

BIPOLAR AFFECTIVE DISORDER AND MEDICATION THERAPY: IDENTIFYING BARRIERS

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This study identified the barriers faced by people with bipolar affective disorder (BAD) regarding the need for continuous medication. The qualitative approach was used, and the methodological framework was based on the Grounded Theory in the light of Symbolic Interactionism. In total, of 14 people with BAD, who were being attended at the Outpatient Unit for Mood Disorders of a university hospital, and 14 relatives indicated by them participated in the study. The data collection was carried out through interviews and observation. Two categories emerged from the results, describing the barriers faced by people with BAD: to have affective and cognitive losses and to have several limitations. People with BAD feel ambivalent regarding medication adherence, as they perceive that, no matter the direction they take, it will lead to a context of prejudice, losses and limitations in various spheres of daily life.

DESCRIPTORS: bipolar disorder; self medication; interpersonal relations

TRASTORNO AFECTIVO BIPOLAR Y POR TERAPIA MEDICAMENTOSA: IDENTIFICACIÓN DE BARRERAS

Este estudio identificó las barreras enfrentadas por las personas con Trastorno Afectivo Bipolar (TAB) ante la necesidad de usar continuamente medicamentos. De enfoque cualitativo, tuvo como referencia metodológico, a la Teoría Basada en los Datos, bajo la perspectiva de la Interacción Simbólica. Participaron del estudio 14 personas con TAB, las cuales seguían tratamiento en un servicio Ambulatorio para Trastornos del Humor de un hospital universitario y 14 familiares señalados por los mismos. Las principales formas de obtención de datos fueron la entrevista y la observación. Los resultados mostraron dos categorías que describen las barreras enfrentadas por las personas con TAB: manifestar olvidos afectivos y cognoscitivos y la aparición de varias limitaciones. Se constató que la persona con TAB sienten ambivalencia con relación al seguimiento medicamentoso, pues perciben que cualquiera que sea la dirección adoptada, las conducirá al preconceito, pérdidas y limitaciones en las diversas esferas de su vida.

DESCRIPTORES: trastorno bipolar; automedicación; relaciones interpersonales

TRANSTORNO AFETIVO BIPOLAR E TERAPÊUTICA MEDICAMENTOSA: IDENTIFICANDO BARREIRAS

Este estudo identificou as barreiras enfrentadas pela pessoa com Transtorno Afetivo Bipolar (TAB) frente à necessidade de uso contínuo de medicamentos. Foi utilizada a abordagem qualitativa, tendo como referencial metodológico a Teoria Fundamentada nos Dados, à luz do Interacionismo Simbólico. Participaram do estudo 14 pessoas com TAB que estavam em acompanhamento em um ambulatório de transtornos do humor de um hospital universitário e 14 familiares indicados pelas mesmas. A entrevista e observação foram as principais formas de obtenção de dados. Os resultados revelaram duas categorias que descrevem as barreiras enfrentadas pela pessoa com TAB: ter perdas afetivas e cognitivas e ter várias limitações. Constatou-se que a pessoa com TAB sente-se ambivalente em relação à adesão à terapêutica medicamentosa, pois percebem que, qualquer que seja a direção adotada, ela o conduzirá a um contexto de preconceito, de perdas e limitações nas várias esferas da vida cotidiana.

DESCRIPTORES: transtorno bipolar; automedicação; relações interpessoais

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INTRODUCTION

Around 450 million people suffer from mental disorders, result of a complex interaction of genetic and environmental factors⁽¹⁾. In this context, Bipolar Affective Disorder (BAD) is considered a chronic disorder, characterized by the existence of acute and recurrent episodes of pathological change of mood. Recovery after the acute phase is usually significant, but less complete and free from consequences than would be desirable⁽²⁾. Considering the compromised level, measured by several parameters, BAD is responsible for 5 to 15% of new and longer psychiatric hospitalizations, absorbing considerable health system resources. It is also estimated that inadequate treatment is responsible for the larger part of costs deriving from the disorder.

Because BAD is a chronic disease, adherence to the treatment is essential to increase chances of a better prognosis. Efficacy is directly related to adherence. The development of psychopharmacology including the generalized use of antipsychotic, antidepressant and anxiolytic medication⁽³⁾ was initiated in the 1950s. These medications represent, since 1970, an economy of more than 40 billion dollars in the United States; 13 billion in treatment costs and 27 billion in indirect costs. Without these modern treatments, patients usually spent a quarter of their adult life in hospital and half of it disabled⁽⁴⁾.

However, there is a great and severe problem in BAD treatment adherence, whose consequences are lack of disorder control, increased avoidable hospitalizations, and increased costs of healthcare. Because of their magnitude, non-adherence and low adherence to the therapy constitute a public health problem. Literature has appointed some reasons for non-adherence to medication treatment: patients do not believe they are ill, do not see a reason to take the medication; patients believe the medication will hurt them; patients may be suffering from the medication's unpleasant side effects and believe it causes more limitations than relief in their daily life, among others⁽⁵⁾.

This way, the proposal to study the medication treatment issue among people with BAD meets the increased interest in the issue and the need to optimize treatment of this clientele. The importance of this study is reinforced by epidemiological and development aspects of BAD. Based on large population studies, estimates of the prevalence of BAD

are around 1% for type I and II bipolar disorder. Because of the introduction of the concept of bipolar spectrum, enlarging the BAD threshold, estimates are higher, around 5 to 8%. Affected individuals have higher rates of unemployment and are subject to using medical services and being hospitalized⁽⁶⁾.

Because of scarce studies on medication treatment adherence that focus on the phenomenon in the patient, and the awareness that the use of medication is a necessary reality in the daily routine of people with BAD, we believe that a better understanding of the associated and determinant factors of this reality, from the perspective of those who experience it, will allow for the testing of interventions that optimize adherence and might improve the control of the disorder and subsequent re-hospitalizations. Additionally, a study of this nature can contribute to discussions with the health team involved in the treatment, aiming to improve the care delivered to patients with BAD and their families.

OBJECTIVE

Identify, in the perspective of patient and family, barriers faced by the person with BAD regarding the need to continuously use the medication required to control the disorder.

METODOLOGY

This study is part of a doctoral dissertation entitled: "Between the devil and the deep blue sea: the meaning of medication therapy for people with bipolar affective disorder, according to their perspectives and those of family members" defended in 2006. After approval by the Research Ethics Committee of the Hospital das Clinicas of the University of Sao Paulo at Ribeirão Preto, Medical School, the study was carried out in the households of people with BAD, who were under treatment at the Outpatient Unit of Mood Disorders (OCMD) of a large university hospital in the interior of Sao Paulo, Brazil.

Because it is a qualitative study, the number of participants with BAD and their respective family members was not pre-defined, though it resulted in a process of "theoretical sample". Theoretical sample means that the selection of participants is guided by the emergent analysis. Thus, a selection criterion is

that of theoretical relevance for the discovery and development of the phenomenon under study⁽⁷⁾.

Several techniques were used to determine the patients and family members to be interviewed: participant observation and informal interviews with patients and family members, during the period in which they were waiting to be attended at the OCMD; verification of the patient's file and inquiries among physicians and nurses to obtain data regarding the patients' medication therapy. "Snowball" sampling was also used. This method consists in the definition of a sample through reference by people who share or know others who have the characteristics of interest for the study interest⁽⁸⁾.

The study inclusion criteria of patients were: having medical diagnosis of BAD; using psychotropic medicament; being able to verbally express and consent, in writing, the participation in the study. A family member of each patient was also interviewed, indicated as the more involved person or responsible for the treatment, and who consented, in writing, to participate in the study.

Taped interviews with 14 people with BAD, and participant observation during household visits, were used as the main strategies of data collection between February 2005 and January 2006. The interview was the basic source of data collection, complemented by the researcher's field notes taken during visits to the outpatient clinic and to households. The semi-structured interview was initiated with the following question to the patient: "Tell me how it is for you to use medication prescribed by the physician of the psychiatric outpatient clinic", and to the family member: "Tell me how it is for your relative to use the medication prescribed by the physician of the psychiatric outpatient clinic". The guiding questions directed the points of the study to be explored. New questions were added according to the participants' answers and interview techniques were used to clarify and support the experience ("could you tell me a little bit more about it?", "What is your idea in relation to this matter?", among others).

The data analysis was methodologically based on the Grounded Theory (GT), in the light of Symbolic Interactionism. Considering that the basic premise of GD is constant comparison, the data collection and analysis were carried out concomitantly. This way, the first step of this analysis is the data transcription per se, followed by the coding process. The coding procedures are presented in three stages that

complete each other: open coding, axial coding and selective coding⁽⁹⁾.

The open coding is part of an analysis the specifically serves to name phenomena through a detailed exam of data, line by line⁽⁹⁻¹⁰⁾. The mutual comparison of codes gave rise to the categories, which were integrated through axial coding. The identification of categories allowed for the selective coding that generated the central category "Between the devil and the deep blue sea" in relation to the medication therapy, revealing the ambiguity of the medicament as a symbol. In this phase, all concepts and categories were systematically related to the central category and, from this point, their relations were analyzed. We opt, in this article, to present barriers faced and described by people with BAD in relation to the need for the continuous use of medication to control the disorder. The analysis process resulted in two categories: to have affective and cognitive losses, and several limitations. In order to preserve the patients' anonymity, we opt to identify them by the letters of the alphabet. The family member of each patient had an "F" added to the letter of the alphabet assigned to him(er).

RESULTS

The participants' reports revealed that the disorder and its medication impose barriers to the person with BAD as described in the following categories.

To have affective and cognitive losses

To have affective losses

The patients' emotional fragility due to the disorder crises oftentimes results in affective difficulties. They complain that, when they manage to find a partner, the relationship suffers from influences exerted by the partner's family. The family members' reports confirm these influences. The partner's family deems that, because the patient is a person with mental disorder, (s)he might not be able to provide the care a family requires:

There were the affective losses also, the three boyfriends I had, I lost them because of my disorder. He said his family sat to talk and decided that I would not be a good partner for him... would not be able to be a good mother, to take care of children in a big city by myself. So, he thought I would not be self-sufficient for that (G)

It was really hard, my family put a lot of pressure for me to separate. When people say the woman divorced the husband because he is mentally ill I do not judge at all, I say: It is really very difficult. We live together because we have a different proposal in life (FH).

Sexual impotence, due to both symptoms present in the depressive phase of the disorder as side effects of the medication, can make marital relationship even more difficult. This aspect is very complex in men's case because of the cultural factors imposed on their sexual behavior. When the person with BAD does not meet the sexual role idealized by society, (s)he feels not only physically but also morally impotent:

Up to a certain time, I was in a relationship with a person, and it didn't work, I'm with a problem of, how do you say? Of libido, completely. It is difficult, I say like, how are you going to have a relationship with a person and suddenly you don't answer, I wasn't even having any erection anymore. It is something that bothers; it is a huge emotional burden for me. (I)

Risperdal trashed me, left me completely unable to have sexual relationships with my wife, I complete abstained for a year and four months, completely crazy. (E)

In addition to affective losses, the person with BAD also experiences cognitive losses, result of the disorder symptoms and medication side effects.

To have cognitive losses

People with BAD evaluate their performance in cognitive tasks as harmed by the medication treatment. They complain of difficulties in concentrating, even in pleasant activities, and lack of memory, including in relation to tasks they perform daily, such as reading, organizing personal belongings, among others:

I can't...forgetfulness... I can't remember anything... my memory is good-for-nothing... my mind doesn't work... (I)

I started to lose organization in daily life. I started to lose things, didn't know where I put it, started to lose some notions, I read it and couldn't keep it and I've always liked reading a lot, I'd see a movie and didn't understand. (L)

The cognitive losses, such as difficulty in memorizing, associated to other aspects inherent to the development of the disorder, can become a source of several limitations in daily life.

To have several limitations

To have limitations to study

Despite their desire to study, some people with BAD do not manage to keep themselves in school, usually because of the frequent and long periods of absence due to crises and hospitalizations. Those who have previous experiences with crises feel afraid of making new attempts when they resume their studies. Those who manage to study have to live with the possibility of a crisis to occur in the classroom and, when it occurs, they feel vulnerable to prejudice. Their reports reveal frustrated attempts to resume studies:

I tried to study, it's just that, I don't know if it's because of the fear, I didn't manage. In 81, I had a crisis because I went to school and couldn't study, I only finished sixth grade, I wanted to finish because, then, I could have some direction in life, but I couldn't. (D)

I got in the way, because if you're in the classroom, and have a crisis and people have a prejudice against you... and you need to take medication and cannot leave the classroom... then the medication makes you sleepy, no teacher would understand it. I used to go to the Secretary of Education, so that I wouldn't lose the year, they don't understand either... I lost almost two years because of my problem. (K)

The limitations to study associated to the crisis and the medication side effects can also result in limitations at work.

To have limitations at work

The patients' reports express their difficulty, after manifestations of the disorder, in maintaining a job or even finding a place in the job market. Factors that may contribute to this limitation in the patients' perspective include the disorder symptoms and the perception, according to them, of the lack of emotional structure to assume the responsibility any job requires. They perceive themselves as not prepared for work. Even when they manage to keep a job, they frequently have their functional performance harmed by the medication side effects, such as shaking and sleepiness, among others. Their reports reveal that the medication assumes a negative connotation of something that limits their actions:

I haven't worked for ten years. Since then, it wasn't lack of desire, it was a lack of condition, really, of structure... I got a job, and had no conditions to face it. (E)

... there, at my job, it is very hectic and because of it, sometimes I got blocked, the medication... the blurred vision, shaking, all these got in the way, sure! (C)

It limited, because before I'd do a thousand things at the same time and I managed. I can't speed up too much or I'm

going to blow a valve, the physical doesn't react as it used to...I think it is because of the drugs in the organism, the side effects. (F)

Because of the disorder crises and psychiatric hospitalizations, it is not unusual for the person with BAD to get health leaves and be dismissed when the leave ends. The functional limitation as a consequence of the medication side effects, including sleepiness, is another factor of risk for discharge of these patients. There are situations in which, despite their desire to keep working, the patients do not manage to keep up productivity at work, and retirement for disability is necessary. If, for some, retirement represents a gain, for others, it might represent a loss of financial resources and autonomy, and also losses in social relations and self-esteem. The reason is that, in addition to the label of mental patient, with the retirement, the person also gets the disability label from society:

When my disease aggravated more and more, my employers didn't want me anymore...there was a job in which I got a health leave for a year..., then the day I went back, they said: look, unfortunately there's another person in your place. (D)

...the work, I retired, you know... because of dis-a-bili-ty, I left the bank because of disability ... I couldn't manage to work, how do you work? I took a lot of medication, sat on the floor... then, they took me out. (N)

Limited capacity to work is generally associated to financial limitations.

To have financial limitations

The financial limitation is also related to the symptoms of the disorder, both in the maniac and depressive phases. In the maniac phase, the unjustified optimism, self confidence, grandiosity and weak judgment lead the person with BAD to recklessly get involved in pleasant activities, such as excessive expenditures, debts, precipitated business, which can produce destructive economic actions. In the depression phase, on the other side, the person feels exhausted, impotent and can get focused on his(er) internal world. Due to his(er) anguish, (s)he can forget to comply with commitments of several kinds, including financial ones. Such attitudes, judged with a low level of criticism during a maniac or depressive episode, can cause harmful consequences:

I started to spend too much, to buy things without being able to, you know? Compulsively. (E)

I lost a car because I didn't pay it during the depression phase. (L)

People with BAD who have their follow-up in the public service generally receive medication prescriptions provided by the Brazilian Single Health System (SUS). However, there are times when these medications are not available in the health services, or prescribed medications are not provided by the public services. In these cases, patients need to buy them and, as they generally use high doses, they perceive that this compromises their family budget. This aspect is also evidenced in the family members' reports:

Of course, (it compromises the income), you see I take 280 pills of lithium per month.. (I)

She (patient) did not want to take depakene the doctor prescribed because it was making her sick, then he (doctor) prescribed valpakine. This is better, only that I have to buy it and it is really difficult... (FB)

Limitations at work, with consequent financial limitations, and the medication side effects can result in the patients' limited leisureed time.

To have limited leisure

Sleepiness is a side effect mentioned by patients with BAD that causes limitations in leisure activities. As patients usually have to take medications at night, they perceive themselves as not able to have any nocturnal leisure activity. Also, diarrhea, when present, makes the patient feel embarrassed to attend public places, which in turn compromises his(er) leisure. This context evidences that the person with BAD, based on previous experiences, privileges interaction with the medication to the detriment of interaction with social objects in daily life, as the reports of patients and family members reveal:

Diarrhea is bad because you cannot go out... my schedule is taking medicine at 10pm, after 10 I don't go anywhere. It is a limitation... Will I take it and sleep on the street? Will I sleep standing up? There is no way, so I have to take it and go to bed. (D)

He played soccer, exercised, today he can't anymore, he barely walks, only the necessary inside the house. He says it's too tiresome (FH).

Another limitation mentioned by the person with BAD, present in his(er) daily routine, refers to the ability to drive vehicles.

To have limitations to drive vehicles

Despite their desire to conduct vehicles, people with BAD do not have the courage to do it, afraid that the medication side effects, such as

sleepiness, diplopia, dizziness, among others, can cause accidents. There are patients who want and like to drive, but are influenced by other people, including family, who deem that, due to the use of psychotropic medication, they should not drive. Although there are family members who deemed that driving is allowed, which is not only a right of people with BAD, but also a favorable aspect for their self-esteem and autonomy, this was reduced many times, due to the stigma and the disorder crises, as the reports below reveal:

... I drive well, I like to drive, it's something I do well, there're people who think that, because I take medication, I can't drive. (K)

... she can't drive, and she wants to, because she's distracted, she doesn't pay attention... and she wants to drive again, we are scared to death. (FL)

So, why don't you (physician) get him his driver's license? Only because he's a psychiatric patient? Because if he drives and gets independent, I mean, he'll free me and he, his self-esteem will get high... So, this would be very important for him. (FH)

People with BAD express, in their reports, that they live with many obstacles that need to be overcome and resolved, so that quality of life can be assured.

DISCUSSION

The experience of the disorder crises is gradually accompanied by losses and limitations in several spheres of daily life for the person with BAD⁽¹¹⁾. The reports in this study evidenced affective and cognitive losses, financial limitations, limitations at work, among others. The data presented corroborate with the literature, indicating that progressive losses and limitations are associated, among other factors, to the medication side effects and symptoms in moments of crises. When in crisis, especially in the maniac phase, patients can present aggressive behaviors directed to family members and other people in their social environment⁽¹²⁾. Behaviors like grandiosity, compulsive buying and psychomotor agitation are also frequent in this phase of the disorder and vulnerable to prejudice and rejection by the social group⁽¹³⁾, as evidenced in the reports of people with BAD in this study.

Because the patient experiences intense anguish when in the depression phase, (s)he has no

motivation to work, take care of oneself or keep up ties⁽⁴⁾. Therefore, almost always, psychiatric hospitalizations are necessary in both phases of the disorder, when symptoms are exacerbated.

Crises and hospitalization prevent the permanence of the person with BAD in the work environment, and cases of health leave with subsequent discharge⁽¹⁴⁾ are frequent. In this study, patients expressed difficulties to keep their job or even to get into the job market, after the manifestation of the disorder, as a result of social prejudice or because they felt incapable. As a consequence, they experience financial and social losses and limitations. In the literature on this topic, some studies corroborate with these results⁽¹⁵⁻¹⁶⁾. When they get unemployed, they lose their acknowledged social roles and their self-esteem, experiencing feelings of social exclusion and, even when the benefits of social security alleviate financial problems, they feel ashamed of having income from public sources and unable to provide for the family's needs⁽¹⁶⁾.

There is cognitive deterioration for some people with affective disorder and studies that evaluated performance in cognitive tasks showed, among other aspects, deficiencies in attention and memory tests⁽¹⁷⁾. Regarding affective losses, the rate of divorces is approximately two to three times higher if compared to individuals considered "normal"⁽¹⁸⁾. Around 50% of all spouses report they would not have married or had kids with the patients if they knew they would have a mood disorder⁽¹⁹⁾.

Because driving automotive vehicles requires concentration, attention, fast reflexes, psychomotor speed, capacity of decision, among other abilities, mental disorders interfere in this activity in different ways: through psychopathological symptoms, due to the association with abuse and/or dependence of substances and pharmacological treatment⁽²⁰⁾. Thus, it is verified that the capacity to drive can be harmed both in the presence of medicament adherence, due its side effects, as in its absence, due to the exacerbation of psychopathological symptoms, corroborating with the results in this study.

FINAL CONSIDERATIONS

Reports showed that the fact they are people with BAD or are treated with psychoactive medication does not impede, but makes it difficult for them to

remain in school, work, to form family units, and participate in other social activities. In this perspective, the ambivalence observed in relation to the medication therapy expresses their desire to adhere to the medication or not. Patients perceive that, whatever direction they adopt, it will lead them to a context of prejudice, losses and limitations in several areas of their daily life, both due to the side effects of the medication, when they opt for adherence, and due to the disorder crises and re-hospitalizations, especially because of the lack of medication.

Thus, the findings in this study entail direct implications for care to the person with BAD in medication treatment, allowing for the implementation of actions according to their demands. Among these strategies, we can suggest: adequate psycho-educative process to patients and families, aiming to improve their knowledge and sharing of experiences; stimulate patients to question the several aspects of the medication therapy, working as partners in the treatment; and adopt the household visit, especially for those people with BAD identified as at risk for non-adherence to the medication therapy.

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