an iterative manner. Children were able to navigate the app’s features with minimal guidance and could illustrate symptoms such as mouth pain from oral mucositis and vincristine-induced jaw pain using the app.

Phase 1 & 2 data guided the creation of “Color Me Healthy,” a personalizable, game-based app that supports children in daily symptom reporting. Children receive rewards for completing key tasks in the app. A feasibility and acceptability trial is forthcoming.

### Conference Learning Gaps

Pediatric oncology nurses need to recognize and respond to symptoms children experience as a consequence of their disease and its treatment. Mobile technology-based resources can support children in communicating their symptoms in a developmentally meaningful manner.

### Learner Outcome

Attendees will be able to describe the process for designing a child-centric technology-based resource for symptom assessment that engaged children with cancer and pediatric oncology healthcare providers as co-designers.

### **Paper Presentation: Reasons, Hopes, Risks, Expectations: Qualitative Interviews of Parents Consenting to Genomic Sequencing for their Child**

#### Author(s)

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### Basis of inquiry

With recent advances in genetic testing technology and data analysis genomic sequencing is rapidly being incorporated into clinical care for patients diagnosed with cancer. However, little is known about why parents of children with cancer consent to genomic sequencing and how they understand and weigh the risks, benefits, and uncertainty inherent in genetic testing.

### Purpose/Objectives

This qualitative inquiry was part of the Genomes 4 Kids study (G4K) which included somatic and germline sequencing in a cohort of 301 prospectively identified pediatric oncology patients with leukemias, central nervous system (CNS) or non-CNS solid tumors who underwent treatment at St. Jude Children's Research Hospital. The aims of this aspect of the study were to identify reasons for participation given by parents enrolled in the larger study, what they perceived to be risks and benefits, and what they expected or hoped to learn from participation.

### Methods

Grounded theory methodology guided this aspect of the research. A convenience sample of 31 parent interviews (representing 31 patients) from the total study sample of 301 children and adolescents diagnosed with cancer who agreed to be interviewed after enrollment in a genomic sequencing study were interviewed by 2 trained interviewers. Interviews were completed in person, audio-recorded and transcribed. An open-ended interview guide was used. The constant comparative method was used for data analysis. Codes were generated and analysis was completed jointly by 5 study team members.

### Findings or Outcomes

Altruism was the most commonly cited reason for study participation as well as the most frequently reported benefit of study participation. Other frequently cited benefits included gaining knowledge about the child's cancer, determining if the cancer was hereditary (thereby indicating risk for other family members) and contributing to research. The most frequently cited hopes or expectations for study participation were determining if the cancer was hereditary followed by the desire to be proactive and begin treatment or surveillance as early as possible if needed. A majority of parents recalled that risks such as the possibility of receiving positive results (and the implications of such findings) and concerns for insurance discrimination were explained, however many perceived there to be no risk associated with the study for their child.

### Conference Learning Gaps

Pediatric hematology/oncology nurses' roles include supporting patients and families as they make difficult decisions related to their child's care and treatment. Understanding the rationale for genomic sequencing as well as the potential risks, benefits, and uncertainty that may result from sequencing will allow nurses to provide more compassionate and informed care.



### Learner Outcome

The learner will be able to recall parental reasons, risks, benefits, hopes and expectations for enrolling their child in a genomic sequencing study.

### **Poster Presentation: A Global Health Nursing Fellowship: Pediatric Oncology Nursing Education in Uganda**

#### Author(s)

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#### Basis of inquiry

Pediatric Oncology nurses in high income countries have access to a variety of educational opportunities to guide them in the care of oncology patients. They have access to a comprehensive nursing orientation, educational materials such as the core curriculum as well as certification opportunities in pediatric hematology/oncology nursing and chemotherapy/biotherapy. Nurses in developing countries enter the profession at different skill levels and do not receive formal training within the specialty that they work in. In low income countries, approximately 80 % of children are diagnosed with cancer with a survival rate of about 20% compared to their children in high income countries. In 2015, at the request of the Medical University of Science and Technology (MUST) in Mbarara, Uganda, the global health program at Massachusetts General Hospital (MGH) developed an initiative to develop an oncology nursing curriculum and establish standards of care for the oncology nurses at Mbarara Regional Referral Hospital (MRRH).

#### Purpose/Objectives

The purpose of an identified pediatric oncology nursing curriculum at MUST/MRRH was to augment the opening of an 18 bed inpatient/outpatient pediatric oncology unit in 2017. A total of six nurses participated in the nurse training with only one nurse having had prior pediatric experience. A pediatric oncology nurse was selected as the nurse fellow to help train the nurses in the unique care this population require as well as the safe administration of chemotherapy and management of complications related to treatment. The goals of the program were to adequately prepare nurses to care for pediatric oncology patients.

#### Methods

A needs assessment was conducted prior to the start of training to identify the nurses learning needs. The results of the assessment showed a need for a better understanding of the most common pediatric cancers and treatment options as well as the lack of education regarding safe handling of hazardous medications and protocols for managing pediatric oncology patients. A curriculum was created using the APHON Chemo/Bio Provider manual and the Essentials of Pediatric Hematology/Oncology Nursing.



Clinical training included chemotherapy protective equipment and how to verify/calculate chemotherapy. Practice test questions were also utilized upon course completion to assess understanding of the content.

#### Findings or Outcomes

Upon completion of the training, the nurses verbalized an increased knowledge of common pediatric cancers and their treatment. The nurses were able to demonstrate safe administration of chemotherapy and upon a return visit had maintained the standards. The nurses demonstrated increased critical thinking skills when interacting with colleagues and reported feeling decreased anxiety when speaking to families about cancer and its treatments. Ongoing communication with the nurses and the pediatric oncology team at MGH occurs every other week via Skype to discuss challenging cases as well as to reinforce education.

#### Conference Learning Gaps

This poster will provide an overview of a global nursing fellowship and the development of a pediatric oncology curriculum to provide education to nurses in a low income country. It will contain visuals of educational materials that were created for the nurses to reference.

#### Learner Outcome

1. The learner will be able to identify the need for a nursing core curriculum to train nurses in the care of pediatric oncology patients in low income countries.
2. The learner will be able to identify educational challenges for nurses in a low income country.

### **Poster Presentation: The Adolescent Young Adult (AYA) Navigator increases AYA directed first contact in the Adult Oncology Setting**

#### Author(s)

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#### Basis of inquiry

AYAs with cancer have unique needs/concerns that are often overlooked during the initial cancer diagnosis. It has not been demonstrated that the introduction of a navigator dedicated to AYAs with cancer in the adult oncology setting successfully facilitates early contact and assessment of AYA specific concerns in the new diagnosis period.

#### Purpose/Objectives



This project examines the impact of introducing the AYA navigator role in a Canadian Health Institution on early contact and assessment of AYA specific concerns in the new diagnosis period.

### Methods

Clinical practice based content

In Alberta, Canada, the patient navigation program improved patient satisfaction with their cancer experience through increasing access to specially trained registered nurses with oncology expertise who guide and support patients and families through their cancer journey. While an AYA oncology program was established at the Cross Cancer Institute in 2014, the ability to make early contact with AYAs at time of diagnosis was challenging for the AYA oncologist and cancer center psychosocial team. In 2017, a pilot project of an AYA patient navigator was grant funded with the goal of making early contact with more than 90% of newly diagnosed AYAs and to assist patients, families, friends, and health professionals throughout the unique AYA cancer journey.

The AYA patient navigator received training through the provincial patient navigation program and worked closely with AYA oncologist for AYA specific training and mentorship. A list of all referred cancer patients between ages 17 and 29 was automatically generated on a bi-weekly basis by the electronic medical record (EMR) system for the AYA patient navigator. The AYA patient navigator attempted early contact with all newly diagnosed AYAs to identify specific needs/sources of distress, offer early access to psychosocial support, and provide information on AYA specific support resources. A follow up plan was developed with the AYA. A referral pathway was developed for AYA patients requiring additional support during their cancer journey. Data on AYA navigator encounters was collected using a specific AYA form in the EMR identifying the time point in patient cancer journey and the patient concerns supported by the navigator.

### Findings or Outcomes

Implementing AYA navigation support raised first line contact with AYA specific assessment and services from under 5% to over 85% percent of all AYAs between 17 and 29 years old with a new diagnosis of cancer.

### Conference Learning Gaps

Poster will assist nurses to better understand the unique needs/challenges faced by AYAs early into diagnosis and consider strategies such as the AYA navigator as a key team member in ensuring early contact and assessment of AYA with cancer. Poster will include a case study with review questions to consider. Graphical demonstration of expressed needs of AYAs will visually stimulate discussion of the poster viewer.

### Learner Outcome

The learner will demonstrate an understanding of the success of the AYA navigator in ensuring early contact and assessment of AYAs newly diagnosed with cancer.