Danish Childhood Cancer Registry

Aim of database: The overall aim is to monitor the quality of childhood cancer care in Denmark; to register late effects of treatment; to analyze complications of permanent central venous catheters (CVCs); to study blood stream infections in children with cancer; and to study acute toxicity of high-dose methotrexate infusions in children with leukemia.

Study population: All children below 15 years of age at diagnosis living in Denmark diagnosed after January 1, 1985 according to the International Classification of Diseases 10, including diagnoses DC00–DD48.

Main variables: Cancer type, extent of disease, treatment, participation in international studies, recurrence of malignant disease, survival, yearly follow-up status, causes of death, and development of secondary malignancies. Type of CVC, causes for removal of the CVC, type of blood stream infection, pathogens isolated, antimicrobial sensitivity, and outcome of antimicrobial chemotherapy.

Descriptive data: Since 1985, 4,944 children below 15 years of age have been registered in the database. There has been no significant change in the incidence of childhood cancer in Denmark since 1985. The 5-year survival has increased significantly since 1985 and is now 86%. The median number of days from diagnosis to initiation of therapy is 7 days and in 80% of the children less than 14 days. Clinical data of 95% of the patients are reported to open international studies.

Conclusion: The survival of Danish children with cancer since 2003 compares favorably with other international population-based studies. The annual reports support the collaboration within pediatric oncology in Denmark.

Keywords: childhood cancer, epidemiology, survival, complications

Aim of the database
The Danish Childhood Cancer Registry (DCCR) is a nationwide clinical quality database whose aim is to report on the quality indicators outlined in Table 1 in all Danish children below 15 years of age at the time of cancer diagnosis. Overall survival and relapse-free survival are analyzed with respect to cancer type, extent of disease, treatment modalities, response to treatment, and recurrence of malignant disease. Since 2014 DCCR also serves as the basis for a national quality study of the use of central venous catheters (CVCs) and of the occurrence of blood stream infections in children with cancer. The aim of this part of the register is to study complications related to the use of CVCs, especially central line associated blood stream infection and mechanical complications (eg, thrombosis, leakage, accidental removal). The database reports on the quality indicators listed in Table 1.
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chemotherapeutic drugs the child has received, which may have implications for the risk of developing late effects of the treatment. All surgeries with the attempt of tumor removal are recorded, including the completeness of tumorectomy. For radiation therapy the total dose and the dates are registered, however data regarding the target or size of the field are not reported. The registered treatment data, which have been agreed upon by the regional pediatric oncology centers in Denmark, are >95% complete. Since it is a primary goal that all children should be treated according to the best international protocols and that clinical data should be reported where possible, it is also registered whether patient data have been reported to international studies. In total, 95% of Danish children with cancer are treated according to an international protocol. Data of 95% of those patients who are treated according to an open protocol are reported to ongoing international studies. This is another national quality indicator (see Table 1) by which the regional pediatric oncology centers in Denmark are evaluated.

Once a year the registrations in DCCR database are cross-checked with the Danish National Patient Registry to detect missing patients, and with the DCR in order to register secondary cancers which may have developed after the child has survived into adulthood. The lag time for identifying secondary cancers via the DCR is about 1 year. Furthermore, on a yearly basis all patients diagnosed after January 2003 are scrutinized for disease status including relapse and relapse therapy, deaths, and emigration (lost to follow-up) by medical record review and by cross-checking the Danish Civil Registration System.

Main results
Since 1985 4,944 children below 15 years of age have been registered in DCCR database. There has been no significant change in the incidence of childhood cancer in Denmark since 1985. The annual incidence varies between 15.5 and 22.2 cases per 100,000 children below 15 years of age (Figure 1). The recurrence-free 5-year survival for all cancers diagnosed between 2003 and 2014 was 74%, and the 5-year survival has increased significantly and steadily from 72% in 1985 to 86% in 2014. Three percent of all newly diagnosed children died from a treatment related cause, mostly children with leukemia and lymphoma. The median number of days from date of diagnosis to initiation of therapy was, in 2014, 7 days and in 80% of the children it was less than 14 days. Sixty-six secondary cancers have been registered in the population of 4,800 children below 15 years of age diagnosed between 1985 and 2014. Data regarding cancer types and survival are annually transferred electronically to the Nordic databases for leukemia, lymphoma, and solid tumors in Stockholm, Sweden. Relevant data are registered to Nordic and other international studies in 95% of children in which this registration is possible. The entire yearly report of DCCR is published on the homepage of the Danish Pediatric Hematology and Oncology (DAPHO) group. Data from DCCR have been outlined in the annual reports from 2008–2014.

Data from DCCR were important in the PhD thesis by Ahrensberg, describing the diagnostic delay from the first symptom to start of treatment in children with cancer in Denmark diagnosed between 2008 and 2012.

Also, data have been included in a Nordic study of the psycho-social effects of having had cancer during childhood.

Funding and administration
DCCR is funded by the Danish Regions and the annual report is coordinated through the organizational umbrella, the Danish Clinical Registries (RKKP). The Danish Childhood Cancer Foundation provides funding for research nurses at the four centers responsible for data collection and registration.

A DCCR database steering group has been appointed with regional representatives from the pediatric oncology centers at the four university hospitals in Denmark, and from the Department of Clinical Epidemiology, Aarhus University Hospital. The chairman of this group, together with the Department of Clinical Epidemiology will write the annual report which will be discussed in the steering committee before publication.

Conclusion
The survival of Danish children with cancer since 2003 compares favorably with other international population-based estimates. The annual reports are stimulating for the col-
laboration within the DAPHO group. The reports focus on areas where there is room for improvement, for example, in connection with the reporting of clinical data according to international clinical trials. Data from DCCR have formed the basis for a series of Danish pediatric oncology PhD studies. An overall survival rate reaching 86% in childhood cancer treatment demonstrates a need to further improve the monitoring of patients for the development of late complications of cancer therapy, including secondary cancers. DCCR has been further developed to allow for recording of late effect parameters related to the treatment given.

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Disclosure
The authors have no conflicts of interest to disclose in this work.

References