

## Interaction between the patients with bipolar affective disorder and the outpatient team regarding medication therapy\*

*Interação entre paciente com transtorno afetivo bipolar e equipe ambulatorial quanto à terapêutica medicamentosa*

*Interacción entre el paciente con trastorno afectivo bipolar y el equipo de consulta externa en relación a la terapéutica medicamentosa*

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### ABSTRACT

**Objective:** To understand the interaction between the patients with bipolar affective disorder (BAD) and the outpatient health care team regarding medication therapy from the perspective of the patients and their family members. **Methods:** This was a grounded theory qualitative study using symbolic interactionism method. Fourteen patients with BAD from an outpatient clinic and 14 family members participated in the study. Interviews and participant observation were used to collect the data. **Results:** Three categories emerged from the data: identifying inaccuracy in the medication orientation, feeling the need of being welcomed by the health care team, and perceiving the need for individualize care. **Conclusion:** There is a need for the implementation of health care services that welcome patients and provide individualized care to facilitate coping strategies with the disease process.

**Keywords:** Bipolar disorder; Patient satisfaction; Drug administration schedule

### RESUMO

**Objetivo:** Identificar, na perspectiva da pessoa com transtorno afetivo bipolar (TAB) e de seu familiar, como ocorre a interação paciente-equipe de saúde relacionada à terapêutica medicamentosa. **Métodos:** Foi utilizada a abordagem qualitativa, com referencial metodológico da Teoria Fundamentada nos Dados, à luz do Interacionismo Simbólico. Participaram do estudo 14 pessoas com TAB de um serviço ambulatorial e 14 familiares. Para obtenção dos dados utilizou-se a entrevista e observação. **Resultados:** Os resultados revelaram três categorias que descrevem o referido processo de interação: identificando falhas nas orientações sobre medicamentos, sentindo necessidade de acolhimento pela equipe de saúde e julgando que o paciente deve ser avaliado na sua individualidade. **Conclusão:** Evidenciou-se a necessidade de implementação, nos serviços de saúde, de espaços de acolhimento como forma do paciente enfrentar seu processo saúde-doença.

**Descritores:** Transtorno bipolar; Satisfação do paciente; Esquema de medicação

### RESUMEN

**Objetivo:** Identificar, en la perspectiva de la persona con trastorno afectivo bipolar (TAB) y de su familiar, cómo ocurre la interacción paciente - equipo de salud relacionada a la terapéutica medicamentosa. **Métodos:** Fue utilizado el abordaje cualitativo, con referencial metodológico de la Teoría Fundamentada en los Datos, a la luz del Interacionismo Simbólico. Participaron del estudio 14 personas con TAB de un servicio de consulta externa y 14 familiares. Para la obtención de los datos se utilizó la entrevista y la observación. **Resultados:** Los resultados revelaron tres categorías que describen el referido proceso de interacción: identificando fallas en las orientaciones sobre medicamentos, sintiendo necesidad de acogida por parte del equipo de salud y juzgando que el paciente debe ser evaluado en su individualidad. **Conclusión:** Fue evidenciada la necesidad de implementación, en los servicios de salud, de espacios de acogida como forma de que el paciente enfrente su proceso salud-enfermedad.

**Descriptores:** Trastorno bipolar; Satisfacción del paciente; Esquema de medicación

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## INTRODUCTION

Bipolar Affective Disorder (BAD) is a chronic disease and it is the most severe form of mood disorder due to its recurrence<sup>(1)</sup>. The number of episodes during life is estimated at nine, on average, and 84% of patients present more than 5 episodes<sup>(2)</sup>. Thus, the occurrence of readmissions is not unusual.

BAD accounts for 5 to 15% of prolonged psychiatric new hospital stay, using considerable resources from health systems<sup>(2)</sup>. Compared to other psychiatric disorders, untreated bipolar patients are among those with high suicide risk, since up to 60% of Bipolar II disorder attempt suicide during the evolution of the disorder<sup>(3)</sup>.

Thus, treatment of bipolar disorders with mood stabilizing drugs, atypical antipsychotics and antidepressant medications is increasingly more important, not only to make patients feel well again, but also to avoid long term unfavorable outcomes<sup>(4)</sup>. However, although treatment with psychotropic medication is a reality in the daily lives of people with BAD, the low adherence to them is a major and serious problem whose consequences are lack of control of the disorder, increase in avoidable hospital stay and increase in health care costs. Because of their importance, non-adherence or small adherence to therapy are public health problems.

Several factors are mentioned in the literature as determiners for adherence to drug therapy. A factor whose importance is increasingly acknowledged is the trust patients have on the medication prescribed, on the treatment as a whole, on the physician responsible for prescription, as well as the trust they put on the health team<sup>(5-7)</sup>.

From the assumption that professional-patients interaction should be established based on respect and loyalty, so that patients feel safe regarding the treatment prescribed, this study aims to identify, from the perspective of BAD patients and their family members, how they define the interaction between patients and outpatient health team with regards to the aspects of the drug therapy prescribed. Understanding these interactions is essential to improve the knowledge of the health-disease process, optimizing care to BAD patients and ensuring the correct and safe use of medication.

## METHODS

The present study was developed, after approval by the Ethical Research Committee of the *Hospital das Clínicas* of the University of São Paulo at Ribeirão Preto Medical School, in the household of people with BAD that were being followed-up in an Outpatient Unit of Mood Disorders (APQH) of a large university hospital from the country side of the state of São Paulo. Because it was

a qualitative study, the number of people with BAD and their respective relatives was not pre-determined, but it resulted from a process of theoretical or intentional sampling, which is part of the methodology used. To determine patients and relatives that would be interviewed we have used several combined techniques, such as: participative observation, informal interviews with patients and relatives while waiting for the appointment at APQH; checking their medical chart and asking physicians and nurses about drug therapy prescribed to patients. We have also used snowball sampling when interviewers gave the name of nine people to be interviewed.

Inclusion criteria determined for patients were: to have a medical diagnosis of BAD; to be taking prescribed psychotropic medication(s) to treat BAD; to be able to express themselves verbally, and to give their written consent to take part of the study. One family member of each patient was interviewed; they were the people most involved with or responsible for treatment and they also gave their written consent to take part in the study.

The recorded interview and participants' observation were used as main strategies to obtain data, and they were conducted from February 2005 to January 2006. The interview, as a basic source for data collection, was complemented by Field Notes developed by the researcher during the visits to outpatient clinic and to patients' household. The semi-structured interview had the following initial question to patients "Tell me how you feel about taking the medications prescribed by physician in the Psychiatric outpatient clinic" and for relatives it was "Tell me how your relative feels about taking the medications prescribed by physician in the Psychiatric outpatient clinic". Questions were guidelines to direct the study points that should be explored. New guiding questions were added to enlighten and support the experience.

Data analysis was based, in terms of methodology, on the Grounded Theory (GT) at the light of Symbolic Interactionism. Considering that the basic assumption of GT is constant comparison, data collection and analysis were parallel to it. Thus, the first step of the analysis is data transcription, followed by coding. Coding procedures are presented in three stages that complement each other: open coding, axial coding, and selective coding<sup>(8)</sup>.

Axial coding was performed following Strauss and Corbin's coding paradigm<sup>(9)</sup>, which involves: the *cause* triggering the phenomenon, the *context* in which it is inserted, the *intervening conditions*, the *action strategies* concerning the phenomenon and their *consequences*.

Selective coding led to the core category "Being between the devil and the deep blue sea" regarding drug therapy, showing the ambiguity of medication as a symbol. In the present article, we have chosen to present the context

described by people with BAD regarding the need for continuous medication to stabilize the disorder. To preserve anonymity of patients involved, they are identified by letters from the alphabet. To identify the relative for each patient the letter “R” was added after the alphabet letter corresponding to the patient.

## RESULTS

Analysis of the interviews enabled the identification of three categories that shows how the interaction patient-health team occurs, especially with the medical team during clinical appointment; it demonstrates the difficulties and strengths of this interaction, as presented next.

### Identifying flaws in medication guidelines

Statements from people with BAD show that these people, in the outpatient clinic appointment, usually do not receive guidelines on the several aspects of drug therapy prescribed to them, their side effects, and their purpose, among others. Even with lack of information they want, there are patients that “*get the medication and take it*” because they consider them important, expressing their total belief in the medical truth. This belief may be justified by the power given to physicians due to their cultural load and professional education. Thus, patients many times do not ask for explanations because they are ashamed to say they did not understand a word or expression used to describe their disorder or treatment, or because they are afraid of being censured. They believe that physicians, who are symbolically the owners of knowledge, are responsible for giving them information on the therapy used.

“...they give us the medication, the prescription. I go and take the medicine... I've never heard about the side effects, they've never explained them to me.” (J)

“...and many patients have kind of... I think they are embarrassed of wanting to know more, to be against something and they think they will be censured.” (D)

“...I want (wanting to know about the medication), but aren't them (physicians) the ones who have to explain? No, I don't know anything, they have never told me...it is important, look these and these and these are the side effects, if they continue we change.” (A)

“...I was misunderstood, even the physician... she said she could not talk to anyone, she does not accept to talk to anyone... I wanted to talk about my wife's medication... They have everything, the best facilities, department, the best building, but they have to change themselves (CR)

The lack of guidance regarding medication is worsened by the way hospital pharmacy distributes them. Many times, drugs are provided without their original

packs, usually they come all together in plastic bags. This type of drug distribution makes patients unsure at the time medication is given, especially when the supplying laboratory is changed and the presentation of the drug is different (color):

“*In the hospital there is no use asking, because they don't tell you...and now, at SUS they give you these big bags with drugs, they no longer come in packs. Then, they put medicines in small bags... you go for the color of the tablet. Then, the next month it comes from another laboratory and the tablet is another color. I already make a mess because I'm neurotic..., and then it comes in another color! So, imagine what the poor soul will do... It's not right! I can't accept this! I've already seen people not explaining. That's why I'm saying this.*” (G)

In the outpatient clinic, patients notice that they are not the only one to experience this when they exchange information with other patients while waiting for physicians' appointment. There are patients who receive guidelines on medication therapy only when they ask for them, however, they say that even by asking, information is incomplete, and sometimes the answer is medication leaflets. There are relatives who also complain about lack of guidance. They think this situation is due to lack of interest and preparation of professionals providing care, expressing depreciation for the appointment:

“*The outpatient clinics, in my opinion, is weak compared to the other places, because I see, for example, when I'm sitting there, many people come to ask questions. And it is not enough (guidance received). There are patients who do not know what the medication is for, they don't know if there will be side effects if they stop taking, if they change the time they take the medicine, if they skip, if they take some hours before or after they were supposed to take...*” (D)

“...let's say it is half an appointment, due to the lack of interest from physicians, lack of ability to teach, and sometimes, the administration there should be better prepared.” (C)

“...I've already asked, but then, they started taking out the leaflets, the things... I sometimes ask the physician but he does not report everything, right.” (K)

“Regarding the treatment itself, I don't know if they tell you...they don't explain either” (RI)

Interviewed patients believe that this lack of interest, together with the deficiency of some patients to read, to ask questions, and/or to position themselves regarding the care received and the prescription of medication that are potentially harmful and that are routinely use by patients with BAD, may put their lives at risk since they favor mistakes in the ministrations of drugs.

“...there are people who can't read, they follow the color of the box. There are many old lay people... it is a complicated treatment because we take medicines that can... kill. If the person takes the wrong medication they may not be here the next day.” (G)

Regarding patients who had a good education level, they feel deceived and underestimated when they receive information on medicines that they know is not right because they had previously read the leaflet. This situation is a risk factor regarding confidence building in the professional-patient relationship which may jeopardize the assessment of the intervention efficiency, as expressed by the statements below:

“...I used to say: “Why do I take Equilid?” “It's because it's good for depression”. And I heard this all the time: “It's good for depression. It's an antidepressant”. And then I thought, did they think I was not going to read the leaflet? I bought the medicine, they did not give it to me there...” (L)

When they were asked about the guidelines received on the medicines in the outpatient clinic, only one patient in the study mentioned nursing guidance, in a critical way, when he said he had to ask to obtain information and guidance was given in the presence of several other patients:

“...you have to ask, you have to go to... guidance and many times there are five, six people at a time...” (C)

This aspect may be related with the way public health services work, usually the demand is high and there is a reduced number of human resources available, significantly contributing to hinder health team-patient therapy relationship. Within this setting, people with BAD feel the need to be heard and to be sheltered by the health team.

### **Feeling the need for being sheltered by the health team**

Reports from patients show that, in the routine of health services demand, professionals have impersonal and fragmented relationships. Because of this situation, people with BAD complain about the difficulty of being heard when they have questions or complaints regarding medication. Their statements show that the physician-patient relationship implies difference in perspectives, and knowledge seems to flow unilaterally:

“I said: Bupropion makes me a bit anxious. But to talk and to walk for them was the same... it seems they do not hear what we say” (L)

“...I know that if I say something I'll have problems, because once I told a physician (about the possibility of changing medication),

and she answered: no, your medicine is lithium it is your medication. But why does it have to be lithium, just this medication? Isn't there another latest generation drug? She said: there is, but these medications are being studied etc, etc, etc. I mean, they do not have, they are not interested, of course, they are not going to be giving everybody a much more expensive medication, I don't know how much lithium costs! I think when I say, sometimes I'm heard, and other times, I'm not...” (I)

Because patients know the physicians caring for them are medical interns and that their decisions are guided by a “professor”, sometimes, they feel the need to talk straight to the one in charge of drug therapy. When they learn they cannot be seen by the “professor”, since their approach is to guide interns and not see patients directly, they complain about the quality of care and express a feeling of “sadness” and “disrespect”. They consider that interns spend most of the time of the appointment with the professor, studying the case and they should rather use this time to get to know the patients better. Therefore, they feel professionals care for them in an “inattentive” and “uncompromising” way. Statements from patients show the need for being heard and sheltered by health professionals:

“...there was an argument between my husband and the professor. He went there to look for her and she said she didn't talk to patients, only to interns. So, this surprised me a lot concerning the quality, you know, I said: “Boy, I give all the attention to the outpatient clinic and when I need I'm not seen”. So, this leaves me very sad...” (C)

“I asked her to come and she said she was there to give guidance to interns not to care for patients.” (L)

“She writes the prescription and she says: I'm going to go there talk to the professor. I mean, he is going to go there talk.... he spends much more time there than here with us... So, I think that if he used his time to be with people, to ask more questions, to know more about patients...” (D)

Most statements refer to communication problems with physicians not to their clinical competence these complaints show the poor relationship between both. In this context, people with BAD feel the need for being assessed in their individuality and to have their subjective values respected.

### **Considering that patients should be assessed in their individuality**

Patients and relatives' statements show their disappointment with intervention standards regarding people with BAD and express their desire for being cared for in their individuality. The analogy they do of outpatient care with “vaccine for cattle” clearly shows their feelings. Because in this kind of procedure the only

objective is to inject chemicals in the animal, and the applier just needs technique for this:

*"Each case is a different case... But it is up to the outpatient care personnel to assess it more carefully, you see? Because... my husband, he uses this statement: there, they are not dealing with a herd that receive a vaccine and that's it... They are people, they are human beings right?"* (C)

*"...I strongly disagree... because I think they should separate... not everybody will take this one... it is just like a herd. For example, within two years, saying to patients: look, those of you who are feeling better, let's change the treatment. But in the hospital, this is not done. The hospital we feel just like the herd that is going to the slaughterhouse and those who want that system follow it..."* (FC)

Thus, they think the care received is "terrible". They feel disrespected as individuals because they do not receive individual scheduling in their appointment. They are all scheduled for 2 P.M and they have to wait to be seen by the physician, some patients will only be seen in the end of the afternoon. They also notice that interns do not arrive on time to start seeing patients. As for patients, if they are late, it will be difficult for them to be seen, thus reinforcing the feeling of being "disrespected". They notice, in the appointment, that the history of their disorder, their inner world, level of suffering, as well as the subjective interpretation they give to their disorder are not considered. They feel their history should be taken into account to determine medication given. They also feel that professionals should look beyond the medication, reaching their emotional level, because they want a medical appointment to be more than a medicine prescription. They believe this type of care is imposed as the only possible in outpatient care, and if patients are not happy they should seek another place for treatment. The following statements show patients' dissatisfaction:

*"Terrible... Terrible... Terrible...and it is not only with us, it is with anyone. They schedule those many sick people... for so many hours and then they see the patients... That kind of care, it is not for people. They treat diseased people as animals when they put them there to receive a vaccine. This is not the treatment for human beings. Human beings have to be respected, they should not tell everybody to come at two... they arrive here when they want... They have an idea of how long the appointment takes, right? Why do they schedule everybody for two? It gets crowded, it's difficult to breath...we feel bad there."* (J)

*"I think it is important to say that physicians, before prescribing medication should know well the history of that person."* (F)

*"I think they are concerned with leaving patients outside the hospital, but they are not concerned with their emotional status, they forget the emotional status of patients can lead to hospital stay. We live on the edge all the time. They have to go beyond*

*medication.... they have to treat patients as people... not as someone who goes there to get medication."* (L)

Regarding the context already described, there are patients who consider their disorder worsened after they started treatment. A patient, because of the interview, used pictures, which were already on the table to show this worsening, as well as the improvement of her condition after she started treatment with a private physician. This specific patient, left outpatient treatment and sought for a private physician because she was dissatisfied with the care received.

*"This picture (she shows several pictures which were already on the table)was taken twenty days after mommy died, mommy died on January, 22nd, a little bit later I started to go there (outpatient clinic)... Look at my face (she shows the picture) I was depressed, but my pieces were all together. Here (she shows another picture) I was already a mice, I was starting treatment there (outpatient clinic)... at first I started losing weight, then I would lie down and not get up, I slept up to eleven hours. I did not feel like doing anything, I did not want to talk, walk, I did not have the strength to stand... then I began to lose my hair, it resembled a rubber band, all curled up...my body ached...Here (she shows another picture) was at the beginning of Topamax already (with a private physician)... Look at them, I'm getting better, right? Now, this one (shows another picture), this was two months ago...it shows that it got better, doesn't it?"* (L)

*"...she even wet her bed... at that time (outpatient treatment) she did not talk right, she was always sad."* (LR)

Just as there are patients who complain about the difficulties in being heard, about the way care is provided and the reduced number of guidelines received regarding the disorder and the medications they use, there are patients who trust the outpatient clinic care. They think that "even though it is bad" it is still the best. This trust in hospitals is related, among other things, with the fact that it is a teaching hospital with technological "resources" and the presence of "professors": However, there are relatives that see intern care as something negative.

*"I continued... I need it, and the hospital... as bad as it is, it is still the best..."* (C)

*"There, in the hospital, there are the professors, here (city where they live) there are no... resources."* (B)

*"... In my opinion they were all interns. I think nobody understood things. They would give a medicine then they changed, and then changed again."* (MR)

Not recognizing early the disorder and the limitations in the interaction with the health team, many times, lead to a late BAD diagnosis, marked by the use of several types and doses of medication in an attempt to stabilize

patients' mood.

## DISCUSSION

These results show that the people with BAD do not find, in the health team that cares for them, sheltering for their distresses. It's worth mentioning that, for the people interviewed in this study, the team was centered in the person of the physician, because only one patient mentioned nursing guidance referring to it as inadequate.

A bibliographic study on nursing management activity in mental health showed that nurses are the professionals that least perform direct care to the population, and most of their time is taken by organizational activities in the institutions they work for<sup>(10)</sup>. The literature<sup>(11)</sup> points out that the difficulty in positioning nurses in multidisciplinary teams is justified because the team does not have a sole working goal and each professional works with a different theoretical reference, hindering a full view of patients who are approached in a fragmented manner.

Care fragmentation was also highlighted by patients and relatives of the present study. Their statements show that when they receive a fragmented care, people with BAD identify problems with the guidelines received for medication and that their experiences and knowledge are not valued by the professionals providing care. Data from this study are in agreement with the literature with patients and relatives complaining that they are not heard by physicians and that they have no place to express their feeling, showing thus the need to be sheltered by the health team<sup>(12-13)</sup>.

The situation experienced by patients with BAD seems to be related with the historical process that is part of the interactions between health professionals and people with mental disorders. Historically, patients and relatives were seen as lay people and, therefore, they could not understand or take part in the process of learning and decision-making regarding treatment, and they should be kept at a distance from the decisions<sup>(14)</sup>.

These aspects were also demonstrated by a study that approached the communication problem between physicians and patients. It showed that in the beginning of the appointment almost all physicians try to establish a relationship of sympathy with patients, however, despite this, several problems clearly occur: 39.1% of the physicians do not explain the problem clearly and concisely and, in 58% of the appointments, physicians do not check patients' level of understanding of diagnoses given. The same study also showed that physicians, in 53% of the appointments, do not check

if patients have understood therapy indications<sup>(15)</sup>.

These factors connected with the fragmented interaction between health team and patients may have significantly contributed to the several questions people with BAD had in the present study, even with regards to the elementary aspects of the drug therapy, making them want to be assessed in their individuality and totality. Also, due to the differences in power, both social and symbolic, between physicians and patients, patients don't often ask for explanations as showed by the statements presented here.

Under this perspective, it is worth mentioning that conceptions and health practices according to the New Paradigm of the Psychiatric Reform, do not accept anymore a fragmented look of subjects, geared only by the disorder, but rather care should be total, respecting subjective values of individuals and fostering their autonomy<sup>(16)</sup>. Several publications mention the important role of health professionals on treatment adherence. With the results from the several studies, it is clear that a decisive factor for adherence to treatment is the trust patients have in prescription, in the health team or in the physician<sup>(17-19)</sup>.

Thus, humanization and communication are important, as well as the need for those prescribing and giving drugs to talk to patients to transform the information received into defined knowledge, since lack of knowledge or questions that patients keep to themselves are important factors related with non-adherence to drug therapy<sup>(20,5)</sup>.

## FINAL CONSIDERATIONS

The results from the present study show the difficult interaction between patients and health professionals demonstrated especially by lack of or incomplete information supplied to patients and by a fragmented care that has direct consequences in their care, especially concerning the use of medication. Some of the consequences are: lack of knowledge of patients and relatives concerning the medication prescribed, lack of confidence regarding drug side effects, potential for non-adherence and/or mistakes in administration of drugs at home, lack of trust in the team and dissatisfaction with the treatment. This context points out to the need for reorganizing the work process so that it is no longer focused on physicians but rather on an interdisciplinary team so that humanized sheltering and psycho education places are introduced to help patients cope with the health-disease process.

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