Abstract

Data on a lay interviewer's use of the Diagnostic Interview Schedule (DIS) to ascertain lifetime psychotic symptoms in patients where these experiences have been previously documented is reported. The subjects in this study had been identified as patients 11 years previously and had participated in several followup research interviews with research psychiatrists. Frequent failure to recall and/or report psychotic symptoms in these patients suggests this technique will seriously underestimate the lifetime occurrence of psychotic symptoms.

The National Institute of Mental Health has undertaken a study to assess the occurrence of specific psychiatric disorders in the general population. To accomplish this goal, a new structured interview schedule was developed: The Diagnostic Interview Schedule (DIS). The DIS is a completely structured schedule which was designed to enable lay interviewers to ascertain current and lifetime occurrence of a broad range of psychiatric symptoms. Automated diagnostic decisions are then computed according to three specific schemes: DSM-III (American Psychiatric Association 1980), Research Diagnostic Criteria (RDC) (Spitzer, Endicott, and Robins 1978), and Feighner criteria (Feighner et al. 1972).

Robins et al. (1981, 1982) have detailed the history and characteristics of the DIS and reported a validity study in which 216 subjects were interviewed independently by a psychiatrist and a lay interviewer; both interviewers used the DIS, but the administration was different. The psychiatrist, like the lay interviewer, was instructed to ask and probe DIS questions as written. However, if the psychiatrist's "final code was still uncertain or was contrary to . . . clinical judgment," the psychiatrist could ask additional questions before coding (Robins et al. 1982, p. 856). Data from each interview were used to compute case assignments to one or more of 19 DSM-III categories or a no-diagnosis category. The Kappa statistic was used to reflect agreement in category assignment with a mean of .69 for all DSM-III categories, but only .60 for DSM-III diagnosis of schizophrenia. (Sensitivity and specificity were 75 percent and 94 percent, respectively, for all DSM-III diagnoses and 65 percent and 94 percent, respectively, for a DSM-III diagnosis of schizophrenia.) These data should not be viewed as test-retest reliability of the DIS diagnoses because the circumstances of the interview were not identical. Following application of the DIS, the psychiatrists expressed doubt regarding diagnosis in only 0–7 percent of instances (3 percent for schizophrenia). The low level of doubt permitted the investigators to assume validity of the computer-generated diagnosis based on the psychiatrists' DIS and to use it as

1 All four psychiatrists recently completed their psychiatric training (three at Washington University) and now work in the Department of Psychiatry at Washington University, where the DIS was designed and many of the rules for classification were articulated. The question as to whether clinicians with different training and experiences in psychopathologic evaluation would have expressed the same satisfaction with the completeness of data or certainty of diagnosis remains unanswered.

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an admittedly imperfect yardstick against which to measure the lay interviewers. This type of comparison is typical of validity studies of psychiatric diagnoses since unimpeachable external standards do not exist for most disorders.

Concerning validity, the most critical question has not yet been addressed. Namely, since lifetime occurrence of some psychotic symptoms and illnesses is sought with the DIS, to what extent did either the lay or psychiatric interviewer accurately uncover these data? All or most manic and schizophrenic subjects were currently identified patients, thus facilitating data collection (i.e., active patients have current psychopathologic experiences which they are accustomed to revealing to clinical interviewers). The question remains as to the ability of a lay interviewer equipped with the DIS to get an accurate lifetime history of psychotic experiences from a stranger in a nonclinical setting. This question is crucial not only in population surveys but in family pedigree studies which provide lifetime prevalence data on psychotic illness.

Methods

The study reported here was designed to compare an individual's recall and reporting of psychotic symptoms with observations made by psychiatrists at the time of acute psychotic illness and at interviews 2 and 5 years later.

The study group consisted of 43 individuals who were examined in the Washington field research center of the International Pilot Study of Schizophrenia (IPSS) during 1968-69, and who participated in followup interviews 2, 5, and now 11 years later. Patients originally selected for the IPSS were recent admissions to one of three hospitals in Maryland who met the following screening criteria: (1) between the ages of 15 and 44; (2) had at least one psychotic symptom; (3) no evidence of organic, drug-related, or alcohol disorders; (4) not hospitalized for more than 2 out of the previous 5 years; (5) no evidence of continuous psychosis for longer than 3 years; (6) agreed to participate in research interviews. The patients were acutely ill and expressed a broad spectrum of severe psychiatric problems. They were evaluated initially within 2 weeks of admission by two psychiatrists using a modified Present State Examination (PSE) (Wing, Cooper, and Sartorius 1974), the Psychiatric Assessment Interview (PAI) (Carpenter et al. 1976), and semistructured interview schedules for psychiatric history and social/demographic information.

Reevaluations were done approximately 2 and 5 years later. Detailed descriptions of the patient group, selection criteria, initial assessments, and 2- and 5-year followup assessments have been reported (World Health Organization 1973; Strauss and Carpenter 1974a, 1974b; Hawk, Carpenter, and Strauss 1975). An index diagnosis (DSM-II; American Psychiatric Association 1968) of schizophrenia was given to 32 patients and of manic-depressive illness to 4 patients. The remaining seven patients received a neurotic or personality disorder diagnosis despite screening criteria requiring presence of a psychotic symptom.

Approximately 11 years after the initial interviews, efforts were made to locate, visit, and interview each of the 68 subjects who were fully evaluated in the 5-year followup interview. Fifty-nine subjects were located. Two subjects refused to participate in the interviews; 10 subjects consented to participate in a brief interview in which only outcome status was ascertained; 2 chronically psychotic subjects could not give informed consent; and 2 subjects had died. Forty-three subjects agreed to participate in the complete 11-year followup interview which consisted of the DIS and a semistructured interview schedule obtaining information relevant to rating outcome for the year before the followup evaluation. The DIS was administered in its entirety with the following exception: questions on tobacco use, substance abuse, and anorexia nervosa were deleted. Outcome variables recorded included duration of hospitalization, quantity and quality of social and occupational functioning, ability to meet basic needs, overall level of functioning, and severity of symptoms the subjects had during the month preceding the interview. The outcome scale, including reliability assessment, has been reported (Hawk, Carpenter, and Strauss 1975). All interviews were conducted by a nonclinician (A.E.P.), who had psychiatric interviewing experience and was specifically trained to administer the DIS by the Washington University group.

Although the composition of the original sample was known to the interviewer, the specific characteristics (including diagnoses) of the individuals interviewed were unknown. Twenty-nine of the 43 subjects who agreed to participate were living in the Baltimore-Washington area and were interviewed in their homes; the remaining 14 were evaluated by telephone.

For each subject, answers to DIS questions were compared to the ratings from the three PSE/PAI exams (initial, 2-year followup, and 5-year followup). The DIS questions
and the corresponding PSE/PAI questions are presented in table 1. These seven items were chosen because questions are similar and are intended to evaluate the same psychopathologic dimension. DIS scores represent the answers to specific questions about symptoms and to a specific set of probes. Probes are used to determine whether the symptoms meet specific levels of severity. The criteria for severity include (1) taking medication, (2) seeing a physician or other professional, and (3) interferences with living. Probes are also used to determine whether a symptom can be entirely explained by physical illness, or as a complication of the use of medication, illicit drugs, or alcohol. Scoring of the symptoms for the DIS has been described elsewhere (Robins et al. 1981). For the data analysis any symptom reported as present, regardless of severity, was counted as positive.

The PSE/PAI scores represent the psychiatrist's judgment about the presence or absence of symptoms experienced during the month preceding the interview. The scores are made on the basis of the evidence elicited or observed during the interview. Scoring of symptoms for the PSE/PAI has been described elsewhere (World Health Organization 1973). Symptoms rated as questionably present were scored as absent in this data analysis.

Results

Initial Characteristics of the Home Interview Subjects vs. the Phone Interview Subjects. Data from the initial evaluation (PSE/PAI and Prognostic Scale) were used to compare subjects participating in the home interviews to subjects participating in the phone interviews (Strauss and Carpenter 1974a; Strauss and Carpenter 1974b). The PSE/PAI items on hallucinations,
delusions, derealization, depersonalization, irritability, depressive mood, anxiety and elated moods, and all items from the Prognostic Scale were examined.

No significant differences in the original characteristics of these two groups were found. A chi-square goodness of fit test was used. Concordance between PSE/PAI and DIS on hallucinations and delusions was contrasted between home interview and phone interview to determine whether there were differences between the two groups. No significant differences in concordance were found based on home versus phone status. Therefore, any differences in the accuracy of the reporting of information between the two groups are unlikely to be the result of differences in the initial composition of the groups or interview status. The two subject groups are combined in other analyses.

The Accuracy of Lifetime Psychotic Symptomatology Recorded. DIS ratings were compared to the earlier PSE/PAI ratings to determine whether the DIS approach was effective in uncovering a history of psychotic illness some time in the past. It should be noted that DSM-II and DSM-III diagnoses are not comparable and that the DIS does not provide the data to generate all DSM-III diagnoses. With regard to psychotic illnesses, the DIS is presumed to provide data to make a lifetime diagnosis of schizophrenia, manic episode, and major depressive episode.

When the PSE/PAI clinical judgment at time of illness episode or follow up was used as the standard, the DIS approach failed to uncover lifetime hallucinations in 36 percent of the instances, delusions in 14 percent of the instances, and ranged from 12 to 80 percent in failure to detect each of the seven specific symptom dimensions (table 2).

Does the DIS Approach Identify Individuals Who Were Previously Diagnosed as Having a Psychotic Illness? DIS (DSM-III) diagnoses were generated for the 36 patients who had an index diagnosis (DSM-II) of either schizophrenia or manic-depressive illness with psychotic features to determine whether the DIS approach was effective in uncovering a history of psychotic illness some time in the past. It should be noted that DSM-II and DSM-III diagnoses are not comparable and that the DIS does not provide the data to generate all DSM-III diagnoses. With regard to psychotic illnesses, the DIS is presumed to provide data to make a lifetime diagnosis of schizophrenia, manic episode, and major depressive episode.

When the index diagnosis was used as the standard, the DIS diagnosed 20 (56 percent) of the patients in the psychotic group with a DSM-III diagnosis of schizophrenia and an additional 4 (11 percent) of the patients with a DSM-III diagnosis of major depressive episode. One of the three patients with a diagnosis of major depressive episode also received a diagnosis of manic episode. Thus, 33 percent of patients known to have had at least one psychiatric hospitalization for a psychotic illness (which was not related to an organic, drug, or alcohol problem) and who were diagnosed by a research psychiatrist as having either schizophrenia or

<table>
<thead>
<tr>
<th>Psychotic symptoms</th>
<th>Total PSE/PAI positive</th>
<th>DIS positive</th>
<th>DIS negative</th>
<th>Sensitivity (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hallucinations</td>
<td>25</td>
<td>16</td>
<td>9</td>
<td>64.0</td>
</tr>
<tr>
<td>Auditory</td>
<td>12</td>
<td>7</td>
<td>5</td>
<td>58.3</td>
</tr>
<tr>
<td>Vision</td>
<td>9</td>
<td>4</td>
<td>5</td>
<td>44.4</td>
</tr>
<tr>
<td>Tactile and somatic</td>
<td>13</td>
<td>4</td>
<td>9</td>
<td>30.8</td>
</tr>
<tr>
<td>Olfactory</td>
<td>5</td>
<td>1</td>
<td>4</td>
<td>20.0</td>
</tr>
<tr>
<td>Delusions</td>
<td>28</td>
<td>24</td>
<td>4</td>
<td>85.7</td>
</tr>
<tr>
<td>Messages</td>
<td>9</td>
<td>5</td>
<td>4</td>
<td>55.6</td>
</tr>
<tr>
<td>Spy</td>
<td>17</td>
<td>15</td>
<td>2</td>
<td>88.2</td>
</tr>
<tr>
<td>Poison-harm</td>
<td>17</td>
<td>13</td>
<td>4</td>
<td>75.1</td>
</tr>
</tbody>
</table>

1 One case rating DIS positive but plausible.
manic-depressive illness at the time of hospitalization 11 years previously were not identified by the DIS as having a history of psychotic illness. It should be noted that this is in all likelihood a conservative estimate of failure to identify psychotic illness because a DSM-III diagnosis of major depressive episode does not require psychotic symptoms to be present.

Comment

There is a need for data concerning the prevalence of psychiatric illnesses, and this need necessitates large-scale studies involving subjects who are drawn from the general population. The formulation of the DIS and the use of trained lay interviewers is an important step toward this goal. We have been concerned, however, that this approach may underestimate the lifetime prevalence of psychotic disorders and that the magnitude of the deficit may not be appreciated because preliminary developmental work with the DIS has been done in circumstances most favorable to the discovery of psychotic experiences and least comparable to the assessment realities in nonclinical populations. Those circumstances include (1) subjects who are identified patients and are accustomed to describing psychopathologic experiences to an interviewer and (2) the clinician’s role may have a halo effect on the interview. That is, patients tend to disclose symptomatic experiences to clinicians and often relate to a research interviewer as though the interview. That is, patients tend to disclose symptomatic experiences to clinicians and often relate to a research interviewer as though the interviewer will be a stranger; the setting will not reinforce clinical expectations and the “authority of the doctor” will not be present. How can one judge the likelihood that under these circumstances subjects will be able to recall and be willing to report psychotic experiences?

The study reported here was the first designed to determine a lay interviewer’s ability to use the DIS to ascertain lifetime psychotic symptoms in patients whose psychotic experiences had been documented during a previous illness episode. The subjects in this study, unlike most subjects to be encountered in nonclinical circumstances, have been previously identified as patients and had participated in research interviews with doctors including followup home interviews. These subjects would, therefore, be unusually familiar with research interview procedures and would have reason to expect that the present interviewer was already familiar with their past experiences. Resistance to recall and reporting may be reduced under these circumstances. Furthermore, we accepted below criteria evidence of psychosis as positive in the DIS while treating questionably present symptoms in the PSE/PAI as negative. Nonetheless, results of this study suggest that the DIS/lay interviewer approach will underestimate the lifetime occurrence of psychotic illnesses. We cannot determine within the present study design the extent to which this failure is based on a lay interviewer being less effective than a clinician, and/or the DIS structured format approach being less effective than an evaluation which includes a clinical judgment and/or the inability or unwillingness of patients to report previous psychotic symptoms.

Whatever the causes of under-reporting may be, if the problem is as significant as these results suggest, the consequence will be serious misinformation concerning the epidemiology of psychotic illness. The sample size for this report is small, and other investigations will be required before any firm conclusions can be reached on the magnitude of the problem of under-reporting. However, concern that previously experienced psychotic symptoms will be seriously under-reported is augmented by considerations such as the following:

- Episodes of psychosis are often accompanied by lack of insight; hence subsequent reflection on episodes of illness may ignore psychopathology never considered by the subject to represent illness phenomena.
- Bizarre, idiosyncratic, and difficult to describe experiences are not easily discussed between people, especially if the experiences in question are in the distant past and the person listening is a stranger.
- Psychological processes of suppression, repression, blocking, denial, retrospective falsification, and the like may impair an individual’s ability to respond fully and accurately to questions. These processes may cause inadequate reporting of many psychopathological attributes, but we would expect the greatest problem with bizarre and perplexing experiences which are alien to the person’s sense of self.
- Social stigma may cause deliberate withholding of information perceived as damaging. Psychotic illness in general and schizophrenia in particular are highly stigmatizing illnesses.

Based on our understanding of the dynamics of interviewing, the nature
of knowing about and reporting psychopathologic experiences, and the results of this specific study, we believe that the lay interviewer/DIS approach may significantly underrepresent the occurrence of lifetime psychopathologic experiences. Further, we argue that psychotic experiences will be more underestimated than nonpsychotic psychopathologic experiences. The consequences of these shortcomings, if our concern is valid, would be to misunderstand the true lifetime prevalence of severe psychiatric illnesses and to judge the relative magnitudes of various psychiatric disorders inaccurately. Data are not yet available to judge the extent to which the false positives for psychosis would counterbalance the false negatives in large-scale epidemiologic studies. However, the false negative problems will seriously flawed research relying on accurate classification of individual cases (e.g., family pedigree studies).

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Acknowledgment

The work reported was supported in part by a grant from the Scottish Rite Schizophrenia Research Program.

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