Schizophrenia™ & Psychosis Action Alliance

Societal Costs of Schizophrenia

& Related Disorders

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The Insight Initiative

Improving Outcomes in Schizophrenia & Psychosis

The Insight Initiative was established in 2020 by the Schizophrenia & Psychosis Action Alliance (S&PAA) to develop a foundation of evidence regarding the societal impacts of schizophrenia and psychosis. By compiling all medical costs and non-medical costs and associated impacts (including incidence and prevalence, mortality rates, effect on caregivers, impacts to the criminal justice system, and effects on homelessness) into a single numerical annual and lifetime estimate, we will provide overwhelming evidence of the full impacts on the United States (US) health care and social support systems which are dramatically failing to provide appropriate care for persons living with schizophrenia and psychosis.

Millions of people in the US are living with or are impacted by schizophrenia. Schizophrenia has a neurological basis, with many studies demonstrating clear evidence of its biological underpinnings, including identification of many genes that may contribute to disease progression. Schizophrenia symptoms typically start in late adolescence to early adulthood as the brain is still developing. Individuals with schizophrenia typically require lifelong treatment with impacts on quality of life beginning at a young age and growing over the course of a lifetime. While approximately half of individuals with schizophrenia improve or achieve remission, others remain untreated or experience periods of life without treatment. Individuals living with schizophrenia often live shorter lives, by as much as 15 years, than the average US life expectancy. While suicide is a contributor to this life expectancy difference, those living with schizophrenia are also at a higher risk for chronic and life-threatening health conditions such as diabetes, cardiovascular disease, and addiction that often go untreated when their schizophrenia is untreated.[1]

For many, there is an urgent need to obtain access to appropriate medical care and treatments. It can be a matter of life and death for individuals to obtain proper treatment through our complicated behavioral and physical health system. A system which too often fails this population.

The Schizophrenia & Psychosis Action Alliance has established the Insight Initiative to gather and share essential, standardized evidence on the comprehensive disease impacts of schizophrenia, psychosis, and related disorders in the US and globally. This report represents the first of what will be a continuous program designed to provide the foundation for researchers and policymakers to improve the outcomes of individuals living with these brain diseases.

Many evidence-based direct services and public policy-based recommendations will emerge as the Insight Initiative continues to address gaps in knowledge through research. Only with more comprehensive, accurate data and analysis can the US develop targeted policies and ultimately a better system of care for people living with schizophrenia. Recommendations based on the initial phase of research results include advocating for federal and state legislative actions such as:

- Directing the National Institute of Mental Health (NIMH) to collect accurate prevalence and incidence data by conducting a system-wide epidemiologic study on schizophrenia and serious mental illness, thereby updating the first Epidemiologic Catchment Area (ECA) program of research commissioned in 1977.
- Significantly increasing the annual NIMH clinical research budget allocations for evidence-based studies with the best potential to improve outcomes for individuals with schizophrenia.
- Reauthorizing the 21st Century Cures Act to include funding for priorities that serve individuals living with schizophrenia.

Rather than continuing to fund our failures, we need to invest in a new and better treatment paradigm that recognizes this disease as a neurological condition and addresses it accordingly. Instead of "flying blind" and basing policies and treatment decisions on incomplete data, we need to concentrate on understanding impacts of the disease, how it is currently managed, the costs, and the failures. Only then can we develop and execute targeted, life-saving care.

The Schizophrenia & Psychosis Action Alliance encourages collaboration and partnership to solve this societal issue and asks all that are interested to join us in this effort.

Background

ABOUT SCHIZOPHRENIA

Schizophrenia is a spectrum of serious neuro-psychiatric brain diseases in which people experience periods during which they interpret reality abnormally. Symptoms of schizophrenia may include a combination of hallucinations, delusions, cognitive impairments, anosognosia (lack of disease insight), and disordered thinking and behavior that impairs daily life.[2,3] Schizophrenia is thought to be a progressive neurodevelopmental disorder with the earliest signs appearing during adolescence as the brain is developing. Eventual diagnosis typically occurs during young adulthood.[4]

Though multiple genetic risk factors for schizophrenia have been identified, experts generally believe that a complex interplay between one's genetics and environment is responsible.[2,5] These risk factors impact both neurodevelopmental and neurodegenerative processes that are considered as potential underlying causes of the symptoms commonly associated with schizophrenia.[5] Disruptions in neurodevelopmental processes and other environmental factors may result in further worsening of symptoms for those with schizophrenia.[6]

DIAGNOSIS AND TREATMENT

A schizophrenia diagnosis typically follows initial episodes of psychosis that occur in an individual's late teens or early twenties. Even before the first episode of psychosis, individuals may show slight changes in their behavior or thought process.[7] Due to the stigma associated with the condition, physicians are known to give patients an interim non-specific psychosis diagnosis when uncertain about schizophrenia until it can be confirmed.[8]

Schizophrenia has a heterogeneous range of outcomes with the most severe cases requiring repeated or continuous hospitalization to individuals with single psychotic episodes who experience complete recovery.[9] However, most people with schizophrenia typically require lifelong treatment as there is no cure for the underlying neurological basis for schizophrenia.[3] Treatment focuses on managing symptoms and improving functionality and is most likely to be successful when initiated early in the course of disease. Early treatment may also help improve long-term prognosis and manage symptoms, thus avoiding serious complications such as psychotic episodes or psychiatric hospitalizations[10], which can help prevent serious consequences such as interactions with the criminal justice system.[11] For many individuals with mental illness, access to care is limited by cost, scarcity of clinicians, restrictive insurance arrangements, and fragmented systems.[12] The National Survey on Drug Use and Health reported that less than two-thirds of individuals with schizophrenia, bipolar disorder, or another serious mental illness received care for their illness.[12] Approximately 50% of individuals with schizophrenia recover or significantly improve over the long-term, confirming that with adequate treatment, people can lead successful and fulfilling lives.[9]

The lack of care in a subgroup of people with schizophrenia can result from a common symptom called "anosognosia," which is a lack of ability to perceive the realities of one's own condition, and it is seen in other neurological disorders such as spinal cord injury and Alzheimer's disease.[13] Anosognosia is estimated to be present in 57-98% of individuals and is most influential on whether a person will voluntarily seek care.[14] As a result of this symptom, approximately half of individuals with schizophrenia do not take their prescribed medications as directed, often leading to poor symptom management and associated disease consequences such as hospitalization or unemployment.[15]

"COSTS" OF SCHIZOPHRENIA

The symptoms of schizophrenia, their downstream effects, and the current response and treatment infrastructure in the US often lead individuals to struggle with issues such as maintaining stable housing, encountering the criminal justice system, and obtaining employment. Studies suggest that as much as 20% of the homeless population meets the criteria for a diagnosis of schizophrenia or a related disorder, though a 2019 systematic review found estimates ranging from as low as 4% to as high as 22%.[16] Further, among those who are incarcerated in prisons or jails, approximately 8–24% suffer from a psychosis-related disorder, depending on the diagnostic definition and incarceration setting.[17,18] Individuals with schizophrenia also experience greater unemployment, underemployment, and work productivity loss compared to the general population.[19–21] Furthermore, they often rely on families and caregivers to assist with daily activities, transportation, care coordination, and financial support.[22–24] These poor functional outcomes can lead to a reduced quality of life and shortened life expectancy (Box 1).[25,26] However, when individuals receive optimal care, they can lead productive and fulfilling lives.[9]

Schizophrenia results in significant monetary costs to the individual, their loved ones, and society. The societal impact of schizophrenia is likely much greater than previously quantified as no single study considers all relevant cost elements. For instance, the most recent economic burden study of schizophrenia conducted in 2013 estimated overall annual costs attributable to schizophrenia (also called "excess costs") to be $155.7 billion (2013 USD).[27] The largest components of this economic burden were costs related to unemployment, caregivers' work productivity loss, and health care costs for those with schizophrenia. However, this study and other similar economic burden studies have overlooked

Box 1: Schizophrenia "Care" in the US

For many historical reasons, the US has two separate health care systems: one for physical health and one for behavioral health. These divergent care systems were established generations ago before an in-depth understanding of brain diseases, commonly classified as behavioral or mental disorders, was available. Individuals experiencing similar symptoms encounter very different pathways of care depending on the disease or condition that caused the symptoms (i.e., diseases classified as "behavioral" or "mental" diseases go through one door of care and diseases classified as "physical" go through another door). The different doors opened to people with conditions classified as "behavioral" or "mental" result in poor outcomes and an unacceptably high burden of disease for individuals, families, and society.

Right Door: An individual with Alzheimer's disease that is found confused, agitated, and delusional is brought to a health care facility. Medical professionals can act in the best interest of these patients and provide life-supportive, necessary care without delay due to their lack of decision-making capacity. Inappropriate behaviors resulting from this brain disease are not criminalized and medical care is not delayed.

Wrong Doors: An individual with schizophrenia who is found confused, agitated, and delusional typically encounters law enforcement as first responders instead of trained medical professionals. The symptoms of schizophrenia, such as lack of disease insight and auditory and/or visual hallucinations, can lead to "inappropriate" behaviors that are often criminalized when encountered by first responders who are not health care providers. This can lead to three common outcomes: (i) transportation to a hospital emergency department for care, (ii) no action, or (iii) arrest, followed by incarceration in county jails.

Two of these outcomes result in the individual not receiving any immediate care for a medical event. Even in the best-case scenario, transportation to an emergency room, individuals with schizophrenia having a psychotic episode may or may not retain the right to self-determination depending on the state/local laws. Because of these variations, health care providers are not always allowed to stabilize individuals or provide acute medical care without agreement by an individual, who at that moment in time, could lack decision-making capacity.

When no action is taken, individuals are allowed to continue to deteriorate medically, resulting in poor health and other societal consequences, such as homelessness and unemployment. When behaviors are criminalized, treatment is overseen by mental health courts without the necessary expertise, not by trained medical professionals.

key cost components of the broader societal costs of the disease, including reduced quality of life and overall life expectancy. In fact, a 2016 systematic literature review of the global economic burden of schizophrenia found that only 38% of studies incorporated all three categories of cost: direct medical, direct non-medical, and indirect costs of the disease.[28] Further, some costs of schizophrenia have not been previously quantified at the population level, including costs of housing (e.g., board and care homes), out-of-pocket costs spent by caregivers, and costs related to reduced quality of life and shortened life expectancy. Thus, the total cost of schizophrenia is likely much greater than previously quantified.

This report is an important first step in exposing the full direct and indirect costs of schizophrenia to individuals and society. The total cost of these disorders must be characterized to motivate crucial policy changes, encourage research investments, and improve care for individuals diagnosed with schizophrenia and their families.

Estimating the Societal Costs of Schizophrenia

METHODS

A multidisciplinary approach was leveraged to quantify the societal costs of schizophrenia (see Box 2 for included population description) based on currently available information. This approach included:

- Targeted review of peer-reviewed scientific (e.g., research studies) and grey literature (e.g., government statistics and reports);
- Health care costs survey analysis; and
- Development of a total cost model based on inputs from the literature review and survey analysis.[29]

High-level research methods and results are described in this report. Additional details and supplemental data are summarized in study documents.[29] For further information, please contact gordon.lavigne@sczaction.org.

Box 2: Population Definition and Source Data

Studies or data typically include individuals diagnosed with schizophrenia and other related disorders (i.e., schizoaffective, schizophreniform, and delusional disorders) as well as non-organic psychosis disorders. Where possible, cost inputs were based on studies that included only schizophrenia and related disorders. Cost inputs from broader populations (e.g., psychosis or any serious mental illness) were used when schizophrenia population-specific data was not available. Total costs were calculated based on prevalence estimates of individuals with schizophrenia.

For the purposes of this report, the description of the included population is referred to as "schizophrenia" for simplicity.

Box 3: Direct vs. Indirect Costs

Direct costs are the value of resources used in the treatment, care, housing, and rehabilitation of people with the condition. For individuals with schizophrenia, systems outside of health care are leveraged to provide "care" and include law enforcement and homelessness services.

Indirect costs represent the value of economic resources lost because of things like disease-related work disability, impacts on quality of life, premature mortality, and caregiver impacts. Indirect costs represent areas of opportunity. When an individual with a disease improves, the indirect impacts of a disease are reduced.

TARGETED LITERATURE REVIEW[30]

A targeted review of peer-reviewed scientific and grey literature explored various costs of schizophrenia and how they have previously been quantified and identified potential gaps. Google Scholar and PubMed were used to identify appropriate peer-reviewed literature. The search strategy included cost-related, disease-related, and specific domain terms including health care costs, criminal justice system-related costs, caregiver burden, housing and homelessness costs, premature mortality, work and employment-related costs, and previous overall economic burden studies. The literature review examined direct health care costs across multiple types of health systems, direct non-health care costs such as criminal justice and housing costs, and indirect costs due to early mortality, under- and unemployment, and caregiver burden (Box 3). Exploration of cost differences based on medication adherence and social determinants of health (e.g., race, ethnicity) did not identify significant sources of data to be included in the total cost model. Searches

were limited to studies published in the past 15 years in the US. Where multiple studies were identified on a topic, those published within the past 3–5 years and with larger and more generalizable samples were preferred. For areas where costs of schizophrenia have not been directly quantified in the literature in the last 15 years (e.g., population- specific costs of incarceration), data from various publications (e.g., government publications, national surveys) and older peer-reviewed publications were leveraged with costs adjusted to 2020 USD.

To obtain population estimates for the number of individuals with schizophrenia who are living in structured housing or long-term care facilities and who are homeless or incarcerated, an additional targeted literature search was conducted.

HEALTH CARE AND EMPLOYMENT COSTS ANALYSIS[29]

Following the completion of the literature review, an analysis of the Medical Expenditure Panel Survey (MEPS)[25] data from 2006–2015 was conducted to quantify trends in the economic burden of schizophrenia. MEPS is a set of large-scale surveys of community-dwelling (i.e., non-institutionalized) families and individuals, their medical providers, and employers across the US, and it is the most complete source of data on the cost and use of health care and health insurance coverage.[25] MEPS is also the only source of health care data that combines detailed information about health care spending with individual and family-level characteristics for the US community population.

To capture individuals who may be given an interim non-schizophrenia diagnosis, individuals with "schizophrenic and psychotic disorders" – the MEPS condition category for this population – were included in the base case analysis and compared with people who do not have such a diagnosis (including those that may have another psychiatric or chronic medical condition), matched on age, gender, index year, residence region, health care plan type, and race/ethnicity. A sensitivity analysis including only respondents with "schizophrenic disorders" was conducted to confirm overall results. The MEPS analysis provided direct medical costs as well as indirect costs due to productivity losses and unemployment for the total cost model. A regression analysis calculated the marginal cost (i.e., excess cost) of being diagnosed with "schizophrenic and psychotic disorders" in MEPS.

TOTAL COST ESTIMATE[29]

Parameters found in the literature review and results of the MEPS data analysis were combined to produce a comprehensive total cost estimate using a prevalence-based approach. To estimate total costs, the average differential cost (i.e., the difference compared to the unaffected population) per person was multiplied by the number of individuals with schizophrenia. Costs were calculated for specific categories (e.g., health care, criminal justice, homelessness, caregiver burden) by subpopulations (e.g., those living in the community, in structured residences or board-and-care homes, without housing, in prison or jail) (Table 1).

TABLE 1: Costs included by setting of "care"

Unique Costs by Setting				
Independent Household	**Supported or Structured Housing**	**Skilled Nursing Facilities/Long-term Care**	**Homeless**	**Prison or Jail**
Not applicable	Supportive residential services, likely to include rent, cost of support staff, and other operating costs of a facility	Residential costs and all costs associated with providing care while in the facility	Homeless remediation costs including homeless shelters, street outreach activities, and crisis response center visits	Labor and time for correctional staff as well as shelter, security, food, and other necessities provided in the facility
Costs Applicable to All Settings				
Caregiver Burden*	**Health Care**	**Other Indirect Costs**	**Employment and Income**	**Justice System Interactions**
• Cost of unpaid labor • Higher health care costs • Work absenteeism • Out-of-pocket costs spent on caregiving	• Inpatient care • Outpatient care • Office-based physician visits • Prescription drugs • Emergency room visits • Home health care	• Reduced health-related quality of life • Shortened life expectancy	• Reduced wages among the employed • Lack of employment • Supportive income from the Social Security Administration (i.e., SSI/SSDI)	• Services provided by police officers, sheriffs, and deputies • Services provided by judicial staff • Services provided by institutions, such as local and county jails and paid legal guardians

*Not included for incarcerated, homeless, or individuals living in long-term care

An excess cost approach (Box 4) was used to estimate the societal costs of schizophrenia.[31] This means that the costs of people with schizophrenia were compared to the costs of people who do not have schizophrenia with the difference being the additional or "excess" cost of schizophrenia. For example, to calculate excess health care costs, average health care costs for those with schizophrenia were compared to those without schizophrenia, and the difference between the two was used as an input in the calculation. This methodology allows for a clearer picture of how much more an individual living with schizophrenia costs in comparison to a person who does not live with schizophrenia. Similarly, for cost categories such as homelessness, the percent of the general population that is homeless was subtracted from the percent of the population with schizophrenia that is homeless to calculate the excess homelessness costs owing to schizophrenia.

Box 4. What Are Excess Costs?

The economic burden estimate presented in this report is the ***excess*** burden of schizophrenia. This means the additional costs or costs attributed to having schizophrenia. Costs for people without schizophrenia were subtracted from the costs of those with schizophrenia to obtain the cost specific to schizophrenia.

It is important to note that some of the estimates used in this report to compute the excess economic costs of schizophrenia are out of date and/or not comprehensive and are therefore subject to uncertainty. Some sources include small sample sizes or non-representative populations. Sources for areas such as law enforcement encounter costs, supportive/structured housing costs, and number of hours per week spent on caregiving were also based on data that may not be nationally representative. To account for some of this uncertainty, various sensitivity analyses were conducted where a range of inputs was tested to estimate the impact on the total costs.

How Many People Are Affected by Schizophrenia?

BACKGROUND

When quantifying the costs of a disease, it is critical to understand how many people are affected (i.e., disease prevalence). Prevalence is the number of individuals in the population with the illness within a specified time period (e.g., 1 year). Determining the prevalence of schizophrenia is complicated by both clinical and methodological challenges.[32] A diagnosis of schizophrenia typically follows initial episodes of psychosis that occur in an individual's late teens or early twenties. But even before the first episode of psychosis, individuals may show slight changes in their behavior or thought process. Many individuals with schizophrenia do not seek care or diagnosis as they suffer from anosognosia (the inability to believe they have a condition with their symptoms or diagnosis).

In addition to diagnostic limitations, a large proportion of individuals with schizophrenia do not always live independently in the community or other settings commonly included in population estimates, such as long-term care facilities. A large portion of this hidden population can be found living in structured residences, homeless, or incarcerated – complicating prevalence estimates.

For instance, nationally representative household surveys [e.g., Medical Expenditure Panel Survey (MEPS), National Health and Wellness Survey] commonly used to estimate health care and productivity loss costs in other diseases only capture individuals who live in private, independent households, and they do not include those who live in structured group homes, long-term care facilities, or those who are homeless or incarcerated.[33] Furthermore, estimates using insurance claims only include individuals who are enrolled in health insurance plans and receive health care. While these sources are commonly used to estimate disease prevalence in the US, they are likely to miss a significant portion of the population with schizophrenia (Table 2).

TABLE 2: Previously published prevalence estimates and their associated limitations

Annual Prevalence Estimate	Data Source	Included Population	Limitations
0.3%[34]	National Comorbidity Survey Replication (NCS-R)	Individuals living in independent households responding to voluntary survey	Likely underestimated. Lack of disease insight associated with schizophrenia may lead to low response rates for this population in household surveys. Further, this does not account for individuals in structured residences, long-term care facilities, skilled nursing facilities, or those that are incarcerated or homeless.
0.51%[35]	Health care insurance claims	Includes individuals that are receiving health care for schizophrenia in all settings except those that are incarcerated	Likely underestimated. Lack of disease insight leads to lower treatment rates or lack of consistent presentation for treatment. Data does not include individuals that did not present for treatment, were not consistently enrolled in health insurance programs, or were incarcerated. Estimate includes assumptions for uninsured individuals receiving care for schizophrenia.
1.0%[36]	Epidemiological Catchment Area (ECA) survey - Wave 1	Individuals in all settings except for those that were homeless	Data from the 1980s from five representative localities across the US. These five catchment areas may not be fully representative of the population nationally, although targeted sampling and weighing approaches were implemented to mitigate this risk. Diagnostic criteria used in this study have evolved since this time and may have been more inclusive. Individuals that were homeless were not included in this study.
1.1%[27]	Epidemiological Catchment Area (ECA) survey - Waves 1 and 2	Individuals in all settings except for those that were homeless	Refined prevalence estimates including one-year follow-up data for individuals followed in the ECA. Estimate limitations include those stated for the original estimate from Wave 1 of this study.
1.6%[37]	Multiplier method estimation using data from the Medical Expenditure Panel Survey (MEPS) and Medicare-Medicaid dual eligible administrative records.	Estimate based on data from Medicaid-Medicare enrollees from government administrative reports and individuals living in independent households responding to voluntary survey	Due to high unemployment and disability rates, individuals with schizophrenia are overrepresented as Medicaid-Medicare enrollees. Using this enriched population may not be representative of all individuals living with schizophrenia. This estimate does not include individuals that are uninsured, not seeking care for schizophrenia, or are incarcerated. However, this method of estimation has been used in settings where populations may be difficult to reach or hidden.

Table updated in October 2021

ESTIMATING PREVALENCE TO CALCULATE TOTAL COSTS

Various studies report prevalence estimates in the US ranging from 0.24% to 1.6%.[34-36] Prevalence estimates globally are based on similarly limited data or research methods and typically fall within this same range. A broad consensus on the actual prevalence of schizophrenia is not available due to the lack of reliable data. With this in mind, this analysis leverages a common method by choosing the mid-point between the most complete potential estimates. Baseline costs were estimated using 0.8% prevalence in 2020.

The one-year prevalence rate of 0.8% of the total US population corresponds to 2,648,021 people living with schizophrenia (Box 5), based on an estimated US population in 2020 of 331,002,651. This estimate is the mid-point between two published estimates available in the literature that cover a large proportion of the population with the disease: a prevalence of 0.51% from a study using health insurance claims[35] and 1.1% from the most recent economic burden study which used the ECA estimate.[27,111] Using these one-year prevalence estimates, the number of individuals living with schizophrenia in 2020 ranges from 1.7 million and 3.6 million people, respectively. These prevalence rates were used as two additional scenarios to estimate total costs.

No recent study or dataset fully and accurately accounts for individuals diagnosed and/or living with schizophrenia in the US. Limited number of studies, old research, and a wide range of reported estimates all support an immediate need for a comprehensive study to accurately estimate the prevalence of schizophrenia.

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Box 5. Prevalence of Schizophrenia

The precise number of individuals living with schizophrenia in the US is unknown. Population estimates are complicated as no data source or study includes all the settings where individuals with schizophrenia are living.

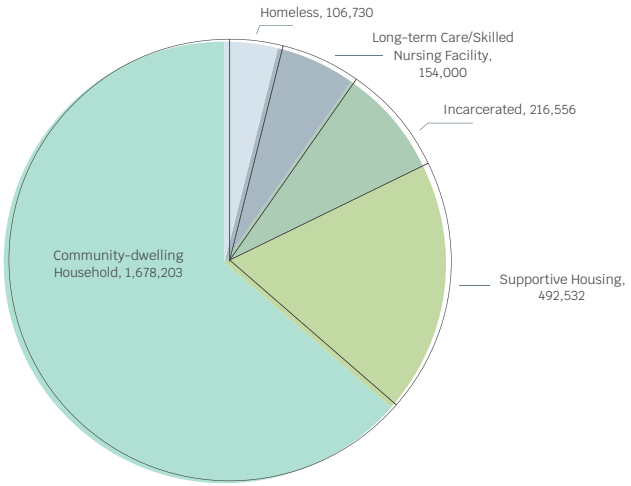
Literature estimates range from 0.25% to 1.6% of the population. The most reliable estimates from the published literature were leveraged to estimate a **conservative one-year prevalence of schizophrenia at 0.8% of the total US population or 2.65 million individuals in 2020.**

ESTIMATING PREVALENCE BY SETTING

Costs relating to schizophrenia can vary by setting. To estimate the total costs of schizophrenia more accurately across all segments, estimates of how many individuals with schizophrenia are in each setting were completed. No single study was available that described the proportion of individuals with schizophrenia in each location. Instead, the estimated schizophrenia prevalence of 0.8% and the reported proportions of individuals with schizophrenia or a psychosis disorder residing in each setting were used:

- 18.6% reside in structured settings[38]
- 11% of those in nursing homes have schizophrenia[39]
- 18.8% of the homeless population has schizophrenia or a related disorder[16]
- 10.2% of inmates have a psychotic disorder[17]

FIGURE 1 : Number of individuals by housing type



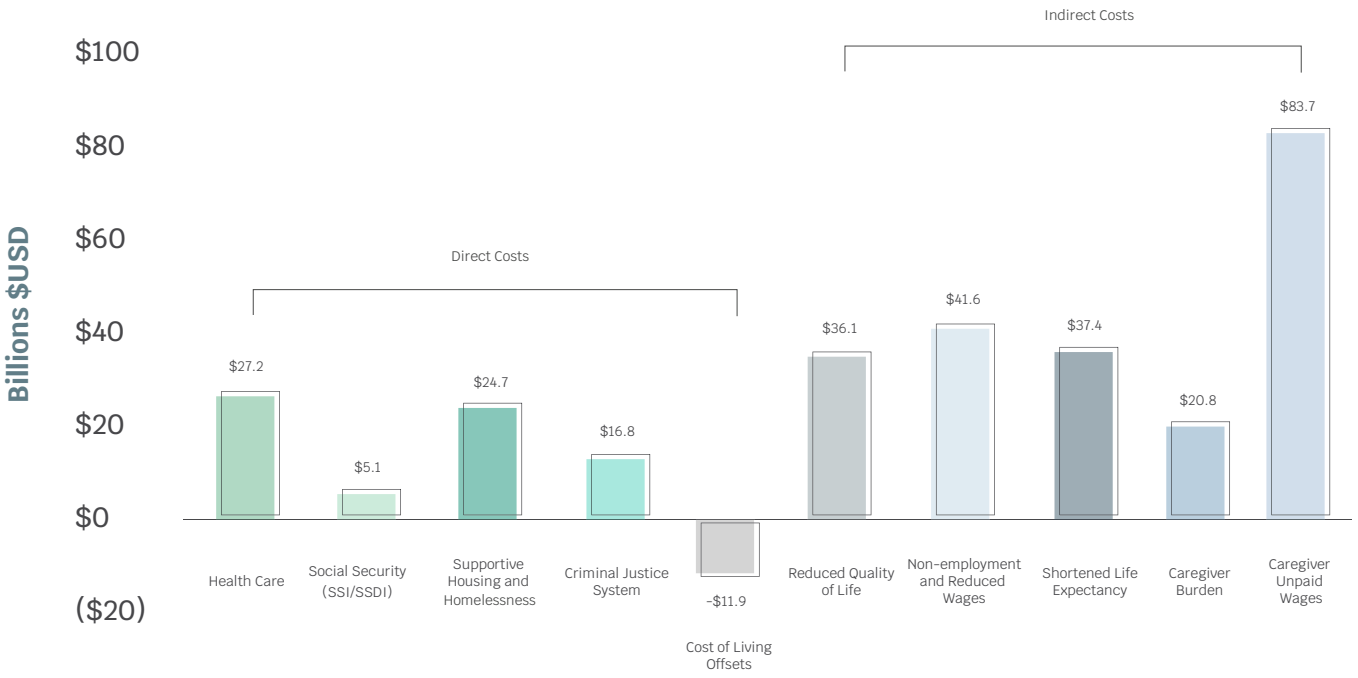
For this schizophrenia prevalence estimate, we assumed that individuals that were not in structured residences, long-term care facilities, homeless, or in jails or prisons lived in independent households. Individuals living in independent community-dwelling households may live by themselves, with family members (e.g., spouse, children, parents), or with friends. While more than one reference by setting was typically available, the most recent and nationally representative data were used. Based on the 0.8% overall prevalence rate, the estimated population with schizophrenia by setting in the US is shown in Figure 1.

Total Cost of Schizophrenia in the US is Estimated at $281.6 Billion in 2020

ESTIMATED TOTAL SOCIETAL COST[40]

The total cost of schizophrenia in the US was estimated for the year 2020 assuming the prevalence of 0.8% (2,648,021 people with schizophrenia in 2020). Costs are grouped by category and type (Figure 2). Using this approach, the societal costs of schizophrenia were estimated to be $281.6 billion in 2020. These costs represent additional costs of schizophrenia on top of costs that are already incurred by those without schizophrenia.

FIGURE 2: The total societal cost of schizophrenia in 2020*



*Rounded to nearest hundred million

Direct costs for individuals living with schizophrenia were nearly $62 billion USD in 2020 of which 36.8% could be attributed to health care, 33.5% to supportive housing (structured residence and long-term care facilities) and homelessness services, and 6.9% to Supplemental Security Income and Social Security Disability Income. Approximately 8% of individuals with schizophrenia are incarcerated resulting in the majority of the 22.8% of direct costs relating to interactions with the criminal justice system and incarceration.

Individuals living with schizophrenia also incur significant indirect costs due to the impact of the disease on their lives, accounting for $115.2 billion in 2020. Individuals with schizophrenia have significantly lower quality of life and reduced life expectancy, accounting for $73.5 billion of costs in 2020. Additionally, while most individuals with schizophrenia are living in community settings, there is a high unemployment rate in this population. When employed, individuals with schizophrenia earn less than people without schizophrenia. Unemployment and reduced wages account for $41.6 billion in indirect costs.

The impact of schizophrenia on caregivers is extremely high. The estimated indirect costs due to caregiver impacts account for over $104.5 billion in excess costs in 2020, or 37% of the total. Most of these costs are due to unpaid caregiving ($83.7 billion) including $20.8 billion due to the excess costs of reduced productivity in addition to higher personal health care costs and out-of pocket costs.

Previous research on the total economic burden of schizophrenia in the US found lower overall excess costs. The most recent study, conducted in 2013, estimated the annual societal cost of schizophrenia at $155.7 billion.[27] Consistent with our 2020 estimate, the 2013 costs associated with the unpaid labor of caregiving, lack of employment, and health care costs comprised large shares of the costs. Importantly, previous studies did not account for all the cost components included in this 2020 analysis, including other costs of caregiving (e.g., caregiver work productivity and out-of-pocket costs), Supplemental Security Income and Social Security Disability Insurance, specific health care costs for different subpopulations, and costs of shortened life expectancy and reduced quality of life.[27]

To determine the effect of various parameters with lower level of certainty on the total cost estimate, a range of inputs (+/- 25% of the value used in the main analysis) were tested independently to estimate the impact on the total costs. These included time spent providing direct care each week, annual cost of incarcerating an inmate with severe mental illness, annual per-person cost of living in an adult residential facility, and employment rates for those living outside an independent household. Increasing or decreasing each of these cost inputs by 25% increased or decreased the total cost estimate by as little as 0.2% (employment rates) to 7.5% (time spent providing care each week).

Finally, two additional population prevalence scenarios (0.51% and 1.1%) were run to provide the range of potential total costs based on the wide range of reported population estimates. Total costs were estimated at $180.6 billion in 2020 using a 0.51% disease prevalence and $386.1 billion in 2020 based on a 1.1% annual prevalence of schizophrenia. Detailed results from all sensitivity analyses are summarized in study reports. For further information, please contact gordon.lavigne@sczaction.org.

LIFETIME COSTS – $3.8 MILLION PER INDIVIDUAL WITH SCHIZOPHRENIA[40]

Schizophrenia impacts individuals and families often beginning in their teenage years and continuing throughout their lifetime.[43] While individual experiences and costs are expected to vary each year, it is important to put context to the full potential scope of the impacts of schizophrenia over an individual's lifetime. An estimate of this lifetime cost was calculated by assuming that 2020 excess costs per person with schizophrenia remain the same each year from diagnosis through death (Table 3), with an average age of diagnosis at age 25.

TABLE 3: Per-person average lifetime cost estimate inputs

Input	Value
Average age of diagnosis	25[41]
General population life expectancy from age 24	55.6 years[42]
Years of potential life lost per death with schizophrenia	14.5 years[25]
Schizophrenia population life expectancy at age 24	41.1 years*

*Estimated number of life-years after diagnosis

Costs prior to diagnosis were not included. Based on this simplified approach, the total excess societal costs incurred over the lifetime of the typical individual with schizophrenia will be $3.8 million from age 25 through death or a simplified average of approximately $92,000 each year of life after diagnosis. This calculation includes a valuation for the lower quality of life experienced by a person with schizophrenia, on average, but does not include any compensation for having a shorter life expectancy than individuals without schizophrenia. This value should be considered an average, and individual lifetime costs may be considerably lower or higher depending on the course of illness, living situation, and other factors throughout the lifetime.

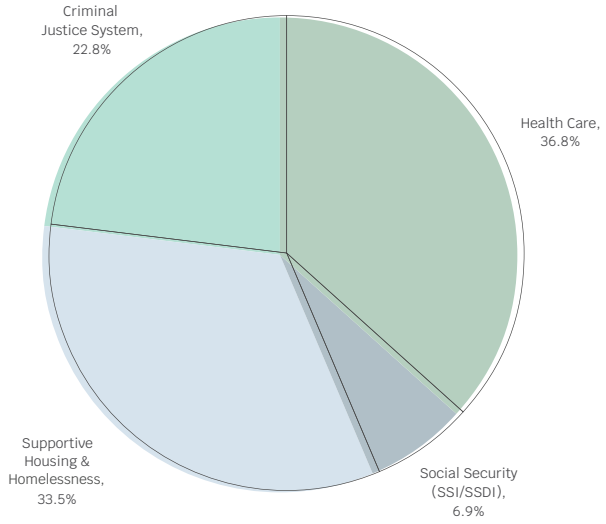
The Estimated Annual Cost of Schizophrenia in the US is

$281.6 BILLION

Direct Costs of Schizophrenia - $62.0 Billion in 2020

In the US, direct costs attributable to schizophrenia were estimated at $62.0 billion in 2020 after adjusting for cost offsets. Direct costs are those that can be directly attributed to patient care and include the products and services associated with disease management. For most diseases, direct costs are predominantly linked to health care providers or health care facilities. Uniquely, individuals living with schizophrenia incur significant direct costs for patient care services that are provided by individuals who are not trained health care providers, including but not limited to, social services, housing authorities, law enforcement, and criminal justice system employees. The approach to managing critical health events in schizophrenia and other similar brain disorders leads to the unique types and distribution of direct costs for patient care across various health and public services (Figure 3). While substantial costs are attributable to health care services, most direct costs are spent providing supportive housing, supplemental or disability income, or trying to manage this disease within the criminal justice system where sufficient health care infrastructure and training are lacking.

FIGURE 3: Direct cost of schizophrenia



COSTS OF HEALTH CARE – $27.2 BILLION IN 2020

For the entire US population living with schizophrenia in 2020, excess health care costs were estimated to be $27.2 billion. This estimate is based on the setting in which health care costs incurred for those living with schizophrenia (Table 4). Most of these costs were spent on those living in the community and in structured housing (92%), followed by health care for the homeless population and long-term care (e.g., skilled nursing facilities-SNF) residents. Health care costs for individuals living in jails or prisons were reported as an aggregate estimate with other incarceration-related costs and are thus reported in a subsequent section.

Previous studies have consistently shown that individuals living with schizophrenia incur significantly higher health care costs than people without schizophrenia, no matter how the individual is insured (private insurance, Medicaid, Medicare).[27,46-48] People with schizophrenia often require treatment with prescription drugs, experience inpatient hospitalizations, are treated by psychiatrists and other behavioral health specialists, and have other comorbid health concerns that all lead to higher health care costs. However, the total cost of health care for those with schizophrenia (i.e., not excess costs) varies widely, with studies reporting annual health care costs for those with schizophrenia from $10,000 to over $30,000.[46-49]

TABLE 4: Health care cost estimate inputs

Input	Value	Estimated Number
Excess health care costs for community and structured residence-dwelling	$11,500[44]	2,170,735
Excess health care costs for long-term care dwelling	$5,400[34]	154,00
Excess health care costs for the homeless population	$12,156[45]	106,730

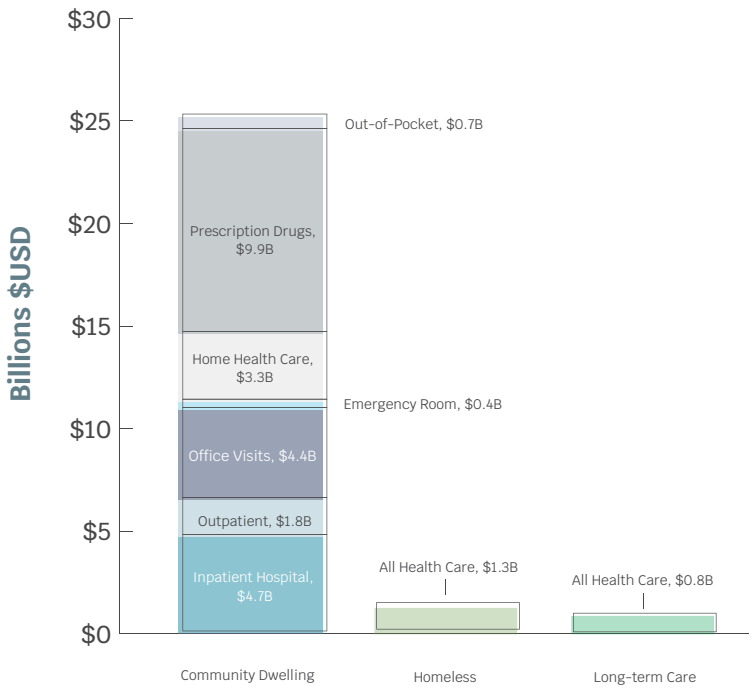
Note: Health care costs for individuals while in prison or jail are accounted for in incarceration costs.

Factors such as the data source, methodology, and sample composition have considerable impact on reported costs – including those reported here. Studies using national survey data may underestimate costs, as the patients requiring the highest level of care are less likely to be captured by and to respond to these surveys.[33] Insurance claims (private, Medicaid, and Medicare) data analyses are also only able to capture patients who receive care and have health insurance for a continuous period. Further, some studies only quantified costs incurred in the first year after diagnosis.[46] This may overestimate costs for the average patient because individuals often struggle to manage symptoms directly after diagnosis, often requiring multiple medication switches and even psychiatric hospitalizations.

To address these limitations, the current analysis applied health care costs specific to each subpopulation living with schizophrenia. Across all published research, however, the costs of inpatient hospitalizations and prescription drugs consistently comprise the largest share of an individual's health care costs (Figure 4). Further, while the current analysis did not explore total direct costs stratified by race or ethnicity due to data limitations, some evidence suggests that patients who are Black have higher inpatient costs, but lower prescription drug costs.[50]

Providing better integrated care can substantially reduce health care costs for those with schizophrenia, primarily by reducing expensive inpatient hospitalizations. For example, one study found that the provision of housing and other support services to homeless residents decreased their number of emergency room visits by 61%.[51] Multidisciplinary initiatives such as California's Full-Service Partnership (FSP) program provide assessment and crisis response, counseling, care coordination, peer support, and other intensive services. Compared to those receiving regular psychiatric care, those enrolled in an FSP incurred $9,000 less in inpatient and emergency room costs over the course of a year.[52] Further, improved medication management and adherence have the potential to substantially reduce health care costs.[53]

FIGURE 4: Excess health care costs by type and setting



SUPPORTIVE HOUSING AND HOMELESSNESS COSTS – $24.7 BILLION IN 2020

People living with schizophrenia are at high risk of having unstable housing.[16,57] Using the average costs for operating adult residential facilities and long-term care facilities, costs for providing homeless remediation services, and the estimated percentage of the population with schizophrenia requiring each of these services (Table 5), the cost of supportive housing and homelessness was a combined $24.7 billion in 2020.

TABLE 5: Supportive housing and long-term care facility cost estimate inputs

Input	Value
Percent of the schizophrenia population living in a structured residence	18.6%[38]
Estimated number of individuals with schizophrenia living in a structured residence	492,532*
Annual per-person cost of living in a structured residence	$33,700[54]**
Percent of LTC residents with schizophrenia	11.0%[39]
Percent of individuals with schizophrenia living in LTC facilities	5.8%*
Total number of LTC residents, 2019	1,400,000[55]
Per-person monthly cost of semi-private room in LTC facility	$7,452[56]
Percent of general population living in LTC	0.42%*
Estimate number of individuals with schizophrenia living in LTC	142,800

LTC=Long-term Care
*Calculated
**Because this parameter originates from a Los Angeles report – where cost of living is substantially higher – a cost of living adjustment factor of 0.7 was applied to better reflect national cost of living.

Costs related to supportive housing

Costs related to supportive housing accounted for most costs in the supportive housing and homelessness costs category at $24.4 billion in 2020. Among those with schizophrenia who have stable housing, many are living in structured residences such as board and care homes, halfway houses, or permanent supportive housing. Previous studies have not accounted for individuals with schizophrenia who reside in such settings. These facilities represent a vital housing resource for individuals living with serious mental illness conditions or experiencing psychosis.[54] The services provided by these facilities may include lodging, food service, supervision, assistance with taking medications, assistance with transportation, and housekeeping.[54] They vary considerably by state and county, with some being publicly-funded supportive housing and others being privately run by homeowners. However, little published research has sought to understand the scope and cost of these residences among people living with schizophrenia. Some evidence suggests that around 20% of the population with schizophrenia lives in a structured residence of some kind.[38]

In terms of cost, the most comprehensive data comes from California – particularly Los Angeles (LA) County. One LA County Mental Health Commission report outlined budgetary considerations for adult residential facilities, exemplifying that a standard facility in the county costs $33,660 per individual to operate (for the year 2020).[54] However, it is important to note that these costs are likely to differ drastically by type of facility and location. To determine the impact of this cost input on the overall cost estimates, this variable was included in the sensitivity analyses.

In addition to supportive housing for adults, elderly individuals living with schizophrenia are much more likely to reside in skilled nursing facilities or other nursing homes compared to older adults without mental illness.[39] According to an analysis from Harvard

Medical School, over 500,000 persons with mental illness (excluding dementia) reside in nursing homes, significantly exceeding the number in all other health care institutions.[58] Housing these individuals is costly; the Genworth Cost of Care Survey found that the monthly median cost of a room in a nursing home facility was approximately $7,500 to nearly $9,000, depending on the type of room.[59] In addition to housing, elderly individuals with schizophrenia also often require high levels of both nursing and psychiatric-related care. Despite these more complex needs, older adults with serious mental illnesses such as schizophrenia are also more likely to be admitted to nursing homes that have more deficiencies in care.[60]

Costs related to homelessness

Costs related to homelessness amounted to $376.9 million in 2020. Multiple studies have found that schizophrenia and other psychosis disorders are among the most common psychiatric illnesses among the homeless, with one meta-analysis finding that nearly 19% of those who are homeless suffer from at least one psychotic disorder.[16] Homelessness also puts individuals at even greater risk of chronic substance use, disability, mortality, and crime victimization.[61,62]

The costs of health care for individuals experiencing homelessness are described in the health care costs section. In addition to costs of health care, public service efforts related to homeless remediation incur costs (Table 6). A 2010 study found that, on average, a chronically homeless individual incurred $3,679 annually in costs related to shelters, crisis response, and street outreach.[64] Notably, this cost estimate does not include costs related to local, county, or state programs that provide transitional housing or other housing support. In some areas of the country, these costs may be even higher.

A previous economic burden study estimated the excess cost of homelessness to be $1.8 billion but assumed that individuals experiencing homelessness reside in shelters every day of the year, which may be a substantial over-estimation.[27] Another economic burden study focused on community-dwelling individuals and did not include homelessness costs.[49]

TABLE 6: Homelessness remediation cost estimate inputs

Input	Value
Number of homeless individuals in the US	567,715[63]
Percent of the general adult population that is homeless	0.2%*
Percent of the homeless population with schizophrenia or a related disorder	18.8%[16]
Estimated number of individuals with schizophrenia that are homeless	106,730*
Annual per-person cost of homeless remediation (shelters, crisis response, street outreach)	$3,679[64]

*Calculated

SUPPLEMENTAL SECURITY AND SOCIAL SECURITY DISABILITY INCOME COSTS – $5.1 BILLION IN 2020

Social Security Administration (SSA) benefits – particularly Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) – can be important sources of income for people living with schizophrenia. Using the SSA's annual statistical report on the SSDI program (Table 7), the excess cost of SSI and SSDI for schizophrenia was estimated at $5.1 billion in 2020.

Previous studies of the economic burden of schizophrenia have not accounted for SSI and SSDI.[27] SSI and SSDI are important programs that provide essential financial support for those who are struggling to make ends meet while also conferring eligibility for health insurance.[66] One cohort study found that 57% of participants with schizophrenia were enrolled in some Social Security benefits at the time of study entry.[67] Further, analysis of data from MEPS[44] found that the average responding person living in an independent household with schizophrenia reported $2,988 per year in SSI or SSDI.

TABLE 7: Supplemental security and social security disability income cost estimate inputs

Input	Value
Average monthly SSI per patient*	$257[65]
Number with schizophrenia receiving SSI	292,684[65]
Number of general adult population receiving SSI	3,400,000[65]
Excess percent with schizophrenia receiving SSI	10%**
Average monthly SSDI per person with schizophrenia	$936[65]
Number with schizophrenia receiving SSDI	463,142[65]
Number of general adult population receiving SSDI	10,000,000[65]
Excess percent with schizophrenia receiving SSDI	14.5%**

SSI= Supplemental Security Income
SSDI=Social Security Disability Income
*Not schizophrenia specific
**Calculated

LAW ENFORCEMENT ENCOUNTERS AND JUDICIAL SYSTEM COSTS – $2.3 BILLION IN 2020

Police and judicial system interactions costs for individuals with schizophrenia are costly, estimated to cost local and state governments over $2.3 billion in 2020. These unique direct care-related costs result from the fact that individuals living with schizophrenia are considerably more likely to have contact with law enforcement.[68] Law enforcement officers are often charged with responding to, handling, and even preventing mental illness crisis situations.[69] As police officers are typically not trained to manage and understand this type of complicated medical condition, these encounters often end with individuals going through the justice system instead of being transported and cared for within the health care system. This may be either due to lack of understanding or through lack of available psychiatric beds.[69] Costs in this estimate include receiving a report, investigating, adjudicating, and carrying out a sentence; services provided by police officers, sheriffs, and deputies; services provided by judicial staff, including public defenders, prosecutors, and private attorneys; services provided by institutions, including local and county jails, state prisons, and paid legal guardians; and police transportation. Estimates did not include costs of lawsuit awards or settlements for things like civil rights violations or improper use of force as this data was not available. Additionally, personal costs relating to crime (e.g., stolen personal items, lost income due to injury from crime) were not available for inclusion.

A large multi-year study of patients with schizophrenia[68] estimated that 46% of individuals encountered law enforcement or the judicial system in 2020. Interactions were mostly non-arrest encounters (e.g., crime victimization, disorderly conduct, major driving violations) with a minority resulting in arrests (e.g., burglary, assault, drug charges, parole, probation). The analysis used the assumption that 4.3% of the general population without schizophrenia had similar interactions with the criminal justice system annually. Consequently, an excess of over 41% of individuals with schizophrenia have encounters with law enforcement or the judicial system. These interactions cost an average of approximately $2,125 per person (Table 8).

TABLE 8: **Law enforcement interactions and judicial system cost estimate inputs**

Input	Value
Percent of the population with schizophrenia interacting with law enforcement/judicial system annually	46%[68]
Percent of the general population interacting with law enforcement/judicial system annually	4.9%*
Annual cost of law enforcement/judicial system contact for an individual with schizophrenia	$2,125[68]

*This value is an assumption based on the ratio of incarceration in the population with schizophrenia compared to the general population. This is slightly more than the annual arrest rate in the general population, which is approximately 3%.

Similar to this estimate, previous studies have found that 30-50% of those with schizophrenia may have contact with the criminal justice system in a given year.[68,70] However – contrary to harmful stereotypes – most of these encounters are not related to violent offenses. In one study where nearly one-quarter of individuals with schizophrenia had a criminal charge filed against them, just 2% of those were for violent crimes.[71] Another study found that 67% of law enforcement interactions among individuals with schizophrenia were related to being the victim of a crime.[68] The burden placed on law enforcement to shoulder a significant level of cost and responsibility for providing care is an important system weakness to be addressed.

Evidence from the criminal justice system overall is limited, with most studies capturing small samples of individuals in single counties or states. Only one other recent study sought to estimate the national economic burden of justice system costs in schizophrenia, and it found that judicial and legal services as well as police protection costs were approximately $3.5 billion for the year 2013 with a general population prevalence of schizophrenia at 1.1%.[27] This analysis used a substantially different methodology, calculating schizophrenia-related costs using national statistics on judicial, legal, and police costs rather than leveraging data collected from patients themselves. However, assuming the same prevalence of 1.1% as in the 2013 study did not change our results substantially.

Despite the limitations of studies in this area, all available data points to a high cost of individuals living with schizophrenia in the judicial, legal, and police systems. A modeling study estimated that the economic burden of recidivism in this population was nearly $47 million for a single state government over a period of three years.[72] Further, law enforcement interaction is associated with higher health care costs; in one study, individuals who were involved with the criminal justice system had 70% higher health care costs than those who did not.[73] The major driver of this difference was the high cost of psychiatric hospitalizations, as individuals who interacted with the justice system were more likely to be hospitalized.

INCARCERATION COSTS – $14.5 BILLION IN 2020

Considerable evidence indicates that people with schizophrenia and other psychotic disorders are overrepresented in the correctional population.[17,74,75] Individuals with schizophrenia are over 10 times more likely to be incarcerated than the general population.[17,76] These issues led to an excess cost of $14.5 billion for the incarceration of those with schizophrenia in 2020, including costs related to shelter, security, correctional staff time and labor, food, and health care.

This report used data on the total US correctional population[76,77], the percent of inmates with schizophrenia or a psychosis disorder[17], and the overall national prevalence of schizophrenia, and it estimates that over 8% of those living with schizophrenia are incarcerated.[17] Comparatively, the incarceration rate for the US adult general population is less than 1%. Further, inmates suffering from mental illness are costly, with annual incarceration costs reaching $50,000 to over $100,000 per year– considerably more than unaffected inmates(Table 9).[78] In contrast, the Bureau of Prisons reported an average annual cost of incarceration for federal inmates was approximately $36,000 in 2018.[79]

Similar to the calculations used in this report, the most recently available report on mental health of US inmates found that 8-11% of prison or jail inmates were diagnosed with schizophrenia or another psychosis disorder.[17] This is a striking finding, considering that schizophrenia affects approximately 1% of the general population.

Factors such as the need for psychiatric care and increased supervision and intervention by correctional staff likely contribute to increased costs for inmates suffering from a psychosis-related illness. In a nationwide survey of county jails, 98.3% reported that inmates with serious mental health conditions caused problems requiring staff intervention, and 57% reported that these inmates required additional attention as compared to other inmates.[80] However, correctional staff is generally ill-equipped to effectively manage these situations.[80] Crucially, these inmates are also at higher risk for experiencing violence or abuse while incarcerated and are more likely to be imprisoned for longer than specified in their original sentence.[74]

TABLE 9: Incarceration cost estimate inputs

Input	Value
Percent of the population living with schizophrenia that is incarcerated	8.2%[17]
Percent of the adult general population that is incarcerated	0.88%[76]
Total number of inmates in the US	2,123,100[77]
Annual cost of incarceration for an inmate with a psychosis disorder, including health care	$75,000[78]**

*This value was calculated from the total prevalence of schizophrenia and the estimated number of inmates suffering from a psychosis disorder.
**Due to lack of comprehensive reports on average incarceration costs specifically for the mentally ill, a midpoint of the lowest and highest mentioned estimates was used.

Few other studies have attempted to estimate total incarceration costs for inmates living with schizophrenia. The economic burden study for 2013 also leveraged various reports and national surveys and estimated total incarceration costs at $3.6 billion.[27] Like this report's estimate, the previous study is limited by the extent of published information, recency of data, and the wide range of estimates reported in the literature on this topic. A sensitivity analysis varying the per-inmate cost of incarceration by +/- 25% in the excess cost calculation was conducted to address this limitation. This analysis had minimal effect on the societal costs of schizophrenia.

DIRECT COSTS NOT INCLUDED

While this analysis represents the most comprehensive assessment of the costs of schizophrenia in the US to date, not all costs were included due to the lack of available representative data and concerns about double-counting costs that were included in other categories. Some of these costs include potential costs of counseling or case management not included in MEPS, personal legal expenses such as obtaining a lawyer, and other support program costs such as food stamps or Section 8 housing. Costs for all federal, state, and/or local programs that may support individuals with schizophrenia were not available for inclusion.[81]

COST OF LIVING OFFSETS

Cost of living offsets were applied to the calculation for total direct costs in recognition of the fact that an individual with schizophrenia would also incur independent housing costs had they not been homeless, living in supportive housing or long-term care, or housed in a prison or jail if they did not have schizophrenia. To account for this, the cost of living for a single person based on the US poverty threshold in 2020 of $12,760[82] was multiplied by the number of individuals with schizophrenia living in supportive housing, long-term care or housed in a prison or jail resulting in an $11.9 billion cost of living offset for individuals in these settings.[40] This methodology is consistent with that of previous research estimating the economic burden of schizophrenia.[27]

The Direct Cost of Schizophrenia in 2020 is

$62.0

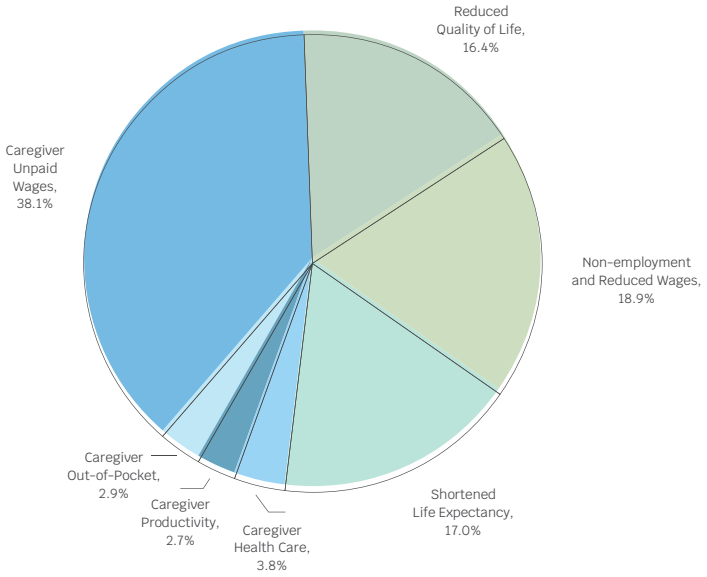
BILLION

Indirect Costs of Schizophrenia - $219.6 Billion in 2020

The indirect costs of schizophrenia are substantial – for people living with schizophrenia and for their caregivers – estimated at over $219.6 billion in 2020. Caregiver impacts account for 47% of these costs (Figure 5). With treatment and medical system support, there is a substantial opportunity to reduce the impact of schizophrenia on associated indirect costs.

While direct costs refer to the value of resources used in the direct treatment, management, or other support for individuals with a certain illness, indirect costs represent the value of economic resources lost due to reduced work productivity, morbidity, mortality, or secondary impact on caregivers (e.g., unpaid labor).[83] Quantifying these costs is essential to understanding the broader societal costs of any disease and can provide important context for understanding the areas where the illness may be most burdensome. For schizophrenia, the value of caregiver burden is enormous, though lack of employment, shortened life expectancy, and reduced quality of life are all substantial societal costs.

FIGURE 5: Indirect costs of schizophrenia



NON-EMPLOYMENT AND REDUCED WAGES COSTS – $41.6 BILLION IN 2020

Individuals living with schizophrenia are much less likely to have gainful employment than those without[20,21], even compared to those who have other serious mental health conditions.[19] Further, even those who are employed have been found to earn lower wages compared with the unaffected population.[84]

Using employment rate metrics for individuals by setting and the average annual US wage for 2020, each unemployed individual with schizophrenia lost over $39,017 in income in 2020. Those who were employed earned $12,727 less than those without schizophrenia (Table 10). Multiplying lost income from unemployment and lower wages by the applicable population with schizophrenia, it was estimated that the societal cost of unemployment and reduced wages was $41.6 billion in 2020.

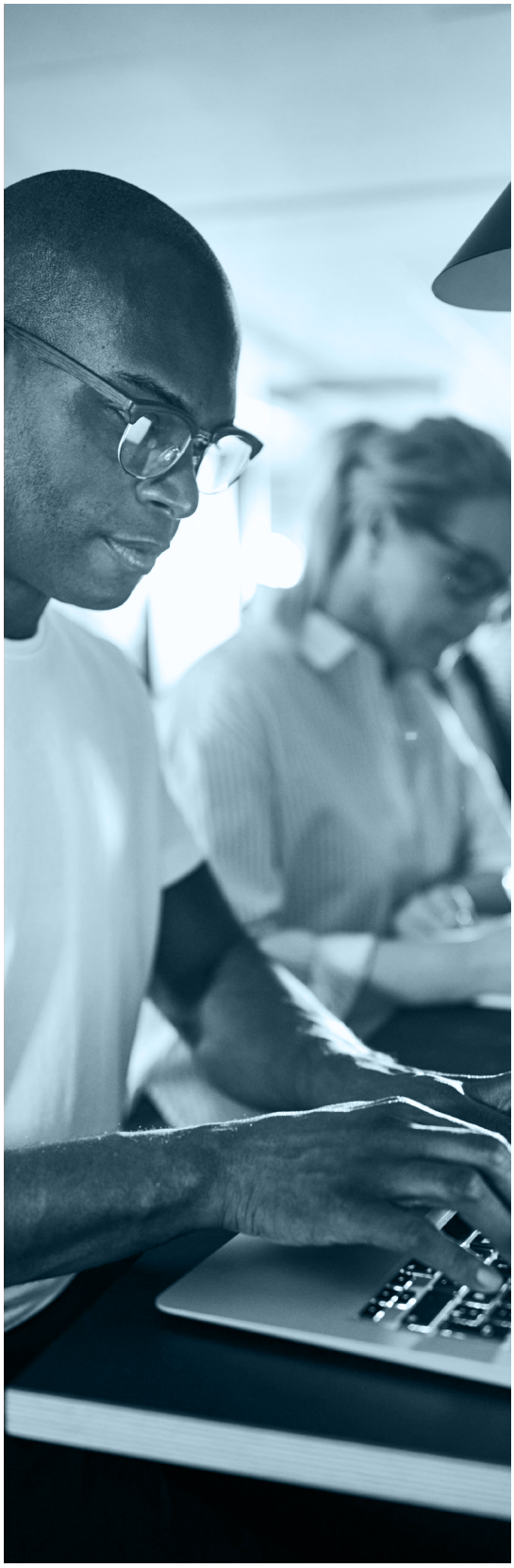
TABLE 10:	Non-employment and reduced wages cost estimate inputs

Input	Value
Employment rate for individuals with schizophrenia in independent households	37.3%[44]
Employment rate for individuals with schizophrenia in supportive housing	12.7%[19,44]
General population employment rate	$63.6%[44]
Percent of population employed, homeless/incarcerated/elderly living in long-term care facilities	0%*
Annual income lost if not employed	$39,017[44]
Annual reduced wages if employed	$12,727[44]

*Assumption

While the current analysis utilized a combination of MEPS data[44] and estimates from published research[19,44], previous studies have used different methodologies to quantify the societal costs of unemployment and reduced wages in this population.[27,49] One economic burden study published in 2016 used parameters from published literature and the Bureau of Labor Statistics and estimated the burden of unemployment and reduced wages to be approximately $61.5 billion, based on a 1.1% prevalence of schizophrenia in the US.[27] This current analysis estimate is lower, however, using a prevalence of 0.8%.

This 2020 analysis is predominantly based on values from community-dwelling individuals surveyed by MEPS. Thus, estimates are likely to be conservative as the most high-risk individuals not captured by MEPS may make even lower wages. Despite this limitation, the employment rates used in this 2020 analysis are consistent with those reported elsewhere where employment rates among those with schizophrenia range from 10-40%.[19,21]



REDUCED QUALITY OF LIFE – $36.1 BILLION IN 2020

Reduced health-related quality of life (HRQoL) for individuals with schizophrenia was valued at $36.1 billion in 2020. Quality of life (QoL) is a broad concept that can be difficult to quantify, especially among individuals living with serious mental health conditions such as schizophrenia. Some researchers have conceptualized QoL as a largely subjective construct, whereas others have argued for the importance of more objective indicators such as housing status, frequency of social interactions, and burden of psychiatric symptoms.[85,86] More specifically, HRQoL is a subset of overall QoL focused specifically on health and is defined as a person's perceived well-being in physical, functional, and mental domains of health.[87] Many validated questionnaires exist to capture the HRQoL of patients across disease areas, and scores on these metrics can be used to assess and compare HRQoL across populations.[87]

One way to quantify HRQoL is by using the quality-adjusted life-year (QALY) method. Frequently used in economic evaluations of medical interventions and in broader disease burden studies, the QALY is a generic measure of disease burden that accounts for both the quality and length of life.[91] The QALY index runs from zero to one. Thus, one year lived in perfect health would receive a value of one QALY; a value of zero equates to being dead.[91] Using health questionnaires, QoL values can be estimated for individuals with specific health conditions. These values are often referred to as health state utility values (HSUVs).

HSUVs for schizophrenia and the general population[88,89] as well as the widely accepted monetary value of a QALY[90] were used to estimate the monetary value of reduced QoL in schizophrenia (Table 11).

No other studies have estimated the monetary cost of reduced quality of life in schizophrenia, though QALYs are frequently used as a measure of disease burden in areas such as oncology.[92,93] Understanding HRQoL in schizophrenia is crucial to identifying potential gaps in care. For example, evidence suggests that some symptoms (e.g., hallucinations, delusions) and poor social relationships are strongly associated with reduced QoL.[94]

TABLE 11: Reduced quality of life cost estimate inputs

Input	Value
HSUV associated with schizophrenia	0.73[88]
HSUV for the general adult population	0.87[89]
Monetary value of a QALY	$100,000[90]
Value of reduced QALY per individual with schizophrenia	$13,800*

HSUV = Health State Utility Value
QALY = Quality-adjusted Life-Year
*Calculated

REDUCED LIFE EXPECTANCY COSTS – $37.4 BILLION IN 2020

Individuals living with schizophrenia often live shorter lives with some studies reporting between 12 to 15 years less than the average US life expectancy.[25,95] While suicide is a contributor to this life expectancy difference, those living with schizophrenia are also at a higher risk for chronic and life-threatening health conditions such as diabetes, cardiovascular disease, and addiction.[96,97]

Using the average years of reduced life expectancy among those with schizophrenia[25], the annual death rate for the general population[98] and for those with schizophrenia[95], and associated health state utility

TABLE 12: Reduced life expectancy cost inputs

Input	Value
Reduced years of life expectancy in schizophrenia	14.5[25]
Standardized mortality ratio for schizophrenia compared to the general adult population	2.6[95]
HSUV associated with schizophrenia	0.73[88]
HSUV for the general adult population	0.87[89]
Monetary value of a QALY	$100,000[90]

HSUV = Health State Utility Value
QALY = Quality-adjusted Life-year

values (HSUV) (Table 12), the current analysis estimated the burden of shortened life expectancy at $37.4 billion in 2020. This value is reflective of all those who – in a counterfactual world – would have been alive in 2020 were it not for their diagnosis of schizophrenia. It is also adjusted for population growth.

It may seem counterintuitive to place a monetary value on lost life. One might assume that a premature death should cost less because the alternative is to incur costs related to health care, housing, and the criminal justice system. However, valuing mortality in monetary terms is commonly used to quantify the costs and benefits of interventions.[99] Accurate characterizations of premature mortality are also important to inform clinical and policy initiatives to improve services and reduce preventable deaths for those with schizophrenia.

The most recent societal economic burden study captured the cost of premature mortality but only costs attributable to suicide and its associated work productivity loss.[27] The study found that the societal costs associated with premature mortality were $3.3 billion in 2013. However, this approach ignores two key elements: (i) not all early deaths among those with schizophrenia are attributable to suicide, and (ii) the value of life extends beyond one's ability to work and earn wages.

Improving longevity for those living with schizophrenia and other serious mental illness conditions is complex and multifaceted. Targeting lifestyle factors – such as nutrition, smoking, and physical activity – have been shown to provide substantial benefit.[100] Cultivating better access and adherence to medications, providing stable housing, and reducing behavioral risk factors such as substance use also may have an effect.[100] Overall, more comprehensive and person-centered integrative care is likely to support better health outcomes and thus increase longevity for those with schizophrenia.

The Cost of Reduced Quality of Life & Life Expectancy is

$73.5 BILLION

CAREGIVER COST ESTIMATES – $104.5 BILLION IN 2020

Schizophrenia posed an enormous impact to caregivers and families, estimated at $104.5 billion in 2020. Family caregivers of individuals with schizophrenia manage a wide array of challenging responsibilities, including managing interactions, providing support with daily activities, coordinating care, and providing financial support. As a result, caregivers themselves often suffer from increased health or mental health concerns and report significant emotional and psychological distress.[22-24] They may be less productive at work and more often absent from work while providing financial support for their loved one. Caregiver impacts were estimated by considering all these factors (Table 13).

TABLE 13: Caregiver cost estimate inputs

Input	Value
Number of individuals needing caregiver (total population minus incarcerated, homeless, and long-term care)	2,170,735*
Percent of individuals with schizophrenia who have a regular caregiver	65%[101]
Total estimated # of caregivers	1,410,977*
Average hours per week providing care	39.7[24]
Average US hourly wage, 2020	$28.74[86]
Work productivity loss for caregivers	$4,300[23]
Excess health care costs for caregivers	$6,000[23]
Average monthly out-of-pocket costs	$373[24]

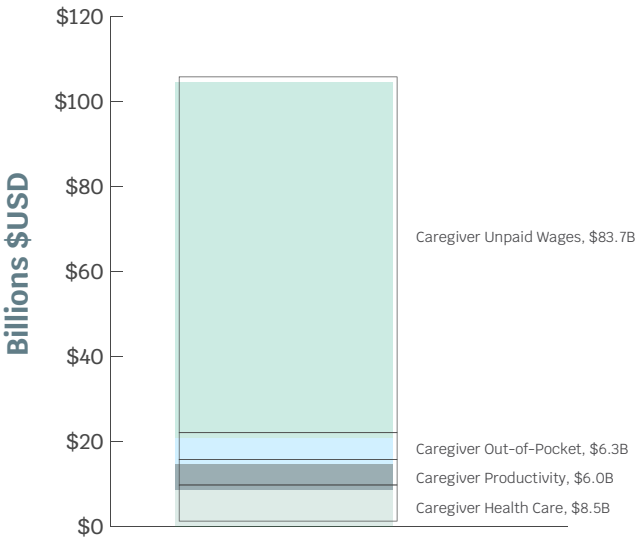
*Calculated. Assumes all care provided by a primary caregiver. Costs of impacts of additional caregivers are not currently included.

The largest share of burden were unpaid labor costs ($83.7 billion), followed by additional health care costs ($8.5 billion), out-of-pocket costs ($6.3 billion), and work productivity loss ($6.0 billion) (Figure 6). Further, due to the considerable variability in reports of the number of hours spent caregiving per week, hours per week providing care was varied +/- 25% in the sensitivity analyses. This did not substantially change the results.[40]

The current analysis aimed to quantify caregiver impacts beyond how they were estimated in earlier work. Previous studies accounted only for the unpaid labor costs related to caregiving in schizophrenia (e.g., the number of hours per week spent providing care), and reported annual total caregiver burdens of $52.5 billion[27] and $23.7 billion[49], respectively.

Though this 2020 analysis is the first to quantify the additional domains of caregiver burden at a national level, previous survey studies have described substantial caregiver impacts. A 2019 survey found that caregivers of those with schizophrenia spent over 120 hours per week "on-call" for their loved one.[24] Three-quarters of caregivers reported experiencing a current physical health issue, and over half reported experiencing stress and anxiety[24], which may be exacerbated when their loved one does not respond to medication.[102] In another survey examining caregiver work-related impacts, caregivers reported being limited in performing their regular work tasks between 20% and 30% of the time. Strikingly, over 25% also reported taking a leave of absence within the past year.[103] Caring for a loved one with schizophrenia also impacts social relationships and sense of personal freedom.[22,102] Further, apart from the illness itself, the stigma surrounding schizophrenia also places a major burden on patients and their caregivers.[102]

FIGURE 6: **Excess costs of caregiver burden in 2020**



INDIRECT COSTS NOT INCLUDED

Not all elements of indirect or intangible costs were included in the current analysis due to data and evidence limitations. For example, the costs of reduced career attainment and reduced wages for caregivers were not included, as no published data effectively quantified this construct. Further, broader impacts to quality of life such as emotional burden and social stigma were not monetized. Thus, the indirect costs of schizophrenia are likely broader and larger than presented here.

TOTAL COST ESTIMATE LIMITATIONS

There are limitations to the analyses presented in this report.

The MEPS data, used to analyze excess health care costs, were not fully representative of the schizophrenia population. Therefore, excess health care costs

calculated from MEPS were only applied to the proportion of the schizophrenia population residing in independent households and those living in structured residences and group homes. As a broader population of individuals was included in the MEPS analysis (see Box 2), a sensitivity analysis was conducted limiting the data sample to MEPS respondents with schizophrenia only (i.e., not including those with other psychotic disorders). The results did not meaningfully differ from those that included other psychotic disorders.[29]

To account for health care costs of individuals with schizophrenia in other settings (i.e., homeless, incarcerated, institutionalized), parameters were identified in the literature specific to the schizophrenia population in these settings. Published literature on the excess costs of schizophrenia in these populations was limited. When schizophrenia-specific costs were not available, costs for psychosis or serious mental illness were used. These patients may not have the same profile as individuals with schizophrenia.

Additionally, direct medical costs of those with undiagnosed schizophrenia were not captured. These patients may have different characteristics than those diagnosed. MEPS collects information about conditions through interviews, and some miscoding may occur as the household participants describe their conditions during the interviews. MEPS data was only available through 2015 for this population.

In some cases, there was limited data in the literature specific to those with schizophrenia or serious mental illness in settings such as homelessness, jails, or prisons. In these cases, we implicitly assumed that the average cost of living in jails/prisons or being homeless with schizophrenia is the same as the average cost of others who live in the same type of setting, and excess proportions were used with these costs. Thus, the excess cost in these settings may not truly reflect the costs for those living with schizophrenia.

The excess cost for reduced health-related quality of life was calculated for a typical individual with schizophrenia and was not stratified by various settings of residence. However, health-related quality of life may differ by the setting and situation for specific subpopulations living with schizophrenia.

Further, there is considerable variability in reports of the number of hours spent caregiving per week. To account for this, the hours per week providing care in the total cost model were varied +/- 25% in the sensitivity analyses. This did not substantially change the results.[40]

Additionally, we know that some direct and indirect costs were not included in the model as costs specific to this population are not available in the literature or in government reports. The extent of missing costs is unclear and will be difficult to determine. A 2013 US Government Accountability Office Report found at least 112 programs across 8 federal agencies supported individuals with serious mental illness.[81] Costs for many of the main programs were included in our analysis; however, it is impossible to know the extent of missing costs due to the limitations of data collection, reporting, and limited coordination of services across these agencies.

Analyses could not be conducted by demographic status subgroups or by treatment status due to inconsistencies in data or studies reporting on race/ethnicity, sociodemographic, or treatment status in population outcomes.

Finally, parameters through 2020 were included to estimate total societal costs. However, the COVID-19 pandemic may have impacted population trends and costs in 2020 and beyond. The impacts of the COVID-19 pandemic were not accounted for due to the lack of data and published research at the time of the analysis.

Research Implications and Future Directions

Despite the significant humanistic and economic impacts of schizophrenia, over the last decades, little progress has been made towards improving care. Schizophrenia-specific research funding in the US has remained static since 2008 at about $250 million per year on average, whereas funding for diseases such as Alzheimer's disease or depression have increased substantially over time.[104] Additionally, research funding for mental health is typically directed towards disease etiology or cause of the disease, rather than across basic and applied research (such as disease management). A 2020 report from the International Alliance of Mental Health Research Funders found that, on average, more than half of global schizophrenia research funding focused on basic science research for the biological underpinnings of the disease rather than translational and applied research such as prevention, evaluation of treatments, management of diseases, and health services.[105] For a disease such as schizophrenia where evidence points to a large economic impact beyond just the health care system, there is a substantial gap in research funding across the various settings that individuals with schizophrenia encounter.

A key component of allocating research funding is to understand the number of individuals living with the disease. An important way to address this gap in knowledge would be to begin collecting standard demographic (race, ethnicity, socioeconomic status) and diagnostic data across federal, state, and local programs that provide services to this population. Collection of this information will enable future comprehensive research of this population.

As shown in this current report, there are many settings that incur the costs of schizophrenia, but there are few published studies that focus on individuals with schizophrenia outside health care systems, such as those who are incarcerated or homeless. Data and studies on these populations have been focused on specific cities or states, which are not nationally representative. More specifically, there is a lack of research on the costs incurred by homeless remediation services and supportive housing for those with schizophrenia. Additionally, there are evidence gaps related to the costs of incarceration, law enforcement, and the judicial system for those suffering with schizophrenia and related disorders. As such, nationally representative research on all populations living with schizophrenia is necessary to have a clear understanding of the true prevalence of the disease and its full costs to the health care system and society.

Currently, schizophrenia and its related disorders are classified as mental or behavioral disorders. Re-classifying or properly characterizing schizophrenia and its related disorders as progressive neurodevelopmental conditions rather than mental health conditions[106] could unlock more research funding as neurological diseases account for 13.2% of global investment in research, compared to 7.4% for mental health conditions.[105]

Despite the substantial societal impact, the National Institutes of Health (NIH) funds $285 million for schizophrenia research[107], which is approximately only 0.1% of the $282 billion disease burden in 2020.

A large proportion of the disease's economic impact is due to indirect costs such as under- or unemployment because the average age of diagnosis for schizophrenia is in the late 20s, leading to many years of additional care needed, lost productivity, and reduced quality of life. Other high-cost neurological conditions, such as Alzheimer's disease (estimated $100,000 per person in 2021, including caregiver burden) are diagnosed much later in life. Thus, the economic impacts consist of relatively little lost productivity[108,109] and overall lifetime costs are more limited than for individuals with schizophrenia. NIH research funding for high-impact diseases such as Alzheimer's as a proportion of the economic burden has increased to an appropriately large $2.6 billion in 2020 or 0.4% of the burden.[108] NIH research funding in 2011 for Alzheimer's was at only $448 million. This analogous situation provides precedence to support a significant increase in research funding across basic science, applied research, and various systems of care to alleviate the large societal costs of schizophrenia.

Further data collection can act as a catalyst to accelerate knowledge of the true scope of schizophrenia and **improve the treatment paradigm.**

Conclusions

Despite the relatively low prevalence of schizophrenia and related disorders, the excess societal cost attributed to the disease is significant and comparable to other brain-based neurological diseases with higher prevalence, such as Alzheimer's disease.[108,109] The largest components of the economic burden of schizophrenia are costs that impact broader society rather than being costs of health care directly associated with the illness. Costs of health care include both treatment costs and the consequences associated with individuals not receiving proper care. The debilitating nature of schizophrenia, early age of onset, limited access to care, scarcity of clinicians, restrictive insurance arrangements, and fragmented physical and mental health care systems lead to negative downstream effects for this patient population that are not evident in other neurological diseases such as Alzheimer's and dementia.[110] This is evidenced by the enormous costs of schizophrenia associated with caregiver burden, lack of employment, reduced quality of life, and shortened life expectancy (Box 6).

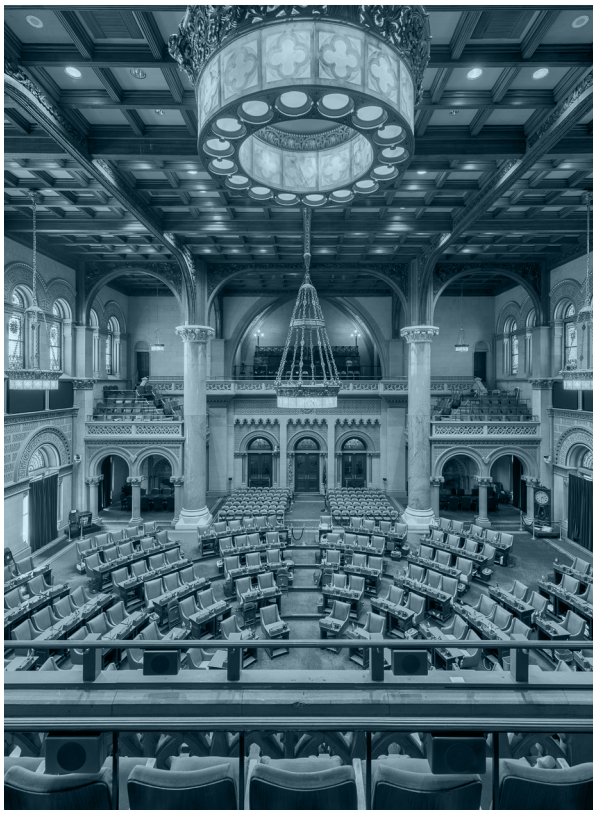
The substantial personal and societal costs of schizophrenia indicate that there are serious unmet needs for this population. Legislation such as the Mental Health Parity and Addiction Equity Act of 2008, as well as the Patient Protection and Affordable Care Act, have sought to improve access and outcomes by mandating parity in the coverage of medical, surgical, and mental health care. However, issues with treatment limitations and stringent prior authorization practices have created barriers to receiving care, leading to negative downstream effects beyond the health care system, such as increased risk of becoming incarcerated or homeless.

Box 6. Key Takeaways

- No recent study or dataset fully and accurately accounts for individuals diagnosed and/or living with schizophrenia in the US.
- Despite the relatively low prevalence of schizophrenia and related disorders, the excess economic burden attributable to the disease is significant at nearly $282 billion in 2020.
- Direct health care costs were $27 billion, accounting for only about 10% of the total economic burden of the disease. Almost 90% of costs are attributable to other direct and indirect consequences of schizophrenia.
- Costs of incarceration and criminal justice involvement among those with schizophrenia were nearly $17 billion in 2020.
- In 2020, the cost of early mortality, reduced quality of life, and lost wages were estimated at $136 billion.
- Schizophrenia posed an enormous burden to caregivers and families in 2020, estimated at $104.5 billion.
- No cure for schizophrenia is available; however, with early diagnosis and proper life-long treatment, individuals living with schizophrenia have unlimited potential.
- Significant investments into research and evidence-based systems are needed to ultimately improve outcomes for individuals with schizophrenia in a comprehensive and coordinated system of care.

There is a need for robust and recent data to better understand the prevalence of schizophrenia in the US and globally. With a wide range of prevalence estimates available, exactly how many people are living with schizophrenia is unknown. To improve outcomes and care in schizophrenia, local, state and federal governments should commit to collecting common data elements (such as race, ethnicity, socioeconomic status, and diagnosis) so that we can measure the impact of these efforts. Without an accurate count, the potential underestimation of the burden of schizophrenia will continue to lead to the under-allocation of needed resources to provide the appropriate care and supportive services that individuals living with schizophrenia have a right to and deserve.

This report fully characterizes the health care and non-health care costs related to schizophrenia and finds that the burden of schizophrenia is vast relative to the low prevalence of the disease in the US at $282 billion in 2020. The findings also support an immediate need for crucial policy changes to improve and access care for individuals with schizophrenia and their families, as well as additional research using more recent and fully representative data sources of all populations affected by this disease.



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