



Foreword

Childhood cancer survival in Europe, 1978–1992:
The EUROCARE Study

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This special issue of the *European Journal of Cancer* (EJC) comprises a set of 16 papers which analyse and discuss the survival rates for children diagnosed with cancer during the period of 1978–1992 in more than 30 European Cancer Registries.

Based on survival data from 45 000 children, this study is the largest in childhood cancer survival ever published. This large database allowed a meaningful analysis of as many as 25 different types of cancer, all defined according to the standard International Classification of Childhood Cancer (ICCC) classification [1]. Some of these cancers are particularly rare and thus it is difficult if not impossible to study them with less extensive data sets. The second important feature of the study is that it is both registry and population-based, i.e. it considers all the cases diagnosed in the populations covered by the contributing, established cancer registries, approximately 45% of Europe, most of the former Soviet Union is not included. This means that survival patterns presented in the various papers largely reflect, the management of childhood cancer in the considered areas and the possible lack of coverage appears to have a minor impact.

Patient data were assembled and analysed through the Eurocare project, a European Union (EU) concerted action which has already generated two International Agency for Cancer Research (IARC) Scientific publications on population-based survival of cancer [2,3] and a special issue in this journal on survival for adults with cancer diagnosed between 1978 and 1989. [4] Approximately 1% of all cancer patients in the EUROCARE II project were children (0–14 years), which is more than the usual 0.5–0.7%. The data from the 30 cancer registries covering patients of all ages that had already contributed to EUROCARE II, were supplemented by additional data from four specialised paediatric oncological registries. Among them were, the national UK and (former West) German registries which together contributed about 65% of all patients, while the inclusion of the Piedmont registry roughly doubled the coverage of the Italian population to 21% and the Dutch childhood

leukaemia registry covered the entire country. The methods of survival analysis had already been developed and standardised and comprise among others age- and gender-standardised comparisons.

The first two papers provide the rationale of population-based survival studies, the sources and methods of data collection and analysis. As always in observational studies, problems and biases are exposed that may hamper straightforward interpretation of results. Sometimes incompleteness may play a role in part inherent to referral data and the type of involved specialists, e.g. neurosurgeons or endocrinologists. The last two papers are also general: the first presents cancer mortality trends from the World Health Organization (WHO)-database since 1955, including also deceased children at age 15–19 years, a summary analysis tries to draw conclusions concerning both the trends in survival since 1978 and geographical variation during 1985 to 1989, for all except the rarest tumours. The 13 cancer or tract-specific papers present and discuss the survival characteristics of childhood cancers, grouped according to the main categories of the ICCC classification. Both age-specific and age-standardised rates are analysed according to gender, country and period of diagnosis. Trends in survival could always be estimated by Cox regression analysis. The survival rates are not only used for comparisons within Europe, often after age adjustment, but also for comparisons with valuable results from the SEER programme, that covered about 10% of American children during the 1980s [5], and from population-based series in Australia, Canada and Japan. The comparisons of the data with the survival results from the USA will be continued.

About 50 authors wrote the four overview and the 13 tumour-specific papers, some of them with multiple contributions, and with a more than supervisory role for the guest editors who all came from the EUROCARE group. Most of the papers were multidisciplinary, involving cancer epidemiologists and biostatisticians, as well as paediatric oncologists. They and other specialised clinicians assisted in the interpretation of the

findings, by considering the results of clinical trials in the various countries. Two well-known experts in childhood cancer epidemiology (Eva Kramarova and Benedetto Terracini) and with respect to mortality (Fabio Levi) collaborated with the EURO CARE group in this work. Furthermore, the EJC editor for paediatric oncology Jon Pritchard also provided valuable comments.

In most countries in Europe, paediatric oncology was organised nationally during the 1970s, although this may not have happened until the 1980s or even the 1990s in other countries. Very likely, improvements may have been realised in the meantime and differences in survival between countries may have disappeared. The data presented here mainly describe survival during the late 1980s and early 1990s. The large sample in this special issue is however a necessary baseline reference for the evaluation of more recent survival data. Fortunately, EURO CARE-3 is already in progress and results from a subsequent analysis of these data until 1995 can be expected within a year. It will also include more long-term data. In the meantime, the data in this special issue will undoubtedly raise discussion. Hopefully, the situation has improved especially in the countries with the poorest prognosis in these analyses presented in this issue.

One source of bias that has the potential to jeopardise comparability in future studies, derives from naïve privacy rules that would demand informed consent

from parents instead of implied consent with the opportunity to opt-out, which they never do. It is time that parent groups have a real say in this matter. They know that it is in their interest that true comparability emerges in Europe and the obscurantism of the past is left behind.

References

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