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Madrid, 20–26 June 1978

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CANCER STATISTICS

Report of a WHO/IARC Expert Committee

A WHO/IARC Expert Committee on Cancer Statistics met in Madrid from 20 to 26 June 1978. Dr L. A. Kaprio, Regional Director, WHO Regional Office for Europe, opened the meeting on behalf of the Director-General. He said that the aims of the meeting were:

(1) to review previous Expert Committee recommendations regarding cancer statistics in order to ascertain that they are relevant to the problems of today and to the information needs of health managers,

(2) to pinpoint gaps in the current scope of statistical work, and

(3) to provide guidance on the collection of reasonably reliable statistics relevant to cancer control.

Dr Kaprio noted that it had been 20 years since cancer statistics had been discussed by a WHO expert committee (*1*). During these two decades, despite considerable progress against many other diseases, the record in cancer control had been rather disappointing. This fact had led WHO to initiate a thorough reappraisal of current policies and programmes and to search for new avenues of action.

The role of health statistics was currently being redefined in the light of the new policy thrust of WHO of securing an acceptable level of health for all by the year 2000, and the meeting of the present Expert Committee was the first major occasion when this strategic reorientation of WHO's health statistics programme would be applied in a specific problem area. It might therefore be expected to set a precedent for action in other fields and to influence future programme development.

1. INTRODUCTION

1.1 Cancer as a global problem

Out of an estimated total of 50 million deaths annually in the world, more than 5 million are attributed to cancer (*2*). In Europe and North America, under present mortality conditions, about one-fifth of the population will die of cancer (*3*).

Until recently, the mortality from cancer was numerically serious relative to the mortality from infectious and nutritional diseases only in

developed countries. However, with increasing control of the latter diseases, cancer is rapidly becoming a major cause of morbidity and mortality throughout the world. More than half the world's population now lives in countries where cancer is among the top ranking causes of death. There can be no doubt that cancer will be a major challenge in the years ahead. A rough WHO estimate, based on expected demographic and health status trends, suggests that by the year 2000 (i.e., within less than a quarter of a century) the number of cancer deaths may rise by more than 50% to approximately 8 million annually. This prediction is based on three trends.

(1) *Changes in the health spectrum and demographic structure of the population*. With successful efforts in developing countries to reduce the number of premature deaths, life expectancy at birth will continue to increase, as will the proportion of a birth cohort surviving to ages in which cancer risks are high. Declining mortality, accompanied in many countries by decreasing fertility, can be expected to work towards a rise in the population in the high-risk age-group, in absolute as well as in relative terms.

(2) *Changes in life styles*. With socioeconomic development, life styles and behavioural patterns can be expected to change. These changes may be associated with an increased risk for certain cancers and a decreased risk for others. At the present time, largely owing to the increased cigarette consumption that so frequently accompanies these developments, the overall trend is towards increased cancer risk.

(3) *Changes in the environment*.[1] Important changes can be anticipated in the environment as a consequence of industrialization and urbanization. Some of these changes may work towards increased cancer risks for the population.

China and Singapore may be mentioned as examples of countries in which the change of disease pattern, from a preponderance of infectious, parasitic and nutritional diseases towards a preponderance of noncommunicable diseases, occurred very rapidly, i.e., within one generation. In these two countries cancer is now a prominent public health concern. It is therefore important that steps be initiated now to prepare health services in developing countries for the tasks they will have to face as infectious, parasitic and nutritional diseases are brought under control.

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[1] For the purposes of the Expert Committee's discussions the word "environment" was used in its broadest sense to include all of man's external surroundings such as air, water, food, general life-style, and occupation.

1.2 Past activities of WHO in cancer statistics

WHO's involvement in cancer research and statistics dates back to the work of the Interim Commission set up to make preparations for the First World Health Assembly in 1948. On the basis of resolutions adopted by the Second World Health Assembly, WHO expanded its programme of health statistics so as to establish, *inter alia*, a subcommittee on the registration of cases of cancer. This subcommittee held three meetings, the first in 1950 (*4*), the second in 1951 (*5*), and the third in 1957 (*1*). In reviewing the work of WHO in the subsequent decades, the important place accorded to health statistics becomes apparent. The work on health statistics in general has, of course, advanced the cause-of-death statistics on cancer as well as those on other diseases. WHO's total role in health statistics is too broad to be reviewed here. Since 1973 the Executive Board and the World Health Assembly have focused their attention on the long-term planning of international cooperation in cancer. As a result, activities in clinical, environmental, biomedical, and health services have been intensified. The standardization of methods in many fields of study has helped to improve the comparability of national, regional, and global data.

With regard to the collection and dissemination of statistical data on cancer specifically, WHO has supported the study of changes in mortality from cancer, the promotion of the establishment of national or regional (local) cancer registries, the coordination of studies on the geographical pathology of cancer, and the standardization of definitions, classifications and nomenclature. The importance of cancer statistics was underlined in a report of the Director-General to the Twenty-sixth World Health Assembly in 1973, which stated that "the compilation of cancer statistics has been a major service to research by WHO since its inception, together with the early introduction of cancer registries and cancer mortality studies. With the emergence of this disease as one of the major causes of death throughout the world and the recognition that many factors are involved in research into and control of the malignant neoplasms, statistical requirements have become more complex, not only as regards collection, but also dissemination of data and their evaluation."

The objectives of WHO's programme in cancer statistics have been defined primarily by two considerations. Firstly, the programme in cancer should not duplicate national efforts in cancer but rather concentrate on those aspects for which the Organization's international character particularly suits it. Secondly, the attack on cancer should be broadly based, encompassing research into etiology, the design and

evaluation of control programmes, investigations into the impact of cancer on the community, and comparative studies of the social and economic consequences of the disease.

Of the possible components of an international cancer programme, statistics is perhaps the one most eminently suited for guidance and action by WHO, which is in a unique position not only to act as a clearing-house for statistical information and statistical studies but also to provide advice and assistance to countries in the collection, processing, and analysis of data on cancer. In brief, the main objectives of WHO's programme in cancer statistics are:

(1) to collect and disseminate data on the magnitude, distribution, and trends of cancer as a world health problem and on the resources assigned to cancer control services;

(2) to promote the development and use of national cancer statistics systems and to recommend international standards, definitions, and procedures aimed at improving the quality, comparability and usefulness of cancer statistics;

(3) to stimulate, coordinate, and support statistical studies in cancer epidemiology, the evaluation of treatment, and the evaluation of cancer control measures;

(4) to collaborate with Member States in promoting the education and training of personnel involved in cancer statistics.

In pursuing these objectives, WHO has maintained liaison with other pertinent international organizations, such as the International Union Against Cancer (UICC) and the International Association of Cancer Registries (IACR), and with national cancer centres and institutes.

1.3 Availability of data

Reliable data on cancer incidence, gathered by standard methods, are published for about 5% of the world population, according to the latest issue of a joint IARC/IACR publication (*6*). Information on a further 10% is potentially available but has not, for various reasons, been included in this publication. Differences in coverage between continents and geographical regions are striking; for instance, northern Europe is covered to an extent of 60% of the population, whereas in western Europe the available information covers only 2%, the composition of these regions being that adopted by the United Nations (*7*).

In interpreting these figures, several factors must be borne in mind. For administrative and financial reasons, cancer registries often cover

populations of only limited size. Little is published on the criteria for selecting registry areas within countries, but, in cases where statistical principles of representative selection prevailed, the registry area may portray the state of affairs in the whole country. Some countries or registry areas may for one reason or another have failed to pass on their data to IARC, or they may have been excluded because of deficiencies in the data.

However, with all their limitations, the available data on cancer morbidity provide a framework for in-depth studies unequalled in degree of detail by information on any other major group of diseases.

The most widely available and uniformly compiled component of cancer statistics is cancer mortality. Cancer mortality data, communicated by Member States to WHO annually, cover about 36% of the world population. Differences between continents are again substantial (Fig. 1 and 2).

Fig. 1

Percentage of population for which cancer mortality data were available to WHO in 1955 and 1975, by continent

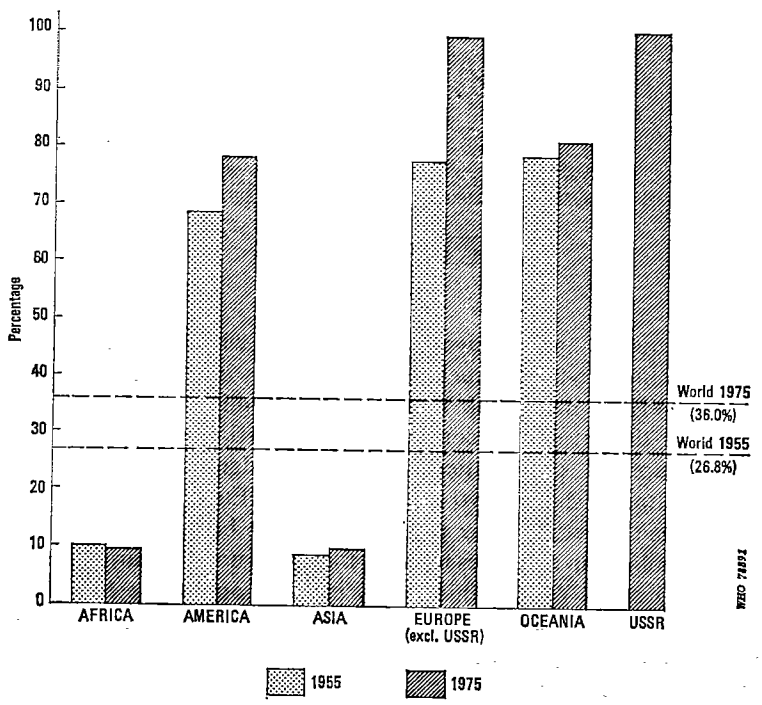
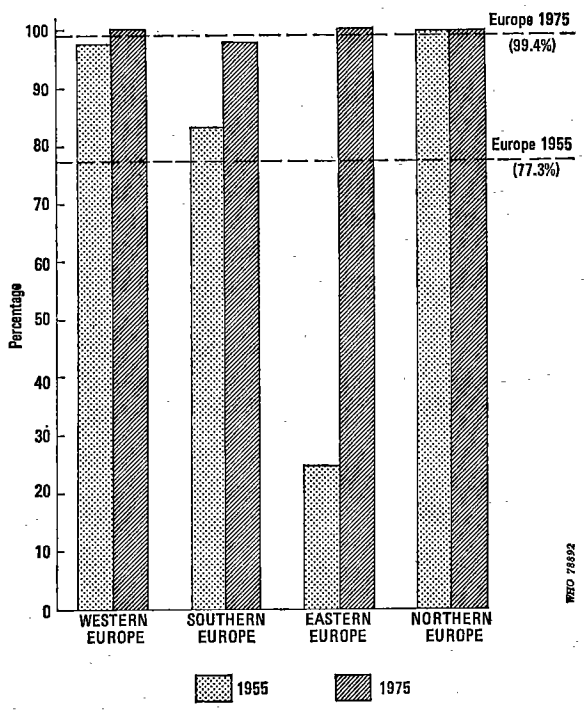


Fig. 2

Percentage of population for which cancer mortality data were available to WHO in 1955 and 1975, by European subregion



The inequality in coverage is also striking when looked at from a different point of view. Data on cancer deaths in developed countries stored in WHO's data bank represent a virtually complete coverage, whereas for the developing countries the proportion is below 5%.

The graphical presentation shows that significant progress was achieved within the past two decades only in Europe and, to a lesser extent, in the Americas. The possibility cannot be ruled out that more data are available in countries but that they have not, for various reasons, been passed on to WHO. This survey includes only those countries for which data for the whole territory and population have been released by the governments concerned. Thus information on cancer mortality, according to the detailed list of the International Classification of

Diseases, is available in WHO's data bank for somewhat more than a quarter of mankind.

2. STRATEGIES FOR THE DEVELOPMENT OF COMPREHENSIVE CANCER STATISTICS

2.1 Scope and objectives

To tackle any specific health problem, it is essential first to assess both its nature and its size. It is an obvious basic function of a health statistical service to collect and analyse in a systematic way quantitative information on the health status of the population and on the determinants and consequences of that health status. This implies that data collection should not be an end in itself but should be applicable to the health needs of the community.

Statistical information in the field of cancer should serve two main objectives:

(1) the study of the epidemiology of malignant disease, including (*a*) trends and differentials in morbidity and mortality and (*b*) etiological factors; and

(2) the evaluation of (*a*) programmes of cancer control and (*b*) survival, with special emphasis on the quality of life of patients.

To put it differently, the objectives of cancer statistics are to shed light on aspects of cancer within an individual country and to compare the characteristics of that country with those of other countries.

Within a country, appropriate statistical indices can serve to characterize the pattern of cancer—by site, sex, age-group, geographical location, etc.—with obvious relevance to the provision of adequate services for diagnosis, treatment, follow-up, and terminal care. If kept in a uniform fashion over a period of time, such statistics will also furnish indications of changes in the impact of the disease, necessitating alterations in the services provided, and will permit the prediction of future requirements. At the same time, the changes observed in the pattern of the disease can be set against environmental and other characteristics in order to monitor the effects of known carcinogenic agents and detect new potential hazards.

Many of the cancer data collected need to be related to other statistical data in order to construct appropriate indices or rates. Although the data recorded by a cancer statistical information system in a particular

country are mainly relevant to the internal affairs of that country, they may also have a significance well beyond its borders, especially those data concerned with the basic behavioural characteristics of malignant diseases.

The cancer statistics that are of greatest importance in making comparisons between countries are those relating to mortality by site, sex and age, preferably in the form of absolute rates, though proportionate mortality or morbidity can also be informative. In this field, unsophisticated statistics can be of considerable importance as long as they are reasonably free of bias and distortion; certainly it is not a field that is a monopoly of the developed countries. Not infrequently the cancer data obtained from a developing country—or even from only a part of the country—have contributed significantly to the global picture of the disease.

In stressing the need for statistical information, it is equally necessary to stress the importance of the quality of that information. Effective methods have to be used to control the quality of the data collected and stored, so that false or misleading information is kept to a minimum.

This is as true for data collected for administrative and planning purposes as it is for data collected for purposes of research. Moreover, in order to validate the analysis of secular trends in cancer statistical data, the standards of quality and the nature of the data collected should not change with time.

Cancer control activities [2] can be evaluated by their effectiveness in reducing morbidity from cancer at specific sites, if at the same time account is taken of other environmental factors that might affect the comparison. In the analysis of follow-up data it is becoming increasingly important to record the quality of survival rather than merely the fact.

It is important to bear in mind that a cancer statistics system is part of a more comprehensive health statistics system and will have many of the characteristics of the larger system, particularly its ways of obtaining, processing, and disseminating data. At the same time, it also forms part of the national cancer programme and will have characteristics that reflect the organization and operation of that programme, which is in turn influenced by the total national health service and its methods of operation. A uniform model for national cancer statistics, containing a minimum data set, would be useful for all countries, particularly those whose cancer statistics are just developing. However, it is recognized, even among the developed nations, that that minimum will be achieved

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[2] For the purposes of the meeting, the term "cancer control" was considered to encompass prevention, early detection, diagnosis, treatment, rehabilitation, and follow-up.

through a multiplicity of methods that depend on the health delivery systems unique to each country.

2.2 Users of cancer statistics

Users of cancer statistics include the whole spectrum of health occupations—health planners; programme managers; those who deliver health care at all levels; health statisticians; epidemiologists; oncologists; teachers and students of public health, epidemiology and statistics; and people in all other disciplines related to cancer prevention and control.

The information needs of the various groups of users differ to a marked extent, as do their requirements with regard to detail and accuracy. It is essential to ensure that cancer statistics reach the people who need them at the time when they want them and that the data are relevant to the purpose in hand. Thus, close contact between all involved in the production and utilization of cancer statistics is indispensable.

For a variety of reasons, however, cancer statistical information is not adequately utilized. Firstly, data collected at national level may be insufficient for the needs of health planners and programme managers; secondly, there may be a lack of communication between producers and users of health statistics so that the data that are available are not usable at the level at which health care is given; thirdly, a knowledge of even simple statistical procedures may be lacking among medical professionals; fourthly, when computers are used, medical professionals may not appreciate the constraints on, or the requirements for, the computer storage of data; and, fifthly, health statisticians themselves may not have a sufficient appreciation of medical problems.

It is recognized that in those developing countries where cancer may not yet be a problem of central importance the collection and use of statistical data may not have the priority that they are accorded in other countries. Nevertheless, the effective control of infectious diseases and of some of the other specific health hazards in developing countries is having the effect of bringing malignant disease into greater prominence. This serves to stress the importance of laying the foundations of cancer statistics now in order to ensure its gradual and realistic development.

3. STATISTICS OF CANCER CASES IN THE POPULATION

For both the study of epidemiological factors and the planning and implementation of cancer control programmes, the collection and analysis

of data on cancer cases in the population are of paramount importance.

The following paragraphs describe some of the problems encountered in the collection of quantitative information on cancer cases in the population—problems that are to a greater or lesser extent common to both developed and developing countries.

3.1 Some problems in the collection and analysis of data on cancer cases

3.1.1 *Lack of basic health services*

Even in some developed countries, there are geographical areas or sections of the population in which basic health services are either absent or inadequate. The situation is much worse in developing countries, where most of the health personnel and resources are concentrated in the cities and towns, leaving the rural areas with hardly any. As a result, statistical information on the general patterns of health and disease is often lacking. There may for instance be no reliable figures for the total population of a particular community or there may be no statistics based on variables such as sex, age, ethnic group, and so on. Even the total number of cases of diseases such as cancer may be unknown. Without population figures for certain communities it is impossible to calculate rates of incidence and prevalence. Thus, before the extent of the cancer problem can be appreciated, age- and sex-specific population data must be obtained, and special surveys may be necessary to determine them (*8*).

3.1.2 *Lack of stability of the population*

Throughout developing countries, there is an increasing tendency for the rural population to migrate to the towns and cities in search of work and a higher standard of living. Only a few countries require permission for internal migration. Therefore, there is no record of such population movements. These movements are, moreover, not unidirectional. People will often earn a sum of money in the cities and then return home to their villages for varying periods of time. Others may return having not found suitable jobs or having become disenchanted with city life. This kind of migration within a country has repercussions on the accuracy of whatever health statistics are available, including those on cancer.

3.1.3 *Problems of identification of individuals in a given sample*

It is virtually impossible to exclude the counting of an individual more than once in a given sample unless he is properly identified or "tagged". In many countries there is no social security system through

which an individual can be positively identified by means of a number, and sometimes the problem is complicated by the lack of surnames; a person is simply known by his or her given name and the father's or mother's name. Often, the names used in such countries are relatively few, and there may be several hundred people with exactly the same name in a particular district. It is easy enough for a person to be counted more than once if, for instance, he or she reappears for further treatment of the same disease at a different hospital—or even at the same hospital (*9*).

3.1.4 *Non-access to, or non-treatment by, medical practitioners trained in classical medicine*

Most of the available data on cancer are based on records from hospitals, clinics, and general practitioners. Therefore cancer statistics will not be indicative of the cancer situation in the community unless a large proportion of cancer cases seek treatment from such institutions or personnel. In many developing countries, large numbers of the population seek treatment for their ills from practitioners of native systems of healing, and as a consequence many cancer cases may never be seen by scientifically trained health workers and therefore never included in cancer statistics for the population. Moreover, the post-mortem examinations performed are usually few in number.

3.1.5 *Confidentiality*

Confidentiality is in many countries a serious obstacle to the collection of data relevant to cancer etiology. The problem is not confined to personal and cause-of-death data but extends also to industrial data, which the manufacturer may wish to conceal from competitors (see section 10.3 and recommendations 12 and 13).

3.1.6 *Non-standardization of data*

A clear indication should be made in statistical publications of the population groups (geographical, racial or others) to which particular statistics refer.

More uniformity is needed in the presentation of statistical information. It is desirable to publish both the numbers of cases and deaths and the corresponding populations by 5-year age-groups. If this is not feasible for financial reasons, this detailed information should be made available to users through standardized computer tape transcripts (*10*).

Sometimes no population denominator is available, e.g., with hospital cases or in communities for which basic demographic data are lacking. In such circumstances, a proportional distribution of the different forms of cancer in relation either to the total number of cancer cases or to the total number of all diseases diagnosed can be calculated. The results of such computations, however, should be interpreted with caution.

The classification of anatomical cancer sites can now be considered satisfactory, although there is still a need for general agreement on the extent of lesions and for diagrams to illustrate them. The WHO publications in the series International Histological Classification of Tumours have largely met the need to improve and standardize the definition, nomenclature, and classification of tumours. However, this classification requires periodic revision to incorporate new concepts.

While the ICD-O (*11*) meets the needs for an internationally acceptable classification in several languages, it should be subject to periodic review to ensure that it reflects current concepts and usage. Tabulation schemes according to the ICD-O system need to be designed for routine international comparisons and other purposes. The uniform coding of tumours is facilitated by a recent publication (*12*) in which the morphology code numbers of the ICD-O are linked to the listings of tumours in the International Histological Classification of Tumours.

3.1.7 *Lack of data-processing facilities*

Sometimes data of reasonable quality may be collected, but it may be almost impossible to process and analyse them owing to lack of appropriate facilities and manpower. Even in developed countries, serious delays may occur in the feedback of information to programme managers and research workers, thus affecting adversely the value of the information.

3.1.8 *Lack of personnel trained in epidemiology and health statistics*

There is all too often a lack not only of medical school graduates and professional statisticians but also of personnel for manning the statistical infrastructure at all levels. This problem constitutes a crucial challenge at both the national and the international level (see section 11 and recommendation 16).

3.2 Morbidity data

The value of morbidity data may be summarized as follows.

(1) They describe the extent and nature of the cancer load in the community and thus assist in decision-making and the establishment of priorities.

(2) They usually provide more comprehensive and more accurate and clinically relevant information on patient characteristics than can be obtained from mortality data, and they are therefore essential for basic research.

(3) They serve as starting-point for etiological studies and thus play a crucial role in cancer prevention.

(4) They can be used for assessing the overall effect of efforts to improve the survival experience of cancer patients.

(5) They are needed for the monitoring and evaluation of cancer activities.

The collection of reliable information is usually demanding in terms of skilled manpower and financial resources and requires the willing collaboration of all concerned with caring for cancer patients. Wherever possible, cancer morbidity data should be checked for consistency against information from other sources, such as that on cancer mortality.

The major contribution to cancer morbidity statistics, whether in developed or developing countries, comes from hospitals.Thus a register of new cases diagnosed in a particular hospital could constitute a *hospital-based* cancer registry. While it is possible to base proportionate morbidity studies on such records, incidence rates require denominator information. If it is possible, for a circumscribed area, to define the population by sex and age, and to obtain details of all new diagnoses of cancer from the same area, then this constitutes a *population-based* cancer registry. The range of data recorded for each case decides the full scope of the registry, but incidence rates by site, sex, and age can at least be produced.

Hospital-based cancer registries have two considerable advantages.

(1) The data are usually more complete and up to date.

(2) The registries are less expensive to operate as they usually receive data passively rather than take active steps to collect them.

However, hospital-based cancer registries may give a rather incomplete picture of the cancer situation in the whole population. For

instance, not all hospitals treating cancer patients may maintain a registry, nor are all patients seen at hospital. Whenever possible, hospital-based registries should gradually develop into population-based registries. Limitations of manpower and financial resources may not permit the immediate establishment of such registries on a national scale. In such circumstances, it may be possible to start in one or two designated areas within a country. Such area cancer registries may serve as models for national registries later. In some very large countries, it may never be possible or advisable to have a single national cancer registry because logistical problems may prove insurmountable. In that case, proper liaison between area registries should be established.

The optimum size of base population for a population-based cancer registry is in the range 2–7 million (*13*), though there are efficient registries outside this range at either extreme. In some circumstances, it may be more practicable to set up a cancer registry to obtain morbidity information (incidence) than to collect mortality data of comparable quality. Although the information from such a cancer registry can strictly refer only to the area in which it is collected, it may be possible, from a knowledge of local circumstances, to extrapolate it in certain directions to widen its applicability. For a large population, it is clearly advantageous either to set up a network of registries to provide adequate sampling of discrete subdivisions or to cover the entire population by a system of contiguous registries.

Despite the great effort and expenditure devoted internationally to the collection of cancer morbidity statistics, relatively little is known about the accuracy of the data collected by cancer registries. Recent studies have shown that errors are quite common. They may occur, for example, in the transfer of information from hospital or clinic notes to the cancer registry or in the coding of information. Despite the guidance given by the ICD, international comparisons may be difficult because of differences in terminology. As cancer registration is so crucial to the compilation of information on cancer, more effort should be made to ascertain the accuracy of such registration. For this reason quality control of cancer registration processes is of the greatest importance (see recommendation 3).

Some countries have made the notification of cancer cases compulsory. While it is true that there is probably a great deal of underreporting in some countries, compulsory notification may not improve matters very much when large numbers of the population do not seek treatment from practitioners trained in classical medicine and will never therefore be notified by them. Compulsory notification may serve to protect the

notifier against possible legal action resulting from disclosure of information to the agency collecting the information but may not in itself improve completeness of reporting.

Other sources of cancer morbidity information are surveys, which may be conducted for a limited period in one or a number of localities but do not usually embrace the whole country. Such surveys suffer from similar drawbacks to those of temporary cancer registries, namely that they are time-limited rather than continuous and that the population base may not be equivalent to that from which the cancer data are derived. Surveys are expensive because staff must be trained specifically for one temporary task. Though they may be repeated, they are usually held at sufficiently long intervals to require a completely fresh training programme. Nevertheless, they may in the long run be less expensive than the maintenance of a continuing cancer registration system, and the training, though costly, does at least ensure a degree of uniformity and specificity often lacking in a system that has evolved over many years. However, despite many reservations, a well functioning population-based registration scheme seems to provide information with the least bias.

There was agreement that previous Expert Committee recommendations concerning strategies for obtaining cancer morbidity data in developing countries need to be reviewed in the light of developments in the past 20 years. It was emphasized that such a review has to allow for differences in the rate of economic progress. While the experience of developed countries constitutes a valuable basis for weighing various options, approaches that may be promising in those countries may be inapplicable in countries with a different administrative, social, and economic infrastructure.

3.3 Mortality data

Cancer mortality data constitute probably the most important source of information on cancer patterns and trends. Their principal virtues are as follows.

(1) They are relatively widely available and generally compiled in a uniform way according to internationally agreed guidelines, particularly in countries where cancer mortality data become routinely available as part of a well functioning vital statistics system.

(2) They are useful for assessing and monitoring cancer as a public health problem.

(3) They contribute to cancer research by describing variations in cancer risks for sites with poor survival experience.

(4) They can be used in migrant population studies for comparing site-specific cancer risks among migrants with those prevailing in the host country and the country of origin.

(5) They are useful as end-points in cohort studies and as a source for record-linkage studies, such as those on survival experience.

(6) They are valuable as an ultimate evaluation measure of cancer control programmes.

These data are also subject to some shortcomings (*14*). The quality of the data may vary from country to country, depending on the statistical system in operation. The quality of the data will vary also according to whether the certifier is medically qualified or not and in the degree of site detail—from none (i.e., just "cancer") to subsite localization (e.g., carcinoma of hepatic flexure of the colon). The relevance of cancer mortality data in estimating incidence or prevalence is dependent on the survival pattern by site. For instance, there will usually be little difference between mortality and morbidity statistics for malignant tumours of the bronchus because survival is short, but squamous or basal cell cancers of the skin are not prominent in mortality statistics because survival is very good.

The Expert Committee agreed that much more attention that hitherto should be paid to studies assessing the quality and international comparability of mortality data. WHO should play a more active role in the promotion of such studies and should disseminate information on their methodology and results (see recommendation 1).

In those developing countries where vital statistics are either non-existent or grossly defective, a reappraisal of current approaches would seem to be highly desirable. There can be no doubt that the ultimate goal should be reliable and comprehensive vital statistics, including cause-of-death data, in all countries of the world. However, this goal seems unlikely to be attained in the near future. In view of the crucial importance of such data, various approaches should be developed and tested that could be adapted to the information needs and statistical potentials of countries at different levels of development (see recommendations 2).

Efforts by WHO to develop criteria and indicators of the quality of cancer mortality data should be expanded and should include an appraisal of measures recommended at previous meetings (*13–15*). Data could be significantly improved by relatively simple schemes, such as the separate

tabulation of medically certified causes of death and those reported by lay people and the creation of special tabulations for areas with relatively well developed health service infrastructures (see recommendation 2).

The recently started series of review articles on cancer differentials and trends in *World health statistics quarterly* was welcomed as a useful source of information on the geographical pathology of the disease—useful not only to epidemiologists, programme managers, and health statisticians but to a wide spectrum of cancer research workers (see recommendation 1).

4. STATISTICS RELATING TO PREVENTION AND EARLY DETECTION

In broad terms, measures of prevention in the field of cancer fall into one of two categories. They are either devices to avoid or to reduce exposure to known carcinogenic factors, or they take the form of publicity exhorting the public at large (or specific high-risk subgroups in particular) to avoid or reduce their own exposure (e.g., to cigarette smoking). Each requires action to be taken and thereby costs to be incurred, but the measurement of the subsequent benefits can be of inordinate difficulty, owing largely to the long latent period of development of most cancers.

Early detection at a pre-invasive stage (*in situ*) or sometimes at a premalignant stage is at present feasible only at certain sites, the best known being the cervix uteri. Though screening campaigns may be conducted in a locality or at a factory by the use of a mobile examination room, they again need to be supported by intensive propaganda and may yet fail to attract those at highest risk. The superficial results of screening programmes may be readily determined by such means as the proportion of suspicious or malignant smears, but it is much more difficult to evaluate the results of treatment, partly because a proportion of *in situ* cancers of the cervix uteri will spontaneously regress even without treatment and partly because of the uncertainties of the population sampling, which may lead to an unrepresentative basis for generalization.

Wherever such programmes are undertaken, data of a statistical kind will be available, some of it medically based, some of it administrative. Again, standard and agreed indices of measurement, mostly describing the costs and range of the programmes, need to be defined. Only after a long period of time will it become possible to relate them quantitatively to the resulting benefits, after taking account of the notion of "lead-

time".[3] It is important that such data should be collected in a systematic way, to evaluate both new screening techniques and existing ones (see recommendations 7 and 8).

5. STATISTICS OF PATIENT CARE AND SURVIVAL EXPERIENCE

It is essential to draw a distinction between the public health approach to these topics (i.e., the evaluation of patient care and survival experience among the population) and the more clinically oriented approaches. Of the latter, the comparison of different treatment methods is itself a specialized topic, undertaken by setting up controlled clinical trials, and the statistics gathered by these means can be separated from the remainder of clinical cancer statistics. Public health statistics are largely required for planning and evaluation. The comparability of statistics, both within a country and between countries, is of great importance in all uses of data.

5.1 Clinical trials

Randomized controlled clinical trials are used to determine which of two or more types of treatment is superior. The outcome of such a trial depends on the analysis of specially collected test statistics, for which purpose routinely collected information such as that from cancer registries is of little use. Clinical trials must be set up for a specific purpose and strictly regulated in order to obtain the optimum results.

5.2 Assessment of clinical efficacy

Examples of the assessment of clinical efficacy are the evaluation of treatment efficacy in relation to extent of disease and the comparison of efficacy at different periods of time (i.e., a form of continuous monitoring). For these purposes, it is necessary to use agreed methods of classification, e.g., by site and extent of disease or histological description of

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[3] "Lead-time" is the advantage gained by screening, i.e. the period between diagnosis by early detection and diagnosis by other means. Unless earlier treatment, which is made possible by earlier detection, is more effective, it is possible that there may be no overall gain in survival time.

the growth. The ICD-O (*11*) is the most important coding system for tumour site and basic histology; it can be supplemented by the TNM system of staging (*16*) for extent of disease. The books published by WHO in the series International Histological Classification of Tumours (*17*) provide standardized definitions of tumour types.

For the measurement of survival experience, a suitably defined assessment of quality of life should be included, as well as the numerically simple and commonly used measurement of duration of life. The definition of the starting-point used for the measurement of survival time has not yet been internationally agreed.[4] The date of initiation of treatment and the date of diagnosis have both been widely used, while the date of appearance of the first symptom has been less frequently used. Developments in the statistical expression and evaluation of survival experience, as well as the use of actuarial and other methods such as probability of cure and years lost due to the disease, emphasize the need for much fuller discussion (see recommendation 5).

The source of data for the measurement of survival experience will in general be a hospital, and it may be organized through a hospital-based cancer registry. Other sources would include national or local registers of deaths and systems used for the follow-up of patients such as polyclinics, dispensaries, health centres, and general practitioners. Where a population-based cancer registry exists together with a follow-up system, the overall results are likely to be more representative of the general pattern of survival of cancer by site than are those from a hospital-based registry, which may exclude patients not treated in or referred to hospital. However, the publication *Cancer incidence in five continents* (*6*) shows that relatively few population-based cancer registries maintain a follow-up system. Even where such data are collected, they are not presented in an internationally agreed and uniform way, so that results are not readily comparable. A WHO feasibility study of data from hospital registries suggested that for a substantial proportion of patients either the efficacy of treatment was overestimated or the clinical stage of the disease was underestimated. In order to bring together information from individual hospitals, efforts to promote standardized reporting should be intensified.

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[4] At a meeting on the standardization of reporting of results of cancer treatment held in Turin, Italy, in 1977 (unpublished WHO document CAN/77.1) the time of diagnosis was recommended as the appropriate starting-point for the overall evaluation of survival experience in patient populations, whereas the start of treatment was recommended as the starting-point in non-randomized trials for assessing different methods of treatment. For controlled clinical trials, survival should be compared from the date of randomization.

5.3 Planning and evaluation

The measurement of cancer patient survival is an indispensable requirement for the evaluation and planning of programmes of cancer control. The term "end-results" has now been superseded by the term "survival experience" (*18*). Survival experience can be used as a yardstick for the assessment of standards of therapy at comparable oncological establishments. Reliable data on survival can best be obtained from hospital-based and population-based cancer registries, if they incorporate arrangements for the long-term follow-up of registered patients and for the ultimate recording of their deaths. The functions of the cancer registry for these purposes are outlined in *The registry in cancer control* (*19*).

In addition to the provision of basic health care facilities for the diagnosis and treatment of cancer, many health services today are involved increasingly in programmes of rehabilitation for cancer patients. These programmes are directed variously towards the physical, psychological, social, and vocational needs of patients, as their conditions demand. Statistics to evaluate such procedures and to measure their impact need to be further developed (see recommendation 6).

5.4 Comparability

One of the most important and valuable features of a statistics system is the ability to compare results over time and between places. By this means it is possible to discover and correct anomalies, to redistribute resources, or to provide competitive incentives. But in addition to comparisons between times and places within a country, it is of increasing importance today to make such comparisons between countries. Here the principal barrier to full comparability is the lack of general agreement on systems of classification and on internationally acceptable criteria for the definition of components of cancer statistics—in particular, criteria that are applicable to differently organized systems of health care. Some of these difficulties have been described in the literature (*18*).

Several attempts have been made to tackle this problem. The Expert Committee agreed that the WHO handbook for standardized hospital-based cancer registers (*20*) and the WHO meeting on the standardization of the reporting of results of cancer treatment (*21*), which was held in Turin in 1977, represented important steps towards achieving international comparability of survival statistics. The Committee noted that a complementary handbook on cancer registration and its techniques had been prepared by IARC (*22*).

6. STATISTICS OF HEALTH SERVICE RESOURCES IN RELATION TO CANCER

It is now generally acknowledged that statistics of health service resources constitute an indispensable component of the data base on which the health service administration depends, as does the effective management of preventive, curative, and environmental services.

The statistics of health service resources is a wide-ranging subject (*23*) and in essential parts underdeveloped. It consists of data on:

— buildings, equipment and facilities,
— manpower, and
— expenditure.

The identification of health service resources allocated to cancer control presents many difficulties, particularly in countries where cancer control is not normally distinguished from other programmes of the general public health service. Moreover, differences in approach to cancer control increase the difficulty and expense of collecting pertinent data. In such circumstances, appropriately chosen samples might provide useful data more economically on at least some of the various resource items, but it may be virtually impossible to determine what is the total effort (in terms of monetary expenditure) devoted to cancer.

In most countries that provide comprehensive cancer control services, there are four types of institution to be considered:

— special oncological centres,
— general hospitals with oncological departments,
— general hospitals without oncological departments, and
— primary health centres (e.g., polyclinics, group practices).

Institutions of the first type provide full diagnostic, treatment, and follow-up services and usually have a full cancer registration system. It is thus relatively simple to obtain information on the use of beds and specialized service facilities (including expensive radiotherapy equipment) and on the personnel involved in relation to cancer patients. The data also permit the analysis of interconnexions between these facilities and

of any combined use. Two specific characteristics of oncological centres that provide a rough measure of their capacity are (1) the number of medical personnel and (2) the number of hospital beds available. The curative and diagnostic potential is measured by the specialized services provided, in terms both of the type of equipment and of the number and expertise of trained personnel.

The availability of statistical data for institutions of the second type depends partly on the size of the hospitals concerned, but the number of beds available for cancer patients and their use should be readily obtainable. Many cancer patients will be treated in departments of gynaecology, general surgery, or haematology, and it is necessary to ensure that they are included in the statistics. Some difficulty may be encountered in evaluating the use of special diagnostic and treatment services (e.g., laboratories and X-ray diagnosis) because it may not be possible to distinguish the specific cancer demand for these services from the demand arising from other diseases.

For institutions of the third and fourth types, relatively little information is usually available. Such bodies are more frequently concerned with follow-up services or with early detection (screening), and they would send on patients requiring further investigation or treatment to an oncological centre or to a general hospital having an oncological department.

In assessing resources available for oncology and whether they are fully utilized, it is important to know the degree of coverage, the accessibility of services, and the acceptability of services—this last being of particular relevance in gynaecology and in areas where other systems of medicine are common. Another aspect of increasing significance is the costing of chemotherapeutic services. Though the drugs used are likely to be very expensive, there are often savings in inpatient bed use because the treatment is given intermittently. A further resource that should be included in the statistics of oncological services is the facility for training of personnel—medical and nonmedical, undergraduate and postgraduate.

Although many of these statistics are primarily of use for planning purposes and consequently specific to an individual country, it would be valuable to be able to compare them between different countries. The basis for such comparisons rarely exists. There is therefore a need to obtain international agreement on both a nomenclature and a classification of (1) health service activities, (2) health manpower, and (3) health expenditure. In addition to their value as a basis for international comparisons, such classifications would also provide practical guidance for

developing countries that are in the process of setting up or improving the health statistics system. All efforts should be made to consolidate and simplify the information on health service resources derived from various sources so that decision-makers can assess the efficiency of health services in general and cancer services in particular. In fact, one of the main advantages of developing comprehensive and coherent cancer statistics is to provide just that coordinating function of sifting the information available, or potentially available, from different agencies for its relevance to cancer control.

7. STATISTICS RELATING TO ENVIRONMENTAL CARCINOGENIC HAZARDS

It has been demonstrated that environmental factors can play a major role in the causation of human cancer. Consequently it is desirable not only to record those factors in the environment that are known or believed to result in an increased cancer risk for man but also to identify new factors as quickly as possible, thereby assessing the overall impact of environmental agents. Any serious attempt to meet these needs requires the gathering of information on specific groups of people (individually or collectively) regarding both their cancer experience and their history of environmental exposure. The study of environmental factors in relation to cancer can in this way serve both to monitor known hazards and to reveal new ones.

7.1 Methods of determining environmental hazards

7.1.1 *Population comparison studies*

In conducting epidemiological studies based on population comparisons, information is required that can characterize the environment shared by a population group. Although much information of this kind exists, its utility is frequently limited by problems of comparability, accuracy, and accessibility and also by the non-uniform exposure of all members of the group to the hazardous agent.

Attention must be paid to the quality of both the numerators and the denominators involved. Often it may not be clear to what specific population group the data collected refer, and without such information population comparisons cannot produce useful results.

7.1.2 *Case-control studies*

In case-control studies, the unit is the individual rather than the group. Cases and controls must be comparable with respect to known confounding factors, and it is important that information be collected on those factors for which they are not comparable. Exposure levels for the factor under investigation must be known for each individual, and sufficient other information must be available to permit matching or stratification with respect to characteristics that might otherwise confound the results of the study. This type of study can present special problems of case ascertainment, accessibility of cases, and limited knowledge or recall of exposures.

7.1.3 *Cohort studies*

A cohort, or study group, is usually chosen because of its special exposure to a specific environmental factor. It may comprise, for example, workers who have been exposed to a particular substance in the course of their occupation. The comparison group may be the general population from which the cohort is drawn, or it may be another cohort of persons thought to have had little or no exposure to the substance in question, but otherwise similar. Alternatively, if the study cohort can be stratified according to level or duration of exposure, one stratum may serve as an internal control. The chief problems in collecting data for such studies are the loss of contact with certain cohort members during follow-up and the difficulties experienced in evaluating the exposure levels for the individuals involved.

7.2 Data elements

The kinds of environmental data necessary for the conduct of various epidemiological studies have already been discussed in a general way, together with some of the problems likely to arise. A further important qualification is that the environmental data need to antedate the cancer data by at least the average latent period, which for most solid tumours is of the order of 20 years. The basic task of data collection is made less onerous by the fact that some of the data needed are already available, although they are sometimes of uncertain origin. Examples are environmental data on climate, soil type, patterns of agriculture, water sources, distribution of industry, pollution, and contamination of foods. The study of possible relationships between environmental factors and the causation of cancer is particularly worth while in areas where the cancer pattern is already well known—e.g., where a good cancer registry already

exists, or where accurate cancer mortality data by site are available (see recommendations 9 and 10).

8. PROJECTIONS OF CANCER FREQUENCY AND RESOURCE REQUIREMENTS [5]

The projection of disease patterns has, in addition to its scientific importance, practical relevance for two groups of users among others, namely:

(1) economic planners, who need it for population projections, and

(2) health planners and administrators who need it for setting priorities in health policy and for formulating and evaluating public health programmes.

Population projections nowadays are generally based on the so-called component method, that is to say, they consider separately each component of population change (i.e., fertility, mortality, and migration) —a procedure that aims not only at improving the projection but also at identifying factors that have policy implications. Recent surveys (*24*, *25*) have shown that in many countries the methods used and the assumptions formulated for the projection of mortality have been overoptimistic, and the subject has sometimes not received the careful attention it deserves. One of the most frequent shortcomings of attempts thus far has been the failure to break down "total mortality" into its cause-of-death components both for retrospective analysis and for projections into the future. The value of such a refinement would consist in (1) improving the mortality component of population projections, and (2) providing more detail of direct concern to the health sector.

The potential value of such a disease-oriented approach to projections is shown by the example of cancer projections. The impact of cancer on a community can be lessened by:

(1) a reduction of the number and intensity of known risk factors so that the incidence of the disease is reduced;

[5] In the discussions of the Expert Committee the term "projection" was used in a broad sense, i.e., a method of describing the implications of certain assumptions about future trends without necessarily attaching any measure of likelihood to them. The term "prediction", however, was used to denote a projection that is most likely to represent the future course of events. A more general discussion of the uses and limitations of health trend projections appears in the report of a consultation on health statistics projections (*26*).

(2) the early detection of the disease if treatment in the asymptomatic or premalignant phase improves prognosis ; and

(3) improvements in treatment efficacy and availability in order to reduce case fatality and residual disability.

The planning and evaluation of cancer control programmes and intervention strategies could be helped by projections of the future frequency of different types of cancer. Such projections would enable government agencies to plan the development of programmes for both personnel and resources, if supplemented by projections of health manpower supply and health manpower requirements.

The Expert Committee stressed that cancer mortality rates do not necessarily follow mathematical patterns and that projections inevitably involve assumptions of a speculative nature. All projections, based as they are on human evaluations of the direction and pace of future changes, have margins of error, which necessarily increase with extension of the time period of projection.

Projections of disease frequencies and resource requirements constitute virtually *terra incognita*. This is true not only for national projections but even more so for badly needed projections for geographical subdivisions within a country. The Committee discussed the "Delphi approach" to the future trends of specific diseases but was unable to reach agreement on its usefulness. The assumptions on which projections are based and the methods used to derive them need to be continually monitored and improved. Assumptions should be clearly stated. The degree of refinement of the methods used must be considered most carefully because it depends not only on the data available but on the uses to which the projections are to be put. The use of sophisticated methods may not necessarily increase the accuracy of the projection. In some developing countries quite simple methods may give useful and informative results.

The value of speculating on the future trends of factors known to influence cancer incidence is hard to determine. Changes in smoking patterns, for instance, may be expected to have a considerable impact on the future course of lung cancer morbidity and mortality, but this prediction may be of limited practical use owing to gaps in the statistical data and to new elements of uncertainty introduced by additional factors. However, if the sole result of making predictions is to reveal limitations in the data base, this result is not without value since it may stimulate efforts to improve the data base. Moreover, predictions are particularly useful in health education because they

demonstrate what could be achieved if measures to reduce risk factors are successful.

When projections are to be used in policy planning and evaluation, a close dialogue should be established between the producer and the user of the projections.

In view of the growing importance of projections of health trends in national and international health planning and information exchange, the development of statistical methods applicable in different socio-economic settings should be given special attention (see recommendation 15).

9. ESTIMATING THE SOCIAL AND ECONOMIC IMPLICATIONS OF CANCER

The concern of WHO with the economic and social cost of disease goes back many years, as demonstrated by the publication in 1951 of Winslow's well known book *The cost of sickness and the price of health* (*27*). The social and economic implications of cancer for its victims and for society at large are vast—millions of years of life lost; tremendous economic resources spent on detection, diagnosis, and treatment; and substantial economic output forgone because of lost human resources. In view of the limited resources, the multiplicity of diseases, and the other social problems demanding attention, it is essential that the magnitude of the economic and social costs of cancer be clearly understood.

It is impossible to quantify the physical pain and mental suffering that must be borne by the cancer victims and their families. In recent years, there has been increased interest in this aspect of the disease burden, as evidenced by research (*28–32*) on the influence of mortality and of specific diseases on the family and its life-cycle as well as on the future course of population change.

Increased effort is needed to refine the methods and develop the necessary data to measure all the different implications of illness. Cancer, like other diseases, produces economic as well as social costs. Fig. 3 shows the various components of the economic cost of illness, and Fig. 4 shows the social implications for the patient and his family.

The economic cost of illness is easier to measure than the cost in quality of life. *Direct* costs are those connected with prevention, diagnosis, and treatment. They include expenditure for care in hospitals or nursing homes, physicians' and nurses' services, drugs, medical research, training

Fig. 3

Measuring the economic cost of illness

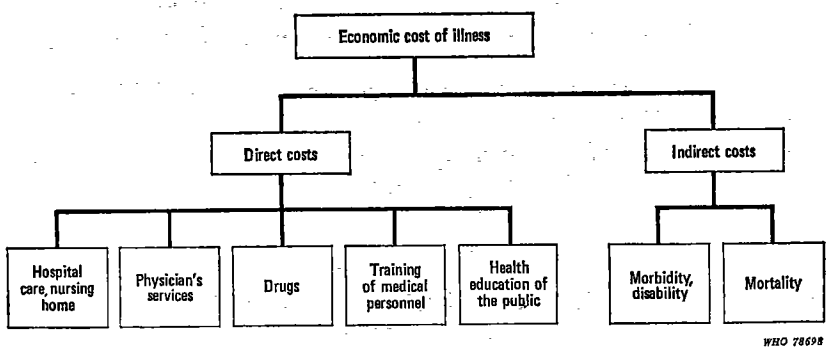
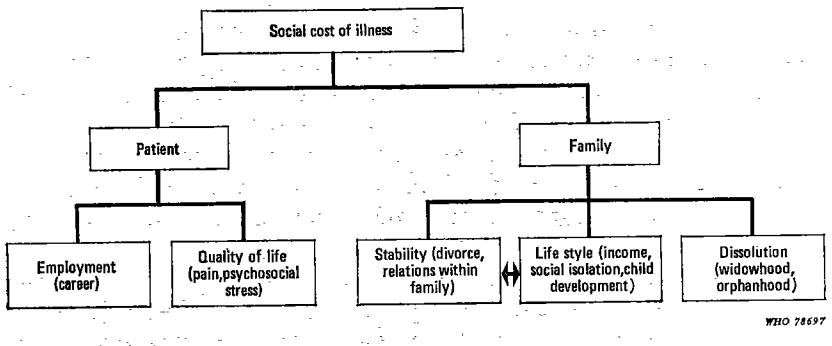


Fig. 4

Measuring the social cost of illness



of medical personnel, construction of facilities, and public health education. They thus represent the value of resources that could be allocated to other uses in the absence of disease. *Indirect* costs are the losses in output because of mortality, morbidity, and disability. A more thorough consideration of these terms will be found in the literature (*33*). Models based on a number of assumptions have been devised for the estimation of these costs, which are an extremely important component of the total economic cost of cancer.

Sometimes there is little difference in the effectiveness of alternative treatments for cancer in terms of survival and recurrence rates, and in these circumstances consideration should be given to the quality of life rather than merely the prolongation of life.

Several scales have been developed to measure particular components of social cost, but their validity has yet to be fully established. This will require surveys of affected individuals unless health-related national surveys already exist and may be used for this purpose.

Concern for the economic and social implications of disease stimulates the collection of new sets of data. For instance, it generates a requirement for a basic data set on the direct cost of illness, including the cost of medical care.

Cancer control programmes would be better supported if greater efforts were made to present the total impact of cancer on the individual, the family, and society. Calculation of the loss to society attributed to cancer should motivate decision-makers to increase support for cancer control and statistical services. Research in this area deserves increased emphasis and support (see recommendation 14).

10. INTEGRATION OF STATISTICAL INFORMATION DERIVED FROM DIFFERENT SOURCES

Data about malignant disease derive chiefly from hospitals or other branches of the health services in a country, whether public or private, which are concerned with the diagnosis, treatment, or follow-up of patients.

Morbidity data may be collected for specific areas from these sources by a cancer registry. A hospital-based registry collects information about cancer patients seen in a hospital or group of hospitals and their ancillary departments (e.g., the histopathological and haematological laboratories).

Mortality data may be collected by another branch of the department concerned with health services. Although the fact of an autopsy having been performed may be mentioned, the report of the findings of the autopsy may only be obtainable elsewhere.

The information obtained may be linked with data from other sources and used in a variety of fields. Three groups of sources may here be distinguished—census and other population data, health service data, and environmental data.

10.1 Census data

The decennial count of the population common in many countries today usually records people according to age, sex, and place of residence.

To these basic items may be added a number of others, sometimes for all the population and sometimes for a fraction only. Occupation is probably the most common addition, and ethnic group another. The census provides the essential denominator data for the calculation of rates of mortality and morbidity and, if it is sufficiently detailed, for the production of further rates by geographical, ethnic, or occupational subdivisions.

The efficient integration of the numerator and denominator information so that both kinds refer to the same groups depends on the equivalence of the boundaries defining the groups. The degree of internal migration, often subject to neither control nor record, may distort the equivalence progressively with the time lapse since the last census. Some countries hold "mid-term" censuses five years after a census; they are often conducted on a sampling basis to reduce the cost.

It is a great advantage if the territorial area covered by a population-based cancer registry corresponds to one of the geographical subdivisions used in the enumeration of the population at the time of the census. If for any reason this is not practicable, the census department should be asked to prepare official estimates of the territory's population from the specialized resources at its disposal.

10.2 Health service data

In the branch of the health service concerned with cancer control statistics (i.e., those dealing with the provision of cancer services, hospitals, treatment, manpower, and the expenditure involved under these heads) the sources of data are usually to be found within the department itself. Data permitting the comparison of cancer services with those provided for other diseases are also generally available from the same source, but again they may need to be supplemented by data from other sources (e.g., private medical services).

10.3 Environmental data

As this subject has been discussed more fully in section 7.1, it is necessary here only to note the principal sources of environmental data.

Perhaps the most useful kind of environmental information that can be collected is a record of the employment history of factory workers and their experience of exposure to hazardous agents. But many problems are involved in the collection and storage of such data, not the least being

those of cost and confidentiality. The latter may refer both to the manufacturer (trade secrets) and to the worker (personal health information). It might prove feasible to establish pilot trials for the collection of environmental data, and some guidance on carcinogenic hazards might be obtained from rapid test methods, such as that of Ames et al., based on bacterial mutagenesis (*34–36*).

10.4 Legal aspects of data collection and utilization

Many of the components of cancer statistics require for their preparation the linkage of records, often from different sources, all relating to a single individual. In some countries, each citizen has a unique personal number that is required to be used in the recording of many different items concerning that individual ; it can thus be used as the link between these items for the purpose of constructing cancer statistics. Without such a number, the name is the single most useful means of identification, in conjunction with sex and date of birth. To use the name of an individual in relation to personal medical information, frequently for purposes that are not strictly medical (e.g., epidemiological studies), may infringe the traditional confidentiality that in some countries attaches to such items. Nearly all countries protect the confidentiality of the doctor-patient relationship, though in differing degrees. In a number of European countries, for instance, the cause-of-death statement is separated from the name of the deceased person from the time of completing the certificate. Many important epidemiological studies have been frustrated by this practice, which makes it impossible to analyse mortality for cohorts exposed to specific hazards. Often such studies constitute the only practicable method of detecting and quantifying the link between a cancer and a specific carcinogen from the records of past experience, and if they cannot be completed many lives may be endangered unnecessarily. It should be possible to devise ways of using the information for scientific purposes while safeguarding the justifiable claims of confidentiality. WHO might usefully organize or encourage meetings of experts precisely with this aim in view (see recommendations 12 and 13).

Other data in government departments or in private hands, as well as certain types of industrial data, may be subject to similar prohibitions on the ground of confidentiality or security. Any general arrangements proposed for the use of confidential information under appropriate safeguards should also apply to these sources. Instances of the misuse, either of the data or of the statistical indices based on them, would no doubt be challengeable in the courts in the usual way.

11. TRAINING OF PERSONNEL

The curriculum in medical schools in both developed and developing countries is often deficient in the teaching of epidemiology and health statistics, and many medical graduates are thus ill-equipped for the task of collecting, analysing, or interpreting statistical information on cancer. Yet such graduates are frequently sent to rural health centres or hospitals where there is rarely anyone who can guide them in the techniques of data collection or analysis. Moreover, there is usually such a heavy load of curative work for them to attend to that not even the statistically inclined physician will be able to find the time to collect and analyse worthwhile data. Even where there is some instruction in epidemiology, it is usually limited to infectious diseases.

Wherever a review of the syllabus is undertaken, interest in public health and public health statistics should be stimulated. Together with improving career prospects, this policy might alleviate some of the recruitment problems in the field of health statistics.

The personnel in need of training include doctors, statisticians, social workers, other categories of health workers, and health record officers. Doctors need a good general knowledge of the aims and requirements of epidemiology and of the principles of medical statistics. They also need to be well informed about the characteristics of the community in which they are to work, its cultural and socioeconomic patterns of life, and its administrative and health services. Health statisticians, in addition to a thorough knowledge of statistics, need special training in oncology and systems of classification of tumours (e.g., ICD-O). They must be fully conversant with the population data available for the construction of rates and indices and with *ad hoc* survey methods of obtaining these data if they are not available. It is valuable if both doctors and statisticians have some familiarity with methods of health education and the use of audiovisual aids. The remaining members of the team should all be aware of the general aims of the programme and of the criteria that must be met to achieve accuracy and comprehensiveness. Social workers in particular must be thoroughly familiar with the culture of the community in which they are to work if they are to be capable of gathering and imparting information effectively. In fact, since fluent and frank communication with members of the community is so essential to the success of their work, it may be best to obtain recruits for training from the local population.

The Expert Committee welcomed the initiative of WHO in issuing or sponsoring a series of manuals (*20*, *37–39*) for training in health

statistics as a valuable contribution to the systematization of this work. This activity should be continued, and every effort should be made to ensure that the special requirements of developing countries are taken into account. The use of training fellowships to allow professionally qualified persons to receive special instruction and to gain experience at existing centres would be a valuable adjunct to the preparation of training manuals.

With regard to WHO's role in the area of education and training of personnel, the emphasis should be on steps designed to strengthen national capabilities. Wherever possible, staff should be trained in socioeconomic and cultural settings similar to those in which they would practise.

12. PRIORITIES FOR FURTHER DEVELOPMENT

It is in the developed countries that most new information is likely to originate concerning industrial carcinogenicity, and it is in the developing countries that most new information is likely to be gathered on ethnic, cultural, and geographical factors in the etiology of cancer. In most developed countries, cancer is the second-ranking cause of death; in the developing countries, it is usually in a lower position. It is worth repeating that, with anticipated demographic changes and progress in medical and social services in these countries, the importance of cancer will increase. Because the impact of the disease is greatest in the upper age range, it is not difficult to outline the future requirements of a cancer care service, given the current demographic data and the current incidence rates of the disease. Such projections, together with those for other major disease groups, permit the forward planning of health service requirements, based essentially on the continuance of certain fundamental patterns such as incidence–age curves (see section 8 and recommendation 15).

In the developing countries the major priority is the setting up of new cancer registries in strategically chosen situations. They may take the form, initially, of hospital-based registries, but the aim should be to transform them as quickly as possible into population-based registries for a defined region. Incidence rates calculated from the data they provide, in association with census data, will then provide internationally comparable statistics as well as the raw material for planning the future provision of cancer care (see recommendations 2, 3, 4).

In the developed countries, especially those with few cancer registries, an early priority should again be to establish such registries, though it

may first be necessary to overcome legal constraints on the acquisition of data. In those countries where good registries already exist, there is usually scope for improving the quality of the data and of the indices based on them. Indeed, the importance of quality control systems in all stages of the work of cancer registries is becoming increasingly recognized, particularly where more advanced registries are concerned. However, quality control is equally relevant and applicable to smaller and simpler registries.

In both developed and developing countries it is of great importance to try to make the data-base for cancer statistics correspond to that for environmental statistics so as to provide matching data sets and thus maximize the potential yield of correlations. It is from these sources that the most useful information on etiology, and thus of preventive measures, can come. But this same process of linkage of matching data sets—often by computer—has, in other fields, caused disquiet on the ground of breach of confidentiality, sometimes leading to prohibition of the exchange of such information. Whatever the justification for these barriers on the grounds of individual freedom and privacy of personal information, their effect is virtually to deny access to one of the richest sources of human etiological data. It is therefore imperative that this type of information should continue to be available for epidemiological analysis, subject to appropriate regulations or the licensing of those to be entitled to use it (see recommendations 9, 10, 11, 12, and 13).

In a less sensitive area, though of comparable importance, are those statistics that may be classed as evaluative. They are used to measure the effects of treatment, and they range from the recording of the crude survival rate to the comparative appraisal of the quality of life after treatment. Although the crude survival rate is simply defined, its value for interpretation and the drawing of inferences is limited, particularly when used for comparison. In consequence, it is necessary to obtain international agreement on the methods of adjustment or standardization for such variables as age and stage of disease. Closely related to the criteria for the evaluation of routine treatment methods are the criteria for the organization and evaluation of clinical trials, in which the requirement of ready comparability between different centres is of especial importance.

The methods of classification, the definitions of the statistical indices, and the uniformity of data collection for both numerator and denominator information are all of central significance in the development of a cancer statistics system. It is in these areas, therefore, that international

discussion and agreement can be of most immediate value (see recommendation 5).

13. CONCLUSIONS

1. The Expert Committee expressed its satisfaction with the endeavours of WHO to implement previous Expert Committee recommendations on cancer statistics. In certain areas, such as the classification of malignant disease and the international compilation, dissemination, and interpretation of incidence and mortality data, considerable progress has been made. The hope was expressed that the momentum would be maintained and that, in its future programme orientation, WHO would pay adequate attention to new developments.

2. The usefulness of developing comprehensive and coherent cancer statistics was emphasized. Such an approach of integrating statistics from various sources in order to obtain as comprehensive as possible a picture of the cancer situation and the burden it places on medical care resources should be of great assistance in cancer prevention and control.

3. The Committee selected the following as new areas requiring urgent attention :

(*a*) the development of guidelines for the collection of cancer statistics in developing countries ;

(*b*) the development of criteria and standards for assessing the quality of life after treatment and the updating of previous recommendations concerning measurement of survival experience ;

(*c*) the generation of data on the relationship between cancer and the environment.

4. The Committee listed the following approaches, which it considered relevant to the whole health sector :

(*a*) the training not only of health statisticians and epidemiologists but of all health professionals in the generation and utilization of health statistics, with the particular aim of strengthening national capabilities in developing countries ;

(*b*) the stimulation of developments in areas of increasing importance in health policy formulation and evaluation, such as the estimation of the social and economic impact of illness and the projection of disease frequency and resource requirements ;

(*c*) the more extensive use of statistical methods for evaluating the accuracy of health-related statistics and the making of vigorous efforts to close certain gaps in statistics—e.g., those on health expenditure ;

(*d*) the development of guidelines on the linkage of data sets on the individual, in order to permit the assessment of health hazards associated with various exposures, full consideration being given to methods of safeguarding confidentiality.

14. RECOMMENDATIONS [6]

Statistics on cancer patients

1. WHO has played a major role in improving the quality, standardization, and utilization of cancer and other mortality statistics during the past three decades. These efforts should be continued by :

(*a*) the publication of detailed data and summary analyses of morbidity and mortality rates by country ;

(*b*) the periodic review of data available on specific cancer sites ;

(*c*) the periodic investigation of the quality of data in different parts of the world, these investigations being carried out in close collaboration with Member countries.

2. Countries that have not hitherto collected mortality statistics should be encouraged to establish cause-of-death reporting for all diseases, including cancer. Initially, such reporting might be limited to selected areas of the country in which the most complete and accurate reporting can be obtained. When applicable, deaths certified by physicians should be distinguished from those reported by others.

3. In carefully selected areas, WHO should continue to encourage the development of cancer registers, both hospital- and population-based, to provide information on cancer patterns and other information for control, planning, and research purposes. Registries should collect the uniform minimum set of data recommended in the *WHO handbook for standardized cancer registers* (*20*). There should be continuous quality control during all phases of cancer registration in accordance with the initiatives of the International Association of Cancer Registries. One criterion for the selection of areas for the development of cancer registries

[6] Wherever WHO is mentioned in these recommendations, it is intended that the reference be to WHO and/or IARC, the distribution of tasks between the two agencies being determined by the agencies themselves.

might be knowledge of unusual environmental exposures in the population.

4. Statistical activities in developing countries should be encouraged, and WHO should establish a subcommittee of the WHO Expert Committee on Health Statistics to study the problems of cancer statistics in such countries. It should determine the priorities for the different kinds of statistics that might be developed and draw up criteria for establishing and evaluating mortality data.

5. A subcommittee of the WHO Expert Committee on Health Statistics should be established to advise on standard terminology, definitions, and methods of statistical analysis that could be used in the description and measurement of survival of cancer patients. This standardization would lead to greater intercountry comparability of survival statistics. Particular emphasis should be given to the development of criteria for measuring the quality of life of cancer patients.

6. Procedures to measure the impact of programmes designed to provide physical, psychological, vocational, and social rehabilitation of cancer patients should be developed and implemented. They would include methods of assessing the cost-benefit and cost-effectiveness of such programmes.

7. WHO should further encourage the collection of data on cancer screening activities. Such data are needed for administrative purposes and for determining the cost and potential risks of screening activities.

8. WHO should continue, and if possible expand, its work of assessing the efficacy of specific forms of cancer screening.

Statistics relating to the detection of environmental carcinogens

9. WHO should coordinate an international effort to survey areas in which cancer patterns are well defined in order to determine the extent and availability of environmental data that may be relevant to human cancer causation. If such data are available, WHO should coordinate the establishment of appropriate mechanisms, national or regional, that could assist in locating, gaining access to, and using such data.

10. Governments should be encouraged to coordinate statistical information from different sources. A particular need is for the coordination of environmental data with information on mortality and morbidity in the local population. In addition, appropriate denominator data are

required for most health statistics, and information on the distribution of cancer must therefore be collected in relation to census categories (e.g., occupational, ethnic, and social).

11. Since a rational approach to cancer prevention lies in the assessment of environmental exposures (e.g., personal habits, diet, and other facets of life style, including occupational history) and the health effects of such exposures, encouragement should be given to research based on the matching of relevant sets of data for individuals, with due regard to the preservation of anonymity.

Data protection and privacy

12. WHO should formulate guidelines for the matching of data sets (such as those referred to in recommendation 11) and thus help governments to resolve the conflict between the wish for complete confidentiality of personal information and the need for identification of health hazards in the population. When governments review their legislation on the confidentiality of statistical information, they should ensure that new regulations permit the continuation of the kinds of research needed to elucidate the causes of cancer and other diseases in humans.

13. WHO should exert its influence to ensure that the identification of carcinogens in the human environment is not obstructed by commercial secrecy.

Cost and projections

14. A subcommittee of the WHO Expert Committee on Health Statistics should be established to review the methodology of studies of the social and economic costs of disease, including cancer.

15. A subcommittee of the WHO Expert Committee on Health Statistics should be established to consider several aspects of health trend projections. The terms of reference would include consideration of whether or not WHO should prepare such projections for global purposes, particularly in relation to its medium- and long-term strategy, and if so to what level of detail. The reliability of various methods and the assumptions on which the methods are based should be evaluated.

Personnel

16. Since the development of statistics on cancer and other health problems is greatly impeded by the shortage of qualified personnel,

including epidemiologists, medical statisticians, computer personnel, and trained field workers, WHO should support activities aimed at strengthening the epidemiological and statistical resources of countries. These activities should include :

(*a*) the continuance and extension of its programme of short courses in health statistics, cancer statistics, occupational statistics, cancer registration, and related subjects ;

(*b*) the development of curricular guidelines that would promote sound training in epidemiology and medical statistics in medical schools, teaching hospitals, and schools for allied health professionals ;

(*c*) the encouragement of statisticians and computer personnel to enter the health field (through the establishment of fellowships, for example) and the provision of short training courses to strengthen their knowledge of health ;

(*d*) the encouragement of governments to establish departments of epidemiology, medical statistics, or preventive medicine in medical schools where such departments do not now exist, provided that qualified staff are available in the country concerned.

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REFERENCES

1. WHO Technical Report Series, No. 164, 1959 (Sixth report of the WHO Expert Committee on Health Statistics).
2. *Recent levels and trends in mortality : a joint United Nations/WHO study* (in press).
3. *World health statistics annual, 1977. Vol. 1 : Vital statistics and causes of death.* Geneva, World Health Organization, 1977.
4. WHO Technical Report Series, No. 25, 1950.
5. WHO Technical Report Series, No. 53, 1952.
6. *Cancer incidence in five continents.* Lyons, International Agency for Research on Cancer, 1976, vol. III (IARC Scientific Publications, No. 15).
7. *Demographic yearbook 1976.* New York, United Nations, 1977, p. 13.

8. Report on a consultation on methodological approaches to cancer health services, Geneva, November 1974 (unpublished WHO document CAN/74.13).

9. CLEMMENSEN, J. In : Shivas, A. A., ed. *Racial and geographical factors in tumour incidence*. Edinburgh, Edinburgh University Press, 1967, p. 4.

10. *World health statistics annual, 1977. Vol. 1 : Vital statistics and causes of death*. Geneva, World Health Organization, 1977, p. 684, Annex II (Users' guide to standardized computer tape transcripts).

11. *ICD-O : International classification of diseases for oncology*. Geneva, World Health Organization, 1976.

12. SOBIN, L. H. ET AL., ED. *A coded compendium of the International Histological Classification of Tumours*. Geneva, World Health Organization, 1978.

13. Report of a meeting on cancer statistics information subsystems, Minsk, September 1976 (unpublished WHO document DSI/CAN/WP/76.16).

14. HANSLUWKA, H. *World health statistics quarterly*, **31** : 159 (1978).

15. Report of a meeting on sources of cancer statistics, Lyons, 1968 (IARC internal technical report 68/003).

16. *TNM classification of malignant tumours*, 2nd ed. Geneva, International Union Against Cancer, 1974.

17. *International Histological Classification of Tumours*. Geneva, World Health Organization (No. 1, 1967 – No. 20, 1978).

18. LOGAN, W. P. D. *World health statistics quarterly*, **31** : 62 (1978).

19. *The registry in cancer control*. Geneva, International Union Against Cancer, 1970 (UICC Technical Report Series, vol. 5).

20. *WHO handbook for standardized cancer registers (hospital based)*. Geneva, World Health Organization, 1976 (Offset Publication No. 25).

21. Report of a meeting on the standardization of the reporting of results of cancer treatment, Turin, 1977 (unpublished WHO document CAN/77.1).

22. MACLENNAN, R. ET AL. *Cancer registration and its techniques*. Lyons, International Agency for Research on Cancer, 1978 (IARC Scientific Publications, No. 21).

23. WHO Technical Report Series, No. 429, 1969 (*Statistics of health services and of their activities*).

24. PRESTON, S. H. *World health statistics report*, **27** : 719 (1974).

25. PRESSAT, R. *World health statistics report*, **27** : 516 (1974).

26. Report of a consultation on health statistics projections (unpublished WHO document DSI/72.3).

27. WINSLOW, C.-E. A. *The cost of sickness and the price of health*. Geneva, World Health Organization, 1951 (Monograph Series, No. 7).

28. ABT, C. C. *Social indicators research*, **2** : 175 (1975).

29. *World health statistics report*, **29** : 220 (1976).

30. FEICHTINGER, G. & HANSLUWKA, H. *Zeitschrift für Bevölkerungswissenschaft*, **4** : 51 (1977).

31. *The impact, costs and consequences of catastrophic illness on patients and families.* New York, Cancer Care Inc. & National Cancer Foundation, 1973.

32. PRESTON, S. H. *Social biology*, **21** : 144 (1974).

33. HODGSON, T. A., JR. The economic costs of cancer. In : Schottenfeld, D., ed. *Cancer epidemiology and prevention.* Springfield, IL, Charles C. Thomas, 1975.

34. AMES, B. N. ET AL. *Proceedings of the National Academy of Sciences of the United States of America*, **70** : 2281 (1973).

35. *IARC monograph programme on the evaluation of carcinogenic risk of chemicals to man : preamble.* Lyons, International Agency for Research on Cancer, 1977 (IARC internal technical report No. 77/002).

36. *Principles and methods for evaluating the toxicity of chemicals. Part I.* Geneva, World Health Organization, 1978 (Environmental Health Criteria 6).

37. CAMPBELL, H., ED. *Manual of mortality analysis.* Geneva, World Health Organization, 1977 (not for sale ; available from Division of Health Statistics, WHO).

38. CHIANG, C. L. *Life table and mortality analysis.* Geneva, World Health Organization, 1977 (not for sale ; available from Division of Health Statistics, WHO).

39. LOWE, C. R. & LWANGA, S. K., ED. *Health statistics : a manual for teachers of medical students.* Oxford, Oxford University Press, 1978.

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