

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

Introduction: Transitioning off cancer treatment is a momentous occasion for pediatric patients and their family, but also brings anxiety and fear, suggesting unmet needs/gaps in services provided at the end of treatment. After examining the process of transitioning off 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 their parents/caregivers.

Identification of the Problem: The experience and needs of pediatric patients and their parents/caregivers at the end of treatment, as reported in the literature, are predominantly descriptive studies with small sample sizes, restricting generalizability of results. Additionally, there is limited research evaluating existing programs and services at the end of treatment. The “Coming off Treatment” questionnaire (COT) (Nagel, et al., 2002) was developed to assess issues important to parents 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.

Purpose:

- a. To adapt the COT into End of Treatment (EOT) questionnaires for both children with cancer and their parents/caregivers.
- b. To validate these EOT questionnaires

Methodology: Oncology Family Advisory Board (FAB) members participated in a two-step process. First, the FAB viewed the adapted questionnaires online, examining each item for relevance and suggested modifications. This was followed by in-person focus group sessions to discuss and rate the relevance of each questionnaire item. Items of the questionnaires were eliminated, maintained, or revised based on participants’ ratings.

Results: By utilizing the FAB as experiential experts, we developed and validated three EOT questionnaires: for children, adolescents, and parents/caregivers. Their relevance ratings established face and content validity for each questionnaire.

Conclusion/Discussion: Validated EOT questionnaires will be used to identify unmet needs of children with cancer and their parents/caregivers at the end of treatment.

Implications for Practice and Research: We are currently replicating this two-step validation process to determine validity of an EOT questionnaire for health care professionals. It is our hope that these questionnaires will be used to determine and guide the development of more comprehensive end of treatment services.