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Patient/Family Education as Translational Science in Pediatric Oncology

Marilyn Hockenberry, PhD, RN, PPCNP-BC, FAAN and Wendy Landier, PhD, RN, CPNP, CPON

This special edition of *JOPON* brings together the culmination of two years of work within the Children's Oncology Group (COG) Nursing Discipline to address patient/family education needs for newly diagnosed pediatric oncology patients. This attention is timely, because there is currently a lack of evidence-based guidelines to direct standardization of informational content and to identify effective methods of providing patient/family education for newly diagnosed pediatric oncology patients. As a result, there is considerable variability in patient/family educational practices across institutions. This is of particular concern for COG, because the quality of education provided to parents/caregivers of children enrolled on pediatric oncology clinical trials has the potential to significantly influence outcomes for individual patients, as well as overall trial results.

Recognizing the knowledge gap regarding best practices, the COG Nursing Discipline identified patient/family education as a high-priority aim for nursing research. In October 2015, a State of the Science Symposium (R13CA196165-Landier/Hockenberry) facilitated the development of expert consensus regarding the essential components of education necessary to adequately prepare parents/caregivers of newly diagnosed patients for a safe discharge home. This consensus conference, "*Patient/Family Education in Pediatric Oncology: State of the Science Symposium*" was attended by 150 interprofessional participants representing 91 COG institutions; registration was limited to allow for strategic interactions between invited experts and participants. Experts from pediatric subspecialties beyond oncology (i.e., type 1 diabetes, premature newborns) who had successfully executed patient/family education programs, specialists in discharge readiness from pediatric acute care, and key stakeholders and interprofessional experts from within pediatric oncology attended the Symposium and played key roles in building expert consensus regarding potentially better practices in patient/family education in pediatric oncology.

The State of the Science Symposium built upon four important research studies conducted by nurses within the COG Nursing Discipline, the results of which are included in this edition of the *Journal*:

- Systematic literature review that identifies available evidence to support the effective delivery of patient/family education
- Delphi research study that ascertains consensus regarding key informational content necessary to adequately prepare parents/caregivers for a safe discharge home following their child's cancer diagnosis

- Comprehensive survey of over 200 COG institutions that characterizes current patient/family education practices
- Qualitative study that describes parental perspectives regarding knowledge acquisition following the diagnosis of cancer in a child

Additionally, this special issue of *JOPON* concludes with a final paper that summarizes the stimulating dialogue, discussion, and expert consensus-building that occurred at the Symposium as a result of the COG initiative aimed at improving patient/family education for newly diagnosed pediatric oncology patients.

In his remarks at the State of the Science Symposium, Dr. Peter Adamson, Chair of the Children's Oncology Group, observed: "We talk about clinical translational research, and in the COG we are very much on the forefront of translating advances made in the laboratory into the clinic...But translational research is much broader than that. If we don't find ways to inform our patients and families of the important aspects of their care, of their treatment, of their follow-up, then we are not going to succeed. The best science in the world is going to come to a screeching halt if we don't improve how we interface with our patients and families, how we educate them. So this is actually part of translational research and very well recognized as a critical component of what we do...And if we don't do that successfully, ultimately we are not going to improve the outcomes for our children."

In this time when scientific discoveries are rapidly changing pediatric oncology practice and therapies are becoming ever more complex, it is even more important to focus on patient/family education, so that our patients and their families receive the information that they need in a way that allows them to fully understand and successfully participate in their treatment.