

Linking scientific research to the bipolar consumer patient

June 5, 2022

In 2017, the National Institute of Mental Health (NIHM) funded \$96 million toward research on bipolar disorder (BD). \$90 million went toward basic clinical research, while approximately \$6.28 million was delegated to pharmacological and psychotherapeutic treatment research. Researchers utilize these funds to learn such things as neurobiology, epidemiology, physiology, biochemistry, neuropathology, phenomenology, and genetics of BD. But where do the actual patients fit in? When it comes to understanding what is going on in current studies about their disorder, patients are left in the dark. The gap between research on BD and patient knowledge is wide. Psychoeducation is one treatment method that is not used often enough for bipolar patients, but even with psychoeducation, the patient is probably not learning about the results of cutting-edge studies and what they mean for the future of BD treatment.

It is our standpoint that the bipolar patient is the expert on their subjective experience with their disorder and that they can make valuable members of their treatment team if they are more informed. Patients become more self-aware and can become better at talking about their symptoms with their doctors when they are educated. We believe that knowledge empowers the patient and gives them the confidence to make better choices regarding their treatment. We now know that psychoeducation can reduce the frequency of new episodes, shorten the length of hospital stays, and promote greater adherence to medication regimens. However, we believe that the psychoeducation patients receive is limited and falls far behind what researchers currently understand about the disorder.

The benefits of psychoeducation are discussed to demonstrate the positive effects of educating patients. We propose a method in which researchers can bridge the gap between the academic study of BD and the bipolar patient population.

1 | DIRECT-TO-CONSUMER ADVERTISING

One avenue patients' have to learn about their disorder is through Direct-to-Consumer (DTC) advertisements. The average TV viewer views approximately about 20h of advertisements per year. The United States and New Zealand are the only two countries that fully permit this practice, spanning television, print media, radio, and online media. DTC advertising is clearly a large component of where consumers are learning about medications and their illnesses. DTC ads in the United States include the symptoms of the disease (either

a newly established disease or an older disease) plus the name and side effects of the drug. People learn about their own conditions through consuming DTC ads. Although the FDA prohibits DTC ads to advertise off-label indications although they are often still used. Psychiatric drugs comprised three of the five most advertised classes of medication and were among the first drugs to attain "blockbuster" status.¹ Clearly, people are learning about drugs from DTC ads, and they are also learning about their condition from the ads. "Talk to your doctor about your 'X'" has become the standard tagline. The question is, are patients getting information from DTC the best way?

An FDA report, released in 2004, said this, "DTC ads help patients have better discussions with their physicians and provide greater awareness of treatments." The study demonstrated that when a patient asked about a specific drug, 88% of the time they had the condition that the drug treated. 80% of physicians believed their patients understood what condition the advertised drug treats. So, physicians think that DTC advertising is sufficient to talk to patients about their disorders and encourages patients to ask their doctors. Furthermore, wherever you stand on the DTC controversy, and it is a controversy, it is imperative that consumers receive a balanced view of their condition and possible treatments. Seeing an ad and talking to their doctor are two good ways, but people learn about their conditions in other ways, as well. Griffiths (23017) found that Internet Support Groups (ISGs) assist in recovery and have been proven to be affective against depression.² ISGs typically are run by medical consumers, in this case, people with BD or other mental health conditions, although ISGs exist for a multitude of mental and physical health conditions. As useful as ISGs are, and as helpful as DTC ads can be, would not it be great if we could combine DTC ads with ISG? In other words, is there a way to combine scientifically valid information, which is not always present in ISGs, with the support group feeling of an ISG? This is where Research and Conversations about Bipolar Disorder Inc comes in, a non-profit run by people with BD and schizoaffective disorder (SZA) that aims to filter and translate scientific information on the disorder to the layperson. This combines the best of DTCs and ISGs peer-to-peer support armed with scientific knowledge.

2 | DOCTOR-PATIENT RELATIONSHIPS

One of the key components of the doctor-patient relationship is educating consumer patients about their condition, and consumer-to-consumer information-sharing groups like the one proposed here in

this paper are not meant to supplement this doctor–patient relationship. For example, patient information leaflet (PIL) is an important component of providing information to consumers, but the information contained in may be too complex for a consumer to understand. Face-to-face interaction with the doctor is essential, but PILs allow to think over their options on their own time and gives them time to reflect on what the doctor said. Written summary after-care for a lay audience has been found to be helpful in the doctor–patient relationship.³ One wonders if doctors are having conversations with patients about healthy lifestyles with BD. We suspect that provider–patient discussions regarding healthy lifestyles are sometimes lacking. Patients have found that these aftercare summaries help them remember these if more serious conversations, such as discussions regarding a healthy lifestyle when one has BD can happen as well. Doctors may not always have the time or the ability or the desire to communicate about a patient's medical problems. This leaves a gaping hole for organizations such as Research and Conversations About Bipolar Disorder Inc to fill the gap that patient–doctor communication is not always addressing. For example, in a study concerning what patients know about ECT (electroconvulsive therapy) before undergoing it for bipolar treatment, it was found that most women felt powerless and were not informed of the risks of ECT. Women felt powerless and victimized by ECT, a treatment occasionally used in the treatment of treatment-resistant bipolar depression.⁴ A gap such as this could easily be remedied by providing patients with understandable, non-biased, accurate information regarding bipolar treatment such as ECT. One study about BD found that patients who had formal education about lithium treatment were 85.6% more likely to adhere to medication compliance⁵ which is significant considering non-adherence rates in BD treatment for long-term prophylactic pharmacotherapy range from 18% to 52%, with a median prevalence of 44.7%.⁵ This study in particular demonstrates how patient knowledge can directly impact medication compliance, which is crucial in BD to prevent future episodes. Overall, the data suggest that patients are not getting adequate knowledge from their physicians, either that the information is too complex for the patients to understand, or it is flat out misleading. The study by Rosa et al.⁵ is particularly important because it shows the efficacy of patient education on medication compliance outcomes.

3 | PATIENTS' PERSPECTIVES

Patients are not experts on the study of BD, but rather, experts on the subjective experience that only those who fall on the BD spectrum can relate to. The controversy between researchers and pediatric bipolar disorder is just one instance. There is, without a doubt, a wide gap between research on BD and the bipolar patient population. To remedy this gap, we suggest that researchers and clinicians attempt to close the gap by teaming up with patients to provide a better understanding of their disorder. We believe that when patients are more informed about their disorder, they are better equipped to help their treatment team establish appropriate pharmacological and psychotherapeutic interventions.

But how do we do this? One organization is at the forefront of this movement to bridge this gap to help patients become better acquainted with their disorder. Research and Conversations About Bipolar Disorder Inc. is a non-profit organization in the state of Maryland that offers an online platform that shares and interprets current research on BD to patients. They also provide guest speakers at the forefront of BD research to discuss recent articles they have published. They also have monthly psychoeducation seminars such as teaching people how to read academic articles. We have found that the more informed patients are about their disorder, the more they are able to collaborate with their clinicians for enhanced treatment and become better self-aware of their own disorder.

CONFLICT OF INTEREST

The author declares that there is no conflicts of interest to report.

DATA AVAILABILITY STATEMENT

No data are available for this editorial.

Katrin I. Kutlucinar¹ 

Kathryn Burrows²

¹Research and Conversations About Bipolar Disorder Inc.,
Kensington, Maryland, USA

²Portland State University, Portland, Oregon, USA

Correspondence

Katrin I. Kutlucinar, Research and Conversations About
Bipolar Disorder Inc., 4108 Wexford Drive, Kensington, MD
20895, USA.

Email: katrin.bcn01@gmail.com

ORCID

Katrin I. Kutlucinar  <https://orcid.org/0000-0002-0352-5983>

REFERENCES

1. National Institute for Health Care Management and Research and Educational Foundation. Prescription drugs and mass media advertising. NIHCM. 2001. Accessed June 5, 2022. <http://www.nihcm.org/DTCbrief2001.pdf>
2. Griffiths KM, Mackinnon AJ, Crisp DA, Christensen H, Bennett K, Farrer L. The effectiveness of an online support group for members of the community with depression: a randomised controlled trial. *PLoS One*. 2012;7(12):e53244. doi:10.1371/journal.pone.0053244
3. Crucefix AL, Fleming APL, Lebus CS, Slowther AM, Fritz Z. Sharing a written medical summary with patients on the post-admission ward round: a qualitative study of clinician and patient experience. *J Eval Clin Pract*. 2021;27(6):1235-1242. doi:10.1111/jep.13574
4. Ejaredar M, Hagen B. I was told it restarts your brain: knowledge, power, and women's experiences of ECT. *J Ment Health*. 2014;23(1):31-37. doi:10.3109/09638237.2013.841870
5. Rosa AR, Marco M, Fachel JM, Kapczinski F, Stein AT, Barros HM. Correlation between drug treatment adherence and lithium treatment attitudes and knowledge by bipolar patients. *Prog Neuropsychopharmacol Biol Psychiatry*. 2007;31(1):217-224. doi:10.1016/j.pnpbp.2006.08.007