Childhood cancer and school

AKADEMISK AVHANDLING
som för avläggande av medicine doktorsexamen vid Karolinska
Institutet offentligen försvaras i Scandiasalen, Karolinska
Universitetssjukhuset, Solna

Fredagen den 11 november, 2011, kl 09.00

av
Margareta af Sandeberg
Legitimerad sjuksköterska, MSc

Huvudhandledare: Docent Lena Wettergren
Karolinska Institutet
Institutionen för neurobiologi, vårdvetenskap och samhälle
Sektionen för omvårdnad

Bihandledare: Docent Eva Johansson
Karolinska Institutet
Institutionen för medicin

Professor Olle Björk
Karolinska Institutet
Institutionen för kvinnors och barns hälsa
Barncancerforskningsenheten

Fakultetsopponent: Docent Annika Lindahl Norberg
Karolinska Institutet
Institutionen för kvinnors och barns hälsa
Uppsala Universitet
Institutionen för folkhäls- och vårdvetenskap

Betygsnämnd: Professor Marianne Carlsson
Uppsala Universitet
Institutionen för för folkhäls- och vårdvetenskap

Professor Pernilla Lagergren
Karolinska Institutet
Institutionen för molekylär medicin och kirurgi

Docent Ingrid Øra
Lunds Universitet
Institutionen för kliniska vetenskaper

Stockholm 2007
ABSTRACT

The school situation is one area identified as being affected during and after treatment for childhood cancer and only studied to a limited extent. A contributing factor to that school absence is not always recommended is uncertainty about whether it increases the risk of infection. Furthermore, there is a lack of valid instruments for the measurement of HRQOL in this population. The overall aim of this thesis was therefore to investigate the school situation and HRQOL of school-aged children (7-16 years) during initial cancer treatment and 4 to 6 years after diagnosis.

The thesis includes four studies with a longitudinal design following a cohort of school-aged children (n=126) diagnosed with cancer and starting chemotherapy and/or radiation therapy, response rate 87%. Data during initial cancer treatment were collected one month (T1), 2.5 months (T2) and 5 months (T3) after the start of initial treatment using a study-specific questionnaire to examine school attendance and a standardized instrument for the measurement of HRQOL: the Disabkids chronic generic module (DCGM-37). Study I reports on data quality and psychometric properties of the DCGM-37. Study II followed school attendance and HRQOL over three different weeks during the first 5 months of cancer treatment. Study III included children who were free from infection the day before the start of two observation periods (19 days) during initial cancer treatment. Demographic and clinical data as well as school attendance were analysed regarding the association to the start of antimicrobial treatment. A median of 5 years after diagnosis 63 of the former patients agreed to participate in a follow-up study of school situation and self-rated independence in survivors of childhood cancer (study IV). In study IV data were collected using telephone interviews with open-ended and structured questions. The survivors’ responses from the structured questions were compared with those from age-matched comparison group drawn from the general population (n=257).

The evaluation of data quality and psychometric properties of the DCGM-37 (study I) indicates that it is a feasible instrument for children with cancer though dimensionality was not entirely supported. Furthermore, the results of study II-III revealed that school attendance significantly increased over the first 5 months of initial cancer treatment while self-reported HRQOL diminished, especially among the girls, which did not change throughout the first five months of treatment. Furthermore, HRQOL was positively related to school attendance. Hospital visits and fatigue were the two most common given reasons for school absence. Children who attended school did not appear to develop more infections than children not attending school. The results of study IV, conducted a median of 5 years after diagnosis, showed that despite that 62% of the survivors considered their school situation to be more or less the same as their peers’ situation, a significant proportion reported difficulties in school because of physical and cognitive limitations. At follow-up, the survivors scored significantly higher on the independence dimension (i.e. on HRQOL) than they did during initial treatment and their scores were significantly higher than the controls.

The present findings underscore the importance of psychosocial care and nursing for children undergoing cancer treatment and continued follow-up of survivors after completion of treatment. Furthermore, given the social benefits of school attendance, our results support the encouragement of school attendance during cancer treatment. Because of the relatively short time of the follow-up, it is not possible to draw conclusions about long-term outcome of the school situation for children with cancer.

Keywords: childhood cancer, health-related quality of life, school, antimicrobial treatment, survivorship