Understanding treatment adherence in affective disorders: a qualitative study

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The objective of this study was to explore the perspective of depressed patients, their family and mental health professionals from their community mental health centre (CMHC) on factors related to treatment adherence. We conducted eight separate focus groups involving patients, their families and their therapists from three CMHCs. A total of 52 persons were involved. The groups explored patients’ and family’s explanatory model of depression, perceptions about the course of the disease, the role of medication and other treatments, the main causes of non-adherence, and interventions which would help increase it. Patients and families had a complex cognitive model of depression, which combined intrinsic vulnerability, psychological suffering during childhood and adolescence, and adverse life events. Drugs as well as other treatments were considered helpful, more so by patients than by family members. Denial of the disease and need to test its continuing presence were the main causes of non-adherence for patients, while adverse reactions did not play a relevant role. Mental health professionals tended to underestimate non-adherence in depressed patients, and did not question their patients about medication adherence. Family members needed more information on depression, on how to manage their relatives, as well as psychological and social support for themselves. The study allowed for the identification of a number of specific interventions aimed at facilitating treatment adherence, such as providing more information to patients and families, and training doctors and nurses in effective prevention and management of non-adherence.

Keywords: patient compliance, depressive disorders, focus groups, mental health services, treatment adherence

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Introduction

Major depression very often requires a prolonged pharmacological treatment, with adverse reactions from mild to potentially serious. As in other chronic or recurrent conditions, adherence to treatment is not optimal (World Health Organization 2003). Estimates of non-adherence to prescribed treatment range from 30% to 60% in epidemiological studies, and are at around 30% in clinical trials (Pampallona et al. 2002). Still, according to Lin-gam & Scott (2002), only 1–2% of all publications on the treatment of affective disorders explore factors associated with medication non-adherence. A number of factors have been posited as the major causes of non-adherence, including the length of treatment, the presence of adverse reactions, the characteristics of the physician, and the attitude of the patient and the family towards the disease and its treatment (Demyttenaere 1997). Although the alliance of therapists, patients, and families is considered important for a satisfactory adherence with treatment of
depression (Meichenbaum & Turk 1987), so far very few studies have incorporated the perspective of the patient and his or her environment in an attempt to understand dropout of treatment (Trostle 1988, Cooper-Patrick et al. 1997).

In order to design a large-scale clinical trial to test adherence-enhancing interventions in depressive disorders, we have recently completed a systematic review of quantitative studies of compliance in depression (Pampallona et al. 2002). A total of 32 studies published between 1973 and 1999 met the review criteria: epidemiological descriptive studies (14); non-random comparisons of control and intervention groups (3); randomized interventions (14); and meta-analysis (1). The epidemiological studies that we reviewed did not identify any systematic pattern of factors associated with increased compliance. In addition, randomized studies did not clearly identify a specific intervention or combination of interventions that may help increasing adherence, although complex interventions seemed to have a greater effect than single ones. The results of the systematic review reinforced the need for carefully designed clinical trials to clarify the effect of single and combined adherence-enhancing interventions.

Besides exploring the quantitative literature on adherence, for the preparation of a future trial, we were also concerned about designing interventions relevant to clinical practice and adequate to the needs of the recipients. Accordingly, we have conducted three series of separate focus groups involving patients, their families and their therapists from three community mental health centres (CMHCs). Focus groups are established as a useful qualitative technique to explore opinions, knowledge, perceptions, and concerns in regard to a particular clinical topic (Trilling 1999). We chose a focus group technique to allow all participants, and in particular patients and their relatives, to freely express their views in an empathic environment. The present study had two objectives:

1. to elicit the point of view of patients, their families and their therapists on the causes and possible remedies of non-adherence to treatment; and
2. to compare their opinions in order to recognize discrepancies which could be addressed by future interventions.

The present paper reports the main results of the focus groups, and discusses the implications of the findings for future interventions targeting patients, family, and mental health professionals.

**Methods**

Three CMHCs, two in Turin and one in Settimo Torinese, a small industrial town in the Turin hinterland, took part in the study. The centres provided a list of patients with a diagnosis of major unipolar depression or bipolar disorder, currently in contact with the CMHC.

It is not current practice to involve psychiatric patients in discussing their experience. For some patients, sharing their views with other persons may represent a stressful experience. Accordingly, we first asked the psychiatrists responsible for each patient whether it was clinically appropriate to contact his or her patient. The psychiatrist made the first telephone call to explain the objectives of the study, followed by a second telephone call by the study co-ordinator, asking for patient’s participation and for his or her agreement to contact a family member for a separate focus group. Even though no intervention was envisaged, we submitted the study for approval to the ethical commission for medical research of the Piedmont Region.

On the basis of the suggestions made in the literature about the factors affecting treatment adherence in depressive disorders (Demyttenaere 1997), we prepared a simple list of questions for patients and family members, adding specific questions for mental health professionals (see Table 1). The list was distributed to each participant at the beginning of the focus group. A moderator and a co-moderator conducted the sessions, while the study co-ordinator took notes.

Focus groups with patients and family were held on the same day, with no interval between the two, so that no exchange was possible between patients and family about the subjects discussed. Each session lasted 1.5 h, and was conducted off-site (at the Italian Medical Association or in the premises of local parishes). At the beginning, we asked permission from the participants to audiotape the session for a more reliable analysis of the discussion. Each audiotaped session was listened to by three of us (P.B., C.T., and G.T.), compared to handwritten notes, and each key statement was transcribed verbatim. After listening to each session, and reading the transcription, we identified 10 recurrent themes that closely mirrored the list of questions which was discussed. We added only one theme, ‘Relationship patient/family’, which was not in the list, because it was raised several times during the discussion. The 10 themes were the following:

1. causes of depressive illness;
2. length and course of the disease;
3. role of drug treatment;
4. role of non-pharmacological treatments;
5. common problems with medications;
6. relationship patient/family;
7. prevalence of non-adherence;
8. methods to assess patient adherence;
9. prevention of non-adherence; and
10. interventions to facilitate adherence.
Themes 7–9 were only used to code therapists’ statements. We read all statements again, and classified each one in the respective theme, and within each theme according to its content. For example, the statement made by a patient: ‘The drug and the doctor make you feel better’ was classified in the theme ‘Role of drug treatment’, with content ‘Useful together with a good doctor/patient relationship’. Eventually, for the sake of conciseness, we summarized the material in five general themes.

Results

Out of 52 patients in the three CMHCs who, according to the psychiatrist in charge, could be contacted, 22 eventually participated. Thirty patients declined to participate because of shyness to talk in public, schedule conflicts, or other unspecified reasons. They did not differ from those who participated as regards sex and age. Out of 14 family members contacted, 13 participated. The main sociodemographic characteristics of patients and family members are summarized in Table 2. Finally, 17 mental health professionals took part in the groups (seven psychiatrists, nine community psychiatric nurses, and one psychologist).

The explanatory model of depression

Only one patient did not attribute her depression to any cause (‘I don’t know where it came from’). The remaining mentioned a combination of causes ranging from psychological suffering in their childhood and adolescence, an intrinsic weakness or vulnerability of their character, stress and lack of understanding at work, difficulty in accepting help from close persons, and specific phases of life, such as pregnancy, menopause and retirement. In addition, 15 patients mentioned an adverse life event, which triggered the first episode of depression.

The explanatory model of family members was very similar to the one provided by patients. Many mentioned the extreme vulnerability of their relatives, which was rooted in childhood or adolescence (eight times), and the occurrence of life events, including family conflicts, which triggered the disease (10 times). Four relatives added that minimal events (‘Someone letting a glass drop’) could rekindle suffering or cause extreme irritability.
Mental health professionals attributed depressive disorders to two main groups of causes: essentially biological (seven times), or essentially ‘environmental’, including family conflicts, major life events, or change in roles (10 times).

The course of the disease
Six patients in our sample believed that depression has a long course, with better and worse periods or a specific seasonality. Two patients believed that it lasts all your life (‘I believe it will never go away’), and two conceived depression as a long but circumscribed episode in someone’s life (‘You have to face it as a disease, not a ever-lasting status’). Four additional patients, all young women no longer on treatment with antidepressants, did not express any belief about long-term prognosis.

Family members also saw depression as a long disease with a cyclical course (five persons), and three as a chronic condition. In contrast, only two mental health professionals considered major depression as a chronic and disabling disorder.

The role of medication and other treatments
All patients but four considered medications as a very important aspect of their treatment. (‘[After taking antidepressants] I started eating again. I feel more vital, I talk to my wife, I drive, I go out.’; ‘I would never have made it without drugs.’; ‘You can decrease a little, but never stop.’; ‘Relapse can come abruptly: you need something to keep high the level of guard.’). Drugs were important, coupled with a good relationship with the doctor (‘The drug and the doctor make you feel better’). Eight patients out of 22 mentioned that non-pharmacological interventions had been useful in their experience, mainly psychological support to clarify the causes of the depression once you felt better (five times), hospitalization (three times), and talking to people who have the same problem (three times). Most patients drew support from close family members, and some mentioned friends and co-workers.

Family members were less enthusiastic about drug treatment than their relatives.

Of all statements made by family members about drug treatment, six were positive and 10 rather negative (e.g. ‘Medication is a crutch.’; ‘If she would take water instead of drugs it would be the same.’; ‘I give my wife eight drops instead of thirty.’; ‘I don’t understand why my husband is taking medication but still relapses. The doctor says everything is OK, but I know he’s not feeling well.’; ‘My daughter should reduce drugs, go out and do something useful for other people.’). Only two family members stated that their relatives should have taken drugs forever. In addition, three mentioned the efficacy of psychological treatment, and 3 the efficacy of hospitalization.

Finally, all mental health professionals considered drugs essential in the treatment of major depression, together with an empathic relation with the patient (seven times). Other important interventions mentioned were the presence of a multidisciplinary team (doctors and nurses) catering for the different needs of patients (six times), psychological treatment when patients were feeling better (five times), and support to the family (five times).

The causes of non-adherence
Although most patients considered drugs as essential for their treatment, not all experiences with drugs were positive. First, it was difficult to accept a psychiatric diagnosis, and hence treatment with psychotropic drugs (six patients). Four patients reported that they had stopped drugs against the advice of the psychiatrist when they started feeling better, to test whether the disease had gone away, but that they relapsed and had to take treatment again. Ten patients mentioned the recent occurrence of milder adverse reactions, adding that adverse reactions were tolerable because the psychiatrist had informed them and they could contact the CMHC for reassurance or to have the dose adjusted. Interestingly, only one patient mentioned the fear of drug addiction, and one the latency period of the drug as cause of non-adherence.

In our sample, relatives did not seem very concerned about drug toxicity, which could be monitored by the CMHC. Three relatives said that antidepressants slowed the patient down, but also depression did. Only one relative mentioned the risk of physical addiction.

Finally, seven mental health professionals considered non-adherence to treatment an unusual problem in depressed patients. Mental health professionals had the impression that their patients complied, perhaps at times reducing the dose on their own. Only two psychiatrists mentioned non-response to treatment as a major clinical problem, especially when the depression was very severe. Adverse reactions were considered as the major potential cause of non-adherence (eight times), followed by the slow onset of action of antidepressant drugs (six times), the non-cooperation of the family (six times), fear of drug addiction (three times), and the need for a long treatment regimen (three times). Once treatment had successfully worked, the next issue was to convince patients to continue it, finding appropriate metaphors to reassure patients that the disease was cured, but that relapses needed to be prevented. Psychiatrists did not directly question patients about adherence with treatment, because it would have implied lack of trust. Adherence was rather assessed indirectly, asking the
family, questioning patients about adverse reactions, and monitoring the clinical progress. Patients reported problems concerning treatment, including adverse reactions and non-adherence, more frequently to nurses than to doctors. According to both nurses and psychiatrists, the most important factors to ensure good adherence were the cooperation of the family (eight times), a good relationship with the patient (six times), forewarning patients about adverse effects (six times), and providing frequent follow-up visits at the beginning of treatment (three times).

What interventions would help increase adherence?

Five patients in our sample indicated the need to get more information, in simple terms, about their condition and a clear plan for the future. Others suggested that doctors should put patients at ease (two times), that the centre should be more accessible in case of need (two times), that the turnover of personnel should be reduced (two patients, ‘When you have told very intimate aspects of your life to a doctor, it is difficult to start everything again with a new one’). Three patients highlighted the need to decrease the stigma attached to depression in the society, although only two directly related the fear of being stigmatized to non-adherence.

The main request of relatives concerned information about the disease and the treatment with antidepressants (eight times). Four relatives indicated the need for psychological help or self-help groups for the family of depressed patients, and two the need for domiciliary assistance to deal with severely disabled patients. Finally, six relatives highlighted the need to decrease the stigma associated with mental disorders in the society.

Mental health professionals indicated that the main intervention to improve treatment of depression, and hence adherence, was to increase the available resources in terms of time and personnel. Providing patients with information material on depression was also suggested three times, self-help groups twice times, and a study group for mental health professionals once.

Discussion

Much research on treatment adherence has focused on the doctor–patient relationship, neglecting the social interaction of patients with other persons, primarily family and friends, whose attitudes and opinions contribute to shape the ‘adherence environment’ where interventions should be applied (Trostle 1988, Smith & Basara 1995). Most of the times, the point of view of patients, family, and health professionals has been studied separately, thus missing the potential knowledge coming from a comparative analysis.

Our study, addressing the concurrent experience of a group of patients, their families, and their therapists, provided – for the first time as far as we know – many very important insights on their concordance and disagreements. It is worth noting that patients who took part in the groups did not differ from those who refused, and they represented an unselected sample of patients in contact with CMHCs, with different patterns and severity of illness, and at different stages of their treatment.

Although patients, families, and therapists showed a great deal of trust and mutual respect, they had different views on specific aspects, which could potentially cause conflicts and lead to less effective therapeutic intervention. One of the major differences we observed concerned patients’ and families’ opinion on the need for and duration of treatment. Patients considered medication as an essential component of treatment, irrespective of the initial causes of illness, to be continued for life or for a very long period. Families recognized the need for treatment in the acute phase of depression, while less or no medication would have been preferable thereafter, substituted by a more active behaviour of the patient. Most relatives indicated the need for additional information on depression. Family caregivers interviewed by Boyle & Chambers (2000) expressed the same need. Providing clear information to relatives may reduce anxiety and promote adherence.

Patients mentioned two key aspects affecting adherence to antidepressant treatment: at the beginning, the difficulty to accept a psychiatric diagnosis and to start treatment, and later the need to test whether depression was still there by stopping medications. Many authors have stressed the problem of denial of the disorder as a major obstacle to treatment (Cooper-Patrick et al. 1997). In addition, reducing or stopping medication to test whether the disease was improving, usually following a period of well-being, was a strategy reported in other conditions, for example, epilepsy (Conrad 1985). Mental health professionals recognized that patients often reduced or interrupted treatment to test the continuing presence of the disease, while they did not indicate denial of depression as a major cause of non-adherence at the beginning of treatment.

Adverse reactions, when adequately managed, did not play a prominent role in contributing to treatment non-adherence in our patients, as it has been reported for other medical conditions (Meichenbaum & Turk 1987, Stockwell-Morris & Schulz 1993). Patients reported serious adverse reactions as a cause of dropout in the past, when forewarning about possible side-effects was not the rule (as one patient put it: ‘In the sixties they gave us drugs without saying anything, and we had incredible adverse reactions!’). However, when the treating team informed patients of side-effects, and the centre (nurses in particular)
was accessible for reassurance and adjustments, adverse reactions were rather well tolerated. Not surprisingly, mental health professionals considered adverse reactions as the main cause of non-adherence (Fawcett 1995), but they seemed to deal with them rather satisfactorily. Interestingly, neither patients nor family considered antidepressant drugs as addictive, in contrast with the concerns expressed by family members of the Pittsburgh study (Frank et al. 1995), and by the general public in a survey conducted by the Royal College of Psychiatrists in the UK as part of the Defeat Depression Campaign (Paykel 1995).

Mental health professionals in our groups did not consider appropriate to openly bring up with their patients the issue of treatment adherence. This may lead to two important consequences. First, when the health professional fails to conduct such an enquiry patients tend to conclude that the practitioner does not attach much importance to adherence to the treatment regimen, and they tend to doubt the efficacy of the treatment. Second, if health professionals do not ask about adherence, they systematically overestimate the rate to which their patients adhere to their recommendations (Meichenbaum & Turk 1987). Actually, psychiatrists in our sample did not consider non-adherence as a major problem with depressed patients, in contrast with the results of epidemiological and clinical studies that indicated a dropout rate from treatment ranging from 30% to 60% (Pampallona et al. 2002). Concerning medication adherence, nurses tended to have a ‘bridge’ role between the patient and the psychiatrist, being more available to listen to problems with medication and to provide reassurance.

In summary, the study highlighted several themes which should be considered when designing specific interventions to improve adherence with treatment in depressive disorders. Mental health professionals clearly need training on prevention, detection, and management of non-adherence in depressive disorders. For nurses, training may enhance their capability to foster patients’ adherence to treatment. A number of clinical trials have shown that nurses may represent a precious resource in depression, by providing support to patients in general practice (Wilkinson et al. 1993, Mann et al. 1998), patient education and medication clinics (Pampallona et al. 2002). Families and patients need additional information on depression, in simple and understandable terms. While education alone will not improve adherence, knowledge will increase mastery over illness and a sense of well-being (Shooter 2003). In particular, families need guidance to accept the need for prolonged treatment, as well as emotional support and assistance at home in critical times.

Finally, patients and families forcefully raised the problem of stigma and discrimination, although it was beyond the scope of the focus groups. Discrimination at work, lack of understanding on the part of the extended family and of friends, stigma associated with taking medications and going to the CMHC made life with depression much more difficult. Other studies have indicated social stigma as a barrier to getting treatment for depression and adhering to it (Cooper-Patrick et al. 1997, Sirey et al. 2001). This problem needs to be addressed by large-scale community interventions.

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References


