Compliance in Follow-Up and Treatment after Discharge Among Chronic Psychotic Patients

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INTRODUCTION

Compliance can be defined as the patient’s acceptance of and adherence to suggestions relating to his or her health (1). The understanding of compliance has a broad scope, wider than, for instance, only the use of prescribed medications. It includes the patient’s attitude and willingness to engage in the recovery process by actively following the suggestions of clinicians. (2).

Non-compliance with treatment has many dimensions: not taking the prescribed medications or using them irregularly; using non-prescribed medications; missing appointments; missing the follow-ups and other behaviors. (3). A leading cause adversely affecting effectiveness of treatment in psychiatric patients is non-compliance with treatment recommendations(4).

Drug administration is the primary mode of treatment for schizophrenia and other psychotic disorders (5). The rate of non-compliance with antipsychotic drug treatment varies from between 11% and 80%; this is a serious problem in clinical practice (2).

In their studies, McGlashan and Carpenter report that two-thirds of patients require hospitalization because of complete or partial non-compliance with the treatment. Within the first year after the first hospitalization, the relapse rate due to non-compliance is 40% (6).

These non-compliance issues increase rehospitalization, morbidity and mortality rates. Rehospitalization leads to occupational and family problems and subsequently decreases the patient’s quality of life (2).

Maintenance treatment arranged after psychotic episodes, decreases the risk of relapse. Non-compliance, generally encountered more often during maintenance treatment, adversely affects the prognosis because it exacerbates symptoms in early period of the disease. Despite all these factors, non-compliance with treatment continues to be a significant issue frequently encountered in clinical practice and it may require the
The primary objective in evaluating non-compliance should be to discover the factors that contribute to non-compliance, and evaluating the level of compliance accurately (2).

Aker et al. reported in their study that reasons for non-compliance with treatment may include factors directly related to the individual’s mental state, i.e. the psychopathology of the patient at the psychotic level, the patient’s anxiety and fear about the medication and the course of the illness. Other factors that play a role in non-compliance with treatment include: the adverse effects of taking the medications; issues about complying with the drug regimen; inadequate social and environmental support; economic difficulties; insufficient information or misunderstanding the nature of the treatment; location of the hospital and conditions in the hospital; patient’s and his or her relatives’ attitude and/or perceptions of medication treatment and mental disease; perceptions that medication can affect social life; cultural beliefs (particularly from figures like psychics, healers and hodjas, seen in Turkish society); and other pressure experienced with regard to treatment (8,9).

Many studies also emphasize that a patient’s family or relatives may have a negative perception of medication (9-11).

**REASONS FOR NON-COMPLIANCE**

**Disease-Related Factors**

Non-compliance is associated with various psychopathological states, organic mental states and especially the content of the delusions. Positive symptoms, i.e. persecutuar delusions, megalomania and delusions of being controlled are often prevalent, and seriously disrupt the treatment compliance. Negative symptoms, i.e. motivation deficiency and apathy, also disrupt the compliance (8,12). Hostility, denial of the disease and psychotic disorganization in the acute phase of illness may also cause to reject treatment.

In studies, the disease duration and excessive number of hospitalizations are reported to be related to non-compliance with treatment. In particular, longer disease duration and frequent hospitalizations can lead patients to believe that they are beyond recovery and treatment will not be effective; this belief also adversely affects a patient’s compliance with treatment (8).

In 2000, Olfson et al. conducted a study on 213 patients with schizophrenia and schizoaffective disorder, evaluated treatment compliance and reported that approximately 50% of the patients showed partial non-compliance and 20% of them showed complete non-compliance within the first three months following hospital discharge (13).

In a study conducted on 37 patients with psychotic disorders, by Aker et al., showed that patients had discontinued the medication and the non-compliance process began within the first 10 days following hospital discharge. Factors affecting compliance in these 10 days included various cognitive disabilities and an inability to evaluate the risk and results of relapse.(8). Serious psychopathology does adversely affect a patient’s insight, creating a vicious circle that further distorts the compliance process. Aker et al. found that serious psychopathology was one of the leading factors in non-compliance with medication treatment (64.9%) (8).

The presence of comorbid diagnoses also adversely affects compliance. Comorbid alcohol or substance abuse diagnoses have been found to distort the compliance the most.

In the studies conducted by Perkins and Lacrotal, they found that depressive symptoms increased in direct proportion to compliance and that when patients’ depressive symptoms increased, their compliance with a medication treatment gradually deteriorated. Emotions like desperation and hopelessness decrease the patient’s ability to believe that treatment will be effective (14,15).

**Lack of Insight**

Lack of insight and non-compliance with treatment are related, and often lead to deterioration in the patient’s mental state. In a review from Lacrot, et al., related to non-compliance with treatment and those risks, they indicate that medication non-compliance was mostly associated with the lack of insight (15).

The patient’s level of insight can be measured
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indirectly by investigating how schizophrenic individuals perceive their symptoms, how they define them, their expectations about the illness and treatment. Lack of insight brings hopelessness and lack of clarity about the illness. As Rusch and Corrigan reported in their studies, lack of insight and compliance may also be caused by projection of defense mechanisms used exaggeratedly (denial and projection) by individuals with neurocognitive deficits, and by the patients with schizophrenia (16,17).

A study Holzinger et al. conducted in 2002 investigated the subjective disease theory and compliance with treatment in schizophrenic patients. The authors described the evaluation of patients in terms of assistance agreement to be the best unique indicator of compliance (16).

There are some patients who do take medications and go to follow-ups regularly, even though they may also lack sufficient insight into their illness; there are also patients who choose not to continue the treatment and have insight. This should be evaluated completely according to the patient (18).

Psychoactive Substance Use

Previous studies have shown that psychoactive substance use in schizophrenic individuals seriously weakened drug compliance. In a study conducted by Bebbington, the strongest relationship with non-compliance was in individuals with comorbid diagnoses, particularly alcohol abuse (19).

A comparative study conducted by Olfson et al. in 2000 reported that schizophrenic individuals who did not adhere to the treatment regimen had more substance abuse or addiction in their medical history compared those who did follow the regimen (13). Whether the relationship between alcohol and drug use and non-compliance with treatment is a factor, as a result or as a coincidental relationship or not, is a controversial issue. This relationship should be assessed for each patient individually.

Factors Related to the Medication Regimen

One of the factors in non-compliance may be that the treatment regimen is complex; others include the delayed appearance of favorable effects; or negative effects that emerge, even after a long period, following discontinuation of the medication; and side effects (5).

Other factors contribute to complicated treatment regimens, i.e. concurrent use of many medications in different forms or the need to administer the medication in divided doses. In the study conducted by Aker et al., an inversely proportional relationship was found between compliance and the number of prescribed medications along dosage frequency. One observation in this study was that the most common type of non-compliance was skipping a dose of daily treatment regimen. Parenteral treatment regimens also seriously weaken compliance. During follow-ups conducted in the Aker et al study, there was a non-compliance rate of 40% for patients using parenteral drugs (8).

The patient may also choose not to take medication because of troublesome side effects. Certain side effects of medication can be embarrassing for the patient and lead to non-compliance. A related study conducted by Misdrahi et al., showed that reasons for stopping to take medication included the occurrence of neurological, endocrine, anticholinergic and extrapyramidal system side effects (2).

Many previous studies report that 40% of patients discontinued medication within the first year and 75% within the second year, because of various side effects (13,20,21).

In another study from Aker et al., non-compliance due to side effects, with a rate of approximately 40%, was ranked in second place (8). Side effects like acute dystonia, acathisia and akinesia, occurring in early stages of the treatment, may further affect compliance. Individuals who experienced deficit syndrome caused by neuroleptics constitute a special risk group for non-compliance. Sedation also leads to non-compliance; prescription of sedative medicines can distort functionality in the areas that affect individual goal-setting and achievement. Sexual function issues - loss of libido, erectile dysfunction, retrograde ejaculation and anorgasmia - are observed at the rate of 80%. A patient’s exposure to such side effects may result in both an exaggeration of his/her psychosis and discontinuation of the medication. Weight gain also adversely affects compliance. (13,20,21).
Interestingly, investigations have suggested that side effects did not have a negative impact on compliance with treatment; in fact they had a positive effect. This paradoxical finding may be the result of an indirect improvement in the clinician-patient relationship, perhaps as a result of the clinician offering information when the patient suffers an adverse reaction to the medication. (18).

Parashos et al conducted a study in 2000 by interviewing patients with schizophrenia and their families (extended) on non-compliance with treatment. The authors highlighted some of the ideas, fears and prejudices that the patients hold about medication. They also examined the negative information and misinformation from those surrounding the patients on treatment compliance. Misstatements included the following: “Using medication leads the individual to lose his/her self-control; long term use of medication causes personality changes; long term use of medication is an indicator of incapability; medications cause addiction and infertility; have to use medication for the entire life is a very bad situation; taking medication causes stigmatization; medications may not work and maybe they are used unnecessarily; individual’s lifestyle changes due to use of medication.” (22).

**Treatment Team**

The beliefs and attitudes of the treatment team play a role in the disease: their knowledge and attitudes about relapse and tardive dyskinesia can also affect patient’s compliance with treatment.

In a 2000 study conducted with Olfson et al, on 213 patients, the authors showed that patients with medication non-compliance had weak therapeutic rapport with the treatment team during hospitalization period and their families refused to let the patients be hospitalized (13).

Continuity in terms of the treatment team is as important as treatment consistency. This issue is widespread (20); it is difficult to maintain the same treatment team for each patient. But success in treatment and rehabilitation for a long-term disease like schizophrenia is highly dependent on the consistency of both the treatment and the treatment team. Continuity, in this case, refers to maintaining the treatment with the same team. This consistency holds advantages for both the patient and the team. The patient and treatment team are able to develop a relationship that includes trust, acceptance and support, greatly contributing to the treatment’s effectiveness. Additionally, a relationship can develop between the team and the patient’s family; offering opportunities for the family to learn more about the disease as well as ensuring that the patient gets assistance in a timely manner. (20).

**Patient-Related Factors**

Age, gender, personal characteristics and mental capacity also affect compliance with the treatment. In some studies, younger individuals, females and certain ethnic groups are more often in non-compliance; but in other studies, older individuals appear to be more non-compliant. Demographic factors do not appear to be significant: non-compliance can be seen in all genders, ages and social classes (15).

History of non-compliance with the treatment in the early stage of illness is a significant indicator of subsequent non-compliance. What the individual believes with regard to the disease, the medication and suggested actions are in line with that individual’s personal characteristics. Narcissism and paranoid personal characteristics, in particular, adversely affect compliance (8).

Premorbid cognitive dysfunction, forgetting, low vision and hearing loss are other patient-related non-compliance factors (17).

**Family-Related Factors**

Compliance with treatment in schizophrenia is affected by many elements, but the role of family among these factors is only slightly emphasized. The family’s approach and attitude towards medication and the disease, and a high level of expressed emotions are other factors that affect compliance with treatment.

A study conducted by Sellwood et al., on 79 families of schizophrenic patients investigated the relationship between what families know about the disease and their expressed emotions around caregiving and treatment compliance. Evaluating that relationship
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can potentially enable an understanding of why the patient is in non-compliance (23).

Aker et al. conducted a study examining how patients’ families viewed drug treatment. Findings indicated that the nature of psychotic disorders played an important role in how the patient’s relatives felt towards drug treatment. The presence of other psychotic patients in the family, similarity of the medications used and observation of side effects influenced some of the negative opinions related to the treatment in the patient and increased the incidence of non-compliance (11).

Another important point is that some family members or relatives simply become weary and discouraged over time, affecting their ability to give care and deal with the results of the illness. This should be taken into serious consideration (18).

**Environmental Factors and Lack of Social Support**

As reported McGlashan et al. in their study, family support, support of friends or having a consistent job also affect compliance. Employed patients may be non-compliant due to concerns about being “stigmatized” by the use of medication or requests for time off to attend treatment; thus they show non-compliance by skipping dose of daily treatment regimen and attending appointments irregularly (6).

The structure of the health system, geographical distance to health centers, waiting times for appointments, social security and cost of medication are also important factors affecting compliance (6).

The lack of social and environmental support seems to be related to disease duration. The patient’s social and environmental support decreases in cases where the caregivers are parents; parents grow older and less physically able to care for the patient – or less interested in caring for the patient - and, eventually, they die. Regular follow-ups, part of compliance, might be interrupted due decreasing social and environmental support, thus increasing the severity of the disease (6).

Previous research has determined a significant relationship between negative attitude toward mental illness and negative course of the illness. Regular visits to psychiatry clinics and taking psychiatric medicine are the factors that reinforce negative perceptions about the illness for the population with tendency to exclude schizophrenics from regular social intercourse. This may also cause the patient to resist seeking treatment (8,9).

In a comprehensive review of 39 publications issued after 1980, Lacro et al. reported that the factors most associated with non-adherence to treatment are as follows: poor insight, negative attitudes and personal responses toward drug use, previous non-adherence to treatment, substance addiction, short term duration of illness, insufficient hospital discharge plan or negative environmental conditions (15). Age, gender, ethnicity, marital status, education level, neurocognitive disorder, severity of psychotic symptoms, type of medication, severity of medication-related side effects, higher antipsychotic dosages, presence of mood symptoms, route of drug administration and family participation were not determined to be factors related to non-adherence to treatment. The absence of relationship between non-adherence to treatment and specific factors such as age, neurocognitive disorder, severity of medication-related side effects and family participation in treatment present an opposing view of clinical data and current publications (15).

Perkins, in another review of publications issued between 1980 and 2002, called attention to factors that could negatively affect compliance, including: easy access to treatment; degree of family or societal support, in addition to the patient’s knowledge of the illness and belief in the benefits of the treatment; and expected side effects of drug treatment (extrapyramidal side effects, neuroleptic dysphoria, acathisia, sexual dysfunction, weight gain) (14). In a 2004 study by Diaz et al., conducted on a small group that included 50 people for whom drug administration was monitored electronically, compliance with treatment within the first three months following hospital discharge was 47%. In this study while no relationship was discovered between the type of antipsychotic drug and treatment compliance, there was a relationship between daily dose frequency and treatment compliance (24).

Psycho-educational programs to increase disease awareness and treatment motivation might be a useful choice. Pitschel-Walz et al, in a 2006 study in Germany on 386 patients showed that regular psycho-educational
training, also attended by families, increased success in schizophrenia treatment. Psycho-educational training was suggested for all patients (25). But in 2005, study conducted by Beverly et al., showed that psycho-educational training does help the treatment. However when compliance with medication is taken as the only basis, it does not produce expected results and does not produce a significant difference in decreasing non-compliance in the long term (26).

Sajatovic et al., investigating hospitalized patients’ attitudes toward antipsychotics reported that their attitudes were not significantly altered during outpatient treatment and there was no significant difference between classic and atypical antipsychotics (27).

In a 2006 study conducted on 221 patients who had just been discharged from a mental hospital, Compton et al. investigated the factors contributing to patient non-attendance of their first appointment following hospital discharge. They determined four important factors: reluctance to be hospitalized and reluctance to be released from hospital (lack of insight); leaving hospital before the end of the treatment; lack of a patient follow-up plan after the hospitalization (introducing the follow-up team to the patient, visiting the treatment location); issues of the patient’s primary support groups; and the lengthy period between hospital discharge and appointment date. Additional factors were side effect experienced by the patient during admission and hospital discharge; unemployment; and what patients thought about efficiency of entire treatment team. Health insurance issues are also among the factors thought to be associated with non-compliance, though this is not relevant to this study. Certain other studies also show that length of time between outpatient follow-up appointments is directly proportional to missing the appointments (28).

In a study conducted by Kruse and Rohland in 2002, they emphasized that attendance at the first appointment following hospital discharge was a good indicator of compliance with the treatment, and they found that patients who made an appointment within the first two weeks following hospital discharge were adhered to treatment four times more than those who made an appointment for follow-up beyond two weeks. They also determined that patients coming from urban areas were five times more likely to attend the first appointment, compared to patients from rural areas; there were also differences between ethnic groups regarding attendance and the first follow-up appointment. They reported that a relationship between socio-economical levels and cultural variables. Geographical distance to the hospital was not determined to be a significant factor in complying with the first appointment. The scarcity of regional centers, treatment motivation of the patients or a preference for private centers and university hospitals was also put forth. Moreover, the importance of reaching the patient and his/her relatives by phone for the first appointment by a nurse or case manager following the hospital discharge was emphasized (29).

In a study conducted on 313 psychotic patients who did not attend their first follow-up appointments, by Kruse et al. in 2002, five important determinants for non-compliance were determined: age (youth); ethnic differences; an inadequate family support system; physical difficulties; lack of health insurance and non-use of antipsychotic drug treatment. In this study, following the medication regimen was a factor increasing attendance at follow-up appointments. Also it was noted that non-attendance at the first appointment was related to increased risk for rehospitalization and increased risk of violent behavior towards themselves and others. With ethnic differences, non-compliance was associated with cultural obstacles rather than financial difficulties (30).

A study conducted by Weinerman et al., investigated whether the appointment time in terms of the hour of the day, had effect on compliance and first appointment attendance findings indicated that the patients who scheduled appointments in the afternoon were more likely to attend and to comply with treatment (31). Zygmunt et al, in a review study of showed that all of the aforementioned interventions are effective. In terms of clinic strategy, introducing the patient to the follow-up team before hospital discharge, and conducting supportive educational interviews about treatment and medications before hospital discharge, were especially effective. Considering psychotic disorders, the authors also emphasized that the relationship between individual diagnoses and specific indicators and symptoms with regard to compliance should be researched (32).
Also, in the review study of Nose et al., interventions conducted prior to hospital discharge were an important factor in patient compliance attendance at their first appointments following hospital discharge – and this was taken as an important indicator for subsequent compliance of the patient. Recommendations are that this should be routine practice in all psychiatric clinics (33).

In a study conducted by Gallucci and et al. in 2005, they stated that non-attendance at the first appointment following hospital discharge was a strong indicator of non-compliance; they emphasized the importance of scheduling the first appointment, especially during the first week and they pointed out that prolonging the first appointment distorted attendance of subsequent appointments. They also stated that being young and a man was a risk factor in non-compliance with the first appointment (34).

In a study conducted by Mitchell and Selmes in 2007, they emphasized that non-attendance at the first appointment in outpatient treatment had prognostic importance different from non-compliance with follow-up appointments. In their study, they found that non-compliance with the first appointment decreased on Fridays, winter months and in the geriatric psychiatry group, and increased with alcohol and substance use disorders and general psychiatry clinics. And they found that the rates of postponing appointments decreased geriatric psychiatry patients, patients for rehabilitation psychiatry, individuals receiving cognitive behavioral therapy and psychosocial therapy. The authors stated that all psychiatric clinics should have a “protocol of non-compliance management” (35).

In a study conducted on 764 patients in a general psychiatry clinic by Kitcheman et al. in 2008, the authors found that “letters of orientation training” sent 24-48 hours before the first appointment significantly increased the compliance and attending the first appointment was an important indicator of compliance with the subsequent follow-ups (36).

In a study published by Orlosky and et al. in 2007, they compared compliance with the first appointment of patients who had been discharged from a general psychiatry hospital in 2003 and 2004 and followed up by a case manager at their homes, with the compliance with first appointments during the previous years when this method had not been used. Consequently they found that 71.6% of the patients who were followed-up by a case manager at their homes showed compliance with their first appointments within the first 7 days following hospital discharge (the rate in the previous years: 66.6%), and 88.3% of them showed compliance within 30 days following hospital discharge (the rate in the previous years: 84.0%) -this program was significantly effective (37).

In a study conducted by Glyndal and et al., they determined that 137 of the patients (32%) within a period of 6 months did not attend their first appointments and efforts to get in touch with these patients (e.g.; phone reminder, making an appointment, outpatient follow-up plan) decreased the non-compliance to 16%. The length of waiting time for the first appointment is also important, particularly for the psychotic and addicted patient groups (38).

In a study conducted by Agara and Onibi conducted on 48 patients with schizophrenia and psychotic depression, they investigated the effect of group psycho-education conducted before hospital discharge on compliance following hospital discharge. Their findings indicated that conducting group psycho-educational training during hospitalization was effective on compliance with appointments following hospital discharge in all psychiatric diagnoses and age groups during nine months (39).

Spiegel and Wissler investigated the effects of periodic visits to the families of patients with schizophrenia conducted by the clinical team, in order to resolve acute problems and interpersonal problems and educate families following hospital discharge on compliance and emphasized the importance of home visits (40).

The investigators reported that assigning patients into four groups, as follows, would be useful: patients not attending their first appointment, patients not attending their follow-up appointments, patients who frequently miss their appointments and patients who discontinue the treatment. Non-attendance at first appointments was always found to be higher than non-attendance at the follow-up appointments. Partial non-compliance was found to be higher than complete discontinuation of the treatment (41). Much of the current literature does not distinguish such differentiations. When
the period of follow-up appointments is taken into consideration, studies show that more than 50% of the patients discontinue the treatment after two years. When dealing with psychotic patients, this rate greatly increases (42). The comparative studies show that the patients not attending follow-up examinations are rehospitalized four times more than those who do attend examinations (43).

Another consequence of non-compliance is seen in emergency rooms. According to a study in England, 28% of suicide victims with mental illness ceased their relations with mental health clinics, 24% of them were discharged from hospital within the last month before their suicide and most of them did not attend follow-ups after hospital discharge (44). But according to a study by Smoller et al.; despite high rates of non-attendance at appointments in mental health clinics, psychiatrists are less inclined to get in touch with these patients compared to physicians in other fields. (41, 45).

Non-compliance with the follow-ups leads to more problems for the caregiver and deteriorates the relationship between patient and caregiver, leading to more problems. One of the most important strategies in coping with non-compliance is a requirement that each clinic have a plan for reaching non-attending patients and resolving those issues. In the 2007 study by Shoffner et al., phone reminders were an effective method of improving compliance with appointments (46).

In a review study of Marder, factors in non-compliance for schizophrenic patients included medication side effects, severity of psychotic symptoms, cognitive disorder, misunderstanding the role of medications in the treatment and patients’ lack of knowledge about their illness were, coping strategies included informing and educating patients about treatment, medications and their side effects and the use of long acting depot (47).

In an article written by Cruz et al., they noted that the rate of non-compliance with appointments was also an indicator of a hospital’s service quality and restated the importance of case management, home visits, provision of transport for hospital appointments and the importance of interventions like individual and group psychotherapies, entertainment and social programs; flexible programs for appointments were also emphasized (48).

CONCLUSION AND RECOMMENDATIONS

The success of strategies to increase treatment compliance are clearly proven. Some actions may address the compliance with treatment. The studies show that number of elements should be taken into consideration in order to ensure that patients with psychotic disorders adhere to treatment. Communication with patients and their families, disseminating information, simplifying the therapeutic plan, planning consultations, and arranging effective but uncomplicated treatment by considering side effects and social support are important in raising compliance rates.

Important issues that should be considered, particularly in our hospital (Bakırköy Research and Training Hospital for Psychiatry, Neurology & Neurosurgery) are as follows:

- rearrangement and simplification of appointments and outpatient clinic interviews and formal procedures,
- telephone reminders for appointments,
- following up via telephone with patients who do not attend appointments or examinations after they are discharged from the hospital,
- issuing a “protocol for coping with non-compliance” for our hospital,
- trying to provide regular education and rehabilitation opportunities for all patients and their relatives,
- creation of a “hospital discharge plan” for leaving the hospital.

Of course, all the issues mentioned above need to be addressed not only by our hospital but also within the structure of the Ministry of Health and by establishing cooperation between these institutions.

It is also important to consider home-based care and treatment options as soon as possible, to establish and develop the concept of “case management”, and to provide educated personnel and interdisciplinary collaboration for this purpose.

Individually, first steps include removing any obstacles to establishing a therapeutic collaboration.
with patients and their families, to treat the disease effectively, to improve insight, to educate the patient and family and to activate social support systems wherever possible. In conclusion, if these issues are addressed effectively, patient compliance in treatment will increase, along with their quality of life; functionality for chronic psychotic patients will increase and their relapses will decrease. In this respect, there is a need for more studies to evaluate and increase compliance.

REFERENCES