

STATUS QUO OF PAEDIATRIC PALLIATIVE CARE IN GERMANY. IMPLEMENTATION OF A NATION-WIDE STUDY.

Friedrichsdorf S, Wamsler C, Zernikow B
Vest Children's Hospital (Vestische Kinderklinik), Datteln, Germany

Background: More than 1.400 children with life-limiting diseases die in Germany every year, 540 of them due to cancer. No data is available about their end-of-life period. Aim: Describing the status quo of palliative care in children with cancer and collecting descriptive data about the end-of-life period in children with cancer and non-malignant diseases. Methods: We performed a structured interview about Paediatric Palliative Care (PPC) practice with all German paediatric cancer centres. Contact was established with consenting parents who lost a child with a life-limiting disease and a telephone survey was performed. Details about the preferred place of death, symptoms and suffering, hospital and home care were noted. Patients: All 76 paediatric cancer departments in Germany were contacted. Consenting parents who lost a child to cancer in 1999-2000 were interviewed, as well as parents who lost their child to a non-malignant disease at the Vest Children's Hospital in 1990-2000. Results: Only few cancer departments provide home care for dying children. Preliminary results show most families felt their medical care was good on the ward, but unsatisfactory at home. Almost all experienced unpleasant symptoms at some time in their terminal stages which were difficult to control. Pain and nausea and vomiting were the commonest symptoms. Discussion: Germany lacks PPC programmes. The majority of children with life-limiting diseases do not have access to home care. The provision of care seems to be better for children with cancer over those with non-malignant diseases. Conclusion: A nation-wide PPC programme has to be established.