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The path towards stability: treatment with medicines in bipolar disorder

Caminho trilhado para a estabilidade: tratamento com medicamentos para o transtorno afetivo bipolar

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Abstract

Objective

The objective of this study was to uncover the experience with medication during treatment for Bipolar Affective Disorder.

Method

Qualitative research was developed using Max van Manen's Phenomenology of Practice method. Semi-structured individual interviews and a focus group were conducted. The data were processed using the thematic analysis technique, facilitated by NVivo® software.

Results

The results revealed five themes: "Before and After Diagnosis", "Mental Health Recovery Is Subjective", "Living Like Alice: Difficulty Achieving Balance", "Medication Helps, But It Doesn't Work Miracles", and "Before and After the Most Effective Medication".

Conclusion

The research contributed to understanding the experience of treatment and mental health recovery.

Keywords: Individuality; Mental health; Mood disorder; Qualitative research.

Resumo

Objetivo

O objetivo deste estudo foi desvelar a experiência vivida com os medicamentos durante o tratamento do Transtorno Afetivo Bipolar

Método

Uma pesquisa qualitativa foi desenvolvida com o método Fenomenologia da Prática de Max van Manen. Entrevistas semiestruturadas, individuais e um grupo focal foram conduzidas. Os dados foram tratados com a técnica de análise temática, facilitada pelo Software NVivo®.

Resultados

Os resultados desvelaram cinco temas: "Antes e depois do diagnóstico", "A recuperação da saúde mental é subjetiva", "Vivendo como Alice: dificuldade para alcançar o equilíbrio", "O medicamento ajuda, mas não faz milagre" e "Antes e depois do medicamento mais efetivo".

Conclusão

A pesquisa colaborou para a compreensão da experiência vivida no tratamento e a recuperação da saúde mental.

Palavras-chave: *Individualidade; Saúde mental; Transtorno do humor; Pesquisa qualitativa.*

In ancient times, historical records associated melancholy and mania with the increase of bodily fluids, particularly black and yellow bile (Associação Brasileira de Psiquiatria, 2016; Goodwin & Jamison, 2007; Pereira, 2002). Mood changes were later identified by psychiatrist Emil Kraepelin as manic-depressive psychosis – a term now obsolete and currently classified as Bipolar Disorder (BD) (Motta, 1913/2012). Until the mid-20th century, there were no truly effective medications for this chronic mental health issue; this changed with the discovery of lithium's therapeutic function (Goodwin & Jamison, 2007). From that point onward, medications became integral to the clinical management of mood disorders, bringing numerous benefits to patients. Nevertheless, significant challenges remain in seeking treatment and maintaining adherence (Parikh & Kennedy, 2004). Mood disorders are often poorly understood by society, due to the many unique aspects surrounding the treatment process. In each episode, patients experience varying levels of acceptance and/or understanding of both the diagnosis and the medications (Inder et al., 2010). A particular challenge in this process arises during periods of normal mood, when patients, relatives, friends, and close acquaintances tend to question the diagnosis and the need for medication. During asymptomatic phases, it is common to develop hope of one day being cured and discontinuing therapy, which can lead to feelings of disappointment. In this phase, it is therefore especially important to recommend other interventions, such as psychotherapy and psychosocial measures (Inder et al., 2010; Miasso, 2006). In addition, there may be delays in establishing the diagnosis and prescribing the most appropriate medications (Goodwin & Jamison, 2007).

Technological interventions, such as medications that are routinely used in medicine, must not render the patient passive in their health-disease trajectory, as this undermines their active role in the care process (Guimarães & Meneghel, 2003).

In this movement, some scholars were already working on applying phenomenology's theoretical assumptions to psychopathology. The German psychiatrist Jasper (1987) stood out as a pioneer for presenting a more systematic and robust approach in his works. Building on the theoretical framework of phenomenology, the goal was to create a psychopathology model that could provide a path to access patients' experiences, combining clinical practice with knowledge from the humanities (Correia et al., 2018; Portugal & Holanda, 2019). Contrary to the traditional path of somatic-based psychopathology, Jaspers discussed "the subjective phenomena of morbid psychic life", emphasizing the importance of describing patients' lived experiences. The author considered meticulous investigation to be of great importance in establishing practices for future clinical cases, as a detailed understanding of individual experiences also reveals similarities in other cases (Jasper, 1987).

Manifestations during the course of psychological suffering – such as a delusion – should be understood as integral parts of this process. Recognizing illness as a process that is lived through, rather than as something wrong with the individual, allows for a treatment approach that embraces the person as a whole, rather than only their symptoms. Instead of judging, it is essential to learn from the health-disease process, considering that "what seems like a symptom may be a form of resistance to mortification, the last recourse of self-production" (Torre & Amarante, 2001, p. 11).

Contemporary authors emphasize the importance of studying the patient's healthcare experience to answer specific questions about the therapeutic relationship, potential impacts of treatment, recovery process and its dynamics, coping strategies, and other related aspects. When illness arises, a process of subjective reorganization also occurs (Moura et al., 2011). Treatments are complex processes involving daily decision-making and can be studied by specifically exploring the patient's relationships with medications or with a particular illness. Experiences are shared and transcend contextual differences (Ledford et al., 2010). In this context, the aim of this study was to understand the lived experience of patients undergoing pharmacological treatment for Bipolar Disorder.

Method

This research employed van Manen's (1990, 2007). Phenomenology of Practice method, grounded in phenomenological philosophical thought, which seeks to understand the lived experience of a given phenomenon. The following steps were undertaken: disseminating the research and its objectives to invite key informants with relevant experience; conducting interviews centered on the phenomenon under study; transcribing the interviews verbatim; processing data using thematic analysis; and presenting the results in themes and sub-themes (van Manen, 1990).

Participants

Regarding participants, all were over 18 years of age, legally competent, and self-declared as diagnosed with Bipolar Disorder (BD). One Focus Group (FG) member reported that their diagnosis was still under investigation, but according to their psychiatrist, the clinical picture suggests BD. All participants were undergoing medication treatment for the clinical condition under study. No further distinctions were made based on sex, education, family income, or geographic region of residence. A certain homogeneity was observed in terms of age range, with diagnosis established at an average age of 22.8 years, except for one participant, who was diagnosed in childhood, around seven years of age. Participant G3 was not considered for this average, as their diagnosis has not been fully established. Most participants were diagnosed by a psychiatrist, with only one participant receiving the same diagnosis from a psychologist (i4). Regarding gross family income, four participants had an income between three and four minimum wages (R$3.636,00 to R$4.848,00), two between five and ten minimum wages (R$6.060,00 to R$12.120,00), two had incomes above ten minimum wages (> R$12.120,00), two between one and two minimum wages, and one did not report gross family income as they did not respond to the Google® form. In terms of education, four participants had not completed higher education, five had completed higher education, and two had completed a stricto sensu graduate program, with one holding a master's degree and one holding a doctoral degree.

Instrument

An interview guide was prepared by the authors, with questions designed to steer both individual semi-structured interviews and the focus group.

Procedures

The primary strategy for inviting participants was through the distribution of a Google® Form, through which 17 individuals indicated their willingness to participate in either a group and/

or an individual interview. Two participants were directly invited by the researchers (AFSAN, AFRF) via remote contact. Subsequently, when contact was made to schedule the interviews, only 10 individuals agreed to participate. Initially, seven individual interviews were conducted. Upon observing sufficient content density and an absence of new information related to the experience under study, only two additional interviews were conducted to confirm data saturation. The researchers determined that data saturation had been reached and did not invite further participants for the study (Bauer & Gaskell, 2008). Thus, a total of nine individual interviews and one FG with three members were conducted, with one person participating in both interview formats.

For data collection, the semi-structured interview technique was used, with a single interview guide. Participants signed the Informed Consent Form (ICF) in advance. Interview audio recordings were made and subsequently transcribed. The online transcription software Reshape® was used for four individual interviews; the remaining interviews were manually transcribed by the first author. The two interview techniques complemented each other: the individual interviews allowed each participant to narrate their experience in detail, while the focus group facilitated dialogue and interaction among members regarding shared experiences. The literature indicates that FGs can be highly beneficial in phenomenological research; this technique was successfully employed in the study by Love et al. (2020), as it made it possible to grasp understandings and narratives, as well as ideographic identities. Furthermore, according to Bradbury-Jones et al. (2009), FGs enhance data credibility and positively contribute to the interactional context promoted by the group setting.

After transcription, the data were processed using thematic analysis. Initially, a preliminary analysis was conducted using an Excel® spreadsheet. Subsequently, the data were coded, a process that involves dividing the data into themes and sub-themes, thereby revealing the structure of the phenomenon studied (van Manen, 1990). To facilitate and organize the analysis work, NVivo 14® software was used

Regarding ethical aspects, this study is part of a larger project: "Clinical, economic, humanistic, cultural, and educational outcomes of medication therapy management services in the Brazilian Unified Health System", which received approval from the Research Ethics Committee of the Universidade Federal de Minas Gerais (UFMG, Federal University of Minas Gerais) on May 28, 2014, under registration CAAE-25780314.4.0000.5149.

Results

The individual and FG interviews were analyzed separately. Table 1 shows the data characterizing the focus group sample and Table 2 shows the data characterizing the individual interview sample. From the data processing, the results were jointly uncovered, aligning with the core structure of the phenomenon, and will be presented in five themes and sub themes: 1) Before and after BD diagnosis; 2) Mental health recovery is subjective; 3) Living like Alice: difficulty in achieving balance: 3.1. "Half-dead snake"; 3.2. Comorbidities; 3.3. Risky behavior; 4) Medication helps, but it does not work miracles, and 5) Before and after the most effective medication.

Table 1

Characterization of the focus group sample

Participant	Sex	Age	Marital Status	Gross Family Income	Education	Time since Diagnosis	Diagnosing Professional	Current Prescription
G1	F	26	Single	Up to 1 minimum wage salary (R$1.212,00)	Complete Higher Education	7 years	Psychiatrist	Lithium and lamotrigine
G2	F	23	Single	From 3 to 4 minimum wage salaries (R$3.636,00 to R$4.848,00)	Incomplete Higher Education	4 years	Psychiatrist	Valproic acid, lamotrigine, and clonazepam
G3	F	23	Single	From 3 to 4 minimum wage salaries (R$3.636,00 to R$4.848,00)	Incomplete Higher Education	Diagnosis under evaluation	Psychiatrist	Valproic acid and aripiprazole

Note: F: Female; G: Group.

Table 2

Characterization of the individual interview sample

Participant	Sex	Age	Marital Status	Gross Family Income	Education	Time since Diagnosis	Diagnosing Professional	Current Prescription
i1	F	36	Common-law marriage	>R$12.120,00	Doctorate	10 years	Psychiatrist	Lamotrigine, risperidone, mirtazapine
i2	M	55	Married	>R$12.120,00	Complete Higher Education	29 years	Psychiatrist	Tranylcypromine, lithium, clozapine, and amisulpride
i3	F	23	Single	R$3.636,00 to R$4.848,00	Incomplete Higher Education	4 years	Psychiatrist	Valproic acid, lamotrigine, and clonazepam
i4	F	28	Single	R$1.212,00 to R$2.424,00	Master's Degree	7 years	Psychiatrist and Psychologist	Lamotrigine and quetiapine
i5	F	33	Married	R$6.060,00 to R$12,120.00	Complete Higher Education	4 years	Psychiatrist	Lithium and valproic acid
i6	F	24	Single	R$6.060,00 to R$12.120,00	Incomplete Higher Education	7 years	Psychiatrist	Lamotrigine and pregabalin
i7	M	24	Single	R$3.636,00 to R$4.848,00	Incomplete Higher Education	17 years*	Psychiatrist	Lithium, quetiapine, lurasidone, and Vyvanse
i8	F	38	Married	R$3.636,00 to R$4.848,00	Complete Higher Education	21 years	Psychiatrist	Lithium and topiramate
i9	F	26	Married	Not informed	Complete Higher Education	3 years	Psychiatrist	Carbamazepine

Note: F: Female; M: Male.

Theme 1: Before and after Bipolar Disorder diagnosis

Bipolar disorder is primarily associated with mood variation between stages of depression and euphoria; however, the symptomatology is highly complex. Participants' accounts highlight mood swings involving discouragement, somnolence, reactivity, impatience, aggressiveness, agitation, impulsivity, a sense of superiority, and other symptoms, in addition to the challenges faced before and after the diagnosis was established.

For i6, upon first diagnosis of depression and being prescribed many medications simultaneously made the acceptance process even more difficult, as it brought a pessimistic outlook; while depression could potentially be cured, BD is a chronic condition. In the case of i6: "It was quite difficult (...). The depression diagnosis was already hard to accept, but finding out it was bipolar disorder was even worse, because, with depression at least, I thought I would improve and could stop taking the medication".

Although i9 has been stable for three years without any current complaints, this participant faced difficulties, as the initial diagnoses were Attention Deficit Disorder with Hyperactivity (ADHD) and panic disorder, leading to inadequate treatments that exposed her to severe adverse side effects.

Upon receiving the diagnosis of BD, the experiences involved negative feelings such as fear, embarrassment, and denial. Difficulty in accepting the diagnosis mainly arises because it is deemed a chronic mental health condition. In the words of i1: "You carry the diagnosis and the use of medication with you for the rest of your life". And according to i3: "(...) I know it's cyclical, that it will happen, that I am in treatment, but I would rather not go through this. There is also stigma, as people start to look at you differently".

For i8, receiving the diagnosis and starting medication use was traumatizing. The participant reported that their psychiatrist did not fully understand their concerns and struggles at that time: "The doctor said: 'Look, I don't understand why you're complaining about taking medication because, in the past, treatments consisted of electroshock chairs'. That day, I felt like I was losing my dreams!"

In the case of i7, the parents kept the BD diagnosis a secret, only disclosing it to them in adulthood. Regarding this discovery, i7 said, "The diagnosis explained all the behavioral oddities of my entire life, since adolescence". Despite his optimistic outlook, he recounted the incident with regret, believing that if he had known from the start, he would have been more confident and would not have stopped taking the medication for 10 years.

Feelings of uncertainty permeated FG discussions regarding the diagnosis and medication treatment. Participant G3 reported that her diagnosis of BD has not yet been finalized, and her condition is still being evaluated by a psychiatrist, although there is strong evidence supporting the disorder. Participant G2 has an established diagnosis, yet due to his instability, the psychiatrist is reevaluating the case, and he is undergoing adjustments in pharmacotherapy.

For other participants in this study, receiving a BD diagnosis was viewed positively, as it provided relief and a sense that their experiences, symptoms, behaviors, and reactions made sense, had an explanation, and were shared by others.

Theme 2: Mental Health Recovery is Subjective

The treatment process is permeated by subjectivity, which must be considered for mental health recovery. The dosages needed for the medication to be effective are unique and pose a challenge to objectivity, with each participant reporting the need to adapt to different prescriptions and dosages. G1's initial experience with lithium was negative, but she is now adjusted to the medication, maintaining the same dosage and formulation, despite experiencing some side effects. For G1, lithium has been the most effective treatment thus far, while G2 had a terrible experience with the same medication. Participant G3 takes valproic acid, which makes her "communicative, though not excessively euphoric, facilitating social interaction".

To illustrate the difficulty of treating BD, G1 offered a comparison:

> A diabetic takes their medication and can measure their blood sugar levels. They know if the medication has taken effect or not! In bipolar disorder, this is not possible! You take the medication, but you don't know if it will truly prevent a crisis. So, it's not a limitation of the medication, but of the body itself, of the nature of the disorder.

Participant G1, although noting that lithium has been the most suitable among the medications used so far, is unsure if the symptoms of nausea and fatigue she is experiencing are related to the medication. Participant G2, on the other hand, mentions valproic acid as the most effective medication but is also experiencing instability, raising doubts about the treatment.

> The experience of living with BD is subjective. Not everything in the disorder is clearly evident. It is necessary to consider the patient's experience, even when adjusting the medication dosage. Even so, it doesn't always prevent a crisis. (G1)

> Lithium carbonate, for me, has been the most effective medication because I struggle with adaptation. The medications used by G2 and G3 cause many side effects for me. In fact, I am experiencing nausea and fatigue, so I will see my psychiatrist to determine if these are effects of lithium. (G1)

> I take valproic acid, but recently I had a severe crisis and needed to increase the dose. My psychiatrist is considering introducing risperidone. I am unsure if valproic acid is the best medication, but so far, it has provided the greatest stability. (G2)

Theme 3: Living like Alice: Difficulty in Achieving Balance

The difficulty of managing BD to achieve stability is clearly evident in the data analysis, encompassing the journey from overcoming severe and successive crises to reaching stability. The process of finding the "middle ground" and achieving mood balance was extensively discussed in the FG as a consensus point. Participant G2 reported experiencing an internal struggle during a crisis, as manic or hypomanic episodes often emerge at the peak of depression: "One curious thing is that my manic episodes arise... many are triggered at the height of my depression. It's as though I'm so depressed that my other side surfaces". They perceive themselves as divided into two poles, each battling to take control.

Following this account, which all other participants agreed with, G1 drew a comparison to Lewis Carroll's Alice in Wonderland:

> You mentioned that, and I remembered Alice in Wonderland! She's trying to find the way out, but she's too big to get through the door. She shrinks but forgets the key on the table. She eats the cake and grows again.

The recollection of this scene from a fictional work engaged all participants and resonated with them, fostering interaction. In the story, Alice eats the cake and grows large, drinks the potion and shrinks, and there's a key to open the door. Participant G2 added:

> I see it as if it were mania and depression, and the key is actually the medication. And the house represents normality. You try to reach the key, to find your normality, but you don't know how to control yourself. So, it's a lot of trial and error, you know? And entering this house, grabbing the door key to get out. I associate it like this: the cake, the potion, and the key, with mania, depression, and the medication.

"Half-Dead Snake"

The pharmacotherapeutic management has undergone adjustments over time for all participants until an ideal prescription was reached. To achieve this, trials with different medications were conducted. Symptom improvement was therefore gradual. Participant i9 described this process as a "half-dead snake". This term refers to the difficulty and slowness in resolving a problem, used here as an analogy for the participant's path to stability, even after finding success with carbamazepine.

> A half-dead snake is when there's something very bad happening, and you keep trying to solve the problem until you succeed. This was the feeling I had upon starting the medication, as I gradually improved and achieved stability month by month. (i9)

Meanwhile, i2, who had not yet reached full stability, described treatment resistance and the need for frequent dosage adjustments within the same month: "(...) I basically tried all the medications, with no result. Medications were ineffective; I used one, then another, without success, then switched again".

Currently, i1 reported finding success with risperidone, but reaching stability with this medication required approximately one year of adapting to the side effect of emotional indifference.

> After I started using risperidone, it was the worst feeling in the world, horrible (...) I know it was a side effect of the medication; at the time, the doctor explained to me, "The effect is called a state of indifference, which can be caused by the antipsychotic". (i1)

Access to pharmacogenetic testing made a difference for participant i9. Her experience contrasts with the other participants who did not undergo this test; carbamazepine was selected for them based on test results and proved effective, as no further medication changes were needed, only dose adjustments, thereby shortening the path to stability.

"Comorbidities"

Most participants presented comorbidities, including ADHD, anxiety, diabetes mellitus, hypothyroidism, thrombophilia, panic disorder, and restless legs syndrome. This posed a challenging situation for both individuals affected and professionals managing BD, as medication reconciliation was necessary. Reports indicate that i8's hypothyroidism and i2's diabetes mellitus were caused by chronic use of lithium and clozapine, respectively. Prolonged lithium use led i8 to develop thyroid issues, requiring hormone replacement with levothyroxine. Participant i7 reported difficulties reconciling medications for BD and ADHD, as lisdexamfetamine and methylphenidate tend to trigger manic or hypomanic episodes.

"Risky Behavior"

Participants in this study described behaviors such as excessive work/activity, lack of quality sleep, excessive alcohol consumption, overuse of legal stimulants like coffee and energy drinks, illicit drug use, routine changes, or discontinuation of medication. Excessive alcohol use by i1, i5, i6, and i7 negatively impacted their routine and treatment adherence. Participant i5, for instance, often prioritizes recreational moments involving alcohol, temporarily halting prescribed medication, which affects stability.

Suicidal ideation and suicide attempts emerged as life-threatening risks for i1, i5, i6, i7, and i9, associated more with depressive episodes and less with manic episodes. The depressive episode experienced by i7 led to the planning and execution of a suicide attempt (SA), resulting in hospitalization, while i6's SA required urgent care. According to i7: "And then I started to get very, very, very depressed. And had suicidal ideation. This was at the end of last year. In late September, I attempted suicide. This triggered despair in my parents".

Suicidal ideation was present in i5's mind before medication use: "I've always been a sensitive person. Commonly sensitive. But without being medicated, before treatment, everything hurt too much. Living was too painful. I had episodes of suicidal ideation".

The participants' statements make it clear how vital medications are in their lives, as they are not only necessary but essential.

Theme 4: Medication Helps, but It Does Not Work Miracles

The pharmacological treatment for BD benefited all participants in this study, significantly improving their clinical condition. However, even after positive experiences, the consensus was that pharmacological treatment alone is insufficient and has limitations, as the following statements illustrate:

> I believe in medication, but it doesn’t solve everything on its own. It can’t be just that, additional aspects are needed. (G1)
>
> I agree that pharmacological treatment indeed has a very positive effect; it’s essential! I completely agree with G1, but on its own, it’s not enough. (G2)
>
> I agree with what G2 said. I also think that medication isn’t able to address the ‘whys’. I believe that psychological treatment is very important in this regard. Combining both treatments at the same time is essential. (G3)

The perception of medication as a support system was unanimous, meaning it is part of an integrated approach to achieving and maintaining stability. According to i7: “Medications do what I can’t do naturally; they provide the biochemical stability for my brain, but it’s just a support”.

Medication can assist in promoting psychological balance, but to address the impact of stressors identified as crisis triggers, clinical management should incorporate non-pharmacological approaches. Certain approaches are cited as crucial for overcoming crises, namely, striving for quality of life, mechanisms and specific therapies for controlling substance use and abuse, and psychological therapies.

Regarding quality of life, aspects include healthy eating, physical activity, and challenges or facilitators in family and social relationships, all noted as extremely important factors for stability.

Everyday interactions with family, friends, and colleagues can also generate conflicts and stress that “trigger crises”. A “negative environment”, even when the patient is on a suitable medication and dosage, may not be sufficient to maintain balance. In family settings, difficulties arise related to lack of knowledge, prejudice, and stigma, which associate the participants’ symptoms with pejorative characteristics – such as laziness. Negative remarks and judgments impact adherence to treatment. Participant G1 stated that, before experiencing her first crisis, she was perceived as a “typical tired teenager”. Similarly, G2 reported: “I was lying on the floor and couldn’t do anything. I was seen as lazy. Those closest to us don’t understand our suffering, don’t feel what we’re feeling, and so they criticize.” Regarding stigma, G2 stated: “I believe there is a stigma surrounding mental disorders, and this entirely affects treatment adherence”.

The feeling of being misunderstood during crises is common. Participants expressed frustration toward those who doubt the intensity and origin of their symptoms. G2 reported:

> They’ve already tried to exorcize me, as I experience many psychosomatic symptoms during crises. In my last crisis, I couldn’t distinguish left from right. I also had a vertigo episode and collapsed. During this incident, a group from the church gathered and attempted to exorcise me.

Living with family is challenging and turbulent. For i1, her family members’ approach to caregiving is questionable, as she reported not receiving the necessary treatment during a depressive episode in adolescence, influenced by her mother: “They worried but belittled me, saying I was incapable and couldn’t do anything on my own. My family is completely dysfunctional (...) there are cases of child sexual and psychological abuse, among many unpleasant and harmful situations”.

Regarding the same issue, G2 reported:

> I agree that medication helps prevent crises. However, the environment must be considered, as the more stress we experience, the worse it gets! In such a context, the 'medication doesn't hold back the crisis'; it might slightly contain it, but it's not always enough.

The participants discussed the importance of family support, both financially and in monitoring the signs and symptoms of the illness, as evidenced in a statement from i7: "(...) my mother said, 'Look, I'll pay for a private psychiatrist for you.' She then began to forgo paying household bills to cover the cost of a private psychiatrist".

Another therapeutic approach experienced by all participants was psychotherapy. Participant i6 noted that therapies primarily helped in learning to recognize signs and symptoms, as well as in adhering to treatment. Similarly, i5 found that therapy enabled better management of symptoms and helped distinguish between crisis-inducing symptoms and personal characteristics.

Theme 5: Before and After the Most Effective Medication

The experience with medication use involves both positive and negative aspects. Certain adverse effects were cited as obstacles to pharmacological adherence – for instance, participant i3 experienced severe constipation due to lithium, leading to treatment discontinuation. Participant i7 reported difficulty adhering to medications causing excessive somnolence, such as quetiapine; therefore, his psychiatrist included lurasidone in the prescription as an alternative antipsychotic, maintaining quetiapine at a low dose of 25 mg for use if needed. Another crucial issue for i7 was the lack of resources to purchase the high-cost medication, lutab (lurasidone), which led to crises and instability as the treatment was interrupted for months. Only later was he able to secure funding to start using the medication, achieving stability for the past two months.

Severe adverse effects also prompted the discontinuation of medications, such as suicidal ideation with lisdexamfetamine and hypomania/mania with methylphenidate, lisdexamfetamine, and antidepressants. Participant i8 discontinued valproic acid use due to joint stiffness. Other effects, such as excessive weight gain, heartburn, dizziness, excessive drowsiness, and severe nausea/vomiting were also cited as reasons for discontinuation. On the other hand, some medications, despite causing adverse and side effects, were tolerated and used correctly due to the stability they provided.

At times, each participant's opinion led to decisions influencing significant directions in the course of treatment. Participants i1 and i4 reported actively participating in changes to their treatments: i1 suggested using mirtazapine, and both i1 and i8 proposed adjusting the timing of medication administration to nighttime. Participant i6 requested the suspension of quetiapine, as it caused excessive nausea, and lithium, which neutralized their mood, leading to emotional blunting.

Thus, participants in the FG report living with chronic medication use and many uncertainties. They are uncertain whether the treatment is the most suitable for their bodies. Participant G2 also expressed concern about the long-term effects of medication on the body, having started treatment at age 14: "One thing that bothers me a bit is the effects of the medication on my body, because I'm straining my liver, straining my kidneys. What will become of my future?". G2 further stated: "As G1 mentioned regarding the cost-benefit issue, if I don't undergo treatment today, how will I be tomorrow? So, I don't see any rational reason not to pursue pharmacological treatment".

The participants reported that they were previously seen as lazy, among other pejorative labels. Upon experiencing the benefits of medication, they began to view themselves differently, stating that from then on, they recognized their ability to distinguish between symptoms related to BD and their personal characteristics.

> We end up building beliefs of incompetence and irresponsibility. We internalize that this is who we are, when most of the time, it was the manifestations of the symptoms. Understanding this in the context of one's life history, restructuring these beliefs, and looking at oneself with more compassion was essential in therapy. (i5)

The discrepancy in self-reported behaviors following the use of the most effective medication was a common point for most participants. For G3, suicidal ideation and mood fluctuations, which were recurrent, became controlled, decreasing in frequency and intensity with treatment. For some, the change was so abrupt that it took time to recognize themselves again.

> Before the medication, everything was the complete opposite of what it is today. My friends said it was as though I had died and they put someone else in my place. I watch an old video of myself and notice the difference. Even my voice, you know? (i9)

> There is a life before and after lithium. My life has improved a lot. My main symptoms were irritability and impatience. That has improved tremendously, really. Since resuming the treatment properly, depressive episodes have also significantly decreased. (i5)

The participants weigh the pros and cons of medication use, concluding that the benefits are more significant. Despite the challenges, mood and behavioral stability improve with medication, and positive meanings are attributed, such as "brakes", "safety", and "prevention". These terms are directly related to crisis prevention, reduction, and an increased sense of safety. The medication protects them from severe crises, enhances awareness of risky situations, reduces negative thoughts, and regulates changes in the perception of what is real.

Discussion

The data analysis allowed for an understanding of the experience lived during treatment for BD. Theme 1 presented the relationship of the study participants before and after the diagnosis. The use of medication to restore mental health began even before the diagnosis of BD, resulting in negative impacts for participants who underwent inappropriate treatments. This situation caused issues with adaptation to the medication(s), absence of pharmacotherapeutic response, and adverse effects (mild, moderate, and severe) – for example, constipation, nausea, onset of crises, and suicidal ideation.

The literature describes this initial turbulent scenario as a reflection of the complexity of the clinical picture, the similarity of symptoms, particularly the overlap between BD and unipolar depression. However, managing the different clinical presentations requires specific approaches and medications for a positive treatment response (Morishita et al., 2021).

Most participants in this study exhibited the first symptoms during adolescence and childhood. Despite this, with the exception of i2, they were diagnosed late, a situation that frequently occurs for patients with BD (Alves & Oliveira, 2023; Goodwin & Jamison, 2007; Keramatian et al., 2022; Maassen et al., 2018; Miasso, 2006; Morishita et al., 2021; Proudfoot et al., 2009). Studies identify several reasons for the delay in diagnosis, such as: lack of investigation or reporting of symptoms during manic or hypomanic phases and differential diagnoses, particularly BD versus unipolar depression and BD versus ADHD (Keramatian et al., 2022; Maassen et al., 2018). Moura et al. (2019) highlighted the fear of exposure to the stigma faced by individuals with BD, a feeling that negatively affects recovery and inhibits the search for help. The same result is presented in Siegel-Ramsay et al. (2023), regarding the experience of stigma by participants in various social environments, as well as in the review study by Warwick et al. (2019), which revealed the subtheme "stigma", its implications on social relationships, and its negative impact on the individuals' perception of self-identity.

In this sense, it is particularly important to note that delays in receiving a diagnosis, for any of these reasons, worsen the patient's prognosis (Keramatian et al., 2022; Morishita et al., 2021). One study indicated that patients with BD II experience greater diagnostic delays than those with BD I. Individuals who developed BD symptoms during childhood had a longer delay compared to those who developed the disorder in adulthood. Moreover, those who concurrently suffered from anxiety and had a SA experienced even greater delays in diagnosis, while those who experienced psychotic symptoms and were hospitalized were diagnosed more quickly (Keramatian et al., 2022). Among the other participants in this study, i9's access to pharmacogenetic testing was noteworthy, which determined her treatment with carbamazepine, with which she has been stable for three years, avoiding exposure to multiple medications after the BD diagnosis. In contrast, i7 faced financial difficulties in purchasing the medication that best supported his mental health stability. The impact of socioeconomic inequalities on access to and the type of treatment offered to individuals with BD is real. Karanti et al. (2021) assessed the relationship between educational level and variations in treatment offered, showing that individuals with higher levels of education are more likely to discuss and question pharmacotherapy, receive fewer prescriptions for first-generation antipsychotics and tricyclic antidepressants, and have greater access to psychoeducation and psychological therapies (Karanti et al., 2021). After the diagnosis, participants exhibited various nuances in accepting the diagnosis, transitioning to the reality of living with a chronic disorder.

Theme 2 presented the subjective aspects involved in mental health recovery, particularly regarding adjustment to medication. It highlighted the importance of listening to patients in clinical settings, as patients' subjective experiences and social context both reorganize over the course of treatment, and both factors must be consistently considered for therapeutic success (Guimarães & Meneghel, 2003; Megale & Teixeira, 1998; Mori & González Rey, 2012; Moura et al., 2011; Torre & Amarante, 2001).

Theme 3 – "Living like Alice: Difficulty in Achieving Balance" – and its subthemes described in detail the participants' experiences during the challenging period of adapting to treatment. In the subtheme "half-killed snake", participants initially reported the journey to find stability. Some medications were added to the prescription to test the best treatment options; however, the process led to negative experiences with adverse effects, a lack of therapeutic response, and clinical worsening. The process of determining the optimal pharmacotherapy for each patient involves trial and error, as outlined in Ordinance No. 315, Clinical Protocol, and Therapeutic Guidelines for Bipolar I Disorder, which recommends treatment lines to be followed in the established order, respecting the individuality of each patient (Ministério da Saúde, 2016; Yatham et al., 2018). This process of trial and adjustment to reach the closest ideal pharmacotherapy is well-documented in the literature (Alves & Oliveira, 2023; Ledford et al., 2010; Maassen et al., 2018; Miasso, 2006). The process of establishing a diagnosis is slow, and pharmacological treatment can be complex. A literature review on pharmacological treatments for BD indicated differences and similarities between the approaches taken in Brazil and those in other countries (Alves & Oliveira, 2023). The study by Siegel-Ramsay et al. (2023), which employed grounded theory methodology, found that the process of adapting to medication can take months and that exposure to adverse effects and a lack of therapeutic response cause both physical and emotional harm. The difficulty in managing medications to achieve mood stability is also a finding presented in studies by Miasso (2006) and Ledford et al. (2010).

In relation to the subtheme "comorbidities", studies indicate that most individuals with Bipolar I or II Disorder have at least one other clinical or psychological condition; therefore, drug management must be individualized (Krishnan, 2005). According to Bessonova et al. (2020), the economic impact of comorbidities among patients with bipolar disorder is significant, encompassing both direct expenses related to clinical management and indirect costs tied to reduced productivity. The authors emphasize the need for interventions that enhance health management to improve patient outcomes. The establishment of multidisciplinary programs involving pharmacists and psychiatrists within primary care could be one approach, as it would prevent the need for emergency interventions and contribute to continuous care, medication adherence, and cost reduction. The impact of improper management of comorbidities in BD, particularly when substance abuse is involved, directly affects close relationships, especially family members. This improper management generates negative experiences, such as feelings of exhaustion and an inability to provide care, worsens interpersonal relationships, and heightens the stigma associated with patients who have BD (September & Beytell, 2019).

The subsequent subtheme addressed "risky behaviors" during crises occurring in the absence of treatment or with inadequate treatment. These behaviors included SA, suicidal ideation, alcohol abuse, exposure to illicit substances, and actions that put one's life at risk without awareness of their severity. This finding is concerning: in a sample of 11 participants, 66% reported suicidal ideation, and 33% reported a history of SA. According to the study by Dome et al. (2019), the suicide rate among individuals with BD ranges between 4% and 19%, while the rate of those who engage in SA is between 20% and 60%, indicating an increased risk of suicide compared to the general population (Dome et al., 2019; Fernandes & Scippa, 2013), with a risk up to 30 times higher (Dome et al., 2019). Fernandes and Scippa (2013) suggest that this behavior may be associated with impulsivity, aggressiveness, and the predominance of depressive episodes throughout the disorder. Medication is an important ally in suicide prevention for BD patients, whether through the use of lithium, the main drug studied for this risk, or anticonvulsants such as valproic acid and carbamazepine. Thus, it is crucial that treatment is continued and initiated at the appropriate time, without delays, to prevent future complications (Fernandes & Scippa, 2013).

Substance abuse is also a reality for some individuals with BD, posing a significant challenge to treatment adherence and maintenance (Preuss et al., 2021). According to Ribeiro et al. (2005), among mental health issues, BD has a higher prevalence of psychoactive substance misuse, particularly alcohol abuse. This may be explained by the environment conducive to substance use during depressive episodes, as well as economic factors, neurochemical changes triggered by chronic use, or withdrawal. The study also highlighted that exposure to substances is not a root cause but may trigger crises and/or manifest typical BD symptoms. The authors conclude that multidisciplinary care involving family support is the most promising approach to achieving successful treatment (Ribeiro et al., 2005).

In addition to substance abuse, individuals with BD may face other health issues. Participants in this study reported diagnoses of ADHD, anxiety, and panic, along with comorbidities such as diabetes and hypothyroidism, often attributed to chronic psychotropic use. This issue was reported by participants treating both BD and ADHD and diabetes mellitus, who required medication adjustments to achieve balance. According to the study by Krishnan (2005), concomitant diagnoses negatively impact the diagnosis of BD and make its management more challenging.

The theme "Before and after the most effective medication" highlighted overcoming obstacles, adverse effects, uncertainties regarding diagnosis, financial difficulties, and challenges in dose management, among other factors, until treatment adherence was achieved. In the study by Inder et al. (2010), the theme "Living with uncertainties" addresses the distress experienced throughout the course of the disorder. The qualitative review article by Warwick et al. (2019), conducted to compile studies on the distress experienced by patients with BD, also presented "uncertainty" as one of the themes revealed, indicating an anguishing experience that precedes the diagnosis of BD and may persist throughout the course of treatment. This feeling arises both in relation to medication treatment and due to a lack of information about the mental health issue faced.

The symptomatic condition and mood fluctuations of all participants in this study gradually improved, although some continued to exhibit residual symptoms, which did not prevent them from feeling better. Participant i2 reported feeling well at the time of the interview; however, they noted that stable periods do not last long. Their psychiatrist informed them that their body is refractory to medications. The participant also reported having undergone electroconvulsive therapy. The current treatment, which includes clozapine and other medications, reflects treatment refractoriness, as clozapine is considered a last-resort medication due to its adverse effects and the necessity for rigorous laboratory monitoring. In the study by Morton et al. (2022), the results indicate that the well-being desired by patients goes beyond symptom absence; it is linked to the ability to engage in daily life within their social, family, and professional circles and to perform activities with quality. Treatment refractoriness in BD is a complex and challenging condition to establish, as the disorder is characterized by a diverse range of symptoms. This chronic variation can cause neurological cognitive impairment and contribute to medication refractoriness (Fountoulakis et al., 2020; Ministério da Saúde, 2016).

The participants in this study also weighed the pros and cons of following treatment, with a predominant awareness that the benefits outweigh the drawbacks, resulting in adherence to the current medication. Throughout the course of treatment, participants reported making decisions to discontinue medication use at certain times due to beliefs that they did not need medication to improve, because they were unable to maintain use due to moderate to severe adverse effects, financial difficulties, or due to doubts regarding their diagnosis. This same consideration was mentioned in Miasso's (2006) study, which showed that, despite possible toxic effects of medications, participants viewed stability as a positive and compensatory effect. Jaward et al.'s (2018) study presented a similar finding, indicating that non-adherence to treatment at certain times is characteristic of BD. Some possible causes are noted, including adverse effects, substance abuse, and the disorder's course pattern, all of which can cause adherence to fluctuate over time. Furthermore, there were reports of changes in administration times, discussions, and requests from participants to suspend or add medications in their pharmacotherapy – for example, participant i1 began using mirtazapine after discussing and negotiating with their psychiatrist. These decisions are part of the medication experience and represent the knowledge acquired over time about one's own body, mind, and the effects of the medication (Cappleman et al., 2014; Shoemaker & Ramalho de Oliveira, 2008). Decision-making throughout the course of the disorder involved something well-known in BD: individuals reflect on medication use during and after manic episodes due to increased creativity, energy, and productivity. However, they are aware of the dangers of this phase, which exposes them to life-threatening risks, excessive spending, and inappropriate behaviors. This was studied by Bulteau et al. (2018), who also concluded that, initially, participants experienced nostalgia for mania; however, this was not a reason for non-adherence, as they recognized the importance of medication for stability.

The treatment journey, though difficult, proved vital, as the changes experienced before and after using the correct medication were clear and contrasting. Self-reports in this study revealed significant behavioral changes following pharmacotherapy, as noted by both participants and people in their social circles, who had previously perceived them with negative attributes such as laziness or rudeness. After achieving clinical improvement, crisis control, and stability, participants recognized reduced influence of disorder symptoms and understood that many behaviors reflected manic and depressive episodes, which were often mistaken for personal characteristics. This allowed participants to rediscover themselves, viewing themselves with greater kindness. This identity confusion caused by the disorder is reported in the literature. Symptom manifestations can create confusion in self-perception, leading individuals to question who they truly are, and which aspects are symptomatic manifestations (Inder et al., 2008; Siegel-Ramsay et al., 2023).

It was also evident in this study that other factors are necessary for maintaining participants' stability, such as quality of life, family environment, and psychosocial support. The relevance of these factors is highlighted by Parikh and Kennedy (2004) and Goodwin and Jamison (2007), whose studies explain the psychoeducational measures that should be followed in managing the disorder. Psychoeducation is important for reducing the doubts and anxieties of those affected. In Maassen et al.'s (2018) study, participants in the focus groups also established a balance between pharmacological and non-pharmacological measures. Kashani et al.'s (2020) study emphasizes the need for health professionals to provide clear information and guidance throughout treatment, thereby preventing patients from experiencing doubts or confusion regarding their care.

Conclusion

The Phenomenology of Practice method proved suitable for accessing experiences with pharmacological treatment for bipolar disorder. The data obtained through the application of two distinct interview techniques – individual and focus group – complemented each other, enhancing understanding of the phenomenon under study. The process of recovering from acute crises is gradual, involving tumultuous periods that often precede diagnosis. This process includes trials with medications, experiences with adverse effects, lack of response, or clinical worsening until the most suitable prescription is identified. The importance of suitable medication was found to be vital for individuals with BD, as it plays a critical role in improving mood stability. All participants reported improvement and attributed positive meanings to the use of medications, despite many continuing to experience residual symptoms. The importance of non-pharmacological measures was also noted, as these should be included in the care process. Throughout the course of the disorder and treatment, such measures supported and facilitated social interaction, crisis management, handling comorbidities, managing adverse effects, and maintaining medication adherence, along with other subjective aspects of the patient. In conclusion, this study increased understanding of the lived experience of individuals undergoing pharmacological treatment for BD, contributing to the development of care processes.

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