

DBSA Consumer and Family Survey Center 2010 Medications & Perceptions Survey Summary May 2011

Background

The survey was designed to examine attitudes about psychiatric medications among DBSA constituents and others that visit the DBSA website, DBSAAlliance.org. DBSA conducted this survey as part of our ongoing efforts to communicate the viewpoints and experiences of individuals seeking recovery from depression and bipolar disorder. DBSA does not endorse or recommend the use or non-use of any treatment, medication, or resource mentioned in this survey or in reported survey results and comments. For advice about specific treatments or medications, individuals should consult with their physicians and/or mental health clinicians before choosing tools to aid in their recovery.

The questions in this survey are designed in four parts: cost of medication as a barrier to treatment; reasons for not taking medication as prescribed; knowledge of, and access to, education about medications; and perceptions of influencing organizations. This survey received a robust response of almost 1,300 people. An overall summary of survey responses is available in the accompanying slides.

This survey was conducted on the DBSA website, DBSAAlliance.org, and was time limited. The respondents were self-selecting and generally representative of the population that utilizes DBSA's web resources. Participants were instructed to complete this survey *only* if they take, or have a history of taking, psychiatric medication. 68% of survey respondents self-identified as living with a primary diagnosis of bipolar disorder, 27% of survey respondents self-identified as living with a diagnosis of depression, and 5% of survey respondents were unwilling to provide a primary diagnosis.

Results and Discussion

Cost of Medication as a Barrier to Treatment

The results of the survey suggest that while cost of psychiatric medications are a complete barrier for a relatively small number of the respondents (3%), it represents a partial barrier (considerable 21% and somewhat 36%) for the majority of survey respondents (57%).

While 39% of survey respondents indicated that cost of psychiatric medications is not a current barrier to them receiving treatment, subsequent comments indicate that this can be attributed to a wide variety of system and social support resources including, but not limited to, Medicare, Medicaid, the VA, insurance coverage, prescription assistance programs, and community service organizations. Comments further suggest there is considerable worry about the ability to afford proper medications should these support resources be compromised or eliminated.

One third of survey respondents (33%) have sought assistance from pharmaceutical companies' drug assistance programs. Of those seeking support, approximately one third (36%) did not qualify or were unable to attain assistance. The remaining two thirds received some benefit, with 28% of those that sought assistance reporting that the benefits they received helped somewhat, and 36% reporting they benefited a great deal.

If we look at the percentages of ALL respondents (those seeking help *and* those who have not sought help), the results indicate that 13% of all respondents received a great deal of benefit, 10% benefited somewhat. 13% of all survey respondents sought help, but were unable to obtain benefit, while over two thirds of respondents never sought assistance (67%).

When additional comments are examined, the survey results suggest that government, industry, and community resources to assist individuals with the cost of psychiatric medications are *critical* to ensuring that cost of medication is not a barrier to treatment. Further study should investigate whether additional education on the prescription assistance programs, for both clinicians and patients, might help those individuals that are either unaware of these programs or those who are having a difficult time navigating the process to successfully obtain financial support as needed—and to determine if the programs themselves are benefiting as many as they could.

Reasons for Not Taking Medications as Prescribed

Nearly two thirds of survey respondents indicated they had not taken their medication *as prescribed* at least once (64%), while slightly more than one third (36%) indicated that they have/had always taken their psychiatric medications as prescribed.

Of those that indicated that they *had* varied from what was prescribed, 42% indicated that they had done so rarely (once or twice a year), 22% indicated they had done so quarterly (about once every three months), 15% indicated they had done so approximately once a month, and 21% estimated they or had done so weekly.

Upon examination of the responses from ALL respondents (those that indicated all levels of adherence), the results show that 27% of all respondents have deviated from taking their medications as prescribed about once/year, 14% about once/quarter, 10% about once/month, and 14% once/week.

Side effects were cited as the most significant factor—both the primary (33%) and secondary (19%) reasons—for not taking a psychiatric medication as prescribed. An individual's personal belief that he/she no longer needed the medication (15%), cost (13%), and the desire for the individual or their doctor to try something different (11%) bore similar results as the primary factor for non-adherence to taking a medication as prescribed. Only 5% of respondents cited the wish to not be on a psychiatric medication in the first place as their primary reason.

Secondary reasons for not taking medication as prescribed showed that the desire for the individual or their doctor to try something different (18%) was cited about the same amount as side effects (19%), followed in order of prevalence by the belief the individual no longer needed the medication (13%), the wish to not be on a medication in the first place (10%), and cost (9%).

It is worth noting that “I believed that I no longer needed the medication” was a relatively uncommon reason for discontinuing or not taking a psychiatric medication as prescribed. The data clearly doesn't support the common (mis)conception that “*people with bipolar disorder or depression are in denial and think they don't need their medication.*” Side effects are the most common reported reason which suggests that the efficacy or side effects of the medications may play a larger role in non-adherence to medication than the often-held perception that “*consumers are non-compliant.*”

Comments collected elsewhere in the survey reflected individuals' desire for increased transparency on the part of their clinicians and the pharmaceutical industry regarding side effects. These results, especially when reviewed in tandem with comments by respondents, suggest that individuals would benefit from access to more information regarding the both the benefits and potential side effects, of medications.

Knowledge of, and Access to, Education about Medications

Knowledge of categories of medications most common for the treatment of depression and bipolar disorder varied. While it should be acknowledged that individuals are more often familiar with the brand name of a drug rather than a category of drug, brand names were intentionally not referenced in this survey to avoid brand-specific bias and to better gauge how much individuals know about how each of these categories of drugs work and the potential benefits or risks of taking them. It also bears repeating that all of the individuals taking this survey self-reported a history of psychiatric drug use. As such, it would be a reasonable conclusion that the individuals taking this survey would have more knowledge than the general public about these categories of medications.

Respondents were most familiar with the general category of Mood Stabilizers, with nearly three quarters of respondents (71%) reporting that they are very (41%) or fairly (30%) familiar with, or knowledgeable about, this category of drugs. A large majority of respondents (62%) also reported considerable knowledge of Selective Serotonin Reuptake Inhibitors (SSRIs), reporting familiarity/knowledge levels of very (35%) and fairly (27%). Given that this category of drugs crosses treatment of both bipolar disorder and depression, and that all individuals taking this survey self-identified with a history of psychiatric medication use, it is interesting to note that well over one third of respondents (38%) feel they are only a little (23%) or are not at all (15%) familiar with or knowledgeable about SSRIs.

Knowledge of a comparatively newer category of drugs, Serotonin-Norepinephrine Reuptake Inhibitors (SNRIs) and the older category of Monoamine Oxidase Inhibitors (MAOIs) was significantly less, with 40% of respondents reporting they are very (20%) or fairly (20%) familiar with or knowledgeable about SNRIs and even fewer (27%) respondents reported they are very (16%) or fairly (11%) familiar with or knowledgeable about MAOIs. *It should be noted that analysis of responses to question thirteen have not been included in this report due to a typographical error in the survey that may have led to confusion.*

While it would be informative to have a more in-depth analysis of familiarity/knowledge of medications based on brand identity, it is clear from these survey results that many individuals are not familiar with these categories of drugs (even those categories reporting the highest level of familiarity) and as such may not be fully informed as to when, and why, one category of drug might be prescribed over another, and subsequently, the potential benefits or risks associated with each category.

Over half (53%) of survey respondents reported they would be very (21%) or somewhat (32%) likely to take an anti-psychotic medication, even if they believed it would help them. Individuals reported significant, but slightly lower levels of hesitancy for taking anticonvulsants, with 43% of individuals reporting they would be very (13%) or somewhat (30%) hesitant to take an anticonvulsant medication. Recognizing the fact that "anticonvulsants" are used more often to treat mood symptoms than convulsions, and that "antipsychotics" are used more often to treat depression or bipolar disorder than psychosis, more research would provide greater insight into whether

individuals' hesitancy to take anticonvulsants and antipsychotics is more attributable to the efficacy of these types of medications or to the frightening nature of their names.

About one third of individuals (31% and 32% respectively) reported almost equal levels of hesitancy in taking antidepressant or anti-anxiety medications. Even if they believed it would help them, 8% of respondents reported being very hesitant and 23% reported being somewhat hesitant to take an antidepressant while 7% and 25% of respondents reported being very or somewhat hesitant, respectively, to take an anti-anxiety medication.

Given, once again, that all of the respondents have self-reported experience taking psychiatric medications, it is worth noting that hesitancy to take them remains significantly high, with 31% to 57% of respondents indicating reluctance to take the types of medication listed in this survey. This is particularly worth noting given the majority of people (78%) that indicated that psychiatric medications play(ed) a significant (61%) or moderate (17%) role in improving their health. The balance of respondents (22%) reported that psychiatric medications play(ed) a small role (8%) in improving their health, have/had no effect on their wellness (2%) or are/were detrimental (12%) to their health.

The results suggest that individuals would benefit from a greater amount of information regarding psychiatric medications. Respondents reported that the two primary sources for information regarding medications they are considering taking are their psychiatrist (57%) and online resources (28%). The remaining sources were listed as a primary source by much fewer individuals: pharmacist (6%), primary care doctor (5%), others who have taken the medication (2%), counselor/therapist (2%) and friends/family (<1%).

Online resources (33%) and psychiatrists (22%) remain the predominant sources of information regarding medications as individuals' secondary source, with alternate sources reported in significantly lower numbers: pharmacist (11%), others who have taken the medication (10%), primary care doctor (10%), counselor/therapist (10%) and friends/family (4%).

Given this was an online survey, it is not surprising that "online resources" were reported as frequent sources of information. But given the level of concern expressed later in the survey by respondents about the influence of insurance companies and the pharmaceutical industry on treatment choices, a clear need exists for a trusted—one not carrying the perception of bias—provider of information about medications and other treatments.

When one considers that many individuals do not have the resources to see a psychiatrist on a regular basis, it is disconcerting to note the relatively low number of individuals (5% and 10%) that report their primary care doctor as a source for information. This is especially true in light of the prevalence of co-morbid physical health issues often concurrent with mental health diagnoses.

Perceptions of Influencing Organizations

Concern is very high (90%) that both insurance and pharmaceutical companies influence clinicians' prescription choices. Fifty-nine percent of respondents were very and 31% were somewhat concerned about the insurance industry's influence on these choices. Similar numbers of individuals reported concern about influence by pharmaceutical companies, with 57% very and 33% of respondents somewhat concerned.

The majority of respondents (77%) reported a cautious or neutral perception of pharmaceutical companies with the highest number, (57%) of respondents, reporting their perception as “They produce medication that I need, but I am cautious about trusting them.” The next most reported perception (20%) was more neutral, “They produce helpful treatment options and I have neither a positive or negative opinion of them.”

Twelve percent of respondents reported they believe pharmaceutical companies “... are ‘pill pushers’ that shouldn’t be trusted,” while 10% believe “They produce helpful treatment options and I believe that they generally act in patients’ best interest.” Less than 1% of respondents agreed with the statement, “It’s irrelevant as I don’t believe anyone is truly helped by medication.”

Almost one third (29%) of the 763 comments about “what pharmaceutical companies should do *more* of,” expressed a desire for more and/or better research related to treatments. When asked “what pharmaceutical companies should do *less* of,” the largest percentage (37%) of the 660 comments related a desire for less—and less money spent on—advertising.

There were more than 2,695 combined comments on pharmaceutical companies. While 78% of individuals report that psychiatric medications play(ed) a significant (61%) or moderate (17%) role in their wellness, there is considerable concern about issues including but not limited to, the level of transparency regarding the efficacy and side effects of drugs; negative impressions of advertising strategies; the need for affordable medication; an increased emphasis on education; and the desire for rigorous research to develop new treatment options.

Summary and Conclusions

While there are inherent limitations in any open survey that is web-based, the findings of this survey support a number of key themes. Government, industry, and community resources that assist individuals with the cost of psychiatric medications play a *critical* role in ensuring that personal financial limitations are not a barrier to treatment, and these programs must be sustained to ensure that those that benefit from medications can afford to receive them.

Individuals and clinicians could benefit a great deal from access to accurate, unbiased, educational materials about the variety of medications available—together with their potential benefits and associated risks—to treat depression and bipolar disorder. Furthermore, given the level of concern expressed by respondents about the influence of insurance companies and the pharmaceutical industry on treatment choices, it is clear that individuals would have greater trust in information about medications and treatment options that is provided by impartial organizations.