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# Unquiet Treatment: Handling Treatment Refusal in Bipolar Disorder

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## Abstract

Individuals with bipolar disorder (BD) frequently refuse to accept an adequate treatment plan. We describe strategies to help people with BD overcome treatment refusal and accept adequate treatment. We describe several strategies aimed at helping the clinician increase the patient's willingness to accept an adequate treatment plan. We also discuss strategies clinicians can use when negotiating a compromise treatment plan for patients who refuse to accept optimal treatment and for situations where the patient and clinician cannot negotiate a mutually agreeable treatment plan.


*Keywords*: treatment refusal, bipolar disorder, nonadherence, noncompliance

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A talented graphic artist, Jen, sought treatment, reporting that she was feeling down and irritated by others. As a result of an argument with a supervisor, Jen had lost her position as an art instructor several months earlier. She remained unemployed, scraping away at the remains of her savings account. The clinician Jen consulted (the first author) proposed to Jen that they meet for two or three sessions in which the clinician would conduct a comprehensive assessment and offer treatment recommendations for Jen. At that point, the clinician and Jen would decide whether it made sense to work together in therapy. Jen agreed to this plan.

The clinician first conducted the Structured Clinical Interview for DSM-IV (SCID-I/P; First et al., 2007), which revealed that Jen had a history of prior depressive episodes and several suicide attempts leading to hospitalization. Jen also described periods of elevated mood, high energy, and creativity. During these times she felt like Joan of Arc and believed that many of her paintings were products of direct communications with saviors from the past. Jen also had a history of irritability and conflicts with others who doubted these powers. One of these conflicts had cost her a recent job. She stated that her father had had similar experiences and had been "written off" as having bipolar disorder (BD).

The clinician concluded that Jen suffered from significant swings in mood and met criteria for BD and presented this information to her, reviewing with her the DSM-IV (American Psychiatric Association, 2000) symptoms for depression and mania. The clinician also gave Jen information about several empirically supported psychosocial treatments for BD (for summary and key features, see Johnson & Fulford, 2008). This included Family-Focused Treatment (FFT; Miklowitz & Goldstein, 1997), Interpersonal and Social Rhythm Therapy (IPSRT; Frank, 2005),

and Cognitive-Behavioral Therapy (CBT; Basco & Rush, 2006; Newman, Leahy, Beck, Reilly-Harrington, & Gyulai, 2002; Rush, 1998). Jen's clinician recommended pharmacotherapy and CBT for Jen, because this combined treatment plan was supported by efficacy data and the clinician had training in CBT.

However, Jen refused to accept the diagnosis of BD and rejected the clinician's treatment recommendations. She complained that her irritability made perfect sense in light of the unfriendly behavior of her colleagues at work, and she insisted that she did not understand how feeling "good" could constitute a "severe mental illness." She stated that she had come to therapy to get help managing interpersonal conflicts caused by her coworkers and others, and to reestablish herself as a professional, not to be "labeled" as mentally ill and told she needed to monitor her mood swings and take medications.

The clinician found herself in a dilemma. Without treatment, Jen was at risk for exacerbation of her mood disorder, situational danger (she was sleeping in her car), and suicide (she had made several previous attempts). However, if the clinician agreed to treat Jen without addressing her mood swings or providing medication, she would be providing inadequate treatment that was not empirically supported and that might reinforce Jen's view that her mood swings were not problematic. Given Jen's unquiet, indeed, vociferous refusal of an adequate treatment plan, the clinician confronted the difficult dilemma of whether to go forward with a less than optimal treatment or to not treat an ill person. We address this dilemma here and offer strategies to help the clinician think through how to overcome the situation in which a person who has BD refuses to accept an adequate, evidence-based, treatment plan.

*Treatment Refusal: A Dilemma in BD*

Individuals with BD often experience episodes of mania or depression and can experience both simultaneously (mixed state) (American Psychiatric Association, 2000). Both types of episodes significantly disrupt social bonds and occupational performance and put the patient at high risk for harmful behaviors (e.g., Coryell et al., 1993). In fact, up to 29% of individuals with BD attempt suicide (Yuan-Who & Dissever, 1996), and 15 to 19% ultimately die from suicide (Isometsa, 1993; Simpson & Jamison, 1999), a rate 12-15 times greater than that found in the general population (e.g., Angst et al, 2002). Given the toll that BD can take, successful treatment is crucial.

Considerable evidence supports the utility of pharmacotherapy in the treatment of BD (Otto et al., 2005). Adjunct psychosocial treatments further reduce symptoms, prevent relapse, and promote adherence to pharmacotherapy for patients with BD (Craighead et al., 2002). For example, FFT is associated with reduced relapse rates compared to no treatment (11% for FFT vs. 63% no treatment; Miklowitz & Goldstein, 1990). Other empirically-validated treatments for BD include CBT (Basco & Rush, 2006; Newman et al., 2001; Lam et al., 2005; Lam et al., 2003; Lam et al., 1999; Perry et al., 1999; Scott, 1995) and IPSRT (Frank, 2005). Lam and colleagues (2005) showed that CBT was associated with decreased number of days spent in mood episodes and improved social functioning and coping skills. Frank et al. (2005) demonstrated that bipolar patients assigned to IPSRT plus pharmacotherapy had a longer duration between mood episodes and more regular social rhythms than those who received intensive clinical management, a manual-driven approach focused on the medical management of BD (Fawcett et al., 1987).

However, despite the availability of effective treatments, many individuals with BD receive inadequate treatment or no treatment at all. Epidemiological data indicate that only 44% of individuals diagnosed with BD were in treatment when surveyed (Kessler et al., 1997).

Further data suggest that 61% of patients with BD who were surveyed in the National Comorbidity Survey Replication did not receive even minimally adequate treatment (Wang et al., 2005). In this paper, we focus on the role treatment refusal plays in contributing to insufficient treatment utilization in BD.

*Distinction between Treatment Refusal and Nonadherence*

Treatment refusal is rarely explicitly discussed in the clinical literature on BD. When it is discussed, it is generally subsumed under nonadherence (also termed noncompliance) (Basco, Merlock & McDonald, 2004; Cochran, 1984). Although they are certainly related, treatment refusal and nonadherence are distinct phenomena. Treatment refusal entails an explicit rejection of all or part of the treatment plan. In nonadherence, by contrast, the patient agrees to the treatment plan but fails to consistently carry it out.

We believe that it is clinically useful to identify refusal as a phenomenon distinct from nonadherence for two reasons. First, the nonadherent patient is receiving some therapeutic attention, whereas the patient who refuses treatment altogether is receiving none. Any interventions that can entice these patients to enter treatment or stay in treatment have the potential to make a difference in the high morbidity and mortality caused by the disorder. Second, the dilemma faced by Jen's therapist is very different from the dilemma faced by the therapist whose patient agrees to a treatment plan but has difficulty carrying it out. One important difference is that Jen's therapist faces the question of whether to agree to the inadequate treatment plan that Jen is requesting. This question has not, to our knowledge, been discussed in the literature in any detail, despite the frequency with which it arises.

*Pre-Treatment Phase*

To address treatment refusal in BD, we recommend that clinicians explicitly designate a group of early sessions as pre-treatment (Persons, 2008). Pre-treatment refers to an initial phase in which the clinician provides the patient with information about the proposed treatment plan and helps the patient accept it (see Figure 1). It occurs after the clinician carries out an initial assessment, assigns a diagnosis, and develops a case formulation and treatment plan, but before full treatment begins. However, pre-treatment can happen at other point in treatment as well, such as when the clinician wishes to change the direction of treatment or implement a new phase in the existing treatment plan. The general concept here is that before providing treatment (or a change in treatment), the clinician asks for and obtains the patient's agreement to the proposed treatment plan. Throughout this process, it is essential that the clinician thoroughly document the rationale for the treatment plan, the interventions used, and the rationale for the patient and clinician agreeing not to work together if a treatment plan cannot be agreed upon.

Carving out a pre-treatment phase between the assessment and actual treatment is important for several reasons. First, APA ethical principles (American Psychological Association, 1992) do not allow a clinician to provide treatment without first informing the patient about what is being provided and obtaining the patient's informed consent to proceed. Second, a pre-treatment phase can increase the likelihood of treatment compliance and success by requiring the patient to think through whether she is willing to do what is required before starting, instead of simply getting started and seeing how things go. Indeed, moving forward with treatment without obtaining the patient's agreement to comply with the treatment is risky because the patient and clinician can expend a lot of effort, time, and money, yet fail at the end if the patient is unwilling to complete the course of treatment. Third, the pre-treatment phase provides the clinician with a few sessions in which to discuss the BD diagnosis and to help the

patient perceive the need for treatment. This is not to say, however, that treatment cannot begin until the patient accepts the diagnosis. If the patient is not ready to accept the diagnosis right away, as many individuals with BD are not (Frank, 2005), patient and therapist can still agree to work together to address collaboratively established treatment goals (Kingdon & Turkington, 2005), such as reducing mood swings or improving relationships.

The ideas we present here as part of pre-treatment are adapted from empirically-supported approaches for other disorders, including dialectical behavioral therapy (DBT) for borderline personality disorder (e.g., Linehan, 1993; Swenson, Sanderson, Duilt, & Linehan, 2004) and CBT for schizophrenia (Kingdon & Turkington, 2005). In fact, the notion of pre-treatment itself was borrowed from DBT (see also Linehan, 2001). We also borrow extensively from motivational interviewing (MI; Miller & Rollnick, 2002), which was developed to treat individuals who have significant behavioral problems that they are ambivalent about changing, as well as from strategies for handling nonadherence in BD (e.g., Basco, Merlock, & McDonald, 2004). Research is needed to confirm that our suggestions are actually effective in reducing treatment refusal in BD. Future research may also be helpful in identifying processes that promote treatment refusal as well as additional strategies to overcome it.

In the pre-treatment phase, the clinician carries out interventions to inform the patient about the diagnosis and the proposed treatment plan, and to help the patient accept an adequate treatment plan. Strategies include psychoeducation, cognitive restructuring, motivational interviewing, collecting a life chart, involving family members, and collaborating with psychopharmacologists. We recommend that the clinician obtain the patient's informed consent to carry out such interventions before treatment begins. The clinician can inform the patient

directly that she would like to use these early sessions to help the patient understand and think through his treatment decisions, and ask the patient's permission to do so.

*Psychoeducation.* Accurate information about BD and its treatment, including information about the nature and course of treated and untreated BD, can help the patient agree to a top-notch treatment plan. In addition to providing information in the session, psychoeducation can also be accomplished by asking patients to do reading outside of the therapy session, as recommended by Newman and colleagues (2001). Autobiographical works can provide important diagnostic and treatment information while also de-stigmatizing the illness (e.g., Hinshaw, 2002; Jamison, 1994; Simon, 2002). This information can help bipolar patients with the difficult task of understanding and, ultimately, accepting their diagnosis and that their mood swings represent a problem (Frank, 2005). This recommendation is supported by the fact that existing treatment manuals for BD often include a psychoeducation component. For example, both FFT (Miklowitz & Goldstein, 1997) and IPSRT (Frank, 2005) protocols provide patients with information about the symptoms, course, and prognosis of untreated BD.

Jen's clinician recommended that she read the autobiographical writings of Kay Jamison (1994), describing them as the writings of another unique and highly artistic professional woman who had experiences of intense creativity and energized mood. Her clinician suggested that Jen could use the materials to come to her own conclusions about whether BD might account for some of her experiences. After reading Jamison's writings, Jen was able to identify shared experiences with Jamison's descriptions and to openly consider the possibility that she might also have BD.

*Cognitive restructuring.* Cognitive restructuring techniques, which are widely used to treat BD, can also be helpful in addressing beliefs that prompt patients to refuse treatment.

Newman and colleagues (2001) describe strategies the clinician can use to help patients test the reality of "hyperpositive" thoughts and beliefs during a manic episode that interfere with insight and judgment, including about whether treatment is needed. Jen's clinician used cognitive restructuring to address Jen's thoughts about medication, such as "medication is only for people who feel sick" and "if I take medication, I will lose all my good ideas and energy." She also used cognitive restructuring to address Jen's faulty belief that the sole cause of her interpersonal difficulties with coworkers was external (e. g., "They are cruel people."). This work enabled Jen to entertain the possibility that her own irritability and grandiosity may have played a role in the interpersonal conflicts she experienced.

*Motivational interviewing strategies.* Motivational interviewing (MI) strategies (Miller & Rollnick, 2002) were designed to help individuals who have difficulty perceiving the presence or severity of significant behavioral problems and difficulty taking the steps needed to address those problems. Although MI has been most widely used to treat substance abuse, it is now also being used to treat a wide range of disorders and problems. Strategies of accurate empathy, reflective listening, and building self-efficacy can help individuals with BD accept their illness and the need for treatment, and can be more helpful than confrontational tactics that can activate reactance. Lam and colleagues (1999) highlight the importance of fostering autonomy and personal freedom in the person with BD as a way of facilitating his or her acceptance of an adequate treatment plan. One MI exercise for the treatment-refusing person involves helping the person examine the pros and cons of accepting the clinician's proposed treatment plan. This strategy is also used in cognitive therapy for BD to help the patient examine the advantages and disadvantages of experiencing an elevated or manic mood (Newman, 2001). A second MI exercise involves highlighting discrepancies between the patient's current state and his or her

goals and values. For example, Jen's clinician worked carefully with Jen to describe her life goals, which included a career as an artist. Next, the clinician discussed with Jen how her anger towards others who doubted her special powers actually interfered with her ability to keep her job as a graphic artist. This discussion helped Jen see the discrepancy between where she was now (unemployed) and where she wanted to be (employed artist), and increased her awareness of the role of symptoms of BD in widening this discrepancy.

*Developing a life chart.* Collecting information about the course of the patient's mood symptoms over time in order to chart the course of the illness can increase the patient's insight about the effects of a mood disorder on his or her life (e.g., Frank, 2005). A life chart identifies major life event anchors (e.g., school graduation, marriage, divorce, career changes) and links them to periods of depression and mania and symptoms of psychosis. The clinician can carefully work with the patient to identify costs of illness episodes, including hospitalizations, job loss, family conflict, and financial setbacks.

*Involvement of family members*. Family members can be helpful in working with a treatment-refusing bipolar patient in several ways. Patients with BD often have poor insight about their symptoms, particularly during manic episodes (Ghaemi & Rosenquist, 2004), and family members can provide information about the severity and impact of mood episodes that is unavailable to the patient, as evident in the following quote by a patient with BD: "…my husband always knows first, my sister next, and then my best friends. I'm always the last one to know I'm getting manic" (Miklowitz, 2002, p. 187). Family members can also increase the patient's motivation to agree to an adequate treatment plan by increasing the patient's awareness of difficulties experienced by loved ones as a result of the patient's illness (Frank, Kupfer, & Siever, 1995) .

In the case of Jen, the clinician determined that Jen and her two college-aged children had sufficiently positive relationships to warrant involving her family in the pre-treatment phase. After obtaining informed consent from Jen and her family members, the clinician brought Jen's children into a family session and gave them the opportunity to gently let Jen know how frightened they were when she became manic and about the costs her episodes had incurred for them (e.g., paying credit card debts for Jen, constant worry). Jen reported later that this information increased her awareness of the negative consequences of her mood swings on herself and others and her willingness to accept treatment.

*Involvement of psychopharmacologist.* The collaboration between a therapist (i.e., clinician) and medication prescriber, or psychopharmacologist, is another important component in overcoming treatment refusal. Often, the bipolar patient refuses the pharmacotherapy component of an effective treatment plan, so it is essential that a collaborative relationship exist between the two treatment providers. A therapist can involve the psychopharmacologist in treatment in several ways. First, the therapist can contact the medication prescriber to gain information regarding the patient's reaction to, attitudes about, and adherence to the medication regimen. At times the patient may provide additional details regarding this component of his/her treatment to the medication prescriber than to the psychotherapist. Alternatively, the psychotherapist can also share important information on the patient's adherence and attitudes towards medication to the psychopharmacologist. Second, the psychotherapist can monitor pharmacotherapy adherence at every session and work to identify and overcome the patient's reluctance to accept pharmacotherapy. Third, therapist and psychopharmacologist might schedule periodic meetings to brainstorm regarding changes in the patient's clinical status and strategies to increase the patient's willingness to accept a better treatment plan.

A useful strategy for working with a patient who has BD who refuses pharmacotherapy is to ask the patient to agree to a consultation with a psychopharmacologist. The psychotherapist can ask the patient who is not ready to agree to pharmacotherapy to obtain a consultation from a psychopharmacologist for a second opinion on the issue. That is, the therapist asks the patient simply to agree to a consultation, not necessarily to agree to pharmacotherapy. The psychopharmacologist can help the patient identify his or her objections to pharmacotherapy, provide informed answers to the patient's objections to medications, and to review the results with the psychotherapist. This sequence of interventions can be particularly powerful and effective when the psychotherapist and pharmacotherapist are communicating and collaborating closely. This sort of information gathering may increase the patient's willingness to try pharmacotherapy immediately or at a later date. In sum, increased attention in the clinical and research literatures as to how psychotherapy and pharmacotherapy providers can collaborate effectively (e.g., Friedman et al., 2004) has the potential to reduce rates of treatment refusal.

*Compromise Treatment Plan*

Sometimes despite the clinician's best efforts, the patient will not agree to the treatment plan the clinician recommends. In this case, the patient and clinician can begin a process of negotiation to determine if they can agree on a compromise treatment plan. There are several reasons for agreeing to a compromise treatment plan. One is that the information provided by a controlled efficacy study about the treatment that is most likely to help the "average" patient does not provide complete information about which treatment is most likely to help the individual patient who is in the clinician's office at that moment (Howard et al., 1996). For example, although pharmacotherapy plus psychotherapy is the treatment of choice for patients

with schizophrenia, some patients can do well with psychotherapy or pharmacotherapy alone (Kingdon & Turkington, 2004).

Another reason for agreeing to a compromise treatment plan stems from the fact that the patient's refusal to accept the proposed treatment plan may result from his or her symptoms (such as grandiosity and poor insight). These symptoms can make it difficult or impossible for the bipolar patient to know she has a serious problem and is in need of professional assistance. Therefore, the clinician may wish to provide treatment even when the patient is reluctant to accept the diagnosis of BD and the comprehensive treatment it requires. The hope here is that if the patient accepts some elements of the treatment plan, she may improve enough to obtain the insight and judgment needed to accept the other elements later.

The clinician will need to determine the minimal treatment plan to which she can comfortably agree. Different clinicians are likely to make different decisions depending on how much risk they can tolerate, how much professional support they have, the professional setting in which they work, and the unique circumstances of the patient. If the patient lives alone, for example, the clinician may accept a different treatment plan than if the patient lives with a supportive spouse who works well with the patient and clinician. We recommend that clinicians consider undertaking a compromise treatment plan when the following criteria are met: there is a chance the patient can benefit, the clinical situation is not unduly risky, frequent progress monitoring is implemented, and a backup plan has been established and agreed upon if the patient does not make sufficient progress with the compromise treatment plan (Basco, Merlock & McDonald, 2004).

The process of arriving at a compromise treatment plan was not an easy one for Jen and her clinician. It was unquiet, and included many disagreements and difficult discussions. Jen's

clinician began by proposing a high-quality combination treatment plan of pharmacotherapy and psychotherapy. After several difficult discussions in which the clinician evaluated the criteria listed above, Jen and her clinician agreed to a compromise plan of psychotherapy without pharmacotherapy. They also agreed to a backup plan whereby if Jen's condition did not improve or worsened she would obtain a medication consultation from a psychiatrist. Jen and her clinician agreed that the therapy sessions would focus on Jen's goals of obtaining a rewarding job as a graphic artist and improving social relationships as well as psychoeducation about BD and Jen's beliefs about pharmacotherapy, and would at times include members of Jen's family. Jen agreed to monitor progress toward her professional and personal goals and to record her symptoms and report on them at every therapy session. With this agreement in place, Jen's clinician felt comfortable proceeding with a compromise treatment plan.

*Agreeing Not to Work Together*

Sometimes a clinician and patient are simply not able to agree on a treatment plan. In this case, the clinician must refer the patient to another treatment provider. Referring a patient to another provider when the patient and clinician cannot agree on a treatment plan raises complex issues. One is that the clinician must not abandon the patient. Therefore, the clinician may need to spend several weeks working with the patient to find and facilitate a referral. We recommend that the clinician (with the patient's permission) call potential treatment providers, describe the situation frankly, and ask if they would be willing to meet with the patient for a consultation to discuss whether they can work together. Of course, if the patient is in a crisis, the clinician must work with the patient to stabilize the situation before making a referral to another provider.

Another issue is the question of why a patient who would not agree to an adequate treatment plan offered by one clinician would behave any differently with another clinician.

There are several answers to this question. The patient's willingness to agree to a particular treatment offered by a particular therapist may be a dynamic process (Miller & Rollnick, 2002); even if one clinician could not, another clinician may be more successful at inducing the patient to accept an adequate treatment plan. In addition, clinicians differ in their views about what constitutes adequate treatment for any particular patient and in their willingness to accept an inadequate treatment plan.

An alternative to referring the patient out to another clinician or treatment facility is the option of maintaining an "assessment-only" relationship with the patient. This notion can be helpful in community mental health clinics or other settings where the clinician does not have the option to refuse to provide services. In the assessment-only monitoring plan, the patient and clinician agree that no active treatment is being provided, but that they will meet periodically (e.g., monthly) for assessment and progress monitoring. Sometimes the clinician can use MI strategies during the assessment-only phase to point out the effects of the person's untreated illness on his functioning and comfort. Of course, an assessment-only plan is risky. If the patient's situation deteriorates to a crisis the clinician must step forward to provide active treatment to a patient who may be unwilling and uncooperative.

Another option for the patient who refuses treatment is a non-demanding follow-up contact. Motto (1976) randomly assigned individuals who had attempted suicide and had not sought follow-up treatment to receive a postcard with the simple statement, "It has been some time since you were here [in treatment]…hope things are going well for you" or to no contact. Those who received a postcard had significantly lower suicide rates than the no-contact group up to 14 years later. Similarly, Morgan, Jones, and Owen (1993) showed that patients who received a card instructing them to contact hospital personnel if they felt suicidal had significantly lower

suicide rates than patients who did not receive such a card. Thus, sending an occasional postcard to the person with BD who has prematurely ended his treatment may reduce the rate of harmful behaviors and increase the chance that the patient will return to treatment at some point.

## Conclusion

Despite advances in the treatment of BD, limitations remain. One important limitation highlighted in this paper is the paucity of attention given to strategies to overcome treatment refusal. We recommend that treatment protocols for BD, regardless of theoretical orientation, include a module on handling treatment refusal. We offered suggestions here for the contents of such a module. We also hope that future research efforts continue to add to our knowledge of how to best handle and ultimately prevent treatment refusal in BD.

We conclude by noting that treatment refusal is not unique to BD. Individuals who have eating disorders (Halmi et al., 2005), schizophrenia (Kingdon & Tukington, 2004), substance abuse problems (Miller & Rollnick, 2002), and borderline personality disorder (Linehan, 1993) also frequently refuse treatment. We hope that the concepts and strategies described here hasten the development of empirically based strategies to help individuals with a wide range of problems and disorders who can benefit from treatment but are reluctant to accept it.

## Author Note

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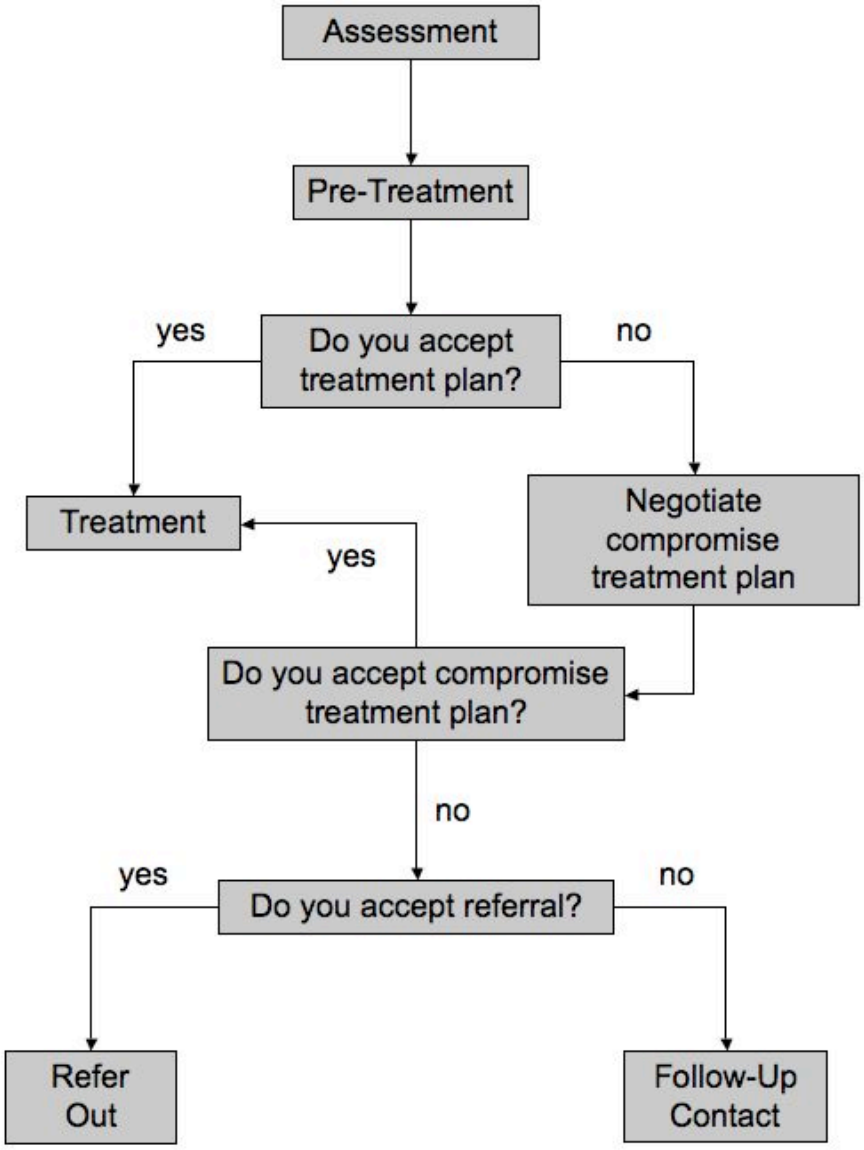
Figure Captions

*Figure 1*. Diagram for handling treatment refusal.

Figure 1.


Assessment
Pre-Treatment
Do you accept treatment plan?
yes
no
Treatment
Negotiate compromise treatment plan
yes
Do you accept compromise treatment plan?
no
Do you accept referral?
yes
no
Refer Out
Follow-Up Contact