

Parents' Experiences in Phase I Pediatric Oncology Trials

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Dates of Support: 04/01/2016– 03/31/2017

Total Award Amount: \$2,500

**Funding Agency: Midwest Nursing Research Society (MNRS)
(0670-000517)**

Abstract:

Rationale: Children with cancer are only enrolled in a phase I clinical trial (P1T) when their cancer is incurable; the mean life expectancy of children enrolled in these trials is just five months. Although 75% of the children will die within a year, parents primarily enroll children based on hope of cure or prolonging life, though this does not reflect the purpose of P1Ts. Some experts suggest that P1Ts burden children with additional medical procedures and toxicities, and could limit palliation opportunities and disrupt the dying and bereavement processes. However, research has not been performed on the benefits or burdens of P1T participation for children or their families. **Purpose:** The purpose of this study is to identify the fundamental commonalities and meaning of P1T participation from the parent perspective. The specific aim is to develop a rich, in-depth, phenomenological description of parents' experiences of having a child with cancer participate in a P1T. **Methods:** Based on Colaizzi's method, an empirical phenomenological approach is planned. Using a broad data-generating question, parents will fully describe their experiences during unstructured interviews (approximately 60 minutes). For context, a demographic form will be completed and information regarding the P1T will be abstracted from clinical trial records. A follow-up call to each participant, 7 to 14 days after the interview, will assess for indications of undue interview-related distress and provide an opportunity for participants to share additional information. Following data analysis, experienced P1T clinicians will be contacted to ascertain the clinical transferability of the findings. **Implications:** The expected outcome is an in-depth description of parents' experiences during their child's participation in a P1T. This description will inform current practice, facilitate development of a conceptual framework, and guide future intervention research focused on enhancing child and parent experiences and well-being during their participation in a P1T.