

Costs of schizophrenia

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Background Schizophrenia is a common and burdensome illness, with implications not only for the health service but for a host of other care agencies – public and private – as well as for patients, families and the wider society.

Method The paper reviews available UK evidence on the cost of schizophrenia (broadly defined) and on the cost-effectiveness of treatment options and alternative care arrangements. New evidence potentially alters our view of the costs of this illness.

Results Aggregating the identifiable direct and indirect costs of schizophrenia for England suggests an annual cost of £2.6 billion, but even this sum omits some indirect impacts which cannot currently be costed. Just over half the identified total is accounted for by the direct costs falling to the NHS, local authorities, charities and the criminal justice system. In helping to tackle this cost burden, there is now a body of evidence on cost-effective community care arrangements, antipsychotic drugs and psychological interventions.

Conclusions Although the costs of schizophrenia are considerable, there are treatments and care arrangements which can reduce this aggregate burden while maintaining or improving effectiveness.

Schizophrenia is the most common serious mental illness. It imposes a burden not only on the patient, but also on carers, the health service and wider society. It is certainly an expensive illness to treat, as evidenced by recently published programme budget figures from the National Health Service (NHS) Executive (1996a). These figures show, for example, the enormous costs of in-patient care – more than 5% of total NHS in-patient expenditure in England – and the sizeable direct costs carried by other health and social care services (Table 1). But these are not the only costs of schizophrenia: voluntary organisations, criminal justice and other agencies also incur costs, and patients and their carers carry economic burdens both directly and indirectly. Recent changes in the structure and funding of the health service in the UK have focused attention on these high and perhaps increasing costs, and have increased the need to develop treatments which make more efficient and fairer use of available resources.

What, then, are the costs of schizophrenia in England, and how might they be reduced while maintaining or improving effectiveness?

DEMOGRAPHICS AND THE COURSE OF SCHIZOPHRENIA

The recent Office of Population Censuses and Surveys (OPCS) surveys of psychiatric morbidity suggest a point prevalence for psychoses of four per 1000 adults aged 16–64 (Meltzer *et al*, 1995, 1996), which is consistent with other estimates, although inevitably there is variation (McCreadie *et al*, 1997). The peak age at onset is in the mid-20s, although it can appear in patients as young as 15. The outcome of the illness is variable and can be relatively mild, with the patient suffering one (16%) or several (32%) episodes and little or no lasting impairment (Shepherd *et al*, 1989). For those experiencing repeated episodes the outcome is worse, with 9% suffering lasting impairment and 43% enduring increasingly severe symptoms and no periods of complete remission (Watt *et al*, 1983).

Patients presenting for the first time often show acute psychotic symptoms – delusions, hallucinations, paranoia – that require prompt hospitalisation. However, the continued policy emphasis on community-based care means that relatively few people with schizophrenia are in hospital at any given time (13%, according to one recent estimate for England; Kavanagh *et al*, 1995). In rural Nithsdale, the percentage was 28% (McCreadie, 1992). Probably few people would see the current balance of care as appropriate, for there is evidence of under-provision of in-patient beds in some inner-city areas (Johnson *et al*, 1997), and many long-stay psychiatric hospital residents could probably be supported more appropriately and cost-effectively in community

Table 1 Direct care costs for schizophrenia, England, 1992/93

Expenditure category	Expenditure on people with schizophrenia	
	Total (£ million)	% of all NHS
In-patient care ¹	652.2	5.37
Out-patient care	0.9	0.04
Primary care	1.8	0.05
Pharmaceutical	32.4	1.06 ²
Community health care	26.2	0.90
Social services (adults) ³	96.5	1.80
All categories	810.0	2.76

Source: Calculated from NHS Executive (1996a).

1. In-patient hospital and community residential/nursing home care funded by the NHS.

2. Schizophrenia and other non-organic psychoses, excluding depression.

3. Includes private and voluntary sector residential/nursing home care funded by local authorities.

settings (see below). However, it is not easy for patients to move out of hospital once stabilised, because of shortages of appropriately supported accommodation (National Health Service Executive, 1996b).

Relapse is relatively common in patients with chronic schizophrenia, often followed by re-hospitalisation. Over a 13-year period, Mason *et al* (1996) found that 82% of first-episode cases relapsed, and 75% had at least one psychiatric re-admission. They found “no evidence to suggest that schizophrenia undergoes a progressive amelioration or deterioration over 13 years of follow-up” (p. 585). With the advent of more intensive services in the community, relapse might result in the mobilisation of a crisis intervention team, but social functioning can remain extremely poor and the long-term pattern of repeated, intensive service usage would probably be similar.

Mortality among people with schizophrenia is at least twice that in the general population (Allebeck, 1989; Anderson *et al*, 1991; Black & Fisher, 1992). Suicide rates are high: for example, the Northwick Park study found that schizophrenia increased the risk of suicide by a factor of 13 for women and 20 for men (Anderson *et al*, 1991; Steering Committee, 1996).

ESTIMATING THE COSTS OF SCHIZOPHRENIA

Care patterns

The care of people with schizophrenia is invested in a diversely constituted support network that includes hospital care (in-patient, day patient and out-patient services, depot injection clinics, secure units); community health care (community psychiatric nurses (CPNs), day care, general practitioner (GP) support); social care services (social workers, sheltered accommodation); non-professional carers (usually close relatives); private sector bodies under contract to the public sector or taking privately-funded patients; and voluntary organisations. There are costs associated with each.

Meta-analyses by Kavanagh *et al* (1995) concluded that 55% of people in England who are receiving some treatment for schizophrenia are living at home at any given time, and a further 16% are living in supported community accommodation. Two-thirds of the 13% of those with schizophrenia in 1994 who were hospital in-patients were on long-stay wards.

Although many people (44%) were in contact with specialist hospital out-patient clinics, the GP was the most commonly used service (55%). This mirrors what Johnstone *et al* (1991) found from their longitudinal research: 10 years after first diagnosis, less than 10% of patients were receiving continuing in-patient care, while more than 90% received their medical care from GPs. In a primary care-led NHS, the GP's role should not be undervalued (Nazareth *et al*, 1995; King & Nazareth, 1996). Although most GPs would have few schizophrenia patients on their lists, and less than 1% of total public expenditure on the care of people with schizophrenia in 1994 was accounted for by primary care, the individual demands they make can be disproportionately large.

Surprisingly few community patients have contacts with CPNs (only 21% of people with schizophrenia; Kavanagh *et al*, 1995). Nevertheless, the role of the CPN is recognised to be growing in importance, as demonstrated by the growth in their numbers in the UK (White, 1991) amid reports of continued shortages. Concerns have been expressed that many CPNs are spending less time on chronically mentally ill patients and more time on milder, shorter-term neuroses and affective disorders (Brooker, 1990). There are also concerns about shortages of skilled social work support available for seriously mentally ill people (Huxley & Kerfoot, 1994).

The voluntary and private sectors have become more important providers of mental health care, particularly of community residential care facilities, where they often offer less expensive alternatives to the public sector (details available from the author upon request). Whether they are more cost-effective remains an open question. Almost half of the expenditure of charities and other voluntary organisations in the mental health field comes from donations and other non-government sources (Kendall & Knapp, 1996).

Direct costs of treatment

The distinction can be made between direct and indirect costs. Direct costs include hospitalisation, residential care, day care, drugs, laboratory testing and social security payments. The direct costs of schizophrenia are large because of the early onset of the illness, its long duration and severe disabling effects. The direct costs to the NHS, for example, amounted to £714 million in

England in 1992/93 (more than twice the amounts suggested by Davies & Drummond (1994) and Smith *et al* (1995)). Aggregating the figures in Table 1, the direct costs of schizophrenia in England and Wales accounted for 2.8% of all attributable NHS and (adult) social services expenditure. This proportion is comparable to figures for other industrialised nations – 2% in The Netherlands, 2% in France and 2.5% in the USA (Rupp & Keith, 1993; Rouillon *et al*, 1994; Evers & Ament, 1995).

Hospitalisation

The bulk of the direct cost of treating schizophrenia in the UK is due to hospitalisation and day care, although these are used by less than half the total population with schizophrenia. Lifetime consequences can be marked: Davies & Drummond (1994) estimated that 97% of the total lifetime direct treatment costs are incurred by the 41% of patients experiencing episodes requiring hospitalisation for more than 2.5 years. With acute in-patient costs exceeding £1000 per patient per week in some hospitals (Netten & Dennett, 1996) and secure accommodation and intensive care costing substantially more (Hyde & Harrower-Wilson, 1995), hospitalisation is an expensive form of intervention, although not necessarily cost-effective.

Relapse costs

In the USA, direct costs have been further analysed to separate those due to first episodes, and those due to re-admission following relapse. Weiden & Olfson's (1995) meta-analysis of relapse studies (some conducted in the UK) found that while first-episode in-patient care cost \$2.3 billion, the direct costs of re-admission in the two years following the first episode – what they called the costs of relapse – were also around \$2 billion. Of this sum, 63% was due to loss of medication response, and 37% to medication non-compliance. These North American costings need qualification before interpretation in the UK context. For example, the hospitalisation rate following relapse appears to be higher in North America than the UK, but the costs calculated by Weiden & Olfson (1995) extended no further than in-patient services. Nevertheless, relapse is clearly costly. People with repeated episodes of schizophrenia requiring hospitalisation or intensive community care could incur direct costs more than 100 times greater than

Table 2 Weekly costs in residential care and hospital

Accommodation type ¹	Weekly costs (£, 1993/94 price levels) ²							
	London facilities				Non-London facilities			
	n ³	Accommodation	Other	Total	n ³	Accommodation	Other	Total
Hospital acute ward	66	950	34	984	31	737	37	774
Hospital long-stay ward	72	738	42	780	127	619	34	653
All hospital	138	840	38	878	158	643	36	669
High-staffed hostel	34	509	71	580	194	281	50	331
Mid-staffed hostel	95	305	115	420	139	190	86	276
Low-staffed hostel	32	190	98	288	54	170	119	289
Group home	98	179	118	297	36	55	146	201
Staffed care home	13	468	165	633	59	419	86	505
All community facilities	272	279	111	390	482	242	80	322

1. Accommodation categories are as developed by Lelliott *et al* (1996).

2. Calculated from data collected by Lelliott *et al* (1996) from eight English and Welsh areas. Cost definitions and measures are explained by Chisholm *et al* (1997). The figures measure both accommodation costs or fees and the costs of non-accommodation services used by residents.

3. Number of individual residents.

the cost of treating a single episode (Davies & Drummond, 1994).

Residential care

A recent English and Welsh study found that (community-based) residential accommodation was significantly less costly than in-patient care (on long-stay or acute wards) even after adjusting for the fact that hospitals tend to accommodate people with more severe symptomatology and greater needs (Lelliott *et al*, 1996; Knapp *et al*, 1997), but outcomes were not measured. For those 1050 people in hospital or community residential accommodation with an ICD-9 diagnosis of schizophrenia, the total costs showed marked variations by types of accommodation, and were considerably higher in London (Table 2). Most of these inter-setting and inter-locality differences persisted after adjusting for differences in resident characteristics. On an annual basis, the costs ranged from an average of £51 000 for an acute in-patient bed in London to an average of £10 000 for a group home place outside London.

Drugs

The proportion of the total direct costs of schizophrenia incurred by drug therapy is relatively modest, at 4.0% in the UK (estimated from the figures in National Health Service Executive, 1996a), 5.6% in France and 1.1% in the Netherlands (Rouillon *et al*, 1994; Evers & Ament, 1995). This comparatively small proportion

should be borne in mind when adjudging the weight of arguments concerning the newer, more expensive agents (Terkelsen & Grosser, 1990). Nevertheless, price has an important influence on drug prescribing today. A recent National Schizophrenia Fellowship and Royal College of Psychiatrists survey of 'social/community psychiatrists' revealed many formal or informal rationing procedures governing the use of clozapine and risperidone (Table 3). Pharmacy and other budget holders in some provider units apparently cavil at the much higher prices of the atypical antipsychotics. These higher prices ought not to constrain prescription of a drug if other costs, such as those incurred by multiple re-hospitalisations, are reduced as a result of increased efficacy, and/or if any increase in costs is

more than balanced by improved patient or other outcomes. Nevertheless, the economic incentive to use a higher-priced drug may be muted if any cost savings that result accrue to someone other than the drugs budget holder.

Other public agencies

Other direct costs are associated with criminal justice services: two recent studies found point prevalence rates of 5% for psychoses among remand prisoners (Birmingham *et al*, 1996; Brooke *et al*, 1996). Perhaps as many as 9% of people with schizophrenia in England are on remand or sentenced to prisons (Kavanagh & Opat, 1994).

Table 3 Restrictions on use of two atypical antipsychotics

Percentage of psychiatrists who . . .	Clozapine	Risperidone
	%	%
. . . have never prescribed this drug	19	12
. . . have no patients on this drug currently	35	25
. . . have five or more patients receiving this drug	25	35
. . . have been challenged about the cost of this drug	46	52
. . . have experienced formal rationing of number of patients prescribed this drug	10	6
. . . have experienced informal guidelines/rationing	14	11
. . . think drug cost inhibits its use	20	17
. . . think drug cost possibly inhibits its use	24	23

Source: Hogman (1996). No other atypical antipsychotics were marketed in the UK at the time of the survey.

Social security

Two financial elements sometimes overlooked are social security (welfare) payments and capital costs. Whether or not social security payments should be included is a matter of debate, for most economists would argue that they are simply transferring payments from one part of the economy to another, but in return for goods or services, and so should be excluded (Smith *et al*, 1995). Others have argued that the money could have been spent in other ways, so that the payments (estimated at £553 million in 1986; Smith *et al*, 1995) should be included if the total impact of the disease is to be understood (Rupp & Keith, 1993). In the aggregations presented below, these social security payments have been excluded, except for those payments for residential care placements by the Department of Social Security under the pre-1990 NHS and Community Care Act (which still applies to people continuously resident in those placements since before April 1993).

Capital

Capital costs are important because care services need land and buildings which may have a high social value in alternative uses – what economists call a high opportunity cost. Many of Britain's hospital buildings were erected in the 19th century and debt repayments will have long since ceased, but there is still an opportunity cost associated with their use. Similarly, new community care schemes sometimes flounder for want of capital finance. Calculating the social opportunity costs of using capital is not always straightforward (McGuire, 1991), but such figures are needed if cost-effectiveness comparisons between treatment strategies are not to be misjudged.

Indirect costs represent lost potential

Indirect costs are incurred by patients, carers and the wider society. One US study reported that direct and indirect costs are approximately equal (Rupp & Keith, 1993), while others have estimated the indirect costs to be three or four times higher than the direct costs (Gunderson & Mosher, 1975; Andrews *et al*, 1985; Davies & Drummond, 1994). Whatever the utility of the actual figures propounded – and leaps of faith are sometimes needed given the limited availability and poor quality of

the relevant data – there is little disagreement that the familial and social significance of schizophrenia can be considerable. Lost employment and family costs have attracted most attention.

Employment effects

Some of the largest indirect costs arise from working time lost through morbidity and mortality, rates for both of which are significantly higher for people with schizophrenia than for the general population (Allebeck, 1989; Anderson *et al*, 1991; Black & Fisher, 1992). The effect of morbidity on income is clearly shown by the small number of people with schizophrenia who are in open employment. The recent OPCS psychiatric morbidity survey found that only 20% of people with psychoses were in paid employment (Foster *et al*, 1996). Other studies have demonstrated similar unemployment rates (e.g. McCreadie, 1992). Using simple estimates of annual average wages and a (general population) unemployment rate of 20% – the approach used by Davies & Drummond (1994) – the annual indirect costs of lost production would have been around £1.2 billion in England in 1992/93.

Family costs

More than half the people with schizophrenia being treated in England live at home, often with a family member. This can impose additional costs through household expenditure, travel costs or lost earnings. There is also the opportunity cost of carer time. Although these indirect costs may constitute only a small proportion of the total cost of schizophrenia, their impact on particular families could obviously be large, although difficult to measure accurately (Creed *et al*, 1997). A North American study has estimated the total value of time committed by family members to the care of the mentally ill to be \$2.5 billion, or an annual \$11 519 per family (Rice *et al*, 1991). Although these estimates incorporate “more than the usual amount of uncertainty”, their magnitude gives a general indication of the degree of financial burden felt by carers (McGuire, 1991).

Intangible costs and quality of life

Some of the costs of schizophrenia cannot be expressed in monetary terms, but are nevertheless significant. They include effects on the patient (e.g. despair and the

side-effects associated with a medication) and on the carer (e.g. isolation, uncertainty, stress). Collectively, these may be treated as intangible costs or as important facets of patient or carer ‘quality of life’.

Negative symptoms

Quality of life in people with chronic schizophrenia may be reduced by intractable negative symptoms, the effects of which are to cause social withdrawal and to push up the direct costs of treatment (e.g. Knapp *et al*, 1995). Two of the many published studies of social withdrawal illustrate what this can mean in practice. In Nithsdale, 39% of day- and out-patients either had no friends or had met none in the previous two weeks, 34% had not gone out socially over the same period, and 33% of the unmarried said they were completely uninterested in going out with a member of the opposite sex. Half had spent no time on any interest or hobby, other than watching television (McCreadie, 1992). In south London, among a sample of people with schizophrenia discharged from (acute) psychiatric in-patient care who were interviewed one year later, 27% were rated as being maximally, very seriously or seriously dysfunctional in terms of underactivity, and 17% as being maximally or very seriously dysfunctional in terms of social interaction (Melzer *et al*, 1991). In these and certain other respects, the south London acute group showed many similarities to discharged chronic populations, but they were in receipt of fewer support services and the costs of their care were lower (Beecham *et al*, 1995).

Side-effects

A number of side-effects have been associated with classical neuroleptic therapy – notably extrapyramidal symptoms (EPS), including dystonias, akathisia, Parkinsonism and dyskinesias – which can further impoverish a patient's quality of life, being variously inconvenient, embarrassing, distressing, painful and life-threatening. These effects are mostly reversible on withdrawal of medication, but tardive dyskinesia is thought to be irreversible. They can contribute to social withdrawal and isolation, and are closely linked to medication non-compliance and subsequent psychotic relapse (Young *et al*, 1986; Kemp & David, 1996). Rather less attention has been devoted to the patient consequences of over-treatment (Sayce, 1995).

Carer quality of life

As with many long-term illnesses, the intangible costs incurred by carers can also be considerable, although it would be wrong to see all carer effects in a negative light (Perring *et al*, 1990; Szmulker, 1996). Day-to-day care of a person with schizophrenia can be both demanding and exhausting. The uninhibited social behaviour of the patient, (stress-related) family disputes and a lack of understanding and sympathy from neighbours and friends can leave carers feeling anxious, depressed, physically ill, guilty or bewildered. A study of 408 families in the USA with a mentally ill family member (80% with schizophrenia) showed that care-giving absorbed most of their spare time (66.5 hours per month) (McGuire, 1991), and employment and financial difficulties could result. Stress, hostility and emotional over-involvement may produce high levels of expressed emotion (EE), causing further deterioration as patients living with high-EE families have a worse prognosis than patients in low-EE households (Mari & Streiner, 1996).

Societal costs

The tax contributions which finance the health service, social services and other direct costs are all societal costs of schizophrenia, and have been discussed earlier. In addition, there are also some more nebulous effects on public perceptions. On the negative side is public concern, fanned by the media (Philo & Secker, 1994), about violent incidents involving psychiatric patients who are insufficiently supported or supervised. There is no doubt that there are numerous acts of violence committed by people with mental health problems (Steering Committee, 1996), but it is at least arguable that the general public's reaction is an exaggerated response to what remains a rare occurrence. Nevertheless, the societal response – whether or not justified by the frequency of such events – is itself an (intangible) cost. Public education campaigns can help to reduce this 'cost' (Wolff, 1997).

Aggregate costs of schizophrenia

It is difficult to aggregate the direct, indirect and intangible costs so as to arrive at a cost for an illness such as schizophrenia. The difficulties are both practical – as the above description of components makes plain –

and conceptual, for it is not always clear what such global figures represent. What is beyond doubt is the high economic cost of schizophrenia to many people and to society generally. Using the previously noted ('top-down') programme budget figures for the National Health Service Executive (1996a), estimates for other direct costs based on the ('bottom-up') calculations by Kavanagh *et al* (1995) and others, and estimates for some indirect costs based on the approaches of Davies & Drummond (1994) and Creed *et al* (1997), the total costs of schizophrenia in England in 1992/93 amounted to approximately £2.6 billion annually. It must immediately be emphasised that this is a lower bound estimate, for it omits the costs of carer time, patient time receiving and travelling to services, and the intangible consequences for quality of life.

CAN COST-EFFECTIVENESS BE IMPROVED?

Can these costs be reduced? Or can these levels of public expenditure and personal cost generate better outcomes for patients, carers or the wider society?

Primary prevention of schizophrenia is currently impossible, since the aetiology of the disease remains unknown. Attempts to reduce the burden therefore focus on treatment of people with established illness. Economic evaluations can be used to identify the costs and cost-effectiveness of treatments and care arrangements, whether organisational, pharmacological or psychological. The ultimate aims of such evaluations are not to cut expenditure but to improve the balance between costs and effects.

Treatment organisation

Long-term care

The changing balance of hospital and community care has obviously been one of the major changes of recent times. However, cost-effectiveness comparisons of community and hospital care require careful interpretation, as research findings depend heavily on the breadth of the cost calculation and the patient groups covered. All of the robust studies of the rehabilitation of long-stay in-patients in community settings have found community-based care to be more cost-effective than hospital care for most patients, and usually there are both lower costs and better patient outcomes. This result applies particularly

to those with less severe mental illness or fewer dependencies (Stilwell, 1981; Hyde *et al*, 1987; Knapp *et al*, 1992, 1995; Donnelly *et al*, 1994; Leff *et al*, 1996; Beecham *et al*, 1997). However, many long-stay in-patients with very challenging needs (the so-called 'difficult-to-place' group) are more costly to accommodate in the current range of community settings than in hospital (Beecham *et al*, 1997), even though their clinical and social outcomes do show improvements. Success depends on having sufficient staffing intensity (Trieman & Leff, 1996), that is, it depends on expending sufficient costs.

Acute care

For acute patients, the economic evidence in favour of community-based care is more equivocal. Assertive community treatment (ACT), pioneered in Wisconsin, has attracted attention and replication (Scott & Dixon, 1995a). The original ACT model generated higher benefits than costs (Weisbrod *et al*, 1980). A London modification of the ACT model – the Maudsley's Daily Living Programme – produced better outcomes, higher patient and family satisfaction and lower costs than standard care in the short term (Knapp *et al*, 1994; Marks *et al*, 1994), but after four years all of the earlier clinical gains and the cost advantage to the community programme were lost (Audini *et al*, 1994; further details available from the author upon request).

The short-term Daily Living Programme results have been repeated elsewhere. A study of hospital and community treatment of psychiatric emergencies found the latter to be a cost-effective alternative over three months, but did not follow-up patients for longer (Merson *et al*, 1996). A third of the sample had schizophrenia. Burns *et al* (1993a,b), looking at another London variant of ACT, found no differences in clinical outcomes but substantially lower costs over the first year compared with standard care; there were no subsequent data collections. Creed *et al* (1997) reported that day treatment is a cost-effective alternative to in-patient treatment for acutely ill patients (41% with schizophrenia) over the one-year period of their study. Thus none of these studies, except the Daily Living Programme, collected data beyond the one-year point.

Organisation of care

The organisation of community care could have a bearing on cost-effectiveness. In one

experiment, giving CPNs roles akin to case management and client advocacy was found to produce no differences in numbers of admissions, length of stay, social functioning, psychopathology, or users' and relatives' satisfaction when compared with the standard organisation of 'generic' CPN services (Muijen *et al*, 1994). The case management arrangement was significantly less costly over the first six months, although not subsequently (McCrone *et al*, 1994). Gray *et al* (1997) had a much narrower focus – social services case management for homeless people with long-term mental illness – and found costs to be lower for the case management group, but not significantly so. In an important analysis, they argued that their sample was large enough to detect clinically meaningful differences but not to detect large cost differences.

The Care Programme Approach (CPA) promises close supervision by nominated keyworkers. Compared with standard care, contact is more likely to be maintained with vulnerable patients under the CPA, but psychiatric in-patient admissions are higher (Tyler *et al*, 1995). Fifty-four per cent of the 400 patients in this study had a schizophrenia diagnosis. Further work by the same team compared CPAs administered by community-based and hospital-based teams following discharge from in-patient care, finding higher costs for the latter without any difference in outcomes (Tyler *et al*, 1997). However, the high use of extra-contractual referrals in one area confounded the findings.

Antipsychotic drug treatments

As we have seen, the cost of relapse – particularly of multiple re-hospitalisations – accounts for a large proportion of the direct costs of schizophrenia. Treatment successes which reduce the number of chronic, relapsing, severely ill patients could potentially have a substantial effect on costs.

Antipsychotic drugs are the first-line treatment for patients presenting with acute psychotic symptoms, and reduce both the incidence of positive symptoms and the risk of subsequent relapse. A problem is that many patients do not want to take them, and non-compliance can push up costs. Weiden & Olfson's (1995) meta-analysis uncovered a range of relapse rates, but overall the rate for the non-compliant patients was three times greater than that for compliant patients.

"Noncompliant patients consume more resources; they are more severely ill at the point of admission than those who are readmitted despite compliance, they are more likely to be admitted compulsorily, they have longer in-patient stays, and they have a higher long-term readmission rate" (Hale, 1993, p. 749).

Non-compliance with drug therapy is influenced by symptomatology, culture and ethnic group, response to treatment, the patient–doctor relationship and insight (Buchanan, 1992; Kemp & David, 1996; McPhillips & Sensky, 1997). Care organisation – particularly case management – might be expected to have an effect, and depot neuroleptics may be better than oral agents in ensuring compliance (Davis *et al*, 1993). Clinicians can also fail to comply with drug treatment regimes, with likely consequences for effectiveness: a survey of 130 psychiatrists in Germany (Kissling & Fleischhacker, 1992) showed that the suggested periods of treatment were much shorter than those recommended in the guidelines of an international consensus conference (Kissling, 1991). This discrepancy appeared to be related to over-estimation of the risk of tardive dyskinesia, and under-estimation of the risk of relapse. Probably the most common reason for non-compliance is the patient's experience of drug-related EPS (Van Putten, 1974; Frances & Weiden, 1987; Kemp & David, 1996), although the methodological difficulties in linking EPS and compliance should be noted (Hummer & Fleischhacker, 1996).

Atypical antipsychotics

The new generation of atypical drugs, including clozapine, risperidone, olanzapine, quetiapine and sertindole, and shortly ziprasidone and others, are different from traditional therapies in their effects on the central nervous system, and they are associated with lower levels of EPS (Kerwin, 1996). Unlike the conventional antipsychotics, the newer drugs may also reduce negative symptoms, albeit modestly. Improved tolerability is expected to lead to improved compliance and reduced relapse rates, in turn producing cost savings. Published evidence is currently only available for clozapine and risperidone.

Clozapine. Internationally, a small number of health economic studies of clozapine have been published, of various designs and qualities (Honigfeld & Patin, 1990; Revicki *et al*, 1990; Meltzer *et al*, 1993; Reid *et al*,

1994; Jönsson & Walinder, 1995; Aitchison & Kerwin, 1997). Critics have focused on narrow costing, retrospective designs, small sample sizes or reliance on decision-modelling with its inherent danger of bias (Frank & Goldman, 1991; Schiller *et al*, 1995; and see Sheldon, 1996). There is the additional problem with simple 'mirror design' studies – which compare patients before and after treatment with a particular drug, with no control group – that the (international) trend towards fewer and shorter hospitalisations could distort comparisons in favour of a new drug (Meltzer, 1996).

On the basis of the available data, clozapine might be expected to lead to savings both in the short term (a reduction in direct costs after two years) and in the long term (a reduction in indirect costs). Carpenter *et al* (1995) argue that if the use of clozapine is restricted to treatment-resistant patients, improvements in treatment are possible that translate into more effective resource utilisation, and thus greater cost-effectiveness. Against this must be set the relatively high drop-out rate sometimes reported with the use of clozapine, which may effectively limit its use. Results to date largely relate to American studies. UK evidence on clozapine is either based on (non-observational) decision models and Delphi panel extrapolations from US evidence (Davies & Drummond, 1993; Matheson *et al*, 1994) or 'mirror design' studies. Using the latter, Aitchison & Kerwin (1997) compared periods of three years before and after clozapine treatment, finding clinical improvements and reduced costs. Cost savings might therefore prove to be substantial for some patients, but more UK evidence is needed before firm conclusions can be drawn.

Risperidone. The evidence is similar for risperidone: as yet no observational studies or prospective trials have been published which examine the cost-effectiveness of risperidone in the UK, although studies conducted elsewhere suggest that cost-effectiveness might be demonstrated in due course. Retrospective analysis of an open-label clinical trial of risperidone in Canada found that the number of days spent in hospital was reduced by 20% following treatment for those who responded to risperidone, but 64% of patients were non-responders (Addington *et al*, 1993). Albright *et al* (1996) pooled retrospective data from five sources for

treatment-resistant patients, finding that service use and costs were lower following risperidone treatment. In Sweden, Lindström *et al* (1995) compared 32 patients before and during risperidone treatment, suggesting reductions in service use, but had no control group (neither did the Canadian studies) and did not adjust for hospitalisation trends. Guest *et al* (1996) took Lindström's Swedish data and attached UK prices, not surprisingly reaching the same conclusion that risperidone appears to reduce direct costs. However, patients who discontinued treatment were dropped from the study (which potentially biases the results) and costs were not calculated for all relevant services or indirect effects. The economic evidence thus suggests that risperidone is likely to prove more cost-effective than conventional antipsychotics, but again fully conclusive evidence is awaited.

Psychological treatments

Some psychological interventions are effective in patients with schizophrenia although few controlled trials have been completed (Scott & Dixon, 1995b; Kuipers, 1996). One of the early trials showed that a combination of psychological treatment (a social intervention to reduce family tension) and antipsychotic drugs was more effective than drugs on their own (Leff *et al*, 1985). The narrow treatment costs are clearly going to be higher in the former case, which again therefore raises the question of (broader) cost-effectiveness.

Improving compliance

Education about the nature of the disease and its management has been associated with significant improvements in compliance compared with control groups (Kuipers, 1996). Boczkowski *et al* (1985), for example, found that compliance with antipsychotic medication could be improved by measures that built the treatment into patients' everyday activities. Interestingly, psychoeducational techniques (discussing the disease and the importance of compliance with drug therapy) were argued to be less successful than doing nothing at all. 'Compliance therapy', in which patients were invited to discuss first their attitude towards their illness, and subsequently the drawbacks and advantages of drug treatment, has had some success. Patients counselled in this way were five times more likely (than a control group) to take their

medication without prompting (Kemp *et al*, 1996), yet costs were no more than standard counselling (details available from the author upon request), making the intervention cost-effective.

Family intervention

The often central role of the family is reflected in the development of family interventions which aim to reduce the impact of family stress and conflict often seen in high-EE households. A recent systematic review of randomised trial findings concluded that family interventions reduce relapse and re-admission rates, improve compliance and may also reduce costs (Mari & Streiner, 1996). However, two of the three economic studies reviewed measured only direct health care costs (Cardin *et al*, 1986; TARRIER *et al*, 1991), which is a little narrow for this kind of intervention for schizophrenia patients. Evidence from China (Xiong *et al*, 1994) and Norway (Rund *et al*, 1994) is built on wider cost measures, and reaches the same conclusion that family interventions can reduce costs while maintaining or improving outcomes, although again these studies are a little flawed. Robust UK economic evidence is awaited.

CONCLUSIONS

The care of people with schizophrenia draws on a range of health care and other services, and is frequently heavily reliant on family or other carers. The chronic, debilitating course of the illness means that direct lifetime costs can be considerable. The direct costs to the NHS are known to be large: at 5.4% of total NHS expenditure on in-patient care, for example, schizophrenia is the third most costly diagnostic group (after learning disability and stroke; National Health Service Executive, 1996a). But we must also remember that there can be substantial indirect costs falling to the health service, social services, the criminal justice system, patients' families, patients themselves and the wider society. To these direct and indirect costs of schizophrenia must be added the intangible (and uncosted) burdens associated with the often economically and socially impoverished lives of patients and carers. A rough estimate of the total direct and indirect costs in England in 1992/93 would suggest that schizophrenia annually costs at least £2.6 billion, and probably rather more.

Traditional pharmacological treatments for schizophrenia can be effective in treating positive symptoms and reducing the risk of relapse. Non-compliance is nevertheless a significant problem, often because patients will not tolerate the accompanying side-effects. The new generation of atypical antipsychotics, with reduced levels of treatment-associated EPS, may thus be able to improve cost-effectiveness by increasing the proportion of patients who remain on medication, without significantly diminishing quality of life. Psychological therapies may also improve compliance by improving the patient's attitude to medication, and family interventions hold the promise of cost-effectiveness.

The available economic evidence for the UK thus remains fairly sparse and some of it is of rather dubious quality, but there has now accumulated a body of evidence which can begin to help purchasers and providers incorporate efficiency (cost-effectiveness) and related considerations into their decisions. There are also quite a number of economic studies of mental health treatments and care arrangements now underway, most of them carefully designed, well integrated with clinical studies and likely to be successfully completed. These should further contribute to our understanding of resource patterns. Moreover because rationing of services between competing demands has been and always will be a fact of life in the NHS, one would hope that the availability of reliable economic evidence can help decision-makers to choose more efficient and more equitable allocations of resources and services.

To date, the available UK evidence suggests that some well-established and some new pharmacological and psychological treatments, as well as some new community care arrangements, have the potential to reduce the direct and indirect costs of schizophrenia (nationally, not just in small research samples) while maintaining or improving patient and family outcomes.

What then are the implications of this economic evidence for the principal stakeholders in Britain's mental health care system? The least important of those stakeholders is the *research community*, which has shown a commendable willingness to incorporate the economic dimension after years of neglect (Knapp, 1997). Early integration of economic evaluations should continue to be encouraged, provided they are well designed (Gray *et al*, 1997).

The consequences of the current accumulation of economic evidence for *users* and *carers* are less clear. It is encouraging that more effective treatments are being introduced, and also that some are of proven cost-effectiveness, so that there is the potential for the economic incentive to reinforce the clinical incentive to adopt these treatments more widely. However, some of the most marked of the current changes in mental health care impose heavy burdens on carers (which are not always adequately measured by researchers or readily recognised by 'formal' services), or they pitch users into seemingly less well supported community placements whose adverse consequences may not be identified by those studies which use only short follow-up periods. Evaluations of treatments must be careful not to create new 'perverse incentives' – by their poor design – which lead to worse rather than better care.

One of the consequences of the NHS internal market has been the greater transparency of both decision-making criteria and the resource effects of those decisions. Both purchasers and providers are more aware of the costs of care, and some of the studies reviewed in this paper will improve the accuracy of those costings. But the internal market has also encouraged budget-holders to draw a narrower boundary around their responsibilities – there are strong (market-enforced) pressures to keep within one's own budget, perhaps at the expense of someone else's budget. For example, the pharmacy manager facing much higher drug prices may recognise the greater cost-effectiveness of the new compounds when viewed in their widest context, but how is the manager to build these savings to *other* budgets into her or his own annual plans? Likewise the manager of a psychology service who may argue that the financial pay-offs to a more expensive but successful course of treatment accrue to other stakeholders in the system.

These considerations are among those which prompted the then Conservative government to invite consultations on the broad organisation of mental health care in their 1997 Green Paper, perhaps through a joint health/social care agency. Whatever the eventual outcome, better inter-agency coordination will clearly be needed to ensure that the effectiveness and cost-effectiveness improvements revealed by recent research are not lost because of the

incentives running through the system. The costs of schizophrenia are large, particularly when viewed in the broadest setting, but the growing body of evidence on cost-effective interventions and organisational structures can and should assist stakeholders in the system to target their resources on needs, and to achieve better outcomes from available services.

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