



Communicating About Health

A Mental Health America Survey of People with
Schizophrenia and Providers

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BACKGROUND

In October 2006, the National Association of State Mental Health Program Directors' (NASMHPD) issued a report about morbidity and mortality in people with serious mental illness (SMI). The report presents a dire picture of the health inequities faced by people with SMI in the public mental health system – people with SMI die, on average, 25 years earlier than the rest of the population. The major natural causes of death among people with SMI were heart disease, diabetes, respiratory disease and infectious disease.

Not only are these diseases treatable, but the risk factors for them are largely modifiable (smoking, obesity, substance abuse, access to care). The report also highlighted the troublesome side effects associated with some antipsychotic medications, including weight gain, diabetes, dyslipidemia, insulin resistance and metabolic syndrome. The report authors concluded that wellness is a central and essential part of recovery from SMI.

Mental Health America is committed to addressing the tremendous disease burden among people with SMI, which we believe represents a serious public health issue. By promoting a holistic approach to health care, mental health consumers and their providers can minimize and prevent medical conditions that contribute to excess mortality and improve overall quality of life.

Project Goals

As a first step in our efforts to promote the health and wellness of people with SMI, Mental Health America conducted a survey of people with schizophrenia and psychiatrists. The goals of the survey were to:

- 1) Examine the extent to which overall health is addressed in mental health settings;
- 2) Examine the dialogue between consumers and providers about treatment options and potential adverse health effects; and
- 3) Explore the degree to which people with schizophrenia are aware of routine healthy living practices.

Consumer Survey

In late 2007, Mental Health America commissioned a nationwide survey of 250 adults (18 years and older) who have been diagnosed by a qualified medical professional as a person with schizophrenia. The margin of error for the survey is $\pm 6.2\%$.

The survey sample was provided through International Communications Research (ICR) by a reputable, online research panel that maintains a nationwide sample of respondents and rigorously checks the quality and validity of its sample.

The survey sought to uncover the health status of people with schizophrenia; the nature of their relationship with their psychiatrists; how treatment and medication decisions are made; and their attitudes towards looking after their overall health.

Psychiatrist Survey

Mental Health America in late 2007 also conducted an online survey with a nationwide sample of 250 licensed, practicing psychiatrists who treat people with schizophrenia. The margin of error for the survey is $\pm 6.2\%$

All data were collected via an online research panel (ePocrates) that has over 145,000 participating physicians, including approximately 18% of all APA-registered psychiatrists. The research panel has been verified through a series of studies as being representative of the larger, national population of physicians (including psychiatrists).

The survey sought to uncover how psychiatrists make treatment and medication decisions and to learn more about the depth and range of care they provide to their patients.

CONSUMER SURVEY

Respondent Characteristics

The following is a summary of the population characteristics of respondents who participated in this first-of-its-kind national online survey of 250 adults with schizophrenia.

Gender: Respondents were slightly more likely to be female (56%) than male (44%).

Age: Almost half of all respondents were less than 35 years old. Specifically, 24% were between the ages of 18-25 and 23% were aged 26-35. Among the 53% who were older than 35, 17% were between the ages of 36-45, 25% were ages 46-54 and 12% were 55 or older. The average age of all respondents was 38 years.

Employment: Slightly more than half of all respondents said they currently have a paid or unpaid job (52%). The likelihood of holding a job appeared to decrease with age—while 71% of respondents aged 18-25 said they have a job, the proportion dropped to 55% among those aged 36-45 and even further, to 27%, among those aged 55 or older.

Household Income: About a third (32%) of respondents were from households that make less than \$20,000 a year, and another third (36%) reported household incomes between \$20,000 and \$49,999. More than one-quarter (28%) were from households with incomes of \$50,000 or more.

Geographic Region: The sample had a mix of respondents from all parts of the country, with 23% of the respondents saying they reside in the Northeast, 25% in the Midwest, 30% in the South and 22% in the Western parts of the country.

Race/Ethnicity: Seventy-six percent of respondents were Caucasian, while 11% indicated they are of Hispanic origin, 9% said they are African American. The remaining respondents were of other ethnicities.

Health Insurance Coverage: Approximately 88% of respondents said they have some kind of health insurance, and the likelihood of having health insurance increased with age.

- While 76% of respondents aged 18-25 said they have insurance, the incidence rose to 93% among those aged 55 and over. Most commonly, respondents said they either have private health coverage (40%) or are covered under Medicare (39%) or Medicaid (33%). In addition, 27% said they have some sort of prescription drug coverage.

Presence of a Caregiver: Overall, 57% of all respondents said they have a caregiver who helps them manage their mental health condition.

- Those with incomes in excess of \$50,000 (61%) were more likely to have a caregiver than those with incomes below \$20,000 (51%).
- Older people were the least likely to report having a caregiver—only 33% of those aged 55 and older said they have a caregiver. Conversely, more than three-quarters of those ages 26-34 reported having a caregiver, more than any other age group.

Mental Health Characteristics

Age of Diagnosis: Exactly 50% of respondents said they were first diagnosed with schizophrenia when they were aged 24 or younger, with 40% indicating that they were diagnosed before the age of 21. On the flip side, 20% of respondents were diagnosed when they were aged 38 or older. The average age of diagnosis for this sample was 27 years.

- Household income appeared to be a predictor of when an individual was first diagnosed. Respondents from poor households (incomes of less than \$20,000) were more likely to have been diagnosed later in life (average age at diagnosis was 30 years), while those from more affluent households (\$50,000+) were more likely to have been diagnosed at an earlier age (average age at diagnosis was 25 years).

Medication: Almost 9 in 10 respondents said they are *currently* taking medicine for their schizophrenia (88%). The vast majority of respondents (82%) said they had changed their medication at least once.

- When presented a list of eight potential side effects, about two-thirds (69%) of respondents said that they had been bothered enough by at least one of these side effects to the extent they had to stop taking their schizophrenia medication.
- Drowsiness (48%), restless fidgeting or pacing (47%), weight gain (46%) and dizziness (38%) were the four most commonly mentioned side effects that prompted respondents to stop taking their medication.

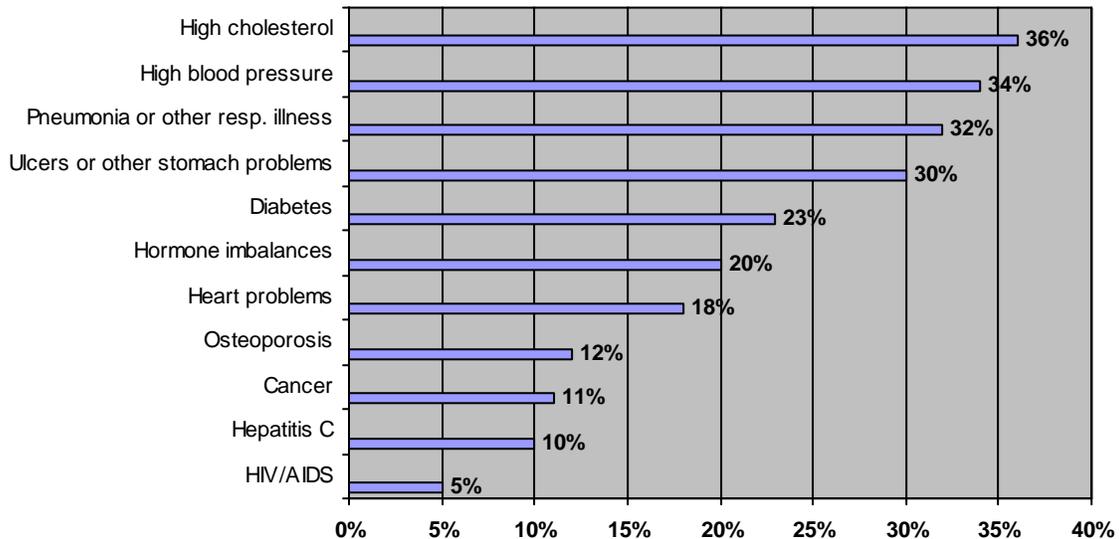
General Health Characteristics

Body Mass Index (BMI): BMI was calculated by asking respondents for their current height and weight. Only 25% of respondents can be classified as having a normal weight. The remainder were mostly obese or overweight (44% and 25% respectively). Only 3% were underweight.

- The data also showed that body weight tended to increase with age; for example, those aged 18-25 were the most likely to have a normal weight (39%), while those aged 46 and older were most likely to be obese (51% of all respondents age 46-54 and 68% of those 55+ were classified as obese).
- Household income also was associated with obesity: those with incomes under \$20,000 were more likely to be obese (49%) than those with incomes in excess of \$50,000 (33%).

Health Problems: Overall, 74% of all respondents had been diagnosed with at least one of 11 medical conditions listed in the survey.

Have you ever been diagnosed with the following health problems?



- Diagnosis of health conditions was related to gender: 69% of male and 77% of female respondents had one or more of the other medical conditions.
- There were some gender differences in the kinds of problems reported. Women respondents were more likely to say they had pneumonia or other respiratory illnesses, ulcers or other stomach problems or hormone imbalances. Men were more likely have high blood pressure.

Consumer Health Status Compared to General Population

Condition	Consumer Sample	General Population
BMI: Healthy	25%	38% ⁱ
BMI: Overweight (Not obese)	25%	35% ⁱⁱ
BMI: Obese	44%	26% ⁱⁱⁱ
High cholesterol	36%	16.5% ^{iv} (age 20 and over)
High blood pressure	34%	22.9% ^v
Ulcers or other stomach problems	30%	6.5% ^{vi}
Diabetes	23%	7.7% ^{vii}
Heart problems	18%	11.8% ^{viii} (Noninstitutionalized adults with heart disease)
Osteoporosis	12%	55% of people over 50 ^{ix}
Cancer	11%	7.1% ^x
Hepatitis C	10%	1.6% ^{xi} (all ages)
HIV/AIDS	5%	.02% ^{xii}

Access to Medical Care

While a solid majority of respondents believe it is easy for them to access medical care when they need it (71%), a worrisomely large proportion find it difficult to do so (27%).

As has been documented in many other studies of access to care, this survey also finds that easy access is least available to those who are most at-risk. Almost one-third of poor respondents (defined as those with annual household incomes under \$20,000) and those who are obese (32% and 30% respectively) say they have difficulty in accessing medical care vs. 23% of those with incomes over \$50,000 and 19% of those who have a normal BMI.

On a related note, 83% of respondents said that they have visited a regular doctor or a nurse for a check up or to discuss physical health concerns sometime in the past year.

The following characteristics are associated with a doctor visit:

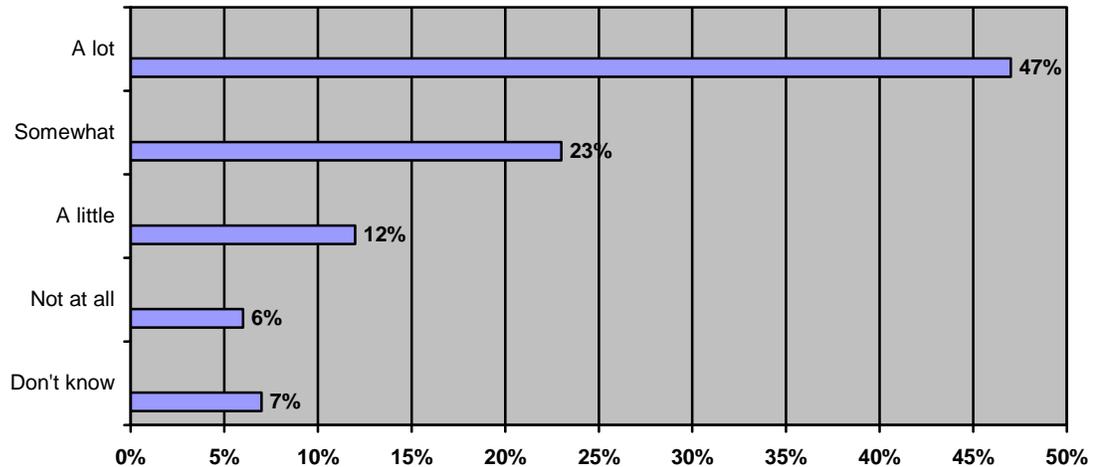
- Age: The likelihood of having visited a regular doctor or nurse increases with age: for example, 93% of respondents aged 55 and older said they had visited a doctor/nurse, compared to 71% of those aged 18-24.
- Sex: Women respondents (88%) were somewhat more likely to have seen a regular doctor than men (76%).
- BMI: Those who were classified as obese were slightly more likely than those with a normal BMI to have seen a doctor (85% vs. 79%)

Surprisingly, household income does not appear to have any impact on the likelihood of having visited a doctor/nurse during the past year.

Attitudes Toward Overall Health

More than four-fifths of all respondents (82%) believe the status of their overall health is connected to their recovery from schizophrenia.

How much do you think your overall health affects your recovery from schizophrenia?



Expectations of Psychiatrist: Respondents were almost equally divided on whether they expect their psychiatrist to focus exclusively on their mental health (48%) or take a more holistic approach and focus on their overall mental and physical health (52%).

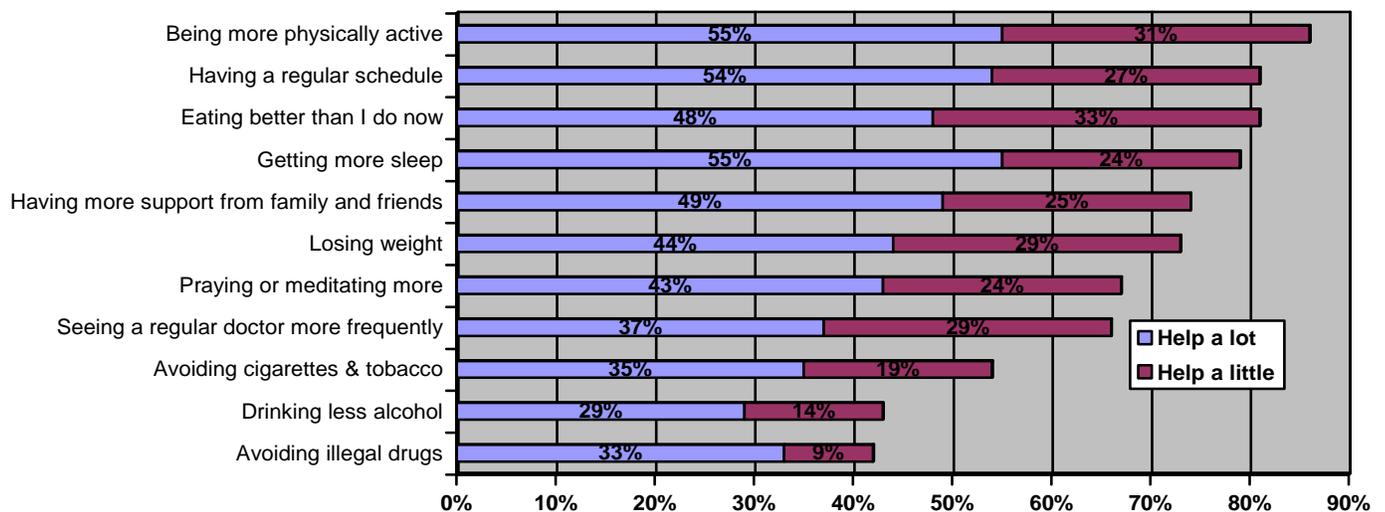
- Men were more likely than women to expect their psychiatrist to focus only on their mental health (54% vs. 43%)

As a point of comparison, the respondents to the psychiatrist survey said that they are responsible for managing their patients' mental illness and symptoms and 73% also believed that they are responsible for ensuring patients receive appropriate care for all health problems. Thus, more psychiatrists say they attempt to provide holistic and comprehensive care, than the proportion of patients' that expect them to do so.

Actions to Improve Overall Health: Respondents were presented eleven actions and asked how much each of these actions would help improve their overall lifestyle. Six of the 11 actions were identified as helping “a lot” or “a little” by approximately three-quarters or more of all respondents. And all but three of the actions were endorsed by at least two-thirds of all respondents.

- Generally speaking, women were more likely than men to believe in the positive impact of an action.
- Those who were overweight or obese were more likely to think that these actions would help their overall lifestyle compared with those whose BMI was in the normal range.

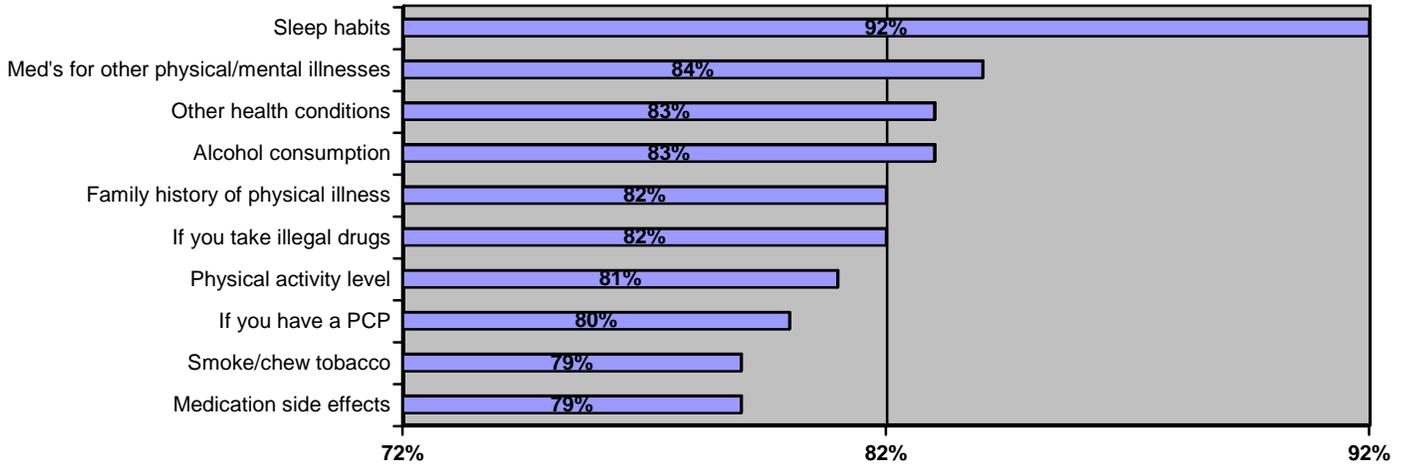
Thinking about your current lifestyle, how much do you think each of the following would help improve your overall lifestyle?



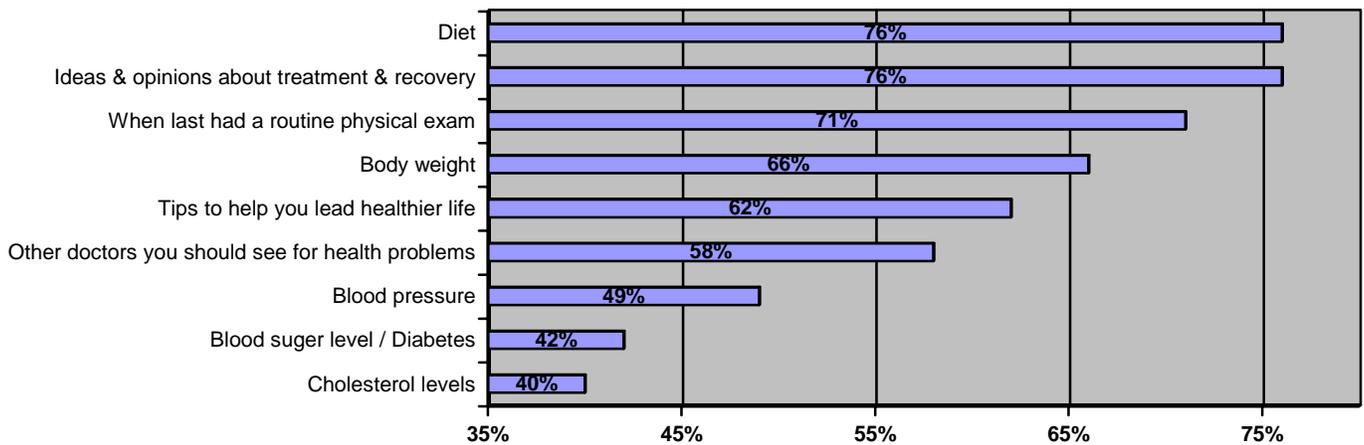
Monitoring of Health & Related Habits

Through a series of 19 items, the survey asked patients how comprehensively their psychiatrists monitor their overall health and lifestyle.

Has your psychiatrist ever asked you about the following / discussed the following with you? TOP 10 RESPONSES



Has your psychiatrist ever asked you about the following / discussed the following with you? BOTTOM 9 RESPONSES



- An overwhelming majority of respondents said their psychiatrist asks them about their sleep habits. No more than 84% of respondents reported discussing any other issue with their psychiatrist.
- Next to their sleep habits, respondents said that their psychiatrists most frequently asked them about what other medications they are taking (84%), their other health conditions (83%), alcohol consumption (83%) and family history of medical illness (82%).
- Other arguably important issues were discussed less frequently. For example, only 49% said they had been asked about their blood pressure, 42% had been asked about their blood sugar or diabetes and 40% said they had discussed their cholesterol levels with their psychiatrist.

There were some interesting differences in responses based on gender, income and BMI:

- Women respondents are significantly more likely than men to have discussed the following: *sleep habits, medicines they are taking for other medical conditions, and side effects of their schizophrenia medicine.*
- For 8 of the 19 issues, respondents from households with annual incomes in excess of \$50,000 were the most likely to have discussed the issue with their psychiatrist, while those with incomes below \$20,000 were the least likely to have done so. These issues are: *sleep habits, alcohol consumption, family history of physical illness, when they last had a routine physical exam, ideas and opinions about treatment and recovery, other doctors they should see to address physical health problems, blood sugar or diabetes, and their cholesterol.*
- Finally, a consumer's BMI classification also seemed to predict how likely they were to discuss certain issues. Paradoxically, those with a normal BMI were most likely to discuss their *physical activity level*, while those who are obese were least likely to do so. More encouragingly, those classified as obese were most likely to discuss their *body weight*, while those who were overweight were most likely to discuss their *blood sugar or diabetes* and their *cholesterol* with their psychiatrists.

Comparison of Consumer and Psychiatrist Responses: When psychiatrists were shown a similar list of 23 items, their responses suggested that they discuss these issues more frequently and regularly with their patients. For example, at least 90% of psychiatrists said they regularly ask their schizophrenia patients about 13 of the 23 items, and no issue was checked by fewer than 75% of the psychiatrists. Neither survey provides any additional information that would help explain the variation between the responses provided by psychiatrists and consumers.

	Consumer	Psychiatrist
Your sleep habits	92%	97%
Medicines you are taking for other physical or mental illnesses	84%	97%
Other health conditions you may have	83%	96%
Your alcohol consumption	83%	99%
Family history of physical illnesses	82%	77%
If you take any illegal drugs	82%	n/a
Your physical activity level	81%	82%
If you have a doctor or nurse that you consider your Primary Care Provider	80%	96%
Whether you smoke or chew tobacco	79%	94%
Tobacco cessation treatment (if relevant)	n/a	82%
Side-effects from your schizophrenia medicine, like weight gain or diabetes	79%	100%
Your diet	76%	77%
Your ideas and opinions about treatment and recovery	76%	95%
When you last had a routine physical exam	71%	81%
Your body weight	66%	92%
Tips to help you live a healthier life	62%	87%
Other doctors that you should see to address physical health problems	58%	98%
Whether they saw another doctor and/or received follow up care recommended	n/a	98%
Your blood pressure	49%	75%
Your blood sugar level / Diabetes	42%	88%
Your cholesterol	40%	82%
Access to social and community supports	n/a	91%
Tips for improving social relationships and handling interpersonal conflict	n/a	83%

PSYCHIATRIST SURVEY

Respondent Profile

Tenure: Respondents ranged from psychiatrists currently in residency (6%) to those with more than 20 years experience (19%). The average number of years in practice was 12.

Patient Load: Over half of all survey respondents (55%) reported that they see 21 or more patients with schizophrenia in an average month. An additional 26% see between 11-20 patients, and 18% see less than 10 patients a month.

Gender: There were more than twice as many male respondents (69%) as female respondents (28%).

Region: Respondents from all parts of the country were represented, with 21% of the respondents indicating they practice in the Northeast; 26% in the Midwest; 35% in the South; and 20% in the West.

Workplace setting: Equal proportions said they work in a public mental health setting (39%) or in a private mental health setting (39%). The remaining fifth (20%) indicated that they work in an integrated healthcare setting.

Use of Guidelines: The vast majority of those surveyed said they apply the American Psychiatric Association/American Diabetes Association monitoring guidelines in their practice (86%). More than half (57%) said that they use other similar guidelines.

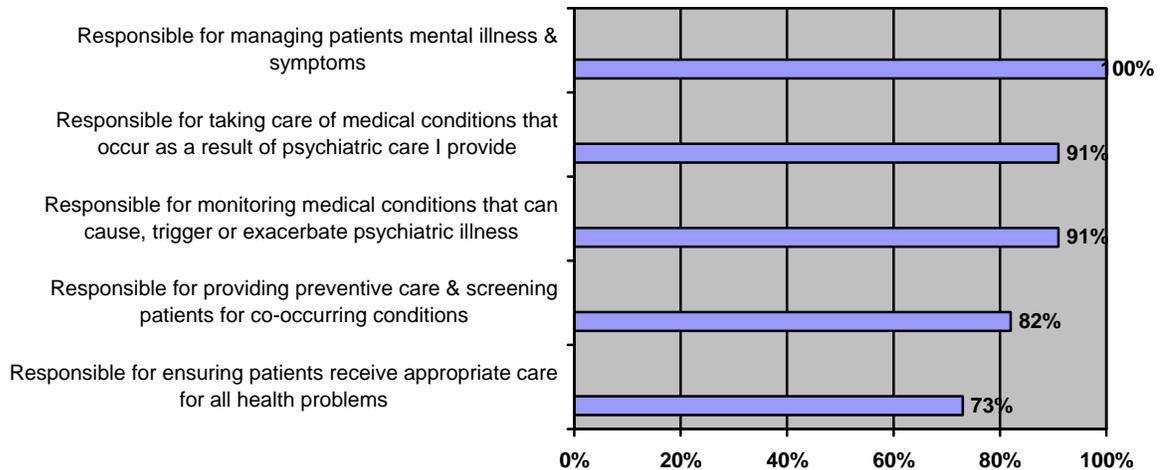
Responsibility to Patients

All psychiatrists surveyed believed they are *responsible for managing their patients' mental illness and symptoms*.

- 91% said they are responsible for *taking care of medical conditions that occur as a result of the psychiatric care they provide, and for monitoring medical conditions that cause, trigger or exacerbate psychiatric conditions*.
- 73% also held themselves *responsible for ensuring patients receive appropriate care for all health problems*.
- 82% said they are *responsible for providing preventive care and screening for co-occurring conditions*.

Psychiatrists that practice in an integrated healthcare setting were somewhat less likely to believe they are *responsible for ensuring patients receive appropriate care for all health problems* (68%) when compared to those in public (76%) or private (75%) mental health settings.

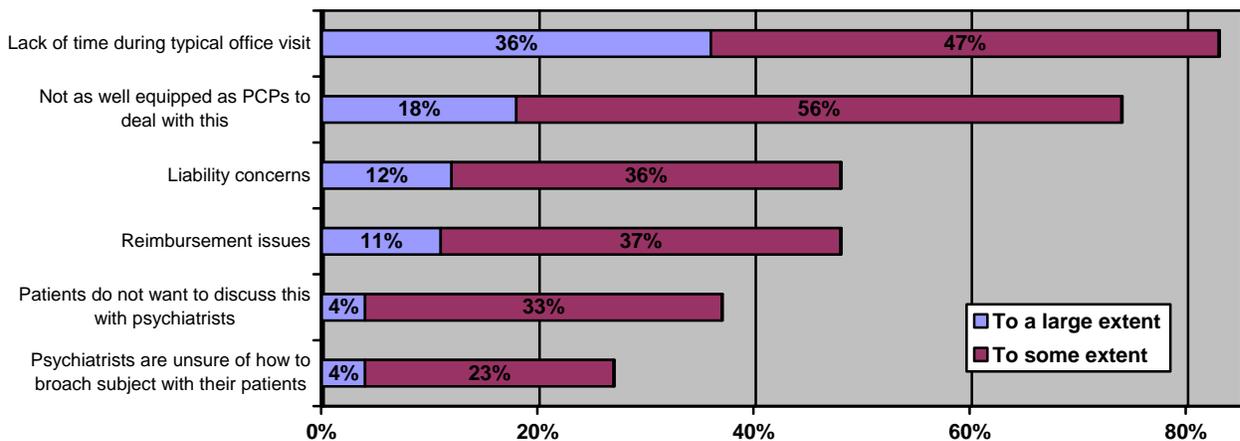
As a psychiatrist, how do you define your responsibility to your patients? Which of the following statements are true for you?



Barriers to Comprehensive Care

The *lack of time during the typical office visit* appears to be the single biggest barrier that prevents psychiatrists from discussing their patient's overall health in a comprehensive manner—83% believe this is a factor, at least to some extent. Another significant barrier is the perception that *psychiatrists are not as well equipped as a Primary Care Provider (PCP) to deal with a patient's overall health in a comprehensive manner* (74% said this is at least somewhat of an factor).

To what extent do the following prevent psychiatrists from discussing their patient's overall and mental health in a comprehensive manner?



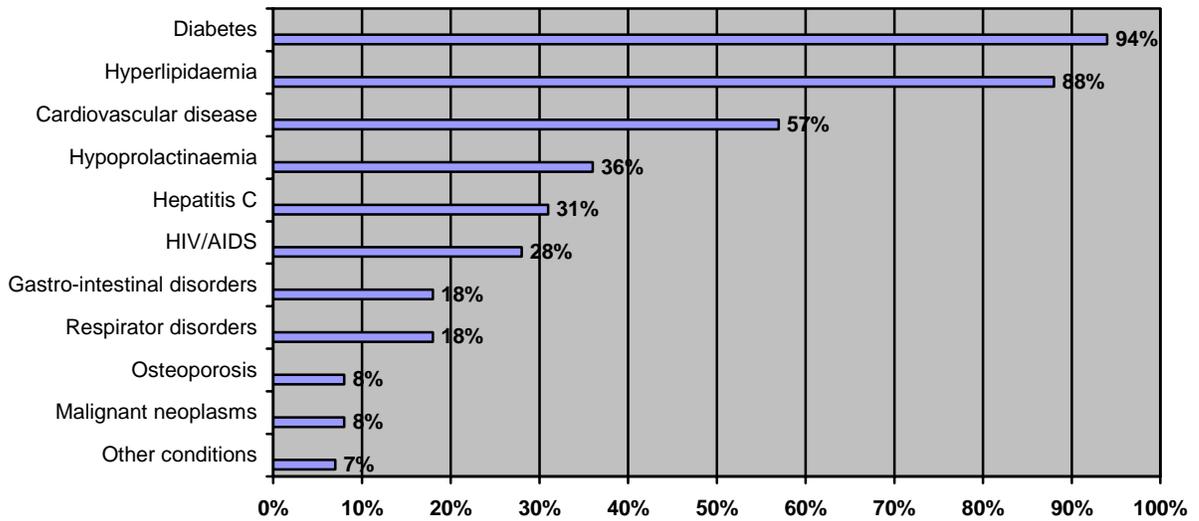
Consumer Care

Screening for Other Conditions: Most psychiatrists said they “regularly” screen their schizophrenia patients for diabetes (94%) and hyperlipidaemia (88%).

More than half (57%) said they regularly screen for cardiovascular disease, and one in every three reported screening for hypoprolactinaemia (deficiency of prolactin in the blood) (36%) and hepatitis C (31%).

Smaller proportions of psychiatrists said they screen for other conditions, like HIV/AIDS (28%), gastro-intestinal disorders (18%) and respiratory disorders (18%).

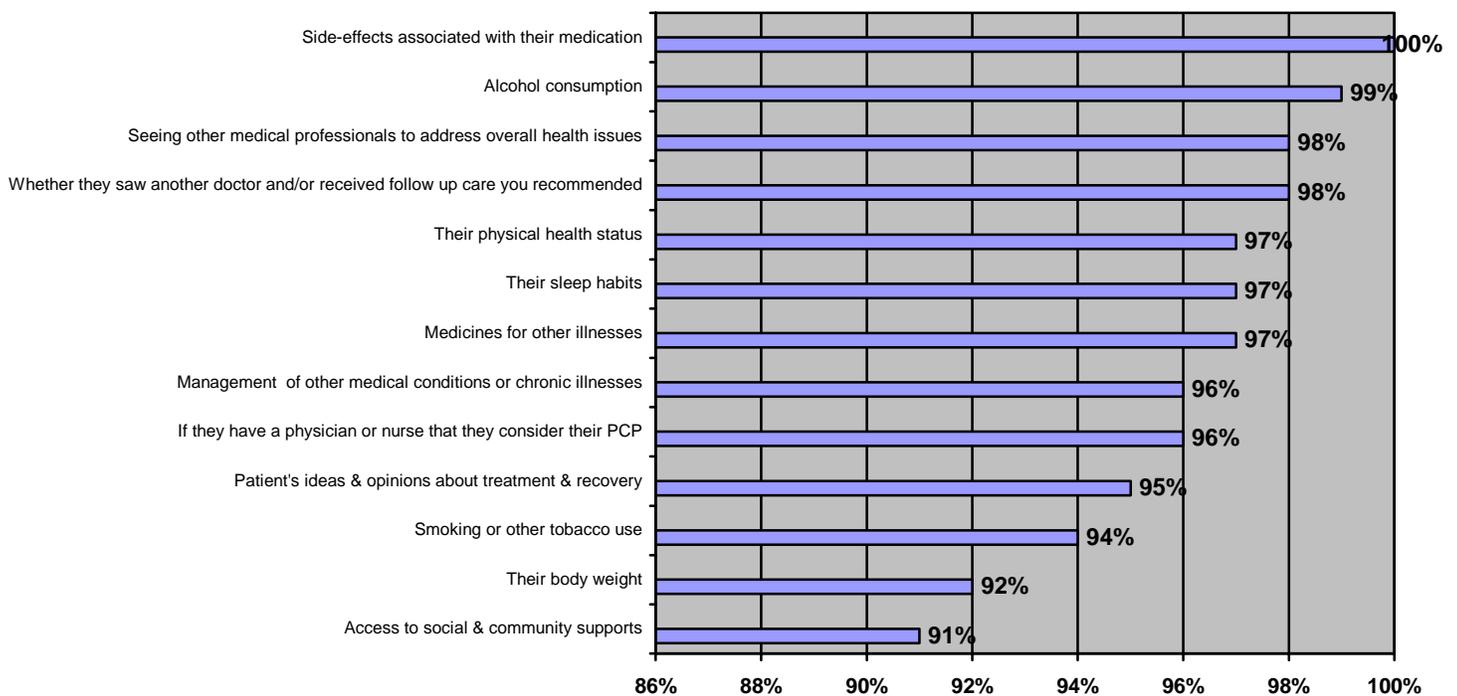
Do you regularly screen your schizophrenia patients (or refer them for screening) for any of the following conditions?



Health Habits & Follow-Up Care: Through a series of 23 items, split into two questions, the survey sought to determine how comprehensively psychiatrists monitor their patients’ health and lifestyle. Some of these items also explored the extent to which psychiatrists recommend additional medical attention and check to see if their patient complies.

- At least 90% of psychiatrists said they regularly ask their schizophrenia patients about 13 out of the 23 issues, and even the least frequently discussed issue (*blood pressure*) was regularly “asked about” by no fewer than 75% of psychiatrists.

Do you regularly screen your schizophrenia patients (or refer them for screening) for any of the following conditions?



Comparison of Consumer and Psychiatrist Responses: As noted above, there is a discrepancy between the degree to which psychiatrists report discussing these issues and patients’ reports of similar discussions. People with schizophrenia were shown a slightly shorter list of 19 items. Overall, they reported a significantly lower incidence of discussing these issues with their psychiatrist. Patients reported highest discussion rates for sleep habits—90% said their doctor had discussed sleep habits with them. Patient-reported discussion rates were lower than that for all other issues, and below 75% for seven of the issues listed here.

Prescribing Medication

Factors Considered When Prescribing Medication: The *long-term effectiveness* and the *long-term safety record of a medication* were the two most important factors that psychiatrists named when determining what medication(s) to prescribe. These factors were judged as “quite” or “extremely” important by 98% and 95% of respondents, respectively.

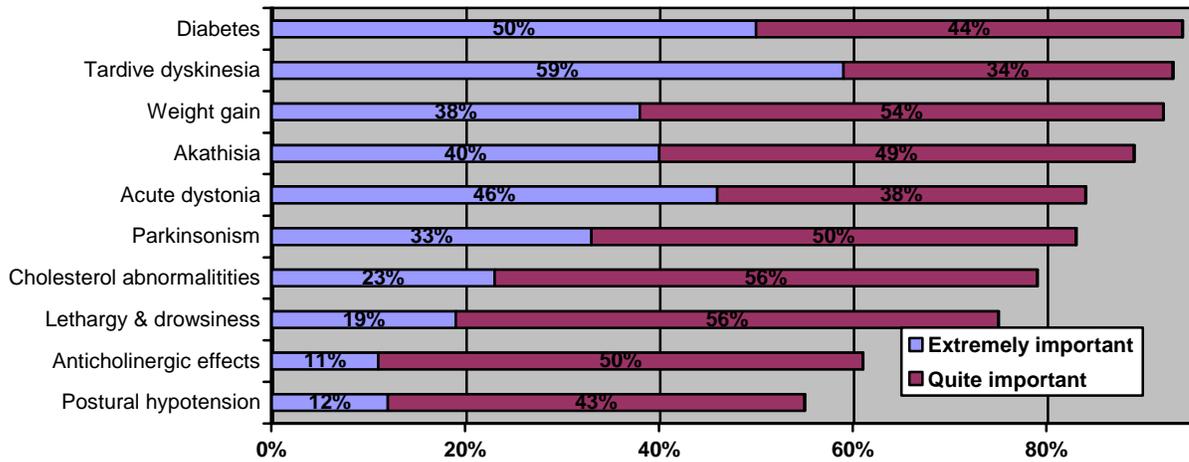
The *effectiveness of the medication in providing short-term relief* (88%), *ease and convenience of taking the medicine* (86%) and *patient preferences* (86%) were also cited as important factors by the vast majority of respondents.

Less important factors, but still deemed “quite important” by about two-thirds, were the *short-term side effects associated with the medication* (66%) and the *cost of the medication* (64%).

Importance Given to Potential Side Effects: Eight out of the 10 potential side effects listed on the survey were considered “extremely” or “quite important” by three-quarters or more of the psychiatrists when determining what medications to prescribe.

- *Diabetes, tardive dyskinesia* (characterized by involuntary movements most often affecting the mouth, lips, and tongue) and *weight gain* were considered “extremely” or “quite important” by more than 90% of those surveyed.
- Between 75% and 90% of respondents said they also thought the following side effects are extremely or quite important when prescribing medication: *Akathisia* (characterized by restless fidgeting and pacing); *parkinsonism*; *cholesterol abnormalities* and *lethargy and drowsiness*.
- *Tardive dyskinesia* was the only potential side effect considered “extremely important” by more than half of respondents (59%).

Thinking about your current lifestyle, how much do you think each of the following would help improve your overall lifestyle?



ⁱ Pleis JR, Lethbridge-Çejku M. Summary health statistics for U.S. adults: National Health Interview Survey, 2006. National Center for Health Statistics. Vital Health Stat 10(235). 2007.

http://www.cdc.gov/nchs/data/series/sr_10/sr10_235.pdf

ⁱⁱ Ibid

ⁱⁱⁱ Ibid

^{iv} National Center for Health Statistics. Health, United States, 2006 With Chartbook on Trends in the Health of Americans. Hyattsville, MD: 2006. <http://www.cdc.gov/nchs/data/hus/hus06.pdf#070>

^v Pleis JR, Lethbridge-Çejku M. Summary health statistics for U.S. adults: National Health Interview Survey, 2006. National Center for Health Statistics. Vital Health Stat 10(235). 2007.

http://www.cdc.gov/nchs/data/series/sr_10/sr10_235.pdf

^{vi} Ibid

^{vii} Ibid

^{viii} Pleis JR, Lethbridge-Çejku M. Summary health statistics for U.S. adults: National health interview survey, 2005. National Center for Health Statistics. Vital Health Stat 10(232). 2006.

http://www.cdc.gov/nchs/data/series/sr_10/sr10_232.pdf

^{ix} National Osteoporosis Foundation. Fast Facts. <http://www.nof.org/osteoporosis/diseasefacts.htm>

^x Pleis JR, Lethbridge-Çejku M. Summary health statistics for U.S. adults: National Health Interview Survey, 2006. National Center for Health Statistics. Vital Health Stat 10(235). 2007.

http://www.cdc.gov/nchs/data/series/sr_10/sr10_235.pdf

^{xi} Centers for Disease Control and Prevention. Viral Hepatitis C Fact Sheet.

<http://www.cdc.gov/ncidod/diseases/hepatitis/c/fact.htm>

^{xii} Centers for Disease Control and Prevention. Estimated numbers of cases and rates (per 100,000 population) of AIDS, by race/ethnicity, age category, and sex, 2005—50 states and the District of Columbia (Revised June 2007). <http://www.cdc.gov/hiv/topics/surveillance/resources/reports/2005report/table5a.htm>