

The Course of Schizophrenia: Some Remarks on a Yet Unsolved Problem of Retrospective Data Collection

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Summary. The retrospective assessment of symptoms and syndromes is a basic measure in research of the longitudinal course of schizophrenia. In spite of its importance there have been few studies evaluating the standard of quality of instruments for retrospective data collection. Combining retrospectively and cross-sectionally collected data on schizophrenic symptomatology in a cohort study over a period of 5 years revealed a significant underestimation of symptoms when assessed in retrospect. The need for studies on the validity of instruments for the retrospective assessment of symptoms is stressed.

Key words: Schizophrenia – Symptomatology – Retrospective assessment – Validity

Introduction

When studying the long-term course of schizophrenia, it is often too time-consuming to start with data collection at first admission of a patient. Therefore, the most important research strategy in longitudinal studies is the retrospective approach. This means that the outcome already exists at the beginning of the study. The description of the course of the disease is only possible by acquiring interview data from the patients involved and key informants and by the resort to information – e.g. records – about events that occurred a long time before.

Even in a prospective research design with fixed cross-sectional symptom assessment at intervals of 6 or 12 months, one cannot do without retrospective data collection. Cross-sectional data collection may provide an ac-

curate measure of symptom levels for the day, or even past month, but it does not reflect the course of psychopathology over an extended period. These assessments, consequently, cover only a limited part of the intervals between the cross-sections.

While preparing the design for a 13-year follow-up of the former WHO Collaborative Study on the Assessment and Reduction of Psychiatric Disability (W. an der Heiden, B. Krumm, unpublished work, 1990), the authors were faced with the problem of the retrospective assessment of schizophrenic courses for the period since the 5-year-follow-up. When reviewing the literature it became evident that – in contrast to the importance of this approach – we indeed know something about reliability but very little about the validity of instruments designed for the retrospective assessment of symptoms (Table 1).

Most of these studies dealt with the reliability aspect of instruments. By far the most common measure of reliability is the retesting of a patient or the agreement between two or more experts who observe the same behaviour-in-situation.

Classical psychometric theory deals with parallel forms, internal consistency and test-retest reliabilities as conceptually distinct indices of measurement precision. Users of observational data have traditionally been concerned with inter observer agreement as an index of reliability, which is conceptually close to parallel forms reliability in traditional psychometrics (Nay 1979). Although achieving reliability is important, it is not enough. Interviewers may agree perfectly but be wrong all the time, owing to the lack of ability and/or willingness of a patient to report on his or her past symptomatology. A reliable measure that has no validity is worthless (Grove et al. 1981). Even a reliable measure does not provide any useful statement about the description or definition of schizo-

Table 1. Instruments for the retrospective assessment of symptoms and diagnosis

Author(s)	Instrument	Purpose	Reliability	Validity
Andreasen et al. (1977)	Family History-Research Diagnostic Criteria (FH-RDC)	Information from patient/relative concerning present/past symptomatology of family members	Inter-rater reliability	Agreement between relative's description and direct evaluation/interview of a proband
Andreasen et al. (1981)	Schedule for Affective Disorders and Schizophrenia – Lifetime Version (SADS-L)	Lifetime diagnosis	Test-retest reliability (within 1 day/6 months)	
Häfner et al. (1990)	Interview for the Retrospective Assessment of the Onset of Schizophrenia (IRAOS)	Assessment of the early course of psychosis in schizophrenia and paranoid psychosis	Inter-rater reliability	
Helzer et al. (1981)	Renard Diagnostic Interview (RDI)	Lifetime psychiatric illness	Test-retest reliability	Diagnostic concordance between the RDI and a "traditional" interview
Keller et al. (1987)	Longitudinal Interval Follow-up Evaluation (LIFE)	Retrospective assessment of the longitudinal course of psychiatric disorders for a 6-month follow-up interval	Inter-rater reliability	
McGuffin et al. (1986)	Past History Schedule in conjunction with Present State Examination (PHS/PSE)	Measurement of lifetime symptoms; history of previous episodes of psychiatric disturbance	Inter-rater reliability	Comparison of interview ratings with hospital case notes
Robins et al. (1982)	Diagnostic Interview Schedule (DIS)	Lifetime diagnosis, current and past psychopathological status		Comparison of independent administrations of the DIS by psychiatrists and lay interviewers and with diagnosis on medical charts
Stieglitz (1990)	Retrospective pretest	Retrospective assessment of symptomatology in therapy research		Correspondence between real and retrospective self-rating after between 0 and 8 months
WHO (1980)	Follow-up History and Sociodemographic Description Schedule (FU-HSD)	Data collection on patient's progress during a follow-up period of 1 year, including mental state		
Wittchen et al (1989)	Diagnostic Interview Schedule (DIS), Composite International Diagnostic Interview (CIDI)	Recall and dating of psychiatric symptoms (age at symptom onset, duration and frequency of illness episodes) for lifetime diagnosis	Test-retest reliability (within a 4-day period)	Comparison of time-related questions in the DIS (age at symptom onset) with assessments by an experienced psychiatrist, including case records
Zimmerman et al. (1988)	Family History-Research Diagnostic Criteria (FH-RDC)	Information from patient/relative concerning present/past symptomatology of family members	Test-retest reliability	

phrenia. With respect to validity it seems questionable whether another instrument is an adequate criterion, because it does not overcome the main problem of retrospective assessment. Even the assessment of an experienced psychiatrist may be an erratic standard (Robins 1985) and hospital records are often too fragmentary.

Analysis and Results

One conceptual problem that has to be overcome when examining retrospective symptom assessment is that nor-

mally there exists no standard or criterion to validate against. To obtain preliminary evidence about the validity of retrospectively assessed symptoms we chose the following strategy. We reanalysed the data of the WHO Collaborative Study on the Assessment and Reduction of Psychiatric Disability (Jablensky et al. 1980; Schubart et al. 1986). The German part of this study was carried out at the Central Institute of Mental Health in Mannheim some years before. Seventy patients who fell ill for the first time in 1978 with a diagnosis of schizophrenia were included in the study. During the first 2 years, the data collection took place at half-year intervals. There

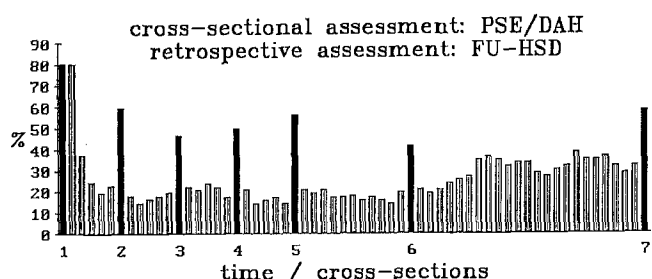


Fig. 1. Patients with delusions and hallucinations during 5-year-period

were two other cross-sectional assessments after 3 and 5 years, so that in total data from seven cross-sections were at our disposal.

For the information assessed here we are only interested in data on the psychopathological status. Psychopathology at the cross-sections was assessed by the Present State Examination (PSE) (Wing et al. 1974). For the retrospective assessment of psychopathological status the Follow-up History and Sociodemographic Description Schedule/FU-HSD (WHO 1980) was carried out. The purpose of the FU-HSD is to help the investigator in obtaining a history of the patients' progress during a follow-up period. The schedule is designed to allow the recording of information about the period between a previous assessment and a present follow-up examination. As a rule, the annual follow-up assessment of the patient should be timed to fall on a date close to the 12th month after the previous assessment. In exceptional circumstances the period covered may also exceed the 1-year interval (WHO 1980). Apart from much other information, the presence of delusions and hallucinations is assessed for each month since the last cross-section.

By combining the PSE data on delusions and hallucinations with the corresponding information from the FU-HSD, it should be possible to obtain a picture about the course of schizophrenic symptomatology. Although the codes in the FU-HSD are used to denote the intensity of symptoms in a manner consistent with the PSE, symptomatology is assessed on a more general level. Thus, we dichotomized the PSE score DAH (subscore DAH: delusions and hallucinatory syndromes) with a cut-off that meant that at least one symptom was clearly present ($DAH \geq 2$).

In a first step we selected all patients with delusions or hallucinations at cross-sections. The idea for the analysis was as follows. If we find a schizophrenic episode in a patient at the cross-sectional assessment – arbitrarily chosen regarding the individual course of the disease – in most cases this episode should be assessed also in the month before, given a mean duration of more than 1 month. According to our data, 68% of the episodes diagnosed with the PSE had begun in the very month of the cross-sectional measurement (FU-HSD: delusions/hallucinations in the month before = 0).

There is no reason to believe that the timing of the cross-sectional measurements related to the course of schizophrenic symptoms in a patient. Thus, the frequency of patients with schizophrenic symptoms at the cross-sections

should not differ significantly from the frequencies at any other time (Fig. 1).

The finding contradicts our hypothesis. At the time of cross-sectional measurement the frequency of schizophrenic symptomatology in our patient cohort was approximately twice as high as in the months of the intervals. According to our analysis, we must conclude that in the retrospective assessment of delusions and hallucinations with the FU-HSD we measure something different from the corresponding items of the PSE.

Conclusion

When interpreting these results, it has to be said that we cannot do without a retrospective research design, at least for shorter periods. Also, we require studies specially designed for examining the validity of retrospective symptom assessment. Our study was not designed for this purpose. With respect to the results, one may assume that the objections are limited to the FU-HSD. If we consider some confounding factors that may influence the retrospective data collection – recall, cooperation of the patient, experience of the interviewer, etc. – it seems more likely that we deal with some general problem that needs to be solved. As a first step the authors are planning a pilot study to evaluate the validity of retrospective symptom assessment (W. an der Heiden, B. Krumm, unpublished work, 1990).

References

- Andreasen NC, Endicott J, Spitzer RL, Winokur G (1977) The family history method using diagnostic criteria. Reliability and validity. *Arch Gen Psychiatry* 34:1229–1235
- Andreasen NC, Grove WM, Shapiro RW, Keller MB, Hirschfeld RMA, McDonald-Scott P (1981) Reliability of lifetime diagnosis. *Arch Gen Psychiatry* 38:400–405
- Grove WM, Andreasen NC, McDonald-Scott P, Keller MB, Shapiro RW (1981) Reliability studies of psychiatric diagnosis. *Arch Gen Psychiatry* 38:408–413
- Häfner H, Riecher A, Maurer K, Meissner S, Schmidtke A, Fätkenhauer B, Löffler W, Heiden W an der (1990) Ein Instrument zur retrospektiven Einschätzung des Erkrankungsbeginns bei Schizophrenie (Instrument for the retrospective assessment of the onset of schizophrenia – “IRAOS”). *Entwicklung und erste Ergebnisse. Z Klin Psychol* 19:230–255
- Helzer JE, Robins LN, Croughan JL, Welner A (1981) Renard Diagnostic Interview. Its reliability and procedural validity with physicians and lay interviewers. *Arch Gen Psychiatry* 38:393–398
- Jablensky A, Schwarz R, Tomov T (1980) WHO collaborative study on impairments and disabilities associated with schizophrenic disorders. A preliminary communications: objectives and methods. *Acta Psychiatr Scand [Suppl]* 285:152–163
- Keller MB, Lavori PW, Friedman B, Nielsen E, Endicott J, McDonald-Scott P, Andreasen NC (1987) The Longitudinal Interval Follow-up Evaluation. A comprehensive method for assessing outcome in prospective longitudinal studies. *Arch Gen Psychiatry* 44:540–548
- McGuffin P, Katz R, Aldrich J (1986) Past and Present State Examination: the assessment of “lifetime ever” psychopathology. *Psychol Med* 16:461–465

- Nay WR (1979) Multimethod clinical assessment. Gardner Press, New York
- Robins LN (1985) Epidemiology: reflections on testing the validity of psychiatric interviews. *Arch Gen Psychiatry* 42:918–924
- Robins LN, Helzer JE, Ratcliff KS, Seyfried W (1982) Validity of the Diagnostic Interview Schedule, Version II: DSM-III diagnosis. *Psychol Med* 12:855–870
- Schubart C, Schwarz R, Krumm B, Biehl H (1986) Schizophrenie und soziale Anpassung. Springer, Berlin Heidelberg New York
- Stieglitz R-D (1990) Validitätsstudien zum retrospektiven Vortest in der Therapieforschung. *Z Klin Psychol* 19:144–150
- WHO (1980) Follow-up History and Sociodemographic Description Schedule (FU-HSD). WHO, Geneva
- Wing JK, Cooper JE, Sartorius N (1974) Measurement and classification of psychiatric symptoms. Cambridge University Press, London
- Wittchen HU, Burke JD Jr, Semler G, Pfister H, Cranach M von, Zaudig M (1989) Recall and dating of psychiatric symptoms. *Arch Gen Psychiatry* 46:437–443
- Zimmerman M, Coryell W, Pfohl B, Stangl D (1988) The reliability of the Family History Method for psychiatric diagnosis. *Arch Gen Psychiatry* 45:320–322