

Patients' perceptions of information received about medication prescribed for bipolar disorder: Implications for informed choice

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Abstract

Background: Previous research suggests that patients are dissatisfied with information provided about medication prescribed for mental illness, but has not identified which aspects of information provision are unsatisfactory.

Methods: 223 members of the Manic Depression Fellowship (MDF) completed the Satisfaction with Information about Medicines Scale (SIMS), a validated measure of patients' satisfaction with various aspects of information provision.

Results: Patients reported highest dissatisfaction with information about potential problems associated with medication; over 60% of participants reported dissatisfaction with information about the risks of side effects and whether the medication would affect their sex lives. Participants were significantly less satisfied with information about potential problems associated with their medication than people prescribed medication for HIV, in a previously reported study ($p < .01$). Those reporting low adherence to medication had significantly lower satisfaction with information scores than those reporting high adherence ($p < .05$).

Limitations: The sample could be prone to selection bias; participants were members of an organisation for people affected by bipolar disorder, whilst the comparator group was a NHS HIV clinic sample. Furthermore, the objective amount and type of information provided was not assessed, therefore the cause of patients' dissatisfaction is not known.

Conclusions: Perceived satisfaction with information is low, particularly in relation to possible drug side-effects. Health practitioners need to elicit individuals' information requirements and tailor information to meet their needs, in order to facilitate informed choice and adherence to treatment. Moreover, they need to provide information in a manner appropriate for a patient's cognitive functioning at different illness phases.

Key Words: bipolar disorder, patient information, patient satisfaction

Introduction

In order to make informed decisions about medication patients require adequate information. Research suggests, however, that patients may be dissatisfied with information received about medication prescribed for mental illness. For example, in a survey of over 2500 members of the Manic Depression Fellowship, National Schizophrenia Fellowship and MIND, 27% of participants reported that their doctors had not talked to them about their medication. Comparable results emerge from inpatient studies, with one reporting that just 61% of patients agreed with the statement "Doctors have explained my treatment clearly to me" (Barker et al., 1996).

Information provision is not exclusively the responsibility of doctors; patients in the UK are cared for by multidisciplinary mental health teams and it is likely that information will come from a variety of sources, including doctors, psychiatric nurses, pharmacists, social workers and support workers. Indeed, following the introduction of non-medical prescribing, patients are increasingly prescribed medication by Nurse and Pharmacist Independent Prescribers. However, studies which have not focussed specifically on satisfaction with information provided by doctors have found similar results. For example, in a questionnaire study completed by 69 patients receiving secondary care for a diagnosis of schizophrenia, 46% reported that they had not been warned about potential side effects of medication (Gray et al., 2005). Similarly, in an interview-based study involving 84 outpatients with a diagnosis of schizophrenia, 56% reported not having received enough information about their medication (Paton and Esop, 2005).

Whilst there is clearly a need to address information provision for patients with mental illness, it is not yet known which specific aspects of information about medication patients find inadequate. The present study used a validated questionnaire (Horne et al., 2001) to profile patients' satisfaction with information about medication prescribed for bipolar disorder.

Methods

259 Manic Depression Fellowship (MDF) members responded to a flyer in *Pendulum*, the organisation's quarterly journal. They were sent a questionnaire booklet with a stamped addressed envelope for its return.

The booklet included the Satisfaction with Information about Medicines Scale (SIMS; Horne et al., 2001), which assesses the extent to which participants are satisfied with 17 aspects of information considered essential for the optimum use of medicines (Association of the British Pharmaceutical Industry, 1988). The questionnaire does not focus on specific information providers (e.g. doctors, nurses, pharmacists) nor on specific formats of information (e.g. written, verbal), rather it assesses patients' overall satisfaction with the information received about their medication. Nine items refer to information received about the Action and Usage of the medication (e.g. what it is for, how long it takes to work; SIMS-AU subscale) and eight items refer to information received about the Potential Problems of the medication (e.g. whether it will have side effects, whether it will interfere with other medication; SIMS-PP subscale). For each item, participants are asked to rate the amount of information they have received, indicating "too much", "about right", "too little", "none received" or "none needed". Participants reporting that the information was "about right" or indicating "none needed" are classified as satisfied (scored 1). Those reporting that the information was "too much", "too little" or indicating "none received" are classified as dissatisfied (scored 0). A satisfaction rating for each subscale is obtained by summing the scores for each item in the subscale. Scores can range from 0 to 9 for the Action and Usage subscale and from 0 to 8 for the Potential Problems subscale (high scores indicate

high satisfaction). Scores for the Action and Usage subscale and the Potential Problems subscale are summed to give an overall satisfaction with information about medicines score.

The questionnaire booklet also included the Medication Adherence Report Scale (MARS; Horne et al., 2001), a five-item scale that asks patients to estimate on a five-point scale (always to never), how often they engage in five types of nonadherent behaviour with their medicines (e.g. forget to take them, take less than instructed, stop taking them, miss out a dose, alter the dose). Scores are summed to give an overall adherence score ranging from 5 to 25, with high scores indicating high adherence. Participants were grouped according to their MARS score, with the third scoring the lowest (<21) classified as low adherers and the two thirds scoring the highest classified as high adherers. (Approximately a third of patients are thought to be low adherers to medication prescribed for bipolar disorder; Scott & Pope, 2002)

An independent samples t-test was used to compare high and low adherers on their overall satisfaction with information about medication score. In addition, independent samples t-tests were used to compare mean satisfaction with information about medicines in the current sample with that reported in a previously published study, involving 115 people who were diagnosed HIV positive and had been offered antiretroviral therapy by an outpatient NHS clinic in Brighton, UK (full methodology reported in Gellaitry et al., 2005). These data were also collected via a postal questionnaire. A sample size calculation conducted using G-Power software (Erdfelder et al., 1996) revealed that this sample size would be sufficient to detect a medium effect size, with 80% power and an alpha of .05.

Results

223 (86%) participants returned completed questionnaires. The mean age of participants was 48 years (range 22-77). 140 (64%) were female and 97 (44%) were married/ with a partner. The mean age of diagnosis was 34 years (range 12-68), with a mean number of hospital admissions relating to bipolar disorder of 4 (range 0-15).

Figure 1 provides a profile of patient satisfaction with the 17 medicines information topics. Over 50% of participants were dissatisfied with the information they had received about how the medication worked, how they could tell if it was working, how long they needed to be on it, whether it had unwanted side effects, what to do if side effects were experienced and whether it could interfere with other medications. Over 60% of participants were dissatisfied with the information they had received about the risks of getting side effects and whether the medication would affect their sex lives. In all cases, dissatisfaction resulted from patients reporting having received too little or no information, rather than too much.

Figure 1 shows differences in satisfaction between this sample prescribed medication for bipolar disorder and a previous sample prescribed medication for HIV. Independent samples t-tests revealed that those prescribed medication for bipolar disorder were significantly less satisfied than those prescribed medication for HIV with information about the Potential Problems of the medication ($t(326) = -4.4, p < .01$), but there was no significant difference between the groups in terms of satisfaction with information about the Action and Usage of the medication ($t(320) = -.54, p > .05$).

An independent samples t-test revealed that those reporting low adherence to medication prescribed for bipolar disorder (scoring less than 21 on the MARS) were significantly less satisfied with information received about medication than those reporting high adherence ($t(192) = 1.66, p < .05$ (1 tailed)).

Discussion

This survey of members of the MDF found a high prevalence of perceived dissatisfaction with information about medication across a range of informational topics considered essential for informed choice and safe usage. Moreover, levels of satisfaction were significantly lower in comparison with a previous study of patients diagnosed with HIV (Gellaitry et al., 2004). In particular, patients reported dissatisfaction with information provided about medication side effects, recently rated the most important aspect of information about medication by patients attending outpatient psychiatry appointments (Perreault et al., 2006).

Limitations

It should be noted that the sample could be prone to selection bias: participants were members of the Manic Depression Fellowship, a user-led organisation providing information and support for those affected by bipolar disorder. However, one would expect that members of the MDF would generally be better informed about medication than a

random NHS sample, and if anything, the results might provide an overly optimistic view of levels of satisfaction with information.

The opportunistic comparison with the HIV sample should be treated with caution as the methodology was not identical in the two groups. Indeed, those in the HIV sample were recruited to the study following an offer of antiretroviral treatment. They may therefore have received information more recently than those in the bipolar sample, potentially influencing their reported satisfaction with information. Ideally the same sampling methods would have been used to enable direct comparisons across illness groups. However, differences in satisfaction between the bipolar and HIV samples were large and may not be an artefact of the study design.

Whilst this study has highlighted low satisfaction with information about medicines amongst patients with bipolar disorder, the reasons for this are not yet known. One explanation could be that patients have not been provided with sufficient information about their medication. Our intention was not to assess the objective amount of information actually provided, rather we wanted to examine patients' perceptions of whether they had received enough information. Previous research, however, suggests that simply providing access to information does not necessarily increase patients' satisfaction with information, as patients do not always attend to the information provided. Indeed, two studies in mental health settings have reported that approximately 50% of patients do not think they have been given written information about medication, even though drug information sheets are now routinely provided (Gray et al., 2005; National Schizophrenia Fellowship, 2000). Similarly, Paton & Esop (2005) reported that providing a touch screen computer in the

outpatient waiting room, giving access to easily accessible information about medication, did not make patients diagnosed with schizophrenia any more satisfied that they had received enough information about medication than those without a touch screen computer in the waiting room.

This blanket approach to information provision may not be successful as information needs differ between individuals; people prescribed the same medicines require different levels of information because they deal with being ill in different ways. Some react by becoming actively involved with their treatment and seek detailed information. In contrast, others respond with more avoidant coping strategies (e.g. by wanting others to “take charge”, and may find additional information unhelpful or even distressing (Weinman, 1990). An important arbiter of the quality of medication information is therefore the extent to which individuals perceive that it has met their specific needs and are satisfied with the information provided (Horne et al., 2001). Further research is required to understand why current information provision does not appear to be meeting the needs of so many of the participants. One possibility is that the information is not sufficiently targeted to meet patients’ individual needs. Information provision may be more effective if individuals’ specific beliefs and concerns are elicited and addressed (Horne, 2003). Another consideration is that bipolar disorder is associated with attention and memory deficits that could hinder acquisition and retention of information about medication (Quraishi and Frangou, 2002).

Clinical implications

The findings have implications for informed choice about medicines, as this study suggests that many participants do not feel they have been provided with satisfactory information, particularly in relation to possible drug side-effects. Attention needs to be given to the format and timing of information provision. Providing information about medicines prescribed for bipolar disorder may be particularly problematic if treatment initiation is involuntary and/or at a time when patients are too unwell to process information. It is likely that one-off information provision at the time of prescribing is not sufficient and that a more long term approach needs to be adopted, encompassing periods of time when the patient is not acutely unwell. Indeed recent NICE guidelines emphasise this, stating that health professionals should provide relevant information (including information about medication) at every stage of assessment, diagnosis and treatment (National Institute for Clinical Excellence, 2006).

The findings also have implications for nonadherence to medication. This study suggests that perceived satisfaction with information received about medication is associated with low adherence. Previous research has found a similar association between satisfaction with information and adherence to medication in chronic illness (Kendrew et al., 2001). Improving patient satisfaction with information about medication may therefore improve levels of adherence to medication. Reviews of adherence interventions in bipolar disorder also emphasise the need for moderate to long term intervention strategies, given the chronic nature of the condition (Sajatovic et al., 2004).

This study has demonstrated the utility of the SIMS for identifying patient satisfaction with information about medicines and identifying areas of unmet need. It could be used as an

audit tool at individual and group levels. It has also illustrated a need for health practitioners to elicit individuals' information requirements and to tailor information to meet their needs, in order to facilitate informed choice and adherence to treatment.

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