

BI POLAR AFFECTIVE DISORDER: MEDICATION ADHERENCE AND SATISFACTION WITH TREATMENT AND GUIDANCE BY THE HEALTH TEAM IN A MENTAL HEALTH SERVICE¹

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Miasso AI, Monteschi M, Giacchero KG. Bipolar affective disorder: medication adherence and satisfaction with treatment and guidance by the health team in a mental health service. Rev Latino-am Enfermagem 2009 julho-agosto; 17(4):548-56.

Bipolar Affective Disorder (BAD) is a chronic disease and requires medication treatment. This study verified the adherence of people with BAD to medication and compared, among adherent and non-adherent patients, satisfaction with the health team and treatment. Twenty-one patients with BAD receiving care in a mental health unit participated in the study. The Morisky-Green test and another instrument elaborated by the researchers were used for interviews. Data were analyzed with qualitative and quantitative approaches. Results showed that the majority of patients did not adhere to the medication treatment due to "non-intentional behavior" (negligence or forgetfulness). The majority reports satisfaction with information received regarding the medication and its effectiveness, though there were reports of collateral effects, doubts and lack of motivation to keep up the treatment. This research shows the need for strategies directed at promoting adherence to medication therapy in patients with BAD.

DESCRIPTORS: bipolar disorder; patient care team; patient satisfaction; drug administration schedule

EL TRASTORNO AFECTIVO BI POLAR: ADHESIÓN AL MEDICAMENTO Y SATISFACCIÓN CON EL TRATAMIENTO Y ORIENTACIONES DEL EQUIPO DE SALUD DE UN NÚCLEO DE SALUD MENTAL

El trastorno afectivo bipolar (TAB) es crónico y requiere tratamiento medicamentoso para su control. Este estudio verificó la adhesión de personas con TAB a la medicación y comparó, entre adherentes y no adherentes, la satisfacción en cuanto al equipo de salud y al tratamiento. Participaron del estudio 21 pacientes con TAB atendidos en un Núcleo de Salud Mental. Fue realizada una entrevista con aplicación de la prueba de Morisky-Gren y de un instrumento elaborado por las investigadoras. Los datos fueron analizados con un abordaje cualitativo y cuantitativo. Los resultados mostraron que la mayor parte de los pacientes no adhiere al tratamiento medicamentoso por "comportamiento no intencional". La mayoría de ellos afirma tener satisfacción con la efectividad del medicamento y con las informaciones recibidas sobre este, sin embargo fueron identificados relatos de efectos colaterales, dudas y falta de motivación para seguir el tratamiento. Esta investigación apunta para la necesidad de elaborar estrategias dirigidas a la promoción de la adhesión a la terapia medicamentosa en pacientes con TAB.

DESCRIPTORES: trastorno bipolar; grupo de atención al paciente; satisfacción del paciente; esquema de medicación

TRANSTORNO AFETIVO BI POLAR: ADESÃO AO MEDICAMENTO E SATISFAÇÃO COM O TRATAMENTO E ORIENTAÇÕES DA EQUIPE DE SAÚDE DE UM NÚCLEO DE SAÚDE MENTAL

O transtorno afetivo bipolar (TAB) é crônico e requer tratamento medicamentoso para seu controle. Este estudo verificou a adesão de pessoas com TAB à medicação e comparou, entre aderentes e não aderentes, a satisfação quanto à equipe de saúde e tratamento. Participaram do estudo 21 pacientes com TAB atendidos em um Núcleo de Saúde Mental. Foi realizada entrevista com aplicação do teste de Morisky-Green e de um instrumento elaborado pelas pesquisadoras. Os dados foram analisados com abordagem quali-quantitativa. Os resultados mostraram que a maior parte dos pacientes não adere ao tratamento medicamentoso por "comportamento não intencional". A maioria deles afirma satisfação com a efetividade do medicamento e com as informações recebidas sobre o mesmo, mas foram identificados relatos de efeitos colaterais, dúvidas e falta de motivação para seguir o tratamento. Esta pesquisa aponta para a necessidade de estratégias direcionadas à promoção da adesão à terapia medicamentosa em pacientes com TAB.

DESCRITORES: transtorno bipolar; equipe de assistência ao paciente; satisfação do paciente; esquema de medicação

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INTRODUCTION

Bipolar Affective Disorder (BAD) consists in a chronic disorder characterized by important mood oscillations between the poles of euphoria (mania) and depression. It affects around 1.6% of the population⁽¹⁾ and has an important influence on patients' life, since it can cause expressive functional prejudices, difficulties for self-care, inadequate behavior and interpersonal relationship problems⁽²⁾.

Continuous medication treatment is necessary for BAD control. Without the treatments currently available, patients used to spend a quarter of their adult life in hospital and half of it with serious functional limitations. The effective medications used, combined with psychotherapy, permit 75-80% of patients with BAD to lead an essentially normal life⁽³⁾.

Efficacy of medication treatment is directly related to adherence to it. However, a common problem in BAD treatment is that patients do not always take medications regularly. This aspect is relevant for health professionals, as non adherence can increase the recurrence of mania, the frequency of depressive episodes, hospitalizations and suicides, compromising the quality of life of patients and relatives and increasing costs for the health system⁽⁴⁻⁵⁾.

The concept of adherence varies among different authors, however, in general, it is understood as the degree to which patients follow medical or health professionals' recommendations, return to the service and maintain the indicated treatment⁽¹⁾. It is highlighted that authors define the term adherence according to their understanding about the role of the actors in the process. The most used terms in English, adherence and compliance, have different meanings. *Compliance*, which in Portuguese can be translated as *obediência*, presupposes a passive role of the patient, and *adherence*, or *aderência*, is used to identify a free choice of people to adopt a certain recommendation or not⁽⁶⁾.

Non-adherence to medication therapy is a phenomenon subject to the influence of multiple factors related to sociodemographic conditions, the disease, therapy, the relationship between health professionals and patients as well as patients

themselves⁽²⁻³⁾. One factor whose importance is increasingly acknowledged is the confidence patients have in the prescribed medication, in treatment as a whole, in the physician responsible for prescribing, and in the entire health team⁽⁷⁾.

Among the presuppositions several authors assume to study adherence, the most evident differences are between those who focus on the phenomenon in patients and those who seek to understand it through external factors. It is highlighted that patient-related factors, harder to control, always have great influence on the adherence issue⁽⁸⁾.

Considering the described aspects and the fact that patient/health team interaction represents a relevant factor for treatment adherence, this study verified the adherence of patients with bipolar affective disorder to the prescribed medication therapy, using the Morisky-Green test⁽⁹⁾, and compared satisfaction with the health team and the medication therapy between patients identified as adherent and non adherent. This kind of study gives important support for the implementation of intervention strategies in health services, directed at medication adherence by BAD patients as well as the quality of care to this clientele.

METHODS

This cross-sectional, descriptive, qualitative and quantitative study was carried out in a Mental Health Service (MHS) in the city of Ribeirão Preto, state of São Paulo, Brazil, which is part of the Unified Health System. The project was developed after authorization by the manager of the mentioned service and approval by the institution's Research and Ethics Committee (Protocol n. 206/CEP-CSE-FMRP-USP).

Participants were patients with BAD who received care in the MHS in May 2007 and who met the following inclusion criteria: having BAD diagnosis given by the physician from the service, having a prescription of medication of continuous use for BAD treatment, being 18 years of age or older, being able to communicate verbally in Portuguese, agreeing to participate in the study and signing the free and informed consent form. Patients who received care in the MHS during the

studied period but who did not meet the inclusion criteria were excluded.

Recorded semi-structured interviews were used for data collection. The degree of adherence was defined by the Morisky-Green test⁽⁹⁾. This test permits to identify the patient's degree of adherence and discriminate if occasional non adherence is due to intentional behavior (questions: "when you feel well, do you at any time not take your medication?" and "when you feel bad, taking the medication, do you sometimes not take it?") or non intentional (questions: "do you, at any time, forget to take your medication?" and "are you, sometimes, careless regarding the time to take your medication?"). The test was validated by other studies and has already been translated and applied in Brazil.

Values of 0 (zero) and 1 were attributed to the answers. The value 1 was attributed to each positive answer in which the admitted frequency was once a month or less, and the value 0 (zero) to other possibilities of frequency. The criteria adopted to classify the degree of adherence were: "adherent" patients who scored 4 points on the Morisky-Green test⁽⁸⁾ and "non adherent" who scored from 0 to 3 points.

To collect information on the patient's perception, an instrument developed by the researchers was used, which investigates: opinion about the care offered by the MHS team, satisfaction with medication treatment and with the orientations received at the MHS, existence of doubts about medications in use and suggestions to improve care. This instrument was applied after carrying out a pilot study to test its suitability.

Descriptive statistics was used for analysis of the data related to medication adherence. A qualitative approach, according to Minayo's presuppositions, was used for data regarding patients' perception about the health team⁽¹⁰⁾.

RESULTS AND DISCUSSION

Characterization of study subjects

In total, 21 patients participated in this study, between 23 and 79 years of age. The table below presents the sociodemographic characteristics of the study participants.

Table 1 – Characterization of subjects participating in the study

| Characteristics | N | % |
|--------------------------------------|----|------|
| Gender | | |
| Female | 18 | 85.7 |
| Male | 3 | 14.3 |
| Total | 21 | 100 |
| Marital status | | |
| Married | 9 | 42.8 |
| Single | 8 | 38.1 |
| Divorced | 3 | 14.3 |
| Cohabiting | 1 | 4.8 |
| Total | 21 | 100 |
| Educational level | | |
| Illiterate | 2 | 9.5 |
| Knows how to read and write | 2 | 9.5 |
| Did not complete primary education | 6 | 28.5 |
| Completed primary education | 7 | 33.3 |
| Did not complete secondary education | 1 | 4.8 |
| Completed secondary education | 1 | 4.8 |
| Completed university education | 1 | 4.8 |
| Completed graduate studies | 1 | 4.8 |
| Total | 21 | 100 |
| Occupation | | |
| Retired | 3 | 14.3 |
| Unemployed | 4 | 19.1 |
| Worker with formal contract | 5 | 23.8 |
| Worker on sick leave | 2 | 9.5 |
| Housewife | 7 | 33.3 |
| Total | 21 | 100 |

It is observed, in Table 1, that most (85.7%) interviewees were female, although any significant difference in BAD distribution between genders has not been proved. The high number of women in this study can be explained by the fact that men with BAD seek health services significantly less than women⁽¹¹⁾.

A higher percentage (42.8%) of married participants was observed. Regarding educational level, most patients had completed primary or university education (52.5%). It is highlighted that 14.3% of patients were divorced, and all got divorced after the appearance of BAD. Of the 21 patients, only 23.8% had a formal job, 19.1% were unemployed, 9.5% were on leave by the National Social Security Institute (INSS) and 14.3% were retired due to the mental disorder. These aspects are relevant as, without a job, people with BAD lose their social roles and their self-esteem, experiencing feelings of social exclusion. Even when social security benefits reduce the financial problems, feelings of worthlessness and failure in providing for family needs can occur⁽²⁾.

The behavior related to medication treatment adherence

Adherence to medication treatment was assessed by the Morisky-Green test⁽⁹⁾, which permits to evaluate if patients' occasional non-adherence is due to intentional behavior (not taking medication because of feeling well or feeling bad) or non-intentional (forgetfulness and careless behavior regarding medication time).

Among the researched patients, most (57.2%) are non-adherent due to non intentional behavior, 14.3% is non-adherent due to intentional behavior and only 28.5% is adherent. These findings corroborate research results that report high non-adherence rates in bipolar disorder, representing 47% at some stage of the treatment, and that nearly 50% of bipolar patients interrupt the treatment at least once, while 30% of them do it at least twice⁽⁴⁾.

Non-adherence to prescribed medication can increase the occurrence of mania and experiences of disorder crises. These are two of the causes related to re-hospitalization and suicide⁽⁴⁾. Also, the crises and hospitalizations are gradually followed by affective and cognitive losses, financial, work, leisure and study limitations, among others in other areas of daily life, compromising the quality of life of patients and their relatives, besides generating high costs for the health services⁽²⁾. Thus, non-adherence to medication is responsible for great frustrations in psychiatry, deserving special attention from health managers who act in this area. These aspects show the importance of putting in practice, in health services, combined interventions aiming to obtain higher rates of adherence and better care support for mental disorder treatments. They also reveal the need for ethical reflection, in which recognizing and respecting individuality and free will is an established and followed parameter in treatment orientation and maintenance⁽¹²⁾.

Adherence to medication treatment and satisfaction with the health team

At this stage, results and discussion will be presented in topics, according to the content

and statements of each group of patients, classified by the Morisky-Green test⁽⁹⁾ into patients who adhered to medication, who unintentionally did not adhere and who intentionally did not adhere.

Opinion regarding care provided by the MHS health team

It was observed that all patients who *adhered* to medication treatment gave positive reports of the health team, mentioning being satisfied with it. This finding supports results of a bibliographic review⁽⁸⁾ on adherence to medication therapy, which identified several publications that show patients' confidence in prescriptions and in the health team as decisive factors for adherence.

Among patients *who unintentionally did not adhere*, it was observed that most (83.33%) of them expressed satisfaction with care offered by the health team. Nevertheless, there are patients who express related dissatisfaction, mainly regarding the time interval between scheduled medical appointments, the lack of availability of the service to receive patients when they were not scheduled to return, the delay and standardization of care (first come first-served care and lack of notice when medical consultations are rescheduled).

...I think care is delayed, I mean... it is difficult to receive us when we need to, at the moment... And the scheduled consultations are very far one from the other, then I believe that it is not very good (A).

The issue of availability and quality is a problem in public services in general, not only in the MHS. After the implementation of the Unified Health System (SUS), theoretically, any person has the right to free care, however, the guarantee of access to quality care is still a distant dream⁽¹³⁾.

In this context, patients' statements reveal their discontentment with the standardization of interventions. They feel disrespected for not having an individual schedule for medical consultations. They complain, thus, of the delay in care, the lack of notices when medical consultations are rescheduled and first come first-served care.

...when the day of the appointment changes, nobody tells us... We arrive here and have to go back... If they schedule the consultation for one o'clock, you are received at two...

Lately, they have scheduled everybody for 1pm, to be received in order of arrival. I believe it is not right to schedule patients in order of arrival (H).

Literature⁽¹⁴⁾ reveals that the failures in care sessions, such as the long delays and postponement of consultations, are daily and "dehumanizing" practices, which need to be rethought to optimize and improve the quality of care.

Among patients who *intentionally did not adhere*, it was verified that, of a total of three patients, one was dissatisfied with care offered by the health team, affirming not to feel safety in the relationship with the physician. However, the report of the patient is not restricted to the physician of the MHS only, but refers to psychiatrists as a whole.

... he (physician) does not give me confidence... He looks like crazy, every psychiatrist is like that... looks more like crazy than we who have a problem (V).

These aspects are relevant as, when patients do not feel safe in the physician/patient relationship, surely they will have difficulties to believe in the prescribed treatment and adhere to it⁽⁸⁾.

Satisfaction with the efficacy of the medication treatment

As to the satisfaction with the efficacy of the medication treatment, it was verified that, of the six patients who *adhered*, three (50%) were satisfied, one (16.7%) had doubts about its efficacy and two (33.3%) patients were dissatisfied.

It is highlighted that, although patients satisfied with the medication in use believe that it is working, all of them, at some point, complained of the collateral effects and the need to experience them.

It is working... I had long hair, I was taking valproic acid, all my hair fell (N).

It is working, but I am gaining weight... I gained 10 kilos (Q).

I think so (that it is working)... but I get sleepy (F).

It is shown through the statements that, when the option is to adhere to the medication treatment, the person with BAD starts to experience the collateral effects of the psychotropic drugs, which can entail physical and emotional consequences. Possible effects include hair loss and

weight gain, changing patients' physical appearance, which can compromise self-esteem, cause discomfort, restrict daily activities and change the social identity⁽²⁾.

Adherent patients, who reported dissatisfaction with the efficacy of the medication, assumed active behavior, seeking medical care to solve the problem.

Now I came here exactly to talk to the physician, I have insomnia, I do not know what happened, I came to talk to him (M).

Regarding patients who *unintentionally did not adhere*, it was verified that, despite the forgetfulness or occasional carelessness in taking the medication, half of them report satisfaction regarding the efficacy of the medication treatment. However, even patients who consider themselves satisfied report on negative aspects, such as always having to take the medication, excess of medication and sleepiness, revealing that satisfaction is not full.

They are really working, but at this moment I am too sleepy, I feel much sleepiness. I talked to him (physician), that is why he decreased it (E).

I believe it is working because I feel fine and do not even think I can be ill... I believe it is too much medication, it could be decreased a little (D).

In the above report, the patient does not consider himself ill and, thus, believes the medication could be decreased. This aspect is relevant, since, at the stage of treatment maintenance, patients can present symptom remission and be careless, compromising the efficacy of the pharmacotherapy⁽²⁾.

The other half of patients who *unintentionally do not adhere to treatment* reported dissatisfaction regarding its efficacy. They mentioned not presenting improvement and going through several readjustments in medication therapy, which can partially be explained by the inappropriate medication use itself.

No... it did not work with Tegretol, fluoxetine, we did some trials, you know... (J).

It does not solve the problem... if you do not take it, it is worse (O).

In the above report, the patient expresses dissatisfaction in relation to the medication treatment, but considers that, if you do not adhere

to it, the situation worsens. Literature⁽²⁾ reveals that the presence of collateral effects and the perception of the need for the medication, considering the crisis and re-hospitalizations, makes ambivalence regarding medication adherence influence the entire trajectory of people with BAD.

The chronic aspect of BAD still imposes a prolonged treatment on patients and, in this context, some can be afraid of "getting addicted" to the medication. Despite this fear and failures in adherence, there are patients who see the medication as a necessary reality for the stability of the disorder.

I am afraid that my organism will be totally dependent as there have been many and many years, because I am young, I mean...we have life expectancy... and this is my reality, I have to take all of them (J).

Among the patients who *intentionally do not adhere* to medication treatment, some express dissatisfaction with the medication because they do not consider themselves ill. The statement below shows that the patient "was taking" the medication, even believing that he "should not" take it, expressing his total belief in the medical truth, making him passive, submissive to the physician's will. This belief can be justified by the power attributed to physicians, due to their cultural burden and professional training.

There is nothing wrong with my head... he (physician) believed I had a head problem... he gave me medication and I was taking it, but I always believed that I should not take to the drug, then I stopped (T).

The above statement and literature reveal that patients with BAD, when they do not perceive themselves as ill, generally do not identify reasons to follow the medication therapy, with frequent abandonment⁽²⁾. In general, professionals see this decision as failure since, according to them, the only acceptable option for users is to follow the health team's orientations. One of the patients who intentionally does not adhere to medication reports that the treatment causes much sleep and prefers to use alcoholic beverages. This aspect is relevant, as it has been proved that improper use of alcohol is the comorbidity most associated to BAD, being able to change its expression, course and prognosis⁽¹⁵⁾.

I already used to drink before starting the treatment, but I stopped and followed the treatment only with medications... But when I realized I was getting in trouble with my private life, then I left the medication because it made me sleepy, I started to drink alcoholic drinks, which made me more content and did not make me sleepy (G).

Participants' statements evidence the hegemony of the biomedical health care model, which results in a social and symbolic power relationship between physician and patient. In this model, professionals who consider themselves as owners of the truth are responsible for guiding those who supposedly do not know anything, so to incorporate habits and attitudes they consider healthier, often ignoring the social, historical and cultural processes in which patients build their identity and knowledge. In this context, the role of patients in their treatment deserves to be discussed, both in professional practice and in research, considering them as social beings, with beliefs, values, expectations, knowledge and who attribute meanings and significations to the use of or resistance to use the medication in their illness process.

Satisfaction with guidance of the team and doubts regarding medication treatment

In this study, all *adherent* patients considered the orientations received from the health team sufficient and did not have doubts about the used medications. It is worth highlighting that information on the medication is a basic condition for treatment adherence. Besides, patients are entitled to have access to it.

Regarding patients who *intentionally did not adhere* to medication, it was observed that most (91.7%) are satisfied with the orientations received from the health team. There are, however, patients who presented doubts about some medications used or were not really convinced of their need.

I am (satisfied with the orientations), because I mean, if I could chose, I would not take it, I would have discharged myself, I would not have the obligation to take the medication, but they say I cannot (U).

The desire to be free from medication occurs in the intention to overcome the stigma of

being a chronic patient, because the act of taking medication regularly shows, all the time, that one is a chronic patient⁽²⁾. The same patient, when asked about the name of the medications in use, answered:

... I do not remember (U).

In the example above, as the patient was feeling fine, she could believe that the medication is not necessary, and not give importance to the information received in the health service. Thus, even when patients affirm satisfaction with the previously received orientations, it is important to motivate them to adhere to medication, to expose their doubts and, mainly, to assume an active role in their treatment.

The patient who *unintentionally did not adhere* and reported dissatisfaction regarding orientations received from the team mentioned forgetting the information. The statement also reveals a previous occasion on which the patient intentionally abandoned the medication treatment and needed hospitalization.

I understand, but then you forget it all, I do not understand anything... Sometimes I do not take it, I have already stopped taking medication... I have been hospitalized (O).

It is highlighted that all patients who *intentionally do not adhere* to the medication treatment affirmed having understood the orientations received from the health team and not having doubts about the used medications. However, even satisfied with the information, these patients sometimes intentionally interrupt the treatment, which demonstrates that the lack of information about the medication is one of the factors that causes non-adherence, but alone does not justify it.

It is worth highlighting that no study participant mentioned nurses when asked about the satisfaction with orientations from the health team, evidencing the non-recognition of this professional as responsible for such activity. Literature corroborates this finding when revealing that, in mental health, nurses are the professionals who least carry out direct patient care, occupying most part of their time with activities to organize the work of the institutions where they work⁽¹⁶⁾.

Suggestions to improve care provided by the health team of the MHS

When patients were asked to give suggestions to improve care offered by the MHS team, only one third of them manifested themselves. Some patients reported that presenting suggestions could be ingratitude, a possible offense to the health service, or negative criticism. This aspect suggests that, many times, patients can assume a passive attitude so as not to displease the professionals who provide care.

If I told something, it would be an offense to people who work here (J).

The offered suggestions included: hiring a higher number of professionals in the service, consultations scheduled by time, multidisciplinary therapeutic support and the introduction of courses like occupational activity, revealing the desire of patients to participate in alternative therapeutic modalities.

...there is a lack of psychiatrists, people from the nursing team, this is an urgent thing for the quantity of patients (S).

I believe it is incorrect to schedule all patients in order of arrival, even because I work... Thus, if it is scheduled for one, at one I will be here... I do not come here to take a day off, not to get a health certificate (H).

I believe there should be more psychologists, there is only one for all these people, there are many people (V).

The only thing I think... there should be, like it was before, jewelry and bead courses, I think it is interesting to have it again for people who are not working... (E).

Although medication treatment is essential, literature shows that associated psychosocial interventions can help to increase the interval between crises, decrease the severity of the episodes, improving the social adjustment of patients between one and another crisis and helping them in treatment adherence. In this context, patients and families should be offered a wide range of therapeutic options. Above all, the presence of the multidisciplinary team in treatment and the easy access to medications, in a systematic and continuous way, can improve the prognosis of this disease⁽¹⁷⁾.

FINAL CONSIDERATIONS

This study examined adherence to medication treatment in 21 patients with BAD and verified that most of these patients do not adhere to the medication due to non-intentional behavior. High degree of satisfaction with the health team was identified, which was higher among adherent patients, showing that satisfaction with the team can be a factor that is influencing, in these patients, adherence to the medication treatment. Most patients affirmed satisfaction with the effectiveness of the medication and with the information received about it, however, even among those satisfied, there were frequent reports of collateral effects, absence of improvement, need for readjustments in the therapy and the fact that they did not consider themselves ill. Other mentions were related to doubts about the medications, forgetfulness about the information and belief that the treatment is unnecessary.

Reports of patients reflect, thus, the lack of listening by health professionals and that they do not understand how patients think, how they give meaning to the world and that they are able to produce and systematize knowledge. It can also

be clearly perceived, in patients' statements, both total belief in the medical truth and disagreement with what is stated by biomedical discourse, depending on the moment in the history of the disorder, which can probably provide a base for the non submission of these patients to treatment, thus characterizing non adherence.

This study brings, hence, important contributions for practice and research in the mental health area, since knowing the origin of the non adherence behavior (intentional or non intentional) is essential to direct the implementation of strategies, in health services, targeting the safety of this clientele in the medication therapy.

In this context, the importance of studies that evaluate the strategies used by health professionals for the education of patients, as well as the need for training on this activity, is highlighted. It is also necessary to endorse the relevance of the implementation of strategies, in health services, that permit patients to expose their doubts, their wishes, difficulties, opinions and experiences related to treatment. For that, such strategies, including educational ones, should focus on adherence as a collaborative relation and, above all, as co-responsible, directed to the humanization of patients and linked to their reality.

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