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## 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 150,000 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 64 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 WPA tsunami programme

AHMED OKASHA

President, World Psychiatric Association

The WPA is concerned with the long-term strategy of assisting in alleviating mental health consequences of disasters, currently the tsunami disaster. The WPA is not a fund raising association, but it can deliver the required technology to those afflicted by the disaster.

The first meeting of the steering committee of the WPA tsunami programme was held in Cairo on February 12, 2005. After presenting and reviewing the actual situation and needs in the region, several proposals for action were discussed.

The WPA will set up a worldwide network of psychiatrists with expertise and commitment to psychosocial disaster relief and who can be contacted to activate relief services in their own and nearby needy countries, according to language and cultural requirements. The WPA agrees on a policy to have a response to disasters that can function at short notice, effectively.

A WPA disaster fund was initiated and is already receiving support from individuals and organizations. Contributions can be sent to the account number 426-5000545-65, J.P. Morgan Chase Bank Routing # 021 000 021. This fund should allow the WPA to help victims not only of the tsunami disaster but also of future man-made and natural disasters, by providing the needed logistics for training of health care workers.

The WPA will collect, in collaboration with the Department of Mental Health and Substance Abuse of the World Health Organization (WHO), the available documents and programmes for disaster interventions. Those which

are valid, reliable and endorsed by the WHO will be linked to the WPA website. Financial support will be provided to the WPA member societies of the affected regions if a clear project with objectives, budget, timetable and expected outcome is presented.

It was decided that an immediate sum of US\$ 10,000 each will be made available to the Indonesian Psychiatric Association and the Sri Lankan College of Psychiatrists, for conducting training of trainers and other health care workers in primary care psychiatry and the management of psychiatric and mental health problems of the survivors of the tsunami disaster for the next year. Further funds are being assigned to long-term activities after the first year, to finalize the translation of the multimedia disaster program prepared by the WPA section on disasters and for the evaluation and implementation of the activities with a special focus on child mental health.

A second meeting of the steering committee of the WPA tsunami programme was held in Athens on March 10, 2005. The transfer of funds to the Indonesian Psychiatric Association and the Sri Lankan College of Psychiatrists has been made and the planned activities have started.

This is an ongoing process, hoping that the WPA can implement its objectives of promoting mental health in the afflicted region taking the cultural, religious and social values into consideration, especially after the feedback and reports received from the afflicted persons showing an extraordinary resilience in coping with the tragedy through their religious and spiritual beliefs.

# The WHO's mental health response to the Asian tsunami

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The World Health Organization (WHO)'s mental health activities relevant to the Asian tsunami of December 2004 started a long time before the tsunami and will continue for years to come. Different departments and offices of the WHO have been active in organizing a mental health response. WHO's essential roles in emergencies include advising the Ministries of Health (MoH) on mental health policy, assisting the MoH in planning and coordinating a response, assisting the MoH in monitoring the quality of outside technical assistance, and assisting with (re)construction to build a sustainable national mental health service capacity. These roles derive from the unique mandate that the WHO has and are quite distinct from the roles played by other agencies, such as non-governmental organizations (NGOs), professional associations and academic departments.

## PRE-TSUNAMI ACTIVITIES

The WHO Department of Mental Health and Substance Abuse has in recent years outlined a normative framework for developing community mental health services (1) and for developing mental health strategies and interventions during and after emergencies (2). After the tsunami, the document "Mental Health in Emergencies" (2) has been the most used mental health document by agencies in the field. The document provides the framework for the pre-tsunami MoH draft mental health policy for Aceh and for current post-tsunami mental health plans of the MoH in Indonesia and Sri Lanka. Key interventions outlined in "Mental Health in Emergencies" can be found also in the influential "Sphere Handbook" (3), which has been widely promoted by key aid organizations as guidance for the multi-sectoral tsunami aid response. WHO staff also wrote a scientific paper on the emerging consensus on mental and social aspects after acute disasters, that coincidentally got published a few days after the tsunami (4). In other words, the WHO's technical advice – whether through its own documents or through other organizations – has influenced social and mental health interventions after the tsunami.

Not long before the tsunami, the WHO developed a mental health plan for conflict-affected Northeast Sri Lanka, in close collaboration with mental health experts from that region. This plan – influenced by the existing organization of services in Jaffna – centers around having one multi-disciplinary team per district. An adapted version of this Northeast plan is presently used by the Sri Lanka government, by WHO Sri Lanka and by a variety of international NGOs with expertise in psychiatry as the

framework for developing long-term post-tsunami community mental health services in the districts of Sri Lanka.

## ACTIVITIES AFTER THE TSUNAMI

WHO's work before the tsunami in Sri Lanka has had an impact on the mental health response after the tsunami.

The existence of WHO regional and country offices made it possible for the WHO to begin providing assistance since the first day of the emergency. Basic WHO documents on mental health in emergency were made available in the field within a few days of the disaster. Senior WHO staff and consultants were on site within 2 weeks and continued to stay for many months. The following key activities have been undertaken.

### Support to the Ministries of Health

The WHO provided immediate support to the MoH in estimating the mental health needs and preparing strategies/action plans to respond to these. It also provided technical assistance in the form of documents, training manuals and advice on the mental health interventions. WHO Headquarters produced a manual on tsunami-affected children (5) and a briefing note on the projected extent of mental health problems with recommended responses (6).

### Coordination

One of the key needs in the post-disaster period is coordination to match offers of assistance with the needs. The WHO has been part of the coordination committees of the countries to ensure an effective and consistent approach for all psychosocial and mental health activities. This role has included screening all offers of assistance, selecting those that are likely to serve the populations best, directing them to the areas with maximum needs, twinning with local institutions and professionals and saying no to offers that are unlikely to be of any value (e.g., short visits by experts, professional counselors who do not speak local languages). Given the massive international response to the disaster, coordination tasks have been substantial.

### Training

The WHO has assisted in training of health and other sector professionals and workers in providing basic mental health care. A phased plan for systematic training is in

place in all countries, using WHO materials adapted to the local situations.

### Strengthening of mental health services

Almost all areas affected by tsunami had poor mental health services before the disaster. WHO is working with the MoH, local institutions and professionals and with international agencies to strengthen mental health services to respond to the pre-existing as well as newly emerging needs. These services are based on the community mental health model and are designed with a clear view of sustainability.

### Resource mobilization

The WHO has mobilized adequate financial and human resources to respond to the needs for the initial six months of mental health activities. Since donor interest often wanes quickly after disasters, WHO is making serious efforts to mobilize large resources to implement the long-term plans that it has developed.

### CONCLUSION

Large scale tragedies such as the one caused by the Asian tsunami pose enormous challenges in terms of men-

tal health care for the affected populations. The WHO is playing a unique role to ensure that the mental health response is quick, appropriate, substantial and sustained. Disasters provide a window of opportunity to develop much needed community-based mental health services in under-resourced regions.

This opportunity – even when its cause is very sad – cannot be missed.

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# The mental health challenge in Sri Lanka from working within the disaster area

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This perspective is based on our experience in working in the disaster-affected areas of Sri Lanka, as part of the regional task force established by the WPA and the Indo Australasian Psychiatry Association (IAPA), in order to evaluate and plan for the required psychosocial and mental health supports for the affected areas.

The mental health problems in Sri Lanka currently include: a) the mental health problems found in normal times; b) a substantial increase in common mental disorders and other mental health problems due to the adverse effects of the recent disaster; c) the mental health problems due to the adverse effects of conflicts in the North and East of the country. The burden of these problems is not only on the mental health system, but also on the general health system, where most patients tend to seek help for mental health problems, which are typically presented in the form of somatic complaints. The required efforts will not only have to centre on the immediate needs of this population with morbidity, but also include medium- and long-term plans aiming at a) building capacities and b) building and enhancing resilience and coping.

Our current experience with the victims of the tsunami disaster suggests a low prevalence of post-traumatic stress disorder (PTSD) as experienced in similar situations in the West. On the contrary, somatization seems to be common, and the somatic complaints are usually presented to physicians, cardiologists and even surgeons.

Due to the lack of mental health resources and the very limited psychological mindedness of these cultures, psychiatric morbidity usually remains unrecognised and not treated. Compounding this has been the influx of well-intended non-governmental organizations, which are bent on offering trauma-focussed interventions to segments of population affected by the disaster. The interventions most often implemented to reduce traumatic stress are one off psychological debriefing and some benzodiazepines. This approach of promoting PTSD case finding and trauma focussed treatment, in the absence of a system wide public health approach considering pre-existing human and community resources, might be not appropriate.

Another recognisable issue is the place of religion, spirituality and rituals in enhancing resilience, coping and rebuilding through acceptance and finding some meaning even in suffering and loss. It was indeed of significance when a woman who had lost her family and all her possessions told us "I have lost everything I had and now I have only my God". This is at a time when some of us in our safe

and comfortable abodes in our cities are debating the existence of a God in the context of this natural disaster. From the interviews of these disaster victims we established that, rather than rocking their faith, this set back has bolstered their belief. If our experience in the affected areas is evenly remotely right, it illustrates the prevalence of faith in the world. Thus, in these resource poor areas, the collaboration of medical and mental health professionals with appropriate traditional resources, such as faith healers, pastoral care, clergy and similar, is seen as an important and necessary engagement and an opportunity in terms of care, provision of meaning and general community support.

We believe that management of this disaster will need to be tailored to each of the regions, that have varying needs, resources and cultures. To address this situation of massive needs and very limited professional resources, many innovative approaches will have to be considered. These will include training alternative professionals and use of community resources such as teachers, appropriate faith healers, clergy and volunteers to empower the population. In the promotion of culturally acceptable forms of coping, some strategies and interventions that have been used successfully in other disaster situations may be considered. One example, borrowed from the Education for Peace program of Lebanon, is the technique not to focus on the child's emotional wounds but to re-establish a sense of normality by providing education and educational materials and fostering an environment in which wounds will heal naturally. As there is evidence of a high correlation between mother's distress and that of the child, the whole family should become the focus of effective support, by increasing communication among family members, strengthening family rituals and sharing of emotions.

Traditional methods of support and community solidarity should be encouraged. With the massive loss of life and large-scale displacement that has taken place, the rebuilding of community support is in reality a way of promoting mental health of the population. The media can have an important positive influence in spreading the mental health promotion message to the general population.

Finally, in all the efforts to help, there is a temptation to implement short-term measures to alleviate suffering. This, however, must be accompanied by a long-term plan to rebuild essential mental health services at the primary, secondary and tertiary levels. This will mean not only empowerment of the people, but preparing the population for future disasters and emergencies.

# The multimodal treatment of eating disorders

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*The treatment of eating disorders is based on a multimodal model, recognizing that these disorders do not have a single cause or a predictable course. The treatment strategy is determined by the severity of illness and the specific eating disorder diagnosis. For the treatment of anorexia nervosa, the key elements are medical management, behavioral therapy, cognitive therapy and family therapy, while pharmacotherapy is at best an adjunct to other therapies. In bulimia nervosa, the treatment of choice is cognitive-behavioral therapy, but a greater improvement in mood and anxiety occurs when antidepressant therapy is added. In binge eating disorder, cognitive-behavioral therapy and interpersonal therapy produce substantial and long-lasting changes and pharmacological treatment has often a useful role.*

**Key words:** Eating disorders, multimodal treatment, cognitive-behavioral therapy, pharmacotherapy, nutritional rehabilitation

The treatment of eating disorders is based on a multimodal model. This model recognizes that eating disorders do not have a single cause or a predictable course. They begin with dieting or restrained eating behavior. Often the dieting is for the purpose of becoming thinner and more attractive, or it may follow a severe stress or physical illness. Behaviors and influences antecedent to the dieting experience can be categorized as problems of biological vulnerability, psychological predispositions, family disturbances, and environmental-societal influences. The integrated effect of these disturbances on dieting behavior propels the individual person into developing an eating disorder. As the dieting continues, starvation effects, weight loss, nutritional effects, and psychological changes occur. A sustaining cycle of core dysfunctional eating behaviors develops with both psychological and physiological reinforcement.

For the anorexia nervosa patient, psychological reinforcement occurs as the patient develops a sense of security and effectiveness while she realizes that dieting and losing weight is something she can control very well with consummate skill. Physiological changes in the dopaminergic, serotonergic and opioid neurotransmitter systems most likely aid in reinforcing the starvation behavior. For bulimia nervosa, the psychological reinforcement comes about when the patient realizes that binge eating can alleviate anxiety in a manner similar to alcohol or drugs. During the process of self-induced purging, dopamine is released in the brain and likely contributes to the physiological reinforcement of the binge/purge behavior.

## RISK FACTORS

There are several different categories of risk factors for developing eating disorders. Familial risk factors have been demonstrated with family studies. If one has a family member or relative with anorexia nervosa, bulimia nervosa or obesity, then one has a greater chance of developing an eating disorder (1). Also, if one has a family member or relative with depression or alcohol/drug abuse/dependence,

one is at a greater risk for developing an eating disorder. Individual biological factors include being mildly overweight or having an early menarche (2).

Genetic studies have shown a significant linkage on chromosome 1 for restricting anorexia nervosa (3) and a significant linkage on chromosome 10 for bulimia nervosa (4). There have been no consistent and replicated findings for polymorphisms of specific genes with association studies. Possible genetic vulnerabilities include a predisposition to a particular personality type, predisposition to a psychiatric disorder (affective or anxiety disorders) or predisposition to neurotransmitter dysfunction. Thus, a genetic predisposition and vulnerability may become manifest under adverse conditions such as inappropriate dieting or emotional stress.

Biological vulnerability can include dysfunction of neurotransmitters such as serotonin, dopamine and norepinephrine that regulate eating behavior. Studies have shown that all three of these neurotransmitters are dysfunctional in eating disorder patients (5-7). Aberrations of neuropeptides regulating eating behavior are also present in eating disorders. Such changes are present in neuropeptide Y, opioids, leptin, cholecystokinin, ghrelin, melanocortins, adiponectin, agouti-related protein, and brain derived neurotrophic factor (8).

Signals from the periphery, including gut-related peptides and adipokines, interact with hypothalamic peptides in the regulation of feeding behavior and body weight. State related changes in nutrition and body weight influence cerebrospinal fluid and plasma levels and receptor activity of neuropeptides (9).

Individual psychological risk factors include a perfectionistic-obsessional personality, which is a risk especially for the restricting type of anorexia nervosa (10). Low self-esteem and a sense of ineffectiveness, lack of confidence and a feeling of inadequacy are risk factors for anorexia nervosa and bulimia nervosa (11). Affective disorders (depression), alcohol and drug abuse are risk factors especially for bulimia nervosa (12).

Individual behavior such as dieting or involvement in activities or professions that emphasize weight control –

such as gymnastics, ballet, wrestling, jockeys, actors and models – are additional risk factors (13).

In addition to the biological and psychological risk factors, there is the influence of social climate. This includes cultural risk factors such as living in an industrialized country, emphasis on thinness as being beautiful, and in the U.S. a significant general weight increase over the past 40 years (14). Stressful life events, such as death of a close relative or friend or sexual and physical abuse, can also be risk factors for the development of an eating disorder (15).

## TREATMENT

Both the severity of illness and the specific diagnosis will determine the treatment strategy for an eating disorder. Guidelines have been developed for the treatment of different degrees of severity of illness and are established from hospitalization to day programs to intensive outpatient therapy to group therapy (16). There are no randomized controlled trials that adequately assess the intensity of treatment. The major categories of eating disorders are anorexia nervosa, bulimia nervosa and binge eating disorder. Variations of these disorders are treated similarly to the major diagnostic category which they approximate.

There are three reviews of new treatment research in eating disorders with critical analyses. These include the Cochrane reviews (17), the Australian and New Zealand practice guidelines for the treatment of anorexia nervosa (18) and the guidelines for treatment of eating disorders by the National Institute for Clinical Excellence in London (19).

### Treatment of anorexia nervosa

For treatment of anorexia nervosa, the key elements are medical management, behavioral therapy, cognitive therapy and family therapy. Pharmacotherapy is at best an adjunct to the other therapies in this disorder. Nutritional rehabilitation and weight restoration are essential. Behavioral therapy is useful in managing weight gain and prevention of binge eating and purging. Cognitive therapy addresses the distorted cognitions of feeling fat, evaluating self-worth solely by body image and the pervasive sense of ineffectiveness and inadequacy. Family therapy is especially effective for children under the age of 18. Fluoxetine may prevent relapse in patients who have obtained at least 85% of a normal weight. Atypical antipsychotics may be useful in reducing severe anxiety and augmenting weight gain (20).

Nutritional rehabilitation programs usually employ emotional nurturance and a variety of behavioral interventions, which involve a combination of reinforcers that link exercise, bed rest, and privileges to target weight, desired behaviors and informational feedback. There are no randomized controlled trials to demonstrate the superiority of nasal gastric tube feeding over oral feeding in nutritional rehabilitation. Advocates claim that such intervention may

hasten weight gain without deleterious effects. Supplemental nocturnal nasal gastric refeeding has been used for better short-term outcome in hospitalized adolescent girls with anorexia nervosa. Other centers have used voluntary nasal gastric tube feeding and have taught patients how to insert their own tube. Adequate controlled trials have not been conducted for this type of intervention.

For individual psychosocial interventions, there continues to be difficulty in recruiting and retaining patients. At least a one-third dropout rate or withdrawal due to relapse complicate the interpretation of randomized controlled trials (21). There is some indication that cognitive-behavioral therapy following weight gain may reduce the risk of relapse (22).

Family therapy is the most effective treatment for adolescents with anorexia nervosa and seems to be equally effective when administered as conjoint or as separated family therapy (23). Overall, 6 months of therapy also seems to be as effective as 12 months; however, patients with severe obsessive-compulsive disorder may require longer treatment (24). There is little formal study of the efficacy of group psychotherapy for the treatment of anorexia nervosa or the usefulness of support groups for this disorder.

Two core assumptions are made about anorexia nervosa in cognitive therapy. First, food avoidance, necessary to maintain a low weight, is essentially a food phobia. Second, anorexia nervosa serves a positive function: it provides an escape from aversive developmental issues and distressing life events often of an interpersonal nature.

One element in cognitive therapy is cognitive restructuring. In this approach the patient must identify specific negative thoughts, list the evidence for these thoughts, list the evidence against the thoughts, form a reasoned conclusion and use the reasoned conclusion to guide her behavior. Another element in cognitive therapy is problem-solving. In this procedure the patient identifies a specific problem, develops different strategies, considers the likely effectiveness and feasibility of each strategy to deal with the problem, selects the best strategy, defines the steps to carry out the strategy, carries out the chosen strategy and then evaluates the entire problem-solving process in light of the outcome. Another essential element in cognitive therapy is monitoring. For this the patients must make daily records of food intake, including the type of food ingested, the time of ingestion and the environment where the ingestion occurred. Monitoring also includes daily records of binge/purge behavior, exercise, mood and interpersonal difficulties (25).

Pharmacotherapy of anorexia nervosa is limited. Cyproheptadine facilitates weight gain in restrictive anorexia nervosa and has an antidepressant effect. Chlorpromazine or olanzapine may reduce severely obsessional, compulsive and agitated behavior; a side effect is weight gain. Fluoxetine may reduce relapse of weight and eating disorder behaviors in weight restored patients.

There are few new randomized controlled trials of pharmacotherapy for anorexia nervosa. These trials have



shown fluoxetine in a dose of 60 mg/day adds no benefit to inpatient treatment of underweight anorexia nervosa patients. Another trial of 35 anorexia nervosa patients that were partially weight restored showed some indication that fluoxetine during weight maintenance may decrease the relapse rate (26). A third trial, which compared three drugs, clomipramine, fluoxetine and amisulpride, in inpatients showed that amisulpride had the best effect on weight gain (27).

From the recent promising pilot studies of pharmacotherapy in anorexia nervosa we can conclude that antipsychotic medications such as olanzapine and quetiapine may be helpful during the weight restoration phase. Citalopram may reduce depression and anxiety during weight restoration. Fluoxetine is not beneficial in weight restoration but may decrease relapse rate in anorexia nervosa patients. Nutritional supplements with L-tryptophan do not increase effectiveness of fluoxetine (28).

There are many problems with these treatment studies of anorexia nervosa. First, there are very few randomized controlled trials. Second, patients are not motivated for treatment. This is evident in that patients do not enter trials and dropout rates are high. Third, medical complications often require withdrawal from trials. Fourth, very small sample sizes are present in completed trials.

### Treatment of bulimia nervosa

The treatment of bulimia nervosa has several key elements. Cognitive-behavioral therapy, which can be conducted as individual or in group format, has a psychoeducational component and requires self-monitoring. Other techniques are cognitive restructuring, problem-solving and cost benefit analyses. Behavioral therapy in the treatment of bulimia nervosa is usually in conjunction with cognitive therapy. In this form of treatment, restricting exposures to cues is common as well as developing alternative behaviors with response prevention techniques to stop vomiting. Interpersonal therapy focuses on interpersonal relationships and classifies the type of interpersonal problem. Pharmacotherapy has shown best results with selective serotonin reuptake inhibitor drugs, which reduce binger/purge behavior. These are preferred because of the lower side effect profile. Tricyclic antidepressants also reduce binge/purge behavior but have greater side effects.

In contrast to anorexia nervosa, treatment studies of bulimia nervosa have proliferated in the past 15 years. Controlled studies of specific therapy techniques such as behavioral therapy, cognitive therapy, psychodynamic therapy and psychoeducation therapy have been conducted in both individual and group therapy format. Multiple controlled drug treatment studies have also been conducted. Often a variety of therapy techniques are used together in either individual or group therapies. There is no way at present to predict which bulimic patient will respond to what type of treatment.

Cognitive-behavioral therapy is the first choice treatment for bulimia nervosa. It was the most effective treatment in 35 controlled studies, which showed 40 to 50% of patients abstinent from bingeing and purging at the end of treatment (16-20 weeks). Reduction in bingeing and purging occurred in 70 to 95% of patients. Thirty percent with no improvement post-treatment showed improvement to full recovery one year after treatment (29).

There is some evidence that treatment programs which include dietary counseling and managing are more effective than those that do not. The nutritional rehabilitation in bulimia nervosa involves establishing patterns of regular, non-binge meals. Increasing caloric intake and expanding macronutrient selection in meals is also important. This will likely correct any nutritional deficiencies that may be present.

Another psychotherapy shown to have some effect in treating bulimia nervosa is interpersonal therapy. Focus psychodynamic psychotherapy was not as effective as cognitive-behavioral therapy in short term trials. Behavior therapy with exposure and response prevention had no additive benefits over cognitive-behavioral therapy. A meta-analysis of 40 group psychotherapy treatment studies suggested moderate efficacy. Groups that included dietary counseling were more effective, as were groups with more frequent visits during treatment. Many clinicians favor a combination of individual and group therapy in the treatment of bulimia nervosa (30).

There are no randomized controlled trials of family therapy in the treatment of bulimia nervosa: it may be considered for adolescents. Self-help manuals and guided self-help manuals use cognitive-behavioral techniques: there are limited trials with varying results; more development of these self-help manuals and larger studies are needed. Dialectical behavioral therapy focuses on training in emotional regulation skills: one study showed significant improvement compared to a waiting list (31).

A summary of pharmacotherapy in bulimia nervosa concludes that all antidepressants are better than placebo for reducing binge eating. Over a dozen double-blind placebo controlled trials of antidepressants have been conducted with a dosage similar to the treatment of depression. Medications improved mood and preoccupation with shape and weight in about 20% of patients. Complete abstinence from bingeing and purging, however, occurred in only 20 to 30%. Some medications that have been effective in reducing binge frequency should not be used in treating bulimics because of their side effects. Bupropion has been associated with convulsions in bulimic patients. Trazodone has been associated with producing delirium in a few bulimic patients. The monoamine oxidase inhibitors can cause hypertensive crises if bulimic patients do not follow the required restricted diet (32).

Fluoxetine in a dose of 60 mg/day is the drug of first choice because of beneficial effects and a favorable side effect profile. If the first trial is unsuccessful there is evi-

dence that another antidepressant trial may be effective. Minimal duration of successful treatment should be 6 months. Baseline laboratory assessments such as cell blood count, serum electrolytes, liver function tests, blood urea nitrogen/creatinine ratio, thyroid function and electrocardiogram should be obtained.

Ondansetron, a 5HT<sub>3</sub> antagonist, decreases afferent vagal activity and has been shown to have a mild effect on reducing binge/purge behaviors in bulimic patients. However this drug has serious side effects of constipation, headaches and abdominal pain. Topiramate has been shown to effectively reduce binge/purge behavior in a double-blind placebo-controlled trial in bulimia nervosa patients: this medication must be initiated in a very low dose of 25 mg/day and gradually increased with a maximum of 400 mg/day. A slow increase of dosage will help prevent side effects of fatigue, paresthesia, difficulty concentrating, and influenza-like symptoms. The opiate antagonist naltrexone, in a dose of 200-300 mg/day, has been shown to reduce binge/purge behavior. However, there is a concern of liver toxicity at this dosage (33).

Three randomized controlled studies comparing cognitive-behavioral therapy and pharmacotherapy showed that the combination was superior to medication alone. One study showed that the combination was superior to cognitive-behavioral therapy alone, while the other two studies did not show this (34).

In conclusion, the treatment of bulimia nervosa can be summarized by stating that binge eating, purging, and core eating disorder attitudes respond best to cognitive-behavioral therapy. A greater improvement in mood and anxiety occurred when antidepressant therapy was added.

### Treatment of binge eating disorder

Binge eating disorder is still considered in the category of eating disorders not otherwise specified. This disorder is distinguished from bulimia nervosa by a lack of compensatory behaviors to counteract the caloric intake and weight gain from binge eating episodes. These patients do not purge, exercise or engage in dieting. Randomized controlled treatment trials have used the same techniques as those for bulimia nervosa. Patients with binge eating disorder have responded well to cognitive behavioral therapy and antidepressants that have been effective in treating bulimia nervosa (35).

A summary of psychotherapy treatment research for binge eating disorder is as follows. Cognitive-behavioral therapy and interpersonal therapy produce substantial and long lasting changes in the specific and general psychopathology of binge eating disorder. Cessation of binge eating is associated with both weight loss and maintenance of this loss over a 1 year period.

Double-blind placebo controlled trials of antidepressants have shown that desipramine, fluvoxamine, fluoxetine, sertraline and citalopram all reduce binge eating and

are associated with weight loss in the treatment of binge eating disorder. Other drugs shown superior to placebo for binge eating disorder are phenytoin and topiramate. There is one positive open study for zonisamide. Pharmacological treatment should be considered as an option in all cases of binge eating disorder, not just those with concomitant mood disorders. It should be considered strongly in those who fail to respond to psychological treatment. One should consider trials of topiramate, a selective serotonin reuptake inhibitor, sibutramine, venlafaxine, bupropion (no purging or history of bulimia nervosa or anorexia nervosa) and zonisamide. Be prepared if necessary to conduct a minimum of three trials to obtain an optimal response. Choose medication based on patient comorbidity and preference in side effect profile. Use doses similar to those for approved indications. Treat for a duration similar to that for bulimia nervosa or major depressive disorder: for example, 6 to 12 months at a level of substantial improvement before attempting discontinuation of the drug. In some cases treatment may need to be continued indefinitely (36).

### CONCLUSIONS

In conclusion, the treatment of eating disorders is based on a multimodal approach. Patients need to be treated with a multidisciplinary team, including a psychiatrist for pharmacotherapy and psychotherapy, a nutritionist for nutritional education and meal planning, an internist or pediatrician for medical care and a family therapist for children under the age of 18.

For the treatment of anorexia nervosa, the key elements are medical management, behavioral therapy, cognitive therapy and family therapy, while pharmacotherapy is at best an adjunct to other therapies. In bulimia nervosa, the treatment of choice is cognitive-behavioral therapy, but a greater improvement in mood and anxiety occurs when antidepressant therapy is added. In binge eating disorder, cognitive-behavioral therapy and interpersonal therapy produce substantial and long-lasting changes and pharmacological treatment has often a useful role.

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# Constructivism and psychotherapy

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*Constructivism is a metatheoretical perspective that embraces diverse traditions in medicine, philosophy, psychology, and spiritual wisdom. Constructive psychotherapy emphasizes complex cycles in the natural ordering and reorganizing processes that characterize all development in living systems. Individuals are encouraged to view themselves as active participants in their lives. Within rich contexts of human relationship and symbol systems, people make new meanings as they develop. Techniques from many different traditions can help people find and refine their sense of balance as they develop.*

Key words: Constructivism, systems, development, psychotherapy

The question has been raised: “What is it about constructivism that is new or different?” This question speaks its own presumption. To ask how constructivism differs from other views is to presume that difference is important. This is one of the ordering principles acknowledged by constructivism. We tend to think in categories, such as similarity and difference. Constructivism is not a new tree in the forest. It is, rather, a glimpse of the connectivity among all trees, along with their elaborately networked supports. What is developing is not just a new theory or model. Constructivism is a perspective on personal psychology, social functioning, and human change. It is both old and new. Unity and diversity are being integrated in ways that speak to traditions of holism and hope. Dialogues are taking place that suggest an evolutionary leap in our understanding of what it means to be human. The emphasis is on connection rather than separation. Differentiation is a necessary and natural part of development, but it can stagnate into separation and isolationism. Integration can sometimes oversimplify or reduce the attention given to important differences. Constructivism is emerging as a metaperspective that recursively recognizes its necessary limitations at the same time that it embraces a hope of continuing development. Brain, body, emotions, and social embeddedness are honored. And spirit – in its marvelous spectrum of meanings – pervades.

Constructivism emphasizes the dynamic structure of human experience. The verb ‘to construct’ means to organize or create order. Structure tends to have connotations of a static phenomenon. Life and human consciousness are anything but static. Hence, one of the central emphases of constructivism is process. Psychological stability is viewed within the context of process, not to be viewed in opposition to process. Consider the apparent stability of the body. The human body recomposes itself every seven years. Just as the human body decomposes and regenerates, a parallel psychological renewal evolves through a synchrony of continuity and change.

Constructivism is a philosophy of participation in which individuals and communities are encouraged to be active in their own unfolding. Constructive psychotherapy includes

a diversity of techniques. It is not defined by specific techniques but rather by the individuation and developmental pacing of different techniques. More importantly, a constructive approach to psychotherapy emphasizes the importance of human relationships in well-being and development. The constructive therapist collaborates with the client in seeking to foster the unique ways that the client achieves proactive change. Hence, the goal of therapy is proactive change vis-a-vis change that happens in the course of human *being*. The collaborative therapeutic alliance is an egalitarian (non-authoritarian) contract that distributes the responsibilities for change. Although the client is the primary change agent, the therapist brings clinical expertise and a human “vested” interest in the change process. Clients are not viewed as objects, but as agents. Psychotherapy is not something done *to* them but *by* them.

## THE ESSENCE OF CONSTRUCTIVISM

Constructivism is expressed in a range of perspectives on human experiencing. Constructivist themes can be found in Asian philosophy (Lao Tzu and Buddha), Western philosophy (Heraclitus, Kant, Vico, Schopenhauer and Vaihinger), and in the works of a plethora of pioneer and contemporary psychologists (Adler, Bandura, Bruner, Bugental, Frankl, Gergen, Goolishian, Kelly, Piaget and Watzlawick). From the diversity of such works as these, one can draw five basic themes that constitute the essence of constructivism. These themes are: a) active agency, b) order, c) self, d) social-symbolic relatedness, and e) life-span development. Succinct statements of each theme will be followed by a brief elaboration.

Constructivism is a meta-perspective from which:

- Human experiencing involves continuous *active agency*.
- Much human activity is devoted to *ordering processes* – the organizational patterning of experience. These ordering processes are fundamentally emotional, tacit, and categorical (they depend on contrasts), and they are the essence of meaning-making.
- The organization of personal activity is fundamentally self-referent or recursive, making the body a fulcrum

of experiencing and encouraging a deep phenomenological sense of *selfhood* or *personal identity*.

- Self-organizing capacities and creations of meaning are strongly influenced by *social-symbolic processes*; persons exist in living webs of relationships, all of which are mediated by language and symbol systems.

Each human life reflects principles of *dynamic dialectical development*; complex flows among essential tensions (contrasts) are reflected in patterns and cycles of experiencing that can lead to episodes of disorder (disorganization) and, under some circumstances, the reorganization (transformation) of core patterns of activity, including meaning-making and both self- and social relationships.

## Activity

Like existential philosophy, constructivism maintains that humans are active participants in their own lives. People make choices that make important differences in their lives and in the lives of all with whom they are connected. Humans are often reactive, to be sure. Constructivism does not deny one's capacity for unreflective reflex and conditioning. But the drive to survive is also fundamentally proactive. We anticipate. We lean into life. We fall forward into our being. And just like the skydiver in free fall, our posture in that process influences its form and direction. We are moving in the midst of forces far greater than ourselves, and yet we have voice and choice within those forces. There are factors outside our command, but we can learn to better read them and to attach more viable meanings and take actions that better serve our movement. And, lest all of this sounds a bit ambitious or audacious, we can also learn the sacred art of stillness and acceptance in the never-ending dance of effort and surrender.

The central point of this first theme is that humans are not passive pawns in life. We are agents that act on and in the world. Hence the emphasis on self-efficacy (1,2) and knowing (3,4). In constructivism, the individual is considered to be an active agent in the process of experiencing.

## Order

The second principle of constructivism acknowledges that we need order. We organize our worlds and we respond to the order within them. We find patterns and create meanings (5-7), and we do most of this by means of which we are mostly unaware. We are creatures of habit, to be sure, and well might we wonder whether it is we who possess our habits or our habits that possess us. Almost as quickly as we learn a new skill, we become mindless of it. It goes underground, so to speak, and enters into the root structure of our life patterning. This process of automaticity applies not only to our physical actions, but also to our patterns of thinking and feeling. Although we may long to change, constancy and integrity maintain a powerful momentum. This is why the most important changes in

our lives may require ruptures and repairs to the very fabric of our lives.

Human mentation is both proactive and generative. We are self-organizing and active in determining our own evolution. Maturana and Varela (8) coined the term *autopoiesis* to represent this human self-organizing capacity. Meaning supercedes the mere processing of sensory-based input. The ordering of one's experience and personal history cataloguing are both highly idiosyncratic and dynamic. As a consequence, meanings can stabilize as well as change with the passage of time. Much of this stabilization and change occurs outside the bounds of our conscious self – at the tacit level (9).

Constructivists contend that “individual human systems organize themselves so as to protect and perpetuate their integrity, and they develop via structural differentiations” (10). This ordering proceeds with self as the reference point in giving meaning to life experience and in the promotion of survival (9). Psychological change lies in the domain of the self, albeit a socially embedded self. Selfhood will be addressed in the following section.

Our emotions develop as powerful biological forces in our self-organization. Emotions serve critical roles in directing our attention, shaping our perceptions, organizing our memory, and motivating our active engagement with the learning that life relentlessly requires of us. We feel our way. Constructivism views emotions as central to human experiencing (11). Feeling is not bad or dangerous or unhealthy. On the contrary, not feeling or fighting against what we are feeling is a more formidable threat to our health and well-being. Our relationships with our feelings are often at least as important as the feelings themselves. This point has important implications for our understanding of what it means to be human and how we may proceed in constructive psychotherapy (12,13).

## Self

We organize our worlds by first organizing ourselves (14).

Biological self-regulation emerges from bodily experiences. Early in life we struggle to separate ourselves from our caregivers – to individuate into a coherent and differentiated identity. The body and its boundaries become an axis for the organization of experience. Like our relationships with our emotions, our relationships with our bodies may become complicated and painful. And at a more abstract level, one's relationship with one's self is of greatest complexity. All psychotherapy is, in a sense, a psychotherapy of the self (9) – an act of assistance in self-organization.

The uniqueness of each self-organizing life is emphasized in constructivism. Terms emphasize individual being (Adler), recursive self-construction (Maturana, Varela), and the personal nature of the order created (15). The unique perspective of the experiencing agent is honored. Moreover, what individuals experience is integrally related to how they have learned to create an orderly reference

point – a metaphorical center. The “who” that is experiencing is one of the most elusive phenomena in consciousness. The self is a process, not an entity. And the self is not separated or isolated. Another way to say this might be that the self is a fluid coherence of perspective from which one experiences. But the sense of self emerges and changes primarily in relationship to others.

Humans develop ever-increasing sets of self-conceptions over time. One’s activated “self” is the one that “reflects meaningful links between the demands of the situation and self-conceptualizations related to those cues” (16). Hence, one’s “active” sense of self is socially influenced and is never a complete representation of one’s being. One goal of constructivism is the self-directed expansion of the client’s self-conceptualizations in ways that promote well-being.

### Social-symbolic relatedness

Much of the order that we seek and the meaning that we create emerges out of what we experience with one another. We are born in relationship and it is in relationship that we most extensively live and learn (1). Our languages lack words to adequately convey our social and symbolic embeddedness. Throughout psychology and philosophy there are creative gestures at capturing the elusive ever-presence of “alterity”, “intersubjectivity”, and “interbeing”. A simplifying analogy would be a fish trying to describe water. Plato was making much the same point in his allegory of the cave. The words that you are now reading are more than symbols on a page of paper. What they invoke in your experience depends on a vast network of relationships (17-19). Some words and concepts will be more familiar than others. The less familiar ones may give you occasional pause, and you may unconsciously interpret them in terms of what is more familiar. What is familiar and comfortable depends on your personal history, the vocabulary and concepts closest to you, and so on. These are, in turn, reflections of your vast connections with people and ideas (past and present).

The active organization of a self takes place “in” a body but also simultaneously “with” and “through” social bonds and systems of symbols. We humans are fundamentally social creatures, and there is no meaningful way of separating our sociality from our symbolic capacities. We may talk about living “in” our heads because we spend so much time thinking, but the form and structure of our thinking is itself relational. One of our favorite ways of organizing our own experience and relating to one another is through stories (3,4). In other words, a large part of our meaning-making is experienced and expressed as narrative (story). Our stories are our selves.

### Lifespan development

Constructivism emphasizes developmental processes (14). Attachment history and the individual’s psychosocial

development shape self-knowledge including self-schemas, abstract rules, and expectations for interacting interpersonally and with the environment (20). The lifelong dynamics of our development are characterized by cycles and spirals of experiencing. Sometimes we develop via “baby steps” of gradual change. Sometimes life demands a large leap. Changes outside of us and inside us may suddenly emerge. When these changes are large, we may undergo a personal revolution characterized by pervasive loss – of meaning, life order, control, identity, and hope. In the face of overwhelming challenges, it is common to do two seemingly opposite things: rigidify and disorganize. We resist the challenge to change. At the same time, however, if the challenge persists or increases, we show signs of variability. Our usual patterns of order begin to disintegrate. This is particularly evident in cycles of energy, moods, sleep, attention, ap-petite and digestion. Our formerly “normal” life – much like Kuhn’s (21-23) “normal science” – begins to deviate from its own norms. Such variability and disorganization – literal “disorder” – are natural expressions of a life that is trying to reorganize itself. The shift from an old order to a new one is seldom easy or painless. But it can be “naturalized” and facilitated by a therapist who appreciates the developmental dynamics of self-organizing systems.

A constructive approach to psychotherapy does not deny the struggles of life or the pain of losing meaning or balance. It does not promise quick and easy solutions to tragedies and lifelong struggles. What constructive therapy does offer is compassion and hope borne of an understanding and trust in the powerful wisdom of life processes re-organizing themselves.

### CONCLUSIONS

The themes elucidated above are evident in constructivists’ conceptualizations of what it means to be human and how to help people change through psychotherapy. Therapy goals, forming and maintaining the therapeutic relationship, change techniques, and ways of appraising change are derived from these principles. Constructivism is focused on possibilities, strengths and personal resources, human resilience, and the promise inherent in lifelong change (24). Distress and disturbance are considered necessary components of significant human change and, to this end, emotional awareness and expression are both honored and promoted. The therapeutic relationship is one of respectful collaboration, trust, safety, and activity. The meaning making achieved through this alliance produces expanded conceptualizations of the past and promotes a future vision of promise.

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# Looking with both eyes open: fact *and* value in psychiatric diagnosis?

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*In this article we argue the case for a proposal: that psychiatry should recognise, embrace and take seriously the role of values, alongside facts, in diagnosis. We present a three-step argument in support of our proposal; we raise a number of key questions from the perspectives of different stakeholders in mental health; and we conclude with a note on the significance of our proposal for building a more equal relationship between patients and professionals.*

**Key words:** Classification, patient-centred, values-based practice, idiographic, abuse of psychiatry

Diagnosis is standardly thought to be an exclusively scientific value-free process. In this paper, we set out a three-step argument to the effect that, notwithstanding the standard model, diagnosis in psychiatry, although no less firmly based on science than diagnosis in any other area of medicine, is also based on values. The argument runs from 1) the initial observation that mental disorder is relatively value-laden compared with bodily disorder, through 2) an interpretation of the value-laden nature of mental disorder as a sign not of scientific deficiency but of values complexity, to 3) the practical resources already available to support diagnoses involving complex values as well as complex facts.

## INITIAL OBSERVATION: MENTAL DISORDER IS RELATIVELY VALUE-LADEN

The observation on which our proposal is based is that psychiatric diagnostic concepts are relatively value-laden compared with their counterparts in (many areas of) bodily medicine.

The relatively value-laden nature of psychiatric diagnostic concepts is shown in two main ways: in the shifting boundary between psychiatric-diagnostic and moral concepts; and in the persistent and increasingly overt

use of value terms in psychiatric diagnostic classifications.

## The shifting moral/medical boundary in psychiatry

High profile examples of the shifting boundary between psychiatric-diagnostic and moral concepts arise in forensic psychiatry with the insanity defence and other determinations of responsibility (1). On one side of the boundary between “mad or bad”, as these determinations are often called, lie such medical-scientific concepts as disease, causes and biological determinism. On the other side lie the moral concepts of guilt, responsibility and freedom of the will. A similar boundary is involved in involuntary psychiatric treatment (2). In both cases the underlying intuition is the same: that with mental disorders we shift across the boundary from moral-humanistic to medical-scientific concepts, from the freedom of action and choice of everyday human discourse to the determinism and causal laws of science.

The boundary is not new, of course. Some have argued that the medical model of mental disorder developed in parallel with the industrial revolution (3). But as early as the fourth century BC, mental health, in Plato’s Republic, had both medical and moral aspects (4). As the American philosopher and

psychologist Daniel Robinson (5) has shown, mental disorder has shifted this way and that across the medical-moral boundary, and in both Christian and Islamic culture, ever since.

The insanity defence, although available in principle for any category of mental disorder, is in practice largely confined to functional psychoses, such as schizophrenia (6,7). The functional psychoses are the focus, similarly, of involuntary treatment (8). Psychiatry’s shifting moral-medical boundary is not confined to the psychoses, however, almost every major diagnostic category having a moral counterpart. The ICD-9, for example, distinguished alcohol dependence syndrome (medical, category 303) from the moral category of drunkenness and “sexual deviations and disorders” (medical, category 302) from the moral category of sexual behaviours that “... serve approved social and biological purposes” (9).

A similar moral-medical boundary is of course apparent with bodily disorders, illness in general excusing from responsibility (10), as when a doctor gives out an “off work” certificate. But the boundary is far more shifting and problematic in psychiatry.

## The value terms within the DSM

The standard model, while acknowledging the shifting moral-medical



boundary for psychiatry past and present, predicts that, with future scientific advances, psychiatric diagnostic concepts will become value-free. This was the prediction, for example, of the American philosopher of science Carl Hempel in the World Health Organization sponsored conference on classification in New York in 1959, from which our current ICD and DSM classifications are ultimately derived (11). Hempel spoke about the requirements for psychiatric classification to become more scientific (12). He noted that the classifications of the day (i.e., in 1959) included terms with “valuational aspects”. Such terms, he suggested, impair the scientific status of a psychiatric classification and, as psychiatry becomes more scientific, so they should gradually disappear.

Hempel’s comments represent an important expression of the standard model given both his status as a philosopher of science and his key role in the development of our current classifications. Nonetheless, in this respect at least, Hempel’s predictions have turned out to be wrong. In DSM-IV (13), the latest and most explicitly evidence-based of our classifications, value terms, far from being eliminated, are more evident than in any earlier edition either of DSM or of ICD (14). The term “bizarre”, for example, is used with reference to one kind of delusion that is characteristic of schizophrenia. In addition:

- a) A number of DSM criteria are actually evaluative rather than factual in form. Criterion A for conduct disorder, for example, covers “... behaviour in which the basic rights of others or major age-appropriate norms or rules are violated”.
- b) DSM includes, for many categories, criteria of functioning, which, again, are explicitly evaluative. Criterion B for schizophrenia, for example, is a criterion of “social/occupational dysfunction”. Criterion B, therefore, is not satisfied by a mere *change* in functioning (a matter of fact); there has to be a change for the *worse* (a matter of value).
- c) DSM’s definition of mental disorder,

in addition to including a further criterion of dysfunction (“... in the individual”), makes explicit that a mental disorder may be defined, in part, by social value judgements. Thus the definition states that “Neither deviant behaviour (e.g., political, religious, or sexual) nor conflicts that are primarily between the individual and society are mental disorders *unless* the deviance or conflict is a symptom of a dysfunction in the individual ...”. If, therefore, a mental disorder may not be defined by social value judgements unless a *further* condition is satisfied (i.e., “... dysfunction in the individual”), then it follows that mental disorder is defined *in part* by social value judgements.

The DSM, we should say straight away, makes clear that its definition of mental disorder requires that there be “*clinically significant* distress or impairment”. In the standard model (of diagnosis as exclusively fact-based), “clinical significance” is assumed to be a concept exclusively of medical science. However, in DSM, “clinical significance” is defined, in particular, by reference to “clinical judgement[s]” of dysfunction; and “clinical judgement” is not further defined other than to point out that the decision whether a condition is clinically significant may be a “*difficult* clinical judgement”. Taking these points together, therefore, there is a *prima facie* case that the “difficult clinical judgement[s]” of clinical significance required by DSM, are, in part, difficult clinical *value* judgements.

#### INTERPRETATION: VALUE-LADEN EQUALS COMPLEX VALUES

Recognising, then, that mental disorders are relatively value-laden compared with bodily disorders is the first (observational) step in the argument supporting our proposal. Whether, though, we embrace the value-laden nature of mental disorder depends on how it is interpreted. This brings us to the second step in our three-step argument.

The standard model, according to

which diagnosis is an exclusively scientific process, allows two interpretive possibilities representing the two poles of the psychiatry/antipsychiatry debate of the 1960s and 1970s: the pro-psychiatry interpretation (of Kendell (15) and others (16)) that psychiatry is underdeveloped scientifically; and the anti-psychiatry interpretation (of Szasz (17) and others (18,19)) that mental disorders are really moral (or “life”) rather than medical problems. We do not have space, here, to consider the wide range of arguments that have been advanced in this debate (20,21). Both interpretations, however, represent, in the terms of our title, one-eye-open views of psychiatry: pro-psychiatry (guided by the standard model) sees only with a fact-eye open; anti-psychiatry (guided by the standard model) sees only with a value-eye open. Neither interpretation, therefore, if our proposal is right, is sufficient to meet the demands of a psychiatry that is complex not only scientifically but also evaluatively.

Other authors, it is true, have recognised that values have a role alongside facts. But in reserving to psychiatric diagnosis a value-free area, they have sought to retain the essence of the standard model: Boorse, for example, reserves disease as a value-free area (22-24); Wakefield, similarly, reserves dysfunction as a value-free area (25). What is needed, then, if our proposal is right, is not a further refinement of the standard model, but a third kind of interpretation altogether, one that, starting from a critique of the standard model itself, allows us to approach psychiatric diagnosis with both fact-eye and value-eye fully open.

One possibility for developing a both-eyes-fully-open interpretation is to start from the resources of philosophical value theory, concerned with the meanings of value terms (26,27), especially the work of a former White’s Professor of Moral Philosophy in Oxford, R.M. Hare (28,29). We will thus briefly outline the both-eyes-fully-open interpretation of the value-laden nature of mental disorder suggested by Hare’s work and then note some of

the many other philosophical possibilities.

### Hare's analysis and a both-eyes-fully-open interpretation of the value-laden nature of mental disorder

The nub of Hare's work, as it is relevant to the proposal of this paper, is two observations about the meanings of value terms:

a) *Two elements of meaning.* The meaning of a value term always contains two elements, a *factual* element as well as an *evaluative element*. This is because the criteria for the value judgement expressed by a value term are *factual* criteria. Thus, to take one of Hare's (non-medical) examples, the *value term* "good strawberry" expresses the *value judgement* "this strawberry is good to eat", the criteria for which include such *facts* about the strawberry in question as that it is red and juicy (28).

b) *Fact-laden and value-laden meanings.* Which of these two elements in the meaning of a given value term, the factual or the evaluative, is most prominent depends on the extent to which the values expressed by that term are shared: value terms expressing *shared values* are relatively *fact-laden* in meaning, value terms expressing *divergent values* are relatively *value-laden*. Hare (29) pointed out that *shared values* have, by definition, the same *factual* criteria which thus become associated with the meaning of the value term in question. For example, people have largely *shared values* about strawberries – most people like a strawberry that is red and juicy. Hence the *value judgement* "this is a good strawberry" will convey the *factual* meaning that the strawberry in question is red and juicy. By contrast, the value judgement "this is a good poem", in another of Hare's examples, expresses a value judgement over which people's values *differ widely*. Hence there will tend to be disputes over the (aesthetic) *values* involved in judging whether a poem is good, with the result that the

meaning of "this is a good poem" remains strongly *value-laden*.

Our required both-eyes-fully-open interpretation of the relative value-laden nature of mental disorder now follows directly from these two observations. Thus, if "disorder", notwithstanding the standard account, is a value term, it will share with all other value terms the features pointed out by Hare. "Mental disorder", then, if "disorder" is a value term, will be more value-laden than "bodily disorder", not, as the standard account implies, for reasons of scientific deficiency, but because the *values* expressed by the value term "disorder" are (relatively) *divergent* in the areas of diagnosis with which *psychiatry* is concerned and (relatively) *shared* in the areas of diagnosis with which *bodily medicine* is concerned. This is consistent with the fact that in psychiatry diagnosis is concerned with areas of human experience and behaviour, such as emotion, belief, desire, volition and sexuality, in which human values are highly diverse (what is good for one is bad for another), whereas in bodily medicine diagnosis is concerned with areas of human experience and behaviour, such as severe bodily pain, threat of death and paralysis, over which human values are relatively shared (what is bad for one is bad for most of us) (30).

### Other philosophical resources for a both-eyes-fully-open interpretation of the value-laden nature of mental disorder

There are many other possible philosophical resources for developing a both-eyes-fully-open interpretation of the relatively value-laden nature of mental disorder.

One whole group of interpretations could start from work in the philosophy of science showing the different ways in which, contrary to the standard model, values and facts work together in science (31): epistemic values, for example, values guiding theory choice, are demonstrably important in the development of DSM diagnostic categories of personality disorder (32).

Another group of interpretations could start from work in moral philosophy showing that values may be redefined in terms of facts (33-35). A third group of interpretations could start from one of the many philosophies that deny the dualism implicit in the standard view: phenomenology (36,37), for example, and related disciplines (38-42), offer fruitful starting points in this respect. Then again, there are the resources of classical philosophy (43) and, coming right up to date, the resources of modern philosophy of mind (44,45).

Each of these approaches, which are in many respects complementary, offers advantages and disadvantages. The interpretation derived from Hare's work has the practical merits of: a) already having been successfully applied in service development and training initiatives in mental health, and b) providing a clear template for research on values in psychiatric diagnosis. It is to these practical applications, then, that we turn next, in the third step in our argument supporting the proposal of this paper.

### PRACTICAL APPLICATIONS: RESOURCES ALREADY AVAILABLE

The practical counterpart of the both-eyes-fully-open interpretation of the value-laden nature of mental disorder derived from philosophical value theory is called values-based practice (46). Values-based practice, like evidence-based practice, is a resource for effective decision-making in healthcare. It starts, much as a political democracy starts, from equal respect for all values; and it relies, again like a political democracy, on "good process" for effective decision-making where values conflict. In this section, we outline briefly the practical resources already available for values-based as well as fact-based approaches to diagnosis, under a) policy, service development and training initiatives, and b) research.

#### Policy, service development and training initiatives

"Good process" in values-based practice depends critically on models

of service delivery that are: a) patient-centred, because values-based practice starts from the values of individual patients, their families and communities (46), and b) multi-disciplinary, because values-based practice depends on the range of different value perspectives represented by a well-functioning multi-disciplinary team for balanced decision-making where values conflict (46).

The development in many parts of the world of mental health services that are based on the principles of patient-centred decision-making and multi-disciplinary teamwork provides a potentially powerful basis for values-based as well as fact-based diagnostic assessment. These two principles, correspondingly, are at the heart of the UK government's "top" policy on mental health, the National Service Framework (NSF, 47). Their links with values-based practice are spelled out in a Values Framework adopted by the body responsible for implementing the NSF, the National Institute for Mental Health in England (NIMHE) (48) (Tables 1 and 2).

Important features of the NIMHE Values Framework as a policy framework for values-based as well as fact-based approaches to diagnosis include, from the Core Principles (Table 1), the first and third of the three "Rs", the

principles respectively of Recognition, that *all* decisions (including decisions about diagnosis) are based on values as well as facts, and of Respect, that decisions start from the values of individual patients; and, from the Policy Implications (Table 2), the explicit exclusion of discrimination (which by definition is inconsistent with the principle of respect); the explicit inclusion of strengths and recovery-based approaches (based on positive values); and the emphasis on the importance of multi-disciplinary working (the key, as noted above, to balanced decision-making where values conflict).

Also important, when it comes to training, is the second of the Core Principles in the NIMHE Values Framework (Table 1), the "R" of "Raising Awareness". At the heart of values-based practice, as a process-based approach to working effectively with complex values, are four key areas of clinical skill: raised awareness of values and of value diversity, reasoning skills, knowledge of values, and communication skills (for both understanding values and resolving conflicts) (46). In the UK, training materials covering each of these four areas have been developed in a partnership between the Sainsbury Centre for Mental Health (a voluntary sector organisation) and the Department of Philos-

ophy and the Medical School at Warwick University (49,50). The NIMHE has supported these training developments and, following the launch of the training manual (51) by the Minister of State with responsibility for mental health, is spear-heading their roll-out as part of a national programme of training (52) within a National Workforce Strategy (53) based on multi-disciplinary team work (54). Training materials are also now being developed specifically for medical students and for primary care physicians, in a joint programme between Warwick University Medical School and the Medical School at the University of Pre-toria.

## Research

As with training so with research, the ground for developing values-based alongside fact-based diagnostic assessment in psychiatry has been well laid, in this case by the ICD and DSM processes to date. DSM-IV, as we noted earlier, makes more explicit than its predecessors, in either the ICD or DSM series, the values implicit in psychiatric diagnostic categories. From the perspective of the standard model, this is a failure of psychiatric science. From the perspective of philosophical value theory, it is a success.

**Table 1** The National Institute for Mental Health in England (NIMHE) Values Framework – Core Principles

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- 1. Recognition** – NIMHE recognises the role of values alongside evidence in all areas of mental health policy and practice.
  - 2. Raising Awareness** – NIMHE is committed to raising awareness of the values involved in different contexts, the role/s they play and their impact on practice in mental health.
  - 3. Respect** – NIMHE respects diversity of values and will support ways of working with such diversity that makes the principle of service-user centrality a unifying focus for practice. This means that the values of each individual service user/client and their communities must be the starting point and key determinant for all actions by professionals.
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**Table 2** The National Institute for Mental Health in England (NIMHE) Values Framework – Policy Implications

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- Respect for diversity of values encompasses a number of specific policies and principles concerned with equality of citizenship. In particular, it is anti-discriminatory because discrimination in all its forms is intolerant of diversity. Respect for diversity within mental health is also:
- *user-centred* – it puts respect for the values of individual users at the centre of policy and practice;
  - *recovery oriented* – it recognises that building on the personal strengths and resiliencies of individual users, and on their cultural and racial characteristics, there are many diverse routes to recovery;
  - *multidisciplinary* – it requires that respect be reciprocal, at a personal level (between service users, their family members, friends, communities and providers), between different provider disciplines (such as nursing, psychology, psychiatry, medicine, social work), and between different organisations (including health, social care, local authority housing, voluntary organisations, community groups, faith communities and other social support services);
  - *dynamic* – it is open and responsive to change;
  - *reflective* – it combines self monitoring and self management with positive self regard;
  - *balanced* – it emphasises positive as well as negative values;
  - *relational* – it puts positive working relationships supported by good communication skills at the heart of practice.
-

Making these values explicit is an important step towards a classification that can support values-based as well as fact-based diagnostic assessment (55). The DSM's criterion B for schizophrenia, for example, requires only minor additions – designed to make fully explicit the evaluative elements in its meaning and the processes required to assess those elements – for it to be a fully-fledged values-based as well as fact-based diagnostic criterion (56,57). The move in the ICD, similarly, towards a family of international classifications is entirely hospitable to values-based approaches (58); and the addition of an idiographic assessment tool, sensitive to the personal and cultural values and beliefs of individual patients, would extend this process further (59,60).

There have also been a number of research initiatives specifically on values-based diagnosis in psychiatry. First in the field was the American psychiatrist and philosopher John Sadler, with a conference at the UT Southwestern Medical Centre, Dallas, that brought together established figures in psychiatric classification with philosophers, neuroscientists, clinicians and patients. Published as a foundational edited collection (61), the Dallas conference was the paradigm for two international research methods meetings funded by the NIMHE in London, in 2003 and 2004, proceedings from which have been published in the form of web-based conferences (48). Sadler has also completed a major review of the values involved in all areas of psychiatric diagnosis (62) and there have been a number of important research initiatives on specific disorders: schizophrenia (36,63), Alzheimer's disease (41) and anorexia nervosa (64).

We should not underestimate the technical challenges here. Drawing on the example of physics (58), as the paradigm natural science, it is clear that research on diagnostic values will require a different (individuated) model of reliability; face validity, too, particularly as assessed by patients and carers, will have greater impor-

tance; and the research process itself will have to include users and carers, as “experts by experience”, on an equal basis with the traditional experts by training (65). Technical issues such as these, however, if the history of science is any guide, will be overcome not by *a priori* reflection but by active engagement in the research programmes to which they relate (66).

## TEN QUESTIONS AND TEN ANSWERS

In this section we consider a number of questions raised by our proposal from the perspectives of a variety of stakeholders. We start with a question from the (imaginary) chair of a taskforce responsible for developing a new classification of mental disorders.

**The taskforce chair's question:** Rather than combining fact and value in psychiatric diagnosis, can't we simply split out the values and focus on the facts?

**Reply:** Hare's model allows us to disentangle fact and value (strictly, description and what he called prescription) (28,29). We could thus, in principle, develop a classification of descriptively-defined *conditions* along the lines, for example, of a descriptive classification of cloud formations (67). Psychiatric classifications, however, are not just of conditions but of *pathological* conditions, i.e. of *negatively evaluated* conditions, of *disorders*. Of course, we *can* split out the evaluative element: the DSM's criteria of good and bad functioning, for example, are split out in a separate classification in the ICD “family” (68). But this amounts to a relocation rather than a resolution of the problems raised by working with complex values in psychiatric diagnosis.

**The clinician's question:** With future scientific advances, in particular discoveries of the brain-based causes of mental disorder, won't values become less important diagnostically?

**Reply:** In a word, “no”. It seems obvious that learning more about the

causes of mental disorder will make values less important in psychiatric diagnosis because so much of the diagnostic process in bodily medicine is taken up with identifying the causes of bodily disorders. But remember that the relatively value-laden nature of mental disorder arises not from scientific deficiency (lack of knowledge of causes) but from greater value complexity. In the future we will indeed know much more about the causes (biological, psychological and social) of human experience and behaviour. But this will do nothing to resolve questions about exactly which kinds of experiences and behaviours are negatively evaluated, and, hence, *pathological*. Should it turn out, for example, that there is a difference in the cerebral anatomy of heterosexual and homosexual people, this would no more show that homosexuality is a “disorder” than it would show that heterosexuality is a “disorder” (30).

**The patient's question:** Everything you say may be true in principle, but it has been helpful for me to think of my depression as a brain disorder. I felt much less stigmatised once this was made clear to me.

**Reply:** Certainly, the idea that mental disorder is no different from any other bodily disorder is helpful to many people. But other models are helpful to other people (69) and of course there are some in the “user movement” who reject the model of pathology outright (70). Our proposal accommodates this feature of mental disorder – that it is understood differently by different people – and avoids the need for a “top” model, a dominant way of thinking about mental disorder, a one-size-fits-all to which everyone has to conform (71).

**The carer's question:** From my perspective, having looked after my son with schizophrenia for ten years, I can easily see how important values are in mental health. But does not your talk (as in the NIMHE Values Framework) of positive values, risk romanticising mental distress and disorder?

**Reply:** That is certainly a risk, and it is crucial to remain fully aware of the burden of distress and suffering from mental disorder (72). But it is also crucial, if we are to respond effectively, to recognise the growing evidence, not least from patients themselves (73,74), that symptom control, which is the focus of the standard model, is often less important than professionals tend to assume. People often have other priorities (a home, a job, etc.) that may actually be prejudiced by over-enthusiastic efforts to control symptoms. Also, the symptoms themselves sometimes have positive aspects [as in hypomania, for example (75)]. Even more important are the positive strengths and resiliences shown by people with mental disorder (76). Values-based assessment thus aims for a balanced approach, not romanticising the problems, but also not neglecting the potential for recovery (77).

**The ethicist's question:** Your premise of respect for diversity sounds like a recipe for the "anything goes" of ethical relativism!

**Reply:** As the NIMHE Values Framework makes clear, values-based practice, far from being a recipe for "anything goes", places strong constraints on practice. These constraints arise partly from the premise of values-based practice itself in respect for diversity (see above), and partly from the fact that human values, although indeed diverse, are not chaotic. Values-based practice, then, in taking the rich variety of human values seriously, is no more likely to lead to relativism in psychiatric diagnosis than it is in ethics or indeed in a political democracy (46).

**The lawyer's question:** That's all very well, but historically psychiatric diagnostic concepts have been notoriously vulnerable to abuse. Will your proposal not make psychiatric diagnosis more vulnerable to being used abusively for purposes of social control?

**Reply:** That is certainly always a risk in psychiatry. But our proposal suggests that in a values-complex area, like psychiatry, it is actually the

standard model that is more at risk in this respect. This is because the standard model, in neglecting values, is neglecting precisely those aspects of diagnosis from which the vulnerability of psychiatry to abuse arises. A study, for example, of the Russian-language psychiatric literature over the period when abuses of psychiatry became widespread in the former USSR (78) showed that the vulnerability of psychiatry in this case arose, not from an inadequate scientific basis for diagnosis, but from a failure to recognise the extent to which Soviet values were influencing clinical judgements (79). Recognising the role of values, therefore, alongside facts in psychiatric diagnosis, should reduce, not increase, the risks of abuse.

**The researcher's question:** My worry is that letting values into diagnosis will lead to biases in scientific research.

**Reply:** This, too, is clearly a risk. But the disentangling of value from fact in Hare's work on value terms is helpful in a number of ways. First, it clarifies what is genuinely scientific (in terms of factually-defined conditions and causal processes) (58,67). Second, it highlights the need for a more sophisticated choice of variables: the experience of delusional perception, for example, contrary to the assumptions of the standard model, may occur in a wide range not only of pathological but also of non-pathological (e.g., spiritual) conditions (63). Hence, studying such experiences in both kinds of condition (normal and pathological) may be more fruitful than concentrating only on abnormal cases.

**The training director's question:** But with the curriculum already so full, how can we afford to take on yet another area of study?

**Reply:** There are resource implications here. But if our proposal is right, training in the skills for values-based as well as evidence-based clinical work is essential if psychiatry, as a branch of medicine, is to be not only

science-led but also patient-centred. Precisely the same point, of the need for values as well as evidence, has been made by those developing evidence-based approaches in medicine (80). As to the practicalities, of time constraints and so forth, the training methods noted above have been designed to be readily adaptable to existing training programmes (51).

**The philosopher's question:** Philosophers have de-bunked the fact-value distinction. So why reintroduce it here?

**Reply:** You are thinking perhaps of the implications of the work of the American pragmatist W.V.O. Quine (81)? But as another American philosopher, Hilary Putnam, has argued, while Quine's work on the analytic-synthetic distinction by implication undermines the idea that fact and value (and indeed other dualisms) are always fully separable, it leaves the *distinction*, as a tool for analysing the meanings of concepts, intact (82). There are, anyway, as we noted earlier, other philosophical resources for developing relevant models of diagnosis that do not rely on the fact-value distinction. But it is the distinction, not the dualism, that is required for utilising the resources specifically of Hare's work; and it is Hare's work, precisely in giving us a clear account of the distinction, that is helpful for policy, training and research in psychiatry.

**The mental health advocate's question:** I want to go back to the question of stigma raised earlier. Many experienced champions of mental health believe we will never make progress until we achieve parity with bodily disorders – will your proposal help us to do this?

**Reply:** Certainly! But not just parity. Why not aim for priority? We are all agreed that stigma is the biggest problem facing everyone concerned with mental health today (83). Our proposal provides a basis for fighting stigma, not by the negative strategy of trying to "catch up" with bodily medicine, which risks reinforcing the prej-

udice that psychiatry is deficient (i.e., needs to catch up), but by the positive strategy of showing that psychiatry is *first in the field* in developing the models of service delivery, the training programmes and the research paradigms needed to work effectively with complex values.

The basis of our proposal, remember, is that we should actively embrace the relatively value-laden nature of mental disorder because it shows psychiatry to be, not deficient scientifically compared with other areas of medicine, but *more complex evaluatively*. So, if this is right, psychiatry has no catching up to do. To the contrary, there is reason to believe that, with scientific advances in the twenty-first century, it is other areas of medicine that will have the catching up to do (46,58,67). This is essentially because scientific advances open up choices, and with choices go values: reproductive medicine, for example, is already becoming more complex evaluatively as a result of advances in “assisted reproduction” (46). In developing the resources to work with complex values, then, psychiatry, in direct contrast with the “psychiatry second” stigmatising attitudes of twentieth century medicine, is leading the field.

## CONCLUSIONS

We have argued the case for our proposal that psychiatry should: a) *recognise* the more value-laden nature of mental disorder, b) *embrace* this as a reflection not of scientific deficiency but of values complexity, and thus c) *take it seriously* by developing the resources to work as effectively with complex values as, in the twentieth century, we developed the resources to work with complex facts. We have reviewed a range of questions raised by this proposal, concluding with the anti-stigma point that our proposal, if fully implemented, could put psychiatry in a leading position in twenty-first century medicine.

Our proposal, it is important to emphasise, requires a decisive shift from the standard model of diagnosis,

as a process that is essentially professional-led, to a model of diagnosis as a project of shared understanding in which patient and professional have equal roles to play.

Philosophical value theory, as the basis of our proposal, while fully securing the importance of the knowledge and skills of professionals, also secures, and on an equal basis, the importance of the values – the unique needs, wishes and beliefs – of individual patients, their families and communities. This is why, in the terms of our title, our proposal is a both-eyes-fully-open proposal. It requires that we have both the traditional fact-eye but also the neglected value-eye fully open.

This is also why, as we saw earlier, our proposal differs radically not only from both anti-psychiatry (value-eye open) and pro-psychiatry (fact-eye open) positions in earlier debates about mental illness, but also from more recent positions which partially recognise the importance of values. This is why, finally, our proposal provides the basis for a new and more equal relationship between patient and professional in the diagnostic assessments that are at the heart of psychiatry as a fully science-led but also fully patient-centred medical discipline.

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# Bug-eyed and breathless: emerging crises involving values

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One might expect support from a long-time colleague and friend of Fulford, Broome and Stanghellini. Indeed, there is little in their thoughtful and definitive essay that I would want to challenge, other than perhaps its relative lack of urgency. I would like to provoke a sense of urgency in my comments through sketching some potential emerging crises driven by value issues in mental disorder classification.

*Genetic and molecular-biology-informed classification and diagnosis.* The simplicity of a classification agnostic about etiology will become untenable as we accumulate knowledge about the molecular and genetic mechanisms of mental disorders. Unfortunately, it appears that the phenotypes associated with these scientific insights will bear limited resemblance to current diagnostic categories (1-4). The values questions will involve how, or if, to assimilate biological etiology into a descriptive classification used by clinicians in an existing “medical-industrial complex”. Equally complex will be to establish the role of non-biological (psychological, sociocultural) etiological factors. We should not overlook the latter’s hierarchical (or not) relationship to biological etiological factors! How will war-trauma related mental disorders look in DSM-VI? How will we weight etiological factors vis a vis diagnosis?

*Diagnosis and crime.* With “both eyes open”, weird paradoxes concerning the relation between crime and mental disorder can be recognized in our current classifications. For instance, in DSM-IV-TR and ICD-10, we have a diagnostic category (pedophilia) largely defined in terms of a criminal behavior (child molestation) and impoverished with regard to associated clinical fea-

tures (4). If this is an exemplar model for crime-related mental disorder classification, why are we not classifying serial murder, serial rape, terrorism, and other patterned criminal behaviors as mental disorders? How are the victimizing paraphilias different from repetitive crime? Appreciation of this paradox leads to tough values questions like: Should we classify (all, some) crimes as mental disorders? Should no crime be classified as a mental disorder? On what evaluative criteria will we parse out criminal behavior from mental illness? Should we parse out criminal behavior from mental illness?

*Gender norms.* In the absence of a generally agreed-upon, non-ideological account of gender norms (5,6), how can deviation from gender norms be the basis for a psychopathological diagnosis? This and related questions will continue to be an issue for diagnoses like DSM-IV-TR’s premenstrual dysphoric disorder and gender identity disorder, and the ICD-10’s excessive sexual drive, among others. What should be the normative image of sex and gender that shapes our conception of psychopathology (4)?

*Cross-cultural validity.* Because of the ICD-10’s and DSM-IV’s accumulating awareness of cross-cultural variation in psychopathology, cross-cultural validity will continue to be a crit-

ical values-related problem for upcoming classifications. If the DSM and ICD categories are not empirically established as universally valid (a practical impossibility), then what should the criteria be for ethically-justified use of DSM/ICD diagnoses in a culturally distinct society? Should all societies be subject to a prevailing Western biomedical model of psychopathology? Should endemic notions of psychopathology be respected? How?

The problems posed by value conflicts in psychiatric diagnosis and classification are real, and will not be solved by scientific advances. Indeed, they will be compounded by scientific advances as we increasingly diversify choices about mental health. We have a lot of evaluative work to do.

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# Keeping an eye on clinical utility

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Fulford et al’s efforts to raise awareness of the interplay between value judgments and scientific facts will undoubtedly be helpful in framing many of the discussions about how to

define particular mental disorders during the next revision of the DSM. While consideration of value diversity was a factor in a number of the DSM-IV discussions (for example, adjusting the criteria set for gender identity disorder so that it did not inappropriately capture tomboys), such considerations were not explicitly and systemat-

ically part of the DSM-IV process.

Beyond that, it is difficult to comment on the practical aspects of Fulford et al's arguments since they neglect to explain with any clarity precisely what their proposal for values-based practice (or "values-based diagnostic assessment") actually entails. Fulford et al appear to be suggesting that patient values be given center stage in the clinical diagnostic assessment process itself. I see at least two problems with this suggestion, in terms of its potential for compromising the clinical utility of DSM-IV and the inevitable interaction of psychopathology with value-determination.

The most important goal of the DSM diagnostic system is to facilitate clinical communication between mental health professionals and to help guide clinical practice. By employing operationalized, standardized, and descriptive criteria, DSM diagnoses allow the clinician to reliably summarize patients' patterns of psychopathology and make evidence-based treatment decisions. The success of this enterprise, however, depends on a reliable application of the diagnostic criteria. Idiosyncratic application of the diagnostic criteria can result in inaccurate diagnoses that can mislead other clinicians who may be part of the treatment team and invali-

date the applicability of empirically based treatment guidelines. For example, consider a clinician evaluating a severely depressed patient who believes that having severe depressed mood is a normal fact of life, resulting in no diagnosis of major depressive disorder despite the fact that the full syndromal criteria are met. Consultants reviewing the diagnosis will be operating under the mistaken assumption that the patient's symptoms are much less severe than they actually are, resulting in clinical confusion rather than clinical communication. Furthermore, the clinician is likely to make inappropriate treatment decisions if he or she assumes that treatments that have been empirically demonstrated to be effective only for mild depressive symptoms (such as supportive psychotherapy) will also work for this severely depressed patient.

A second problem concerns Fulford et al's proposal for having the patient's values about what is pathological "be on an equal footing with the professionals". For many mental disorders, the psychopathology itself may involve distortions in the patient's value system. Take, for example, the diagnosis of pedophilia. Many pedophiles believe that there is nothing pathological about having sex with children. Should the diagnosis of pedophilia

depend on an equal consideration of the patient's value system? If it did, it would be impossible to make a diagnosis of pedophilia for most individuals whose arousal patterns involve having sex with children. Although pedophilia might seem like an extreme example, in fact this problem applies to all disorders in which the symptoms are essentially ego-syntonic, i.e., those disorders in which the person does not appreciate his or her psychopathology as being symptomatic of a disorder. DSM-IV avoids this insight problem by having the clinician's value judgments supercede the patients' in such cases.

Perhaps the best way to integrate values into psychiatric practice is to separate the process of *making* a diagnosis from the process of *applying* the diagnosis for the purposes of clinical management. I agree with Fulford et al's statement that "Symptom control... is often less important than professionals tend to assume. People often have other priorities (a home, a job, etc.) that may actually be prejudiced by over-enthusiastic efforts to control symptoms". It is crucial for clinicians to place their patient's values front-and-center when formulating a treatment plan – otherwise, treatment adherence will inevitably be compromised.

## On winking at the facts, and losing one's Hare: value pluralism and the harmful dysfunction analysis

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Disorder is partly a value concept; conditions that do not cause harm (e.g., benign angiomas, dyslexic dysfunction in a preliterate society where reading is neither taught nor valued) are not disorders. However, disorders are not merely disvalued conditions. Most negative conditions, from ignorance and lack of talent to shortness in an aspiring basketball player, are not

disorders. Nor does need for treatment imply disorder, as in abortion and delinquency (1).

What is the factual criterion that distinguishes disorders from other disvalued conditions? Fulford et al never address this question. By merely winking at the facts in disorder judgments rather than opening their eyes to them, the authors fail to correctly apply Hare's analysis. According to Hare, a value concept like "good strawberry" has three elements: first, a factual domain to which the value is applied

("strawberry"); second, a value term ("good"); and third, a factual basis for the value (e.g., taste and color), which may vary. The authors, focusing on values, ignore the domain specification.

I analyze disorder as harmful dysfunction (HD), with "harmful" a value term based on social judgments, and "dysfunction" a factual term meaning failure of biologically designed functioning (2). The HD analysis fits Hare's model well. Dysfunction is the factual domain, harm is the value applied to the domain, and there are implicit cri-

teria for harm (e.g., suffering, disability) that may vary from culture to culture.

However, “harmful” reflects social, not individual, values. For example, in a literate society, a person who does not value reading still has a dyslexic disorder if incapable of learning to read due to a brain dysfunction; and, in a society valuing reproductive capacity, a sterile individual has a disorder even if he or she does not want children.

The authors argue that values are more diverse regarding mental than physical conditions, so mental disorder is more value-laden. They propose that diagnosis be negotiated with the patient based on the patient’s values. In effect, they make “harm” relative to individual rather than social values in response to growing value pluralism that casts doubt on the very notion of social values.

The proposal inflates the value ladenness of mental disorder and mischaracterizes its consequences. Once the factual domain of disorder is specified as dysfunction, value divergence narrows considerably. For example, people may differ in how much they value joy or hate sadness in response to life’s vicissitudes or as philosophical attitudes, but there is much less difference in how they feel about true depressive disorder in which something has gone wrong with the mind so as to continually generate painful sadness unrelated to actual losses or philosophical insights.

Moreover, the effects of value variation on diagnosis are severely limited because of the dysfunction requirement. Values can disqualify a dysfunction from being a disorder, but values cannot make a non-dysfunction into a disorder.

The authors’ proposal erodes the distinction between disorder, anchored in biological facts, and disvalued conditions in general. The HD analysis suggests an alternative approach. First, limit diagnosis to dysfunctions based on facts, setting aside values to the extent possible. Second, further refine the current approach of using individual values in treatment decisions. Patient values may dictate not treating a dysfunction or treating a non-dysfunc-

tion (e.g., cosmetic surgery, abortion).

Mental medicine faces a dilemma. As society becomes more pluralistic, the assumption of shared social values underlying disorder’s “harm” component becomes problematic; yet adopting the authors’ individual – values approach to harm undermines the distinctiveness and usefulness of the concept of disorder. The answer to pluralism, I suggest, is to make diagnosis more scientific and make treatment decisions more explicitly value laden.

## Recipe for disaster: professional and patient equally sharing responsibility for developing psychiatric diagnosis

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Fulford et al are, of course, correct in asserting that psychiatric diagnosis involves not only facts, but values. They are also correct in emphasizing the stake that patients – and the community – have in how psychiatric diagnosis is developed and applied. No one can doubt that, for example, certain terms that have been used in psychiatric classification, such as “psychopath” and “addict”, have had a stigmatizing effect. It is partly for these reasons that such terms have been avoided in more recent psychiatric classifications. However, Fulford et al have not provided the reader with examples from the current DSM in which the classification would have been better, had more attention been given to examining the implicit values of various diagnoses or the way in which diagnostic criteria were formulated.

What is most remarkable about Fulford et al’s proposal is their assertion that “it requires a decisive shift from the standard model of diagnosis, as a process that is essentially professional-led, to a model of diagnosis as a

Helpfully, the value ladenness of disorder turns out to be much less than the authors suggest once its factual component is understood.

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project of shared understanding in which patient and professional have equal roles to play”. They do not discuss what this means in practical terms, but I can only assume that they are recommending that an equal number of patients and professionals would be members of the work group that develops future revisions of the DSM. The criteria for professionals on the DSM work groups have been some demonstrated (or assumed) clinical or research expertise in psychiatric diagnosis. What would be the criteria for selecting appropriate psychiatric patients on the DSM work group? Would it include psychiatric patients only if they were sympathetic to the concept of psychiatric diagnosis and believed that psychiatric treatment is often helpful? What about psychotic patients who believe that they are being persecuted by psychiatry? Assuming that appropriate patients could be selected, how would they contribute to technical discussions of classification and diagnostic criteria?

Fulford et al fail to note that, beginning with DSM-III, non-professional groups, often led by psychiatric patients, have had input into developing the

DSM manual. Such groups have been sent drafts of the developing DSM and asked to comment and make suggestions or indicate concerns. Why is this kind of non-professional patient input not sufficient?

Yes, psychiatric diagnosis involves

values as well as facts, but Fulford et al's proposal that psychiatric patients and professionals equally share the task of developing psychiatric diagnosis is neither practical nor necessary. If actually implemented, it would be a recipe for nosologic disaster.

order to offer information that will be useful in dealing with illness – a task that takes time which health systems do not have at their disposal. The fact that medical practitioners and their patients are in modern times moving from place to place and from one cultural setting to another more than ever before adds another obstacle to the application of the excellent notion of value based practice. The use of value and evidence-based practice (rather than evidence-based practice) requires more education, possibly also more time and effort by the practitioner: in order to make it popular and generally used, it will be necessary to show that value and evidence-based practice improves the patients' and doctors' quality of life more than evidence-based practice.

The third point mentioned above – about the impact and importance of values in all stages of the medical encounter – is implied in the article: it would have been useful to bring it up more forcibly, because of its importance for the whole of medicine and its role in dealing with illnesses.

In all, I see the effort of Bill Fulford et al as a very useful invitation to re-think medicine and psychiatry and to remain aware of the fact that values influence all of medicine – including the process of treating an illness. This notion might be of particular importance in the training of medical students and students of other health professions, but has its application in other fields as well – perhaps more so in health policy-making than in basic research.

## Recognizing that values matter

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I found the paper by Fulford et al thought provoking, novel in approach and interesting. I regretted however that the paper: a) makes such a sharp distinction between mental disorders and other medical conditions; b) does not discuss the role of culture and the differences in value systems that exist between cultures (and between social class groups within populations of the same cultural background) and c) separates the making of diagnoses from the process of the encounter between a health professional and a patient, a process that includes the definition of problems, their labelling and action to resolve them.

Psychiatrists are probably somewhat more inclined to accept that values and cultural factors in general affect their thinking and their actions than are their colleagues in other medical disciplines: this however does not mean that the impact of culture on “non-psychiatric” medical conditions is not just as powerful in the vast majority of states of ill health. It is therefore to be hoped that the valuable work done by Fulford and others interested in this matter will be brought to the attention of the wider medical world rather than stay cantoned in the field of psychiatry.

Cultures are the scaffolding embedding value systems and their differences are often difficult to capture in quantitative terms. In qualitative terms, however, this is possible and of direct practical importance. The “good process”, Fulford et al say, depends critically on models of service delivery that

are patient centred and on the use of multidisciplinary approaches in medicine. Patient-centredness, however, is by no means a universally accepted way of proceeding in dealing with illness or other matters concerning human life. In some cultures, care has been family centred and public health doctrines of the mid-20th century emphasised the usefulness of that model, since the survival of the community depends on the essential functions of families rather than on the functioning of any individual member of the family. The dependence on family function and the value given to it grow with environmental pressures and the lack of essential support to the community – a situation that is unfortunately turning from an endemic to an epidemic problem in many parts of the developing world.

This brings up another point: a difficulty in the education of new health workers about value-related medical practice. Values change with time (and unevenly) and have to be assessed and re-assessed in a continual fashion in

## Eyes and ears wide open: values in the clinical setting

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The acknowledgement of its inherent complexity and the question on

how to best deal with it have become lately the order of the day in psychiatry (1). Actually, when it comes to mental illnesses, few would dispute that rock-bottom scientific givens are hardly the whole story. Bill Fulford and colleagues take a further step in

the direction of complexity by recognizing the role of values in diagnostic theory and practice and, accordingly, by proposing a sophisticated two-fold approach to psychiatric diagnosis in which values, alongside facts, are seriously considered. In this commentary, we aim at briefly discussing certain far-reaching consequences, in terms of clinical practice, of adopting the approach suggested.

The blurred and ever-shifting medical-moral boundaries in psychiatry result from the Janus-like character of such discipline. There is an agonistic tension at the core of psychiatry (where values play a key role) that cannot be eliminated or bypassed. This is easily noticed in the everyday clinical activity. Thus, it is crucial to realize the extent to which our diagnostic concepts and tools actually mirror such tension and happen to constrain the clinical encounter. The strategy of simply targeting symptoms, within the framework of a supposedly *neat* nosologic system, gives us a fair example.

Even though general goals of patients and clinicians often coincide, this is not always the case. Dissent is particularly likely to take place in matters that are less related to symptom control. One may ask then “which are the legitimate patient’s expectations” or “what should count as a return to normalcy”. This point underscores the need for values disclosure regarding the most basic assumptions of the discipline. As John Sadler has aptly stated: “Psychiatrists work toward helping people with all manner of maladies, from problems-in-living to chronic, debilitating diseases; but what the profession, and its practitioners, believe about the best way to live is their best-kept secret” (2).

It is against such background that human *pathos* should be somehow apprehended in the clinical encounter. Subjective experience of illness is necessarily framed and expressed in language. Thus, one cannot identify any evaluative elements embedded in language unless notions like “meaning” and “understanding” fully come back into play. First-person narrative and

idiographic formulation have a fundamental role here (3). Accordingly, listening becomes the cornerstone of clinical work, which is in complete agreement with the broad definition of respect for the diversity of values within mental health provided by the policy implications of the National Institute for Mental Health in England (NIMHE) Values Framework. However, notwithstanding foreseeable gains for decision-making in healthcare that such patient and process-centered approach may engender, one must be aware that there are other issues at stake that go far beyond a rational value-conflict between patients and clinicians, such as, for instance, the human dividedness and the problem of *akrasia* (acting in a way that is contrary to one’s own best interest). Choice making (about rivalrous goods, evils and forms of life) is the basis of ever-evolving self-cre-

ation. Besides, it may well be that the ends and goals a given person pursues in life may not prove reconcilable at all.

The clinical enterprise takes place inevitably within the realm of practical reasoning. Therefore, we think that notions such as clinical significance, clinical judgement and clinical utility should be brought to the forefront of conceptual and empirical research in psychiatry. Values-based practice seemingly offers a good starting point for such a move.

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# Values and comprehensive diagnosis

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As recognized, but not discussed, by Fulford et al in their paper, there is consonance between attention to values in clinical diagnosis and care and what may be termed the comprehensive diagnostic model. The undeniable importance of values for a science and practice of psychiatry, which Fulford et al are compellingly articulating, is relevant to both the structure and the purposes of comprehensive diagnosis in psychiatry as well as in medicine at large.

The emerging comprehensive diagnostic model (1, 2) aims at understanding and formulating what is important in the mind, the body and the context of the person who presents for care. This is attempted by addressing the various aspects of ill- and positive- health, by interactively engaging clinicians, patient and family, and by employing categorical, dimensional and narrative

descriptive approaches in multilevel schemas. Illustrations of such a comprehensive diagnostic model are at the core of the International Guidelines for Diagnostic Assessment (IGDA) produced by the WPA (3) and the Latin American Guide for Psychiatric Diagnosis (GLADP) produced by the Latin American Psychiatric Association (4).

Fulford et al’s discussion of values in psychiatric diagnosis focuses on their relevance to classification of mental disorders, which corresponds to Axis I of the ICD-10 mental disorders chapter (5) and Axes I and II of DSM-IV (6). It can be pointed out that values are at least equally relevant to the axes in the above diagnostic systems involving functioning/disabilities and contextual factors (psychosocial environmental and personal problems). Issues of meaning, contextualization, and interpretability are quite germane to these axes.

Values are also of substantial importance in the case of Axis IV (quality of life) in IGDA (3) and GLADP (4). It is

widely accepted that the assessment of quality of life should be principally based on the own perspectives of the patient or subject of evaluation. The full range of contents involved, from physical well-being to spiritual fulfillment, are to be addressed in such an axis in a personally- and culturally-informed manner. Attending with such centrality to the person's perspectives attests to and reflects the importance of values for the scientific assessment of a topic increasingly relevant to understanding health and planning health care.

The above considerations on values

and the assessment of health speak additionally to the ethical exigencies of diagnosis and care (7). The fundamental purposes of comprehensive diagnosis are treatment and health promotion focused on the needs and goals of the patient or consulting person.

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## Bridging the gap between fact and values

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The Declaration of Geneva (1), enacted in 1948, enunciates the role and duties of the doctor and views medicine as a vocation. This declaration is rife with value-laden constructs such as consecration, respect, dignity and honour, and draws attention to the implicit value-based constructs defining the fundamental role of the medical profession and its status in society.

The last decade has seen the rise to power of the "evidence-based medicine" movement, where large-scale randomised controlled trials are held up as the gold standard for medical research paradigms (2). A hierarchy of credibility is assigned to various study designs by the Cochrane Library (3), which in turn drives assessments of what constitutes good evidence for different treatment modalities. In the UK, this hierarchy of "best" evidence strongly determines the recommendations of good clinical practice (4). These recommendations in turn determine what treatments are funded within the National Health Service, thus marginalising other approaches which may not be as amenable to "evidence-based" research inquiry (2). This illustrates the power

and influence of this biomedical model on patient treatment, and also the practical importance of this debate.

The ascendance of "fact" in medicine is not new. As early as 1973, Foucault saw the development of modern medicine as a progressive abstraction of illness away from the whole person, to the current focus on cellular or tissue pathology, with a depersonalisation of both the patient and doctor, associated with an increasing reliance on laboratory tests (5). There are interesting ramifications of the "factual" medical model. This emphasis on "evidence-based" treatments, with organisations and professionals dictating what should be made available to patients, contradicts the concurrent movement towards patient-centred care, user involvement in research, and patient choice (6).

There is, however, a danger of going too far in the opposite direction. If only relativistic "values" are seen as valid, then only the person who experiences the phenomenon has the privilege of determining whether he has a problem that requires help, which reduces medicine to an encounter where the customer is always right. A collapse into the totally relativistic realm would be particularly problematic in psychiatry, where insight and ability to make decisions, and even the authentic self, can

be lost in certain stages of certain mental disorders (7-10).

So how do we avoid these equal and opposite errors? Fulford et al suggest a middle path, which allows the consideration of both "fact" and "values". This is an extremely attractive proposition, as it promises to bridge this yawning gap. The main difficulties with this are the academic credibility and practical implementation of this model, not least the re-education of the professionals involved. Fulford et al have clearly made inroads into the latter task, and are able to point to practical resources which are currently available or being developed.

There is a clear need for more research and development in this area, both in order to win more widespread recognition and use, and also to provide a rigorous grounding for the exploration of values. The evidence-based movement did an immense favour to medicine by moving clinical practice away from the realm of the arbitrary and establishing clear methods of investigation (3). In a similar way, the study and discussion of values in medicine in general, and psychiatry in particular, should be amenable to a differently-framed but equally rigorous process of empirical investigation and formulation. Experience is showing

that this is possible, and can prove very fruitful (11, 12). Using Fulford et al's model, this type of research would complement "factual" evidence-based medicine, rather than aim to replace it. This would re-integrate meaning into the research evidence base by taking into account the perspectives and experiences of patients and individual variation, which are stripped from evidence in large-scale randomised controlled trials. This empirical research and development enterprise would probably be a greater challenge for the issue of values than it has been for the domain of facts, but this should not deter us from trying. After all, this cannot be harder than trying to adhere to the

Geneva declaration itself.

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# Looking with both the eyes and heart open: the meaning of life in psychiatric diagnosis

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The definition and classification of mental disorders have long been based on considerations in the realm of cognition. Symptoms and signs, however measured, are described in cognitive terms. Fulford et al argue that we have to be aware of the fact that psychiatric diagnosis is based on both facts and values.

The value systems of individuals are what they can recognize and describe in cognitive terms. For example, "a good strawberry – a strawberry that is good to eat" (or "mental disorder – a mind that is disordered") is a value-laden term that can be rephrased as "a strawberry that is red and juicy" (or a mind that is sad or mad). These qualities – redness and juiciness – are evaluative terms with cognitively-described qualities. Fulford et al further note that, if evaluative elements differ widely, the judgement will be disputed; that is, whether the strawberry is good or the mind is disordered.

Why, then, do judgements about

mental disorders differ from one person to another, depending on their values, in contrast to judgements on bodily disorders? For example, sadness may be recognized as pathological in some individuals but considered normal (physiological) in others. The DSM-IV defines major depressive disorder as a constellation of a certain number of symptoms of "sadness", excluding general medical conditions or the effects of chemical agents. This may occur following "any" type of life event. There is, however, one exception: grief, the "sadness" occurring after bereavement. The DSM-IV excludes from the diagnosis of major depressive episode people with symptoms of "sadness" if they have recently lost a loved one. Only when bereaved people showed psychotic symptoms or suicidality (for whom treatment is imperative) does the DSM-IV allow the diagnosis of a major depressive episode. This may be because the authors of the DSM-IV believed that bereavement is recognized by both professionals and lay people as a situation that generally causes sadness, and is therefore non-pathological – an evaluative judgement.

In the case of grief, who should be included as a "loved one" is entirely subjective, and clinicians heavily rely on the assessment of the extent to which the grieving person has been attached to the lost person. Psychodynamic theory dictates that the bereaved person is unable to withdraw libidinal attachment from the lost person (1). Important here is the meaning of the existence of the lost person to the life of the grieving person. Thus, the values on which psychiatric diagnosis is based are tightly bound to the specific meaning of the event, situation, and people related to a specific person.

Grief "involves the transformation of the meanings and affects associated with one's relationship to the lost person, the goal of which is to permit one's survival without the other while at the same time ensuring a continuing experience of relationship with the deceased" (2). Therefore, the "diagnosability" of such experience largely depends on what the person has found in the event or situation.

I agree that recognizing the values-based view – both facts- and values-eyes open – gives psychiatric diagnosis further richness rather than an imped-

iment. In addition, psychiatrists should open their hearts toward the meanings and affects related to events that individuals experience in relation to their mental disorders. The endeavour of diagnosticians to make their hearts consonant with those of clients will make psy-

chiatric diagnosis an even more fertile ground to understand the human mind.

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# The need for trained eyes to see facts and values in psychiatric diagnosis

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Twentieth century education and training in medical diagnostics produced physicians who could see the facts and recognize the facts in what they saw. We need now a sophistication that not only opens our "values-eye" but also spares us from a "visual agnosia" for values in medical diagnosis and practice. The paper by Fulford et al provides a pathway to this sophistication for the 21st century.

Attaining sophistication in our theoretical and practical knowledge of values in psychiatric diagnosis poses, I believe, profound and exciting clinical, research and educational challenges, of which I shall highlight a couple here.

*To see and recognize the kinds and the scope of values in psychiatric diagnosis.* The trained eye will have a wide-ranging view on the kinds and the scope of values. It would see more than mere bio-ethical values, prescriptive values, normative values and even quasi-legal values. It would see more than principles, virtues, ideals, personal values and religious values. It would also see medical, psychiatric, societal, cultural and aesthetic values. It would see values of good/bad, right/wrong, and of duties, obligations, responsibility, etc. Too narrow a view, in contrast, on the kinds and the scope of values would preclude their recognition, and preclude determining as to whether a particular value should or should not play a role in making a psy-

chiatric diagnosis. Fulford et al give convincing examples of values that pertain legitimately in making a diagnosis. They also give an example of values that should not have played a role, i.e. the abusive influence of political values on psychiatric diagnoses in the former USSR. There remains, however, a question about the (kinds of) values that should or should not pertain in making psychiatric diagnoses. This question is relevant in every clinical encounter, since all diagnostic decisions are based on values in addition to facts. This is also a question that should be researched. This question, whether in practice or research, would be approached best with a trained eye for the various kinds of values.

*To identify and work with values in psychiatric diagnosis.* The practical questions are: How do I identify and even uncover the (hidden) values that pertain in making a diagnosis? And, what do I do about them once identified? These multifaceted questions prompt us to realise that the knowledge and skills to identify and work with values in psychiatric diagnosis are lagging behind in comparison with the knowledge and skills that we have in the science of psychiatric diagnosis. Fulford et al describe the resources that could be drawn on fruitfully in addressing the need for sophistication about values, but much more development is required in training and research as well in the standard diagnostic practice of individual mental health practitioners.

The resources described by Fulford et al, however, stand on solid philo-

sophical foundations and formidable developments are already evident in midstream psychiatry despite the relative early days. Several publications, also by renowned international leaders of psychiatry, have fully embraced the evaluative aspects of psychiatric diagnosis and are grappling courageously with the difficult implications for diagnosis and diagnostic classification systems in psychiatry (e.g., 1-6). These developments will also be taken forward, for example, at the 14th Biennial Conference of the South African Society of Psychiatrists in September 2006, with its theme being "Facts and Values in Psychiatric Practice".

Taking seriously these challenges amongst others would provide psychiatry with trained eyes for facts *and* values in diagnosis, leading the way for the general field of medicine.

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# Coloring our eyes

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In reviewing Fulford et al's paper, I declare that I have to open both my mind and emotions as a black male, mental health survival and approved social worker with a doctorate in philosophy. I stress this position because one of the problems of the paper is that the writers fail to declare their identity (values), and how, in collaborations, friendships and professional associations on an informal or formal level, they apply their own values to keeping both eyes open. Consequently they are made absent, which is implicit to the ways science claims objectivity. Their failure to have a patient perspective from the beginning means that they advocate on their behalf, which undermines the whole premise behind their claim for equality in the relationship between the patient and the professional.

The power and persuasion of the paper is that it names the problems of social value judgments, and rescues seeing the dysfunction in the individual without really exploring how society values are politically influencing clinical judgements. For example, when using the metaphor of the strawberry in relation to the tensions between factual and evaluative elements, the paper hides the deeper problems when colour is used in relation to humans, particularly black young men who rep-

resent the major problems in relation to cultural values and misdiagnosis. So the issue of what is shared or divergent hides the implications of power, especially in relation to white men, which become politically neutral, similar to the presence of the writers throughout this paper.

The paper promotes a reality that value based practice is possible despite the failure to see the personal values that become explicit inside the diagnostic label. The failure to examine these values at the outset means that value based practice becomes reactionary as opposed to proactive, because in the process of looking at our values it may be too painful to admit that we corrupt science by personal labelling before the assessment takes place. This embarrassment to our own bias is not discussed in the paper nor is the loss for professionals to truly give to the patient real partnership in a political democracy in which the patient may reveal a perspective that highlights poor practice and injustice. So, whilst the Institute for Mental Health in England (NIMHE) values framework highlights the "respect" component to the patient, the political and economic pressures placed on the mental health team are not discussed, nor how these pressures influence the four key areas of clinical skills outlined in the paper: raised awareness of values and of value diversity, reasoning skills, knowledge of values and communication skills.

The problem implicit throughout the

paper then becomes the absence of the writers, and how through their values they construct the imaginary stakeholders to respond to their pre-set questions. So the stakeholders' personal histories have also to be made irrelevant to why they ask the questions and how race, class, gender and other personal variables may be operating in the complexity of values and facts in the assessment process. This enables the authors to reinforce as opposed to refute and retest their position about the real complexity of values and facts from a professional-centred approach.

The question by the carer facilitates this defence of romanticising, whilst avoiding to examine the radical personal changes needed to truly move towards a value based practice and to provide evidence of this transition, or to give the accountability to the carer and patient to measure this change. The question on ethical relativism is crucial to the pretence of suggesting that all human values are given equal consideration, which negates the importance of legal considerations when conflicts between the values of patient and psychiatric profession emerge.

In conclusion, a delusion is again in practice in that professionals can share their understanding, but not how in their internal worlds they are really assessing and making value judgements about the patient. By using philosophical theories, none of which reflects a non-European/American heritage, this paper gives licence to opening our eyes to values and facts, whilst we may not need to open our hearts and minds.

*Erratum* - The first reference in the commentary "Looking back and ahead. Suicidology and suicide prevention: do we have perspectives?", by J.P. Soubrier, which appeared in *World Psychiatry*, 3: 159-160, 2004, has been submitted and published in an incorrect form. The correct reference is: Soubrier JP. Suicide prevention as a mission. Opening lecture at the 19th Congress of the International Association for Suicide Prevention, Adelaide, March 1997.

# Demoralization, anhedonia and grief in patients with severe physical illness

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*Within the physically ill population, demoralization has been a valuable concept with which to consider dysphoric states. Moreover, it can be distinguished from other mood states. In this study we replicate previous research and show that demoralization can be distinguished from anhedonic depression and grief. All three correlate more or less equally with measures of depression (e.g., the Beck Depression Inventory), although they are differentiated on styles of coping, and social, family and physical functioning. These results confirm that distinguishing depression with demoralization from depression with anhedonia is both useful and scientifically valid. It sharpens the characterisation of dysphoric states and provides an empirical framework to enhance research into the aetiology and treatment of depression.*

**Key words:** Depression, medically ill, reactive depression, demoralization, adjustment disorders, psychosomatics

Depressive states are common in the medically ill, with prevalence rates between 12 and 30% (1,2). However, there is strong opinion that current or traditional diagnostic systems have failed to adequately capture the range and nature of mood states seen and experienced in the medically ill (3,4) and that there is a lack of “syndromal differentiation” in the classification of depression (5).

In response to these sentiments, we undertook a study of the latent structure of symptoms in the medically ill in order to develop a taxonomy of meaningful syndromes of distress. In a sample of 312 patients hospitalized with a range of physical illnesses, we identified and distinguished dimensions of demoralization, anhedonia, grief, autonomic anxiety and somatic symptoms (6). Demoralization was characterized by feelings of being unable to cope, distress, apprehension, helplessness, hopelessness, personal failing and aloneness; anhedonia by a loss of ability to experience pleasure in things and accompanying loss of interest; grief by feelings of loss with intrusive thoughts about the loss, distress (pangs) and pining (yearning). Demoralized patients were more distressed than patients with anhedonic depression (as measured by the depression and anxiety scales of the General Health Questionnaire), but had less social dysfunction (7). These findings, using a method of numeric taxonomy, suggest that there are different types of depression, distinguishable by prominent anhedonia, demoralization and grief respectively.

In the present study, we aimed to examine whether this taxonomy is replicated in another sample of medically ill patients. Because helplessness and hopelessness are critical to the construct of demoralization, we decided to examine the phenomena in patients for whom no curative treatment was available – cancer patients admitted to a palliative care service and patients with motor neuron disease (MND). A further aim was to examine the convergent and discriminant validity of the factors (provisionally demoralization and anhedonia) by examining the correlations on a range of concurrent measures. We predicted that both anhedonia and demoralization would correlate highly with standard measures of depression which are

themselves non-specific for subtype of depression, but would be differentiated on hopelessness and trait optimism. Hopelessness is central to the construct of demoralization. Trait optimism has been shown to be an important predictor of health-related coping (8) and, in the context of this study, it was hypothesized to be protective against demoralization. Other measures included physical functioning, coping style, social support and trait anxiety/neuroticism.

## METHODS

### Sample

Consecutive patients with metastatic cancer were recruited at the point of referral to five palliative care services in south-east Melbourne. MND patients were recruited from consecutive attendees at specialist clinics in Melbourne and Sydney, and by invitation through the Motor Neuron Disease Associations in Victoria and Tasmania. Exclusion criteria were being too unwell to complete the interview and self-report questionnaires, and inadequate command of the English language. The demographic and illness particulars of the two groups of patients are summarized in Table 1.

Ethics committee approval was gained from all institutions involved and written informed consent obtained from all participants.

### Interview and assessment procedure

The interview was an adaptation of the previously used Monash Interview for Liaison Psychiatry (MILP) (9). The original interview was simplified with the removal of duration and cause questions. Symptoms were considered present if they were present “over the past month”. The attribution of “cause” of physical symptoms (whether the symptom is due to a medical illness, medication, drugs or alcohol, psychogenic or unexplained) is a difficult judgement in this group of patients and consequently we used an “inclusive” approach (10).

**Table 1** Demographic and illness characteristics of the sample

	Motor neuron disease (n=134)	Cancer (n=137)	Total (n=271)
Age (years, mean $\pm$ SD)	62.7 ( $\pm$ 11.4)	67.1 ( $\pm$ 12.4)	64.9 ( $\pm$ 12.1)
Sex (% female)	38	43	41
Country of birth (% born in non-English speaking country)	19	18	18
Marital status (%)			
- Married	71	59	65
- Widowed	10	24	17
Living with (%)			
- Self	13	27	20
- Spouse/Partner	52	58	55
- Other adult	0.7	1.5	1.1
- Family	24	14	19
- Nursing home	11	0	5.2
Educational level (%)			
- Incomplete secondary	33	37	35
- Completed secondary	45	42	44
- Completed tertiary	22	21	21
Religion (%)			
- Christian	70	77	73
- Other	1.5	6.6	4.0
- None	28	17	23
Belief in God (%)	66	69	68
Cancer subtype (%)			
- Lung		31	
- Gastrointestinal		18	
- Prostate		8.0	
- Breast		7.3	
- Haematological		4.4	
- Other		31	
Motor neuron disease subtype (%)			
- Amyotrophic lateral sclerosis	55		
- Bulbar	15		
- Progressive muscular atrophy	6.7		
- Primary lateral sclerosis	6.0		
- Not recorded	18		
Duration of illness (months, mean $\pm$ SD)	30.6 ( $\pm$ 34.7)	4.8 ( $\pm$ 8.6)	17.5 ( $\pm$ 28.2)
Current treatment (%)			
- Steroids	5.2	48	27
- Opioids	7.5	56	32
- Non-opioid analgesics	34	80	57
- Psychotropics	45	48	47
History of previous psychiatric treatment (%)	24	30	27

The original latent class analysis produced a dimension we called “anhedonia”, which consisted of four items. To potentially strengthen this construct we added five additional items relating to interest and enjoyment developed after reviewing other questionnaires, of most relevance being the depression subscale of the Hospital Anxiety and Depression Scale (11).

The interview consisted of a demographic and illness section, and 86 questions in the domains of somatic symptoms, mood, self-concept, suicidal ideation and functioning. All symptom items were coded on a scale of zero to four if they were present “never”, “almost never”, “sometimes”, “fairly often”, or “very often”. Most interviews were conducted in the patients’ homes. For those patients in hospital, a private setting was sought. All patients were allowed to have a friend or relative present during the interview if they wished. The Beck Scale for Suicidal Ideation (SSI), described below, was administered as part of the interview. Self-report instruments were completed thereafter and returned by mail. In a number of cases,

because of death or worsening health, self-report questionnaires were not completed. At conclusion of the study we had 271 completed interview schedules and 251 questionnaires with mostly complete data.

## Instruments

Aspects of physical health and functioning were measured using the Physical Functioning Scale of the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire Core 30 Items (QLQ-C30) and a visual analogue pain scale.

The QLQ-30 is a validated self-report measure of a range of core quality-of-life domains (12). We used the five physical functioning items each scored on a scale of one to four (QLQ-C30 version 3.0). The items are summed and then converted to a score with a range of 0-100 with a higher score indicating better physical functioning. This scale had a Cronbach’s alpha of .84.

The pain analogue scale was a 10 cm line on which

patients rated their current level of pain. This was measured in millimetres and given a score of 0-100.

Depression was assessed with two measures. The Beck Depression Inventory (BDI) provides a dimensional measure of depression and has been well validated over many years' experience (13). We used the BDI-II (14), a revised 21-item version using a 4-point response, with items covering domains of mood (2 items), anhedonia (2 items), hopelessness (2 items), cognitive functioning (2 items), self-concept (6 items), physical symptoms (4 items), psychomotor retardation (1 item), crying (1 item) and loss of interest in sex (1 item). The BDI-II had a Cronbach's alpha of .86 in our sample.

The Patient Health Questionnaire (PHQ-9, 15) is a self-report questionnaire derived from the Primary Care Evaluation of Mental Disorders (PRIME-MD, 16). Its nine questions assess the presence of the DSM-IV criteria for major depressive disorder across a two-week period using a 4-point Likert scale response. When items are summed, a score of 10 or more corresponds to a diagnosis of major depressive disorder with a sensitivity of 88% and a specificity of 88% (15). The PHQ had a Cronbach's alpha of .78.

The degree of hopelessness was measured using the Beck Hopelessness Scale (BHS, 17), a 20-item true-false questionnaire assessing negative expectations about the future. Several studies have demonstrated a high degree of internal consistency and construct validity (e.g. correlations between .62 and .74 with clinical ratings of hopelessness) (18). The Cronbach's alpha of the BHS in our sample was .89.

Suicidal thought and desire for death were measured using the SSI (19). The original scale comprised 19 items, each scored zero, one or two. We removed nine items which seemed inappropriate or too confronting for people with a terminal illness and used items 1, 2, 3, 4, 6, 7, 8, 9, 10 and 14. Internal reliability of these ten items in our sample, using the Cronbach's alpha, was .86.

Dispositional or trait optimism was measured using the revised Life Orientation Test (LOT-R, 20). This is a 10-item self-report questionnaire, each item scored zero to four, giving a range for the scale of 0-40. Cronbach's alpha for this scale in our sample was .71. Dispositional optimism has been shown to correlate positively with active coping and negatively with avoidance in cancer patients (21).

Trait anxiety was measured with the State-Trait Anxiety Inventory (STAI, 22). The "trait" scale asks about "how you generally feel about yourself", with 20 items scored one to four giving a scale range of 20-80. Its validity based on correlation with other trait anxiety measures is good, with correlations ranging between .73 and .85 (22). Trait anxiety and neuroticism are strongly associated with vulnerability to depression, both in the presence (23) and absence (24,25) of physical illness. The Cronbach's alpha for the trait anxiety scale in our sample was .90.

Coping styles were measured using the Medical Coping Modes Questionnaire (26), a 32-item self-report measure using a 4-point Likert scale producing three subscales:

confrontation (with eight items, score range 8-32, Cronbach's alpha= .66); avoidance (seven items, range 7-28, Cronbach's alpha= .61); acceptance-resignation (four items, range 4-16, Cronbach's alpha= .61). In general, a confrontational style is used more frequently by patients with acute life-threatening illness compared to patients with chronic illness (27). On the other hand, acceptance-resignation is typically seen in patients with little expectation of recovery. Effective coping in acute life-threatening situations is negatively linked with the use of avoidance or acceptance-resignation, while patients with chronic illness cope better using acceptance-resignation (28).

Social network and support was measured using the Indices of Social Functioning and Resources from the Health and Daily Living Form (29). From this, three scales were derived: number of close relationships (close friends and "people that can be counted on for real help in time of trouble"), number of social activities with friends (in the last month), and the quality of significant relationship. The latter was derived from six questions rated zero to four, giving a range of 0-24 with a Cronbach's alpha of .73 in our sample. A fourth scale, the number of social network contacts, had too much missing data to be used.

Quality of family relationships was measured using the three scales from the Family Environment Scale (30,31). This has been usefully employed to characterise family functioning in cancer families (32). From the 12-item true-false scale were derived scales for Family Cohesiveness (Cronbach's alpha= .44), Family Expressiveness (Cronbach's alpha= .53) and Family Conflict (Cronbach's alpha= .57).

## Statistical analysis

All data were double-entered into a database and checked. Because the items used in this study were different in content and coding from the original study (6), we undertook exploratory rather than confirmatory factor analysis (principal component analysis with varimax rotation). Cattell's scree test was used to determine the number of components to be retained (33). Scores on retained components were computed for each patient by summing the raw scores of those items that loaded  $\geq .45$ . The constructs defined by these dimensions were then examined using a series of bivariate and regression analyses. Comparisons of components from these analyses and those of the original study (6) were effected by means of the coefficient of congruence (CC, 34) between respective loadings.

Although there are no strict rules for calculation of sample size for factor analyses, samples in excess of 200 are generally required to ensure stability of estimates (35). Following Green (36), the sample size required in a multiple regression equation with up to 10 predictor variables should exceed 130. This assumes moderate effect sizes (e.g. regression beta weights of 0.20, moderate intercorrelations between predictors and alpha=.05). We therefore sought a sample size of 250: 125 cancer patients and 125 motor neuron disease patients.

**Table 2** Loadings of items on principal component analysis

	1	2	3
Hopelessness	<b>.718</b>	.276	.014
Despairing	<b>.711</b>	.226	.090
Brooding	<b>.684</b>	.261	.045
Depressed, down, sad, miserable	<b>.635</b>	.316	.141
Angry	<b>.612</b>	.234	.045
Pessimistic	<b>.605</b>	.310	.114
Discouraged, despondent	<b>.593</b>	.266	.098
Tearful	<b>.583</b>	.013	.071
Anxious, apprehensive	<b>.551</b>	.233	.180
Unable to cope	<b>.547</b>	.286	.141
Wish rather not be alive	<b>.547</b>	.231	-.002
Restless, unable to relax	<b>.535</b>	.091	.045
Panic anxiety	<b>.532</b>	.035	.225
Feelings easily hurt	<b>.525</b>	.217	.006
Self-pity	<b>.513</b>	.294	.112
Keyed up, on edge	<b>.507</b>	.224	.141
Irritable	<b>.504</b>	.118	.117
Detached, depersonalized	<b>.500</b>	.245	.071
Suicidal thought	<b>.481</b>	.043	-.066
Thoughts of death	<b>.477</b>	.110	.149
Helplessness	<b>.475</b>	.261	.058
Feelings of choking	<b>.453</b>	-.073	.230
Less interested in doing things with others	.114	<b>.762</b>	.007
Unable to enjoy doing things with others	-.021	<b>.728</b>	.051
Unable to enjoy doing things by oneself	.073	<b>.723</b>	.164
Less interested in doing things by oneself	.218	<b>.652</b>	.171
Difficult to enjoy things	.211	<b>.583</b>	.192
Socially withdrawn	.137	<b>.552</b>	.099
No longer look forward to things	.415	<b>.543</b>	.042
Lost interest in appearance	.213	<b>.510</b>	.041
Difficulty doing things	.139	<b>.496</b>	.172
Unable to laugh	.212	<b>.457</b>	-.007
Abdominal pain or discomfort	.051	-.019	<b>.614</b>
Nausea	-.124	.044	<b>.596</b>
Vomiting or regurgitation	-.052	-.028	<b>.556</b>
Flushes, chills	.182	-.044	<b>.494</b>
Pain or discomfort in chest	.045	.079	<b>.484</b>
Tired, fatigued	-.021	.240	<b>.480</b>
Dry mouth	.094	.044	<b>.474</b>
Tire easily	-.024	.176	<b>.471</b>
Bloated, distended	.072	.024	<b>.460</b>
Not fully restored after rest	.157	.373	.344
Tense, sore, achy	.392	-.082	.270
Tremble, twitch, shaky	.388	-.145	.206
Back pain	.252	.019	.391
Pains in joints	.396	-.054	.310
Stiffness in joints	.405	-.106	.216
Butterflies, churning in stomach	.333	-.070	.438
Lump in throat	.186	-.040	.305
Trouble swallowing	.371	-.104	.122
Coated tongue, bad taste in mouth	.104	.024	.425
Loose bowels	.074	.011	.271
Frequent bowel movements	-.023	.017	.267
Palpitations, tachycardia	.165	.122	.340
Headaches	.169	.121	.346
Dizziness, light-headed	.090	.135	.291
Numbness, tingling	.136	.056	.304
Difficulty breathing, shortness of breath	-.006	.214	.404
Blurred vision	.000	.181	.332
Loss of mood reactivity	.288	.332	.097
Difficulty sharing others' happiness	.266	.414	-.040
Unable to enjoy a good book	.076	.333	.136
Less talkative than usual	.302	.208	.039
Psychomotor retardation	.163	.242	.256
Psychomotor agitation	.439	.071	.116
Early or middle insomnia	.190	.005	.331
Early morning waking	.097	.182	.348
Easily startled	.334	.087	.128
Losing mind, losing control	.449	.137	.013
Feeling of impending death	.384	.151	.198
Trouble with thinking	-.042	.341	.324
Agoraphobia	.348	.235	-.063
Worthlessness	.337	.279	.001
Lost confidence	.393	.370	.000
Guilt	.306	.282	.068
Suicidal behaviour	.130	.126	.024

## RESULTS

### Factor analysis

Two hundred and seventy one cases had sufficiently complete data to be included in the principal component analysis (PCA). Two items relating to sexual function were infrequently answered and removed. Questions pertaining to grief were only asked if a "gatekeeper" question (Does it feel as if you have lost something?) was answered affirmatively. These items were removed from the main PCA and were considered separately. This left 76 items for the main PCA.

The application of Cattell's scree test to the PCA results clearly indicated that three components should be retained. These three components accounted for 13.2%, 8.3% and 6.8% of the variance, and collectively 28.3% (see Table 2). The first component corresponds well to the concept of demoralization, with its highest loadings being on items of hopelessness, despairing, brooding, depressed, angry, pessimistic, discouraged, tearful, anxious, unable to cope and death wish. The second component is clearly anhedonia, with the highest loadings on lessened interest and inability to enjoy activities either with self or others. The third component consisted of physical symptoms (gastrointestinal symptoms, tiredness). Thirty-five items, nearly half, did not achieve loadings of .45 or more on any of the three components.

For the 212 patients who did acknowledge a "loss", the five grief items were submitted to principal component analysis in the same way as above. All items loaded  $\geq .45$  on a single factor, accounting for 53% of the variance (see Table 3).

A comparison of component 1 from the 3-factor solution with the demoralization dimension from our original study

(6) showed a CC of .87. A comparison of component 2 with the anhedonia dimension from the original study showed a CC of .60. A comparison of the grief component with the grief dimension of the original study showed a CC of .98.

### Development of dimension scores

Scale scores for demoralization, anhedonia and grief were derived by summing the scores for each item loading greater than .45. In the case of grief, only the patients who answered the gatekeeper question affirmatively (n=212) were able to have a grief score computed. In the case of demoralization, the item "feelings of choking" was excluded because it seemed conceptually unrelated, its loading on the PCA was marginal (.453), and it had the weakest correlations with the other items. Cronbach's alpha was .92, .86 and .77 for demoralization, anhedonia and grief respectively. The demoralization and anhedonia scales were correlated .51, demoralization and grief .66 and anhedonia and grief .35.

### Bivariate analyses

Correlations of scale scores with concurrent measures are shown in Table 4. Each scale correlated strongly with

**Table 3** Loadings of grief items on principal component analysis

Thinks about object of loss	.76
Pangs (distress caused by thinking about object of loss)	.82
Memories, mental pictures or dreams about object of loss	.55
Pining and yearning, longing for return of object of loss	.80
Cries about loss	.68

**Table 4** Correlations of demoralization and anhedonia with dimensional measures

	Demoralization (n=229-270)	Anhedonia (n=229-270)	Grief (n=181-212)
<b>Demographic and illness variables</b>			
Age	-0.23***	-0.01	-0.28***
Duration of illness	0.17**	0.01	0.14*
Physical functioning	-0.29***	-0.25***	-0.09
Pain	0.20**	0.22***	0.05
<b>Mood and hopelessness</b>			
BDI-II	0.62***	0.59***	0.37***
PHQ-9	0.55***	0.50***	0.35***
Hopelessness (BHS)	0.45***	0.37***	0.33***
Suicidal ideation (SSI)	0.42***	0.23***	0.28***
<b>Trait or personality measures</b>			
Trait optimism (LOT-R)	-0.36***	-0.29***	-0.22**
Trait anxiety (STAI)	0.64***	0.46***	0.34***
Confrontation coping	0.09	0.01	0.10
Avoidance coping	0.25***	0.09	0.32***
Acceptance-resignation coping	0.45***	0.32***	0.32***
<b>Social and family attributes</b>			
No. social activities/month	0.08	-0.18**	0.18*
No. close relationships	-0.15*	-0.21***	-0.07
Quality of significant relationships	-0.29***	-0.17**	-0.22**
Family cohesiveness	-0.20**	-0.10	-0.06
Family expressiveness	-0.26***	-0.15*	-0.18*
Family conflict	0.11	0.06	0.09

BDI-II – Beck Depression Inventory – II; BHS – Beck Hopelessness scale; LOT-R – Life Orientation Test - Revised; PHQ-9 – Patient Health Questionnaire – 9;

SSI – Scale for Suicidal Ideation; STAI – State-Trait Anxiety Inventory

\* p<0.05, \*\* p<0.01, \*\*\* p<0.001

measures of depression (PHQ-9 and BDI), hopelessness and suicidality. They also correlated with trait anxiety and, to a lesser but significant extent, with trait optimism and acceptance-resignation. Physical functioning and pain correlated with demoralization and anhedonia, but not with grief.

Demoralization and anhedonia were differentiated on a number of variables, with age, duration of diagnosis and avoidance coping all correlating significantly with demoralization (and grief) but not anhedonia. With respect to social and family measures, numbers of social activities and close relationships were more strongly (negatively) correlated with anhedonia, while perceived quality of significant relationships was significantly, but not highly, correlated with all dimensions. On the other hand, measures of family functioning, specifically family cohesiveness and expressiveness, were more highly (negatively) correlated with demoralization.

For the categorical variables (Table 5), there were significant differences for diagnosis (cancer patients being more anhedonic, MND patients being more demoralized), living arrangements (people living with families having highest demoralization and grief), belief in God (those without experiencing more demoralization and anhedonia), past psychiatric history (associated with higher scores on demoralization and anhedonia), major depressive disorder

(associated with higher scores on all measures) and current treatments (antidepressants being associated with demoralization and grief).

### Multivariate analysis

We undertook a series of multiple regression analyses, with demoralization, anhedonia and grief as the dependent variables and various sets of independent variables. Conventional ( $p < 0.05$ ) criteria for statistical significance were adopted. The models with highest explanatory power are shown in Table 6.

For demoralization, trait anxiety and age remained strong contributors, as did, to lesser extents, past psychiatric history, diagnosis (high demoralization in MND patients), coping style (confrontation, acceptance-resignation, avoidance), family cohesiveness and quality of significant relationships. This model accounted for 57% of the variance. For anhedonia, trait anxiety, diagnosis (high anhedonia in cancer patients) and past psychiatric history remained strong contributors, as did physical functioning. Belief in God also contributed, but age did not. This model accounted for 30% of the variance. For grief, trait anxiety, age and diagnosis remained significant, as did confrontation and avoidance coping, and quality of significant relationships, accounting for 33% of the variance.

**Table 5** Association of demoralization and anhedonia with categorical measures (t test and ANOVA)

	Demoralization		Anhedonia	Grief	
	N	Mean	Mean	N	Mean
<b>Sex</b>					
-Female	109	20.82	12.45	183	6.55
-Male	160	20.16	13.10	127	7.46
<b>Living with</b>					
- Alone	54	16.28	14.24	40	5.43
- Spouse/partner	149	19.36	12.38	111	6.93
- Other adult	3	20.33	16.67	3	8.33
- Family	51	27.59	13.71	45	9.36
- Nursing home	14	24.36***	8.79	13	6.08***
<b>Diagnosis</b>					
- Cancer	137	16.91	14.08	96	5.72
- Motor neuron disease	134	24.30****	11.62*	116	8.29****
<b>Belief in God</b>					
- Yes	177	19.12	11.79	137	6.61
- No	85	23.32 *	14.51**	67	7.99
<b>Past psychiatric history</b>					
- Yes	71	25.32	15.45	60	7.92
- No	193	18.55****	11.68****	145	6.74
<b>Major depressive disorder</b>					
- Yes	37	35.51	21.65	32	9.81
- No	212	17.71****	11.49****	164	6.49****
<b>Current treatment with antidepressants</b>					
- Yes	63	26.16	13.22	54	8.35
- No	208	18.87****	12.75	158	6.71*
<b>Current treatment with sedatives or anxiolytics</b>					
- Yes	91	24.34	15.21	68	8.47
- No	180	18.65***	11.68**	144	6.49***

\*  $p < 0.05$ , \*\*  $p < 0.02$ , \*\*\*  $p < 0.01$ , \*\*\*\*  $p < 0.001$

**Table 6** Results of regression analyses

	Coefficient	t	p
<b>Demoralization</b>			
Trait anxiety	0.73	8.69	<0.001
Age	-0.26	-4.21	<0.001
Acceptance-resignation coping	1.00	3.36	0.001
Avoidance coping	0.62	2.99	0.003
Diagnosis	4.08	2.79	0.006
Quality of significant relationships	-0.46	-2.44	0.015
Family cohesiveness	-1.78	-2.17	0.031
Confrontation coping	0.39	2.13	0.034
Past psychiatric history	3.13	1.97	0.05
<b>Anhedonia</b>			
Trait anxiety	0.28	4.92	<0.001
Diagnosis	-3.67	-3.72	<0.001
Physical functioning	0.05	-2.93	0.004
Acceptance-resignation coping	0.51	2.38	0.018
Past psychiatric history	2.57	2.33	0.021
Belief in God	2.01	-1.95	0.052
<b>Grief</b>			
Diagnosis	2.52	4.25	<0.001
Trait anxiety	0.12	3.99	<0.001
Avoidance coping	0.34	3.97	<0.001
Quality of significant relationships	-0.23	-3.03	0.003
Age	-0.06	-2.27	0.025
Confrontation coping	0.17	2.15	0.033

## DISCUSSION

In this study we have sought to re-examine the latent structure of what are principally dysphoric symptoms in a medically ill population. The results mirror the previous finding (6) of three distinct dimensions of demoralization, anhedonia and grief. Although this is a replication study, the form of the data here is not identical to that used previously. As described, we chose two groups of patients in whom helplessness and hopelessness might be expected to be common. Consequently, we did not screen for psychiatric morbidity, but included all available patients. This makes the results more generalizable. Second, symptoms were coded by severity rather than being rated present or absent, more truly representing their dimensional nature. Third, we did not attempt to make attribution judgements about the physical symptoms. Despite these differences, a very similar symptom structure emerged.

In addition, we wanted to examine concurrent – both convergent and discriminant – validity. The first thing to notice is that all three dimensions correlated significantly with common measures of depression, the BDI and the PHQ-9. The BDI is a general depression scale with a number of items in areas covered by demoralization (hopelessness, negative self concept) and anhedonia (loss of interest, loss of pleasure). The PHQ-9 reflects the nine symptom criteria of DSM-IV major depressive episode and therefore includes diminished interest and pleasure, worthlessness and thoughts of death. Furthermore, all three dimensions had a strong association with trait anxiety. The instrument we used to measure this, the STAI, is, in fact, not a pure measure of anxiety but also captures

depression (37). These results therefore support the notion that the three constructs – demoralization, anhedonia and grief – are each components of current conceptualizations of depression. It is of note that it was demoralization that was associated with the greater use of antidepressants rather than anhedonia. This seems to go against a tradition of anhedonia as a marker of a so-called biogenic depression (38) and suggests that, at least intuitively, clinicians are identifying demoralized states as depressions worthy of treatment.

On the other hand, there were differences we can note, particularly in the associations of concurrent measures with demoralization and anhedonia. Physical dysfunction contributed uniquely to anhedonia, whilst lack of family cohesiveness, quality of social supports and avoidance coping were uniquely associated with demoralization. Demoralization itself was not significantly associated with severity of illness or physical functioning in the multivariate analysis. This is not to say that physical disease has nothing to do with demoralization. On the contrary, it is the physical disease and the experience of it that provides the context from which the feelings of helplessness arise. What this result suggests, however, is that, given a situation of serious physical illness, a range of psychological and social factors contribute to the development of demoralization more strongly than physical illness factors. Following the model described by Lazarus and Folkman (39), coping depends on a person's appraisal of the situation – whether it is a threat or a challenge – and on his coping behaviours. Greer and Watson (40) have shown that if patients see their cancer as a threat over which they have little control, they will likely feel helpless and hopeless.



How a person copes with an illness therefore depends on the beliefs and assumptions he brings to the situation – beliefs and assumptions about himself and the disease, about his life and what it should look like, his sense of competence and control (41,42). Serious illness challenges many assumptions, especially of a younger person, leading readily to feelings of helplessness, aloneness and shame (43). The effects of these may be buffered by strong and supportive social relationships. In work not yet published, we have found that demoralization is strongly associated with a weak view of the manageability, comprehensibility and meaningfulness of the world – what Antonovsky has called a “sense of coherence” (44). The idea of control and “controllability of illness” is also important in the development of depression in people with schizophrenia (45).

The concept of demoralization was introduced into psychiatry by Jerome Frank (46), who said “the state of demoralization, in short, is one of hopelessness, helplessness, and isolation in which the person is preoccupied with merely trying to survive”. The epidemiological work of Dohrenwend et al confirmed the validity of the concept (47). McHugh and Slavney incorporated demoralization into their *Perspectives of Psychiatry* framework (48), in which some psychiatric problems are considered diseases of the brain (they include major depression in this group) and some are considered dimensional and psychological in nature. On the other hand, Fava et al (49) and Kissane et al (50) have each developed operationalized criteria for a category of demoralization. The extensive work of Fava et al shows that demoralization is common in the medically ill, with prevalences of 29% in patients with breast cancer (51) and 34% in patients with endocrine disorders (52). The criteria used in these latter studies require that the feeling of demoralization (being unable to cope, hopeless, helpless, giving up, failing to meet expectations) antedates the manifestation of the medical disorder or exacerbates its symptoms. This is consistent with traditional psychosomatics and the idea of Engel (53), but seems a bit restrictive. Our experience is that the syndrome of demoralization occurs commonly in the setting of medical illness and that it is a useful concept even when considered a secondary phenomenon and a response to the predicament of illness.

One of the difficulties has been whether to consider demoralization as normal or as a “disorder”. It is common to hear people say that someone is “just demoralized” as if it is not a serious matter. Slavney (54) believes that demoralization is a normal reaction and places it in the hierarchy of psychiatric disorders below adjustment disorders. This is despite acknowledging that it may involve neurovegetative symptoms, pessimism and suicidality. Other authors describe demoralization as a grief reaction or a situational or reactive depression (e.g., 55). This conflict highlights a slightly different word usage, as well as some confusion surrounding the concept of “normal”. Nevertheless, the evidence for the construct validity of the concept (i.e., that the phenomenon exists) is strong. Further research is

required to ascertain the level of dysfunction associated with demoralization and its value in predicting course and treatment response. Preliminary data suggests that the level of distress associated with demoralization is comparable with or greater than other forms of depression, but the level of social dysfunction is less (7).

With McHugh and Slavney (48) and in contrast to Fava et al (49), we consider demoralization to be best understood as a dimensional phenomenon. However, we do not consider it always to be a “normal” response, even though it may be understandable. Demoralization can be mild or it can be severe, and when it is severe it can lead to profound existential despair and a giving up of life. Consistent with this dimensional view and with the construct described in this paper, we have developed a 24-item self report measure of demoralization measuring aspects of dysphoria, disheartenment, helplessness, sense of personal failure, and loss of meaning and purpose. The scale has high internal reliability, with a Cronbach’s alpha of .94 in a sample of 100 patients with advanced cancer (56).

We turn now to consider anhedonia, which was also clearly identified in the factor analysis. The concept of anhedonia was introduced by Ribot in 1896 to refer to an insensibility to pleasure, in an analogy with analgesia (38). Since then the term has been used more broadly, sometimes referring to a trait of hedonic capacity (57) and sometimes to a state phenomenon (58). In the latter context, Klein has described it as a “sharp, unreactive, pervasive impairment of the capacity to experience pleasure or to respond affectively to the anticipation of pleasure” (58). The importance of anhedonia within the classification of depression has varied over the years (59). It was introduced into DSM-III as a necessary criterion for melancholia (60); in DSM-III-R it was reduced to being one of nine symptoms (61); and in DSM-IV it is one of two symptoms, with mood reactivity, of which at least one is required (62). It seems therefore that the argument by Klein (58) and others (38) that it is the hallmark of a so-called biogenic depression is not fully accepted at this stage.

In this study, anhedonia was associated with worse physical functioning after partialling out the effects of other variables in the regression analysis. Anhedonia has been considered, together with apathy, in the medically ill, as being a disorder with a neurological basis (63,64). Late-stage cancer patients often feel generally ill and have multi-organ disease, in contrast to patients with MND (65), and it is possible therefore that anhedonia in this setting has a very “physical” cause. It is interesting that the two clinical samples differed, with cancer patients being significantly more anhedonic and MND patients more demoralized. This difference may, in part, be related to physical illness factors and in part to the psychological experience of illness, with MND patients tending to be physically healthier, younger and having a longer duration of illness. Issues of differing illness experience require further investigation.

The notion that depression with anhedonia can be distinguished from depression with demoralization also seems pertinent in the elderly. It has been reported that the most frequently experienced negative emotions in older adults with chronic medical conditions are sadness and loneliness (66), both characteristics of demoralization. Conversely, the Baltimore site of the Epidemiologic Catchment Area Program found, in a community survey of patients over 50 years of age with major depression, two distinct groups: those with sadness and those without sadness (termed "depression without sadness") (67). The latter group had anhedonia to meet criteria for major depression. Both groups had similar and significant functional impairment. Further follow-up studies are required to examine whether these two syndromes have different illness courses.

Our results suggest influence from different styles of coping and religiosity. Acceptance–resignation was related to both demoralization and anhedonia, and this is perhaps unremarkable in the sense that some degree of passive "giving-up" may be an adaptive form of behaviour during acute stages of serious illness (68). Demoralization was, in addition, associated with avoidance and confrontation, suggesting that in a demoralized state a wide variety of coping behaviours are used. Belief in God was significantly associated with less anhedonia and less demoralization, although only remained significant for anhedonia in the regression analyses. The role of religious and spiritual beliefs in coping with physical illness deserves more attention, as evidence suggests that spirituality is related to more active rather than passive coping (69) and to better health and well-being (70). Trait optimism is generally associated with maintenance of subjective well-being in times of stress (71,72) and in this study was negatively associated with both anhedonia and demoralization – although not significantly in the multivariate analyses.

This study does suffer from the limitations of cross-sectional research design whereby it is presumptive to make causal judgements. Nevertheless, in a large sample we have confirmed a previously found distinction between depression with anhedonia and depression with demoralization, and again identified the experience of grief in patients with two serious medical illnesses. Concurrent measures show that demoralization and anhedonia are both components of depression as commonly conceived, and yet have different distributions across two different illnesses and different associations with coping and social and family functioning. These findings support the discriminant validity of the concepts. We would argue that research into both the aetiology and treatment of depression would be better advanced by considering these subtypes of depression. The two concepts have different historical roots, with anhedonia associated with beliefs about biogenicity, while demoralization is more cognitively constructed and linked with the role of psychotherapy (46). Nevertheless, empirical evidence is required to confirm whether this or any other important distinction is valid.

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# Stigmatization of people with mental illnesses: a follow-up study within the Changing Minds campaign of the Royal College of Psychiatrists

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*A population survey before the start of the Changing Minds campaign showed that negative opinions about people with mental illnesses were widely held, and that opinions about different disorders differed in important ways. We repeated the survey 5 years later, when the campaign had ended. Interviews were again conducted with a representative population sample (1725 interviews; response rate 65%), enquiring about demographic variables, about eight opinions concerning seven common mental disorders, and whether the respondents knew anyone with one of these mental disorders. The pattern of response in this second survey resembled that in the first. However, there were significant changes. Though often small, apart from reported opinions concerning treatment and outcome, they were all reductions in the percentages of stigmatizing opinions. Seventy seven percent of respondents reported knowing someone with one of the seven disorders. Those who did so in respect of severe depression or panic and phobias were less likely to have stigmatizing opinions about people with the corresponding disorder, but the same did not apply to the other disorders. The greatest proportion of negative opinions was in the 16-19 year age group, and respondents with higher education were less likely than the rest to express such views. We conclude that stigmatizing opinions are frequent in the community but the various disorders are not stigmatized in the same way. Campaigns to reduce stigma should take account of these differences, and of the need to address young people.*

Key words: Stigmatization, public opinions, mental illness

In 1998, the Royal College of Psychiatrists commissioned the Office for National Statistics to carry out a national survey of public opinions about people with mental illnesses. Negative opinions were widespread, especially in relation to people with schizophrenia, alcoholism and drug dependence, who were widely regarded as unpredictable and dangerous (1,2). The survey was repeated five years later. We describe the principal results of this new survey, the changes since the first report, and certain characteristics of individuals that are associated with stigmatizing opinions. Between the two surveys there have been several anti-stigma campaigns, including the "Changing Minds: Every Family in the Land" Royal College of Psychiatrists' campaign (3).

## METHODS

The survey was carried out for the College by the Office for National Statistics using their established National Statistics Omnibus Survey methodology (4). With one exception, described below, the questions were the same as those of the first survey (1). The main features of the method can be summarized as follows.

### The sample

A nationally representative sample of 3,000 addresses (100 addresses in each of 30 postal sectors) in Great Britain was drawn from the Post Code Address File of the Office for National Statistics. At addresses shared by more than one household, one household was selected at random. In each household, one person aged 16 years or over (an "adult") was chosen randomly. This means that people

in households with few adults had a higher probability of selection than people in households with many adults. A weighting factor was applied to correct for this inequality. Proxy interviews were not taken.

### The interview

The interviews were carried out in July 2003, five years after the first survey. Questions were asked about seven disorders: severe depression, panic attacks or phobias, schizophrenia, dementia (e.g., Alzheimer's disease), eating disorder (e.g., anorexia nervosa, bulimia nervosa), alcoholism, and drug addiction.

Interviewers asked whether respondents knew anyone with any of these seven psychiatric disorders. This question was the only one that differed between the two surveys. In 1998, interviewers had asked the more general question whether respondents knew anyone with mental illness, without mentioning specific disorders. In neither survey were respondents asked whether they themselves had experienced a mental illness.

Respondents were then asked how far each of eight statements applied to people with each of the seven disorders. The statements were: *dangerous to others, unpredictable, hard to talk with, feel different from the way we feel at times, have only themselves to blame for their condition, could pull themselves together if they wanted, would not improve if given treatment, will never recover fully*. For each item, respondents were asked to choose a point on a five point scale, the extremes of which bore anchoring statements: for example *dangerous to others – not dangerous to others*.

Region of residence, age, gender and ethnicity were recorded. Regarding occupation, respondents in the second survey were assigned to three groups: managerial/professional; intermediate; and routine/manual (since the classification in general use at the time of the first survey was slightly different, this analysis was of the second set of data only). Respondents were also assigned to one of four groups according to annual income: less than £5,000; £5,000 but less than £10,000; £10,000 but less than £20,000; £20,000 and more.

Also recorded was the age at which respondents left full-time education, as a proxy for highest educational level achieved, and whether there were children under 16 years of age in the household.

### Statistical methods

The responses recorded on the 5 point scales were converted into scores as follows: scores 1 and 2 were coded as negative, scores 4 and 5 were coded as positive, and those who were unsure or could not answer the question were assigned to the central code 3. Sampling errors between surveys were calculated using the standard method assuming random samples. Except where stated, attention is drawn, in the results section, only to differences that are significant at the 95% confidence level. With so many comparisons, results must be interpreted cautiously.

In order to compare the responses of people with different characteristics, two composite scores were derived from the original scores. An *overall opinion score* was obtained by summing the scores on the 5-point scales relating to 5 of the 8 opinions, omitting the two opinions about outcome and also the rating concerned with feeling different. The resulting scores, which vary from 5 to 25, with 5 as the most negative response, were grouped into negative (5-12), neutral (13-17) and positive (18-25). We omitted the two statements that refer to prognosis, because negative responses may reflect knowledge rather than prejudice, for example the opinion that dementia has a poor prognosis. We omitted responses to the statement about feeling different for the reasons presented later. This method of calculating an overall opinion score gives equal weight to each of the five opinions, and it can be argued that some opinions should be given greater weight, for example opinions about dangerousness. However, there is no generally agreed way of weighting the opinions, so we did not attempt it.

A *summary score* was obtained by adding the five overall opinion scores for each of the seven disorders. The resulting score varies from 7 to 21, with 7-10 the most negative and 18-21 the most positive.

The effects of individual characteristics were examined by comparing the percentages of respondents with and without the relevant variable, whose responses led to negative overall opinion scores and summary scores in the most negative group.

## RESULTS

### The sample

Interviews were obtained with 1725 people aged 16 years and over. This response rate of 65% is close to that obtained in similar surveys carried out by Office for National Statistics, and to the 67% response rate in the 1998 survey.

### Personal knowledge of someone who has had mental illness

In 1998, 52% of respondents said yes to the single question "Do you know someone with mental illness?". In 2003, the question was rephrased and asked about each of the seven illnesses. In response to these seven more specific questions, 77% said that they knew at least one person with one of the specified illnesses. Almost half the sample (47%) reported knowing someone who had experienced severe depression; about a third knew someone with alcoholism (37%), dementia (34%), or panic and phobias (33%); about a quarter knew someone with drug addiction (23%), or an eating disorder (22%); and 15% knew someone with schizophrenia.

In general, men were rather less likely than women to answer that they knew someone with a mental disorder (74% vs. 80%) and to know someone with any of the individual conditions, with the exceptions of drug addiction (M/F: 25/22) and alcoholism (M/F: 40/34). Respondents aged 16-24 were more likely than those 65 and over to answer that they knew someone with drug addiction (43% vs. 8%), alcoholism (42% vs. 21%) and eating disorder (36% vs. 8%). The percentages of respondents in other age groups who knew someone with these disorders lay between these extremes. On the other hand, respondents aged 65 and over were more likely than those aged 16-24 to answer that they knew someone with dementia (40% vs. 20%).

In terms of socio-economic status, the main finding was that respondents in managerial and professional classes were rather more likely than other respondents to say that they knew someone with at least one of the mental illnesses (82% vs. 75%).

### Opinions about people with mental illnesses

#### *Opinions expressed in 2003*

Table 1 reveals that the percentage of respondents endorsing the eight negative opinions differed between the seven disorders. The greatest variation in this percentage was in relation to *danger to others*, ranging from 75% for drug addiction and 66% for schizophrenia, to only 7% for eating disorder. The corresponding percentages in relation to *unpredictability* form a similar pattern, while the percentages for *blameworthiness* were greatest for drug addiction (60%) and alcoholism (54%) and smallest for

**Table 1** Percentages agreeing with negative statements, 1998 and 2003

	Severe depression		Panic attacks		Schizophrenia		Dementia		Eating disorder		Alcoholism		Drug addiction	
	1998	2003	1998	2003	1998	2003	1998	2003	1998	2003	1998	2003	1998	2003
Danger to others	23	19**	26	23*	71	66**	19	20	7	7	65	64	74	75
Unpredictable	56	53	50	50	77	73*	53	54	29	27	71	70	78	78
Hard to talk to	62	56**	33	26**	58	52**	60	56*	38	33**	59	55*	65	64
Feel different from us	43	30**	39	25**	57	37**	61	42**	49	33**	35	25**	48	33**
Selves to blame	13	11	11	10	8	6*	4	4	34	33	60	54	68	60**
Could pull self together	19	17	22	20	8	8	4	5	38	35	52	50	47	45
Not improved if treated	16	15	14	15	15	12*	56	50**	9	10	11	12	12	11
Never fully recover	23	25	22	21	51	42**	82	79*	11	15**	24	29**	23	26**

Differences from the 1998 data: \*  $p < 0.05$ , \*\*  $p < 0.005$

schizophrenia (6%) and dementia (4%). The percentage endorsing negative statements about *treatability* also differ between the disorders, with 50% endorsing the opinion that dementia will not recover with treatment, but only 11% choosing this response for drug addiction. The statement “will never recover completely” was endorsed by 79% in relation to dementia but only 15% for eating disorder, while 42% chose this response for schizophrenia.

The greatest percentage of negative opinions was in relation to drug addiction, especially opinions about *dangerousness*, *unpredictability* and *being hard to talk with*. Alcoholism and schizophrenia were close behind on these three variables, but whereas more than half the respondents thought that people with drug addiction and alcoholism were *to blame for their condition*, only 6% expressed this opinion about people with schizophrenia.

#### Comparison of responses in 1998 and 2003

The pattern of responses in 2003 is similar to that found in 1998, suggesting that the seven disorders are recognized consistently and that there are real and enduring differences of opinion about them. The percentages of people expressing negative opinions changed in a number of instances over the 5 years. This change was generally a decrease, often small. Of the 27 (out of a total of 56 items) which changed significantly, the 24 concerning opinions about people with the given mental illnesses were all decreases. All three increases were in relation to opinions about prognosis, with more respondents choosing the statements that people with eating disorder, alcoholism and drug addiction will never fully recover. Of the 24 decreases, seven were responses to the statement *feel different from the way we feel at times* and these decreases were often greater than those for any of the other statements. Some interviewers reported that some respondents found this statement difficult to understand. Nevertheless, the overall pattern of the data on this statement was consistent with clinical expectations. Thus, three times as many people reported that they felt unable, at times, to empathize with people with schizophrenia and dementia as reported being able to do so. For eating disorder and drug addiction the ratio was two to one. For depression it

was three to two, whilst for panic attacks and alcoholism the numbers were nearly equal. Moreover, the changes in the *empathy* item are closest to those in the *hard to talk to* item, which can be considered to reflect related aspects of communication with people with mental illnesses. Even when the *empathy* result is discarded, the pattern of change between the two surveys remains the same, with decreased percentages for 14 of a possible 49 items and increased percentages for just the items concerning prognosis. Nevertheless, in view of the doubt about some respondents' understanding of the statement concerned with feeling different and also because the relatively large changes in it might unduly distort the two sets of summary scores, we excluded it from that aspect of the analysis.

#### Overall opinions about each disorder

Table 2 shows that, in 2003, drug addiction was viewed unfavourably by the greatest percentage of respondents, with 74% of respondents recording overall negative opinions and only 5% recording positive ones. Alcoholism, with 66% overall negative opinions and only 6% positive ones, is next. Dementia, with only 3% overall negative and 35% positive opinions, was viewed most favourably, fol-

**Table 2** Overall attitudes (%) toward each disorder by year of interview

	Year of interview	Negative (5 to 12)	Neutral (13 to 17)	Positive (18 to 25)
Severe depression	2003	16	56	28
	1998	20	59	21
Panic attacks	2003	14	50	36
	1998	14	54	31
Schizophrenia	2003	21	70	9
	1998	22	71	7
Dementia	2003	3	62	35
	1998	4	59	37
Eating disorder	2003	13	55	32
	1998	14	58	28
Alcoholism	2003	66	28	6
	1998	69	25	6
Drug addiction	2003	74	21	5
	1998	77	19	4

lowed by panic attacks (14% negative and 36% positive) and eating disorder (13% negative and 32% positive). Severe depression (16% negative and 28% positive) is in an intermediate position. Schizophrenia has 21% negative and only 9% positive overall opinions and 70% of neutral ones. This is the highest percentage of people with overall neutral responses for any of the seven disorders; the lowest are for alcoholism and drug addiction.

### *Changes in overall opinions*

Table 2 shows that the pattern of overall opinions was similar in the two surveys. For none of the disorders was there an increase in the percentage of respondents expressing overall negative opinions over this period and there were small decreases for depression (from 20% to 16%), alcoholism (69% to 66%) and drug addiction (77% to 74%). The percentage of overall positive opinions increased slightly for depression (21% to 28%), panic attacks (31% to 36%) and eating disorder (28% to 32%). Only for dementia was there a small decrease. In both surveys, the proportion of respondents expressing overall neutral opinions was high for all disorders except alcoholism and drug addiction. This percentage decreased slightly over the five years for depression (59% to 56%), panic attacks (54% to 50%) and eating disorder (58% to 55%). On both occasions, schizophrenia attracted the greatest percentage of overall neutral opinions (71% in 1998 and 70% in 2003).

### *Opinions about the outcome of mental illnesses*

We summed the scores on the scales relating to prognosis and response to treatment to give a composite outcome score varying from 2 to 10. We grouped these composite scores into three categories: poor (2-4), neutral or uncertain (5-7) and good (8-10). These outcome scores differed between the seven disorders: 70% of respondents had poor outcome scores for dementia and only 6% had good outcome scores. In contrast, only 9% had poor outcome scores for eating disorder and 65% had good outcome scores. For schizophrenia, 25% had poor outcome scores and 29% had good ones. For the other disorders, between 16 and 18% had poor outcome scores and 52-53% had good ones. For all except one of the disorders, between about a quarter and a third of ratings were neutral or uncertain. The exception was schizophrenia, with almost a half (46%) of overall ratings in this category.

### **Effects of personal characteristics**

#### *Age and gender*

Respondents aged 16-19 years were more likely than the rest to have negative overall opinion summary scores for every disorder except panic attacks (Table 3). For example, for depression, 36% of 16-19 year olds had negative overall opinion scores, compared with fewer than 20% of

**Table 3** Percentage with negative views by age (combined data 1998 + 2003)

	16-19	20-24	25-44	45-64	65 and over
Severe depression	36	18	17	15	19
Panic attacks	15	9	15	13	16
Schizophrenia	31	26	21	21	20
Dementia	7	1	2	3	5
Eating disorder	21	12	11	13	15
Alcoholism	85	77	74	64	55
Drug addiction	87	83	81	74	64

those in every other age group. Likewise, 31% of 16-19 year olds had negative overall opinion scores for schizophrenia, compared with 20-26% of those aged 25 years and over. For drug addiction and alcoholism, there was a trend across the age groups with the greatest percentage of negative summary scores among the younger respondents (87% for drug addiction and 85% for alcoholism). On the summary scores, 49% of 16-19 year olds were in the two negative categories compared with 36% for the other age groups combined. Also, compared with the rest, far more of the 16-19 year olds were in the most extreme negative category (22% vs. 8%).

Compared with women, men were rather more likely to have overall negative opinions for depression (20% vs. 16%), panic attacks (17% vs. 12%), schizophrenia (24% vs. 20%) and eating disorder (15% vs. 12%). For dementia, alcoholism and drug addiction, however, the corresponding differences were not significant. On the summary scores, 40% of men were in the two negative groups compared with 34% of women (the percentages in the extreme negative category were: men 10%; women 8%).

#### *Region of residence, ethnicity, occupation and income*

There was no consistent pattern of variation by region of residence, either in the overall negative opinion scores or in the summary scores and the few and scattered positive findings may not reflect real differences between regions. Thus, respondents in Scotland were more likely than those in other regions to have negative attitudes to people with a drug addiction, whilst respondents in Wales were less likely to report negative attitudes towards those with depression or dementia.

It was not possible to examine relationships between reported opinions and ethnic backgrounds, because the number of non-white respondents was too low, even when the data from the two surveys were combined.

Regarding occupation, those in routine or manual occupations were more likely to have overall negative opinions for severe depression, compared with people whose current or last job was managerial or professional (18% vs. 11%). This was also true for schizophrenia (25% vs. 17%),

and eating disorder (17% vs. 9%), but not for alcoholism (65% and 66%) or drug addiction (73% and 74%). Few of either group had overall negative opinions for dementia (4% and 1%). On the summary scores, 38% of those in routine and manual occupations had scores in the two negative categories, compared with 30% in each of the other two socio-economic classes. Most of the difference was in the percentages in the most extreme negative category (11% vs. 6% respectively).

Compared with those in the lower income groups, a smaller proportion of respondents with a gross personal income of £20,000 a year or more had overall negative opinions for depression (13% vs. 19%), schizophrenia (17% vs. 23%), and eating disorder (10% vs. 14%). The responses of the high-income group concerning the other disorders fell between those of the three lower income groups. On the summary scores, 32% of the group with incomes of £20,000 per annum or more were in the most negative category, compared with 35-41% of people in the other income groups.

### Education

Respondents who stayed in education after the age of 18 years (Table 4) were less likely than those who left earlier to have negative overall opinions for severe depression, schizophrenia and eating disorder, but not for alcoholism or drug addiction. Few in any group had negative overall opinions for dementia. Fewer of those whose education continued after the age of 18 years had summary scores in the most negative category, compared with those whose education did not extend beyond 18 years (4-5% vs. 8-9%). Respondents who were still in education at the time of the survey contained the highest percentage of those with the summary scores in the most negative category (15% vs. 4-9% for those with education beyond 18 years and 8-9% for the rest)

### Knowing someone with a mental illness

Compared with the rest of the respondents, a smaller proportion of those who knew someone with depression had overall negative opinions for this disorder (12% vs. 18%). Similarly, a smaller proportion of those who knew

**Table 4** Percentage with negative views by age left full-time education (combined data 1998 + 2003)

	Up to 14	15 to 18	19 to 25	26 or over	Still in education
Severe depression	20	19	12	12	27
Panic attacks	16	14	14	14	13
Schizophrenia	19	24	17	17	19
Dementia	5	3	2	2	6
Eating disorder	16	14	8	11	16
Alcoholism	56	69	67	66	85
Drug addiction	62	78	75	78	89

**Table 5** Overall attitudes toward each disorder (%) by whether respondent knows someone with that disorder

	Respondent knows someone with the disorder			
		Negative (5 to 12)	Neutral (13 to 17)	Positive (18 to 25)
Severe depression	Yes	12	53	35
	No	18	58	23
Panic attacks	Yes	10	41	49
	No	16	55	29
Schizophrenia	Yes	20	65	15
	No	21	71	8
Dementia	Yes	2	62	36
	No	3	62	35
Eating disorder	Yes	11	47	41
	No	13	58	29
Alcoholism	Yes	66	27	6
	No	66	28	6
Drug addiction	Yes	75	18	6
	No	74	22	4

someone with panic attacks had overall negative opinions for panic disorder (10% vs. 16%). Those who knew someone with any of the other disorders were no less likely than the other respondents to have overall negative opinions for the corresponding disorder. Compared with the other respondents, a slightly smaller proportion of those who knew someone with schizophrenia held overall neutral opinions for this disorder (65% vs. 71%) and a slightly higher percentage had positive ones (15% vs. 8%). Similar differences were found for the responses of people who knew someone with an eating disorder (neutral scores 47% vs. 58%; positive scores 41% vs. 29%).

People who knew someone with the corresponding mental illness were more likely than the rest to rate as poor the outcome of depression (20% vs. 14%), schizophrenia (30% vs. 20%), dementia (75% vs. 63%) and alcoholism (21% vs. 16%) (Table 5).

### Respondents with a child under 16 in the household

Respondents with at least one child under the age of 16 years in the same household were rather more likely than the rest to have overall negative opinions for alcoholism (73% vs. 66%) and drug addiction (80% vs. 74%) but not for the other disorders. However, the group with a child under 16 years in the same household did not have a greater percentage of respondents with summary scores in the most negative categories.

## DISCUSSION

The survey was carried out on our behalf by the Office for National Statistics, using well-tried procedures for data collection and analysis. Its shortcomings are those of other large-scale surveys of representative samples of the population. The response rate was 65%, which is close to the



usual rate achieved in comparable surveys by the Office for National Statistics but nevertheless incomplete. Also, as in all opinion surveys, we cannot be certain that expressed opinions accurately reflect true opinions or that opinions reflect actual behaviour. Therefore, as in any population survey, conclusions should be drawn cautiously. Nevertheless, the broad similarities in the pattern of responses obtained in the present survey and in that conducted in 1998 encourage confidence in the reliability of the procedures.

We asked about opinions on seven psychiatric disorders whereas most other investigations of stigma have enquired about a general concept of mental illness. We did this because many people with major psychological distress presenting to doctors now receive a psychiatric diagnosis and it is important to know what stigma attaches to it. It is sometimes suggested that the stigma attached to a psychiatric diagnosis does harm that outweighs any benefits from the diagnosis. We do not share this view. It is true that diagnostic labels focus attention on general features, often of an adverse kind and, in this way, are potentially stigmatizing (5). However, labels with damaging and dismissive connotations have long been attached to people with mental disorders (6), and modern diagnoses are more specific and can be a valuable guide to prognosis and treatment. In any case, since stigma is attached to diagnoses, it is most important to find out more about it so that it can be reduced and eventually overcome.

### Stigmatizing opinions in 2003

Stigmatizing opinions were endorsed commonly by men and women from all social classes, living in all parts of the country. There were, however, differences in the nature and extent of the stigma attached to the seven disorders. The most stigmatized of the disorders were drug addiction, alcoholism and schizophrenia. People with schizophrenia are likely to find that two thirds of the people they meet think that they are *dangerous*, that three quarters think they are *unpredictable*, and that half think that they will be *hard to talk with*. People with alcoholism and drug addiction are even more stigmatized, for not only do many people think that they are *dangerous*, *unpredictable* and *hard to talk with*, but three in five people think that they are *to blame for their condition* – an opinion endorsed by only 6% in relation to schizophrenia.

Compared with people with schizophrenia, those with severe depression will encounter fewer people who think them *dangerous* – about one in five – but as with schizophrenia, about half will think that they are *unpredictable* and *hard to talk with*. These last two opinions are likely to discourage those who hold them from making the closer contact with depressed people that could lead them to change their other opinions. Looked at from the opposite standpoint, however, a substantially greater proportion of people expressed positive opinions than negative ones

about people with depression, panic and phobic disorders, dementia and eating disorder.

### Knowing someone with mental disorder

In the first survey we asked the general question whether respondents knew someone with mental illness and 52% said yes. This figure is close to the 49% of respondents who said that they knew someone with mental illness in another recent survey (7). In the present survey, interviewers asked separately about knowledge of someone with each of the seven disorders, and about three-quarters of respondents replied affirmatively. It is possible that, on the first occasion, some respondents did not consider, for example, eating disorder as a mental disorder. If so, this could account for the differences between the two survey responses. Opinions about the people with psychiatric disorders are subject to many influences, including accounts in the media and, in some cases, personal knowledge of a person with the illness. The importance of personal knowledge varies between the seven disorders: almost half the respondents knew someone with severe depression, but only one in six knew someone with schizophrenia. For the rest, about one in three knew someone with alcoholism, dementia or panic attacks; about one in four knew someone with an eating disorder or with drug addiction. As would be expected, the elderly were more likely to know someone with dementia, and the young were more likely to know someone with drug addiction, alcoholism or eating disorder.

Respondents who knew someone with depression or panic and phobias were rather less likely to express stigmatizing opinions about the corresponding disorder, but this was not the case with personal knowledge of someone with one of the other disorders. However, people who knew someone with schizophrenia or eating disorder were a little less likely to record neutral opinions and a little more likely to record positive ones. People who knew someone with depression, schizophrenia, dementia and alcoholism were also rather more likely to think that the outcome of the corresponding condition was poor. It seems therefore that personal acquaintance does not always modify negative opinions that have been arrived at in other ways. Meanwhile, there is also some evidence that expertly guided contact with people with chronic mental illness severe enough for them to need collective supervised community care, can lead to increased knowledge and empathy in members of the public (8).

### Neutral opinions

The neutral category is for respondents whose opinion is undecided or uncertain. When the overall measure is used, 70% of respondents recorded overall neutral opinions about schizophrenia, compared with only 21% for drug addiction and 28% for alcoholism. For the other dis-

orders, about a half of the respondents recorded such opinions. These substantial percentages of people with neutral or uncertain opinions are a potential target for anti-stigma campaigns, for it seems possible that their opinions might be more amenable to positive change than those of people whose opinions are negative. If this is correct, it is noteworthy that the largest percentage of neutral opinions was about schizophrenia.

### Changes between 1998 and 2003

The most striking change over the 5-year interval was that fewer people endorsed the statement that people with any of the seven disorders feel different from us. This change ranged from 10 to 20%, which is substantially greater than the changes in any other opinion. The opinion *feel different from us* was included because it might reflect an aspect of empathy, and lack of empathy is an important aspect of stigma. Because the changes are larger than those in any other variable, and because some respondents had difficulty in understanding the statement, it is necessary to consider alternative reasons for the decrease. It is unlikely that it is due to a change in procedure, since the statement was worded and presented to respondents in exactly the same way on the two occasions. The fact that the percentages changed for all seven disorders suggests that the findings are not random responses. Nevertheless, because the greater size of the changes is unexplained, we thought it safer to exclude this opinion from analyses in which overall opinions were considered. However, we do not wish to ignore it. If it does reflect real change, then we regard it as a potential forerunner to other less negative public opinions concerning people with mental illnesses.

The Royal College of Psychiatrists and other organizations have campaigned against stigmatization during the 5 years between the two surveys. However, the positive changes between the two occasions cannot be ascribed to these campaigns, because opinions are subject to so many other influences. Nevertheless, the results can suggest whether stigmatization is changing. A recent study (7) reported that, while the majority of respondents expressed caring and sympathetic views of people with mental illness, attitudes had become less positive between 2000 and 2003. Our findings were about individual disorders, rather than a global concept of mental illness, and we found some small improvements. For example, although overall opinions about schizophrenia changed little over the 5-year period, about 5% fewer respondents endorsed the opinions that people with schizophrenia are dangerous and unpredictable. Further surveys will be needed to determine whether the changes that we observed are part of a lasting trend to improvement.

Our findings suggest that anti-stigma campaigns should be directed not to mental illness in general, but to specific disorders. This is because the stigma attached to the various disorders is not all the same. Thus, the majority of our

respondents endorsed the opinion that people with schizophrenia are *dangerous, unpredictable* and *hard to talk with*, but few thought that they are *capable of pulling themselves together*. On the other hand, very few respondents endorsed the opinion that people with eating disorder are *dangerous* but a third thought that they *could pull themselves together*. However, there were some common themes, notably that respondents thought that people with all seven disorders would be *hard to talk with*. Campaigns to reduce stigmatization need to address both the specific and the general opinions, whilst recognizing the social handicaps that can be features of mental illness, in messages tailored to each disorder. They will require that both knowledge and contact skills (9) are appropriately enhanced.

### Opinions about prognosis and the effects of treatment

Opinions about prognosis and treatment were generally realistic. Thus, although half of the respondents endorsed the opinion that dementia responds poorly to treatment, only 10-15% said this of the other disorders. Opinions about outcome were similar. These findings suggest that there is a basis of understanding of at least some aspects of mental disorders on which future anti-stigma campaigns might build.

### Characteristics associated with stigmatizing opinions

Among the respondents to these two surveys, stigmatizing opinions were endorsed by men and women of all ages, living in all parts of Great Britain. There were nevertheless some features that help to characterize people who endorsed negative opinions. Regarding age, the most negative opinions were endorsed by 16-19 year olds: one in three endorsed overall negative opinions about people with schizophrenia and depression, compared with about one in five in the other age groups, and a striking 85% endorsed overall negative opinions about people with alcoholism and drug addiction. Also, respondents in the 16-19 age group were more likely than the rest to choose the most extreme overall opinions. The findings concerning alcoholism and drug addiction are in contrast with the reported wide use of alcohol and drugs by young people. The finding may suggest that the young people who use these substances do not think of themselves as potential abusers and do not identify with those who are. If so, the findings would be relevant to campaigns that seek to prevent drug abuse among young people by warning of the consequences of addiction.

Stigmatizing opinions were expressed by a smaller proportion of those who had received higher education than of those whose education had stopped at age 18 years. While this finding may point to the value of education in reducing stigmatization, it could also reflect the processes of selection for higher education, or the greater choice of socially acceptable responses to questions by some respondents in the higher education group. Nevertheless this finding, together with those concerned with age, suggests

that anti-stigma campaigns should pay particular attention to young people. This was a feature of the recent campaign by the Royal College of Psychiatrists (see 10).

Stigmatizations of people with mental illnesses are fuelled by many things. Media attention still often focuses public attention on the most negative attributes of mental illnesses (11). Moreover, people observe or read about evident problems of the “visible” minority of people with chronic and severe mental illness, and also those with personality disorder (which has attracted much media attention these last few years and which we did not include in our survey). They may then generalize their conclusions, assuming that everyone with a mental illness will have the same severe problems. If Murray and Lopez (12,13) are correct, then ‘one in four’ of us will experience a mental illness personally at some stage of our lives. Correspondingly, we are likely to encounter such illness at some stage in ‘one in four’ of those around us, or, as the Royal College campaign put it, within ‘every family in the land’. Stigmatizations by others, such as we have identified here, may be coupled with self-stigmatizations (14,15). Together they make it even harder for people with a mental illness to acknowledge their problems and seek help. Real progress in the care of people with mental illnesses requires that stigmatizations are reduced alongside improvements in prevention, treatments and self-help strategies.

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# Global suicide rates among young people aged 15-19

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*Global suicide rates among adolescents in the 15-19 age group, according to the latest World Health Organization (WHO) Mortality Database, were examined. Data for this age group were available from 90 countries (in some cases areas) out of the 130 WHO member states. The mean suicide rate for this age group, based on data available for the latest year, was 7.4/100,000. Suicide rates were higher in males (10.5) than in females (4.1). This applies in almost all countries. The exceptions are China, Cuba, Ecuador, El Salvador and Sri Lanka, where the female suicide rate was higher than the male. In the 90 countries (areas) studied, suicide was the fourth leading cause of death among young males and the third for young females. Of the 132,423 deaths of young people in the 90 countries, suicide accounted for 9.1%. The trend of suicide rates from 26 countries (areas) with data available during the period 1965-1999 was also studied. A rising trend of suicide in young males was observed. This was particularly marked in the years before 1980 and in countries outside Europe. The WHO database is the largest of its kind and, indeed, the only information source that can currently be used for analysis of global mortality due to suicide. Methodological limitations are discussed.*

Key words: Suicide, young people, causes of death

Suicidal behaviour is a major health concern in many countries, developed and developing alike. At least a million people are estimated to die annually from suicide worldwide (1). Many more people, especially the young and middle-aged, attempt suicide (2).

Over the last few decades, while suicide rates have been reported as stable or falling in many developed countries, a rising trend of youth suicide has been observed. In 21 of the 30 countries in the World Health Organization (WHO) European region, suicide rates in males aged 15-19 rose between 1979 and 1996. For females, suicide rates rose less markedly in 18 of the 30 countries studied (3). Various possible explanations for these rising suicide trends – loss of social cohesion, breakdown of traditional family structure, growing economic instability and unemployment and rising prevalence of depressive disorders – have been presented.

Some worldwide analyses of suicide trends and rates in the world have been published (4-7), but very little is known worldwide about the causes of death and suicide rates among young people aged 15-19.

The purpose of this study was to present an overall picture of suicide among adolescents worldwide using available data from the WHO database, and to evaluate the role of suicide as a cause of death in the 15-19 age group.

## METHODS

Data on causes of death and population for each country (area) were downloaded from the WHO Mortality Database website in February 2004. Statistics on causes of death and population in the 15-19 age group were available for 90 countries (areas) in the year 1980 or later. From 71% of these 90 countries (areas), there were data relating to the year 1995 or later, and roughly half had data for

2000 or later. For 30%, there were figures dating back to before 1995.

The downloaded data files were converted into SPSS files. Data files with different versions of the International Classification of Diseases (ICD) were merged and analysed by gender, age group, cause of death and calendar year.

The following codes for certain suicide in the WHO Mortality Database were used: in ICD-7 classification, codes A148 and B049, including E963, E970-E979; in ICD-8 classification, codes A147 and B049, including E950-E959; in ICD-9 classification, codes B54 and C102, including E950-E959; in ICD-10 classification, codes X60-X84 (in some countries code 1101, including codes X60-X84).

The mean suicide rate in the 15-19 age group was calculated by collating the numbers of suicides in the latest year with available figures in the population from all the 90 countries (areas). Moreover, to avoid confounding country effects with time effects, only countries that reported data for the same year were selected. Therefore, suicide rates in 63 countries in 1995 were also analysed and compared, since the largest number of countries (areas) reported suicide and population data for that year.

A few countries were excluded from the analyses since the population in the 15-19 age group numbered less than 10,000.

In order to evaluate suicide trends, suicide rates from all countries (areas) with data available throughout the period 1965-1999 were examined. Rates in European and non-European countries were compared.

The total number of deaths for the 90 countries (areas) with the latest available data was divided by the number of deaths in each diagnostic category to arrive at percentages for causes of death in each category. The "other causes of death" category includes many different causes that account for relatively small numbers of deaths, such as dis-

eases of the blood and blood-forming organs; diseases of the eye, ear, skin and subcutaneous tissue, musculoskeletal system and connective tissue, and genito-urinary system; certain conditions originating in the perinatal period; and various symptoms, signs and ill-defined conditions.

## RESULTS

For 90 countries (areas), data were available both on causes of death and on the population aged 15-19. The numbers of suicides and rates per 100,000 persons aged 15-19 and the latest year in which data were available for each country (area) are presented in Table 1.

A total of 12,064 cases of suicide (8,801 males and 3,263 females) from 90 countries (areas) were analysed. The mean suicide rate for 15-19 year-olds in the 90 countries (areas), based on data in different years for the various countries, was 7.4/100,000 (10.5 for males and 4.1 for females).

There were 13 countries with suicide rates 1.5 times or more above the mean: these included Sri Lanka, with the highest suicide rate, followed by Lithuania, Russia and Kazakhstan. In 24 countries (areas) suicide rates were above, but less than 1.5 times, the mean: this category included Norway, Canada, Latvia, Austria, Finland, Belgium and the USA. The remaining 53 countries (areas) had below-average suicide rates (Table 1).

**Table 1** Suicide numbers and rates per 100,000 young persons aged 15-19 in 90 countries (areas), according to the WHO Mortality Database, February 2004 (latest available data for each country or area)

Country (area)	Year	Number			Rate		
		Males	Females	Total	Males	Females	Total
Sri Lanka	1986	388	424	812	43.9	49.3	46.5
Lithuania	2002	54	12	66	38.4	8.8	23.9
Russian Federation	2002	2,384	499	2,883	38.5	8.3	23.6
Kazakhstan	2002	240	78	318	31.2	10.5	21.0
Luxembourg	2002	3	1	4	23.5	8.2	16.0
New Zealand	2000	31	11	42	22.3	8.2	15.3
El Salvador	1993	44	52	96	13.2	15.8	14.5
Belarus	2001	100	16	116	23.6	3.9	14.0
Estonia	2002	13	1	14	24.1	1.9	13.2
Turkmenistan	1998	41	21	62	16.6	8.8	12.8
Ukraine	2000	375	92	467	19.6	4.9	12.4
Ireland	2000	34	7	41	19.8	4.3	12.3
Mauritius	2000	5	6	11	10.1	12.5	11.3
Norway	2001	21	8	29	15.3	6.2	10.9
Canada	2000	173	52	225	16.3	5.2	10.8
Latvia	2002	16	4	20	16.9	4.4	10.8
Kyrgyzstan	2002	42	13	55	15.2	4.8	10.0
Virgin Islands (USA)	1980	1	0	1	20.0	0.0	9.8
Barbados	1995	1	1	2	9.6	9.8	9.7
Austria	2002	37	9	46	15.1	3.8	9.6
Trinidad and Tobago	1994	6	6	12	8.9	10.5	9.6
Finland	2002	25	6	31	15.0	3.8	9.5
Uzbekistan	2000	170	86	256	12.5	6.4	9.5
Belgium	1997	46	12	58	14.5	3.9	9.3
Cuba	1996	23	45	68	6.1	12.5	9.2
Ecuador	1991	40	64	104	6.9	11.4	9.1
Iceland	1999	1	1	2	9.0	9.3	9.1
Australia	2001	95	25	120	13.8	3.8	8.9
Singapore	2001	10	8	18	9.2	7.8	8.5
Suriname	1990	3	1	4	12.5	4.3	8.5
Poland	2001	242	39	281	14.1	2.4	8.4
Switzerland	2000	27	8	35	12.6	4.0	8.4
Croatia	2002	21	3	24	14.0	2.1	8.2
USA	2000	1,347	269	1,616	13.0	2.7	8.0
Grenada	1988	0	1	1	0.0	15.6	7.8
Slovenia	1987	8	2	10	12.0	3.1	7.6
Hungary	2002	37	12	49	11.2	3.8	7.5
Guadeloupe	1981	2	1	3	8.8	4.6	6.8
Japan	2000	335	138	473	8.8	3.8	6.4
Uruguay	1990	11	5	16	8.3	3.9	6.2
Bulgaria	2002	25	6	31	9.2	2.3	5.8
Czech Republic	2001	33	6	39	9.5	1.8	5.7
Argentina	1996	122	67	189	7.1	4.0	5.6
Costa Rica	1995	13	7	20	7.1	4.0	5.6
Germany	2001	207	54	261	8.7	2.4	5.6
Thailand	1994	189	154	343	6.1	5.1	5.6
Colombia	1994	120	73	193	6.7	4.2	5.5

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**Table 1 (continued)** Suicide numbers and rates per 100,000 young persons aged 15-19 in 90 countries (areas), according to the WHO Mortality Database, February 2004 (latest available data for each country or area)

Country (area)	Year	Number			Rate		
		Males	Females	Total	Males	Females	Total
Venezuela	1994	80	41	121	7.1	3.8	5.5
Republic of Korea	2001	110	85	195	5.9	4.9	5.4
Hong Kong	1999	12	12	24	5.1	5.3	5.2
France	1999	150	48	198	7.5	2.5	5.0
Denmark	1999	13	1	14	9.0	0.7	4.9
Israel	1999	24	2	26	8.7	0.8	4.9
Paraguay (reporting areas)	1987	5	7	12	3.9	5.6	4.7
Romania	2002	59	18	77	7.0	2.2	4.7
Netherlands	2000	35	8	43	7.4	1.8	4.6
Sweden	2001	15	7	22	5.7	2.8	4.3
Brazil (South, South-East and Central West)	1995	286	128	414	5.7	2.6	4.2
Puerto Rico	1992	14	0	14	8.3	0.0	4.2
United Kingdom	1999	122	33	155	6.5	1.8	4.2
Republic of Moldova	2002	13	2	15	7.1	1.1	4.1
China (selected rural and urban areas)	1999	179	253	432	3.2	4.8	4.0
Belize	1995	0	1	1	0.0	7.9	3.9
Slovakia	2002	13	4	17	5.8	1.9	3.9
Chile	1994	38	8	46	6.2	1.3	3.8
Mexico	1995	263	117	380	5.1	2.3	3.7
Spain	2000	71	18	89	5.3	1.4	3.4
Panama	1987	6	2	8	4.6	1.6	3.1
Albania	2001	4	5	9	2.8	3.3	3.0
Dominican Republic	1985	10	12	22	2.7	3.2	2.9
Italy	2000	57	25	82	3.6	1.7	2.7
Macedonia	2000	1	3	4	1.2	3.7	2.4
Tajikistan	1999	11	3	14	3.3	0.9	2.1
Portugal	2000	9	3	12	2.6	0.9	1.8
Greece	1999	10	2	12	2.7	0.6	1.7
Guyana	1984	2	0	2	3.4	0.0	1.7
Armenia	2002	2	1	3	1.3	0.6	1.0
Peru	1983	13	7	20	1.3	0.7	1.0
Jamaica	1985	2	0	2	1.4	0.0	0.7
Azerbaijan	2002	5	0	5	1.1	0.0	0.6
Syrian Arab Republic (part)	1985	5	0	5	1.0	0.0	0.5
Georgia	2000	1	0	1	0.6	0.0	0.3
Egypt	1987	0	1	1	0.0	0.04	0.02
Bahamas	1995	0	0	0	0.0	0.0	0.0
Guatemala	1984	0	0	0	0.0	0.0	0.0
Kuwait	2001	0	0	0	0.0	0.0	0.0
Malta	2002	0	0	0	0.0	0.0	0.0
Philippines	1996	0	0	0	0.0	0.0	0.0
Saint Lucia	1988	0	0	0	0.0	0.0	0.0
Saint Vincent and Grenadines	1986	0	0	0	0.0	0.0	0.0
Total		8,801	3,263	12,064	10.5	4.1	7.4

The mean suicide rate for males and females together in the 63 countries (areas) for which data for the year 1995 were available was 8.4/100,000, slightly higher than that (7.4/100,000) in the 90 countries (areas) described above, mainly owing to the higher suicide rate in males (Table 2). Among these, 13 countries (including Russia, New Zealand, the Baltic states, Kazakhstan, Norway, Canada and Slovenia) reported suicide rates of 1.5 times the mean or more. Sixteen countries (including Ukraine, Switzerland, the USA, Austria, Ireland, Belgium, Hungary and Portugal) showed suicide rates above, but less than 1.5 times, the mean. Thirty-four countries had below-average suicide rates (Table 2). More than two-thirds of the countries listed in Table 2 are European countries.

In 26 countries (areas), data were available for the whole period studied, 1965-1999. Table 3 presents suicide rates for

each country (area), broken down by gender, during three periods (1965-1979, 1980-1989 and 1990-1999). A rising trend of suicide rates in the 15-19 age group was observed in males from both non-European and European countries, while the trend was fairly stable or declined slightly in females. Suicide rates among both young males and females were higher in non-European than in European countries during the whole period 1965-1999 (Table 3, Figure 1).

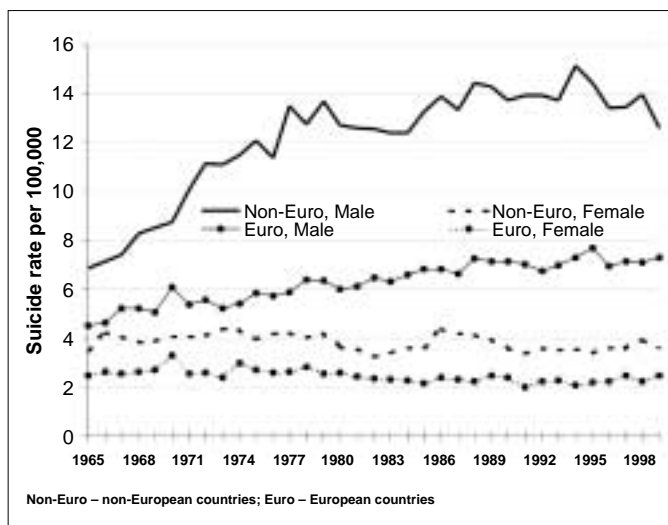
Causes of death were examined for 90 countries (areas). The data covered the same years as the data presented in Table 1. A total of 132,423 deaths from all kinds of causes in the 15-19 age group in the 90 countries (areas) (Table 4) were analysed. The most common cause of death for both males and females was "transport accidents", which accounted for approximately one-fifth of deaths. Suicide ranked fourth as a cause of death for males, and third for

**Table 2** Suicide numbers and rates per 100,000 young persons aged 15-19 in the 63 countries (areas) for which data are available for the year 1995

Country (area)	Number			Rate		
	Males	Females	Total	Males	Females	Total
Russian Federation	1,988	509	2,497	36.5	9.6	23.2
New Zealand	45	14	59	33.0	10.6	22.0
Lithuania	42	8	50	32.7	6.4	19.7
Kazakhstan	222	69	291	29.3	9.2	19.3
Latvia	21	5	26	25.1	6.1	15.7
Estonia	12	3	15	23.6	6.2	15.1
Finland	42	6	48	25.1	3.7	14.7
Belarus	89	16	105	23.7	4.3	14.0
Kyrgyzstan	36	26	62	16.1	11.8	14.0
Norway	28	8	36	20.3	6.1	13.4
Canada	217	47	264	21.4	4.9	13.3
Cuba	41	58	99	10.5	15.5	12.9
Slovenia	15	4	19	19.3	5.5	12.6
Mauritius	8	5	13	14.7	9.4	12.1
Ukraine	334	93	427	18.1	5.2	11.7
Switzerland	32	14	46	15.7	7.2	11.6
Czech Republic	72	19	91	16.2	4.5	10.5
USA	1,616	274	1,890	17.4	3.1	10.5
Austria	44	3	47	18.6	1.3	10.2
Ireland	29	5	34	16.9	3.1	10.1
Barbados	1	1	2	9.6	9.8	9.7
Iceland	2	0	2	18.7	0.0	9.5
Bulgaria	43	15	58	13.4	4.9	9.3
Australia	87	27	114	13.4	4.4	9.0
Luxembourg	1	1	2	8.8	9.2	9.0
Belgium	38	17	55	12.1	5.6	8.9
Hungary	65	9	74	15.3	2.2	8.9
Croatia	24	5	29	14.2	3.1	8.8
Poland	234	46	280	14.2	2.9	8.7
Republic of Moldova	21	8	29	11.4	4.4	7.9
Republic of Korea	181	108	289	8.9	5.6	7.3
Sweden	27	9	36	10.3	3.6	7.1
Turkmenistan	28	4	32	12.1	1.8	7.0
China (selected rural and urban areas)	227	373	600	4.9	8.7	6.7
Slovakia	27	5	32	11.1	2.1	6.7
Germany	220	66	286	9.9	3.1	6.6
Singapore	8	5	13	7.7	5.2	6.5
Israel	22	9	31	8.5	3.7	6.1
Costa Rica	13	7	20	7.1	4.0	5.6
Denmark	15	2	17	9.1	1.3	5.3
France	151	51	202	7.7	2.7	5.3
Romania	78	26	104	7.8	2.7	5.3
Uzbekistan	89	34	123	7.6	3.0	5.3
Argentina	113	60	173	6.7	3.6	5.2
Japan	287	136	423	6.6	3.3	5.0
Hong Kong	14	6	20	6.4	3.0	4.7
Brazil (South, South-East and Central West)	286	128	414	5.7	2.6	4.2
United Kingdom	106	31	137	6.0	1.8	4.0
Belize	0	1	1	0.0	7.9	3.9
Spain	100	21	121	6.2	1.4	3.9
Mexico	263	117	380	5.1	2.3	3.7
Tajikistan	15	6	21	5.2	2.1	3.6
Malta	1	0	1	6.8	0.0	3.5
Netherlands	21	11	32	4.4	2.4	3.5
Albania	5	4	9	3.7	2.7	3.2
Italy	81	22	103	4.4	1.2	2.9
Portugal	15	8	23	3.7	2.0	2.9
Greece	9	6	15	2.3	1.6	2.0
Macedonia	1	1	2	1.2	1.2	1.2
Armenia	2	1	3	1.2	0.6	0.9
Kuwait	1	0	1	1.7	0.0	0.9
Azerbaijan	4	0	4	1.2	0.0	0.6
Bahamas	0	0	0	0.0	0.0	0.0
<b>Total</b>	<b>7,859</b>	<b>2,573</b>	<b>10,432</b>	<b>12.4</b>	<b>4.2</b>	<b>8.4</b>

**Table 3** Suicide rates per 100,000 young persons aged 15-19 in 26 countries (areas) with data available for 1965-1999

Country (area)	Males			Females			Total		
	1965-79	1980-89	1990-99	1965-79	1980-89	1990-99	1965-79	1980-89	1990-99
Mauritius	5.08	6.16	11.69	9.02	11.06	13.17	7.04	8.58	12.42
Canada	13.75	20.74	19.85	3.38	3.65	4.95	8.66	12.40	12.59
USA	10.22	15.30	16.48	2.84	3.66	3.38	6.57	9.59	10.11
Hong Kong	3.01	3.38	5.87	4.65	3.63	4.95	3.81	3.50	5.43
Japan	10.61	7.46	6.60	6.91	3.99	3.24	8.79	5.77	4.96
Singapore	4.99	5.19	6.33	7.48	7.42	4.37	6.20	6.27	5.38
Australia	9.12	14.13	16.89	3.50	3.05	4.15	6.37	8.72	10.68
New Zealand	7.49	17.51	28.60	2.96	4.24	9.80	5.28	11.01	19.33
<b>Non-European countries</b>	<b>10.34</b>	<b>13.17</b>	<b>13.83</b>	<b>4.08</b>	<b>3.78</b>	<b>3.59</b>	<b>7.25</b>	<b>8.58</b>	<b>8.84</b>
Austria	16.67	19.43	16.70	5.26	6.60	3.68	11.08	13.13	10.36
Bulgaria	7.55	10.22	12.20	5.15	5.89	4.25	6.38	8.11	8.32
Denmark	6.14	9.18	8.02	2.99	3.31	2.43	4.61	6.32	5.29
Finland	18.94	24.54	25.90	4.99	5.25	4.65	12.12	15.09	15.51
France	6.54	7.95	7.62	3.25	2.85	2.80	4.92	5.46	5.26
Greece	1.51	2.61	2.17	1.72	1.72	0.76	1.61	2.18	1.49
Hungary	19.56	16.23	13.81	8.01	6.82	3.94	13.92	11.67	9.00
Iceland	9.97	20.91	26.72	0.66	0.00	6.71	5.45	10.67	16.91
Ireland	2.57	6.80	14.96	0.68	1.12	3.09	1.65	4.03	9.17
Italy	2.52	2.93	4.23	1.87	1.05	1.35	2.20	2.01	2.82
Luxembourg	9.24	12.00	13.04	3.20	6.24	4.57	6.28	9.18	8.91
Netherlands	3.78	4.09	5.62	1.22	1.76	2.37	2.53	2.95	4.03
Norway	7.04	15.71	17.37	1.92	3.45	6.63	4.54	9.74	12.12
Portugal	4.83	5.30	2.88	3.77	4.62	1.68	4.30	4.96	2.29
Spain	1.89	4.03	4.85	0.79	1.16	1.43	1.35	2.63	3.18
Sweden	8.69	8.46	8.27	5.48	3.84	4.23	7.12	6.21	6.30
Switzerland	14.87	18.63	13.64	5.35	4.58	4.29	10.16	11.77	9.09
United Kingdom	3.49	4.95	5.92	1.84	1.42	1.65	2.68	3.23	3.85
<b>European countries</b>	<b>5.50</b>	<b>6.61</b>	<b>7.13</b>	<b>2.67</b>	<b>2.35</b>	<b>2.26</b>	<b>4.11</b>	<b>4.53</b>	<b>4.75</b>
<b>All countries</b>	<b>9.12</b>	<b>11.41</b>	<b>12.14</b>	<b>3.73</b>	<b>3.40</b>	<b>3.26</b>	<b>6.46</b>	<b>7.49</b>	<b>7.82</b>



**Figure 1** Suicide rates per 100,000 young persons aged 15-19 in 26 countries (areas) with data available for 1965-1999

females. Suicide accounted for 9.1% of all deaths among male and female adolescents together: 9.5% and 8.2% respectively (Table 4).

A similar rank order of different categories of causes of death was also seen from the analysis of mortality data for the 63 countries (areas) from which data were available for the same year, i.e. 1995 (data not shown).

Suicide rates varied substantially among the countries, by a factor of up to 100. However, it must be borne in mind that some countries have small populations and that there can be major random variations in the annual number of suicides.

Although the data presented here are an acceptable basis for evaluating the global impact of suicide on young people, it should be kept in mind that relevant data are still lacking from a number of countries. For a more definitive and correct view of suicide worldwide, data collection from these countries is needed.

## DISCUSSION

Suicide data are still not available in many countries. In the present study, data from only 90 countries (areas) out of the world's 192 nations were available for the 15-19 age group in the WHO Mortality Database, which is the largest database in the world on this topic. The WHO mortality statistics are commonly broken down by gender and age. However, some countries do not report deaths broken down for the 15-19 age group, and there are only 130 member states of WHO.

The reliability of suicide statistics is often questioned (4). Suicides are underreported for cultural and religious reasons, as well as owing to different classification and ascertainment procedures. Suicide can be masked by many other



**Table 4** Causes of death for young persons aged 15-19 in 90 countries (areas), according to the WHO Mortality Database, February 2004 (latest available data for each country or area)

Causes of death	Male		Female		Total	
	N	%	N	%	N	%
Transport accidents	19,643	21.2	6,919	17.4	26,562	20.1
Other accidents	19,274	20.8	5,084	12.8	24,358	18.4
Assault	13,735	14.8	2,108	5.3	15,843	12.0
Suicide	8,801	9.5	3,263	8.2	12,064	9.1
Neoplasms	5,017	5.4	3,585	9.0	8,602	6.5
Diseases of the circulatory system	4,966	5.4	3,484	8.8	8,450	6.4
Diseases of the nervous system	3,765	4.1	2,230	5.6	5,995	4.5
Diseases of the respiratory system	2,878	3.1	2,061	5.2	4,939	3.7
Infective and parasitic diseases	2,580	2.8	2,116	5.3	4,696	3.5
Diseases of the digestive system	1,420	1.5	940	2.4	2,360	1.8
Congenital malformations, deformations	1,061	1.1	817	2.1	1,878	1.4
Endocrine, nutritional and metabolic diseases	850	0.9	859	2.2	1,709	1.3
Mental and behavioural disorders	457	0.5	188	0.5	645	0.5
Other causes	8,296	8.9	6,026	15.2	14,322	10.8
<b>Total</b>	<b>92,743</b>	<b>100.0</b>	<b>39,680</b>	<b>100.0</b>	<b>132,423</b>	<b>100.0</b>

diagnostic categories of causes of death. Unfortunately, in cases of young people, death due to suicide is often misclassified or masked by other mortality diagnoses. This makes the global picture of death by suicide even graver.

International comparability of data is also discussed. The information used in this paper, which reflects the official figures reported to WHO by member states, is based on death certificates signed by legally authorised personnel – usually doctors or police officers in the respective country. Usually these professionals have specific routines. How these routines differ between countries and regions, and how they influence suicide statistics, remains to be demonstrated through comparative studies of mortality statistics.

Moreover, it should be borne in mind that reporting of mortality statistics to WHO is subject to delays that vary from one country to the next. Accordingly, years for which data are available are not always the same. Data from 71% of the 90 countries (areas) included in the analysis covered the period 1995-2002. Around half (44 countries) had data for the year 2000 or later. Among these 44, most were in the European region. The remaining countries' data were from the period 1980-1994. After performing the analyses for the 90 countries (areas), we repeated the same analyses for the 63 countries (areas) in which the suicide data and mortality statistics were available for the year 1995. The results concerning suicide rates and the ranking of suicide as a cause of death were fairly similar in the two analyses (with a slightly higher global suicide rate for young people in the analysis for the year 1995).

During the period studied, different ICD classifications were used. This may have been an additional source of misclassification in the mortality statistics.

The mean suicide rate of 7.4/100,000 (10.5 for males and 4.1 for females) may be perceived as a reasonable estimate for the 15-19 age group and used as a basis for evaluating suicide rates among adolescents in different local communities.

In the calculation of suicide rates, the numbers of suicides in two large countries with more than 1,000 suicides in the 15-19 age group (Russia, with 2,883 cases in 2002 and USA with 1,616 in 2000) accounted for 37.3% of the total, thus heavily influencing the mean rate. Interestingly, these two countries' suicide rates were markedly different. The Russian rate was 23.6/100,000, more than 3 times the mean (7.4), whereas that in the USA was 8.0, fairly close to the mean. Sri Lanka had an extraordinarily high suicide rate in the 15-19 age group: at 46.5/100,000, it was more than six times the mean rate. Unfortunately, data for recent years are not available for Sri Lanka.

Suicide rates for young people in the 15-19 age group are, as for other age groups, higher in males than in females. Young males' overall suicide rate was 2.6 times that of females. Exceptions were found in a number of non-European countries, like Sri Lanka, El Salvador, Cuba, Ecuador and China, where suicide rates for females 15-19 years old exceeded those of males in the same age group. This fact urgently calls for further investigations.

Data from the latest 35-year period (1965-1999) show a marked difference in suicide rates between European and non-European countries. The high rates in non-European countries call for more attention. One reason for the lower suicide rates in European countries (although suicide rates in this region also vary widely from one country to another), beside cultural and psychosocial factors, may possibly be the physicians' awareness of the importance of adequately treating people with psychiatric disorders, psychosocial problems and harmful stress. However, this does not apply to the whole European region, since countries in transition show very high suicide rates, both for adults and for young people.

The fact that suicide rates are higher in males than in females has long been widely recognised. However, this study shows that suicide as a cause of death in the 15-19 age group is very similar in both sexes: 9.5% in males and 8.2% in females.

Suicide is one of the leading causes of death among young persons of both sexes. It is the leading cause of death in this age group after transport and other accidents and assault for males, and after transport and other accidents and neoplasms for females.

Scrutiny of the data for individual countries has revealed differences both in suicide rates and in the ranking of leading causes of death. These differences seem to be due to social, cultural and other factors, which call for further investigation.

In conclusion, suicide among young people is a major health problem in many societies, and preventive measures are strongly recommended (2).

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# Post-traumatic stress disorder in children

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*In the past ten years, there has been increasing recognition that children who have been exposed to traumatic events can, like trauma-exposed adults, develop post-traumatic stress disorder (PTSD). Practitioners therefore need to be able to recognise and treat post-traumatic stress reactions in children. However, the direct application of adult diagnostic criteria for PTSD can result in the misdiagnosis of post-traumatic stress reactions in children, while research has only recently begun to investigate the effectiveness of different treatments for children with PTSD. This article discusses issues regarding the assessment and diagnosis of post-traumatic stress reactions in children at different developmental stages, considers neurobiological, cognitive and other factors that are theorized to increase the risk of PTSD in trauma-exposed children, and evaluates current psychotherapeutic and pharmacotherapeutic treatments for childhood PTSD. The need for more systematic research on the management of PTSD in children is noted.*

**Key words:** Post-traumatic stress disorder, children and adolescents, diagnosis, psychotherapy, pharmacotherapy

Post-traumatic stress disorder (PTSD) first appeared in the DSM-III in 1980. The impetus for the development of this diagnostic category arose primarily from the need to account for the characteristic array of symptoms displayed by Vietnam veterans in the United States, and as such PTSD was conceptualized around traumatized adults. However, since that time there has been increasing recognition that children, too, can develop severe and debilitating reactions to traumatization.

Studies indicate that children can develop PTSD after exposure to a range of traumatic stressors, including violent crime, sexual abuse, natural disasters, and war. Where relatively standardized assessment methods have been used, the incidence of PTSD among child survivors of specific disasters ranges from 30 to 60% (1,2). As yet there are no epidemiological studies of the prevalence of PTSD among children in the general population; however, community studies in the United States have consistently indicated that around 40% of high school students have experienced some form of domestic or community violence, and between 3 and 6% have PTSD (3,4).

High rates of trauma exposure and evidence of PTSD among child populations suggest that mental health practitioners worldwide need to be able to recognize those post-traumatic reactions in children that require intervention, and offer timely and effective treatments. This is particularly critical given the substantial challenges that post-traumatic stress poses to the healthy physical, cognitive and emotional development of children and adolescents (5).

## DIAGNOSIS AND ASSESSMENT

The DSM-IV-TR describes three symptom clusters in PTSD: persistent re-experiencing of the trauma (e.g., intrusive memories and flashback experiences, often triggered by exposure to traumatic reminders, and recurring trauma-related nightmares); avoidance of traumatic reminders (including places, people, and conversations) and a general numbing of emotional responsiveness; and chronic phys-

iological hyperarousal, including sleep disturbances, poor concentration, and hypervigilance to threat. The DSM notes that, in children, re-experiencing may occur through repetitive play involving trauma-related themes, rather than through memories, and nightmares may have generalized, rather than trauma-specific, content. Following a traumatic experience, it is normal and expectable for children and adults to exhibit some intrusive, avoidance and hyperarousal symptoms, which remit spontaneously within a few days or weeks. In order to meet the PTSD diagnosis, at least one re-experiencing symptom, three avoidance/numbing symptoms and two hyperarousal symptoms should be present for at least one month, and must cause significant distress or functional impairment. When symptom duration is less than one month, a diagnosis of acute stress disorder (ASD) is made.

Childhood PTSD lends itself to both over- and under-diagnosis, especially when assessments are not thoroughly or expertly conducted. There are a number of assessment instruments available to aid the diagnosis of PTSD in children. Several structured psychiatric interviews for children, such as the Diagnostic Interview for Children and Adolescents - Revised (DICA-R, 6) and the Diagnostic Interview Schedule for Children-Version IV (DISC-IV, 7), include a PTSD module. Similarly, the Schedule for Affective Disorders and Schizophrenia for School Age Children (K-SADS, 8) contains a PTSD module reflecting both DSM-III-R and DSM-IV criteria.

There are also some PTSD-specific interviews, such as the Clinician-Administered PTSD Scale - Child and Adolescent Version (9), the Child PTSD Checklist (10), and the Child PTSD Symptom Scale (11). Finally, a number of scales are available for assessing the severity of PTSD symptoms in children, such as the Child Post-Traumatic Stress Reaction Index (12), the Child and Adolescent Trauma Survey (13) and the Trauma Symptom Checklist for Children (14).

While PTSD in older adolescents is similar to adult PTSD, there are two major limitations of the PTSD diagnostic criteria when assessing post-traumatic pathology in young children. Firstly, eight of the eighteen PTSD criteria

require a verbal description of internal states and experiences, a task beyond the cognitive and expressive language skills of young children (15). The clinician must therefore attempt to infer from behavioral observations whether the child's thoughts and feelings are consonant with PTSD symptoms. Direct reports from parents, teachers and other observers in the child's milieu are an important component of the evaluation, although it should be borne in mind that parents often minimize the child's PTSD symptomatology (15). The DISC-IV, DICA-R and K-SADS all determine diagnostic status on the basis of combined child and parent reports. The use of multiple assessment instruments and multiple informants to measure PTSD across different areas of functioning is therefore recommended (15). That said, nothing can replace a properly conducted and comprehensive clinical interview.

Secondly, while traumatized children often display the core symptom clusters of adult PTSD, they also commonly present with an array of symptoms not typically assessed by existing structured interviews and scales. These may include the loss of recently acquired developmental skills (regression), the onset of new fears or the re-activation of old ones, accidents and reckless behavior, separation anxiety (often manifested in anxious clinging), and psychosomatic complaints such as stomach aches and headaches (16,17). Additionally, young children may express post-traumatic anxiety through hyperactivity, distractibility and increased impulsivity, symptoms that may be confused with attention-deficit/hyperactivity disorder. The persistence of PTSD symptoms coupled with an accumulation of post-trauma adversities can also produce a secondary depression and, when the traumatic context also includes the death of a family member, children can present with complicated grief and bereavement (5). Therefore, while a structured interview may seem to indicate that a traumatized child does not fully meet the DSM's "adulto-centric" (2) diagnostic criteria for PTSD, there may nonetheless be a range of post-traumatic responses that warrant intervention.

Thirdly, recent findings support the hypothesis that children with subthreshold criteria may not differ significantly from children meeting all three cluster criteria (re-experiencing, avoidance, hyperarousal) with regard to functional impairment and distress. In a study by Carrion et al (18), children with subthreshold PTSD had functional impairment that was specific to PTSD symptoms and was not due to comorbidity. This suggests that it might be more precise to make a diagnosis of PTSD in children and adolescents based on the intensity of symptoms and their relationship to functional impairment, than on the threshold number of symptoms.

Fourthly, while prospective studies in adults have shown that ASD is associated with later PTSD (19,20), there is little published empirical data regarding this entity in children. A recent prospective study in children has raised questions about the appropriateness of the current diagnostic criteria, in that 60% of children with traffic-

related injuries in the study who went on to develop PTSD did not meet criteria for even subsyndromal ASD within the first month of injury (21). These findings suggest that it is crucial to include developmental and social contextual factors possibly mediating or moderating the transformation of ASD into PTSD (e.g., age, gender, psychiatric morbidity, other life events, family functioning, parental psychopathology) in the assessment of ASD in children (22).

## ETIOLOGY AND RISK FACTORS

Since not all children (or adults) who experience a trauma will go on to develop PTSD, identification of etiological mechanisms and risk factors for development of the disorder has been an important recent thrust in PTSD research.

Neurobiological theories have to a large extent implicated adrenergic, serotonergic, dopaminergic, gamma-aminobutyric acid, opioid, N-methyl-D-aspartate, and neuroendocrine systems in the pathophysiology of PTSD (23). Current evidence indicates that traumatized children, like traumatized adults, demonstrate altered hypothalamic-pituitary-adrenal (HPA) axis circadian rhythmicity, although there is little consensus on whether cortisol levels are elevated or reduced in pediatric PTSD. For example, a recent study in adolescents did not find evidence for enhanced suppression of morning cortisol in multiply traumatized adolescents with or without PTSD (24), in contrast to reports in adults with PTSD. In adults, recent data suggest that low cortisol levels may be an early predictor rather than a consequence of the disorder. For example, in a study examining cortisol responses in the acute aftermath of rape, low cortisol was associated with a prior rape or assault (risk factors for PTSD) but not with the development of PTSD *per se* (25). These findings have not yet been replicated in child and adolescent PTSD.

Brain imaging studies that have specifically assessed the effects of childhood trauma and PTSD on brain volumes are limited. De Bellis et al (26) found no evidence of reduced hippocampal volumes in survivors of childhood abuse, but did demonstrate smaller intracranial, whole brain and corpus callosum volumes, which may suggest an impact on global brain development. In a follow-up analysis, controlling for socio-economic status (27), the authors found that brain volumes positively correlated with age of onset of PTSD and negatively correlated with the abuse. Debate continues on whether reduced hippocampal volumes predate or follow the development of PTSD and to what extent this predicts response to trauma. However, the findings of a recent study in twin-pairs discordant for trauma exposure and PTSD suggest that lower preexisting hippocampal volumes may, in fact, predispose a person to develop PTSD after trauma (28).

Cognitive-behavior theories have highlighted the involvement of information-processing and learning in the development of PTSD. For example, Foa et al (29) suggest that, following a trauma, a fear network that stores information about sources of threat is formed, and these trauma-related representations are activated by external and internal cues.

In people with PTSD, this fear structure includes an especially large number of stimuli elements and is therefore easily accessed. Similarly, Keane et al (30) propose that the PTSD fear response develops through a process of classical conditioning, whereby fear comes to be associated with cues present during the actual trauma (e.g., gunfire), as well as through a process of stimulus generalization, whereby any stimuli associated with these cues (e.g., a car backfiring or a firecracker exploding) also produce a fear response. Continued avoidance of traumatic cues reinforces the fear response, which has no opportunity to be “un-learned”.

Etiological formulations of childhood PTSD must necessarily incorporate a developmental perspective. For example, subjective cognitive appraisals of traumatic events vary with the developmental level of the child, as does the way in which traumatic memories are encoded and recalled (5). Much remains to be understood about the role of developmental factors in the neurobiological, cognitive and other mechanisms that may create a vulnerability to PTSD.

There is some evidence that, as for adults, the risk of PTSD in children increases with physical proximity to the trauma and previous trauma exposure, and (due to biological and/or socio-cultural factors) may be greater for girls than for boys (see 31 for a review). Additionally, for children, parental trauma-related distress increases the risk of developing PTSD (15), since it affects the parent’s capacity to create a post-trauma climate of safety and security and to emotionally contain the child’s fear and anxiety.

## TREATMENT

Intervention with children with PTSD is typically multimodal, including treatment for the child, intervention with parents or caregivers, and optimizing the support provided by the school environment. Before psychotherapeutic work can begin, it is important that the physical safety of the child be established, particularly if the child has been the victim of abuse; this may entail liaison with appropriate agencies (e.g., social services, police or the legal system). Current practice parameters recommend that the first-line treatment for PTSD in children should be psychotherapy, and psychopharmacology should be considered as an adjunctive treatment in those children who have prominent comorbid depressive or panic symptoms (15). Recent evidence suggests that some medications may also be effective in addressing the core symptoms of PTSD in children.

As the systematic empirical study of the efficacy of PTSD interventions for children is still in its infancy, there is as yet no empirical evidence to demonstrate either the superiority of psychotherapy over medication, or that the combination of the two is more effective than either one alone.

### Psychotherapy

Psychotherapeutic interventions for children are generally based on those developed for traumatized adults, with age-

appropriate modifications, although there is less empirical evidence regarding the effectiveness of these interventions for children than there is for adults. Intervention with the child usually includes the following components: psychoeducation, direct exploration of the trauma, symptom management techniques, exploration and modification of inaccurate cognitive attributions regarding the trauma (15,32).

The effectiveness of cognitive-behavioral therapy (CBT) for PTSD in children has been empirically demonstrated more often than other interventions, although randomized controlled studies of CBT are still few (33). Arguably the most rigorous studies (usually random assignment to well-defined manualized treatment versus comparison treatment or waitlist control) have focused on trauma-focused CBT in sexually abused children (34), although CBT treatments have been extended to children exposed to other types of trauma (35,36). These studies have added to the growing evidence supporting the efficacy of trauma-focused CBT on measures of PTSD, depression, and behavior problems in children with PTSD (37).

Typically gradual exposure is used with children and this consists of detailed discussion of the traumatic experience, and memories, thoughts, and feelings that occurred associated with the event. This can be facilitated by having the child or adolescent write a report about the trauma, which the child and therapist can re-read during therapy sessions (38). This helps the child to develop a sense of mastery over symptoms and overwhelming feelings. Distorted cognitive assumptions regarding the trauma (e.g., self-blame) are also explored, and alternative, more realistic, assumptions are developed. Other psychotherapeutic interventions supported by anecdotal evidence but, as yet, little empirical data include psychodynamic therapy and eye movement desensitization and reprocessing (33).

There is also general consensus that parents should be included in the psychotherapeutic intervention for children with PTSD (15,33,39). At a minimum, this should entail some psychoeducation, including normalization and explanation of post-traumatic responses, and information on how these can be managed in the child’s home environment. Where the parents appear to be experiencing significant emotional distress as the result of the trauma, intervention should also assist them to explore and resolve these feelings, so that they can better respond to the child’s emotional needs. Psychoeducation can also be provided to the child’s teachers, so that they may understand and be responsive to the child’s emotional needs, and develop appropriate expectations and behavioral management techniques.

Little is known about the potential benefits or harm of providing early psychosocial interventions to children in the immediate aftermath of trauma (40). It has been suggested that there may be inherent dangers in exposing traumatized children to a psychosocial intervention prematurely, as one runs the risk of sensitizing children to traumatic reminders of the event without permitting timeous resolution of the experience (40).

To date, no empirical studies have evaluated psychological debriefing for children and adolescents within the first month of a traumatic event. However, studies in adults suggest that psychological debriefing may result in poorer long-term outcomes than no debriefing at all. Based on empirical evidence, trauma-focused CBT can be recommended as an early intervention (1-6 months post-trauma) for symptomatic children, particularly in the context of sexual abuse (40).

## Pharmacotherapy

Pharmacological agents for childhood PTSD have received little empirical investigation. Effective pharmacological agents are ideally those which: a) target disabling symptoms, b) improve the quality of life of the child/adolescent allowing for normal growth and development in the long-term, and c) facilitate the process of psychotherapy by allowing traumatized children to deal with emotionally distressing material and work through their distress (41).

Adrenergic agents (e.g. the  $\alpha_2$ -adrenoreceptor antagonists clonidine and guanfacine, and the  $\beta$ -adrenoreceptor antagonist propranolol) reduce sympathetic arousal and have been shown to be effective in treating the hyperarousal, re-experiencing, and impulsivity seen in PTSD. In two open-label trials, oral clonidine (0.05 to 0.1 mg/day) (42) and clonidine transdermal patches (0.1 to 0.2 mg/day) (43) were effective in reducing PTSD symptoms in children, particularly anxiety, arousal, insomnia, and impulsive and aggressive behavior. Guanfacine was reported to be effective in reducing nightmares in a single case study (44). Propranolol significantly reduced intrusion and arousal symptoms over 5 weeks in 8 of 11 abused children with PTSD (45).

Selective serotonin reuptake inhibitors (SSRIs) are widely used to treat adult PTSD. Consistent with controlled data in adults, there is emerging evidence for their efficacy in anxiety disorders other than PTSD in children and adolescents (46). While there are no published controlled trials of SSRIs in childhood PTSD, some open-label data exist for citalopram in adolescent PTSD, showing efficacy on all three symptom clusters (47). Given that the SSRIs target broad-band symptom clusters and have a favorable side effect profile, they are likely to be used as first-line agents in PTSD. Other serotonergic agents such as nefazodone and cyproheptadine have been used in this age group, but safety data are lacking (48,49).

While randomized clinical trials have demonstrated the efficacy of tricyclic antidepressants and monoamine oxidase inhibitors in adult PTSD, no controlled studies have been reported in pediatric PTSD. The dopamine blocking agent risperidone (50) and the anti-kindling medication carbamazepine (51) have demonstrated promise in small open studies of children and adolescents respectively with chronic PTSD.

The utility of benzodiazepines for pediatric PTSD has not been established. Lack of evidence for their efficacy in reducing ASD/PTSD symptoms in traumatized adults

coupled with an unfavorable side effect profile make them a less than ideal choice in youth.

There are almost no controlled studies to guide the use of very early medication interventions in traumatized children (40). There has been one published double-blind randomized study in children with ASD in the context of acute burns. Imipramine was compared to chloral hydrate over a 7 day period in 25 children with ASD (52) and was found to be superior in treating ASD symptoms. In a more naturalistic study, Saxe et al (53) investigated the use of an opiate medication (morphine) as a possible preventive agent in children with burns-related PTSD. The dose of morphine administered to children during hospitalization for burn injuries was associated with a significant reduction in PTSD symptoms over a 6-month period.

## CONCLUSIONS

PTSD is increasingly recognized to be a prevalent and disabling disorder in children and adolescents, in both the developed and the developing world. Although much remains to be learned, there have been important advances in understanding its risk factors and pathogenesis. Research on the management of PTSD in this age group is itself relatively young, and there is an urgent need for additional randomized controlled trials. Nevertheless, we now have a number of interventions at our disposal.

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# The 13th World Congress of Psychiatry (Cairo, September 10-15, 2005)

**AHMED OKASHA**

President of the Congress

The 13th World Congress of Psychiatry will take place in Cairo, Egypt from 10 to 15 September, 2005. This is the first time in the history of the WPA that an African and an Arab country hosts the World Congress.

Ancient Egyptians knew mental disorders 5,000 years ago. In spite of the mystical beliefs, psychiatric patients were cared for and treated as well those with physical ailments. In the country that has given birth to the foundations of civilization, we will organize the Congress under the theme "5,000 Years of Science and Care –

Building the Future of Psychiatry", thus discussing the old and the new with a view on future progress.

The Congress will review the state of the art as regards all the complexities of today's psychiatry. Four Plenary Lectures will be delivered by the WPA President and President Elect, the Egyptian Nobel laureate in Physics A. Zewail, and the winner of the Jean Delay Prize 2005. Thirteen Key Lectures and 12 Special Lectures will be given by eminent experts of various areas of psychiatry. There will be 16 Special Symposia, 10 Forums, 4 Debates, and 6 Film and Video Sessions. Furthermore, we have received 282 submissions of Symposia, 86 of Workshops and Courses, 651 of

Oral Papers, 824 of Posters, and 157 of New Research Papers.

For the first time in a World Congress, there will be Master Clinical Case Conferences with the participation of worldwide pioneers in clinical psychiatry and an active involvement of the audience. In fact, over 90% of the participants in the Congress will be clinicians, who need to return home with a matrix for upgrading knowledge and skills.

For further details on the Congress, please visit the website [www.wpa-cairo2005.com](http://www.wpa-cairo2005.com).

You are welcome to Egypt to enjoy the recent developments in our profession, while hosted by a country which is the cradle of civilization.

## WPA scientific meetings highlights

**PEDRO RUIZ**

WPA Secretary for Meetings

The year 2004 has been extremely productive insofar as WPA scientific meetings were concerned. Besides 30 co-sponsored scientific meetings covering 13 WPA Zones, of which 13 were co-sponsored by WPA Member Societies, 15 WPA sponsored scientific section meetings were also conducted, which included the WPA Sections on Religion, Spirituality and Psychiatry; Affective Disorders; Mass Media and Mental Health; Women's Mental Health; Law, Psychiatry and Ethics; History of Psychiatry; Suicidology; Psychiatric Rehabilitation; Addiction Psychiatry; and Transcultural Psychiatry.

The highlights of the year, however, have been four WPA sponsored scientific meetings. Each of them depicted a major event and a major contribution to the overall efforts of the WPA Operational Committee on Scientific Meetings' goals and objectives.

On June 10-13, 2004, a WPA Regional Meeting was held in Prague, Czech Republic, in connection with the national conference of the Czech Psychiatric Society. This Regional Meeting led to the first phase of the organization of the 14th World Congress of Psychiatry, to be held in Prague, Czech Republic in the fall of 2008.

On September 17-19, 2004, a WPA Regional and Inter-Zonal Meeting took place in Lahore, Pakistan. Over 20 regional countries representing more than 1,000 psychiatrists attended this scientific event, which focused on the unique mental health needs of this Region. Besides the full WPA leadership represented by all members of the WPA Executive Committee, representatives of the Royal College of Psychiatrists were also quite active in the scientific and professional efforts of this event. Haroon Rashid Chaudry, the WPA Zone Representative for this Region, depicted strong leadership and excellent vision about the needs,

problems and solutions related to the mental health delivery system of the countries involved in this relevant scientific event. Additionally, this WPA Regional and Inter-Zonal Meeting was the first one ever organized in this WPA Zone.

On November 10-13, 2004, a WPA International Congress was held in Florence, Italy, under the auspices of the Italian Psychiatric Association and the strong leadership of Mario Maj. Professor Maj was not only the Chair of the Organizing Committee of this Congress but also represented the WPA Executive Committee as WPA Secretary for Publications. Under the able direction of Professor Maj, this outstanding scientific event symbolized the aspirations of the WPA insofar as high quality of scientific contributions to the field is concerned. This Congress offered an up-to-date and current global actualization of the most relevant treatment approaches in the field of psychiatry. This goal



was fully accomplished not only in terms of the high quality of scientific presentations but also in terms of its emphasis on evidence-based treatment outcomes.

The worldwide appeal for this Congress was well highlighted by its results: 6,847 participants, with a worldwide mix of 5,009 from high income countries, 658 from upper middle income countries, 505 from lower middle income countries and 226 from low income countries, as well as 269 trainees/students. Also, 180 accompanying persons. This very successful Congress was the best attended scientific meeting in Europe in 2004, and only surpassed worldwide by the Annual Meeting of the American Psychiatric Association (APA).

The scientific efforts of this outstanding Congress led to 1523 presentations, which were included in the 16 Update and Special Lectures, 14 Advanced Courses; 104 Interactive, Special, Section and Zonal Symposia; 9 Forums, 53 Workshops, 15 New Research Sessions, 3 Poster Sessions and 19 additional Sponsored Scientific Events.

Undoubtedly, this Congress signifies the best that the WPA can offer with respect to scientific meetings, and Professor Maj needs to be recognized for his outstanding leadership and industriousness in this regard.

On December 3-5, 2004, a WPA Regional Meeting was held in Craiova, Romania, under the strong leadership and vision of Tudor Udristoiu, President of the Romanian Psychiatric Association. This scientific event, the first one ever organized by the WPA in the Eastern Europe and Balkans Region, was directed to the mental health and psychiatric leadership of this very important Region. Besides the mental health and psychiatric leaders from Romania, this scientific meeting was also attended by psychiatric and mental health leaders from Armenia, Bulgaria, Hungary, Greece, Republic of Macedonia (FYROM), Russia, Serbia and Montenegro, and Turkey.

The outcome of this very relevant scientific event was a declaration (the Craiova Declaration), which was nice-

ly crafted to address the most essential mental health problems of Eastern Europe and the Balkans. This Declaration will lead to the formal organization of a Psychiatric Association for Eastern Europe and the Balkans, the enhancement of the existing WPA Institutional Program for Eastern Europe and the Balkans, the development of a relevant mental health action plan for this Region, and the collaboration and development of partnerships with governmental, intergov-

ernmental (WHO, United Nations, World Bank, UNESCO, etc.) and non-governmental organizations directed to improve the mental healthcare delivery system in this Region. This scientific meeting certainly represents the best that the WPA can offer to developing nations and Zones in which not enough WPA attention and priority was given in the past.

Hopefully, these outstanding scientific meetings will lead the path for future WPA scientific meetings and events.

## WPA publications: an update

MARIO MAJ

WPA Secretary for Publications

During the period 2002-2005, the objectives of the WPA's programme of publications have been: a) to disseminate information about clinical, service and research developments to the largest possible number of psychiatrists across the world; b) to promote a truly international debate on current psychiatric practice and research, involving psychiatrists from all WPA Zones; c) to contribute to increase the visibility and improve the image of the Association.

These objectives have been pursued by the publication of the new official journal of the WPA, *World Psychiatry*, and the production of 21 books. I will focus briefly here on the books.

### *The series Evidence and Experience in Psychiatry*

The series *Evidence and Experience in Psychiatry* aims to compare research evidence and clinical experience about the diagnosis and management of the most common mental disorders. Each volume of the series covers a specific mental disorder, by means of a set of systematic reviews of the research evidence, each followed by many commentaries produced by psychiatrists from various countries and representing different schools of thought. The publisher is Wiley.

The fifth volume of the series, dealing with bipolar disorder, was published in 2002; it includes contributions by 134 experts, representing 28 countries; it has been reprinted four times. The sixth volume of the series, dealing with eating disorders, was published in 2003; it includes contributions by 106 experts, representing 25 countries; it has been reprinted twice. The seventh volume of the series, dealing with phobias, was published in 2004; it includes contributions by 110 experts, representing 24 countries; it has been reprinted twice. The eighth volume of the series, dealing with personality disorders, was published in 2005; it includes contributions by 123 experts, representing 29 countries. The ninth volume of the series, dealing with somatoform disorders, will be published in September 2005; it includes contributions by 125 experts, representing 35 countries.

A second edition of the first four volumes of the series, dealing respectively with depressive disorders, schizophrenia, dementia and obsessive-compulsive disorder, was published in 2002. In this edition, all the systematic reviews have been revised and updated.

Several volumes of the series have been or are being translated into various languages, including Russian, Spanish, Portuguese, Italian and Turkish. A special low-price edition of some of the volumes has been produced for the Indian market.

All the volumes of the series have received very positive reviews in international psychiatric journals. The revenues from the sales of the volumes have been the third most significant source of income for the WPA during the period 2002-2004.

#### The volumes originating from the 12th World Congress of Psychiatry

In the year 2004, three volumes based in part on presentations delivered at the 12th World Congress of Psychiatry have been produced by the WPA. The publisher is Wiley.

The first volume, entitled *Early Detection and Management of Mental Disorders*, is unique in the international literature in providing an overview of the early diagnosis and management of all the most common mental disorders, including schizophrenia, bipolar disorder, depression, eating disorders, anxiety disorders and Alzheimer's disease.

The second volume, entitled *Disasters and Mental Health*, reviews the psychological consequences of disasters and their management, and provides a survey of the experiences following various disasters worldwide. It has been widely disseminated in the affected areas after the tsunami disas-

ter and is currently being translated into several languages.

The third volume, entitled *Families and Mental Disorders*, describes the family burden related to the most common mental disorders, the currently available family interventions for those disorders and the experience of caregivers' groups worldwide.

#### The volume *Essentials of Clinical Psychiatry for sub-Saharan Africa*

This volume, which will be published in July 2005, is based on a collaboration between the WPA, the World Health Organization and the recently established African Association of Psychiatrists and Allied Professionals. Fifty-two authors, all of whom have worked or are currently working in Africa, have contributed to the volume, which covers all the aspects of clinical psychiatry taking into consideration the special circumstances and needs of sub-Saharan Africa. The publisher is Masson.

#### The volume *General Psychopathology for Clinicians*

This volume, which will appear in early 2006, will fill a significant gap in the current psychiatric literature, by

covering all the aspects of modern general psychopathology, using a language and a style accessible to all psychiatrists worldwide. It will be produced in three languages: English, Spanish and Portuguese. The publisher will be Wiley.

#### The series *Images of Psychiatry*

This series aims to provide a picture of the past and present of psychiatry in individual countries or groups of countries. A volume on Poland was published in 2002; one on Spain in 2004; one on Romania in 2005; one on German-speaking countries will appear in September 2005. A volume on Latin America is in preparation.

#### The series *Anthologies in Psychiatry*

The books of this series contain classical texts produced by psychiatrists of a given country or group of countries never published up to now in English, accompanied by essays on their authors. Volumes containing classical texts originally produced in Spanish and Italian were published in 2002.

A volume including texts originally produced in German will appear in September 2005.

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