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## **Written information on bipolar affective disorder: The patients' perspective**

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### *Aims and Methods*

The mental health information available to patients with Bipolar Affective Disorder is variable in quality. We conducted a qualitative survey in an urban outpatient department to elicit the opinions of patients with Bipolar Affective Disorder on the written information provided by three health information providers.

### *Results*

Patients' responses were positive for each leaflet. Patients' preferred leaflets produced using quality assurance tools. Twenty to 30 percent had difficulty understanding the leaflets. Medical jargon and verbosity were common criticisms.

### *Clinical Implications*

Professional bodies such as the Royal College of Psychiatrists play an important role in providing patients with written information. Quality assurance standards should be used in the production of patient information. A tool measuring patients' appraisal of information may ensure information is appropriate to their requirements.

### **Keywords:**

Affective disorders, Patient information leaflets, Quality assurance, Internet.

## **Introduction**

Providing patients with coherent, relevant information has implications for several aspects of mental healthcare, including engagement with services, concordance with treatment and informed consent. Health information enables patients to communicate more effectively with medical professionals, enabling them to take an active role in making decisions about their treatment, as is recommended by the Royal College of Psychiatrists.<sup>1</sup>

The growth in mental health information providers may be viewed as a positive development in educating both sufferers of mental illness and other members of the general public. In recent years, the establishment of organisations such as DISCERN,<sup>2</sup> have published rating instruments to evaluate the quality of information provided to the public, and guidelines to assist information providers in developing relevant, high quality and evidence-based information for users. Despite the general agreement of health organisations' regarding the benefits of providing patients with written information, there is a paucity of research on patients' opinions of the available mental health information and this may reflect the absence of user involvement until recently.

Mental health information produced by the various health organizations for patients varies in its focus and may not be appropriate to its target population. Some qualitative studies have found that certain patient groups wish to have more information regarding the aetiology, treatment options and potential medical complications available to them than is currently available.<sup>3</sup> Other studies have shown that patient information leaflets must be tested on patients to ensure that they are patient oriented,<sup>4</sup> a finding strongly supported by a study which found a large gap (as much as five years) between patient

reading levels and the comprehension levels demanded by written materials provided for them.<sup>5</sup>

A randomised controlled trial conducted in an orthopaedic centre in London showed that patients given information leaflets prior to surgery scored higher on a questionnaire of recall than those who had given verbal consent only.<sup>6</sup> This has significant implications for the issue of informed consent.

There is also evidence that providing patients with information about their condition reduces stress.<sup>7</sup> Among patients with psychiatric illness there is evidence that, contrary to fears that providing negative information would reduce treatment adherence, the opposite occurred.<sup>8</sup>

The purpose of the present study is to examine patient preferences regarding a selection of the informational literature available to them on Bipolar Affective Disorder and to elucidate which changes would make this more acceptable to the readership.

## **Method**

The study was conducted in the Mater Misericordiae University Hospital, Dublin, Ireland. Psychiatric outpatients with a diagnosis of Bipolar Affective Disorder who were currently attending outpatient clinics in the hospital or were attending a community clinic were included in the study.

Patients were excluded if they were inpatients at the time of the study, if they were currently judged as too unwell to participate in the study or if they had difficulties with English or literacy.

All patients eligible for inclusion were asked to participate in the survey. Participants were contacted either during attendance at the outpatient clinics, by telephone or in writing. Those who agreed to participate in the study were asked to read each information leaflet and complete the questionnaires (Table 1) on each of the three leaflets and to state which they rated as best overall.

The leaflets examined were those provided by the Royal College of Psychiatrists, London, a voluntary organization in Ireland (Aware) and a United Kingdom-based patient information website run by general practitioners (<http://www.patient.co.uk>).

Basic demographic data was collected from each participant (age and gender). The leaflets took approximately one hour to read and complete and patients were advised that they would be reimbursed with a gift voucher to the value of twenty euro for their time.

Patients were provided with a stamped addressed envelope to return the questionnaires which were completed at home.

As there was no tool in existence to assess the suitability of information leaflets for patients and their satisfaction with this information, the authors of this study developed a questionnaire for this purpose.

Each questionnaire (Table 1) contained 15 statements examining three aspects of the leaflet;

1. Comprehensibility
2. Information content
3. Impact of the leaflet on the patients understanding of their illness

Patients indicated whether they agreed or disagreed with each statement in the questionnaire.

Participants were blinded to the source of each leaflet. The leaflets and questionnaires were stapled together in different order and participants were asked to read the leaflets in the order received, so as to reduce order bias.

## **Results**

A total of 45 patients with bipolar disorder were invited to participate in the study, of whom 27 participated. Of those who participated, 59.3 percent (n=16) were male, and the median age of all participants was 44 years (range: 17 to 70). Those who participated (n=27) did not differ from those who did not participate (n=18) in terms of gender (Chi Square 0.805, p=0.527) or age (Mann-Whitney U 161.500, p=0.059).

Table 1 near here

### ***Relationship between gender, age and order of leaflets received on leaflet ratings.***

No relationship was found between rating 'Which leaflet was best' and gender (Chi=2.253, df=2, p=0.324), age group (Chi=5.205, df=6, p=0.518) or the order in which the leaflets were read (Chi=7.464, df=10, p=0.681).

### ***Which leaflet was best?***

Of the 27 patients who participated in the study, 25 (92.6%) responded to this section of the survey. Fifty-two percent (n=13) of the sample rated the leaflet from the Royal College of Psychiatrists website as best, with 28% (n=7) of the sample preferring the leaflet provided by patient .co.uk and the remaining 20 percent (n=5) preferring the information leaflet provided on the Aware website.

### ***Comprehensibility***

The majority of respondents found each of the leaflets comprehensible (see Table 1): it is noteworthy however that 23.1 percent of patients felt there were more than a few areas that they could not understand in the patient.co.uk leaflet and almost 30 percent thought the Aware leaflet could have been clearer.

### ***Information Content***

Respondents were less satisfied with the amount of information contained in the Aware leaflet (80 percent satisfied) than the patient.co.uk and Royal College of Psychiatrists leaflets (92.6 and 92.3 percent respectively).

Only 53.8 percent of respondents felt that the Aware leaflet provided enough information around lithium monitoring and when to contact their doctor, compared with 84.6 and 92.3 percent of respondents for the patient.co.uk and the Royal College of Psychiatrists leaflets respectively.

Between 70 and 80 percent of respondents wanted more information regarding rare but potentially dangerous complications of the medication they were taking for each of the leaflets.

The Royal College of Psychiatrists leaflet performed particularly well in providing information about lifestyle, details of support groups and other sources of information compared with the other two leaflets.

### ***Impact***

Respondents felt that the information contained in the Royal College of Psychiatrists leaflet would help them to manage their condition more effectively (96.2 percent agreed) compared with the Aware and patient.co.uk leaflets (88.9 and 81.5 percent respectively).

Between 65 (Aware leaflet) and 73 percent (patient.co.uk leaflet) of patients felt less anxious about having Bipolar Affective Disorder as a result of reading the leaflets.

Despite rating the Royal College of Psychiatrists leaflet as the best overall, respondents felt that the Aware leaflet would be more useful to patients recently diagnosed with Bipolar Affective Disorder.

### ***Effects of Comprehensibility and Information Content on Impact of leaflets***

The effects of 'Comprehensibility' and 'Information Content' on the 'Impact' of the leaflets were explored. The odds ratio was calculated for each leaflet for the general statement measuring the 'Impact' of the leaflets 'I think that this leaflet has given me information that will help me to manage my condition more effectively' and each of the statements 'There were more than a few areas that I could not understand' (Comprehensibility) and 'I was satisfied with the level of information in the leaflet' (Information Content).

No significant relationship was found between the statements assessing 'Comprehensibility' and 'Impact' (OR= 0.444, 95% CI=0.032 – 6.188) for the Aware

leaflet. However, a significant relationship was found between ‘Information Content’ and ‘Impact’ (OR=4.889, 95% CI=1.304-18.327), with those who were satisfied with the ‘Information Content’, rating the Impact of the leaflet higher.

No relationship was found between ‘Comprehensibility’ and ‘Impact’ for the patient.co.uk leaflet (OR=0.353, 95% CI=0.043-2.867) or between ‘Information Content’ and ‘Impact’ (OR=5.250, 95% CI=0.269-102.424).

No relationship was found between ‘Comprehensibility’ and ‘Impact’ for the Royal College leaflet (OR=1.211, 95% CI=1.000-1.460), or Information content and ‘Impact’ (OR=1.043, 95% CI=0.960-1.134).

### **Results from Free Comments Section**

At the end of each questionnaire, respondents were invited to make comments. It was envisaged that the statements from the questionnaires would act as prompts to assist patients in completing this part of the study, providing the opportunity to elaborate upon their answers or to raise issues felt to be of importance.

The comments were categorised into four themes; general, comprehensibility, information content and impact. The general comments category was included to present the overall perceptions of the leaflet e.g. “the leaflet was written in a considerate manner” or “the leaflet was optimistic”.

Thirteen respondents (48 percent) made comments in this section of the questionnaire for the Aware Leaflet, and the Royal College of Psychiatrists leaflet and ten respondents (37 percent) for the patient.co.uk leaflet.

### *General comments*

Patients responded positively to the three leaflets, particularly the leaflet provided by the Royal College of Psychiatrists.

### *Comprehensibility*

23.1 percent of respondents commented that the Aware leaflet was verbose. Whilst 50 percent of respondents commented that the patient.co.uk leaflet was easy to understand, a further 20 percent commented that it contained confusing medical jargon, citing as examples “Transcranial Magnetic Stimulation” and “Vagal Nerve Stimulation”. 30.8 percent of respondents commented that the Royal College of Psychiatrists leaflet was “clear” or “easy to understand”. 7.7 percent of respondents commented that “the short paragraphs” made the Royal College of Psychiatrists leaflet “easier to read”, “especially for people who had difficulty concentrating”.

### *Information content*

23.1 percent of respondents commented that they found the vignettes in the Aware leaflet useful, however, 23.1 percent also commented that the Aware leaflet did not contain enough information about medications and their side effects, or information on other support groups or information sources for Bipolar Affective Disorder. 23.1 percent of respondents commented that medications and side effects were explained particularly well in the Royal College of Psychiatrists leaflet. Whilst 15.4 percent of respondents commented that the Royal College of Psychiatrists leaflet contained a sizeable number of self-help groups, support groups and contacts for further information, 20 percent commented that the patient.co.uk leaflet did not contain enough information about support or self-help groups.

Thirty percent of respondents commented that the patient.co.uk leaflet explained medication in a clear and informative manner and 20 percent of respondents commented that this leaflet included up to date information.

30.8 percent of respondents commented that the Royal College of Psychiatrists leaflet contained useful information for family, friends or carers.

### *Impact*

Referring to the patient.co.uk leaflet, thirty percent of respondents commented that they did not like the use of words such as ‘antipsychotic’ and ‘anticonvulsant’ medication and twenty percent of respondents commented that they felt anxious being told that the mechanism of action of medications, such as lithium and the anticonvulsants, were unknown.

### **Discussion**

This study suggests that the overall quality of information on Bipolar Affective Disorder available in printed form from the selected online health services (Aware, patient.co.uk and the Royal College of Psychiatrists) is of a high standard and is understood by the majority of patients. However, a significant proportion of the study sample, approximately 20 to 30 percent, had some difficulty in understanding a number of areas within each leaflet. The respondents’ comments indicate that concise explanations and the absence of medical jargon may assist patients’ comprehension of written information. This would also help to address the issue of varying literacy levels within patient groups.

Some information which medical professionals regard as desirable and which patients also wish to have, for example, the need for blood tests, side effects of medication, and when patients should seek medical advice is less consistently included in the leaflets of different organisations. The information leaflet provided by the Royal College of Psychiatrists was consistently rated more highly than the other two on its content, suggesting that professional bodies have an important role in patient education.

Of note, the two leaflets which were rated most highly both used quality assurance guidelines produced by internet based health information organisations; DISCERN and HONcode.<sup>9</sup> With the growing number of internet based organisations producing health information it is important that doctors take an active role in directing patients to websites which use quality assurance instruments in their development.<sup>10</sup> Websites and organisations usually stipulate if they have used quality assurance instruments in the production of health information leaflets.

A number of issues relating to informed consent were raised in this study. Patients with Bipolar Affective Disorder wish to know more about the potential side effects of medication that they are receiving, an issue of particular relevance if patients are to be involved in decision making about their treatment. In light of the concerns expressed around specific aspects of medication, such as their mechanism of action, providing clear explanations and information early in the course of the illness may be reassuring and may help to reduce the stigma associated with taking medication, as is evidenced by their dislike of words such as ‘antipsychotics’ and ‘anticonvulsants’. This might also improve treatment adherence rates and ultimately long-term outcomes, as has been demonstrated in research conducted by other medical specialties.<sup>11</sup>

The finding of a significant relationship between ‘Information Content’ and ‘Impact’ for the Aware leaflet suggests that special attention should be paid to this when developing leaflets. The wide confidence intervals undermine the robustness of this particular

finding, coupled with the failure to identify such a relationship in the other two leaflets, although it was consistent with the findings in another study.<sup>12</sup>

An interesting finding of this study was that whilst patients rated the Royal College of Psychiatrists leaflet as the best of the three leaflets, they rated the Aware leaflet highest in terms of its usefulness to patients recently diagnosed with Bipolar Affective Disorder.

This finding indicates that patient's requirements for information may vary depending on their stage of illness.

The absence of a tool to measure patient satisfaction and to gather feedback on the informational sources around bipolar affective disorder necessitated the authors' production of such a tool for the purpose of this study. Whilst the tool used in this study exhibits face-validity, it may be appropriate for the development of a tool which also demonstrates content validity and internal consistency.

This study has a number of strengths and weaknesses that need to be highlighted. One of its strengths is that its findings can be generalised to patient groups from other inner-city outpatient departments although the corollary, that the needs of patients from other locations such as those from rural areas or those of other socio-economic groups, may not be identified in this study. Patients were blinded to the source of the leaflets and there did not appear to be any relationship between the order in which patients read the leaflets and their rating of the leaflets. The main limitation is its small size; 60 percent of all patients with Bipolar Affective Disorder within the study population participated in the

survey, however participants and non-participants did not differ on basic demographic data. Other limitations include the study's restriction to one service and the fact that duration of illness was not controlled for. The use of a new instrument to measure views on the schedules might be considered a weakness. However, since no such instrument exists, a pragmatic decision was made to use this instrument which has face validity. This instrument should be the subject of detailed psychometric examination since it could have a place in future studies of this type.

In summary, this study emphasises the important role of mental health professionals in directing patients toward written information and internet websites. Furthermore, professional mental health organisations should be involved in developing or revamping such informational tools. There is a strong argument to be made for involving patients in such initiatives in the future.

### **Declaration of interest**

A grant was provided by Janssen-Cilag to reimburse patients for their participation in the study.

Author PC is editor of the Psychiatric Bulletin.

Table 1. Results from questionnaire

Area assessed	Response to statement n (%)		
	Aware	patient.co.uk	RCPsych
<b>Comprehensibility</b>			
I could understand most of what was mentioned in the leaflet (agree)	27/27 (100)	26/27 (96.3)	26/27(96.3)
There were more than a few areas that I could not understand (disagree)	20/25 (80)	20/26 (76.9)	21/25 (84)
The leaflet could have been clearer in what it was saying (disagree)	17/24(70.8)	20/25 (80)	19/24(79.2)
<b>Information content</b>			
I felt that the information in the leaflet was relevant to me (agree)	22/27(81.5)	25/27 (92.6)	24/27(88.9)
I was satisfied with the level of information in the leaflet (agree)	20/25 (80)	25/27 (92.6)	24/26(92.3)
I would want to know more about any rare but potentially dangerous complications of my medication (agree)	21/26(80.8)	21/27 (77.8)	18/26(69.2)
The leaflet tells me about the need for blood tests, side effects of medications, when to contact my doctor (agree)	14/26(53.8)	22/26 (84.6)	24/26(92.3)
The leaflet contained a number of different treatments for my condition e.g. different medications, psychotherapy (agree)	20/26(76.9)	22/25 (88)	21/25 (84)
The leaflet contained information about lifestyle to help me stay well e.g. avoiding alcohol and drugs (agree)	21/26(80.8)	22/25 (88)	25/26(96.2)
The leaflet recommended other resources (books/ organizations/ websites) if I needed to get more information.	26/27(96.3)	22/26 (84.6)	25/25 (100)
The leaflet had information on support groups that I could contact (agree)	25/26(96.2)	22/25 (88)	25/25 (100)
<b>Impact</b>			
I think that this leaflet has given me information that will help me to manage my condition more effectively (agree)	24/27(88.9)	22/27 (81.5)	25/26(96.2)
Reading the leaflet made me less anxious about my illness (agree)	17/26(65.4)	19/26 (73.1)	18/25 (72)
I would know how to get more information about my condition (agree)	25/27(92.6)	26/27 (96.3)	26/26 (100)
I think this leaflet would be useful to other people who had recently been diagnosed with Bipolar Affective Disorder (agree)	25/26(96.2)	24/27 (88.9)	20/24(83.3)

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