THE ROLE OF EPIDEMIOLOGY IN ACHIEVING CLINICAL BEST PRACTICE

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Introduction

The escalation of health care costs during the 1980s and 1990s resulted in the demand for accountability of the health care industry by policy makers, health service providers and consumers. This call for accountability has provided the impetus for the rapid development and progression of *evidence-based medicine* philosophy. The Cochrane Collaboration internationally has lead to the analysis of clinical trial data and also lead to its dissemination via the Web. Priorities identified in the *National Health Information Development Plan*[1] and the *Taskforce on Quality in Australian Health Care*[2] emphasised the importance of record linkage of health data to assess health outcomes, and the increasing demand by the health care industry and consumers for explicit standards of care for the evaluation of surgical practice and outcomes.

Governments and health authorities are increasingly taking seriously their responsibility in ensuring best outcomes. This has been seen with its support of Cochrane Centres and, more recently, with its establishment of Australian Council for Safety and Quality in Health Care (ACSQHC). Rather than concentrating on bureaucratic issues associated with quality, funding is finally being made available to clinicians to enable them to improve outcomes. There has also been a realisation that many of the adverse events that occur are associated with structure and process of health care delivery, rather than individual clinician error.

Providing the best practice information and encouraging evaluation, however, is only part of the story. To try to encourage uptake of what is known to be best practice, the Federal Minister for Health and Aged Care established the National Institute of Clinical Studies in December 2000. Its role is to work with consumers, health professionals and health organisations to close the gaps between evidence and clinical practice in those areas that will effect significant change in health outcomes.

There are multiple reasons as to why best practice does not occur. First, it may be lack of research data confirming what is best practice. Second, there may be a failure to disseminate that information for clinicians. There also could be structural impediments in the way the health care system is organised to prevent best practice at individual clinician level but also in teamwork. This potentially applies to the multidisciplinary care of cancer.

A further, and major, impediment is the evaluation of health care and its outcomes for the individual clinician, organisation, and its subsequent feedback to those clinicians and organisations to 'close the loop'. Herein lies the value of epidemiology. Epidemiology is the study of the distribution and determinants of morbidity in populations[3]. It focuses on the factors that influence health, the control of disease and disability and the measurement of health outcomes and it is integral to public health. It can define the population-requiring

service and, with record linkage, as occurs in Western Australia, can track long-term outcomes of care.

In keeping with the move to assess the quality and outcomes of surgical care, the Quality of Surgical Care Project (QSCP)[4] was established in Western Australia (WA) in 1996 as a collaborative venture of the Royal Australasian College of Surgeons (WA), Department of Public Health (University of WA) and the Health Department of WA, and facilitates multidisciplinary collaboration towards better planning, provision and evaluation of surgical services. The QSCP is a unique quality assurance program in Australia with a focus to promote best practice in surgical and procedural care. The specific objectives of the QSCP are to:

1   describe the clinical epidemiology of selected diseases requiring surgical care;

2   monitor trends in utilisation of surgical procedures;

3   establish benchmark standards of surgical care;

4   compare results with national and international standards of best practice;

5   evaluate and compare the outcomes of new procedures with those of established surgical procedures;

6   recommend and evaluate the implementation of appropriate changes in surgical practice; and

7   disseminate the results of the evaluation process to surgeons, the RACS, health service managers and policy makers, and consumers.

The surgical procedures for review have been selected on the basis of national priority, in consultation with the RACS and with input from the Australian Safety and Efficacy Register of New Interventional Procedures-Surgical (ASERNIP-S).

The QSCP's contribution to quality assurance in surgical care in Australia is possible due to the existence of the unique WA Record Linkage Project.[5] Record linkage of health service data will allow the development of models to evaluate health service outcomes, particularly at the community level and is one of the top priorities of the federal Government. Large-scale, systematic applications of record linkage in health research are uncommon due to the necessary commitments to long-term planning and inter-agency cooperation. The WA Health Services Research Linked Database (WA Linked Database) brings together around 9 million records and consists of population-based hospital morbidity data, birth and death records, mental health services data, cancer registrations and midwives' notifications, linked back to 1980[4]. In addition, it is intended, in future extensions, to include data on primary, residential and domiciliary care and health surveys. Linkage is performed using probabilistic matching of patient names and other identifiers. Geocodes for spatial analysis are assigned using address linkage and mapping software. The use of record linkage in health services research has attracted support because it has distinct advantages over methods involving case series based at one or more hospitals or clinics[4,6-8]. The real value is that the determined surgical outcomes are for all patients of all surgeons, ie all comers not just those in clinical trials or teaching institutions.

Hospital-based cancer registers are the most common source of information on the processes and outcomes of cancer care[8]. Although they are rich in detail on the disease and its

management and outcomes, these collections are not representative of the care and outcomes of cancer in the whole population. To complement the knowledge-base provided by these specific registers, the integration of data on care and outcomes from administrative systems of health care institutions covering the whole population offers the possibility of representative information at comparatively little cost[4,5,7,8].

Clinical epidemiology

The WA Data Linkage Project has already been used to evaluate the demographics, clinical epidemiology and outcomes of cancer care including colorectal cancer[9,10]; breast cancer[11]; benign prostate hyperplasia[12,13]; oesophageal, stomach, and pancreatic cancer; and ovarian, cervical and uterine cancers. These features include age-specific and age-standardised incidence and mortality trends back to 1982; procedural treatment patterns, including shifts in practice; post-operative complications; hospital readmission by time period, eg within 30-days; and survival analysis including crude, actuarial, Kaplan-Meier and relative survival. This data is of particular value for the less common cancers requiring major surgery as the concentration of cases in limited specialist centres may improve outcomes. It is planned that surgeons will be provided with state-wide standards as well as their own results and so be able to compare themselves against these standards. In rectal cancer for example, concentration of practice has resulted in lower local recurrence rates and sexual dysfunction[14], as well as a trend in Western Australia towards performing sphincter-saving operations (anterior resection), as opposed to abdominoperineal resection[9,10]. This has resulted in marked improvements in the quality of life of these patients. This latter trend (10% improvement between 1988-9[5]) has been supported by the use of circular stapling devices, improved operative technique, the acceptance of a distal clearance of 2cm in low rectal cancers and an increased public awareness of alternatives to permanent colostomy. While the shift in surgical practice is consistent with the international recommendation to preserve the anal sphincter and is comparable to other recently-published community series, it is still well below the standard reported in specialist centres. This means that for low rectal tumors, patterns of rectal repair may need to change even further.

Prevalence modelling

Historically, planning of cancer services tends to have been based on estimates of cancer incidence rather than prevalence. The prevalence of a disease is the number of patients alive with the disease at a specified point in time, whereas the incidence of a disease is the number of new cases in a defined period of time. However, recent innovations in methods to measure cancer prevalence that take account that many patients may be cured mean that we can now make meaningful estimates of cancer prevalence that allow for greater precision in the planning of cancer services. This is particularly desirable due to the wide range of services that are available, for example, post-operative adjuvant therapy, physical and psychosocial support services and palliative care.

At the simplest level, all cancer registries that collect follow-up information may calculate cancer prevalence in terms of the number of patients diagnosed in the last X years. These estimates need not be affected by the length at which the Cancer Registry has been in existence. A registry that has only been in existence 12 years, for example, can still produce estimates of the number of prevalent patients diagnosed in the last year, the last five years or the last 10 years. Such estimates of prevalence are more useful than trying to estimate the number of all prevalent patients as any trend data will be based on a varying number of years' data. In addition, the time since diagnosis is reflective of the type of treatment required by the patients. This approach has been used by the European and Nordic Cancer Registries as well as South Australia and Western Australia[15-18].

An estimate of the proportion of prevalent patients who will require treatment for their disease at present or in the future may also be calculated using a relative survival model as proposed by Coldman et al[19]. Using relative survival, a "time to cure" can be calculated[19]. This is the stage at which the relative

Table 1

Cancer incidence, prevalence, hospital admission rates and length of stay in hospital, Western Australia, 1997

	Cancer type						
	All	Bladder	Breast (f)	Colorectal	Leukaemia	Lung	Prostate (m)
Incidence*	3.5	0.1	1.0	0.5	0.1	0.4	0.8
Prevalence measures*:							
Active prevalence	7.4	0.1	2.5	0.9	0.2	0.4	4.0
Diagnosed in last year	2.7	0.1	1.0	0.4	0.1	0.2	0.9
Diagnosed in last 5 years	11.2	0.2	4.7	1.4	0.2	0.5	5.3
Diagnosed in last 10 years	16.7	0.3	7.3	2.1	0.3	0.6	6.4
Admission rate1†	2.9	9.4	2.4	4.9	18.9	3.3	0.3
Admission rate2†	1.3	6.1	0.7	1.0	6.9	1.6	0.3
Length of stay1††	11.0	22.4	5.0	14.1	66.8	15.8	2.1
Length of stay2††	8.7	18.7	3.2	8.7	43.7	13.1	1.8

*   Incidence and prevalence per 1000 population
†   Admission rate per 1000 prevalent patients (active prevalence)
††   Average length of stay per prevalent patient (active prevalence)
1 = including chemotherapy and radiotherapy
2 = excluding chemotherapy and radiotherapy

survival curve straightens out, when there is no longer any excess mortality from the disease. The proportion of patients who die before this point will be those who have ongoing disease requiring treatment.

Having defined a population of patients requiring treatment for cancer, it is then possible to study service utilisation in that group of patients. For example, record linkage of hospital morbidity data to Cancer Registry data, as in the WA health services research-linked database, allows the calculation of hospital admission rates and length of stay in hospital per prevalent patient[12]. This is illustrated in Table 1.

Prevalence measures provide a more accurate indicator of the level of disease in the community than incidence measures and will better reflect the mix of cancer patients presenting to General Practitioners. Recent research in Western Australia shows that the active prevalence of cancer is rising and indicates that General Practitioners, as well as cancer specialists, will be increasingly required to provide on-going care to patients who are living with active disease, many for a considerable number of years[18]. As stated in the latest report of the South Australian Cancer Registry, "Trends in prevalence are of direct interest to health-service planners and should be included routinely in outputs of population-based cancer registries"[17].

Survival analysis

The observed survival rate from cancer represents the proportion of cancer patients that survive for a specified time after diagnosis. The relative survival rate adjusts the observed survival rate for expected mortality and thus takes into account that the patient may die from a cause not specifically associated with their cancer.

While South Australia has been producing reports on cancer survival for a number of years, more recently reports on survival have also been published by New South Wales, Western Australia and Queensland and the first national reports on cancer survival in Australia are planned for release shortly[21-23]. Despite various problems with data quality and in comparing data between Australian States and Territories and other countries we can now begin to monitor cancer survival over time and to compare cancer survival in Australia with other countries. Without such data we have no basis by which to compare the effectiveness of treatment programs, to see if new treatment regimes are improving patients outcomes and to identify the structures, processes and outcomes of care that may give patients in one state/country an advantage over those in another state/country.

Monitoring of population-based data on cancer survival ensures that we consider the outcome of care for all cancer patients and not just those who are eligible for clinical trials. To inform patients of their prognosis following cancer diagnosis, accurate survival data by age-group, sex, period of diagnosis, histological type of cancer and cancer stage is required.

The WA Record Linkage Project has renewed the vision initially proposed by Hobbs and McCall three decades ago and provides the facility to produce routine measures of the performance of health services[24]. The increased public awareness of the benefits of record linkage, and the facility to include additional datasets such as the state electoral roll, specific hospital-based cancer registers, and Commonwealth datasets like the Pharmaceutical Benefits Scheme and National Death Index will increase the potential of record linkage to contribute to the investigation of disease aetiologies, prevalence modelling, identification of factors influencing health and the utilisation of health services, and establish standards for surgical care and consequently planning and

allocation of resources. An imperative of these research activities is that the results are provided to clinicians and organisations to close the loop if research outcomes are to contribute to the knowledge base of evidence-based medicine and influence clinical practice. □

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