

PATIENT PERSPECTIVES ON PROVIDER COMPETENCE: A VIEW FROM THE DEPRESSION AND BIPOLAR SUPPORT ALLIANCE

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“In theory, there is no difference between theory and practice. But, in practice, there is.”

—Jan L.A. van de Snepscheut, Educator (1953–1994)

Health care providers want the very best for the patients they treat, and spend years studying treatment and keeping their medical knowledge current. But how providers put this knowledge into practice, more often than not, has a greater impact on outcomes than the knowledge itself.

The Depression and Bipolar Support Alliance (DBSA) is a national patient-directed advocacy organization. Our mission is to improve the lives of people living with depression and bipolar disorder. DBSA is committed to empowering patients and their loved ones to become partners with their health care providers. This empowerment is achieved through education, improved communication, and setting wellness goals agreed upon by both health care provider and patient.

In 2003, more than four million people, including patients, their loved ones, and providers asked for help from DBSA. The challenges these people struggled with revealed some basic but significant factors that are crucial to recovery for all people receiving mental health care.

For optimum recovery, three factors must be in place: communication that is clear, thorough, and collaborative; treatment plans that include patient input, preferences, and needs; and recovery-oriented treatment that instills hope.

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CLEAR, THOROUGH, AND COLLABORATIVE COMMUNICATION

DBSA believes the responsibility for quality communication lies with both patients and providers. We know that a disconnect in communication and perception often exists between patients and providers. It is critical for both parties to work together to eliminate this disconnect for the best possible treatment outcomes.

Patients and advocates understand that it is not easy for physicians to take the time they would like, given the unreasonable time constraints of a typical appointment. However, patients have the best chance to recover when they can talk and feel they are being heard. Two-thirds (66%) of DBSA constituents stated in a 2003 online survey (DBSA, 2003) that they would like their psychiatrists to listen better. Depression and bipolar disorder are illnesses of isolation. As such, they cry out for conversation. To be truly effective listeners, providers who have not struggled with mood disorders must understand how the world looks through the patient's eyes.

Empowerment is achieved through education, improved communication, and wellness goals agreed upon by both provider and patient.

To measure listening acumen, health care providers should ask themselves questions such as:

- Do I understand how severe the pain of waiting for a medication to work can be? While it does not make sense, do I understand why the temptation to stop taking medication before it becomes fully effective is so strong? Do I understand how frustrating the words “give it time” can be?
- Do I understand the impact of changing treatment plans repeatedly? Do I realize the way each treatment that hasn't worked can erode hope?
- Does it make sense to me that a patient would often prefer to stop taking a medication and risk acute symptoms rather than gain 50 pounds?
- Do I know how patients feel when, after years of treatment, their healthcare providers still appear to know little or nothing about their lives beyond their illness? Do I know what they want from treatment beyond symptom reduction?
- Do I see my patients as individuals with families, lives, hopes, and needs, or do I regard them as symptom clusters, test scores, and diagnoses?

- Have I ever asked my patients how they would like me to interact with them and their loved ones?

Treatment satisfaction is directly linked to patients' understanding of the important issues pertaining to their treatment. In a study of 881 primary care doctors and 1000 patients with depression (DBSA, 2000), more than 40% of patients who were very dissatisfied with their primary care physician's treatment said they left their appointments with a less than adequate understanding of these issues. Conversely, 75% of patients who were very satisfied with their treatment said they fully understood what their treatment entailed.

In a 2003 DBSA online constituency survey, when patients were asked, "Does/did your physician explain your *disorder* to your satisfaction," nearly half (43% of those treated by a psychiatrist, and 47% of those treated by a primary care doctor) said no. When patients were asked whether their physician explained their *treatment* to their satisfaction, again, nearly half (44% of those treated by a psychiatrist, and 43% of those treated by a primary care doctor) said no.

Many factors influence productive health care provider/patient conversations. Patients' symptoms affect their perceptions, ability to listen, and understanding of treatment. Providers' time constraints and full practices affect their attention to individual patients. But the cause of the disconnect matters much less than what can be done to rectify the situation.

These findings suggest that patient education is an important unmet need. DBSA encourages patients and their families to get answers to all their questions and concerns from their physician, therapist, or other health care practitioner in the office, and not to leave their appointment until all their questions and concerns are addressed. DBSA reminds health care providers to share information in language that patients can understand, and to ensure that patients have understood this information by asking them to repeat it in their own words, encouraging them to write things down, and/or providing written materials free of medical jargon. These materials should address the patient's real life concerns, in addition to the medical facts about their illness.

TREATMENT PLANS THAT INCLUDE PATIENT INPUT, PREFERENCES, AND NEEDS

Once patients fully understand how their treatment is progressing and what options are available to them, they need their providers to include

them as their partners in making treatment decisions. This can succeed only if providers believe that patients have the most complete understanding of their own illness and the impact that the illness and its treatment have on their lives.

Two-thirds stated in a 2003 online survey that they would like their psychiatrists to listen better.

Patients want to be involved in making and implementing treatment choices. In DBSA's 2000 primary care study, more than two-thirds (70%) of patients reported that they would prefer to discuss all treatment options and decide the best plan of action jointly with their physicians. Nearly three-quarters of the physicians (71%) reported that they discussed all treatment options with their patients. Yet a serious disconnect exists, as only one-third of patients (36%) reported that their physician asked about their preferences or willingness to tolerate certain side-effects before deciding which antidepressant to prescribe. In addition, only 54% of the patients responded that their primary care physicians discussed options with them, and that the best course of action was jointly decided. Most disturbing, the survey showed that the physicians of approximately one-quarter of the patients prescribed a treatment the patients did not prefer. The disconnect is obvious: the majority of physicians believed that they discussed all treatment options with their patients, yet only about half of the patients believed that this discussion occurred.

To determine the level of patient input into treatment, providers should ask themselves questions such as:

- Do I believe my patients have the best understanding of their illness?
- Have I explained the full range of treatment options available? Do I include my patients in treatment decisions?
- Have I told my patients what results, both positive and negative, might occur with each method of treatment? Do I know my patients' preferences with regard to side effects?

RECOVERY-ORIENTED TREATMENT THAT INSTILLS HOPE

The mental health advocacy community defines "recovery" as both a process and an outcome. Physicians are trained to think in terms of out-

comes, that is, the goal of treatment is the reduction or elimination of symptoms. Recovery goes far beyond this outcome. A. Kathryn Power, Director of the Center for Mental Health Services in the Substance Abuse and Mental Health Services Administration, defines recovery as, “The processes by which people are able to live, work, learn, and participate fully in their communities. [These processes include:] the ability to live a fulfilling and productive life despite a disability, a reduction or complete remission of symptoms, [and] the ability to make important decisions affecting one’s own life.”

When a practice is oriented toward recovery, the patient is seen as a partner in care, offered real and meaningful treatment choices, and assisted in setting and implementing life goals.

DBSA educates patients and their families to seek wellness—full, well-rounded, productive, and satisfying lives, not just a cessation of symptoms. Wellness and recovery aren’t easy to define. Patients have their individual definitions and these definitions change as wellness progresses. Providers must understand their patients’ concepts of wellness in order to make certain objectives which are attainable and beneficial life goals. Patients and health care providers must agree upon wellness goals in order for there to be an understanding of how the treatment will affect the patient and what the overall results will be.

A recovery-oriented practice is based upon mutually agreed goals. The patient believes wellness is possible, regardless of the severity of symptoms, because the provider instills hope and the belief that wellness is possible. Hope is critical to recovery from all illnesses, but is particularly important to the treatment of illnesses that affect patients’ thinking, behavior, and self-perception. Years of misdiagnosis, under-treatment, or incorrect treatment that lead to devastating life consequences can leave patients with little hope. They often internalize society’s stigma, and they blame themselves for their illnesses. They may believe that treatment does not work. Messages of hope and reassurance from care providers have a great deal of power to improve outcomes. On the other hand, those who feel their health care providers have given up on them are far more likely to give up on themselves and their treatment.

Living with a mood disorder can be a daily struggle. This struggle can be exhausting and demoralizing, and patients need to know they have help and support in the fight. So often, the symptoms of mood disorders leave patients ill-equipped to maintain relationships. They need people, especially health care providers, to emphasize that they are not at fault and that they deserve the best possible quality of life. They need to know that their providers believe they can recover and will continue to work with them until they reach wellness.

75% of patients who were very satisfied with their treatment said they fully understood what their treatment entailed.

Loss of hope can be powerful enough to lead to loss of life, the worst possible outcome. As one family member put it:

We were all huddled around my sister's bed in the hospital. Her doctor pulled my father aside and told him that most frequently people with bipolar II disorder end up killing themselves. I watched my family as one by one my father took each person aside and solemnly told them this news. I watched as the hope they were holding onto so tightly was extinguished from their faces. I watched my sister too, and though nobody said a word about what the doctor had said, I could literally see the fight go out of her in that short half hour of time. Being the good and obedient daughter she had always been, she killed herself a few weeks later (E-mail to DBSA, 2004).

Could this suicide have been prevented with communication, collaboration, and hope? We will never know. What we do know is that patients who live through the worst episodes of their illness say that these three factors helped keep them alive. These factors, in their view, are key elements of provider competence.

The implementation of collaborative, wellness-focused treatment plans builds on the recommendations of the Surgeon General (U.S. Department of Health and Human Services, 1999), the President's New Freedom Commission on Mental Health (2003), and the U.S. Center for Mental Health Services (2003). A wellness orientation can be as simple as encouraging patients to think independently, or as comprehensive as reorienting a treatment plan to build recovery goals and strategies. Ultimately, patients are asking providers: "Please work *with us*; not *for us*, not *in our best interest*, and not *on our behalf*, but truly *with us*, so we can live full and rich lives." This would be a practice that both patients and providers could truly celebrate.

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