2 Epidemiology

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The increase in the proportion of old people in the population has given prominence to mental illness in old age. Society is forced to make decisions about how many and which services to provide to the older community. Mental illness is one of the largest areas of activity in the health service, with mental disorders of the elderly an important part of it.

Demographic trends

The population of the UK is roughly 58 million, 16% of whom are over the age of 65. By the year 2034, the total population is projected to be around 60 million and 24% will be aged 65 or over (Government Actuary's Department, 1996). The number of people aged over 85 will have risen from one to two million. At the beginning of this century the population was much smaller (33 million) and the proportion of older people much less (5% aged over 65) (Central Statistical Office, 1979).

This substantial ageing of the population is a new phenomenon, occurring over the last century following reduction in infant mortality, control of infectious diseases and improvement in sanitation, living standards and nutrition. These changes, along with declining birth rates in developed countries, have resulted in the sharp increase in the proportion of elderly in the population. This increase is projected to continue for the UK (Table 2.1), which has among the highest proportion of elderly in Europe. Although the overall increase has slowed down, this conceals the continuing increase in the very oldest age groups. This is of major importance to health and social services because of the concomitant increase in chronic disease and disability and their cost.

The fourth age

The change in demographic pattern in developed countries has led to the concept of the third age, a time of fulfilment of potential after

Table 2.1 Projected population in hundred thousands (adapted from Government Actuary's Department, 1996)

	1994	2004	2014	2024	2034
65–74	52	49	60	65	79
75–84	30	33	33	43	47
85+	10	11	13	15	20
Total > 65	92	93	107	123	147
Total population	583	598	608	612	603
% > 65	15.7	15.6	17.6	20.2	24.3

retirement, followed by the fourth age, a period of dependence and pre-terminal illness (Laslett, 1990). This view remains controversial but is consistent with the suggestion that the elderly might suffer less morbidity as mortality is reduced (Fries, 1989). This means that a large proportion of the population would survive to a given point and then suffer a short period of illness followed by death; prolonging the third age and shortening the fourth. In fact, while life expectancy has increased slightly over the past 20 years, it is not yet clear whether disability-free life expectancy is correspondingly longer.

Implications of the demographic trends

Financial

As the proportion of pensioners increases and the proportion of the working population decreases, it follows that each member of the workforce will have to find more money to contribute to those on state support. This may occur without great strain to the economy (as occurred during the earlier part of this century) by adjustments to present working conditions. These could include raising the retirement age, or encouraging more people to take out private pensions. Alternatively, a drop in living standards may be acceptable for society to care for its older members, or a growing standard of living may be shared across all groups of society.

Health

There is little doubt that the changes in demography will have major implications for health services. The very old have more disability (Office of Population Censuses and Surveys, 1988) and more psychiatric illness than the old. A meta-analysis by Jorm *et al* (1987) found that the prevalence of dementia doubles for every 5.1 years above the age of 65. It is likely that there will be a need for more services for the elderly mentally ill.

Social services

Recent years have seen an increase in the number of elderly cared for in residential and nursing homes (see Chapter 15). Presently, the vast majority of older people live independently, or are looked after by informal carers such as wives or daughters. However, the very old, those living alone and those limited in activity are the most likely to require help from statutory services (Livingston *et al*, 1990*b*). It is therefore likely that the number of people requiring support from the social services will continue to increase.

Epidemiological terms

Epidemiology

Epidemiology is the study of the distribution of illness in populations and its application to the control of health problems (Last, 1988). This information can be used by clinicians, managers and politicians in planning and running effective health care services. Epidemiological studies can be used to:

(a) identify the causes and contributory factors of disorders (including genetic and environmental risk);
(b) provide data on morbidity and mortality;
(c) assess the effectiveness of interventions in defined populations.

Prevalence

This is the number of cases of a disorder in a population. It is a proportion, expressed as cases per unit population. It is dependent on incidence, recovery and survival, as well as other factors relating to population movement such as migration.

Incidence

This is the number of new cases of a disorder in a population, developing over time. It is expressed as cases per unit population per unit time.

Standardised rates

When populations have different age and gender distributions, it is important to deal with standardised rates. These are rates adjusted to take account of these differences. If rates are standardised, it reduces the chance of interpreting differences between groups, when only the age or gender structure differ.

Sources of information

Routine sources

(a) Census information from the 10 yearly censuses carried out by the Office of Population Censuses and Surveys (OPCS). This includes socio-demographic details but little information directly relevant to mental health.
(b) Mortality statistics, which includes data about suicides.
(c) Local morbidity data from hospitals or districts. The quality of data has been poor but is improving.
(d) General practice data. This is also of variable quality.

Recently, there has been an increasing availability of morbidity data in the UK as a result of the changes in the National Health Service. These data are mainly of use in examining the process, rather than the outcome of health service activity, and are not easily broken down into accurate diagnostic groups.

Non-routine sources

Research

Most of the information on mental illness in the elderly has been collected in research carried out by academic or service researchers. The methods used in these studies are described below.

Surveys

Sources such as the General Household Survey, or ad hoc surveys set up by the OPCS (e.g. the Disability Survey) can provide useful data, but none are capable of including detailed enough information to answer questions about mental disorder. National surveys have included components on mental health and provide important information on samples chosen to be representative of the population of the country, but they have been somewhat limited by brevity and lack of follow-up and have not provided information on older populations. There are data emerging from large scale population studies of the older population which will be of value (Anonymous, 1997).

Case registers

In some areas case registers for specific conditions in defined populations have been set up (e.g. in Camberwell for Alzheimer's disease and schizophrenia). These are usually limited to those cases known to services. Criteria for the disorder covered by the register

Box 2.1 Sources of epidemiological information

Censuses
Mortality statistics and coroners courts
Hospital or trust figures
General practitioner data
Case registers
Surveys

may change over time, as may fashions in referral and treatment, which hampers time comparisons.

Types of study

Descriptive studies

Cross-sectional studies

Cross-sectional studies provide estimates of the magnitude of a disorder in the population. They are particularly appropriate for more common disorders such as dementia. For rarer disorders such as schizophrenia, alternative strategies including admissions, prescribing patterns or community service contact may be more appropriate. Conditions which relapse and remit, such as depression, are best examined by current mental state and mental state over a specified period before the interview. These studies are particularly useful for service planning.

Longitudinal studies

A limitation of cross-sectional studies is that prevalence is affected by survival and recovery, which may differ from population to population. Longitudinal studies follow cohorts of individuals who are initially disease free, to measure how many develop the disorder. If accurate records are available on a known cohort, retrospective studies can be carried out, for example, birth cohort studies. However, longitudinal studies present the difficulties of establishing and keeping track of a cohort and are often not helpful in the elderly, or in conditions that remit and relapse. More recent longitudinal studies, such as the Caerphilly Study (Chadwick, 1992), have multiple measurements at baseline and multiple end-points, including cardiovascular outcomes and cognitive and service measures.

Case-control studies

Case-control studies compare groups with and without disease for exposures or risk factors.

Ecological studies

Comparisons of populations can provide important insights into aetiology. This can be achieved by looking across regions within countries, across countries, across ethnic groups and geographical setting, by looking at migrants and comparing them with those who do not migrate, and by comparing those born between certain years (cohorts) or across time (periods). This can be done retrospectively or prospectively.

Expression of risk

(a) Relative risk: odds ratios (estimates of relative risk) calculate how much more likely a case is to have a given risk factor than a control. Relative risk is calculated as the incidence in the exposed population, divided by the incidence in the non-exposed population. It provides evidence of temporal association, but not causation.
(b) Absolute risk: this measures the absolute increase in risk of developing a disorder given a particular exposure or risk factor.
(c) Attributable risk: this is a measure of the risk of disease for an individual who has been exposed, or who has a risk factor. It is the difference in incidence rates for those exposed and those not exposed.

There are three major sources of error:

(a) Confounding variables: these variables have their own relationship to the risk factors and can therefore cause a spurious result or hide a positive association.
(b) Selection bias: the control group should reflect the study group, except for the risk factor studied.
(c) Information bias: it is often easier to obtain risk factor information from cases than controls.

Stages in epidemiological studies

The question

Studies are carried out to answer different questions and the results must be interpreted accordingly. An illustration of this is a survey to assess

the requirement for long-stay geriatric beds. Such a survey only needs to examine a given population, in a fashion which identifies people with severe dependency or with behavioural difficulties. This does not provide, for example, an estimate of the prevalence of dementia.

Case definition

Having identified the question, the next step is clarifying the definition of caseness. There is a tendency for the literature to dichotomise normality and illness, whereas most disorders lie on a continuum of severity (Barker & Rose, 1990). Therefore, not only can the detailed criteria of case definition be different between studies, but also the severity defined as case level. A particular difficulty is the definition of suicide and attempted suicide. Criteria become increasingly elaborate in order to formalise arbitrary decisions about whether an individual is a case. The blurring of normality and caseness is particularly apparent in mental illness and in the elderly, where many factors interact such as physical illness, psychological illness and social well-being.

Increasingly, standardised criteria are being used. ICD–10 (World Health Organization, 1993) and DSM–IV (American Psychiatric Association, 1994) are used widely in epidemiological studies. The Diagnostic Interview Schedule (Robins *et al*, 1981) and the Canberra Interview contain information specifically to fulfil current diagnostic criteria (Social Psychiatry Research Unit, 1992). DSM–IV grappled with cross-cultural issues, which are a considerably source of difficulty with current criteria (Fabrega, 1992).

Sampling

Studies are only interpretable if it is clear who has been studied. There are a variety of possible sampling frames which have been used to estimate the importance of a disorder to the community. These include hospitals (Adelstein *et al*, 1968); nursing homes (Ames *et al*, 1988); total populations using the electoral register (Lindesay *et al*, 1989); age-selected populations from family health service authority lists (Chadwick 1992); or the door-to-door census approach (Livingston *et al*, 1990*a*). The sample can be complete, randomly selected or systematic (e.g. every third person on a list). If not complete, the sample may be stratified by age or gender, or other selected characteristics such as occupation or socio-economic group, so that some groups are not relatively over-represented.

Screening versus diagnosis

For some studies it is sufficient to collect a limited amount of information such as a cognitive scale, but for others a full diagnostic work-up is required. Because this is time-consuming and expensive, this type of interview is rarely applied to whole populations. A sampling procedure, on the basis of answers to a screening interview, allows the selection of individuals with a high probability of diagnosis (e.g. O'Connor *et al*, 1989). Occasionally diagnostic interviews are applied by clinicians to whole populations but this is unusual (e.g. Brayne & Calloway, 1989). An alternative method is for trained non-medical interviewers to apply an interview, which can be run through a computerised algorithm to provide a standardised 'diagnosis'. This approach is used in the Canberra Interview and the Geriatric Mental State Examination (AGECAT; Copeland *et al*, 1986).

Interviews

The information necessary to make a diagnosis can be collected from an individual in a face-to-face or telephone interview, collected by written questionnaire or extracted from case records. The data collection can be highly structured, which limits the qualitative nature of the data but eases standardisation, or it can be semi-structured which can increase qualitative data but cause problems with standardisation. The Cambridge Examination for Mental Disorders of the Elderly (Roth *et al*, 1988) and the Geriatric Mental State Examination (Copeland *et al*, 1986) are examples of highly structured questionnaires which contain most elements of a full psychiatric interview.

Interviewers

Data collection can be carried out by a variety of interviewers. These can be trained lay interviewers or qualified professionals. The choice of interviewer depends on the requirements of the interview, for example a physical examination will usually require a doctor. High

Box 2.2 Stages in epidemiological studies

Establishing the question(s)
Defining caseness
Sampling
Interviewing
Analysis and presentation of data

interrater reliability is achieved by the use of highly structured data collection and training and continuous monitoring of data collectors.

Quality control

Repeatability

There is a variation in the way that raters apply the same set of diagnostic criteria or interview schedule. This can be reduced by training, but not eliminated. Interrater reliability is more likely to be systematic than intra-interviewer variability, which is more likely to be random. There is, of course, variability in the respondent also. All these issues are well recognised in psychiatry, but make difficulties for comparative and aetiological studies since the error caused by such variation can obscure any real effects (Eaton *et al*, 1989).

Validity

The gold standard against which most instruments are compared is the clinical diagnosis. In the US this is often a consensus diagnosis, which is more reliable than individual diagnosis. If alternatives are available, such as neuropathological measures or progression of a disorder to a level where the diagnosis is not in doubt, they are preferred but have seldom been used to date. For example, in Alzheimer's disease where a pathological measure of disease is available, it is often difficult to obtain brain specimens.

Response rates

Response rates are important in understanding whether results truly represent the basic population, or whether they may be biased. Some studies report on the demographic characteristics of non-responders, but it is rarely possible to infer accurately what bias may have been introduced, unless further information is collected such as recorded admissions or general practitioners' notes. In practice this is often not possible and results are taken at face value.

Conclusion

Epidemiology involves the systematic study of disease in the population. The difficulties in old age psychiatry of defining disorders and populations have meant that studies have often had apparently conflicting results. More recently, bigger, systematic studies have helped to reach a consensus on the prevalence of depression and

dementia. Larger cohort and case-control studies should help clarify aetiological and service issues.

References

Adelstein, A. M., Downham, D. Y., Stein, Z., *et al* (1968) The epidemiology of mental illness in an English city. *Social Psychiatry*, **3**, 47–59.

American Psychiatric Association (1994) *Diagnostic and Statistical Manual of Mental Disorders* (4th edn) (DSM–IV). Washington, DC: APA.

Ames, D., Ashby, D., Mann, A. H., *et al* (1988) Psychiatric illness in elderly residents of Part III homes in one London Borough. *Age and Ageing*, **17**, 249–256.

Anonymous (1997) *Cognitive Functioning and Ageing Study (CSAS), MRC Update no 2*, Spring. London: Medical Research Council.

Barker, D. J. P & Rose, G. (1990) *Epidemiology in Medical Practice*. London: Churchill Livingstone.

Brayne, C. & Calloway, P. (1989) An epidemiological study of dementia in a rural population of elderly women. *British Journal of Psychiatry*, **155**, 214–219.

Central Statistical Office (1979) *Social Trends*, Vol. 9. London: Central Statistical Office.

Chadwick, C. (1992) The MRC multicentre study of cognitive function and ageing: a EURODEM incidence study in progress. *Neuroepidemiology*, **11** (suppl. 1), 37–43.

Copeland, J. R. M., Dewey, M. E. & Griffiths-Jones, H. M. (1986) A comprehensive diagnostic system and case nomenclature for elderly subjects: GMS and AGECAT. *Psychological Medicine*, **16**, 89–99.

Eaton, W. W., Kramer, M., Anthony, J. C., *et al* (1989) Conceptual and methodological problems in estimation of the incidence of mental disorders from field survey data. In *Epidemiology and the Prevention of Mental Disorders* (eds B. Cooper & R. Helgason). London and New York: Routledge.

Fabrega, H. (1992) Diagnosis interminable: towards a culturally sensitive DSM–IV. *Journal of Nervous and Mental Disorder*, **180**, 5–7.

Government Actuary's Department (1996) *1994-Based National Population Projections*. Series PP2, no. 20. London: HMSO.

Fries, J. F. (1989) Compression of morbidity: near or far? *Millbank Quarterly*, 208–232.

Jorm, A. F., Korten, A. E. & Henderson, A. S. (1987) The prevalence of dementia: a quantitative integration of the literature. *Acta Psychiatrica Scandinavica*, **76**, 469–479.

Laslett, P. (1990) *A Fresh Map of Life*. Cambridge: Cambridge University Press.

Last, J. M. (1988) *A Dictionary of Epidemiology IEA*. Oxford: Oxford University Press.

Lindesay, J., Briggs, K. & Murphy, E. (1989) The Guys/Age Concern Survey. Prevalence rates of cognitive impairment, depression and anxiety in an urban elderly community. *British Journal of Psychiatry*, **155**, 317–329.

Livingston, G., Hawkins, A., Graham, N., *et al* (1990*a*) The Gospel Oak study. Prevalence rates of dementia and depression and activity limitation among elderly residents in inner London. *Psychological Medicine*, **20**, 137–146.

—, —, —, *et al* (1990*b*) The Gospel Oak Study. Use of health and social services by the dependent elderly in the community. *Health Trends*, **22**, 70–73.

O'Connor, D. W., Pollitt, P. A., Hyde, J. B., *et al* (1989) The prevalence of dementia as measured by the Cambridge Examination for Mental Disorders of the Elderly. *Acta Psychiatrica Scandinavica*, **79**, 190–198.

Office of Population Censuses and Surveys (1988) *The Prevalence of Disability Among Adults*. London: HMSO.

Robins, L. N., Helzer, J. E. Croughan, J., *et al* (1981) National Institute of Mental Health Diagnostic Interview Schedule. *Archives of General Psychiatry*, **38**, 381–389.

Roth, M., Huppert, F. A., Tym, E., *et al* (1988) *CAMDEX. The Cambridge Examination for Mental Disorders of the Elderly*. Cambridge: Cambridge University Press.

Social Psychiatry Research Unit (1992) The Canberra Interview for the Elderly: a new field instrument for the diagnosis of dementia and depression by ICD–10 and DSM–III–R. *Acta Psychiatrica Scandinavica*, **85**, 105–113.

World Health Organization (1993) *The ICD–10 Classification of Mental and Behavioural Disorders. Diagnostic Criteria for Research*. Geneva: World Health Organization.