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An economic evaluation of schizophrenia–1991

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Abstract

In 1991, the costs for schizophrenia, which has a lifetime prevalence of 1.5% among adult Americans, totaled \$65 billion. Costs were broken down into their direct and indirect components. Direct costs, which totaled \$19 billion dollars, consisted of treatment-related expenditures such as those for inpatients and outpatients, as well as nontreatment-related expenditures such as those for the criminal justice system used by individuals with schizophrenia. The direct costs were fairly similar to those of other recent estimates of the cost of schizophrenia. Indirect costs, which were \$46 billion dollars, included the lost productivity of both wage earners (\$24 billion) and homemakers (\$4.5 billion), individuals who were in institutions (\$4.5 billion) or who had committed suicide (\$7 billion), and caregivers who took care of schizophrenic family members (\$7 billion). Our method for calculating the indirect costs was slightly different than methods used in prior studies, which may account for our estimates being higher. The method for determining each expenditure is provided, and the implications of these staggering costs are discussed.

Introduction

Schizophrenia and schizophreniform disorders have a combined 1.5% lifetime prevalence among adult Americans [1]. In 1991, almost 3 million American adults between the ages of 18 and 65 years were or would be schizophrenic sometime during their lives. These individuals require extensive services, and contribute to a dramatic loss of productivity. We estimate that, in 1991, schizophrenia cost the United States \$19 billion in direct expenditures and \$46 billion in lost productivity, a total of almost \$65 billion.

Methods

General issues

Direct and indirect costs—The aggregate economic cost of an illness is usually made up of two major components. The first of these is the *direct consumption cost* or *direct cost*, which consists of the actual dollar expenditures on medical care related to helping the patient function. Direct costs are the expenditures by federal, state, and local governments, private individuals, families and groups, and philanthropic organizations for current and future (research and training) care, prevention, and treatment. There are however, substantial direct costs that are not strictly treatment related. For example, many schizophrenic individuals are in jails and prisons; while we might hope that these institutions provide treatment, treatment is not these institutions' primary function. In this analysis we have therefore broken the direct costs into *treatment-* and *nontreatment-related* direct costs (negative externalities). Economic losses, especially lost productivity due to illness, are known as *indirect consumption costs* or *indirect costs* and are the other component of the aggregate economic cost. Lost productivity implies "... not only that the individual fails to operate at his maximum capacity but that society could and would utilize him at his maximum if he could operate there" [2].

A major assumption involved in these calculations is that if direct expenditures were not being spent on ill individuals, the money would be used to make the nation more competitive in the market-place. A similar assumption is made about indirect costs, namely that if the patient could work, and if those who are providing uncompensated services to him could work for compensation, their efforts would go into making a marketable product. Consequently, this form of economic evaluation is viewed in relationship to the gross national product (GNP) or gross domestic product (GDP).

Inflation adjustments—When treatment-related direct costs were initially determined for a year other than 1991, they were adjusted to 1991 values by the Medical Care Consumer Price Index (CPI-U) [3]. Since nontreatment-related direct and indirect costs were more difficult to sort into their appropriate index components, the yearly CPI-U for all indexed items was used for these computations. The notation $_{\text{ADJ-CPI}}$ indicates that a cost underwent the appropriate CPI-U adjustment.

The population considered—The estimated 1991 costs included the 50 states, the District of Columbia, and United States territories. The territories contributed less than 2% of the total, but were included because they must be considered as part of the total national cost. It is likely that the direct costs did not include all costs for the territories, since a number of information sources, which often were not clear about the geographical scope upon which their estimates were based, probably did not include the territories. When data were obtained for a year other than 1991, the notation $_{\text{ADJ-POP}}$ indicates that an adjustment was made for population increases [4].

Use of the mean daily census—Inpatient and outpatient costs were generally determined using the mean daily censuses, rather than patient admission or discharge rates.

This made it unnecessary to determine the cost of patients experiencing multiple admissions, and avoided the problem of determining the average length of stay.

The Epidemiologic Catchment Area study and other sources of data

Data from current published sources were used when possible. Usually, these data needed to be updated. In those situations where estimates were required, information from informed individuals was acquired. It is a given that whether data came from published sources or had to be estimated, their trustworthiness is highly variable. When data were deemed to be less reliable, we used them in a way that we believe underestimated the true cost, thus providing a conservative estimate of the total cost of schizophrenia.

We relied heavily on the “first wave” of the National Institute of Mental Health (NIMH) Epidemiologic Catchment Area (ECA) survey for much of the data on prevalence and productivity [5]. This survey represents the largest study ever undertaken for the purposes of determining the amount and kinds of psychiatric illness extant in a population. It is also probably the best available survey of any medical disorder for the general population of the United States.

Use of 1-year versus lifetime prevalence—Normally, one would look at the cost of an illness during a year such as 1991 by counting only those individuals who had symptoms during that year. We held to this principle for direct treatment-related expenditures, but took a different approach for other expenditures. While for many illnesses it is likely that only those individuals with “active” symptoms would be actively treated, this is not necessarily true for chronic illnesses such as schizophrenia; treatments for schizophrenia are only capable of suppressing symptoms. It is likely that some individuals with well-controlled symptoms would not be counted as having active illnesses, although they would be included in the lifetime prevalence rates. In the ECA study, a diagnosis of active schizophrenia was made only if there were positive or productive symptoms such as hallucinations or delusions. These symptoms may not be present early or late in the course of schizophrenia, and some patients have symptoms such as hallucinations and delusions only rarely. The more incapacitating symptoms are more subtle (loss of drive, interest, and attention), but are very likely to reduce productivity. It is thus possible that an individual who reported no hallucinations or delusions during the last year, but had had them at one time would be classified as having schizophrenia in remission by the ECA study. Certainly, some of these individuals would be functioning normally. Others, however would be functioning poorly because of their residual symptoms.

Most of the productivity data used here came from the same survey as the prevalence data and has been expressed as lifetime prevalence. In our calculations, those individuals who had returned to normal lives did not contribute to the lost productivity for schizophrenia. Therefore, including them in the lifetime prevalence rate does not inflate the cost of schizophrenia. We similarly assumed that family care would be provided to individuals who would not have been considered actively ill during the last year according to the ECA study, since some of these individuals would have substantial residual symptoms. Finally, we also used lifetime prevalence rates for individuals in shelters, jails, and prisons.

Direct costs

Assumption of normalcy—We assumed that a considerable amount of the estimated direct expenditure attributable to schizophrenia would have occurred whether or not the individuals were schizophrenic. For example, a certain percentage of those schizophrenic individuals in jails and prisons would be there regardless of whether or not they were schizophrenic. To allow for this assumption, the lifetime prevalence of schizophrenia in the general population (1.5%) was subtracted from the lifetime prevalence of schizophrenia in jails, prisons, and shelters. Not subtracting this figure would lead to an overestimate of the associated costs. The notation $_{\text{ADJ-NOR}}$ indicates that this adjustment was made. A similar adjustment was not made for crime and the criminal justice system because the baseline rates were derived only from those patients admitted to psychiatric hospitals. Individuals who were not hospitalized in the last year were not considered to have contributed to the crime expenditure.

Insurance administrative costs and overhead—Public institutions and third-party health payers such as Medicaid, Medicare, Blue Cross/Blue Shield, and other public and private health care organizations have administrative costs associated with processing claims, as well as collecting and distributing tax revenues and premiums. These administrative charges are made up through taxes, premiums, and donations. To account for these costs, we added 8.6% (the published administrative cost for Blue Cross/Blue Shield for 1990 [6]) to all direct care expenditures except those provided by the Veterans Administration and the Department of Defense. These federal organizations are self-insured and have presumably calculated their administrative expenses into their published costs. The notation $_{\text{ADJ-INS}}$ indicates insurance overhead was added.

Capital costs—Several authors [2, 7] have argued that because there is no opportunity to use the publicly supported grounds and structures (where much of mental illness is treated) for commercial purposes, they represent a large hidden cost. As land values have increased and cities have spread into communities where large psychiatric hospitals have been for many years, there has been a substantial increase in the value of these properties. This is particularly true of the older psychiatric hospitals that tend to occupy large amounts of land. A recent study by Rosenheck et al. has estimated that the lost opportunity capital costs of the Veterans Administration hospitals were 6% of other operating expenses for inpatients, and 4% for outpatients [8]. We used these values to estimate the lost opportunity capital costs of all governmental institutions (no value was given to lost opportunity capital cost for private facilities, although one could argue that there should be such an estimate for not-for-profit institutions). For institutions where inpatient and outpatient costs were aggregated, we used the 6% value since most of the costs associated with such institutions are attributable to inpatient care. The notation $_{\text{ADJ-CAP}}$ indicates that the appropriate inpatient or outpatient capital costs were added.

Indirect cost issues

Prevalence- and incidence-based analysis—Direct costs and lost productivity are calculated according to either prevalence- or incidence-based analysis. Prevalence-based analysis assigns the direct costs and lost productivity to the year in which they occur, with

the exception of lost productivity due to premature death, which is assigned entirely to the year of death. Incidence-based estimates assign all present and future direct costs and lost productivity to the year in which the costs began and therefore require the translation of future expenditures and lost productivity into current values, using the concept of discounted dollars. Another difference between prevalence- and incidence-based analyses is that prevalence-based methods look at all cases in which the disorder is present during the year, while incidence-based analysis examines only those individuals in whom the disease began that year.

Generally, prevalence-based analyses use aggregated figures, while incidence-based analysis requires a much more detailed knowledge of the component costs. While we primarily used a prevalence-based method, we attempted to break costs into as many components as the data allowed. We deviated somewhat from previous prevalence approaches by using averages or midpoints of populations whenever possible in order to make maximum use of the limited data available, as well as to facilitate computations.

A component of indirect costs that can make it difficult to compare one study with another is the degree to which secondary output losses are considered [9]. Legitimate components of indirect costs include the loss of productivity by others in a work force because they are coworkers of individuals with schizophrenia, the amount of time devoted by family members to caring for a schizophrenic, and time away from work of jurors who participate in the trial of an individual with schizophrenia. How far to extend these ripples of lost productivity is unclear. It seems reasonable to extend them to first-degree relatives who not only suffer a significant financial burden, but also have a substantial decrease in their quality of life. Further extension of this ripple effect, at least for schizophrenia, would probably add little to the total cost, although it is possible that for some disorders, particularly those where the entire cost is not so high, the extension of lost productivity to other workers in the workplace or other settings would make up a substantial percentage of the lost productivity. The only extension made beyond first-degree relatives was for victims of crime, since they were included in the available criminal data [4].

There are several forms of lost productivity associated with illness. The major divisions are between those individuals who work or would be expected to work for compensation if they were healthy, and those who would not be expected to work for compensation. The latter includes individuals who perform household work (homemakers), which has been estimated to account for 25–40% of the GNP [10]. Household workers, like those working for monetary compensation, can be producing at full or partial capacity, or not at all. Estimating the lost productivity for those who are working or would be expected to work if they were not ill requires knowing the average compensation (wages plus benefits) for working individuals. For an incidence-based estimate, where future earnings are discounted, it is necessary to project an increase in compensation over time since most individuals are compensated less when starting their careers than after those careers have been established. There is one other item that should probably go into estimates of lost productivity: profit. The compensation and profit attributed to an individual equal that individual's total economic value to society, and together go into making up the nation's GDP. However, since profit varies from year to year and would add an uncertain component to these

calculations, it was not estimated here, though it might be important when comparing costs across economic systems (i.e., capitalism versus socialism).

Since placing a value on household work is not as simple as calculating the lost productivity for compensated individuals, a number of methods have been developed to estimate the value of this work [9, 11]. To determine the value of household work that a schizophrenic individual would have been expected to perform but did not, we used the method of Peskin (1984) who used both the time men and women spent on specific household tasks and the wages that an individual performing those tasks would earn [12]. Similarly, we used the average 1991 *wage* to calculate the opportunities lost through family care. One might argue that we should have used compensation, but in this instance we relied heavily on the work of others who have used wages.

Results

A breakdown of actual and estimated costs of schizophrenia in 1991 is displayed in Table 1.

Direct costs

Treatment-related direct costs

Inpatient hospital care: Many of the data obtained from state and county mental hospitals, psychiatric services of nonfederal general hospitals, and multiservice hospitals do not separate inpatient from outpatient expenditures. In practical terms, the blurring of the costs associated with inpatient and outpatient treatment is more than simply an accounting issue, since patients often are not fully discharged when they leave the hospital. For example, there are many forms of partial hospitalization and extended leave. In our calculations, when there was no simple means of separating inpatient from outpatient expenditures, all expenditures were attributed to inpatient costs. This does not affect the total expenditures, but increases the inpatient expenditures at the expense of outpatient costs.

The average annual expenditure was calculated for private hospitals, state and county mental hospitals, Veterans Administration hospitals, nonfederal general hospitals, multiservice hospitals, the Department of Defense, and the Indian Health Service. The percentage of patients who were being treated for schizophrenia was assessed [13]. Insurance and capital costs were added to the total when applicable. Approximately one-third of the private hospitals allowed psychiatrists and other professionals to charge separately for their services [14]. The value of these services, calculated from the CHAMPUS (Civilian Health and Medical Program for Uniformed Service) data set, was added to the private hospital total [15].

Veterans Administration hospitals have expenditures in addition to that specifically targeted at psychiatric inpatient care, which include administrative, educational, and research costs. The figures obtained from the Department of Defense reflected the total mental health care costs of “direct health care”. All active duty servicemen (including those from the public health service), retirees, the dependents of both, and a small percentage of others (designees of the Department of Defense) are treated through direct care in hospitals run by the Department of Defense. Exceptions to this occur only if specific services are not available in

those hospitals (i.e., there is no heart surgeon), and in such a situation, CHAMPUS supplies the care (G. Willauer, personal communication, 1992).

The figures obtained from the Indian Health Service reflected only direct inpatient costs, since it was assumed that contract costs had been included elsewhere. These figures did not include the costs of alcohol and drug abuse (B. Douglas, personal communication, 1993).

The total inpatient expenditure for schizophrenia in 1991 was approximately \$10,820 million_{ADJ-CPI, INS, CAP}.

Outpatient care: Most outpatient care expenditures were included under inpatient expenditures as discussed earlier. The average annual expenditure for free-standing outpatient clinics, Veterans Administration, the Department of Defense, Indian Health Service, and private care were calculated, and the percentage spent on schizophrenia for each was assessed. When applicable, insurance and capital costs were added to the total. Figures for Veterans Administration outpatient clinics included the share of administrative, research, and training expenditures attributable to schizophrenic outpatients in 1991.

This total also included expenditures for case management of individuals with schizophrenia. We were not able to separate case management from the other service costs provided by inpatient and outpatient facilities. Part of case management expenditures were therefore included in the estimate of inpatient and outpatient expenditures. For a number of years, however, many communities have provided case management services that are independent of traditional psychiatric services. In our efforts to obtain previously unestimated costs of case management for schizophrenia, we reviewed several studies [18-23] and conducted a number of interviews. Based upon interviews with several commissioners of state mental health systems, field workers, and scientists who are examining this issue, we learned that it is likely that attempts were made to provide some form of case management to most of the individuals with schizophrenia who had sought any form of psychiatric help in 1991. Again, based upon these interviews, we estimate that about 50% of case management came from outside traditional mental health resources and had therefore not been counted in the estimated inpatient and outpatient service costs. We then contacted the supervisor of the Northern Virginia Outpatient Services, an organization that primarily serves individuals with chronic schizophrenia. She estimated that, in 1988, their workers spent 1.5 h with each chronic schizophrenic patient per week. It is unlikely, however, that most patients on a national level have weekly contact with a case manager, unless there is a crisis. The experts we interviewed felt that the average patient probably met with their case manager once a month.

In 1991, outpatient expenditures for schizophrenia totaled approximately \$1,200 million_{ADJ-CPI, POP, INS, CAP}.

Nursing homes and intermediate and domiciliary care: The number of nursing home residents with schizophrenia was calculated and multiplied by the average yearly expenditure per patient. Insurance and capital costs were added. In addition to traditional inpatient and outpatient care, the Veterans Administration also operates intermediate care

beds and domiciliary care facilities [24]. The cost for the psychiatric part of these services was calculated (excluding pharmacy expenditures, nursing, or other overhead costs), and the percentage of that total used to treat individuals with schizophrenia was assessed. Capital costs were not added to domiciliary care since these patients receive care in their own home.

In 1991, the total nursing home and intermediate and domiciliary care and freestanding partial care center expenditure for schizophrenia was approximately \$5,840 million_{ADJ-CPI, INS, CAP}.

Medication: The cost of most inpatient, other institutional, and some outpatient medications used to treat schizophrenia was included as part of the aggregate expenditures in the appropriate sections. In order to derive an expenditure that was not previously used, we assumed that the outpatient expenditure for medications was not previously included. A recent study of the adult, non-institutionalized population estimated that 485,491_{ADJ-POP} individuals were taking antipsychotic medication in 1991 [25]. We assumed that all individuals taking antipsychotics were schizophrenic (cost associated with antipsychotics used to treat other disorders would be more than counterbalanced by the additional medications used by schizophrenic individuals whose costs were not included here). Based on this figure and on the annual cost of these medications we calculated that the cost of medications for individuals with schizophrenia in the community in 1991 was approximately \$115 million_{ADJ-INS}. The cost for medications represents the actual cost to the family devoid of any federal or insurance aid.

Treatment for drug and alcohol abuse: In our estimate, we used items that were not tabulated in previous sections of this study. Figures for specialty and federal institutions, office-based physicians, support costs, motor vehicle accidents, and social welfare administration, based on estimates from another study, were used [26]. In 1991, the total cost of treating substance abuse in individuals with schizophrenia was approximately \$300 million_{ADJ-CPI}.

Supported living and shelters: Transitional living, such as half-way houses or bed and board housing, were partially accounted for in other categories, such as transfer costs. With the exception of shelters, we could not, however, provide a reasonable estimate for the rest of the cost associated with these living arrangements and, therefore, did not include them here. The cost of shelters, which provide a number of services not found in ordinary housing, has not previously been estimated. Surveys of shelter users are relatively consistent in their finding that a high percentage of individuals who use shelters have psychiatric disorders, and that a high percentage of those particular individuals have schizophrenia. We reviewed several studies [27-29], and determined that approximately 14.5%_{ADJ-NOR} of shelter occupants are schizophrenic, although this is likely to be a conservative estimate. The cost of providing shelters for individuals with schizophrenia in 1991 was approximately \$410 million_{ADJ-NOR, CPI}.

Non-treatment-related direct costs (negative externalities)

Law enforcement judicial system: There are many components to the costs of crime, including the cost of police and fire contact, pretrial investigations, property damage, lost victim productivity, as well as all adjudication, jury, and private defense costs. Unfortunately, data are limited on the amount of contact individuals with schizophrenia have with the police, the fire department, or the criminal justice system. We made the conservative assumption that only some of those schizophrenic individuals whose behavior was severe enough to be admitted to a hospital had such contact. This assumption was made, in part, because our most useful data associating schizophrenia with the crime rate came from a hospital admission study [30]. In 1991, there were 369,596 schizophrenic individuals admitted to psychiatric hospitals one or more times [5].

One cost originates from police contact with schizophrenic individuals following behavior disturbances (examples include public intoxication, loitering, disorderly conduct, and other misdemeanors) [31, 32]. In order to estimate the crime costs attributable to schizophrenic individuals, we used a study that surveyed 219 schizophrenic patients admitted to California's Napa Valley State Hospital over a 19-month period [30]. Over the previous 8 years, 55 of those patients had been arrested for violent or potentially violent crimes. Based on the number of crimes committed by the group described in this study, we developed a ratio of the total number of crimes committed by individuals with schizophrenia.

We assumed the expense for adjudicating violent and nonviolent crime attributable to schizophrenia was proportional to the cost for the general population. We also calculated the total cost of private legal services for the criminal defense attributable to individuals with schizophrenia [33], as well as the total victim loss attributable to admitted schizophrenic patients.

The lifetime prevalence of schizophrenia in jails is 4.4%_{ADJ-NOR} [34]. We based our cost estimate on the average daily jail population [35] and on the cost of maintaining an inmate in that jail [36]. The lifetime prevalence of schizophrenia in prisons is 5.2%_{ADJ-NOR} [36]. Other data used included the number of individuals in state and federal prisons [37] and the average cost of giving an inmate annual medical care [38]. The total expenditure for schizophrenic inmates in jails and prisons was \$1,340 million_{ADJ-NOR,CAP}.

In 1991, the total cost of crime due to schizophrenia, including jails and prisons, was approximately \$2,000 million.

Suicide and suicide attempts: There is considerable excess mortality associated with schizophrenia and it is largely due to suicide [39, 40]. The expenditures associated with suicide and suicide attempts that stand out are the medical costs for attempted suicides, investigational costs for completed suicides, and lost productivity (covered in indirect costs).

Most reviews of the subject indicate that suicide attempts and suicide are most common early in the course of the illness [39]. We assumed that approximately 33.4% of individuals with schizophrenia will make at least one suicide attempt [41], that individuals with schizophrenia only make one such attempt in their lives (this is undoubtedly an

underestimate), and that the one suicide attempt is serious (to some degree this assumption, which probably leads to an overestimate of the cost of suicide attempts, balances the underestimate of the number of attempts by a single individual). To estimate the number of suicide attempts per year, we assumed that they take place entirely during the first year of illness and calculated the number of suicide attempts from the mean age of onset and the lifetime prevalence of schizophrenia. Although costs of hospitalizations in psychiatric facilities were covered under inpatient psychiatric costs, serious suicide attempts require the use of ambulance services, emergency rooms, and inpatient medical services. It was assumed that all suicide attempts were from poisonings, an assumption that does not include those attempts that require costlier surgical procedures.

It was estimated that 8.2% of individuals with schizophrenia kill themselves and that the average age at suicide is 31 years [41]. The number of schizophrenic individuals who killed themselves in 1991 was 8,734_{ADJ-POP}. Each completed suicide is associated with medical investigational costs. Interviews were conducted with law enforcement officials in the District of Columbia and Maryland to determine police expenditures for the investigation of a suicide, and the cost from the District of Columbia Medical Examiner's office was also obtained.

In 1991 the total cost of suicide and suicide attempts was approximately \$190 million_{ADJ-CPI,POP}.

Research and training: In 1991, the National Institute of Mental Health spent roughly \$51 million on direct grants for research and training in schizophrenia (C. Willabee, personal communication, 1992). States, private organizations, and pharmaceutical companies contributed about \$20 million. In 1991, research and training costs for schizophrenia were approximately \$71 million.

Adjustment for transfer costs: The normal consumption of goods and services is considered part of the total level of output of both the services and the goods of society, and is one of the benefits of society. Ideally, these societal benefits are present whether or not an individual is ill. A portion of the estimated direct expenditure attributable to schizophrenia, namely that for food, clothing, lodging, and basic medical expenses, is the minimal cost of living and would be incurred if the individuals were not schizophrenic. These are not costs of schizophrenia and should be subtracted from the total direct costs. To estimate these transfer costs, the poverty level for a one-person household under age 65 years was used. In 1991, this was \$6,331_{ADJ-CPI} [43]. The number of schizophrenic individuals occupying hospital, nursing home, shelter, intermediate and domiciliary, prison, and jail beds had an associated transfer cost of approximately \$2,320 million_{ADJ-CPI} which was subtracted from the direct costs.

The total direct cost for schizophrenia in 1991, including all medical, substance abuse, shelters, criminal, suicide, research, and training costs, were approximately \$18,600 million. This estimate includes an adjustment for transfer costs.

Indirect costs

General aspects

Gender: In the ECA study [5], there is a statistically nonsignificant trend for females to have a higher lifetime prevalence of schizophrenia than males. On the other hand, schizophrenia tends to be identified earlier in males, and males have a more severe course. Furthermore, when very strict criteria were used, males were reported to have a higher prevalence. Since males earn more than females, we took a conservative approach and assumed that the prevalence of schizophrenia for males and females is the same.

Skilled and non-skilled workers: The ECA study provides values for the earnings of both skilled and unskilled (farmers, operators, fabricators, laborers, and forestry personnel with the exception of managers) workers who have schizophrenia (L. Robins, personal communication, 1992). Average wages have been determined for each group [4].

Calculation of average compensation: The total compensation for all full-time workers has also been determined [43]. To calculate the average full-time total compensation for skilled and unskilled workers, the difference between cash and noncash incomes was obtained. In 1991, the weighted average compensation (wages and salary payments to all full-time workers including executive bonuses, tips, payments-in-kind, employer contributions for social security insurance, director fees, private pensions, and welfare funds, etc.) for all full-time workers, both skilled and unskilled, was \$33,692_{ADJ-CPI}. Lost productivity estimates assumed an individual would be productive from age 18 years to his or her 65th birthday, which is the common age of retirement.

Lost earnings of schizophrenic individuals

Paid and potentially paid individuals with schizophrenia: To calculate lost compensation, it was necessary to use lifetime prevalence rates, since data on the percentage of individuals with schizophrenia who were working are provided in this form [5]. Compared with 56.3% of the general adult population who were employed, only 42.8% of individuals with schizophrenia were currently employed [5]. Furthermore, compared with the general population, individuals with schizophrenia were overrepresented in unskilled jobs by 20% and underrepresented in skilled jobs by 60%, meaning that they were partially disabled. We determined the combined lost productivity for individuals with schizophrenia, including those who were not working (and would have been working had they not been ill) and those who were working but were partially disabled.

Unpaid work, nonmonetary production, or homemaking: As with the paid or potentially paid schizophrenic individuals, there were two forms of lost productivity; the first assumed total disability and the second, partial disability. It was assumed that the percentage of individuals with schizophrenia who were both homemakers and nonproductive equaled the percentage of individuals with schizophrenia who were totally disabled potential wage earners.

Lost productivity from those in institutions: In 1991, there were 192,820_{ADJ-POP} individuals with schizophrenia between the ages of 18 and 65 years in psychiatric

institutions, shelters, nursing homes, jails, and prisons. During their stay at the institution, the individuals occupying those beds could be considered to be nonproductive. Since the estimates of lost productivity are based on household samples and, therefore, fail to take the institutionalized population into account, their totals were added.

Premature mortality, suicide: The conventional way of estimating the lost productivity of those individuals who killed themselves would be to project the earnings for the rest of their lives and discount them into 1991 dollars. Discounting inflates the cost for the current year by bringing future earnings into it. There are at least two alternatives that consider the effects of past deaths on current productivity: the “cohort method” and the “steady-state method.” The cohort method examines what would have happened to productivity had the individual not died. It adjusts for both changing populations and the increased earnings of individuals who were not old enough to have reached their maximal earning at the time of their death. The steady-state method, which we used because of its simplicity, assumes that the same number of people die each year from an illness. The lost productivity therefore depends on the number of years an individual would be expected to be productive, the average age of retirement, and the number of people who die during that year. This method, while simple, overestimates the loss by using the number of individuals dying in the present year, which, in a growing society, will be higher than the number who died in the past. At the same time, it underestimates the lost productivity by failing to consider that healthy individuals would be paid greater salaries later in life.

Lost family productivity: Family caregivers are largely, but not exclusively, parents who are taking care of their schizophrenic child. These parents may have wished to reenter the work force after their children had grown, or they may have returned to school and improved their position in the work force. Similarly, many who receive wages must take time away from work to care for their family member and therefore are less well compensated than they would have been otherwise. Since we only considered schizophrenic individuals aged 18 years and over in our cost of schizophrenia estimates, it is our assumption that the family who takes care of an ill family member is doing so rather than working for compensation. Therefore, we used the 1991 weighted mean of the average compensation of a wage earner and a homemaker to calculate the opportunities lost through family care.

The estimate of time lost to family caregiving is based on a 1985 survey of members of the National Alliance of the Mentally Ill (NAMI), which ascertained how many hours of care families provide to their schizophrenic family member [45] (cited in [7]), Sixty-five thousand families belong to NAMI, and 64% of these families have one or more schizophrenic members [46]. However, only a small percentage of families with a schizophrenic member belong to NAMI. Since there is little basis for determining the amount of time the average non-NAMI family spends with their schizophrenic family member, a conservative estimate was made that they average one-third the amount of time spent by the average NAMI family. Use of this conservative value also takes into consideration that some individuals with schizophrenia have no family working on their behalf, and that, in 1991, not all individuals with a lifetime diagnosis of schizophrenia

needed family help. Furthermore, those individuals with schizophrenia living in institutions were not included in this estimate. Also, while lifetime prevalence rates are likely to increase the number of individuals needing help in 1991, individuals who had the symptoms of schizophrenia prior to age 18 (including those who became schizophrenic as children) were not included in this estimate. In the initial Franks study, most of the time contributed by family members was for caregiving, but some time was also attributed to recreation and other activities [7]. Since the identified schizophrenic in the survey was almost always an “adult child,” it seems reasonable to assume that the vast majority of this time would not have been spent had the individual not been schizophrenic.

The total indirect costs, including lost wages, decreased work performance of compensated workers and homemakers, family caregiving, suicide, and the lost productivity of those individuals in institutions was approximately \$46,520 million in 1991.

In 1991, then, the total cost of schizophrenia was \$65,180 million

Discussion

It should come as no surprise that schizophrenia is a very expensive illness. We believe that the estimated expenditures are conservative, although they are higher than other recent estimates. As more information becomes available, and more elements of the costs are identified, the cost of schizophrenia will probably be found to be even greater than the estimate presented here.

Many issues will come to mind when looking at these costs. One issue that requires consideration is the overlap between the costs associated with schizophrenia and other illnesses, especially since these estimates are for individuals with schizophrenia and schizophreniform illness. It is not unusual to consider both schizophrenia and schizophreniform illness as each being comprised of more than a single disease. For example, some individuals given the diagnosis of schizophreniform disorder may ultimately be diagnosed as having a bipolar disorder. To the degree that this is true, the cost of schizophrenia will be inflated at the expense of bipolar and other psychotic disorders. However, mis-identified individuals in the estimate of the cost of bipolar disorder, which follows this paper and which uses the same data base, will not be counted twice. If the costs of one illness are higher at the expense of the other, the total cost of the two disorders together should not be compromised.

The same problem could be encountered if the costs of substance abuse and schizophrenia were added without considering that they may consist of overlapping expenditures. In essence, the sum of the parts would be more expensive than the whole. Because of the nature of schizophrenia, we argue that most individuals with schizophrenia abuse drugs and alcohol due to their schizophrenia and that the costs should therefore be attributed to schizophrenia rather than to substance abuse. Nevertheless, any attempt at adding the cost of the two problems should subtract the overlapping costs from one or the other side.

For those who see this staggering cost and want to know how to reduce it, we point out that the ratio of non-treatment-related to treatment-related direct costs is about 12%. The major

portion of non-treatment-related direct costs stem from schizophrenic individuals interacting with the law enforcement/judicial system. The indirect costs, however, which make up 71% of the total, are where the real burden lies. This high cost only crudely reflects the devastation that this illness causes for millions of individuals.

The numbers presented are intended to be meaningful when compared with the GDP. The lost productivity and capital costs, however, are “would-have-beens.” The lost productivity or lost opportunity costs assume a loss to the GDP. However, were these losses added to the real GDP, one would have to assume a slightly greater GDP than exists.

We compared our figures with those of other studies. In a 1975 study, Gunderson and Mosher estimated that schizophrenia cost the United States an adjusted total of \$40 billion_{ADJ-CPI} for 1991 [47]. Using an incidence-based approach and Australian data, one study has estimated that schizophrenia cost the United States an adjusted total of \$19 billion_{ADJ-CPI} in 1991 [48].

Recently, Rice and Miller have estimated that for 1991, the cost of schizophrenia was \$34 billion_{ADJ-CPI} [49]. Since much of our analysis is derived from methods developed by Rice and her colleagues, a comparison of the results should help explain some of the differences in our estimates. Even though much of the data for the two studies was derived from different sources, and our study included a number of elements not found in the one conducted by Rice and Miller, the estimated direct costs of the two were surprisingly similar. Our study subtracted the basic cost of living for all institutionalized individuals (transfer costs), included capital costs, and included the population of United States territories. Still, our direct costs were \$18.6 billion and Rice and Miller’s were \$19.5 billion_{ADJ-CPI}.

The major difference in our studies was in the treatment of three specific indirect costs: suicide, compensation of workers, and family caregiving. When determining an estimate for the cost of suicide, we assumed a greater number of premature deaths than did Rice, which contributed to our higher cost. There is also a substantial difference in the way we estimated lost earnings. Rice and Miller discounted future earnings in order to bring them into today’s dollars. We, on the other hand, assumed that individuals who killed themselves in the past would have remained productive until their 65th birthday had they not killed themselves, and therefore did not discount what they would have earned.

Rice and Miller used a timing model for the lost productivity of compensated workers that attempted to match the lost earnings by age, gender, and impairment. We calculated lost earnings by first determining an average compensation for all full-time employees and then adjusting for degree of disability. We believe, however, that we used similar estimates of lost earnings for homemakers.

To estimate the cost of family caregiving we went beyond the lost compensation for NAMI members and presented estimates for non-NAMI members as well. For NAMI members we used the full estimate from the Franks survey and 33% of that figure for all other families, minus those with family members in institutions [45]. Rice and Miller used 33% of the Franks figure for all families. The major difference lies in the fact that we estimated that

there were more individuals with schizophrenia living in the community than did Rice and Miller. We suspect that their method underestimates a large group of individuals who require considerable family assistance. These differences in the calculation of indirect costs are significant enough to account for the discrepancy between our two estimates.

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Table 1

Costs of schizophrenia-rounded totals in millions

<i>Direct costs</i>		
Treatment-related:	Total inpatient costs	\$10,820 million
	Total outpatient costs	\$1,200 million
	Total nursing home, inter mediate, domiciliary care costs	\$5,840 million
	Medication	SI 15 million
	Substance abuse	\$300 million
	Shelters	\$410 million
	Non-treatment-related:	Total crime (includes jails/prisons)
Suicide		\$190 million
Research/training		\$70 million
Transfer costs		– \$2,320 million
Subtracted from direct costs		
Total direct costs		\$18,600 million
<i>Indirect costs</i>		
	Lost productivity, homemakers	\$4,500 million
	Lost productivity, institutions	\$4,500 million
	Lost productivity, suicide	\$7,000 million
	Lost family, productivity	\$7,000 million
	Lost compensation	\$23,600 million
Total indirect costs		<u>\$46,500 million</u>
<i>1991 Total (direct and indirect)</i>		<u>\$65,200 million</u>