

## Publication

### Burden of treatment in the face of childhood cancer: A quantitative study using medical records of deceased children

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Lived experiences of childhood cancer patients and their families have been described as interrupted and as a loss of normal life. Apart from symptoms due to the cancer disease, families continuously experience burden of treatment. Since coping capacities are unique to each individual, we captured variables that offer objective measures of treatment burden, with a particular focus on the disruptive effects of treatment on families' lives. Our sample was comprised by 193 children that died of cancer. Medical records were extracted retrospectively. Quantitative data were statistically analysed with respect to variables related to treatment burden. Deceased children with cancer and their families faced a significant burden of treatment. Results revealed that deceased leukaemia patients had a higher number of inpatient stays, spent more time in the hospital both during their illness and during the last month of their life, and were more likely to die in the hospital when compared to deceased patients with CNS neoplasms and with other diagnoses. Our findings highlight the disruptive effects of treatment that are likely to have a great impact on families' daily life, that go beyond exclusively focusing on side effects, and that needs to be taken into account by the treating staff. © 2018 John Wiley & Sons Ltd.

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