

Publication

Palliative care in Swiss pediatric oncology settings: a retrospective analysis of medical records

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Purpose This study examined the provision of palliative care and related decision-making in Swiss pediatric oncology settings. The aim was to determine if and when children who died from cancer received palliative care, whether there were differences by cancer diagnosis, and inclusion of children in decision-making regarding palliative care. **Methods** Using a standardized data extraction form, a retrospective review of medical records of deceased pediatric patients was conducted. The form captured information on demographics, diagnosis, relapse(s), treatments, decision-making during palliative care, and circumstances surrounding a child's death. **Results** For 170 patients, there was information on whether the child received palliative care. Among those, 38 cases (22%) did not receive palliative care. For 16 patients, palliative care began at diagnosis. The mean duration of palliative care was 145 days (Mdn = 89.5, SD = 183.4). Decision to begin palliative care was discussed solely with parent(s) in 60.9% of the cases. In 39.1%, the child was involved. These children were 13.6 years of age (SD = 4.6), whereas those not included were 7.16 years old (SD = 3.9). Leukemia patients were less likely to receive palliative care than the overall sample, and patients with CNS neoplasms received palliative care for a longer time than other patients. **Conclusions** There are still high numbers of late or non-referrals, and even children older than 12 years were not involved in decision-making regarding palliative care. These results do not align with international organizational guidelines which recommend that palliative care should begin at diagnosis.

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