

Chemotherapy versus supportive care alone in pediatric palliative care for cancer: comparing the preferences of parents and health care professionals

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Reference: Tomlinson D, Bartels U, Gammon J, Hinds PS, Volpe J, Boufett E, Regier DA, Baruchel S, Greenberg M, Barrera M, Llewellyn-Thomas H, Sung L. *CMAJ* 2011. DOI:10.1503/cmaj.110392

Abstract:

Background: The choice between palliative chemotherapy (defined as the use of cytotoxic medications delivered intravenously for the purpose of our study) and supportive care alone is one of the most difficult decisions in pediatric oncology, yet little is known about the preferences of parents and health care professionals. We compared the strength of these preferences by considering children's quality of life and survival time as key attributes. In addition, we identified factors associated with the reported preferences.

Methods: We included parents of children whose cancer had no reasonable chance of being cured and health care professionals in pediatric oncology as participants in our study. We administered separate interviews to parents and to health care professionals. Visual analogue scales were shown to respondents to illustrate the anticipated level of the child's quality of life, the expected duration of survival and the probability of cure (shown only to health care professionals). Respondents were then asked which treatment option they would favour given these baseline attributes. In addition, respondents reported what factors might affect such a decision and ranked all factors identified in order of importance. The primary measure was the desirability score for supportive care alone relative to palliative chemotherapy, as obtained using the threshold technique.

Results: A total of 77 parents and 128 health care professionals participated in our study. Important factors influencing the decision between therapeutic options were child quality -of-life and survival time among both parents and health care professionals. Hope was particularly important to parents. Parents significantly favoured chemotherapy (42/77, 54.5%) compared with health care professionals (20/128, 15.6%; $p < 0.0001$). The opinions of the physician and child significantly influenced the parents' desire for supportive care; for health care professionals, the opinions of parents and children were significant factors influencing this decision.

Interpretation: Compared with health care professionals, parents more strongly favour aggressive treatment in the palliative phase and rank hope as a more important factor for making decisions about treatment. Understanding the differences between parents and health care professionals in the relative desirability of supportive care alone may aid in communication and improve end-of-life care for children with cancer.

Strengths:

- Case scenarios were standardized for medical and prognostic variables.
- Case scenarios were presented to parents and health care workers in a standardized manner (ie: scripted, by the same person)
- Interviewed parents and health care workers with experience in pediatric palliative care.

Weakness:

- Case scenarios were purely hypothetical. Parent and health care worker responses were hypothetical.
- Only considers one mode of palliative treatment.
- Doesn't give insight into the rationale for participants choices.
- Treats variables (ie: quality of life and length of survival) as independent of one another. This oversimplifies the complexity of parental and clinical decision making and limits the real world applicability of the findings.

Relevance to Palliative Care:

- Demonstrates significant differences in preference between parents and health care providers regarding pediatric end-of-life care
- Stresses the importance of patient/family centred care