

Publication

Access to specialized pediatric cancer care in Switzerland

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BACKGROUND: Specialized pediatric cancer centers (PCCs) are thought to be essential to obtain stateof-the-art care for children and adolescents. We determined the proportion of childhood cancer patients not treated in a PCC, and described their characteristics and place of treatment. PROCEDURE: The Swiss Childhood Cancer Registry (SCCR) registers all children treated in Swiss PCCs. The regional cancer registries (covering 14/26 cantons) register all cancer patients of a region. The children of the SCCR with data from 7 regions (11 cantons) were compared, using specialized software for record linkage. All children <16 years of age at diagnosis with primary malignant tumors, diagnosed between 1990 and 2004, and living in one of these regions were included in the analysis. RESULTS: 22.1% (238/1,077) of patients recorded in regional registries were not registered in the SCCR. Of these, 15.7% (169/1,077) had never been in a PCC while 6.4% (69/1,077) had been in a PCC but were not registered in the SCCR, due to incomplete data flow. In all diagnostic groups and in all age groups, a certain proportion of children was treated outside a PCC, but this proportion was largest in children suffering from malignant bone tumors/soft tissue sarcomas and from malignant epithelial neoplasms, and in older children. The proportion of patients treated in a PCC increased over the study period (P <0.0001). CONCLUSIONS: One in six childhood cancer patients in Switzerland was not treated in a PCC. Whether these patients have different treatment outcomes remained unclear

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