Explanatory models of depression and treatment adherence to antidepressant medication: A qualitative interview study

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A R T I C L E   I N F O

Article history:
Received 4 July 2011
Received in revised form 18 April 2012
Accepted 28 April 2012

Keywords:
Depressive disorder, major interview
Patient Compliance Qualitative research

A B S T R A C T

Background: Adherence to antidepressant medication is a challenging clinical issue, which reduces treatment efficacy: 30–60% of all patients commencing treatment with antidepressants are estimated to stop taking the medication within the first 12 weeks. Patients’ personal beliefs about depression and antidepressants are regarded as central influences on adherence.

Objectives: The aim was to gain detailed insight into patients’ personal accounts of depression and use of antidepressant medication and to relate these accounts to the patients’ self-reported level of adherence.

Methods: In-depth, qualitative interviews of 16 depressed patients one, four, eight and twelve months after hospital discharge supplemented by diagnostic interviews and self-report measures. Kleinman’s notion of “explanatory model” was used as the theoretical perspective on the patients’ illness narratives. Interview transcripts were analysed thematically with “explanatory models” as the starting point.

Results: Patients had ambiguous experiences of depression and antidepressants. Patients explained their illness and the medical treatment in experience-near terms. Explanations of the reasons for depression were psychosocial and biology and medicine were not central. However, taking antidepressant medication was a meaningful part of being admitted to hospital, and the adoption of the rhetoric and practices of biomedicine strengthened patients’ sense of control and hope for recovery. If medicine was ineffective, the explanatory models legitimised alternative strategies towards recovery, including non-adherence.

Conclusions: The patients’ reasons for adhering to antidepressants included a range of diverse psychosocial issues, and could be regarded as a central part of their common sense illness management.

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What is already known about the topic?

- 30–60% of all patients commencing treatment with antidepressants stop taking the medication within the first 12 weeks.
- Patients’ beliefs about their illness and about taking medication are central influences on their adherence.

- Antidepressant medicine has a paradoxical effect on users’ lives: It normalises the depressive symptoms, but can also stigmatisate the user.

- Depressed persons have psychosocial models of depression, which give them a sense of direct and personal influence on their own recovery.

What this paper adds

- Depressed persons have psychosocial models of depression, which give them a sense of direct and personal influence on their own recovery.
• Depressed persons cannot feel any direct effects of their antidepressant medication, but they accept taking it initially because it gives them a sense of control and hope for recovery.
• Non-adherence was only present in situations where the medicine per se did not work.

1. Background

Medicine adherence may be defined as “the extent to which patients follow the instructions they are given for prescribed treatments.” (Haynes et al., 2008, p. 2). Low adherence to treatment with antidepressants is widespread: 30–60% of all patients commencing treatment with antidepressants are estimated to stop taking the medication within the first 12 weeks (Lingam and Scott, 2002; WHO, 2003). Low adherence to antidepressant medicine is an intractable clinical challenge, which reduces treatment efficacy and increases the risk of relapse and reoccurrence of depression. Adherence is related to – but not synonymous with – concordance, which is a normative concept concerned with the quality of the interactions between patients and doctors during the treatment process (Horne et al., 2005).

Systematic reviews of interventions designed to increase adherence to antidepressants indicate that educational interventions alone are ineffective and that there is some evidence suggesting that complex interventions, combining educational, behaviourial, affective and/or provider-targeted strategies, may be effective in improving adherence and treatment outcomes (Chong et al., 2011; Oestergaard and Moldrup, 2011). These recent reviews emphasise that medication taking is multifactorial health behaviour and that complex interventions may be effective because they address several psychosocial dimensions of patients’ lives. This observation represents a specific challenge for researchers wishing to isolate the effects mediated solely through changes in adherence, but also for researchers aiming at identifying the active elements of complex interventions in treatment delivery models.

Patients’ personal beliefs about their illness and medication are regarded as central influences on medicine taking and adherence (Horne et al., 2005; Lehane and McCarthy, 2007), and patients’ common sense understanding may have a stronger influence on decisions about taking medicine than the advice given by health care professionals (Horne et al., 2005). In general, these beliefs have been explored with the aim of understanding the wider psychosocial contexts of patients’ use of medication, and how they take medicine as part of their daily management of their illness. Qualitative research indicates that lay beliefs about medication may be changeable and contradictory. For example, patients are reported to take prescribed medicine, while they at the same time actively resist it by developing strategies for minimising their intake (Pound et al., 2005). An exploration of patients’ beliefs does not address all dimensions of adherence, as it is only concerned with patients’ intentions to take medicine. It cannot account for unintended non-compliance, such as slips or lapses.

In a meta-ethnography, Malpass et al. (2009) interpreted 16 qualitative studies of taking antidepressants. The meta-ethnography included studies with samples of patients who were prescribed antidepressants for depression, but some samples also included other illnesses. Malpass et al. identified a psychological lay evaluation process through which patients cope with decisions related to medicine taking and with moral issues, such as stigma and legitimisation of their sick role. To some extent these findings reflect the presence of the two major research traditions in this field: the focus of the health care sciences on treatment and the social sciences on social identity.

The seminal qualitative study of users of antidepressant medicine was made by Karp (1993). Karp identified an antidepressant medication career with four stages, which reflected a strong reluctance towards the biomedical model of depression and a continuous ambivalence towards antidepressant medication. Ambivalence towards antidepressant medicine has been a consistent finding in subsequent qualitative studies, but the aversions towards biomedicine have not been found consistently. This was probably related to Karp’s snowball sampling strategy, which led to the inclusion of relatively highly educated, articulate and critical medicine users. Later studies have emphasised that users of antidepressants find it difficult to feel any effect of their antidepressants, but that they continue taking the medication because of uncertainty and fear of relapse (Grime and Pollock, 2003; Verbeek-Heida and Mathot, 2006). Grime and Pollock interpreted such behaviour as signs of psychological dependency on the antidepressant medication. Furthermore, studies indicate that antidepressant medication has a paradoxical function (Garfield et al., 2003; Verbeek-Heida and Mathot, 2006): Antidepressant medication normalises the users’ lives by reducing symptoms of depression, but, simultaneously, taking the medication stigmatises the users and makes them feel less normal. These issues call for more cooperative, concordance-oriented, approaches to antidepressant treatment, which also aim at addressing stigma and normalising taking medication (cf. Garfield et al., 2003; Givens et al., 2006). Adherence and beliefs about antidepressant medicine change at different stages of illness and during different treatment phases, therefore we will focus on depressed patients in the first year following an admission to hospital.

1.1. Aims of the study

The aim of this qualitative study was to gain detailed insight into depressed patients’ personal beliefs about their illness and antidepressant treatment in the first twelve months after a hospital admission, and to explore how these beliefs were related to their self-reported level of adherence to treatment with anti-depressants.

2. Methods

In-depth, semi-structured qualitative interviews were conducted with 16 patients one, four, eight and twelve months after discharge from a hospital admission for
depression. The interviews were supplemented by the diagnostic interview Schedules for Clinical Assessment in Neuropsychiatry (SCAN), and the self-report measures Antidepressant Compliance Questionnaire (ADCQ), Beck Depression Inventory II (BDI-II) and Symptoms Checklist 92 (SCL-92). It was hypothesised that adherence would decrease between the interviews.

2.1. Theoretical perspective

We adopted Kleinman’s (1980) concept “explanatory model” to be sensitive to and to explore the patients’ personal beliefs about illness and treatment. According to Kleinman, an explanatory model is the patients’ explanation of a particular episode of illness, and explanatory models may therefore be partially idiosyncratic and partially in accordance with culturally acknowledged notions of illness and disease. Explanatory models give meaning to the persons’ experience of illness and their choice of treatment. Explanatory models may explain five interrelated issues pertaining to an episode of illness: (1) the aetiology of the illness, (2) the timing and mode of onset of symptoms, (3) pathophysiology, (4) the course of illness, including the sick role, (5) the appropriate treatment of the illness (Kleinman, 1980). Laypersons’ explanatory models typically reflect a highly adaptable understanding of illness that may integrate a diverse range of experiences. Kleinman suggests that the analysis of illness narratives is a source of insight into the patients’ unique understandings of their condition (Kleinman, 1988).

2.2. Setting and sample

The study was conducted at a regional healthcare trust in Southern Denmark in 2008–2009. Participants were recruited from three general psychiatric wards at two general hospitals that admitted patients from urban and suburban areas. Purposeful, non-probability sampling was used to select “information-rich” participants (Patton, 2002), from whom we could learn about the explanatory models of persons diagnosed with depression. Through a five-month inclusion period clinical nursing staff invited patients to participate in the study. The inclusion criteria were a discharge diagnosis of a depressive episode/disorder (ICD-10 F32.0-F33.9) and a prescription for antidepressant medication. The exclusion criteria were: age <18 years, severe cognitive impairment, severe personality disorder, and inability to understand and express oneself in Danish. The cooperative sampling procedure made it difficult to assess the exact number of those who were excluded and those who refused to participate. However, based on database information from one of the wards it was estimated that about 40% of all who fulfilled the inclusion criteria were excluded and that the sample included about 70% of the eligible participants. The sample included 16 participants and there were no dropouts during the study, see Table 1.

The timing of the first interview was chosen to allow the informants time to recover after their depression and still be able to recall details from the admission. The three follow-up interviews were made with regular intervals over a one-year period; during this period a substantial number of the patients should have stopped taking their medicine and it would be possible to follow changes in their explanatory models.

2.3. Data collection

The qualitative interviews were designed to systematically identify the participants’ explanatory models of their illness. A thematically structured interview guide was designed to support the development of a trusting relationship and to ensure the relevance of the interviews’ thematic content (Kvale and Brinkmann, 2009). All participants were asked the same primary interview questions (see a basic outline in Table 2), which were supplemented by a range of follow-up questions targeting the specific participant’s response and personal biography. The interview guide was tested before the first interview and the test-experiences were used to modify its structure slightly. The same interview themes were addressed at all interviews. Preliminary analyses between the interviews were used to prepare additional follow-up questions to further explore continuities and discontinuities in issues central to each individual participant.
Table 2
Basic outline of the interview guide.

<table>
<thead>
<tr>
<th>Explanatory model</th>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aetiology</td>
<td>How have you been? What had happened to you?</td>
</tr>
<tr>
<td></td>
<td>Why do you think you became depressed?</td>
</tr>
<tr>
<td>Timing and onset of symptoms</td>
<td>What had happened when you first got the feeling that something was wrong?</td>
</tr>
<tr>
<td>Pathophysiology</td>
<td>Where did you look for help?</td>
</tr>
<tr>
<td></td>
<td>How would you explain depression to someone who did not know the condition?</td>
</tr>
<tr>
<td></td>
<td>Do you have a medical condition comparable to diabetes?</td>
</tr>
<tr>
<td></td>
<td>How does anti-depressant treatment work?</td>
</tr>
<tr>
<td>Course of illness and sick-role</td>
<td>How will depression affect your life and health in the future?</td>
</tr>
<tr>
<td></td>
<td>How can future illness be prevented?</td>
</tr>
<tr>
<td>Treatment</td>
<td>Have you been embarrassed about your depression?</td>
</tr>
<tr>
<td></td>
<td>What has been effective in healing your illness?</td>
</tr>
<tr>
<td></td>
<td>Do you take your antidepressants as prescribed?</td>
</tr>
<tr>
<td></td>
<td>What motivates you to take anti-depressants?</td>
</tr>
</tbody>
</table>

A trained and experienced research interviewer (N.B.) conducted all interviews. They took place in the participants’ homes. The interviews were audio-recorded and transcribed by trained transcribers into ‘written’ language by leaving out hesitations, extra linguistic expressions, etc. The accuracy of the transcriptions was checked by an independent comparison of text and sound. The average duration of the 64 interviews was 72 min (range: 30–147). The first author and a bilingual assistant translated the data extracts presented in the paper.

Furthermore, participants were interviewed using the semi-structured diagnostic interview SCAN (Wing et al., 1998). Interview ratings and anamnestic data from medical files were entered into a computerised scoring sheet (I-Shell SCAN, version 2.1), which provided diagnoses according to definitions in the International Classification of Diseases (ICD-10) (WHO, 1993), see Table 3.

Three questionnaires were administered at both interviews to obtain additional data on adherence, ADCQ (Kessing et al., 2005), severity of depression, BDI-II (Beck et al., 2005), and general psychiatric distress, SCL-92 (Derogatis, 2007). The self-report data were used as contextual information in the interpretative process, where qualitative data were triangulated with quantitative data, see Table 3.

Table 3
Quantitative data.

<table>
<thead>
<tr>
<th>Measure</th>
<th>1 month</th>
<th>4 months</th>
<th>8 months</th>
<th>12 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCAN diagnosis</td>
<td>2 F31.3</td>
<td>7 F32.1-F32.2</td>
<td>7 F33.1-F33.2</td>
<td></td>
</tr>
<tr>
<td>Mean BDI-II (SD)</td>
<td>17.0 (11.6)</td>
<td>14.0 (14.6)</td>
<td>11.0 (11.0)</td>
<td>9.0 (6.5)</td>
</tr>
<tr>
<td>Mean SCL-92 (Global Severity Index) (SD)</td>
<td>0.98 (0.52)</td>
<td>0.67 (0.63)</td>
<td>0.55 (0.71)</td>
<td>0.50 (0.56)</td>
</tr>
<tr>
<td>Mean ADCQ component 1: perceived doctor patient relationship (SD)</td>
<td>3.1 (0.4)</td>
<td>3.1 (0.4)</td>
<td>3.1 (0.4)</td>
<td>2.9 (0.4)</td>
</tr>
<tr>
<td>Mean ADCQ component 2 preserved autonomy (SD)</td>
<td>2.9 (0.5)</td>
<td>2.7 (0.5)</td>
<td>2.7 (0.5)</td>
<td>2.8 (0.4)</td>
</tr>
<tr>
<td>Mean ADCQ component 3 positive beliefs about antidepressants (SD)</td>
<td>3.2 (0.4)</td>
<td>3.2 (0.4)</td>
<td>3.2 (0.4)</td>
<td>3.3 (0.4)</td>
</tr>
<tr>
<td>Mean ADCQ component 4: partner agreement (SD)</td>
<td>3.7 (0.4)</td>
<td>3.7 (0.5)</td>
<td>3.4 (0.5)</td>
<td>3.6 (0.4)</td>
</tr>
<tr>
<td>Classification of interview responses: number of informants describing antidepressant medication as beneficial</td>
<td>12</td>
<td>10</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Classification of interview responses: number of informants reducing or forgetting to take antidepressant medication (&gt;5 days)</td>
<td>2</td>
<td>2</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

The first step was an open, data-driven coding process, which took place in between interviews and after reading the transcripts in full. The aim was to develop an initial understanding of the whole dataset. The interpreter (N.B.) wrote résumés of each interview, kept a detailed research-diary and coded the transcripts for central issues. The first step led to the identification of 36 preliminary themes, which were represented in a “data-display” (Miles and Huberman, 1994). The second step was to focus on data concerning explanations of illness and treatment. Kleinman’s (1980) conception of “explanatory models” was used to focus on these parts of the data-display and to define 24 codes, which were used to code the whole dataset. This part of the analysis was computer-assisted with NVivo 8 software for classifying, sorting and arranging qualitative data (www.qsrinternational.com). The third step was a detailed comparative interrogation of the thematic content of the codes by exploring similarities and differences between participants as well as across time for each individual participant. The aim was to develop a balanced and nuanced interpretation of the participants’ explanatory models.

Aiming at increasing the credibility (internal validity) of the interpretative process, the interpretations were systematically and rigorously challenged by: (1) Checking interpretations for representativeness across the whole dataset. (2) Triangulating qualitative data with quantitative data. (3) Examining and explaining unexpected findings. (4) Actively attempting to falsify interpretations.
(5) Critically reviewing interpretations with peers. (6) Using participant feedback at the second interview to check preliminary interpretations (Miles and Huberman, 1994).

The emergent and cyclic features of qualitative research contribute to the overall credibility of a qualitative study as it allows researchers to reflect on preliminary interpretations and adapt their data collection and analytic strategies to fit the particular dataset and research context (Coffey and Atkinson, 1996; Patton, 2002).

Finally, the interview–responses were classified as to (1) whether the informants described antidepressants as beneficial or not, and (2) whether they forgot or altered their medication for more than seven days without consulting their therapist(s) or not, see Table 3.

2.5. Ethics

In line with Danish legislation the regional research ethics committee and the Danish Data Protection Agency were notified about the study; neither agencies had any objections to the study. All participants gave their consent to participate based on written and verbal information about the study. Data were handled anonymously.

3. Results

First, we will present central issues in the informants’ explanatory models pertaining to their medicine taking and adherence. Last, we will present quantitative data on the informants’ self-reported psychological health, level of depression and level of adherence.

3.1. Aetiology: explaining the cause of the illness

All informants accounted for aetiology in terms of external psychosocial events triggering their illness rather than internal psychological or biological mechanisms causing the illness. All informants explained their illness as a response to an array of external stressors. Through their illness narratives, the informants tried to make sense of their illness experiences by linking them to patterns of stressful events in their personal biography. These accounts were proximal in the sense that they were in line with the informants’ personal and everyday experience.

Interviewer:

What do you think caused the first depression?

Informant 110 (1st interview)

I had just lost my dad and my mother-in-law. We were newcomers over here. The whole family was in Copenhagen. I worked at home and had no job. I had to get an everyday life with the kids established. My husband was working and I didn’t know anyone. I think that did it.

Most respondents qualified their stress explanations by linking their ability to cope with stressful events to personality traits, such as a tendency to take care of others rather than themselves. And some hypothesised that some of these personality traits could be hereditary and linked to their family’s history.

Two respondents described their stressful situation as also having a strong biological basis: pregnancy and medication–interactions respectively. The additional emphasis on biology reduced the symbolic impact of the illness, which appeared both treatable and as an illness the person was not personally accountable for.

Informant 1 (2nd interview):

I have chosen to believe that my brain didn’t have enough of some substance, which coincided with some external circumstances and made me feel ill. I will not question this belief because it has been a big help knowing that you are diseased. You can be cured and now you get some medicine that will help.

All informants acknowledged that their illness had a biological dimension when they were asked directly, but the biological explanations were very general descriptions of substances in the brain and not central to their understanding of the reasons for their illness.

Informant 15, (4th interview)

I am aware that my body is supplied with substances [the medicine] that my brain does not produce enough of. I get that, and that they are really important substances inside my brain, that do this and that, but I don’t know how it gets in and works. I know that it is something I need. And that is ok. I’m fine with that.

3.2. Timing of onset of symptoms: explaining illness

The most comprehensive accounts of the informants’ beliefs about the depression were evident in the descriptions of the timing and onset of illness. The informants would organise overall illness narratives explaining how they had succumbed after a period of strain, which could range from a few weeks to a lifetime. The organisation of the narratives depicted informants’ illness as an understandable response to extraordinary psychosocial events, which also legitimised the informants’ help-seeking actions and their illness behaviour.

The eight informants, who had been admitted for the first time, identified recent and a relatively distinct index–events that had triggered the illness. This identification created an image of the illness as relatively isolated event caused by external forces and, therefore, manageable. These index–events included for example: “divorce”, “death in the family”, “serious disease in the family”, and “physical injury”.

Informant 2 (1st interview)

I was tired and couldn’t eat and lost weight and was sad all the time. And I fell and hurt my back. That was where it all started. ( . . . ) Well, I was examined and was told that I had osteoporosis, and I got medicine for that, and from then on it’s only been downhill.

In the subsequent interviews, seven of these eight informants downsized the significance of these triggering
events and described their depression as linked to much longer periods with fatigue and stress, or as linked to personality traits. For instance, Informant 2 began to account for an earlier onset than the previous index-event “physical injury”.

Informant 2 (3rd interview)

At that point, I didn’t realise that I was ill. I was just tired. I remember hanging out the laundry and talking to the neighbour. I said, “I am so tired that I am completely burnt out”. And then all the rest happened [fall and injury].

The informants, who had been admitted before, did not include distinct index-events in their narratives and did not alter the basic organisation of their narratives across the four interviews. This may be because they had learned to recognise certain illness experiences and their gradual appearance. Five of these informants were unable to explain what triggered one or more of the latest depressive episodes, and they described depression as a persistent, unfair and unpredictable ailment that could return when it was least expected and in spite of taking preventive measures.

3.3. Pathophysiology: manifestations of illness

The informants were at different stages in their illness careers, and that influenced how they identified their illness. The six informants, who were severely depressed for the first time, stated that it had taken them a relatively long time to recognise their condition as depression, and four continued to doubt whether they really had suffered from a depression. It was difficult for them to link their idiosyncratic symptoms and distress to their lay conception of depression: A properly depressed person should be profoundly sad, tearful and be self-pitying. However, several informants continued to understand their illness as something different, such as “nerves”, unexplainable bodily pain, stress, or lack of energy.

Interviewer:

The doctors called it a depression. What would you call it?

Informant 4 (3rd interview)

I don’t know. I haven’t figured anything out. They are doctors and if they say I had a depression, then I had a depression. I haven’t found out. Just that things got really bad.

The 10 informants, who had suffered from several depressive episodes, had adopted the term “depression” to account for their experiences of distress. Often, the illness narratives also included direct references to health care staffs’ advice or counselling that had been seminal for the informants’ understanding of their illness. For instance a non-technical description of the mind as a backpack that can only carry a certain amount of weight before the carrier succumbs. Such metaphorical explanations were easily adopted in to informants’ explanatory models as they were in line with their lay understanding of the illness, and the metaphors legitimised the ill persons’ experiences and actions.

3.4. Course of illness and sick role

Taking antidepressant medication contributed to a legitimisation of the illness by emphasising seriousness and the informants’ efforts at getting better. However, at the same time, it represented a certain level of acceptance of an undesirable and potentially stigmatising illness. Therefore, it was important for all the informants to differentiate their illness from less serious depressive illnesses that could be cured by an act of will or with a prescription for Prozac from a general practitioner. They also differentiated themselves from the really mentally ill, who were described as crazy. In this way they created a balanced image of suffering from a legitimate and serious mental illness, not weakness, and being accountable, not mad. In the 1st interview, Informant 15 explicitly defined her fear of electricity as “silly thoughts”, not “psychosis”. In later interviews, she acknowledged the irrationality, but maintained a distance to true madness.

Informant 15 (4th interview)

I am not usually someone who is psychotic or does psychotic things or anything. This happened because of deep, deep depression, so I don’t think much about it now.

In the first two interviews, six informants tended to organise relatively hopeful narratives that depicted future depressions as almost impossible. The disbelief in future depression was based on the premises, that a similar array of stressful events would be extremely unlikely and that their new personal coping strategies, such as taking medicine exactly as prescribed, would suffice in reducing stress.

Informant 14 (1st interview)

In a year from now, and I feel good, like I do now, they will say: “We will reduce the tablets now”. (...) Then you must trust them: that there is virtually no risk of relapse. Why would another event [a similar index-event] happen that could make it return? The depression wouldn’t come by itself. Something would have to occur for you to get such a thing again.

In the latter interviews, the informants’ certainty about the future was reduced and substituted by more cautious narratives, where new episodes of depression were deemed quite possible. Informant 14 experienced two setbacks between the 1st and the 4th interview. He was frustrated by this and articulated existential concerns about getting depressions:

Informant 14 (4th interview)

I do not think about getting depressed again. When I’ve had the setbacks, I’ve thought, “Why do I have to feel so miserable? Why am I being punished so hard? I have already been severely punished. Why do I get the depressions? Why doesn’t life just run smoothly?”
In the first months after the admission, all informants feared that the illness had not completely gone and they anxiously interpreted mental or bodily signs as possible symptoms indicating prolonged illness. This was linked to a general uncertainty about how they could expect to feel and while taking (new) antidepressive medication during recovery.

All informants emphasised the importance of being treated by available and committed therapist(s) who had insight into their particular situation. However, fourteen informants did not feel involved in the decision to start antidepressant treatment.

**Interviewer:**

**Did you cooperate with the psychiatrist about your medication?**

**Informant 15 (1st interview)**

No. But it is hard to cooperate with someone who doesn’t know what she’s talking about. I can say how I feel and they’ll decide if it’s this or that causing it. Then we increase or decrease or shift to something else. It’s been adjusted since my discharge [...]. I don’t know what the different pills do for me. It’s difficult to cooperate and suggest changes when you don’t have the necessary insight.

The informants took the prescribed antidepressants in expectation of a cure and expressed a hopeful readiness to take any drug that could give relief. The start of the medical treatment was described as part of a highly conventionalised sick role: a natural part of the treatment regime during a hospital admission, where patients submit to medical authority.

**Interviewer:**

**Do you remember what you thought about starting on this medication?**

**Informant 3 (4th interview)**

I didn’t think anything at all because it was at the hospital and I was under treatment. And they said to me “now try these out”.

The experience of serious illness and the conventionalised sick role during admission made the informants accept medicine without being concerned about the particular treatment models or the medicine per se. This changed in the months after discharge where an increasing number of informants started to question side effects and the dangers of medicine dosages and of interactions.

### 3.5. Medication as appropriate treatment

All the informants were prescribed antidepressant medication in different dosages and 15 informants took more than one psychotropic drug. They had trouble making sense of how the professionals’ changing prescriptions of dosages and drugs worked and affected them (see quote by Informant 15 above). From four months and onwards, none of the informants could feel any positive effects of the medicine prescribed during admission. The six informants, who took antidepressant medicine for the first time, had been desperately disappointed by the timeframe – several weeks – before the medicine would maybe work and that there was no quick cure, which they would normally expect from treatment during a hospital admission.

Antidepressant treatment was ambiguous and frustrating for all the informants, who were uncertain about both effects and side effects. Nine informants experienced a gradual recovery and had no severe side effects; this increased their sense of control and pushed their initial doubts about depression and medicine into the backgrounds of their lives. Some were longing to stop taking the medicine, but very cautious of trying, as it could disrupt the recently established balance in their health.

**Interviewer:**

**Do you take the medicine?**

**Informant 9 (4th interview)**

Yes, I mean, Noritren was reduced to 200 mg. They advised me to do so at the hospital. And I was meant to take five tablets of Lithium daily, two in the morning and 3 in the evening. I dropped the two in the morning. I told Lisa [the therapist], and she said, “That is for you to decide, it is your life”. So I have reduced it a little on my own. (…) I could not express myself because of cramps in my face, in my mouth, when I spoke. I still have shaky hands. It was terrible.

The adoption of the rhetoric and practices of medication increased the informants’ sense of control over their ambiguous and uncertain condition. Medical norms for treatment, doses, and blood sample values were interpreted as positive manifestations of illness, which corresponded with their ambiguous, subjective experiences of illness. In the same vein, the recommended period of treatment was interpreted as a guarantee that the illness would be cured and that there was a greatly reduced risk of relapse (see quote by Informant 14, 1st interview, above).

Fifteen informants experienced side effects, but most of the side effects were regarded as minor and acceptable,
such a dry mouth or mild tremor. However, a few side effects were interfering with the informants’ social life and were therefore harder to accept, such as weight gain or the sense of no longer feeling like oneself. For some, it was impossible to decide, whether their symptoms were caused by the depression or by medicine, or which problem was worst, depression or side effect (see quote by Informant 9 above).

The informants’ explanatory models were proximal and experience-near and they depicted treatment as fundamentally ambiguous. The explanations of the reasons for their illness were psychosocial, and medicine was not central. However, antidepressant medicine was a central part of the explanatory models because it drew on a restitution narrative (Frank, 1995), which includes a basic linkage between illness, medical treatment, recovery, and possible relapse. In this sense, taking medicine contributed to an increased sense of certainty, control and hope for the future. Nine informants were in a gradual recovery process, which meant that the ambiguity of medication became unimportant, and they preferred taking medicine rather than risking relapse. Seven informants’ expectations of restitution and cure were disappointed by little or no effect of the medicine and/or intolerable side effects. Their explanatory models aimed at legitimising non-adherence and other personal initiatives as rational ways of gaining control over complex problems that include illness and medical treatment.

3.6. The quantitative dataset

Quantitative results are presented in Table 3. It was not meaningful to perform statistical tests on the basis of the particular study design and therefore only raw scores are presented. The SCAN interviews identified two informants with hypomanic episodes, which indicated that they had bipolar disorders. Reductions in the mean BDI-II scores (from 17.0 to 14.0) and in mean SCL-92 scores (from 0.98 to 0.67) indicated that the informants were recovering from depression and suffered less general psychiatric distress.

ADQ-scores indicated that the informants were adhering to antidepressants continually. Only the scores of the component “perceived autonomy” were slightly reduced (from 2.9 to 2.7). However, the classification of the qualitative interview-data indicated that an increasing number of informants were not adhering to the prescribed medication (from 2 to 6 informants) and were explicitly questioning the benefits of taking antidepressants (from 2 to 8 informants).

4. Discussion

This prospective analysis explored depressed patients’ explanatory models of illness and treatment and was a rare study of medication adherence (compared to a large number of studies of non-adherence). The informants drew on different explanatory resources in order to comprehend depression and antidepressant treatment, and, as suggested by Kleinman (1980), their explanatory models were complex and adaptable. In line with previous research, the analysis indicated that the majority of depressed patients believe that the aetiology of their depression is psychosocial, and do not draw on specific biological explanations (Hansson et al., 2010). We suggest that psychosocial explanations dominate because they can be used to create concrete opportunities for personal action and management of illness since common sense links them with personal experiences and biography. However, taking antidepressants entails the dual process of explaining illness and medication as well as negotiating social identity (Malpass et al., 2009). Therefore, the common sense character of the psychosocial explanations could also be seen as important contributions to patients’ efforts to legitimise the depressive illness as a normal response to life events – rather than as madness (cf. Kangas, 2001).

Depressive patients are often uncertain about their illness because of the diffuse and ambiguous character of the symptoms and the effects of antidepressants (e.g. Verbeek-Heida and Mathot, 2006). A synthesis of qualitative studies of medicine taking concluded that people resist taking prescribed medicine because of concerns about the medicine per se, such as side effects and developing dependence, tolerance and/or addiction (Pound et al., 2005). Informants in the present analysis expressed concerns about the medicine, and non-adherence was linked to situations where the medicine per se did not work. Furthermore, the results resembled findings from an interview study of long-term users of antidepressants, which indicated that fear and uncertainty about discontinuing made patients adhere to their medication even though they believed that it was more normal to resist it (Verbeek-Heida and Mathot, 2006). This could be an indicator of psychological dependency and a lack of personal control. In line with previous qualitative research (Garfield et al., 2003; Karp, 1993), the analysis also indicated that medical antidepressant treatment can give patients a sense of hope for the future. We suggest that the informants’ belief in doctors’ advice and use of medication was a socially legitimate management of uncertainty and illness, which gave them a sense of control and hope for returning to normal life. This could be interpreted as subjugation to biomedicine (Foucault, 1990 [1976]), but numerous instances of idiosyncratic explanations suggest a complicated relationship where patients unintentionally resist submission.

The high level of intended adherence to antidepressants was related to the informants’ common sense strategies for conventionalised illness management, and not to a correct medical understanding of the benefits and risks of antidepressants. The complexity of patients’ common sense beliefs may be part of an explanation as to why it has proven very difficult to identify predictors of non-adherence to antidepressants (ten Doesschate et al., 2009). More research is needed on depressive patients’ beliefs about their illness and treatment and how they relate to clinical factors, such as stages of illness, and their adherence to antidepressants (cf. Chong et al., 2011).

The results should be interpreted with some caution. There are no golden standard measures of medication use and adherence, and the self-reported measure of intended
adherence was an indirect measure, which may vary from actual levels of medication use (cf. Lingam and Scott, 2002). In the same vein, the study explored the participants’ reflections on their disease and treatment, which may differ from their actual behaviour.

The strengths of this explorative qualitative study include a clearly defined sample and methods that allow informants to express and elaborate on their experiences of illness and taking antidepressants at some length during two interview sessions. The approach proved to be highly relevant as the informants’ experiences of these issues were often ambiguous and tentative. The qualitative design with large amounts of data from a small sample does not allow a generalisation from the sample to a larger population, but the detailed descriptions of the sample allow readers to transfer results case-to-case (Miles and Huberman, 1994).

Kleinman’s concept of “explanatory models” proved to be a fruitful way of structuring the interview guide, but seemed less fruitful as an interpretative framework for exploring adherence to antidepressant medication. Kleinman’s concept included an important examination of belief about treatment, which was advantageous compared to the issues forwarded in alternative models, such as the self-regulatory model of illness (Diefenbach and Leventhal, 1996). Kleinman developed the idea of the explanatory model while teaching medical students about illness conceptions in different societal sectors and the five issues resemble traditional pathological nosography. This may explain why the strength of the concept was the emphasis on the flexible adaptable accounts of the actual illness experience. However, participants in the present study were very concerned with negotiating the moral and social aspects of their depression and Kleinman’s concept did not provide a strong basis for integrating these aspects in an overall interpretation of the participants’ adherence to antidepressant medication, and therefore we chose to further emphasise these aspects in the analysis. Finally, a thematic rather than a case-by-case presentation of findings may not give the most comprehensive insight into the flexibility of explanatory models.

A single researcher performed all interviews and coding procedures, which facilitated a comprehensive understanding of the individual informant’s perspective in relation to the whole dataset. To minimise this researcher’s personal influences on conclusions, the interpretative process was computer assisted and supported by a critical group of peers, who systematically challenged credibility of preliminary findings (the more specific strategies for challenging conclusions are outlined in the methods section above). Furthermore, the second interview included member checking by means of an exploration of themes and preliminary interpretations from the first interview.

The qualitative interviews indicated that an increasing number of informants were in doubt about the effects of their antidepressants. However, ADCQ scores indicated that adherence did not decrease between interviews. These differences may be caused by the different methods of data collection, in which the structured questionnaires were less sensitive to change and personal ambivalence towards antidepressants compared to the lengthy open-ended interviews. Furthermore, ADCQ scores were relatively high. Standard scores are not available for the ADCQ, but in Kessing et al.’s cross sectional survey study (Kessing et al., 2005) of adherence among Danish patients with depressive and bipolar disorders, mean scores are reported to be lower than in the present study (mean total scores: 2.27), which indicates less adherence to antidepressants. The continually high levels of adherence may be related to the study design: (1) The severity of the recent depression may have threatened informants to accept and continue taking the prescribed antidepressant treatment. (2) The recruitment procedure may have included the most cooperative and adherent informants. (3) The interviews and the informants’ relationship to the interviewer may have a positive effect on adherence, as the interviews allowed the informants to articulate their concerns about taking antidepressants.

5. Conclusion

It was very challenging for patients to explain depressive illness. The patients drew on different explanatory resources in order to comprehend their depressive illness and antidepressant treatment. There was an explanatory incoherency between the psychosocial explanations of the aetiology of depression and reasons for taking medicine. However, both sets of explanations served to increase patients’ sense of personal control over their uncertain situation and ambiguous bodily experiences.

Clinical interventions could to an increasing extent be directed towards assisting depressed patients in managing their uncertainty about their illness and the effects of medicine. This may be done by developing experience-near explanations of depression and treatment. Finally, clinicians could engage more strategically with patients who do not profit from antidepressant medication and collaborate towards finding alternative forms of treatment and/or develop a higher level of acceptance of the illness.

Conflict of interest

None.

Funding

The study was supported by The Danish Ministry of Health and Prevention and by Aase and Ejnar Danielsen’s Foundation. The funding agencies did not influence the research process.

Ethical approval

Appropriate approval was given by the Danish Data Protection Agency.

Acknowledgements

The study was supported by The Danish Ministry of Health and Prevention and by Aase and Ejnar Danielsen’s
Foundation. The funding agencies did not influence the research process.

References