

# The economics of schizophrenia care in Europe: the EPSILON study

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## SCHIZOPHRENIA AND PUBLIC MENTAL HEALTH

The public health impact of schizophrenia can be gauged according to a number of criteria, covering: (i) frequency; (ii) severity; (iii) consequences; (iv) availability and acceptability of interventions; and (v) public concern (Thorncroft & Tansella, 1999). Concerning the first three of these criteria, one of the more powerful ways to demonstrate the broad personal and societal impacts of an illness like schizophrenia is to show how disabling it can be, both in absolute terms and in comparison with other health problems. As the latest World Health Report from the WHO (World Health Organisation, 2001) makes plain, the chronic course and debilitating effects of schizophrenia combine to create an illness which imposes very considerable clinical, social and economic consequences on societies throughout the world, resulting in it being a leading contributor to global and regional levels of disability and overall disease burden (for example, 5% of all years lived with a disability in 15-44 year olds, and 2.8% for all ages).

From an economic perspective, this societal burden can be couched not only in terms of a far-reaching set of needs for formal health care provision that absorb high levels of public expenditure, but also in other domains of support such as housing, employment, criminal justice services and informal care (Knapp, 1997). The estimated indirect annual cost of lost production in the UK, for example, is £1.7bn, and it is the single largest disease

category in terms of health service expenditure, accounting for 9% of in-patient health service expenditure. Cost of illness studies demonstrate the absolute magnitude of costs associated with the disorder (0.5% to as high as 3.5% of gross national health care expenditure), the high proportion of direct costs still tied up in hospital care (often well over 50%) and the relative contribution of lost productivity and mortality to overall cost estimates (approximately 50%).

## THE EFFECTIVENESS AND COST-EFFECTIVENESS OF SCHIZOPHRENIA TREATMENT

Moving to our fourth public health criteria, the availability and acceptability of interventions, the accumulated effectiveness and cost-effectiveness evidence regarding treatment responses to the burden of schizophrenia provides encouraging but hardly remarkable indications. As a first step, two Cochrane systematic reviews have clearly shown the superiority but limited acceptability of older anti-psychotic drugs such as chlorpromazine or haloperidol over placebo (Thornley *et al.*, 2001; Joy *et al.*, 2001), while the arrival of so-called atypical antipsychotics has made available to patients and clinicians a set of pharmacological treatment options that are no less efficacious and somewhat more tolerable. There is also now an accumulation of evidence that clearly demonstrates cost-effectiveness in randomised trials (e.g. see Essock *et al.*, 2000; Hamilton *et al.*, 1999; Rosenheck *et al.*, 1999). The economic evidence for psychosocial interventions is less prevalent - mainly because few studies have yet been completed - but there are positive findings that point to the cost-effectiveness of family interventions to reduce the impact of family stress and conflict often seen in households with high expres-

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sed emotion (Xiong *et al.*, 1994) and of a short psycho-educational programme to improve patient adherence with medication recommendations (Healey *et al.*, 1998).

There are also now numerous studies pointing to the economic consequences of different organisational arrangements for providing mental health care. Until about a decade ago, most such attention was focussed on the development of community alternatives to long-stay inpatient care, following the (often partly political) decisions to close the old asylums. More recently, however, attention has turned to the precise forms of community care that can deliver the best patient, family and social outcomes. The evidence is perhaps less straightforward than might previously have been thought, and the effectiveness and cost-effectiveness evidence less equivocal (Burns *et al.*, 2001), so that the search goes on across most mental health systems for improved care arrangements.

#### **INTERNATIONAL COMPARISONS OF SCHIZOPHRENIA CARE: THE EPSILON STUDY**

The multiplicity of care arrangements for people with schizophrenia that have emerged in different countries, together with the responsibility of governments and health care agencies to ensure that resources are targeted appropriately, has led to a growing interest in comparative studies of disease burden, both within and between individual countries. To date, multi-national studies of schizophrenia have focused on establishing the prevalence of the disease and assessing outcomes cross-culturally rather than examining the relationship between inputs, processes and outcomes.

The EPSILON (*European Psychiatric Services: Inputs Linked to Outcome Domains and Needs*) study, by contrast, is a comparative, cross-sectional study of the characteristics, needs and life qualities of people with schizophrenia in five European countries, the services they receive, and the associated costs and satisfaction levels. The aim of the economic component of the EPSILON study was to develop and apply appropriate methods and instrumentation for the cross-cultural measurement of service utilisation and costs for people with schizophrenia, which could be used subsequently to undertake comparative economic analyses across a number of European countries. The overall aims, hypotheses and methods of the EPSILON study, and a description of the participating sites, are detailed elsewhere (Becker *et al.*, 2000). The two primary objectives of this study were to pro-

duce standardised versions of five instruments (see Becker *et al.*, 2002) in key areas of mental health service research in five European languages, and to compare, across five European centres (Amsterdam, Copenhagen, London, Santander and Verona), social and clinical data for people with schizophrenia, the mental health care they receive and the associated costs.

A prevalence sample of people with schizophrenia in contact with mental health services in the three months preceding the start of the study was taken in each site, identified from either case registers (Copenhagen and Verona) or the caseloads of specialist services (elsewhere). All sites had broadly sectorised mental health care delivery. Cases identified were diagnosed using the Item Group Checklist (IGC) of the Schedule for Clinical Assessment in Neuropsychiatry. Only patients aged 18-65 with an ICD-10 F20 research diagnosis were included. Individuals resident in prison, secure residential services or hostels for long-term patients, and hospital inpatients continuously resident for more than one year, were excluded in order to concentrate on those in current 'active' care by specialist mental health teams. Local services were described using the European Service Mapping Schedule (Johnson *et al.*, 2000).

#### **METHODS FOR ECONOMIC ANALYSIS IN MULTI-NATIONAL MENTAL HEALTH STUDIES**

In the multi-national EPSILON study, information was obtained on each patient's service utilisation, employment status, income level and living situation. Subsequent to a review of alternative methods of data capture (including psychiatric case registers and health information systems), a structured interviewer-administered instrument was developed. The instrument is a substantial development of the Client Service Receipt Inventory developed some years ago (Beecham & Knapp, 1992). The CSSRI-EU was translated into the local languages and subjected to cross-cultural validity checks via the focus groups composed of health and social care professionals, users and carers (Chisholm *et al.*, 2000). This process resulted in modification of content and language - in particular adjustments to categories of employment, income, housing and service provision - to achieve face validity and semantic equivalence across sites.

For each service unit costs were calculated in each site - with one or two exceptions - to cover: salaries of staff employed in direct patient care and management; facility operating costs (cleaning, catering, consumables, etc.); overhead costs relating to the service (personnel,

finance, etc.); and capital costs (buildings and equipment). Unit costs were converted into UK pounds using 'purchasing power parities' (PPPs), which are the rates of currency conversion which eliminate price level differences between countries and which are routinely calculated by the OECD in collaboration with the Statistical Office of the European Communities.

### HEALTH ECONOMIC RESULTS FROM THE EPSILON STUDY

Full results are presented elsewhere (Knapp *et al.*, in press), but one of the most important findings was of widespread and considerable differences between the participating sites both in the proportions of patients in contact with services and in the absolute levels of service utilisation. These can be seen from figure 1, which gives the proportional contributions to total service costs by site. By attaching costs to service utilisation patterns, resources employed across a number of sectors are converted into the common metric of money, which usefully highlights the considerable financial implications of

providing care for people with schizophrenia. Our estimates of total average costs of care, ranging widely between £1,558 per annum in Santander to £9,934 in Copenhagen, are broadly in line with previous local estimates of annual mean cost for this client group (Bonizzato *et al.*, 2000; Evers & Ament, 1995; Haro *et al.*, 1998; McCrone *et al.*, 1998). It is worth emphasising, however, that behind the estimated total annual cost per patient for the whole sample of 404 subjects (£5,038), there is not only a six-fold variation between sites but also a much larger variation within sites.

The observed cost variations have been explored at the individual level through multivariate cost analyses, which provide an empirical baseline from which to examine differences within and across sites in the patterns of relationship in costs and their associations with individual needs, psychopathology, socio-demographic features, service history and service satisfaction. Site-specific analyses demonstrated a number of (intuitively logical) associations between costs and higher needs, greater symptom severity and longer psychiatric history, but not for quality of life or service satisfaction; these associations were broadly mirrored in pooled analyses, with the addition of the hypothesised association with servi-

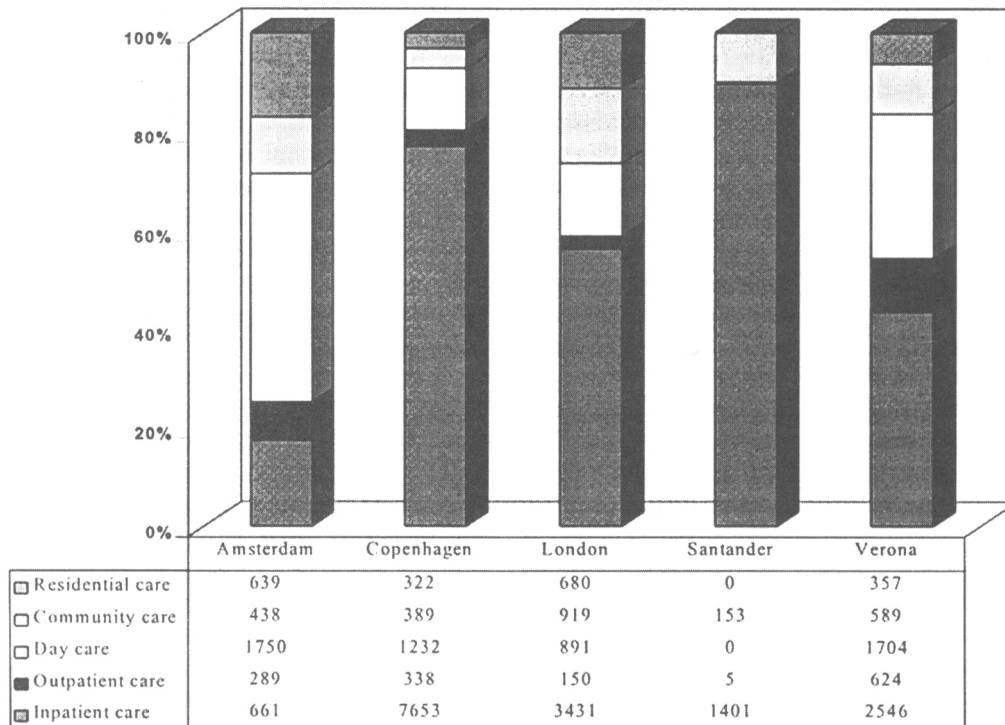


Figure 1- Direct service costs of schizophrenia (GBP, PPP) in five European countries.

ce satisfaction. We also found key site-level characteristics to have an important bearing on cost variations. In particular, there is a link between rates of service uptake and local levels of service availability, support for which is given by a post hoc comparison between total service costs and available inpatient hospital and residential care places (see figure 2). For example, the fourfold difference in residential places between Copenhagen (381 per 100,000 population over 18 years) and Santander (93 places) closely mirrors the difference in service costs for these sites. In other words, supply-side factors might heavily influence the utilisation and hence costs of care packages.

In addition to the description of the multifaceted costs of care for people with schizophrenia and the elucidation of key patient- and site-level influences on these costs, the EPSILON data set also provides a basis for examining the relative magnitude of these costs seen from the wider perspective of the health care sector as a whole. Figure 3 illustrates the mean service costs associated with schizophrenia care in the five EPSILON sites (on this occasion measured in international dollars), relative to per capita health expenditure in the five respective countries. Annual costs per case exceed per capita health care expenditures by 300-900% across the five centres. In the Danish, English, and Italian sites, these costs are more than 800% of the average per capita pu-

blic health care expenditure in these countries. Costs of care in the Dutch site were 433% and in the Spanish site 282%, most likely owing to the very low admission rate in the former sampled population and the relatively modest set of public health care services available to the latter sampled population at the time that the EPSILON study was carried out. Summarising and comparing data in this way is certainly subject to a number of limitations and should accordingly be treated with caution – for example, sampled populations or localities may not be representative of their respective clinical populations or countries – but nonetheless do seem to show that there is a clear and marked excess economic burden associated with schizophrenia in Europe.

### IMPLICATIONS FOR MENTAL HEALTH POLICY AND RESEARCH IN EUROPE

Schizophrenia has major public health implications, not only in terms of the devastating consequences of illness on quality of life, but also in terms of excess mortality from natural as well as unnatural causes (Harris & Barraclough, 1998). Many people with schizophrenia not only suffer dreadful symptoms and debilitating treatment side-effects, but also stigmatisation, low chances of employment, social exclusion and (all too often) social and

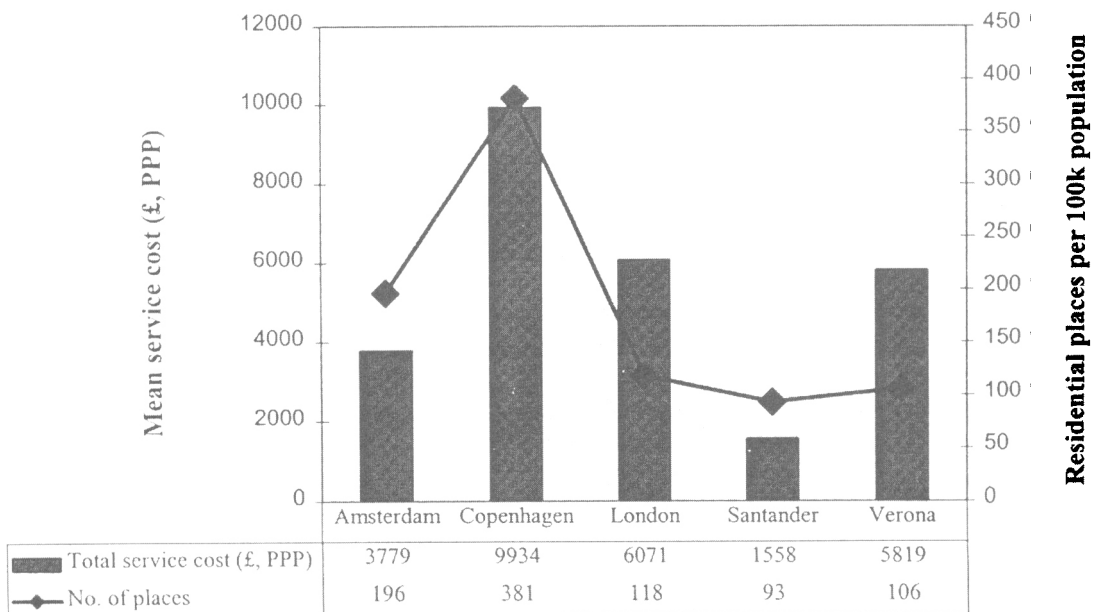


Figure 2 - Schizophrenia care: cost and places.

economic impoverishment. Social isolation and homelessness are also common, and family strain is a widely reported consequence of the illness. Not surprisingly, therefore, health system decision makers are energetically searching for interventions that can improve health and quality of life. But, in this search, they also need to be aware of their resource constraints. It is not enough to be pursuing effectiveness, fundamental though that is to any health system. It is also necessary to address cost-effectiveness: to seek to achieve health and quality of life improvements in affordable and efficient ways. And a starting point for any cost-effectiveness discussion or enquiry is an understanding of the economic consequences of the condition under investigation.

The economic impact of schizophrenia on health systems and more widely depends on the structure of those systems and, of course, on a country's overall commitment to treatment and support. But although the economic impact of schizophrenia will vary from country to country, it is clear that some pervasive patterns emerge from the available evidence. The EPSILON study – being unusual in its purposive collection of equivalent data from five sites across Europe – contributes to that evidence. One immediate conclusion to draw from the EPSILON study is that the health system context has quite a bearing on the economic consequences of a chronic illness. Another is that the aggregate cost of schizophrenia is high. Third, and despite the fact that all five countries in the EPSILON study have reduced their numbers

of in-patient psychiatric beds quite noticeably over recent decades, hospitalisation remains a major cost factor. However, and fourth, the extent of the transition from a hospital-dominated to a community-centred mental health system is visible from the evidence on the number and range of other services used by patients across most sites. Social services and housing agencies (positively) and the criminal justice system (negatively) are becoming increasingly important in the planning of societal responses to long-term mental health problems. Fifth, beyond these 'formal' service patterns are the less well measured but at least equally important 'informal' supports on which so many people with schizophrenia rely. Families are often the first line carers for schizophrenia patients, and although their inputs were not costed in EPSILON, other parts of the research programme demonstrate the importance of this often under-recognised source of support.

The EPSILON study has provided many insights into schizophrenia care, as seen through the lens of a multi-country study. Such multi-national cost comparisons, however, need to be understood in terms of, and take into account, differential levels of service access and availability, since these supply-side factors clearly have a potentially important influence on the interpretation of resource utilisation and cost findings at the level of sampled populations. Where it is not possible to do so – because the relevant data have not been collected, or because there are not statistical techniques to control ade-

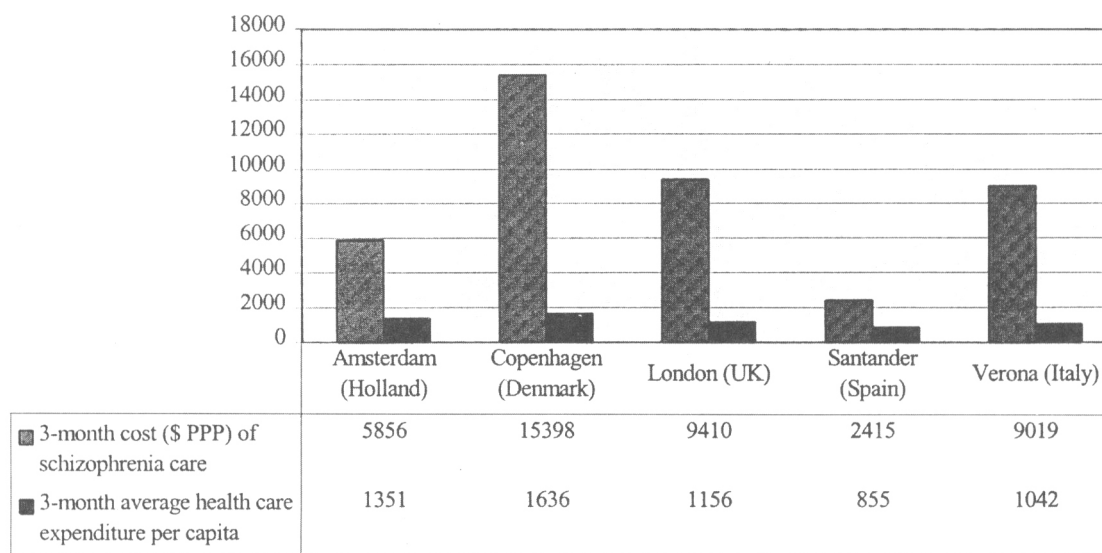


Figure 3 - Comparative cost of schizophrenia care relative to average per capita expenditures (\$US PPP, 1997/98).

quately for such influences – analytical findings from pooled, multi-national data can still reveal the extent of individual or inter-site differences but cannot provide a full, integrated explanation of the relative contribution that individual versus site-level factors make to these observed differences. Accordingly, one priority for future European endeavours in mental health services research should be to work from the platform established in the EPSILON study in order to gain a much deeper understanding of what our health systems can achieve – and at what cost.

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