

Although physicians and especially psychiatrists should be the primary providers of treatment for schizophrenia and other associated mental illnesses that require anti-psychotic medication, you may and probably will have people in your care from time to time who are on these medications and will need help both with issues of daily life as well as with living with the side affects from the anti-psychotic medications. The following article contains a couple of checklists for help in managing the side affects, a frequent reason people go off their medications. You might tuck these away for future reference. FYI

### **Helping Hearts Heal**

**Dan L. Boen, Ph.D., HSPP, Licensed Psychologist**

**Director Christian Counseling Centers of Indiana**

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### **An Innovative Approach to Clinical Communication in Schizophrenia: The Approaches to Schizophrenia Communication Checklists**

*Sharon G. Dott, MD, Peter Weiden, MD, Penelope Hopwood, MB, ChM, MSc, A. George Awad, MB, BCh, PhD, Jonathan S.E. Hellewell, MB, John KNesevich, MD, Lili Kopala, MD, alexander Miller, MD, and Carl Salzman, MD*  
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Dr. Dott is clinical associate professor in the Department of Psychiatry and Behavioral Sciences at the University of Texas Medical Branch in Galveston; Dr. Weiden is professor at the State University of New York Health Sciences Center in Brooklyn, NY; Dr. Hopwood is member of the Cancer Research Campaign Psychological Medicine Group at the Christie Hospital National Health Service Trust in Manchester, UK; Dr. Awad is professor of psychiatry at the University of Toronto, Ontario's Clarke Institute of Psychiatry in Canada; Dr. Hellewell is consultant psychiatrist in the Department of Community Psychiatry at the Trafford General Hospital in Manchester; Dr. Knesevich is psychiatrist at Neuroscience Options Inc. in Amherst, NH; Dr. Kopala is psychiatrist in the Department of Psychiatry at Dalhousie University in Halifax, NS; Dr. Miller is professor of psychiatry in the Department of Psychiatry at the University of Texas Health Science Center in San Antonio; and Dr. Salzman is professor of psychiatry in the Department of Psychiatry at Harvard University Medical School in Cambridge, MA.

### **Abstract**

Side effects from antipsychotic medications can have a profound effect on patients' lives and may adversely affect their willingness to comply with treatment. Identification of side effects through improved communication between psychiatrists, other members of the healthcare team, and their patients might increase treatment compliance. The Approaches to Schizophrenia Communication (ASC) Steering Group developed two simple, practical checklists for use in the busy clinical setting. The ASC—Self-Report (ASC-SR) checklist is completed by the patient and comprises a list of the more common or clinically important side effects of antipsychotic treatment. The ASC-Clinic (ASC-C) checklist is completed by both clinician and patient together, being used as the basis for a semi-structured interview. In a multicenter pilot study set up to evaluate the utility of

checklists, 86% of patients responding considered the ASC-SR to be useful in communicating their problems to psychiatrists and other members of the healthcare team. All healthcare team respondents found both checklists to be helpful when discussing side effect problems with their patients. Moreover, 41% and 47% of healthcare team respondents reported that the ASC-SR and ASC-C, respectively, had assisted them in identifying side-effect problems not previously acknowledged. Preliminary evaluation of the ASC-SR and ASC-C in this multicenter pilot study suggests that both tools were user-friendly, encouraged communication between patients and healthcare professionals about antipsychotic drug side effects, and could readily be integrated into everyday clinical practice.

## **Introduction**

Atypical antipsychotics are a new group of drugs combining efficacy in treating the symptoms of schizophrenia with a tolerability profile superior to that of the conventional agents. There has been renewed interest in the side effects of treatment and their influence on compliance, outcome, and subjective well being. Side effects from antipsychotic medications can profoundly impact patients' psychological, physical, and social functioning and may adversely affect their willingness to comply with treatment.<sup>1-5</sup> Indeed, a study of patients who had refused antipsychotic medication reported that 35% of this population cited the side effects of treatment as the reason for their refusal.<sup>2</sup> Similarly, in a study of patients who had stopped taking their antipsychotic medication, 50% had done so in response to side effects they had experienced.<sup>6</sup> Furthermore, Finn and colleagues<sup>7</sup> reported that patients considered the side effects of medication to be as distressing as the symptoms of schizophrenia itself.

A number of studies have suggested that psychiatrists may not always appreciate the distress that the side effects of antipsychotic medication can have on patients' everyday lives.<sup>2,4,6-8</sup> Hoge and colleagues<sup>2</sup> reported that psychiatrists were less likely to attribute noncompliance with medication to antipsychotic side effects than were patients (7% vs 35%, respectively). Furthermore, other studies have indicated substantial disagreement between patients' and psychiatrists' estimations of the distress caused by the side effects of conventional antipsychotic medications.<sup>4,6-8</sup> Overall, this indicates that some of the side effects of antipsychotic drugs are being underrecognized by clinicians in clinical practice. For example, the diagnosis of extrapyramidal symptoms (EPS) was underrecognized among inpatients diagnosed by clinicians when compared with independent "blind assessments" by clinical researchers using standard ratings.<sup>9</sup> Similarly, Peuskens and colleagues<sup>10</sup> reported that sexual dysfunction in patients receiving antipsychotic medication is often under-recognized, suggesting that this might be linked to a reluctance to discuss these personal issues with patients. The results of an international attitudinal study of psychiatrists and patients further support the evidence for under-recognition of both EPS and prolactin-related side effects among clinical and nursing staff.<sup>6</sup>

These observations suggest that an improvement in communication between psychiatrists, other members of the healthcare team, and their patients may facilitate

identification and resolution of side effects. Over the longer term, enhanced communication might be expected to result in improved compliance with treatment. In response to these concerns, the Approaches to Schizophrenia Communication (ASC) Steering Group, comprising psychiatrists from the United States (US), Canada, and the United Kingdom (UK), working in academic, public, and private healthcare settings was organized to explore current issues in the day-to-day care of patients with schizophrenia and to identify areas in which improvements in the standard of care could readily be made. The single greatest area of unmet need in the clinical treatment of schizophrenia was identified by the ASC group as communication between patients and their caregivers about side effects and subjective experiences with treatment. The ASC group concluded that improvements in the recognition and appreciation of antipsychotic side effects in clinical practice might most easily be achieved by developing a simple checklist, designed to facilitate communication about side effects between patients and their healthcare teams. The ASC group developed two simple, practical checklists for use in the busy clinical setting: one to be completed by the patient—The ASC—Self-Report (ASC-SR) checklist—and the other to be completed by a healthcare professional—The ASC-Clinic (ASC-C) checklist. Although a number of symptom and side-effect rating scales have already been introduced (eg, Liverpool University Neuroleptic Side-Effect Rating Scale, Self-Rated Well-Being on Neuroleptics, Rating of Medication Influences Scale, and Drug Attitude Inventory),<sup>4,5,11,12</sup> the ASC group considered that there was a need for a further, brief, and clinically focused instrument. This would have the effect of providing a template for discussion between doctors and patients about treatment, its side effects, and the effect on their lives. This may in turn assist in the early identification of potential problems and help to avoid poor compliance with or discontinuation of treatment. Such an instrument needed to be succinct, for easy adaptation in routine clinical practice, unlike the existing scales, for which utility in the busy clinical setting may be compromised by problems of complexity, the requirement for staff training in their use, and the time needed to complete an assessment. This paper reports the results of a multicenter pilot study evaluating the use of the two ASC communication tools.

## **Methods**

### *Development of the Communication Tools*

The ASC-SR and ASC-C were developed using the Checklist for Patients on Endocrine Therapy (C-PET) communication tool as a starting point.<sup>13</sup> This earlier instrument had been developed after a similar collaborative meeting involving clinicians concerned with the issue of communication about side effects of hormonal treatment for cancer. Simple in design and uncomplicated to use, the C-PET has been widely adopted by healthcare professionals in the field. The C-PET comprises a list of common side effects of hormonal therapy, and patients are required to work down the list identifying side effects that they have experienced, further selecting the side effects that they wish to discuss with their clinician or nurse. The checklist has been designed to occupy a single sheet of paper, which patients can easily complete either at home or at the clinic.

Like the C-PET, the ASC-SR, the simpler of the two ASC instruments (Table 1), comprises a single sheet on which there is a list of the more common or clinically important side effects of antipsychotic medications. Patients are invited to work through the list, identifying those symptoms that they have experienced recently, and selecting those that they wish to discuss with their clinician. The side effects listed on the checklist were selected on the basis of the reported prevalence of specific antipsychotic side effects in the published literature, together with the collective experiences of the ASC group members working in clinical practice.

Compared with the ASC-SR, the ASC-C checklist is a more elaborate instrument, designed for completion by both clinician and patient working together, using the instrument as the basis for a semi-structured interview (Table 2). Like the ASC-SR, the ASC-C is constructed around a series of potential side effects, although each item is presented together with a series of suggested questions that can be used by the clinician to probe for the presence of a side effect. In addition, rather than simply indicating the presence of the side effect, patients are invited to rate the degree to which the problem is causing them distress. To facilitate use of the ASC-C, and in recognition of the fact that the instrument is likely to be used by nonpsychiatric workers, a practically oriented workbook and glossary have been developed.

## **Evaluation**

In view of the fact that the checklists were designed as communication tools to highlight side effects rather than quantify them, rigorous and formal psychometric testing and validation was considered by the ASC group to be inappropriate. Nevertheless, a practical evaluation of the two checklists was warranted. This took place in a multicenter pilot study involving a total of 10 centers in the US and Canada. Group members agreed to pilot the use of the instruments in their own clinical settings and to ensure that all clinicians, caseworkers, patients, and caregivers involved in this work completed both the communication tools and an evaluation form designed to provide feedback about the simplicity, value, and practicality of using these tools in clinical practice.

Patients, caregivers, and members of the healthcare team answered the question, "Has the ASC-SR helped you to discuss problems with your doctor/patient?" using one of the following statements: "not at all," "a little," "quite a bit," or "very much." In addition, healthcare team members were asked to classify the ASC-C and ASC-SR forms as "unfavorable," "neutral," or "favorable."

## **Results**

### *ASC-SR Checklist*

- Patient and Caregiver Feedback

Completed ASC-SR forms were received from 152 patients. The ASC-SR was well received by both patients and caregivers, with over 80% indicating that they had

understood the purpose of the checklist and had found it easy to use. Eighty-nine percent of respondents considered the range of side effects presented in the ASC-SR to be appropriate and 82% stated that the choice of responses met their needs. Although a few respondents recommended that the questions relating to sexual and menstrual problems should be excluded, a high proportion of patients identified these side effects as problems and indicated a readiness to discuss these problems with their psychiatrists. Eighty-six percent of respondents considered the ASC-SR to be useful to them in communicating their problems to psychiatrists and other members of the healthcare team, ranging from very useful (20%) to a little useful (34%) (Figure 1). In addition, feedback from patients and caregivers indicated that 71% would value receiving more information from their healthcare team about their medication and possible side effects.

- Healthcare Professional Feedback

The ASC-SR was well received by all members of the healthcare team. All healthcare team respondents (N=21) reported that they had understood the purpose of the ASC-SR checklist and had found it to be helpful when discussing side effect problems with their patients. In response to the question "Has the ACS-SR helped you to discuss side effect problems with your patients?" 42% of healthcare workers answered "a little," 47% answered "quite a bit," and 8% said "a lot" (Figure 2). Furthermore, 41% of respondents reported that the ASC-SR had assisted them in identifying side effect problems that had not previously been acknowledged. Sixty-two percent of healthcare team respondents stated an overall favorable impression, suggesting that communication tools could prove useful in the clinical setting (Figure 3).

In terms of patient understanding of the ASC-SR, 67% of the healthcare professionals reported that their patients had found the instructions and terminology used in the communication tool easy to follow, requiring no further explanation.

#### *ASC-C Checklist*

- Healthcare Professional Feedback

Feedback on the ASC-C was received from 21 healthcare professionals; ASC-C forms were completed for 119 patients. Almost all professional respondents indicated that they had found the ASC-C to be of use in facilitating discussion of problems concerning side effects with their patients. Furthermore, almost half (47%) reported that the ASC-C has assisted them in identifying previously unrecognized side-effect problems in patients, and 88% stated an overall favorable impression of the ASC-C (Figure 3), indicating its potential usefulness in the clinic.

## **Discussion**

Preliminary evaluation of the ASC-SR and ASC-C in this multicenter pilot study suggests that both tools may be useful in encouraging communication between patients and healthcare professionals about antipsychotic drug side effects and the distress they are

causing the patient. Furthermore, the finding that these communication tools were able to assist healthcare professionals in identifying previously unrecognized side effects that were distressing to the patient is particularly promising. This identification may help to redress the reported imbalance between psychiatrists' and patients' perceptions of distress caused by antipsychotic drug side effects.<sup>4,6,7-8</sup> Indeed, identifying and addressing the side effects most distressing to patients may lead to increased compliance and hence improve treatment outcomes.

A similar communication tool—the C-PET<sup>13</sup>—developed to aid communication between cancer patients and healthcare professionals regarding the distress of drug-induced side effects, has proven helpful in oncology clinical practice. Although the concept of communication tools is new in psychiatry, the encouraging results obtained from this pilot study show the potential benefit of communication tools in assisting management of schizophrenia. Further investigation of the ASC-SR and ASC-C in larger populations of patients with schizophrenia and in a broader clinical setting is particularly merited, as this study shows. The communication tools were judged to be user-friendly, both by patients and healthcare professionals, and capable of being readily integrated into everyday clinical practice.

There is now a UK ASC, based on the ASC-SR, but with Anglicized wording,<sup>14</sup> while the US version has undergone further evaluation, described by Miller and Dassori.<sup>15</sup> In addition, there is also a version under modification in South Africa. Initial pilot work in these countries is proving most encouraging. Evidence suggests that ASC instruments are relevant to clinical psychiatry, can readily be incorporated into routine clinical work, and are highly regarded by both clinicians and patients.

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  - Please direct correspondence to: Sharon G. Dott, MD, Department of Psychiatry and Behavioral Sciences, University of Texas Medical Branch, Route 0189, 301 University Boulevard, Galveston, TX 77555-0189. Tel: 409.741.3536; fax: 409.741.1310; e-mail: sdott@utmb.edu.

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333 Hudson St., 7th Fl., NY, NY 10013, Phone: 212-328-0800, Fax: 212-328-0600