THE DEVELOPMENT OF AN ONLINE RESOURCE MANUAL FOR PARENTS CARING FOR THEIR CHILD AT HOME FOLLOWING SURGERY

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Abstract

Background: Every day, children all over the world undergo both emergent and elective surgical procedures. With our rapidly changing health care system, children are discharged home quicker than ever before with the responsibility of care placed on the parents and caregivers of the child. Additionally, the use of the internet is continuously increasing, with parents using the internet for health information for their children on a regular basis. The development of an online resource manual for parents caring for their child at home following surgery was completed using various methodologies.

Methods: The methodologies used to help inform the need, content, and strategies for the development of the online resource included a literature review, environmental scan, and consultations. The Model of Instructional Design by Morrison, Ross, Kalman, and Kemp (2013) was used to guide the development of this project.

Results: Results from the literature review concluded that the most common parental learning needs in caring for their child at home following surgery include pain assessment and management, and cast care. Health literacy and readability of materials for low literacy levels were other common themes throughout the literature. Results from both the environmental scan as well as consultations showed that online resources are a popular avenue for parents and play a vital role in discharge planning and teaching.

Conclusion: For the purposes of this practicum, a paper version of an online resource for parents was developed consisting of six main modules. Integration of the resource into an online platform can be done when available resources and support can be confirmed.

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List of Appendices

The purpose of this report is to describe the development of the practicum project, which involved the development of an online resource for parents caring for their child at home following surgery. The report includes the project's background and rationale, a summary of the methodologies used including the use of an instructional design model, a summary of the actual developed resource, how this project has allowed the demonstration of advanced nursing practice competencies, and finally what the next steps of such a project should be.

Background and Rationale for Practicum

Every day, thousands of children across Canada and all over the world undergo both emergent and elective surgical procedures. With our rapidly changing health care system, children are discharged home quicker than ever before with the responsibility of care placed on the parents and caregivers of the child. As a pediatric nurse, I have seen both the benefits and challenges of early discharge postoperatively. Being in hospital poses its own social, emotional, and financial strain on families. Alternatively, being home and caring for a child postoperatively raises a lot of questions and concerns if families do not receive adequate discharge instructions or were distracted during discharge teaching (Browne, Flanigan, McComisky, & Pieper, 2007; Smith & Daughtrey, 2008; Weiss et al., 2008; Wong, Hockenberry, & Wilson, 2011).

The idea of developing an online resource came from my experience as a pediatric nurse at the Janeway Children's Hospital. Overall, the majority of my working experience has been on the surgical inpatient unit J4Surgery. In my practice, children and families are discharged almost daily following recovery from surgery. Upon discharge, pamphlets

are given out and discharge teaching for parents is completed by the nurse. Discharge teaching includes concepts parents need to know when caring for their child at home, such as pain control, dressing changes, and returning to normal mobilization, while they continue to recover. The types of pamphlets that exist are minimal, some are outdated and not evidence based, and those that do exist are for the most common surgeries. When a patient is discharged following a surgery in which there is no pamphlet to guide discharge teaching, the nurse will use his or her own knowledge and experience to teach parents.

Additionally, parents telephone from home on a regular basis asking questions in relation to their child's surgery, and what they should do. These telephone calls often made me wonder about the consistency and reliability of our discharge teaching. Does it differ from nurse to nurse? Are all nurses giving out the same information? In a way, an informal needs assessment of this unit had already been underway, with a strong need for this type of resource identified.

Resource guides will always be an important part of caregiver support and health specific information. There will always be room for improvement, growth, and increased content on existing websites, and it is known that caregivers have an interest in online based health-specific information (Hasman & Zafron, 2010). The use of the internet is continuously increasing, with parents using the internet for health information for their children on a regular basis. With non-credible websites being used, and a plethora of inaccurate health information available, health professionals need to develop credible, easy to use resources online for parents (Goldman, 2014). The rationale for this practicum was two-fold: to improve the recovery process of children by increasing parents'

knowledge of postoperative surgical care, and to improve the discharge teaching process to make it more streamlined and consistent.

Practicum Goal and Objectives

The overall goal for my practicum was to develop an online resource for parents of children who have undergone surgery. The resource would be easily accessed, would use language and style suitable to those with limited literacy skills, and would provide evidence-based postoperative information and discharge teaching instructions that parents need to know after their child has had surgery.

The key objectives of this practicum were:

1. To identify the learning needs of parents caring for their child postoperatively through review of the literature and consultation with key stakeholders.

2. To investigate the methodology, content, and focus of the online resource through review of the literature, an environmental scan, and consultation with key stakeholders.

3. To identify appropriate methodology of instructional design and readability of educational materials as it relates to the development of the online resource.

4. To demonstrate advanced practice nursing competencies as it relates to the development of an educational resource.

Overview of Methodology

The methodologies used to help inform the need, content, and strategies for the development of the online resource included a literature review, environmental scan, and

consultations. A complete report of the literature review can be found in Appendix B, a report of the environmental scan in Appendix C, and a report of the consultations in Appendix D.

Summary of Literature Review

The primary method behind the literature search was to inform the need for a resource, the content of the resource, and the methodology of creating the resource. To facilitate this, Memorial University's OneSearch was used to access relevant databases such as CINAHL and PubMed. Keywords used included "postoperative", "parents", "pediatrics", "discharge teaching", "educational resources", "health literacy", "consumer health information", "instructional design models", and "parental learning needs". While the literature was limited to English documents, an attempt was also made to limit the publishing year to be no later than 2000 however, some outliers had to be included for the sake of relevance. Three major themes were examined within the literature. The themes were, rationale for an online resource, content for the online resource, and methodology of the development of an online resource.

Rationale for an online resource. Results from the literature review indicated that internet use is among the most popular forms of media today. Internet use by the public has continuously been on the rise since its inception and has been a source of a large breadth of knowledge for both physicians and patients alike (Briones, 2015; Goldman, 2014; McInerny, Adam, & Campbell, 2009). A study by Knapp et al. (2010) showed that 60% of parents use a combination of internet sources and their physician as their primary sources of health information. Another study showed 56% parents in a

pediatric emergency room stated that they had used the internet to search for health-related information. Of those parents, 8.5% had searched their child's symptoms online right before bringing them to be seen in the emergency department (Goldman, 2014). With this high percentage of people using the internet as their primary source of health information it is imperative that the information found be relevant, up to date, and trustworthy.

Although Google is one of the most popular search engines for health-information, health care workers do play a part in influencing what sites patients visit (Sebelefsky et al., 2015). The use of the internet for harnessing health information has been coined with the term e-health (Briones, 2015). E-health has varying definitions across the literature, but in general it can be defined as the use of technology, mainly the internet, to improve or enable health and health care. Briones (2015) conducted 50 interviews of young adults to determine how they make meaning of online health information. Results indicated that people feel e-health improves their physician visits, and it made health information more easily accessed (Briones, 2015). Therefore, it could be said that if the appropriate online resources exist for nurses and physicians to give to parents and caregivers, it is likely they will use them.

Additionally, parents have identified a need for continuously available online resources to support, not necessarily replace discharge teaching (Smith & Daughtrey, 2008; Swallow et al., 2012). Weiss et al., (2008) studied parental readiness for discharge in relation to their discharge teaching in a qualitative study of 135 parents. Results suggested that the delivery of discharge teaching by nurses is associated with increased readiness for discharge, as well as less coping difficulty at home. While many variables

were analyzed in the correlational study by Weiss et al. (2008), one part did show that many parents felt they were given more information on discharge then they needed to know. The authors also concluded that the skill in which the nurse delivered the information was directly associated with parent's readiness for discharge. With this in mind, it seems that an online resource with consistent information can be a valuable support system for parents to reach out to when they are home and have questions.

Content for an online resource. In regards to reviewing the literature for appropriate content for the online resource, it was important to know what the needs of parents were when caring for their child postoperatively. Results from the literature review indicated the top parental needs included pain assessment and management, and cast care.

Pain. The most common theme that emerged from the literature was postoperative pain control for children at home. The sub-themes that emerged were pain assessment, pharmacological pain management and non-pharmacological pain management. Pain is described as an unpleasant sensory experience and is felt regardless of age, developmental stage, and type of surgery. It can negatively affect wound healing if not managed properly (Ball, Bindler, & Cowen, 2014; Wong, Hockenberry, & Wilson, 2011) For these reasons, pain assessment management are the most important concepts in postoperative care and is consequently one of the most important concepts in discharge planning and teaching with parents of children (Ball & Bindler, 2006; Browne, Flanigan, McComisky, & Pieper, 2007).

Finley, Chambers, McGrath, and Walsh (2003) presented a quantitative study on the effectiveness of the Parent's Postoperative Pain Measure (PPPM) as a way for parents

to measure postoperative pain in children aged two to six years. The PPPM included 15 behavioral items that parents simply said "yes" or "no" to their occurrence. The items included things such as whining or complaining more than usual, crying more easily than usual, acting quiet, having less energy, looking flushed, refusing to eat, playing less than usual, not doing the normal things he/she does, acting worried, along with many others.

Sutters, Savedra, and Miasowski (2011) describe the pain control program "Pediatric PRO-SELF" as an effective program for parents caring for children at home following tonsillectomy. The program is an adaptation from a similar adult program used in cancer care. Components of the Pediatric PRO-SELF program include an information booklet, medication record, a timer, and a pain management diary. Although designed for use in children who have had their tonsils out, its use could easily be transferred to the care of any child who has undergone any type of surgical procedure.

In regards to pain management, the literature revealed that the most commonly used pharmacological pain medicines are acetaminophen, ibuprofen, and codeine. However, pain medication is only as effective as the dose given and the interval that it is given (Dorkham, Chalkiadis, Sternberg, & Davidson, 2013; Unsworth, Franck, & Coonara, 2007). Following a thorough search of the literature, Dorkham et al. reported that parent's attitudes and misconceptions about analgesia cause them to under dose their children. They discovered that 52% of parents were concerned about addiction, 73% were concerned about adverse effects, and most concerning was that 37% of parents thought that analgesics work better if they are given less. This goes against everything that is known about adequate pain control using analgesics. Similarly, Idvall, Holm, and Runeson (2005) stated that parents often experience difficulties providing pain relief, with

the main cause being parents' negative attitudes, lack of knowledge, and concerns about drug addiction. Educating parents on the proper pharmacological management of their child's pain at home would address the issues of parental knowledge, attitudes towards narcotics and drug addiction concerns. The literature also revealed that when parents had access to postoperative analgesia information, parents were significantly more satisfied and knowledgeable about pain control, and their children had better postoperative pain compared to those parents who did not have this information (Bailey, Sun, Courtney, & Murphy, 2015)

Helgadottir and Wilson (2014) used a randomized controlled trial to determine the effectiveness of educating parents about distraction techniques to minimize pain at home following tonsillectomy. The authors of this study discovered that education on distraction techniques combined with education on medication for pain decreases overall pain behavior scores (p < 0.001). Similarly, a qualitative study by Idvall, Holm, and Runeson (2005), showed that distraction was the most frequently used type of cognitive-behavioral strategy for pain relief. Similar to Helgadottir and Wilson, (2014) distraction was described by Idvall et al. as watching TV, talking, thinking of something else, and reading.

Cast Care. The other common parental need postoperatively that was evident within the literature was cast care. Since injuries account for a large proportion of children's hospitalizations (Browne, Flanigan, McComisky, & Pieper, 2007) it seems only logical that orthopedic procedures and cast care would be a top priority of parents caring for their child at home following surgery. Such cast care includes keeping the cast clean and dry, ensuring the child does not poke anything sharp inside the cast, keeping the limb

elevated as much as possible to reduce swelling, checking the toes or fingers to ensure

they are warm and pink, and being alert for drainage, odor, and increased pain (Ball,

Bindler, & Cowen, 2014).   Appropriate cast care aids bone healing and growth, increases

the child's comfort level, and reduces the chance of infection (Wong, Hockenberry, &

Wilson, 2011).

Throughout the literature, it was evident that parents have specific concerns in

relation to cast care such as incontinence care, transportation with a cast, skin care, and

positioning. Another common but frustrating issue for parents with a child in a hip spica

cast is trying to maintain skin integrity with a child who is incontinent (Reed, Carroll,

Baccari, & Shermont, 2011). Likewise, in a descriptive cross-sectional study by Demir,

Erden, Bulut, Carboga, and Elbas (2015), 97% of parents reported issues at home while

caring for their child in hip spica cast, including toileting their child, cast care, skin care,

and personal hygiene. Similarly, Clarke and Dowling (2003) provided an analysis of

available literature for caregivers of hip spica casts to determine pertinent issues. The

main focus for caregivers were guidelines related to positioning, feeding, sleeping,

moving and handling, and travelling by car. Following a thorough review of the literature,

Clarke and Dowling (2003) created a troubleshooting guide for parents and health

professionals caring for a child with a hip spica cast.

Following an increase in telephone calls to the nursing unit from parents with

questions, Reed, Carroll, Baccari, and Shermont (2011) determined that they needed a

standardized teaching guide for parents. They developed a staff-led educational program

to teach parents how to care for their child at home with a hip spica cast. After

developing standardized teaching guides, Reed et al. (2011) then went on to evaluate the

effectiveness of these guides on parents comfort level and skill with the care of their child's cast. Their results showed that 100% of parents caring for a hip spica cast for the first time found the educational materials provided useful, and only 5% of patients returned to hospital with skin breakdown.

Methodology of Resource Development. The next logical step of the literature review was the methodology of developing an online educational resource for parents. Morrison, Ross, Kalman and Kemp's (2013) Model of Instructional Design was used to help develop the resource. Given its popular use throughout instructional design, it would be the most appropriate model to use for this resource's development. Health literacy and readability of materials were two other key themes found in the literature in relation to instructional methodology and educational resource development.

Model of Instructional Design. The Model of Instructional Design by Morrison, Ross, Kalman, and Kemp (2013) is a circular model depicting the various concepts and components relevant to an instructional design plan. In the center of the model, are the nine concepts central to instructional design. These are instructional problems, learner characteristics, task analysis, instructional objectives, content sequencing, instructional strategies, designing the message, development of instruction, and evaluation instruments. Surrounding these nine central concepts, in an oval shape are the eight processes that continue on an ongoing basis throughout the lifespan of an instructional design project. These processes are planning, implementation, project management, support services, revision, summative evaluation, formative evaluation, and confirmative evaluation (Morrison et al., 2013).

This model was helpful in informing the development of the online resource for parents in a number of ways. Firstly, the learner characteristics proved to be very important to keep in mind during the resources' development. It was imperative that the resource be written at a level that all parents will be able to read and understand, regardless of their education level. Secondly, the literature review as well as the environmental scan and consultations with key stakeholders helped inform the instructional objectives by narrowing in on the specific content of the resource. The instructional objectives will ultimately be the specific concepts that parents need to know in order to care for their child at home following surgery. The environmental scan and consultations also helped to inform how to design the message and develop the instruction. The online resource developed will not be teaching parents per say, but rather providing them with the necessary information should they choose to seek it out. Therefore, the components of the design model such as evaluation instruments, summative evaluation, and formative evaluation, will not be relevant to this specific educational resources' development. However, it could certainly be a point to research for the future and other similar resources.

Health Literacy. Within the educational resource literature, there is much attention given to the concept of health literacy. Today, adults who have a reading level of less than ninth-grade are said to have basic or below-basic literacy, and have inadequate health literacy (Fagnano, Halterman, Conn, & Shone, 2012). Within Canada, over 60% of adults and 88% of seniors are not health literate (Public Health Agency of Canada, 2014). With low literacy being associated with adverse health outcomes (DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004) it is important to keep the concept

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of health literacy in mind during the development of an education resource. There are a number of ways in which this can be facilitated. The material should be at a maximum reading level of grade six (Polishchuk, Hashem, & Sabharwal, 2012). Some sources even recommend a maximum level of grade five (Ball & Bindler, 2006; Parnell, 2015). To ensure this, sentences should be as short as possible, using basic terminology especially when speaking of medical concepts (Ball & Bindler, 2006; Mayer, 2002; Parnell, 2015; Polishchuk et al., 2012). To ensure readability of materials is at an acceptable level, Polishchuk et al. (2012) recommend the Flesch-Kincaid grade formula which is as follows: 0.39 x (average number of words per sentence) + 11.8 x (average number of syllables per word) – 15.59. The resulting number from the formula corresponds with the appropriate U.S grade level.

Summary of Environmental Scan

As part of the development of any major project, it is important to know what types of similar programs or resources already exist. To do this, an environmental scan of online resources available for parents in Pediatric hospitals across Canada was completed through the Canadian Pediatric Surgical Nurses Interest Group (CaPSNIG) and the Canadian Association of Pediatric Health Centres (CAPHC, 2011) as well as a review of the printed discharge instructions currently available for parents on the surgical inpatient unit of the Janeway Children's Health and Rehabilitation Centre. The specific objectives of the environmental scan were threefold: to review content of online resources for parents already made available in pediatric hospitals across Canada, to investigate the methodology and content of these resources including the language and literacy levels

used, and to determine if the resources currently available on J4Surgery are up to date and evidence-based, and can be used in the development of the online resource.

Data collection methods. In order to collect relevant data from all pediatric hospitals across Canada, CaPSNIG were contacted via email in order to inquire as to if an online resource at their hospital exists and if so, a link for the website was requested. Members were also asked if in their experience, the resource was beneficial. Because of the low response rate from CaPSNIG members, an alternative approach to search for current online resources was used. Utilizing the CAPHC (2011), a list of pediatric hospitals and their websites across Canada was found. Each of these websites were then reviewed to see if an online resource for that hospital existed. Additionally, copies of all printed discharge teaching instructions available on the pediatric surgical inpatient unit J4Surgery, were collected. They were reviewed for content, age, and their applicability to the development of the online resource.

Results. Overall, a total of eight online resources in existence across pediatric hospitals in Canada were identified either by members of CapSNIG or through the CAPHC database. A total of ten printed discharge instructions were found on J4Surgery for review.

Through email conversations with CapSNIG members, three online resources already in existence within Canada were identified. These were aboutkidshealth.org, a patient education library from Hamilton Health Sciences, as well as a family resource website from BC Children's Hospital. Unfortunately, the three respondents did not answer the second question on the letter of inquiry, as to if parents found this type of

resource beneficial.

Aboutkidshealth.org is a website based out of The Hospital for Sick Kids in Toronto, Ontario. It is organized with a database of conditions and diseases including common surgical procedures listed alphabetically with an option to search using key words. There are also separate pages for pregnancy related topics, nutrition, drugs and medications, and safety information. The webpage even contains "how-to" videos for parents, such as how to administer liquid medication to your child, and how to stop nosebleeds.

The Hamilton Health Sciences patient education library is broad and encompasses both adult and pediatric health information. When the term "appendectomy" is searched, two pdf documents are found, one titled "appendectomy" and the other "appendectomy (child)". When you click on the documents, a printable, pdf document opens with basic information explaining what an appendectomy is, what happens before, during, and after surgery, and basic care for a child at home following an appendectomy. There are no pictures or diagrams.

BC Children's Hospital. The BC Children's Hospital website is described as a one-step library for borrowing books, getting pamphlets, and downloading videos to find health information. Unfortunately, this website was a bit more complicated to use. When the term "appendectomy", "appendicitis", and "appendix" were searched for, all separately, no results were found. The term "surgery" was then searched for and it returned 166 results of varying content.

Alberta Children's Hospital. Alberta Children's Hospital home page on their website, has a main navigation bar which includes a tab just for parents. Within the parents tab, there a simple easy to use website with a small number of PDF documents including preparing your child for surgery, caring for your child at home following surgery, and also instruction sheets for teenagers.

Children's Hospital of Eastern Ontario. The Children's Hospital of Eastern Ontario's (CHEO) website for online resources for parents has an A-Z library of common illnesses and diseases. It also has broad topics such as surgery and anaesthesia listed, which when clicked opens a printable PDF document.

Fraser Health. Fraser Health is an integrated health authority of many hospitals located in British Columbia. Their website has an online resource for parents on child and youth health information. The resources are generalized to nutrition, dental, speech and language, immunizations, and school health topics.

IWK Health Centre. The IWK Health Centre is located in Halifax, Nova Scotia. Their website does contain a resource page for parents on information about their child having surgery. However, the information is mainly logistical in nature related to preparing for surgery and who would be on the team involved in their child's care.

Regina Qu'Appelle. The Regina Qu'Appelle website offers a Health A-Z section of their website with a large number of topics. Included among these are printable, PDF documents of discharge instructions for various surgical procedures. There are both adult and pediatric specific information.

J4Surgery Resources.

The following printed pamphlets are available and used on J4Surgery as part of discharge teaching:

- Home care following tonsillectomy and adenoidectomy

- Alveolar bone grafting: Post op instructions

- Instructions for patients: Ear tubes

- Post-operative care following inguinal orchidopexy

- Home care following spinal surgery

- Parents guide to clubfoot correction

- Post-operative care following circumcision

- Discharge orders for cleft lip repair

- Head injury

- Cast care: Patient information.

These pamphlets have no specific references, except for referencing the Janeway Children's Hospital. The majority of pamphlets are dated 2012, with the oldest pamphlet dated 2007. All of the pamphlets contain general information on when to return to normal activities, a normal diet, and what parents should watch out for in regards to signs and symptoms of infection.

Summary of Consultations

Seven consultations, in the form of interviews, were completed involving a novice nurse, a senior nurse, the clinical educator, the surgical outpatient nurse coordinator, a Janeway emergency room/telephone advice line nurse, the Janeway Resource Centre librarian, and a pediatric surgeon. All consultations were conducted at the Janeway Children's Hospital and Rehabilitation Centre.

The objectives for the consultations were as follows:

1. To understand what health professionals believe to be the most important parental needs in caring for their child postoperatively at home.
2. To determine what topics health professionals believe to be a priority for the development of an online resource for parents.
3. To gather expert opinions and knowledge in the field of pediatric surgery that will help inform the development of an online resource for parents.

Results. After data had been analyzed using content analysis, results were grouped into five major themes: parents need knowledge about pain control, parents need reassurance, returning to normalcy, when to return to hospital, and rationale for an online resource.

All nurses who were consulted as well as the pediatric surgeon brought up the concept of pain control postoperatively. Specifically, that parents need to know how to adequately assess their child's pain, as well as be able to appropriately treat it. Two

consultants made reference to parents being fearful of certain medications to control their child's pain.

All consultants brought up the concept of parents needing reassurance postoperatively. This includes reassurance that what their child is experiencing is normal, and that what they are doing is ok. One nurse said a very common but simple question among parents is "Am I doing everything right? Can I be doing anything better?" When asked if they thought an online resource would benefit parents, almost all consultants talked about the positive reassurance it would give parents within their response. "Parents need comfort and support that everything is ok". "An online resource would definitely benefit parents; it would give them peace of mind".

All consultants were in agreement that the most common questions parents have about their child's postoperative care relate to when their child will be able to return to normal. This included returning to a normal diet, returning to school, returning to their normal activities, and returning to sports. Other things included when they can take off their dressing if they have one, when they can go back to taking showers, and when they can have a bath. While some of the answers to these questions vary depending on the type of surgery, most consultants agreed that there are commonalities among most surgeries about when to return to school, sports, showers, and usual activities.

All consultants except the Janeway Resource Centre Librarian stated that one of the most important concepts to include within the online resource for parents is information on when they should bring their child back to their doctor or return to the emergency department. It was thought among all consultants that more often than not,

parents return to hospital with their child for minor concerns that do not require the use of an emergency room.

Throughout the consultations, there were many different reasons identified as to why and how an online resource would benefit parents. Unanimously, all consultants agreed that an online resource would be of great benefit to parents, families, and caregivers alike for caring for a child postoperatively. Four out of seven consultants brought up internet usage when asked how an online resource would benefit parents. Three consultants agreed that since parents are going online regardless, it is important for a large hospital such as the Janeway to have a specific reference that parents can trust. The Janeway Resource Centre librarian was very enthusiastic with the possibility of the development of an online resource for parents, as she stated it is something she was hoping to have developed over the next few years. She said there is already an easy to use, information management system called "LibGuides" in which information can easily be added into a pre-set template online. She thought the online resource for parents could easily be added to the Janeway Resource Centre website, in which she already manages.

Summary of Parent Resource Manual

Due to the nature of the practicum, a paper version of the online resource was developed in such a way that it could be easily transferred into an online format if required. Content of the resource was decided upon by taking the combined key themes that had emerged from the literature review, environmental scan, and consultations. These content themes include pain assessment and management, returning to a normal diet,

returning to normal activities, cast care, when to return to the emergency department, and important phone numbers.

The resource starts with an introduction to parents as to why this resource is important to them, followed by key learning objectives. From there, pain is the first main module of the resource. Pain assessment, including different strategies and tools parents can use at home to assess their child's pain is described. Pain management, including pain relief with and without medication is discussed in detail including different types of analgesics, and different distraction techniques parents can use.

The second main module of the resource is about returning to normal activity following surgery. General guidelines are given regarding when children can return to various sports and activities following certain types of surgeries. This is presented in a table format. Also included in this section are guidelines on bathing and showering after a child has had surgery.

The third main module of the resource concerns returning to a normal diet following surgery. General guidelines are given as to when children can start eating regularly, and tips about dealing with things such as upset stomach, nausea, and vomiting.

The fourth main module of the resource pertains to cast care. Information to care for the cast, ways to assess a child for proper circulation, and pointers on how to take a bath or a shower with a cast on is discussed. Additionally, when to bring your child back to the emergency department or cast room is presented.

The last two smaller sections of the resource include a list of reasons as to why a parent should bring their child back to the emergency department after surgery, and a list of important phone numbers they may need once they are home if they were to have any questions or concerns. References are provided after each section as well as at the end of the resource.

Readability was ensured throughout the writing of the resource by using short sentences and simple words. Medical terminology was avoided when possible. After each draft was written, the Flesch-Kincaid grade formula (Polishchuk et al. 2012) was applied to each paragraph throughout the resource to determine the average reading grade level. An acceptable literacy level was reached when the average grade reading level of the resource was between six and seven. In order to ensure that the resource was visually appealing to the public, colored headings and images depicting the various themes were integrated throughout each section. Finally, the resource was sent back to consultants originally interviewed, for feedback and comments. Very little feedback was obtained, however all feedback was considered when developing the resource. See Appendix A for the resource in its entirety.

Advanced Nursing Practice Competencies

The completion of this practicum has helped me demonstrate multiple Advanced Nursing Practice Competencies. Advanced Nursing Practice competencies were created to ensure the RN meets the specific knowledge, theory, personal attributes and clinical skills to work in their role safely, ethically and competently (Canadian Nurses Association, CNA, 2008). The ANP framework, as defined by the Canadian Nurses

Association (2008), encompass a wide range of clinical, research, leadership, and consultation and collaboration competencies. Throughout the development of each aspect of this practicum, I feel these competencies have been demonstrated simultaneously while allowing me to represent what it means to be an advanced practice nurse.

Clinical

Clinical competencies within the ANP framework have been met through the development of this practicum in a number of ways. The advanced practice nurse uses clinical experience, research, and related knowledge to develop and plan needs-based programs and resources (CNA, 2008). This was demonstrated throughout the development of my practicum through the use of research and literature reviews to assess and determine the need for such a resource, and to determine the most appropriate content within the resource. Another key clinical competency within the ANP framework is to develop educational programs based on needs and priorities. Directly, this has been completed through the recognition of the need for such a resource manual and its direct development process as well.

Additionally, as a pediatric nurse having direct client interactions with parents and families, I have gained experiential knowledge in discharge teaching that has helped with the development of this resource.

Research

The completion of this practicum has allowed me to develop ANP research competencies in a number of ways. "Generating, synthesizing and using research is

central to advanced nursing practice" (CNA, 2008, p. 23). Through the use of an

integrated literature review, I have critiqued, interpreted, and applied evidence-based

findings into the development of the online parent resource manual. This included

critiquing each study using a critical appraisal tool kit (Public Health Agency of Canada,

2015) to evaluate its usefulness within the practicum, as well as giving each study used a

rating of strong, medium, or weak. During the consultation process, research

methodology was used to conduct interviews, maintain confidentiality, and to collect,

analyze, and interpret the data obtained. Also, through the presentation of this practicum

to my colleagues and university, I have disseminated new knowledge through formal and

informal channels.

The literature review had direct impact on the content of the resource, and can

therefore be said to be evidence-based in nature. The literature informed the most

common parental learning needs postoperatively were pain assessment and management,

and cast care. Therefore, these are two main modules included within the resource. The

literature also helped informed the rationale for an online resource, as well as ways to

ensure readability and attractiveness.

Leadership

I have demonstrated the leadership competencies put forth by the ANP framework

(CNA, 2008) during this practicum in various ways. Having the motivation and insight to

see the need of an online resource within my work environment demonstrates a key

leadership skill. Advocating for such changes and improvements with a health care

system is important. By teaching parents to be effective postoperative caregivers at home,

I have taken a step in the right direction of advising clients and the community on issues related to health. I have demonstrated leadership within my own workplace through this practicum as being an agent for change in the eyes of my colleagues and peers by developing something that they strongly felt was needed for parents.

Consultation and Collaboration

"The ability to consult and collaborate with colleagues across sectors and at the organizational, provincial, national and international level is a characteristic of nurses in advanced practice" (CNA, 2008, p.26). This was demonstrated directly through the entire consultation and environmental scan processes. Through the environmental scan, I was able to consult with other nurses and health care authorities at a national level to determine the type of similar resources used in their areas. Additionally, I was able to connect with people through the consultation process at an organizational level, to gather expert opinions and knowledge in relation to pediatric surgery and what the resource itself should contain.

In my practice, I maintain a close relationship with my colleagues and collaborated with them again once the resource was developed in order for them to review and provide feedback. This type of collaboration process was also informally completed prior to the starting the practicum, and some colleagues had come to me to discuss the need for such a resource for parents on our unit. Additionally, collaboration occurred between myself the Janeway Resource Centre librarian, to put the resource online as a template until the approval process is complete.

Throughout the development of this practicum, consultation and collaboration was an ongoing, circular process between my supervisor and myself in order to edit drafts, improve wording and clarity of reports, and maintain an overall comprehensiveness.

Next Steps

There are a number of necessary steps that would have to be taken in order for this resource to be fully successful in the future. These steps would include an approval process, an upload to being fully online, and a plan for an evaluation.

Approval for this resource would ultimately have to be made by the Program Director of the Children's and Women's Health Program within Eastern Health. The resource should be taken to a regional Children's and Women's Health Program policy meeting where multiple representatives of the program throughout the region meet to discuss, review, and update policies for the program. The Program Director sits on this committee and it would be a good first step in the getting the approval process started.

For the purposes of this practicum, a paper version of the online resource was developed. Once the approval process has been completed, the next step would be to put the resource online. The librarian for the Janeway Children's Hospital and Rehabilitation Centre has already expressed interest through our mutual consultations and collaboration in the development of the resources' online capabilities. As already discussed within the consultation report (see Appendix D) there already exists a platform, LibGuides (Springshare, 2013), in which the resource could easily be transferred online. Once it is online, an educational plan for nurses would have to be implemented so that all nurses

within the hospital are aware the resource exists, and so they have the knowledge of how to properly access it to show the parents and families of their patients.

Once online, and full consultation and approval has taken place, this resource has a lot of potential for growth and expansion. Modules can be quickly edited with up to date information as research and practices evolve. Expansion can easily take place with adding modules to include other relevant health topics for parents including diabetes education, asthma education, and allergy information to name a few. There could also be a "further reading" section for parents added as well, with further outside websites and resources made available as links for parents to visit if they choose to. Over time, the resource has the potential to evolve into a large, accessible, fully comprehensive health database for parents of the Janeway Children's Hospital and Rehabilitation Centre.

In the future, an evaluation of the resource would be valuable. Currently, within LibGuides there already exists a way to track the number of views on the site for when the resource becomes available online. Also, there is a way within LibGuides to ask users if they found the resource helpful when they are leaving the website (Springshare, 2013). This way, parents would get an opportunity to express their opinions, level of satisfaction, and how much the online resource helps with their abilities to care for their child at home following surgery.

Conclusion

In conclusion, all four objectives for this practicum were met. Learning needs of parents caring for their child postoperatively, appropriate development of readability for

low literacy levels, and instructional design were all identified through the methodologies of a literature review, environmental scan, and consultation and key stakeholders. From there, a resource for parents was developed. The resource includes evidenced-based information that parents need to know in order to care for their child at home following surgery.

There are many potential implications for this resource. Increasing parental knowledge of postoperative care of their child at home can increase their confidence and readiness for discharge from hospital. By empowering parents with this knowledge we have the potential to decrease the average length of stay in hospital for surgical pediatric patients as well as improve their postoperative outcomes. Finally, by making this information online and accessible it is in turn increasing the accessibility of health care and health care information for parents and the public.

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Appendix A: Parental Resource Manual: Caring For Your Child At

Home Following Surgery

"COVER of Resource Manual"

Parent Resource Manual:

A Guide to Caring for Your Child at Home following Surgery

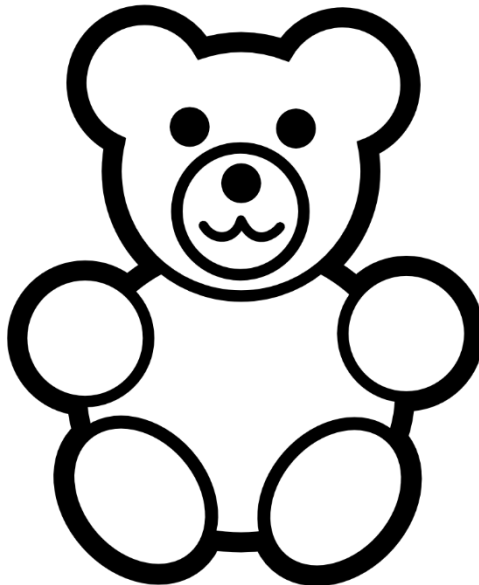# Developed by © Kelli L. Pitcher BNRN

May 2016

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Introduction

Why is this resource important to you?

Many children will need surgery for some reason or another during their childhood. Once your child is discharged, you may like some extra information to help your child recover as quickly as possible. This resource has been developed to supplement the information given to you while your child was in hospital. It was written so parents like you will have more knowledge about what your child will need to properly recover from surgery.

By reading this resource you will learn about:

❖ Pain: assessing your child's pain and how you can help with the pain

❖ Returning to a normal diet after surgery

❖ Returning to normal activities after surgery

❖ When to bring your child back to the Emergency Department

❖ Cast Care: how to care for your child's cast at home

❖ Important contact numbers to use if questions arise

Pain

Some points to know about pain after surgery:

- ❖ Pain is natural and normal to experience after surgery

- ❖ Some children feel and express their pain in different ways

- ❖ Proper pain control will speed healing and recovery time

- ❖ Improper pain control can delay healing and actually increase the chances of having complications such as:

  - Difficulty falling asleep or staying asleep

  - Problems with eating

  - A decrease in drinking that can cause dehydration

  - Behavioural problems or "acting out"

  - Delayed wound healing

  - Increased anxiety

  - Increased risk for infection

(Ball, Bindler, & Cowen, 2014; Wong, Hockenberry, & Wilson, 2011)

Assessing your Child's Pain

Knowing that your child is having pain is the first step in treating it. However, it is not always that easy, especially in younger children. Not all children and toddlers know how to express that they are having pain. Some commonly used pain words before the age of 6 are: *owie, boo-boo, ache, stinging, cutting, burning, itching, hot, and tight.*

It is important to remember that as a parent, **you know your child the best**. You are the best person to determine whether or not they are having pain.

There are many different ways to determine how much pain your child is having. The following scales can be used both in hospital and when you return home:

Rating your child's pain*: the preschooler and school-aged child:*

Wong-Baker FACES® Pain Rating Scale

0	2	4	6	8	10
No Hurt	Hurts Little Bit	Hurts Little More	Hurts Even More	Hurts Whole Lot	Hurts Worst

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Used with permission.

The above scale can be used for preschool and school-aged children to rate their pain. To use it, explain to your child that each face represents a person with no pain, some pain, or a lot of pain. Face 0 does not hurt at all. Face 2 hurts a little bit. Face 4 hurts a little more. Face 6 hurts even more. Face 8 hurts a lot. Face 10 is the worst pain imaginable, but they do not have to be crying to feel Face 10. Ask

your child to point to the face that comes closest to the amount of pain they are feeling (Wong-Baker FACES Foundation, 2016). Let your child decide for themselves – do not suggest a face or point to a face for them. This will keep their answers as accurate as possible. Mild pain would be 0 to 2, medium pain would be 4 to 6, and strong pain would be more than 8.

Rating your child's pain: *The older school-aged child and teenager:*

This age group can rate their pain on a scale from 0-10. You may have seen doctors or nurses ask your child this while in hospital. To use it, explain to your child that on a scale from 0-10, 0 **means *No Pain*** and 10 means ***the worst pain they have ever felt***. Once they understand this, ask them to rate their pain from 0-10. Mild pain would be 0 to 3, medium pain would be 4 to 6, and strong pain would be more than 7.

Rating your child's pain: *Babies or those that cannot speak:*

Your child may not be able to talk to tell you that they are having pain. Watch your child carefully to see how they are acting. Look and see if they *are frowning, kicking their legs, grinding their teeth, pulling their legs up to their stomach, moaning or crying, or being very stiff*. All of these activities could mean they are having pain. Other signs could mean pain as well, such as *not playing as their usual, being unusually quiet, or reversing back to younger behaviours such as thumb sucking or wetting the bed.*

(Sutters, Savedra, & Miaskowski, 2011.;The Hospital for Sick Children, 2016; Wong, Hockenberry, & Wilson, 2011)

Pain Relief with Medication

Once you know how to properly assess your child's pain, the next important step is to know how to relieve it quickly and effectively. Normally, if your child is in pain on the day he or she goes home, you can give some pain medicine regularly during the rest of the day, and the next few days too, if needed. Giving pain medicine regularly in the first few days after your child is home will help him or her to hurt less.

Don't wait to give pain medicine

Pain relief works best when you don't wait until your child is in a lot of pain before you give the medicine. If you wait, it may take longer for the pain to go away.

Use a timer, such as an alarm clock or a timer on your phone or computer if you have difficulty remembering to give your child their medicine. Set the timer for 4 hour intervals, including during the night. Use this as a reminder to assess their pain and give them more medication. You may find it difficult to wake a sleeping child to give them medicine, but in the first few days this is **very important** to keep their pain under control

After the first few days, when your child hurts less, give the medicine only when he or she needs it.

Commonly used pain medication:

Tylenol (Acetaminophen)

If your child is having **mild** pain, you can use regular acetaminophen every 4 hours. The amount of medicine you should give depends on your child's age and weight. Always follow the directions on the side of the bottle to find out the right amount. Acetaminophen is a safe medicine to give your child. There will be no major side effects when you give this medicine as explained on bottle.

Opioids (Morphine, Hydromorphone)

You can give your child an opioid if he or she is having a **medium** amount of pain at home. The amount of medicine to give depends on your child's weight. You can check with your child's doctor, nurse, or pharmacist to find out the amount to give. The directions should be on the bottle from the pharmacy. Opioids are safe medications to give your child in the first few days after surgery.

Atasol 30s (Codeine and Acetaminophen)

This medication is a combination of an opioid and acetaminophen. It can be used as a liquid medication for younger children, or pills for older children and teenagers. You can give your child opioids and acetaminophen together if he or she is having a medium amount of pain in the first few days after the operation.

Advil (Ibuprofen), Toradol, and Others

There are many other different types of pain medicines that could be prescribed to your child when you leave hospital. It sometimes depends on the type of surgery they had and how much pain is to be expected. Some of these medications, such as Advil and Toradol, have more risks than other common pain medications. Always follow your doctor's, nurse's, or pharmacist's guidelines.

Different medicines for different pain

The type of pain medicine your child should get depends on how much pain your child has. For example:

- ❖ **Mild pain**: Give acetaminophen. This medicine is also called Tylenol, or Tempra. Give only 1 of these 3 same medicines to your child.

- ❖ **Medium pain**: Give acetaminophen plus an opioid to your child.

- ❖ **Strong pain**: Call the telephone advice line, or bring them to the Emergency Department

(Browne, Flanigan, McComiskey, & Pieper, 2007; Chorney, Twycross, Mifflin, & Archibald, 2014; The Hospital for Sick Children, 2016.)

Pain Relief without Medication

As a parent, there are many things you can do for your child to help ease their pain *without the use of medications*. For the most part, these techniques can be used at the same time medication is being used, to help decrease the amount of medication your child needs. Once your child has started to fully recover, some of these approaches can help replace the need for medication all together.

Relaxation Techniques

- Taking a warm bath

- Massage or back rubs

- Cuddling

- Napping/taking frequent play breaks

- Drinking warm fluids such as warm milk or hot chocolate

- Reading

- Blowing bubbles

Distraction Techniques

- Watching T.V

- Reading

- Playing video games

- Playing a board game

- Puzzles

(CHEO, 2016; Chorney, Twycross, Mifflin, & Archibald, 2014)

Returning to Normal Activity

Like any parent, you may be wondering at what point your child will be able to return to their normal, everyday activities like play and sports. You may also be wondering when your child will be feeling up to doing these activities. It is important to remember that **every child recovers from surgery at a different rate**. When they are ready to play as before, they will certainly let you know!

Adequate Rest after surgery is equally important as returning to normal activities. You may notice your child needing to take frequent breaks from playing. Also, they could be napping more than he or she did before. This is very normal and should not be discouraged after surgery. Getting enough rest is important to allow the body time to heal properly.

Always follow your doctor or nurse's instructions regarding returning to gym and sports following surgery. You can use the following table as a guide for the different types of surgeries your child may have had, and the general rules for returning to sports. **Remember**, if your doctor has given you instructions that differ, **always follow your doctor's guidelines**:

Type of Surgery	Activity Guidelines
Abdominal surgery (ex. appendectomy, bowel surgery)	No gym or sports, especially contact sports for 4-6 weeks
Orthopedic surgery (ex. cast on leg or arm)	Returning to sports after cast removal will depend on physiotherapy. Usually 6-8 weeks.
Ear, nose, & throat surgery (ex. tonsillectomy, adenoidectomy)	No gym or sports for 2 weeks
Plastic surgery	No gym or sports for 4-6 weeks

Taking a Bath or Shower

You and your child may be wondering when they can return to their normal routine of bathing or showering. If your child spent time in hospital after their surgery, they may have had a bed bath or a shower if it was advised. Your doctor or nurse will explain to you before you go home about bathing and taking showers. The most important thing to remember is **keeping the surgical area clean and dry**. The following table should help serve as a guide to bathing instructions. **However, always follow your doctor or nurse's advice if there are differences than what you see here:**

Type of Surgery	Bathing Guidelines
Abdominal surgery (ex. appendectomy, bowel surgery)	May shower 24 hours after surgery while keeping incision covered with a dressing. NO BATHS until 4 weeks after surgery
Orthopedic surgery (ex. cast on leg or arm)	Refer to cast care section of this resource
Ear, nose, & throat surgery (ex. tonsillectomy, adenoidectomy)	May return to usual bathing/showering routine immediately after surgery
Plastic surgery	May shower 24 hours after surgery while keeping incision covered with a dressing. NO BATHS until 4 weeks after surgery

(Ball, Bindler, & Cowen, 2014; Browne, Flanigan, McComiskey, & Pieper, 2007; CHEO, 2016; The Hospital for Sick Children, 2016; Wong, Hockenberry, & Wilson, 2011)

Returning to a Normal Diet

By the time your child has been discharged home from hospital, he or she would have moved through the stages of returning to normal eating to some degree. This starts with clear fluids, and eventually working up to eating a regular diet. While this may have went well in hospital, some children eat differently when they are in their own environment. You may find your child eats a lot more at home than they did in hospital, or that they are eating less. Both are normal.

Important things to keep in mind:

❖ **Staying hydrated**. Even if your child is not eating as much as they normally would, they should be drinking lots of fluids. This can include things like water, juice, fruit smoothies, popsicles, Gatorade, etc.

❖ If your child is **nauseous** or complains of a bad belly, they still may be feeling the effects of the anesthesia (the medicine used to put them asleep for surgery). **Gravol** can be given to most children- remember to always follow the directions on the label. Also, **a bland diet can help with an upset stomach**. Foods like plain bread or toast, pasta, cereal, rice, apple sauce, and bananas are easy on the stomach compared to spicy, rich foods.

❖ **Offer small, frequent meals**. This can help with an upset stomach as well as help with a slower appetite. If your child cannot tolerate normal sized meals, it is more important to get small, nutritious snacks into them than nothing at all.

❖ **Certain types of surgeries require following a strict diet**. *One example of this is the removal of tonsils.* If your child has had their tonsils out, your nurse will give you a pamphlet to follow in addition to these guidelines. It is important to offer your child only soft foods for two weeks when they have had their tonsils out. *Another example of this is having their gallbladder out*. This type of surgery sometimes requires following a fat free diet. These types of rules will be explained to you and your child before you leave hospital.

(Ball, Bindler, & Cowen, 2014; Browne, Flanigan, McComiskey, & Pieper, 2007; CHEO, 2016; Health Canada, 2011; The Hospital for Sick Children, 2016; Wong, Hockenberry, & Wilson, 2011)

Recommended Number of Food Guide Servings per Day

	Children			Teens		Adults			
Age in Years	2-3	4-8	9-13	14-18		19-50		51+	
Sex	Girls and Boys			Females	Males	Females	Males	Females	Males
Vegetables and Fruit	4	5	6	7	8	7-8	8-10	7	7
Grain Products	3	4	6	6	7	6-7	8	6	7
Milk and Alternatives	2	2	3-4	3-4	3-4	2	2	3	3
Meat and Alternatives	1	1	1-2	2	3	2	3	2	3

*Taken from Canada's Food Guide from Health Canada (2011).

*The above table should be used as a guide to the amount of servings from each food group you child needs to be eating for a balanced diet.

When to Return to Hospital

In general, once you are home most of your questions should be directed to the Janeway Hospital Telephone Advice Line. However, there are certain situations that you should **not wait to ask about** – your child should be brought back to the emergency department right away.

These things include:

- ❖ Large amount of bleeding or oozing from the incision
- ❖ Stitches or sutures that have broken open
- ❖ Redness, swelling, or heat around incision
- ❖ Foul odor from incision or wound
- ❖ Greenish color discharge from incision or wound
- ❖ Dehydration (signs include a dry lips and tongue, dark urine, decreased energy)
- ❖ Severe pain that is not relieved with the medications you have at home
- ❖ Unable to wake child easily once they are asleep (this is especially important if they have been taking opioids for pain)
- ❖ Fresh bleeding from the mouth or nose
- ❖ Throwing up (vomiting) that does not stop
- ❖ Fever above 38.5
- ❖ Stomach pain or distention (fullness or swelling)

*If your child has a **cast**, there are other unique situations to watch out for. Please refer to cast care section*

(Ball, Bindler, & Cowen, 2014; Browne, Flanigan, McComiskey, & Pieper, 2007; IWK Health Centre, 2016; The Hospital for Sick Children, 2016; Wong, Hockenberry, & Wilson, 2011)

Cast Care

A cast is put on when needed to support a broken bone or treat an injury while your child heals. The length of time it needs to remain in place varies and depends on the injury.

Things to Do:

- ❖ Keep the cast clean and dry.
- ❖ Keep the arm or leg elevated on pillows to help decrease swelling. It is important to keep the arm or leg higher than then the level of their heart.
- ❖ Check the skin around the cast often for blistering, rubbing, or irritation. The skin should be clean and dry.
- ❖ Encourage your child to move their fingers/toes often
- ❖ Check circulation. Do this by feeling if their toes or fingers are warm and if they look pink. Your nurse should show you how to do this before you leave hospital.
- ❖ If your child complains of being itchy underneath their cast, a hair dryer on cool setting can be used to blow air inside their cast

Things NOT to Do:

- ❖ Do not allow your child to put anything in their cast to scratch
- ❖ Do not remove their cast or allow them to remove the cast themselves
- ❖ Do not get the cast wet
- ❖ Do not remove padding
- ❖ Do not use powder or lotion inside the cast
- ❖ Do not wear jewellery on the casted arm or leg
- ❖ Do not walk on a cast until the doctor or nurse has told you so

Keeping Clean With a Cast:

- ❖ If your child has an **arm cast**:
  - ➢ Your child can shower or bathe. Use a towel and a plastic bag sealed over the top of the cast and make sure to keep the cast out of the direct water stream. The towel will help absorb condensation.

- ❖ If your child has a **leg cast below the knee**:
  - ➢ It is best to take baths only. Use a towel and a bag sealed over the top but keep the leg out of the tub.
  - ➢ It is not safe to stand on one leg so showers are not recommended with leg casts.

- ❖ If your child has a **long leg cast**:

  - ➢ They cannot shower or bathe safely, and will need sponge baths.

RETURN TO THE EMERGENCY DEPARTMENT OR CALL THE CAST ROOM IF ANY OF THE FOLLOWING OCCUR:

❖ Unusual smell under the cast

❖ Your child complains of burning, tingling, or numbness

❖ Drainage through the cast

❖ Increased swelling

❖ Inability to move fingers or toes

❖ Slippage of the cast

❖ Cast becomes cracked, soft, or loose

❖ Sudden, unexplained fever or chills

❖ Increased pain or pressure under cast that cannot be controlled

❖ Fingers or toes that are blue or white

❖ Cast becomes wet

❖ Something gets stuck in the cast

(Ball, Bindler, & Cowen, 2014; Browne, Flanigan, McComiskey, & Pieper 2007; CHEO, 2016; Clarke & Dowling, 2003; IWK Health Centre, 2016; Janeway Children's Hospital Foundation, 2015; Janeway Resource Centre, 2016; Sparks, Ortman, & Aubuchon, 2004)

Important Phone Numbers

There are always going to be times you have questions that cannot be answered within this resource. The following is a list of important phone numbers you may want to have when you are discharged from hospital:

*Janeway Hospital Telephone Advice Line:

(709) 722-1126*

(24/7 Advice from a Pediatric Registered Nurse)

Janeway Hospital Poison Control Line:	**(709) 722-1110**
J4Surgery Nursing Desk:	**(709) 777-4373**
Janeway Hospital Surgical Day Care:	**(709) 777-4334**
Janeway Hospital Cast Room	**(709) 777-4254**
Dr. Hodder	**(709) 777-4151**
Dr. Price	**(709) 754-4666**
Dr. Akhtar	**(709) 777-4130**

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Appendix B: Literature Review

Development of an Online Resource for Parents Caring for their Child at Home Following Surgery:

A Literature Review

Kelli Pitcher

Memorial University

Table of Contents

Every day, thousands of children across Canada and all over the world undergo both emergent and elective surgical procedures. With our rapidly changing health care system, children are discharged home quicker than ever before with the responsibility of care placed on the parents and caregivers of the child. As a pediatric nurse, I have seen both the benefits and challenges of early discharge postoperatively. Being in hospital poses its own social, emotional, and financial strain on families. Alternatively, being home and caring for a child postoperatively raises a lot of questions and concerns if families do not receive adequate discharge instructions or were distracted during discharge teaching (Browne, Flanigan, McComisky, & Pieper, 2007; Smith & Daughtrey, 2008; Weiss et al., 2008; Wong, Hockenberry, & Wilson, 2011). My experiences as a nurse have helped inform my decision to develop an online resource for parents caring for their child following surgery. A literature review will identify the need for such a resource, to identify appropriate content of the resource, and what methodology will be appropriate to use in its development. The purpose of this paper is to review relevant literature to inform the development of an online resource for parents caring for their child following surgery. First, the methods and search strategies will be presented, followed by an overview of findings presented via themes identified, as well as a discussion of the conceptual model relevant to the development of the resource. Finally, a conclusion will be drawn based on strengths and limitations within the literature review.

Search Strategy

The primary method behind the literature search was to inform the need for a resource, the content of the resource, and the methodology of creating the resource. To

facilitate this, Memorial University's OneSearch was used primarily to access relevant

databases such as CINAHL and PubMed. Keywords used included "postoperative",

"parents", "pediatrics", "discharge teaching", "educational resources", "health literacy",

"consumer health information", "instructional design models", and "parental learning

needs". The Public Health Agency of Canada's critical appraisal tool kit was used to

appraise a total of 14 studies (see appendix A). Using the tool kit, studies were critically

appraised for their strengths and weaknesses, including study design, methodology,

sample selection criteria, relevant outcomes, and limitations. Additionally, through the

use of the tool kit an overall study quality was assigned to each research article, whether

it was weak, moderate, or strong. While the literature was limited to English documents,

an attempt was also made to limited the publishing year to be no later than 2000 however,

some outliers had to be included for the sake of relevance.

Results

Overview of Results

The results of the literature review will first present the rationale of why an online

educational resource is needed. This will include both the rationale for educational

resources for parents in general, as well as a more focused discussion on the importance

of the online aspect of the resource. Secondly, the content of the resource will be

discussed. What do parents need and want to know at home to care for their child

following surgery? Lastly, the methodology of the development of the resource from

literature sources will be discussed, including models of instructional design, health

literacy, and readability of written materials.

Why is an Online Resource Important?

Internet use by the public has continuously been on the rise since its inception and has been a source of a large breadth of knowledge for both physicians and patients alike (Briones, 2015; Goldman, 2014; McInerny, Adam, & Campbell, 2009). In fact, a study by Knapp et al. (2010) showed that 60% of parents use a combination of internet sources and their physician as their primary sources of health information. Another study showed 56% parents in a pediatric emergency room stated that they had used the internet to search for health-related information. Of those parents, 8.5% had searched their child's symptoms online right before bringing them to be seen in the emergency department (Goldman, 2014). With this high percentage of people using the internet as their primary source of health information it is imperative that the information found be relevant, up to date, and trustworthy.

Although Google is one of the most popular search engines for health-information, health care workers do play a part in influencing what sites patients visit (Sebelefsky et al., 2015). The use of the internet for harnessing health information has been coined with the term e-health (Briones, 2015). E-health has varying definitions across the literature, but in general it can be defined as the use of technology, mainly the internet, to improve or enable health and health care. Briones (2015) conducted 50 interviews of young adults to determine how they make meaning of online health information. Results indicated that people feel e-health improves their physician visits, and it made health information more easily accessed (Briones, 2015). Therefore, it could be said that if the appropriate online resources exist for nurses and physicians to give to

parents and caregivers, it is likely they will use them. Furthermore, the status quo of most hospital discharge information resources are pamphlets and information booklets however, there continues to be a large number of Canadian hospitals switching over their health information from physical materials to digital, online platforms (Sium, Giuliani, & Papadakos, 2015). Ultimately, parental education is paramount to ensure a positive outcome following hospital discharge (Briones, 2015; Browne, Flanigan, McComisky, & Pieper, 2007; Clarke & Dowling, 2003; Robinson & Miller, 1996; Wong, Hockenberry, & Wilson, 2011).

Educational resources, be it online or written information is most often associated with discharge teaching, but can occur at different times throughout a hospital admission as well such as preoperatively (Robinson & Miller, 1996; Weiss et al., 2008). Parents have identified a need for continuously available online resources to support, not necessarily replace, discharge teaching (Smith & Daughtrey, 2008; Swallow et al., 2012). Weiss et al., (2008) studied parental readiness for discharge in relation to their discharge teaching in a qualitative study of 135 parents. Results suggested that the delivery of discharge teaching by nurses is associated with increased readiness for discharge, as well as less coping difficulty at home. While many variables were analyzed in the correlational study by Weiss et al. (2008), one part did show that many parents felt they were given more information on discharge then they needed to know. The authors also concluded that the skill in which the nurse delivered the information was directly associated with parent's readiness for discharge. With this in mind, it seems that an online resource with consistent information can be a valuable support system for parents to reach out to when they are home and have questions. Additionally, having an online resource available

would increase parent's readiness for discharge and ease their potential anxieties about going home (Robinson & Miller, 1996; Smith & Daughtrey, 2008; Swallow et al., 2012; Weiss et al., 2008).

Written resources that reinforce hospital-provided discharge teaching will increase parental understanding of information that they may have not heard or overlooked during their child's hospitalization (Browne, Flanigan, McComisky, & Pieper, 2007; Smith & Daughtrey, 2008; Wong, Hockenberry, & Wilson, 2011). There are many elective, minor surgical procedures done in pediatrics through day-surgery, and others in which the child is admitted overnight. In both cases, the total time of admission is usually less than 24 hours (Browne et al., 2007). A study by Scrimin, Haynes, Altoe, Bornstein, and Axia (2009) investigating the anxiety and stress levels in mothers and fathers in the first 24 hours after their child's surgery discovered that the type of surgery and stress symptoms were both related to parental anxiety. The parents of children who underwent major surgery had higher levels of stress than those whose children went through minor surgery. The authors concluded that dependant on the type of surgery and parent's apparent anxiety and stress symptoms, communication and support should be tailored in order to maximize effective communication (Scrimin et al., 2009). Similarly, a randomized controlled trial by Botngard, Skranes, Skranes, & Dollner (2013) determined that parents who had access to an online resource developed for parents (intervention group) were significantly more satisfied with the health information they received in hospital than those who did not have access to the online resource (control group). Therefore, it can be said that while discharge teaching is extremely important before the family leaves the

hospital, they may not have a complete understanding of all the information with their high levels of anxiety and should be able to have access to information they may have questions about at home (Botngard et al., 2013; Goldman, 2014, Scrimin et al., 2009).

Parental Needs Postoperatively

Independent of the type of surgery a child undergoes, there are general postoperative discharge instructions given to every family. These include monitoring for signs of infection, assessing for pain and administering analgesics as necessary, and administration of other medications as needed (Ball, Bindler, & Cowen, 2014; Wong, Hockenberry, & Wilson, 2011). Additionally, specific instructions should be tailored to the surgical procedure and the child's condition. As an example, specific cast care instructions should be given to a family of any child who is returning home with a cast following surgery (Ball et al., 2014; Wong et al., 2011). In a study by Smith and Daughtrey (2008) parents consistently stated that they wished they had received more information upon discharge about their child's illness. They also found that parents wished for an opportunity to receive trusting and reassuring advice about their child once they are discharged. The topic of pain was in abundance throughout the literature and included pain assessment, monitoring, and management. Other than pain control, the amount of literature on parental needs in caring for their child postoperatively is lacking, except for limited studies on cast care and other orthopedic conditions which will also be included in this review.

Pain. The most common theme that emerged from the literature was pain control in children postoperatively at home. Pain is described as an unpleasant sensory

experience and is felt regardless of age, developmental stage, and type of surgery. It can negatively affect wound healing if not managed properly (Ball, Bindler, & Cowen, 2014; Wong, Hockenberry, & Wilson, 2011) For these reasons, pain assessment and pain management are one of the two most important concepts in postoperative care and is consequently one of the most important concepts in discharge planning and teaching with parents of children (Ball & Bindler, 2006; Browne, Flanigan, McComisky, & Pieper, 2007).

    Pain assessment. Finley, Chambers, McGrath, & Walsh (2003) presented a quantitative study on the effectiveness of the Parent's Postoperative Pain Measure (PPPM) as a way for parents to measure postoperative pain in children aged two to six years. The PPPM included 15 behavioral items that parents simply said "yes" or "no" to their occurrence. The items included things such as whining or complaining more than usual, crying more easily than usual, acting quiet, having less energy, looking flushed, refusing to eat, playing less than usual, not doing the normal things he/she does, acting worried, along with many others. Internal consistency and internal reliabilities of the measure was proven using Cronbach's alpha (0.81 – 0.88). Furthermore, correlational analysis showed the PPPM items were correlated with the child's self-report of pain. Overall, the study proved that the use of the PPPM is a reliable and valid measure for parents to use at home to measure postoperative pain among children. Additionally Finley et al. (2003) provided more evidence for the PPPM by proving its construct validity including the specificity and sensitivity using two studies with a total of 75 and 28 children respectively.

Sutters, Savedra, & Miasowski (2011) describe the pain control program "Pediatric PRO-SELF" as an effective program for parents caring for children at home following tonsillectomy. The program is an adaptation from a similar adult program used in cancer care. Using Orem's general theory of nursing and Orem's self-care deficit theory as the theoretical framework behind the intervention, the Pediatric PRO-SELF "was designed to provide parents of children undergoing tonsillectomy with the necessary knowledge and skills to manage their child's postoperative pain at home and to coach them on how to optimize the prescribed analgesic regimen" (Sutters et al., 2011, p. 282). Components of the Pediatric PRO-SELF program include an information booklet, medication record, a timer, and a pain management diary. Although designed for use in children who have had their tonsils out, its use could easily be transferred to the care of any child who has undergone any type of surgical procedure.

Pharmacological pain management. The most commonly prescribed medications postoperatively are acetaminophen, ibuprofen, and codeine. However, pain medication is only as effective as the dose given and the interval that it is given (Dorkham, Chalkiadis, Sternberg, & Davidson, 2013; Unsworth, Franck, & Coonara, 2007).

Following a thorough search of the literature, Dorkham et al. reported that parent's attitudes and misconceptions about analgesia cause them to under dose their children. They discovered that 52% of parents were concerned about addiction, 73% were concerned about adverse effects, and most concerning was that 37% of parents thought that analgesics work better if they are given less. This goes against everything that is known about adequate pain control using analgesics. While the study by Dorkham et al. clearly state that is it not a meta-analysis or systematic review, they make a note to say the

strength of the evidence is not assessed which makes the validity of their findings questionable. Similarly, Idvall, Holm, and Runeson (2005) stated that parents often experience difficulties providing pain relief, with the main cause being parents' negative attitudes, lack of knowledge, and concerns about drug addiction. Additionally, they stated that parents may deny their children pain medication as a way for them to learn to cope with difficult situations, or out of fear they will become accustomed to using drugs to solve other problems.

Educating parents on the proper pharmacological management of their child's pain at home would address the issues of parental knowledge, attitudes towards narcotics and drug addiction concerns. In support of this, a double-blind randomized control trial by Bailey, Sun, Courtney, and Murphy (2015) sought to evaluate children's pain management when a specific analgesia information sheet was given to parents during their discharge teaching. Results showed statistically significant ($p < 0.001$) higher satisfaction and knowledge among parents who had access to the postoperative analgesia information sheet. Even more importantly, children had better postoperative pain control at day five ($p < 0.05$) when their parents had access to the information sheet, compared to those whose parents did not (Bailey et al., 2015). Similarly, Chorney, Twycross, Mifflin, and Archibald (2014) conducted a systematic review of the literature on interventions to improve parental management of pediatric pain postoperatively at home. Out of 147 articles reviewed, results showed that the most important intervention for nurses to teach parents for managing pain was around-the-clock dosing of pain medications.

Non-pharmacologic pain management. Helgadottir and Wilson (2014) used a randomized controlled trial to determine the effectiveness of educating parents about

distraction techniques to minimize pain at home following tonsillectomy. The authors of this study discovered that education on distraction techniques combined with education on medication for pain decreases overall pain behavior scores ($p < 0.001$). However there was no difference in pain intensity using RM-ANCOVA. Pain behavior scores, pain intensity scores, and level of distractibility were all measured using highly valid and reliable tools previously tested and used in other research. Data analysis was also described in detail as the authors stated they used G*Power for sample size, independent t-tests, x2 tests, paired t test, pearson correlation, and RM-ANCOVA. In this study, parents were taught about distraction as a type of play for their child. The type of play was tailored to the child's interests and age, and was divided into either active or passive play. The term active play includes role playing, puzzles, board games, etc. and the term passive play includes watching TV, listening to music, reading to the child, telling stories, etc. The choice between active or passive play depended on the pain intensity scores, with a higher score leading to more active play (Helgadottir & Wilson, 2014).

Similarly, a qualitative study by Idvall, Holm, and Runeson (2005), showed that distraction was the most frequently used type of cognitive-behavioral strategy for pain relief. Similar to Helgadottir and Wilson, (2014) distraction was described by Idvall et al. as watching TV, talking, thinking of something else, and reading. In this particular study, parents and their children were interviewed separately one day after the child's tonsillectomy. Other forms of non-pharmacological pain management strategies described by Idvall et al. included relaxation (sleeping, resting), thermal regulation (eating ice cream, drinking water), massage, comforting/reassurance, therapeutic touch, positive reinforcement, helping with daily activities, and creating a comfortable environment.

Despite the study's small sample size and the fact that the children interviewed were of different ages which may skew results, it still is interesting to see how distraction is used among families postoperatively.

Cast Care. Since injuries account for a large proportion of children's hospitalizations (Browne, Flanigan, McComisky, & Pieper, 2007) it seems only logical that orthopedic procedures and cast care would be a top priority of parents caring for their child at home following surgery. Fortunately, the child with a cast is usually fairly stable and healthy from a medical point of view. However, caring for a cast, especially on a child who is normally very active, can be daunting task for anyone. Such cast care includes keeping the cast clean and dry, ensuring the child does not poke anything sharp inside the cast, keeping the limb elevated as much as possible to reduce swelling, checking the toes or fingers to ensure they are warm and pink, and being alert for drainage, odor, and increased pain (Ball, Bindler, and Cowen, 2014).   Appropriate cast care aids bone healing and growth, increases the child's comfort level, and reduces the chance of infection (Wong, Hockenberry, & Wilson, 2011).

Hip Spica Casts. Hip spica casts are generally used to correct developmental dysplasia of the hip and femoral fractures (Ball, Bindler, & Cowen, 2014; Clarke & Dowling, 2003). In most cases, the child has to remain in the cast for six to twelve weeks in which case they must be cared for by the family (Reed, Carroll, Baccari, & Shermont, 2011; Sparkes, Ortman, & Aubuchon, 2004). In a study by Newman and Fawcett (1995), while home caring for their child with a cast, none of the mothers in their sample could attend school and half the mothers had to quit their job, as a result of having to care for their child. In the study, mothers addressed concerns such as how to move the child

(handling), how to bring the child places (transportation), how to position the child, and how to lift their child. The authors also identified that 74% of their sampled mothers stated they need more information about caring for their child at home in a cast. Another common but frustrating issue for parents with a child in a hip spica cast is trying to maintain skin integrity with a child who is incontinent (Reed, Carroll, Baccari, & Shermont, 2011). Likewise, in a descriptive cross-sectional study by Demir, Erden, Bulut, Carboga, and Elbas (2015), 97% of parents reported issues at home while caring for their child in hip spica cast, including toileting their child, cast care, skin care, and personal hygiene. Similarly, Clarke and Dowling (2003) provided an analysis of available literature for caregivers of hip spica casts to determine pertinent issues. The main focus for caregivers were guidelines related to positioning, feeding, sleeping, moving and handling, and travelling by car. Following a thorough review of the literature, Clarke & Dowling (2003) created a trouble shooting guide for parents and health professionals caring for a child with a hip spica cast.

Following an increase in telephone calls to the nursing unit from parents with questions, Reed, Carroll, Baccari, and Shermont (2011) determined that they needed a standardized teaching guide for parents. They developed a staff-led educational program to teach parents how to care for their child at home with a hip spica cast. After developing standardized teaching guides, Reed et al. (2011) then went on to evaluate the effectiveness of these guides on parents comfort level and skill with the care of their child's cast. Their results showed that 100% of parents caring for a hip spica cast for the first time found the educational materials provided useful, and only 5% of patients returned to hospital with skin breakdown. However, with only a sample size of 20

patients and parents the significance of these results is questionable. There is also no mention within the study of any validity, reliability, or statistical analysis, but results are still promising.

Methodology of Resource Development

The next logical step of the literature review was the methodology of developing an online educational resource for parents. How is an educational resource best developed for parents? Morrison, Ross, Kalman and Kemp's (2013) Model of Instructional Design will be used to help develop the resource. Given its popular use throughout instructional design, it would be the most appropriate model to use for this resource's development. Health literacy and readability of materials were two other key themes found in the literature in relation to instructional methodology and educational resource development.

Model of Instructional Design. The Model of Instructional Design by Morrison, Ross, Kalman, and Kemp (2013) is a circular model depicting the various concepts and components relevant to an instructional design plan (see Appendix B). In the center of the model, are the nine concepts central to instructional design. These are instructional problems, learner characteristics, task analysis, instructional objectives, content sequencing, instructional strategies, designing the message, development of instruction, and evaluation instruments. Surrounding these nine central concepts, in an oval shape are the eight processes that continue on an ongoing basis throughout the lifespan of an instructional design project. These processes are planning, implementation, project management, support services, revision, summative evaluation, formative evaluation, and confirmative evaluation (Morrison et al., 2013).

This model will be helpful in informing the development of the online resource for parents in a number of ways. Firstly, the learner characteristics will be very important to keep in mind during the resources' development. It will be imperative that the resource is written at a level that all parents will be able to read and understand, regardless of their education level. Secondly, this literature review as well a future environmental scan and consultations with key stakeholders will help inform the instructional objectives by narrowing in on the specific content of the resource. The instructional objectives will ultimately be the specific concepts that parents need to know in order to care for their child at home following surgery. The environmental scan and consultations will also help to inform how to design the message and develop the instruction. The online resource that will be developed will not be teaching parents per say, but rather providing them with the necessary information should they choose to seek it out. Therefore, the components of the design model such as evaluation instruments, summative evaluation, and formative evaluation, will not be relevant to this specific educational resources' development. However, it could certainly be a point to research for the future and other similar resources.

Health Literacy. Within the educational resource literature, there is much attention given to the concept of health literacy. Health literacy can be defined as "the degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions" (Patient Protection and Affordable Care act, 2010 as cited in Parnell, 2015, pg. 9). Today, adults who have a reading level of less than ninth-grade are said to have basic or below-

basic literacy, and have inadequate health literacy (Fagnano, Halterman, Conn, & Shone, 2012). In the United States in 2003, over 75 million had combined basic and below basic health literacy, with the majority of adults having intermediate health literacy (Fagnano et al., 2012). Within Canada, over 60% of adults and 88% of seniors are not health literate (Public Health Agency of Canada, 2014). With low literacy being associated with adverse health outcomes (DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004) it is important to keep the concept of health literacy in mind during the development of an education resource.

In a quantitative study to describe the relationship between a caregiver's health literacy and their use of health information sources Fagnano, Halterman, Conn, and Shone (2012) found that 37% of a total of 304 caregivers had limited health literacy, 94% of families received their health information from a health care professional, 51% received their health information from written sources, and 30% from the internet. Using logistic regression analysis, Fagnano et al. determined that caregivers with adequate health literacy were more than twice as likely to get their health information from family and friends, whereas those with limited health literacy were more likely to use the internet for the same information. With this in mind, it is noteworthy that if people of low health literacy are using the internet for health information frequently, it shows the need for, if not increasing the need for, increased readability of low literacy levels within the online information.

According to Polishchuk, Hashem, and Sabharwal (2012) when developing an educational resource, it is understood that the health literacy of the target population

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should be set at a default of below basic health literacy, in order to encompass all levels

and ensure understanding of the material by all who may view it. There are a number of

ways in which this can be facilitated. The material should be at a maximum reading level

of grade six (Polishchuk et al., 2012). Some sources even recommend a maximum level

of grade five (Ball & Bindler, 2006; Parnell, 2015). To ensure this, sentences should be as

short as possible, using basic terminology especially when speaking of medical concepts

(Ball & Bindler, 2006; Mayer, 2002; Parnell, 2015; Polishchuk, Hashem, & Sabharwal,

2012). As examples, when writing about the trachea, the word instead should be wind or

breathing pipe, and abdomen should be belly or stomach. Also, the active voice should be

used when developing sentences rather than the passive voice, and numerals should be

used rather than spelling out a number (Ball & Bindler, 2006; Robinson & Miller, 1996).

Mayer (2002) provides even more suggestions when preparing easily understood patient

information, such as asking the right questions during the planning process. For example,

what will be my overall communication plan? Who is my target audience? How will the

information be distributed? Mayer (2002) also recommends using colorful visuals or art

to help illustrate and stress certain points, and getting feedback from other health

professionals to ensure it will used effectively before going live with the material to your

patients. To ensure readability of materials is at an acceptable level, Polishchuk et al.

(2012) recommend the Flesch-Kincaid grade formula which is as follows: 0.39 x (average

number of words per sentence) + 11.8 x (average number of syllables per word) – 15.59.

The resulting number from the formula corresponds with the appropriate U.S grade level.

Unfortunately, one limitation to this formula is that it not does take into consideration an

individual's ability to comprehend visual materials such as pictures, figures, and tables (Polishchuk et al., 2012).

Fortunately, the internet can improve the health literacy of many people in a number of ways (Leroy, 2008). With the internet increasing the availability of health information, consumers are becoming more familiar with how to navigate the internet in search of health information more effectively. Technology, along with available website design programs and word processors makes the process of ensuring readability of online materials at low reading levels relatively simple. With web design becoming increasingly more complex in its capability, and visual aids being used to deliver information in a number of ways to compliment different learning styles, the internet is becoming an efficient place to learn (Leroy, 2008)

Gaps in the Literature

It became apparent very quickly during the initial search of the literature, that while educational resources are important, specific information as to what parents need or want to know in order to care for their child following surgery is lacking. Except for pain control and care of a child in a hip spica cast, there is little to no research to be found in this area. Pain control, infection prevention, and wound care are the most important aspects of postoperative care at home following surgery. While appropriate cast care both indirectly and directly are aspects of infection prevention and wound care, there are many other common pediatric surgical procedures in which no research in relation to parental care could be found. Wound care for open and laparoscopic appendectomy for an example, is a very common pediatric surgical procedure. There are a few possible reasons

as to why research in these areas may be lacking. To begin with, community health nursing is an important part of our health care system. Most children with surgical wounds and burns are referred to community health for wound assessments and removal of sutures. Depending on the type of surgery and wound, many nurses will visit the child on a daily basis. This could be a major factor influencing the amount of research done regarding parents caring for a wound at home, if the responsibility has normally been given to the community health nurse. Secondly, most children with acute surgical wounds are kept hospitalized for the first 24-48 hours during the most critical period of wound healing. This could also be attributing to the lack of parental wound care research. However, this is not to say that if parents had more information available to them in relation to wound care or infection prevention, there be less emergency room visits, or less calls to the pediatric telephone advice line. Would rates of postoperative surgical site infections be decreased if parents had more knowledge of infection prevention and wound care? These are the types of questions in which more research is needed in order to answer.

Conclusion

This review of the literature relevant to the development of an online resource for parents caring for their child at home following surgery has helped inform its need, content, and methodology. Educational resources help parents be ready for discharge, ease their anxiety levels, and ultimately improve their child's surgical outcome (Ball & Bindler, 2006; Clarke & Dowling, 2003, Wong, Hockenberry, & Wilson, 2011). Also, the internet is here to stay and will continue to be present in our patients' lives for years to

come – and parents will continue to use it for health information. Nurses and health

professionals can provide evidence-based, easily accessible, and easily understood health

information for them in an online format. Pain management is the top priority of parental

needs postoperatively, followed by cast care, with the assessment of pain being at the

forefront of pain management (Ball et al., 2014; Chorney et al., 2014; Helgadottir et al.,

2014; Wong et al., 2011). In order to facilitate the development of the resource,

Morrison, Ross, Kalman, and Kemp's (2013) Model of Instructional Design will be used

as the overall design model. Additionally, various aspects of ensuring readability for all

literacy levels will be used including the Flesch-Kincaid formula. While some gaps in the

literature exist in relation to what else parents need to know when caring for their child at

home other than pain management and cast care, the environmental scan as well as

consultations with key stakeholders will assist in informing this part of the resource.

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Appendix A: Literature Summary Tables

Author/Date	Study Design/Sampling/Setting/ Characteristics	Variables and Measures/Reliability/ Validity	Relevant Outcomes	Limitations
Idvall, Home, and Runeson; 2005.	Design: Cross-sectional study Purpose: To investigate the experiences of childrens' management of pain, and to investigate parental views of the same. Sampling: 6 children were interviewed, a consecutive sample with inclusion and exclusion criteria. Setting: A country hospital in Sweden.	- Each child and their parents were interviewed separately. -Visual Analog Scale (VAS) was used for the child to rate their pain they experienced postoperative at home. VAS scale is considered to be a proven valid & reliable scale. -Interviews used pre-selected, open-ended questions. -Data from the interviews were then categorized using unitization.	- Child perceived several different things to decrease their pain: distraction (watching tv, reading), sleeping, having a positive attitude, thermal regulation, having someone present, and assistance with daily activities. -Both parents and children expressed the need for more knowledge on non-pharmacological pain management strategies. - Strength of Study Design: Weak Overall study quality: Medium (based on PHAC CAT).	-Small sample size -Children interviewed were of ranging ages and with combined sample size, is hard to generalize information.

Author/Date	Study Design/Sampling/Setting/ Characteristics	Variables and Measures/Reliability/ Validity	Relevant Outcomes	Limitations
Knapp, Madden, Marcu, Wang, Curtis, Sloyer, and Shenkman; 2010	- <u>Design</u>: Cross-sectional survey - <u>Sample</u>: 129 parents of children with a life-threatening illness - <u>Setting</u>: Florida, USA - <u>Purpose/Characteristics</u>: Telephone survey to understand any relationship between characteristics of parents and their preferred sources of information related to their child's health, and to assess their e-health literacy.	- <u>Outcome measures</u>: Study sought to know what parents' choices of information sources are, what sources they actually used (internet/physician/both), and their e-health literacy (eHEALS scale was used to determine e-health literacy). -Bivariate analyses were used. -eHEALS scale has been validated with a high internal consistency (α = 0.88)	- 72% of parents said their doctor was their primary source of health information for their child. - 19% said Internet - 9% said other sources (ex.library, friends) -60% said they use both the internet and their physician for health information -49% of respondents use the internet daily -Strength of Study Design: Weak. Overall study quality: Medium (based on PHAC CAT)	- Response rate 66% - Most families were of low-income, could prevent data from being generalizable to broad socioeconomic status groups.

Author/Date	Study Design/Sampling/Setting/ Characteristics	Variables and Measures/Reliability/ Validity	Relevant Outcomes	Limitations
Helgadottir and Wilson; 2014.	Design: Randomized controlled trial. Purpose: To determine the effectiveness of teaching parents to provide distraction in addition to medication to decrease pain postop in children at home. Sample: 93 children and their parents. Families had to meet inclusion criteria such as undergoing tonsillectomy surgery. Setting: National University hospital in Iceland.	Interventions: medication pain management education (control group) and medication + distraction pain management education (intervention group). Measurements: Wong-Baker faces pain rating scale (reported as previously validated and reliable), Parent's postoperative Pain Measure (PPPM) with concurrent validity supported, and the Distractibility subscale of the Behavioral Style Questionnaire.	- Using RM-ANCOVA to adjust for pain intensity, pain behavior scores were lower on day 1 postop when parents were educated to use distraction techniques in additions to analgesia ($p<0.001$). -No difference in pain intensity in the two groups. -Strength of Study Design: Strong. Overall study quality: High (based on PHAC CAT)	- High attrition rate (69 children out of 93 recruited) - Short time span (2 days total of the study).

Author/Date	Study Design/Sampling/Setting/ Characteristics	Variables and Measures/Reliability/ Validity	Relevant Outcomes	Limitations
Scrimin, Haynes, Altoe, Bornstein, and Axia; 2008.	Design: Cohort Study Purpose: To examine the impact of pediatric surgery on parents' anxiety and stress, and to identify factors that cause this anxiety in the first 24 hours after a child's surgery. Setting: Children's Hospital, Italy. Sampling: 154 parents were recruited.	Measurements: State-trait anxiety inventory, Post-traumatic stress symptom inventory (dependant measures), and Social Network questionnaire, Parent health locus of control scale (independent measures). All measures had been previously used in studies with proven validity and reliability.	- All parents reported some level of anxiety and stress. - The type of surgery their child had affected the level of stress and anxiety felt by the parents. -The number of acute stress symptoms was predicted by parent gender, as well as level of education. -Strength of Study Design: Moderate. Overall study quality: Medium (based on PHAC CAT).	- Study was limited to the first 24 hours post op and does not give a picture of outside this time period. - Only one caregiver from the family was included in the study.

Author/Date	Study Design/Sampling/Setting/ Characteristics	Variables and Measures/Reliability/ Validity	Relevant Outcomes	Limitations
Weiss, Johnson, Malin, Jeroke, Lang, and Sherburne; 2008.	Design: Correlational descriptive study Purpose: To identify predictors and outcomes of parental perceptions of their readiness for their child's discharge. Sample: 135 parents Setting: Children's medical centre, Midwestern USA.	Variables: parent and child characteristics, parental readiness for discharge, nursing practices related to discharge, and post discharge support. Instruments: Readiness for hospital discharge scale, Quality of Discharge Teaching Scale, Care Coordination Scale, and Post discharge coping difficulty scale (reliability and construct validity confirmed using Cronbach's alpha for all scales).	-Parents reported overall high levels of readiness for discharge. -The only statistically significant predictor of readiness for discharge was number of other children in the home ($p<0.03$). - Strength of Study Design: Weak. Overall study quality: Medium (based on PHAC CAT).	-Instruments were developed and used specifically for this study and should be proven reliable before use in future studies.

Author/Date	Study Design/Sampling/Setting/ Characteristics	Variables and Measures/Reliability/ Validity	Relevant Outcomes	Limitations
Polishchuk, Hashem, and Sabharwal; 2012.	Design: Cross-sectional descriptive study Sampling: 212 patient education materials were analyzed. Setting: Materials were web-based but study was conducted out of New Jersey. Purpose: To determine the readability of education materials found online for patients using the Flesch-Kincaid formula	Measurements: Readability of each website was calculated using the Flesch-Kincaid formula. Web sites were found using various Orthopedic surgical websites. - Intraobservor/ Interobserver reliability determined using ICC. (ICC of .9-1.0 is considered excellent correlation). -Statistical analysis performed on FK calculations to determine means and CI.	- Only 5 (2%) of the 212 education materials had a readability level of grade six or lower. - 38 (18%) had a readability level of grade eight or lower. -Intraobserver reliability measurement was excellent with an ICC of 0.98 and a mean difference of 0.2 grades between 2 time points. -Strength of Study Design: Weak. Overall study quality: Medium (as per PHAC CAT)	- FK formula does not take into account all factors that can change a person's ability to understand information. - Sample of health information chosen may not be representative of all types of health information. -Health literacy of target population was unknown.

Author/Date	Study Design/Sampling/Setting/ Characteristics	Variables and Measures/Reliability/ Validity	Relevant Outcomes	Limitations
Fagnano, Halterman, Conn, and Shone; 2012.	Design: Cross-sectional study Sample: 304 children and their families Setting: Rochester, New York Purpose: To describe sources of information parents use for asthma; to describe their access to the internet; to determine the association between caregivers' health literacy and use of health information sources.	Measurements: Survey of families to determine: health information services, use of the internet, and health literacy. -Likert's scales with known validity/reliability were used. -Health literacy measured using REALM (Rapid Estimate of Adult Literacy in Medicine), previously validated. -Statistical analysis performed on data using SPSS software.	- Caregivers with satisfactory health literacy were significantly more likely to report getting health information for their child from their family or friends, the internet, or written sources. - Almost half the families reported having access to the internet with over half (52%) said they used the internet for health information in the past year. -Strength of Study Design: Weak. Overall study quality: Medium (based on PHAC CAT)	- Survey used was brief (may not have given a complete picture of every type of health information source used). -Health literacy was measured using REALM – known to measure pronunciation and not understanding of words. -Findings can only be generalized to a similar population.

Author/Date	Study Design/Sampling/Setting/ Characteristics	Variables and Measures/Reliability/ Validity	Relevant Outcomes	Limitations
Sebelefsky, Karner, Voitl, Klein, Voitl, and Bock; 2015.	Design: Cross-sectional study Purpose: To examine the health seeking behaviors via the internet of parents attending a pediatric outpatient clinic. Sampling: 553 anonymous questionnaires were given out to volunteers at a medical clinic. Setting: A pediatric medical centre in Vienna, Austria.	- Questionnaire contained 14 items: some demographic information, questions on general internet use, and questions on internet use for the purpose of finding out health information. -Questionnaire itself had not been used before, and therefore was not validated before it was used. -Statistical methods used for data analysis include the Mann-Whitney U-test, Spearman correlation, Pearson correlation, Fishers exact test, and multivariate analysis.	-94.4% of parents surveyed use the internet to obtain health information related to their child. - The most commonly used online resources were Google (91.4%), websites run by doctors (84.8%), Wikipedia (84.7%), and the outpatient clinic's website (76.4%). -Younger parents (p=0.022) and parents of younger children (p<0.01) are more likely to use the internet to find health information for their child. -Strength of Study Design: Weak. Overall study quality: High (based on PHAC CAT).	-10% drop out rate -Questionnaire not validated or proven reliable.

Author/Date	Study Design/Sampling/Setting/ Characteristics	Variables and Measures/Reliability/ Validity	Relevant Outcomes	Limitations
Unsworth, Franck, and Choonara; 2007.	Design: Randomized Clinical Trial Purpose: To determine if the use of a self-report pain scale would increase the use of analgesia in children. Sampling: 88 children and their parents (72 actually completed). Randomly assigned to two groups. Group A received information related to analgesics only, while Group B received the same information as Group A plus instructions on how to use the Wong-Baked FACES pain scale. Setting: United Kingdom	Measurements: Wong-Baker FACES pain scale given to parents and children of group B, as well as analgesia information. This pain scale has been previously validated and proven reliable. -Mann-Whitney U-test was used, Student's t-test, and SPSS to assist with statistical analysis.	- There was no difference in the total number of analgesics given to children in both groups. -The median number of doses of analgesia in Group A was 15, and Group B was 14. -Shows that self-reporting pain scales alone does not improve pain management postoperative in children at home. -Strength of Study Design: Strong. Overall study quality: High (as per PHAC CAT).	-Relatively small sample size. -Only surgery undertaken by participants were tonsillectomy, adenoidectomy, and adenotonsillectomy. Similar surgeries and therefore results cannot be generalized to other surgical procedures.

| Author/Date	Study Design/Sampling/Setting/Characteristics	Variables and Measures/Reliability/Validity	Relevant Outcomes	Limitations
Newman and Fawcett; 1995.	Design: Cross-sectional study Sampling: 35 mothers whom had a child in a body cast. Setting: Pediatric clinic, Southern New England, USA Purpose: To discover the challenges that parents have while their child is in a body cast and what effects it has on their usual activities.	Measurements:An open-ended questionnaire was given to parents, while some parents were interviewed using the same questionnaire. Content analysis was performed on data to categorize mothers' responses.	- 54% of mothers stated that having a child in a body cast required them to adjust every aspect of their life. -Unanimously, mothers stated they needed respite care so that they could leave the house. -74% of mothers stated that needed more information about caring for their child in a body cast. -Strength of Study Design: Weak. Overall study quality: Low (based on PHAC CAT).	-Small sample size -Quantitative measures could have helped to quantify care givers' responses and give more of a relationship to the variables.

Author/Date	Study Design/Sampling/Setting/ Characteristics	Variables and Measures/Reliability/ Validity	Relevant Outcomes	Limitations
Demir, Erden, Bulut, Carboga, and Elbas; 2015.	Design: Cross-sectional study Purpose: To determine what sorts of problems face parents when providing care for their child after developmental dysplasia of the hip (DDH) surgery. Sampling: 33 parents of children who had undergone DDH surgery. Setting: Turkey	-Survey was conducted via telephone 4-6 weeks postop as well as at the hospital postop. -SPSS software, frequencies, means, percentages, and Chi-square tests used to analyze the data. -No reported validity or reliability of survey by authors.	- 97% of parents had physical, psychological, and social problems on top of caring for their child. -97% had issues with knowing had to toilet their child with a hip spica cast, 87.9% had issues with cast care, and 84% had issues with skin care and hygiene. -Strength of Study Design: Weak. Overall study quality: Medium (based on PHAC CAT).	-Low sample size - No validity or reliability testing mentioned by the authors in regards to the survey used.

Author/Date	Study Design/Sampling/Setting/ Characteristics	Variables and Measures/Reliability/ Validity	Relevant Outcomes	Limitations
Bailey, Sun, Courtney, and Murphy; 2015	Design: Randomized control trial (double blinded) Purpose: To evaluate pain management in children who have had their tonsils out using oxycodone when a information sheet is used in postoperative teaching. Setting: Private Hospital in Queensland, Australia Sampling: 60 patients enrolled with specific inclusion criteria (children 2-6 years of age undergoing tonsillectomy + others).	-Oxycodone information sheets were randomly given to half of participants. -Other half were given information on other analgesics. - Survey tools given for parents to use included the FLACC scale, Wong-Bakers FACES scale, and parent satisfaction scale. -Both FLACC and FACES scale have proven validity and reliability.	-There were statically significant differences between the two groups. -There was higher levels of parent's satisfaction, knowledge of oxycodone use, and superior management of the child's pain control with the use of the information sheet. -Univariate analysis showed the information sheet had a significant effect on children's pain perception on day 5 and 7 postop. -Strength of Study Design: Strong. Overall study quality: High (based on PHAC CAT).	- Questionable selection bias related to sampling. - Study made no attempt to control for specific differences in individuals prior knowledge level or education.

Author/Date	Study Design/Sampling/Setting/ Characteristics	Variables and Measures/Reliability/ Validity	Relevant Outcomes	Limitations
Botngard, Skranes, Skranes, and Dollner; 2013	Design: Randomized Controlled Trial Purpose: To see whether or not multimedia based information presented to parents' is more effective than verbal information when caring for children with breathing difficulties. Sampling: 101 parents, assigned randomly to either the intervention or control group. Setting: An urban, pediatric acute ward in Norway.	-Participants were either assigned to intervention group receiving multimedia based information and verbal information or control group receiving verbal information only. -No reference made by authors to any validity or reliability of information sources.	- At discharge, parents of both groups were satisfied were nursing care. - 1-2 weeks post discharge, parents who received the multimedia information were more satisfied with the health information they were given. -Strength of Study Design: Strong. Overall study quality: Medium (based on PHAC CAT)	-Lack of blinding may have skewed results as parents were aware of what group they were in.

Author/Date	Study Design/Sampling/Setting/ Characteristics	Variables and Measures/Reliability/ Validity	Relevant Outcomes	Limitations
Briones, 2015	Design: Cross-sectional study Purpose: To explore how young adults assess the quality of health information and how they give meaning to this information. Sampling: 50 participants took part in interviews. Setting: VA, USA	- Sample questions in interview included "Do you think the internet is helpful in making decisions about your health?", "How do you know the accuracy of online information?". -Open ended questions helped guide discussion. - Data analysis was done through transcription and then using the grounded theory approach, including the constant comparative method.	- Participants stated they cross reference and cross check websites to ensure their credibility, and by looking up the company in which you are reading. -Some participants stated they stayed away from personal blogs. -Participants used the internet because it saves time, is easily accessed, and verifies and justifies their health concerns. -Strength of Study Design: Weak. Overall study quality: Medium (based on PHAC CAT).	- Young adults (college students) may not be representative of everyone who uses the internet for health information. -Quantitative analysis would have provided more statistically significant information

Appendix B: Instructional Design Model
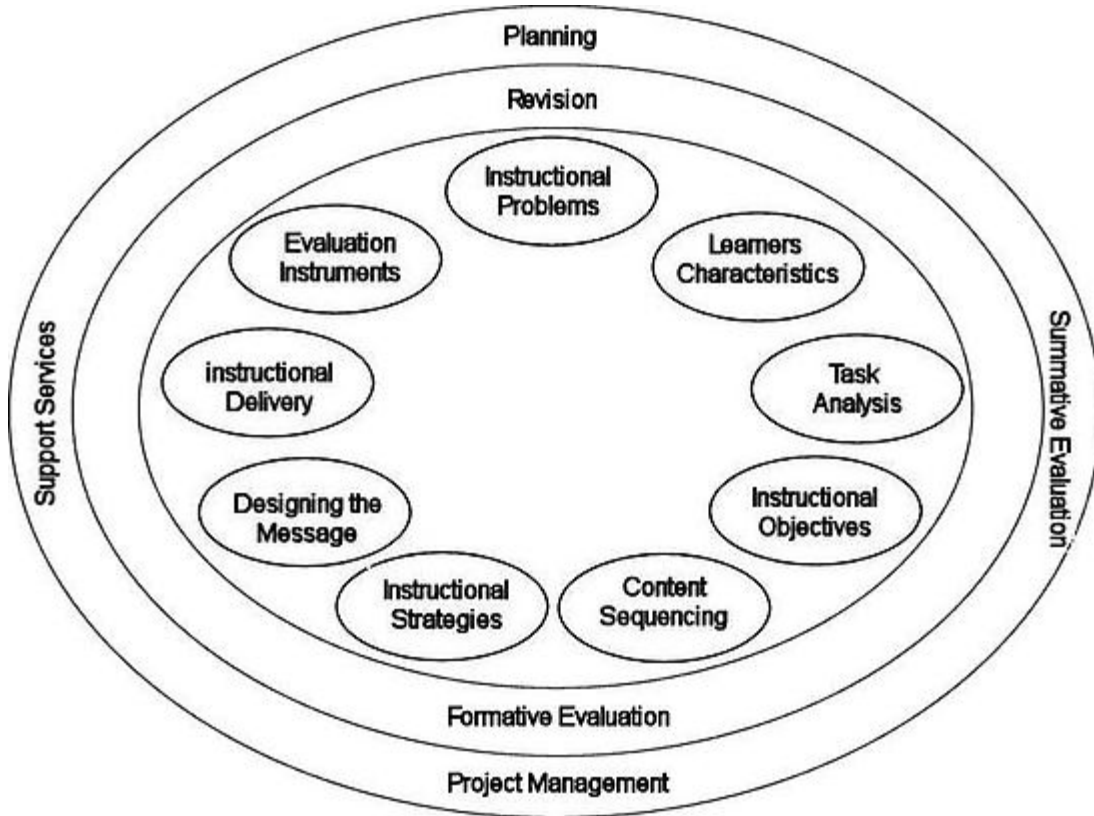
The Model of Instructional Design by Morrison, Ross, Kalman, and Kemp (2013)

Retrieved from http://www.instructionaldesigncentral.com/instructionaldesignmodels

Appendix C: Environmental Scan Report

Development of an Online Resource for Parents Caring for their Child at Home
Following Surgery: An Environmental Scan

Kelli Pitcher

Memorial University

As a nurse working on a pediatric surgical unit the need for an online resource for parents caring for their child following surgery has been identified as a long-standing priority as current discharge pamphlets were not meeting all parental needs. Having an easily accessible and easily understood resource that is available online to parents would help address this need. The use of the internet for harnessing health information has been coined with the term e-health (Briones, 2015). E-health has varying definitions across the literature, but in general it can be defined as the use of technology, mainly the internet, to improve or enable health and health care. Briones (2015) conducted 50 interviews of young adults to determine how they make meaning of online health information. Results indicated that people feel e-health improves their physician visits, and it made health information more easily accessed (Briones, 2015). Although Google is one of the most popular search engines for health-information, health care workers do play a part in influencing what sites patients visit (Sebelefsky et al., 2015). Therefore, it could be said that if the appropriate online resources exist for nurses and physicians to give to parents and caregivers, it is likely they will use them. Furthermore, the status quo of most hospital discharge information resources are pamphlets and information booklets however, there continues to be a large number of Canadian hospitals switching over their health information from physical materials to digital, online platforms (Sium, Giuliani, & Papadakos, 2015).

    As part of the development of any major project, it is important to know what types of similar programs or resources already exist. To do this, an environmental scan of online resources available for parents in Pediatric hospitals across Canada was completed

through CAPSNIG and CAPHC as well a review of the printed discharge instructions currently available for parents on the surgical inpatient unit of the Janeway Children's Health and Rehabilitation Centre.

Objectives

The specific objectives of this environmental scan were as follows:

1. To review content of online resources for parents already made available in pediatric hospitals across Canada.

2. To investigate the methodology and content of these resources already in use. This included the language and literacy levels used, as well as visual media aids used.

3. To determine what resources are currently available on J4Surgery, if they are up to date and evidence-based, and if they can be used in the development of the online resource.

Methodology

In order to collect relevant data from pediatric hospitals across Canada, the Canadian Pediatric Surgical Nurses Interest Group (CaPSNIG) were contacted via email (see Appendix A) to inquire if an online resource exists at their hospital and if a link to their website could be shared. Members were also asked if in their experience, parents found the resource beneficial. CapSNIG is an informal group of pediatric surgical nurses across Canada that connect via email to ask questions and share ideas regarding pediatric surgical nursing, general pediatric nursing, and policy and procedure. Members also get an opportunity to meet face to face on a yearly basis at an annual conference organized

for both pediatric surgical nurses and pediatric surgeons (CaPSNIG, 2016). Because of

the low response rate from CaPSNIG members, an alternative approach to search for

current online resources was used. Using the website for the Canadian Association of

Pediatric Health Centres (2011), a list of pediatric hospitals and their websites across

Canada was found. Each of these websites was then reviewed to see if an online resource

for that hospital existed. For the purpose of this summary, only those hospitals in which

an online resource for parents exists will be discussed.

Additionally, copies of all printed discharge teaching instructions available on the

pediatric surgical inpatient unit J4Surgery, were collected for review. They were

reviewed for content, age, and their applicability to the development of the online

resource.

Ethical Considerations

CaPSNIG (2016) members are nurses who have volunteered their email address to

a central group leader to be part of an ongoing exchange of information. For this reason,

an official letter of consent was not needed. Consent was implied, through the use of their

email address within the CaPSNIG group and their decision to respond to the e-mail. A

brief overview of the project and the rationale for the environmental scan was given to

members via email (see Appendix A). Confidentiality and data security was maintained

throughout the entire process through the use of a password protected personal computer.

It was concluded through the use of the Health Research Ethics Screening Tool

(see Appendix B) that an REB review was not necessary. Institutional approval for this

project had already been ascertained through Karen Rice, Division Manager of Pediatric

Inpatient Services which includes J4Surgery as well as through Crystal Northcott,

Program Consultant for the Children's and Women's Health Program, under which

J4Surgery is a part of.

<div align="center">

Results

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Overall, a total of eight online resources in existence across pediatric hospitals in

Canada were identified either by members of CapSNIG or through the CAPHC database.

A total of ten printed discharge instructions were found on J4Surgery for review.

CapSNIG

Through email conversations with CapSNIG members, three online resources

already in existence within Canada were identified. These were aboutkidshealth.org, a

patient education library from Hamilton Health Sciences, as well as a family resource

website from BC Children's Hospital. Unfortunately, the three respondents did not

answer the second question on the letter of inquiry, as to if parents found this type of

resource beneficial.

Aboutkidshealth.org. Aboutkidshealth.org is a website based out of The Hospital

for Sick Kids in Toronto, Ontario. It is organized with a database of conditions and

diseases including common surgical procedures listed alphabetically with an option to

search using key words. There are also separate pages for pregnancy related topics,

nutrition, drugs and medications, and safety information. The webpage even contains

"how-to" videos for parents, such as how to administer liquid medication to your child,

and how to stop nosebleeds.

When the term "appendectomy" is searched on the webpage, an information page displays key information on what the appendix is, where it is located within the body, and how appendicitis happens. There is general overview of the surgical procedure, and a separate paragraph on how to care for the child at home following an appendectomy. The information page contains a visual depiction of where the appendix is located within the body. Sentences are short (maximum 5-9 words each) and language is simplified. When certain terminology is used, such as "vomiting", the simpler term "throwing up" is written in parentheses following the word. When searching other common surgical procedures such as tonsillectomy and adenoidectomy, it was noted that they are all referenced with one or multiple nurse's names, their status, and the year. No information page viewed had any date older than 2009. This indicates up to date information. The website states they are funded by the Public Health Agency of Canada, Great West Life, and Sun Life Financial.

Hamilton Health Sciences. The Hamilton Health Sciences patient education library website is located at http://www.hamiltonhealthsciences.ca/body.cfm?id=1486. Is it a simple, easy to use website with a search bar for patient health information. The library is broad and encompasses both adult and pediatric health information. When the term "appendectomy" is searched, two pdf documents are found, one titled "appendectomy" and the other "appendectomy (child)". When you click on the documents, a printable, pdf document opens with basic information explaining what an appendectomy is, what happens before, during, and after surgery, and basic care for a

child at home following an appendectomy. There are no pictures or diagrams. The document is dated from 2001 and the only reference or credit is Hamilton Health Sciences Centre. There is an option to select the information in different languages. The sentences are short, simple, and easy to read.

BC Children's Hospital. The BC Children's Hospital family resource website is located at https://libraries.phsa.ca/fsrc. The website is described as a one-step library for borrowing books, getting pamphlets, and downloading videos to find health information. Unfortunately, this website was a bit more complicated to use. When the term "appendectomy", "appendicitis", and "appendix" were searched for, all separately, no results were found. The term "surgery" was then searched for and it returned 166 results of varying content. For example, there were pamphlets available for download related to the first 24 hours after an anaesthetic, in different languages. From here, you have to copy and paste a link into a separate browser into to view. This is much too complicated and time consuming for families to find information when they need it.

In contrast, when "tonsillectomy" was searched, one pdf document was found titled "pain medication following a tonsillectomy". This printable document gives specific details on how and when to medicate your child on day one, two, and three-five days after his or her surgery. Sentences in pamphlets found on this website were sometimes lengthy, and simple language was not used at all times.

Canadian Association of Pediatric Health Centres (CAPHC)

Using the website for the Canadian Association of Pediatric Health Centres (2011)

a list of pediatric hospitals and their websites across Canada was found. Each of these websites was then visited to see if an online resource for that hospital existed. For the purpose of this summary, only those hospitals in which an online resource for parents exists will be discussed. Those websites that were not in English were also excluded.

Alberta Children's Hospital. Alberta Children's Hospital home page on their website, http://www.albertahealthservices.ca/facilities/ach/ has a main navigation bar which includes a tab just for parents. Within the parents tab, there a simple easy to use website with a small number of PDF documents including preparing your child for surgery, caring for your child at home following surgery, and also instruction sheets for teenagers. The content of these are vague, and include basic simple instructions with the main focus on emergency numbers if there are concerns at home. There are no information documents for specific surgeries.

Children's Hospital of Eastern Ontario. The Children's Hospital of Eastern Ontario's (CHEO) website for online resources for parents is located at http://www.cheo.on.ca/en/kaitlinatkinsonfrl. The website has an A-Z library of common illnesses and diseases. It also has broad topics such as surgery and anaesthesia listed, which when clicked opens a printable PDF document. Although specific surgeries are not available, the surgery pamphlet has general instructions for parents including when to fast their child, talking to their child about surgery, what to expect postoperatively, and how to prevent infection.

Fraser Health. Fraser Health is an integrated health authority of many hospitals located in British Columbia. Their website, http://www.fraserhealth.ca/health-

info/children-and-youth/ has an online resource for parents on child and youth health information. The resources are generalized to nutrition, dental, speech and language, immunizations, and school health topics. In a different area within their online resource portal is a Health A-Z area with a search bar for health information. This part is generalizable to adults mostly, and does not have specific surgical topics. It does have a general surgery information page that is written for adults.

IWK Health Centre. The IWK Health Centre is located in Halifax, Nova Scotia. Their website, http://www.iwk.nshealth.ca/ does contain a resource page for parents on information about their child having surgery. However, the information is mainly logistical in nature related to preparing for surgery and who would be on the team involved in their child's care. There is no specific surgery information such as information for caring for someone postoperatively.

Regina Qu'Appelle. Located at http://www.rqhealth.ca/, The Regina Qu'Appelle website offers a Health A-Z section of their website with a large number of topics. Included among this are printable, PDF documents of discharge instructions for various surgical procedures. There are both adult and pediatric specific information. For example, there is a cleft lip surgery pamphlet in PDF form that is printable. It includes information on what to expect before surgery, the day of surgery, and after surgery. Also, there is a section on how to care for your child post cleft lip surgery including information on keeping the surgical site clean.

J4Surgery Resources

The following printed pamphlets are available and used on J4Surgery as part of discharge teaching:

- Home care following tonsillectomy and adenoidectomy

- Alveolar bone grafting: Post op instructions

- Instructions for patients: Ear tubes

- Post-operative care following inguinal orchidopexy

- Home care following spinal surgery

- Parents guide to clubfoot correction

- Post-operative care following circumcision

- Discharge orders for cleft lip repair

- Head injury

- Cast care: Patient information.

These pamphlets have no specific references, except for referencing the Janeway Children's Hospital. The majority of pamphlets are dated 2012, with the oldest pamphlet dated 2007. All of the pamphlets contain general information on when to return to normal activities, a normal diet, and what parents should watch out for in regards to signs and symptoms of infection. Some pamphlets talk about when it is ok to shower and take a bath following surgery, and others include specific information on when you should

return to hospital if symptoms arise. The only pamphlet that includes information on pain control is the pamphlet on home care following tonsillectomy and adenoidectomy. Pain control information is lacking in all other pamphlets. It is interesting to note that one there is no pamphlet on one of the most common surgeries on J4Surgery: appendectomy. Other surgeries in which there is no pamphlet for is hypospadias repair, cholecystectomy, craniotomy, ORIF (orthopedic), laparotomy for bowel obstruction, Nissan fundoplication, and pyleoplasty.

Conclusion

Overall, it is interesting to see the type of online resources available to parents in the major health centres across Canada. Of eight resources navigated, aboutkidshealth.org was the most comprehensive and easy to use. However, Hamilton Health Science's resources were also extremely simplistic in nature when trying to find a document. The resources found on BC Children's Hospital website were more complicated to navigate and retrieve the appropriate information. The resources that already exist on J4Surgery, while useful, could be more comprehensive and detailed. Minimal pamphlets exist, and there are many common surgeries and procedures in which there is no pamphlet. This need could be eliminated with the development of an online resource. It would also be easier to keep the pamphlets and information up to date with the latest evidence-based practice. The findings of this scan will help shape the development of an online resource by identifying commonalities among available surgical information such as pain control, returning to normal activities, returning to a normal diet, and complications to watch for and when to notify a physician. One limitation to this environmental scan was that many

of the websites did not list their sources of information, if any. While it can be said that

information on hospital-based websites are trustworthy and would be based on evidence-

based information, it would be helpful to have sources identified for cross-referencing.

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Appendix A

Letter of Inquiry for Environmental Scan

Hello,

My name is Kelli Pitcher and I am currently completing my Masters of Nursing through Memorial University. As part of this program, I am developing an online resource for parents caring for their child at home following surgery, as I have determined our current resources are not fully meeting their needs. To help facilitate this, I am completing an environmental scan of other similar online resources across Pediatric hospitals in Canada. Your contact information was obtained through the Canadian Pediatric Surgical Nurses Interest Group (CaPSNIG).

Please answer the following questions:

- Does the hospital in which you currently work have any type of online-based resource for parents?

If yes, please provide the website:

- In your experience, have parents found this type of resource beneficial?

Thank you for your time,

Kelli Pitcher BN RN

Appendix B

Health Research Ethics Authority Screening Tool

	Question	Yes	No
1.	Is the project funded by, or being submitted to, a research funding agency for a research grant or award that requires research ethics review	☐☐	☐X
2.	Are there any local policies which require this project to undergo review by a Research Ethics Board?	☐☐	☐X
	IF YES to either of the above, the project should be submitted to a Research Ethics Board. **IF NO** to both questions, continue to complete the checklist.	☐☐	☐☐
3.	Is the primary purpose of the project to contribute to the growing body of knowledge regarding health and/or health systems that are generally accessible through academic literature?	☐☐	☐X
4.	Is the project designed to answer a specific research question or to test an explicit hypothesis?	☐☐	☐X
5.	Does the project involve a comparison of multiple sites, control sites, and/or control groups?	☐☐	☐X
6.	Is the project design and methodology adequate to support generalizations that go beyond the particular population the sample is being drawn from?	☐X	☐☐
7.	Does the project impose any additional burdens on participants beyond what would be expected through a typically expected course of care or role expectations?	☐☐	☐X
LINE A: SUBTOTAL Questions 3 through 7 = (Count the # of Yes responses)		1	
8.	Are many of the participants in the project also likely to be among those who might potentially benefit from the result of the project as it proceeds?	☐	☐X

9.	Is the project intended to define a best practice within your organization or practice?	☐X	☐
10.	Would the project still be done at your site, even if there were no opportunity to publish the results or if the results might not be applicable anywhere else?	☐X	☐
11.	Does the statement of purpose of the project refer explicitly to the features of a particular program, Organization, or region, rather than using more general terminology such as rural vs. urban populations?	☐X	☐
12.	Is the current project part of a continuous process of gathering or monitoring data within an organization?		x
LINE B: SUBTOTAL Questions 8 through 12 = (Count the # of Yes responses)		3	
	SUMMARY **See Interpretation Below**		

Interpretation:

- If the sum of Line A is greater than Line B, the most probable purpose is **research**. The project should be submitted to an REB.

- If the sum of Line B is greater than Line A, the most probable purpose is **quality/evaluation**. Proceed with locally relevant process for ethics review (may not necessarily involve an REB).

- If the sums are equal, seek a second opinion to further explore whether the project should be classified as Research or as Quality and Evaluation.

These guidelines are used at Memorial University of Newfoundland and were adapted from ALBERTA RESEARCH ETHICS COMMUNITY CONSENSUS INITIATIVE (ARECCI). Further information can be found at: http://www.hrea.ca/Ethics-Review-Required.aspx.

Appendix D: Consultation Report

Consultation Report for the Development of an Online Resource for Parents Caring for
their Child at Home Following Surgery

Kelli Pitcher

Memorial University

Every day, thousands of children across Canada and all over the world undergo both emergent and elective surgical procedures. With our rapidly changing health care system, children are discharged home quicker than ever before with the responsibility of care placed on the parents and caregivers of the child. As a pediatric nurse, I have seen both the benefits and challenges of early discharge postoperatively. Being in hospital poses its own social, emotional, and financial strain on families. Alternatively, being home and caring for a child postoperatively raises a lot of questions and concerns if families do not receive adequate discharge instructions or were distracted during discharge teaching (Browne, Flanigan, McComisky, & Pieper, 2007; Smith & Daughtrey, 2008; Weiss et al., 2008; Wong, Hockenberry, & Wilson, 2011). My experiences as a nurse have helped inform my decision to develop an online resource for parents caring for their child following surgery. A literature review on the rationale, content, and methodology of the development of an online resource has already been completed as well as an environmental scan of other pediatric hospitals across Canada. The next step is the development of any major project is to consult with key stakeholders. The literature review helped inform the basis of key questions during the consultations, including finding out what the most critical parental needs postoperatively are, and how an online resource would benefit parents. Consultations were conducted with experts in the area of pediatric surgery at the Janeway Children's Health and Rehabilitation Centre as part of the development of the resource. Prior to commencement of the consultations, an approved consultation plan was finalized.

Objectives

The objectives for the consultations were as follows:

4. To determine what health professionals believe to be the most important parental needs in caring for their child postoperatively at home.

5. To determine what topics health professionals believe to be a priority for the development of an online resource for parents.

6. To gather expert opinions and knowledge in the field of pediatric surgery that will help inform the development of an online resource for parents.

Consultation Methodology

Setting

All consultations were conducted at the Janeway Children's Hospital and Rehabilitation Centre. The Janeway Children's Hospital is Newfoundland and Labradors' tertiary care centre for children up to eighteen years of age. It has 42 acute care beds, 6 intensive care beds, 25 neonatal intensive care beds, 7 acute psychiatric beds, and 6 operating rooms. In 2015 alone, there were 51, 286 patients admitted to the acute care beds (Janeway Children's Hospital Foundation, 2015). All consultations took place either in a conference room or in the respective colleagues' office.

Consultants

Seven consultations were completed involving a novice nurse, a senior nurse, the clinical educator, the surgical outpatient nurse coordinator, a Janeway emergency room/telephone advice line nurse, the Janeway Resource Centre librarian, and a pediatric

surgeon. The novice nurse had been working in the area of pediatric surgery for less than a year, and graduated from her undergraduate nursing program in 2015. The senior nurse had been working in the area of pediatric surgery for most of her career, with a total of 36 years of nursing experience.

The clinical educator is a nurse who had been working in the area of pediatric surgery her entire nursing career, and who had been in the position of clinical educator for less than one year. This leadership position had given her opportunities to advance her knowledge and skills in the areas of nursing education and policy development. Her expertise, knowledge and experience made her an ideal candidate for consultation.

The surgical outpatient nurse coordinator is a nurse with over 30 years' experience as a pediatric nurse with most of those years being in the area of pediatric surgery. In her current position, she sees patients and families on the continuum of care as inpatients, and as outpatients in follow-up clinic. She is involved in a lot of home care teaching with families, organizing supplies for families for complex care, and has completed some nursing education with staff as well. Her expertise, knowledge and experience made her an ideal candidate for consultation.

The Janeway emergency room/telephone advice line nurse has many years of experience working in both the Janeway Children's Hospital Emergency Room as well as the Janeway's telephone advice line. As many of these professionals have dual roles, this nurse was chosen to provide information as to why parents call the telephone advice line after their child has had surgery, as well as why parents bring their child back to the emergency room postoperatively.

The pediatric surgeon chosen for consultation had been working as a surgeon at the Janeway Children's Hospital for seven years. Prior to that, he had worked and trained in a variety of pediatric hospitals across Canada. He was chosen to provide the perspective of a professional with a strong medical background who works with parents of children of all ages throughout the transition from preoperative, intraoperative, and postoperative period through to recovery.

The Janeway Resource Centre Librarian had been a librarian at the Janeway Resource Centre for three years. The Janeway Resource Centre is a small resource centre that focuses on children's and women's health information. It consists of a lending library, in which books can be borrowed on a variety of health topics. Electronic books are available as well. The centre also consists of a physical space where families can use the internet, send a fax or use a copy machine, have a cup of coffee, and allow their child to play in the small play area (Janeway Resource Centre, 2016). She was consulted for her unique knowledge and experience with online resources and online libraries.

Data Collection

Data was collected through the use of interviews, no longer than 30 minutes in length. Interviews were guided using pre-set questions (Appendix A), however some questions were modified based on responses, and clarification was requested when needed. All interviews were completed by the project developer, in-person, at a time when it was convenient for the consultant. Detailed notes were taken during the interviews and responses were read back to consultants to ensure accuracy. Consultants' names were not used during note taking, only their role to ensure confidentiality.

Data Analysis

Interview notes were transcribed into a password protected personal computer. Data was analyzed using content analysis. Interview notes were read and reread to identify common themes. Common themes were organized under similar consultants, and outlier responses were identified as well.

Ethical Considerations

All consultants were given a verbal background of the project, and were asked to participate on a voluntary basis. All consultants were made aware that confidentiality would be maintained by not using their names within the report. Confidentiality and data security was maintained throughout the entire process through the use of a password protected personal computer. It was concluded through the use of the Health Research Ethics Screening Tool (see Appendix B) that an REB review was not necessary. Institutional approval for this project had already been ascertained through Karen Rice, Division Manager of Pediatric Inpatient Services which includes J4Surgery as well as through Crystal Northcott, Program Consultant for the Children's and Women's Health Program, under which J4Surgery is a part of.

Results

All consultants were asked a set of four core questions. The Janeway Resource Centre Librarian, pediatric surgeon, and telephone advice line nurse were asked additional questions unique to their role (Appendix A). The themes identified from the

consultants' responses helped identify content for the developments of the online resource as well as identify the rationale for its development.

Theme One: Parents Need Knowledge about Pain Control

All nurses who were consulted as well as the pediatric surgeon brought up the concept of pain control postoperatively. Specifically, that parents need to know how to adequately assess their child's pain, as well as be able to appropriately treat it. Two consultants made reference to parents being fearful of certain medications to control their child's pain. One comment was "morphine scares parents when they do not have enough knowledge regarding its use and benefits". The emergency room/telephone advice line nurse shared that one of the most common reasons parents bring their child back to the emergency room postoperatively is poor pain control, specifically that parents are afraid to administer the appropriate dose, or the child is refusing to physically take the medication and parents are afraid to administer it when they really need it.

Theme Two: Parents need Reassurance

All consultants brought up the concept of parents needing reassurance postoperatively. This includes reassurance that what their child is experiencing is normal, and that what they are doing is ok. One nurse said a very common but simple question among parents is "Am I doing everything right? Can I be doing anything better?" When asked if they thought an online resource would benefit parents, almost all consultants talked about the positive reassurance it would give parents within their response. "Parents need comfort and support that everything is ok". "An online resource would definitely

benefit parents; it would give them peace of mind". The telephone advice/emergency room nurse said a very common question among parents who call into the advice line is "my child is experiencing _____, is this normal?" while most often what they are experiencing is a very common, normal postoperative complaint. Two consultants brought up the fact that a resource being online could be used by parents preoperatively as well, in order to be prepared for what to expect postoperatively. This way, parents would be more reassured by what their child is going through when they have known what to expect prior to surgery.

Theme Three: Returning to Normalcy

All consultants were in agreement that the most common questions parents have about their child's postoperative care relate to when their child will be able to return to normal. This included returning to a normal diet, returning to school, returning to their normal activities, and returning to sports. Other things included when they can take off their dressing if they have one, when they can go back to taking showers, and when they can have a bath. While some of the answers to these questions vary depending on the type of surgery, most consultants agreed that there are commonalities among most surgeries about when to return to school, sports, showers, and usual activities. Two consultants made similar comments that these types of basic questions often get overlooked or forgotten about in the initial high stress postoperative period, and having the information available online to parents would be an easy way for them to retrieve it once their stress levels have reduced. The Janeway Resource Centre librarian stated that the most common topics sought out in her library by parents are emotional topics, such as coping with loss

or coping with a diagnosis, anxiety in children, and parenting resources. When asked if she ever gets asked questions from parents related to postoperative care, she said unfortunately not but the libraries current location is attributing to the low level of visitors and traffic within the library. If the library was in a more central location within the Janeway Hospital, she states she would see a lot more parents with a larger variety of questions.

Theme Four: When to Return to Hospital

All consultants except the Janeway Resource Librarian stated that one of the most important concepts to include within the online resource for parents is information on when they should bring their child back to their doctor or return to the emergency department. It was thought among all consultants that more often than not, parents return to hospital with their child for minor concerns that do not require the use of an emergency room. These issues include minor bleeding, poor pain control, child not eating or drinking adequately, fears of infection, and concerns related to cast care. The pediatric surgeon in particular stated that a list of appropriate signs and symptoms for when to contact their surgeon/family doctor/return to emergency should be listed. He also said that this same list should be distributed to surgeons and doctors so that parents and physicians are all on the same page. During the same discussion of when to return to hospital, three consultants specified that a list of contact information should also be available to parents on the online resource so they always have an up to date list of phone numbers for appropriate nursing units and physician offices.

Rationale for an Online Resource

Throughout the consultations, there were many different reasons identified as to why and how an online resource would benefit parents. Unanimously, all consultants agreed that an online resource would be of great benefit to parents, families, and caregivers alike for caring for a child postoperatively. Four out of seven consultants brought up internet usage when asked how an online resource would benefit parents. It was said how this generation goes online to search for everything, and that having a reliable, accurate resource for parents to use is a high priority. One consultant said "Most people have smart phones and iPads now a days, they could look things up while in hospital as well as at home. They are just going to Google what they want anyway, we need to be able to provide them with a hospital-owned source of information that they can trust". Another consultant said "People lose papers and pamphlets. It is important to have them (pamphlets) but people are moving towards internet and social media usage for access to the same information. We need to make sure we are supplementing and not substituting. We need to keep our pamphlets and paper copies for those without access to the internet". Three consultants agreed that since parents are going online regardless, it is important for a large hospital such as the Janeway to have a specific reference that parents can trust.

The Janeway Resource Centre librarian was very enthusiastic with the possibility of the development of an online resource for parents, as she stated it is something she was hoping to have developed over the next few years. She said there is already an easy to use, information management system called "LibGuides" in which information can easily

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be added into a pre-set template online. She thought the online resource for parents could easily be added to the Janeway Resource Centre website, in which she already manages. She also brought up the fact that her current, online library which is also integrated into the physical library for book requests, could all be integrated into the one website. For example, if a parent wishes to learn about pain control, a link could easily be made to the books and resources already available through the Janeway Resource Centre on the topic of pain control in children.

Conclusion

The results from these consultations have helped further develop the rationale for the development of an online resource for parents caring for their child at home following surgery, as well as add to the content of this resource. The rationale for an online resource identified from the consultations was directly in agreement with the literature in regards to internet usage among parents and families. In regards to content of the resource, pain control was a prominent theme among both the consultations and literature review. This will be an important topic during the development of the online resource. Additionally, topics such as returning to normal activity, sports, and a normal diet will be included as well as when they should return to the emergency department.

Overall, objectives for the consultations were fulfilled. It was determined that health professionals believe that parents need to know about pain control, returning to normalcy, when to return to the emergency department, as well a sense of reassurance postoperatively. These consultations allowed for the gathering of expert opinions and

knowledge in relation to pediatric surgery, to help inform the development of an online

resource for parents.

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Appendix A

Guiding Questions for Consultations

1. In your experience, what are the most common questions parents ask regarding their child's care postoperatively?
   1a. (For physician and ER nurse only) What are some of the reasons parents bring their child to the ER department postoperatively?

2. What would you identify as the most critical parental need(s) that parents have during their child's postop recovery period?

3. Would an online resource benefit parents in caring for their child postoperatively? How so?

4. When the online resource for parents is developed, what would you consider to be the most important topics to include?

5. (For Librarian Only) What online platforms or resources already exist that could assist in the development of this online resource?

6. (For Librarian Only) What are the most common health information topics parents seek out in your library?

Appendix B

Health Research Ethics Authority Screening Tool

	Question	Yes	No
1.	Is the project funded by, or being submitted to, a research funding agency for a research grant or award that requires research ethics review	☐	X
2.	Are there any local policies which require this project to undergo review by a Research Ethics Board?	☐	X
	IF YES to either of the above, the project should be submitted to a Research Ethics Board. **IF NO** to both questions, continue to complete the checklist.	☐	X
3.	Is the primary purpose of the project to contribute to the growing body of knowledge regarding health and/or health systems that are generally accessible through academic literature?	☐	X
4.	Is the project designed to answer a specific research question or to test an explicit hypothesis?	☐	X
5.	Does the project involve a comparison of multiple sites, control sites, and/or control groups?	☐	X
6.	Is the project design and methodology adequate to support generalizations that go beyond the particular population the sample is being drawn from?	X	☐
7.	Does the project impose any additional burdens on participants beyond what would be expected through a typically expected course of care or role expectations?	☐	X
LINE A: SUBTOTAL Questions 3 through 7 = (Count the # of Yes responses)		1	
8.	Are many of the participants in the project also likely to be among those who might potentially benefit from the result of the project as it proceeds?	X	☐

9.	Is the project intended to define a best practice within your organization or practice?	X	☐
10.	Would the project still be done at your site, even if there were no opportunity to publish the results or if the results might not be applicable anywhere else?	X	☐
11.	Does the statement of purpose of the project refer explicitly to the features of a particular program, Organization, or region, rather than using more general terminology such as rural vs. urban populations?	☐	X
12.	Is the current project part of a continuous process of gathering or monitoring data within an organization?		**X**
LINE B: SUBTOTAL Questions 8 through 12 = (Count the # of Yes responses)		**3**	
	SUMMARY **See Interpretation Below**		

Interpretation:

- If the sum of Line A is greater than Line B, the most probable purpose is **research**. The project should be submitted to an REB.

- If the sum of Line B is greater than Line A, the most probable purpose is **quality/evaluation**. Proceed with locally relevant process for ethics review (may not necessarily involve an REB).

- If the sums are equal, seek a second opinion to further explore whether the project should be classified as Research or as Quality and Evaluation.

These guidelines are used at Memorial University of Newfoundland and were adapted from ALBERTA RESEARCH ETHICS COMMUNITY CONSENSUS INITIATIVE (ARECCI). Further information can be found at: http://www.hrea.ca/Ethics-Review-Required.aspx.