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## EDITORIAL

The Istanbul International Congress  
and the ongoing building of our field  
J.E. MEZZICH

129

## SPECIAL ARTICLES

Early detection of schizophrenia:  
current evidence and future perspectives  
H. HÄFNER, K. MAURER

130

Quality of life in mental disorders:  
challenges for research and clinical practice  
H. KATSCHNIG

139

Should general psychiatry ignore  
somatization and hypochondriasis?  
F. CREED

146

## FORUM – PSYCHIATRIC REHABILITATION TODAY

Psychiatric rehabilitation today: an overview  
W. RÖSSLER

151

### Commentaries

Caveats for psychiatric rehabilitation  
R.P. LIBERMAN

158

The underutilization of psychiatric rehabilitation  
R. CANCRO

159

The diffusion of two successful  
rehabilitation models  
R. WARNER

160

Identifying psychiatric rehabilitation  
interventions: an evidence and value  
based practice  
M. FARKAS

161

Psychosocial rehabilitation and severe  
mental disorders: a public health approach  
A. BARBATO

162

Psychiatric rehabilitation in the era  
of globalization  
M.G. MADIANOS

163

Psychiatric rehabilitation and its present  
role in developing countries  
P. DEVA

164

Psychiatric rehabilitation today:  
an African perspective

166

F.N. KIGOZI, E. KINYANDA

A plea for the 22 UN standard rules  
and a request to redefine psychiatry

166

R. VAN DER MALE

## RESEARCH REPORTS

Risk factors for schizophrenia.

168

Follow-up data from the Northern Finland  
1966 Birth Cohort Study

M. ISOHANNI, J. MIETTUNEN, P. MÄKI, G.K. MURRAY,  
K. RIDLER ET AL

The relationships between depression  
and remission in first-episode psychosis  
P. OOSTHUIZEN, R. EMSLEY, D. NIEHAUS,  
L. KOEN, B. CHILIZA

172

Understanding of the term “schizophrenia”  
by the British public

177

J. LUTY, D. FEKADU, A. DHANDAYUDHAM

## MENTAL HEALTH POLICY PAPERS

World Health Organization’s Mental  
Health Atlas 2005: implications for policy  
development

179

S. SAXENA, P. SHARAN, M. GARRIDO CUMBRERA,  
B. SARACENO

Ethics in psychiatry: a framework  
F. LOLAS

185

## LETTER TO THE EDITOR

188

## WPA NEWS

An agenda for change: the role of the  
WPA in global psychiatric education

189

A. TASMAN

Advancement of scientific knowledge through  
international collaborative research

190

M.R. JORGE



## The World Psychiatric Association (WPA)

The WPA is an association of psychiatric societies aimed to increase knowledge and skills necessary for work in the field of mental health and the care for the mentally ill. Its member societies are presently 130, spanning 113 different countries and representing more than 180,000 psychiatrists. The WPA organizes the World Congress of Psychiatry every three years. It also organizes international and regional congresses and meetings, and thematic conferences. It has 65 scientific sections, aimed to disseminate information and promote collaborative work in specific domains of psychiatry. It has produced recently several educational programmes and series of books. It has developed ethical guidelines for psychiatric practice, including the Madrid Declaration (1996). Further information on the WPA can be found on the website [www.wpanet.org](http://www.wpanet.org).

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# The Istanbul International Congress and the ongoing building of our field

**JUAN E. MEZZICH**

President, World Psychiatric Association

The 2006 WPA International Congress took place in Istanbul on 12-16 July. This encounter of psychiatrists of the world was, in the view of many, one of WPA's most successful.

We all arrived at the old Constantinople, to six hundred years of Ottoman history, to the City where the Bosphorous engages Europe and Asia, to recommit ourselves to the WPA founders' aspiration of a unified professional identity across geographic and linguistic barriers. We experienced the vibrations of ancient civilizations, harmonizing mind, body and context and energizing the exploration of new insights and new realities.

The design and construction of the Istanbul International Congress was facilitated by having from its outset, for the first time, a set of congress developmental principles. These follow: to observe an overall theme, *Psychiatry: Uniqueness and Universality*; to advance scientific excellence, with an emphasis on bio-psycho-social integration; to present the richness of our diverse world, with focus in this Congress on European and intercontinental crossroads; to promote international collaboration at all levels, emphasizing WPA/World Health Organization (WHO) perspectives; to optimize continuing professional development, with a focus on young psychiatrist programs; to advance the current WPA Strategic Plan, highlighted by *Institutional Consolidation and Global Impact: Towards a Psychiatry for the Person*; and to promote the participation of WPA Member Societies and Scientific Sections.

The polarities embedded in the overall theme, *Psychiatry: Uniqueness and Universality*, stimulated programmatically the articulation of the scientific with the humanistic, the objective with the subjective, the standardized with the personalized, explanation with understanding, and the clinical with public health. About fifty invited speakers, including some of the most prestigious scientists and clinicians in our field, from all continents, offered lectures covering innovations in fundamental areas such as the neurosciences, psychodynamics and social psychiatry, as well as key psychopathological problems and new care approaches, the challenges posed by disasters and violence, and, last but not least, the conceptualization of a person-centered psychiatry. Well over a hundred symposia on topics covering virtually every aspect of our field were organized by Scientific Sections, Zone Representatives, Member Societies, industry, and colleagues at large. Over fifty courses and workshops offered opportunities for interactive learning. Eleven film sessions exhibited various facets of creativity and mental health. Almost fifty warmly received clinical case conferences encompassed discussions by eminent clinicians of cases prepared by young psychiatrist Fellows according to WPA's International Guidelines for Diagnostic Assessment. The Program on Psychiatry for the Person held its

first full-day workshop aimed at setting the bases for specific projects on conceptual, historical and ethical framework, clinical diagnosis (contributions to ICD-11 and the design of an integrative diagnostic model), clinical care (curricula and educational aids for multidisciplinary training of clinicians) and public health (epidemiological and public policy initiatives).

The institutional development of WPA was also potently moved forward in Istanbul. Over one hundred hours of organizational meetings covered encounters of the Executive Committee, Board, Advisory Council, General Forum, Standing and Operational Committees, and many Scientific Sections. New institutional pages were open with the meetings of the WPA Regions (Americas, Europe, Africa and the Middle East, and Asia/Australasia), each run by the corresponding Zonal Representatives with the participation of Member Society leaders. And a strong Fellowship Program and Young Psychiatrist Council meeting documented WPA's commitment to the future of our field. Extending the impact and alliances of WPA, meetings and scientific activities took place with international organizations such as the WHO, the World Federation for Mental Health, the World Federation of Neurology, and the World Organization of Family Doctors. This wide range of activities documents the increasing importance of International Congresses in the life of WPA, particularly concerning participative governance and interactive functioning.

A cultural program of unusual richness touched our most intimate fibers... from an arts exhibit highlighting the expressions of the human face in health and illness, to vibrant classic and popular concerts, to films challenging our understanding of the mind, to visits to historical monuments contrasting epochs and cultures. And multiple opportunities were extended for relaxed discussions, meeting old friends and making new ones, in the most pleasant of settings.

All the above could easily explain the success of the Istanbul Congress and the satisfaction felt by its many participants coming from over a hundred countries. But this Congress was more than the sum of its parts. The extraordinary organizational skills and graceful touch of its main architect, Levent Küey, with the collaboration of his strong team, our esteemed Turkish Member Societies and an outstanding professional congress organizer, pulled all elements together into a most stimulating and delightful event.

Illustrating the pleiad of congratulations received immediately after the Istanbul Congress, a respected academic psychiatrist of intercontinental experience e-mailed this: "I am not in the habit of writing letters to organizers after each meeting... With a remarkably well delivered congress, you have set up a new standard for WPA". Melbourne and Prague are taking notice.

# Early detection of schizophrenia: current evidence and future perspectives

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*Research into the early course of schizophrenia has identified a prepsychotic prodromal stage (mean duration: 4.8 years) and a psychotic prephase (mean duration: 1.3 years). Comparisons of individually matched samples have demonstrated prodromal symptoms common to schizophrenia and moderate to severe depression. It is not until positive symptoms emerge that psychosis and mood disorders become distinguishable from each other. In both disorders the prodromal stage early produces functional impairment and related social consequences. Hence, early intervention is of great public health relevance. This intervention is targeted at manifest symptoms and not at the underlying, still unknown disease process. Cognitive-behavioural therapy at the prepsychotic prodromal stage seems to favourably influence the short-term illness course. In the psychotic prephase, a combination with low-dose antipsychotics seems to have some efficacy. The aim of early recognition by the instruments discussed in this paper is to permit the identification of the largest possible proportion of at-risk persons as early as possible and their referral to appropriate treatment.*

**Key words:** Schizophrenia, prodromal symptoms, depression, early recognition, early intervention

In the last two decades, widespread attention has been accorded to the insight that, in psychosis, the first contact with mental health services is frequently preceded by a period of evolving disorder whose duration is of several years (1-5). Early recognition and early intervention have fanned hopes of preventing or postponing psychosis onset, reducing severity of illness or at least ameliorating the personal and social consequences involved. In the wake of the pioneering work of McGorry and his Melbourne-based group, early recognition and intervention centres for psychosis have sprung up in many countries (6).

Kraepelin (7) already described “minor changes in mood, which may be recurrent or persist for weeks, months or even for years as the only premonitory signs of an imminent mental disorder”. The first systematic analyses of the prodrome of schizophrenia were conducted by Sullivan (8) and Cameron (9,10), with the aim of initiating early intervention, but these attempts failed. After World War II, Conrad (11) and Docherty et al (12) proposed stage models of evolving illness, but these models could not be adequately replicated (13) and failed to offer an opportunity for developing effective approaches to early intervention.

In the past two decades, a series of instruments for the early recognition of schizophrenia have been developed. Their aim was the identification of persons at a high enough risk for psychosis to permit diagnostic discrimination and justify early intervention. Because population-based prospective studies of onset and early illness course are impractical, due to the low incidence rate of schizophrenia and the high frequency of an uncharacteristic type of onset, these instruments were developed on the basis of retrospective studies. The psychopathological phenomena that can be used for early diagnostic discrimination and/or for predicting the onset of a psychotic episode in practice include: a) characteristic prodromal signs and symptoms; b) neuropsychological deficits assessed in cognitive tests (14); c) characteristics of the illness course.

Potent biological markers that would facilitate the early recognition of psychotic disorders are not yet available. In the Edinburgh high-risk study (15) and the Melbourne-based early-intervention programme (16), high-risk probands who transitioned to psychosis showed a significant volume reduction in the hippocampus-parahippocampus area in comparisons with high-risk probands without transition to psychosis. This finding of high theoretical interest, however, cannot yet be harnessed in practice.

## RECONSTRUCTING THE EARLY COURSE OF SCHIZOPHRENIA AND ITS CONSEQUENCES

In the ABC Schizophrenia Study (3), we studied a population-based sample of 232 patients with a first episode of schizophrenia spectrum disorder (ICD-9: 295, 297, 298.2, 298.4), aged 12 to 59 years, compared with age- and sex-matched healthy individuals from the study area. The patients were assessed using the Interview for the Retrospective Assessment of the Onset and Course of Schizophrenia and Other Psychoses (IRAOS) (17). On the basis of these data, we defined two stages in the early illness course, which have implications for risk identification and intervention: a) a prepsychotic prodromal stage, from the first sign of illness until the first psychotic symptom, with a mean duration of 4.8 years (median 2.33); b) a psychotic prephase, from the first positive symptom until first admission, with a mean duration of 1.3 years (median: 0.8 years), 1.1 years until the climax of the first episode plus 2 further months until first admission. Lower medians than means reflect a preponderance of shorter durations. Eighteen percent of the cases had an acute type of onset of four weeks or less, 15% a subacute type of four weeks to one year, and 68% a chronic type of one year or more. Only 6.5% of onsets occurred with positive symptoms alone (18).

Table 1 gives an overview of selected studies on the

**Table 1** Mean duration of the prephase of schizophrenia from onset (first sign, first psychotic symptom) until first contact or first admission in selected studies (modified from 26)

Authors	N	Duration from first sign (years)	Duration from first psychotic symptom (years)
Gross (1) (Germany, 1969)	290	3.5	
Lindelius (19) (Sweden, 1970)	237		4.4
Huber et al (2) (Germany, 1979)	502	3.3	
Loebel et al (20) (USA, 1992)	70	2.9	1.0
Beiser et al (21) (Canada, 1993)	70	2.1	1.0
McGorry et al (4) (Australia, 1996)	200	2.1	1.4
Lewine (22) (USA, 1980)	97		1.9
Häfner et al (3) (Germany, 1995)	232	4.8	1.1
Johannessen et al (23) (Norway, 1999)	43		2.2
Ho et al (24) (USA, 2003)	156	2.7	1.4
Köhn et al (25) (Germany, 2005)		5.9	

duration of untreated illness (DUI) and/or untreated psychosis (DUP). Results on DUI differ more markedly, because of the difficulty of precisely defining illness onset and the lack of suitable assessment instruments in a majority of studies. In about three-quarters of cases, schizophrenia onset occurs with slowly mounting depressive and negative symptoms involving increasing functional impairment and cognitive dysfunction (27).

DUP, assessed in a great number of studies, depends on the conspicuousness and velocity of symptom accumulation, help-seeking behaviour and the availability of appropriate mental health services (28-30). DUP can be shortened by improving the last two factors. An awareness programme educating and alerting both the population and health services of a region in Norway presumably helped to reduce DUP from 2.5 years to 0.5 years (31).

In a majority of studies, a prolonged DUP turned out to be a predictor of an unfavourable illness course (4,20,32-36). It was associated with a more severe course of the first episode and all the consequences associated with the latter (e.g., greater risks, more inpatient days, higher costs) (35-37). A small number of studies have also reported sustained neuropsychological deficits, higher scores on negative symptoms and disorganization, and an unfavourable functional outcome (38-40). It is still an unsettled question whether a prolonged DUP is also associated with more psychotic relapses, as reported by several authors (32,41), because long-term follow-ups are rare.

**Table 2** The ten most frequent earliest signs of schizophrenia (independent of the course) reported by the patients (modified from 3)

	% Total (n = 232)	% Men (n = 108)	% Women (n = 124)
Restlessness	19	15	22
Depression	19	15	22
Anxiety	18	17	19
Trouble with thinking and concentration	16	19	14
Worrying	15	9	20*
Lack of self-confidence	13	10	15
Lack of energy, slowness	12	8	15
Poor work performance	11	12	10
Social withdrawal, distrust	10	8	12
Social withdrawal, communication	10	8	12

\*Significantly more frequent in females,  $p < 0.05$

Kraepelin (7) assumed that florid bouts of illness (psychotic episodes) lead to a certain amount of irreversible consequences, which he called defects. This construct implies that schizophrenia has a deteriorating course consisting of downward steps produced by each psychotic episode (42). Reviving Kraepelin's model, Wyatt (43) and Lieberman et al (44) postulated that untreated psychosis might constitute an active morbid process toxic to the brain. That process has to be treated and suppressed early enough, in order to prevent it from becoming chronic (44,45). McGlashan and Johannessen (46) hypothesized that the plasticity of the brain can be preserved by both antipsychotic medication and social stimulation at that sensitive stage. Lieberman et al (44) interpreted the results of a 2-year controlled clinical trial as indicating that the administration of proper doses of olanzapine can halt the process of toxic brain damage.

In our sample of 232 patients with a first illness episode, we also studied the emergence of functional impairment and social deterioration (18,47). Table 2 shows the ten most frequent initial signs of schizophrenia, equally frequent in men and women, except worrying, an item which is also more frequent in women in general population studies. The early emergence of indicators of functional impairment, such as trouble with thinking and concentration or loss of energy and social withdrawal, indicates that there is an early risk of social decline.

We chose six social roles indicating the attainment of a basic social status in adulthood in most cultures: finished school education, finished occupational training, regular employment, own income, own accommodation and marriage or stable partnership. Table 3 shows that, at the time of illness onset, persons who will later become psychotic do not yet differ from their sex-matched healthy peers. At first admission, however, some significant differences clearly indicate a trend of social disadvantage in the early illness course. With regard to the social roles accom-

**Table 3** Social role performance at the onset of the first sign of mental disorder and at first admission in patients with schizophrenia compared to sex- and age-matched population controls (modified from 18)

Social role	Subjects fulfilling social role at onset of first sign of mental disorder (%)		Subjects fulfilling social role at first admission (%)	
	Patients (n=57)	Controls (n=57)	Patients (n=57)	Controls (n=57)
School education	65	61	93	95
Occupational training	37	44	63	65
Employment	33	42	44	58
Own income	37	42	49	74*
Own accommodation	46	51	63	75
Marriage or stable partnership	47	58	25	68**

\*p< 0.01, \*\*p<0.001

plished at a young age, e.g. finishing school and occupational training, patients do not differ significantly from controls, because illness onset does not occur frequently enough at that young age. A maximum of social decline occurs in the domain of marriage and stable partnership, indicating deficits in communication and mating behaviour, which were shown to be a powerful risk factor for psychosis by the Swedish (48) and the Israeli (49,50) conscript studies.

In schizophrenia spectrum disorder, the bulk of social decline occurs with the emergence of functional and social impairment in the early illness course. After the remission of the first psychotic episode, the means of the social indicators show no clear-cut trend of either deterioration or improvement in comparison with healthy controls (18,47, 51). In the long-term, neuropsychological test results (52, 53) tend to be characterized by a plateau rather than progressive deterioration.

Once it was established that the early course of schizophrenia is the most active stage in the overall illness course and produces the bulk of mostly permanent consequences (18,47), attempts of early intervention became to be seen as all the more important.

The first studies tentatively indicating the effectiveness of interventions administered in the early course were published by McGorry et al (54), Lewis et al (55) and Bechdolf et al (56). In the first study, one group of patients at ultra high risk (UHR) were treated with a combination of low-dose risperidone and cognitive-behavioural therapy and a control group with standard therapy over six months. In the second study (55), cognitive-behavioural therapy was compared with a standard treatment. In both studies, UHR was defined, among other criteria, by indicators of attenuated psychotic experience. Consequently, the probands were close to transition to psychosis. At one-year follow-up, both studies showed significantly fewer transitions to full-blown psychosis in index cases compared with controls. In the third study (56), the intervention consisted of cognitive-behavioural therapy administered at the prepsychotic prodromal stage. The intervention significantly reduced prodromal symptoms and

showed a trend to reducing transition to psychosis, but the results need replication, due to the shortness of the follow-up period and the small sample size.

#### EARLY RECOGNITION AND DEFINITION OF RISK

Optimal early recognition should allow as many persons at increased risk for psychosis as possible to benefit from early treatment, but that objective involves a serious dilemma: both the prediction of a psychotic episode and its diagnostic discrimination from other disorders will be the more reliable the more criteria based on DSM-IV or ICD-10 categories are fulfilled. It seems that diagnostic and predictive accuracy can only be obtained at the cost of delayed intervention. An inaccurate risk assessment at the early stages of illness would produce a large proportion of false positive cases. This issue has triggered a debate on the ethical aspects involved (57,58), because a premature treatment of schizophrenia risk would cause unnecessary distress and probably also stigma to the patients and their families, while reducing the rate of false positives could exclude a large proportion of people at risk from early treatment.

Basically, there are two solutions to this dilemma: a) enhancing the risk by assessing characteristic premonitory symptoms at a later stage of the prodrome and b) additionally considering premorbid risk factors. Such criteria were included in the definition of UHR (59): a) attenuated and brief limited intermittent psychotic symptoms (BLIPS); b) a loss of 30 points or more in the Global Assessment of Functioning (GAF) score in six weeks, plus a family history of schizophrenia or schizotypal personality. In Melbourne, the proportion of correctly predicted psychosis onsets on the basis of these criteria was about 40% over a period of one year (60). That proportion would probably have been even larger if the period considered had been longer. A psychosis risk enriched in that way, a number needed to treat (NNT) of 4 (54) and the signals of incipient psychosis used are of a magnitude that makes early intervention seem ethically and economically sensible.

Lifetime risk factors (at least one first-degree relative with schizophrenia, pre- and perinatal complications) were also included in the risk definition used in the early recognition and intervention programme of the German Research Network on Schizophrenia (61,62). Further factors indicating a slightly enhanced risk are childhood developmental delays (63), social and communication deficits in adolescence (48,50) and cannabis misuse (27,64,65).

A “clinical” approach to risk enhancement has been used by Klosterkötter et al (5). They studied patients suspected of suffering from schizophrenia who were referred to one of several German university hospitals for diagnostic clarification. From among these persons, 160 probands at risk for schizophrenia were followed up for a mean period of 9.6 years. Seventy-nine developed psychosis according to DSM-IV criteria, with a mean duration of prodromal phase of 5.6 years (5). At inclusion in the study, the authors assessed “basic symptoms” (66,67) by the Bonn Scale for the Assessment of Basic Symptoms (BSABS) (67). These symptoms close to psychosis onset are naturally of a greater discriminatory and predictive power for transition to a full-blown psychosis than unspecific prepsychotic prodromal symptoms. The percentage of correct predictions was 78%, with a negative predictive value of .96 and a positive predictive value of .70. The rate of false positives was very low (20.6%). Such a high predictive power and diagnostic specificity were possible only by studying probands at a highly specific risk during a long period. The advantage of this approach is an optimally low NNT. Its disadvantage is that only a small proportion of at-risk cases in the population, which Warner (57) estimates at 2%, will get a chance of secondary prevention.

Methods of risk enhancement limited to psychotic illness and focusing on early signs of psychosis miss the usually longer prepsychotic prodromal stage, which is frequently accompanied by cognitive and functional impairment and social decline. Many of those who increasingly suffer from serious symptoms and lose their quality of life at the prodromal stage of psychosis go untreated. Phillips et al (68) have stressed the urgent need for bringing to treatment the largest possible proportion of those people who are already suffering from illness-related prodromal symptoms bound to lead to a psychosis or possibly some other serious mental disorder. Awareness programmes can improve help-seeking behaviour and pathways to care. Screening of people at high risk can be accomplished by consecutive filters built in the health care system, as suggested by van Os and Delespaul (69) with reference to Goldberg and Thornicroft (70). The first stage of hierarchical risk enhancement relies on the self-selection of persons consulting primary health services because of mental problems. That requires a screening instrument which permits the identification of persons mainly at a moderate risk. These at-risk persons are then referred to a more detailed examination by means of an early-recognition inventory of a higher discriminatory and predictive power. This stage of risk identification

should be located at specialist mental health services or early-intervention centres, which also have at their disposal a battery of neuropsychological tests and neurobiological instruments. Such a multi-stage early recognition inventory used in a consecutive system of filters is undergoing prospective validation in the German Research Network on Schizophrenia and at the same time in Italy and Israel.

## THE PRODROMAL STAGE IN SCHIZOPHRENIA AND DEPRESSION

In a prospective population study of 3021 probands aged 14 to 24 years, followed up over 3 to 5 years (follow-up: N=2538), Wittchen et al (71) demonstrated that the risk for psychosis onset increases with an increase in depression (OR: 2.9) or anxiety (OR: 1.9) and decreases when depression (OR: 0.69) or anxiety (OR: 0.61) decreases. We postulated that there must be a consecutive-functional association between these two syndromes (27).

In order to explore what the two disorders have in common and what distinguishes them, we studied a population-based subsample of 130 first-admission cases of schizophrenia spectrum disorder aged 12 to 59 years, individually matched to 130 first-admission cases with a diagnosis of moderate (F32.10, 32.11) or severe (F32.2, 32.30, 32.31) depression and 130 healthy controls from the population of the study area.

Patients at first admission and controls were assessed retrospectively by the IRAOS and additionally by the Present State Examination (PSE) (72), the Scale for the Assessment of Negative Symptoms (SANS) (73), the Psychological Impairments Rating Schedule (PIRS) (74), and the Disability Assessment Schedule (DAS) (75,76), to gather data on positive and negative symptoms, functional impairment and social disability both at first admission and 6-month follow-up. In 81% of the patients with schizophrenia and 80% of the depressed patients, the illness course preceding first contact was more or less natural, i.e., uninfluenced by an antipsychotic or antidepressive medication. The interval from the first sign of illness to first admission was significantly longer in depression (7.3 years) than schizophrenia (5.3 years). As Table 4 shows, schizophrenia and depression share eight of the ten most frequent initial symptoms, with fairly similar ranks. Significant differences are limited to nervousness/restlessness and blunted affect, more frequent in schizophrenia, and depressed mood, more frequent in depression. A diagnostic distinction does not seem feasible at this early stage.

With the exception of dissociative behaviour, the period prevalence of the ten most frequent symptoms in the early course of schizophrenia and depression (from onset to first admission) differs significantly from healthy controls in the same period of age (Table 5), but five symptoms have an almost equal prevalence in the two disorders.

Thus, the two illness groups are similar to each other, but

**Table 4** The ten most frequent initial symptoms in patients with a first admission for schizophrenia or a depressive episode matched by age and sex (modified from 27)

Symptoms	Patients with schizophrenia (n=130)		Patients with depressive episode (n=130)	
	%	Rank	%	Rank
Worrying	19.2	4	14.1	5
Headaches, other aches and pains	10.3		13.2	8
Nervousness, restlessness	21.9	2	6.2**	
Anxiety	23.2	1	15.4	4
Difficulties of thinking, concentration	17.1	5	16.5	3
Depressed mood	20.6	3	34.9*	1
Loss of self-confidence	11.9	8	14.0	6
Social withdrawal	11.6	9	13.3	7
Disturbed sleep and/or appetite	15.0	6	21.9	2
Loss of energy, slowness	13.5	7	8.5	10
Loss of libido	4.1		8.5	10
Oversensitivity	3.3		9.3	9
Other changes in affect (blunted, etc.)	11.1	10	0.8**	

Significantly different between patients with schizophrenia and depression:  
\*p<0.05, \*\*p<0.001

clearly distinguishable from healthy controls, in the early course. We interpreted the core symptoms of schizophrenia and depression at the prodromal stage (depressive and nega-

tive symptoms and functional impairment) as a common prodromal core syndrome. In both disorders that core syndrome frequently persists also in the further course (77).

The early social course, as based on social behaviour and social role attainment assessed by the DAS, indicated considerable social impairment at this early stage. Two years before first admission, more than 50% of the patients in both illness groups differed significantly from controls, showing DAS scores  $\geq 2$  in the domains of work performance, household activities, communication and leisure activities.

In order to gain a precise picture of symptom accumulation, we depicted the onset of all 65 IRAOS symptoms on the basis of five clinical categories, on a time axis until first admission (Figure 1). In both disorders, onset is frequently marked by depressive symptoms. They are followed and in part overlapped by a large number of negative symptoms. A clear-cut difference becomes visible only after the onset of and a steep increase in psychotic symptoms in the last time window, on average one year before first admission. In severe depression, the few psychotic symptoms do not show any increase over time.

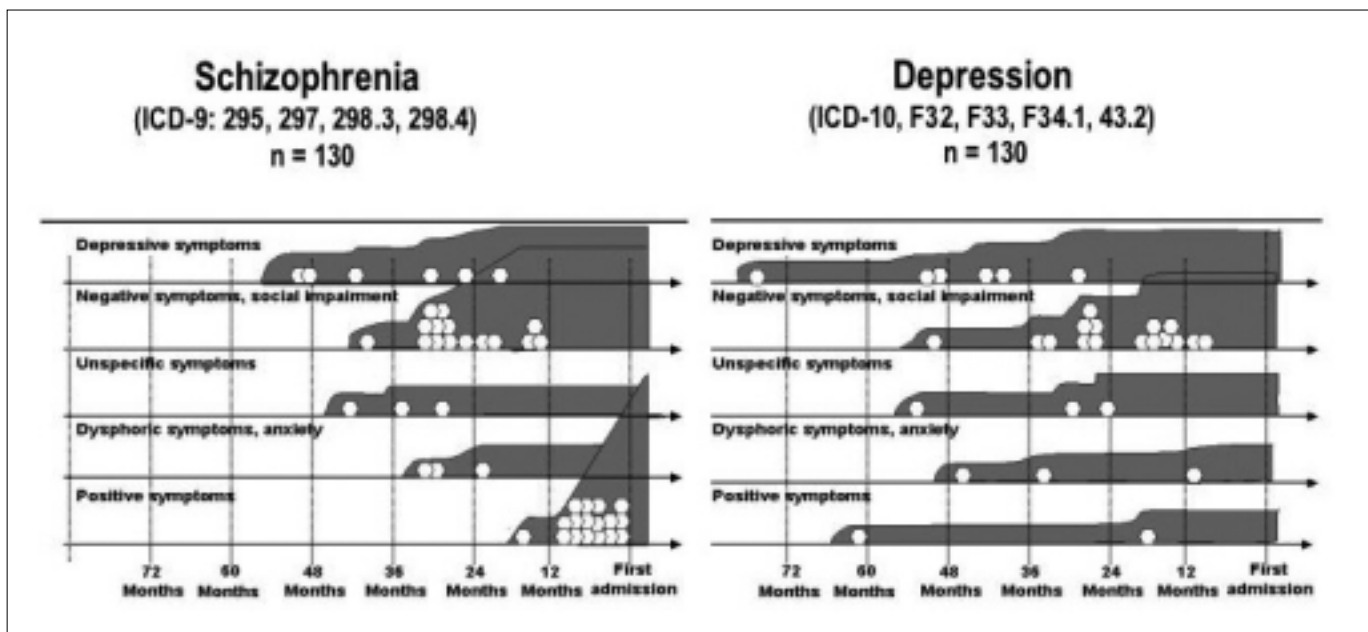
These results strongly suggest that severe depression and schizophrenic psychosis share a prepsychotic prodromal stage at which it is hardly possible to distinguish them reliably. The aim of early intervention at the prepsychotic prodromal stage is to alleviate depressive and negative symptoms, functional impairment and its social consequences by cognitive-behavioural therapy and social skills training (55,61). There is no indication for antipsychotic pharmacological treatment until psychotic symptoms occur.

**Table 5** Period prevalence of the ten most frequent symptoms in the early course of schizophrenia and depression and among healthy controls (modified from 27)

Symptoms	% Schizophrenia (n=130)	% Depression (n=130)	% Controls (n=130)	Schizophrenia vs. depression	Schizophrenia vs. controls	Depression vs. controls
Worrying	74.6	94.6	26.9	***	***	***
Headaches, other aches and pains	49.2	66.9	30.8	**	**	***
Nervousness, restlessness	88.3	81.5	27.7		***	***
Anxiety	88.1	81.5	26.9		***	***
Difficulties of thinking, concentration	93.8	96.9	20.8		***	***
Depressed mood	84.9	100.0	46.9	***	***	***
Loss of self-confidence	68.3	89.2	35.7	***	***	***
Social withdrawal, suspiciousness	79.8	90.8	13.8	*	***	***
Disturbed appetite and/or sleep	93.8	98.5	43.4		***	***
Loss of energy/slowness	82.5	93.8	15.4	**	***	***
Irritability	65.4	68.5	26.2		***	***
Delusional mood	68.3	4.6	0.0	***	***	*
Delusional misinterpretations, delusions of reference	80.3	6.2	0.0	***	***	**
Oversensitivity	22.3	52.3	25.4	***		***
Dissocial behaviour	15.3	14.6	22.3			
Reduced spare-time activities	63.5	89.1	15.5	***	***	***
Reduced interests/citizen role	33.9	87.7	3.8	***	***	***

\*p<0.05; \*\*p<0.01; \*\*\* p<0.001





**Figure 1** Timepoint of onset of symptoms by five clinical categories in the early course of schizophrenia and depression before first admission (modified from 27)

## ASSESSMENT INSTRUMENTS FOR DETECTING PEOPLE AT RISK

Assessment instruments for detecting people at risk for schizophrenia include screening instruments and early-recognition instruments (78). The aim of screening instruments is to detect in the population the largest possible proportion of persons at an increased risk. These are short interviews mostly designed for use with people seeking help because of mental problems in primary health services. Some are also designed as self-rating questionnaires. A more in-depth risk assessment at specialist mental health services or early intervention centres requires detailed scales for measuring a prodromal syndrome or an incipient psychotic episode. Some instruments also assess subjective distress caused by the symptoms, symptom severity and course over time.

### Screening instruments

The PRODScreen was developed by Heinimaa et al (79) in Finland, on the basis of the Structured Interview for Prodromal Symptoms (SIPS), the IRAOS and the BSABS, for the early recognition of persons at an increased risk for psychosis. It can be used for self rating or as a telephone interview. PRODScreen measures symptoms in general (9 items) and attenuated or full-blown psychotic symptoms (12 items), as well as social functioning (7 items). It is not suitable for the assessment of mood disorders.

The Prodromal Questionnaire (PQ) was developed by Loewy et al (80) as a quick alternative to a complete early-recognition inventory, the SIPS. The PQ consists of as

many as 92 items for prodromal and psychotic symptoms. It is aimed at pre-detecting persons at risk in order to spare negative cases the full-length SIPS.

The Youth Psychosis at Risk Questionnaire (Y-PARQ) (81) was designed for identifying at-risk persons at the prepsychotic prodromal stage before they reach an UHR status. Y-PARQ asks 92 questions on positive, affective and negative symptoms of prodromal schizophrenia. It is also valid for recognizing mood disorders. The instrument has been tested on children and students.

Within the PRIME, the early intervention programme of the McGlashan group, two screening instruments have been developed: the SIPS screen and the Early Screening Test for Schizophrenia and Psychosis. The SIPS screen was developed by Miller et al (82) for screening persons at an increased risk for psychosis. Twelve items attained a sensitivity of .90 and a perfect specificity in a sample of 36 patients compared with the SIPS evaluation. The Early Screening Test for Schizophrenia and Psychosis is a 7-point scale for measuring psychotic thought disorder, paranoid and other delusional experiences as well as perceptual abnormalities. It was designed for detecting first-episode psychosis and is available in the Internet.

The Early Recognition Inventory based on the IRAOS (ERIRAOS) (62) is a 2-tier early recognition inventory, which consists of a screening instrument, Checklist (CL), and a Symptom List (SL) for detecting persons at an increased risk for psychosis or mood disorder. The 17-item CL can be used as an interview or a questionnaire in primary health services. It measures changes in the most distressing symptoms and documents a family history of schizophrenia and pre- and perinatal complications. A weighted cut-off score indicates

an increased risk for psychosis or mood disorder and the necessity for referral to a specialist mental health service for further assessment by means of the SL.

### Early-recognition instruments

The Comprehensive Assessment of At-Risk Mental States (CAARMS) (83) is designed for the prospective assessment of sub-threshold psychotic symptoms in UHR groups (59). Besides the UHR criteria, it assesses indicators for transition to psychosis. It permits the reconstruction of the development from attenuated and frequently fluctuating symptoms to a full-blown psychosis. The dimensions measured are: disorders of thought content (TC), perceptual abnormalities (PA), conceptual disorganization (CD), motor disturbances (MD), disorders of emotion and affect (EA), impaired energy (E) and impaired tolerance to normal stress (S). Hence, the focus lies on psychotic stages or stages close to psychosis onset.

The SIPS is a semi-structured interview related to the SIPS Screen (82) mentioned above. Psychosis is diagnosed by the Scale of Prodromal Syndromes (SOPS). The SIPS/SOPS measures, on a six-point severity scale, a group of five psychotic symptoms, a group of six negative symptoms and a group of four disorganization symptoms. Also the severity of current symptoms (6 points) and that of prepsychotic symptoms (5 points) are measured. It does not assess changes in psychopathology. Designed for the purpose of identifying incipient psychosis, the instrument is less suitable for assessing prepsychotic prodromal stages or the risk for mood disorders.

The BSABS (67) assesses self-perceived “basic symptoms”, mental problems at the prepsychotic prodromal stage or close to psychosis onset. The BSABS comprises subscales on “dynamic deficiency”, “disturbances of thought, perception and motor action”, “coenaesthesias”, “disturbances of the central autonomic nervous systems” and “sleep disturbances”.

On the basis of this instrument, Schultze-Lutter and Klosterkötter (84) developed the Schizophrenia Prediction Instruments – Adult Versions (SPI-A), designed for the assessment of seven groups of basic symptoms: overstrain, emotional deficits, cognitive impediments, cognitive disturbances, “body perception” disturbances, perception and motor disturbances and “estrangements”. Gradients of change in symptom development or risk for mood disorders are not assessed. The instrument is aimed at and has been successfully validated on patients with schizophrenia and persons at a high risk for psychosis (84).

The IRAOS (17) and the ERiraos were developed within the ABC Schizophrenia Study (3) for the assessment of the onset and early course of schizophrenia. The IRAOS includes sections on “social biography”, “pathways to care” and an empirically generated list of 65 symptoms (17). The instrument, later expanded to include symptoms

of mood disorders, permits the assessment of symptom onset and duration in the early illness course.

The ERiraos, based on the IRAOS, is designed for use after the screening instrument CL. It includes 70% of the IRAOS symptoms, supplemented by selected items from other validated early-recognition instruments. It comprises a total of 110 signs, subsumed in 12 symptom groups. To map the course of symptom development, also symptom severity and changes therein are rated on a monthly basis. Subjective distress is assessed in the month of interview. The ERiraos permits the assessment of the prepsychotic prodromal stage, of the affective and the schizophrenic symptom dimensions and of course or changes over time.

### CONCLUSIONS

Research into the early course of schizophrenia has identified a prepsychotic prodromal stage (mean duration: 4.8 years) and a psychotic prephase (mean duration: 1.3 years). Comparisons of individually matched samples have demonstrated prodromal symptoms common to schizophrenia and moderate to severe depression. It is not until positive symptoms emerge that psychosis and mood disorders become distinguishable from each other. The onset of both disorders is marked by depressive mood. In a risk period of 3 to 5 years, an increase in depression and anxiety as prodromal symptoms is associated with a higher, their decrease with a lower risk for psychosis. Depression can be seen as an integral part of the disease process leading to psychosis. In both disorders the prodromal stage early produces functional impairment and related social consequences. Hence, early intervention is of great public health relevance and gives hope of ameliorating illness symptoms and the consequences involved.

Early intervention is targeted at manifest symptoms and not at the underlying, still unknown disease process. Cognitive-behavioural therapy at the prepsychotic prodromal stage seems to favourably influence the short-term illness course. In the psychotic prephase, a combination with low-dose antipsychotics seems to have some efficacy. Long-term effects have not yet been demonstrated.

The aim of early recognition by the instruments discussed in this paper is to permit the identification of the largest possible proportion of at-risk persons as early as possible and their referral to appropriate treatment. Early recognition centres should focus not only on the psychotic prephase and risk for schizophrenic psychosis, but also on providing early recognition and intervention in mood disorders.

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# Quality of life in mental disorders: challenges for research and clinical practice

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*The term quality of life (Qol) has become a rallying cry for all those who strive to integrate patients' subjective experience of their life during illness into clinical care. With its intuitive appeal, Qol seems to be understood by everyone involved in managing health and disease. However, when examining the ever increasing research literature, it becomes clear that many methodological questions still beset this field, since neither a commonly accepted definition nor a gold standard for measuring Qol exist. On the contrary, one is irritated by the myriad of different instruments and it remains questionable how valid and comparable research results obtained with different instruments are. It is argued that, especially when attempting to measure Qol in mental disorders: a) in addition to "subjective", also "objective" (i.e., external) assessment is needed; b) the inclusion of psychopathological symptoms in Qol instruments has to be controlled for; c) in addition to well-being and satisfaction, also functioning and environmental assets have to be assessed; d) different life areas have to be considered separately, and e) changes over time have to be taken into account. A concluding section in the paper reflects on the still largely missing transfer of research results into clinical care.*

**Key words:** Quality of life, well-being, satisfaction, measurement, mental disorders

In the scientific medical literature, the term Qol is used with many different meanings and refers to an only loosely related body of work on psychological well-being, social and emotional functioning, functional performance, life satisfaction, social support, etc. It seems that all non-medical aspects of disease are subsumed under the umbrella term of Qol, without a generally accepted definition, and it is justified to conclude that Qol is a term describing a *field* of interest rather than corresponding to a *single variable* – much in analogy to the term “disease” – and that there is no simple way of measuring Qol, just as there is no simple way of measuring disease. Nevertheless, year by year, literally thousands of scientific medical publications are forthcoming purporting to measure a single entity called Qol.

The present article explores the tension between the common sense meaning of Qol and the attempts to pin it down to a measurable concept – with the laudable motive of adding the much needed human aspect to the ever increasing preponderance of technological aspects in medicine, thereby using the same scientific approach as biological clinical research, namely quantification, operationalization and clinical trials, commonly regarded as the evidence based approach to obtaining knowledge in the field of medicine (1).

This undertaking is still beset by numerous methodological pitfalls and biases which often make findings difficult to interpret and sometimes lead to wrong conclusions. After briefly describing the rise of the Qol concept in medicine, the main part of this article will therefore discuss these methodological challenges for Qol research in relation to mental health. Also, since the necessary link between quality of life research and medical practice is still weak – with a tendency of ‘l’art pour l’art’ research dominating in academic environments, and marketing research in industrial ones – a concluding section will deal with new developments in the mental health field which may pave the way for integrating the Qol approach into clinical practice.

## THE RISE OF THE QUALITY OF LIFE CONCEPT IN MEDICINE

The concept of Qol has its main roots outside the health care field, in the positive psychology movement (2) and in social indicator research of the 1960s and 1970s (3). In medicine, it started to be used indirectly in the 1980s in what has been called health status research, when, among others, instruments for assessing social functioning (such as the Short Form-36, SF-36) were developed (4).

The first documented use of the term in the medical literature dates 40 years back. In a 1966 article on transplantation medicine, Elkinton criticizes medicine as doing the “tuning with unprecedented skill” but having “trouble with the harmony”, and goes on to ask: “What is the harmony within a man, and between a man and his world – the *quality of life* – to which the patient, the physician, and society aspire?” (5).

Over the following two to three decades, the numbers of medical publications on Qol rose only slowly. Since the early 1990s, in nearly all fields of medicine a tremendous increase can be observed. According to a Medline search, more than 7000 papers were published on Qol in 2004, a more than threefold increase over 1995.

As a way of stressing the psychosocial aspects of diseases, the Qol concept seems to have replaced the notion of the “biopsychosocial model of disease”, proposed by Engel in 1977 (6) to counterbalance the deficiencies of the “reductionist” biomedical model. Today the “biopsychosocial model of disease” has not reached anything like such a wide acceptance in the medical literature as the Qol concept (7).

The medical specialty where the Qol concept gained first prominence was oncology, where, with the arrival of “aggressive” treatments, the question arose whether one should trade off a longer survival time (with unpleasant treatments) for a better quality of life (without treatment).

"I'd rather die with my own hair on", says a character in David Lodge's novel "Paradise News", when asked why she refuses chemotherapy for cancer. In psychiatry, similar issues have been prevalent for a long time. The question whether "the cure is worse than the disease" arose, for instance, in asylum psychiatry (8), as well as in the treatment of schizophrenia with conventional neuroleptic drugs (9).

Angermeyer and Kilian have recently reviewed the QoL concepts used in the literature and have distinguished three models (10): a) the "subjective satisfaction model" (the level of QoL experienced by an individual depends on whether or not his/her actual living conditions meet his/her needs, wants, and wishes) (11); b) the "combined subjective satisfaction/importance model" (which gives different weights to different life domains) (12); and c) the "role functioning model" (the individual enjoys a good quality of life if he/she performs adequately and his/her needs are satisfied appropriately) (13). The authors go on to present their own "dynamic process model of QoL" with the interacting components of the environment, the person and cognitive adaptation processes (10).

Albrecht and Fitzpatrick (14) have identified four uses of the QoL concept in relation to medicine: a) as an outcome measure in clinical trials and health services research; b) for assessing the health needs of populations; c) for the planning of clinical care of individual patients, and d) for resource allocation. Of these, the first two relate to research, which will be discussed below.

## RESEARCH AND MEASUREMENT

Today QoL measures are increasingly employed as an outcome variable in clinical drug trials, not the least because regulatory authorities are asking for this type of information (15-17). A similar use as outcome measure can be found in health services research (18,19). Moreover, studies describing QoL in various diagnostic groups, in clinical settings and in epidemiological surveys, are increasing in number and are usually carried out with the purpose of demonstrating how large the "burden" of a specific mental disorder is. A number of methodological assessment issues have still to be resolved, though, before definite conclusions can be reached in these areas.

### The "subjective" vs. "objective" issue

In the health care field, the term QoL has become a rallying cry for all those who strive to integrate patients' subjective experience of their life during illness into clinical care, mainly by relying on patients' *subjective* assessment of their QoL (20,21). In somatic medicine, this is fully appropriate, since a subjective view of this kind had been neglected by medicine for a long time. Corresponding to this notion, most QoL assessment methods are either straight-

forward self-rating scales or, if applied as an interview, explicitly pick up the patient's point of view. This emphasis of today's medical QoL research on subjectivity and on individual persons' well-being and satisfaction with life (or specific life domains), as well as on the individual's perception of his/her daily functioning, is more related to the happiness than to the social indicator research tradition.

When dealing with mental disorders, this widely accepted position of concentrating on the subjective perspective of the patient is prone to measurement distortions. Reports about subjective well-being often tend to simply reflect altered psychological states, as Atkinson et al (22) and Katschnig et al (23) have shown for depression. In addition, subjective reports about functioning in social roles and about material and social living conditions may be distorted for several reasons, which can be called "psychopathological fallacies" and which cannot be easily corrected. These include the "affective fallacy", the "cognitive fallacy", and the "reality distortion fallacy".

The most relevant of these fallacies is the *affective* one, since it tends to be overlooked and might lead to wrong conclusions (23). It has been shown that people use their momentary affective state as information in making judgements of how happy and satisfied they are with their lives in general (24). A depressed patient will usually see his/her well-being, social functioning, and living conditions as worse than they appear to an independent observer (25,26) or to himself/herself after recovery (27). The opposite is true for a manic patient who, quite naturally, rates his/her subjective well-being as excellent, but also evaluates social functioning and environmental living conditions as unduly favourable.

Mechanic et al (28) have shown that depressed mood (in addition to perceived stigma) is a powerful determinant of a negative evaluation of subjective QoL in patients suffering from schizophrenia (29). Both in research and clinical practice, the affective fallacy can lead to wrong conclusions. For instance, in general medicine, QoL measures might disguise the presence of a comorbid depression which, as a consequence, might not be discovered and therefore not treated (30). In research on the effectiveness of antidepressant drugs, the very improvement of symptoms implies that the patient views the self, the world, and the future more positively (25); this will automatically show up in a QoL instrument measuring subjective well-being and satisfaction with life, leading investigators to conclude that a specific drug does not only improve symptoms but also QoL – which in some sense is true, but is basically a tautological statement.

The *reality distortion* and *cognitive* fallacies are less problematic, since they are more readily recognized. At times, patients suffer from delusions and hallucinations, which distort their perception of themselves and their surrounding. Taking a deluded or hallucinating patient's judgement on his/her quality of life as granted would constitute the *reality distortion fallacy*. The *cognitive fallacy* concerns wrong evaluations by patients who are unable to

assess intellectually their life situation, as is the case, for instance, in dementia and mental retardation.

Thus, while the patient's own view seems to be *necessary*, the question arises whether the subjective view is *sufficient* to assess Qol in persons suffering from a mental disorder. Becker et al (12,31) contend that, in the field of psychiatry, Qol assessment has to be carried out not only via the patient, but also via professional helpers and key informants, as a rule family members and friends. Accordingly, in addition to a patient version, the authors provide also a "professional" and a "carer" version of their Wisconsin Quality of Life Index (W-QLI). There is empirical evidence for this position: Sainfort et al (32) have demonstrated that such assessments differ between patients and their relatives. It has also been shown that persons suffering from schizophrenia, when moved from a mental hospital to the community, showed no improvements in life satisfaction ratings, despite "objectively" improved living conditions and increased leisure activities (33,34).

These observations warrant the conclusion that additional evaluations by professionals and by family members and friends are necessary to complement the patient's own subjective assessment. However, assessment by other persons is not *per se* objective, and the term "objective" may be misleading. "External assessment" is probably more appropriate than "objective assessment", since such an evaluation might reflect the subjective view of the assessors themselves.

This Qol assessment issue brings into the forefront a basic problem of psychiatry – the necessity to reflect the different viewpoints which exist in society, e.g. about whether a psychiatric disorder is present or not and whether something should be done about it or not. Most often, there is disagreement on this matter between the patient, his family, professionals, and the society at large, and such disagreement should at least be documented (35). In practice, however, even if one acknowledges the necessity to include the "external" perspective, this cannot be easily achieved, if the relevant resources are not available.

### **Psychopathological symptoms and measures of well-being: a case of measurement redundancy**

The above issue becomes even more salient in the light of the next problem. Most Qol instruments used in medical patients contain "emotional" items, mostly relating to the field of depression and anxiety. Some authors even speak of an "emotional-function domain" or of a "pleasant affect" versus "unpleasant affect" component (2). Here, the psychological tradition of measuring quality of life by "well-being measures" becomes tautological, since, if the item content of both measures is largely overlapping, Qol measures are necessarily correlated with measures of psychopathology.

The use of Qol as an outcome measure in clinical trials and evaluative studies has increased over recent years, but

– given the lack of a clear-cut definition and the very broad concept of Qol – there is a danger that therapeutic strategies are promoted on the basis of ill-demonstrated benefits for Qol itself. One example is the Quality of Life Scale (QLS) (36), which has often been applied in clinical trials of the atypical antipsychotics to show improvement in Qol. An analysis of the item content of the QLS shows that it mainly describes negative symptoms. Another example is the Quality of Life in Depression Scale (QLDS) (37), which is made up mainly of depressive symptoms (23). A cautionary stance should therefore be taken by regulatory bodies (which increasingly demand that a new drug is not only improving symptoms but also Qol) that it is not just a new label (Qol) which is glued on an old bottle (symptoms).

If Qol is studied in the mental health field, it is strongly recommended to always control for the presence of psychopathological items in Qol instruments used for a specific study, i.e. to check the correlations found between Qol measures and psychopathological symptoms for possible spuriousness because of simple item overlap. Also, when studying Qol in somatic disorders, at least depressive and anxiety symptoms should be assessed, in order to evaluate their possible impact on the Qol measures. This is especially important in view of the high comorbidity of somatic with mental disorders, especially if the former are chronic (30).

### **Beyond well-being: functioning and environmental assets**

If Qol is to be assessed in persons suffering from mental disorders, the exclusion of contextual factors from many Qol measures is an even greater problem.

Calman (38) has elegantly defined quality of life as "the gap between a person's expectations and achievements". This gap can be kept small in two ways: living up to one's expectations or lowering these expectations. Lowering one's expectations is an adaptational psychological process. Happiness research has shown that most people are happy and that, by and large, this does not depend a great deal on environmental factors (2). Obviously, a large gap between expectations and achievements is not easily bearable, and most people lower their expectations (or don't have too high expectations to start with). Otherwise, the finding that people living in Detroit and Madras, the rich and the poor, the young and the old, are on average equally happy, could not be explained.

It has also been noted that many persons suffering from long-term mental disorders report themselves satisfied with life conditions which would be regarded as inadequate by external standards. It seems that these persons lower their standards over time and thus keep the gap between expectations and achievements narrow: if one cannot possibly achieve one's aims, these aims are changed, a phenomenon which could be called "standard drift fallacy".

Nevertheless, it is true that "achievements" do not

depend only on subjective factors, but also on the actual opportunities available in one's environment. If Qol assessment is to lead to specific actions, then the inclusion of environmental factors seems necessary. It is contended here that Qol, understood in this way, has to be differentiated at least according to three components: psychological well-being/satisfaction, functioning in social roles, and contextual factors (both social and material).

The need to include contextual factors into the assessment of Qol is especially pressing in the case of persons suffering from mental disorders, where such factors interact with the patient's disorder more than in somatic disorders. Income, social support, and living conditions (also called "standard of living") can be intimately related to psychopathology (39).

The needs assessment approach in social psychiatry brings in the environment (40,41). Also, community psychiatry as such is including the environment into its spectrum of helping activities. Working with family members, providing a day structure, offering jobs, are only a few such examples. Katschnig et al (23) have developed an action-orientated framework for assessing quality of life in depressed patients, which includes the aforementioned three components of well-being/satisfaction, functioning in social roles and contextual factors. They give examples of how helping activities could be classified according to these components: some act on psychological well-being (e.g., antidepressants), some on role functioning (e.g., social skills training), and some on environmental circumstances (e.g., providing money or housing). Also, public health programmes aiming at the promotion of mental health and improvement of the Qol of whole populations do in fact take all these factors into consideration (42).

### **Qol profile vs. global Qol measures**

Keeping patients with persisting mental disorders in mental hospitals might have had the advantage of fulfilling the most basic human needs (physiological such as food and security such as shelter), but higher human needs (like that for autonomy) were neglected in these settings (43). On the other hand, in the era of community psychiatry, patients with persisting mental disorders do have the possibility of gaining autonomy, but often at the possible expense of not getting their basic human needs fulfilled.

Psychiatric patients have the specific problem of being stigmatized when they declare themselves as being mentally ill, which seems necessary if they want to obtain the means for survival, including their additional needs for treatment (drugs, social security benefits, etc.). Such stigma jeopardises autonomy, since patients are excluded from society, while they want to be "one of us", as qualitative research shows (44). Many psychiatric patients are thus in a no-win situation as far as the fulfilment of their needs is concerned, and many give up some of their expectations

and "cut their coat to their cloth" (45).

In addition to having specific additional needs for treatment, psychiatric patients are disadvantaged since they usually have fewer resources to cope with life problems, fewer social and cognitive skills, and fewer environmental assets, especially money. In many studies on the quality of life of patients with schizophrenia in the community, lack of money is a prominent complaint, probably because it stands for autonomy.

From this discussion it becomes clear that single Qol measures are not appropriate, given the many different needs and the different importance attached to different life domains by different patients (12). A Qol profile is more appropriate (46). For planning interventions and assessing outcome in a single patient and in clinical trials, a structured multi-dimensional use of the Qol concept is necessary, which covers different specific life domains, such as work, family life, money, etc. Some psychiatric Qol instruments separate such domains from each other – e.g., the Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q) (47) and the W-QLI (12) – while others do not. For economic evaluation, a single index might be convenient, but this approach simplifies matters to such a degree that it becomes more difficult to understand what the figure obtained actually means (48).

Instruments for assessing patients' needs are in fact multi-dimensional, like the Needs for Care Assessment instrument of the Medical Research Council Unit in London (MRC-NCA) (40) and the Camberwell Assessment of Need (CAN) (41), implying that different actions are necessary for different needs in different life areas. A specific Management Orientated Needs Assessment instrument (MONA) following these lines has actually been developed by Amering et al (49) in Vienna. This instrument also covers the possibility that the patient regards some life areas as more important than others in terms of actions to be taken.

### **Qol and time**

Health related Qol assessments usually refer to a specific point in time or time period. However, there are quite a few time aspects involved when making such assessments.

First, the question arises whether the meaning of Qol remains the same in an individual person over time. As has been shown by Bernhard et al (50), the meaning of Qol does not remain constant over time in patients who undergo treatment for severe diseases. In particular, the weight given to Qol domains changes over distinct clinical phases. Also, Morgado et al (27) found that, after remission, depressed patients re-assess their social adjustment as having been wrongly evaluated too negatively while they were still in their depressive episode.

Secondly, each of the three different components of quality of life – subjective well-being and satisfaction with different life aspects, objective functioning in social roles,



and environmental living conditions (standard of living, social support) – has different time implications. Subjective well-being, which is largely dependent on the actual affective state, can fluctuate quickly. Functioning in social roles may break down rather quickly, though it more often takes some time. Environmental living conditions – both material and social – change only slowly in most cases. Thus, a depressed patient whose subjective well-being declines quickly while depression is worsening, may still go on to function in his/her social roles. Even if this person does break down in functioning, the material living conditions and social support might still be unchanged for some time. On the other hand, once social functioning has deteriorated due to the long duration of the disease, while environmental assets, both material and social, have diminished, a patient might recover quickly in his psychological well-being, but not in social roles functioning. Also, it might take some time before environmental living conditions are re-established, if they are at all.

Thus, if Qol is equated with “subjective well-being”, then “changes in quality of life” might be observed after short psychopharmacological intervention. However, if functioning in social roles is being considered, the chances are less clear-cut that drugs might lead to quick improvement. Finally, if social support and material living conditions are to improve again, it will probably take much longer and need other than psychopharmacological interventions.

A third, more complex time issue can best be characterized by the “gap” between a person’s expectations and achievements described by Calman (38). If this gap is small, Qol is high. In this perspective, for each person, the issue arises of what is more important to him/her: a good quality of life today or one tomorrow, i.e. keeping the gap narrow now or tomorrow? There are numerous ways for persons suffering from mental disorders of achieving a short-term harmony between expectations and achievements, the use of quickly acting psychotropic substances (such as tranquilizers or alcohol) being the most common of these. In the long term, of course, substance abuse might develop and lead to a widening of this gap, following a vicious circle which implies decreased psychological well-being, loss of functioning in social roles, and deteriorating environmental and social living conditions. In the era of the predominant use of the first generation neuroleptics, patients experienced exactly this dilemma: while the prophylactic use of neuroleptics decreased the frequency of relapses, the side effects were often so disturbing that many patients were in the dilemma of having to choose between sustaining the side-effects “now” (i.e., the immediate “costs”) and then have a good quality of life “tomorrow” (i.e., the future benefits), or not experiencing side effects “today”, and having an increased risk of relapse “tomorrow”. It seems that quite a few patients preferred the “better quality of life now” *versus* the “better quality of life tomorrow” (9). The new atypical antipsychotics might change this situation.

## FROM ASSESSMENT TO ACTION

Today, in clinical trials and health services research, Qol measures are often included in order to *describe effects* of treatments or of special ways of delivering these treatments; but, as a rule, they are not themselves a *target of intervention*. In this respect some new developments are under way which may have long reaching consequences for the whole health field, including not only treatment and rehabilitation, but also prevention, and finally also promotion of health.

The use of Qol instruments in everyday clinical practice to improve clinicians’ awareness of patients’ disabilities and general well-being, while having been judged as uncommon in the early 1990s (51), seems to gain ground now. One reason for this development is the advent of computer assisted monitoring in clinical practice (52-54). Needs assessment instruments for patients suffering from mental disorders, such as the MRC-NCA or the CAN, might thus find their way into clinical routine (40,41).

Other developments can be observed which might contribute to supplementing the traditional disease-oriented clinical paradigm not only in research but also in daily practice by a Qol approach. For instance, Frisch (55) coined the concept of “quality of life therapy”, which he links to specific assessments by his structured Quality of Life Inventory (QOLI), i.e. the Qol *assessment* is taken as a basis for specific Qol *interventions*, meaning interventions that focus on enhancing Qol – in a similar way as a psychiatrist elicits psychopathological symptoms, makes a diagnosis and then decides which specific psychiatric treatments to be used. The difference in Frisch’s approach (which he exemplifies for the case of depression) is his focus of action on Qol instead of symptoms (56).

Another new development in clinical settings which focuses on interventions on non-disease aspects is so-called “motivational interviewing” (MI) (57). MI aims at changing life styles of patients and is used mainly in the substance abuse field, but increasingly also in other health fields (58).

While in MI the term Qol is not directly used, one could nevertheless say that this technique aims at improving Qol. The same holds true for some ongoing activities in the mental health care field. The so-called recovery movement *de facto* also puts emphasis on Qol interventions, without calling them as such (59,60). In Vienna we have developed management tools and services for improving Qol in persons suffering from mental disorders including their families. A new psycho-educational tool for use in schizophrenia focuses as much on Qol issues as on disease aspects (61), and a family-orientated residential facility (“Pension Bettina”) functions as a “school for living with schizophrenia” (62). These and similar programmes – e.g., patients, caregivers and professionals discuss, outside the traditional familial therapeutic and institutional context, the experiences and consequences of psychosis and ways to cope (“dialogue”) – emphasize empowerment, advocacy, and self-help (63). This philosophy is in line with the principles

of “promotion of mental health”, which can also be regarded as a means of improving quality of life in whole populations – in healthy persons, in those at risk for, and in those already suffering from a mental disorder (42).

Obviously, activities are going on and still developing in the field of mental health care, which regard QoL as equally important as disease aspects. The request of QoL data by regulatory authorities for new pharmacological treatments to be admitted to the market is also a sign of increasing awareness of QoL needs of persons suffering from mental disorders.

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# Should general psychiatry ignore somatization and hypochondriasis?

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*This paper examines the tendency for general psychiatry to ignore somatization and hypochondriasis. These disorders are rarely included in national surveys of mental health and are not usually regarded as a concern of general psychiatrists; yet primary care doctors and other physicians often feel let down by psychiatry's failure to offer help in this area of medical practice. Many psychiatrists are unaware of the suffering, impaired function and high costs that can result from these disorders, because these occur mainly within primary care and secondary medical services. Difficulties in diagnosis and a tendency to regard them as purely secondary phenomena of depression, anxiety and related disorders mean that general psychiatry may continue to ignore somatization and hypochondriasis. If general psychiatry embraced these disorders more fully, however, it might lead to better prevention and treatment of depression as well as helping to prevent the severe disability that may arise in association with these disorders.*

**Key words:** Somatization, hypochondriasis, diagnosis, somatoform disorders, depression

Somatoform disorders have been described recently as “one of the most controversial and challenging areas of modern psychiatry” (1). In spite of this claim, psychiatrists and health service planners tend to neglect these disorders (2,3). They are not usually included in national surveys of mental health and unmet need (4-6), and accurate estimates of burden have not been established (3). This brief review aims to examine some of the reasons underlying this state of affairs.

## DIAGNOSTIC DIFFICULTIES

One main reason why somatization disorder has been omitted from population-based surveys is its apparent rarity. The original DSM-III definition of the disorder was so restrictive that only 15 people out of a general population-based sample of 3798 were found to have the disorder (prevalence of 0.38%) (7). This, together with the prolonged questioning required to establish it, probably accounts for the fact that the diagnosis has been dropped from most subsequent national surveys.

In fact, a systematic review found that the prevalence of somatization disorder and hypochondriasis, as defined by DSM-III, was so low in population-based or primary care samples that researchers could not examine associated features reliably (8). Instead, many researchers abandoned the DSM-III diagnosis of somatization disorder in favour of more practical definitions such as abridged somatization (4 somatoform symptoms in men and 6 in women) or multisomatoform disorder (9,10). Subsequently, the DSM-IV allowed a diagnosis of “undifferentiated somatoform disorder”, in which one or more medically unexplained symptoms lead to distress or impairment.

This multiplicity of definitions has led to wide variation in the prevalence of somatization disorder. For example, in a primary care study, less than 1% of patients met DSM-IV criteria for somatization disorder, 6% met abridged criteria,

24% met the criteria for multisomatoform disorder and 79% met the criteria for undifferentiated somatoform disorder (11). These proportions are similar to those reported in two systematic reviews (8,12). Other studies have found a prevalence of ICD-10 somatization disorder of 2.7-10.1% in primary care (13,14). This lack of consensus about the diagnosis and its prevalence does not encourage planners of population-based surveys to include somatization disorder. Much work remains to be done to establish the appropriate number of symptoms and associated impairment to define the disorder satisfactorily.

A similar situation pertains to the diagnosis of hypochondriasis. This also appears to be rare in non-specialist settings, so that alternative diagnostic criteria have been developed (8). One study found that 2% of primary care patients met diagnostic criteria for hypochondriasis, but 14% were bothered by the thought of having serious undiagnosed disease (15). In fact, disease conviction alone is an independent predictor of both impaired functioning and medical help seeking (16,17) and “abridged” hypochondriasis is no less disabling than the full diagnosis of hypochondriasis even after controlling for concurrent depression (17). On this basis, subthreshold hypochondriasis was included in a trial of cognitive behavioural therapy for hypochondriasis (18).

The relationship between illness worry and health anxiety is not clear, and some researchers have used a definition that includes both the number of somatic symptoms as well as disease fear, bodily preoccupation, and disease conviction (19).

The concept of “disorder” in relation to somatization and hypochondriasis has to be established in the light of the fact that both the number of bodily symptoms and illness worry are distributed continuously in primary care or population-based samples. There is a linear relationship between the number of bodily symptoms and impairment and healthcare use (15,20,21), though this may not be so for illness worry (21). In the light of present knowledge, the precise cut-off points which are clinically useful in pri-

mary and secondary care are not clear. Any new diagnostic classification (e.g., DSM-V) should encourage further research rather than, like the DSM-IV, artificially impose a cut-off which may later prove to be incorrect.

## CONCURRENT ANXIETY AND DEPRESSIVE DISORDERS

Although there is good evidence that depression and anxiety are closely associated with the number of somatic symptoms (22), two large studies in primary and secondary care found that medically unexplained symptoms as a whole were not associated with these psychiatric disorders (23,24). Even one third of those patients attending primary care who report five or more medically unexplained symptoms do not have a psychiatric disorder (25). In secondary care medical clinics, where medically unexplained symptoms are more common (35-50% of all attendees), two-thirds do not have anxiety, depressive or related disorders (21,24,26-28). So, it is quite wrong to think of numerous somatic symptoms solely as a manifestation of depressive or anxiety disorders, and these data do not support the notion that somatization disorder does not really exist and can be subsumed into anxiety and depression disorders (29). Even more compelling is the fact that successful treatment of somatization or hypochondriasis with cognitive behavioural therapy or antidepressants is not necessarily accompanied by a significant reduction of anxiety and depression (30-32).

This notion came about because an early definition of somatization required the presence of a psychiatric disorder underlying the somatic symptoms (33) and influential studies of somatization in primary care identified patients with depressive and anxiety disorder who presented somatic symptoms to the general practitioner (33,34). This method of patient recruitment does not include the many primary care patients who have “medically unexplained” symptoms but do not have anxiety and depressive disorders (12).

The real importance of concurrent anxiety and depressive disorders in relation to somatization and hypochondriasis is that the associated impairment of functioning is greater when both occur concurrently – the two types of disorder appear to be additive in their effect on functioning (35). If the concurrent depressive disorder is successfully treated, functioning improves (36).

It must be recognized, therefore, that the relationship of anxiety and depression with somatization or hypochondriasis is complex. We can recognize at least three groups of patients with somatization or hypochondriasis. In one group the bodily symptoms or preoccupation are accompanied by anxiety or depression, and when the latter is successfully treated the somatic symptoms improve. A second group also has concurrent anxiety or depression, but successful treatment of the latter may lead to improved functioning while the somatic symptoms change little (30,32,36,37). A third group have definite somatization or hypochondriasis, but do

not have concurrent anxiety or depression; the cognitive or perceptual changes which underlie somatization or hypochondriasis occur alone.

## WHY SHOULD GENERAL PSYCHIATRY PAY MORE ATTENTION TO SOMATIZATION?

There are several reasons why general psychiatry should be more interested in somatization and hypochondriasis.

First, some general psychiatrists and public health doctors are concerned about the high prevalence and poor treatment of depressive disorder. They need to be aware that depressive disorder occurring in conjunction with numerous somatic symptoms is less likely to be recognized and treated than depression that presents psychologically (38,39). Secondly, there is some evidence that somatization may precede the onset of depressive disorder (40), and paying more attention to marked somatization in primary care may provide us with a rare opportunity to prevent the onset of depressive disorder. Third, somatization and illness worry are independent predictors of frequent attendance at primary care – even after depression and anxiety are controlled (16,41,42). We need to understand the reasons for this as it may help reduce the burden of these disorders on the healthcare system.

Lastly, the aetiologies of somatization and depression are closely allied but not identical. Therefore, research about the causes of somatization and depression together may be more informative than research into depression alone. For example, there are preliminary findings that somatization and depression may be genetically and environmentally distinct, but with overlapping genetic predisposition (43) and a different relationship with stress – adversity being associated with somatization and depression with other life events (44). New onsets of somatoform conditions, which include somatization, have been associated with female gender, lower social class, the experience of any substance use, anxiety and affective disorder, and traumatic sexual and physical threat events (45). Understanding in more detail the independent and overlapping risk factors for depression and somatization will help us to develop more effective interventions.

An example is found in reported history of sexual abuse. This is said to be a risk factor for somatization as well as depression, but we do not know whether it is a risk factor for “pure” somatization, i.e. that which occurs without concurrent depression. On the other hand, it does appear that somatization mediates the association between reported history of sexual abuse and frequent healthcare use more precisely than depression, suggesting that there may be a specific link between abuse and sensitivity to bodily symptoms (46,47). Furthermore, we found that both reported abuse and depression independently predicted increased pain threshold when improvement in severe irritable bowel syndrome patients occurred following psychotherapeutic or

antidepressant treatment (48). Many of these patients fulfilled the criteria for somatization disorder.

In fact, the evidence concerning childhood adversity as a risk factor for somatization or hypochondriasis is conflicting (49,50), and such adversity may predict a person's response to bodily symptoms (leading to persistent symptoms and marked functional disability) rather than their onset (51).

## RECENT RESEARCH FINDINGS

Several myths regarding somatization have been overturned by recent research, indicating the need for a fresh look at the phenomenon.

Previous research has considered somatization primarily in relation to bodily symptoms which are "medically unexplained, disabling and/or lead to medical help seeking". This alone could have accounted for the association with functional impairment and healthcare use of many previous studies. In fact, the number of bodily symptoms and degree of illness worry are associated with impairment and healthcare use whether they are medically explained or not (16,21,52,53); the relationship is a general one and not confined to patients with medically unexplained symptoms.

It has long been thought that somatization disorder and hypochondriasis were chronic disorders, but in primary care both disorders resolve in approximately 50% of people over a year (8). As mentioned above, resolution may be associated with reduction of anxiety and depressive symptoms, but this is not a consistent finding (8,54).

The traditional idea that somatization is more common in developing, rather than developed, cultures has not stood up to scrutiny, with high incidence rates being reported from European and South American centres in a World Health Organization study (54).

Patients with somatization or related disorders differ from those with an anxiety or depressive disorder in the attribution of their symptoms to "organic", "bodily" or external causes, such as a germ, virus, environment, ageing or genetic vulnerability (55-58). Patients with both somatoform and depressive or anxiety disorders have both psychological and "organic" attributions. A change from somatic to psychological attribution has been associated with improved outcome (59), whereas persisting dysfunctional somatic attributions in irritable bowel syndrome patients have been associated with continuing frequent medical consultations (60). If we understood better how these attributions develop, we would be in a much better position to treat people successfully.

Recent qualitative research suggests that general practitioners' responses to patients' symptoms, rather than patients' demands, may underlie the ordering of investigations for organic disease, which carry the potential to reinforce somatic attributions (61). This may provide an opportunity to prevent persistent somatization.

## CONCLUSION

The material reviewed above supports the notion that somatoform disorders are one of the most controversial and challenging areas of modern psychiatry (1). These disorders are particularly challenging to psychiatrists exposed only to patients who have become severely disabled by chronic disorder. Under these circumstances psychiatrists often protest that early intervention might have prevented numerous secondary problems. Such early intervention will not be achieved unless general psychiatrists who also work in primary or secondary general medical care encourage medical and nursing staff to adopt early and appropriate management of all patients who present numerous bodily symptoms or marked illness worry.

The challenges presented to research are also formidable. Longitudinal, population-based studies are necessary if we are to understand the risk factors for these disorders and their associated features of impaired functioning and high healthcare use. At present such studies are very limited. Better diagnostic accuracy is essential, and it is to be hoped that the authors of DSM-V draw upon the appropriate expertise and most up-to-date research in formulating sensible criteria to avoid the mistakes of DSM-IV (62). Further treatment studies are needed, but these need to be carefully designed to account for the different degrees of severity seen in primary and secondary care (63) and in patients with and without concurrent depressive disorders. It is to be hoped that the growth of knowledge in this area will encourage more multidisciplinary research groups to include these disorders in their research endeavours.

Until the clinical and research effort is greatly increased, somatization and hypochondriasis will remain a major public health concern because of considerable unmet need. It will be unfortunate if these disorders only receive attention because of the high health costs they incur – the suffering experienced by so many people deserves help in its own right. No other group is likely to research and improve the care of this group of people. Therefore psychiatrists, who understand much about their unmet need, should take up the challenge.

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# Psychiatric rehabilitation today: an overview

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*All patients suffering from severe and persistent mental illness require rehabilitation. The goal of psychiatric rehabilitation is to help disabled individuals to develop the emotional, social and intellectual skills needed to live, learn and work in the community with the least amount of professional support. The overall philosophy of psychiatric rehabilitation comprises two intervention strategies. The first strategy is individual-centered and aims at developing the patient's skills in interacting with a stressful environment. The second strategy is ecological and directed towards developing environmental resources to reduce potential stressors. Most disabled persons need a combination of both approaches. The refinement of psychiatric rehabilitation has achieved a point where it should be made readily available for every disabled person.*

**Key words:** Psychiatric rehabilitation, severely mentally ill, sheltered housing, supported employment, case management, assertive community training

The goal of psychiatric rehabilitation is to help individuals with persistent and serious mental illness to develop the emotional, social and intellectual skills needed to live, learn and work in the community with the least amount of professional support (1). Although psychiatric rehabilitation does not deny the existence or the impact of mental illness, rehabilitation practice has changed the perception of this illness. Enabling persons with persistent and serious mental illness to live a normal life in the community causes a shift away from a focus on an illness model towards a model of functional disability (2). Therefore, other outcome measures apart from clinical conditions become relevant. Especially social role functioning – including social relationships, work and leisure as well as quality of life and family burden – is of major interest for the mentally disabled individuals living in the community.

## THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH

Long-term consequences of major mental disorders might be described using different dimensions. A useful tool was provided by the International Classification of Impairment, Disability and Handicaps (ICIDH), first published by the World Health Organization in 1980 (3). The ICIDH has been recently revised. The revised International Classification of Functioning, Disability and

Health (ICF) (4) includes a change from negative descriptions of impairments, disabilities and handicaps to neutral descriptions of body structure and function, activities and participation. A further change has been the inclusion of a section on environmental factors as part of the classification. This is in recognition of the importance of the role of environmental factors in either facilitating functioning or creating barriers for people with disabilities. Environmental factors interact with a given health condition to create a disability or restore functioning, depending on whether the environmental factor is a facilitator or a barrier.

The ICF is a useful tool to comprehend chronically mentally ill in all their dimensions, including impairments at the structural or functional level of the body, at the person level with respect to activity limitations, and at the societal level with respect to restrictions of participation. Each level encompasses a theoretical foundation on which a rehabilitative intervention can be formulated. Interventions can be classified as rehabilitative in the case that they are mainly directed towards a functional improvement of the affected individual. As such, the nature of an intervention is defined by the goal which is addressed by the intervention.

## TARGET POPULATION

Although the majority of the chronically

mentally ill have the diagnosis of schizophrenic disorders, other patient groups with psychotic and non-psychotic disorders are targeted by psychiatric rehabilitation. Today all patients suffering from severe mental illness (SMI) require rehabilitation. The core group is drawn from patients with persistent psychopathology, marked instability characterized by frequent relapse, and social maladaptation (5).

There are other definitions currently used to characterize the chronically mentally ill (6). They all share some common elements, i.e. a diagnosis of mental illness, prolonged duration and role incapacity.

Up to 50% of persons with SMI carry a concomitant diagnosis of substance abuse (7). The so-called young adult chronic patients constitute an additional category that is diagnostically more complicated (8). These patients present complex patterns of symptomatology difficult to categorize within our diagnostic and classification systems. Many of them also have a history of attempted suicide. All in all they represent an utmost difficult-to-treat patient population.

## CONCEPTUAL FRAMEWORK

The overall philosophy of psychiatric rehabilitation in mental disorders comprises two intervention strategies. The first strategy is individual-centred and aims at developing the patient's skills in

interacting with a stressful environment. The second strategy is ecological and directed towards developing environmental resources to reduce potential stressors. Most disabled persons need a combination of both approaches.

The starting point for an adequate understanding of rehabilitation is that it is concerned with the individual person in the context of his or her specific environment. Psychiatric rehabilitation is regularly carried out under real life conditions. Thus, rehabilitation practitioners have to take into consideration the realistic life circumstances that the affected person is likely to encounter in his or her day-to-day living (9).

A necessary second step is helping disabled persons to identify their personal goals. This is not a process where those persons simply list their needs. Motivational interviews provide a more sophisticated approach to identify the individuals' personal costs and benefits associated with the needs listed (10). This makes it also necessary to assess the individuals' readiness for change (11,12).

Subsequently the rehabilitative planning process focuses on the patient's strengths (9). Irrespective of the degree of psychopathology of a given patient, the practitioner must work with the "well part of the ego" as "there is always an intact portion of the ego to which treatment and rehabilitation efforts can be directed" (13). This leads to a closely related concept: the aim of restoring hope to people who suffered major setbacks in self-esteem because of their illness. As Bachrach (9) states, "it is the kind of hope that comes with learning to accept the fact of one's illness and one's limitations and proceeding from there".

Psychiatric rehabilitation cannot be imposed. Quite the contrary, psychiatric rehabilitation concentrates on the individual's rights as a respected partner and endorses his or her involvement and self-determination concerning all aspects of the treatment and rehabilitation process. These rehabilitation values are also incorporated in the concept of recovery (14). Within the concept of recovery, the therapeutic alliance plays a crucial role in engaging the patient in

his or her own care planning (15). It is essential that the patient can rely on his or her therapist's understanding and trust (16), as most of the chronically mentally ill and disabled persons lose close, intimate and stable relationships in the course of the disease (17). Recent research has suggested that social support is associated with recovery from chronic diseases, greater life satisfaction and enhanced ability to cope with life stressors (18). Corrigan et al (19) have found that the most important factor facilitating recovery is the support of peers. Therefore, psychiatric rehabilitation is also an exercise in network building (20).

Finally, people with mental disorders and their caregivers prefer to see themselves as consumers of mental health services with an active interest in learning about mental disorders and in selecting the respective treatment approaches. Consumerism allows the taking of the affected persons' perspective and seriously considering courses of action relevant for them (21). In this context, physicians should also acknowledge that disagreement about the illness between themselves and the patient is not always the result of the illness process (22).

## CURRENT APPROACHES

As a general rule, people with psychiatric disabilities tend to have the same life aspirations as people without disabilities in their society or culture (23). They want to be respected as autonomous individuals and lead a life as normal as possible. As such they mostly desire: a) their own housing, b) an adequate education and a meaningful work career, c) satisfying social and intimate relationships, and d) participation in community life with full rights.

### Housing

The objective of psychiatric reforms since the mid 1950s has been to resettle chronically mentally ill persons from large custodial institutions to communi-

ty settings. Providing sheltered housing in the community for the long-term patients of the old asylums was one of the first steps in the process of deinstitutionalization. Most long-stay patients can successfully leave psychiatric hospitals and live in community settings (24).

Ideally, a residential continuum (RC) with different housing options should be provided. RC ranges from round-the-clock staffed sheltered homes to more independent and less staffed sheltered apartments which eventually allow individuals moving to independent housing in the community (25). Critics of RC contended that: a) up to date RC is rarely available in communities, b) RC does not meet the varying and fluctuating needs of persons with serious mental illnesses, and c) RC does not account for individuals' preferences and choices. Supported housing, i.e. independent housing coupled with the provision of support services (26), emerged in the 1980s as an alternative to RC. Supported housing offers flexible and individualized services depending on the individual's demands. In the meantime, rehabilitation research could demonstrate that supported housing is a realistic goal for the majority of people with psychiatric disabilities (27). Once in supported housing, the majority stay in housing and are less likely to become hospitalized. Other outcomes do not yield consistent results (27).

### Work

The beneficial effects of work for mental health have been known for centuries (28). Therefore, vocational rehabilitation has been a core element of psychiatric rehabilitation since its beginning. Vocational rehabilitation is based on the assumption that work does not only improve activity, social contacts etc., but may also promote gains in related areas such as self-esteem and quality of life, as work and employment are a step away from dependency and a step to integration into society. Enhanced self-esteem in turn improves adherence to rehabilitation of individuals with impaired insight (29).

Vocational rehabilitation originated in psychiatric institutions, where the lack of activity and stimulation led to apathy and withdrawal of inpatients. Long before the introduction of medication, occupational and work therapy contributed to sustainable improvements in long-stay inpatients. Today occupational and work therapy are not any longer hospital-based, but represent the starting point for a wide variety of rehabilitative techniques teaching vocational skills (5).

Vocational rehabilitation programs in the community provide a series of graded steps to promote job entry or re-entry. For less disabled persons, brief and focused techniques are used to teach how they can find a job, fill out applications and conduct employment interviews (30). In transitional employment, a temporary work environment is provided to teach vocational skills, which should enable the affected person to move on to competitive employment. But all too often the gap between transitional and competitive employment is so wide that the mentally disabled individuals remain in a temporary work environment. Sheltered workshops providing pre-vocational training also quite often prove a dead end for the disabled persons.

One consequence of the difficulties in integrating mentally disabled individuals into the common labour market has been the steady growth of cooperatives, which operate commercially with disabled and non-disabled staff working together on equal terms and sharing management. The mental health professionals work in the background, providing support and expertise (2).

Today, the most promising vocational rehabilitation model is supported employment (SE). The work of Robert Drake and Deborah Becker decisively influenced the conceptualization of SE. In their "individual placement model", disabled persons are placed in competitive employment according to their choices as soon as possible and receive all support needed to maintain their position (31,32). The support provided is continued indefinitely. Participation in SE programs is followed by an in-

crease in the ability to find and keep employment (33,34). Links were also found between job tenure and non-vocational outcomes, such as improved self-esteem, social integration, relationships and control of substance abuse (32,35,36). It was also demonstrated that those who had found long-term employment through SE had improved cognition and quality of life, and better symptom control (32,36).

Although findings regarding SE are encouraging, some critical issues remain to be answered. Many individuals in SE obtain unskilled part-time jobs. Since most studies only evaluated short (12-18 months) follow-up periods, the long-term impact remains unclear. Currently we do not know which individuals benefit from SE and which do not (37). After all, we have to realize that the integration into the labour market does by no means only depend on the ability of the persons affected to fulfil a work role and on the provision of sophisticated vocational training and support techniques, but also on the willingness of society to integrate its most disabled members.

### **Building relationships**

In recent years, social skills training in psychiatric rehabilitation has become very popular and has been widely promulgated. The most prominent proponent of skills training is Robert Liberman, who has designed systematic and structured skills training since the mid 1970s (38). Liberman and his colleagues packaged the skills training in the form of modules with different topics. The modules focus on medication management, symptom management, substance abuse management, basic conversational skills, interpersonal problem solving, friendship and intimacy, recreation and leisure, workplace fundamentals, community (re-) entry and family involvement. Each module is composed of skills areas. The skills areas are taught in exercises with demonstration videos, role-play and problem solving exercises and in vivo and homework assignments (39).

The results of several controlled studies suggest that disabled individuals can be taught a wide range of social skills. Social and community functioning improve when the trained skills are relevant for the patient's daily life and the environment perceives and reinforces the changed behaviour. Unlike medication effects, benefits from skills training occur slowly. Furthermore, long-term training has to be provided for positive effects (31,40-42). Overall, social skills training has been shown to be effective in the acquisition and maintenance of skills and their transfer to community life (39,43,44).

### **Keeping relationships**

As a consequence of deinstitutionalization, the burden of care has increasingly fallen on the relatives of the mentally ill. Informal caregiving significantly contributes to health care and rehabilitation (45). Fifty to ninety per cent of disabled persons live with their relatives following acute psychiatric treatment (46). This is a task many families do not choose voluntarily. Caregiving imposes a significant burden on families. Those providing informal care face considerable adverse health effects, including higher levels of stress and depression, and lower levels of subjective well being, physical health and self-efficacy (47). Additionally, not all families are equally capable of giving full support for their disabled member and willing to replace insufficient health care systems. Caregivers regularly experience higher levels of burden when they have poor coping resources and reduced social support (48). But families also represent support systems, which provide natural settings for context-dependent learning important for recovery of functioning (49). Therefore, there has been a growing interest in helping affected families since the beginning of care reforms (50).

One area of interest deals with the expectations of relatives concerning the provision of care. Relatives quite often feel ignored, not taken seriously and also feel insufficiently informed by health professionals. They also may feel that their

contribution to care is not appreciated or that they will be blamed for any patient problems. It is no surprise that there is a lot of frustration and resentment among relatives considering the physical, financial and emotional family burden.

Family intervention programs have produced promising results. Family interventions are effective in lowering relapse rate and also in improving outcome, e.g. psychosocial functioning (51). Possibly, family interventions can reduce family burden. Furthermore, the treatment gains are fairly stable (52). But we also have to appreciate that it is not clear what the effective components of the different models are (53). Additionally, family interventions differ in frequency and length of treatment. There are also no criteria for the minimum amount of treatment necessary.

Finally, we have to be aware that most family interventions were developed in the context of Western societies during deinstitutionalization. Family caregiving might be quite different in a different cultural context. This refers to other cultures in total as well as to minority groups in Western societies (45,48,54).

### **Participation in community life with full rights**

As practitioners, we are often confronted with the deleterious effects of stigma and discrimination in the lives of people with serious mental illnesses. Numerous studies have examined stigmatizing attitudes toward people with mental illness (55-62). In recent years, the scientific interest in the perspective of the labeled individual has increased too. There is extensive empirical evidence of the negative consequences of labeling and perceived stigmatization. These include demoralization, low quality of life, unemployment and reduced social networks (63-67). Once assigned the label "mental illness" and having become aware of the related negative stereotypes, the affected individuals expect to be rejected, devaluated or discriminated. This vicious cycle decreases the chance of recovery and normal life.

On the other hand, well-integrated

people with mental illness exhibit better outcomes regarding psychopathology and quality of life (68). The importance of social integration is underlined even more when considering the subjective availability of support: perceived social support predicts outcome in terms of recovery from acute episodes of mental illness (69), community integration (70), and quality of life (35,71,72).

On the basis of comprehensive research in this area during the last decade, several strategies have been developed to fight the stigma and discrimination suffered by those who have mental illnesses (73). Different research centres developed interventions directed to specific target groups relevant for destigmatization, e.g. students (74) or police officers (75). Persons in contact with mentally ill individuals quite often have a more positive attitude. Contact with the mentally ill persons also reduces social distance (62), which is a strong argument in favour of community psychiatry. Other initiatives have targeted stigma by means of more comprehensive programs. The WPA launched one of the internationally best-known programs in 1996 (76). All these initiatives make clear that efforts in re-integrating persons with serious mental illness into community life must be accompanied by measures on the societal level.

### **DEVELOPING ENVIRONMENTAL RESOURCES**

Effective psychiatric rehabilitation requires individualized and specialized treatment, which has to be embedded in a comprehensive and coordinated system of rehabilitative services. But, even when a variety of services are available, they are poorly linked in many cases, and costly duplication may occur.

While developing community support systems, it became obvious that there was a need to coordinate and integrate the services provided, as each involved professional concentrates on different aspects of the same patient. Therefore, as a key coordinating and integrating mechanism, the concept of case management (CM) originated. CM

focuses on all aspects of the physical and social environment. The core elements of CM are the assessment of patient needs, the development of comprehensive service plans for the patients and the arrangement of service delivery (77).

Over the past two decades, a variety of different models of CM have been developed which exceed the original idea that CM mainly intends to link the patient to needed services and to coordinate those services. Today, most clinical case managers also provide direct services in the patient's natural environment. This model is called intensive case management (ICM). ICM is difficult to distinguish from assertive community treatment (ACT).

Stein and Test have developed the basic components of ACT in the 1970s (78). The original program was designed as a community-based alternative to hospital treatment for persons with severe mental illnesses. A comprehensive range of treatment, rehabilitation and support services in the community is provided through a multidisciplinary team. ACT is characterized by an assertive outreach approach, i.e. interventions are mainly provided in the natural environment of the disabled individuals (79).

Research on CM and ACT yielded "mixed" results (80). While the traditional office-based CM approach obviously is less successful, the ACT model was found to be more beneficial when compared with standard care (81). ACT can reduce time in hospital (37), but has moderate or only little effects on improving symptomatology and social functioning (82). The differing features of the respective services might explain the international variation. Six regularly occurring features of successful services were identified: smaller case loads, regularly visiting at home, a high percentage of contacts at home, responsibility for health and social care, multidisciplinary teams and a psychiatrist integrated in the team (83).

### **THE ROLE OF THE PSYCHIATRIST IN REHABILITATION**

The final ingredient of a successful

ACT approach, namely a psychiatrist integrated in a community team, inevitably leads to the question: what is or can be the role of a psychiatrist in rehabilitation? According to Cancro (84), "A properly trained psychiatrist will be able to prescribe psychosocial interventions, such as social skills training, as well as prescribe medication. This does not mean that the individual psychiatrist should be able to do everything from social skills training to vocational rehabilitation to psychoeducation to family support. It does mean, however, that the psychiatrist must know what is needed and where it can be found and must be able to play a role in directing a team of professionals who can serve these patients. Not only will the patients benefit from such an approach but so will our discipline".

Psychiatric rehabilitation is by its very nature multidisciplinary, because of the many different competencies required (85). It goes without saying that monitoring medication is a key task of the psychiatrist. But pharmacotherapy in psychiatric rehabilitation needs some special consideration. Symptom control does not necessarily have the highest priority, as some side effects of pharmacological treatment can weaken a person's ability to perform his or her social roles, and impair vocational rehabilitation. As such, it is no surprise that non-compliance with medication taking is one of the most serious problems in the long-term treatment of persons with serious mental illness (86). Many patients living in the community want to take responsibility for their medication themselves. Training in self-management of medication (87) emphasizes patients' autonomy and increases acceptance of and responsibility for treatment. This also includes the change of medication without consultation within certain limits.

As a matter of course, most psychiatrists do not acquire all relevant skills needed in psychiatric rehabilitation during their training, which is predominantly hospital-based. Young psychiatrists today are primarily trained in diagnostic procedures and prescription of medications directed almost exclusively

to symptom control, and not trained in integrating pharmacological and psychosocial interventions (88). Another side effect of hospital-based training is that young psychiatrists are confronted with the negative developments of difficult-to-treat patients who are frequently re-hospitalized. This is possibly one of the reasons why we found that psychiatrists in institutional settings do not hold fewer stereotypes of mentally ill people than the general population, nor display a greater willingness to closely interact with mentally ill people (89). Therefore, it would be beneficial if the community training of young psychiatrists could take priority over hospital-based training. More training opportunities to experience the patients in the "real world" would allow psychiatrists in institutional settings to develop a more positive perspective and better understanding of persons with severe and persistent mental disorders.

## OUTLOOK

Up to date, major developments in psychiatric treatment and care have evolved from psychiatric rehabilitation. This is the most visible part of psychiatric care and as such represents the link to society. The attitude of the public towards psychiatry is mostly influenced by what rehabilitation accomplishes or not. In fact, the US President's Freedom Commission on Mental Health (90) declared that helping affected persons to achieve functional recovery is the main purpose of the mental health care system.

The refinement of psychiatric rehabilitation has achieved a point where it should be made readily available for every disabled person. But we have to be aware that there is a long way between research and practice. Lehman and Steinwachs (91), for example, assessed the patterns of usual care for schizophrenic patients and examined the conformance rate with the treatment recommendations based on existing scientific evidence. The conformance rate was modest, generally below 50%. It seems to be obvious that

current treatment and rehabilitation practice has to be substantially improved in the light of the rehabilitation research available.

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# Caveats for psychiatric rehabilitation

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Psychiatric rehabilitation has come of age, as Rössler has amply illustrated in his fine overview of the current status of the field. However, as with any new treatment approach, broad, summary statements may fail to capture the considerable individual variation in response to psychiatric rehabilitation. Rössler suggests that evidence-based practices are indicated for all persons needing psychiatric rehabilitation. This is a misconception popularized by wholesale acceptance of research findings as though they would meet the needs of all patients regardless of their individual attributes. By their very definition, evidence-based practices are validated by large-scale studies in which means, standard deviations and statistical tests of mean differences between treatment conditions obscure differences between individuals that have profound implications for choice of treatment. Decisions about the type and amount of treatment must be made for each individual, considering their uniqueness, responses to prior treatments and phase of their illness. "One suit does not fit all". Evidence-based treatments should be carefully selected and adapted for each individual.

For example, assertive community treatment – one of the most popular evidence-based practices – is helpful to individuals who are high utilizers of hospital care and who are reluctant to voluntarily attend a mental health center or clinic. However, for the thousands of patients who have successfully reached a stable phase of their disorder, assertive community treatment is likely to be viewed as unnecessary, intrusive and not desirable. If rehabilitation practices

such as social skills training and behavioral family therapy are used, patients are more self-directed and do very well with much less intensive forms of continuing treatment.

Contrary to Rössler's imperative regarding rehabilitation, not "all patients suffering from severe mental illness require rehabilitation". Again, we must assess each patient as an individual to make sure that the rehabilitation prescription is congruent with the person's history, severity and phase of illness, assets, deficits and aspirations. Individuals who have had a good premorbid adjustment, do not have concurrent substance abuse, serious negative symptoms or cognitive impairments and possess effective social skills can recover from schizophrenia and bipolar disorders without *comprehensive and intensive rehabilitation* once their intrusive symptoms are removed by appropriate medication (1).

In these cases, treatment can be streamlined to periodic medication reviews with a psychiatrist and supportive therapy to assist patients to realize their personal goals. Other basic elements that can be readily accomplished in league with pharmacological stabilization of symptoms are three-six months of education of the patient and family about benefits and side effects of medication, self-directed use of medication, negotiation of medication issues with the psychiatrist, recognition of warning signs of relapse and development of a relapse prevention and emergency plan. The knowledge and skills for illness management can be taught in three-six months, with refresher sessions as needed, using the Medication and Symptom Management Modules, components of the UCLA Program for Social and Independent Living Skills (2,3). In short, individualization of assessment and treatment is essential for determining each patient's personal goals, need for skills training, family intervention, vocational rehabilitation and community re-integration (4).

This brings us to Rössler's statement that "rehabilitation planning focuses on the patient's strengths, irrespective of the degree of psychopathology". In line with

clinical realities, rehabilitation must begin concurrently with pharmacological efforts to remove symptoms and deviant behaviors that interfere with learning skills and living in normal community settings. There should be no distinction made between "treatment" and "rehabilitation". Surveys have documented that patients report persisting symptoms as their highest priority for treatment. Separating the rehabilitation from the treatment function is both fatuous and harmful. Rehabilitative interventions, such as motivational interviewing and family communication, can be used to engage the patient with psychotic symptoms to accept medication (1,2).

Another rehabilitation intervention during the acute and stabilizing phases of a serious mental disorder is the Community Re-Entry Module. This educational and skill building program is useful for establishing continuity of care from inpatient to outpatient phases. The program teaches patients in hospitals and day treatment programs illness management skills as well as how to re-engage in community life, deal with the stressors of life after discharge and make connections with long-term, outpatient treatment (5). Pharmacotherapy and psychosocial rehabilitation are inseparable. They are two sides of the same coin (6).

As pointed out by Rössler, the Individual Support and Placement (IPS) method of supported employment is the best evidence-based service for vocational rehabilitation for the seriously mentally ill. However, it has distinct limitations that practitioners and patients must understand to avoid unrealistic expectations in planning for competitive work. Less than 50% of the seriously mentally ill elect to participate in IPS. Consistent with individualization of treatment and rehabilitation, there are other options for the non-participants, including transitional employment (1,2) and psychosocial rehabilitation offered in the context of day treatment centers (7).

While cumulatively 40-55% of mentally ill persons enrolled in IPS who express a strong interest in working obtain jobs, over 50% of them are no longer



working by six months after placement. In fact, research indicates that only 10-40% who participate in IPS are working in competitive jobs at any one time during a year after beginning the program (8). Moreover, only about 25% of the patients in supported employment studies suffer from schizophrenia; the remainder have bipolar disorder, depressive disorders or personality disorders. Over an 18-month period, patients enrolled in supported employment showed no significant increase in self-esteem, mood or quality of life (9). A new skills training program, the Workplace Fundamentals Module, when combined with IPS, has yielded longer tenure for patients working in competitive jobs (10).

Rössler's overview of the current status of psychiatric rehabilitation is comprehensive and clearly and cogently written. It should be disseminated widely to mental health professionals, the vast proportion of whom have little or no understanding of rehabilitation. However, a section on illness management (11), now considered an evidence-based practice for rehabilitation, should be ideally added. Psychiatrists must realize they have an important role to play in rehabilitation. Medication can never teach patients anything, including why and how to properly use medication. Without having the benefit of a motivating, educational, skills-based and family oriented therapeutic relationship, psychiatrists will continue to prescribe medications with attrition and non-adherence rates becoming the norm rather than the exception (12).

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# The underutilization of psychiatric rehabilitation

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Rössler's paper is an excellent summary of what has been the traditional understanding of the term "psychiatric rehabilitation". The focus of the paper is on the patients who suffer from severe and persistent mental illnesses. As the author points out, most of these cases carry the diagnosis of schizophrenia, but other categories of psychiatric illness are included as well. He defines the goal of psychiatric rehabilitation as to assist these disabled individuals to develop better emotional, social, and intellectual skills that are necessary to function in the real world. The task is to maximize their functioning and to minimize their dependency on institutional settings and/or organizations. Concepts such as sheltered housing and supported employment permeate the paper, because this has been the traditional target population for psychiatric rehabilitation. It is as if the population of psychiatric patients is divided into two categories: the severe and persistent illnesses and those who can expect full recovery. Clinical

experience suggest otherwise.

Many patients, who would not be described as persistently ill, nevertheless display residual functional aberrations. They may, for example, remain somewhat anxious and phobic in particular situations, not enough so to be disabled, but enough so to be uncomfortable. They may have to use avoidance or other strategies to minimize their discomfort. In other words, there is some residual impairment of functioning which may not achieve the level of a serious and persistent mental illness but, nevertheless, goes beyond full recovery. While clinical experience varies among clinicians and settings, it must be recognized that many patients do not achieve a full resolution of symptoms. They may well be recovered in the sense of being no different than they were pre-morbidly, but pre-morbidly they may well have had symptomatology, which while not disabling was also not nonexistent.

The basic patient-centered and environmentally-centered approaches remain equally valid for this large group of potential beneficiaries. In many settings, this group of patients is treated pharmacologically with very little in the way of psychosocial intervention. The

pendulum has swung too far. The depressed patient who responds to a pharmacologic agent but who continues to live his/her life in the same fashion remains at risk for a relapse. The assessment of that patient's lifestyle and the relative presence or absence of psychosocial support is critical to the future well-being of the patient. Careful evaluation of how the patient is living and the changes that should be made to improve the prognosis cannot be rendered with a prescription for a drug. The critical assessment of the patient's environment and the guidance of that patient to make changes in the environment are essential. It is equally essential that the patient change his/her self-image. If they do not see themselves as deserving of love and respect, they will not expect

let alone demand it. If they see themselves as only useful to others, but not worthy, this too will be damaging to the prognosis. We can see clearly how the patient-centered and environmentally sensitive approaches are necessary in a condition which we do not usually consider to be a chronic, let alone severe and persistent mental disorder.

Virtually every mental disorder has some impact on the quality of the patient's life. It cannot be a mental illness without some involvement of thinking and feeling. When these higher mental functions are impacted negatively, there will be a broad range of adaptive consequences. Many of these existed in the person's life long before the onset of a diagnosable illness. Yet, to leave these components of the clinical syndrome

untreated is a clinical error.

Whether one prefers to utilize a term other than "rehabilitation" is a question more of semantics than of meaning. The ultimate task of the clinician is to improve the quality of the patient's life, wherever such improvement can be made. The clinician's interventions should not be restricted to merely the more severe manifestations of the disorder, but also extend to what can be conceptualized as predisposing and/or accessory features. It is the role of the psychiatrist to fulfill the function of being both the physiologic and the psychological healer. It is only the psychiatrist who is trained and competent in both areas and who can bring the mixture of skills necessary to achieve the maximum benefit for the patient.

## The diffusion of two successful rehabilitation models

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Rössler's article outlines the future direction for rehabilitation psychiatry. I will add some comments on two rehabilitation models – one American and one European – which have proven successful and are diffusing strongly in different parts of the world: the psychosocial clubhouse and the social firm. Though not discussed in Rössler's article, they are likely to play an increasingly important role in psychiatric rehabilitation.

*Psychosocial clubhouses* like Fountain House, in New York City, and Thresholds, in Chicago, have gained prominence by establishing a model in which people with mental illness are involved in running a programme that meets many of their recreational, social and vocational needs. In the clubhouse setting, clients are referred to as "members" and work with staff in running operations – e.g., putting out the club-

house newsletter, preparing and serving food, and staffing the reception desk. The clubhouse is open evenings, weekends and holidays, providing a refuge for people who may live in cramped, cheerless housing. Clubhouses are located separately from the mental health agency, and psychiatric treatment is not part of the programme. The emphasis instead is on developing work skills and job opportunities for the members.

Fountain House was founded in 1947 by ex-patients of Rockland State Hospital and for 30 years was the only one of its kind, enjoying an international reputation and entertaining hundreds of visitors each year. In 1976, Fountain House launched a national training program and in 1988 a national expansion effort. The International Center for Clubhouse Development was established in 1994 (1). By 2003, there were over 300 certified clubhouses worldwide: 191 in the USA, 29 in Scandinavia, 23 in Canada, 22 in the British Isles, and others in Australasia, Japan, Korea, Germany and Russia (2).

Foremost among the basic components of the clubhouse model is the so-called "work-ordered day", a structured 8-hour day in which members and staff work side-by-side on clubhouse work units. New members need not volunteer for work until they feel ready but, being assigned to a work group upon enrolment, gentle pressure to become involved is ever present. Another crucial element of the model is the democratic decision-making. Members and staff meet in open session to discuss policy and planning; no staff-only or member-only meetings are permitted. Those who are familiar with the "therapeutic community" model from the 1960s and 1970s will recognize the rehabilitative potential of transferring power from treatment providers to the person with mental illness in this way. Other components are employment programs, such as transitional or supported employment, and community support for members (1,2).

The attractions of the model for people with mental illness, most of whom are not well-off, include good food; a comfortable social environment; a sense of community and mutual support; empowerment, which flows from the democratic philosophy; and access to employment. Observers point to cer-

tain weaknesses, however. The clubhouse movement has conducted almost no randomized control trials and consequently has a weak evidence base. There is, also, a cult-like quality to the clubhouse movement which, for some service organizers, is an obstacle to adoption.

*Social firms* are businesses created with a dual mission: to employ people with disabilities and to provide a needed product or service. The model was developed for people with mental illness in Italy in the 1970s and, by diffusion, has gained prominence in Europe. In Trieste, Italy, origin of the first social firms, the annual income of the health-service cooperatives in 2004 amounted to \$14 million and several additional social firms had been established by non-governmental agencies. The Hotel Tritone, one of the original businesses, has proven particularly successful and a hotel franchising venture is planned. All office- and street-cleaning contracts for the municipality of Trieste are currently awarded to social firms. Over 300 people with mental illness are employed in the Trieste cooperatives as full-wage workers or as trainees.

The first German social firm was founded in 1978: by 2005 there were over 500 such companies in Germany with a combined workforce of 16,500, 50% being disabled. These non-profit companies commonly produce foods, technical products, or services like moving and house-painting (3). Prior to 1997, there were just six social firms in Britain. Since then, the number has grown to 49 financially independent businesses, plus 70 “emerging” social firms that still require a subsidy. In 2005, British social firms were employing over 1,500 people, two-thirds being disabled, mostly with mental disabilities. Catering and horticulture are the largest business sectors (4). Technical assistance provided by Italian and German support organizations to Social Firms UK, another support entity, has fostered this growth (3). Independent of European influence, social firms have also developed in Canada and the US. Virtually all of the psychiatric work rehabilitation services in Toronto, Ontario, are offered

through social firms, and most of these businesses are operated solely by people with mental illness. Social firms have also been developed in Japan and Korea, free of European influence.

The success of individual social firms is enhanced by locating the right market niche, selecting labour-intensive products, the public orientation of the business, and links with treatment services. The growth of the social-firm movement is aided by an advantageous legal framework, policies favouring employment of the disabled, and support entities that facilitate technology transfer. Advantages of the social-firm model include opportunities for empowerment, the development of a sense of community in the workplace, and worker commitment resulting from the organization’s social mission.

Time will tell if these rehabilitation models will continue to diffuse at the same rate as recently. If they do, they will become substantial elements of rehabilitation psychiatry in the future.

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# Identifying psychiatric rehabilitation interventions: an evidence and value based practice

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Psychiatric rehabilitation is a field that is over thirty years old, rooted in the principles of physical rehabilitation, with its own knowledge base, philosophy and interventions (1-3). Rössler’s article does an excellent job in reviewing the basic concepts and characteristics of psychiatric rehabilitation and some of the evidence based interventions or program models that have, rightly or wrongly, come to be associated with it.

Value based medicine has emerged as a twin concept to evidence based medicine and acknowledges the importance of the patient’s perception of the relevance of an intervention (4). Value based practice for individuals with serious mental illnesses starts with the notion that recovery, or the taking back/

regaining of a *meaningful* life (1,5), has become not only scientifically possible (6), but also is perceived as *the* relevant mission for services (6-8). The overall purpose of a psychiatric rehabilitation service, as compared to other types of services, is to contribute to this outcome by enhancing functioning in a role valued by society and selected by the individual (1). The fundamental values of psychiatric rehabilitation, as integral an element of the field of rehabilitation as its evidence base, include the critical importance of empowerment and choice, partnership, hope, a focus on an individual’s strengths and interests as well as limitations, and an outcome or results orientation, among several others (3,9).

Whether or not a particular intervention is considered to be a rehabilitation intervention, therefore, is not defined by the simple fact that it focuses on skills or supports for individuals with serious

mental illnesses. It is defined rather by its contribution to the primary outcome of enhanced functioning in a valued role *and* the congruence of the value base of the intervention itself. Is the person more able to be successful and satisfied as a mother, tenant, landlord, lawyer, janitor or student as a result of the intervention offered? Or is the intervention effective only at improving grooming skills? Is grooming the critical skill to become a student? Is skills training used to manage symptoms? It has long been clear that there is only a weak correlation between symptoms and role functioning (1,10,11): improving symptom management, while critically important to treatment outcomes, is not, therefore, a rehabilitation intervention. Those case management interventions that are effective in preventing rehospitalization and maintaining stability, but not in achieving a valued role, are also not rehabilitation interventions.

Equally, practices that include effective interventions not congruent with the value base of rehabilitation are not, strictly speaking, psychiatric rehabilitation. Interventions that are imposed on individuals, as Rössler points out, are not consistent with rehabilitation. Individuals cannot be subtly coerced into participating in rehabilitation. Engaging individuals depends upon their current state of readiness to begin thinking about a valued role (9). Readiness can be developed, if the individuals are interested but not ready (6,7). Interventions not focused on an individual's choice of role are not consistent with rehabilitation. Interventions that don't assess and build upon the person's strengths and interests are not consistent with rehabilitation. Choice, partnership and hope can be facilitated through processes such as values clarification, problem solving processes and a myriad of other techniques designed to help an individual use his/her strengths and interests to choose, get and keep his/her valued role.

This process can be used in any effective program model (e.g., supported employment) (13) and has been demonstrated to be successful even for the most disabled individuals (1,14,15).

In order to maximize the multidimensional

process of recovery, access to a wide array of services is recommended, if services are used at all (8,16). This requires that psychiatrists be clear about the expected contributions and outcomes of each, to avoid confusion and unmet expectations due to inaccurate labeling of services. Psychiatric rehabilitation services should be those which are effective in facilitating success and satisfaction in valued roles through a process clearly congruent with accepted rehabilitation values.

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# Psychosocial rehabilitation and severe mental disorders: a public health approach

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Ten years ago the World Health Organization consensus statement on psychosocial rehabilitation – the use of the term *psychosocial*, instead of *psychiatric*, must be noted – implied, as indi-

cated by Wulf Rössler in his careful review, a shift from an illness model towards a social functioning model (1). This underlying premise leads to two broad intervention areas: the first is aimed at improving the individuals' competencies, the second is aimed at introducing environmental changes to improve individuals' quality of life. However, in the following years much

more emphasis has been put on the development of individual-based approaches, leading to a narrow view of psychosocial rehabilitation as a set of more or less defined techniques targeted at chronic mental disorders and enlightened by a generic humanitarian concern for the fate of the mentally ill.

Although the development and refinement of effective skill-building intervention models are welcome, we need to strike the balance by reframing the vision of psychosocial rehabilitation as a public health strategy and examining its implications in terms of practice, research and policy.

To this respect, the following key issues can be briefly outlined:

- Psychosocial rehabilitation is not a *technique*. It is a *strategy* operating at the interface between the individual, its interpersonal network and the wider social context.
- The standpoint of psychosocial rehabilitation has to be *humanistic*, not *humanitarian*. The humanistic approach blends together an ethical and a scientific position.
- The target of psychosocial rehabilitation is *functional disability*, not *chronicity*. We have evidence that problems in social functioning can be observed at the first onset of many mental disorders, raising the need for early rehabilitation approaches. Even in acute conditions, such as the post-traumatic stress disorders occurring in the aftermath of disasters, the role of rehabilitation has to be recognized.
- The target of psychosocial rehabilitation are the *psychosocial risk factors* leading to the development and maintenance of social disability related to mental disorders. A growing body of methodologically sound investigations shows the significant role in major mental disorders of social/environmental risk factors, such as migration (2), urban living (3), racial discrimination (4), childhood traumas (5).
- The overarching goal of psychosocial rehabilitation can be summarized under the heading of *social inclusion*. Therefore, attention has to be paid to the *social/interpersonal out-*

*come indicators*, as distinct from clinical outcome (6).

Within this frame of reference, consumers, clinicians, researchers and policy makers have to play their roles. The contributions of psychiatrists will depend on their capacity in developing and strengthening the skills recently indicated by Rosen in his description of the “community psychiatrist of the future” (7). I hope we will be able to meet this challenge.

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# Psychiatric rehabilitation in the era of globalization

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Rössler's paper focuses first on interventions centered on the disabled individuals, aiming to enhance or develop their emotional and social skills, and then on the socio-ecological strategies supporting the rehabilitative process. Ten years ago the consensus statement jointly produced by the World Health Organization and the World Association for Psychosocial Rehabilitation also defined psychosocial rehabilitation as a strategy that facilitates the opportunity for individuals, impaired or disabled by a mental disorder, to reach their optimal level of functioning in the community, by both improving their competencies and introducing environmental changes (1). The psychiatric rehabilitation process focuses primarily on the patient's existing capabilities based on the “well part of ego”, but the restoration of these abilities is not mechanical and linear. Patients' civil rights and aspirations are always taken into account, but their needs of adequate education, work, housing and community

acceptance are often confronted by legal, socio-cultural and economic constraints. Psychiatric rehabilitation interventions and techniques such as case management, social skills training, assertive community treatment and others have been proven to be effective, but their strengths are weakened or even neutralized when the socio-cultural and economic environments are negative or even hostile to the recipients of the psychiatric rehabilitation programs (2,3).

Work is a basic rehabilitation goal and obtaining a job (full or part time) is always a desirable ambition. The question is how to get a job when unemployment rates are high. In most Western states, economic recession is a chronic phenomenon. This could cause difficulties even to supported employment programs. Moreover, the economic recession is always linked with psychosocial programs budget cuts.

Globalization of economy has brought serious economic changes (market economy), increasing unemployment rates (investments are moving to cheap labour countries), privatization of social institutions, high social mobility, transformations in the family structure, and

marginalization of socially disadvantaged groups (e.g., unskilled workers, minority groups and disabled persons).

The growing economic insecurity causes a considerable burden especially to families with a member suffering from serious mental illness. These families are often facing profound economic hardship (4,5). Poverty has a significant negative impact on psychological well-being, self-esteem, health (physical and mental) and the quality of life in general (6). Particularly low levels of quality of life in its various domains (social relations, leisure activities, nutrition, housing) are experienced by individuals suffering from serious mental illness and their family members (7).

Moreover, the ongoing processes of deinstitutionalization of long-stay inpatients are involving the family and the community. When the family and the local community are unprepared or unable to accept the deinstitutionalized patients, those patients are likely to become homeless, or are trans-institutionalized. In these cases, psychiatric rehabilitation sounds ironic.

Apparently the era of globalization is having negative implications for the provision of effective psychiatric rehabilitation programs. The question is whether

the impact of globalization can be eliminated or even "neutralized" for the benefit of the patient and the family. The answer is positive. There are solutions like the empowerment of the international movement of families and users of psychiatric services, with parallel efforts for self-actualization and self-determination of any suffering person. At the community level, the atmosphere could be changed by the systematic implementation of various mental health interventions directed at the modification of the local community's beliefs and attitudes towards the interactions of the mentally ill (8). The encouragement of volunteerism in the field of mental health and the exploitation of any available community resource for food, housing and work could somehow replace the absence of the social welfare state.

Psychiatric rehabilitation is a multi-dimensional and dynamic process, involving three parties: the patient/family, the state and the community. The process is taking place in a specific socio-economic environment, not in a vacuum. Every professional in this field has to be optimistic as well skeptical or critical to the role of the environment as a major factor in the implementation of effective psychiatric rehabilitation.

## Psychiatric rehabilitation and its present role in developing countries

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Psychiatric rehabilitation, or psychosocial rehabilitation as is nowadays more often termed, is a science in psychiatry that has had a limited role in the actual practice of managing mental illnesses. Even in developing countries the emphasis on rehabilitation as a component of managing severe mental illness is often neglected in favour of instituting newer generations of medi-

cines with the premise that these will produce dramatic improvements in symptoms and subsequently in the level of functioning of the patient. This is borne out by the surprisingly limited role of psychiatric rehabilitation in the training programmes for psychiatric residents. With this lack of understanding, emphasis and training in the field of rehabilitation in psychiatry, the World Health Organization came out in 1996 with a consensus statement on psychosocial rehabilitation (1). This statement defines psychosocial rehabilita-

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tion as a process that facilitates for individuals who are impaired, disabled or handicapped by a mental disorder to reach an optimal level of independent functioning in the community. This core statement is further elaborated with objectives through steps that reduce symptomatology by pharmacological and psychosocial means, reduce iatrogeny, improve social competence, reduce discrimination and stigma, and improve family and social support and consumer empowerment.

The aims of psychosocial rehabilitation in developing countries, while largely similar to those in developed countries, have several other important additions (2). The economic problems that affect non-mentally ill persons in developing countries are often made worse by mental illness, which, in the

absence of any national insurance system, unemployment benefits or social security, places a heavy burden on the patient and his or her family. The social stigma of mental illness too is high, as the individual and his or her family become stigmatized in many ways, including the reduced chances of marriage for children or siblings of the ill person. To make matters worse, the opportunities for rehabilitation in developing countries are very much lower, as institutionalized mentally ill patients lack staff trained in basic principles of psychosocial rehabilitation. Even where rehabilitation is practiced, the aims are seldom the same as those described above. Repeated making of baskets or rugs with little incentive or psychological and social measures to improve the quality of life does little to rehabilitate the mentally ill in the true sense of the concept of psychosocial rehabilitation.

In many developing countries, training is rarely available for occupational therapists, psychologists or social workers. Psychiatrists are few, with many countries having 1 psychiatrist for 300,000 to 1 per one million of population. In these circumstances, the psychiatrist is most often occupied by numerous medical, administrative and leadership duties that leave him or her little time to work with rehabilitation units, even if there is one.

There are also other conceptual differences between psychosocial rehabilitation in developed and developing countries. These include the emphasis on housing in developed countries, where individualism, availability of public housing and social insurance help the need for provision of houses for the mentally ill. In developing countries, that of housing is usually not a question, as the mentally ill person's family is expected to look after him or her. It is only the destitute or the abjectly poor or those totally rejected by kith and kin who present as those with housing problems. The focus on recreation, leisure time activities and recreational therapy is also not as acute as is seen in developed countries. The strong family ties and strong sense of religion and culture in many developing coun-

tries contribute to fill up spare time when participation in family centered daily activities is over.

In many developing countries the aim of rehabilitation is not fully understood. This may result in the most difficult and sometimes misdiagnosed mental patients being sent for rehabilitation, in the mistaken impression that somehow the process of rehabilitation by non-doctors will solve the problem. The high cost of the newer medicines with fewer side effects poses major problems in the less well-to-do countries, where all medicines have to be bought without subsidy or through out-of-pocket expenses. Relapses due to poor compliance, because the patient is unable to afford the medicines, contribute to negation of rehabilitative efforts.

While much has been said and written about milieu therapy in psychiatry, the process of rehabilitation is not dependent on the atmosphere or milieu alone. The rehabilitation unit has to be both conducive as well as structured to make the activities help the individual overcome his or her inhibitions and social problems. Mentally ill and particularly severely mentally ill often have had premorbid difficulties with social skills and have psychological conflicts which remain unresolved despite treatment with medicines. The cost-effective way to address these psychological difficulties is to introduce group therapies that offer opportunities to bring about personal growth and change. But skills in conducting group therapy are not easily available in many developing countries whose psychiatrists have had limited training in psychotherapeutic skills in their post-graduate training.

The return of the mentally ill to a functioning and productive state is a crucial goal. In most developing countries, any person who has truly recovered from any illness is expected by his or her family to be productive and fully or at least partly functional. Thus, recovery followed by unemployment or being poorly functional is not only frowned upon but in some may contribute to rejection and additional stigma even within the family. Thus, an important aim of any psychosocial rehabil-

itation is to get the recovering patient back to employment or at least assume a functional and productive role. Any other outcome can be a source of stress to patient and family. In developed countries which expect the state to support the mentally ill through social security arrangements or safety nets, the return to work may not take the same role as in developing countries. Therefore, many rehabilitation programmes in developing countries focus a lot of their energies in getting the mentally ill involved in income generation activities. These include selling of craft work made by patients undergoing rehabilitation, selling of cooked food made by patients, and where possible sale of products from farms run by patients. In the more industrializing countries, simple subcontract work, such as assembly of electrical components or packing of goods from factories, adds to the occupational rehabilitation work. The profits from these sales or industrial work are shared with the patients, which adds to the sense of achievement that rehabilitation activities bring about.

The efforts at rehabilitation of the chronically mentally ill will obviously come to naught if the prevention of relapses is not a part of the rehabilitation process. To this end family and patient education sessions are conducted in many countries now. These include taking family and patient as allies in detection and early prevention of relapses, medication education, discussion on the side effects, and provision of a "hotline".

While psychosocial rehabilitation is an important part of the overall process of successful management of chronic mental illnesses, its importance has not been recognized in many developing countries, and its practice is still rare compared to the use of medicines to "cure" illnesses.

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# Psychiatric rehabilitation today: an African perspective

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Developing countries, such as those in sub-Saharan Africa, face many challenges in trying to establish and offer psychiatric rehabilitation services. Many of these countries cannot commit to health the minimum of US\$ 12 per capita recommended by the World Health Organization (WHO) and also face severe human resource constraints, making the running of a Western style psychiatric rehabilitation service such as that described by Rössler virtually impossible (1,2). Most of the countries on the continent have largely adopted and are in various stages of implementing the primary health care strategy, which emphasizes integration of health services, including mental health, and community involvement, building on the supportive family networks and taking advantage of the rehabilitative resources available in communities (1-3).

Building on the strength of the extended family social support system found in most of the continent, indigenous models of psychiatric rehabilitation have been developed. One such model is the rehabilitation villages in Tanzania, first established in 1969, modeled on the pioneering work by Lambo in the Aro Village in Nigeria (4,5). These Tanzanian rehabilitation villages offer psychiatric services similar to those available in hospitals in an environment intended to duplicate the social and economic milieu of a rural community. The staff who run these villages include agricultural and livestock officers, nurses, nursing assistants, artisans who perform occupational therapy and traditional healers. A psychiatrist and a medical social worker who undertake weekly visits to these villages work with the local therapeutic team and the patients and their relatives on formulating and implementing a rehabilitation plan for each patient (5). A

major drawback of these psychiatric rehabilitation "villages" is their inability to co-exist with urban centres.

Civil society organizations have also undertaken to provide psychiatric rehabilitation on the continent. One example is Basic Needs, which operates in Uganda, Tanzania, Ghana and Kenya (6). Basic Needs addresses the mental health needs of people in community settings using the sustainable livelihood approach. In this model, mentally ill patients and their caregivers are actively supported to participate in consultation workshops and self-help groups. This organization, working in partnership with various stakeholders including government, also helps to identify and ease bottlenecks to accessing mental health services in the communities. Once the mentally ill patients are feeling more stable, they are encouraged and facilitated through programs such as microfinancing to return to work. The Basic Needs model is not only in agreement with the primary health care strategy, which is the guiding principle in health care delivery in most of the countries in Africa, but also provides a flexible model that can be implemented in

both rural and urban settings.

In summary, although both the WHO-supported primary health care model and some indigenous models of psychiatric rehabilitation have been implemented on the continent with various levels of success, there is a paucity of studies on the cost-effectiveness and sustainability of these approaches to psychiatric rehabilitation in the region. The challenge to today's mental health workers in Africa is how to scientifically assess the cost-effectiveness of each of these models and how to enhance them with lessons learnt elsewhere.

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# A plea for the 22 UN standard rules and a request to redefine psychiatry

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Wulf Rössler gives a comprehensive description of the state of psychiatric rehabilitation today. The shift of focus from an illness (in fact a medical) model to a model of functional disability in psychiatric rehabilitation is much welcome. Proper housing, education, work, satisfying relationships and participation in the community are basic

conditions for people to recover and therefore goals of the client movement.

By using the adjective "psychiatric", rehabilitation is placed in the domain of psychiatry. Proper housing, education, access to work or other valued activity and full participation in the community fail to have consistent links with psychiatry on the level of planning, financial structures or political priorities. For this reason the implementation of the 22 United Nations (UN) standard rules on



the equalization of opportunities for persons with disabilities (1) is essential. It is very important that national and local authorities implement these standard rules, although lack of financial resources is an obstacle for many countries.

Rössler claims that a psychiatrist should have a role in the process of rehabilitation. However, I would like to emphasize the role of the client movement. Local client organizations can help to organize peer support, which appears to be very successful (2). National and international client organizations (3; [www.enusp.org](http://www.enusp.org); [www.wnusp.org](http://www.wnusp.org)) can support the implementation of the UN standard rules. Another aspect that makes the client movement important is the range of methods for pursuing recovery developed by people who have been on the receiving end of mental health services (e.g., 4; [www.basisberaad.nl](http://www.basisberaad.nl); [www.hearing-voices.org](http://www.hearing-voices.org)). Self-help groups, crisis card and psychiatric will are concepts that deserve much more attention. The idea of empowerment has been constructed with a lot of input from clients (5).

Rössler concludes his overview by

observing there is still a long way to go from results we have collected by research to daily practice. The advancements are considerable although some modesty would not hurt. First of all, there is some controversy regarding the academic status of schizophrenia (6-8). Despite its ambiguous status, this diagnosis has an overwhelming impact on people's life. Secondly, medical science plays a dominant role in psychiatry, and therefore still is the academic domain of body and mind.

The beneficial effects on mind (and body) of the Ayurveda from India and of Chinese medical practice cannot be denied, but are difficult to fit in with the current paradigm of medical science. Thirdly, recently new challenging information has been gathered about the functioning of the brain. These findings call for an urgent need to redefine psychiatry. The famous book "Discours de la méthode", first published in 1637, was written by René Descartes (9) because he wanted to propose an academic framework in which the scientific developments of that time could be accommodated. We will be lucky if by

2037 we will have a similar framework for psychiatry.

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# Risk factors for schizophrenia. Follow-up data from the Northern Finland 1966 Birth Cohort Study

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*This paper updates single risk factors identified by the Northern Finland 1966 Birth Cohort Study up to the end of year 2001 or age 34. Impaired performance (e.g., delayed motor or intellectual development) or adverse exposures (e.g., pregnancy and birth complications, central nervous system diseases) are associated with an increased risk for schizophrenia. However, upper social class girls and clever schoolboys also have an increased risk to develop schizophrenia, contrasted to their peers. Individuals who subsequently develop schizophrenia follow a developmental trajectory that partly and subtly differs from that of the general population; this trajectory lacks flexibility and responsiveness compared to control subjects, at least in the early stages. We propose a descriptive, lifespan, multilevel systems model on the development and course of schizophrenia.*

**Key words:** Schizophrenia, risk factors, developmental trajectory, multilevel systems model

Subtle developmental deviances in motor, cognitive, emotional, behavioural, and brain structural domains are often present in individuals who later develop psychosis. This strongly suggests that some aspects of causation are established before overt psychosis, and that these same factors impact adversely on various developmental trajectories (1-3). The Northern Finland 1966 Birth Cohort (NFBC 1966) aims to explore risk factors and developmental pathways to schizophrenia over the lifespan.

There are numerous proposed putative risk factors for schizophrenia (see 3,4 for reviews), but few prospective studies exist concerning the stability of developmental deviance and related phenotypic anomalies in schizophrenia. The NFBC 1966 has produced critical findings on the predictors of schizophrenic psychoses, e.g., unwanted pregnancy (5), obstetric complications (6), and delayed development at age 1 (7). Here we update these single risk factors up to the end of year 2001 or age 34. In particular, in this paper we explore whether deviation from the norm in either direction (i.e., either inferior or superior performance) could be a risk factor for schizophrenia.

## METHODS

Within the NFBC 1966, we recruited 12,058 subjects born in 1966; 96% of all births in the region (1). In the follow-up at age 34, we used standard cohort approaches and a nested case-control design. We had 10,458 controls and 111 DSM-III-R schizophrenia cases in risk analyses. For each risk factor, crude and adjusted odds ratios are presented, along with population attributable risk (PAR) per-

centage, and variance explained. Total variance explained for the entire adjusted model is presented.

## RESULTS

In Table 1 the significant risk factors within the NFBC 1966 by age 34 are presented. When adjusted for other variables, the rank order of risk factors changes substantially. Risk factors associated with relatively large crude odds ratio (e.g., perinatal brain damage) are associated with low PAR (e.g., 5%). Early developmental milestones related to standing, walking and potty training are associated with modest crude odds ratio, but relatively large PAR. When the risk factors are combined, only 9.1% of the variance can be explained. Not only "poor" performance is associated with elevated risk of schizophrenia: upper social class girls and clever schoolboys had an increased risk to develop schizophrenia, contrasted to their peers.

## DISCUSSION

Compared to the general population, individuals who develop schizophrenia demonstrate subtle developmental deviances in motor, cognitive, emotional and behavioural domains. It is possible to identify risk factors for schizophrenia; however, they explain only a small proportion of variance and currently appear to have limited heuristic value. The results presented in recent reviews (4) are congruent with our findings and demonstrate similar developmental delays among preschizophrenic individuals.

**Table 1** Most essential risk factors for schizophrenia in the Northern Finland 1966 Birth Cohort by age 34. Statistically significant risk factors are highlighted in bold

Risk factors	Crude statistics				Adjusted odds ratio	
	OR	95% CI	R <sup>2</sup> %	PAR%	OR	95% CI
Male gender	<b>1.8</b>	<b>1.2-2.7</b>	0.8	29	<b>1.8</b>	<b>1.1-2.8</b>
Parental psychosis*	<b>3.9</b>	<b>2.3-6.6</b>	1.5	11	<b>4.1</b>	<b>2.3-7.4</b>
Birth weight <2,500 g	<b>2.2</b>	<b>1.1-4.6</b>	0.3	4	1.4	0.6-3.4
Perinatal brain damage	<b>5.7</b>	<b>2.6-12.5</b>	1.1	5	<b>2.9</b>	<b>1.1-7.9</b>
Central nervous system infection	<b>2.9</b>	<b>1.1-8.0</b>	0.3	2	<b>3.7</b>	<b>1.3-10.6</b>
Unwanted pregnancy	<b>2.0</b>	<b>1.2-3.2</b>	0.6	10	<b>1.8</b>	<b>1.1-3.0</b>
Not in normal school grade	<b>4.4</b>	<b>2.7-7.1</b>	2.4	15	<b>4.4</b>	<b>2.5-7.7</b>
Late learning to stand (12 months or later)	<b>2.0</b>	<b>1.4-3.0</b>	1.1	24	1.4	0.8-2.4
Late learning to walk (12 months or later)	<b>1.9</b>	<b>1.2-3.0</b>	0.9	33	1.3	0.7-2.3
Potty trained at the age of 1 year (no)	<b>1.8</b>	<b>1.2-2.6</b>	0.7	19	1.5	1.0-2.3
Excellent school performance (in males)	<b>3.3</b>	<b>1.4-7.9</b>	0.7	7	<b>4.3</b>	<b>1.7-10.7</b>
Social class I (in females)	<b>2.4</b>	<b>1.0-5.8</b>	0.1	9	<b>4.5</b>	<b>1.6-13.4</b>

OR = odds ratio; CI = confidence interval; R<sup>2</sup>% = how much variation is explained; PAR% = Population attributable risk percentage

\* Information from Finnish Hospital Discharge Register, 1972-2000

Variance explained by the total model: R<sup>2</sup>=9.1%

Usually, impaired performance (e.g., delayed motor or intellectual development) or adverse exposures (e.g., pregnancy and birth complications, central nervous system diseases) are associated with an increased risk for schizophrenia. Paradoxically, for some measures we found that the deviation from the norm in either direction was associated with an increased risk for schizophrenia. For example, within NFBC 1966, superior school performance was associated with increased risk for suicide in psychotic persons but with decreased risk among the non-psychotic population (interaction school performance x diagnosis:  $p = 0.01$ ) (8).

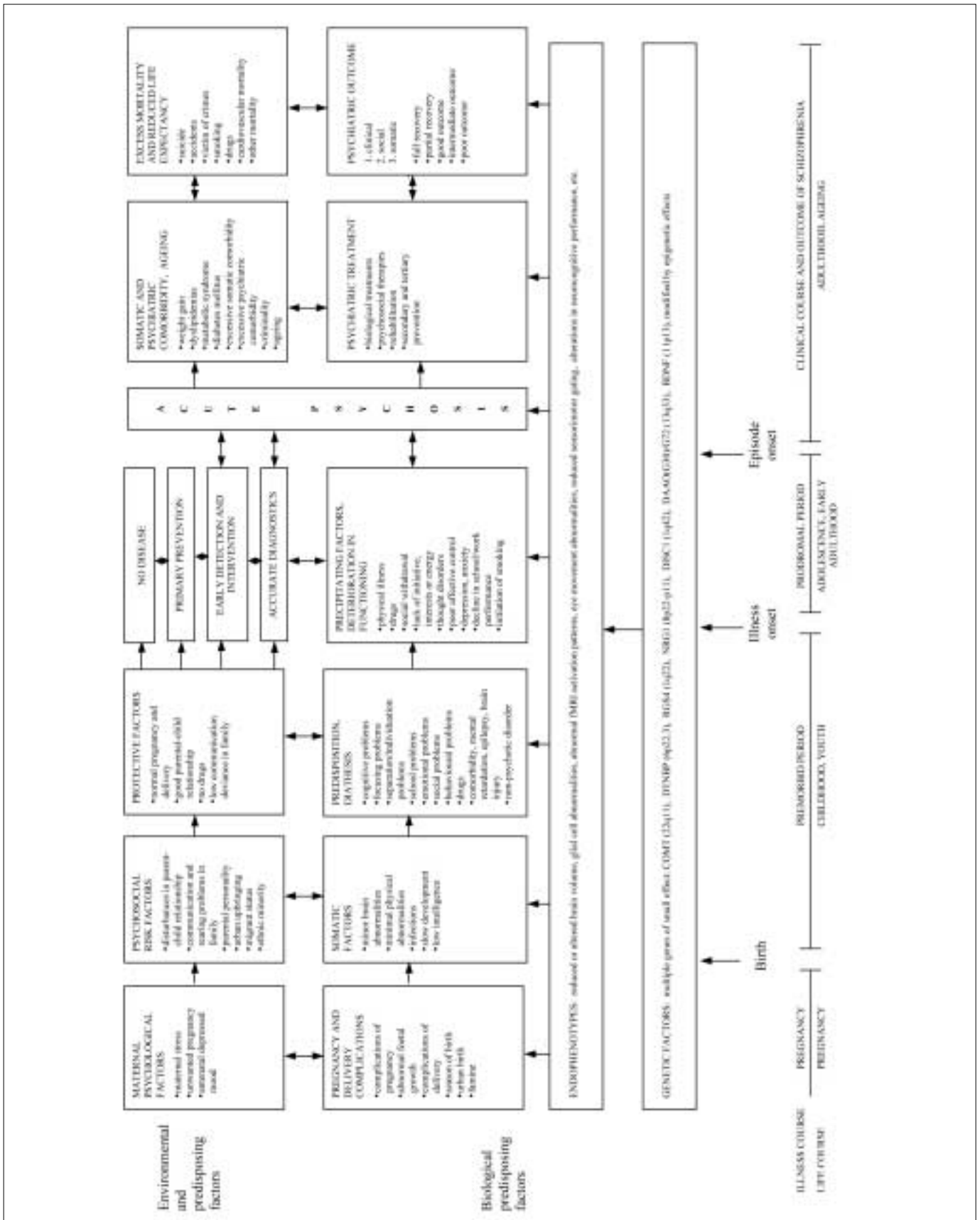
Apart from the material presented in Table 1, research based on the NFBC has revealed other subtle deviances in the lifespan trajectory of individuals with schizophrenia compared to health members of the cohort. We were able to demonstrate that individuals with psychosis followed a developmental trajectory that partly and subtly differed from that of the general population. In preschizophrenic persons, the developmental pathway to adolescence appears stricter and lacks flexibility and responsiveness when contrasted to non-psychotic controls. There may be some continuity also in general population: infants within the NFBC 1966 who developed slightly more slowly (though still within the normal range of development) did less well at school and had a decreased chance of going on to higher education (9).

In schizophrenia, diagnostic accuracy may be limited and diagnostic transformations occur. Current diagnostic systems offer moderately good reliability among trained diagnosticians but not necessarily between scientists and clinicians (10). There are major problems concerning both validity issues and clinical practices, e.g., marked delay in diagnostics (11). In NFBC 1966, diagnostic disagreement or discordance (schizophrenia vs. no schizophrenia) be-

tween clinicians and researchers existed in 43% of cases, especially in cases with marginal symptomatology, minimal contacts to the treatment systems, late illness onset, good outcome and comorbidity (12).

Within the longitudinal data from the NFBC 1966, there is a different degree of developmental continuity or persistence of deviances in schizophrenia and the general population. The developmental continuity in the neuromotor area between 1 and 16 years among children who developed schizophrenia was significantly stronger (Spearman's  $r$  between 0.2 to 0.3) than non-psychotic controls ( $r$  between 0.05 to 0.1) (13). For cognition, within the NFBC 1966, those who had slight delays in developmental milestones during early life also performed worse on tests of cognitive function in adulthood. Whilst schizophrenia subjects developed slightly later and had poorer cognitive function in adulthood, the pattern of association between infant motor development and adult cognition was similar in schizophrenia and the general population (14). The cognitive pathway from infancy to adulthood was not qualitatively different in the schizophrenia group compared with the general population (15). There were quantitative differences (e.g., poorer performance seen in both infancy and adulthood in subjects with schizophrenia). These findings are consistent with the hypothesis that, in schizophrenia, mild infant motor developmental delay and adult cognitive deficits (at least in some domains) are age dependent manifestations of the same underlying neural process.

In Figure 1, we present a descriptive, multilevel lifespan model of the developmental pathway to schizophrenia and of the course of the illness. This descriptive model has its main focus on time-dependent (longitudinal), measurable epidemiologically identified properties. However, this model also has hierarchical multilevel features. The data from the NFBC 1966 provide tangible evidence of the



**Figure 1** Descriptive life span and multilevel model of schizophrenia. Known aetiological and disease course components are presented. Hypothetical ideas on protective factors are not necessarily evidence-based.

complexity and subtlety of these pathways, but the variables now available only allow glimpses of potential genome and endophenotype levels. Current studies are examining candidate genes and endophenotypes and we hope to be able to use the developmental phenotypes and endophenotypes to sharpen gene association studies. Gottesman et al (16) have outlined an innovative model incorporating a dynamic developmental interplay among molecular genetic, environmental and epigenetic factors.

This model has value from several perspectives. It contains information on both the longitudinal, lifespan, dynamic, time-dependent and time-varying pathway, and the transversal, structural, multilevel, multidimensional, hierarchical pathway. Both these dimensions can illuminate hidden layers of complexity between genotype and disease. In the absence of an understanding of the complete systems, we only see the surface manifestations of the underlying processes. Descriptive phenotype-level risk factors and phenomena (e.g., age learned to walk, birth complications, unwanted pregnancy) are only partly heuristic and their explanatory and predictive power is modest.

In conclusion, individuals with psychosis follow a developmental trajectory that partly and subtly differs from that of the general population. The NFBC 1966 has allowed us the opportunity to observe glimpses of this complex process. It is necessary to develop theoretical frameworks of the developmental pathway of schizophrenia based on a more detailed, dynamic and multilevel approach, as proposed by modern systems theory and systems biology (17). Presently, it is not possible to construct a detailed model that captures all the features underlying the development of schizophrenia. We know too little about the inputs and mediating factors in the matrix of genes and environmental factors that gently guide development. However, we can conclude that the developmental trajectories in schizophrenia are different in subtle but informative ways compared to those of healthy individuals. For those who develop schizophrenia, the developmental pathways, at least in the early phase, seem "stricter". They may be less flexible and less able to buffer perturbations. These findings provide tantalizing glimpses into the component causes of schizophrenia, and emphasize the value of birth cohort studies.

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# The relationships between depression and remission in first-episode psychosis

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*This study assessed changes in depressive symptoms over time in 57 patients with first-episode psychosis, and investigated the relationships of these symptoms during the acute psychotic episode and the post-psychotic period with treatment outcome. Assessment instruments included the Calgary Depression Scale (CDS) and the Positive and Negative Syndrome Scale (PANSS). For the evaluation of treatment outcome, recently proposed operational remission criteria were used. PANSS factor analysis identified a depression/anxiety factor (PANSS-D/A) at baseline, which separated into "pure" depression (PANSS-D) and anxiety (PANSS-A) factors at 24 months. There were strong correlations between the CDS and the PANSS-D/A, PANSS-D and PANSS-A scores at baseline, but at 24 months significance was lost between CDS and PANSS-A. Compared to non-remitters, patients who achieved remission had significantly higher baseline CDS scores, but depressive symptoms resolved with antipsychotic treatment. Non-remitting patients had relatively low baseline CDS scores, but their depressive symptoms persisted throughout the study. These findings suggest that depressive symptoms in the acute psychotic episode differ from those in the post-psychotic period in terms of their phenomenology, temporal relationship to psychosis, and treatment response.*

**Key words:** Schizophrenia, depression, remission, outcome, factor analysis

While schizophrenia and depression have historically been regarded as separate disorders, it is now well recognized that depressive symptoms are common in schizophrenia (1). Prevalence estimates differ considerably, probably as a result of differences in samples studied (e.g., acute *versus* chronic) and assessment instruments used. Reported prevalence rates vary between 7% and 70% (2,3). Depressive symptoms pose a challenge for the clinician, as they may mimic negative symptoms (4) and antipsychotic-induced akinesia (5) or akathisia (6), and are therefore frequently difficult to recognize. Furthermore, depressive symptoms in schizophrenia may have several different origins, requiring specific treatment interventions. For example, they may represent a psychological response to the illness and its accompanying adverse life events (7). Alternatively, they may be due to substance abuse (4), or reflect a comorbid major depressive disorder or anxiety disorder, or be induced by antipsychotic treatment (8). Finally, it has been suggested that depressive symptoms may represent a core feature of the schizophrenic illness itself (9,10).

It has been noted that most depressive symptoms occur concurrently with the acute psychotic symptoms, and resolve once antipsychotic treatment is implemented and the psychosis remits (10). However, there are patients with schizophrenia who experience persistent depressive symptoms that are not responsive to antipsychotic treatment alone. A depressive syndrome was found in 12.9% of patients with chronic schizophrenia, and these symptoms persisted beyond 3 months in 60% of the subjects (3). Another study found that 30 to 40% of schizophrenia patients evidenced full depressive syndromes during the longitudinal course of their illness (11). These persistent (or emergent) depressive symptoms may be particularly important in the post-psychotic period, as they have been associated with an increased risk of relapse (7), suicidality (12), and impaired social and vocational functioning (11,13,14).

Although the relationship of depressive symptoms to treatment outcome is still a subject of some debate, it would appear that their presence in the acute phase of the illness is associated with a favourable outcome (15-17). On the other hand, when present in the chronic course of schizophrenia, depressive symptoms appear to be negative prognostic indicators (13,18).

Studies of depressive symptoms in schizophrenia have used a variety of measures, including the depression factor of the Positive and Negative Syndrome Scale (PANSS) (16), the depression factor of the Brief Psychiatric Rating Scale (BPRS) (19), and the Montgomery-Asberg Depression Rating Scale (4). However, the Calgary Depression Scale (CDS) was the first scale specifically designed and validated for the evaluation of depressive symptoms in patients with schizophrenia (20). The CDS is based on items selected from the Hamilton Depression Rating Scale and the Present State Examination (20). Exploratory factor analysis indicated that the CDS is monodimensional (21). The items of the scale have been shown not to overlap with negative symptoms and extrapyramidal symptoms (22-24), but in one study a correlation was found with positive symptoms (25). A high degree of correlation has been reported between CDS and PANSS-D scores (26). The PANSS-D factor includes a number of anxiety items, and may be more correctly referred to as the PANSS depression/anxiety factor.

The primary purpose of this study was to assess changes in depressive symptoms over time in patients with first-episode psychosis, and particularly, to investigate the relationships of these symptoms in the acute psychotic episode and in the post-psychotic period with treatment outcome. One problem in previous studies was the lack of standard outcome measures. To overcome this, we used recently published operationally defined criteria for remission (27).

## METHODS

This was a post-hoc analysis of a sample comprising 57 participants in a prospective study of first episode of psychosis admissions to the Stikland-Tygerberg academic hospital complex in Cape Town, South Africa. Full details of the study participants and methodology have been described elsewhere (28). Briefly, inclusion criteria comprised inpatients or outpatients aged 16 to 55 years meeting DSM-IV diagnostic criteria for schizophreniform disorder, schizophrenia or schizoaffective disorder, who had been exposed to less than four weeks of antipsychotic treatment. Exclusion criteria were a DSM-IV axis I diagnosis other than schizophreniform disorder, schizophrenia or schizoaffective disorder, alcohol or drug dependence, depot antipsychotic treatment, a significant general medical condition and mental retardation. The study protocol and patient information and consent procedures were approved by the Institutional Review Board of the University of Stellenbosch. Subjects and/or their guardians provided written informed consent.

Subjects were treated with low doses of haloperidol in an open label design according to a fixed protocol. Briefly, doses were restricted to 1 mg/day for the first four weeks. For non-responders ( $\leq 20\%$  reduction in PANSS total score), the dose was increased to 2 mg/day for three weeks, followed by weekly increments of 1 mg/day until response was achieved, or intolerable side effects developed, or a maximum dose of 10 mg/day was reached. Any non-responders at this stage were switched to thioridazine, up to a maximum of 600 mg/day. Non-responders after three weeks of thioridazine at maximum dose were switched to treatment with clozapine. Downward titration of haloperidol was permitted at any point if side effects emerged. Lorazepam was permitted for sedation, and orphenadrine and benzhexol were prescribed for the treatment of extrapyramidal symptoms.

Although the participants were assessed with a variety of instruments, those relevant to this study were the Structured Clinical Interview for DSM-IV (SCID) (29), the PANSS (30) and the CDS (20). The subjects were evaluated weekly with the PANSS and the CDS for the first 9 weeks (or until they were stabilized), at 12 weeks, and then at three-monthly intervals over a two-year period, with additional unscheduled assessments when required.

In an attempt to improve the assessment of treatment outcome, we used recently proposed operational criteria for remission (27). These criteria define remission according to a threshold of severity of items representing the three major symptom domains identified in factor analyses (negative, psychosis and disorganized factors) and the five criteria specified in DSM-IV for a diagnosis of schizophrenia. The symptom severity threshold for the PANSS comprises a score of 3 (mild) or less on each of the following eight items: delusions, conceptual disorganization, hallucinatory behaviour, blunted affect, social withdrawal, lack of spontaneity, mannerisms/posturing and unusual thought content. These criteria must have been met for at least six months.

Factor analysis was performed on the PANSS individual items at baseline and at 24 months, by the method of maximum likelihood. A principal component analysis was performed as a guide for choosing the number of factors. The factor solution was rotated using the equamax procedure. When selecting the number of factors we considered the following: those with eigenvalues greater than unity, inspection of the scree plot, and percent variance explained by the solution. The Pearson product moment correlation coefficient ( $r$ ) was used to investigate relations between CDS and PANSS factors. For assessing changes in CDS scores over time for remitters *versus* non-remitters, a general linear model repeated measures analysis of variance was conducted. Student's  $t$  test was used to compare the remitting and non-remitting subjects in terms of CDS and PANSS factor scores. Analyses were performed on the intent to treat (ITT) population (all subjects who received treatment and provided efficacy data for at least one visit), with the last value carried forward (LVCF). A significance level of 0.05 was used throughout.

## RESULTS

The participants' mean age was  $28.2 \pm 8.6$  years, and 29 (50.8%) were female. Three patients failed to complete at least one post-baseline assessment, so that the ITT sample for the analysis comprised 54 participants. Twenty-three (40%) achieved the full remission criteria. Twenty-eight (49%) were followed for the entire 24 months. Reasons for discontinuation were: lost to follow-up ( $N=23$ ), withdrawn from trial ( $N=5$ ), and deceased ( $N=1$ ).

On the basis of the scree plot inspection, we chose a five factor solution for the PANSS individual items at baseline, accounting for 60% of the variance. The third principal component was a depression/anxiety factor, comprising the items anxiety, guilt feelings, tension and depression, which accounted for 11.5% of the variance. The factor analysis for the PANSS individual items at 24 months yielded a different picture. Again limiting the number of factors to five, the depression/anxiety factor separated into "pure" depression (guilt feelings and depression) and anxiety (anxiety and tension) factors, accounting for 7.8% and 8.6% of the variance, respectively. The separation into depression and anxiety factors is consistent with a previous PANSS factor analysis in a large first-episode psychosis sample (31). Although the item somatic concern did not load with any of the components, we decided to include it in our further analyses in the interest of consistency with the majority of previously published studies (31). Thus, we used three PANSS factors: a depression/anxiety factor (PANSS-D/A), a depression factor (PANSS-D) and an anxiety factor (PANSS-A).

As expected, there were very strong correlations between the CDS and the PANSS-D/A, PANSS-D and PANSS-A at baseline. However, at 24 months, while the correlation between CDS and PANSS-D remained highly

**Table 1** Correlations between the CDS and the PANSS-D/A, PANSS-D and PANSS-A factors during the acute psychosis phase (baseline) and the post-psychotic period (24 months)

	Calgary Depression Scale (CDS)			
	Baseline		24 months	
	r	p	r	p
PANSS-D/A	.76	<0.0001	.53	<0.0001
PANSS-A	.51	<0.0001	.03	0.8
PANSS-D	.83	<0.0001	.90	<0.0001

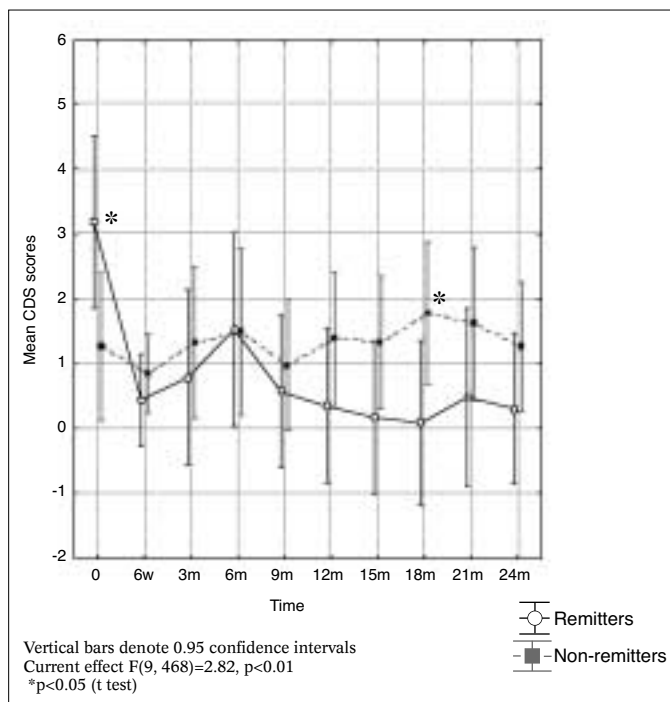
PANSS-D/A - Positive and Negative Syndrome Scale depression/anxiety factor; PANSS-A - PANSS anxiety factor; PANSS-D - PANSS depression factor

significant, significance was lost between CDS and PANSS-A (Table 1).

Relationships between depressive symptoms and the other symptom domains of psychosis were sought by examining correlations between CDS, PANSS-D/A, PANSS-D and PANSS-A factors, and the other PANSS factors at baseline. Results are shown in Table 2. The only significant correlation was between the PANSS-D factor and the PANSS negative factor at baseline.

Changes in CDS scores over time for the remitters and non-remitters are depicted in Figure 1. Patients who achieved remission had significantly higher baseline CDS scores, but depressive symptoms resolved with antipsychotic treatment. Non-remitting patients had relatively low baseline CDS scores, but depressive symptoms persisted throughout the study. In the maintenance phase of treatment, non-remitting patients generally had higher levels of depressive symptoms, the difference reaching statistical significance at 18 months, but not at the other time points.

Differences between remitters and non-remitters in the



**Figure 1** Changes in CDS scores over time for remitters and non-remitters

CDS and PANSS factor scores during the acute psychotic (baseline) and maintenance (24 month) phases are given in Table 3. In the acute phase, depressive and anxiety symptoms tended to be higher in the remitters, reaching significance for the CDS scores. In the maintenance phase, there was a trend in the opposite direction: higher scores were observed in the non-remitters.

**Table 2** Correlations of CDS, PANSS-D/A, PANSS-D and PANSS-A factors with other PANSS factors at baseline

	PANSS negative		PANSS disorganized		PANSS positive		PANSS excited	
	r	p	r	p	r	p	r	p
PANSS-D/A	.09	0.5	-.09	0.5	.04	0.7	-.04	0.8
PANSS-A	.01	0.9	-.13	0.3	.03	0.8	.01	0.9
PANSS-D	.40	0.002	.07	0.6	-.03	0.8	-.18	0.2
CDS	.21	0.1	.02	0.8	.016	0.9	-.06	0.6

CDS - Calgary Depression Scale; PANSS - Positive and Negative Syndrome Scale; PANSS-D/A - PANSS depression/anxiety factor; PANSS-A - PANSS anxiety factor; PANSS-D - PANSS depression factor

**Table 3** Mean CDS, PANSS-D/A, PANSS-D and PANSS-A scores at baseline and at 24 months in remitters and non-remitters

	Baseline			24 months		
	Remitters	Non-remitters	p	Remitters	Non-remitters	p
CDS	3.2±4.1	1.3±2.2	0.03	0.5±0.6	1.5±3.6	0.22
PANSS-D/A	11.9±5.5	9.6±4.3	0.09	6.6±2.3	7.5±3.0	0.24
PANSS-A	7.7±3.3	6.4±3.5	0.15	4.2±1.7	4.6±2.4	0.43
PANSS-D	5.8±3.0	4.8±2.1	0.15	3.5±1.0	4.0±2.4	0.3

CDS - Calgary Depression Scale; PANSS-D/A - Positive and Negative Syndrome Scale depression/anxiety factor; PANSS-A - PANSS anxiety factor; PANSS-D - PANSS depression factor



## DISCUSSION

This study confirms previous findings that depressive symptoms are more prominent during the acute psychotic phase than in the post-psychotic phase of schizophrenia (10,15,32,33). The majority of these symptoms resolve shortly after initiation of antipsychotic therapy. The levels of depression in the post-psychotic phase are generally low, although such symptoms persist or emerge in some patients.

Our study provides further evidence that depressive symptoms in the acute psychotic phase are positive prognostic indicators (15-17,32). Although less clear cut, depressive symptoms in the post-psychotic phase of the illness appear to be associated with poorer outcome. In fact, 4 of 31 (13%) non-remitters had CDS scores  $\geq 3$  at endpoint, compared to none of 23 remitters. This finding is consistent with some previous studies where persistent depressive symptoms were associated with a poorer outcome (13,14). The lack of clear statistical significance in our study may be due to our relatively small sample size.

It would seem that depressive symptoms experienced during an acute psychotic episode are fundamentally different from those experienced in the post-psychotic period. The former appear to be temporally related to the psychosis itself and improve as psychotic symptoms resolve, in response to antipsychotic treatment. In contrast, persistent depressive symptoms are not responsive to antipsychotic therapy alone and they may require additional treatment interventions. In this regard, second-generation antipsychotics appear to be more effective than conventional antipsychotics (34). Although not effective in treating depressive symptoms in actively psychotic patients (35), antidepressant supplementation may be effective (36,37), as well as a mood stabilizer (38). It could be further argued that some persistent negative symptoms may in fact be masked depressive symptoms. The significant association between the PANSS-D factor and the PANSS negative factor found in our study could be explained on this basis. Further, a recent finding that negative symptoms respond favourably to antidepressant supplementation would support this hypothesis (39).

The superiority of the CDS over the PANSS in detecting depressive syndromes is apparent in our study. However, it may be that the two scales are measuring different things. The PANSS-D/A factor may reflect a mixed depression and anxiety syndrome occurring more commonly in the acute phase of psychosis, while the PANSS-D is more closely associated with the CDS and detects a purer depressive syndrome. Thus, it may be that acute and chronic depressive symptoms differ not only temporally and in terms of response to treatment, but also phenomenologically.

Limitations of our study include the relatively small sample, the inherent limitations of factor analysis (40), and the fact that our study was not designed to examine the origins of the depressive symptoms. To further elucidate the nature of depressive symptoms in schizophrenia, future studies should focus on the relative contributions of factors such as

environmental stress, substance abuse and family history of mood disorders. In the meantime, clinicians would do well to be aware of the importance of depressive symptoms in schizophrenia, and treat such symptoms vigorously should they persist.

## Acknowledgement

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# Understanding of the term “schizophrenia” by the British public

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*A postal survey of a representative sample of UK adults was conducted. Subjects were asked “What do you understand by the term ‘schizophrenia’?”. Four hundred four completed questionnaires were received (81% response rate). Forty-two percent of respondents mentioned at least one first rank symptom of schizophrenia or gave a description that reasonably approximated to any diagnostic feature as stated in ICD-10. Forty percent mentioned “split” or “multiple” personality. Thirty-eight percent described auditory hallucinations or “hearing voices”. Fifteen percent mentioned “delusions” or described passivity experiences. Only 6% of subjects mentioned violence in their descriptions.*

**Key words:** Schizophrenia, public understanding, public education

According to ICD-10 classification of mental and behavioural disorders, schizophrenia is characterized by gross disturbances of thought, perception and affect, in the face of clear consciousness and intellect. Although there is some concern about misrepresentation of severe mental illnesses such as schizophrenia by the media, a positive trend in public perception has been noted (1). This study aimed to examine the understanding of the term “schizophrenia” by the British public.

## METHODS

The study was carried out in a representative sample of 500 UK adults, drawn from a panel of over 1000 subjects who were recruited for a previous study using direct mail shots and adverts in local newspapers (2). Subjects were asked to answer the question “What do you understand by the term ‘schizophrenia’?”, by writing a short sentence or description.

Responses were classified into eleven different categories as shown in Table 1. Reasonable descriptions of “schizophrenia” were accepted to include any first rank symptom or diagnostic feature as stated in ICD-10, including auditory or visual hallucinations, thought disorder, delusions or passivity experiences. Common lay descriptions that approximated to these clinical symptoms were also accepted as reasonable, including hearing voices, seeing things, disconnection from reality, losing touch with reality, feeling controlled by an outside force. The expression “split personality” was not accepted as a reasonable description of schizophrenia. Other common descriptions that were not accepted as reasonable included unstable or multiple personality, “paranoia”, “mental illness” or “mental disorder”, and any other disturbance involving “mood”, “emotion” or “personality”, as well as any reference to violence. We did not expect respondents to provide a description that distinguished between schizophrenia and other psychotic disorders.

## RESULTS

Four hundred four completed questionnaires were received (81% response rate). A further three questionnaires were illegible and were therefore disregarded. The mean age of respondents was  $44.7 \pm 1.4$  years; 37% were male; 58% of the subjects were in paid employment, the rest were retired, unemployed, students or housewives. The mean age leaving full-time education was  $18.6 \pm 0.5$  years with a median of 16 years.

Forty-two percent of respondents mentioned at least one first rank symptom of schizophrenia or gave a description that reasonably approximated to a diagnostic feature as stated in ICD-10. Forty percent mentioned “split personality” or “multiple personality”; 38% mentioned auditory hallucinations or “hearing voices”; 15% mentioned “delusions” or described passivity experiences. Only 6% of subjects mentioned violence in their descriptions (Table 1). No respondents gave any indication of the duration of the symptoms that would be required to meet diagnostic criteria for schizophrenia.

**Table 1** Diagnostic features of schizophrenia mentioned by the British public

Split/multiple/unstable personality	58%
Auditory hallucinations/“hearing voices”	38%
Mental disorder or illness	21%
Delusions/passivity experiences	15%
Unstable mood/emotional imbalance	10%
“Paranoia”	7%
Visual hallucinations/“seeing things”	6%
Violence	6%
Thought disorder	5%
Psychosis/disconnection from reality	4%
Other forms of disturbed behaviour (besides violence)	4%
At least one first rank symptom or reasonable diagnostic symptom	42%

## DISCUSSION

Irrespective of the particular medical school training, many psychiatrists use a mental map of Schneiderian first and second rank symptoms as a screening tool. Interestingly, a substantial number of lay participants in this survey were able to clearly identify most of these symptoms. Out of the eleven categories used to group the narratives of the participants, five were the major features in diagnosing schizophrenia. Hearing voices was the commonest (38%).

There is some inconsistency in findings from research using lay groups in the community as subjects. A study in US comparing 542 people with mental health professionals showed a wide gap in the perceptions and beliefs concerning schizophrenia, where the lay people thought it was more of an emotional set of symptoms with psychosocial causations, the removal of which will lead to improvement (3). Similar findings were documented in studies done in Kuwait, Taiwan and Japan (4,5). On the contrary, a study from Switzerland on a representative population sample consisting of 844 subjects reported a correct vignette detection rate of 73.6% (6). Our study is unique because we did

not use vignettes, and the recognition rates are half way between the extremes discussed in other studies above.

Our data highlight the importance of health education and further research on public understanding of mental disorders.

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# World Health Organization's Mental Health Atlas 2005: implications for policy development

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*In 2005, the World Health Organization (WHO) launched the second edition of the Mental Health Atlas, consisting of revised and updated information on mental health from countries. The sources of information included the mental health focal points in the Ministries of Health, published literature and unpublished reports available to WHO. The results show that global mental health resources remain low and grossly inadequate to respond to the high level of need. In addition, the revised Atlas shows that the improvements over the period 2001 to 2004 are very small. Imbalances across income groups of countries remain largely the same. Enhancement in resources devoted to mental health is urgently needed, especially in low- and middle-income countries.*

**Key words:** Mental health, mental health policy, mental health services, inequities, human resources, developing countries, mental health indicators

Reliable information on mental health resources and services is essential to enhance attention to mental health needs, to measure inequities, to identify priorities and to plan mental health services, if the low priority accorded to mental health in overall health is to change (1). Such information is urgently needed, because mental disorders are highly prevalent and cause considerable suffering and disease burden.

In 2000, the World Health Organization (WHO) initiated the Mental Health Atlas project, to fill the gap in global information on mental health resources and services (2). The objectives of this project included collection, compilation and dissemination of global information about mental health resources and services in each country (3-6).

In 2005, the WHO launched the second edition of the Atlas (7), consisting of revised and updated information from countries. Information related to policy, programmes, financing and mental health resource indicators (beds, personnel, services for special populations and availability of drugs) was sought from the Ministry of Health of each country. Triangulation of data was achieved through an exhaustive literature search on mental health resources in low- and middle-income countries on Medline and Embase Psychiatry and from documents received from countries, travel reports submitted by WHO staff, country data collected by WHO Regional Offices, and feedback from experts and Member Societies of the WPA. Finally, all information was verified by the focal points for mental health in the Ministries of Health.

All the 192 WHO Member States and 11 Associate Members, Areas and Territories are covered by Mental Health Atlas 2005. This represents approximately 99% of the world's population. Some limitations should be kept in mind when viewing the findings of Atlas 2005. While best attempts have been made to obtain information from countries on all variables, some could not provide specific details on a few issues. Common reasons for missing data are that some of these data simply do not exist within the coun-

tries or accurate national figures are unobtainable under the decentralized organization of many countries.

The present report looks into the pattern of findings from the perspective of income groups of countries according to the World Bank. The 197 WHO Member States and Associate Members, Areas and Territories that are listed by the World Bank form the universe for the report.

## THE CURRENT SITUATION

### Mental health policy and legislation

As shown in Table 1, specific policies on mental health are present in 63.1% of countries. A mental health policy is present in 50.8%, 69.1%, 65.7%, and 70.5% of low-income, lower middle-income, upper middle-income and high-income countries, respectively. Clearly, the low-income countries are lagging behind. Most countries that reported having a policy also had all the essential components incorporated into it, such as treatment issues, prevention, rehabilitation, promotion and advocacy. About 78% of countries have legislation in the field of mental health, though there are larger disparities between the income groups of countries, with 92.7% of high-income countries having specific mental health legislation, and 69.2% and 74% of lower middle-income and low-income countries having such legislation. The presence of substance abuse policies showed a still greater disparity, with 55% of low-income and 86.4% of high-income countries reporting their presence. Similarly, provisions for disability benefits for the mentally ill had been made in only 55.2% of low-income in comparison to all high-income countries.

The majority of policies and legislations on mental health are relatively recent. Almost 63%, 57% and 62% of the countries have developed their mental health policy, enacted their existing legislation, and developed their substance abuse policy since the 1990s. However, 14% of the

**Table 1** Policies, services and resources for mental health in different countries by income groups (according to the World Bank)

	Low	Lower-Middle	Upper-Middle	High	Total
<i>Policies and legislation</i>					
Mental health policy (N=195) (%)	50.8	69.1	65.7	70.5	63.1
Mental health legislation (N=173) (%)	74.0	69.2	81.3	92.7	78.3
Substance abuse policy (N=194) (%)	55.0	74.1	72.2	86.4	70.6
Disability benefits (N=190) (%)	55.2	87.0	80.0	100	78.9
<i>Budget and financing</i>					
Specified budget for mental health (N=190) (%)	70.2	63.6	77.1	74.4	70.5
Mental health budget as percentage of health budget (N=101) (median)	1.0	2.1	3.0	6.8	2.5
Most common method of financing mental health care (N=186) (%)					
- Tax based	15.1	19.9	12.4	15.6	63.0
- Out-of-pocket payment	12.9	4.3	0	0	17.2
- Social insurance	0	2.2	5.9	7.0	15.1
<i>Community and primary care</i>					
Community care for mental health (N=189) (%)	51.7	52.8	88.6	93.0	68.3
Mental health in primary care (N=194) (%)	76.3	87.3	100	93.2	87.6
Facilities for management of severe mental disorders in primary care (N=192) (%)	55.2	45.5	71.4	79.5	60.9
Training for primary care personnel (N=191) (%)	60.3	60.0	52.8	61.9	59.2
<i>Beds per 10,000 population</i>					
All psychiatric beds (N=190) (median)	0.2	1.6	7.5	7.0	1.7
Mental hospital beds (N=182) (median)	0.2	1.4	4.8	4.3	1.0
General hospital beds (N=178) (median)	0.04	0.1	0.6	1.2	0.2
<i>Mental health professionals per 100,000 population</i>					
Psychiatrists (N=187) (median)	0.1	1.0	2.7	9.2	1.5
Psychiatric nurses (N=176) (median)	0.2	1.1	5.3	31.8	2.2
Psychologists (N=177) (median)	0.04	0.6	1.8	11.0	0.7
Social workers (N=168) (median)	0	0	2.0	18.0	0
<i>Mental health programmes for special populations</i>					
Children (N=186) (%)	34.5	74.1	74.3	86.4	64.9
Elderly (N=184) (%)	17.9	51.9	65.7	81.8	51.3
Minority (N=187) (%)	5.3	13.0	12.1	37.2	16.0
Indigenous (N=187) (%)	7.0	20.4	18.2	20.9	16.0
<i>Monitoring systems for mental health services</i>					
Reporting system (N=190) (%)	62.1	81.8	82.9	81.0	75.8

legislations (half of these in low-income countries) date from before 1960, when many of the current effective methods for treating mental disorders were not yet available and the human rights environment was still developing.

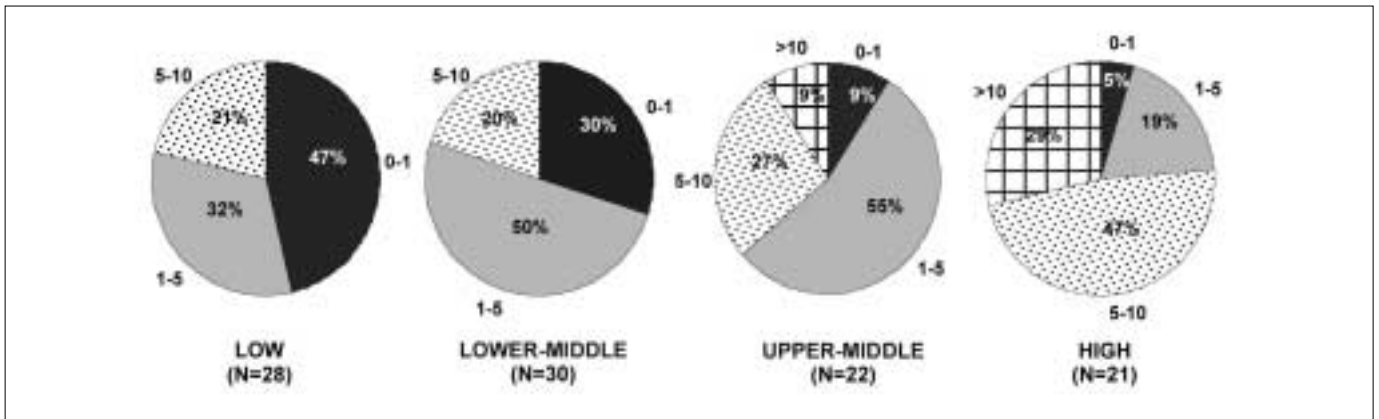
### Mental health budget and financing

In spite of the importance of a specific mental health budget within the total health budget, about 30% of the countries reported not having a specified budget for mental health care. Of the 101 countries that reported their mental health budget, 25% spend less than 1% of the total health budget on mental health. The median figures for percentage of health budget spent on mental health in low-income, lower middle-income, upper middle-income, and high-income countries, respectively, are 1%, 2.1%, 3%, and 6.8%. About 47%, 30%, 9%, and 5% of low-income, lower middle-income, upper middle-income, and high-income countries, respectively, spend less than 1% of their health budget on

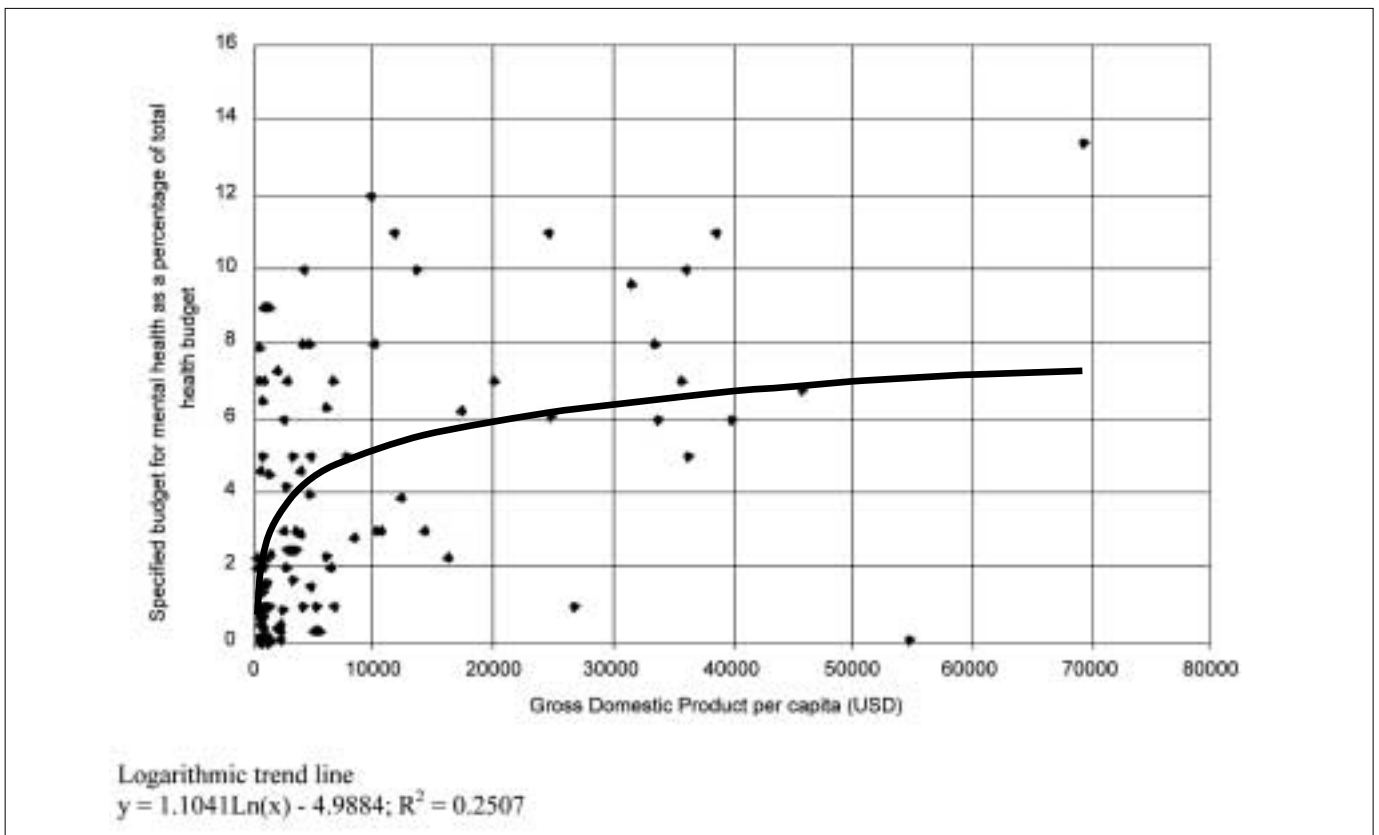
mental health care (Figure 1). On the contrary, more than three-fourths of high-income countries, in comparison to about one-third of upper middle-income and one-fifth of low-income and lower middle-income countries, spend more than 5% of their total health budget on mental health. There is a clear need to increase the resource allocation to mental health care in several countries. This should be eminently feasible in the middle- and high-income countries.

Examination of the percentage of total health budget spent on mental health *versus* the Gross Domestic Product (GDP) shows that countries that have higher GDP tend to earmark higher percentages of their total health budget for mental health. A logarithmic trend line (Figure 2) confirms this relationship. This illustrates the double disadvantage suffered by mental health in low-income countries: they have, even proportionally, a lower mental health budget.

The tax based method is the preferred one for financing mental health care in 63% of countries. However, the quantum of care that is covered by the tax-based systems may vary across countries. Other methods include out-of-



**Figure 1** Percentage of total health budget spent on mental health in different income groups of countries (N=101).



**Figure 2** Specified mental health budget as a proportion of total health budget by Gross Domestic Product per capita (N=101).

pocket payment in 17.2%; social insurance in 15.1%; external grants in 3% and private insurance in 2% of countries. All countries with out-of-pocket payment as the dominant method of financing mental health care belong to low-income or lower middle-income categories. On the other hand, almost all countries with social insurance as the dominant method of financing mental health care belong to high-income or upper middle-income categories.

Out-of-pocket payment is unsatisfactory because severe mental disorders can lead to heavy financial expenditure. Mental health care should preferably be financed through

taxes or social insurance. Private health insurance is also inequitable, because it favours the more affluent sections of society and is often more restrictive in the coverage of mental illness than in the coverage of somatic illness.

### Community care for mental health

Globally, 68.3% of countries reported to have at least some community care facilities for mental health. These facilities are present only in 51.7% of the low-income coun-

tries versus 93% of high-income countries. However, the extent of coverage of the community care within the countries as well as its quality remains variable.

Further development of community-based services is necessary, because such services can lead to early intervention and limit the stigma of taking treatment. Community care also has a better effect than institutional treatment on the outcome and quality of life of individuals with chronic mental disorders. Shifting patients from mental hospitals to care in the community is cost-effective and respects human rights.

### **Mental health facilities at primary level of care**

Mental health in primary care can be defined as the provision of basic preventive and curative mental health at the first level of the health care system. In many countries, a non-specialist who can refer complex cases to a more specialized mental health professional provides such care. Most mental disorders can be managed effectively at primary care level if adequate resources are made available. Shifting mental health care to primary level also helps to reduce stigma, improves early detection and treatment, leads to cost efficiency and savings, and partly offsets limitations of mental health resources through the use of community resources (1).

Mental health facilities at primary level are reported to be present in 87.6% of countries. However, only 60.9% of countries reported to actually provide treatment facilities for severe mental disorders at the primary care level. Only 45.5% and 55.2% of lower middle-income and low-income countries provide treatment facilities for severe mental disorders at the primary care level, in comparison to 79.5% of high-income countries. Half to three-fifths of countries across income groups provide training facilities for primary care personnel. This is obviously an area for concerted efforts all over the world.

### **Psychiatric beds**

There are approximately 1.84 million psychiatric beds in the world, but in 39% of countries there is less than one psychiatric bed per 10,000 population. This is true for 85% of low-income and 36% of lower middle-income countries, in comparison to 11% of upper middle-income and 5% of high-income countries. The median number of beds per 10,000 population in low-, lower middle-, upper middle- and high-income countries is 0.2, 1.6, 7.5 and 7% respectively.

Globally, 72% of psychiatric beds are located in mental hospitals and the rest in other settings, including psychiatric units in general hospitals and community services. In low- and middle-income countries, 74% to 83% of psychiatric beds are located in mental hospitals, compared with 64% in high-income countries. The lower figures for high-income in comparison to low- and middle-income coun-

tries testifies to the trend towards deinstitutionalization in these countries.

Community care is the most appropriate set-up for treating patients with mental disorders. However, inpatient facilities are essential for managing patients with acute mental disorders. Efforts should be made to reduce the number of mental hospital beds and create more facilities in general hospitals and long-term community rehabilitation centres.

### **Human resources**

The median number of psychiatrists per 100,000 population varies from 0.1 in low-income to 9.2 in high-income countries. Two-thirds of low-income and one-tenth of lower middle-income countries have less than 1 psychiatrist per 100,000 population, compared to none in upper middle-income and high-income countries.

The median number of psychiatric nurses per 100,000 population varies from 0.2 in low-income countries to 31.8 in high-income countries. Nearly 47% and 25% of low-income and lower middle-income countries have less than 1 psychiatric nurse per 100,000 population, compared to less than 3% of the upper middle-income and high-income countries.

The median number of psychologists in mental health per 100,000 population varies from 0.04 in low-income countries to 11% in high-income countries. Approximately 69%, 24%, and 11% of low-income, lower middle-income, and upper middle-income countries have less than 1 psychologist per 100,000 population, compared to none of the high-income countries.

The median number of social workers working in mental health per 100,000 population varies from 0 in low-income and lower middle-income countries to 18% in high-income countries. About 66% and 38% of low-income and lower middle-income countries have less than one social worker per 100,000 population, in comparison to less than 4% of upper middle-income and high-income countries.

It is obvious that there is a shortage in the number of mental health professionals in the world as a whole, and that there is also a wide variation between countries. Mental health professionals form the backbone of the mental health care delivery system. Their input is required not only in patient care but also in policy advice, administration and for training other personnel. Hence, manpower development is an urgent policy imperative.

### **Programmes for special populations**

Programmes for special populations are those addressing the mental health concerns (including social integration) of the most vulnerable and disorder-prone groups of population. Programmes for indigenous people (16%) and minori-



ty groups (16%) were found in very few countries. Programmes for elderly persons were reported to be present in 51.3% and programmes for children in 64.9% of countries.

The gradient between low-income, middle-income and high-income countries in provision of services for special populations is marked. Even in countries where programmes for vulnerable populations exist, they are neither uniform in quality nor do they provide comprehensive coverage. Most low- and middle-income countries only have programmes available in a few specialized centres or areas. There is an urgent need to enhance attention to the mental health needs of vulnerable populations and to reduce inequities in mental health services.

### **Mental health information systems**

Across the world, annual mental health reporting systems exist in 75.8% of countries, though their quality and coverage vary enormously. About three-fifths of low-income and four-fifths of middle- and high-income countries reported that they had these systems.

There is a need to improve the monitoring of mental health of communities, by including indicators of numbers of individuals with mental disorders and the quality of their care, as well as more general measures of mental health, in health information and reporting systems of countries. Monitoring can help in assessing the effectiveness of mental health prevention and treatment programmes, and it also strengthens arguments for the provision of more resources.

### **PROGRESS FROM 2001 TO 2004**

A comparison of data collected in the year 2001 and in 2004 seems appropriate and necessary to assess changes over time. Some changes in data occurred because the method of data collection improved. Many countries responded to queries in 2004 that they had been unable to answer previously and a new Member State was added.

Overall, there was a marginal increase in number of countries with mental health policies and mental health legislation. More countries were providing disability benefits in some form.

A worrisome trend was observed in financing of mental health care. A decrease in emphasis on social insurance (-8.9%) and an increase in emphasis on private insurance (+8%) were observed in lower middle-income countries, and a decrease in emphasis on social insurance (-8.3%) occurred in high-income countries.

More countries were providing community mental health services than before. This change was most marked in upper middle-income countries (+13.8%). An increase (+6%) was noted in terms of availability of mental health services in primary care in upper middle-income countries.

There was a decrease in median number of beds per

10,000 population in high-income countries (-1.2 per 10,000 population) and an increase in middle-income countries, specially upper middle-income countries (+2.3 per 10,000 population). There was a decrease in proportion of mental hospital beds in comparison to all psychiatric beds (-11.7%) in low-income countries. Also, a global trend towards an increase (+3.9%) in proportion of general hospital psychiatric beds to total psychiatric beds was observed.

Globally, there was an increase in the number of mental health professionals. The greatest increase was noted in the number of psychologists engaged in mental health care (median: +0.2 per 100,000 population), especially in upper middle-income countries (+1.10), and in the number of social workers engaged in mental health care (median: +0.1 per 100,000 population). There was an increase in the median number of psychiatrists per 100,000 population in high-income countries (+1.5) and a global decrease in the number of countries with less than one psychiatrist (-5.1%) and psychologist (-6.7%) per 100,000 population. This trend was more marked in middle-income countries.

There was an increase in services for children and elderly in the lower middle-income (+13.3% and +5.6%, respectively) and upper middle-income (+7% and +9.6%, respectively) countries.

Regarding mental health reporting systems, an increase (+9.3%) in the number of countries with such systems was noted in lower middle-income countries.

### **COMMENTS**

It is clear that mental disorders cause considerable burden on individuals, families and societies and are of immense public health importance. Yet, they are under-recognized, under-treated and under-prioritized the world over, despite the fact that effective management options are available and psychiatric care provision does not require sophisticated technologies. The results of Mental Health Atlas 2005 demonstrate that the resources that the world spends on mental health are grossly inadequate in comparison to the needs. The infrastructural, financial and human resources available for mental health are a small fraction of what are needed even to provide basic care to the population.

Inequalities across the countries remain large, especially between low-income and high-income countries. The WHO has consistently argued for a substantial enhancement in resources invested in mental health (1,8). Mental Health Atlas 2005 data clearly show that this need persists unabated.

The Governments, as the ultimate stewards of mental health, need to assume the responsibility for ensuring that the complex activities required to improve mental health services and care are carried out. Mental health policy, programmes and legislation are necessary steps for significant and sustained action. These should be based on current knowledge and human rights considerations.

The Mental Health Atlas 2005 represents the result of WHO's massive effort to provide information on mental health resources and services for advocacy, planning and monitoring change over time. The high volume of hits and downloads on the Atlas website ([www.who.int/mental\\_health/evidence/atlas/](http://www.who.int/mental_health/evidence/atlas/)) reveals that it has been able to fill a real need among the global mental health community. Overall, we hope that the data will assist health planners and policy-makers within countries to identify areas that need urgent attention. The country profiles can also help to set realistic targets by enabling comparisons across countries within similar income groups.

Countries should be assisted in the development of mental health policies. Old policies should be revised, bearing in mind the current situation of the country. Countries with limited resources should develop policies that will help them to achieve realistic goals and improve their mental health facilities. Countries without a policy can seek help by studying policies developed by other countries and by adapting them to their own needs. The WHO provides technical support to assist with the development of comprehensive mental health policies (9).

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S. Saxena, M. Garrido Cumbreira and B. Saraceno are staff members of the World Health Organization. The authors alone are responsible for the views expressed in this publication and they do not necessarily represent the decisions, policy or views of the World Health Organization.

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# Ethics in psychiatry: a framework

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*Defining bioethics as the rational use of dialogue in the formulation, justification, and application of ethical principles, with the aim of generating good practices in research, clinical practice, and advocacy, this paper focuses on methods for bioethical deliberation relevant to psychiatry. Stressing that bioethics fuses the two main ethical traditions in Western thought, the deontological and the teleological, the paper emphasizes the three conditions that any intervention, if considered in the context of bioethics, should fulfil: it should be appropriate to the problem at hand, it should be good (in the sense that it does good to those who receive it but also to those who perform it), and it should be just (in the sense that its outcomes can be generalized to the whole of society). Some implications of these notions for the practice and teaching of psychiatry are presented.*

**Key words:** Bioethics, ethical principles, deontology, teleology

As in other fields of medicine, ethical analysis and reflection in psychiatry can center around many different activities, the aim always being to generate behavior in accordance with individual beliefs, societal customs, cultural norms and respect for human dignity (1).

Among these activities, clinical practice, scientific research, teaching and advocacy are the most visible. Since bioethics is the rational use of dialogue to formulate, conceptualize, and solve dilemmas facing practitioners and researchers, and values are “universals of meaning” which may be interpreted differently by people in different circumstances or positions in life, the new bioethics wave has centered around the establishment of social institutions of a dialogical character (2). In fact, national commissions, institutional review boards, research ethics committees, hospital ethics committees are all expressions of one and the same goal: to bring together different opinions, expectations, forms of expertise, social interests, and to practice the art of deliberation and confrontation in a tolerant and democratic spirit.

In this regard, bioethics manifests the conviction that survival of humankind depends heavily upon finding ways of dealing with differences in philosophical orientation, moral conviction, and ideological makeup. In fields such as medicine, where trust and respect for human dignity are expected, the imperative today is to have every and all decisions endowed with what we may call “ethical sustainability”. This means that decisions should be taken considering not only their viability, their economic sustainability and the satisfaction they may provide, but also in accord with their sustainability over time, their base upon sound and reflective values, and their acceptability in a given cultural context. This is particularly true for decisions taken in the context of scientific rationalities by members of the scientific community (3).

However widespread and accepted the practice of ethics committees in research and clinical settings is, it should be noted that, under special circumstances or in places where quick decisions are needed or not enough manpower is available, other forms of assuring ethical sustainability might be considered. Ethical consultation is

one example, where experts in the field of practical moral reasoning advise practitioners on a given subject or discuss a case. Casuistic analysis by competent scholars may also be of help. In any case, the notion of ethical sustainability through interdisciplinary thinking and dialogical analysis is essential to the key goal to be attained.

There are two main ethical traditions in Western thought relevant to psychiatry. One is the deontological tradition, variously expressed in ethics of obligations, ethics of convictions or, as Max Weber put it, “*Gesinnungsethik*”. This position is usually associated with Kantian philosophy. The other tradition is called teleological, because the main emphasis is placed on the consequences of actions and the attendant responsibility of actors and agents: Weber called it “*Verantwortungsethik*”. Although it may be said that each and every instance of ethical decision-making partakes of the two traditions, practice shows that in medicine practitioners and researchers are more often invited to reflect upon their responsibility towards other people than to show allegiance to a certain belief. No man or woman of science may be obliged to do something against his or her conscience and every person is expected to respect the dignity of human persons and not to harm them. But to be beneficent and to do good is no obligation but rather a conquest of an autonomus moral agent endowed with the ability to empathize with others and think in their good. This is sometimes called “moral imagination” and is part of the implicit knowledge we would like every physician and psychiatrist to possess (4).

## PRINCIPLES OF BIOETHICS AND ETHICS CODES

In the practice of psychiatry, adherence to accepted codes of ethics is important, but the existence of a written code, in and by itself, does not constitute assurance of ethical behavior in the practitioners. As a matter of fact, such codes usually express what the practitioners would like to be and not what they actually are. The practice of psychiatry, perhaps more than the practice of other medical specialties, places a heavy emphasis on dealing with people

that may not always feel the need for expert assistance or may be so incompetent as to not realize what their real necessities are. Ethical training demands careful attention to this particular kind of challenge.

Psychiatric research, on the other hand, faces the same demands as biomedical or biological research, with the proviso, however, that it may incorporate areas that would fall on what we may loosely call “the social sciences”. Such is the case, for instance, of studies on the efficacy of the psychotherapies or on the implementation of alternative models for mental health care, where perceptions of the subjects and participants cannot be excluded as “research noise” and become part of the very interventions under study. Among other considerations, the placebo debate in psychiatry is far more complicated than in purely organic medicine (5).

It must be recalled that the first ethical imperative in research is technical proficiency and that a research protocol without adequate consideration of previous work, faulty research design, or improper handling of data is already unethical, even before it starts. There is no need, if such features are present, to waste the time of an ethics review committee in a needless exercise of analysis.

Perhaps the most widely known documents regarding the ethics of human research are the Declaration of Helsinki, the Belmont Report (6), the Council of International Organizations for Medical Science (CIOMS) Guidelines (7) and the European Guidelines. Key topics in all these documents are informed consent on the part of research participants, independent review of ethical aspects of the proposals, community benefits after completion of clinical trials, distinction between research with therapeutic benefits for participants and research with the sole aim of furthering knowledge, and research with vulnerable populations or incompetent subjects. Consideration is also given to conflicts of interests, financial or otherwise, research with children and pregnant women, and the dilemmas associated with confidentiality, privacy and the dissemination of scientific or factual information.

It has become customary to use the conceptual framework of principlism to address and formulate ethical dilemmas in medicine. According to this position, there exist *prima facie* principles, at an intermediate level between universal values and practical norms of conduct. The Belmont Report introduced the idea that the principles behind moral reasoning in research with human subjects can be subsumed under general headings such as *autonomy*, *beneficence*, *non-maleficence*, and *justice*. Textbooks and a wide body of literature have given currency to the usefulness of formal principles in dealing with case analysis. It should be noted, however, that the term “formal” in this context means that each of the principles may have different expressions or contents in different cultures or institutional environments. Autonomy, for example, although univocal in grammatical sense, is different in an Islamic society and a secular community and, while highly appreciated in some regions of the world, may have

a different value in others. The same holds true for justice and beneficence. This caveat does not imply relativism, but suggests that some degree of cultural sensitivity is essential for an adequate understanding of the contents of each formal principle and the details of its extension and impact in a particular society.

Another aspect that should be noted refers to the relative importance of the principles when applied to particular cases or situations. Although useful, codes of ethics do not indicate which principle should be given priority or preference in a given situation. More often than not, true ethical dilemmas stem from a collision between principles, that is, for instance, when to privilege autonomy over beneficence or vice versa. This is one of the tasks of an ethics committee, along with adequate evaluation of risks and benefits of research or healthcare interventions.

## BIOETHICAL CHALLENGES IN PSYCHIATRIC RESEARCH AND PRACTICE

Psychiatrists and other mental health professionals face the challenge of dealing with human beings in conditions of high vulnerability and establishing relationships with people which are intimate but detached. That is, a psychotherapist or clinical psychiatrist should be in possession of all relevant information about a person in order to be effective, but at the same time he or she should maintain the necessary distance in order not to assume roles different from that of a therapist (friend, lover, mentor) and keep a scientific point of view. Research in some aspects of mental health is charged with emotional undertones, but this fact should not preclude a technical stance in all matters related to design and conduction. No justification can be given for flaws in a scientific study, even if this is carried out for very humane purposes.

Any intervention, if considered in the context of bioethics, should fulfil at least three conditions. First, it should be *appropriate* to the problem at hand. Second, it should be *good* in the sense that it does good to those who receive it but also to those who perform it. Third, it should be *just*, in the sense that its outcomes can be generalized to the whole of society.

If these “coordinates” of rightful action are kept in mind, along with respect for human dignity, then everybody will understand that a good professional recognizes the *duty* to inform subjects or patients and the *right* of these to be informed in order to attain the goals of the scientific enterprise and the healthcare professions.

In addition to clinical practice and psychiatric research, as previously noted, there are other contexts in which ethical behavior is imperative. Teaching psychiatry presents important challenges. Students should know how to help protecting confidentiality and privacy, avoiding stigmatization and refraining from involving personally in the lives of those whom they treat. Learning by doing and learning

by example, two key strategies in psychiatric teaching, demand conscious effort on the part of faculty members.

Professional activities also involve ethical dimensions. Aside from the duties towards patients, there are duties and obligations towards fellow members of the profession or colleagues at the same institution. Conflicts of interests are all those situations in which a manifest motive does not coincide with a secondary motivation, either consciously or unconsciously present. Prestige and the need to advance a career may sometimes collide with truthfulness and friendly relations with peers.

These and other challenges have in psychiatry particular undertones. It is necessary to devise ways in which teaching of traditional ethics is complemented by the dialogical enterprise called bioethics, for it is in the context of deliberation and discussion where tolerance and understanding of diversity can improve the art of healing and curing.

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# Letter to the Editor

Cloninger's article published in the June 2006 issue of *World Psychiatry* (1) makes very important points relevant to psychiatrists all over the world, and in particular to those working in developing countries.

One of the major hurdles for advocacy of mental health care in developing countries is the low value attached to mental health by the general population. We consider this a result of the predominant "deviancy" model of mental disorders, which Cloninger refers to as "an excessive focus on stigmatizing aspects of mental disorders". The general population believes that mental disorders are affecting only a small proportion of people, and consequently are not relevant to them as part of their day-to-day life. We feel that it is only by shifting from the deviancy to the normalcy model (i.e., mental life as something which is a part of everyone's life) we will call the general population's attention to mental health issues.

We shared Cloninger's article with a large number of people who are not psychiatrists. Their response was very positive, ranging from "this is what I was looking for" to "thank you for showing that mental health is more than absence of mental disorders".

The development of a sound science of well-being is a welcome step. The strength of Cloninger's approach is the outlining of simple but measurable dimensions of well-being and gathering of scientific evidence to support the idea. Too often the field of well-being and happiness has been dominated by subjective opinions and anecdotal accounts. Now there is a growing scientific basis for ideas considered to have only face validity (2).

All of the ideas expressed by Cloninger are certainly part of the Indian knowledge and daily practice. Everyday we witness thousands of people pursuing one or another component of well-being through methods described as yoga, meditation, art of living, to name a few. The practice of focusing attention in the present moment on one's own intention and somatic state, such as the breath, has been a mainstay of mindful awareness practices over thousands of years in the East. Now, research demonstrates that such practices are associated with enhanced physiological, psychological and interpersonal functioning (3).

We would like, however, to highlight four limitations of the current state of development of science in this area. Firstly, well-being is very much rooted in the culture of people. There is no universal concept of well-being and there will never be one, as cultures are different in giving importance to different components of mental life. One example is the variation across societies in the importance given to group norms versus individual choices. Secondly, there is no evidence, at present, of changes in the prevalence, pattern and course of mental disorders among those who practice well-being approaches. Thirdly, we are cur-

rently unable to explain the universal distribution of mental disorders, suicide, and substance abuse, in spite of the variations in the cultural, social, religious and related factors in the different communities. It appears as though there is a disconnect between all that we think is important for mental health and what happens in the real life. Fourthly, the current controversies about spirituality and religiosity/fundamentalism make psychiatrists feel uncomfortable working in this field (4).

We would like to propose the following areas for future work: a) the study of mental health in practitioners of well-being programmes in the general population (such studies can identify a specificity of the effects in terms of age, sex, social group or persons experiencing specific situations like grief, disaster or conflict situations); b) the simplification of the actions to be taken by the individuals to pursue well-being, along with local adaptations to take into account cultural norms and social practices, so that they may become a part of routine life and easily integrated into the life of all individuals; c) longitudinal studies in practitioners of well-being programmes exploring the occurrence of disorders/resiliency in different life situations like grief, exposure to trauma, disasters and conflict situations.

We foresee that in the future psychiatry will be moving from mental illness to mental health, and that psychiatrists of the future will not only be working with mentally ill persons, but with all people with a desire to be well and remain free of mental illnesses. Towards this larger goal the contributions of Robert Cloninger are significant and in the right direction.

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# An agenda for change: the role of the WPA in global psychiatric education

**ALLAN TASMAN**

WPA Secretary for Education

This is clearly the most exciting time in history for the field of psychiatry. The expansion of our knowledge base, as the result of advances in clinical description, neuroscience, and other areas related to etiology and treatment, have led to important developments in our approaches to the diagnosis and treatment of individuals with psychiatric illnesses. For example, there has been an increasing recognition of the impact of cultural influences and spiritual beliefs as important factors influencing presentation of illness and symptomatology. Another illustration of dramatic changes is reflected in the field of pharmacogenetics: it is clear that within the next decade psychiatrists will have the capacity to use sophisticated genetic analyses to help make optimal pharmacologic and psychotherapeutic treatment decisions. A major challenge for our profession is to accelerate the process of translating research and scientific advances into a form that can be readily utilized by practitioners. This is especially important in areas of the world with few mental health resources or systems of care. Such translational efforts provide a major educational opportunity within psychiatry, and the WPA is well positioned to become an even more effective force in leading such efforts. Our ability to highlight all aspects of a biopsychosocial model and to widely promulgate educational materials throughout the world cannot be matched by any other organization.

The last decade has been a time of major advances in the educational programs within the Association. The array of WPA educational materials that have been produced in recent years is impressive (all materials are posted on the WPA website, [www.wpanet.org](http://www.wpanet.org)) and includes: a) Essentials of the World Psychiatric Association International Guidelines for Diagnostic Assessment;

b) Teaching and Learning About Schizophrenia; c) Autism and Related Disorders – The Basic Handbook for Mental Health, Primary Care, and Other Professionals; d) WPA/PTD Educational Program on Depressive Disorders; e) Core Curriculum in Psychiatry for Medical Students; f) Core Training Curriculum for Psychiatry; g) ICD-10 Training Kit (prepared in collaboration with the World Health Organization, WHO); h) Social Phobia; i) Mental Health in Mental Retardation; j) The ABCs for Mental Health, Primary Care, Other Professionals; l) The Professional Development of Young Psychiatrists; m) The WPA Bulletin on Depression; n) The WPA Educational Program on Sexual Health; o) the soon to be completed Educational Program on Personality Disorders.

Thus, it can be seen there is an extensive array of programs not only relating to guidelines for diagnostic assessment and treatment of a range of psychiatric disorders, but also to the development of core curricula in psychiatry for both medical students and post-graduate trainees, as well as other issues of professional development. Collaboration with the WHO has been an important aspect of a number of projects, both completed and in development. For example, the Director of the WHO Department of Mental Health and Substance Abuse and I are now collaborating on the development of an educational program on evidence based psychopharmacotherapy, geared especially to the audience of young psychiatrists.

In addition, the WPA has worked to develop a network of global educational leaders available to provide educational and clinical consultation to colleagues around the world. The WPA anti-stigma institutional program, the institutional program for Eastern Europe and the Balkans, and the newly developed institutional program on Asian psychiatry provide other opportunities for educational outreach.

As these initiatives come to fruition, we have a number of opportunities for greater progress in providing a variety of programs which meet the educational needs of psychiatrists working in all regions, in all clinical settings, and in countries in varying states of development regarding mental health resources and services. The WPA must work to ensure that all patients and their treating psychiatrists have access to state-of-the-art educational materials which will allow for optimal treatment, especially in those parts of the world which lack the resources to provide these educational programs locally. To implement such a system, it is essential that the WPA work closely with national societies to further advance the quality of patient care around the world. The key to improving the quality of our patient care is excellence in education and availability of educational resources to all psychiatrists.

A number of priorities are embodied in the workplan for the present triennium. Priorities for educational development over the coming years include the following:

- We must ensure that our outstanding diagnosis and illness-oriented educational programs are available to all psychiatrists. This will require an acceleration of our plans for translation of these programs into a number of additional languages, with the ultimate aim of every country's primary languages being utilized. In addition, we must ensure that these materials are made available in a format in which psychiatrists in all parts of the world have ongoing access to the information. This is especially of concern in areas of the world where access to internet-based programs, journals, or textbooks is presently insufficient.
- In many parts of the world, there are severe shortages of psychiatrists and other mental health personnel to provide adequate clinical services to

those in need. Primary care physicians or primary care nurses often provide psychiatric care to individuals in these parts of the world. A priority for the WPA will be the development of new educational programs for primary care clinicians, especially in developing countries, and new programs regarding the interface between medical illness and psychiatric illness.

- We will devote substantial attention to our evolving program to promote the professional development of young psychiatrists. In this regard, we will work in an expanded educational collaboration between the WPA and the WHO to enhance the ability of the WPA to reach young psychiatrists in all parts of the world. In addition, other underserved areas of the world, such as Eastern Europe and the Balkans, the Middle East, the Indian subcontinent, Africa, some parts of Central and South America, and Central and Southeast Asia, are important regions for targeted educational attention.
- To build on our past successes, it will be essential to increase our collaboration with the WPA Sections, the scientific arm of our Association, to accelerate the process of translating scientific and research advances into educational programs to improve clinical care around the world. In this regard, a new initiative has just begun which will involve the development of a variety of courses which will be available to those sponsoring congresses, either at the level of national societies or regionally.
- Collaboration with the WPA anti-stigma program will occur in order to develop more materials for public education, which take into account the cultural variations across various regions and within various countries. This will include the initiation of programs to increase the translation of these materials into languages accessible to the general public around the world. In this regard, we have an opportunity to use our educational liaison network to assist us in collaboration on this important program.

In addition to these projects geared toward the development of educational programming, several other initiatives are underway to improve the functioning of our educational programs within the WPA itself. These include the following:

- We will develop further interactive mechanisms between the WPA and national societies using the WPA's Zonal Representatives in order to better understand the specific national and regional needs for the development of new WPA educational programs. This will allow us to better allocate our resources to the areas of greatest need.
- We will continue the elaboration of our program for continuing medical education (CME) credits so that these become even more widely accepted by national and international accrediting groups and psychiatric societies around the world. Such a development will enhance the quality and the utilization of our WPA sponsored and co-sponsored educational programming.
- A new system of interaction between those planning WPA regional meetings or co-sponsored meetings and

the WPA educational liaison network and consultant networks will be developed to provide further resources for those who are planning programs for national and regional congresses.

- Within the WPA Board and Executive Committee, the Secretary for Education will continue to work to identify and obtain resources to support the expansion and acceleration of development of all of the priority initiatives noted above.

As can be seen, we have an extensive and ambitious agenda for the development of our educational programs over the coming years. With an outstanding Operational Committee on Education and with our extensive access to educational expertise from colleagues around the world, I feel confident that we will be successful. Not only is this an exciting period in our field, but also within the WPA, and especially regarding the development of our educational programming. I invite anyone interested in assisting with any aspect of our programs to contact me at: [allan.tasman@louisville.edu](mailto:allan.tasman@louisville.edu). I am excited about the future, and look forward to collaborating with many of you as we move forward.

## Advancement of scientific knowledge through international collaborative research

**MIGUEL R. JORGE**

WPA Secretary for Sections

The WPA has experienced a significant growth during the last two decades, particularly regarding its political role and administrative organization, number of Member Societies and Sections, and activities in the fields of meetings, education, and publications.

Particularly, its 65 current Sections – through their leadership and members – are developing different activities such as organizing scientific meetings and sessions within national and interna-

tional congresses; producing educational material, guidelines and consensus/position statements; publishing journals and/or books; promoting research, and establishing collaboration with national and international organizations.

The WPA Executive Committee has recently awarded six different Sections' research projects with partial financial support, in order to enhance its institutional involvement in the development of scientific research. During 2005, G. Christodoulou, past WPA Secretary for Sections, and the former Operational Committee for Sections were responsi-



ble to conduct the selection process and submit some of the research projects to the Executive Committee for a final decision. These projects are summarized below.

**Section on Art and Psychiatry:  
“Exploring and changing the attitude towards the mentally ill in the society through their art” (Main proponent: A. Kopytin)**

The goal of this project is to explore and change the public attitude towards the mentally ill and their artwork through arranging a series of interactive exhibitions and accompanying events, such as workshops and discussions, with different segments of the Russian population. Exhibitions will comprise artworks made in spontaneous creative activities and art therapy sessions by patients with various mental disorders.

Research methods include the use of questionnaires and semi-structured interviews specifically developed to assess discriminating and stigmatizing attitudes and their changes as a result of anti-stigma interventions. Additionally, a narrative method will be used, by which exhibition attendees will be asked to share their responses to artworks and create stories using them as stimuli. Both quantitative and qualitative analysis of data will be used to compare different groups of respondents and to verify to what degree responses change as a result of interactive exhibitions.

**Section on Interdisciplinary Collaboration: “The impact of war and natural disasters on newborn babies and their future health” (Main proponent: U. Halbreich)**

The specific aims of this project are: a) to retrieve information on babies born with low birth weight (LBW) and/or pre-term delivery (PTD) and other delivery adversities from delivery room charts in Baghdad (Iraq), former Yugoslavia countries and the Tsunami disaster areas following periods of wars and disasters; b) to compare this infor-

mation to that concerning deliveries during the pre-war and disaster periods.

It has been previously reported that, during or immediately following violent conflicts and a decrease in individual safety, the prevalence of LBW and PTD is higher than during periods of peace. If this finding is confirmed in this study, the affected children may be identified, and their developmental, physical, behavioral and mental health variables may be followed up, and preventive interventions may be developed and assessed.

**Section on Mass Media and Mental Health: “Detection and modification of prejudice against psychotic disorders within the social context” (Main proponent: M.A. Materazzi)**

This research is meant to delve into prejudice as a variable within the social context and, in particular, into community-linked prejudice against mental sufferers.

A community will be chosen and an in-depth promotion field work will be carried out. The first workshop will include all the district social sectors without, however, exceeding 100 people present. Thereafter, different workshops will be organized for each different sector once a month. An opinion survey will be administered to participants before the first workshop begins and afterwards to check out whether any modification has occurred.

**Section on Measurement Instruments in Psychiatric Care: “Cross-cultural adaptation of the Schedules for Clinical Assessment in Neuropsychiatry (SCAN)” (Main proponent: A. Janca)**

The main objective of this study is to produce a cross-culturally applicable adaptation of the World Health Organization (WHO)'s Schedules for Clinical Assessments in Neuropsychiatry (SCAN).

The project objective will be approached in three phases. The initial phase will consist of an anthropological

analysis of SCAN to detect those aspects which are not cross-culturally applicable. An annotation will be used to adapt SCAN and produce an alternative SCAN interview schedule in which cultural sensitivity is established. The results of phase 1 will then be considered in the key informant interviews and focus group discussions held during phase 2. During phase 3 of the project, one interviewer will administer the modified version of SCAN as well as the original SCAN 2.1 to sixty individuals of two distinct cultural backgrounds. The diagnostic outputs from the standard and adapted SCAN schedules will be compared and analyzed using the kappa statistics.

**Section on Quality Assurance: “Rehabilitative psychoeducation of bipolar patients and quality of life” (Main proponent: F. Lolas)**

This study aims to evaluate qualitatively and quantitatively the incorporation of a psychoeducational intervention in the treatment of bipolar patients.

Specific objectives will be: to identify factors affecting treatment adherence; to identify factors influencing recurrence; to compare levels of adherence and recurrence in patients under psychoeducational intervention and controls; to evaluate quality of life in patients receiving the psychoeducational intervention and controls using the scales of hostility and anxiety through verbal content analysis; to evaluate the level of stigma in patients receiving the psychoeducational intervention and controls; to propose bioethics as a tool to justify the psychoeducational interventions, aiming to improve quality of life for bipolar patients and their social integration.

**Sections on Schizophrenia and on Stigma and Mental Disorders: “Antistigma modules for mental health professionals: development and implementation of educational modules for mental health professionals for the destigmatization**

**of patients with schizophrenia”  
(Main proponents: W. Gaebel  
and A.E. Baumann)**

This project aims to develop specific educational modules for antistigma training of mental health professionals (so called “antistigma modules”), which shall be translated and adapted in all

countries participating in the WPA Antistigma Programme and in other countries. The modules shall include: a) methodological information about the conduction and evaluation of antistigma training of mental health care staff; b) information for special needs of the target group (raising the awareness on stigmatizing attitudes and discriminat-

ing behavior).

Train-the-trainer seminars and evaluation services shall be then offered in collaboration with the WPA Section on Schizophrenia, the WPA Section on Stigma and Mental Disorders, the centers participating in the WPA Antistigma Programme and the WPA Member Societies.



