

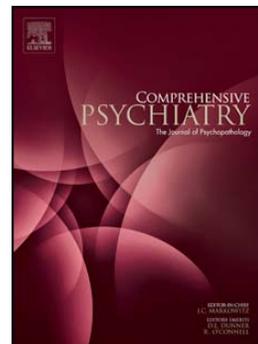
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Illness perceptions and adherence in bipolar disorder: an exploratory study

Priscillia Averous, Elodie Charbonnier, Marie Claude Lagouanelle-Simeoni,  
Antoine Prosperi, Lionel Dany

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**Author names and affiliations:**

Priscillia Averous <sup>a,b</sup>

<sup>a</sup> Aix Marseille Univ, LPS, Aix-en-Provence, France

<sup>b</sup> Unimes, LPS, Nimes, France

priscillia.averous@etu.univ-amu.fr

Elodie Charbonnier <sup>a,b</sup>

<sup>a</sup> Aix Marseille Univ, LPS, Aix-en-Provence, France

<sup>b</sup> Unimes, LPS, Nimes, France

elodie.charbonnier@unimes.fr

Marie Claude Lagouanelle-Simeoni <sup>a,c</sup>

<sup>a</sup> Aix Marseille Univ, LPS, Aix-en-Provence, France

<sup>c</sup> APHM, Conception, Service d'évaluation médicale, Marseille, France

marie-claude.simeoni@univ-amu.fr

Antoine Prosperi <sup>d</sup>

<sup>d</sup> Centre Hospitalier Montperrin, Aix en Provence, France

antoine.prosperi@ch-montperrin.fr

Lionel Dany <sup>a,e,f</sup>

<sup>a</sup> Aix Marseille Univ, LPS, Aix-en-Provence, France

<sup>e</sup> Aix Marseille Univ, CNRS, EFS, ADES, Marseille, France

<sup>f</sup> APHM, Timone, Service d'Oncologie Médicale, Marseille, France

lionel.dany@univ-amu.fr

**Corresponding author:**

Elodie Charbonnier

University of Nimes, Unimes - Rue du Docteur Georges Salan

CS 13019 - 30021 NIMES Cedex 1- FRANCE

elodie.charbonnier@unimes.fr

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**Abstract:**

**Background:** According to the Self-Regulation Model, illness perceptions influence an individual's coping (such as the taking of treatment) and emotional response to their illness. Emerging research suggests that this model could be used to explore illness perceptions in mental health. The aim of this exploratory study is, firstly, to measure and describe illness perception in French patients with a bipolar diagnosis and, secondly, to explore associations between illness perceptions and adherence in this population.

**Method:** Thirty-eight French patients with bipolar disorder completed the Illness Perception Questionnaire for Schizophrenia (except the identity dimension). We measured medication adherence with the Medication Adherence Rating Scale.

**Results:** Our results showed that patients with high perceptions concerning treatment control, low perceptions of negative emotions of their mental illness, low perception of consequences and high comprehension of their disorder had a better adherence

**Conclusions:** illness perceptions can provide a framework for understanding adherence in bipolar disorder, and the findings could have important clinical and research implications

**Keywords:** Illness perceptions, Bipolar disorder, Adherence, Self-Regulation Model

## 1. Introduction

Bipolar disorder is one of the most severe and chronic mental disorders. Bipolar patients have low adherence rates [1,2]. A survey from eight European countries estimated that 57% of bipolar patients were partially or non-adherent to medication [3]. Non-adherence in bipolar disorder is associated with higher rates of relapse and hospitalization [4], so it is necessary to understand the reasons behind non-adherence better. The Self-Regulation Model (SRM) developed by Leventhal, Nerenz and Steele [5] introduces a relationship between illness perceptions, health outcomes and coping. In this model, illness perceptions have been proposed to influence an individual's coping (such as the taking of treatment) and emotional response.

Previous studies [5] have suggested that illness perceptions were classified in accordance with five sets of attributes or dimensions: identity, control, timeline, consequences and cause. Identity refers to the label a patient has assigned to their illness and the symptoms associated with this label. The timeline dimension refers to an individual's perception of the course of the illness or condition. Consequences reflect someone's evaluation of the impact (including physical, emotional, social and economic outcomes) that the illness or condition might have on their life and activities. Control is the search for effective strategies available to control or cure the illness or condition. Control can be divided into personal control, reflecting beliefs about personal abilities to control the illness, and treatment control, reflecting the beliefs about the treatment's effectiveness in curing or managing the illness. Finally, the cause dimension is related to the factors believed to be the cause of the illness or condition.

Initially, the SRM was mainly used for somatic diseases. In somatic illnesses, the importance of understanding variation in emotional and behavioral responses to illness has been clearly recognized, especially the influence of illness perceptions on recovery and effective coping. More recently, the SRM has been used to explore illness perceptions in mental health. A recent review of the literature [6] indicated that this model can be applied to persons with mental disorders (psychosis, eating disorders, depression and bipolar disorder). According to Lobban, Barrowclough and Jones [7], the SRM is a useful framework for understanding and exploring illness perceptions in mental health as well as physical health. However, they specify that modifications are necessary. For example, in the Illness Perception Questionnaire for Schizophrenia (IPQS) 'illness' was replaced by 'mental health problem' [8].

The SRM has been very little used in people with bipolar disorder. Lobban et al. [9] used the Brief Illness Perception Questionnaire (BIPQ) [10] modified for bipolar disorder (they replaced “illness” with “mood swings”) and studied the role of beliefs on symptomatology (severity of depression) and time to relapse. They showed that bipolar patients with low personal control of their mood swings and who perceived they were making less effort to get well reported higher levels of depression. Beliefs about severity of consequences, identity and degree of personal concern affected time to relapse. Representations about severity of consequences and personal effort affected the likelihood of greater fluctuations of depressed mood. But they emphasized that the nature of these effects is likely to be complex and requires further research. Oflaz et al. [11] also used the BIPQ (translated into Turkish) and demonstrated differences in illness perceptions between dropouts (patients who stop their treatment or lack contact with a treatment center for at least one month to one year) and attended bipolar patients, more specifically in four subscales: consequences, treatment control, identity and emotional representations. The dropout patients perceived fewer consequences, were less affected by their disorder and mostly thought that their treatment did not control their disorder than did attended patients. Their scores suggest that they failed to fully comprehend the significance of their illness and could be in denial. Hou, Cleak and Peveler [12] focused more specifically on the impact of illness representation on adherence in bipolar disorder with the Revised Illness Perception Questionnaire (IPQ-R). They observed significant differences between adherent and non-adherent in two dimensions: “consequences” and “timeline”. The non-adherent thought that their illness caused more negative effects on their life and would have a longer-term impact than did adherents.

The component and the expression of illness beliefs are not well documented in the context of bipolar disorder. Furthermore, the influence of illness perceptions on adherence in bipolar disorder has not yet been fully understood. The aim of this exploratory study is, firstly, to measure and describe illness perceptions in French patients with a bipolar diagnosis and, secondly, to explore associations between illness perceptions and adherence in this population.

## 2. Material and methods

### 2.1. Sample and procedure

There were 38 participants, with a mean age of 42.4 years (SD 14.01 years; range 19-75; 9

male, 29 female). They were recruited from a psychiatric center in France before a psychoeducation program. Criteria for inclusion were that patients should have a clinical diagnosis of Bipolar I or II with no major depressive, hypomanic, manic or mixed episode in the last 2 months and be taking psychiatric medications (mood stabilizers, and/or antidepressants, and/or antipsychotics). All subjects gave their informed consent for inclusion before they participated in the study. Research measures were carried out by a clinical investigator at the psychiatric center, during a face-to-face interview. The Aix-Marseille University Ethics Committee approved this research.

## 2.2. Measures

### 2.2.1. Illness Perception Questionnaire for Schizophrenia (IPQS)

We used the Illness Perception Questionnaire for Schizophrenia (IPQS) [8], the most valid measure for psychiatric disorder, in the absence of a questionnaire specific to bipolar disorder. The IPQS is an adaptation of the Illness Perception Questionnaire–Revised (IPQ-R) [13] for people with a diagnosis of schizophrenia. In IPQS, ‘illness’ was replaced by ‘mental health problem’ and ‘symptom’ was replaced by ‘experience’ [8]. In our research, items and instructions of the English version of the IPQS were translated and adapted for the French language via a back and forth translation procedure. Firstly, the English IPQS was translated into French by an English native speaker specialized in this research field. Then, a French native speaker translated this document back into English. The two translations (English to French and French to English) were compared in order to ensure that they were both faithful to the original and that the items in the French version were clear. The identity dimension was excluded because it was too specific to schizophrenia.

Illness perceptions were assessed from 47 statements on a 5-point Likert-type scale, ranging from 1 (“strongly disagree”) to 5 (“strongly agree”) grouped into 8 dimensions. For the dimension “Timeline Acute/Chronic” (6 items), a high score denoted a chronic vision of their disorder (e.g., “My mental health problems are likely to be permanent rather than temporary”). For dimension “Timeline Cyclical” (4 items), a high score denoted a cyclical perception (e.g., “Some of my symptoms will be there all the time but others will come and go”). The dimension “Consequences” (11 items) assessed the level of negative impact of mental health problems on their life (e.g., “My mental health problems cause difficulties for those who are close to me”). A high score illustrated substantial negative consequences. The

dimension “Personal Control” (4 items) corresponded to perceived personal control (e.g., “There are some things that I can do to control my symptoms”). The dimension “Personal Blame” (3 items) assessed self-blame (e.g. “If I were a stronger person, I would get better”). For the dimension “Treatment Control” (5 items), a high score illustrated a strong belief that treatment would be helpful in managing their disorder (e.g., “My treatment can control my mental health problems”). The dimension “Illness Coherence” (5 items), evaluated how patients understood their illness. A high score denoted a sense of not having a coherent understanding of their disorder (e.g., “I don’t have any understanding of my mental health problems at all”). And the dimension “Emotional Representation” (9 items) corresponded to emotional response (e.g., worry, anxious, angry) to their mental health problems (e.g. “My mental health problems make me feel afraid”). A high score denoted a strong negative emotional response as a result of the mental health problems. The IPQS also includes 26 common causes for the development of disorders. Four items in the IPQ-R were eliminated in the IPQS because they were not relevant to mental disorders and 12 items were added (“taking illicit drugs”, “my family’s behavior”, “lack of friends or people who care about me”, “chemical imbalance in the brain”, “a trauma”, “death of a loved one”, “money worries”, “someone spiked my drink”, “lack of sleep”, “thinking about things too much”, “my upbringing”, and “being bullied at school”). Each item was rated as to how much the respondent agreed or disagreed that this item could have been a causal factor in the development of their mental health problems (ranging from 1 “strongly disagree” to 5” strongly agree”).

#### 2.2.2. The Medication Adherence Rating Scale (MARS)

The Medication Adherence Rating Scale (MARS) is a ten-item self-report measure of medication adherence. The original binary response option (no/yes) was used. This scale is based on two measures of compliance: the Drug Attitude Inventory (DAI) [14] and the Medication Adherence Questionnaire (MAQ) [15]. These compliance measures were combined to produce a compliance scale. Total score ranged from 0 (poor adherence) to 10 (good adherence). Three subscales were evaluated [16], the medication adherence behavior (e.g., “Do you ever forget to take your medication?”), the attitude to taking medication (e.g., “My thoughts are clearer on medication”) and the negative side-effects and attitudes to psychotropic medication (e.g., “I feel weird, like a “zombie”). In our research, we used the French translation of the MARS [1]. This translation followed an internationally accepted methodology in 3 steps: forward translation, backward translation, and patients’ cognitive debriefing [18].

### 2.3. Statistical analyses

Descriptive analysis of socio demographic, adherence, illness perceptions and illness causes were expressed as means, standard deviations (SD), median, minimum and maximum. We measured inter-dimension Spearman's correlation for IPQS and Cronbach's alpha coefficient for each dimension to assess the reliability of these dimensions. Then all, we conducted a linear regression analysis predicting adherence including illness perceptions, gender and age. Data were analyzed using SPSS version 23.

## 3. Results

### 3.1. Descriptive analysis

The mean MARS score was 6.18 (SD = 2.09), with a range of 1–10. The median score was 6. The mean of “medication adherence behavior” (0-4) was 2.34 (SD = 1.07), the mean of “attitude to taking medication” (0-4) was 2.71 (SD = .90) and the mean of “negative side-effects and attitudes to psychotropic medication” (0-2) was 1.13 (SD = .94). We observed no differences between men and women.

Table 1 illustrates characteristics of illness perceptions. Median scores suggest that participants tended to perceive their disorder as having a moderate effect on their lives and on their emotions. The sample viewed their mental health problems as being chronic and cyclical. They thought their treatment to be very helpful in controlling their disorder. They perceived high personal control, low self-blame and moderate coherent understanding of their disorder. We observed no differences between men and women. Cronbach's Coefficient Alphas of four dimensions (timeline cyclical, consequences, personal control and emotional representation) were in the desired range (.7–.9). Cronbach's Coefficient Alphas of three dimensions (timeline acute/chronic, treatment control and illness coherence) were acceptable (range .5-.6). The dimension assessing personal blame was clearly unreliable.

Insert Table 1

From the most causal attributions concerning illness (Table 2), two broad themes emerged. Firstly, environmental factors with items such as “stress or worry”, “a trauma”, “death of a loved one”, “my family's behavior” or “family problems”. Secondly, internal factors related to

biological functioning (“chemical imbalance in the brain”) or psychological functioning (“thinking about things too much”, “my personality”, “my own behavior”). We observed no differences between men and women except for one cause: “brain damage or abnormality” ( $M_{\text{women}} = 1.86$  vs  $M_{\text{men}} = 2.89$ ;  $U = 64$ ;  $p = .02$ ).

Insert Table 2

### 3.2. Inter-correlations of illness perceptions

Intercorrelations between illness perceptions are presented in Table 3. Three dimensions: “emotional representations”, “illness coherence” and “treatment control” were associated. The dimension “consequences” was significantly related to “emotional representations” and “treatment control”. The dimension “Timeline cyclical” was significantly related to “consequences” and “treatment control”. And the dimension “Timeline chronic” was associated with the dimension “personal control”.

Insert Table 3

### 3.3. Adherence and co-factors

The bivariate correlations between adherence and illness perceptions are presented in Table 4. A number of significant correlations between these variables emerged. Inspection of the correlation matrix revealed that high adherence (high total MARS score) was significantly associated with low consequences, low emotional representations, high belief that treatment would be helpful and high coherent understanding of their disorder. All subscales of adherence were negatively related to the dimensions “consequences” and “emotional representation” except the medication adherence behavior. The medication adherence behavior was negatively associated with “illness coherence”. So, the more coherent was their understanding of their disorder (low score “illness coherence”), the more they exhibited medication adherence behavior. Beliefs about efficiency of treatment were associated at all subscales of adherence except “Attitude to taking medication”.

Insert Table 4

We conducted an additional correlation analysis between adherence and illness causes. A total

MARS score was associated with three causes: “being bullied at school” ( $r = -.51$ ;  $p = .001$ ), “diet or eating habits” ( $r = -.48$ ;  $p = .002$ ) and “poor medical care in my past” ( $r = -.40$ ;  $p = .01$ ). Attitude to taking medication was also correlated with three causes: “poor medical care in my past” ( $r = -.44$ ;  $p = .006$ ) and “diet or eating habits” ( $r = -.37$ ;  $p = .02$ ) and “my upbringing” ( $r = -.32$ ;  $p = .05$ ), and adherence behavior was correlated with two causes: “hereditary” ( $r = .46$ ;  $p = .003$ ) and “a germ or virus” ( $r = -.32$ ;  $p = .05$ ). “We also conducted an additional correlation analysis with age. Age was associated with “emotional representation” ( $r = -.34$ ;  $p = .04$ ), total MARS score ( $r = .34$ ;  $p = .04$ ) and four common causes: “diet or eating habits” ( $r = -.45$ ;  $p = .005$ ), “my mental attitude e.g.; thinking about life negatively” ( $r = -.41$ ;  $p = .01$ ), “alcohol” ( $r = -.37$ ;  $p = .03$ ) and “brain damage or abnormality” ( $r = -.36$ ;  $p = .03$ ),

### 3.3. Regression analysis

The regression coefficients indicated that emotional representations ( $B = -.70$ ;  $p = .0001$ ;  $R^2 = .47$ ) and treatment control ( $B = .53$ ;  $p = .001$ ;  $R^2 = .28$ ) were significant predictors of adherence.

## 4. Discussion

This study provides evidence that illness perceptions could be a heuristic framework for understanding adherence in bipolar disorder. Illness perceptions were associated with medication adherence behavior, attitude to taking medication and negative side-effects and attitudes to psychotropic medication. Our results showed that patients with high perceptions concerning treatment control, low perception of negative emotions about their mental illness, low perception of consequences and high comprehension of their disorder had better adherence. These results suggest that improving illness perceptions in patients with bipolar disorder, particularly by increasing treatment control perceptions and understanding of their disorder and reducing consequence perceptions and emotional representations, may help to improve adherence.

Moreover, perceptions of treatment control appear to be good predictors for adherence. Patients who have little faith in the role of medication in controlling their disorder, or who thought that there were alternative ways of controlling their disorder, appeared to be less likely to take it

[19]. But, even if bipolar patients mostly believe their treatment is effective on overall mood, functional level and stress levels, they still struggle to take it regularly [20]. The main obstacles would be difficulties with medication routines, worry about medication side effects and denial of illness severity. This suggests that illness perceptions about treatment control (medications perceived as being helpful, with specific beneficial effects on mood or functional status) are essential in the decision to take it. So, promoting health beliefs that support appropriate pharmacotherapy and empowering patients to take it could improve treatment adherence. But, it is also necessary to understand treatment perceptions, patients' worries about medication and side effects but also the possible difficulties of taking it, in order to empower patients to take control of their treatment and their illness. Indeed, although our results showed a non-significant relationship between personal control and adherence, Darling, Olmstead, Lund and Fairclough [21] have demonstrated that non-adherent patients did not feel as though they had personal control over their illness. So, for future research, we believe that a mixed-method approach, both qualitative and quantitative, could give us a better understanding of the role of illness perceptions, more specifically perceptions of treatment control, in adherence. Qualitative research methodologies may therefore be required to explore this topic in a more elaborate way. Moreover, qualitative research has found that assessing illness perceptions in bipolar patients can be therapeutic, allowing patients to consider new issues and clarify their illness [22].

Emotional representations and consequences were also associated with adherence, and emotional representations appeared to be a good predictor of adherence. But inconsistent findings have been reported in the literature between these dimensions and adherence. Hou, Cleak and Peveler [12] found non-significant differences between adherent and non-adherent for emotional representations but they showed that adherent patients perceived fewer consequences than non-adherent, while Oflaz et al. [11] observed that dropout patients perceived fewer emotional responses and fewer consequences than attended patients. In this research, authors highlight the fact that dropout patients could be in denial (they perceived very few symptoms in the dimension identity). So, these divergences in the literature can be explained by the level of insight. We demonstrated that patients with a high understanding of their disorder were more adherent and were less emotionally affected. Insight leads to recognition of the problem, to be more realistic and better able to apprise the consequences of their problems or report more difficulties [23]. Baines and Wittkowski [6] suggested that patients who understand their disorder were more likely to engage with services and be more

open to seeking professional help, and Novick et al. [24] have demonstrated an association between insight and adherence. So, patients in denial would not be emotionally affected by their disorder and may consider that their illness did not have consequences on their life because they do not recognize their disorder and they do not take their treatment, while patients with a high understanding of their disorder would also not be affected emotionally by their disorder with little impact on their life because they take their treatment and manage to stabilize their symptoms. Therefore, phases of bipolar disorder are important. Indeed, previous studies showed that insight in bipolar patients depending on affective states. More precisely, in mania, insight is lower than in depression and euthymia [25-26], and individuals suffering from mania exhibit less insight about the effectiveness of treatment and the social consequences of the disorder [27-29]. This suggests that it is necessary to assess insight and clinical outcomes with illness perceptions, and during different affective phases of bipolar disorder, in order to better understand how illness perceptions interact with adherence for further investigations

For causal attributions, most of the studies were conducted with psychosis patients and generally tended to find no significant relationship between biological causes and treatment adherence [30–32]. For depression, O'Mahen, Flynn, Chermack and Marcus [33] showed that hereditary attributions were not significantly associated with treatment use and Lynch, Kendrick, Moore, Johnston and Smith [34] showed that greater endorsement of genetic factors is associated with less adherence. But no research associating adherence and causal attributions has been conducted on bipolar patients. Our results show the role of attribution as being causal on adherence. Patients with environmental conceptions (such as “being bullied at school”, “diet or eating habits” or “poor medical care in my past”) were less adherent. But causes referring to biological conceptions of their disorder (such as “chemical imbalance in the brain” or “hereditary”) were not associated with adherence. However, studies have shown that internal causal attributions were more associated with good psychosocial adjustment (including adherence) for patients. These causal attributions are different in their “nature”; the biological causal attribution is more an internal causal attribution than an environmental one, which is an external cause. So, this area of research could provide a better understanding of the effects of causal attributions on bipolar patients and their coping with their disorder, and deserves to be developed.

A number of methodological limitations need to be acknowledged including: sample, recruitment and measure of illness perceptions. Firstly, the small sample size limited the

statistical power and precision of the results. Secondly, our participants were recruited before the psychoeducation program. Initially, our protocol aimed at assessing modification in illness perceptions following a psychoeducation program. But the high number of patient dropouts did not allow this project to proceed. Thirdly, there was no French scale assessing illness perceptions and specific to bipolar disorder. So, we had the IPQS translated, which may have reduced the reliability and validity of the measure. Despite these limitations, it is the first research in France investigating illness perceptions and adherence in French people with bipolar disorder. So, future research with larger and more representative samples of French bipolar patients is needed to replicate and confirm these findings. Moreover, future studies should include comprehensive measures of insight in order to better understand how illness perceptions interact with adherence and during different affective phases of bipolar disorder.

## 5. Conclusion

In conclusion, these findings have important clinical and research implications. These suggest that illness perceptions (treatment control, coherence, consequences and emotional representations) play an important role in adherence and show that the SRM can be applicable and pertinent for French persons with bipolar disorder. These first results can be used to develop new targets for intervention strategies to foster treatment adherence and improve clinical outcomes. To improve adherence, clinicians should ensure that patients understand their disorder and needs, in order to check patients' perceptions about whether medications can help control their illness and explore patient concerns on their treatment. Moreover, clinicians must assess the negative impact of the disorder on the patient's life and their emotions.

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Table 1: Descriptive characteristics of illness perceptions (IPQS)

Illness perceptions	Items	Mean (SD)	Median	Min	Max	Alpha
Treatment Control	5	4.10 (.55)	4.1	2.80	5	.56
Personal Control	4	4.07 (.71)	4.25	2.25	5	.81
Timeline acute/chronic	6	3.92 (.55)	4	2.67	4.83	.67
Timeline cyclical	4	3.89 (.76)	4	2	5	.73
Emotional Representation	9	3.45 (.84)	3.56	1.78	4.89	.87
Consequences	11	3.31 (.73)	3.45	1.91	4.91	.81
Illness Coherence	5	2.70 (.69)	2.8	1	4	.57
Personal Blame	3	2.65 (.71)	2.67	1.33	4.33	.22

Table 2: Descriptive characteristics of the potential causes in the development of their bipolar disorder (ranging from 1 to 5)

Illness Causes	Mean (SD)	Median	Min	Max
Stress or worry	4.08 (0.97)	4	1	5
A trauma; something disturbing or shocking that happened in my life	3.97 (0.97)	4	1	5
Chemical imbalance in the brain	3.66 (1.09)	4	1	5
Thinking about things too much	3.45 (1.43)	4	1	5
My family's behavior	3.40 (1.28)	4	1	5
Death of a loved one	3.32 (1.23)	4	1	5
Hereditary; it runs in my family	3.30 (1.25)	3.5	1	5
Family problems	3.24 (1.30)	4	1	5
My personality	3.24 (1.09)	3	1	5
My own behavior	3.21 (1.34)	4	1	5
Overwork	3.03 (1.30)	3	1	5
Lack of sleep	3.00 (1.49)	4	1	5
My mental attitude e.g.; thinking about life negatively	2.84 (1.39)	3	1	5
Lack of friends or people who cared about me	2.45 (1.33)	2	1	5
Being bullied at school	2.40 (1.39)	2	1	5
Money worries	2.35 (1.36)	2	1	5
Chance or bad luck	2.32 (1.42)	2	1	5
My upbringing	2.26 (1.31)	2	1	4
Poor medical care in my past	2.13 (1.34)	2	1	5
Brain damage or abnormality	2.11 (1.20)	2	1	5
Taking illicit drugs	2.08 (1.51)	1	1	5
Alcohol	1.92 (1.30)	1	1	5
Diet or eating habits	1.82 (1.06)	1.5	1	5
Someone spiked my drink with illicit drugs	1.74 (1.15)	1	1	5
Pollution in the environment	1.58 (0.76)	1	1	4
A germ or virus	1.32 (0.74)	1	1	5

Table 3: Inter-dimensional Spearman's correlations between illness perceptions (IPQS)

	Timeline acute/chronic	Timeline cyclical	Consequences	Personal Control	Personal Blame	Treatment Control	Illness Coherence
Timeline acute/chronic	1						
Timeline cyclical	.31						
Consequences	.18	.65***					
Personal Control	.32*	.17	.10				
Personal Blame	.01	.18	.20	-.23			
Treatment Control	.09	-.32*	-.55***	.27	-.32		
Illness Coherence	-.25	.17	.30	-.12	-.04	-.54***	
Emotional Representation	.03	.63***	.81***	-.02	.16	-.55***	.42**

\*p &lt; 0.05, \*\*p &lt; 0.01, \*\*\*p &lt; 0.001

Table 4: Spearman's correlations between illness perceptions (IPQS) and adherence (MARS)

	Medication adherence behavior	Attitude to taking medication	Negative side-effects and attitudes to psychotropic medication	Total MARS Score
Timeline acute/chronic	.20	-.004	-.08	.07
Timeline cyclical	-.14	-.35*	-.37*	-.41**
Consequences	-.29	-.49**	-.51**	-.59***
Personal Control	.14	-.39*	-.07	-.10
Personal Blame	.11	-.16	.02	-.04
Treatment Control	.38*	.28	.34*	.47**
Illness Coherence	-.47**	-.22	-.27	-.44**
Emotional Representation	-.30	-.48**	-.69***	-.68***

\*p < 0.05, \*\*p < 0.01, \*\*\*p < 0.001