

**Development of an Interactive Workshop to Improve Nurse Management of  
Paediatric Cancer Pain**

by

© Dee A. Belbin

A practicum report submitted  
to the School of Nursing in partial fulfillment of the  
requirements for the degree of

**Master of Nursing**

**School of Nursing**

Memorial University of Newfoundland and Labrador

**October 2017**

St. John's      Newfoundland and Labrador

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

### Abstract

**Background and Purpose:** Poorly managed pain may cause unnecessary suffering for children with cancer and their families. To effectively manage paediatric cancer pain, nurses must understand the ways in which suffering impacts quality of life for children and families. The purpose of this practicum was to develop an interactive, education workshop to improve pain communication and management by paediatric oncology nurses. An interactive, evidence-informed workshop based upon relational inquiry (Hartrick Doane & Varcoe, 2015) was developed to offer nurses insight into child and family perspectives of the pain experience and effective nursing actions to reduce suffering. **Methods:** Two methods were used in the development of this workshop. A literature review was conducted on paediatric cancer pain and consultations with key stakeholders identified local issues influencing the quality of pain management by nurses. **Results:** Key findings were assimilated to guide the development of the one-day education workshop. First, cancer pain is a multidimensional experience with emotional, physical, and spiritual components. Second, a relational approach to cancer pain assessment requires nurses to inquire about the nature and meaning of pain, its impact on quality of life, and strategies children and families find useful to alleviate suffering. Third, effective and timely communication between children, families, and the oncology team could improve the quality of pain care delivered. **Conclusion:** An interactive workshop using Hartrick Doane and Varcoe's (2015) relational inquiry approach could improve nurses' pain communication and guide holistic interventions to alleviate suffering for children with cancer and their families.

# INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

## Acknowledgements

This practicum project has been inspired by the courage of the children and families of the local paediatric oncology unit as well as the nurses committed to improving the wellbeing and quality of life of these children and families. It has been a privilege to advocate for this quality care initiative on behalf of these brave children and families and their excellent nurses.

There are several individuals who have supported me throughout this program and during this project that I would like to acknowledge.

First, I would like to thank my husband and children for their unwavering support during the course of this challenging three-year program.

Second, I would like to thank my practicum supervisor, Dr. Joy Maddigan for her dedication, enduring support, and exceptional professionalism throughout this project. I will never be able to thank you enough for your outstanding contribution to this project.

Third, I would like to thank my nurse manager, Karen Rice, and the members of the multidisciplinary paediatric oncology team for their kind support and the exceptional contribution they made to this project.

Finally, I would like to thank my fellow students, particularly Ava Hatcher, for your endless support during this program.

# INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

## Table of Contents

Abstract	i
Acknowledgments	ii
Table of Contents	iii
Introduction	1
Background	1
Rationale	2
Goal and Objectives	3
Methodologies	4
Summary of the Literature Review	5
Methodologies	5
Lived Experience of Paediatric Cancer Pain	6
Obtaining Relief from Cancer Pain	7
Educational Interventions to Improve Nurse Management of Childhood Cancer Pain	9
Nursing Implications	10
Summary of Consultations	11
Development of Workshop	12
Advanced Nursing Competencies	14
Next Steps	16
Conclusion	17
References	20



## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

Appendix A Literature Review	25
Literature Review Tables	63
Appendix B Consultation Report	80
Appendix C Interactive Workshop on Paediatric Cancer Pain	107
Introduction to Workshop	108
Understanding Suffering: A Nursing Approach to Paediatric Cancer Pain- An Interactive Workshop for Oncology Nurses	112
Workshop Handouts	198

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

### Development of an Interactive Workshop to Improve Nurse Management of Paediatric Cancer Pain

From the time of diagnosis until the end of life, children with cancer experience recurrent episodes of acute and chronic pain (Patterson, 1992). Cancer pain in children can be challenging to manage as it originates from different sources and changes in intensity over time (Van Cleve, Muñoz, Riggs, Bava, & Savedra, 2012). Infants and children with cancer lack the skills to describe the nature and severity of the pain they experience (Stevens, 2007; Van Cleve et al., 2012). Families often report that nurses lack effective pain communication skills leading to inadequate pain relief (McDonald, LaPorta, & Meadows-Oliver, 2005; Van Cleve et al., 2012). Poorly controlled cancer pain negatively impacts the quality of life of a child and their family (Montoya-Juárez et al., 2012).

Many paediatric oncology nurses report they lack the knowledge and skills to effectively assess and manage cancer pain (Enskär et al., 2007). For the past year, oncology nurses on the Janeway Health and Rehabilitation Centre (Janeway) Medicine Unit have requested education to guide more effective nursing interventions to alleviate suffering for children with cancer and their families. In addition, members of the Janeway multidisciplinary paediatric oncology team have considered how to improve pain communication between children, families, and health care providers. Finally, many members of the multidisciplinary oncology team have expressed concerns over the quality of cancer pain care delivered to children and families.

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

As part of my studies under the Master of Nursing program, I have considered what could be done to address the concerns I have observed respecting the assessment and management of paediatric cancer pain in the workplace. During the Quantitative Research course in Winter Semester 2016, I submitted a research proposal for an education module to improve nurse management of paediatric cancer pain. In April 2016, I discussed the results of the literature review for the Quantitative Research course research proposal with members of the managerial and paediatric oncology education team for our unit.

At the end of May 2016, the paediatric oncology education team provided Janeway Medicine nurses with education on the pathophysiology of physical pain, pharmacologic and non-pharmacologic interventions, dose-limiting side effects of pain medications, and end of life pain assessment. After these education sessions, the paediatric oncology education team conducted chart audits to determine if there had been a change in clinical practice after the education sessions. In November 2016, the oncology education team advised that chart audits did not reflect an increase in the frequency or documentation of pain assessment and management strategies after the May 2016 education sessions.

In addition, I discussed the challenges of integrating new knowledge into clinical practice with the oncology education team. I shared my observation that there is a lack of effective cancer pain communication between members of the multidisciplinary paediatric oncology team. For example, oncology nurses do not document the discussions they have with children and families about pain. The multidisciplinary

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

oncology team therefore lacks documented pain assessments that report the nature, frequency, severity, duration, and location of pain. Moreover, I have observed that Janeway oncology nurses rarely chart non-pharmacologic pain interventions; thus, it is challenging for the oncology team to assess the effectiveness of these strategies.

Currently, Janeway oncology nurses do not report assessment of the child and family's experience with cancer pain. In this practicum project, Hartrick Doane and Varcoe's (2015) relational inquiry approach was used to explore the meaning of cancer pain with children and families and strategies to improve the quality of pain communication. Hartrick Doane and Varcoe's (2015) relational inquiry method was used to develop an interactive, evidence-informed workshop to assist oncology nurses to improve the quality of pain management on this paediatric unit. A relational inquiry approach to paediatric cancer pain could explore the meaning assigned to pain and the lived pain experience in order to alleviate suffering, prioritize family values, and build capacity for the child and family to advocate for better care.

### **Goal and Objectives**

The primary goal of this practicum project was to develop an interactive, evidence-informed workshop to assist nurses to improve the quality of pain communication and guide holistic interventions to alleviate suffering for children with cancer and their families. The objectives addressed in this practicum project included the following:

1. Evaluation of the literature on the lived experience of cancer pain for children and adolescents and strategies they find useful to obtain relief. Recent evidence on

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

education interventions for oncology nurses was also appraised. Findings from the literature were synthesized into key themes in an integrated literature review.

2. A consultation plan was implemented based upon the key themes from the literature review. Semi-structured interviews were conducted with senior and novice frontline paediatric oncology nurses (n = 4) and the nurse manager. Separate focus groups were held with the team of paediatric oncologists (n = 3) and members of the pastoral services team (n = 3). Consultation participants shared their perspectives on existing cancer pain education resources for nurses, nursing strengths and needs related to pain management, and current challenges influencing the quality of pain care.
3. The literature review and consultation data, together with Hartrick Doane and Varcoe's (2015) relational inquiry method, were used to create an interactive workshop to improve the quality of cancer pain communication and management by paediatric oncology nurses.
4. Competencies of advanced nursing practice were demonstrated throughout the stages of development of this interactive, evidence-informed workshop.

### **Overview of Methods**

Two methods were used to implement the practicum objectives. First, an integrated literature review was conducted to appraise recent evidence on the lived experience of cancer pain in children, suffering in paediatric oncology, the meaning of cancer pain for children and families, pain communication, nurse management of cancer pain, and education interventions for nurses. Second, key stakeholders from the

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

multidisciplinary oncology team were consulted to obtain their perspectives on current resources, the strengths and learning needs of nurses in the delivery of pain care, and factors that impact pain management. The findings from the integrated literature review and stakeholder consultations were used to create an interactive workshop to improve nurse management of paediatric cancer pain.

### **Summary of the Literature Review**

#### **Methods**

A search of the literature on the lived experience of cancer pain for children and families and nurse management of paediatric cancer pain was conducted in CINAHL, PubMed, OneSearch, and Google Scholar. Inclusion criteria for this integrated literature review included studies published in the last 10 years, written in the English language, and related to cancer pain management in children and adolescents. The search terms for this literature review included “lived experience of childhood cancer pain”, “meaning of childhood cancer pain”, “meaning of suffering in childhood cancer”, “spiritual distress in childhood cancer”, “barriers to cancer pain management in children”, “nurse management of childhood cancer pain”, and “nursing intervention cancer pain in children”.

After a comprehensive review of the recent evidence on childhood cancer pain, 16 studies were selected for this integrative literature review including nine quantitative studies and seven qualitative studies. The three key themes from the literature review included the lived experience of paediatric cancer pain, obtaining relief from cancer pain, and educational interventions to improve nurse management of childhood cancer pain. The complete literature review is attached in Appendix A of this practicum report.

### **Lived Experience of Paediatric Cancer Pain**

The recent literature on the lived experience of paediatric cancer pain demonstrates that it is a multidimensional phenomenon with physical, emotional, and spiritual elements. Many factors contribute to the cancer pain experience in children and adolescents. In order to develop effective care plans to alleviate suffering, nurses must understand how these multifaceted dimensions contribute to the pain experience of children and families.

Physical pain may be experienced acutely or chronically. Acute physical pain arises from diagnostic procedures, chemotherapy and radiation side effects, infection, and surgical sites (Cicogna, Nascimento, & de Lima, 2010; Rocha et al., 2015). Tumor invasion, inflammation, alterations of the gastrointestinal tract, and headaches are commonly reported sources of chronic pain in children with cancer (Cicogna et al., 2010; Rocha et al., 2015). Physical pain limits a child's sleep, mobility, play, social activities, and functional capacity to perform daily tasks (Cicogna et al., 2010; Rocha et al., 2015). Physical pain negatively impacts quality of life for children with cancer and their families. Poorly managed pain can lead to frustration, erosion of trust, and deterioration of the therapeutic relationship if children and families feel that nurses do not adequately address pain concerns (Van Cleve et al., 2012).

Another element of cancer pain discussed in the literature was emotional pain. Children with cancer and their families may suffer emotional pain as they undergo health transitions experienced throughout the course of treatment. Displacement in hospital away from normal routines and social support networks causes emotional pain for

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

children with cancer and their families (Rocha et al., 2015). Emotional pain may also arise from loss of family routines, enjoyed pastimes, social isolation, loss of normalcy, and limited ability to plan for the future (Cicogna et al., 2010; Rocha et al., 2015). Body image changes associated with weight loss, loss of strength, loss of muscle mass, and acne from use of steroids can create emotional distress for adolescents with cancer (Cicogna et al., 2010). Enduring uncertainty and pervasive anxiety can create emotional distress for children and families as they struggle to integrate comprehensive treatment schedules with work, school, fiscal, and family responsibilities.

A third element of cancer pain discussed in the literature was spiritual pain. Older children and adolescents realize that cancer is serious and could lead to death. These young people may experience spiritual distress manifested as despair, hopelessness, and social withdrawal as they struggle to cope with curative therapies that have side effects that cause great suffering (Cicogna et al., 2010; Essig, Steiner, Kuehni, Weber, & Kiss, 2016). Some adolescents reported that the suffering experienced during treatment was so significant that it caused them to consider withdrawing from therapy despite knowing that their chance of survival would be lessened (Essig et al., 2016). Some young people expressed feelings of betrayal and anger towards God when their prayers for comfort or cure remain unanswered (Kamper, Van Cleve, & Savedra, 2010). Children and adolescents report that they may not feel comfortable disclosing spiritual distress to friends and family but may share their concerns with nurses (Essig et al., 2016; Kamper et al., 2010).

### **Obtaining Relief From Cancer Pain**



## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

Children and families report use of diverse strategies to obtain relief from cancer pain (Cicogna et al., 2010; Kamper et al., 2010; Rocha et al., 2015). Considering what interventions may be useful to alleviate suffering requires children and families to reflect on the meaning of pain as well as their beliefs, values, and priorities regarding its management (Essig et al., 2016; Fortier et al., 2012; Kamper et al., 2010; Rocha et al., 2015; Zwaanswijk et al., 2007). Inquiring into the pain experiences of children and families, interventions they have found useful to alleviate suffering, and care priorities could help nurses develop care plans to promote quality of life.

There are several non-pharmacologic interventions that children report using to reduce suffering. In randomized clinical trials, heated pillows, bubbles, and music significantly reduced anxiety and pain of children with cancer during needle-related diagnostic tests (Héden, Von Essen, & Ljungman, 2009; Nguyen, Nilsson, Hellström, & Bengtson, 2010). Children also report using rest, entertainment, social support, and play to redirect their attention until pain subsides (Cantrell & Matula, 2009; Cicogna et al., 2010; Rocha et al., 2015;). Some children with cancer report that medication alone does not effectively reduce their pain in the absence of non-pharmacologic interventions (Rocha et al., 2015). A majority of children in one study reported meditation, prayer, thinking about a higher spiritual power, and reflection helped them obtain relief from cancer pain (Kamper et al., 2010).

Children with cancer and their families report that effective communication could assist them to prepare for painful procedures and manage the challenges of curative therapy. Children and families need adequate information about the benefits and effects

of treatment in order to make informed care decisions (Essig et al., 2016; Karlsson et al., 2014; Zwaanswijk et al., 2007). Older children and adolescents have a right to participate in treatment decisions and require clear information to permit them to play an active role in care planning (Essig et al., 2016; Zwaanswijk et al., 2007). Providing anticipatory guidance through open communication and sufficient time to prepare for procedures can reduce anxiety and the perception of pain for children with cancer and their families (Cicogna et al., 2010; Héden et al., 2009; Karlsson et al., 2014; Nguyen et al., 2010; Rocha et al., 2015). Valuing, respecting, and engaging children and their families during collaborative planning can strengthen therapeutic relationships and could increase the likelihood of treatment compliance (Essig et al., 2016; Zwaanswijk et al., 2007).

### **Educational Interventions to Improve Nurse Management of Childhood Cancer Pain**

There are very few recent studies describing effective interventions to improve nurse management of cancer pain. In addition, the findings across the studies have been inconsistent. Interventions included in the literature review consisted of an education day or a comprehensive education approach.

**Education day.** Single day education interventions on cancer pain used video demonstrations modeling pain care, case studies with group discussions, and the development of unit specific resources to promote integration of new skills into clinical practice (Gustafsson & Borglin, 2013; O'Shea, Wallace, Griffin, & Fitzpatrick, 2011; Patiraki et al., 2006). Gustafsson and Borglin (2013) found a significant difference in pain knowledge scores for nurses four weeks after they had attended a workshop that

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

used case studies to guide group discussions on pain assessment and that provided the nurses with a pocket guide to assist with implementation of new skills. O'Shea, Wallace, Griffin, and Fitzpatrick (2011) used a conceptual framework for spiritual pain care and case studies to lead group discussions to model spiritual interventions for nurses. O'Shea et al. (2011) reported significant improvements in perceived self-efficacy to provide spiritual care as well as nurse attitudes towards spiritual interventions. Patiraki et al. (2006) found that pain education videos and case studies with group discussions significantly increased nurse knowledge scores.

**Comprehensive education approach.** Some of the researchers reporting a comprehensive approach to cancer pain education used conceptual frameworks and Advanced Practice Nurses (APNs) to serve as change agents and a source for staff integrating new knowledge into clinical practice (Idell, Grant, & Kirk, 2007; McMillan, Tittle, Hagan, & Small, 2005; O'Shea et al., 2011). Significant improvements in knowledge and pain re-assessment practices were achieved after using an APN to introduce education and address challenges staff experienced while integrating new skills in practice (Idell et al., 2007). After attending a comprehensive pain course, nurses scored significantly higher in the areas of pain knowledge and attitudes towards its management (McMillan et al., 2005). Following an extensive pain course, nurses also reported improved readiness to serve as a pain resource nurse (McMillan et al., 2005).

### **Nursing Implications**

In order to manage pain effectively, oncology nurses need to understand how children and families perceive the experience and meaning of pain, its impact on quality

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

of life, and interventions useful to obtain relief. Providing nurses with education on multidimensional pain, how its elements interrelate, and comprehensive strategies children and families find useful to reduce suffering could improve management of pain. In addition, nurses could benefit from improved understanding of the role of communication and its significance in pain management. Offering nurses education on the use of Hartrick Doane and Varcoe's relational inquiry method could provide a more holistic approach to pain assessment that promotes quality of life.

Use of the relational inquiry conceptual framework by Hartrick Doane and Varcoe (2015) could strengthen the design of a workshop and bridge the theory to clinical practice gap by demonstrating the relevance of this approach when collaborating with children and families. A workshop that uses case studies, small group work, and unit specific resources to allow nurses to integrate new knowledge in practice settings may improve nurse self-efficacy and readiness. Using an APN to serve as a change agent, educator, and supportive resource to integrate new knowledge into clinical practice may improve sustainability of new skills and staff satisfaction with the quality of pain care.

### **Summary of Consultations**

Eleven professionals with expertise in paediatric cancer pain were consulted in the development of this interactive workshop. Open-ended questions were asked during each consultation to encourage participants to share their professional experience of providing pain care to children with cancer and their families. Individual, semi-structured interviews were conducted with three senior nurses, one novice nurse, and the nurse manager for paediatric oncology services. One focus group was held with the team of paediatric

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

oncologists (n = 3). A separate focus group was conducted with the team from Pastoral Services (n = 3). Field notes were made during the individual interviews and focus groups to record data. Content analysis was used to group common meaning units into key themes (Streubert & Carpenter, 2011). The complete consultation report is attached in Appendix B of this practicum report.

### **Consultation Results**

The key findings from the consultations were consistent with the themes identified in the literature review. First, cancer pain is a multidimensional experience with physical, emotional, and spiritual components and its management requires a holistic approach. Second, cancer pain can be difficult to assess and manage in young children. Third, the quality of life of children and families can be negatively impacted by the many elements of cancer pain. Fourth, the quality of communication between children, families, and the multidisciplinary oncology team requires improvement. Fifth, Pastoral Services has a role to play in the management of cancer pain and clarification of their role is needed. Sixth, consultation participants agreed that education on cancer pain is specialized and should be offered to nurses in an interactive way designed to support integration of new knowledge into clinical practice. Consultation participants stated that they preferred case studies, group discussions, and unit specific resources to guide implementation of education into practice. The key findings from the consultations were integrated into the workshop content to provide a learning experience that addressed the identified learning needs of nurses.

### **Development of the Workshop**

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

An interactive workshop on cancer pain was created for paediatric oncology nurses based upon the strengths and learning needs identified in the literature review and consultations. The workshop begins with an introduction to the relational inquiry approach to nursing developed by Hartrick Doane and Varcoe (2015). Nurses will then be introduced to the World Health Organization's (2012) definition of multidimensional cancer pain and the necessity of a holistic approach for its effective management. Workshop modules two, three, and four describe the factors associated with emotional pain, physical pain, and spiritual pain and how the holistic pain experience influences quality of life for children and families. Modules two through four also examine the relational inquiry approach to explore child and family pain experiences, perspectives on the meaning of pain, and strategies useful for its management. The fifth module of the workshop focuses on communication and its significance in pain management. The complete interactive workshop is attached in Appendix C of this practicum report.

An exemplar family was created for the workshop case studies to allow nurses to discuss in small groups how workshop concepts apply to a child and family experiencing emotional pain, physical pain, spiritual pain, and communication challenges as they undergo health transitions during cancer treatment. Handouts were created to assist nurses during the four case studies on emotional pain, physical pain, spiritual pain, and pain communication. These handouts will be made into a pocket guide for nurses to use in clinical practice after the workshop. This experiential learning approach can prepare nurses to integrate new nursing skills into clinical practice.

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

The experiential design of the workshop was developed to compliment the strengths and needs of the nurses who will receive the education. Nurses on this unit identified education on nursing interventions for cancer pain as a high priority. The majority of paediatric oncology nurses on the unit already have strong therapeutic skills that they use to support children and families. In addition, the nurses on this unit work as a unified team. Engaging these nurses to consider how to apply their strong therapeutic communication skills and novice relational inquiry skills to improve pain assessment could improve the quality of pain care in this paediatric oncology unit.

### **Advanced Nursing Competencies**

In order to practice nursing at an advanced level, a nurse with a graduate level education must be able to demonstrate effective clinical, research, leadership, and consultation and collaboration competencies (CNA, 2008). Paediatric oncology nursing is recognized as a specialized area of nursing (Patterson, 1992). Carper (1978) suggested that synthesis of theoretical knowledge, scientific literature, and caring relationships shared with those enduring suffering could help nurses evaluate strategies to promote wellbeing. In this practicum, I used the relational knowledge gained through my work with children with cancer and their families to appraise the literature and its potential usefulness in practice. I utilized a conceptual framework, Hartrick Doane and Varcoe's (2015) relational inquiry approach, to ground the workshop content in nursing knowledge to bridge the theory to practice gap. Using my clinical experience in a specialized area of nursing to develop a quality care initiative to address a gap in current education and resources demonstrates my clinical competencies.

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

Through an integrated literature review, I developed a plan to create an education workshop to improve cancer pain management on the Janeway Medicine Unit. The education workshop I developed will disseminate recent evidence on paediatric cancer pain to nurses on my unit. The evidence-informed knowledge grounded in the literature also guided the development of a consultation plan with key stakeholders to improve nurse management of cancer pain. Utilizing research to develop a quality care initiative to improve nurse management of paediatric cancer pain demonstrates research competencies in support of my advanced level of practice.

Through collaboration with my Practicum Supervisor and consultation with the oncology team, I demonstrated an ability to effectively partner with key stakeholders in the development of a quality improvement initiative. Throughout the development of this workshop, I collaborated with my Practicum Supervisor to ensure that the constructive feedback offered was integrated to strengthen the design. By consulting with members of the paediatric oncology team, I acquired valuable insight into the intrapersonal, interpersonal, multidisciplinary, and organizational strengths and needs related to pain management by oncology nurses at the Janeway. Identification of the learning needs and preferences of nurses assisted me to design a continuing education workshop to improve management of paediatric cancer pain.

By identifying this significant gap in clinical practice and acting as a change agent to improve the quality of cancer care, I demonstrated the leadership skills necessary to practice at an advanced level of nursing. Developing a workshop to build capacity for paediatric oncology nurses to improve the quality of pain care is strongly aligned with



## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

Eastern Health's 2017-2020 strategic initiative entitled "Lighting the way/ Navigating together" (Eastern Health, 2017b). Eastern Health is committed to child and family focused care. The workshop I created will help oncology nurses engage children and families to consider what would constitute quality of life and which pain interventions might help them achieve this goal. By creating a workshop that supports the strategic plan of my organization, I have demonstrated leadership skills in support of my advanced level of practice.

### **Next Steps**

The next step in the development of this interactive workshop will be coordination with the nurse manager to present this education to nurses on my unit. Three months after the education is delivered, I will re-interview consultation stakeholders to determine what impact, if any, the workshop has made to pain assessment and documentation practices, communication with the multidisciplinary team, number of consultations for emotional and spiritual pain, and stakeholders' level of satisfaction with the quality of pain care. This information will be used to identify opportunities for continuing education on paediatric cancer pain. It is anticipated that nurses integrating new knowledge into clinical practice will require ongoing support and the opportunity to discuss workshop concepts. Coffee break education sessions on our unit offer a forum to present additional case studies to reinforce workshop knowledge, discuss applicability of workshop concepts to clinical scenarios, and address identified challenges. In addition, if nurses on the unit successfully adopt relational inquiry into practice, my long-term plans

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

include using the format I created through this practicum process to develop additional cancer symptom management workshops on fatigue, nausea management, and mucositis.

The next steps in the development of this workshop also include dissemination of the content and data at three nursing research conferences. First, I plan to submit an abstract in September 2017 to the Pediatric Nursing Journal (2016) for potential inclusion in their conference scheduled for July 2018. Second, I plan to submit an abstract to the Canadian Association of Nurses in Oncology (2017) for potential inclusion in their conference scheduled for Fall 2018. Third, I will submit an abstract to Eastern Health's (2017a) Annual Nursing Research Symposium to discuss the findings of this quality care initiative.

### **Conclusion**

There have been many lessons learned during the course of these two practicum semesters that have helped me develop the skills necessary to practice nursing at an advanced level. Through an integrated literature review, I assessed gaps between current paediatric oncology research and clinical practice that require improvement on my unit. The literature review demonstrated my research competencies in support of an advanced level of practice. In addition, I used the findings of the literature to develop a consultation plan to assess the learning needs of nurses, perspectives of key organizational stakeholders, and barriers to quality pain management for children with cancer and their families. After I gathered data through focus groups and semi-structured interviews with key stakeholders, I used content analysis to develop categorical themes to guide the creation of the education workshop (Streubert & Carpenter, 2011).

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

Through collaboration with my Practicum Supervisor and consultation with the oncology team at the Janeway, I have demonstrated an ability to effectively partner with key stakeholders in the development of a quality improvement initiative. By identifying this significant gap in current clinical practice and acting as a change agent to improve the quality of cancer care, I have demonstrated the leadership skills necessary to practice at an advanced level of nursing.

Most importantly, I learned how to integrate the findings of the literature review and consultations to create an interactive workshop for oncology nurses to improve the quality of pain management on my nursing unit. As I could not locate any research studies reporting the use of Hartrick Doane and Varcoe's (2015) relational inquiry approach, it was extremely challenging to develop this workshop creating a new method for holistic management of childhood cancer pain. I had to rely on my clinical practice skills to determine the types of questions that could guide relational inquiry into the lived experience of cancer pain suffered by children and their families. I also had to rely on my clinical practice skills to determine how to present this education to nurses on my unit.

Despite the numerous challenges, it is my belief that current nursing practice could be improved by integration of this education workshop. Nurses on our unit are deeply motivated to improve the quality of pain management for children with cancer and their families. This practicum project has been inspired by the courage of the children and families of our unit as well as the nurses committed to improving the wellbeing and quality of life of these children and families. It has been a privilege to advocate for this

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

quality care initiative on behalf of these brave children and families and their excellent nurses.

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

### References

Canadian Association for Nurses in Oncology (2017). *First Announcement 2017*.

Retrieved from: <http://www.cano-acio.ca/page/firstannouncement17>

Canadian Nurses Association (CNA). (2008). *Advanced nursing practice: A national*

*framework*. Retrieved from: [https://www.cna.aiic.ca/~media/cna/page-](https://www.cna.aiic.ca/~media/cna/page-content/pdf-en/anp/_national_framework_e.pdf)

[content/pdf-en/anp/\\_national\\_framework\\_e.pdf](https://www.cna.aiic.ca/~media/cna/page-content/pdf-en/anp/_national_framework_e.pdf)

Cantrell, M. A. & Matula, C. (2009). The meaning of comfort for pediatric patients with cancer. *Oncology Nursing Forum*, 36(6), E303-E309.

doi: 10.1188/09.ONF.E303-E309

Carper, B. A. (1978). Fundamental patterns of knowing in nursing. *Advances in Nursing*

*Science*, 1(1), 13-24. Retrieved from:

<http://www.journals.lww.com/advancesinnursingscience>

Cicogna, E. D. C., Nascimento, L. C., & de Lima, R. A. G. (2010). Children and

adolescents with cancer: Experiences with chemotherapy. *Revista Latino-*

*Americana de Enfermagem*, 18(5), 864-872. Retrieved from:

<http://www.eerp.usp.br/rlae>

Eastern Health (May 2017a). *Nursing education and research council: 12<sup>th</sup> annual research symposium*. Retrieved from:

<http://clpnnl.ca/sites/default/files/inline-files/>

Eastern Health (June 22, 2017b). *Strategic plan: 2017-2020: Lighting the way/*

*Navigating together*. Retrieved from:

<http://www.easternhealth.ca/WebinWeb.aspx?d=2&id=2379&p=2377>

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

- Enskär, K., Ljusegren, G., Berglund, G., Eaton, N., Harding, R., Mokoena, J., . . . Moleki, M. (2007). Attitudes to and knowledge about pain and pain management, of nurses working with children with cancer: A comparative study between UK, South Africa, and Sweden. *Journal of Research in Nursing*, 12(5), 501-515. doi: 10.1177/1744987107080455
- Essig, S., Steiner, C., Kuehni, C. E., Weber, H., & Kiss, A. (2016). Improving communication in adolescent cancer care: A multiperspective study. *Pediatric Blood & Cancer*, 63(8), 1423-1430. doi: 10.1002/pbc.26012
- Fortier, M. A., Wahi, A., Maurer, E. L., Tan, E. T., Sender, L. S., & Kain, Z. N. (2012). Attitudes regarding analgesia use and pain expression in parents of children with cancer. *Journal of Pediatric Hematology Oncology* 34(4), 257-262. doi: 10.1097/MPH.0b013e318241fd07
- Gustafsson, M. & Borglin, G. (2013). Can a theory-based educational intervention change nurses' knowledge and attitudes concerning cancer pain management? *BMC Health Services Research*, 13(328), 1-11. doi: 10.1186/1472-6963-13-328
- Hartrick Doane, G. & Varcoe, C. (2015). *How to nurse: Relational inquiry with individuals and families in changing health and health care contexts*. Philadelphia: Wolters Kluwer Lippincott Williams & Wilkins
- Héden, L., Von Essen, L., Ljungman, G. (2009). Randomized interventions for needle procedures in children with cancer. *European Journal of Cancer Care*, 18(4), 358-363. doi: 10.1111/k/1365-2354.2008.00939.x

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

- Idell, C. S., Grant, M., & Kirk, C. (2007). Alignment of pain reassessment practices and National Comprehensive Cancer Network Guidelines. *Oncology Nursing Forum*, 34(3), 661-667. doi: 10.1188/07.ONF.661-667
- Kamper, R. L., Van Cleve, L., & Savedra, M. (2010). Children with advanced cancer: Responses to a spiritual quality of life interview. *Journal for Specialists in Pediatric Nursing*, 15(4), 301-306. doi: 10.1111/j/1744-6155.2010.00253.x
- McDonald, D. D., LaPorta, M., Meadows-Oliver, M. (2005). Nurses' response to pain communication from patients: A post-test experimental study. *International Journal of Nursing Studies*, 44(1), 29-35. doi: 10.1016/j.ijnurstu.2005.11.017
- McMillan, S. C., Tittle, M., Hagan, S. J., & Small, B. J. (2005). Training pain resource nurses: Changes in their knowledge and attitudes. *Oncology Nursing Forum*, 32(4), 835-842. doi: 10.1188/05.ONF.835-842
- Montoya-Juárez, R., Garcia-Caro, M. P., Calderón, C. C., Rio-Valle, J. S., Sorroche-Navarro, C., & Quintana, F. C. (2012). Suffering in children experiencing a terminal disease: The perspective of parents and professionals. *Revista Da Escola De Enfermagem Da Usp*, 46(6), 1300-1305. doi: 10.1590/S0080-62342012000600003
- Nguyen, T. N., Nilsson, S., Hellström, A.-L., & Bengtson, A. (2010). Music therapy to reduce pain and anxiety in children with cancer undergoing lumbar puncture: A randomized clinical trial. *Journal of Pediatric Oncology Nursing*, 27(3), 146-155. doi: 10.1177/1043454209355983

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

- O'Shea, E. R., Wallace, M., Griffin, M. Q., & Fitzpatrick, J. J. (2011). The effect of an educational session on pediatric nurses' perspectives towards providing spiritual care. *Journal of Pediatric Nursing*, 26(1), 34-43.  
doi: 10.1016/j.pedn.2009.07.009
- Patiraki, E. I., Papathanassoglou, E. D. E., Tafas, C., Akarepi, V., Katsaragakis, S. G., Kampitsi, A., & Lemonidou, C. (2006). A randomized controlled trial of an educational intervention on Hellenic nursing staff's knowledge and attitudes on cancer pain management. *European Journal of Oncology Nursing*, 10(5), 337-352. doi: 10.1016/j.ejon.2005.07.006
- Patterson, K. L. (1992). Pain in the pediatric oncology patient. *Journal of Pediatric Oncology Nursing*, 9(3), 119-130. doi: 10.1177/104345429200900304
- Pediatric Nursing Journal (2016). 33<sup>rd</sup> Pediatric nursing conference: Call for abstracts.  
Retrieved from: <http://www.pediatricnursing.net>
- Rocha, A. D. F. P., Sposito, A. M. P., de Bortoli, P. S., Silva-Rodrigues, F. M., de Lima, R. A. G. & Nascimento, L. C. (2015). Oncologic pain relief: Strategies told by adolescents with cancer. *Texto & Contexto Enfermagem*, 24(1), 96-104.  
doi: 10.1590/0104-07072015002120013
- Stevens, B. (2007). Pain assessment and management in infants with cancer. *Pediatric Blood & Cancer*, 49(S7), 1097-1101. doi: 10.1002/pbc.21347
- Streubert, H. J. & Carpenter, D. R. (2011). *Qualitative research in nursing: Advancing the humanistic imperative*. Philadelphia: Wolters Kluwer Lippincott Williams & Wilkins



## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

Van Cleve, L., Muñoz, C. E., Riggs, M. L., Bava, L., & Savedra, M. (2012). Pain experience in children with advanced cancer. *Journal of Pediatric Oncology Nursing*, 29(1), 28-36. doi: 10.1177/1043454211432295

World Health Organization (WHO). (2012). *WHO guidelines on the pharmacological treatment of persisting pain in children with medical illnesses*. Geneva: World Health Organization. Retrieved from:  
[https://apps.who.int/iris/bitstream/10665/4450/1/978921458120\\_Guidelines.pdf](https://apps.who.int/iris/bitstream/10665/4450/1/978921458120_Guidelines.pdf)

Zwaanswijk, M., Tate, K., van Dulmen, S., Hoogerbrugge, P. M., Kamps, W. A., & Bensing, J. M. (2007). Young patients', parents', and survivors' communication preferences in paediatric oncology: Results of online focus groups. *BMC Pediatrics*, 7(35), 1-10. doi: 10.1186/1471-2431-7-35

Appendix A

Literature Review for the Development of an Interactive Workshop  
to Improve Nurse Management of Paediatric Cancer Pain

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

### Abstract

Poorly controlled cancer pain can negatively impact the quality of life for children and families. Cancer pain can be difficult to assess in children and adolescents. Nurses need effective strategies to assess the multidimensional aspects of cancer pain. Hartrick Doane and Varcoe's (2015) relational inquiry approach is the theoretical framework for developing this education workshop on paediatric cancer pain. This literature review examines the lived experience of cancer pain in children and adolescents and strategies they find useful to obtain relief. This review also discusses current pain education interventions reported for oncology nurses. Inclusion criteria for this review included English language studies on cancer pain management in children published within the past ten years. Sixteen studies were selected for this integrative review including seven qualitative and nine quantitative studies. Results of this review confirm that cancer pain is a multidimensional experience with physical, emotional, and spiritual components. Many strategies are needed to guide effective management of cancer pain including assessing child and family priorities, offering anticipatory guidance to alleviate pain and anxiety, and empowering children and families to communicate their needs. There is a lack of quality studies reporting effective pain management education for oncology nurses. A relational inquiry approach may help nurses understand children's pain experiences, the meaning of cancer pain, and help children and their families to alleviate suffering. The results of this literature review will be used to develop a consultation plan to assess the learning needs of nurses in order to develop an education workshop to improve nurse management of paediatric cancer pain.

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

### Development of an Interactive Workshop to Improve Nurse Management of Paediatric Cancer Pain

Children and adolescents with cancer experience recurrent episodes of acute and chronic pain. Cancer pain can be challenging to manage as it originates from different sources and changes in intensity over time (Van Cleve, Muñoz, Riggs, Bava, & Savedra, 2012). Acute pain can result from venipuncture, lumbar puncture, bone marrow aspiration, radiation, chemotherapy side effects, surgical recovery, and infection. Sources of chronic cancer pain include tumor invasion and inflammation. The World Health Organization (WHO) (2012) recommends that children with chronic cancer pain or increased treatment pain be managed using a two-step approach. For mild pain, the WHO (2012) recommends the use of non-opioids and adjuvants. Children with severe pain should first be given a strong opioid that may be combined with non-opioids and adjuvants. Non-pharmacologic interventions should be combined with pharmacologic treatments to provide comfort and reduce suffering (WHO, 2012).

Many children with cancer lack the skills to describe the nature and severity of the pain they experience (Van Cleve et al., 2012). Families often report that nurses lack effective communication skills needed to interpret expressions of pain in children and adolescents (Essig, Steiner, Kuehni, Weber, & Kiss, 2016). Poorly controlled cancer pain can lead to altered daily function, interrupted sleep, loss of enjoyment of social activities, and emotional distress (Rocha, et al., 2015). These impairments negatively impact quality of life for both child and family.

The World Health Organization (WHO) describes pain as a

“multidimensional phenomenon with sensory, physiological, cognitive, affective, behavioral, and spiritual components. Emotions (affective component), behavioral responses to pain (behavioral component), beliefs, attitudes, spiritual and cultural attitudes about pain and pain control (cognitive component) all alter the way that pain is experienced” (WHO, 2012, p. 17).

Effective assessment of pain therefore requires a comprehensive assessment of the lived pain experience for both the child and family. It is essential for nurses to ask children and families about the impact of cancer pain on their lives. Oncology nurses rely upon child self-report and family experiences to discover how a child expresses pain as well as the strategies useful to alleviate suffering. Psychosocial, physical, and spiritual pain support should begin before diagnosis and continue throughout the child’s lifetime irrespective of curative treatment (WHO, 2012, 2017). Each child and family has the right to quality pain care that minimizes suffering and promotes holistic wellbeing (WHO, 2012).

Despite nurses’ use of child self-report and age-appropriate paediatric pain tools to assess and record pain levels, there remains a disconnect between the child and family’s experience of pain and the achievement of adequate cancer pain relief (Cicogna, Nascimento, & de Lima, 2010; Van Cleve et al., 2012). While pain tools can be useful to assess the severity of physical pain, most are not designed to guide assessment of the embodied cancer pain experience that constitutes emotional, psychosocial, spiritual, and physical suffering of the child and family. Many children, adolescents, and families

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

describe communication challenges that can lead to ineffective management of cancer pain. Objective measurement of cancer pain may lead to a lack of agreement between the child's experience, the parent's perspective, and nurse observation of pain expression (Fortier et al., 2012; Van Cleve et al., 2012). Children and parents report that differences in child, family, and nurse assessment of cancer pain can lead to erosion of trust, frustration, and breakdown of the essential therapeutic relationship required to achieve comfort for the child (Essig et al., 2016; Van Cleve et al., 2012). Improving nurse assessment of pain could therefore promote greater insight into the contextually lived experience of cancer pain and offer children, adolescents, and their families better strategies to meet pain management needs.

### **Theoretical Framework**

Hartrick Doane and Varcoe (2015) developed a family focused approach to nursing to assess the contextual factors that influence how people and families adjust to changes in health. In their relational inquiry method, Hartrick Doane and Varcoe (2015, p. 298) recommend nurses consider family beliefs, priorities, relationships, and family patterns of communication. Through relational inquiry, nurses help individuals and families consider the meanings assigned to health changes. Nurses using a relational inquiry approach explore the impact of being displaced in hospital on family routines, social supports, and enjoyed pastimes. Through contemplation of client and family strengths, patterns of relating, value systems, and priorities, nurses can help families identify strategies to meet their psychosocial, physical, and spiritual needs. In these ways, a relational inquiry approach to family focused nursing can help examine the

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

factors that influence quality of life and help people consider how they may improve wellbeing (Hartrick Doane & Varcoe, 2015).

While no studies discuss the application of relational inquiry to paediatric oncology care or cancer pain management, relational inquiry offers nurses a practical approach to consider the contextual dimensions of childhood cancer pain. A relational inquiry approach could be used to examine the psychosocial, physical, and spiritual impact of cancer pain on children and adolescents. Exploring the meaning a child and family assigns to cancer pain can guide nurses to assess how the embodied pain experience is impacting the child's physical, emotional, and spiritual wellness (Rocha et al., 2015). Assessing how children perceive comfort could help nurses identify the strategies children use to cope with pain, values important to their wellbeing, and barriers to effective pain management (Cantrell & Matula, 2009). Consideration of the patterns of relating between child and family as well as nurse and family relationships could help identify barriers to effective pain communication and management (Essig et al., 2016). For all of these reasons, Hartrick Doane and Varcoe's (2015) relational inquiry approach offers a useful theoretical guide for the development of an education workshop to help nurses better manage cancer pain in children and adolescents.

Hartrick Doane and Varcoe's (2015) relational inquiry approach requires nurses to consider how power imbalances and communication challenges could create inequities within acute care settings that may disempower children and families. When nurses rely on objective pain assessment skills and tools instead of inquiring into the experience of the child and family, the nurse's perspective may be perceived to be more accurate than

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

the subjective report of the child and family (Van Cleve et al., 2012). If the nurse substitutes their perspective of pain for the subjective experience of the child and family, then the pain level recorded by the nurse may not match the actual pain experience of the child. Children and parents become frustrated when they believe that the child's pain experience is not valued and acted upon by nurses, thereby leading to a breakdown in the therapeutic relationship (Essig et al., 2016; Van Cleve et al., 2012).

In addition, failure to accurately describe the child's pain experience in the medical record can lead to poor communication within an oncology team charged with providing comfort to the child. Communication challenges within oncology teams can lead to poorly controlled pain and could cause children and families to feel disempowered if they believe their perspectives and needs are not adequately addressed. It is therefore essential that paediatric oncology nurses consider the role of potential power imbalances and communication challenges and the impact these barriers may have on children and families experiencing cancer pain. For all of these reasons, Hartrick Doane and Varcoe's (2015) relational inquiry approach could assist nurses to prioritize the pain needs of children, help children and families become empowered to advocate for better pain care, and act as advocates to improve the quality of cancer pain communication and management.

A literature review was conducted to assist with the development of an education workshop for paediatric oncology nurses to improve management of cancer pain. The purpose of this paper is to report the methods of the literature review and summarize key themes arising from a critical appraisal of the studies. The findings of the literature



## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

review will be used to guide consultation with key informants to assess the learning needs of nurses and to develop an education workshop on paediatric cancer pain management.

### **Methods**

A search of the literature on nurse management of paediatric cancer pain was conducted in CINAHL, PubMed, OneSearch, and Google Scholar. The guiding questions for this literature search were:

1. What is the lived experience of childhood cancer pain?
2. What meanings do children, adolescents, and families assign to cancer pain?
3. What strategies do children, adolescents, and families find useful to alleviate cancer pain?
4. How does communication influence effective pain management in paediatric oncology?
5. What education interventions have been used to improve nurse management of cancer pain?

### **Inclusion criteria**

The criteria guiding this literature review included studies published in the last ten years, written in the English language, and related to cancer pain management in children and adolescents. No studies were found describing the application of relational inquiry to cancer pain or clinical practice.

### **Sample and selection**

The Health Sciences Centre (HSC) Librarian of Memorial University of Newfoundland and Labrador was consulted prior to beginning the search for this

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

literature review. The HSC Librarian provided information on the features of search engines that narrow or expand search parameters, manage search results in folders, and create citation lists (M. Swab, January 4, 2017). The search terms for this literature review included “lived experience of childhood cancer pain”, “lived experience of cancer pain in adolescents”, “lived experience of cancer pain in children and families”, and “lived experience of families enduring childhood cancer”. The search also included “meaning of childhood cancer pain”, “meaning of cancer pain for children, adolescents, and families”, “meaning of suffering in childhood cancer”, “meaning of comfort for children with cancer” and “spiritual distress childhood cancer”. Other search terms included “barriers to cancer pain management in children”, “barriers in childhood cancer pain”, “paediatric cancer pain”, “cancer pain in children”, “paediatric cancer pain management”, “cancer pain in children in acute care”, and “nurse assessment of paediatric cancer pain”. In addition, “nursing intervention cancer pain in children” was searched. Alternatives of “oncology”, “paediatric”, “pediatric”, and “nurse” were also searched.

The search for studies describing the lived experience of childhood cancer pain yielded two studies in CINAHL and PubMed, two additional studies in OneSearch, and two studies in Google Scholar for a total of six studies. The search for studies describing strategies children and families find useful to alleviate discomfort of childhood cancer pain included 344 studies in CINAHL, 260 studies in OneSearch, 426 studies in Google Scholar, and 105 studies in PubMed. Pain communication in children provided 11 studies in CINAHL, 188 studies in OneSearch, 173 studies in Google Scholar, and 30

studies in PubMed. The search for nursing interventions to alleviate cancer pain in children and adolescents yielded 27 studies in CINAHL, 143 studies in OneSearch, 525 studies in Google Scholar, and 25 studies in PubMed.

### **Exclusion and final sample**

After reading the abstracts of the studies, a final selection of studies was made for complete reading and review of methodological challenges (n = 250). The overwhelming majority of studies written about cancer pain related to adult oncology (n = 69). Many studies on the burden of childhood cancer were excluded because they did not adequately distinguish between the experience of cancer pain and distress associated with other symptoms (n = 50). End of life pain management studies were excluded as end of life pain is often intractable and requires complex physician interventions (n = 31). Literature reviews (n = 13) were excluded. Many studies were excluded because they focused on the needs of health care providers and parents instead of children with cancer pain (n = 36). Research studies that did not include nursing interventions were excluded from the sample for this review (n = 30). Finally, some of the qualitative studies were rejected because they lacked sufficient detail to establish the trustworthiness of the phenomenon of cancer pain in children (n = 5).

Overall, 16 studies were selected for this integrative literature review including nine quantitative and seven qualitative studies. A comprehensive account of each study is condensed into a Literature Summary Table and attached to the Appendices at the end of this review.

### **Results**

### **Lived Experience of Paediatric Cancer Pain**

The first primary theme of this literature review is the lived experience of paediatric cancer pain. Cancer pain in children and adolescents is a multidimensional experience that must be effectively managed by paediatric nurses in acute care settings. For this integrative review, the lived experience of paediatric cancer pain has been separated into the experiential sub-themes of physical, emotional, and spiritual pain.

**Physical pain.** In the area of childhood cancer, few researchers have reported the lived experience of physical pain of children and adolescents. For this literature review, three studies were included to describe the lived experience of physical pain of children and adolescents with cancer (Cicogna et al., 2010; Rocha et al., 2015; Van Cleve et al., 2012).

In a qualitative study, Cicogna et al. (2010) explored the chemotherapy experiences of children and adolescents with cancer (n = 10). Through semi-structured interviews, participants were asked to describe the impact of chemotherapy on their quality of life. Participants reported that chemotherapy has many side effects that cause headaches and gastrointestinal pain. Physical pain was also experienced during needle procedures including venipuncture, biopsies, and lumbar puncture.

In a qualitative study, Rocha et al. (2015) explored the lived experience of cancer pain in adolescents (n = 9). Semi-structured interviews were used to identify the acute and chronic pain episodes experienced during cancer treatment. Participants reported that acute pain was experienced after surgery and during venipuncture, needle-related

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

procedures, and chemotherapy. Episodes of chronic pain related to alterations of the gastrointestinal tract after onset of chemotherapy and headaches.

Limits of these two studies were the potential for social desirability and recall bias. In the Cicogna et al. (2010) study, there were more adolescents than children participants and this may have created variability in the way the two groups interpret pain. Rocha et al. (2015) had a predominantly female sample and it is therefore possible that the results may have been influenced by gender differences in pain experiences. Both studies were conducted in Brazil it is therefore possible that cultural perspectives of how pain is experienced could influence the findings or applicability of results to other populations. Age variation, gender differences, and cultural perspectives on the pain experience were cofounders that were not adequately addressed in these studies.

Notwithstanding these limitations, each of these qualitative studies presented thick descriptions using quotes from children and adolescents with cancer and their families to provide insight into the world of cancer and challenges experienced when enduring pain. Participant quotations across studies offered a consistent portrayal of the difficulties of cancer pain and its impact upon children and their families. These uniformities support the credibility of these studies and their descriptions of the lived experience of childhood cancer pain. For all of the foregoing reasons, I would rate the overall strength of these two qualitative studies as strong.

In a descriptive, cross-sectional study, Van Cleve et al. (2012) examined pain and its management in children with cancer ( $n = 62$ ). Individual interviews were conducted with children to determine the frequency and intensity of cancer pain over five months.

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

Van Cleve et al. (2012) found a significant difference,  $p < 0.001$ , in the frequency that children and adolescents reported pain, 56%, in comparison to the frequency that nurses recorded pain, 23%. These researchers also observed a significant difference,  $p < 0.001$ , in the level of severity of child self-reporting of pain compared to the lower pain level documented by the nurse.

Limits of this descriptive study included its weak descriptive design, lack of randomization and a control group, and the inability to monitor changes in cancer pain over time. In addition, many participants were too unwell to provide data at all collection times due to illness and this could have influenced the results. A key strength of the study was the triangulation of pain data between the medical record and self-report to enhance confirmability of pain data. Another strength of the study was the measurement of current pain to limit recall bias. Finally, Van Cleve et al. (2012) offered strong evidence to demonstrate that children are able to offer good descriptions of pain levels, frequency, and locations. For all of these reasons, I would rate the overall strength of this descriptive study as medium.

Physical pain often limits the child's ability to ambulate, perform self-care, play, attend school, and participate in social activities (Cicogna et al., 2010; Rocha et al., 2015). Pain may also reduce the quality of sleep and lead to fatigue (Cicogna et al., 2010; Rocha et al., 2015). Feeling debilitated from cancer pain may limit enjoyment of time with family and friends (Cicogna et al., 2010; Rocha et al., 2015). Diagnostic procedures, frequent blood work, headaches, and physiologic alterations of the gastrointestinal tract can cause physical pain for many children with cancer (Rocha et al.,

2015). Children with cancer and their parents express frustration when they feel the child's report of pain is not adequately addressed (Van Cleve et al. 2012).

Nurses must assess the effect of physical pain on sleep, functional capacity, and the activities of daily living. Assessment is essential to determine the impact of cancer treatment on the child to guide effective strategies to mitigate pain before and after procedures and chemotherapy. Chronic pain must be assessed and managed to promote daily enjoyment of play, rest, and social activities with family and friends. Inquiry into the child's physical pain experience should be comprehensive and demonstrate that the pain plan is child and family focused to prioritize comfort and deliver quality care.

**Emotional pain.** Two of the studies outlined above described the impact of emotional pain in the context of childhood cancer (Cicogna et al., 2010; Rocha et al., 2015). Children and adolescents with cancer experience emotional pain associated with displacement in hospital away from family and friends at home (Cicogna et al, 2010; Rocha et al., 2015). Loss of family routines, boredom, and social isolation can create distress as children and families struggle with the loss of their safe haven while trying to establish normalcy in the public domain of acute care. The loss of self-possession associated with being under constant scrutiny may be perceived as disempowering, alienating, and undignified (Cicogna et al., 2010; Rocha et al., 2015). Being unable to play, attend school, and plan for the future can lead to emotional distress as life carries forward seemingly uninterrupted without the unwell child and family. A significantly altered appearance can also cause adolescents great suffering (Cicogna et al., 2010). Assessment of the meaning of the experience of cancer, suffering associated with

hospitalization, and perceived loss of self-possession could help nurses identify family priorities and support systems to reduce emotional pain.

**Spiritual pain.** Three qualitative studies included in this literature review described spiritual pain in children and adolescents with cancer (Cicogna et al., 2010; Essig et al., 2016; Kamper et al. 2010). Cicogna et al. (2010) is discussed above in the lived experience of physical pain.

In a qualitative study, Essig et al. (2016) used focus groups to examine cancer communication from the perspectives of adolescents who are childhood cancer survivors (n = 16), parents (n = 8), Paediatric Oncologists (n = 12), and Nurses (n = 18). Adolescent cancer survivors stated that they realize cancer is gravely serious and often struggle to integrate curative treatment needed to survive with their own personal priorities. Survivors reported feelings of despair and social withdrawal as they struggle to cope with curative therapy in the face of overwhelming suffering. Nurses reported that while children with cancer may not disclose their deepest concerns with family and friends, they often share these worries with their nurses.

Kamper et al. (2010) used a longitudinal, qualitative design to describe children's reports of cancer pain, its impact on quality of life, and the role of spirituality in pain reduction (n = 60). Through interviews, children and adolescents discussed the impact of cancer on their spiritual quality of life as well as physical, emotional, and spiritual pain associated with treatment. The overwhelming majority of participants, 82%, were able to express their spiritual concerns and identify strategies useful to alleviate suffering. Some



## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

participants stated that while they prayed to help cope with cancer pain in the past, they no longer did this as they felt abandoned by God and had lost their faith.

The short-term nature of both studies, one data point for Essig et al. (2016) and five months for Kamper et al. (2010), prevented long-term assessment of spiritual pain over time. Kamper et al. (2010) had a greater proportion of female and Hispanic participants than males and other ethnicities. This could influence the findings in relation to how different genders and cultures perceive spiritual expression. Recall and social desirability bias may also have influenced participant responses in both studies.

A key strength of these studies was the use of rich descriptions using quotations to explain the impact of spiritual pain experienced by children and adolescents with cancer. Participant quotations offered a consistent portrayal of the challenges of despair and hopelessness endured by children and adolescents with cancer. These uniformities support the credibility of these studies and their descriptions of the experience of spiritual pain. For all of these reasons, I would rate the overall quality of the spiritual pain studies as strong.

Many children and adolescents with cancer remain hospitalized for months after diagnosis to receive daily blood work, repeated diagnostic investigations, and chemotherapy. The majority of children and adolescents with cancer are aware of the reality that they have cancer and require curative interventions to survive. Pain causes some children and adolescents to experience feelings of despair and fear death (Cicogna et al., 2010). For some adolescents, these feelings of hopelessness were so intense that they contemplated withdrawing from curative treatment (Cicogna et al., 2010; Essig et

al., 2016). Some young people report spiritual distress when their prayers for comfort or cure remain unanswered (Kamper et al., 2010). Many children and adolescents may endure this pain in silence fearing disclosure may be too burdensome to share with family and friends (Kamper et al., 2010).

Assessment of spiritual pain may assist nurses in gaining deeper insight into the complex spiritual and emotional needs of children, and could promote better oncology team collaboration to address the child's embodied pain experience. Children who have concerns about death sometimes share their thoughts with nurses (Essig et al., 2016). In this sacred space, nurses can provide a child with a safe haven to disclose fears about the meaning of cancer pain and their concerns that it may herald relapse or approaching death (Essig et al., 2016). For children and adolescents experiencing a crisis of faith, referral to pastoral services could help rebuild a sense of peace and alleviate suffering. Young people experiencing depression, anxiety, or emotional distress related to spiritual concerns may also benefit from speaking with a psychologist.

### **Obtaining Relief From Cancer Pain**

The second primary theme of this literature review is obtaining relief from cancer pain. Obtaining relief from cancer pain may reflect an individual or family journey of discovery representing the values, priorities, and needs of children and their families. Assessment of these relational concerns requires nurses to possess exceptional therapeutic skills to assess the physical, supportive, and existential needs of children and families in acute care settings. For this integrative review, the second primary theme of

obtaining relief from cancer pain has been separated into the relational sub-themes of considering priorities, anticipatory guidance, asserting control, and finding peace.

**Considering priorities.** One descriptive study and three qualitative studies in this literature review describe some of the elements children with cancer and their families consider important when evaluating the need for pain medication and the quality of care they receive (Cantrell & Matula, 2009; Essig et al., 2016; Fortier et al., 2012; Zwaanswijk et al, 2007). The study by Essig et al. (2016) was discussed above in relation to spiritual pain.

Fortier et al. (2012) used a descriptive, cross-sectional design to explore parental perceptions (n = 187) on how children express pain and under what circumstances pain medication may be necessary. During outpatient clinic visits and hospital admissions, parents completed questionnaires on their beliefs related to the need for medication and how children demonstrate pain. Parents reported several misconceptions related to cancer pain treatment including side effects, addiction, and therapeutic administration of medications. Parents shared many misconceptions related to how children express pain including crying and attention seeking behaviors.

Cantrell and Matula (2009) used a qualitative design to explore the meaning of being cared for and comforted by paediatric oncology nurses. Childhood cancer survivors (n = 11) discussed their experiences with nursing care in individual interviews or a focus group. Survivors stated that they evaluated actions and words of nurses to determine whether they believed the nurse offered genuine presence and cared for them. Some of the values prioritized by survivors included time spent by the nurse to gain an

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

understanding of who they are as a person and recognition of their personal qualities.

When nurses support family members, survivors report that this action shows support for the child who relies on family to alleviate suffering. Finally, survivors reported that non-caring actions by nurses negatively impact the therapeutic relationship with both the child and family.

Zwaanswijk et al. (2007) used a qualitative design to gain insight into the interpersonal, informational, and decision-making preferences through focus groups with children with cancer ( $n = 7$ ), child and adolescent cancer survivors ( $n = 18$ ), and parents ( $n = 11$ ). Each group of participants confirmed the importance of open, honest communication from health care providers in building effective therapeutic relationships. Participants stated that they need concise written and verbal information on treatment options to make informed decisions. Children with cancer and survivors explained that they have a right to participate in decisions impacting their care and want clear information to select care that meets their needs.

The descriptive study by Fortier et al. (2012) study was limited by a weak design and lacked a control group. Both Fortier et al. (2012) and Cantrell and Matula (2009) had a predominance of female participants. Fortier et al. (2012) used a primarily Caucasian sample. The gender and ethnic characteristics of the sample in these two studies could influence the findings in relation to how different genders and cultures perceive pain and its need for treatment. All three of these studies collected data at only one time interval and this prevented the assessment of changes over time. Finally, all three studies were limited by the potential for social desirability and recall bias.

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

Strengths of the Fortier et al. (2012) study include use of self-report data to identify barriers that may influence administration of pain medication and the use of reliable and validated questionnaires. A key strength of the two qualitative studies was the use of quotations to show the significant impact that nursing actions have on children with cancer, their families, and the quality of therapeutic relations (Cantrell & Matula, 2009; Zwaanswijk et al., 2007). In addition, both qualitative studies demonstrated how communication strengthens or impedes the quality of effective cancer pain management. For all of the foregoing reasons, I would rate the Fortier et al. (2012) study as medium and the two qualitative studies, Cantrell & Matula (2009) and Zwaanswijk et al. (2007), as strong.

As pain is subjectively experienced, nurses must assess how individual children and adolescents express their pain (Essig et al., 2016; Fortier et al., 2012). Parents may have difficulty interpreting a child's expression of pain (Fortier et al., 2012). The child's self-report of pain should therefore be used when appropriate to establish a more accurate measure of pain. Young children can describe the activities they can do during a good day and what they are unable to do when their pain is too severe. In addition, nurses must examine parental concerns about the use of medication to assess barriers that could impede therapeutic dosing (Fortier et al., 2012). Nurse assessment of how children and adolescents communicate their pain and how parents interpret these expressions of pain could lead to the identification of barriers that may negatively impact effective pain management.

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

When nurses offer genuine presence and relational inquiry into the experience of cancer pain and priorities for obtaining relief, strengths and struggles become a shared focus to guide discussion of strategies to alleviate suffering. Children and adolescents believe that nurses show they care by taking the time to understand who they are as a person, talking about feelings and worries, and offering presence in times of hardship (Cantrell & Matula, 2009; Essig et al., 2016; Zwaanswijk et al., 2007). As children and adolescents rely on their families to support them, providing care to families offers comfort to the child (Cantrell & Matula, 2009). Self-reflection and assessment of how nurses may support children and families can create more effective therapeutic relationships and build a foundation to assess cancer pain.

**Anticipatory guidance.** Five studies in this literature review describe some of the elements children with cancer and their families consider important when preparing for treatment procedures (Cicogna et al., 2010; Hedén et al., 2009; Karlsson et al., 2014; Nguyen et al., 2010; Rocha et al., 2015). Two of these qualitative studies have been discussed in the section above on physical pain (Cicogna et al., 2010; Rocha et al., 2015).

In a randomized controlled trial, Hedén, Von Essen, and Ljungman (2009) tested the effect of bubbles ( $n = 14$ ) or a heated pillow ( $n = 14$ ) compared to usual care on children's fear, pain, and distress during needle-related cancer procedures. A parent, nurse, and researcher separately assessed each child. Parent reports of fear and distress were significantly lower when using bubbles compared to usual care,  $p < 0.05$ . Parental report of fear was also significantly lower when using the heated pillow in comparison to standard care,  $p < 0.05$ .

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

In a randomized, controlled trial, Nguyen, Nilsson, Hellström, and Bengtson (2010) tested the effect of music ( $n = 20$ ) on pain and anxiety during and after lumbar punctures (LP) compared to usual care ( $n = 20$ ). Pain scores were significantly lower for the music group during LP,  $p < 0.001$ . After the LP, pain scores in the music group were also significantly lower,  $p < 0.003$ . Anxiety scores were lower both before,  $p < 0.001$ , and after,  $p < 0.001$ , the LP in the music group.

Karlsson, Englund, Enskär, and Rydström (2014) used a qualitative design ( $n = 21$ ) to explore the meaning of supporting one's child during needle-related procedures. Parents reported that they monitor their child's responses during procedures to determine how best to support them. Some parents struggle to control their own feelings of distress during needle procedures and this can influence their ability to effectively support the child. Parents report that adequate information, more preparatory time, and addressing the child's concerns could alleviate procedural distress.

Limits of all three studies included the use of a convenience sample and the potential for social desirability bias. The assessors were not blinded in two of the studies (Hedén et al., 2009; Nguyen et al., 2010). The study by Hedén et al. (2009) was limited by failure to assess self-report of pain or measure anxiety with a validated tool. In addition, the three studies collected data once which limited the ability to assess for changes over time. Finally, Karlsson et al. (2014) used a sample of predominantly females and this could have influenced findings in relation to gender perspectives on needle procedures.

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

Strengths of two studies included the random allocation of participants, use of a control group, and a valid and reliable tool to measure pain (Hedén et al., 2009; Nguyen et al., 2010). Hedén et al. (2009) used three assessors to evaluate the dependent variables. Blinding of the assessors and use of child self-report of pain strengthened the Nguyen et al. (2010) study. A key strength of the qualitative study by Karlsson et al. (2014) was the use of quotations to demonstrate the significant impact that needle procedures have on families as well as the potential positive influence of nursing actions to reduce suffering for both children and parents. For all of the foregoing reasons, I would rate the overall strength of these three studies as strong.

Nurses must adequately prepare children and adolescents for procedures to limit pain and anxiety (Cicogna et al., 2010; Hedén et al., 2009; Nguyen et al., 2010; Rocha et al., 2015). Difficulties children and adolescents experience during medical procedures can increase the risk of anxiety leading to fear of future pain (Cicogna et al., 2010; Rocha et al., 2015). Nurses must ensure that children and adolescents have sufficient information, pre-medication, and time to prepare for procedures (Karlsson et al., 2014). In addition, nurses should ask parents what role, if any, they would like to play during procedures. Assessment of supportive needs and past experiences related to procedures may help nurses assist the child and family to prepare for difficult diagnostic tests and alleviate anxiety (Karlsson et al., 2014).

**Asserting control.** One descriptive study, two randomized, controlled trials, and three qualitative studies described above discussed strategies children and families find



## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

useful to maintain control over cancer pain (Essig et al., 2016; Hedén et al., 2009; Kamper et al., 2010; Nguyen et al., 2010; Rocha et al., 2015; Zwaanswijk et al., 2007).

Nurses should assess the strategies children and adolescents use to alleviate cancer pain. Distraction, rest, prayer, music, entertainment, and family and social supports were identified as strategies children and adolescents use to reduce cancer pain (Kamper et al., 2010; Rocha et al., 2015). Listening to music, bubbles, and heated pillows may also help promote comfort during painful needle procedures (Hedén et al., 2009; Nguyen et al., 2010). While many young people with cancer rely on medication for severe pain, some children report that medication does not effectively reduce their pain in the absence of non-pharmacological interventions (Rocha et al., 2015). Identification of client-focused pain reducing strategies can promote comfort and lead to more effective management.

Children and adolescents report that they want to collaborate in treatment decision-making and be consulted in the development of a plan to manage their care (Essig et al., 2016; Rocha et al., 2015). Listening to the concerns of children and adolescents builds trust and empowers young people to become more involved in their care. Valuing and respecting the wishes of children and adolescents can strengthen therapeutic relationships and may increase the likelihood of treatment compliance (Essig et al., 2016; Zwaanswijk et al., 2007). Adolescents may prefer a greater level of pain to the side effects that medications may have on their enjoyment of social activities with friends and family (Essig et al., 2016; Zwaanswijk et al., 2007). When nurses help children and young people reflect on their pain experience and what strategies they find

useful, this promotes autonomy and empowerment in creating a collaborative pain care plan.

**Finding peace.** One descriptive and one qualitative study described in this literature review discussed strategies that help children and adolescents with cancer find peace (Kamper et al., 2010; Rocha et al., 2015). The details of these two studies were reported above.

Nurses should assess whether children and adolescents use spiritual strategies to alleviate pain. Some young people find meditation, prayer, thinking about God, and reflection offers comfort and helps redirect their thoughts until pain subsides (Kamper et al., 2010; Rocha et al., 2015). Nurses who listen attentively and value child beliefs can create therapeutic spaces where children can share how they find the strength to cope with enduring cancer pain (Kamper et al., 2010; Rocha et al., 2015). Assessment by nurses of sources of strength may help children and adolescents reflect on how they perceive suffering and combat its challenges, which can lead to a comprehensive approach to alleviate pain.

### **Educational Interventions to Improve Nurse Management of Childhood Cancer Pain**

The third primary theme of this literature review is educational interventions to improve nurse management of childhood cancer pain. While this theme has a different focus than the other two primary themes, the development of a workshop for paediatric nurses requires a review of current literature to determine the effectiveness and utility of oncology pain education interventions. There are very few current studies that report

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

nurse education interventions with respect to cancer pain. As cancer pain is more complex than surgical pain or other forms of acute pain, this literature review will focus on education interventions related to oncology. Recent studies on the use of education interventions to improve nurse management of cancer pain have utilized educational videos, case studies to generate discussion on pain strategies, education on cancer pain policies, pain rounds, pain resource nurses, and intensive pain courses. There have been inconsistent findings across the studies to show the effectiveness of education to improve management by nurses of cancer pain. For this review, the third primary theme of educational interventions to improve nurse management of childhood cancer pain has been separated into two sub-themes. These sub-themes are education day and comprehensive education approach.

**Education day.** Three studies in this literature review describe education sessions provided to oncology nurses during an education day (Gustafsson & Borglin, 2013; O'Shea, Wallace, Griffin, & Fitzpatrick, 2011; Patiraki et al., 2006).

In a quasi-experimental study, surgical oncology nurses ( $n = 33$ ) attended a two-hour workshop using case studies to lead group discussion on cancer pain assessment (Gustafsson & Borglin, 2013). Surgical oncology nurses also received a "pocket-size guide" and training on new cancer pain assessment requirements (Gustafsson & Borglin, 2013, p. 3). Four weeks after the education, there was a significant difference in nursing pain knowledge scores of intervention nurses compared to control nurses ( $n = 27$ ) who did not receive this training,  $p < 0.028$ .

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

In a one group pre and post-test study, paediatric nurses ( $n = 18$ ) received education to improve nurse attitudes towards spiritual care to children and families (O'Shea et al., 2011). A conceptual model of spiritual care was used to develop the education program and guide group discussions to demonstrate how to apply spiritual care concepts and therapeutic interventions to case studies. Nursing diagnoses related to spiritual distress were used to guide group discussions. After the education session, there was a significant increase in both perceived self-efficacy to provide spiritual care to children and families,  $p < 0.01$ , and nurse attitudes towards offering this care,  $p < 0.00$ . Strong correlations were noted between individual beliefs and willingness to provide spiritual care,  $p = 0.00$ .

In a randomized controlled trial ( $n = 112$ ), viewing education videos and using case studies for group discussions on cancer pain were shown to significantly increase knowledge scores,  $p < 0.0001$ , in comparison to viewing a non-pain related nursing history video (Patiraki et al., 2006). Nurses who completed pain knowledge tests before and after the cancer pain videos scored significantly lower in the areas of distraction,  $p = 0.008$ , non-pharmacological strategies,  $p = 0.02$ , and management of chronic pain,  $p = 0.02$ , in comparison to nurses who watched the pain videos and only completed post-tests.

The primary strength of these studies included the convenience of providing a one-day training session in comparison to more extensive education courses over several days. In addition, standardized demonstrations through videos, case studies, and group discussions could improve consistency of staff pain assessments and enhance ability to

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

apply new pain skills in clinical practice. Strengths of Gustafsson et al. (2013) included the introduction of a unit-specific bedside reference and a new pain assessment policy to improve consistency of staff pain assessments. Use of a conceptual model in the O'Shea et al. (2011) study strengthened the design and helped teach nurses how to practically offer spiritual care to life-limited children and their families (O'Shea et al., 2011).

There was only one randomized controlled trial in these education day studies (Patiraki et al., 2006). While this study had a strong design with randomization and control groups, the effect of the pre-testing in one intervention group could not be excluded as a confounder (Patiraki et al., 2006). In addition, these studies were conducted across a diversity of cultures including Greece, Sweden, and the United States. As nursing education and certification requirements may vary internationally, it is possible that effectiveness of nursing education interventions could differ across cultures. Sample sizes across each of these studies were small. It is therefore possible that larger samples of nurses may have achieved differing results in response to the pain education. None of the studies used blinding to control confounding. Only two studies had a control group (Gustafsson & Borglin, 2013; Patiraki et al., 2006). Finally, none of the studies monitored the effect of the education interventions over time to assess for long-term clinical practice changes or organizational outcomes. For all of these reasons, the overall quality of the evidence for these education day interventions is weak.

**Comprehensive education approach.** Two studies in this integrative review utilized a comprehensive education approach to cancer pain education (Idell, Grant, & Kirk, 2007; McMillan, Tittle, Hagan, & Small, 2005).

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

In a pre and post-test design, Advanced Practice Nurses (APNs) developed education to introduce new cancer pain guidelines to one group of oncology nurses ( $n = 42$ ) (Idell et al., 2007). A research utilization framework was used to develop the education intervention. Additionally, APNs provided individual and staff support to intervention nurses to reduce staff and organizational barriers in this change process. After the education sessions, nurses began to lead pain rounds on the units to address client concerns and assess pain care plans. After this educational initiative, significant improvements were noted to both nurse pain knowledge scores,  $p = 0.001$ , and routine pain re-assessment practices,  $p = 0.004$ .

In a one group pre and post-test design, nurses ( $n = 18$ ) participated in a 32-hour comprehensive pain course to become pain resource nurses in clinical oncology units (McMillan et al., 2005). After this week long course, significant improvements were observed in both nurse pain knowledge,  $p < 0.001$ , and attitudes towards clients experiencing pain,  $p < 0.007$ . Unfortunately, nurse attitudes towards pain management did not significantly improve after the education course,  $p < 0.055$ . The nurses who became pain resource nurses stated in follow-up interviews that the education improved their pain management self-efficacy and prepared them to serve as pain resource nurses.

Use of a research utilization framework to develop the educational interventions strengthened the design of the Idell et al. (2007) study. Using APNs as change agents to improve cancer pain assessment practices, offer individual and unit feedback to address change process barriers, and the adoption of nurse led pain rounds to reinforce new nursing knowledge strengthened the design of the Idell et al. (2007) study. Another

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

strength of these education programs was the use of case studies and group discussions to supplement comprehensive education and enhance practical application of new cancer pain skills.

A limitation of these two comprehensive approaches is the practicality of providing staff with lengthy education sessions. Another important limitation is the feasibility of acquiring appropriately trained APNs to develop cancer pain education and successfully integrate the pain round model. The uncontrolled before and after approach used in both studies was a weak design. Both studies had small samples, lacked a control group, and participants were not blinded and therefore failed to address important confounders. Neither study assessed the long-term effect of the educational training over time. Finally, the evaluation tool used in the Idell et al. (2007) study was not validated and may not yield reliable results. For all of the foregoing reasons, I would rate the overall quality of the comprehensive education approach studies as weak.

### **Clinical Implications of Nurse Interventions**

Notwithstanding the methodological challenges noted, these five pain education intervention studies were able to demonstrate significant improvements to nurse knowledge and attitudes. However, none of these studies assessed the effectiveness of these interventions over time. While education may promote short term increases in knowledge, it can be challenging to sustain these effects. Education interventions that use conceptual or theoretical models to guide development appear to be more comprehensive in their scope and may have increased capacity to improve the perspectives of nurses (Gustafsson & Borglin, 2013; Idell et al., 2007; O'Shea et al.,

2011). Use of APNs and pain resource nurses may be an important source of support for oncology nurses who are integrating new pain skills and policies into clinical practice (Idell et al., 2007; McMillian et al., 2005). Clinical resources in the form of pain management policies, guidelines, and unit-specific pain references may promote integration of new knowledge in clinical practice by promoting a culture of commitment to quality care initiatives (Gustafsson & Borglin, 2013; Idell et al., 2007; O'Shea et al., 2011). A needs assessment could help determine the feasibility of each potential education approach with respect to client needs, organizational strengths, and potential integration barriers. Therefore, key stakeholders such as nursing managers, staff, clinical educators, and other multidisciplinary practitioners may be helpful to assess learning needs in the development of staff education.

**Development of an education workshop.** Despite the weak evidence found on pain education interventions, this literature review has provided some important insights that could improve the quality of an education workshop. First, use of a theoretical model such as relational inquiry may improve the strength of an education design and could improve sustainability of nurse knowledge and attitudes to cancer pain management. Second, as a pre-test may potentially confound assessment of increases in knowledge, a post-test only education design may more effectively measure actual knowledge gains. Third, group discussions that use case studies and unit specific policies can help nurses recognize the relevance of education to their clinical practice setting. Fourth, cancer pain education that is developed based upon the strengths of nurses acquiring the knowledge, identified learning needs, and current barriers to effective pain



## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

management may promote greater integration of new knowledge into clinical practice.

Fifth, a comprehensive approach may be necessary to increase the sustainability of new nursing knowledge into practice over time. Finally, APNs can offer significant support by serving as a change agent, role model, clinical educator, and supportive resource for nursing staff acquiring new pain management skills.

### **Conclusions**

There is a significant gap in the literature in relation to the lived experience of childhood cancer pain, meaningful approaches to alleviate suffering, pain communication, and education interventions to improve nurse management of cancer pain. When children and families feel that their pain experience does not receive priority by nurses, an irrevocable breakdown of the therapeutic relationship may occur. The physical, emotional, and spiritual elements of pain and their complexities may lead to latent pain expression by children. Children may not understand the depth of their feelings or the source of their discomfort. Some young people may conceal their distress for fear of worrying their family. Some children and adolescents may have families who do not recognize their expressions of pain or the need for its management. Many barriers may impact a child's lived experience of pain including the child's perception of pain, whether the child believes pain management is a family priority, and how to express their discomfort to nurses in a way that secures relief. In a setting where understanding pain requires examining the child's lived pain experience, how can nurses expect to gain a clear understanding of a child's suffering by measuring pain objectively? Therefore, part

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

of the gap in effective cancer pain management may be the assessment approach traditionally used by paediatric nurses.

While no recent studies have reported the use of relational inquiry to develop interventions to improve cancer pain management, this approach could offer some helpful insight for oncology nurses. Relational inquiry offers nurses an approach guided by therapeutic use of self to inquire into the contextual lived experiences of children and families (Hartrick Doane & Varcoe, 2015, p. 298). A relational inquiry approach may help nurses consider the multiple dimensions of physical suffering, emotional pain, and spiritual distress that have been described by children and adolescents with cancer in the studies outlined in this literature review. By conceptualizing cancer pain in this holistic way, nurses could become more attuned to the experiences of people, better able to listen for the meaning of pain, and more effectively help children and their families to alleviate suffering.

Nurses are ideally positioned to use their therapeutic presence to help children and their families explore meaning, consider what quality of life would constitute, and help them navigate a path in search of wellbeing. Bearing witness to the child's suffering, oncology nurses are entrusted with the sacred duty of offering comfort when existential concerns are disclosed by a child too afraid to share their troubling feelings with anyone else. It is through this shared journey that oncology nurses can bring comfort to those who are hurting, help ease spirits, and banish despair. Nurses therefore need dynamic education to better prepare them to faithfully navigate these transcendent paths with children and their families. For all of these reasons, development of this education

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

workshop could provide oncology nurses with greater understanding of cancer pain and the substantial impact it has on children and their families.

References

- Cantrell, M. A. & Matula, C. (2009). The meaning of comfort for pediatric patients with cancer. *Oncology Nursing Forum*, 36(6), E303-E309.  
doi: 10.1188/09.ONF.E303-E309
- Cicogna, E. D. C., Nascimento, L. C., & de Lima, R. A. G. (2010). Children and adolescents with cancer: Experiences with chemotherapy. *Revista Latino-Americana de Enfermagem*, 18(5), 864-872. Retrieved from:  
<http://www.eerp.usp.br/rlae>
- Essig, S., Steiner, C., Kuehni, C. E., Weber, H., & Kiss, A. (2016). Improving communication in adolescent cancer care: A multiperspective study. *Pediatric Blood & Cancer*, 63(8), 1423-1430. doi: 10.1002/pbc.26012
- Fortier, M. A., Wahi, A., Maurer, E. L., Tan, E. T., Sender, L. S., & Kain, Z. N. (2012). Attitudes regarding analgesia use and pain expression in parents of children with cancer. *Journal of Pediatric Hematology Oncology*, 34(4), 257-262.  
doi: 10.1097.MPH.0b013e318241fd07
- Gustafsson, M. & Borglin, G. (2013). Can a theory-based educational intervention change nurses' knowledge and attitudes concerning cancer pain management? *BMC Health Services Research*, 13(328), 1-11. doi: 10.1186/1472-6963-13-328
- Hartrick Doane, G. & Varcoe, C. (2015). *How to nurse: Relational inquiry with individuals and families in changing health care and health care contexts*. Philadelphia: Wolters Kluwer Lippincott Williams & Wilkins.

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

- Hedén, L., Von Essen, L., & Ljungman, G. (2009). Randomized interventions for needle procedures in children with cancer. *European Journal of Cancer Care*, 18(4), 358-363. doi: 10.1111/k/1365-2354.2008.00939.x
- Idell, C. S., Grant, M., & Kirk, C. (2007). Alignment of pain reassessment practices and National Comprehensive Cancer Network Guidelines. *Oncology Nursing Forum*, 34(3), 661-671. doi: 10.1188/07.ONF.661-671
- Kamper, R. L., Van Cleve, L., & Savedra, M. (2010). Children with advanced cancer: Responses to a spiritual quality of life interview. *Journal for Specialists in Pediatric Nursing*, 15(4), 301-306. doi: 10.1111/j/1744-6155.2010.00253.x
- Karlsson, K., Englund, A.-C. D., Enskär, K., & Rydström, I. (2014). Parents' perspectives on supporting children during needle-related medical procedures. *International Journal of Qualitative Studies*, 9, 1-11. doi: 10.3402.qhw.v9.23759
- McMillan, S. C., Tittle, M., Hagan, S. J., & Small, B. J. (2005). Training pain resource nurses: Changes in their knowledge and attitudes. *Oncology Nursing Forum*, 32(4) 835-842. doi: 10.1188/05.ONF.835-842
- Nguyen, T. N., Nilsson, S., Hellström, A.-L., & Bengtson, A. (2010). Music therapy to reduce pain and anxiety in children with cancer undergoing lumbar puncture: A randomized clinical trial. *Journal of Pediatric Oncology Nursing*, 27(3), 146-155. doi: 10.1177/1043454209355983
- O'Shea, E. R., Wallace, M., Griffin, M. Q., & Fitzpatrick, J. J. (2011). The effect of an educational session on pediatric nurses' perspectives towards providing spiritual care. *Journal of Pediatric Nursing*, 26(1), 34-43.

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

doi: 10.1016/j.pedn.2009.07.009

Patiraki, E. I., Papathanassoglou, E. D. E., Tafas, C., Akarepi, V., Katsaragakis, S. G., Kampitsi, A., & Lemonidou, C. (2006). A randomized controlled trial of an educational intervention on Hellenic nursing staff's knowledge and attitudes on cancer pain management. *European Journal of Oncology Nursing*, 10(5), 337-352. doi: 10.1016/j.ejon.2005.07.006

Rocha, A. D. F. P., Sposito, A. M. P., de Bortoli, P. S., Silva-Rodrigues, F. M., de Lima, R. A. G., & Nascimento, L. C. (2015). Oncologic pain relief: Strategies told by adolescents with cancer. *Texto & Contexto Enfermagem*, 24(1), 96-104. doi: 10.1590/0104-07072015002120013

Swab, M. (January 4, 2017). Interview by D. A. Belbin [Handwritten notes]. Health Sciences Library of Memorial University of Newfoundland and Labrador.

Van Cleve, L., Muñoz, C. E., Riggs, M. L., Bava, L., & Savedra, M. (2012). Pain experience in children with advanced cancer. *Journal of Pediatric Oncology Nursing*, 29(1), 28-36. doi: 10.1177/1043454211432295.

World Health Organization (WHO). (2012). *WHO guidelines on the pharmacological treatment of persisting pain in children with medical illnesses*. Geneva: World Health Organization. Retrieved from: [http://apps.who.int/iris/bitstream/10665/44540/1/9789241458120\\_Guidelines.pdf](http://apps.who.int/iris/bitstream/10665/44540/1/9789241458120_Guidelines.pdf)

World Health Organization (WHO). (2017). *WHO definition of palliative care*. Retrieved from: <http://www.who.int/cancer/palliative/definition>

Zwaanswijk, M., Tate, K., van Dulmen, S., Hoogerbrugge, P. M., Kamps, W. A., & Bensing, J. M. (2007). Young patients', parents', and survivors' communication preferences in paediatric oncology: Results of online focus groups. *BMC Pediatrics*, 7(35), 1-10. doi: 10.1186/1471-2431-7-35

Appendix A

Literature Review Tables



Table A-1 Literature Summary Table for Van Cleve et al. (2012)

<u>Author/Date &amp; Ethics</u>	<u>Study Design/ Sampling/Setting Characteristics</u>	<u>Variable and Measures/ Reliability/Validity</u>	<u>Relevant Outcomes</u>	<u>Limitations</u>	<u>Strengths of Study Design/Quality of Study</u>
<p>Van Cleve et al. (2012)</p> <p>- Abbreviations used: Memorial Symptom Assessment Scale (MSAS)</p> <p>Ethics: Ethics approval from IRB, parental consent, &amp; child assent. No conflicts declared.</p>	<p>- Descriptive, cross-sectional study to examine pain &amp; its management in children with cancer.</p> <p>- Convenience sample collected from 4 U.S. children's hospitals, (n = 62 children with cancer ages 6 to 17 years).</p> <p>- Data collected at 10 points over 5 months.</p> <p>-Only 8 children gave data at all collection times.</p>	<p>- Self-administered MSAS for pain, internal reliability, <math>r = 0.76</math> to <math>0.87</math>.</p> <p>- Convergent &amp; discriminate validity confirmed (<math>p &gt; .05</math>).</p> <p>- Construct validity corresponds with med administration record in chart (<math>p &gt; .05</math>).</p> <p>-Interviews recorded.</p> <p>- Descriptive &amp; parametric statistics, paired t tests, Chi-square analysis of presence, frequency, and intensity at data collection times.</p> <p>- <math>\alpha &lt; 0.05</math></p>	<p>Significant difference in frequency of reported pain, 56%, compared to nurse recording of child pain, 23% (<math>p &lt; 0.001</math>).</p> <p>Significant difference of pain intensity reported compared to level recorded by nurses (<math>p &lt; 0.001</math>).</p> <p>Non-opioids provided more than opioids (<math>p &lt; 0.013</math>).</p>	<p>-No random sample or control group and convenience sample was a weak design.</p> <p>-Short-term duration of study prevented long term client &amp; health system outcomes.</p> <p>-Many children were too unwell to give data at all 10 points.</p> <p>-Potential for social desirability bias.</p>	<p>-Pain data triangulated by self-report and medication administration record.</p> <p>-Capture of present pain data reduces recall bias.</p> <p>-Children able to describe pain level, intensity, and location.</p> <p>-Nurse perception can be a barrier to effective management.</p> <p>-Study quality was Medium.</p>

Table A-2 Literature Summary Table for Essig et al. (2016)

<u>Author/Date &amp; Ethics</u>	<u>Study Design/ Sampling/Setting Characteristics</u>	<u>Design/Methodology</u>	<u>Key Findings/Results</u>	<u>Strengths/Limitations</u>	<u>Conclusion &amp; Rating</u>
Essig et al. (2016) Abbreviations used: Adolescents (adoles.) Focus Groups (FG or FGs) Doctors (Drs.) Nurses (RNs) Joint team of Drs. & RNs (HCPs) Communication (commun.)  Ethics: Ethics approval from IRB & informed consent. No conflicts declared.	-Qualitative study to explore different perspectives on communicating with adolescents with cancer, their parents, Drs., & RNs. -Multiple FG sites across Switzerland. -Purposive sample of survivors (n=16), parents (n=8), Drs., (n=12) & RNs (n=18) for combined sample (n = 54). -11 FGs lasting 1.5 hours each.	- Qualitative, exploratory study. -FGs recorded & transcribed. -FG discussions on commun. challenges in childhood cancer & how it could be improved. -Findings of 4 themes presented & verified- (1) adoles. cancer commun. framework is unique, (2) how adoles. perceive & what they know about illness, (3) who decides? & (4) lost in translation between child & adult cancer.	-Adoles. realize cancer is gravely serious & still struggle to fit it into the life they desire -Adoles. want to participate in treatment decisions & may disagree with parents & team. -Adoles. may be viewed as indifferent or withdrawn, have conflicting priorities, or may feel their concerns (pain) are disregarded by HCPs.	Methodology matches study aims. -Solid argument of why study important. -Design that used FGs to develop key themes related to the difficulties commun. in adoles. cancer enhanced authenticity & credibility. -Use of participant quotes enhances credibility & trustworthiness of findings. -Findings are logical & flow from design. -Potential for social desirability and recall bias.	-Adoles, parents, and HCPs may have very different perspectives & treatment priorities. -Adoles., parents, and HCPs need good communication to improve care. -HCPs need education to improve commun. with adoles. and their parents. -Study quality was Strong.

Table A-3 Literature Summary Table for Rocha et al. (2015)

<u>Author/Date &amp; Ethics</u>	<u>Study Design/ Sampling/Setting Characteristics</u>	<u>Design/Methodology</u>	<u>Key Findings/Results</u>	<u>Strengths/Limitations</u>	<u>Conclusion &amp; Rating</u>
Rocha et al. (2015)  Abbreviations used: Adolescents (adoles.) Non- pharmacologic (non-pharm.)  Ethics: Ethics approval from IRB. Parental consent, & child assent. No conflicts declared.	-Qualitative study to identify pain experiences of adolescents with cancer & relief strategies.  - Convenience sample one hospital in Brazil. (n = 9 adoles. ages 12 to 18 years). (6 females, 3 males).  - One semi- structured interview, recorded & transcribed.  -Medical records reviewed.	- Qualitative, exploratory study. -Interviews recorded to confirm data authenticity, pain data compared to chart.  -Semi-structured interviews of adoles. lived experience of cancer pain & strategies used.  -Content analysis used to analyze meaning units. Categories analyzed and developed into 2 themes, (1) pain and painful experiences and (2) relief of cancer pain.	-Cancer pain has physical, and emotional, and spiritual components. -Cancer pain arises from procedures & side effects of cancer therapies.  -To reduce pain, adoles. use both non-pharm. strategies and medication. -Talking with adoles. about their pain experience and what they find useful may lead to better management.	-Methodology matches study aims. -Solid argument of why study important. -Use of participant quotes enhances credibility & trustworthiness of findings. -Findings are logical & flow from design.  -Potential for social desirability and recall bias.  -As more females vs males in sample, gender differences may influence results.	-Strong evidence of impact of lived cancer pain experience on adolescents.  -Adoles. describe pain as a multidimensional experience.  -Adoles. use many strategies to reduce cancer pain.  -Medication alone is ineffective to alleviate adoles. cancer pain.  -Study quality was Strong.

Table A-4 Literature Summary Table for Cicogna et al. (2010)

<u>Author/Date &amp; Ethics</u>	<u>Study Design/ Sampling/Setting Characteristics</u>	<u>Design/Methodology</u>	<u>Key Findings/Results</u>	<u>Strengths/Limitations</u>	<u>Conclusion &amp; Rating</u>
Cicogna et al. (2010) Abbreviations used: Adolescents (adoles.) Chemotherapy (chemo) Non- pharmacologic (non-pharm.)  Ethics: Ethics approval from IRB, parental consent, & child assent. No conflicts declared.	-Qualitative study to explore chemotherapy experiences of children and adoles. with cancer.  - Convenience sample one hospital in Brazil. (n = 10 children & adoles. ages 8 to 18 years). (Predominantly adoles. sample).  - Semi-structured interviews, recorded & transcribed.  -Medical records reviewed.	- Qualitative, exploratory study. -Interviews recorded to confirm data authenticity (chemo treatment data compared to chart).  -Semi-structured interviews to capture adolescent's lived experience of chemo & strategies to reduce its effects.  -Thematic analysis used to analyze meaning units. Categories analyzed and developed into 3 themes- (1) diagnostic itinerary, (2) the chemo & (3) support network.	-Chemo caused physical, and emotional, and spiritual suffering.  -To reduce pain children & adoles. report using both non- pharm. & medications.  -Talking with children & adoles. may lead to better understanding.  -Effects of chemo caused despair & consideration of discontinuing treatment.	-Methodology matches study aims. -Solid argument of why study important. -Use of participant quotes enhances credibility & trustworthiness of findings. -Findings are logical & flow from design.  -Potential for social desirability and recall bias.  -As more adoles. vs children in sample, age differences may influence results.	-Strong evidence of impact of lived chemo experience on children & adoles.  -Children & adoles. experience chemo as painful, anxiety provoking, and multidimensional.  -Children & adoles. use many strategies to reduce chemo discomfort.  -Study quality was Strong.

Table A-5 Literature Summary Table for Fortier et al. (2012)

<u>Author/Date &amp; Ethics</u>	<u>Study Design/ Sampling/Setting Characteristics</u>	<u>Variable and Measures/ Reliability/Validity</u>	<u>Relevant Outcomes</u>	<u>Limitations</u>	<u>Strengths of Study Design/Quality of Study</u>
Fortier et al. (2012) - Abbreviations used: Medications (meds) Medication Attitudes Questionnaire (MAQ) Health Care Providers (HCPs)  Ethics: Ethics approval from IRB & informed consent. No conflicts declared.	-Descriptive, cross-sectional study to examine parent attitudes toward pain medication & parent perceptions of how children express pain.  - Convenience sample collected from 1 U.S. children's hospital, (n = 187 parents of children with cancer).  - Data collected only once. No missing data.	-Self-administered MAQ assessed parent attitudes towards using meds to treat pain. MAQ reported to have good reliability & validity.  -PPEP self-report to assess parent beliefs about how children express pain. Reported to have good construct & content validity.  -Descriptive & Pearson correlations, linear regression model to identify predictors of parent attitudes. - $\alpha < 0.05$ .	-Parent perceptions of child pain can be barriers to pain treatment. -76% agree side effects are cause for concern. -63% agree pain meds additive. -42% believe meds should be limited. -41% believe child will always report pain. -36% agree child expresses pain by crying or whining. -30% agree pain is attention seeking.	-No random sample or control group and convenience sample was weak  -Single data collection point prevented long term assessment.  -Potential for social desirability and recall bias.  -50% Caucasian & 78% mothers in sample could influence findings due to racial or gender perspectives on child pain.	-Identified several misconceptions parents have about use of meds and how children express pain.  -HCPs should assess parent knowledge of cancer pain, attitudes related to pain meds, and perceptions of how children express pain as these may be barriers to effective cancer pain management.  -Study quality was Medium.

Table A-6 Literature Summary Table for Cantrell & Matula (2009)

<u>Author/Date &amp; Ethics</u>	<u>Study Design/ Sampling/Setting Characteristics</u>	<u>Design/Methodology</u>	<u>Key Findings/Results</u>	<u>Strengths/Limitations</u>	<u>Conclusion &amp; Rating</u>
<p>Cantrell &amp; Matula (2009)</p> <p>Abbreviations used: Focus Group (FG) Nurses (RNs) Childhood cancer survivors (CCS) Adolescents (adoles.)</p> <p>Ethics: Ethics approval from IRB &amp; informed consent. No conflicts declared.</p>	<p>-Qualitative study to explore the meaning of being cared for and comforted by oncology RNs during childhood cancer treatment.</p> <p>- Purposive sample one hospital in U.S. (n = 11 adoles. &amp; young adult CCS ages 18 to 30 years of age). (8 females, 3 males).</p> <p>-One semi-structured interview (n = 7). -FG to discuss experiences with comfort (n = 4).</p>	<p>- Qualitative, exploratory study.</p> <p>-Interviews &amp; FG recorded.</p> <p>-Triangulation of interview &amp; FG strengthens study confirmability of experiences of comfort and caring by RNs in context of childhood cancer.</p> <p>-Hermeneutic data analysis to identify meanings &amp; themes.</p> <p>-Use of participant quotes enhances credibility &amp; trustworthiness of findings.</p>	<p>- CCS evaluate RNs to assess for genuine presence and caring.</p> <p>-CCS value time RNs spend getting to know them and feel special when recognized for their individual qualities.</p> <p>-CCS need support of their family; therefore, they need RNs who also care for and support their family.</p> <p>-Non-caring RN actions negatively impact therapeutic relationships with child and family.</p>	<p>Methodology matches study aims.</p> <p>-Solid argument of why study important.</p> <p>-Design that used FG and interviews to develop key themes related to the lived experience of being cared for and comforted by RNs enhanced authenticity and credibility.</p> <p>-Findings are logical and flow from design.</p> <p>-Potential for social desirability and recall bias.</p> <p>-As more females vs males in sample, gender differences may influence results.</p>	<p>-Strong evidence of impact of being comforted by RNs.</p> <p>-Experience of being comforted is essential to building strong therapeutic relationships.</p> <p>-CCS appraise RNs interactions to evaluate the genuineness of caring.</p> <p>-Study quality was Strong.</p>

Table A-7 Literature Summary Table for Kamper et al. (2010)

<u>Author/Date &amp; Ethics</u>	<u>Study Design/ Sampling/Setting Characteristics</u>	<u>Design/Methodology</u>	<u>Key Findings/ Results</u>	<u>Strengths/Limitations</u>	<u>Conclusion &amp; Ratings</u>
Kamper et al. (2010) Abbreviations used: Spiritual Quality of Life Questionnaire (SQL) Adolescents (adoles.) Health Care Providers (HCPs)	- Longitudinal, qualitative study to present children's responses to SQL and discuss clinical implications. - Convenience sample collected from 1 U.S. children's hospital, (n = 60 children with cancer, ages 6 to 17 years old).	-Interviewers used SQL to assess child spiritual quality of life. -Face validity assessed by piloting SQL. -Interrater reliability 90%. -Content analysis of SQL by developing meaning units into themes. Participant quotes used to describe spiritual quality of life experienced in cancer.	-Children with cancer describe their spiritual quality of life, pain, and comfort. -Emotional & spiritual pain described as losses of functional ability, social supports, and activities.	-Methodology matches study aims. -Solid argument of why study important. -Findings are logical and flow from design. -Use of participant quotes enhances credibility and trustworthiness of findings. -Potential for social desirability and recall bias. -42% male & 68% female; 55% Hispanic & 30% Caucasian in sample could influence findings in relation to racial or gender perspectives of child spiritual expression.	-Overwhelming majority of study participants reported how prayer helps when they are unwell. -HCPs should assess whether prayer/meditation helps with pain. -All strategies children and adoles. use to improve their quality of life should be assessed and supported by nurses. -Study quality was Strong.
Ethics: Ethics approval from IRB. Parental informed consent and child assent. No conflicts declared.	-Interviews every 2 weeks for 5 months. -Some missing data if child too unwell or died during study.	-Descriptive statistics - $\alpha < 0.05$	-78% report using prayer or meditation when unwell. -82% report prayer helps.		

Table A-8 Literature Summary Table for Hedén et al. (2009)

<u>Author/Date &amp; Ethics</u>	<u>Study Design/ Sampling/Setting Characteristics</u>	<u>Variable and Measures/ Reliability/Validity</u>	<u>Relevant Outcomes</u>	<u>Limitations</u>	<u>Strengths of Study Design/Quality of Study</u>
Hedén et al. (2009)  Abbreviations used: Adolescents (adoles.) Visual Analogue Scale (VAS)	-Randomized controlled trial to see if children have less fear/distress/pain at needle insertion using bubbles vs heated pillow vs usual care.  - Convenience sample at 1 Swedish children's hospital, (n = 28 children with cancer, ages 2 to 7 years old) was randomized into separate groups ( 1/2 received bubbles & 1/2 heated pillow.)	-VAS completed by a parent, a nurse, and a researcher. -VAS has been validated and is reliable for measuring pain.  -VAS used to measure pain, fear, and anxiety; however, not tested for validity or reliability for fear and anxiety.  -Descriptive statistics, paired t-tests, non-parametric statistics, and parametric statistics.  - $\alpha < 0.05$	-Parent VAS recording showed significantly less fear and distress when using bubbles vs usual care ( $p < 0.05$ ).  -Parent VAS recording showed significantly less fear when using heated pillow vs usual care ( $p < 0.05$ ).	-Despite random allocation, a convenience sample was used. -Data collection at 1 clinic visit prevented long term assessment.  -Assessors were not blinded which may have introduced bias.  -Self-report of child might have been a better indicator of pain.	-Although not blinded, 3 assessors independently measured variables.  -Use of parent as proxy reporter is often used for young children.  -All strategies children/adoles. use to improve their quality of life should be assessed and supported by nurses.  -Study quality was High.



Table A-9 Literature Summary Table for Karlsson et al. (2014)

<u>Author/Date &amp; Ethics</u>	<u>Study Design/ Sampling/Setting Characteristics</u>	<u>Design/Methodology</u>	<u>Key Findings/Results</u>	<u>Strengths/Limitations</u>	<u>Conclusion &amp; Rating</u>
Karlsson et al. (2014) Abbreviations used: Needle Related Medical Procedures (NRMP) Nurses (RNs) Ethics: Ethics approval from IRB & informed consent. No conflicts declared.	-Qualitative study to explore the meaning of supporting one's child during NRMPs. - Purposive sample one hospital in Sweden. (n = 21 parents of children ages 3 to 7 requiring NRMPs). -After NRMP, semi-structured interviews, recorded & transcribed. (n=14 mothers; n=3 fathers; n= 4 with both parents present).	- Qualitative, exploratory study using a phenomenological approach. -Interviews recorded to confirm data authenticity. -Data analysis to identify meaning units and themes. -Use of participant quotes enhances credibility & trustworthiness of findings. -Use of bridling and reflexive journaling to limit effects of pre-understanding on results.	-Parents monitor child response to assess supportive needs during NRMPs. -Parents struggle to control their feelings sometimes during NRMPs and this can influence their support of the child. -Parents would like adequate information & anticipatory guidance to help their child better prepare for NRMPs.	Methodology matches study aims. -Solid argument of why study important. -Design that used interviews to develop key themes related to the lived experience of supporting a child during a NRMP enhanced authenticity and credibility. -Findings are logical and flow from design. -Potential for social desirability bias. -As more mothers than fathers were interviewed, gender perspectives on NRMPs could influence findings.	-Strong evidence to show parents need RN support in NRMPs. -RNs should assess the role parents would like to play in NRMP. -Preparation for NRMPs requires good information & anticipatory guidance. -Study quality was Strong.

Table A-10 Literature Summary Table for Nguyen et al. (2010)

<u>Author/Date &amp; Ethics</u>	<u>Study Design/ Sampling/Setting Characteristics</u>	<u>Variable and Measures/ Reliability/Validity</u>	<u>Relevant Outcomes</u>	<u>Limitations</u>	<u>Strengths of Study Design/Quality of Study</u>
Nguyen et al. (2010)  Abbreviations used: Adolescents (adoles.) Lumbar Puncture (LP) Numerical Rating Scale (NRS) State-Trait Anxiety Inventory (STAI)  Ethics: Ethics approval from IRB. Parental informed consent. No conflicts declared.	-Randomized controlled trial to see if children have less pain and anxiety at LP using music vs usual care.  - Convenience sample at 1 Vietnamese children's hospital, (n = 40 children with cancer, ages 7 to 12 years old) was randomized into separate groups. (n = 20 listened to music before and during LP). (n = 20 usual care).  Ethics approval from IRB. Parental informed consent. No conflicts declared.	-NRS used for pain self-report. NRS has been validated and is reliable for measuring pain. -STAI used to measure child anxiety before and after LP.  -Interviews post- procedure with children to gain better understanding of child's LP experience.  -Chi square and Mann Whitney U test to compare data between groups. - $\alpha < 0.05$	- Pain scores during and after LP significantly lower for music group than usual care ( $p < 0.001$ ; $p < 0.003$ ).  -Anxiety scores before and after LP significantly lower in music group ( $p < 0.001$ ; $p < 0.001$ ).  -In interviews, music children reported feeling more calm and less pain during this LP than other LPs they had in the past.	-Despite random allocation, a convenience sample was used.  -Data collection at 1 clinic visit prevented long term assessment of efficacy of distractors over time.  -Potential social desirability and recall bias.  -Participants not blinded and this could have influenced results.	-RCT design was strong. -Blinding assessors strengthened study.  -Use of music for LPs could help reduce pain and anxiety.  -Nurses should assess the strategies children and adoles. find helpful during procedures and provide anticipatory guidance to reduce pain and anxiety.  -Study quality was High.

Table A-11 Literature Summary Table for Zwaanswijk et al. (2007)

<u>Author/Date &amp; Ethics</u>	<u>Study Design/ Sampling/Setting Characteristics</u>	<u>Design/Methodology</u>	<u>Key Findings/Results</u>	<u>Strengths/Limitations</u>	<u>Conclusion &amp; Rating</u>
Zwaanswijk et al. (2007)  Abbreviations used: Adolescents (adoles.) Childhood Cancer Survivors (CCS) Focus Groups (FGs) Health Care Providers (HCPs)  Ethics: Ethics approval from IRB & informed consent. No conflicts declared.	-Qualitative study to gain insight into the interpersonal, and decision-making preferences of childhood cancer patients, parents, and CCS in FGs.  - Purposive sample from 2 hospitals in Netherlands. (n = 7 children and adoles. with cancer ages 8-17); (n = 11 parents); (n = 18 child & adoles. CCS who were ages 8-17 at the time of diagnosis and completed cancer treatment in the past 5 years).	- Qualitative, exploratory study. -Interviews recorded and transcribed to confirm data authenticity. -Data analysis to identify meaning units and themes. -Use of participant quotes enhances credibility and trustworthiness of findings.	-Children with cancer, CCS, and parents value open, honest communication from HCPs.  -Children with cancer and CCS want to be included in decision making & have a right to clear information to assist them to make treatment choices.  -Children and CCS value being spoken to as people, not patients.	Methodology matches study aims. -Solid argument of why study important. -Design that used FGs to develop key themes related to the information and communication needs of children, CCS, and parents of childhood cancer enhanced authenticity and credibility.  -Findings are logical and flow from design.  -Potential for social desirability and recall bias.	-Strong evidence to show need for clear information and therapeutic relationships.  -Informed consent requires cancer patients receive good information.  -Children have a right to be included in decisions related to their care.  -Study quality was Strong.

Table A-12 Literature Summary Table for Gustafsson &amp; Borglin (2013)

<u>Author/Date &amp; Ethics</u>	<u>Study Design/ Sampling/Setting Characteristics</u>	<u>Variable and Measures/ Reliability/Validity</u>	<u>Relevant Outcomes</u>	<u>Limitations</u>	<u>Strengths of Study Design/Quality of Study</u>
Gustafsson & Borglin (2013) Abbreviations used: Nurses (RNs) Nurses' Knowledge and Attitudes Survey (NKAS)  Ethics: Ethics approval from IRB. Informed consent. No conflicts declared.	-Controlled before and after study with non-equivalent RN control group.  - Convenience sample at 2 Swedish surgical units serving cancer patients. (n = 33 intervention RNs). (n = 27 controls).  Intervention: 2 hour workshop on pain; using case studies to guide discussions and a pocket pain guide.  -Control RNs only completed NKAS at study points.	-NKAS completed by both groups at baseline, 4 weeks, and 12 weeks. -NKAS valid and reliable.  -Descriptive, Chi square and Mann Whitney U test, Wilcoxon sign test, to assess data to compare data between groups.  - $\alpha < 0.05$	- Significant differences in intervention group NKAS scores from baseline to 4 weeks in comparison to control group (p < 0.028).	-High attrition in both groups due to staff turnover.  -Data collection at 4 and 12 weeks prevented long- term assessment RN and organization outcomes over time.  -Only able to compare data at baseline and 4 weeks due to high attrition.  -Not blinding participants may have influenced the results.	-CBA design was moderate. -Use of conceptual framework to develop education strengthens the design. -Case studies enhanced practical application of conceptual framework and new cancer pain guidelines to client scenarios.  -Pocket pain pocket guide could help RNs apply new skills.  -Study quality was Medium.

Table A-13 Literature Summary Table for Idell et al. (2007)

<u>Author/Date &amp; Ethics</u>	<u>Study Design/ Sampling/Setting Characteristics</u>	<u>Variable and Measures/ Reliability/Validity</u>	<u>Relevant Outcomes</u>	<u>Limitations</u>	<u>Strengths of Study Design/Quality of Study</u>
Idell et al. (2007)  Abbreviations used: Advanced Practice Nurses (APNs) Nurses (RNs) Nurses' Knowledge and Attitudes Survey Regarding Pain (NKASRP) Pain Competency Evaluation (PCE)	-Uncontrolled before and after study. Pre/post test intervention study.  - Convenience sample at 1 U.S. cancer hospital. (n = 42 oncology nurses).  -APNs gave individual feedback to RNs to improve cancer pain skills.	-NKASRP completed by RNs at baseline and post-intervention.  -NKASRP valid and reliable.  -Descriptive & paired t test.  - $\alpha < 0.05$	- Significant differences in NKASRP scores at post-test ( $p < 0.001$ ). -Pain reassessment significantly improved ( $p < 0.004$ ).  -RN PCE scores significantly increased ( $p = 0.000$ ).  - APNs, nurse led pain rounds, and new guidelines helped improve pain care quality and RN pain culture.	-Small sample.  -No control group.  -No assessment of long-term RN & organization outcomes.  -Not blinding participants may have influenced the results.  -PCE not validated but used in other work by City of Hope Cancer Centre and their policies.	-UCBA design was weak. -Use of research utilization framework strengthens design.  -APNs to guide education strengthens study.  -Case studies enhanced practical application of new cancer pain skills.  -New guidelines and pain rounds could standardize pain care on unit.  -Study quality was Weak.
Ethics: Ethics approval from IRB. Informed consent. No conflicts declared.	-APNs helped nurses develop and lead pain rounds to address pain concerns to improve pain management.				

Table A-14 Literature Summary Table for McMillan et al. (2005)

<u>Author/Date &amp; Ethics</u>	<u>Study Design/ Sampling/Setting Characteristics</u>	<u>Variable and Measures/ Reliability/Validity</u>	<u>Relevant Outcomes</u>	<u>Limitations</u>	<u>Strengths of Study Design/Quality of Study</u>
McMillan et al. (2005) Abbreviations used: Pain Resource Nurses (PRNs) Nurses (RNs) Nurses' Attitudes Survey (NAS) Pain Management Principles Knowledge Test (PMPKT) Ethics: Ethics approval from IRB. Informed consent. No conflicts declared.	-Uncontrolled before and after study. Pre/post test intervention study. - Convenience sample at 1 U.S. cancer hospital. (n = 18 oncology nurses). -Intensive 32 hour pain education course given to 18 oncology nurses who trained to become PRNs.	-PMPKT completed by RNs at baseline and after course. -PMPKT has content validity and reliability (r = 0.84). -NAS developed by nurses with expertise in oncology pain management. Internal consistency (r = 0.86). Test-retest reliability (r = 0.89). -Descriptive & paired t test. - $\alpha < 0.05$	- Significant differences in nurse pain knowledge from baseline to post-test (p < 0.007).	-Small sample. -No control group. -No assessment of long-term RN and organization outcomes. -Not blinding participants may have influenced the results. -While attitudes improved after education, improvement in attitudes towards client pain were not significant (p < 0.055).	-UCBA design was weak. -Use of case studies enhanced practical application to new cancer pain skills. -Study quality was Weak.

Table A-15 Literature Summary Table for O'Shea et al. (2011)

<u>Author/Date &amp; Ethics</u>	<u>Study Design/ Sampling/Setting Characteristics</u>	<u>Variable and Measures/ Reliability/Validity</u>	<u>Relevant Outcomes</u>	<u>Limitations</u>	<u>Strengths of Study Design/Quality of Study</u>
O'Shea et al. (2011) Abbreviations used: Nurses (RNs) Spiritual Care Perspectives Scale Revised (SCPS-R) Self-Perceptions of Spirituality (SPS) Ethics: Ethics approval from IRB. Informed consent. No conflicts declared.	-Uncontrolled before and after study. Pre/post test intervention study.  - Convenience sample at 1 U.S. cancer hospital. (n = 18 Paediatric Oncology RNs).  -30 minute education session using case studies and spiritual nursing diagnoses to demonstrate how to apply spiritual care assessment principles in clinical practice.	-SCPS-R valid and reliable measure to assess nurses spiritual care practices. (Cronbach's $\alpha = 0.82$ ).  -SPS is a valid and reliable instrument to measure personal perceptions of spirituality (Cronbach's $\alpha > 0.90$ ).  -Descriptive and paired t test.  - $\alpha < 0.05$	- Significant differences in RN perspectives on providing spiritual care ( $p = 0.00$ ) indicating more positive attitudes after education.  -Significant improvement in self-efficacy to provide spiritual care ( $p < 0.01$ ).  -Strong correlations between beliefs & willingness to provide spiritual care ( $p = 0.00$ ).	-Small sample.  -No control group.  -No assessment of long term RN, client, or organization outcomes.  -Not blinding participants may have influenced the results.	-UCBA design was weak.  -Use of case studies enhanced practical application of new spiritual care education for children's nurses working with life-limited children.  -Study quality was Weak.

Table A-16 Literature Summary Table for Patiraki et al. (2006)

<u>Author/Date &amp; Ethics</u>	<u>Study Design/ Sampling/Setting Characteristics</u>	<u>Variable and Measures/ Reliability/Validity</u>	<u>Relevant Outcomes</u>	<u>Limitations</u>	<u>Strengths of Study Design/Quality of Study</u>
Patiraki et al. (2006) Abbreviations: Nurses (RNs) Greek Nurses' Knowledge and Attitudes Survey Regarding Pain (GV-NKASRP)	-Randomized controlled trial. 4 Solomon group experimental design. - Convenience sample at 1 Greek cancer hospital randomized into four groups. (n = 112 oncology nurses). -Intervention RNs watched 4 videos on cancer pain and used case studies to discuss pain management.	-GV-NKASRP has good construct validity ( $p < 0.001$ ). Test-retest reliability, $r = 0.68$ ; (Cronbach's $\alpha = 0.82$ ). -Descriptive, paired t test ANOVA, Chi-square, Mann-Whitney U, and Pearson's correlation coefficient. - $\alpha < 0.05$	- Significant increases in knowledge scores in intervention nurses compared to control nurses ( $p < 0.0001$ ). -RN's in pre/post test intervention group scored significantly lower than post-test only intervention RNs on: distraction ( $p < 0.008$ ), non-pharmacologic strategies, ( $p < 0.02$ ), and chronic pain management ( $p < 0.02$ ).	-Small sample. -Post-tests immediately after intervention education. -No assessment of long term RN, client, or organization outcomes. -Not blinding participants may have influenced the results. -Effect of pre-testing could not be excluded as confounder.	-Randomized controlled design Strong. -Use of videos and group discussions with case studies may reinforce learning of cancer pain management principles. -Study quality was Medium.
-4 groups of RNs: 1. Pre/post test intervention group 2. Post test only intervention group 3. Pre/post test control group 4. Post test only control group  Ethics: Informed consent & ethics approval.					



Appendix B

Consultation Report

Consultation for the Development of an Interactive Workshop  
to Improve Nurse Management of Paediatric Cancer Pain

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

### Development of an Interactive Workshop to Improve Nurse Management of Paediatric Cancer Pain

#### **Brief Overview of the Project**

Childhood cancer is the leading disease cause of death in Canadian children (Ellison & Janz, 2015). Cancer presents in different locations and infiltrates more rapidly in children than adults (Ellison & Janz, 2015). In Canada, the estimated incidence rate of childhood cancer is 161 per one million children (Ellison & Janz, 2015). The rate of childhood cancer is approximately 50% higher in children less than five years of age than it is in older children (Ellison & Janz, 2015). Children under five years of age lack the expressive language, numeracy, cognitive, and comparative skills required to interpret their pain level and describe its characteristics and severity using a pain assessment tool (Hicks et al., 2001; von Bayer et al., 2009). These developmental factors make assessment of childhood cancer pain more challenging than it is in adult oncology.

The purpose of this practicum project is to develop an education workshop to offer nurses an interpersonal approach to improve management of paediatric cancer pain. Hartrick Doane and Varcoe's (2015) relational inquiry approach to nursing will be used in this workshop to present a practical approach to assessment of the paediatric cancer pain experience. Pain assessment in children with cancer requires nurses to discuss with families how the child expresses pain, the child and family's perspective on effective pain control, and the impact of pain on quality of life. It is anticipated that this workshop will assist paediatric nurses to understand the multidimensional aspects of cancer pain, use of the therapeutic relationship as a foundation for effective pain management, and the

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

experiential and relational perspectives of children and families that influence pain and its control. Through relational inquiry into the child and family perspectives on pain and priorities for its management, nurses can collaborate to build a more effective pain care plan and reduce suffering.

### **Objectives for Consultation**

In order to design an education workshop that will address the learning needs of paediatric oncology nurses, it was necessary to consult with key stakeholders to obtain insight. This included perspectives on current resources, staff strengths and needs related to the delivery of pain care, and the factors that influence effective pain management by nurses. The findings of the literature review demonstrate that childhood cancer pain is a multidimensional experience with physical, psychosocial, and spiritual elements. The reviewed literature also supports a comprehensive approach to pain management planning which would include stakeholders of various disciplines including nurses, oncologists, and the Pastoral Services team. The objectives for this consultation included the following:

1. To identify cancer pain learning needs of paediatric nurses;
2. To obtain stakeholder perspectives on barriers impacting quality pain management;
3. To obtain suggestions on how to improve cancer pain communication;
4. To seek guidance on how to improve the quality of physical, psychosocial, and spiritual pain support for children with cancer and their families;
5. To obtain insight into nurse willingness to assess spiritual pain; and

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

6. To assess the content and learning preferences of nurses for cancer pain education.

### **Setting of Practicum**

The setting of the practicum project was the Paediatric Medicine, Hematology, and Oncology Unit located on the fourth floor of the Janeway Children's Health and Rehabilitation Centre (Janeway) located at 300 Prince Philip Drive, St. John's, Newfoundland and Labrador (NL) A1B 3V6. I work as a paediatric oncology nurse on this unit.

### **Key Stakeholders**

The first key stakeholders were the frontline nursing staff. A purposive sample of frontline nurse volunteers was recruited by enclosing the Invitation Letter (Appendix A) in a sealed envelope for staff on the Janeway Medicine and Janeway Medical Daycare Units. A total of 31 letters were distributed to both nursing units. Notice of the Invitation Letters was sent via staff internal email. The sampling goal was to interview two senior paediatric oncology nurses and two novice nurses. The final sample included three senior nurses and one novice nurse ( $n = 4$ ).

Frontline nurses were interviewed to gain insight on the challenges they experience in providing effective cancer pain management. All frontline nurses interviewed were certified Association of Pediatric Hematology Oncology Nurses (APHON) with at least one year of experience providing cancer care to children. Frontline nurses were separately interviewed using a semi-structured format with open-ended questions to generate insights into issues relevant to cancer pain management and education needs.

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

The second key stakeholder was the nurse manager who organizes nursing care on the Paediatric Medicine, Hematology, and Oncology Unit and the Medical Day Care Unit at the Janeway. I arranged to meet with the nurse manager and conducted a one-on-one, semi-structured interview. At the beginning of the interview, I provided an introduction to the project and asked open-ended questions to allow the nurse manager the opportunity to share her insights on current cancer pain management by nurses and areas for improvement.

The third group of stakeholders was the team of paediatric oncologists at the Janeway. The Chief Oncologist requested that I meet with all three paediatric oncologists as a group. I therefore arranged a focus group ( $n = 3$ ) with the team of paediatric oncologists to discuss current issues related to nurse management of cancer pain at the Janeway and obtain suggestions on how the quality of pain care may be improved. The format of the focus group was semi-structured. I provided an introduction on the purpose of the project and asked open-ended questions to generate discussion on nurse management of cancer pain at the Janeway.

As the literature review identified spiritual pain and the use of spiritual strategies to alleviate suffering, the final key stakeholders that were included in the development of this education workshop was Pastoral Services at the Janeway. I discussed this project with two members of the clergy who indicated that Pastoral Services was prepared to consult on this project. I contacted Janeway Pastoral Services to arrange a focus group ( $n = 3$ ) with members of their team. The focus group questions included spiritual pain in children with cancer, assessment of spiritual care needs, perspectives on barriers to

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

spiritual care interventions, and how to improve management of spiritual pain for children with cancer and their families at the Janeway.

### **Data Collection**

Consultation data was collected from key stakeholders through two focus groups with the paediatric oncologists and Pastoral Services and individual semi-structured interviews with the remaining consultation participants. As the key stakeholders have expertise working with children with cancer and their families, they represented a purposive sample (Streubert & Carpenter, 2011). Open-ended questions were used to guide the semi-structured focus groups and individual interviews (Appendix B). The focus groups and interviews were conducted at times and locations determined by the consultants. The data was collected during telephone interviews (n = 3) and personal interviews on the Janeway Medicine Unit or the nearby professional offices of key stakeholders (n = 8). The focus groups and interviews each lasted approximately 30 to 45 minutes.

### **Data Management and Analysis**

Content analysis was used to manage the data gathered during consultations (Streubert & Carpenter, 2011). Field notes from the focus groups and semi-structured interviews were analyzed. First, in vivo analysis of participant's words and the field notes for each interview were open coded (Streubert & Carpenter, 2011). Open coded data were developed into meaning units and the focus groups and interviews were comparatively analyzed. Common meaning units were used to develop preliminary themes from the focus groups and interview data. As the data analysis progressed,

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

preliminary themes were further analyzed to determine if there were similarities that could be grouped into categorical themes (Streubert & Carpenter, 2011). The review of the data continued until all possible themes emerged. Data analysis was conducted under the guidance and direction of the Practicum Supervisor, Dr. Maddigan. Categorical themes from the consultation data were compared to the findings of the literature review. Thereafter, key themes from the consultation data and literature review will be used to develop the education workshop on childhood cancer pain.

### **Ethical Considerations**

Prior to data collection, a copy of the Consultation Plan was forwarded to the nurse manager for Janeway Medicine and Medical Daycare. After receiving organizational permission from the nurse manager to conduct interviews and focus groups, Invitation Letters (Appendix A) provided participants with an overview of the project and invited expert opinions in the development of the education workshop. Participation as a consultation participant was voluntary. Participants were informed that this is a quality care initiative approved by the manager of Janeway Medicine and Medical Daycare to improve nurse management of childhood cancer pain.

As this project involves development of a staff education workshop, it is not a research study. For this reason, the guidelines established by the Human Research Ethics Authority Screening Tool (Appendix C) did not require that ethics approval be obtained prior to consultation with key organizational stakeholders. Consultation participants were therefore advised that ethics approval was not required for this quality care initiative.

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

Participants were advised that they were identified as key stakeholders for this education workshop based upon their expertise working with children with cancer and their families. The focus groups and interviews were scheduled at times and locations selected by the respective participants. In addition, the participants were advised of ethical considerations related to the voluntary nature of their participation, confidentiality protection, and data security.

Participants were informed that a random alphanumeric code would be assigned to their interview data to ensure that the information they shared in this project would remain private and non-identifiable. I am the only person to have access to the code key. Data security information was disclosed to consultants to offer assurance that information collected would be safely stored and destroyed after the completion of the project. The code key and consultation data are stored in a locked cabinet under my control. Any electronic data developed during analysis will be maintained on a password-protected computer that is stored in a locked location. Participants were also notified that the Practicum Supervisor, Dr. Maddigan, and I would be the only individuals able to access the consultation data.

Consultation participants were asked to re-affirm their verbal consent prior to beginning the focus groups or interviews. Participants were informed that if it becomes necessary to use quotations from an interview, participants would be offered the opportunity to review the quotation, the context of its intended use, and confirm its validity prior to inclusion in any of the reports related to this project. Process consent



## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

will be used to provide participants the opportunity to continue their participation or withdraw at any point during the project (Streubert & Carpenter, 2011).

### **Findings**

#### **Frontline Nurses**

There were several primary themes identified in the interviews with the frontline nurses. The first primary theme was factors that impact effective pain management by nurses. Two sub-categories of factors, organizational factors and child and family factors, were identified and will be discussed separately. The second primary theme was cancer pain and its impact on quality of life. The third primary theme was education and pain interventions.

**Organizational factors.** There were several organizational factors identified by the frontline nurses that impact the delivery of effective pain management by nurses. The most commonly reported organizational factor was delays in adjusting pain medications. Issues identified with delays included the requirement of oncologist approval to change medication orders, the lack of a developed protocol to adjust narcotics within dosing ranges, and the occasional inaccessibility of oncologists. It was noted that there have been occasions when a child's pain changes from well managed to a sudden acute episode of severe pain. Frontline nurses reported occasions when a child was in pain for a prolonged period of time while the resident was paging the oncologist on call. Further organizational factors included inconsistent nurse documentation of pain and the inexperience of novice nurses and junior residents in managing acute pain episodes. Finally, frontline nurses reported the need for improved communication of cancer pain

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

between members of the multidisciplinary paediatric oncology team. It is important for nurses, paediatric residents, and oncologists to have effective and timely communication of pain episodes to improve the delivery of cancer pain management for children.

**Child and family factors.** Frontline nurses identified several factors in relation to children and families that impacted effective pain management. The first factor was the challenge of assessing pain in young children. Many young children are not old enough to accurately describe the pain they experience. Nurses stated that some children do not report that they are in pain. For this younger paediatric population, it is necessary to observe behavioral signs of pain or ask parents whether they believe the child is in pain.

Frontline nurses also identified family perspectives on medications were a factor that influenced effective pain management. While each of the nurses recognized the important role families play in caring for the sick child, parental fears of addiction and side effects can impede narcotic administration when the child requires pain treatment. All nurses agreed that it is important to educate families on the safety of the doses administered, dispel misconceptions about addiction, and offer re-assurance that side effects would be appropriately managed. Nurses stated that parental education on available pain medications could empower families to advocate for pain medications during treatment and palliation.

**Pain and quality of life.** The second primary theme identified by frontline nurses was cancer pain and its impact on quality of life. Nurses reported that physical, emotional, and spiritual pain negatively impacts quality of life for the young person with

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

cancer, their immediate and extended family, and close family friends. Prolonged hospitalization stresses family finances when both parents are caring for the child and are unable to work. Many small communities offer support by organizing blood drives, fundraising for the family, and social support. While nurses stated that their primary focus was assessing and treating physical cancer pain, they also observed emotional and spiritual pain in children with cancer and their families. Nurses agreed that younger children exhibit fewer signs of emotional and spiritual pain than older children and adolescents.

Frontline nurses also reported that older children and adolescents often show signs of withdrawal and depression during hospitalization as their normal routines, activities, and social relationships are disrupted. Many adolescents with cancer suffer when they lose friends and significant others because they are too unwell to continue social activities and sexual relationships. Altered body image was also identified as a source of great emotional distress for adolescents. Finally, ineffective coping with pain and uncertainty was noted to be prevalent in older children, adolescents, and their families. Nurses have observed parental signs of anxiety, depression, and potential risk of self-harm during times of uncertainty or palliation.

Frontline nurses reported older children and adolescents also express spiritual pain through questioning God, why they were chosen to have cancer, and whether they will survive. Palliative older children and adolescents discussed their spiritual pain and end of life wishes with these nurses. Some older adolescents have considered terminating

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

treatment as they confronted hopelessness and despair. The frontline nurses also reported that some parents show signs of spiritual pain during periods of uncertainty or palliation.

**Education and interventions.** The final primary theme from interviews with frontline nurses was education and pain interventions. One frontline nurse did not feel that further education could improve pain assessment, management of cancer pain, or pain communication. This nurse believed that therapeutic communication skills, empathy, and compassion are not improved with additional education. From the perspective of this nurse, the best interventions for cancer pain are narcotics, talking with the child and family about what they find useful to alleviate pain, and developing a child focused strategy to obtain relief from suffering.

The remaining three frontline nurses stated their belief that continuing education on cancer pain is needed. Learning needs identified by these nurses included pain assessment and tools, the importance of documentation, and pain interventions. Nurses identified several strategies useful to alleviate physical pain including narcotics, distraction techniques, warm blankets, and special positioning. Interventions useful for emotional and spiritual pain included offering presence, empathetic listening, and supportive care. Nurses expressed that they believed anticipatory guidance to prepare families for end of life pain and symptom management would help both children and families. One frontline nurse stated that case studies are a helpful way to assist learning.

### **Nurse Manager**

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

Two primary themes were identified from the interview with the nurse manager. The first primary theme was organizational factors that influence the quality of pain care delivery. The second primary theme was continuing education.

**Organizational factors.** The nurse manager identified several organizational factors that may influence the quality of pain care delivery at the Janeway. These included limited education provided to staff on cancer pain, lack of adequate paediatric pain assessment tools, and inconsistent pain assessment and documentation practices by nurses. Also, it was noted that there is an education to practice gap as previous cancer pain education and pain policies have not been successfully integrated into clinical practice. In addition, budgetary constraints have limited the organization's ability to develop continuing oncology education for nurses. Finally, the nurse manager reported that communication within the multidisciplinary paediatric oncology team has been identified as an ongoing challenge during the management of end of life pain.

**Continuing education.** The nurse manager identified several learning needs for nurses caring for children with cancer and their families. Nurses require continuing education on pain assessment, documentation, and interventions to manage pain for children with cancer. This education should include the different types of pain and strategies to improve pain communication within the multidisciplinary paediatric oncology team. As oncology education is specialized, it should be offered during oncology education days in a format designed to engage learners.

### **Paediatric Oncologists**

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

There were two primary themes identified in the focus group with the paediatric oncologists. The first primary theme was factors that influence the quality pain management. Two sub-categories of factors included organizational factors and child and family factors. The second primary theme was education and interventions.

**Organizational factors.** The first primary theme identified from the focus group with paediatric oncologists was organizational factors that influence the quality of pain management for children with cancer and their families.

The first organizational factor that can influence pain management is pain communication between multidisciplinary members of the paediatric oncology team. It was noted that nurses do not consistently document pain assessments, descriptions of the location and intensity of pain, or report the effectiveness of pain interventions used to alleviate pain. Cancer pain data should be accessible for the oncologists in a centralized location on the vital signs sheet to facilitate timely adjustment of the pain care plan. In addition, the oncologists recommend improvements in reporting practices between nurses to ensure that all staff caring for children with cancer are aware of the recent pattern of pain and the pain care plan. Finally, it was noted that the oncologists primarily receive information about cancer pain from paediatric residents who may be unaware of the location or severity of pain. It was noted that there have been instances of delayed reporting of pain to the oncologists. This may lead to a child experiencing pain for a prolonged period of time without relief. It is important for nurses, paediatric residents, and oncologists to have effective and timely communication of pain episodes to improve the delivery of cancer pain management for children.

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

The second organizational factor identified was nurse knowledge and beliefs related to cancer pain. The oncologists identified several continuing education needs for nurses including side effects of pain medications, use of non-pharmacologic pain interventions, the impact of emotional distress and sleep on pain, and pain expression in children. In addition, it was noted that pain requires prioritization and consistent management to improve the quality of care. Finally, the oncologists reported that each child has a different end of life pain trajectory and medication needs. End of life pain is complex, changes over time, and can be intractable in some children. For these reasons, the oncologists noted that nurse concerns relating to end of life pain care plans should be clarified with the oncologists.

**Child and family factors.** The oncologists described several child and family factors that impact the quality of cancer pain management. First, many families have misconceptions about the medications used to treat cancer pain. Families express concerns about addiction and side effects. Some families may not perceive the need for narcotics to control pain. Family members may also have difficulty interpreting signs of pain or its intensity in young children. Adolescents sometimes refuse medications because the side effects limit their ability to enjoy preferred activities.

**Education and interventions.** The second primary theme from the focus group with oncologists was education and pain interventions. The oncologists noted that nurses need continuing education on the narcotic administration policy at the Janeway that outlines the frequency of pain assessment and recording of pain data on the vital signs sheet. Pain can be multidimensional and challenging to manage. Many non-

pharmacologic strategies are useful to support children experiencing pain. Recognition of signs of pain expression in children remains an ongoing learning need for nurses. Finally, the oncologists noted that nurses should address misconceptions about pain medications in order to help families understand why medications are necessary.

### **Pastoral Services**

There were three primary themes identified during the focus group with Pastoral Services. The first primary theme was organizational factors that influence effective delivery of spiritual interventions. The second primary theme was spiritual pain and its impact on quality of life. The third primary theme was education and spiritual interventions.

**Organizational factors.** The first primary theme identified in the focus group with Pastoral Services was organization factors that influence effective delivery of spiritual interventions. The first organizational factor identified was the admitting process. At the time of admission, families may choose not to receive visits from Pastoral Services. If a family elects not to receive visits, then Pastoral Spiritual will not offer care unless they are consulted. The second organizational factor that was reported by Pastoral Services was staff uncertainty of their role. While Pastoral Services has a regular presence in the adult hospital, many paediatric staff may lack clarity on the role that Pastoral Services can contribute within the multidisciplinary team. The third organizational factor identified in the focus group with Pastoral Services was that nurses' beliefs on religion, spirituality, and non-traditional spirituality could influence how nurses



## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

perceive families from different backgrounds. It was noted that this could impact consultation to Pastoral Services or whether consultation would even be suggested.

**Spiritual pain and quality of life.** The second primary theme from the focus group with Pastoral Services was spiritual pain and its impact on quality of life for children with cancer and their families. Spiritual pain was described as questioning faith, feelings of betrayal or anger towards a higher power, hopelessness, and despair. Pastoral Services observed that the normalcy of daily life ceases to exist from the moment of diagnosis and that this spiritual pain is enduring. Spiritual pain can cause a loss of hope as families live through continuing uncertainty. For all of these reasons, spiritual pain has a negative impact on quality of life.

**Education and spiritual interventions.** The third primary theme from the focus group with Pastoral Services was education and spiritual interventions. First, it was noted that nurses need education on how personal spiritual beliefs may influence the care they provide. Increased awareness can help nurses set their personal beliefs aside and prioritize the values of families. Second, nurses need education on how emotional distress associated with cancer diagnosis, relapse, treatment, and palliation may lead to spiritual pain. Third, nurses need continuing education on helpful spiritual interventions they can use with children and families. These interventions include presence, empathetic listening, and supportive care. Fourth, it was observed by Pastoral Services that nurses need continuing education on the role Pastoral Services can play within the multidisciplinary paediatric oncology team. In the adult hospital, Pastoral Services is routinely consulted to assist adults with cancer experiencing spiritual pain. Pastoral

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

Services developed a program to help adults with cancer find ways to continue to live a meaningful life and plans to develop a similar program for paediatric oncology. For all of these reasons, the focus group with Pastoral Services emphasized that they can play a valuable role within the multidisciplinary paediatric oncology team.

### **Implications for Workshop**

The consultation findings as described above support the findings in the literature review in several key areas. First, the consultation results and literature review both describe cancer pain as a multidimensional experience with physical, psychosocial, and spiritual elements. Second, cancer pain can have a significant impact on quality of life for children and families. Third, pain expression in young children can be challenging for nurses and families to interpret and ongoing education is needed to improve assessment. Fourth, nurses need a standardized process for pain assessment and documentation to facilitate timely and effective pain communication within the multidisciplinary oncology team. Fifth, Pastoral Services has a role to play within the multidisciplinary oncology team and clarification of their role is needed. Sixth, a comprehensive approach to pain management requires effective communication between children, families, nurses, and physicians to identify client focused strategies that alleviate suffering. These commonalities will therefore be integrated into the workshop on cancer pain for paediatric nurses.

Other areas identified for inclusion in the workshop are education on emotional and spiritual pain. Frontline nurses acknowledged emotional and spiritual suffering of children and families but admitted that the primary care focus is physical pain. Greater

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

awareness is needed to identify triggers for emotional and spiritual pain and resources and strategies to help children and families who are suffering. Education on spiritual pain assessment should also include discussion of how personal spiritual beliefs may influence nursing care.

These consultation findings also justify the use of relational inquiry as the conceptual framework for development of this education workshop. The overriding theme within the consultation findings is communication issues that impede delivery of quality pain management. Improved pain communication between child, family, and nurses can help identify the nature and severity of pain, what comforts the child, and reassure the child and family that pain is prioritized. Comprehensive assessment of the impact of physical, emotional, and spiritual pain on quality of life can help nurses consider what organizational resources and interventions can help alleviate suffering for the child and family. A relational inquiry approach could also improve timely adjustments of pain medications by oncologists, assessment of potential anxiety and depression by the psychologist, and alleviation of spiritual pain by Pastoral Services. For all of these reasons, relational inquiry is a useful conceptual framework for this workshop.

Finally, there was concurrence in the consultation findings and the literature review on the format of the education workshop. Based on the findings, an education workshop on cancer pain will be delivered separately from other staff education. The workshop will use case studies, group discussions, and activities designed to engage learners to interact with the new knowledge through application. Pastoral Services has

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

offered to share spiritual assessment tools and speak to nurses about spiritual pain during the workshop.

### **Conclusion**

The data obtained through consultation with key stakeholders provides an important organizational context to guide development of a continuing education workshop for paediatric oncology nurses. These consultations provided valuable insight into intrapersonal, interpersonal, multidisciplinary, and organizational strengths and needs related to pain management by oncology nurses at the Janeway. The organizational data and the literature review can promote greater integration of the education workshop knowledge into clinical practice. The specific learning needs and preferences of nurses can assist with creating a format that will best suit nurses' continuing education needs. For all of the foregoing reasons, it was important to conduct consultations with key stakeholders to assist in the development of a continuing education workshop that meets the needs of staff, the organization, oncology children, and their families.

References:

- Ellison, L. & Janz, T. (2015). *Health at a glance: Childhood cancer incidence and mortality in Canada*. Retrieved from: <http://www.statcan.gc.ca/pub/82-624-x/2015001/article/14213-eng.pdf>
- Hartrick Doane, G. & Varcoe, C. (2015). *How to nurse: Relational inquiry with individuals and families in changing health care and health care contexts*. Philadelphia: Wolters Kluwer Lippincott Williams & Wilkins
- Hicks, C. L., von Baeyer, C. L., Spafford, P. A., van Korlaar, I., & Goodenough, B. (2001). The Faces Pain Scale-Revised: Toward a common metric in pediatric pain measurement. *Pain*, 93(2), 173-183. doi: 10.1016/S0304-3959(01)00314
- Streubert, H. J. & Carpenter, D. R. (2011). *Qualitative research in nursing: Advancing the humanistic imperative*. Philadelphia: Wolters Kluwer Lippincott Williams & Wilkins.
- von Bayer, C. L., Spagrud, L. J., McCormick, J. C., Choo, E., Neville, K., & Connelly, M. A. (2009). Three new datasets supporting use of the Numerical Rating Scale (NRS-11) for children's self-reports of pain intensity. *Pain*, 143(3), 223-227. doi: 10.1016/j.pain.2009.03.002

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

### Appendix A

#### **Invitation Letter**

Dear Potential Participant,

I am developing an education workshop on cancer pain for Janeway Paediatric Nurses and I am inviting you to share your experiences. This workshop is being developed as part of the graduation requirements for my Master of Nursing degree at Memorial University of Newfoundland and Labrador. Consultation with members of our team is a requirement for this workshop. I would appreciate the opportunity to meet with you for approximately 30 minutes to learn your views on the management of childhood cancer pain.

This workshop will provide nurses with education on the physical, emotional, and spiritual elements of cancer pain. A literature review has been completed on childhood cancer pain to identify relevant issues. By sharing your professional experience in working with children with cancer and their families, you will contribute to improving the quality of cancer pain management at the Janeway. In addition, your contribution will identify useful strategies that can improve quality of life for children with cancer and their families.

Your participation is voluntary and you may rescind your consent at any time. If you consent to an interview, you may refuse to answer any question asked. All information collected is confidential and will be locked in a secure filing cabinet until the project is completed and will then be destroyed. Only the Practicum Supervisor, Dr. Joy Maddigan, and I will be able to access this information.

If you have any questions regarding the development of this education workshop or your role as a participant, please contact Dee Anne Belbin, BNRN, at (709) 763-xxxx or via email at [g32dab@mun.ca](mailto:g32dab@mun.ca). Please retain a copy of this letter for your records. Participation in the interview will constitute informed, voluntary consent.

Respectfully,

Dee Anne Belbin BNRN

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

### Appendix B

#### **Interview Questions for Frontline Nurses**

1. What impact does physical, psychosocial, and spiritual pain have on quality of life for children with cancer?
2. How do you as an oncology nurse view family and their role, if any, in cancer pain management?
3. What strategies have you observed children and families use to reduce cancer pain and suffering?
4. What has worked best for you to alleviate cancer pain for children?
5. What observations have you made regarding feelings of hopelessness or despair in children with cancer and their families?
6. In what ways can nurses improve current practice with regard to assessment and management of physical, psychosocial, and spiritual cancer pain?
7. What factors influence cancer pain communication with children, families, and the cancer team?
8. What barriers impact the delivery of quality cancer pain management?
9. What learning needs and education content are priorities for nurses on Janeway Medicine in the management of cancer pain?

#### **Interview Questions for the Nurse Manager**

1. What staff education and resources have been provided to prepare nurses in the delivery of effective pain support to children with cancer and their families?

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

2. In what ways can nurses improve current practice with regard to assessment and management of cancer pain?
3. What barriers impact the delivery of quality cancer pain management?
4. What learning needs are priorities for nurses on Janeway Medicine in the management of cancer pain?
5. What content is appropriate to include in an education workshop for the management of cancer pain?
6. What format is most suitable for the delivery of this education?

### **Interview Questions for Focus Group with Paediatric Oncologists**

1. What nursing activities assist the paediatric oncology team to deliver effective cancer pain management at the Janeway?
2. What information does the paediatric oncology team need to develop effective cancer pain management plans?
3. What factors influence cancer pain communication within the multidisciplinary paediatric oncology team?
4. What factors influence cancer pain communication with children and families?
5. What barriers impact the delivery of quality cancer pain management?

### **Interview Questions for Focus Group with Janeway Pastoral Services**

1. What observations have you made regarding the influence of hopelessness or despair in children with cancer and their families?
2. How does spiritual pain impact quality of life for children with cancer and their families?



## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

3. What strategies are useful to alleviate spiritual pain for children experiencing hopelessness or despair?
4. What roles can Pastoral Services play to alleviate physical, emotional, and spiritual pain in children with cancer?
5. Under what circumstances do you feel that you would be most helpful as a member of the care team for children with cancer and their families?
6. What barriers impact the delivery of spiritual pain management at the Janeway?
7. How might spiritual pain assessment and management be improved by the care team at the Janeway?

# INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

## Appendix C

### 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
	<b>IF YES</b> to either of the above, the project should be submitted to a Research Ethics Board. <b>IF NO</b> 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	<b>A: SUBTOTAL Questions 3 through 7 = (Count the # of Yes responses)</b>	<b>0</b>	
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>B SUBTOTAL Questions 8 through 12 = (Count the # of Yes responses)</b>	<b>4</b>	

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

	responses)		
	<b>SUMMARY See Interpretation Below</b>		

### Interpretation:

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

Understanding Suffering: A Nursing Approach to Paediatric Cancer Pain-  
An Interactive Workshop for Oncology Nurses

# Understanding Suffering: A Nursing Approach to Paediatric Cancer Pain- An Interactive Workshop for Oncology Nurses

Dee Anne Belbin

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

### Understanding Suffering: A Nursing Approach to Paediatric Cancer Pain-

#### An Interactive Workshop for Nurses

Poorly managed cancer pain has been a topic of great interest within the local paediatric oncology team in St. John's, Newfoundland and Labrador. Members of the multidisciplinary oncology team have identified additional education as a need to reduce suffering for children and their families as current resources and pain assessment methods require improvement. The purpose of this interactive workshop is to introduce nurses to a holistic approach to pain communication and interventions to alleviate emotional, physical, and spiritual pain experienced by children and families suffering with cancer. It was developed as a one-day continuing education session and this document contains the information and materials designed for the effective delivery of the workshop.

Paediatric oncology nurses attending this workshop will explore multidimensional cancer pain and factors that influence the holistic child's and family's perspective on wellness and quality of life. A nursing model, incorporating Hartrick Doane and Varcoe's (2015) relational inquiry approach is integrated throughout the workshop. This model offer nurses a holistic approach to cancer pain assessment and nursing actions to reduce suffering. Workshop participants will examine recent evidence on emotional, physical, and spiritual pain, and consider how a relational inquiry approach could help children and families with cancer identify strategies to promote quality of life. Nurses will also consider the significance of communication in pain management and quality of care experienced by children with cancer and their families.

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

This interactive workshop on cancer pain has five primary components. First, nurses will receive an introduction to multidimensional cancer pain and the need for a holistic approach to pain assessment. This first section of the workshop is also designed to introduce nurses to Hartrick Doane and Varcoe's (2015) relational inquiry approach to nursing and its relevance in pain assessment. Second, nurses will consider how the experience of cancer treatment may lead to emotional pain for hospitalized children and their families and discuss holistic nursing actions to reduce suffering. Third, nurses will explore physical cancer pain, the elements of multidimensional pain, and strategies children report to obtain relief. Fourth, nurses will consider spiritual pain and discuss the impact of health transitions in cancer treatment for children and families and interventions that may promote spiritual health. Finally, the role of communication in cancer pain management and its importance in the delivery of pain care will be examined. Presentation slides have been developed to address each of the five workshop components and are included in the next section of this document.

The workshop has been created to assist oncology nurses to integrate new relational inquiry skills into clinical practice. Most importantly, the workshop is designed based upon the identified learning needs of nurses and to compliment the strengths of nurses who are targeted for this education. The majority of paediatric oncology nurses who will receive this education already have strong therapeutic communication skills that they use to support children and families. In addition, these nurses have a strong sense of connection and work as a unified team. Engaging these nurses to apply their strong

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

therapeutic communication skills and novice relational inquiry skills to improve pain assessment could enhance the quality of pain care on this paediatric oncology unit.

Workshop concepts are discussed using four case studies. An exemplar family was created for the case studies to provide nurses the opportunity to work in small groups. The case studies explore a child and family's experience with emotional pain, physical pain, and spiritual pain as they undergo health transitions during cancer treatment, as well as challenges with communication. Using an experiential learning approach offers nurses an opportunity to apply new knowledge to a clinical setting and improve the quality of pain care. Workshop handouts were developed to assist the small groups to create cancer pain plans and identify nursing actions to alleviate suffering. In addition, the workshop handouts will be made into a pocket guide and provided to each attending nurse for use in clinical practice. The workshop agenda, all handouts, and the evaluation form are included in the final section of this document.

In conclusion, this interactive workshop was designed based upon the strengths and learning needs of nurses targeted for the education. The education offered in the workshop is relevant for paediatric oncology nurses to facilitate learned skills into clinical practice. The knowledge developed in this workshop is intended to lead to better understanding by oncology nurses of pain communication and management in order to improve pain care delivery.



# Understanding Suffering: A Nursing Approach to Paediatric Cancer Pain

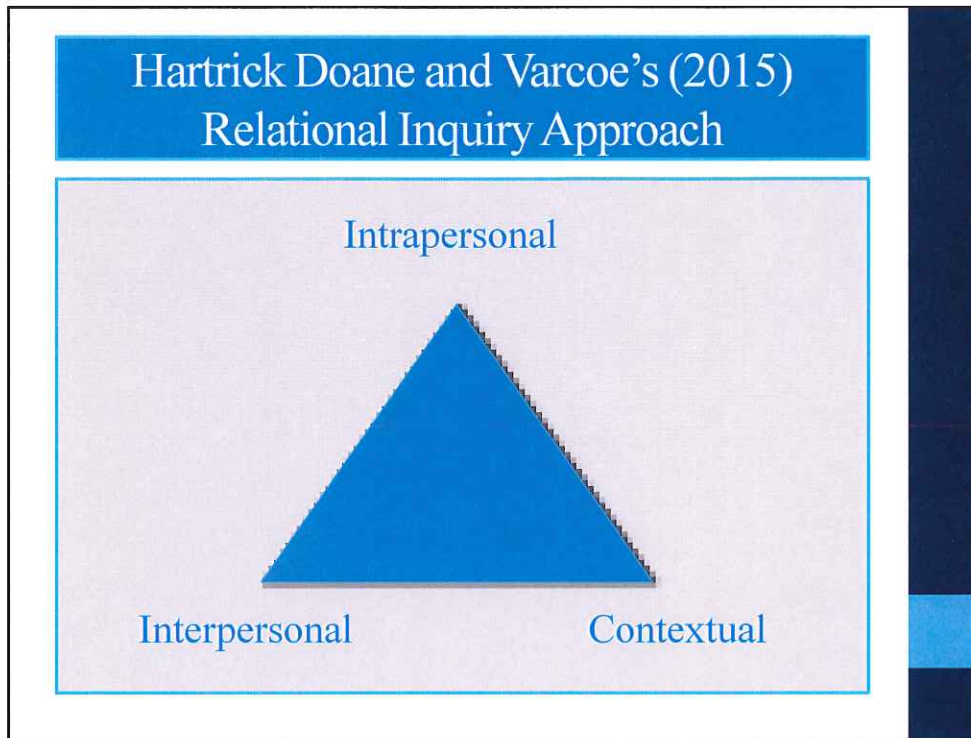
Dee Anne Belbin  
Nursing 6661

## Introduction to the Workshop

This workshop on paediatric cancer pain has been designed to help oncology nurses consider and develop within their own practice a relational inquiry approach to suffering. (Hartrick Doane & Varcoe, 2015).

This workshop on paediatric cancer pain has been designed to familiarize oncology nurses with a nursing approach that they may want to consider and implement within their own practice.

Developed by two nurses, this practice-based approach, termed *relational inquiry*, provides a holistic process for intervening effectively in the management of childhood cancer pain.



Hartrick Doane and Varcoe's (2015) relational inquiry offers nurses an approach to assess the dynamic factors that influence how children and families respond to health challenges.

In a relational inquiry approach, nurses seek insight into the lives of people and help clients consider how they might improve their quality of life during health challenges.

To provide holistic nursing care to children and families, we must consider how the experiences of people effect their capacity to participate in care.

Each child, parent, and health care provider has their own perspective of the world and these differing perspectives influence their response to health challenges.

Spending time getting to know children and families is a regular practice of nurses of our unit. Our nurses are exceptionally skilled at building strong therapeutic relationships with children and families. For this reason, the integration of a relational inquiry approach within your own practice offers a holistic progression of the excellent nursing skills you have already mastered.

## Hartrick Doane & Varcoe's (2015) Relational Inquiry Approach

Under the relational inquiry approach, intrapersonal, interpersonal, and contextual factors are not mutually exclusive. Rather, they blend together to shape a person's perspective of their level of wellness and quality of life.

Intrapersonal	Interpersonal	Contextual
Individual: <ul style="list-style-type: none"> <li>• Beliefs</li> <li>• Life experiences</li> <li>• Values</li> <li>• Hopes for the future</li> <li>• Health</li> </ul>	Family patterns of: <ul style="list-style-type: none"> <li>• Behavior</li> <li>• Communication</li> <li>• Role expectations</li> <li>• Shared experiences</li> </ul>	Internal and External Challenges: <ul style="list-style-type: none"> <li>• Uncertainty</li> <li>• Loss of Normalcy</li> <li>• Hospitalization</li> <li>• Ability to cope with evolving health challenges</li> </ul>

Intrapersonal factors are those personal qualities that influence how we perceive ourselves and the situations around us, including our personal beliefs, life experiences, values, hopes for the future, and care needs.

Interpersonal factors influence the relationships between people. These include family patterns of behaviour, communication styles within families, role expectations, and the shared experiences of family members that have shaped individual and collective abilities to respond to changes in health.

Contextual factors include our previous life experiences and current internal and external challenges people confront during illness. These include uncertainty, loss of normalcy, hospitalization, and coping with evolving health challenges.

In the relational inquiry approach, nurses seek knowledge of these dynamics to help people identify health priorities and participate in planning care that meets their needs (Hartrick Doane & Varcoe, 2015).

## Relational Inquiry Approach

A relational inquiry approach offers paediatric oncology nurses a way to improve understanding of and intervention for

- Emotional, physical, and spiritual pain;
- The meaning of pain to the child and family; and
- The types of interventions families believe could best meet their needs.



## Workshop Objectives

Workshop participants will have the opportunity to:

- Define and explore examples of emotional, physical, and spiritual pain experienced by children with cancer and their families.
- Examine evidence about the impact of emotional, physical, and spiritual pain on children and families.
- Define and explore examples of pain communication issues experienced by children with cancer and their families.
- Examine evidence about the impact of ineffective communication on the quality of pain care provided by paediatric oncology teams.

## Introduction to Cancer Pain

The World Health Organization (WHO, 2012, p. 17) describes pain as a “multidimensional phenomenon with sensory, physiological, cognitive, affective, behavioral, and spiritual components.” Each of these factors influence the perception of pain.

“Cognitive”	“Affective”	“Behavioral”
“Beliefs, attitudes, spiritual and cultural values about pain and pain control”	“Emotions”	“Behavioral responses to pain”
		(WHO, 2012, p. 17)

## Multidimensional Cancer Pain

### Physical Pain

- Acute pain from venipuncture, lumbar puncture, bone marrow aspiration, chemotherapy side effects, radiation, surgical sites, and infection.
- Chronic pain from tumor invasion and inflammation.

### Emotional (Affective) Pain

- Emotional pain from anxiety, fear, uncertainty, loss of social supports, body image changes, loss of normalcy, and disempowerment.

### Spiritual Pain

- Spiritual pain from despair, fear of death, and concern about how the family may cope if the child does not survive.



## A Case Study Approach

- Throughout this workshop, a hypothetical family and their experiences will be used to offer participants the opportunity to discuss and apply the course concepts within small groups.
- The next section will introduce the Donwell family, the exemplar family created for this workshop.

## Introduction to the Child and Family

Parents: Linda and Gerald Donwell of Moose Lake, NL

- Child: Beatrix Donwell, age 10
- Siblings:
  - Gavin Donwell, age 13, brother
  - Gemma Donwell, age 9, sister
  - Bryan Donwell, age 2, brother

## The Donwell Family

- Gerald is the sole proprietor of a small business.
- Linda works in early childhood development.
- Gerald's parents and two brothers live near Moose Lake.
- They also have many close friends in the area.
- Linda is from Prince Edward Island where her family resides.

## Beatrix and Gemma

- Beatrix is 11 months older than Gemma.
- After school, the girls relax in the privacy of the room they share.
- On weekends, they spend time with a close group of friends.
- The girls enjoy taking music and dance lessons together.

## Hospital Admission in St. John's

- Linda relocated to St. John's where Beatrix is admitted for induction chemotherapy for Precursor B cell Acute Lymphoblastic Leukemia. Linda is on a leave of absence from work.
- Gerald remains at home with Gavin, Gemma, and Bryan.
- Gerald's mother and sisters-in-law help with the household and childcare duties.
- While Beatrix misses her entire family, she is particularly distressed because she misses her sister Gemma.

## Donwell Family Pain Assessment

During this workshop, we will discuss multidimensional cancer pain, including:

- Emotional pain;
- Physical pain; and
- Spiritual pain.

In addition, this workshop will highlight communication issues and opportunities that frequently impact the quality of cancer pain care.

## Emotional Pain Objectives

Participants will have an opportunity to:

1. Define and provide examples of emotional pain experienced by oncology children and their families.
2. Describe the impact of emotional pain and identify nursing strategies to help alleviate emotional pain in children with cancer and their families.
3. Begin working in small groups on the Donwell case study and assess how emotional pain may be impacting a child and family.



## Definition of Emotional Pain

According to Athey and Overholser (2016), emotional pain is:

- “a sustained, intolerable, distressing experience related to a negative evaluation of one’s self or one’s abilities” (p. 119);
- Emotional pain helps “prepare individuals to respond to threats to their wellbeing” (p. 119); and
- May be experienced when one “cannot maintain adequate levels of social support, self-efficacy, safety, love, order, or meaning” (p. 119).

Using a relational inquiry approach to emotional pain can help nurses explore how the experience of childhood cancer has:

Influenced a child or parent’s ability to cope with illness;

Impaired self-confidence or limited their ability to carry out day to day activities of life; and

Negatively impacted their ability to meaningfully participate in relationships with significant others (Hartrick Doane & Varcoe, 2015).

Note: Athey and Overholser (2016) cited the work of Meerwijk and Weiss (2011) in making these comments on emotional pain.



## Children with Cancer and their Families

- Emotional pain can impact children and families across the continuum of cancer treatment.
- Major milestones such as diagnosis, diagnostic testing, changes in treatment plans, relapse, and the end of life can be triggers for emotional pain (Rocha et al., 2015).
- Sustained uncertainty also creates enduring emotional pain for children and their families (Rocha et al., 2015).
- Emotional pain may negatively impact quality of life for children and families in many ways.

*What have you observed during these treatment milestones about the impact of emotional pain on children and families?*

## Altered Daily Function

Children with cancer and their families experience alterations in many aspects of daily functioning including:

- Sleep disturbance;
- Nausea;
- Loss of appetite; and
- Weakness and loss of strength (Rocha et al., 2015).

Emotional distress associated with fatigue can influence the way one perceives physical pain.

## Admission to Hospital

Acute care admission creates significant disruption to the routines of children and families including:

- Loss of home and school routines;
- Lack of privacy; and
- Continuous surveillance of the child's bodily functioning (Cicogna et al., 2010; Rocha et al., 2015).

## Power Imbalances in Acute Care

Hospitalization can create situations that may prioritize institutional policies over parental authority including:

- Hospital routines and regulations;
- Centralized control of information and treatment schedules;
- Limitations on access to oncologists; and
- Communication challenges experienced by families (Essig et al., 2016; Zwaanswijk et al., 2007).

Each of these situations has the potential to create a power imbalance that privileges the practices of the health care institution over the preferences of families. While families consent to treatment created by paediatric oncology teams, some families report feeling that their authority is lessened when decisions about hospital length of stay and treatment schedules are directed by health care providers. Regimented treatment schedules make it difficult for families to integrate cancer care needs with work schedules, family activities, and financial responsibilities. The stress of managing these competing interests can cause families to feel a sense of disempowerment as they struggle to adapt to the changes that occur after a diagnosis of childhood cancer (Essig et al., 2016; Zwaanswijk et al., 2007).

## Daily Activities Disrupted

Many activities and social support networks are disrupted during hospitalization for cancer care including:

- Limited access to siblings and family members who live at a distance;
- Inability to attend school;
- Loss of recreational activities with friends; and
- Potential loss of friendships or sexual relationships if an adolescent is too unwell to participate (Rocha et al., 2015).

*What observations have you made about the impact of hospitalization on the social supports of children with cancer and their families?*

## Significantly Altered Appearance

In adolescents, treatment induced changes to body image can lead to emotional pain including:

- Hair loss;
- Weight loss;
- Loss of muscle mass; and
- Acne from steroids (Rocha et al., 2015).



## Fear and Anxiety

Children with cancer and their families can experience fear and anxiety arising from different sources including:

- Treatment and diagnostic procedures;
- Continuous uncertainty;
- Fear of relapse; and
- Fear of death (Héden et al., 2009; Nguyen et al., 2010; Rocha et al., 2015).

Fear and anxiety may worsen the experience of physical pain for children with cancer (Héden et al., 2009; Nguyen et al., 2010; Rocha et al., 2015).

Nurses must assess fear and anxiety. Many children and parents have fears of procedures related to needle insertions and require effective preparation and support. All families and many children experience continuous uncertainty and fear of relapse. Many children fear death but will not discuss this as they worry about upsetting their families.

***How do children with cancer and their families express fear and anxiety?  
What have you found helpful to reduce fear and anxiety?***

## Strategies to Reduce Emotional Pain using a Relational Inquiry Approach

Nurses can use many strategies to help reduce emotional suffering for children and families including:

- Ask children and families to share the impact of hospitalization and cancer treatment on their routines;
- Clarify the care priorities of children and families;
- Assess the supportive care needs of families; and
- Offer genuine caring.

Using a relational inquiry approach, nurses can explore what families find useful to help alleviate their worries and address their needs (Hartrick Doane & Varcoe, 2015).

These strategies require that priority be given to spending time with the child and family especially time when physical care is not required.

Spending time getting to know children and families is a regular practice of nurses of our unit. Our nurses are exceptionally skilled at building strong therapeutic relationships with families. For this reason, the integration of a relational inquiry approach within your own practice offers a holistic progression of the excellent nursing skills you have already mastered.



## Supporting Children and Families using a Relational Inquiry Approach

- Ask children and families to share their experiences to gain insight into the impact of pain on quality of life;
- Listen and value child and family priorities;
- Explore and promptly address concerns;
- Offer genuine presence during times of hardship; and
- Respect the rights of older children and adolescents to have a voice in their care (Essig et al., 2016; Hartrick Doane & Varcoe, 2015; Rocha et al., 2015; Van Cleve et al., 2012).

Encourage children and families to advocate for care that meets their needs.  
Ensure that the child's right to a voice in their care is respected and valued.

## Assess Strengths and Challenges using a Relational Inquiry Approach

- Assess the emotional impact the admission is having on the quality of life of the child and family;
- Ask what supports the child and family find helpful;
- Inquire how nurses can help the child and family prepare for procedures and treatment; and
- Address concerns promptly to ensure the child and family feel their priorities are valued (Essig et al., 2016; Hartrick Doane & Varcoe, 2015; Zwaanswijk et al., 2007).

## Assess Supportive Needs Using a Relational Inquiry Approach

- Assess current level of coping with emotional pain:
- Determine whether the child or family could benefit from additional supports;
- Consider whether consultation or modification of the current care plan may be necessary; and
- Partner with families to determine what supports may best meet their needs (Essig et al., 2016; Hartrick Doane & Varcoe, 2015; Zwaanswijk et al., 2007).

Questions to consider when assessing supportive needs:

In what ways might emotional pain be negatively impacting quality of life for this child and family?

How might the child's and family's experiences influence their ability to cope with the changes they are living through?

*In your experience, what supports do families commonly look for?*

## Genuine Caring

Nurses show children that they care about them through actions and words that show commitment to the child, including:

- Spending time with the child and understanding their special qualities; and
- Caring for the child's family and recognizing the valuable role they play in supporting the child.

Children observe and remember nurses who commit uncaring acts, use insensitive words, and break their promises. These actions may erode trust and damage the therapeutic relationship between nurse and child (Cantrell & Matula, 2009).

## Case Study: Addressing Emotional Pain

You are assigned to care for Beatrix today. Beatrix and her Mom, Linda, have been living at the Janeway for the past several weeks during the induction phase of chemotherapy. Today Beatrix is scheduled for a bone marrow aspiration and biopsy to determine if she has achieved remission.

- Beatrix turns away when you enter the room to begin her pre-procedural checklist. Beatrix tells you that she needs more time to prepare because she wants to call her sister Gemma before she goes to school.
- Linda is in the family room pacing. She is stoic when you ask if she is ready to review the procedural paperwork.

## Case Study: Addressing Emotional Pain

You ask Linda how you may be of help. She explains that she is nervous because she lacks faith in the medical system. Linda took Beatrix to the family doctor for weeks because she believed something was wrong. Beatrix was eating less, lost weight, had less energy, and low back pain. As Beatrix had a recent fall during dance practice and mononucleosis was present in their community, the family doctor did not conduct further testing.

- Linda states she is worried that delays in obtaining a diagnosis may worsen Beatrix's outcome. She is afraid of what the results of today's tests may reveal and what it could mean for Beatrix and the family.



## Case Study: Addressing Emotional Pain

1. Discuss how the experience of preparing for bone marrow aspiration and biopsy at the end of induction chemotherapy may be impacting Beatrix and Linda. How might this experience also influence Beatrix's Father and siblings?
2. What information would help you better understand what Beatrix and Linda are experiencing? How might inquiring into their experience guide your response?
3. In what ways could you support Beatrix and Linda as they prepare for today's testing?

Within your group, develop a plan to help address the family's emotional pain. Share your group's findings with the class.

## Physical Pain Objectives

Participants will have an opportunity to:

1. Define and provide examples of physical pain experienced by children with cancer.
2. Describe the impact of physical pain on children with cancer and their families.
3. Discuss interventions that may help children with cancer obtain relief from pain.
4. Continue working in small groups on the Donwell case study and assess how physical pain may be impacting a child and family.



## Definition of Physical Pain

The International Association for the Study of Pain describes physical pain as:

- “An unpleasant sensory and emotional experience associated with actual or potential tissue damage” (Downing et al., 2015, p. 24).
- Downing et al. (2015, p. 25) classify pain as:
  - Nociceptive
    - “stimulation of pain receptors of the skin, mucosa, muscles, or organs” or
  - Neuropathic
    - “structural damage to the nerve itself”

Discuss acute versus chronic pain episodes.

## Pain Expression in Children

- Gold standard for pain assessment is child self report of pain.
- Infants and young children lack the numeracy and cognitive skills to describe the nature and severity of their pain (Van Cleve et al., 2012).
- Some children may exhibit behavioral signs of pain such as a furrowed brow, grimacing, guarding, and resistance to movement.
- Some children, however, become stoic, withdraw from play or social activities, and sleep in response to pain (Rocha et al., 2015).

Not all children will report pain to a parent or nurse. Not all children will cry when they experience pain.

## Parental Interpretation of Pain

- Nurses often rely on parents to help assess children's pain.
- For the parent to believe the child requires pain relief, the parent must:
  - Correctly interpret the child's signs of pain; and
  - Believe that pain interventions are necessary (Fortier et al., 2012).
- Many parents worry about side effects and addiction which could lead to poorly controlled pain.

42% of Fortier et al. (2012) parents believed that analgesia medications should be limited.

*What have you learned in your practice about the ability of parents to interpret children's pain correctly?*

*What have you observed about parental concerns related to pain medication side effects and addiction?*

*How do these parental concerns impact the quality of pain control the child receives?*

It is important for nurses to assess parental beliefs about pain medications and concerns about side effects and addiction. Better understanding of parental perceptions on whether pain medications are useful or necessary can provide the opportunity to offer education to reduce these barriers.

## Nurse Interpretation of Pain

Nurses sometimes record their objective assessment of the child's pain instead of the severity of pain reported by the child or family (Van Cleve et al., 2012).

Prioritizing the nurse's perspective of pain over the child and family report of pain can lead to:

- Non-therapeutic dosing of analgesia;
- Poorly controlled pain;
- Child and parental frustration;
- Erosion of trust; and
- Child and family disempowerment (Essig et al., 2016; Van Cleve et al., 2012).



## Pain Assessment using a Relational Inquiry Approach

Ongoing assessment should be conducted to determine current pain status and interventions the child and family find helpful.

- Where does the child experience pain and how severe is it?
- How does pain impact the child's sleep, diet, functional capacity, and enjoyment of play?
- In what ways does pain impede the child and family's enjoyment of activities?
- What kinds of activities does the child enjoy when pain is well managed?
- What meaning does the child and family assign to pain?

Baseline pain assessments should be conducted on admission and at the beginning of each shift.

Ongoing pain assessments should continue every four hours with vital signs unless the child reports pain. If pain is reported, then assess, treat, and re-assess within one hour of oral medications and by policy for the intravenous route. Continue to re-assess pain and interventions until the child's pain is well-controlled. It is important to document all pain assessments on the vital signs sheet as this is where the oncologists report they look to determine a child's pattern of pain over time. It is also important to write a detailed note of the nature, severity, and location of the pain experienced by the child as well as the interventions that were effective to obtain relief.

These questions are offered to guide routine assessment during non-acute episodes of pain. Engaging children and families to share their experience of pain and its impact on quality of life can help identify effective pain management actions (Hartrick Doane & Varcoe, 2015).

During acute pain episodes, the most important aspects are the nature and severity of pain and any functional limitations the child has been experiencing.

## Pharmacologic Interventions

The WHO (2012) guidelines for children with cancer pain recommend a two step approach to analgesia:

- For mild pain, treat with a non-opioid and/or adjuvant; and
- For severe pain, treat with a strong opioid and/or a non-opioid and/or adjuvants.

## Non-Pharmacologic Interventions

What strategies do children report helpful to obtain relief?  
Reported strategies include:

- Heated pillows or blankets;
- Distraction;
- Music, movies, videogames, or crafts;
- Sleeping;
- Prayer; and
- Special positioning (Cicogna et al., 2010; Kamper et al, 2010; Rocha et al., 2015).

Some children find that narcotics alone will not alleviate their pain in the absence of a non-pharmacologic strategy (Rocha et al., 2015).

These are strategies that may be useful to reduce suffering while waiting for analgesia to take effect.

Using a relational inquiry approach, nurses should assess what strategies children find helpful to reduce pain (Hartrick Doane & Varcoe, 2015).

Gaining insight into the child's perspective can guide more effective nursing actions to alleviate suffering and is consistent with a holistic approach to care (Hartrick Doane & Varcoe, 2015).

Empowering children and families to seek solutions that meet their needs and collaborate in the pain care plan can improve quality of life (Hartrick Doane & Varcoe, 2015).

## Case Study: Addressing Physical Pain

You are assigned to care for Beatrix today. She is receiving her third dose of IV Vincristine later this afternoon. During the morning assessment, you notice that Beatrix has not eaten her breakfast. You ask if she is experiencing nausea. She says that she does not feel nauseated; however, her mouth and abdomen “hurt”. Her last reported bowel movement was four days ago. Her abdomen is mildly distended.

- You ask Beatrix to rate her pain. She rates her mouth pain as a 5 out of 10 and her abdominal pain as a 7 out of 10.



## Case Study: Addressing Physical Pain

You page the resident and advise them of Beatrix's mouth soreness, abdominal pain, and date of last bowel movement. You report that vital signs are: heart rate of 100, blood pressure of 120/70, respiratory rate of 24, oxygen saturation of 94% on room air, and an oral temperature of 37.4° C. The resident replies that they are in the emergency room and will assess Beatrix upon their return. In the meanwhile, the resident advises you to give oral Tylenol.

After speaking with the resident, Beatrix's mother, Linda, comes to the nursing station to find out whether the resident is en route to assess her daughter. Linda advises that the pain is worsening. You go to reassess Beatrix. Her vital signs are unchanged; however, she is now grimacing in pain and says her abdominal pain is now 8 out of 10.

## Case Study: Addressing Physical Pain

1. What could be creating discomfort for Beatrix?
2. What nursing interventions would you consider most appropriate to assist Beatrix obtain relief? In what ways might you support Linda?
3. What actions might you advocate for to address Beatrix's worsening abdominal pain?
4. If the resident is unavailable due to their duties in the emergency room, would you consult the oncologist on call? Explain your group's rationale.

Develop a plan to help address the child's physical pain.  
Share your group's findings with the class.

As cells within the gastrointestinal tract divide rapidly, they can be susceptible to side effects of chemotherapeutic agents like Vincristine (Gray et al., 2016). Vincristine slows gastric motility and can impact autonomic nerves in the bowel (Cancer Care Ontario, 2016; Carraro, Rivetti, Romano, & Fagioli, 2012; Gray et al., 2016; Kline, Hesselgrave, O'Hanlon-Curry, & Rae, 2011).

Gastrointestinal side effects which may present after Vincristine infusion include mucositis, constipation, abdominal pain, paralytic ileus, abdominal obstruction, or bowel perforation (Cancer Care Ontario, 2016; Kline et al., 2011).

Good assessment of acute gastrointestinal pain and symptoms as well as effective communication between team members can improve outcomes (Carraro et al., 2012; Gray et al., 2016).

## Spiritual Pain Objectives

Participants will have an opportunity to:

1. Define and provide examples of spiritual pain experienced by children with cancer.
2. Describe the impact of spiritual pain on oncology children and their families.
3. Discuss interventions that may help children with cancer obtain relief from spiritual pain.
4. Continue working in small groups on the Donwell case study and assess how spiritual pain may be impacting a child and family.

## Spiritual Health in Children

- Michaelson et al. (2016, p. 246) define children's spiritual health as:
  - "The capacity for awareness of the sacred qualities of life, and is experienced primarily in the four domains of relationship to self, to others, to nature, and to the transcendent."

## The Four Dimensions of Spiritual Health (Michaelson et al., 2016)



These four elements of spiritual health are not mutually exclusive parts of a whole. Rather, they blend together to shape a person's perspective of the sacred aspects of life that promote inner peace. Using a relational inquiry approach, nurses consider factors such as what special qualities makes a person who they are, what shapes how they relate to significant others, what comforts them during times of distress, and what promotes a sense of inner peace? When nurses have a better understanding of these unique qualities of a person, we can better serve people as they experience health challenges (Hartrick Doane & Varcoe, 2015).



## Relating to Self

The first domain of spiritual health focuses on a child's self-perception, sources of joy, and values (Michaelson et al., 2016).

- These include:
  - Self confidence;
  - Special accomplishments;
  - Enjoyed activities;
  - Personal goals; and
  - Sense of purpose.

Relationship with self can impact the way a child relates to others and their response to pain and illness (Michaelson et al., 2016).

## Relating to Others

The second domain of spiritual health focuses on a child's experience of relationships with others (Michaelson et al., 2016).

- These include:
  - Bonding with family;
  - Experiences of having needs met by others;
  - Peers and significant others; and
  - Trust and confidence in health care providers.

The child's experience of being able to rely upon the support of others can impact therapeutic relationships and the response to care (Michaelson et al., 2016).

## Relating to Nature

The third domain of spiritual health focuses on a child's interactions with the environment (Michaelson et al., 2016).

- These include:

- Sense of connection to nature;
- Enjoyment of outdoor activities;
- Connection to pets and wildlife; and
- Participation in civic groups (e.g. Scouting or outdoor organizations).

Positive interactions between a child and the environment can contribute to well-being (Michaelson et al., 2016).



## Relating to the Transcendent

The fourth domain of spiritual health focuses on a child's experiences with a higher spiritual power, hope, or inner peace (Michaelson et al., 2016).

- These include:
  - Considering meaning;
  - Meditation;
  - Yoga;
  - Guided imagery;
  - Listening to music; and
  - Prayer.

Exploring ways to obtain peace may help children who are suffering (Michaelson et al., 2016).

## Definition of Spiritual Pain

Oberholzer (2016, p. a3454) described spiritual pain for children with life-threatening illness as:

- “A loss of meaning and purpose in life”;
- “A diminished sense of love and relatedness”; and
- “A lack of forgiveness”.

These elements of spiritual pain are not mutually exclusive parts of a whole. Rather, they may collectively contribute to a person’s hopelessness or despair. Using a relational inquiry approach, nurses talk with families to gain insight into:

How has the experience of cancer changed the child and family’s vision of their life and hopes for the future?

In what ways has this experience influenced the child and family’s ability to obtain peace?

When nurses have a better understanding of how spiritual pain impacts quality of life and the ability to manage daily health struggles, we can better assist children and families to find more meaningful ways to obtain comfort (Hartrick Doane & Varcoe, 2015).

Some children may wonder if they have done something to contribute to their diagnosis, worry they are being punished for past behaviour, and express concerns that God has forsaken them. Children and families find it difficult to understand why a child relapsed when treatment protocols were dutifully followed by the family (Kamper et al., 2010; Oberholzer, 2016).

***During your nursing experience, what kinds of things have you observed that may indicate a child or family was enduring spiritual pain?***

## Spiritual Pain Triggers

For many oncology children, spiritual pain rises and recedes throughout the course of treatment; however, certain events can worsen suffering, including:

- Diagnosis;
- Prolonged hospitalization;
- Side effects of treatment;
- Physical pain;
- Loss;
- Uncertainty;
- Relapse; and
- Palliation (Cicogna et al., 2010; Foster et al., 2012; Rocha et al., 2015).

## Expressions of Spiritual Pain

Many children may not recognize their spiritual pain while others may conceal their suffering from their family (Kamper et al., 2010).

- Signs of spiritual pain include:
  - Anger;
  - Fear;
  - Questioning why;
  - Withdrawal (play, activities, relationships); and
  - Sense of hopelessness.

Spiritual distress may worsen if the child's prayers for comfort or cure remain unanswered.

Expressions of spiritual pain may have similar manifestations as emotional pain. In both types of pain, the child or family may express anger, fear, withdrawal, and hopelessness. It is important for nurses to seek insight into what the child and family are experiencing in order to guide effective nursing actions. It is possible that losses related to the experience of having cancer and undergoing treatment may have both emotional and spiritual pain components. When nurses have a better understanding of what is happening with the child and family, we can better assess the nursing activities and collaborative actions that offer comfort and reduce suffering (Hartrick Doane & Varcoe, 2015; Kamper et al., 2010).

## Barriers to Spiritual Care

There are several barriers that may impede nurses' abilities to recognize that a child may be experiencing spiritual pain, including:

- Admission process;
- Personal beliefs of nurses;
- Lack of awareness; and
- Lack of clarity of the role of Pastoral Services.



## Spiritual Pain Interventions using a Relational Inquiry Approach

Nurses should reflect on how their personal spiritual beliefs may impact their approach to care.

- Inquire how the child's and family's experience has influenced their:
  - Sense of who they are;
  - How they relate to the world;
  - Sense of peace and harmony; and
  - Beliefs and values (Carel, 2007, 2008; Hartrick Doane & Varcoe, 2015; Kamper et al., 2010; Rocha et al., 2015).

Kamper et al. (2010) found that an overwhelming majority of children use some form of prayer or meditation (78%) with 59% stating it helps with symptom management.

Rocha et al. (2015) participants reported that medication alone does not effectively reduce their pain in the absence of non-pharmacologic interventions.

Emotional, physical, and spiritual pain are experienced simultaneously within the holistic person to collectively influence the experience of pain (Hartrick Doane & Varcoe, 2015). For pain interventions to be effective, all aspects of multidimensional cancer pain must be considered and addressed.

## Spiritual Pain Interventions Using a Relational Inquiry Approach

Nurses can help children with cancer and their families by providing:

- Genuine presence;
- Patience;
- Acceptance;
- Empathetic listening;
- Caring for parents and siblings; and
- Creating normalcy
  - Playing; and
  - Valuing the holistic child (Cantrell & Matula, 2009; Hartrick Doane & Varcoe, 2015; Richardson, 2015).

These therapeutic communication skills can help paediatric oncology nurses support children with cancer and their families experiencing multidimensional cancer pain.

These caring actions towards children and families are regularly implemented within the clinical practice of nurses of our unit. Our nurses are exceptionally skilled at building strong therapeutic relationships with families. For this reason, the integration of a relational inquiry approach within your own practice offers a holistic progression of the excellent nursing skills you have already mastered.

## Spiritual Pain Interventions

- For some children with cancer and their families, Pastoral Services can provide an important role within the multidisciplinary paediatric oncology team.
- Early intervention can help Pastoral Services establish the trust and rapport essential to help families who are at risk for spiritual distress.
- Early intervention through Pastoral Services may reduce the risk of spiritual suffering and promote well-being.
- Collaboration with Pastoral Services can ensure that nursing activities to reduce suffering are more effective, as all components of cancer pain are addressed.

Pastoral Services may not be desired by every child and family. However, it is important to recognize that Pastoral Services is a resource within the hospital that can provide an important role in alleviating spiritual pain for some children and families.



## Case Study: Addressing Spiritual Pain

- At 2:00 p.m. on Friday afternoon, Dr. Smith enters Beatrix's room to speak with her and her Mom, Linda. Dr. Smith advises that Beatrix's bone marrow tested positive for minimal residual disease; thus, Beatrix has relapsed.
- Dr. Smith asks if Gerald can come to St. John's so that the paediatric oncologists can meet with the parents together on Tuesday afternoon to review Beatrix's care plan.
- Linda asks Dr. Smith "Where do we go from here?" Dr. Smith replies that when a child relapses, the team of paediatric oncologists review potential treatments and make a joint decision on care. This decision will be made on Tuesday.

## Case Study: Addressing Spiritual Pain

- After Dr. Smith leaves, Linda calls Gerald to discuss the meeting scheduled for Tuesday. Gerald leaves Gavin, Gemma, and Bryan with his parents and drives to St. John's.
- You enter the room as Linda finishes her conversation with Gerald. Linda is very upset that she does not have a sense of what will happen next or what this may mean for Beatrix's chance of survival. She is crying and pacing the floor.
- Beatrix is lying on the bed facing the wall. She now has her headphones on and is listening to music. Her eyes are closed. When you try to speak with Beatrix, she does not acknowledge your presence or open her eyes.

## Case Study: Addressing Spiritual Pain

1. Discuss how the experience of being notified of relapse may be impacting Beatrix, Linda, and their family.
2. What information might help you better understand what Beatrix and Linda are experiencing? How might inquiring into their experience guide your response?
3. In what ways could you support Beatrix and her parents as they await the meeting next Tuesday?
4. How might the oncology team's process for joint decision making impact Beatrix, Linda, and the family over the next few days?
5. Would your group consider a consultation with Pastoral Services? Explain your group's rationale.

## Communication Objectives

Participants will have the opportunity to:

1. Define and provide examples of pain communication challenges experienced by children with cancer and their families.
2. Discuss the impact of ineffective communication on the quality of pain care provided by paediatric oncology teams.
3. Work through the final component of the Donwell case study and assess how pain communication may be impacting a child and family.

## Pain Communication Defined

Canivet et al. (2014) describe effective cancer pain communication as having three primary components:

1. To encourage children and families to express their concerns about pain, its meaning, and the impact on quality of life;
2. To enable children and families to explore pain management strategies that they find useful to obtain relief; and
3. To build capacity to enable children and families to advocate for quality pain care that meets their needs.

Children and families need to examine their own ideas about pain so that their experience is better understood by them and the health care team.

Discussions about these experiences and what strategies people find useful to obtain relief can empower children and families to collaborate in the design of pain care plans.

Engaging in a relational inquiry approach to pain communication allows nurses to support children and families to find their own solutions to improve quality of life (Hartrick Doane & Varcoe, 2015).



## Pain Experiences of Children and Families

- Many children, adolescents, and families describe communication challenges that can lead to ineffective cancer pain management.
- Children and families report that many nurses lack effective communication skills to interpret expressions of pain in children and adolescents (Essig et al., 2016).
- Better pain communication improves the quality of pain care provided to children with cancer and their families (Azize, Humphries, & Cattani, 2011).

## Factors Influencing Pain Communication by Children

Azize et al. (2011) describe several factors that may cause children not to report pain including:

- Lack of expressive and receptive language skills in young children;
- Illness may alter a child's ability to communicate pain;
- The emotional distress of being hospitalized may cause children to withdraw from conversation;
- Previous experiences of not having pain needs properly met may cause children to feel their pain is not prioritized; and
- Children may not report pain because they worry about causing their family distress.

### Intrapersonal:

Does the child have expressive or receptive language challenges that could be limiting their ability to report pain?

Does the child experience shyness or have other personality traits that may limit their willingness to discuss their feelings?

Is the child's emotional or behavioural response to pain inhibiting the ability to talk about what they are experiencing?

What has the experience of reporting pain been like for this child?

### Interpersonal:

How have family members and health care providers responded to the child's report of pain in the past?

Are family members able to accurately interpret the child's pain expression?

What is the family's perspective on the appropriateness of analgesia for pain?

Are there differing perspectives between the child, family, and health care provider on what the severity of pain may be?

### Contextual:

Are there situational factors that may make it difficult to obtain an accurate assessment of the pain? (For example, withdrawal, underlying illness, or organizational factors within the health care setting).

Are there environmental issues which may be influencing the pain experience? (A lack of privacy, assignment in a double room, or situation anxiety that might arise from being away from home). (Hartrick Doane & Varcoe, 2015).

## Pain Communication Challenges in Acute Care

- Family patterns of communication may influence reporting of cancer pain (Essig et al., 2016).
- Prioritization of curative therapies on oncology wards may lead to less recognition and emphasis on pain control by health care providers.
- Failure to describe the child's pain experience in the medical record can lead to poor communication within the oncology team as well as inadequate pain control.
- Delays in timely and effective pain communication within the multidisciplinary paediatric oncology team may lead to unnecessary suffering due to poorly controlled pain.



## Impact of Communication Challenges

- Poorly controlled pain may cause children and families to feel disempowered if they believe their perspectives and needs are not adequately addressed.
- Nurses must consider the role of communication challenges and potential power imbalances within acute care. These barriers negatively impact the quality of pain care delivered to children with cancer and their families.

## Pain Communication Rights of Children and Families

- Each child and family has the right to quality pain care that minimizes suffering and promotes holistic well-being (WHO, 2012).
- Children and families require concise written and verbal information to assist them to make informed pain management decisions.
- Older children and adolescents have a right to participate in pain management decisions and be consulted in the development of a plan to meet their needs (Essig et al., 2016; Rocha et al., 2015).

## Role of the Therapeutic Relationship in Pain Management

Nurses should use their therapeutic skills to help children and families explore the meaning of cancer pain and consider what quality of life would constitute.

- Effective pain care requires nurses to engage children and families to describe the pain experience (Canivet et al., 2014; Hartrick Doane & Varcoe, 2015).
- Empowering children and families to participate in pain care decisions can reduce barriers to pain management.

## Pain Communication Strategies using a Relational Inquiry Approach

Nurses use many therapeutic skills to build effective, trusting relationships with children and families, including:

- Genuine presence;
- Empathetic listening;
- Honest, open communication;
- Use of open-ended questions to promote reflection;
- Supporting children and families to explore the meaning of pain and how best to obtain relief;
- Valuing the priorities of children and families; and
- Respecting the rights of the child and family to participate in the formation of care plans.

## Case Study: Addressing Communication

You have been assigned to care for Beatrix. During report, the previous nurse advises that “Beatrix was having a bit of difficulty getting up to the washroom, so I placed a commode near the bed.”

When you ask the nurse for clarification, you are advised that “Beatrix says that she has pain in her lower left back and left hip and this was making it difficult for her to walk to the washroom.” The nurse reports that the resident assessed Beatrix and 5 mg of oral Morphine was ordered and given three hours ago.

## Case Study: Addressing Communication

After report, you assess Beatrix. Beatrix is lying on her right side and appears to be uncomfortable. You ask Beatrix if she can tell you what has been happening with her back and hip.

Beatrix says that when she returned from her pass, she noticed that her back was hurting and she had difficulty putting her pajama bottoms on. Beatrix was also having trouble lying on her left side. Beatrix explains that “After I found it hard to walk to the washroom, Mom and I decided to tell the other nurse what was happening.”



## Case Study: Addressing Communication

Beatrix says that the Morphine did not help with her pain or her ability to move. You ask Beatrix if any other pain strategies used by the resident or other nurse relieved her pain.

Beatrix hesitates then says that she “did not want to bring it up again”. Beatrix begins to cry and explains “The nurses were really busy and I didn’t want to bother them. The doctor had to go see another kid, too. Besides Mom was really upset. She kept asking the doctor why I was having hip pain. The doctor didn’t really have an answer. Then Mom called Dad and they were both worried about me. I thought if I didn’t bring it up anymore that Mom and Dad wouldn’t worry.”

## Case Study: Addressing Communication

During your assessment of Beatrix, you observe that she has difficulty moving her left hip and is limping on her left leg. She is grimacing when turning in the bed and holds her left hip for support when repositioning. She reports her left hip and lower left back pain as each being 7 out of 10. Her vital signs are heart rate of 106, blood pressure of 124/84, respiratory rate of 24, oxygen saturation of 94% on room air, and a temperature of 37.5° C.



## Case Study: Addressing Communication

Before paging the resident to re-assess Beatrix, you review the chart to see how the current pain report compares to the pain level prior to the oral Morphine given three hours ago.

The previous nurse did not record a pain assessment score or provide a detailed account of the pain. Instead, the nurse wrote “D: Patient complained of pain at 4:30. A: Resident to bedside to assess and ordered Morphine. Same given. R: No further complaints of pain.” The previous nurse also did not record pain re-assessment after giving Morphine.

## Case Study: Addressing Communication

You page the resident and report the current pain assessment, vital signs, and explain that the 5 mg of Morphine given three hours ago has not relieved Beatrix's pain. The resident states that they are busy in the emergency room and will be up in one hour. The resident does not want to order any further Morphine until the child has been re-assessed. The resident advises you to give Beatrix Tylenol for comfort as she is not febrile.

## Case Study: Addressing Communication

1. What could be the cause of Beatrix's pain?
2. What further action would you take at this time?
3. How might communication between the child and Mother have influenced the reporting of pain?
4. How might communication between members of the team have influenced the quality of pain care delivered to Beatrix?
5. In what ways could better communication between child, Mom, and the team lessen the physical discomfort and emotional distress experienced by Beatrix?

Beatrix may be experiencing symptoms of osteonecrosis- a common and significant challenge for children with ALL (Elmantaser et al., 2010; Kunstreich et al., 2016; Marchese et al., 2008).

Back pain and hip pain should be investigated with x-rays, minimum, and preferably with MRI to determine if there is necrosis or fracture of the bones in the hip (Elmantaser et al., 2010; Kunstreich et al., 2016; Marchese et al., 2008).

Failure to properly document the original pain assessment by the previous nurse can create an incomplete record of pain making it difficult to assess the pattern of pain over time.

Failure to re-assess pain and accurately probe and report the client's response to Morphine may lead to unnecessary suffering.

## Key Concepts from the Donwell Family Case Studies

Throughout the case studies in today's workshop, we have observed that the cancer pain experience can include:

- Fear and anxiety;
- Emotional distress;
- Physical pain;
- Uncertainty;
- Loss;
- Spiritual despair; and
- Ineffective communication.

Each of these factors negatively impacted a child and family's quality of care.

## Key Concepts from the Donwell Family Case Studies

The case studies also demonstrated how use of relational inquiry can guide nursing actions to alleviate suffering by providing:

- Genuine presence;
- Empathetic listening;
- Honest, open communication;
- Open-ended questions to promote reflection;
- Exploring the meaning of pain and how to obtain relief;
- Valuing priorities of the child and family; and
- Encouraging the child and family to participate in the formation of care plans.

## Key Concepts from the Donwell Family Case Studies

### Holistic Approach to Multidimensional Cancer Pain:

- The strategies we have used in creating care plans for the Donwell family comprise a set of fundamental relational inquiry and therapeutic communication skills;
- Nurses can use these skills to alleviate suffering for oncology children and families experiencing cancer pain.



## Conclusion

- Cancer pain is a multidimensional experience with emotional, physical, and spiritual components.
- To effectively manage cancer pain, nurses must understand how suffering impacts the quality of life of children and families.
- A relational inquiry approach to communication can help identify needs, reduce emotional distress, physical discomfort, and spiritual despair.

## Conclusion

- Supporting children and families to participate in pain care plans helps them feel respected, valued, and empowered.
- Finally, improving the quality of pain care can increase the level of satisfaction experienced by oncology children and their families during hospitalization.



## Final Thoughts

What ideas were shared during today's workshop that stood out to you?

Does anyone have any final thoughts they would like to share?

## References

- Athey, A. & Overholser, J. (2016). Learning from physical pain to help with the management of emotional pain. *Journal of Contemporary Psychotherapy*, 46(3), 119-227. doi: 10.1007/s10879-016-9330-4
- Azize, P. M., Humphreys, A., & Cattani, A. (2011). The impact of language on the expression and assessment of pain in children. *Intensive and Critical Care Nursing*, 27(5), 235-243. doi: 10.1016/j.iccn.2011.07.002
- Cancer Care Ontario. (August 2016). *Vincristine*. Retrieved from:  
<https://www.cancercareontario.ca/sites/ccocancercare/files/vincristine.pdf>
- Canivet, D., Delvaux, N., Gibon, A.-S., Brancart, C., Slachmuylder, J.-L., & Razavi, D. (2014). Improving communication in cancer pain management nursing: A randomized controlled study assessing the efficacy of a communication skills training program. *Supportive Care in Cancer*, 22(12), 3311-3320. doi: 10.1007/s00520-014-2357-2
- Cantrell, M. A. & Matula, C. (2009). The meaning of comfort for pediatric patients with cancer. *Oncology Nursing Forum*, 36(6), E303-E309. doi: 10.1188/09.ONF.E303-E309
- Carel, H. (2007). Can I be ill and happy? *Philosophia*, 35(2), 95-110. doi: 10.1007/s11406-007-9085-5
- Carel, H. (2008). Living in the shadow of illness. *RSA Journal*, 154(5535), 26-29. Retrieved from:  
<http://www.jstor.org/stable/41379894>

## References

- Carraro, F. Rivetti, E., Romano, E., & Fagioli, F. Two cases of paralytic ileus in onco-hematologic patients. *Pediatric Reports*, 4(1), e3. doi: 10.4081.pr.2012.e3
- Cicogna, E. D. C., Nascimento, L. C., & de Lima, R. A. G. (2010). Children and adolescents with cancer: Experiences with chemotherapy. *Revista Latino-Americana de Enfermagem*, 18(5), 864-872. Retrieved from: <http://www.eerp.usp.br/rlae>
- Downing, J., Jassal, S. S., Mathews, L., Brits, H., & Friedrichsdorf, S. J. (2015). Pediatric pain management in palliative care. *Pain Management*, 5(1), 23-25. doi: 10.2217/pmt.14.45
- Elmantaser, M., Stewart, G., Young, D., Duncan, R., Gibson, B., & Ahmed, S. F. (2010). Skeletal morbidity in children receiving chemotherapy for acute lymphoblastic leukemia. *Archives of Disease in Childhood*, 95(10), 805-809. doi: 10.1136/adc.2009.172528
- Essig, S., Steiner, C., Kuehni, C. E., Weber, H., & Kiss, A. (2016). Improving communication in adolescent cancer care: A multiperspective study. *Pediatric Blood & Cancer*, 63(8), 1423-1430. doi: 10.1002/pbc.26012
- Fortier, M. A., Wahi, A., Maurer, E. L., Tan, E. T., Sender, L. S., & Kain, Z. N. (2012). Attitudes regarding analgesia use and pain expression in parents of children with cancer. *Journal of Pediatric Hematology Oncology*, 34(4), 257-262. doi: 10.1097/MPH.0b013e318241fd07
- Foster, T. L., Bell, C. J., & Gilmer, M. J. (2012). Symptom management of spiritual suffering in pediatric palliative care. *Journal of Hospice & Palliative Care*, 14(2), 109-115. doi: 10.1097/NJH.0b013e3182491f4b

## References

- Gray, E. J. Darvishzadeh, A., Sharma, A., Ganeshan, D., Faria, S. C. & Lall, C. (2016). Cancer therapy-related complications in the bowel and mesentery: an imaging perspective. *Abdominal Radiology*, 41(10), 2031-2047. doi: 10.1007/s00261-016-0799-3
- Hartrick Doane, G. & Varcoe, C. (2015). *How to nurse: Relational Inquiry with individuals and families in changing health care and health care contexts*. Philadelphia: Wolters Kluwer Lippincott Williams & Wilkins
- Héden, L., Von Essen, L., & Ljungman, G. (2009). Randomized interventions for needle procedures in children with cancer. *European Journal of Cancer Care*, 18(4), 358-363. doi: 10.1111/k/1365-2354.2008.00939.x
- Janeway Pastoral Services. (April 6, 2017). Interview by D. A. Belbin [handwritten notes]. Janeway Pastoral Services Department.
- Kamper, R. L., Van Cleve, L., & Savedra, M. (2010). Children with advanced cancer: Responses to a spiritual quality of life interview. *Journal for Specialists in Pediatric Nursing*, 15(4), 301-306. doi: 10.1111/j/1744-6155.2010.00253.x
- Kline, N. E., Hesselgrave, J. E., O'Hanlon-Curry, J., & Rae, M. L. (2011). *The pediatric chemotherapy and biotherapy curriculum* (3rd ed.). Chicago: Association of Pediatric Hematology/Oncology Nurses.
- Kunstreich, M., Kummer, S., Laws, H.-J., Borkhardt, A., & Kuhlen, M. (2016). Osteonecrosis in children with acute lymphoblastic leukemia. *Haematologica*, 101(11), 1295-1305. doi: 10.3324/haematol.2016.147595

## References

- Marchese, V. G., Connolly, B. H., Able, C., Booten, A. R., Bowen, P., Porter, B. M., . . . Kaste, S. C. (2008). Relationships among severity of osteonecrosis, pain, range of motion, and functional mobility in children, adolescents, and young adults with acute lymphoblastic leukemia. *Physical Therapy, 88*(3), 341-350. doi: 10.2522/ptj.20070108
- Meerwijk, E. & Welss, S. (2011). Toward a unifying definition of psychological pain. *Journal of Loss & Trauma, 16*(5), 402-412. doi: 10.1080/15325024.2011.572044
- Michaelson, V., Trothen, T., Ascough, H., & Pickett, W. (2016). Canadian children and spiritual health: Foundations for spiritual care. *Journal of Pastoral Care & Counseling, 70*(4), 244-256. doi: 10.1177/1542305016680630
- Nguyen, T. N., Nilsson, S. Hellström, A.-L., & Bengtson, A. (2010). Music therapy to reduce pain and anxiety in children with cancer undergoing lumbar puncture: A randomized clinical trial. *Journal of Pediatric Oncology Nursing, 27*(3), 146-155. doi: 10.1177/1043454209355983
- Oberholzer, A. E. (2016). Children's experience of holiness in health care. Are we rendering effective spiritual care? *HTS Theologiese Studies Theological Studies, 72*(4), a3454-a3460. doi: 10.4102/hts.v72i4.3454
- Richardson, H. R. L. (2015). More than just child's play: Symbolic expressions of illness and spirit. *International Journal of Children's Spirituality, 20*(2), 100-113. doi: 10.1080/13644X.2015.1030595
- Rocha, A. D. F. P., Sposito, A. M. P., de Bortoli, P. S., Silva-Rodrigues, F. M., de Lima, R. A. G., & Nascimento, L. C. (2015). Oncologic pain relief. Strategies told by adolescents with cancer. *Têxto & Contexto Enfermagem, 24*(1), 96-104. doi: 10.1590/0104-07072015002120013

## References

Van Cleve, L., Muñoz, C. E., Riggs, M. L., Bava, L., & Savedra, M. (2012). Pain experience in children with advanced cancer. *Journal of Pediatric Oncology Nursing*, 29(1), 28-36. doi: 10.1177/1043454211432295

World Health Organization. (2012). *WHO guidelines on the pharmacological treatment of persisting pain in children with medical illnesses*. Geneva: World Health Organization. Retrieved from: <http://apps.who.int/iris/bitstream/10664/44540/1/9789241458120>

Zwaanswijk, M., Tate, K., van Dulmen, S., Hoogerbrugge, P. M., Kamps, W. A., & Bensing, J. M. (2007). Young patients', parents', and survivors' communication preferences in paediatric oncology: Results of online focus groups. *BMC Pediatrics*, 7(35), 1-10. doi: 10.1186/1471-2431-7-35

**Understanding Suffering: A Nursing Approach to Paediatric Cancer Pain-  
An Interactive Workshop for Nurses**

- |             |   |                           |
|-------------|---|---------------------------|
| <b>I.</b>   | <b>Introduction to the workshop</b>   | <b>8:30 – 9:15 a.m.</b>   |
|             | <ul style="list-style-type: none"><li>• Welcome and introductions, overview of the agenda and plan for the day</li><li>• Overview of the Relational Inquiry approach to nursing<ul style="list-style-type: none"><li>• Introduction to multidimensional cancer pain</li><li>• Introduction to the exemplar family</li></ul></li></ul> |                           |
| <b>II.</b>  | <b>Exploring emotional pain</b>   | <b>9:15 – 10:45 a.m.</b>  |
|             | <ul style="list-style-type: none"><li>• Overview of emotional pain<ul style="list-style-type: none"><li>• Key nursing interventions</li><li>• Small group work with the Donwell family and report back</li></ul></li></ul>  |                           |
|             | <b>Coffee/Stretch Break</b>   | <b>10:45 – 11:15 a.m.</b> |
| <b>III.</b> | <b>Physical pain</b>  | <b>11:15 – 12:30 p.m.</b> |
|             | <ul style="list-style-type: none"><li>• A review of physical pain in children with cancer<ul style="list-style-type: none"><li>• Non-pharmacological nursing interventions</li><li>• Small group work and report back</li></ul></li></ul>   |                           |
|             | <b>Lunch</b>  | <b>12:30 – 1:15 p.m.</b>  |
| <b>IV.</b>  | <b>Understanding spiritual pain</b>   | <b>1:15 – 2:45 p.m.</b>   |
|             | <ul style="list-style-type: none"><li>• Introduction to spiritual health and spiritual pain<ul style="list-style-type: none"><li>• Resources and nursing interventions</li><li>• Small group work and report back</li></ul></li></ul>   |                           |
| <b>V.</b>   | <b>Pain communication and documentation</b>   | <b>2:45 – 4:00 p.m.</b>   |
|             | <ul style="list-style-type: none"><li>• Pain communication challenges: child, family, and team<ul style="list-style-type: none"><li>• Effective nursing interventions and strategies</li><li>• Small group work and report back</li></ul></li></ul>   |                           |
| <b>VI.</b>  | <b>Wrap up and conclusion</b>   | <b>4:00 – 4:30 p.m.</b>   |
|             | <ul style="list-style-type: none"><li>• Group debrief<ul style="list-style-type: none"><li>• What did you like about the workshop? Not like?</li><li>• What was helpful? Not helpful?</li></ul></li><li>• Evaluation and conclusion</li></ul>   |                           |



**Hartrick Doane and Varcoe's (2015) Relational Inquiry Approach to Nursing**

Under the relational inquiry approach, intrapersonal, interpersonal, and contextual factors are not mutually exclusive. Rather, they blend together to shape a person's perspective of their level of wellness and quality of life. These factors may influence a child and family's perspective of the experience of cancer pain.

Table 1  
Factors Influencing Pain Experiences of Children

Intrapersonal	Interpersonal	Contextual
<ul style="list-style-type: none"> <li>• Beliefs</li> <li>• Life experiences</li> <li>• Values</li> <li>• Hopes for the future</li> <li>• Health</li> </ul>	<ul style="list-style-type: none"> <li>• Behaviour</li> <li>• Communication</li> <li>• Role expectations</li> <li>• Shared experiences</li> </ul>	<p>Internal and External Challenges:</p> <ul style="list-style-type: none"> <li>• Uncertainty</li> <li>• Loss of Normalcy</li> <li>• Hospitalization</li> <li>• Ability to cope with evolving health challenges</li> </ul>



**Questions to Consider When Assessing Multidimensional Cancer Pain in Children**

**Intrapersonal:**

Does the child have expressive or receptive language challenges that could be limiting their ability to report pain?

Does the child experience shyness or have other personality traits that may limit their willingness to discuss their feelings?

Is the child's emotional or behavioural response to pain inhibiting the ability to talk about what they are experiencing?

What has the experience of reporting pain been like for this child?

**Interpersonal:**

How have family members and health care providers responded to the child's report of pain in the past?

Are family members able to accurately interpret the child's pain expression?

What is the family's perspective on the appropriateness of analgesia for pain?

Are there differing perspectives between the child, family, and health care provider on what the severity of pain may be?

**Contextual:**

Are there situational factors that make it difficult to obtain an accurate assessment of the pain? (For example, withdrawal, underlying illness, or organizational factors within the health care setting).

Are there environmental issues that may be influencing the pain experience? (For instance, could a lack of privacy or situation anxiety that might arise from being away from home limit disclosure of pain).

### Multidimensional Cancer Pain in Childhood Cancer

The World Health Organization (WHO, 2012, p. 17) describes cancer pain as a “multidimensional phenomenon with sensory, physiological, cognitive, affective, behavioral, and spiritual components.” Each of these factors can influence the perception of pain. The table below outlines causes of emotional, physical, and spiritual pain that may be experienced by children with cancer and their families during health transitions.

Table 2  
Multidimensional Cancer Pain

Emotional Pain	Physical Pain	Spiritual Pain
<ul style="list-style-type: none"> <li>• Anxiety</li> <li>• Fear</li> <li>• Uncertainty</li> <li>• Loss of social supports</li> <li>• Body image changes</li> <li>• Loss of normalcy</li> <li>• Disempowerment</li> </ul>	<p>Acute Pain:</p> <ul style="list-style-type: none"> <li>• Venipuncture</li> <li>• Lumbar puncture</li> <li>• Bone marrow aspiration</li> <li>• Chemotherapy side effects</li> <li>• Radiation</li> <li>• Surgical site</li> <li>• Infection</li> </ul> <p>Chronic Pain:</p> <ul style="list-style-type: none"> <li>• Tumor invasion</li> <li>• Inflammation</li> </ul>	<ul style="list-style-type: none"> <li>• Diagnosis</li> <li>• Prolonged hospitalization</li> <li>• Pain</li> <li>• Loss</li> <li>• Uncertainty</li> <li>• Relapse</li> <li>• Palliation</li> </ul>

**Case Study: Addressing Emotional Pain**

You are assigned to care for Beatrix today. Beatrix and her Mom, Linda, have been living at the Janeway for the past several weeks during the induction phase of chemotherapy. Today Beatrix is scheduled for a bone marrow aspiration and biopsy to determine if she has achieved remission. Beatrix turns away when you enter the room to begin her pre-procedural checklist. Beatrix tells you that she needs more time to prepare because she wants to call her sister Gemma before she goes to school.

Linda is in the family room pacing. She is stoic when you ask if she is ready to review the procedural paperwork. You ask Linda how you may be of help. She explains that she is nervous because she lacks faith in the medical system. Linda took Beatrix to the family doctor for weeks because she believed something was wrong. Beatrix was eating less, lost weight, had less energy, and low back pain. As Beatrix had a recent fall during dance practice and mononucleosis was present in their community, the family doctor did not conduct further testing. Linda states she is worried that delays in obtaining a diagnosis may worsen Beatrix's outcome. She is afraid of what the results of today's tests may reveal and what it could mean for Beatrix and the family.

1. Discuss how the experience of preparing for bone marrow aspiration and biopsy at the end of induction chemotherapy may be impacting Beatrix and Linda. How might this experience also influence Beatrix's Father and siblings?
2. What information would help you better understand what Beatrix and Linda are experiencing? How might inquiring into their experience guide your response?
3. In what ways could you support Beatrix and Linda as they prepare for today's testing?

### Case Study: Addressing Physical Pain

You are assigned to care for Beatrix today. She is receiving her third dose of IV Vincristine later this afternoon. During the morning assessment, you notice that Beatrix has not eaten her breakfast. You ask if she is experiencing nausea. She says that she does not feel nauseated; however, her mouth and abdomen “hurt”. Her last reported bowel movement was four days ago. Her abdomen is mildly distended. You ask Beatrix to rate her pain. She rates her mouth pain as a 5 out of 10 and her abdominal pain as a 7 out of 10.

You page the resident and advise them of Beatrix's mouth soreness, abdominal pain, and date of last bowel movement. You report that vital signs are: heart rate of 100, blood pressure of 120/70, respiratory rate of 24, oxygen saturation of 94% on room air, and an oral temperature of 37.4° C. The resident replies that they are in the emergency room and will assess Beatrix upon their return. In the meanwhile, the resident advises you to give oral Tylenol. After speaking with the resident, Beatrix's mother, Linda, comes to the nursing station to find out whether the resident is en route to assess her daughter. Linda advises that the pain is worsening. You go to reassess Beatrix. Her vital signs are unchanged; however, she is now grimacing in pain and says her abdominal pain is now 8 out of 10.

1. What could be creating discomfort for Beatrix?
2. What nursing interventions would you consider most appropriate to assist Beatrix obtain relief? In what ways might you support Linda?
3. What actions might you advocate for to address Beatrix's worsening abdominal pain?

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

4. Since the resident is unavailable due to their duties in the emergency room, would you consult the oncologist on call? Explain your group's rationale.

**Case Study: Addressing Spiritual Pain**

At 2:00 p.m. on Friday afternoon, Dr. Smith enters Beatrix's room to speak with her and her Mom, Linda. Dr. Smith advises that Beatrix's bone marrow tested positive for minimal residual disease; thus, Beatrix has relapsed. Dr. Smith asks if Gerald can come to St. John's so that the paediatric oncologists can meet with the parents together on Tuesday afternoon to review Beatrix's care plan. Linda asks Dr. Smith "Where do we go from here?" Dr. Smith replies that when a child relapses, the team of paediatric oncologists review potential treatments and make a joint decision on care. This decision will be made on Tuesday.

After Dr. Smith leaves, Linda calls Gerald to discuss the meeting scheduled for Tuesday. Gerald leaves Gavin, Gemma, and Bryan with his parents and drives to St. John's. You enter the room as Linda finishes her conversation with Gerald. Linda is very upset that she does not have a sense of what will happen next or what this may mean for Beatrix's chance of survival. She is crying and pacing the floor. Beatrix is lying on the bed facing the wall. She now has her headphones on and is listening to music. Her eyes are closed. When you try to speak with Beatrix, she does not acknowledge your presence or open her eyes.

1. Discuss how the experience of being notified of relapse may be impacting Beatrix, Linda, and their family.
2. What information might help you better understand what Beatrix and Linda are experiencing? How might inquiring into their experience guide your response?
3. In what ways could you support Beatrix and her parents as they await the meeting next Tuesday?

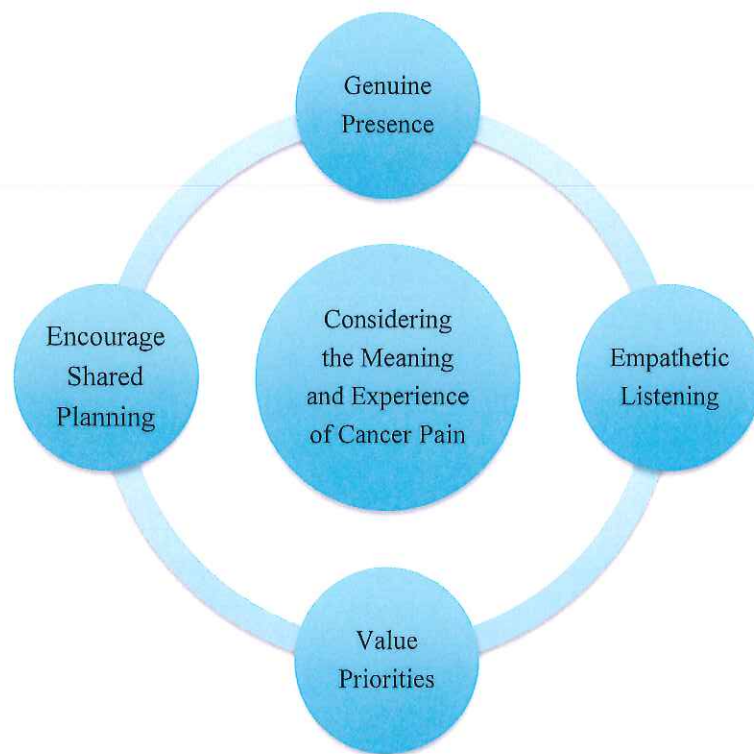
## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

4. How might the oncology team's process for joint decision-making impact Beatrix, Linda, and the family over the next few days?
5. Would your group consider a consultation with Pastoral Services? Explain your group's rationale.

### **Pain Communication Strategies Nurses Can Use to Support Children**

Hartrick Doane and Varcoe's (2015) relational inquiry approach offers nurses insight into pain communication strategies nurses can use to alleviate suffering including:

- Genuine presence;
- Empathetic listening;
- Honest, open communication;
- Open-ended questions to promote reflection;
- Exploring the meaning of pain and how to obtain relief;
- Valuing priorities of the child and family; and
- Encouraging the child and family to participate in the formation of care plans.





### **Case Study: Addressing Pain Communication**

You have been assigned to care for Beatrix. During report, the previous nurse advises that “Beatrix was having a bit of difficulty getting up to the washroom, so I placed a commode near the bed.” When you ask the nurse for clarification, you are advised “Beatrix says that she has pain in her lower left back and left hip and this was making it difficult for her to walk to the washroom.” The nurse reports that the resident assessed Beatrix and 5 mg of oral Morphine was ordered and given three hours ago.

After report, you assess Beatrix. Beatrix is lying on her right side and appears to be uncomfortable. You ask Beatrix if she can tell you what has been happening with her back and hip. Beatrix says that when she returned from her pass, she noticed that her back was hurting and she had difficulty putting her pajama bottoms on. Beatrix was also having trouble lying on her left side. Beatrix explains “After I found it hard to walk to the washroom, Mom and I decided to tell the other nurse what was happening.”

Beatrix says that the Morphine did not help with her pain or her ability to move. You ask Beatrix if any other pain strategies used by the resident or other nurse relieved her pain. Beatrix hesitates then says that she “did not want to bring it up again”. Beatrix begins to cry and explains that “The nurses were really busy and I didn’t want to bother them. The doctor had to go see another kid, too. Besides Mom was really upset. She kept asking the doctor why I was having hip pain. The doctor didn’t really have an answer. Then Mom called Dad and they were both worried about me. I thought if I didn’t bring it up anymore that Mom and Dad wouldn’t worry.”

During your assessment of Beatrix, you observe that she has difficulty moving her left hip and is limping on her left leg. She is grimacing when turning in the bed and holds her left hip for support when repositioning. She reports her left hip and lower left back pain as each being 7 out of 10. Her vital signs are heart rate of 106, blood pressure of 124/84, respiratory rate of 24, oxygen saturation of 94% on room air, and a temperature of 37.5° C.

Before paging the resident to re-assess Beatrix, you review the chart to see how the current pain report compares to the pain level prior to the oral Morphine given three hours ago. The previous nurse did not record a pain assessment score or provide a detailed account of the pain. Instead, the nurse wrote “D: Patient complained of pain at 4:30. A: Resident to bedside to assess and ordered Morphine. Same given. R: No further complaints of pain.” The previous nurse also did not record pain re-assessment after giving Morphine.

You page the resident and report the current pain assessment, vital signs, and explain that the 5 mg of Morphine given three hours ago has not relieved Beatrix’s pain.

## INTERACTIVE WORKSHOP ON PAEDIATRIC CANCER PAIN

The resident states that they are busy in the emergency room and will be up in one hour. The resident does not want to order any further Morphine until the child has been re-assessed. The resident advises you to give Beatrix Tylenol for comfort as she is not febrile.

1. What could be the cause of Beatrix's pain?
2. What further action would you take at this time?
3. How might communication between the child and Mother have influenced the reporting of pain?
4. How might communication between members of the team have influenced the quality of pain care delivered to Beatrix?
5. In what ways could better communication between child, Mom, and the team lessen the physical discomfort and emotional distress experienced by Beatrix?

## Workshop Evaluation Form

1. In what ways has attending the workshop changed your perspective on multidimensional cancer pain?
2. What knowledge did you gain that you may integrate within your clinical practice?
3. What concepts from the workshop did you find most intriguing?
4. Based on what you learned in today's workshop, what would you suggest to help improve cancer pain assessment and management on our unit?
5. If you could improve one thing about today's workshop, what would it be?

2. What knowledge did you gain that you may integrate within your clinical practice?

3. What concepts from the workshop did you find most intriguing?

4. Based on what you learned in today's workshop, what would you suggest to help improve cancer pain assessment and management on our unit?

5. If you could improve one thing about today's workshop, what would it be?