

**NATIONAL INSTITUTES OF HEALTH  
NATIONAL INSTITUTE OF NURSING RESEARCH  
OFFICE OF THE DIRECTOR/OFFICE OF RARE DISEASES**

**Working Group  
Moving the Research Agenda Forward for Children With Cancer  
August 5-6, 2003  
Four Points Sheraton  
Bethesda, Maryland**

**Executive Summary**

The National Institute of Nursing Research (NINR) and the Office of the Director/Office of Rare Diseases (ORD) at the National Institutes of Health (NIH) convened the workshop "Moving the Research Agenda Forward For Children With Cancer" on August 5-6, 2003 in Bethesda, Maryland.

**BACKGROUND**

There have been great advances in pediatric cancer in the past 25 years. Collaborative, multi-center research has transformed cancer in children from an almost universally fatal disease to one that is curable in greater than 75% of the patients. However, much more can be done. Even though pediatric cancer is considered a rare disease, extrapolating from approximately 8,600 cases in 2000, it is estimated that there will be 9,000 cases in 2003. In order to meet the needs of these children and their families, the focus of research in pediatric cancer should be broadened from the disease to a focus on the child.

This workshop brought together experts from many diverse fields such as nursing science, pediatric oncology, psychology, medical anthropology, and communication sciences among others. These experts discussed issues related to diagnosis, treatment, quality of life, survivorship, relapse and end of life care in order to develop and move the research agenda forward for children with cancer in the 21<sup>st</sup> century.

**I. WELCOME**

Dr. Patricia Grady, PhD, RN, FAAN, Director of the National Institute of Nursing Research (NINR), welcomed participants on behalf of the Institute and workshop Co-Chairs, Martha Hare, PhD, RN and Pamela Hinds, PhD, RN. Pediatric cancer research is important and relates to several of NINR's Areas of Opportunity for 2004 including chronic disease and self-management. Dr. Hare then articulated the purpose of the workshop: *to identify theoretical and methodological challenges of a research agenda that examines the interaction of psychosocial, behavioral, cultural and biological issues in order to ensure the best possible life course for children with cancer.*

**II. OVERVIEW**

The **objectives** of the workshop were to:

- Highlight key findings from biobehavioral and sociocultural research in pediatric cancer including the impact of the findings on current practice
- Identify gaps in biobehavioral and sociocultural research in pediatric cancer
- Consider appropriate strategies and methods for addressing gaps in the current research in pediatric cancer, particularly research on biobehavioral and/or sociocultural issues

In order to meet these objectives, the workshop was organized into the following topics:

- Current state of research
- Issues in symptom management and quality of life during treatment

- The child as a member of a family and community
- Surviving childhood cancer
- Relapse and end-of-life care
- Moving the research agenda forward

Papers were presented in each of these areas and were followed by group discussions.

### **III. DISCUSSION**

There was consensus among participants that biobehavioral and sociocultural aspects of the pediatric cancer experience are understudied areas. Despite great advances, cancer is the leading cause of death, from disease, in children outside of the immediate newborn period. Therefore, it is understandable that research has focused more on survival and cure than on the biobehavioral/sociocultural issues faced by pediatric cancer patients. A paradigm shift may be necessary to view the whole life course as a continuum. As one presenter put it, "There is no such thing as 'after the cancer experience.' Once someone has cancer, he/she has it forever." In this paradigm, survivorship is a crucial area for further study, and for those who are not long-term survivors, dying may be viewed as living with an incurable disease. The needs of families – many of whom are young families – who go on living after the loss of a child should be considered.

Conceptual models were presented. Although the models dealt with different phases in the cancer trajectory, they all included a large number of interactive variables. While variables specific to genetic and biological make-up, treatment, quality of life, and cost were included with different degrees of emphasis, a take-home message was that interactions and effects at the level of the whole person, family and society require study.

Intervention studies are needed. The timing and location of such studies is an issue that warrants discussion. In general, it was agreed that multi-institutional studies of behavior and health-related quality of life (HRQOL) are needed in the same way as they are for biomedical interventions. However, before large-scale studies are fielded, feasibility /pilot studies in a limited number of, or single, institutions are needed in this developing area of science.

Although the multidisciplinary approach has been used in intervention studies, training and education geared toward a truly interdisciplinary research endeavor are necessary in order to address the complexity of the concerns currently being raised. These include such areas as: genetic issues in the prevention and treatment of childhood cancer; late effects years after the conclusion of cancer treatment; the impact of childhood cancer on family dynamics and functioning; the impact of social, behavioral and family outcomes on the child's maturation and development as an adult; and the relational nature of caring, especially at the end-of-life. At an even higher level of abstraction, interdisciplinary research is needed to address the interaction of therapy with the patient's genetic and social environments. The areas that workshop participants discussed in detail are presented below.

#### *Areas for Interdisciplinary Research*

While there have been a number of studies in the area of symptom management and HRQOL, there is much more to do. For more effective interventions to be developed, researchers need to elucidate the process that results in a good outcome. Symptoms are experienced as clusters although they are usually studied individually. It is not known which symptoms are most distressing to children, their families or to healthcare providers. This is an important area of research for the dying child and for the child on

active treatment where the goal is a cure. Other methodological and logistical issues in health-related quality of life (HRQL) research are linked to differences in interpreting data and the definition of the term. Furthermore, if knowledge is to be translated into practice, such knowledge needs to be linked to efforts to change policies at the level of individual institutions, insurers, and state and federal government.

*Research questions concerning symptom management and HRQOL include:*

- ❖ Which interventions work best with which children? Consider age, ethnicity, family dynamics, language.
- ❖ What promotes adherence to treatment when the child is at home?
- ❖ What is an appropriate definition of HRQOL for the pediatric population?
- ❖ Do we need different instruments or have we reached saturation for measuring HRQOL in this population?
- ❖ Is it feasible to add biological markers to assessments of HRQOL?

Family interventions need to be brief and evidence-based. To date, interventions with highly specified goals and outcomes appear more successful than general approaches. Family-based assessments should consider nuances of language and culture. All family intervention studies need good process components as part of the research design so that the interventions can be replicated if successful.

Little is known about the perspective of adolescents/young adults (AYA) who fall into a gap in research between the child and the adult. There is less improvement in outcomes relative to younger and older patients. Furthermore, the patient may be treated either in a pediatric unit or in an adult unit. If the young person is treated in an adult unit, symptom management may be extrapolated from adult data, for example, patients may receive more medication if treated as an adult, but more distractions if treated as a child.

*Research questions concerning family and developmental issues include:*

- ❖ What factors need to be considered in developing appropriate family interventions; e.g., age, ethnicity, race, socioeconomic status, primary language?
- ❖ How can all family members best be reached? What are the best ways of reaching fathers, siblings, extended kin or non-traditional caretakers? Again, consider a variety of psychosocial, cultural and economic variables.
- ❖ Why don't AYAs experience progress in long-term survival similar to children or even older adults?
- ❖ What are age-appropriate biobehavioral and psychosocial interventions for AYA's?

Research is greatly needed on the survivorship experience. Although the body of evidence is growing, more needs to be known about their quality of life and how survivors do or do not integrate into society. One possible approach to researching this concern is to stratify prognostic factors looking at the type of cancer, method and intensity of treatment, age at diagnosis, gender, ethnographic and socioeconomic factors. We know that cancer treatments can make patients more susceptible to obesity, second malignant neoplasms, special education needs and other problems. Factors that contribute to cancer-related morbidity include host factors, pre-morbid conditions, genetic factors, tumor factors, treatment factors, aging and health behaviors. Even those survivors who are enjoying good health may face a many of issues. Survivors of pediatric cancer sometimes feel abandoned after leaving the cancer clinic since most of the health care professionals that now care for them see very few survivors of pediatric cancer and are not aware of the issues they face. The AYA cancer survivor is particularly "invisible," as one presenter noted, in current research. There is a lack of support from the healthcare system for specialized survivor care and long-term follow-up programs – moving from adolescence through adult life. This is a key area for study and intervention.

*Research questions on the survivorship experience include:*

- ❖ What is the relationship between type of treatment and later risks for morbidity (physical or psychosocial)?
- ❖ What factors promote beneficial health behaviors as the survivor of pediatric cancer moves through adolescence and into adulthood?
- ❖ What is the relationship of social support to resilience in this population?
- ❖ Can density of support be defined? Which groups or individuals need more support than others? What types of support are effective in promoting a positive psychosocial adjustment during and after treatment?

The trajectories of dying and models of care for patients, parents, siblings and healthcare providers at the end-of-life are not known. Areas of research could include end-of-life treatment decision-making; the epidemiology of dying in children/adolescents; the experience of surviving the death of a child; the cost of dying and the impact of cost factors on policy making; and outcomes of symptom interventions. One presenter pointed out that, if healthcare providers can't diagnose dying, then they are unable to link the patient to the appropriate model of care delivery. Another presenter shared a paradigm based on the nature of the suffering that results from a threat to one's relationship with the physical and psychological self, family, community and others and with a transcendental source of meaning. A complete response to suffering demands a renewed vision of medicine and a reshaped model of care. The processes of the spiritual experience are complex and poorly understood and need to be conceptualized. Research is needed on how society faces mortality and how that perspective influences social relationships within society. Process mapping may be a useful methodology for looking at the value of care and its impact on patients, families and providers. In fact, providers are an under-researched group resulting in a lack of data on the survivorship experience of compassionate caregivers, either informal caregivers or professional providers.

*Research questions in end-of-life care include:*

- ❖ What is the process by which perceptions of the trajectories of dying differ among patients, families and healthcare providers?
- ❖ How does social integration influence the experience of suffering, death and bereavement?
- ❖ How does the perceived availability of a supportive social network help parents care for their child?
- ❖ Which social support functions are most effective at different points in the disease trajectory? Who should provide them?
- ❖ What characteristics of recipients lead to the demand for different support functions?
- ❖ What are processes that link social and spiritual support to physical and psychological health?

*Moving the Research Agenda Forward*

Workshop participants agreed that an interdisciplinary approach -- perhaps embracing new models of research design -- to biobehavioral and sociocultural issues in pediatric cancer would be fruitful. Gaps in biobehavioral and sociocultural research mean that there are gaps in the care being delivered to patients and their families. Participants agreed that a research agenda examining the interaction of psychosocial, behavioral, cultural and biological issues in children with cancer must consist of a number of components that may pose challenges. The table below summarizes key areas for future research suggested by workshop participants, theoretical and methodological challenges, and possible approaches or solutions for meeting those challenges. It should be noted that the challenges and solutions may overlap several areas for future research; i.e., there is not a one-to-one correspondence between a research area, challenge or approach.

<i>Key Areas for Future Research</i>	<i>Theoretical and Methodological Challenges</i>	<i>Approaches for Meeting Challenges</i>
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<ul style="list-style-type: none"> <li>- Identification of symptom clusters and management of symptoms.</li> <li>- Quality of life during and after treatment.</li> <li>- Social, behavioral and family consequences of survivorship (e.g., special education, survivor guilt, social integration, resilience).</li> <li>- Intervention studies (including biologic mechanisms of action at work in effective behavioral interventions).</li> <li>- Prevention/amelioration of late effects and risk taking behaviors.</li> <li>- Factors related to end-of-life decision-making and care.</li> <li>- Family dynamics and coping (including gender and cultural differences).</li> <li>- Developmental/maturational issues.</li> </ul>	<ul style="list-style-type: none"> <li>- Concept and theory development to frame research.</li> <li>- Appropriate measures for different age groups, cultures and ethnic groups.</li> <li>- Maintaining cohorts in longitudinal study designs.</li> <li>- Understanding mechanisms of action of specific interventions</li> <li>- Research with diverse study populations - cultural sensitivity vs. generalizability .</li> <li>- Integration of biological and behavioral variables within the same studies.</li> <li>- Lack of reimbursement from third party payers for biobehavioral/ psychosocial research interventions.</li> </ul>	<ul style="list-style-type: none"> <li>- Build interdisciplinary teams across clinical settings.</li> <li>- Interdisciplinary education including training in diverse fields for the same individual.</li> <li>- Integrate health-related quality of life (HRQOL) variables within Children's Oncology Group (COG) clinical trials.</li> <li>- Pursue questions related to behavioral and psychosocial issues by utilizing databases and cohorts from the Childhood Cancer Survivor Study (CCSS).</li> <li>- Integrate qualitative and quantitative methodologies throughout the research program.</li> <li>- Study communication issues within and across organizational, professional, and ethnic cultures.</li> </ul>
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#### **IV. CONCLUSION**

This workshop provided a unique and exciting opportunity for researchers from many diverse disciplines to formulate a research agenda to study the interaction of psychosocial, behavioral, cultural and biological issues for children with cancer. Participants agreed that new theoretical frameworks and conceptual models in longitudinal study designs are needed to meet this challenge. The voice of the child has not been heard to date and is critical. Next steps include identifying areas of scientific priority, fostering collaborative interventions and identifying funding mechanisms. This is an important area of study and one that fits with NINR's Areas of Opportunity for 2004.

#### **ATTACHMENTS**

1. Agenda
2. List of participants



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Moving the Research Agenda Forward for  
Children with Cancer

***National Institutes of Health***  
**National Institute of Nursing Research**  
**and**  
**Office of Director/Office of Rare Diseases**

**Four Points Sheraton Bethesda**  
**Ambassador II Room**  
**August 5-6, 2003**

August 5, 2003

8:15 am – 8:45 am Moderator's Meeting

8:45 am – 9:15 am Light Refreshments and Registration

9:15 – 9:30 am

***Welcome***

Dr. Patricia Grady  
Director, National Institute of Nursing Research  
(NINR)

9:30 – 9:40 am

***Purpose of the Workshop and Charge to the Group***

Drs. Martha Hare & Pamela Hinds

**Current State of Research**

**Moderator: Pamela Hinds, Ph.D., R.N., St. Jude Children's Research Hospital**

9:40 - 10:40 am

***Advancing the Research Agenda for Childhood Cancer***

- Ida (Ki) Moore, Ph.D., R.N., University of Arizona

***Success Through Collaboration & Expanded Discipline Needs for Future***

- Gregory Reaman, M.D., Children's Oncology Group

*Moderated Discussion*

10:40 – 10:50 am

BREAK

Issues in Symptom Management and Quality of Life During Treatment

Moderator: Janet Stewart, Ph.D., R.N., University of Pittsburgh

10:50-12:15

***Symptom Management Research in Children with Cancer***

- Marilyn Hockenberry, Ph.D., R.N. Baylor College of Medicine  
***Cancer Care Communication – Cross-Cultural Challenges***

- Elisa Sobó, Ph.D., Children's Hospital of San Diego  
*Health-Related Quality of Life in Pediatric Oncology*

- **Andrew (Drew) Bradlyn, Ph.D., University of West Virginia**  
*Moderated Discussion*

***12:15 – 1:30 PMLUNCH***

The Child as a Member of a Family and Community

Moderator: Janice Phillips, Ph.D, R.N., NIH/NINR

1:30 pm – 3:30 pm

***Family Assessment and Intervention***

- Anne Kazak, Ph.D., Children's Hospital of Philadelphia

***Sources of Stress and Concern of Latino Children and Their Parents***

- Frances Munet-Vilaro, Ph.D., R.N., University of Washington

***The Adolescent/Young Adult Experience –***

- Joan Haase, Ph.D., R.N., Indiana University-Purdue

***Integrating the Child into Home and Community***

- Michael Harris, M.D., Tomorrow's Children's Institute, Hackensack, New Jersey  
*Moderated Discussion*

3:30 – 3:45 pm

BREAK

**Summary and Discussion of Day One**

**Moderators: Drs. Martha Hare and Pamela Hinds**

3:45 – 4:15 pm

- What are the areas of progress?
- What are the opportunities for research?
- What are the challenges?
- How can the challenges to research be met so the opportunities can be developed?

Good Evening

4:15 – 4:30 pm

Final Comments, suggestions for dinner and housekeeping items

Wednesday, August 6, 2003

8:30 – 8:50 am            Light Refreshments

8:50 -9:00 am            **Welcome Back**  
Drs. Martha Hare & Pamela Hinds

**The Long View- Surviving Childhood Cancer**

*Moderator: Claudette Varricchio, D.S.N., R.N., NIH/NINR*

9:00- 10:20 am

***What do CCSS Study Data Tell us About Long-Term Outcomes?***

- Malcolm Smith, M.D., NIH/NCI

***A Model for Monitoring Late Effects After Childhood Cancer***

- Melissa Hudson, M.D., St. Jude Children's Research Hospital

*Moderated Discussion*

10:20 – 10:30 am        BREAK

Relapse and End-of-Life Care

*Moderator: Yvonne Bryan, Ph.D., R.N., NIH/NINR*

10:30 – 11:40 am

***End-of-Life Research in Pediatric Cancer***

- Pamela Hinds, Ph.D., R.N., St. Jude Children's Research Hospital

***Alleviating Suffering***

- Javier Kane, M.D., University of Texas Health Sciences Center

*Moderated Discussion*

Moving the Research Agenda Forward

**Moderators: Drs. Martha Hare and Pamela Hinds**

11:40 am – 12:15 pm Discussion – Audience and Panelists

*For Day 2:*

- What are the areas of progress?
- What are the opportunities for research?
- What are the challenges?
- How can the challenges to research be met so the opportunities can be developed?

For both days:

- How can the identified areas of priority be incorporated into a research agenda for children with cancer and their families in the early 21<sup>st</sup> century?
- How can emerging areas of interest be facilitated?
- How can methodological issues to the emerging research agenda be met?
- How can barriers to high quality research be overcome?

12:15 - 12:30 PM

***Thank You and Farewell***



Moving the Research Agenda Forward for  
Children with Cancer  
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