

The Challenges of Conducting Research in Pediatric Palliative Care

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The difficulties facing researchers in pediatric palliative care are numerous, but they can be divided into those which relate to the methodology used and the ethics of conducting research in this area, and to the extent to which outcome measures used and results achieved could be useful for evaluation purposes.

In designing studies in pediatric palliative care, investigators have to deal in general with a number of issues. Attrition due to death, small numbers, problems with randomization, and difficulties of collecting data from terminally ill young children and their parents may contribute to some of the difficulties in conducting trials. One of the main ethical problems is the denial of a service or treatment to the control group. It is also difficult to avoid exposure of the control group to the experimental effect. Contamination and confounding, commonly encountered in palliative care research, could provide major threats to the validity of studies in this area. Factors related to diagnosis and age of the child as well as the perception of pain and other symptoms and ways of coping could confound the study results. Furthermore, the outcomes chosen for assessment may not be sensitive enough to capture the benefits of the service and the effectiveness of the treatment. Finally, the difficulties terminally ill children, parents, and caregivers may encounter in completing questionnaires may present another problem the researcher has to deal with in conducting such studies.

This presentation will give an overview of the challenges facing researchers in the field of pediatric palliative care. Emphasis will be placed on studies assessing the needs of children, parents, and caregivers for care provision. Evidence-based palliative care remains an important priority in this field. Research on effectiveness and efficiency of pediatric palliative care services warrants as a result more attention in the future. This lecture will end by making recommendations with regard to suitable evaluation methods in this patient population.