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Social Disability in Schizophrenia: The Controlled Prospective Burghölzli Study*

I. Case-Finding, Research Design, and Characteristics of Samples

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Summary. The Psychiatric University Hospital Zürich ('Burghölzli') is taking part in the 'WHO Collaborative Study on the Assessment and Reduction of Psychiatric Disability'. This multicenter project aims to assess the development of social disability for schizophrenic psychoses of relatively recent onset.

This paper provides a brief review of underlying concepts, the prospective procedure, and the screening criteria applying to all centers. The research team at 'Burghölzli' has greatly extended the general design. Apart from the "obligatory" assessment of 69 first admitted schizophrenics (initial assessment on first hospitalization or outpatient treatment and follow-ups after 1, 2, and 5 years) we have also interviewed a control sample of 60 healthy persons (including a 2-year follow-up) and an 'extreme' sample of 46 chronic schizophrenic outpatients legally entitled to disability pension. Moreover, we have used several supplementary assessment instruments.

This paper is to discuss the purpose of our extended research design. All cohorts are described with respect to screening criteria, sampling procedure, and some basic characteristics; furthermore, a review is given of the additional assessment instruments. It is intended to provide basic information for subsequent papers dealing with results from the study.

Key words: Schizophrenia – Social disability – Longitudinal research design – Case-finding – Control sample

Introduction

As a sequal to the International Pilot Study of Schizophrenia (WHO, 1973, 1979), the WHO initiated a new pilot project in 1976: the WHO Collaborative Study on the Assessment and Reduction of Psychiatric Disability Associated with Schizophrenic Disorders. This multicenter study has three major aims (Jablensky et al. 1980).

— To explore the applicability, reliability, and validity of a set of instruments and procedures designed to evaluate the functional impairments and disabilities in a population of potentially severe disorders in several countries.
— To collect data on the 'natural history' of such impairments and disabilities in different sociocultural environments through consecutive follow-up assessments.
— To identify predictors of levels of social functioning.

The study is conducted simultaneously by research centers in Turkey (Ankara), the Netherlands (Groningen), Sudan, (Khartoum), the Federal Republic of Germany (Mannheim), Bulgaria (Sofia), Yugoslavia (Zagreb) and Switzerland (Zurich). All apply an identical prospective research design, identical screening criteria and assessment instruments. Underlying concepts, design, development of instruments, and training of interviewers have already been described in detail by WHO (Jablensky et al. 1980) and some research centers (Schubart et al. 1982; Schwarz and Michael 1977; Wiersma et al. in press). In the present paper we want to summarize only the central concepts of 'psychological impairment' and 'social disability' that have been adopted provisionally for the purpose of the collaborative study (see also Jablensky et al. 1980; Schwarz and Michael 1977).

— Psychological impairment is defined as the loss or restriction of mental functions which are normally present, e.g., memory, gnosis, skills of communication and interaction, etc.
An impairment may be symptomatic of a particular disease, but a symptom or a sign of a disease is not necessarily an impairment.
Impairments may be temporary or permanent.
All research centers use the widely know 'Present State Examination' (PSE, Wing et al. 1974) for the evaluation of symptoms and the 'Psychological Impairment Rating Schedule' (PIRS) for that of impairments.
— Social disability is defined as a disturbance caused by the presence of impairments. It means a dysfunction in the performance of specific social roles (occupational, recreational, family related, etc.), that would normally be expected of an individual by the social group or community to which he belongs. Such expected roles are usually age- and sex-specific. In order to assess disturbances in role functioning in a transculturally meaningful way, a new instrument had to be especially elaborated for the purpose of the study: The 'Disability Assessment Schedule' (DAS).

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It is assumed that variables of social setting play an important role in determining the extent to which impairments may lead to disability; it is the result of complex interactions between so-called 'intrinsic factors' (impairments and underlying disorder) and 'extrinsic factors' (the social context including work, family life events, etc.).

The concepts mentioned above are similar to those described by Wood (1975) and also show parallels with the considerations of Ruesch (1969), Ruesch and Brodsky (1968), Ruesch et al. (1972), Schwarz and Michael (1977), and Wing (1976).

Although the transcultural research concept of the study determines sampling criteria, assessment methods, and follow-up periods (1, 2, and 5 years subsequent to initial assessment), all collaborating centers have been free to introduce supplementary features by investigating specific problems, using additional instruments, increasing follow-ups, etc. Several centers have seized this opportunity, e.g., the researchers in Mannheim reassess their sample more frequently (6-month periods subsequent to initial assessment) than specified by the general design; the team in Groningen uses an additional Dutch form of the Social Adjustment Scale (Weissman and Paykel 1974).

This paper is to describe the complex design of the Burghölzli study. In contrast to the other centers it is characterized by the assessment of additional samples (especially a normal control cohort) and the use of several supplementary instruments.

2. Samples

In the course of the study, we have assessed four different samples. Three of them are to be described here: a sample of first-admission schizophrenics, a control group of healthy people, and a cohort of chronic schizophrenic outpatients.

2.1. Schizophrenia Sample

2.1.1. General Sampling Procedure for the WHO Study. The study focuses on psychiatric patients whose condition would have serious implications for social and public health. Since in most countries patients with a clinical diagnosis of schizophrenia are at increased risk of disability, all research centers have been requested to select and assess a series of 70 patients who meet specified criteria for functional psychoses of a nonaffective type and of a relatively recent onset. Table 1 shows the screening criteria for the Burghölzli prospective study. In general, these screening criteria are more or less the same for all participating research centers. Existing differences have been described by Jablensky et al. (1980).

2.1.2. Screening Procedure in Zurich. Between February 1, 1978, and September 30, 1979, when the demanded sample size had been achieved, we considered all new schizophrenic inpatients and outpatients of four (later five) of the seven psychiatric hospitals of the canton of Zurich (1.1. million inhabitants in 1978).

For the same period of time we compared our sample with the total of all first admitted schizophrenics of the canton of Zurich. As far as possible we considered the formal screening criteria (age, residence, supplementary diagnosis), whereas more specific criteria like period of onset or symptomatology could not be controlled. From the results of these analyses we conclude that our 'schizophrenia sample' represents about 70%–75% of the total number of patients who suffered their first schizophrenic episode (defined pragmatically by the screening criteria) within the screening period.

Table 2 shows the clinical diagnosis of our 'schizophrenia sample' stated at the initial hospitalization/treatment. Considering the symptomatological screening criteria, it is not surprising that paranoid schizophrenia is the most frequent category in the sample. Originally, the sample comprised 70 persons, but one individual had to be excluded retrospec-

Table 1. Screening criteria for schizophrenia sample

1. Age 15–44 years
2. Residence in the canton of Zurich (a priori defined catchment area)
3. Absence of organic brain disease (including epilepsy)
4. Absence of severe mental retardation
5. Absence of severe sensory defects (e.g., blindness, deafness)
6. Absence of chronic or severe alcohol or drug dependency
7. Onset of psychotic illness dating back not more than 12 months prior to screening date
8. Sufficient knowledge of the German language
9. Presence of at least one item of box A
   or
   presence of at least two items of box B
   or
   presence of box C *and* presence of at least one item of box B

A: 1. Hallucinations of any type
2. Delusions of nonaffective type
3. Clear-cut change to a bizarre or grossly inappropriate behavior
4. Thought and speech disorder other than simple retardation or acceleration

B: 1. Psychomotor disorder other than simple retardation or overactivity
2. Overwhelming fear or anxiety
3. Marked social withdrawal (avoids communication with others)
4. Marked self-neglect

C: Preceding diagnosis of schizophrenia made by a psychiatrist

Table 2. Clinical diagnosis of schizophrenia sample according to ICD-9 subgroups

No. of patients	(%)	Diagnostic subgroup	ICD-9
6	8.7	Hebephrenic type	295.1
3	4.3	Catatonic type	295.2
48	69.6	Paranoid type	295.3
6	8.7	Acute schizophrenic episode	295.4
1	1.4	Latent type	295.5
5	7.2	Schizoaffective type	295.7
69			

tively, after the end of the sampling period, due to a false diagnosis (the 'schizophrenic state' at initial assessment turned out to have been induced by an overdose of antidepressants).

We contacted the patients through their treating psychiatrist who had previously been informed about the project in general and the screening criteria in particular. At the Psychiatric University Hospital "Burghölzli" ('residence' of the research department), all consecutive admission reports could be controlled and screened directly, whereas patients from other hospitals had to be reported on by their treating doctors, which we tried to ensure by weekly telephone inquires. Nevertheless, we could not prevent the patients of the "Burghölzli" being slightly overrepresented in our sample (statistical tendency). In order to check for sampling effects we compared the subsamples "Burghölzli" and "other hospitals" for a variety of different variables (diagnostic, type of onset, distributions of sex, age, and other sociodemographic variables). As none of the analyses showed any significant difference between the samples we assume this sort of sampling bias to be negligible.

Patients and key persons (if available) were informed about the study (including subsequent follow-ups) during a first visit, and asked to cooperate. Two independent interviewers (clinical psychologists) carried out the initial interviews with patient and key person using a series of different assessment instruments. The patient interviews were often rather time-consuming and exhausting for both patient and interviewer (3 h on average).

2.2. *Assessment of 'Contrasting Samples'*

It seems reasonable to presume that the overall design of the WHO study will yield fairly homogeneous samples across all participating centers. This in turn will provide the basis for investigating the effects of the different cultural settings on the development of social disability. Furthermore, each center will be able to observe the 'movement' of its sample or of single individuals over a period of 2–5 years and demonstrate the 'path' from a starting point (or starting configuration) to an end point (configuration). The first problem, however, already arises in defining the starting point. The most essential task of the study is the assessment and rating of disability. The interviewer has to decide whether and to what extent the assessed individual is deviant from norms valid for the social group to which he belongs.

This approach requires intensively trained and highly sensitive investigators in order to guarantee that they may function as reliable and valid assessment instruments. Schubart et al. (1982) and Wiersma et al. (in press) have pointed out that rather high values of interrater reliability can be achieved in the assessment of disability by using the DAS—or, in a more ironical style, interviewers and raters are prone to use the same glasses in searching for disability. This well-known methodological problem has been one of the motivating factors for our additional assessment of a sample of normal subjects. In this way, we expected to get information about constructions called 'normal social adjustment', 'normal performance of social roles', or 'no dysfunction'. We also hoped to provide a baseline for comparing the premorbid functioning of first admission schizophrenics with that of healthy control subjects.

The second problem evolves from describing the outcome—absence/presence of social disability—of our schizophrenic sample. After completing the 5-year follow-up we will be able to describe the outcome (for the restricted observation period) in detail, and numerous analyses may help to evaluate variables of predictive value for outcome state and course. However, we still do not know much about the relative position of our sample "five years after initial assessment" (meaning 5–6 years after onset of the psychosis) as compared to 'potential outcome conditions'. We have attempted to obtain information about one potential outcome by assessing a sample of nonhospitalized chronic schizophrenics (described in more detail below).

Finally, a further question has led us to initiate the assessment of a third 'contrasting sample': Can we find a structure of social disability that is specific to schizophrenia?

To clarify this we selected a sample of nonhospitalized unipolar depressives in order to evaluate their social functioning in a symptom-free interval. The results of this collateral study are not yet available; the detailed description of this cohort will be the subject of a future publication.

2.2.1. Normal Control Sample. This random sample ($N = 60$), stratified for sex and age (according to the corresponding distribution for the schizophrenic sample) has been selected from a community (7800 inhabitants) in a rural district of the canton of Zurich. None of the selected persons have ever received psychiatric treatment.

The control subjects were interviewed in 1979 by a graduate student of psychology who had been thoroughly trained in using the assessment methods (described in Section 3) beforehand.

Moreover, the sample was reassessed in 1981. This 2-year follow-up was performed to measure the 'stability' of social adjustment (Isele and Conen, in preparation).

2.2.2. Chronic Schizophrenia sample. As already mentioned above the investigation of this sample ($N = 46$) should give an idea about the variety of social outcome that might be relevant for some of the first admission schizophrenics. The rather specific character of this sample is best illustrated by the screening criteria:

a) Present age: Not more than 60 years
   Age at onset of psychosis: not more than 44 years
b) Diagnosis of schizophrenia
c) Absence of mental retardation, organic brain disease, severe sensory defects, chronic or severe alcohol or drug dependency
d) Duration of illness: at least 5 years
e) Disability pension: legally entitled to disability pension due to psychotic condition
f) Present situation: not hospitalized in a psychiatric hospital
g) Sufficient knowledge of the German language.

One of the most distinguishing screening criteria is the formal entitlement to disability pension as a result of the schizophrenic psychosis. Important, too, is the inclusion of outpatients only in order to exclude extreme cases of lifelong hospitalization with the severest forms of social disability.

Inevitably, this screening procedure will yield a highly selected subgroup of chronic schizophrenics, but we hope that it is one of relevance for comparisons with our acute schizophrenic sample after completing its last follow-up.

All of the chronic patients have been in contact with a psychiatric outpatient service. They were asked to cooperate by their treating psychiatrists and interviewed by another graduate student of psychology.

Table 3. Design of the study

Assessment instruments	Other WHO centers, all assessments	Burghölzli prospective study							
		WHO study schizophrenia sample				Normal control sample		Chronic schizophrenics single assessment	Depression sample single assessment
		Initial assessment	1-year follow-up	2-year follow-up	5-year follow-up	Initial assessment	2-year follow-up		
WHO study instruments:									
Present State Examination (PSE)	+	+	+	+	+	–	–	–	–
Psychological Impairment Rating Schedule (PIRS)	+	+	+	+	+	–	–	–	–
Disability Assessment Schedule (DAS)	+	+	+	+	+	–	–	–	–
Psychiatric History/Follow-up History and Sociodemographic Description (PHSD/FU-HSD)	+	+	+	+	+	–	–	–	–
Diagnostic and Prognostic Assessment (DPA)	+	+	+	+	+	–	–	–	–
Burghölzli instruments:									
Sociodemographic Data (SDD)	–	+	+	+	+	+	+	+	+
Scales for Assessing Social Adjustment (SSA)	–	+	+	+	+	+	+	+	+
Frankfurter Complaint-Questionnaire (FBF)	–	+	–	–	+	–	–	+	–
Life Events Inventory	–	+	–	–	–	+	–	–	–
Personality Inventory (AUPI)	–	–	–	–	–	+	+	–	–
Brief Psychiatric Rating Scale	–	–	–	–	–	–	–	+	–
Depressiveness-Scale (D-S)	–	–	–	–	–	–	–	–	+

+ = instrument used
– = instrument not used

3. Assessment Instruments

The design of the Burghölzli prospective study is also characterized by the use of a variety of instruments in addition to the methods used by all research centers. It is important to mention that our 'contrasting samples' have not been assessed with WHO instruments but with Zurich instruments only. It was possible to avoid this procedure for both pragmatic and practical reasons. Table 3 reviews the instruments for the disability project in Zurich for the different samples and follow-ups. The WHO instruments have been described by Jablensky et al. (1980). As this paper focuses on the special design of the Burghölzli study we want to give a brief description of the Zurich instruments only.

3.1. Sociodemograyphic Data (SSD)

This inventory consists of sociodemographic items usually assessed in social sciences. In general it collects data about age, sex, marital status, employment status and situation, living situation, income, etc. There is some similarity to sections of corresponding WHO instruments (PHSD, FU-HSD), but the SDD inventory 'measures' this in a more detailed way.

3.2. Scales for Assessing Social Adjustment (SSA)

SSA originally means "Schätzskalen zur Erfassung sozialer Anpassung" (Malzacher and Merz unpublished observations 1980). This is the name of a semistructured interview especially designed for the Burghölzli study. It contains 60 items covering 11 areas of social role functioning. The theoretical background has been described by Isele and Angst (1982), a review of the single items will be given in a subsequent publication (Isele et al. 1985). To show the potential comparibility of our data with those of other projects we would mention that two widely used scales have been adopted to set up the item pool of the SSA: the Structured and Scaled Interview to assess Maladjustment (SSIAM, Gurland et al. 1972a, b) and the Social Adjustment Scale (SAS, Weissman and Paykel 1974).

In addition, a separate form for interviewing key persons has been developed. Most of the items must be rated on operationalized 5-point scales. Two investigations evidence the validity of the scales (Ebnöther 1980, Fehr-Suter 1981), and a previously performed computation of interrater reliability coefficients (based on live interviews of 9 patients assessed by two raters) showed acceptably high coefficients of weighted kappa (Cohen 1968): Median: 0.79, 1st quartile: 0.63, 3rd quartile: 0.88 (Isele and Conen, in preparation).

The SSA is the most important instrument in our project. Due to the transcultural design of the study the corresponding DAS can measure social role functioning only in a global manner. Detailed information about specific interpersonal skills have to be summarized in single role scores. Compared to the DAS, the SSA is more discerning and reflects various facets of

social functioning. It should thus be able to detect differences between samples on a more subtle level.

First results concerning the premorbid social adjustment of first admission schizophrenics as compared to normal controls have been summarized by Isele and Angst (1982) and will be described in more detail in a subsequent publication (Isele et al. 1985).

3.3. Frankfurter Complaint Questionnaire (FBF)

FBF originally means "Frankfurter Beschwerde-Fragebogen" (70-item form). This questionnaire serves to assess the so-called 'basic disturbances' or 'primary impairments' of schizophrenia (Süllwold 1977, 1981). These disturbances of psychic function are considered to form the basis for the appearance of schizophrenic symptoms, or, in the case of slow development of a psychosis, precede them. Süllwold has described 8 categories of disturbances as a result of a factor analysis (of the original 103-item form):

— Disturbances of expression and receptive speech
— Minimal perceptual disturbance
— Loss of automatization (self-acting abilities)
— Interference with motor reactions
— Interference with thoughts
— Sensory disturbance
— Indications of paranoia
— Penetrating displeasure.

With regard to the development of social disability the following formulations of Süllwold should be cited: "With increasing duration of the illness the 'loss of self-acting abilities' increases and certain reactions designed to cope with the loss become more prominent. This supports the assumption that in the long run the termination of schizophrenia depends on appropriate development of reactions which can compensate the disturbances" (1977, p 82).

We have tried to assess these basic deficiencies in our schizophrenic sample by giving the FBF to the patients just before discharge from hospital (first admission) with instructions to rate the items for the previous 2 weeks. The results of this investigation have been reported by Isele and Angst (1982). Final conclusions about the relevance of such 'basic disturbances' to our schizophrenia sample cannot be presented until completion of the 5-year follow-up.

3.4. Life Events Inventory

The results of the comparison (matched pairs) between schizophrenics and normal controls concerning the frequency of experiencing life events (assessed for two 3-month periods prior to onset of psychosis or interview respectively) have already been presented in great detail (Malzacher et al. 1981; Isele and Angst 1982). We have used a translated and modified (formulation of additional items) form of the Life Events Inventory of Tennant and Andrews (1976, 1977).

The following had to be assessed for each item:

— Occurrence (according to fixed time periods)
— Subjectively experienced stress (adaptation time)
— Desirability of the event
— Independence of the event (from the mental disorder).

The main result can be summarized in few words, our results did not support the 'triggering hypothesis'. We could not find any differences between normal control subjects and schizophrenics with respect ot the frequency of experienced life events in any assessed period.

3.5. Personality Inventory (AUPI)

The AUPI (Baumann and Dittrich 1975, 1976) is a questionnaire to measure four personality dimensions:

— Extraversion
— Psychoticism
— Neuroticism
— 'Frankness' (lie scale)

The AUPI (92 items) has been used to ensure the 'normality' of the control sample at the initial assessment and the 2-year follow-up.

3.6. Brief Psychiatric Rating Scale (BPRS)

The BPRS (Overall and Gorham 1962) has been used only for the chronic sample to control the effects of symptomatology on social adjustment. The BPRS consists of 16 items measuring psychopathological syndromes on 7-point scales.

3.7. Depressiveness Scale (D-S)

D-S originally means "Depressivitäts-Skalen" (v. Zerssen 1975). These scales (two parallel forms with 16 items each) are rated for the sample of depressives only (4-point scales) and are mainly used for control purposes (interaction of current depressiveness with social adjustment).

4. Basic Characteristics of Samples

This report constitutes a general outline only. It is intended to provide basic information for a series of subsequent publications dealing with specific topics of the study. Therefore, we offer a brief survey on some general characteristics only and not a comprehensive description of our samples. Table 4 presents the distribution of sample size, age, marital status, and duration of illness. Since the chronic schizophrenics are intended explicitly to constitute an 'extreme group', it seems inappropriate to compare this sample with others except in age at first hospitalization (not specified for the chronic schizophrenics in Table 4). With respect to this variable neither parametric nor nonparametric comparisons yielded any significant differences between acute and chronic schizophrenics samples and separated for sex).

The search for differences between normal controls and acute schizophrenics elicits significant results regarding the marital status. These results are essentially caused by the low rate of married men in the schizophrenic sample, since the significance stands for the total samples ($\chi^2 = 7.8$, 1 *df*, 0.01) and for the men ($\chi^2 = 6.6$, 1 *df*, 0.01), but not for the women.

The analysis of sex differences within each sample provided significant results for the chronic schizophrenics only. If we dichotomize the marital status for statistical reasons into 'single' and 'once married', the difference between men and women becomes even clearer, as already indicated in Table 4; 50% of women have once been married, but only 4% of men ($\chi^2 = 10.2$, 1 *df*, 0.01).

Finally it seems important to mention that the 'acute' schizophrenics really deserve this label as only 15% experienced the onset of symptomatology more than 3 months prior

Table 4. Basic characteristics of samples

		Control sample			First onset schizophrenics			Chronic schizophrenic outpatients		
		Male	Female	Total	Male	Female	Total	Male	Female	Total
Sample size		30	30	60	32	37	69	24	22	46
Age (years)	Mean	26.6	25.7	26.2	24.5	24.8	24.7	41.8	41.3	41.5
	Median	26.5	25.5	26.0	22.5	24.4	23.9	40.2	38.5	40.2
	Minimum	15	15	15	16	17	16	25	20	20
	Maximum	40	39	40	39	40	40	60	59	60
Marital status	Single	15	16	31	26	26	52	23	11	34
	Married	15	14	29	6	11	17	—	7	7
	Separated	—	—	—	—	—	—	1	2	3
	Divorced	—	—	—	—	—	—	—	1	1
	Widowed	—	—	—	—	—	—	—	1	1
Duration of illness[a]	Mean[b]	—	—	—	40	44	42	15;7	15;8	15;8
	Median	—	—	—	15	16	15	13;0	14;0	13;2
Length of previous hospitalizations	Mean[b]	—	—	—	—	—	—	7;2	5;4	6;4
	Median	—	—	—	—	—	—	4;6	2;1	2;9

[a] For the first onset schizophrenics, 'duration of illness' means the period between onset of symptoms (according to screening criteria!) and admission to hospital; for the chronic schizophrenics, the period between first hospitalization and date of assessment.
[b] The measuring units are different for the schizophrenic samples. The figures mean days for the first onset schizophrenics, respectively years and months for the chronic schizophrenic sample

to hospitalization. Nevertheless, we must consider the fact that 'symptomatology' relates explicitly to the screening criteria (boxes A and B of Table 1) and thus primarily means 'active' florid symptoms. More subtle symptoms or unspecified prodromi may precede the conditions leading to hospitalization. Therefore, onset of symptomatology does not necessarily imply onset of psychosis. We will have to reconsider this problem for the interpretation of 'premorbid' adjustment in the subsequent paper (Isele et al. 1985).

5. Discussion

The purpose of this paper is to provide basic information on concepts, design, instruments and samples of our study in order to serve as a general introduction to subsequent publications. The study is part of a multicenter project of WHO and thus should contribute to transcultural comparisons of the development of social disability in schizophrenia. In Zurich the research design prescribed by WHO has been greatly extended, we have used additional assessment instruments and investigated supplementary samples.

Apart from transcultural aspects, the general design of the WHO project will "only" yield information concerning the development of social disability within a defined period. Moreover it will—perhaps—be possible to identify predictors of outcome or factors determining the 'course' of social disability. However, we still do not know anything about the 'positions' of the starting points (social adjustment at first admission) with respect to healthy people. There is also no information about the positions of the end points (social adjustment at 5-year follow-up) with respect to the variety of possible outcomes. Our supplementary assessment of normal controls and chronic schizophrenic outpatients will certainly not solve these problems completely, but it might enable us to observe the individual schizophrenic's development of social disability within a—hypothetical— continuum between normal adjustment and the condition of legal entitlement to disability pension.

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The goals of the project are twofold:
(1) to develop standardized methods and instruments for the evaluation of impairments and disabilities in psychiatric patients, and
(2) to increase knowledge about the nature, course and susceptibility to interventions of impairments and disabilities occurring in association with mental disorders in various socioeconomic and cultural settings.

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