Pergamon

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Foreword

THIS SPECIAL Issue of the *European Journal of Cancer* presents the latest 5-year survival figures from the EUROCARE Study for adult cancer patients, newly diagnosed from 1985–1989. Where possible, trends in relative survival from 1978–1989 are also described. For the first time, EUROCARE data on non-Hodgkin's lymphomas, myeloma, skin melanoma, prostate and thyroid carcinoma are reported. Data on childhood cancer will appear in subsequent publications and, for all patients, more detailed data will be available in a new IARC monograph [1]. Relative survival rates are presented, adjusting for differences in the general mortality in the various countries, which can differ by almost twofold, and between the sexes (the article in this issue by Micheli and colleagues is particularly illuminating in this respect; pp. 2271–2278. Taking into account the age-distribution of the populations and cancer patients in the different European countries, age-adjusted relative survival rates are also presented here for each country and for Europe.

The EUROCARE study aims to analyse and explain variation in population-based survival of cancer patients in Europe. It started in 1990 with 33 recognised cancer registries from 12 countries. Currently, data on 3.5 million patients from 17 countries are included, largely diagnosed from 1978–1992; 11 countries are from the European Union and 4 from Eastern Europe. By 2000, the period of diagnosis will be extended to 1994 and the follow-up until 1998. If Russia and the Ukraine are excluded, approximately 15% of the population of Europe is currently covered by EUROCARE.

One of the underlying aims of EUROCARE was (and still is) to attain comparability of population-based survival of cancer patients within Europe by standardising data collection, management and presentation, so allowing interpretation of the, sometimes substantial, intercountry differences. The first major EUROCARE publication, based on almost a million cancer patients, newly diagnosed from 1978–1985 and actively followed for at least 5 years [2], highlighted large variations in relative survival, especially in elderly patients. Differences may have been expected between prosperous and less prosperous countries, but were somewhat unexpected between countries with equal wealth and health insurance, for example, between Denmark and Finland for tumours amenable to surgery. Stage at diagnosis and quality of care—which includes access to and supply of adequate specialised care—were considered important determinants of this variation. For particular tumours, subsite and histological type were also of major importance. However, there were also clear, unequivocal differences in survival, probably related to socio-economic circumstances and to the level of spending on the health service.

The first publications and presentations provoked much discussion in many countries on the quality of oncological care. These had been preceded in the EUROCARE study group by extensive discussions on the quality of the data, i.e. the completeness and accuracy, but also on the definition of malignancy and date of diagnosis. Greater precision is required for survival data than for incidence data. Overall, these discussions led to improvements in registry practices and also stimulated reorganisation of oncological care in certain countries, which had often already been felt necessary by experts. The direction of this change has generally been to subspecialisation, with an increase in supply and regionalisation or centralisation of complex treatments. The increasing demand for oncological care, especially in the elderly, may have hindered radical changes.

As the EUROCARE study started only in 1990, the results of this reorganisation are unlikely to be reflected in the data presented in this Special Issue on patients newly diagnosed from 1985–1989. However, by considering the trends from 1978–1989, based on data from 20 selected registries in 13 countries, improvements for some tumours in certain countries are perceptible.

WARNINGS TO THE READER?

It is fashionable to make league tables of quantitative endpoints and institutional performance, even when complex processes in medical care are involved. Therefore, there is the possibility that the results presented in this Special Issue will be used in a manner to which they were not intended. As such, some caveats need to be mentioned here.

In interpreting the results, it is important to discern a pattern rather than to look at isolated figures from individual registries or countries. Some authors have tried to relate the survival figures to incidence and mortality data, such as those described for 1990 by Black and colleagues [3]. Comparisons with data from the SEER programme found that differences were generally small, except for tumours amenable to early detection, which may also indicate arbitrary classification of pre-invasive lesions. Differences in survival can sometimes be explained by random variation, which tends to affect smaller registries or countries more than the larger ones, where intracountry variation may be concealed. Another reason for the variation could be selection bias, which occurs in registries that cover small areas in larger countries. A more positive outcome is likely to have occurred in these areas compared with uncharted areas, reflecting the fact that the presence of a registry is often indicative of an area where there are people or institutes dedicated to oncology. Overall, in our view, quality of care, in the widest sense, is the major determinant for the variation in the figures. Of course, the general life expectancy and socio-economic level play an important role (see Table 6 of the Introduction, pp. 2139–2153. The latter is also likely to be an important determinant of quality of care.

WHAT NEXT?

With respect to the EUROCARE Working Group, we hope that these publications will lead to many additional, specific, cohort studies with this unique dataset, either by the group itself, by members of the group or by various clinical and epidemiological research groups that will want to become involved. It is clear that usage of the data has already improved the quality of the data and, thus, also its availability in the near future. In the coming years, possibilities for analysis will only increase. For instance, special attention to rare entities is warranted in this large database as well as special studies on patterns of care, including staging practices. With long-term follow-up of patients, i.e. 15 years for patients diagnosed from 1978–1980, the EUROCARE database provides an opportunity to examine as yet unanswered questions, for example: what is the proportion of people potentially cured and free from cancer? When can long-term survivors be considered to be free from cancer? How long are those not cured expected to survive? To what extent do improvements in survival with time reflect either the increasing probability of cure, or the prolonging of survival of patients not cured? In this respect, the first analysis has been made for colon cancer [4]. Studies of prevalence, as an indicator of care requirements, will also be carried out in EUROPREVAL.

We hope that this Special Issue will provoke further discussion on optimising oncological care within Europe and that not only oncology experts, but also other experienced clinicians will find common ground in persuading the various medical societies, politicians and insurance companies to improve care systems. Learning from the 'good' countries or regions seems more fruitful than devising a new, theoretical, ideal system. Further studies to explain differences in survival and to answer important, as yet unanswered questions are still needed, so the full potential of the EUROCARE database is yet to be completely realised.

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