

Announcement

Due to the numbers and quality of papers submitted, JECH will from 1992 be published six times a year, in February, April, June, August, October, and December. This will greatly reduce publication delays.

Editorial

The epidemiology of indications

As the dust clouds from the NHS reforms begin to clear, a large hole is becoming discernible where the epidemiology of indications might be. A central strand to the current reforms is that the balance of health care is to be guided more by the needs of the populations served than by historical patterns of provision. The assessment of health needs has long been seen as one of the uses of epidemiology,¹ and is accepted as a key function of the practising professions that draw upon the discipline. The suggestion that patterns of provision should be guided by health needs assessments may have seemed an innocuous, even platitudinous, statement at the time of the introduction of the reforms.² It has therefore proved somewhat mortifying, at least to those practitioners expected to deliver what the discipline nominally offers, to discover the poverty of the relevant epidemiological research record. A cursory scan through each of the broad health care activities where purchasing authorities are expected to make informed decisions reveals, with notable exceptions,³ an impressive dearth of pertinent evidence.

There is a considerable body of evidence concerning health needs as these are reflected in the general health status of the population, but remarkably little is known about levels of population needs for health care. However clear the distinction between the terms "health needs" and "health care needs" may appear to be, when it comes to "health needs assessment" these two distinct attributes have become confused. One expression of this confusion is the administration of "health profiles" to local populations in order to advise purchasing authorities on appropriate levels of health care provision. This activity is better seen as a displacement activity that is professionally reassuring at a time of uncertainty, rather than as a productive means of "health needs assessment". Research activity has been concerned almost exclusively with the probability of neediness, and not with the distribution of those who might be expected to benefit from particular interventions. The established measures of need^{4,5} are no more than independent variables of uncertain relevance to the decisions about the need for health care that concern those engaged in commissioning provision. Ambiguous references to health needs assessment can be avoided by using the term "health care requirements" rather than "health needs" to refer to the needs for particular services.⁶ The global view of health needs can then be complemented by a focus upon the requirements for particular interventions.

Just as studies of the volume of health care activity offer insights into the priorities of health care professionals, so the undeveloped state of population studies of health care

requirements reflects the priorities of epidemiologists. There are two broad categories of explanation for this predicament: there may be problems of commitment; alternatively there may be problems of method.

The justification for the funding of epidemiology is in its application. While this may be true in general terms, in practice the priorities of the discipline are influenced strongly by the tradition in academic life which decries "applied" work. There is therefore an inverse relationship between the time scale of potential applications of research and their perceived merit. Investment in this sort of research likely to be most relevant for informing the balance of health care provision has been less likely to be rewarded than long term aetiological research, however pedestrian that may have been. These problems are common to other disciplines that bridge theory and practice. For example one prominent anthropologist confessed, "the anthropologist often offers his help, but seldom condescends to give it".⁷ There may be some echoes here in the priorities of epidemiologists. This general problem of commitment has been compounded by a more focused disinterest in the conditions which are of immediate concern to purchasing authorities. This is especially the case for the waiting list conditions.⁸

Whatever barriers the research priorities of the discipline may offer, it is essential to confront the proposition that a research base is illusory for decisions that may properly be dominated by politics and expediency. The constituent characteristics of health care requirements do present particular problems of measurement. It is therefore important to consider each of these characteristics in turn and judge whether they are amenable to valid measurement.

To date studies of the conditions that concern health authorities have concentrated upon the distribution of particular forms of pathology as ascertained by a narrow range of diagnostic measures, to the exclusion of variables that relate to wider aspects of requirement. The case of total hip replacement can be used to illustrate the problem. Many studies of the prevalence of radiographic hip and knee osteoarthritis have been published, which in total have involved the examination of some 20 000 individuals.⁹ However the relationship between radiological change and symptomatology is uncertain. Further, the indication for surgery must take account of other factors such as the presence of comorbidity. While the requirement for joint replacement surgery must have some relationship with levels of disease as ascertained in these studies, the relationship is so uncertain as to make the available findings largely valueless for informing

the decisions facing purchasing authorities. The only study that has attempted to address the question of the requirement for surgery in the treatment of this condition was undertaken by a geriatrician,¹⁰ perhaps in itself an implicit indictment of the prevailing priorities for epidemiologists.

Similar limitations are apparent in relation to other conditions where decisions must be made concerning the appropriate levels of provision. There are pressures to increase the provision of coronary artery bypass surgery, but no population data are available to inform a view on what may be adequate levels of provision. The epidemiology of cataract¹¹ does not encompass those attributes that impinge upon the decision to treat. Data concerning the population distribution of benign prostatic disease are largely confined to evidence based upon prostatic morphology and histology, though again there is an uncertain relationship between these characteristics and symptoms of prostatism. The evidence is no more balanced for non-surgical conditions. Stroke is a good example here: "More is known about stroke than about most other neurological diseases, but there are no detailed studies of the prevalence of specific disabilities and problems. For example we do not know the number of patients with asphasia or epilepsy, the number needing support from home care services, the number in long term hospital care, or the number unable to leave their house . . . Further, little is known about the ideal balance between home and hospital services or the value of special wards".¹² With one notable exception,¹³ the relationship between stroke and disability, and hence health care requirements, has not been drawn.

Levels of health care requirement depend not just upon the prevalence of the condition, but upon the prevalence of cases of the condition where treatment would be indicated, tolerated, and desired by the particular sufferer, and also approved of in general as a proper use of the health budget. These latter characteristics, the acceptability of the intervention to the individual and the more general priority that it may attract, present particular problems of interdisciplinary collaboration. But the former characteristics are no more than a formal expression of the indications for treatment.

The broad methodology for deriving such criteria for intervention, which must accommodate the paucity of formal evidence concerning effectiveness and reach authoritative and clinically convincing consensus, is well described.^{14 15} An interest in defining the indications for treatment is given added momentum in the USA by a wish to control the escalating costs of health care; defined criteria of appropriateness offer a mechanism for limiting entitlement for reimbursement. The method would be the same whether one is concerned with the decision to treat, or with the population distribution of indications. The American work on appropriateness has not been complemented with an interest in examining the distribution of such indications in the population, as the American health system provides little relevance for a population perspective. The translation of threshold criteria into population research instruments is a relatively straightforward task, whether these are derived for a particular piece of population research, or simply adapted from a set of clinical criteria. Definitive work of this sort is clearly contingent upon adequate data on the outcome of treatment for differing categories of patient, in that adequately supported indications for intervention must depend upon evidence that the intervention is effective. Nevertheless, those aspects of health care requirements that represent the population distribution of formal clinical indications do not raise particularly controversial research questions.

The question of individual preferences raises a different set of issues. The relative neglect of what could rather passively be termed acceptability results in clinicians and epidemiologists making assumptions about what treatments people may or may

not want. This question of acceptability entails more than the veneer of sensitivity that is seen as appropriate for the consumer age. Acceptability is at the heart of the definition of requirement, and its measurement can affect health care requirements in major respects. For example in the case of one of the elective surgical procedures where the NHS appears to have failed in satisfying demand, prostatectomy, the relationship between the severity of symptoms and the degree to which people are concerned by them is not strong.¹⁶ An acknowledgement of possible patient preferences for "watchful waiting" rather than immediate surgery would result in a major downward revision in assessments of the requirement for prostatectomy.¹⁷

When deciding whether or not to treat, clinicians do consider a range of non-clinical characteristics of the person and their experience. When discussing the preparation of guidelines surgeons often comment that each patient's circumstances are different, so that it is not practical to generalise these concerns about the broad impact that the condition has upon the person's life, and the particular benefit that may follow treatment. The problem of surgical variation does not seem to follow differing interpretations of appropriateness,¹⁸ but the possibility that such variation may be explicable in terms of variations in clinicians' views of the salience of treatment should be considered. These formal indications of the uncertain relationships between people's own observations and conventional clinical categories are markers of a crucial methodological question. The process of obscuring the experiences and preferences of subjects with the dominant rubric of clinical assumptions can be seen as an intimate example of the process of medicalisation. The fact that the technical interventions of surgery are properly the monopoly of the medical profession does not imply that the conventional pathophysiological framework for describing a disorder should provide the key discriminators. This is particularly the case where the condition concerned is distressing rather than life threatening. Where distress is the issue, the sufferer's view of the level and quality of the distress must be a key issue in deciding whether treatment is indicated, and whether the outcome of treatment is favourable.

It is accepted that lay views of illness are characterised by a rationality distinct from the medical view. The task of retrieving people's experience in their own terms is the particular province of anthropology and interpretative sociology. In order to avoid the fallacy of assuming that the views of subjects and clinicians coincide, any study of requirement or outcome must begin with an ethnography of the particular predicament. In the case of particular conditions this general observation may have clear implications for methods of determining requirement for or outcome of treatment. For example, ethnographic studies of rheumatoid arthritis indicated that the pain is interpreted in terms of its impact upon particular obligations or activities;¹⁹ simple pain scales are therefore of questionable value. One reason why similar research has not been done in relation to common conditions and interventions may be that the criteria are assumed to be clear cut. The prostatectomy research suggests that many areas assumed to be without controversy are likely to repay intensive enquiry.

The final characteristic of health care requirements, the wider priority that the intervention is to be accorded, is safely beyond the bounds of epidemiology, though within the concerns of public health. Indeed guidance upon priorities for health care is one of the key expectations for the contribution of public health medicine within purchasing authorities. A key disciplinary contribution comes from health economics, though the available research has to date concentrated upon single conditions, and not attempted major comparisons between interventions for different conditions. The potential role of formal methods in determining public preferences is

not clear. The only major attempt that has been made to derive a set of priorities from the principles of cost-benefit analysis produced a result so counterintuitive that the list had to be modified on informal grounds to produce a more credible set of priorities.²⁰ Nevertheless a longer term complement to the epidemiology of indications must be a rigorous approach to the reflection of public priorities, presumably entailing variants of the Oregon Health Services Commission at appropriate levels of the health system.

There is no immediate expectation that practising epidemiologists will provide empirical solutions to these more general problems, but there is a strong expectation that they will guide patterns of provision through "health needs assessments". Even a relatively modest extension of disease epidemiology into the realm of the population distribution of indications for treatment results in an inescapable confrontation with the traditional distaste for qualitative methods and individuals' experience. The reforms of the NHS are being implemented with the assumption that one of the discipline's implicit promises will now be redeemed. The failure to accumulate relevant evidence has arisen not only by default. If the discipline is to be able to satisfy a proportion of the inordinate expectations upon it, these problems of method will have to be confronted.

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