


Session 102 -- Pediatric Oncology Nursing Research:
Transforming Practice Through Science Together



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Speaker Disclosures

- Pamela Hinds & Lauri Linder served as editors for the featured textbook, *Pediatric Oncology Nursing: Defining Care Through Science* (2020).
- Amy Newman & Julia Challinor have no industry relationships to disclose.

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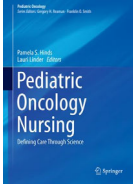
Introduction



Dr. Pamela S. Hinds

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Creating a Hardcover Text in 2020 – Why?



- *The Invitation*
- *The Plan*
- *The Chance*

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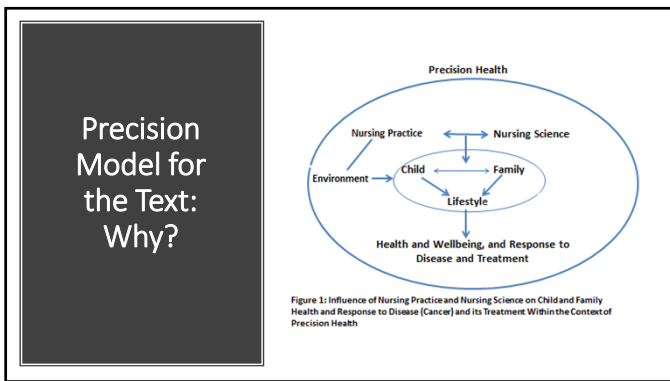
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Precision Model for the Text: Why?

Because we now have in pediatric oncology nursing the evidence-based information needed to give the right nursing care, to the right child at the right time

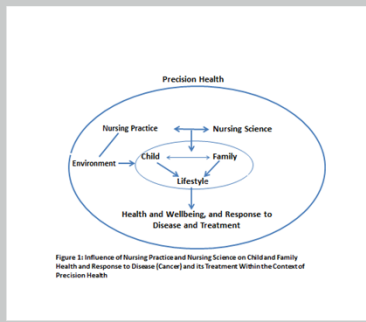


Figure 1: Influence of Nursing Practice and Nursing Science on Child and Family Health and Response to Disease (Cancer) and Its Treatment Within the Context of Precision Health

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From Research Directly to Practice! From Practice Questions to Research!

Translation from Research to Practice - What we need to practice

- 89 evidence-based findings deemed ready for use in pediatric oncology nursing care

Questions From Practice to Research - What we need to study next

- 88 questions ready to be asked and answered using research and other evidence-generating methods

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Highlights of Research Findings



Dr. Amy R. Newman

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Areas Ready for Translation into Practice



- Treatment Decision Making
- Symptom Management
- Patient-Reported Outcomes
- Exercise & Physical Activity
- Genetics/Genomics
- Palliative and End-of-Life Care

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Treatment Decision Making

Kimberly A. Pyke-Grimm, Ginny L. Schulz, Helen Pearson, and Katherine Patterson Kelly

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Treatment Decision Making



- Treatment decision making is complex due to the varying decisions which have to be made about diagnosis, treatment options, toxicity, and outcomes of treatment.
- Shared decision making is complicated by the triadic relationship of parent/caregiver, child and clinician.

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Treatment Decision Making

- Ability & inclination of patients and their families based upon personal, cultural and situational variables
- Decisional situations exist throughout the cancer treatment continuum
- Is cure possible or probable?
- Child & adolescent perspectives

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Treatment Decision Making: Future Directions

- Family level analysis of treatment decision making
- Implementation of strategies & interventions to promote involvement of children, families, and members of healthcare team
- Continued development of treatment decision making measures
- Examination of short- and long-term outcomes
- Exploration of communication and treatment decision making

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Symptom Management

Suzanne Ameringer, Catherine Fiona Macpherson, and Lindsay Jibb

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• Symptoms: Self-reported perception of an individual's experience of disease or physical disturbance (Oddy, et al., 2003)

• Symptom clusters: Clustering of symptoms occurs when patients experience multiple related symptoms concurrently (Zhao, et al., 2010)

• Symptoms are of clinical, research & policy concern because they are the most common reason that patients seek healthcare (Rutledge & McGuire, 2004)


• Assessment & management of symptoms is a hallmark of nursing practice (Corwin, et. al)


<https://www.piqsels.com/en/search?q=handprint>

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Symptom Management

- Every child's symptom experience is unique
- Family beliefs & expectations influence the child's symptom experience
- Symptoms are distressing, burdensome & affect development, functional capacity, & quality of life
- Symptoms may abate over time, but can persist even into survivorship


 Inpatient setting


 Outpatient setting

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Symptom Management: Future Directions


- Relationships between specific disease and/or specific treatment & specific symptom experiences
- Relationships between symptom severity & symptom distress
- Inter-individual differences in symptom experience unexplained by disease and/or treatment
- Approaches to symptom management in pre-verbal/just-verbal/non-verbal children who may experience sub-optimal symptom management due to lack of self-report
- Effect of social interactions with peers and health care clinicians on symptom experience
- Use of technology-based interventions for child & family symptom assessment & management in the outpatient environment

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Patient-Reported Outcomes

Deborah Tomlinson, Changrong Yuan, Lei Cheng, and
Pamela S. Hinds

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Patient-Reported Outcomes: Any report of the status of a patient's health condition that comes directly from the patient

<https://www.fda.gov/media/77832/download>

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Patient-Reported Outcomes (PROs)

- Children as young as 8 years of age can understand & respond to PRO measures
- If children are not asked to report on their subjective experiences, it is highly unlikely that they will spontaneously do so
- Pediatric PRO measures have been validated in groups of pediatric oncology patients at varying times during treatment & survivorship
- Collecting both child & parent-proxy PROs concurrently is possible & informative as the two sets of experiences likely differ from each other & collecting both is more informative of a family treatment experience

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Patient-Reported Outcomes: Future Directions

- Determining the clinical value of pediatric PROs collected at purposefully selected time points
- Documenting the collective clinical value of including patient, parent-proxy, and clinician reports
- Continuing & extending the testing of psychometrically strong pediatric PRO measures across cultures & countries

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Exercise & Physical Activity

Kathy Ruble, Ho Cheung William Li, Clifton P. Thornton, and Mary C. Hooke

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• "...for children, play is a critical form of physical activity and for the child with altered health conditions can be anything but simple or insignificant"

(Ruble, Li, Thornton, & Hooke, 2020, p. 153)



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Exercise and Physical Activity

- Inactivity is an acute toxicity of cancer and its treatment
- Regular physical activity can enhance an individual's physical & psychosocial well-being
- Misconceptions must be corrected & the benefits of regular physical activity promoted to children with cancer & their families
- Barriers within home, hospital, and school along with cancer symptoms & treatment side effects and the attitudes of family & friends can limit physical activity

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Exercise & Physical Activity: Future Directions

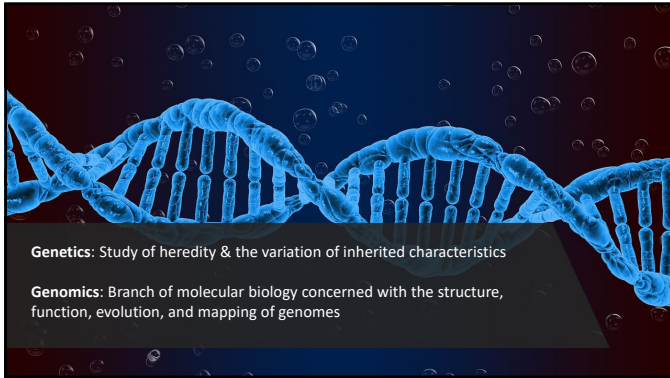
- Develop & evaluate guidelines for physical activity during cancer treatment
- Evaluate appropriate & effective interventions to promote the adoption & maintenance of regular physical activity among children with cancer
- Use technology to promote physical activity
- Partner with non-profit voluntary organizations to develop & sustain programs promoting physical activity

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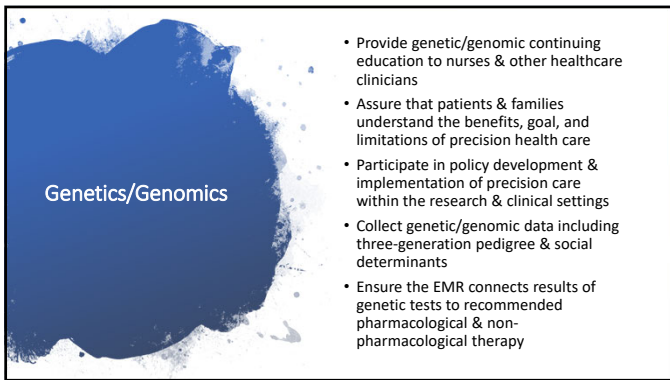
Genetics/Genomics

Belinda N. Mandrell, Stacy Hines-Dowell,
and Masakazu Nishigaki

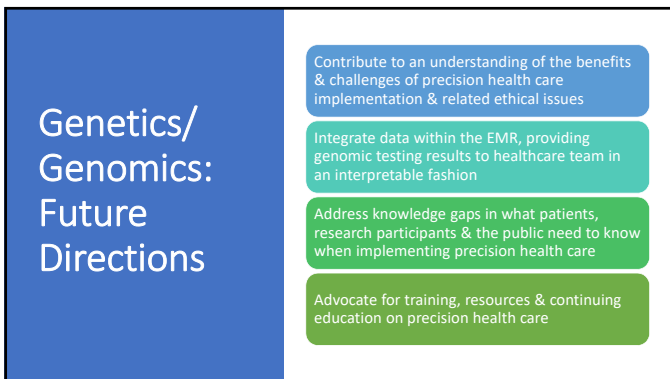
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Palliative & End-of-Life Care

Amy R. Newman, Stacey Crane, Jessica L. Spruit,
Samia Alharrasi, and Cindy J. Bell

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Palliative and End-of-Life Care

Pediatric palliative care (PPC) in oncology is the active total care of the child's body, mind, and spirit and involves giving support to the family

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Palliative and End-of-Life Care

- All pediatric patients with cancer & their families should receive care grounded in palliative care principles from the time of diagnosis through bereavement or survivorship
- Parents, adolescents & young adults prefer that diagnostic & prognostic information be disclosed in an honest, but hopeful manner, regardless of prognosis
- Parents & patients, when appropriate, should be engaged in planning end-of-life care
- Goal of cure & quality of life are not mutually exclusive

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Palliative & End-of-Life Care: Future Directions

- Additional training for healthcare clinicians to better understand the basic tenets of palliative care
- Inclusion of the child's perspective as well as that of patients & families from non-dominant cultures
- Description of the role of palliative care in transition to survivorship and outcomes related to early integration of palliative care
- Establishment of comprehensive, reproducible bereavement programs with measurement of psychosocial, emotion, and spiritual outcomes among parents & family members

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Pediatric Oncology Nursing Research in Low- and Middle-Income Countries



Dr. Julia Challinor

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Govt of Ghana URGENT FREE treatment for childhood cancer

Pediatric Cancer Patients at Santa Marcelina Hospital

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Nursing Research

- 137 articles
- Five languages
- 2008 to 2018
- Communicate **nursing** research findings pertaining to pediatric oncology issues from L&MIC (low- and middle-income countries) across all six World Health Organization (WHO) regions





Figure 1. The six WHO regions

<http://www.euro.who.int/en/about-us/governance/who-regions>

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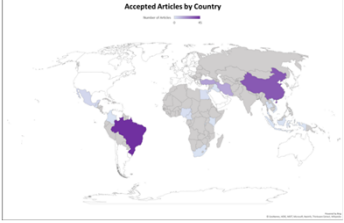
Pediatric Oncology Nursing Research

- Nursing research evidence presented
- Informs personalized and precision health in L&MIC
- To ensure care is culturally acceptable and considers...
 - Environment
 - Nursing practice
 - Nursing science
 - Family
 - Lifestyle behaviors
- Response to disease and treatment of this large patient population



The world map, based on population levels of children (14 years and younger).

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Languages and numbers of initially identified studies

Language	# of records	Included
Arabic	809	0
French	1246	0
Persian	1	1
Spanish	1718	5
Chinese	414	25
Portuguese	85	25
English	1407	81
Total	5680	137

Total # of included studies

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What did we find in the 137 articles?

- **Descriptive**
 - Parent/caregiver experience
 - Traditional/complementary medicine
 - Symptoms
 - Child experience
 - Nutrition
- **Instrument development (12)**
 - Nursing workload
 - Fatigue in children
 - Infection risk for children
- **Nursing Practice**
 - Palliative care
 - Staff perceptions of children's fatigue
 - Lived experiences of undergraduate nurses' rotation in pediatric oncology
 - Children's cancer-related fatigue
 - Nurses' knowledge & handling of chemotherapy
- **Intervention**
 - Spiritual program for parents
 - Massage therapy for patients
 - Caregiver support
 - Parent/caregiver education
 - Music therapy for children getting LPs
- **Literature Reviews**
 - Distraction for pain control
 - Nursing care
 - Nursing stress and burnout
 - QoL for patients including adolescents
 - Fatigue
 - Palliative care
 - Theses and dissertations
 - Traditional/complementary medicine
 - Children's lived experiences
 - Symptoms during treatment

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Johns Hopkins Nursing Evidence-Based Practice Research Evidence Appraisal Ranking

Strength of evidence

- 99/137 studies were level III
 - quantitative non-experimental design
 - systematic review of any study design

Evidence

- Strong - RCT* or meta-analysis of RCT
- Quasi-experimental
- Non-experimental, qualitative, or meta-synthesis
- Expert opinion
- Literature reviews

*randomized controlled trial

Quality

- 10 studies were *high* quality = A
- 105 studies were *good* quality = B
- 22 studies were *low* quality = C

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Top 5 topics researched in L&MIC compared to high-income countries (HIC) and those found only in HIC publications (2008-2018)

JOPON Journal of Pediatric Oncology Nursing; CN Cancer Nursing; EJON European Journal of Oncology Nursing
APJON Asian-Pacific Journal of Oncology Nursing

Top 5 most frequent topics addressed in both L&MIC and HIC studies						Top 5 topics addressed in HIC studies but NOT in L&MIC studies					
	JOPON	CN	EJON	APJON	Sub-total		JOPON	CN	EJON	APJON	Sub-total
Nursing practice	28		6	1	35	Brain tumors	16		1		17
Survivors	21	4	2		27	Sickle Cell Disease	9				9
Parent/ mother /grandparent experience	18	2	3	1	24	Siblings	8	1			9
Adolescents/ young adults	13	1	1		15	Bone Marrow Transplant /Stem Cell Transplant	6	1	3		9
Parent/ patient/ family education	10	1			11	Clinical trial	5	1			6

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Strengths

- Doing research with no funding
- Large number of publications
- Collaboration between academic and clinical nurses
- Availability of large samples of children and adolescents

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Areas for improvement

- Most studies were descriptive
- Vague recommendations for future studies
- Lack of research from Asia and Africa
 - e.g., Philippines, India, Pakistan, Thailand
- Substantial number of articles available only in non-English languages
 - Chinese and Portuguese
- Most published in closed-access journals thus limiting access

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Precision Health

L&MIC nursing research presented here is establishing the beginning database for precision health approaches in the future in these settings



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Topics of L&MIC Nursing Research

- Child, parent & guardian experiences during treatment
- Symptoms, such as, pain & fatigue
- Traditional & complementary medicine
- Psychometric testing of instruments to measure coping & quality of life in local languages & in culturally appropriate ways
- Intervention studies, particularly from the Middle Eastern Region, China & Brazil

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Support to Disseminate and Share L&MIC Pediatric Oncology Nursing Research Findings

We call upon the international pediatric oncology nursing community as well as our physician colleagues and other stakeholders to increase their support of pediatric oncology nursing research dissemination

- *In open access journals*
- *International conference presentations*
- *Cross-border nursing & multidisciplinary research collaboration*

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Implementing Research in Practice



Dr. Lauri Linder

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Implementing research findings into practice

Where do we go from here?

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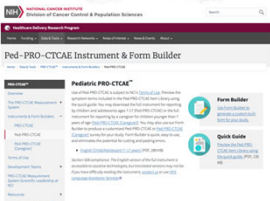
Cross-cutting themes across pediatric oncology nursing science

- Recognition of the **individual child**
- Recognition of **each family as distinct**
- Incorporation of **cultural values and preferences** into the plan of care
- **Optimizing the care environment** through family-centered care, education, and clear communication
- Attention to **assessment** and utilization of available **validated resources** to guide assessment

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What is being implemented into practice ...

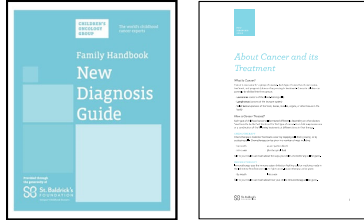
Pediatric patient reported outcome measures -- resources to support children's self report of the impact of cancer treatment



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What is being implemented into practice ...

Patient and family education – providing essential content as part of the initial education of patients & families at the time of diagnosis



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What is being implemented into practice ...

Technology to support education – consider best practices for teaching and learning as well as benefits in achieving the objectives of the activity



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Advancing nursing science
Taking our next steps together ...

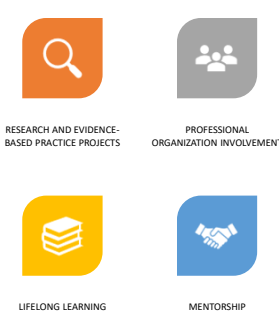
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**Directions for future research:
Cross-cutting themes**

- **Longitudinal** study designs
- Study **methods** that support inclusion of underrepresented groups
- **Biologic mechanisms** underlying symptoms and late effects of treatment
- **Implementation** and **intervention** studies that measure **outcomes**
- **Environmental factors** influencing the health of the child and family
- Needs of the **healthcare team**
- Advancement of **global healthcare** for children with cancer

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Taking our next steps ...



RESEARCH AND EVIDENCE-BASED PRACTICE PROJECTS PROFESSIONAL ORGANIZATION INVOLVEMENT

LIFELONG LEARNING MENTORSHIP

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2020
INTERNATIONAL YEAR
OF THE NURSE AND
THE MIDWIFE

Thanks to all the nurses who investigate children and adolescents with cancer and their families **and** nurses who care for them

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