How important are estimates of cancer prevalence?

This edition of Annals of Oncology contains two related articles on cancer prevalence [1, 2]. The first describes the EUROPREVAL Project, its methods and some broad findings, while the second gives details of cancer prevalence estimates based on data from several European Cancer Registries. EUROPREVAL is a natural extension of another exercise in quantitative gigantism, the EUROCARE-2 study [3], and takes advantage of data obtained from the quality assurance programmes put in place, in this instance by 38 cancer registries in 17 countries.

One might ask why these papers have appeared in Annals of Oncology? First, EUROPREVAL represents a considerable scientific effort to measure a dimension of the cancer burden that is not immediately accessible from the more commonly available cancer incidence, mortality and survival trends. As such, these prevalence estimates should be of more than a passing interest to the world of oncology. Secondly, the project has promoted collaboration and the adoption of common standards between several cancer registries and thus, for the first time, provides comparable data on cancer prevalence in different European populations.

The primary importance of prevalence estimates is to gain an understanding of the proportion of people in a given population at a given point in time who remain alive after having received a diagnosis of cancer. Such statistics should be useful to agencies charged with planning for the provision of health and oncology services such as continuing therapy, including the treatment of subsequent disabilities, continuing medical consultations, screening for recurrences and second primary cancers, and for long-term counselling and support. Unfortunately, some previous sporadic reports of prevalence by cancer registries have not proved to be very useful due to data limitations and the lack of completeness, or a standard methodology [4]. The utility of EUROPREVAL is measured by the extent to which it has made progress in addressing the problems of previous studies, and the validity of its prevalence estimates for different cancers and different populations.

Perhaps not unexpectedly, the two EUROPREVAL papers show that there is variation in prevalence estimates between countries and also between cancer types, e.g. from 1169 per 100000 in Poland to 3046 per 100000 in Sweden. A degree of variation in prevalence is to be expected because of its dependence on the underlying incidence rate and on other parameters, such as the population’s mix of cancer types, the extent of screening programmes, the stage distribution at presentation and access to treatment facilities. On the other hand, the observed variation in prevalence estimates can be influenced by differences in data quality and coding conventions, e.g. differences in levels of loss to follow-up, the proportion of cases known only from death certificates, the migration of cancer sufferers in and out of the population, the diagnosis of multiple cancers in the same person and, perhaps most importantly, the completeness of prevalence estimates prior to cancer registration.

These sources of possible error are directly related to the quality of cancer registry functions and to the length of time that a registry has been in operation. In attempting a standard analytical approach across all participating registries, EUROPREVAL has not been able to address all of these factors completely. Loss to follow-up of <1% was considered negligible, the proportion of death-certificate-only diagnoses (reported as an index of probable underestimation) ranged from 0% to 2.8%, and migration and the occurrence of multiple primary cancers were not dealt with. A correction factor was applied to try to take prior prevalence into account [5], with completeness being estimated at <90% in registries with ≥ 20 years of follow-up, and at <50% in registries with only 5 years of follow-up. In the longest established registries, observed prevalences were generally within 10% of estimated prevalences, except for Hodgkin’s disease and cervical cancer. These exceptions were found to have arisen as a result of substantive changes in the treatment of Hodgkin’s disease and the early detection of cervical cancer over this time period, which were not taken into account.

This finding provides a cautionary tale for those who would use these data for health service planning purposes at a national level or for international comparisons. Prevalence estimates are susceptible to the forces that drive the incidence of, and survival from, specific cancer types, particularly with respect to those cancers that are not uniformly and rapidly fatal. The national promulgation of screening and early detection programmes and the adoption of new therapeutic agents and procedures varies from country to country depending on their level of relative wealth and economic development, and it is not surprising to find that, internationally, these socioeconomic indices are highly correlated with prevalence (Micheli et al. 2002, Table 3) [2]. A poorer country’s cancer mix will tend towards cancers of poor prognosis and those of a more advanced stage, and this caseload, coupled with a lower expenditure on health, will inevitably deliver a lower overall cancer survival rate and a comparatively low cancer preval-
ence. On the other hand, the high level of detection of prostate cancer due to the widespread use of the prostate-specific antigen test in some of the wealthier countries leads to greatly enhanced prevalence because disease of very low case fatality can be diagnosed.

Total prevalence based on a complete estimation of survivors of all cancer types has a rather limited application. Many long-term survivors will, essentially, be cured of their cancer and may place little additional burden on the health services than others of their age. As the majority of prevalent cases are over 65 years of age, some form of age adjustment is necessary, especially if the countries being compared have different population age–sex structures. EUROPREVAL has done this by adjusting each country’s cancer incidence, survival and prevalence to the world standard population. Comparisons, of course, are odious and their only obvious value in this context is to encourage the appropriate allocation (prioritisation) of resources to cancer control within national health systems. Such thinking is assisted not only by information on prevalence, but also by similar data on temporal trends in cancer-specific incidence and survival. It is also useful when planning service provision to consider subfractions of prevalence, as the cancer survivors prevalent within a short time period from diagnosis may still be undergoing primary treatment and active follow-up, whereas longer term survivors will be on less intensive regimes. In this regard, EUROPREVAL provides prevalence estimates, for each country and 11 cancer types, at 2, 5, 10 and 15 years after diagnosis, presenting the data in tabular annexes and graphical formats.

While one’s retinas baulk at absorbing the dense tables of rates and proportions, the graphs permit the salient features of the information to be assimilated at a glance. In the paper by Micheli et al. [2], Figure 13 has special appeal because it combines incidence, survival and prevalence for the 17 countries in a single figure. Generally, for total cancer the prevalence proportion is about fives times the incidence rate, but there are exceptions to the trend that seem to be largely due to differences in survival. Poland and Scotland are towards the extremes with respect to incidence and both fall below the average for prevalence due to the lower than average survival rates, while Sweden, with a comparatively low incidence, has above average prevalence and survival.

These findings obviously beg the question of why this should be. The beginnings of an answer to this could be made by examining similar plots for each cancer type and collecting further clinical data from the populations that are outliers from the trend. It would be interesting, for example, to explore the reasons for Sweden’s high survival rate: to what extent it is due to early detection, to its mix of cancer types, stage distribution, treatment or to other factors? We await future EUROPREVAL outputs that may begin to address these questions by incorporating population-based information on cancer staging.

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References