

DBSA 2010 Medications & Perceptions Survey Results

Survey Purpose

This survey was conducted to provide individuals living with bipolar disorder or depression the opportunity to express their opinions and attitudes towards psychiatric medications.

The survey, and subsequent results, are neither meant to advocate for or against the use of psychiatric medications.

DBSA believes medications are one of several treatment options (including but not limited to talk therapy, self-help, medications, and peer support) that an individual might find helpful. The decision to take, or not to take, any medication is best made by an individual in collaboration with a trained clinician(s).

Survey Demographics

This survey was conducted on the DBSA website, DBSAlliance.org, and was time-limited. The respondents were self-selecting and generally representative of the population that utilizes DBSA's web resources.

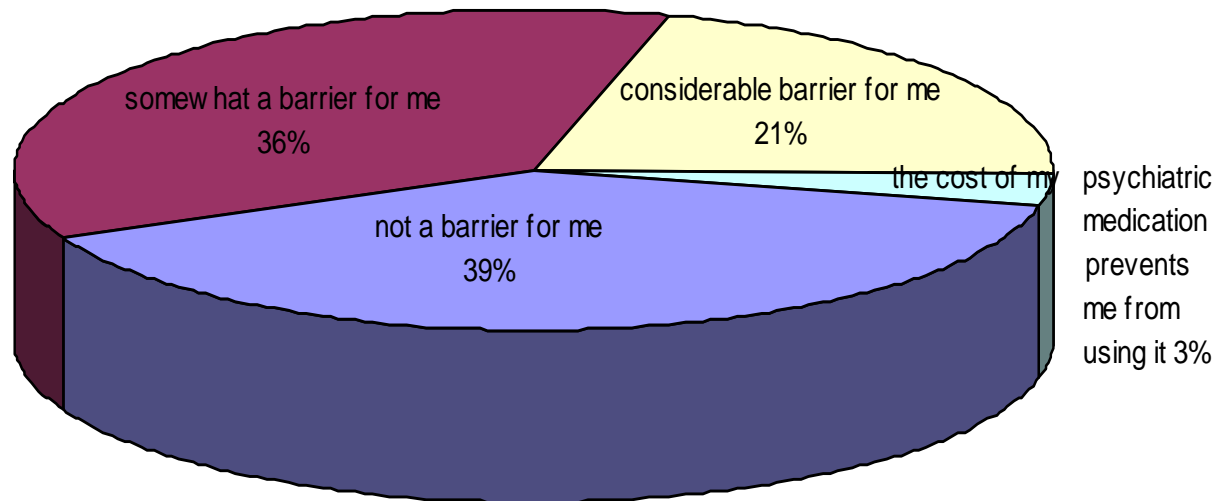
Sample Size: 1286
(open, web-based, single-occurrence participation)

Participation Requirement: Individuals were invited to participate in the survey only if they take, or have ever taken, a psychiatric medicine.

Primary Diagnosis: 68% bipolar disorder, 27% depression, 5% unwilling to provide diagnosis

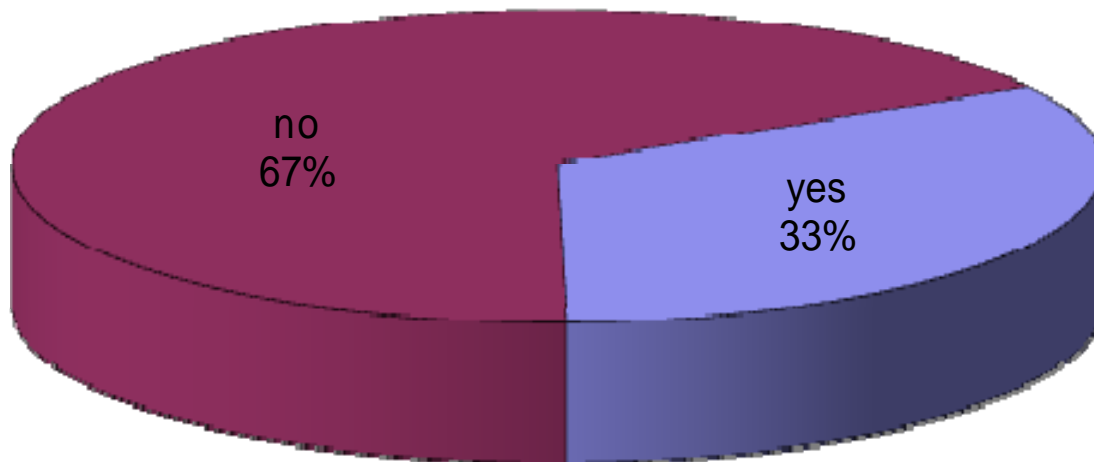
1) How great of a barrier to treatment is the cost of your psychiatric medication(s)?

not a barrier for me	507	39%
somewhat a barrier for me	465	36%
considerable barrier for me	270	21%
The cost of my psychiatric medication prevents me from using it.	44	3%



2) Have you ever sought assistance from pharmaceutical companies for prescription cost assistance?

yes	425	33%
no	861	67%
I am not/have never been on medication.	0	0%



3) If yes, did you benefit from assistance?

Chart reflects responses (%) for ALL respondents

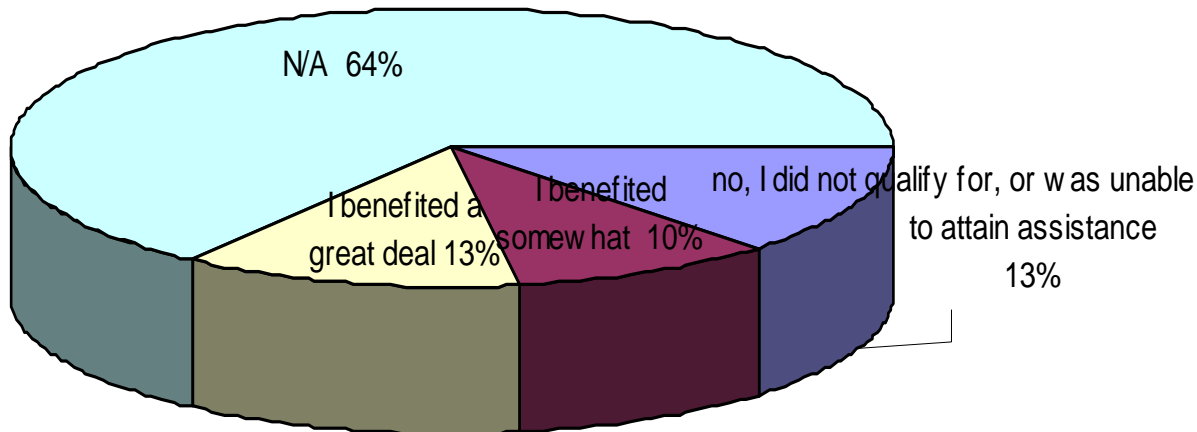
No, I did not qualify for, or was unable to attain, assistance.	164	13%
I benefited somewhat.	126	10%
I benefited a great deal.	161	13%
N/A (have not sought assistance)	835	64%

Reponses (%) for only those who HAVE sought assistance:

= 36%

= 28%

= 36%



4) Additional comments about seeking prescription drug assistance:

Sample Comments: *(See handout with all 337 comments.)*

At the time, about eight years ago, my doctor had to fill out a barrage of forms every month for me to be eligible to receive any benefit... it was a huge hassle. My doctor ended up just giving me samples. When the samples changed or were no longer available I stopped the medication. There's nothing like the humility that goes with having to beg for needed but cost inhibitive medications month after month. Some of the most effective drugs were not within my reach because of cost.

I am unable to take the meds I need because I cannot afford them. I am currently having issues due to being out of 1 of my meds and not able to pay for more. I also have tried to make some meds last longer by only taking 1 pill a day rather than the 3 pills a day that is prescribed.

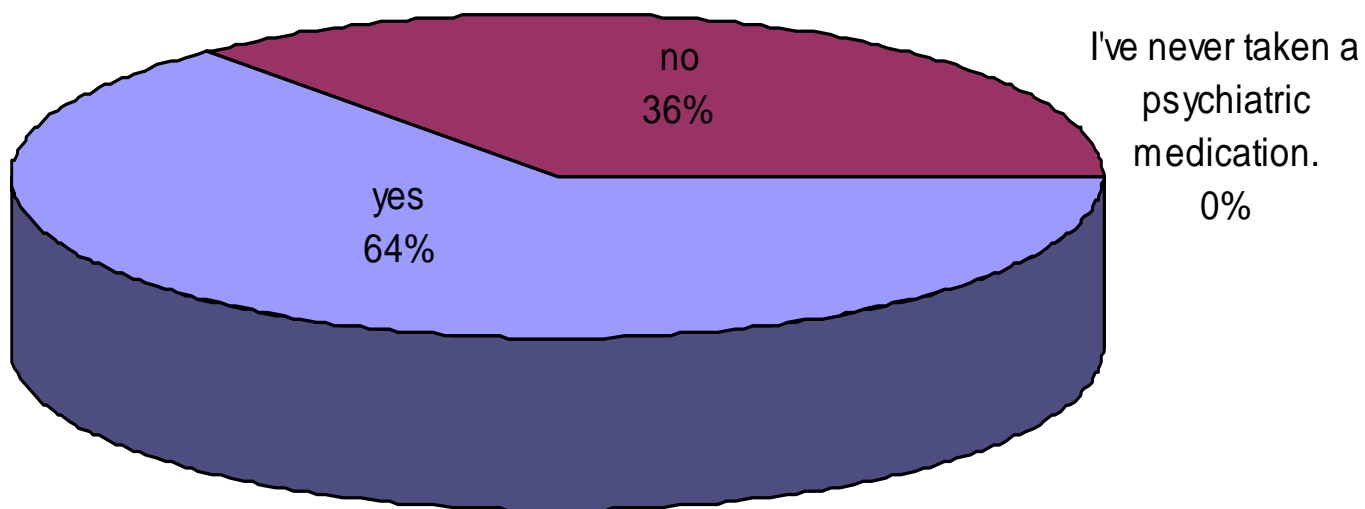
I attempted to obtain assistance and had great difficulty completing the application process. It was not user-friendly and I became frustrated and gave up.

I have at times been able to get significant quantities of meds thru assistance programs with the help of my doctor.

I have had extreme difficulties in obtaining my psychiatric medications prior to getting to work with a scholarship medication coordinator at the clinic I receive care. There have been many times that I have gone without my psych meds because I didn't have insurance or the financial means to pay for them and I did not have access to either scholarship medication or samples. Right now, I get all my psych meds on scholarship or free from the clinic I go to. Without these services, I would not be able to be on meds.

5) Have you ever not taken a psychiatric medication as prescribed?

yes	821	64%
no	465	36%
I've never taken a psychiatric medication.	0	0%



6) If you answered yes, that you have not taken a psychiatric medication as prescribed, how frequently did that happen?

Chart reflects responses (%) for ALL respondents

rarely (once or twice a year)	344	27%
quarterly (every 3 months)	182	14%
monthly (once a month)	126	10%
weekly (once a week)	177	14%
N/A (answered no)	456	35%

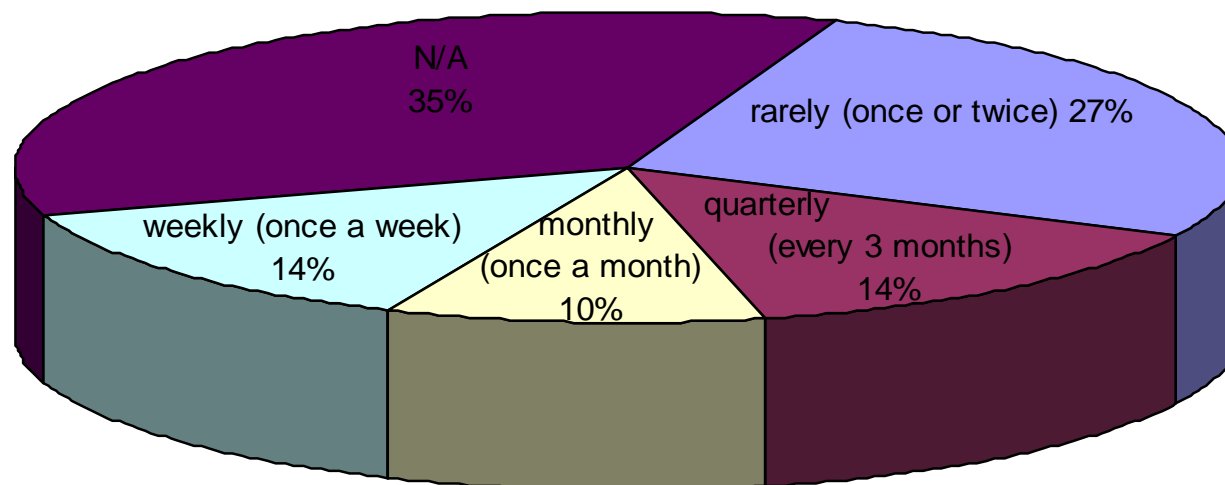
Responses (%) for only those who answered YES

= 42%

= 22%

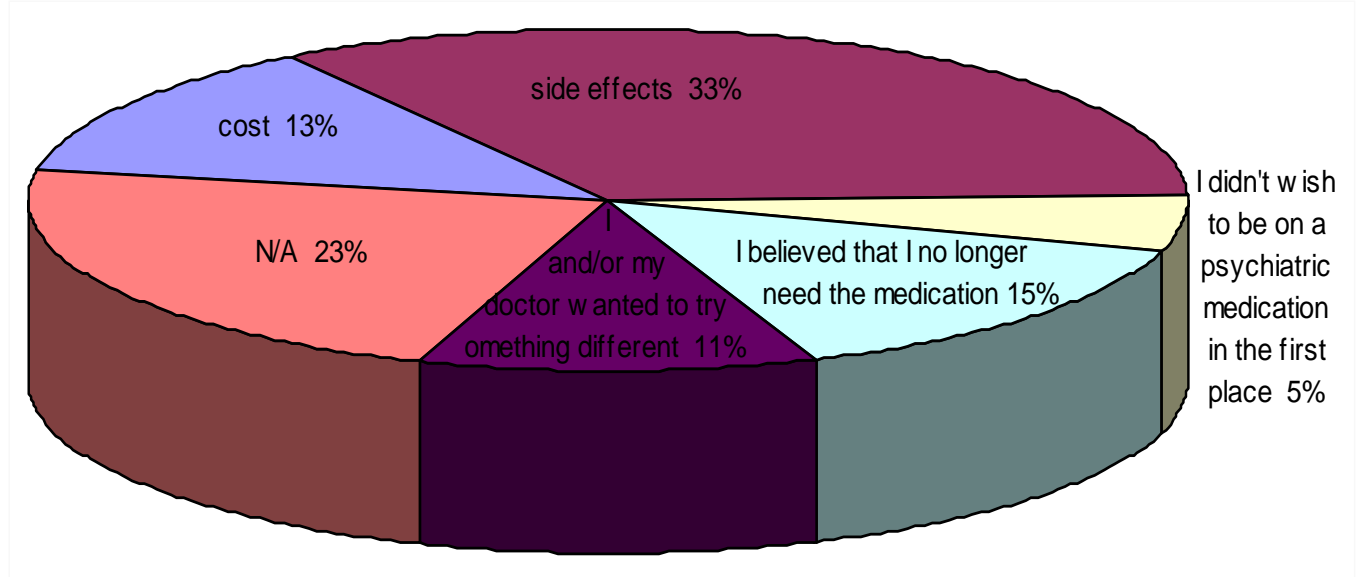
= 15%

= 21%



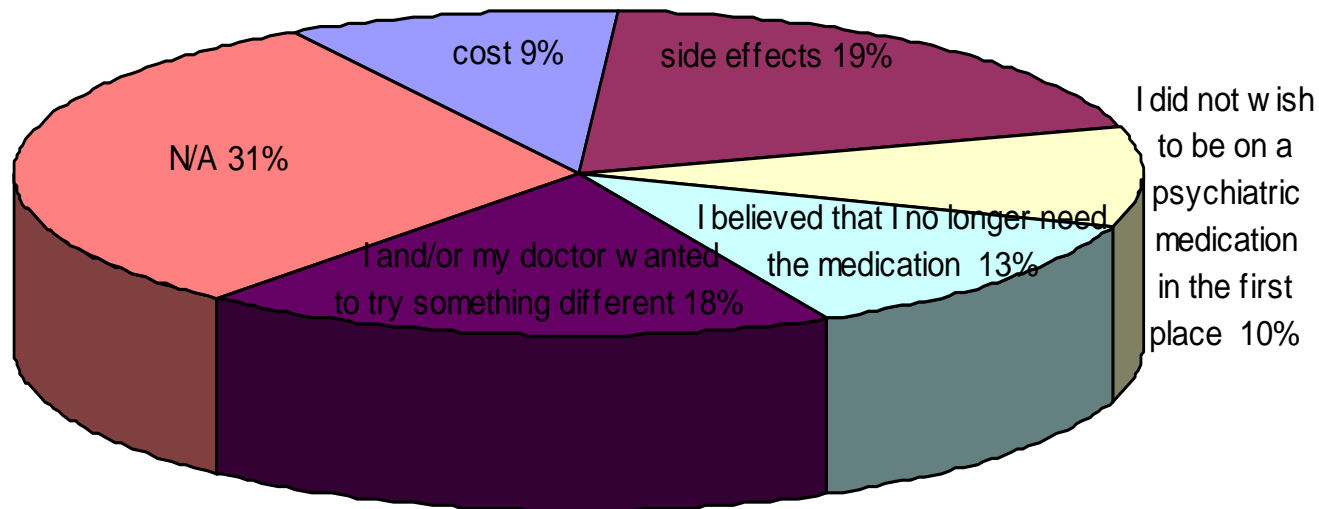
7) If you have ever stopped taking—or not as prescribed—a psychiatric medication what was your primary reason?

cost	167	13%
side effects	434	33%
I did not want to be on a psychiatric medication in the first place	67	5%
I believed that I no longer need the medication	187	15%
I and/or my doctor wanted to try something different	141	11%
N/A	290	23%



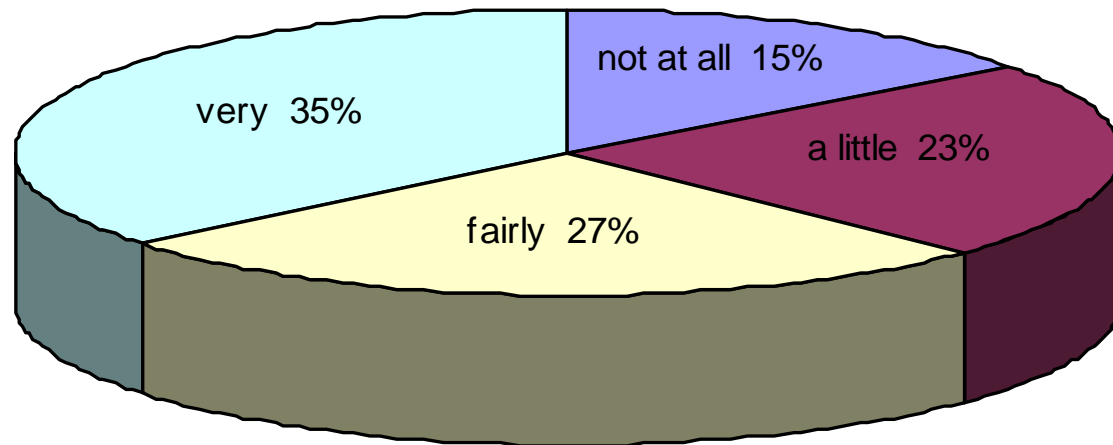
8) If you ever stopped taking—or not as prescribed—a psychiatric medication what was your second most important reason?

cost	121	9%
side effects	247	19%
I did not want to be on a psychiatric medication in the first place	127	10%
I believed that I no longer need the medication	162	13%
I and/or my doctor wanted to try something different	237	18%
N/A	392	31%



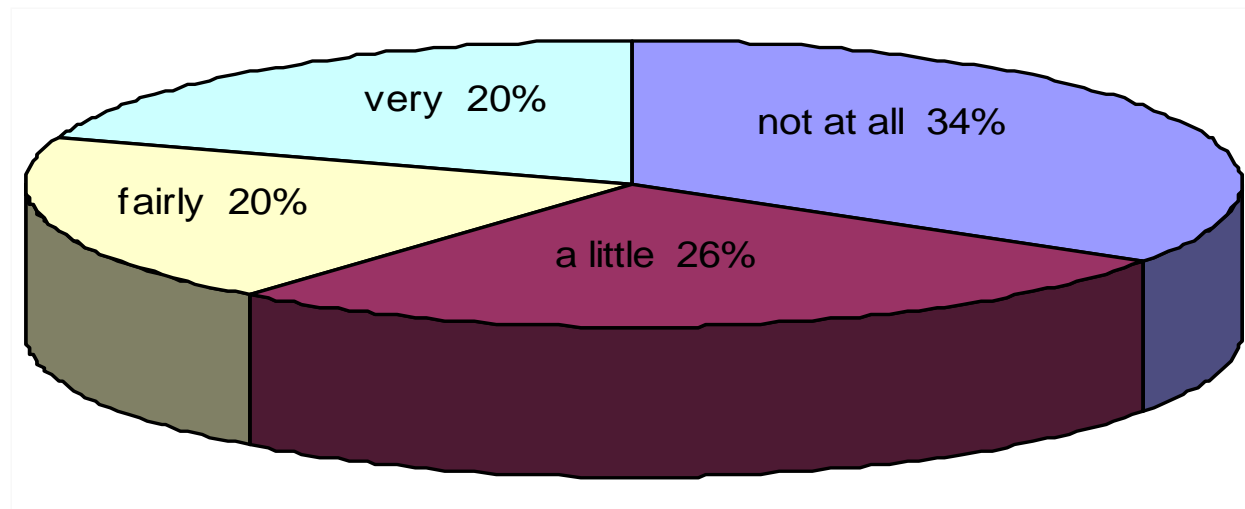
9) How familiar with or knowledgeable are you about Selective Serotonin Reuptake Inhibitors (SSRIs)?

not at all	188	15%
a little	290	23%
fairly	343	27%
very	465	35%



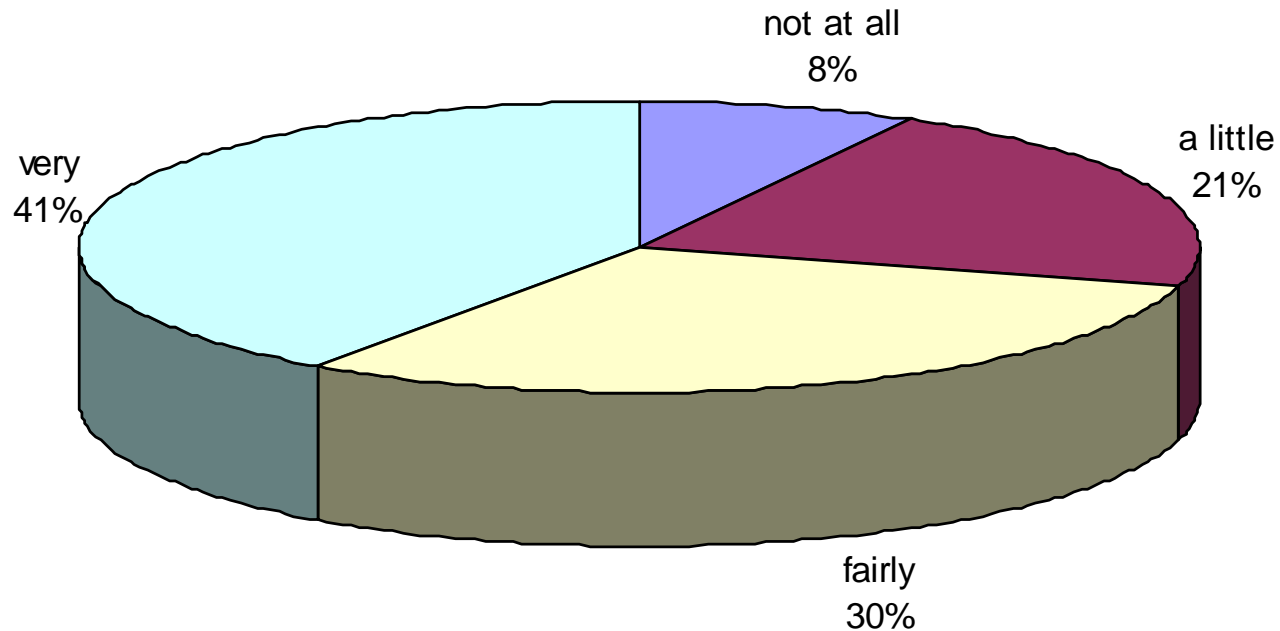
10) How familiar are you with or knowledgeable are you about Serotonin-Norepinephrine Reuptake Inhibitors (SNRIs)?

not at all	441	34%
a little	340	26%
fairly	251	20%
very	254	20%



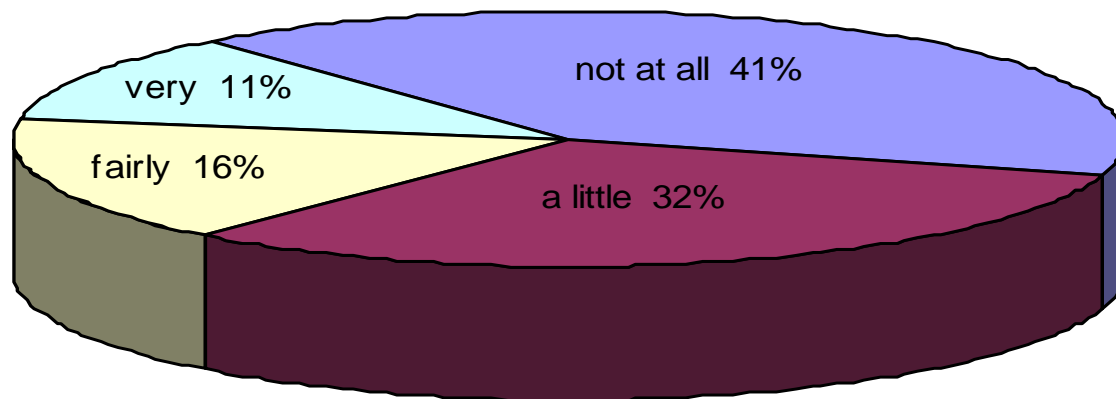
11) How familiar are you with or knowledgeable are you about Mood Stabilizers?

not at all	102	8%
a little	276	21%
fairly	389	30%
very	519	41%



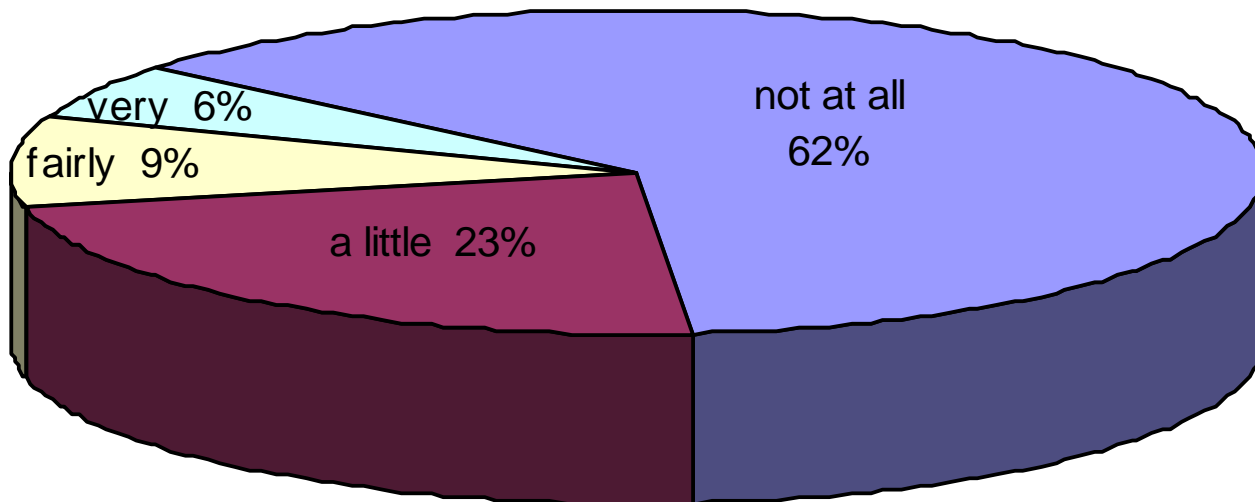
12) How familiar with or knowledgeable are you about Monoamine Oxidase Inhibitors (MAOIs)?

not at all	521	41%
a little	412	32%
fairly	207	16%
very	146	11%



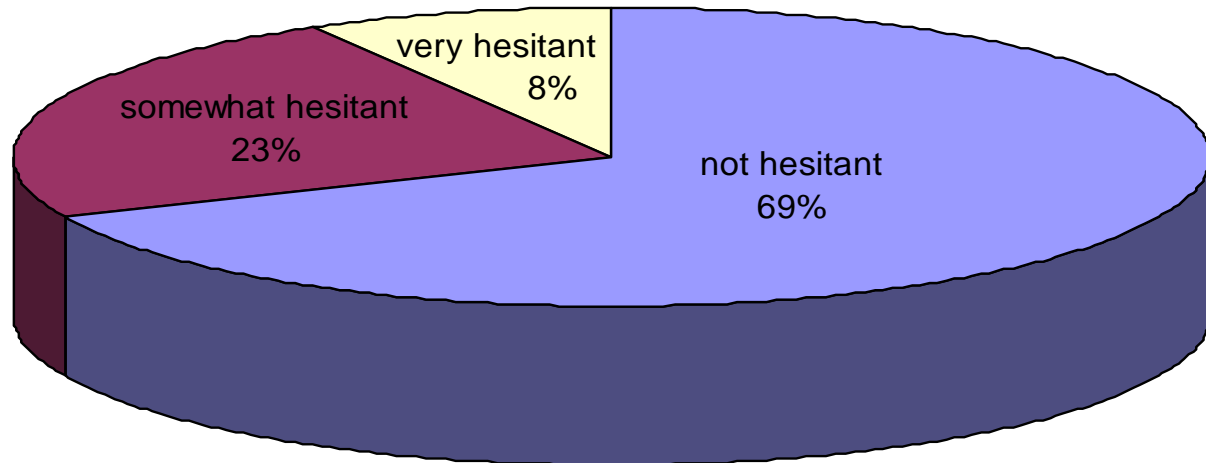
13) How familiar with or knowledgeable are you about Norepinephrine and Dopamine Reuptake Inhibitors (NDRIs)?

not at all	804	62%
a little	292	23%
fairly	117	9%
very	73	6%



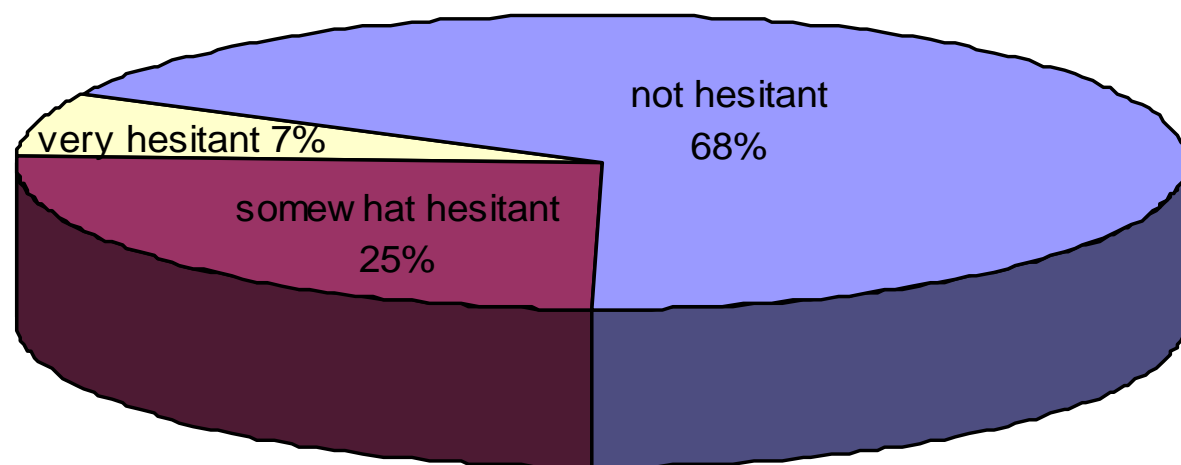
14) How hesitant are/would you be to take an antidepressant if you believed it would help you?

not hesitant	878	69%
somewhat hesitant	300	23%
very hesitant	108	8%



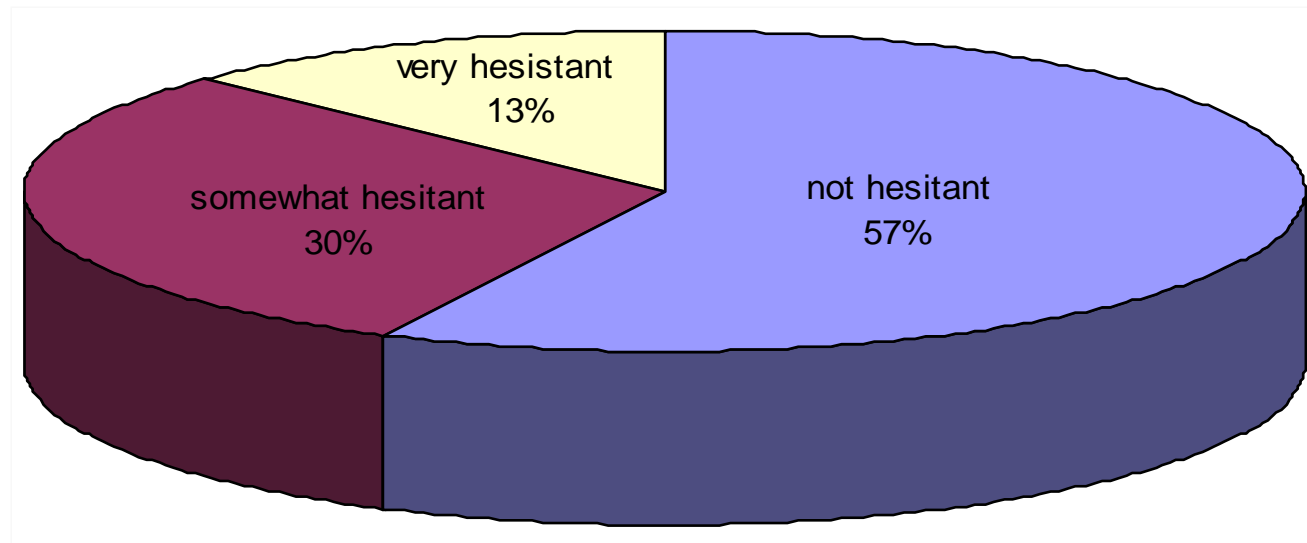
15) How hesitant are/would you be to take an anti-anxiety medication if you believed it would help you?

not hesitant	868	68%
somewhat hesitant	324	25%
very hesitant	94	7%



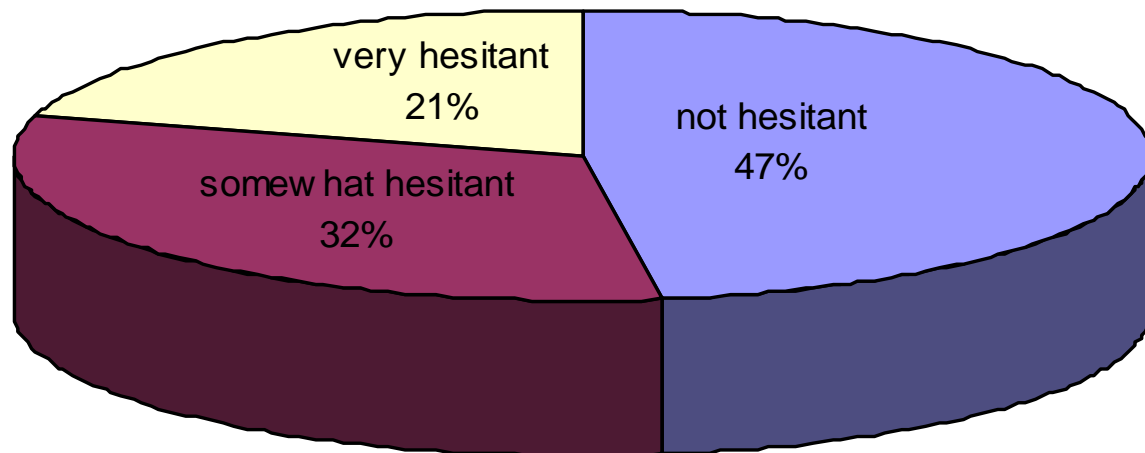
16) How hesitant are/would you be to take an anticonvulsant if you believed it would help you?

not hesitant	737	57%
somewhat hesitant	385	30%
very hesitant	164	13%



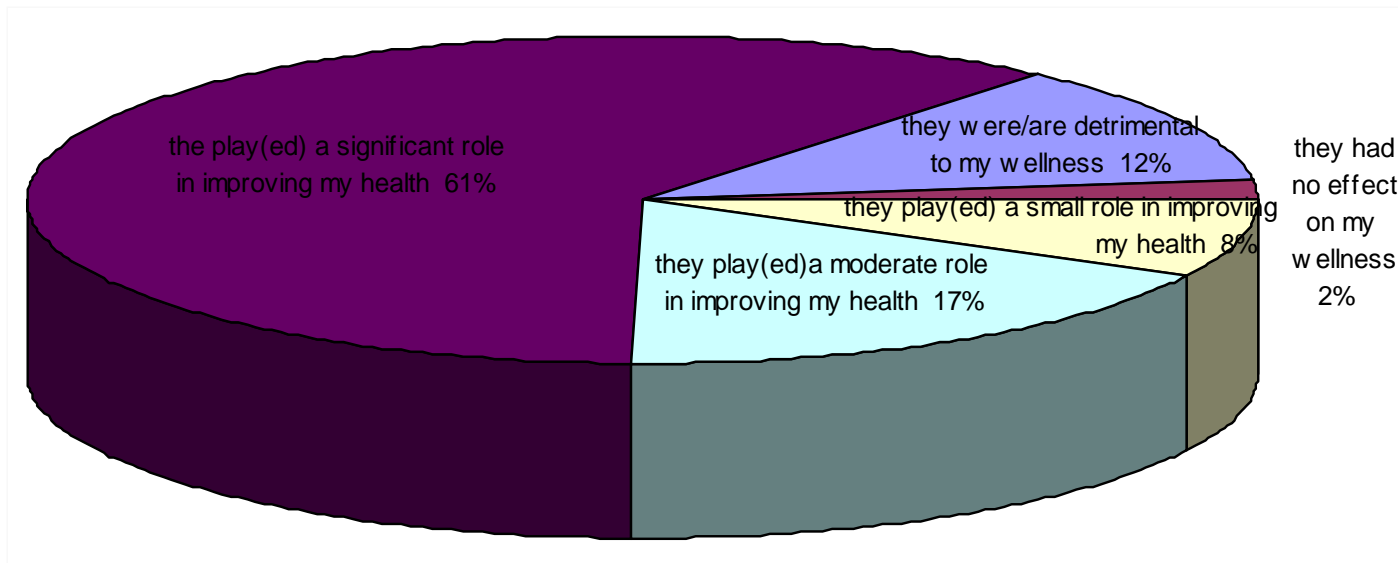
17) How hesitant are/would you be to take an antipsychotic if you believed it would help you?

not hesitant	613	47%
somewhat hesitant	408	32%
very hesitant	265	21%



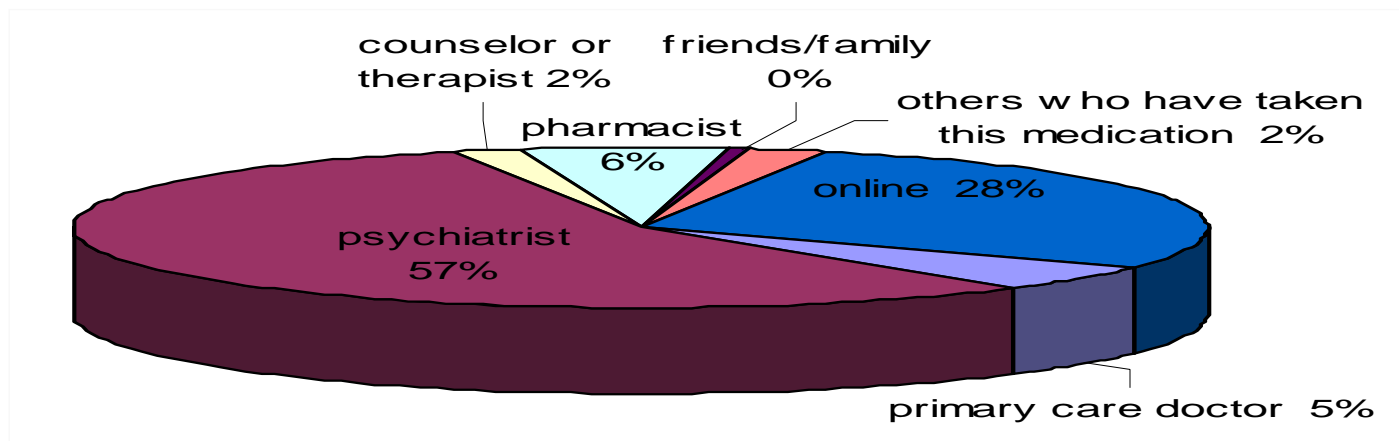
18) What role did/does psychiatric medications play in your treatment?

They were/are detrimental to my wellness.	152	12%
They had no effect on my wellness.	26	2%
They play(ed) a small role in improving my health.	102	8%
They play(ed) a moderate role in improving my health.	223	17%
They play(ed) a significant role in improving my health.	783	61%



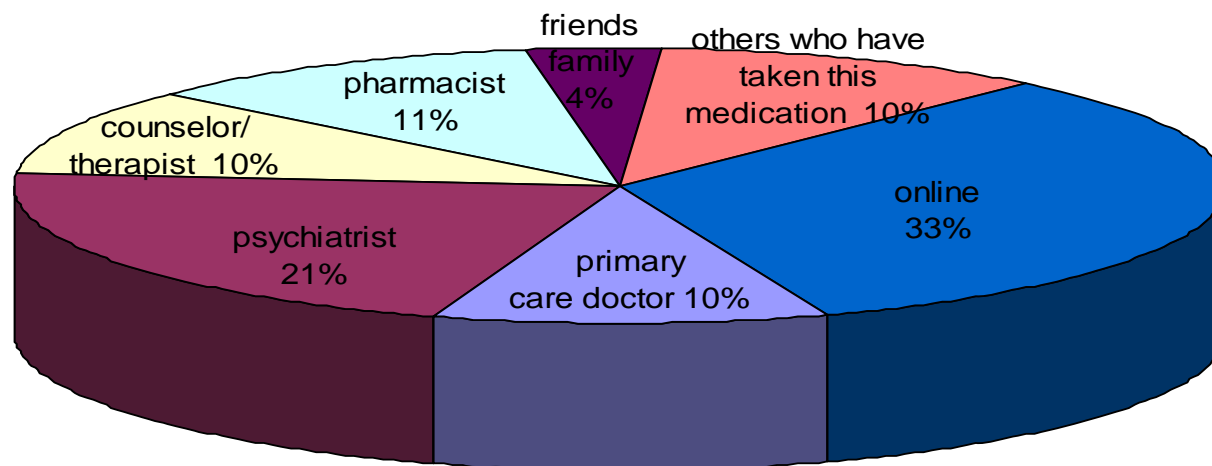
19) Where do you most often get information about medications you are considering taking?

primary care doctor	68	5%
psychiatrist	721	57%
counselor/therapist	25	2%
pharmacist	77	6%
friends/family	4	0.31%
others who have taken this medication	31	2%
online	360	28%



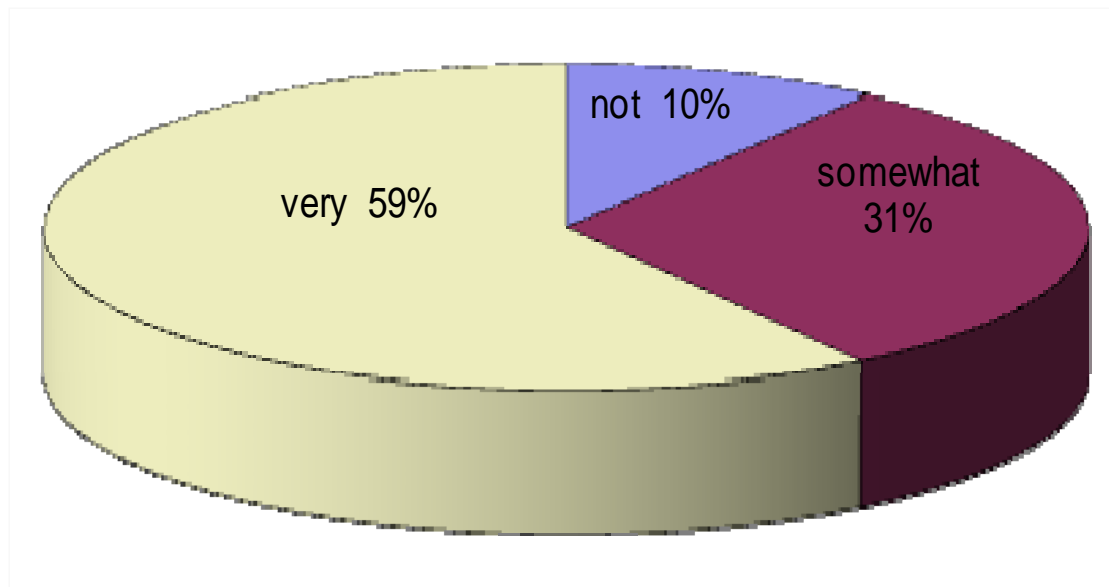
20) Where is the second place you most often get information about medications you are considering taking?

primary care doctor	134	10%
psychiatrist	276	22%
counselor/therapist	133	10%
pharmacist	139	11%
friends/family	46	4%
others who have taken this medication	135	10%
online	423	33%



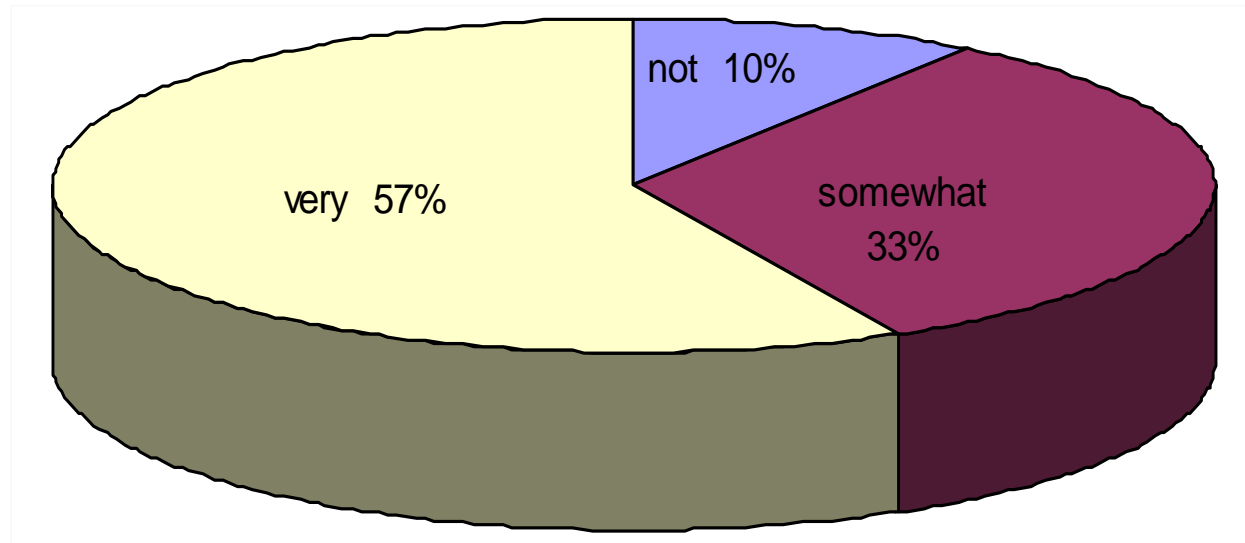
21) How concerned are you about insurance companies' influence on clinicians' prescriptions choices?

not	126	10%
somewhat	395	31%
very	765	59%



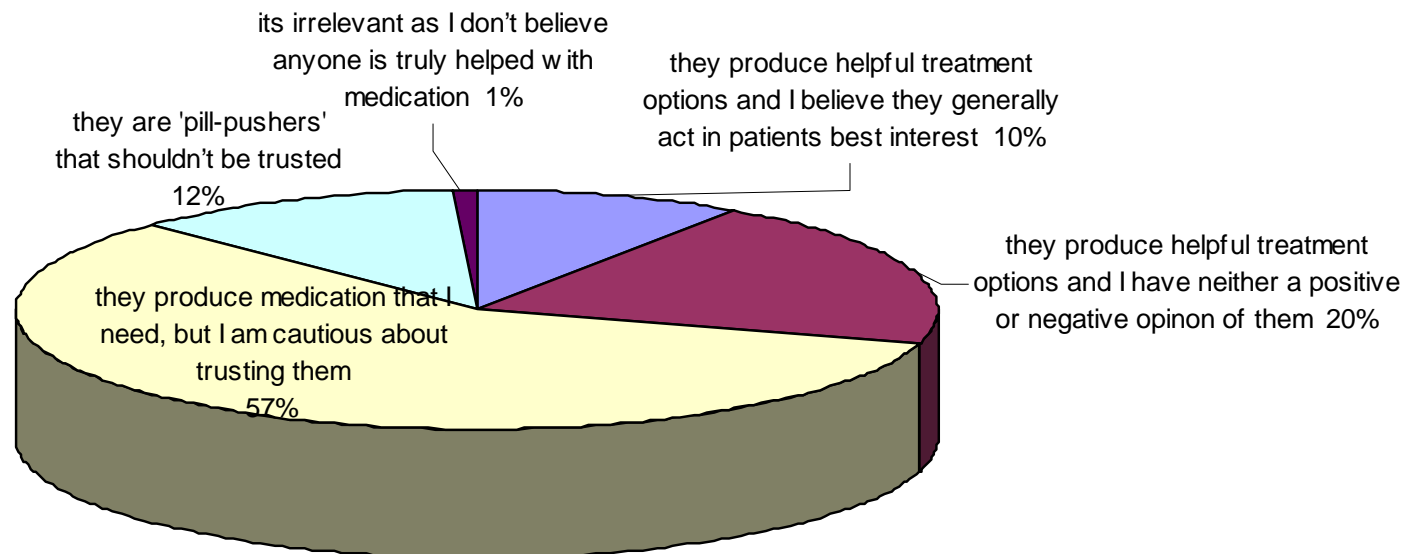
22) How concerned are you about pharmaceutical companies' influences on clinicians' prescriptions choices?

not	126	10%
somewhat	419	33%
very	741	57%



23) What is your perception of pharmaceutical companies?

They produce helpful treatment options and I believe they generally act in patients best interest.	123	10%
They produce helpful treatment options and I have neither a positive or negative opinion of them.	259	20%
They produce medication that I need, but I am cautious about trusting them.	744	57%
They are 'pill-pushers' that shouldn't be trusted.	149	12%
It's irrelevant as I don't believe anyone is truly helped with medication.	11	1%



24) Additional comments regarding pharmaceutical companies:

Sample Comments: *(See handout for all 494 comments.)*

Advertising on TV makes it seem like the companies are just pushing pills and trying to get more and more people on drugs.

All medications have benefits and risks which must be balanced in deciding on a medication. The risk of large liability from lawsuits is a major reason for the high prices of medications. FDA approval should shield pharmaceutical companies from damage liability suits.

I am very angry at the pharmaceutical companies. They spend millions of dollars on advertising, but are not concerned about cost to the consumer. Don't they understand that people like me are poor. I cannot afford my psychiatric disability. I am a gold mine for the pharmaceutical companies, but a pariah for the health insurance companies!

I being a pharmacist and very familiar with the medications have many mixed emotions about them at times. I know they are necessary for many people and greatly improve their quality of life. I know from dealing with drug representatives that they give a skewed picture of the drug they are representing at times down right deceitful. I find it disturbing that when they are strongly detailing a area doctors are very receptive to them and we see dramatic increases in their drug RXs. It at times just seems as though the latest and newest drug without and consideration as to cost and if they are any real improvements in them. I feel that many doctors just go by what drug reps say without any comparison on their own.

I believe they tweak medications just a bit so they can call them a new med and charge exorbitant prices when the current drug becomes generic eligible. I've tried over 15 drugs to treat bipolar disorder, OCD, and GAD with little success. The current system of guess and check or trial by patient leaves me feeling helpless and hopeless.

25) What is the most important thing you think the pharmaceutical companies don't understand regarding psychiatric medications and the people who use them?

Sample Comments: *(See handout for all 778 comments.)*

Effects on females are different than the effects on males. Research studies usually don't reflect this discrepancy.

A lot of mentally ill people don't have good health care and can't afford their medicine because they can't hold jobs because of their illnesses.

Although they list side effects of the medications, It doesn't seem like they are doing anything to prevent them from happening, They just assume we don't mind since it might help with mental stability. I don't think they see many of us as desperate.

CAN YOU MAKE ONE YOU ONLY HAVE TO TAKE ONCE A MONTH? Having Bipolar I for over 30yrs - it is a total fight each and every day to make your self take the damn stuff!!! or make it milder so you can still feel like yourself at least a little bit.

Cost; need for honesty when it comes to all the side effects; sometimes they release meds before they are actually safe, then later have to take them off the market.

How coercive their use becomes during crisis and how little they recognize serious adverse events, e.g. urinary retention, short term memory loss, akathisia, etc.

How important it is to produce non-weight gaining medications. I know they know, but it should be a requirement now. I am one example of someone who almost reached the point of Metabolic Syndrome.

How important they are to a person like myself. Not crazy enough to be committed but unstable enough to have to take a handful of pills just to function in daily life. It's scary!

26) What do you want the pharmaceutical companies to do MORE of?

Sample Comments: *(See handout for all 763 comments.)*

Research & development (29% of comments)

Broaden their scope of "recovery ideas"

Promoting other wellness tools in addition to the medicines - be more up front about the impacts of the medicine - positive and negative

Tell the truth about ALL clinical trials, not just the ones that support them. Make trials valid by using proper numbers of people, all ages and both genders.

Get GOOD medication that doesn't have horrible side effects. At least tell us about the side effects (the truth) so we can make an informed choice. It's hard to make an informed choice once you are drugged to high heaven.

Honest research with honest disclosure of ALL study results.

Long-term tracking of side-effects for children and young adults starting to take their drugs.

Test out and create anti-anxiety type drugs that can be taken under the tongue or inhaled, like heart medications. It would help with self-medication issues, particularly smoking, for anxiety.

Yes. They can stop selling the meds for such outrageous amount of money. Pharmaceutical companies make way to much money to keep charging prices we can't pay. This adds tremendously to hopelessness.

27) What do you want the pharmaceutical companies to do LESS of?

Sample Comments: *(See handout for all 660 comments.)*

Advertising. (37% of comments)

Charge exorbitant amounts of money long after they have paid for their research and made a reasonable profit.

I want them to be less involved in the review of drugs. I want drug review conducted by independent experts. Perhaps the drug companies could setup a blind fund to help pay for independent review of the drugs, but have not input on the outcome.

Make minor changes to drugs to prevent generic release or encourage use of "new" drug with no real additional benefits. Less advertising and promotion of products.

Less aggressive detailing, less stringent rules to get patient assistance to purchase meds, and to stop price-fixing similar drugs or being motivated by expiring patents.

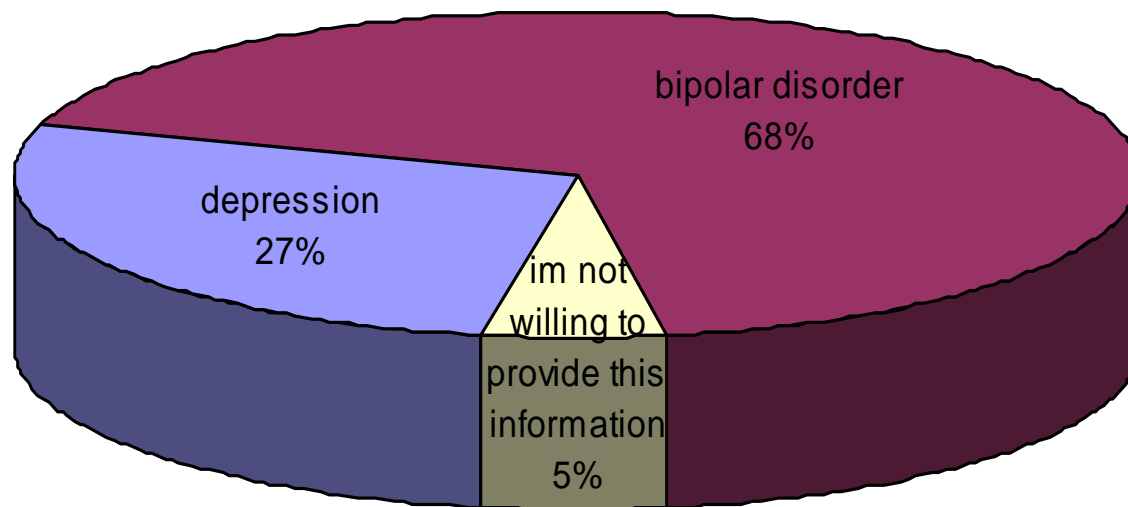
Less lobbying Congress to change the laws to give them longer profit times on important meds that people need.

Conducting market-driven human research trials in a morally egoistic fashion that's operated solely from their self-interest of profit, while discounting the total best interest of society.

Pharmaceutical companies need to have less influence on the doctors. It seems they stop in the doctor's office and drop off a large amount of samples, which then the doctor pushes off on his/her patients.

28) What is your primary mental health diagnosis?

depression	349	27%
bipolar disorder	869	68%
I'm not willing to provide this information	68	5%



DBSA 2010 Medications & Perceptions Survey Results

Thank you to all who participated in this survey!

Additional questions regarding this survey may be directed to programs@DBSAlliance.org.