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Editorial Comment

Cancer registries contribute to quality improvements in clinical care for all European cancer patients

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Despite preventive measures, the diagnosis and care of cancer patients will use an ever-increasing proportion of the clinical resources for health care in Europe due to its ageing population. For example, in the five Nordic countries, the annual number of incident cancer patients will increase by one third between now and 2020—even in the absence of any increase in risk [1]. The proportion of elderly patients, with their specific care needs, will rise by more than that in most countries [2]. To date, much of the research on the quality of clinical cancer care and consecutive guideline development has been based on the study of clinical case series, often in randomised trials. However, such studies cannot always be generalised, based as they are on selected groups of patients. As a result, population-level understanding of quality outcomes has been limited, especially for elderly patients.

Within Europe, there is much to be achieved through the exchange of experiences and the establishment of norms of 'best practice', and by providing a basis for common analyses. At the European Community level, the European Network of Cancer Registries (ENCR), originally funded by the Europe against Cancer Programme of the European Commission, has been able to bring together and standardise cancer registration activities [3] and, the EUROCARE working group, comprised from a selection of the same registries has engaged in comparative analyses of relative survival since the early 1990s [4]. With the perspective of extending the role of population-based cancer registries, ENCR organised a Workshop on the Evaluation of Clinical Cancer Care in Veldhoven, The Netherlands, in December 2001. The contributions to this workshop have been published as a monograph [5] that introduces the framework, subject matter, methods, study designs and problems in the assessment of quality of clinical care. It provides cancer registries and the clinical community with advice on how to proceed with different types of quality assessments at the population-level. Contributions to (planning of) structure and assessments of process and outcome features are delineated. In addition, it provides an illustration of the exchange of information on quality standards, and highlights the importance of further training and networking between the different disciplines in this multi-disciplinary field and collaboration is sought with the various clinical disciplines.

Traditionally, the population-based cancer registry has had a public health focus, dominated by a primary interest in cancer cause and prevention. At the same time, cancer registries interface with health care policymakers to provide information needed for the planning and evaluation of cancer control programmes [6]; increasingly, scenarios have been developed for long-term planning of vital resources such as radiotherapy. In recent years, increasing attention has been paid to examining variations in the process of care for the cancer patient, between different providers, or different groups of patients (clients). In this respect, auditing of the process of clinical care has followed a similar path as the evaluation of cancer screening programmes. For the latter, because of the complexity and huge investment of public money involved, it has been accepted for some time that a capacity to monitor the screening process and its outcome is an essential component of the programme itself, and that the cancer registry is ideally suited to this role [7].

Trends in mortality from cancer are only partly a correct measure of the success (if any) of cancer control

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activities in different populations, because they are affected by both incidence and survival. Moreover, the effect of cancer control activities on mortality will often be quite delayed, and data on detection and incidence, on the one hand, and on cancer patient survival, on the other hand, can give a more immediate insight into changes in outcome after diagnosis [8].

The analysis and publication of survival data by cancer registries has a history as long as cancer registration itself. However, population-based survival statistics had attracted little attention at the policy-making level until the publication by the EUROCARE group of international comparisons of survival, published extensively in this journal for adults [9] and also in children [10] and a recent update [11]. The results demonstrated substantial international variations, and had a galvanising effect, profoundly influenced policy-making in some countries, e.g. in the United Kingdom (U.K) and Denmark. The findings from high-resolution studies on colorectal and breast cancer have focused attention on the reasons for these differences, with stage at diagnosis being most important factor.

Survival measures can be refined into, e.g., disease-free survival, or by evaluating the quality of life between treatment and death in terms of disability or side-effects of treatment. Measurement of quality of life normally requires quite complex data collection, by interview or observation, from individual patients, for which guidance was developed by Detmar and Aaronson [5]. Quantification of outcome of cancer care in these various ways is important when considering alternative strategies of intervention. Sometimes economic considerations also play a role with respect to inputs (costs) required to achieve given improvements in outcome, elaborated by Wolstenholme [5].

The full benefits of specific procedures that have been demonstrated in randomised controlled trials will rarely be evident at the population level, where the patients being treated are more heterogeneous, and may be less likely to derive benefit from the intervention. This is especially relevant for the elderly who can comprise more than 50% of all new patients in certain areas. The objective of measuring population level survival is to give an indication of the possible role of the care process as a determinant of survival differences. The important role of co-morbidity as a factor which can profoundly influence the choice of therapy, quality of life and prognosis of individual patients and groups, has undoubtedly also been neglected in the past; some experience has already been gained by a cancer registry in Europe [12].

A wide range of indicators of the quality of the process of clinical care has been used in different studies. The location (e.g. type of hospital) of treatment for specific cancers has been found to vary considerably for different groups of patients, and this probably reflects the type of facilities available, and the level of expertise of the therapists. The technical expertise of physicians and surgeons may be a function of their familiarity with the appropriate diagnostic and therapeutic methods, as measured in terms of caseload. The importance of these, admittedly indirect, indicators of quality of care in determining outcome has been shown extensively in the west of Scotland [13]. Auditing the nature of the diagnostic and therapeutic procedures actually performed provides a more direct indication of the quality of care. However, if the focus is effectiveness of care, then the choice of indicators should be known to have an effect on its outcome. Simple issues such as delay (for example between diagnosis and therapy) may be relatively easy to measure, and provide information on the equity of access, as well as potentially influencing outcome. Scarcity in the supply of adequate specialised care has also proved essential in this respect [14].

Systematic review of the process of clinical care has been developed from an activity that was the concern of groups of clinicians (cancer committees, grand rounds), through to a more systematic approach using the hospital cancer registry [15]. The methodological framework was in fact provided by Donabedian [16] and Rutstein [17]. Clinical databases are either an extension of the hospital registry or represent a pooling of data from multiple hospitals, all collecting a defined set of variables, which include such clinical details as stage, treatment given, and follow-up for recurrences and metastasis. The National Cancer Database of the United States is perhaps the best-known example of the latter [18], but the Munich Cancer Registry also increasingly provides such data for a number of tumours.

What is the role of the population-based cancer registry (PBCR) in all of this? From the point of view of the epidemiologist, public health specialist, policy-maker and politician, for whom the focus of interest is the community, rather than a single institution, the results of studies on self-selected and often atypical subgroups of patients (such as those reaching comprehensive cancer centres) will often also be inadequate to measure progress over time. As a very minimum, the PBCR can be used to examine how typical the subset of patients that have been studied are, with respect to the caseload in the population as a whole. However, traditionally, the dataset collected by PBCR's is limited with respect to variables suitable for clinical care studies, confined, for example, to the hospital or specialty of treatment, nature of first therapy (surgery, radiotherapy, chemotherapy, yes or no) and outcome (dead or alive). The quality of information, or completeness of other key variables—especially the extent of disease—is often as good as that which is provided by the various clinicians. Good data is a sign of better quality. Nevertheless, in general, the key issue that remains is whether PBCRs should attempt to expand their dataset, like

those of hospital registries, to capture more information on co-morbidity, diagnostic and staging procedures, extent of disease at diagnosis and at surgery, the nature and sequence of treatments, and follow-up in terms of recurrence and metastasis. For sure, there is a trade-off between the enormous amount of work involved and the benefits of such an expansion. At the very least, studying the care process requires a review of individual case records; quality of life studies will require additional interaction with patients. The most realistic approach is probably to restrict such studies to samples of the registry database—confined to selected cancers, for representative samples of cases. The EUROCARE "high-resolution" studies provide an example of international comparative data [19,20]. It is clear that estimating the value of recent changes in detection, staging and therapy requires a more stringent approach.

Do we really need PBCR's for this type of study? Probably they could be done in an *ad hoc* manner, if a suitable sampling frame could be identified from which to draw the case series for study. However, the cancer registry is already ideally placed to do just that, as well as being a source of expertise in the techniques of sampling, abstracting, data management, analysis and interpretation that well conducted community-based studies require. The evolution of cancer registries from registers of cases, through "information services" to "intelligence units", reflects a widening of activities to ensure that all aspects of cancer control—prevention, early diagnosis, treatment and rehabilitation—receive the quantitative appraisal needed for improvements to be made.

We expect the clinical community to recognise the worth of cancer registry databases, and join forces with epidemiologists to evaluate the quality of care through clinical research, so that such studies are not only partially undertaken and implemented late. It is clear that the registry can also be used for a better planning of future resource needs to sustain the desired quality level [14], because poor process and outcome tend to follow inadequate provision of care [16].

If it remains possible in the near future, comparative assessment of oncological care indicators, as developed in the EUROCHIP project during 2002, may also propel and sustain the process of oncological care across Europe towards a better outcome [21].

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