

Bad on the net, or bipolars' lives on the web: Analyzing discussion web pages for individuals with bipolar affective disorder

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Abstract

OBJECTIVE: The main therapeutic approach in the treatment of bipolar affective disorder is the administration of drugs. The effectiveness of this approach can be increased by specific psychotherapeutic interventions. There is not much knowledge about self-help initiatives in this field. Anonymous internet communication may be beneficial, regardless of the fact that it is non-professional. It offers a chance to confide and share symptoms with other patients, to open up for persons with feelings of shame, and to obtain relevant information without having a direct contact with an expert.

METHODS: Qualitative analysis of web discussions used by patients with bipolar disorder in Czech language was performed. Using key words “diskuze” (discussion), “maniodeprese” (manic depression) and “bipolární porucha” (bipolar disorder), 8 discussions were found, but only 3 of them were anonymous and non-professional. Individual discussion entries were analyzed for basic categories or subcategories, and these were subsequently assessed so that their relationships could be better understood.

RESULTS: A total of 436 entries from 3 discussion web pages were analyzed. Subsequently, six categories were identified (participant, diagnosis, relationships, communication, topic and treatment), each having 5–12 subcategories. These were analyzed in terms of relationships and patterns.

CONCLUSIONS: Czech discussion web pages for people suffering from bipolar disorder are a lively community of users supporting each other, that may be characterized as a compact body open to newcomers. They seem to fulfill patients' needs that are not fully met by health care services. It also has a “self-cleaning” ability, effectively dealing with posts that are inappropriate, provocative, criticizing, aggressive or meaningless.

INTRODUCTION

Bipolar affective disorder (BAD) is a chronic disabling and often life-threatening condition affecting approximately 1 out of 25 individuals in the population (Kessler *et al.* 2005). It belongs to ten most disabling diseases (WHO 2001). For bipolar patients, pharmacological and biological treatments have been developed, currently representing the main therapeutic approach (NICE 2006). Despite important advances in psychopharmacological treatment, numerous patients remain symptomatic between episodes of the disease, many others discontinue their medications or relapse in spite of adequate pharmacological therapy (MacQueen *et al.* 2003, Latalova *et al.* 2012). The effectiveness of biological approaches to therapy may be significantly increased by psychosocial interventions such as psychoeducation and psychotherapy (Scott *et al.* 2007, Praško *et al.* 2013). Although these approaches were usually developed using quantitative research methods, they may not cover some important needs of bipolar patients if results were obtained by physicians' evaluation based on structured interviews or scales (Latalova *et al.* 2014). These patients' needs may be better understood by studying their spontaneous utterances on patient web pages.

An incentive for the survey was the fact that at our department, an internet psychoeducational program called e-PROBAD has been tested, currently involving 50 bipolar patients. The program has been created based on previous research into bipolar patients' problems and needs (Praško *et al.* 2013). Now, it is also important to determine whether the program covers all essential needs of patients (the lived world); it may be that certain needs, commonly not communicated by patients, appear in their mostly anonymous communication on discussion web pages. It was assumed that bipolar patients need to share their needs and experiences with other individuals having the same disorder. Anonymity may allow them to communicate in a way different from non-anonymous communication.

The qualitative research aimed at mapping topics and needs of persons holding online discussions on BAD, identifying the main topics, patterns of interaction and written communication, topics leading to reactions and responses, and determining to what extent the responses correlate – or do not correlate – with expert opinions. Such a qualitative survey may enhance health professionals' perception of patient needs and experiences and contribute to improvement of treatment programs. The basic questions asked at the beginning of the survey were as follows:

1. What is the benefit of web discussions to persons suffering from BAD?
2. What is their meaning to them?
3. What do people communicate? What sort of information?
4. Are there any detectable patterns of mutual communication in the interactions?

5. Who enters the interactions?
6. Is there an apparent sense of entries depending on who enters?
7. Do individual participants assume some typical roles?
8. If yes, how?
9. Which types of entries provoke responses or discussions and which do not, that is, are ignored?
10. Which entries are longer and which are shorter?
11. Which entries are acceptable for others and which are less acceptable?
12. What attitudes do participants have to each other? How can this be determined?
13. Are there also references to information, apart from mutual interactions?

METHODS

The following Czech key words were selected based on clinical relevance and entered into the internet search engine Google.cz: “diskuze” (discussion), “maniodeprese” (manic depression) and “bipolární porucha” (bipolar disorder). As of 11 March 2014, the search engine provided a total of 12,100 results. Subsequently, links to articles, books, reviews, professional discussions, TV programs, etc. were excluded. As a result, eight candidate discussion web pages were selected. Of those, five were not anonymous and lay and thus were not included. Therefore, three anonymous and non-professional discussion web pages were selected for the final analysis.

Individual discussion entries were printed and read through by three psychiatrists. Separately, they intuitively determined basic categories and subcategories that were discussed afterwards. Following the final definition of categories and subcategories, content analysis of individual entries was performed to evaluate their presence and relations.

RESULTS

A total of 436 entries from 3 discussion web pages were analyzed. When reading through them, various areas suitable for analysis gradually emerged that were categorized into six main topics (see the Table 1).

Participants

The first distinct category was that of participants, comprising both patients, most commonly involved in discussion throughout the analyzed web pages, and family members, especially patients' partners or parents, mostly asking about treatment experiences and possible help. Patients themselves prevailed significantly, usually assuming the same roles in discussions. A frequent role was a “questioner”, defined as someone trying to get some information from others. Questioners described their symptoms to find out if they have BAD, asked about similar experiences and

Tab. 1. Categories and subcategories.

CATEGORIES	SUBCATEGORIES
Participant	questioner, responder, expert, comforter, adviser, relative, troll, healer, moralist, loner, star, non-belonger
Diagnosis	symptoms, identification, mutual diagnosis, rejection
Relationships	acceptance, support, closeness, detachment, non-acceptance
Communication	questions, story, sharing, comfort, advice, encouragement, empty talk, rejection, criticism, heroic epic, expert's report, cross-references
Topic	sex, death, childhood, partner, alcohol, symptoms
Treatment	hospitalization, outpatient ward, doctor selection, psychologist, drugs, recommendations

sought information about therapy, medication and its side effects. „Hi, I have bipolar d/o; I'd like to know what drugs you use and what experiences you have with them and, generally, what life with bipolar d/o is like.” A smaller proportion of questioners were relatives or friends, mostly inquiring about how to treat their relatives whose behavior is suggestive of mental illness. They asked if it was BAD or not. „Hello, I urgently need advice. My friend had some sort of an attack on three consecutive days.” They usually were responded to rapidly, often immediately. If responders did not know the answer they referred questioners to the main authority of the web page who may be called a “star”. Among the stars, there was the “star of all stars” to whom also participants in discussions on other web pages referred whenever they did not know the answer. The star of all stars was a participant acknowledged by others as being an expert. He analyzed all difficult questions, gave advice, described his experiences, referred to textbooks and texts in which information could be found but mostly dealt with questions himself. „If you would like to correspond ask Martin whether he is willing to do so.” “Martin, let me ask you, did you have any BAD symptoms as a child?” Apart from the star, there were several “advisers” on each server, giving advice on less difficult issues and sharing their own experiences with similar situations and how they coped. They often reacted more readily than the star, as if some adviser was always online. If the star considered some answers insufficient, he or she usually added his or her own contribution. “P: I've just read in the book that on average, lithium is used for 2 (!) months...” “M: That is an error (2 years), that's not possible!” The star apparently suffered from BAD symptoms as well. This created a sense of authenticity without decreasing the star's importance. Interestingly, the star did not appear to be aggressive. His or her recommendations were presented clearly and with good grace, in an unobtrusive way. The star did not reproach advisers for providing insufficient or incomplete answers and just joined them. Sometimes, the advisers also assumed roles of “comforters” if they noticed someone suffering or having a problem. “OK, so you don't want to analyze that. Just write how your kids are and how you are enjoying your holidays.” However, some comforters were not advisers and rather affirmed

their fellowship. They empathized, stated their experiences and encouraged hope for improvement. Apart from the star and advisers, an “expert” came in, providing information gained not from his or her experiences but by reading them somewhere. The group did not seem to be disturbed by these entries but it was not tempted to react much either. “Here is what I have read... BAD I – the presence of mania; no risk of rapid cycling; BAD II – mania not present (only hypo); a risk of rapid cycling; women are more likely to be rapid cyclers...” Very rarely, a “troll” appeared, an outsider not having a common BAD experience with the others but criticizing someone or even the entire group. However, trolling did not stimulate activity of the others; they let it wane, unnoticed. “Filip: relax, do not react to such posts.” If attempts at trolling were more massive and intensive, the discussion came to a halt for as long as several days and resumed as if it had never been disturbed, that is, the problem resolved itself. Rare entries were noticed that were made by individuals in a role of “healers”. They mostly offered alternative approaches or hypnosis. However, these posts were left without comments from the community. “If someone taking drugs against depression for years and fighting and fighting were interested in alternative treatment based on an approach completely different from psychiatric, write to me at...” On one occasion, a “researcher” appeared, asking them to fill in a questionnaire to be used for her thesis. Her thanks expressed some time later suggested that she actually had sent several questionnaires to the participants, some of whom had responded. Rarely, someone assumed a role of a “moralist”, mostly producing no reaction. Rather, comforters empathized or identified with those who were criticized. An interesting reaction occurred when the star disclosed that he or she was suffering when feeling down or hopeless. This stimulated activity of the entire community that empathized, raised hope, provided support; but nobody dared to give advice. If the star did not reappear for a long time, the community was curious. “Hi, hope everyone had a great Easter. Martin, how are you? Hello Martin, I'm glad to hear from you. If you feel like talking, send me an email.” They discussed the fact that they had not heard from the star. Interestingly, though, there were no posts doubting that the star would return.

Diagnosis

This category was relatively frequent. Discussion participants knew about their diagnosis and identified with it; most of them were able to cope with the fact. Significantly fewer participants usually had no doubts about having mental illness. Most of their questions aimed at finding the accurate diagnosis, the BAD I and BAD II subtypes, and potential confusion with schizoaffective disorder. The discussion was also joined by participants identified with borderline personality disorder who saw features common to both disorders, in particular emotional instability. *"Thank you very much for the posts. I have read a little about that BPD and I would almost say that it may be something like that. I have always had sort of mood swings but now it's really far from normal."* Questions were also asked about associated diagnoses, in particular psychoactive substance (marihuana) or alcohol abuse. *"Hi... depression today... treated with wine."* Participants identified with the diagnosis mainly asked about drugs, experiences with them and the adverse effects. They shared information about symptoms and experiences with various phases of the disease and identified with the group through the diagnosis. Identification through the diagnosis and symptoms appeared to play an important role in the group's solidarity and mutual understanding. It seemed to facilitate openness and confidence as well as confiding and sharing that produced friendliness and intimacy of the entire group. *"It is like that in my case. In my BAD II, phases really are shorter and therefore cycling is more rapid."* Diagnosing each other was less frequent. Participants were rather reserved, usually recommending a consultation with a doctor. When someone confided symptoms that – in the others' opinion – were clearly not associated with BAD, he or she received neutral information from an adviser that the diagnosis was likely to be different. But he or she was not rejected because of a different diagnosis. *"A person with psychosis and a lack of insight cannot be viewed as an adult thinking human being but as an ill person detached from reality... so you'd better shut up, Julia... you may just hurt someone."* Occasionally, the diagnosis as such was rejected in a post. There was only a tolerant reaction to it but no other interactions. Sometimes, "loners" appeared who only disclosed some information about themselves but did not interact with others.

Relationships

Interpersonal reactions showed very good relationships, helpfulness, acceptance, support and, frequently, intimacy of opening up. Participants often remembered earlier posts of an individual and his or her "life on the web", referring to what he or she had written. They often communicated about personal matters, partners, current conflicts and successes, holiday plans and experiences. *"Hello Martin, I've just come back from a fantastic holiday and now it may freeze here in the Czech Rep. :o) How are you? Hope everything's OK!"*

Detachment could be observed in relation to trolls, moralists and other "non-belongers", i.e. those not belonging to the live community, both because of their style of communication and because they did not identify with the diagnosis and did not share personal matters about themselves. However, we did not come across a case of someone being rejected based on his or her post.

Communication

Several means of communication were observed. These included questions, as mentioned above, concerning symptoms, therapy and its adverse effects, as well as more personal questions such as those on how participants felt and on someone who had not been heard of for a long time; that is, questions showing interest. *"Hell, there's nothing going on here. Is that good or bad? :-)"* Another communication type was a story of participants giving an account of their experiences, sometimes even pieces of their past lives; in fact, they opened up to others. Apparently, stories were popular as they allowed to share similar experiences, things they understood, reactions to similar situations in the past, etc. Sharing both a common fate and typical experiences seemed to strengthen interaction and feelings of fellowship and was thus frequent. *"I've been feeling well for some time, considering. I swallow my pills as I should and try (with a greater effort now) to stick to sort of a daily routine. Well, the last week's been a bit more difficult but it's too short a time for a discussion post."* Another type of communication was comforting someone not feeling well or in trouble. In such situations, advice and encouragement was noted; sometimes, once again, sharing similar experiences and one's own solutions. More complex situations usually led to an "expert's report" which was accepted from advisers and especially from the star, literature references or an incentive to visit a psychiatrist. *"Jana, you can't make it without drugs! Your psychiatrist must be kind of strange if he refuses to prescribe drugs – that is something I haven't heard of!"* Occasionally, something that may be labelled as "empty talk" was observed, that is, a slogan, incoherent speech or nonsensical statement. These mostly went unnoticed but not criticized or rejected. Criticism or rejection were extremely rare and could only be assumed where there was no reaction to a post. Also rare was a "heroic epic", with someone showing off or boasting excessively; once again, this was almost never commented on. *"When a psychiatrist makes a mistake. Basically, it is the same as when a surgeon makes a mistake and amputates your healthy leg instead of the diseased one."*

Topics

The most frequent discussion topics were BAD, its symptoms and therapy as well as treatment experiences. However, there were also topics such as childhood, parenthood, partnership, studies/career or lifestyle. These usually provoked a discussion, that concentrated on a

particular topic for as long as there were things to discuss. There, information, advice, shared experiences, expert opinions and references were mixed together.

Retrospective accounts of the development of symptoms were common, including the first symptoms in childhood such as anxiety, sleep disturbance or mood swings. "Kate: I definitely was not OK when I was a child. I remember severe anxiety attacks, waking up at night, hypochondriac thoughts, etc." Participants tended to compare themselves with their parents, describing their personalities, behavioral patterns, typical reactions and the general atmosphere in the family. It was not uncommon that they reflected on achievements and failures, recollect and describe various periods in their lives affected by the disease which had been unrecognized at that time. Commonly, there were statements such as "I was suffering like that for 10 years." or "At that time, no one thought it could be bipolar d/o." Participants usually appreciated their partners, claiming that it was difficult to live with them. On the other hand, bipolar patients' partners considered leaving their ill partners, shared their feelings of exhaustion, fear from unpredictable events and expressed doubts over the future. "If it were to continue in that way I'm not sure I would cope." Interestingly, fear from the future was only expressed by women (patients' partners); on the other hand, admiration and gratitude for help from healthy partners was stated exclusively by men. Moreover, men were the only participants boasting in discussions: "I've had bipolar d/o for 20 years; me and my wife have built a small house and raised two boys." However, it was apparent that irrespective of gender, participants had considerable respect for BAD, being aware of its potential consequences. Healthy female partners of bipolar patients were somewhat more pessimistic about the possibility of maintaining the partnership. Bipolar women were concerned about being able to do their jobs and lacking energy to raise their children. Neither engaged nor single women were worried that they would have to live without a partner or alone. Partners of female bipolar patients were not noticed in discussions or did not discuss. Bipolar men were not afraid of not having a job. As for raising children, they somehow automatically expected their partners to manage that. Engaged ones were not concerned about being left by their partners. But single bipolar males thought they would not find a partner at all or would be left by her soon after.

Lifestyle topics were less frequent than partnership, children and career. If they did appear, a significant impact of stress, fast working pace and having to work to deadlines was mentioned. Another negative impact of BAD on life reported in discussions was spending money in mania followed by financial difficulties. Overall, consequences of mania rather than depression were perceived as a menace, with participants describing arguments in the family and at work, conflicts with colleagues or threat to the position. Although depres-

sion was described as unpleasant, no accounts of its negative consequences were noticed. "Hi. I've had mood swings for five years but it was only this year that I realized that my spring mania had caused a whole heap of problems – debts, loss of job."

Treatment

This was made a separate category which was rather frequent and at the same time it aroused our professional interest. An important topic attracting interest was hospitalization. Experiences from hospital stays, both positive or negative, attracted attention. Interestingly, discussion participants never objected to hospital admissions, as if they understood that sometimes they were necessary. "I was hospitalized. It took about 3 months for my mania to subside and within one month, it switched to long-lasting severe depression." Other posts were concerned with physician selection, queries and information on differences between consultations with physicians and with psychologists. Important topics were also drugs, their evaluation, sharing experiences with drugs, dosages, drug combinations and adverse effects. Questions on drugs were usually answered by those having personal experiences with medications that were apparently long-lasting. "I also take, among other drugs, lamotrigine (the brand name Lamictal) at a dose of 150 mg and I'm very satisfied with it. I haven't noticed any side effects and since I started with it, I have been more stable than before." No case was noted of advisers, experts or stars warning against the use of drugs or recommending to avoid them. In fact, all the analyzed web pages stated that drugs were important if one wanted to remain in remission. Discussions generally clearly supported the use of psychopharmaceuticals. When side effects were discussed, these mostly included weight gain or sedation. Common phrases were "drug combination", "looking for a suitable combination" or "finding a suitable combination". When warnings were expressed, these were against combining medications with marijuana but not with alcohol. Alcohol-related warnings were noted in discussions on "self-treatment efforts" without the use of drugs. By contrast, combining medications with moderate doses of alcohol was declared as relatively safe.

DISCUSSION

Responses to questions

1. What is the benefit of web discussions to persons suffering from BAD?

Web discussions provide their participants with a chance to confide, to obtain additional information, to share their experiencing, to feel belonging to a group and fellowship, to learn from others, an opportunity to advise others, etc.

2. What is their meaning to them?

This is mostly a virtual community living its own life on web pages, in which the members have a place to belong and fulfill many human needs such as acceptance and help, safety, appreciation, encouragement or strengthening hope.

3. What do people communicate? What sort of information?

The communication is open, with numerous topics; prevailing information is on BAD, its treatment, drugs, adverse effects, impact on couple relationships, work and family.

4. Are there any detectable patterns of mutual communication in the interactions?

Numerous communication patterns are found on the web pages, from simple questions and answers to shorter stories, advice, experts' reports or sample solutions.

5. Who enters the interactions?

The most common participants are identified patients as well as their relatives and friends; less frequently patients with other diagnoses, rarely students planning to carry out research or persons offering alternative approaches to therapy.

6. Is there an apparent sense of entries depending on who enters?

The discussions suggest that their participants have a relatively clear idea of what they want to learn or share. Most of them enter the communication having certain knowledge of BAD. The content of discussions shows that they want to communicate their symptoms through experiences, frequently offering mini-stories and situations to demonstrate the presence of symptoms. Some participants seem to particularly benefit from describing symptoms in written form as they can think them through carefully or assign meanings that may be missed during common conversations with professionals. The key moment of discussions is probably the sense of sharing and confidence that any problem will be listened to and responded to in some way.

7. Do individual participants assume some typical roles?

Several stable roles have been identified such as an expert, adviser, comforter, analyst, referrer, troll, critic and stranger.

8. If yes, how?

Participants enters communication with a question, call for help, advice, etc. They usually stick to their roles and communicate using repeatedly similar communication patterns.

9. Which types of entries provoke responses or discussions and which do not, that is, are ignored?

Most frequently, participants are attracted by call for help, usually responded to by several individuals, followed by telling a story which tempts people to share similar experiences. They are also attracted by thoughts about the meaning of life and even about taking one's own life that usually mobilize the others.

10. Which entries are longer and which are shorter?

The longest entries were usually accounts of experiences with therapy and participants' own stories. Shorter was common information concerning drugs and adverse effects and reports of who is doing right now.

11. Which entries are acceptable for others and which are less acceptable?

The vast majority of them is accepted and responded to providing it is not trolling.

12. What attitudes do participants have to each other? How can this be determined?

The relationships are tolerant, helping, empathizing, caring for each other and showing interest.

13. Are there also references to information, apart from mutual interactions?

There are references to information on other web pages or professional literature. Interestingly, references to particular physicians or psychologists have not been noted.

The purpose and importance for patients

Without exaggeration, it may be said that on each analyzed server, a core self-help community was created, caring for the needs of its members, sticking with and supporting them, providing them with information on the diagnosis, symptoms and treatment and caring for their emotional experiencing. However, it was open to newcomers, offering them integration if they were identified as belonging to the group of bipolar patients.

An interesting finding was that no one was excluded from a discussion; if somebody entered it with a question or statement about oneself, he or she always got at least one answer. Another feature was generally considerable reciprocity, helpfulness, participants' non-stigmatizing approach to each other, willingness to empathize, help or share similar experiences. Most opinions were consistent with those of professionals. The community as a whole seemed to be aware of the latest information on BAD.

Potential suggestions for care

Discussion web pages may be recommended to bipolar patients as an environment where they may share their experiences and find their place in a community of contributors. Given the significant supporting role of discussion web pages for bipolar patients, it is advisable to establish such a web page directly as a part of a psy-

choeducational program for these patients, allowing a feedback on the program through mutual discussion.

Limitations

Any qualitative research is also affected by the observers' attitudes, necessarily reflected in topic selection, definition of categories and the way of interpretation.

CONCLUSIONS

When analyzing web page discussions for people suffering from bipolar disorders, a lively community of users supporting each other was discovered, that may be characterized as a compact body open to newcomers. Apparently, it fulfills many of the patients' needs that are not – and cannot be – fully met by health care services, in particular by having openly reflecting and helping functions, and thus promoting the participants' health.

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