

Diagnosis and Treatment of Mood Disorders

DBSA online survey, January-July 2008

	Response Percent	Response Count	
1. What is your current diagnosis?			
Bipolar Disorder	72.60%	143	
Depression	27.40%	54	
		197	answered question
		1	skipped question
2. What treatment do you currently receive for your bipolar disorder or depression?			
Medication	89.80%	177	
Talk Therapy	56.90%	112	
Group Therapy (inc. day treatment and support groups)	22.30%	44	
None	4.10%	8	
Other (Sample of comments provided below in italics.)	9.14%	18	
		197	answered question
		1	skipped question
<p><i>(Canine therapy, yoga, acupuncture, nutritional therapy, physical exercise, Natural medication and lifestyle adjustments, Prayer and Bible Study, Vocational Rehabilitation, Depression Impact Group (DIG) sponsored by my church</i></p> <p><i>"I occasionally see a county mental health therapist. (Same as psychiatrist) My funds are basically 0 since dealing with Uterine Cancer and other things. So, in the area that I live in, there aren't many avenues for support for me."</i></p> <p><i>Meditation, light therapy, vitamin B complex, Unitarian Women's Group focusing on Native American beliefs, Peer Support, "no income or insurance for meds, had to go off of them at the first of the year"</i></p>			
3. What type of health care provider do you currently see for your bipolar disorder or depression?			
Psychiatrist	73.40%	141	
Primary Care Physician (family physician, internist, OB/Gyn, etc.)	21.40%	41	
Talk therapist (psychologist, social worker, etc.)	50.00%	96	
Case Manager	4.20%	8	
None	4.70%	9	
Other (Sample of comments provided below in italics.)	8.33%	16	
		192	answered question
		6	skipped question
<p><i>Acupuncturist, Advanced Nurse Practitioner, Mental Health Center, Foundations-A Place for Education & Recovery - Canton, Oh.</i></p> <p><i>"Psychiatric nurse practitioner (medication management), psychiatrist provides both medication management and therapy - I see her twice weekly."</i></p>			
4. Do you feel that your current mental health care is culturally appropriate (is sensitive to your ethnic background and personal concerns)?			
Yes	81.70%	156	
No	18.30%	35	
		191	answered question
		7	skipped question

5. Please explain why your current mental health care IS or IS NOT culturally appropriate for you.

(Sample of comments provided below in italics.)

		101 97	answered question skipped question
<p><i>My ethnicity doesn't play a part in my care at all. My dr. also treats me for FM and my mental health and FM overlap. He listens to me and understands.</i></p> <p><i>My Doc. tries to be culturally sensitive, but sometimes he misses the mark. I think sometimes he misunderstands due to our cultural differences, yet he puts so much effort into understand and if Im in a place where I can be communicative it tends to work out. When I'm not able to communicate then it causes some minor problems, but not enough for me to feel the need to seek different counsel.</i></p> <p><i>Adolescent with mood disorder. African American who finds it difficult to find Doctors/therapists who are people of color.</i></p> <p><i>My psychiatrist does not have enough time to spend with me to get to know me outside of symptoms. We have not discussed family, country of origin, social life, or any of those issues. I feel this hampers our interaction, potentially leaving huge chunks of my life out of our physician-patient relationship.</i></p> <p><i>My talk therapy is respectful of my religious and family culture.</i></p> <p><i>I am able to see the gender, race and age of a psychiatrist of my choosing. However it did take much effort on my part to accomplish this.</i></p> <p><i>I chose a Muslim psychiatrist because I am a Muslim and felt more comfortable with a diagnosis from someone who shared a common belief structure. There was no ulterior motive.</i></p> <p><i>I could not find a talk therapist/psychiatrist to meet my needs on a cultural level so I went back to just seeing my PCP to get my meds.</i></p> <p><i>I'm with a low-income mental health care provider and I feel my "pdoc" is experienced with different ethnicities as well as income levels.</i></p> <p><i>My therapist was/is very open to learning about African American culture. I must admit initially I felt there was a learning curve but she did her homework :). I recommended books for her to read and explained in sessions about my experiences and culture. I am a geechee. Now she recommends books to me. But she has learned much and the fact that she is a woman and I am a woman helps. The fact that she is a Russian-Jewish immigrant that came here as a child helps too. I changed my psychiatrist from White Protestant male (too much white male privilege to deal with) to a male of color. This seems to be working much better.</i></p> <p><i>Due to the fact, I am in a very stigmatized/diverse cultural group & that is one of the GLBT Community! And my talk therapist? is a Caucasian male, who does not address any GLBT issues EVER! So I stop seeing him.</i></p> <p><i>Thanks for asking.</i></p> <p><i>and ethnic background, they don't see the unique aspects of my disease as it relates to being a Black female. I do feel that there are additional challenges I face as a black, professional, christian woman with bipolar disorder. For example, the primary reason I don't have family support is b/c Blacks believe mental illness is a "White" disorder and a character flaw best addressed by being a stronger Christian. Also, the pressure to be a cliché "Strong, Black Woman" causes me to hold up a resilient-looking mask and does not allow me to be vulnerable and display weakness, pain, struggle, etc. The Aunt Jemima stigma is very real for black women; we are to be caretakers not be taken care of. Also, Blacks sometimes feel that mental illness is a generational issue that we will mature out of. My choice to live outside of these ignorant stereotypes is a unique struggle all unto itself. It is necessary for my wellness but stands as another stressor that often exacerbates my illness. I often feel my only two choices are to be overwhelmed and stressed trying to hide my illness or to be overwhelmed.</i></p> <p><i>He has asked about my spiritual beliefs of our ancestors & what I practice. How it can help me.</i></p>			

My current mental health care is not culturally appropriate for me because they don't really understand my symptomology, which is very culturally based since I am Creole. Things like lack of hair care signal severe depression. My mania is very severe as was for my mother. Reactions to medications are either very resistant or very sensitive (coma). Resistant to ECT too. My paternal grandmother who was a vodun practitioner talked to spirits all the time and was thought to be "crazy Gertie".

Not appropriate toward working mothers

There is no support group for me in my area because I can't find one and second there is no interpreter available. Sad but true!

My therapist and I share the same spiritual values and beliefs and are able to incorporate them into our counseling work. My nurse practitioner and I have worked together a long time and knows a lot about my values and culture, and respects them. She is compassionate and astute in how she deals with issues that come up.

Sometimes I feel like my depression or the psychosis related to mania is exacerbated by race. What might be a natural disappointment or anger due to a racist attitude/interaction is confused for an aspect of my diagnosis by my therapist. I do not know if my caregivers can relate or understand that.

My culture has nothing to do with my mental health because it is a biological disease not a cultural one.

6. Have you been misdiagnosed (given the wrong diagnosis) in the past?			
Yes	64.00%	126	
No	36.00%	71	
		197	answered question
		1	skipped question
7. How were you misdiagnosed in the past? (Sample of comments provided below in italics.)			
		97	answered question
		101	skipped question

Diagnosed as having depression, when bipolar disorder is correct diagnosis (most frequent answer)

S.A.D. and depression were diagnosed first and second. Then diagnosed with insomnia. Ultimately diagnosed with Bipolar Disorder.

I am not sure. I have so many labels, all of them cannot be right.

They failed to treat or diagnosis PTSD

I was told that there was nothing wrong with me.

First, Was told there was nothing wrong with me, then diagnosed with multiple personalities, took 3 years to figure out that I have bipolar

In the past, I have been told I had depression when I actually had serious physical health issues. Also, almost all of my previous mental health providers have evaluated my mental illness as far less serious. Most start with a diagnosis of anxiety or depression. It generally takes weeks/months for them to realized that I am dealing with significant, debilitating bipolar II. I think b/c I don't present myself as a dramatic, falling apart, total mess (ie even w/ the illness I try to put my best foot forward) I am often underdiagnosed. I also think this again relates to being a Black woman as well; we tend to be a proud population. We hold it together until we break. The medical community needs to be better educated on how some patients with same illness can present different symptoms as a result of varying cultural norms. Black women just are not as likely to present themselves as the classic "damsel in distress."

Failed to recognize my Traumatic Brain Injury, another time I would have been diagnosis as an alcoholic

I was diagnosed with Borderline Personality Disorder solely based on the fact that I was a self-injurer/cutter. Seeing a different mental health professional, who did an honest and complete assessment on me, informed me that I was not Borderline, and that the only criteria I met was the self-injurer symptom. I was told that I was just depressed and everyone feels sad sometimes and it will pass.

ADHD

My depression was diagnosed as hystionics

Too often I have been diagnosed based upon the presenting symptoms instead of the overall history. A former PCP refused to see my depression as a symptom of fibromyalgia in which he did not believe. Once I went to a rheumatologist who dealt with me as a whole person, my treatment improved and depression has almost completely resolved.

8. What type of health care provider misdiagnosed you in the past?

Psychiatrist	67.30%	72	answered question skipped question
Primary Care Physician (family physician, internist, OB/Gyn, etc.)	26.20%	28	
Talk Therapist	6.50%	7	
Other (Sample of comments provided below in italics.)		20	
		101	
		91	

Psychologist

Neurologist

All of the above

When a new dr. comes in i'm diagnosed different

Psychiatric nurse practitioner

Public psychiatric hospital

9. Many factors can lead to an incorrect psychiatric diagnosis. Some are listed below. Please select all that you think might have played a part in your misdiagnosis.

Other psychiatric illnesses (e.g. personality disorder, anxiety, etc.)	71.30%	67	answered question skipped question
Other medical illnesses	40.40%	38	
Substance use and addiction	19.10%	18	
Legal problems	8.50%	8	
Money problems	22.30%	21	
Type of insurance/No insurance	22.30%	21	
Discrimination (Race, gender, sexual orientation, etc.)	18.10%	17	
Other (Sample of comments provided below in italics.)		35	
		94	
		104	

Time of diagnosis (most frequent answer)

Was not aware of the depth of my symptoms and presented myself differently than I felt out of concern for a "bad" diagnosis. However, key, probing questions were not asked. Had they been, I'd like to think I would have volunteered more information.

Didn't spend enough time in evaluation - just sent me to a therapist

Intermediate testing with no quality control of plan and desired or expected improvement

Family dysfunction which due to cultural understanding we were not allowed to talk about problems at home. I was taught at a young age not to fully disclose feelings or agitation

Stigma--I was not as candid and honest as I should have been, mostly because I did not want to be a psychiatric patient. Mostly, however, I was not asked the questions about moods in a way that I would understand them and answer them.

Bad facilities and lack of direct contact between patient and psychiatrist. The diagnosis depended on student nurses, observation and notes.

Simply too adhered to the DSM IV and unwilling to deviate even slightly.

Isolation & loneliness-->

CHAOS IN THE CHURCH OF SCIENTOLOGY

Not caring enough to ask the right questions. And trying out the latest medicines on the market and

"Of course someone with as many kids as you must be depressed" (had 3 at the time I heard this). "Most stay at home moms feel the way you do" "Well, you don't have anything to keep your mind occupied" and various other type comments from health care professionals.

Physician's indifference, teenager unable to articulate feelings.

Too often I've seen doctors just choose a diagnosis so that insurance would pay more money, or just to make it easier on themselves when it comes to admission in the hospital.

Treatment providers expect complacency and passivity, (especially back 8-10 years ago) from consumers.

10. How long was it between your misdiagnosis and your current diagnosis?

		105	answered question
		93	skipped question
	months	10	
	1 year	5	
	1-2 years	7	
	few	1	
	2 years	5	
	2-3 years	5	
	3 years	4	
	3-4 years	1	
	4 years	5	
	5 years	7	
	6 years	3	
	7 years	2	
	7 + years	3	
	8 years	2	
	8 + years	1	
	9 years	1	
	10 years	8	
	10 + years	3	
	11 years	1	
	12 years	3	
	13 years	1	
	14 years	1	
	15 years	5	
	16 years	2	
	18 years	1	
	20 years	6	
	20 + years	1	

	21 years	1
	25 + years	1
	27 years	1
	29 years	1
	30 years	1
	35 years	1
11. What effect did the misdiagnosis have on your life? (Sample of comments provided below in italics.)		
		101 answered question 97 skipped question
<p><i>It postponed the process of finding the right medications and interfered with my personal and professional life. Also, I would have rather gone through all the trials and errors (side effects) of finding the right meds when I was younger. Then again, I might have given up more easily... I had multiple hypomanic episodes. Went through a lot of money I didn't have or was supposed to be saved for my future. Was hypersexual and took many sexual risks. Had racing thoughts which made studying and working difficult. My misdiagnosis made life much more difficult, in that my medications weren't appropriate, I was confused about what I had and how to deal with it, and I feel that I wasted many years of my life Two failed marriages. Current marriage was in freefall. I had no explanation for the uncontrollable irrational, impulsive, sometimes violent behaviors That is hard to tell. I lost a couple of jobs because of my mood disorder. However, new medications weren't available either. I might not have had those positions in the first place I was hospitalized several times and attempted to take my life more than once.</i></p> <p>We don't have enough time or paper for this one. Time, talented, and opportunities lost and wasted. <i>Felt like someone was trying to label me and put me away for their own sake of organization - not willing to investigate the problem and get to know (about) me, my health status, my life position/situation and other influencing factors affecting my health. Caused a lot of confusion, home domestic abuse, wrong medication, anger at the system for not knowing what I was having problems with Borderline Personality Disorder has an enormous stigma attached to it. Mental health workers, seeing that diagnosis in my file, automatically treated me (in a condescending manner) based on the diagnosis alone, and not actually getting to know me. I was treated as less than a person, and my heart goes out to people who really do have Borderline Personality Disorder, because the stigma is entirely unfair, and often misconstrues the truth. It affected my personal life; relationships with my children, family and friends in very negative ways. I did not have any understanding of what was causing my extreme mood swings. DUE TO MISDIAGNOSIS MY DISORDER MAY HAVE BEEN PASSED ON TO MY CHILDREN Getting medicine that was wrong for my real illness had me so drugged up that I literally was out of my head. I do not remember things that happened, nor do I remember anything that I said or did. Lost my job, my home. I now live with my brother, who saved me from all this. I became very negative, very afraid to leave the house, would not see people that I knew, locked myself up in the house and stayed away from everyone. I continued to cycle but because the highs felt good I didn't realize I was Bipolar until I was in a manic state that cost me thousands of dollars. I lost contact with most of my friends and family. I still managed to keep it hidden from my current employer and co-workers.</i></p>		

It was very disruptive, especially when I had my first manic episode and everyone thought I was just being irresponsible

I was treated differently by care providers. Overmedicated. Undermedicated. Bilateral ECT for over 6 months that caused severe memory damage. Lost job, was in coma for 3 months, lost house and children to state. 5150, 5250, 5260, 5270. Stuck on disability with severe medical and psychiatric problems.

I felt hopeless, misunderstood, angry.....

None, I ignored it

*I have been fired from just about every job I have had. It has affected my ability to interact with people confidently; it has created suspicion and mistrust of other individuals I come in contact with... **Basically, the misdiagnosis has had a serious negative effect on my quality of life.***

A lot of shame, especially because of the very negative stigma Borderline Personality D/O has in the MH community. I used to work in the MH field, with mostly therapists. I remember the comments and jokes made about BPD patients that were made.

It made it very difficult for me to recover and function.

12. Have you ever changed health care providers for your bipolar disorder or depression?			
Yes	72.40%	134	answered question skipped question
No	27.60%	51	
185 answered question 13 skipped question			
13. Why did you change health care providers for your bipolar disorder or depression?			
I moved	33.10%	39	answered question skipped question
My insurance changed	38.10%	45	
I was unhappy with my provider	67.80%	80	
Other (<i>Sample of comments provided below in italics.</i>)		32	
		118	answered question
		80	skipped question
All of the above			
...financial reasons forced me to change			
<i>I've also had a high turnover in therapists at the local mental health center. They often leave due to burnout.</i>			
<i>My psychiatrist told me he could do nothing more for me</i>			
<i>The doctor left the practice</i>			
<i>Sometimes I just wanted another opinion for confirmation</i>			
14. Do you feel that your family (significant other, spouse, children, brothers and sisters, etc.) understands your illness and supports you?			
Yes	56.80%	104	answered question skipped question
No	43.20%	79	
		183	answered question
		15	skipped question
15. What type of insurance coverage do you have for your bipolar disorder or depression?			
Medicaid	18.70%	32	answered question skipped question
Medicare	25.70%	44	
VA (Veteran's benefits)	0.60%	1	
PPO	36.30%	62	
HMO	16.40%	28	
None	17.50%	30	

<i>Other (Sample of comments provided below in italics.)</i>			21 171 answered question 27 skipped question
<i>San Francisco Dept of Health: Richmond Area Mental health Services (I like them very much)</i>			
<i>OHIP</i>			
<i>Good coverage for medications. No coverage for counseling or Psychiatrist, thus my Primary Care Physician and I work out the medication program.</i>			
<i>Oregon Health Plan</i>			
<i>AARP Supplement</i>			
<i>Mass Health</i>			
<i>I am living in Germany we have a must -health insurance</i>			
<i>HEALTH SYSTEM IN NEW ZEALAND</i>			
<i>It is a medicare advantage plan which is a PFFS.</i>			
16. Are you?			
	Male	23.60%	43
	Female	76.40%	139
			182 answered question 16 skipped question
17. How do you describe your ethnic background?			
	African American or Black	13.70%	25
	Latino or Hispanic	7.10%	13
	Caucasian or White	77.00%	141
	American Indian or Native Alaskan	5.50%	10
	Native Hawaiian or other Pacific Islander	1.10%	2
	Asian	1.10%	2
	Other		10
			183 answered question 15 skipped question
18. What is your current age in years?			
	under 18	4.90%	9
	18-25	3.30%	6
	26-35	18.10%	33
	36-50	39.00%	71
	51-65	29.70%	54
	over 65	4.90%	9
			182 answered question 16 skipped question