



Treatment Advocacy Center Briefing Paper

What percentage of Individuals with severe mental illnesses are untreated and why?

SUMMARY: Recent American studies report that approximately half of all individuals with severe mental illnesses have received no treatment for their illnesses in the previous 12 months. These findings are consistent with other studies of medication compliance for individuals with schizophrenia and manic-depressive illness (bipolar disorder). The majority (55 percent) of those not receiving treatment have no awareness of their illness (anosognosia) and thus do not seek treatment. Stigma and dissatisfaction with services are relatively unimportant reasons why individuals with severe mental illnesses do not seek treatment.

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35 percent untreated

In the five-site Epidemiologic Catchment Area (ECA) survey carried out in 1980-1985, it was reported that 35 percent of individuals with schizophrenia and 35 percent of individuals with bipolar disorder had received no treatment in the previous 12 months.

Health care reform for Americans with severe mental illnesses: report of the National Advisory Mental Health Council. *American Journal of Psychiatry* 150:1447-1465, 1993.

50 percent untreated

In a follow-up study at the Baltimore site of the ECA study, one half of the individuals with schizophrenia who were living in the community were receiving no treatment. According to the authors, "all of the untreated schizophrenic subjects were in need of mental health care at the time of the survey."

Von Korff M et al. Prevalence of treated and untreated DSM-III schizophrenia. *Journal of Nervous and Mental Disease* 73:577-581, 1985.

42 percent untreated

In another follow-up of the ECA study data, it was established that 42 percent of individuals with severe mental illnesses (as defined by the NIMH Advisory Mental Health Council) were not being treated.

Narrow WE. Mental health service use by Americans with severe mental illnesses. *Social Psychiatric Epidemiology* 35:147-155, 2000.

54 percent untreated

Using data for the National Comorbidity Survey (NCS) carried out in 1990-1992, the authors report that 54 percent of individuals with serious mental illness (broadly defined) had received no treatment in the previous 12 months.

Kessler RC et al. The prevalence and correlates of untreated serious mental illness. *Health Services Research* 36:987-1007, 2001.

Reasons for not seeking treatment

The recent study by Kessler et al., cited above, included interviews with the individuals with serious mental illnesses to ascertain why they were not receiving treatment. The majority - 55 percent - denied that they had any problem. Thus, they had limited awareness of their illness, also called anosognosia; this lack of awareness is known to be caused by changes in the frontal lobe and other areas of the brain due to the disease process. The 45 percent who acknowledged that they needed treatment (and thus had awareness of their illness) but still were not receiving treatment cited many reasons for this. These included (respondent could check several reasons):

- 32% "wanted to solve problem on own"
- 27% "thought the problem would get better by itself"
- 20% "too expensive"
- 18% "unsure about where to go for help"
- 17% "help probably would not do any good"
- 16% "health insurance would not cover treatment"

Other reasons were cited much less frequently:

- 7% "scared about hospitalization against own will"
- 6% "concerned about what others might think"
- 5% "not satisfied with available services"
- 1% "could not get an appointment"
- 0% "language problem"

This study thus contradicts claims that many individuals with serious mental illnesses do not seek treatment because of fears of involuntary hospitalization, stigma, or dissatisfaction with available services.

It is commonly claimed that "if you make the psychiatric services attractive enough and culturally relevant, then individuals with serious mental illnesses will utilize them." This appears to not be true. Very few individuals cited "not satisfied with available services," "could not get appointment," "language problem," etc., as a reason why they were not in treatment. The greatest reason for non-treatment by far was the person's lack of awareness of their illness. Such individuals will not voluntarily utilize psychiatric services, no matter how attractive those services are, because they do not believe that they have an illness.