

Partnering with Families to Validate Questionnaires Assessing Unmet Needs of Children, Adolescents, and Parents/Caregivers at the End of Active Cancer Treatment

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Purpose: Transitioning off active cancer treatment is a momentous occasion for pediatric patients and their family; however, it also brings anxiety and fear. These worrisome emotions suggest unmet psychosocial needs, and potential gaps in services provided at the end of active treatment. After examining this population's needs and responses to the process of transitioning off active cancer treatment, the hematology/oncology nursing research workforce group wished to determine if the current practices at our institution are meeting the needs of our patients and parents/caregivers.

Research Question: How do we determine if current services are meeting the needs of children, adolescents, and parents/caregivers during the transition period at the end of active cancer treatment?

Synthesis of ROL: The experiences and needs of pediatric patients and their parents at the end of active treatment are reported in the literature, but most are descriptive studies with small sample sizes, restricting generalizability of results. Additionally, there is limited research evaluating existing programs/services currently provided at this period of transition. The "Coming off Treatment (COT)" questionnaire was developed to assess issues important to families of children completing cancer therapy. Although this survey has been utilized in two studies to date, no psychometric information based on the COT has been published. The lack of validated tools to assess services and determine unmet needs prompted the nursing research workgroup to collaborate with our Oncology Family Advisory Board (FAB) to validate 2 questionnaires adapted from the COT for use with our study populations.

Procedures: By utilizing the FAB as experiential experts, we validated the adapted COT questionnaire for parents/caregivers and for children/adolescents between the ages of 8 and 21 years. First, the FAB viewed the adapted questionnaires online, examining each item for relevance and suggested modifications. This was followed by a focus group session to discuss and rate the relevance of each questionnaire item. Items and formatting of the questionnaires were eliminated, maintained, or revised based on participants' ratings.

Results: Six FAB members participated in this two-step process. Their relevance ratings established face and content validity of each questionnaire. These questionnaires will be used to assess current services and identify unmet needs of children with cancer and their parents/caregivers at the end of active treatment.

Discussion: We are replicating this two-step process to determine validity of a questionnaire for health care professionals. It is our hope that these questionnaires will be used to guide the development of more comprehensive end of treatment services. Further, instrument utilization will determine reliability, and ensure the integrity and relevance of future studies.

