

Parents' Experiences in Phase 1 Pediatric Oncology Clinical Trials

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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. Parents' other reasons for enrollment include ensuring continuity of care, maintaining quality of life, and altruism. 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. This study is the first step towards understanding the lived experience of pediatric oncology P1Ts.

Purpose / Specific Aims: 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. The research question is: What is the essence of the experience of being the parent of a child with cancer who participated in a P1T?

Design: Phenomenological research is used to describe the essence (i.e. the fundamental commonalities and meaning without which a phenomenon would not be what it is) of the lived experiences of people in similar life situations. Based on Colaizzi's method, an empirical phenomenological approach is planned to develop an in-depth description of parents' lived experiences.