



Original Research

Site of childhood cancer care in the Netherlands



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Abstract Background: Due to the complexity of diagnosis and treatment, care for children and young adolescents with cancer preferably occurs in specialised paediatric oncology centres with potentially better cure rates and minimal late effects. This study assessed where children with cancer in the Netherlands were treated since 2004.

Methods: All patients aged under 18 diagnosed with cancer between 2004 and 2013 were selected from the Netherlands Cancer Registry (NCR) and linked with the Dutch Childhood Oncology Group (DCOG) database. Associations between patient and tumour characteristics and site of care were tested statistically with logistic regression analyses.

Results: This population-based study of 6021 children diagnosed with cancer showed that 82% of them were treated in a paediatric oncology centre. Ninety-four percent of the patients under 10 years of age, 85% of the patients aged 10–14 and 48% of the patients aged 15–17 were treated in a paediatric oncology centre. All International Classification of Childhood Cancers (ICCC), 3rd edition, ICCC-3 categories, except embryonal tumours, were associated with a higher risk of treatment outside a paediatric oncology centre compared to leukaemia. Multi-variable analyses by ICCC-3 category revealed that specific tumour types such as chronic myelogenous leukaemia (CML), embryonal carcinomas, bone tumours other type than osteosarcoma, non-rhabdomyosarcomas, thyroid carcinomas, melanomas and skin carcinomas as well as lower-staged tumours were associated with treatment outside a paediatric oncology centre.

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Conclusion: The site of childhood cancer care in the Netherlands depends on the age of the cancer patient, type of tumour and stage at diagnosis. Collaboration between paediatric oncology centre(s), other academic units is needed to ensure most up-to-date paediatric cancer care for childhood cancer patients at the short and long term.

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1. Introduction

Children with cancer are treated in paediatric oncology units, other academic units or non-academic hospitals. Expert opinions and evidences suggest that specialised paediatric oncology care is essential to guarantee most up-to-date treatments (i.e. maximal cure rates and minimal late effects) for children and young adolescents with cancer [1–6]. Effective therapies have been developed for most types of paediatric cancers in the last decades [5,7–13]. Where and how to treat an adolescent cancer patient (15–19 years) is a difficult question because the adolescents can have specific childhood cancers, but also adult types of tumours [14–15]. Previous hospital-based studies showed better survival rates for adolescents and young adults with leukaemia treated on paediatric protocols compared to adult protocols [16–18]. Also patients older than 16 years with Wilms tumours can often be cured by multimodal treatment following the Society of Paediatric Oncology (SIOP) 93/ Society for Paediatric Oncology and Haematology (GPOH) protocol [19].

The upper age limit for referral to a paediatric oncology centre differs among countries from 14 to 21 [1,3,19–23]. In the Netherlands, parents and paediatric oncologists expressed the intention to treat children and young adolescents aged under 18 with cancer in a paediatric oncology centre. Population-based cancer registries in Ontario (Canada), Utah and Georgia (USA) as well as in France, Switzerland and the United Kingdom [UK] (Europe) showed that over 80% of children (≤ 14 years) and 32–65% of young adolescents (15–19 years) with cancer were treated in paediatric centres [3,20,22–25] (Table A.1). However no in-depth analyses on the type of tumour have been described.

The overall aim of this study was to investigate the trends in the site of treatment for children (0–17 years) with cancer in the Netherlands. Furthermore, differences in: (1) age groups, (2) gender, (3) time and (4) types of cancer were studied in relation to the site of treatment.

2. Methods

2.1. Study population

To get insight into the trends in the site of treatment for children with cancer we identified children with cancer in the existing registries of the Netherlands Cancer

Registry (NCR) and the tumour registry of the Dutch Childhood Oncology Group (DCOG) for a 10-year period since January 2004.

2.2. Netherlands Cancer Registry

Registration of patients with cancer is covered by the population-based NCR since 1989. Notification occurs primarily through the national registry of all pathology and haematology departments, with additional reporting by hospital discharge registries. Following notification, trained registration personnel collect relevant information from the medical records at the hospitals. The NCR showed a completeness of 96% of all patients diagnosed with cancer in the Netherlands [26].

In 2013, 81 general hospitals and eight academic centres were included, seven of the latter with a paediatric oncology centre.

2.3. Dutch Childhood Oncology Group tumour registry

Since 2003, children with cancer (aged under 18) treated in one of the seven paediatric oncology centres are registered in the DCOG tumour registry. Trained personnel collect relevant information from medical records. Until now there are no studies which evaluated the completeness of this registry.

2.4. Types of childhood cancer

Both registries (i.e. NCR and DCOG) code topography and morphology according to the International Classification of Diseases for Oncology (ICD-O), 3rd edition published by the World Health Organization (WHO) in 2000. The ICD-O codes were classified in main diagnostic groups and subgroups according to the international classification of childhood cancers (ICCC), 3rd edition [27]. This classification includes tumours with malignant behaviour, except for tumours of the central nervous system (CNS) and intracranial germ cell tumours, these tumours may have a non-malignant behaviour code. The number of ICCC-3 categories was reduced by combining:

CNS tumours and intracranial/intraspinal germ cell tumours (ICCC main group III and ICCC group Xa), embryonal tumours (ICCC main groups IV–VII. Of note; this category also contains carcinomas and unspecified tumours ($N = 31$)), bone and soft tissue tumours (ICCC main groups VIII and IX), germ cell

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