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ONGOING RESEARCH

Role of Support Personnel in Rehabilitation. . . Researchers at the University of Alberta, Faculty of Rehabilitation Medicine, are working on a national study of the role and use of support personnel in the rehabilitation disciplines in educational and health care facilities, now and in the future. The multi-phased project is almost complete, with the final report due December 31, 1992. For further information, please contact Jacquie Forward, Project Coordinator, Department of Speech Pathology and Audiology, University of Alberta, Room 2-70 Corbett Hall, Edmonton, Alberta T6G 2G4. Phone: (403) 492-0835.

Taking Charge of Psychotropic Drugs

by Peter Stastny, M.D.

Millions of people take psychotropic drugs for "mental illnesses" on the recommendation of psychiatrists. However, the debate about the value of these drugs continues. Much evidence for their toxic, often irreversible and disabling effects has been provided (Breggin, 1988; Lehmann, 1989; Keshavan & Kennedy, 1992; Kane & Lieberman, 1992). Consumers of psychotropic drugs report considerably greater distress from the side-effects of these drugs than mental health professionals

(Campbell and Schraiber, 1989). Mainstream psychiatry, on the other hand, emphasizes their beneficial effects on the course and outcome of most psychiatric disorders (e.g. Torrey, 1983). Anyone trying to decide whether to take these drugs is caught between these perspectives and left without straightforward answers. To continue taking psychiatric medication after becoming aware of their toxicity could be seen as acting in a self-destructive fashion. To heed the warnings leaves the impossible choice between relapse and drug-induced dysfunction.

In spite of this intractable dilemma, a significant proportion of persons who advocate against psychiatric abuse and for empowerment of survivors continue to take antidepressants, neuroleptics, "mood stabilizers" and other psychiatric drugs. To suggest that they are making self-destructive choices means stripping them of the right to treat their bodies and minds the way they choose.

In my work I consulted with numerous individuals struggling with this problem. My main philosophy was to support them in their decisions regarding these substances, while searching for non-pharmacological avenues toward recovery and empowerment. This has not been a smooth road. Many painful compromises were made, at times leading to greater self-fulfillment, at times to greater suffering. Nevertheless I have been affirmed in my conviction that "consumer-control" in all aspects of psychiatric treatment is the key to success. The physician's role in psychiatry should never go beyond giving sound medical advice and support, while providing objective feedback about a person's health.

Informed Consent

The right to make decisions about taking psychiatric drugs implies that such choices are made based on adequate information about all adverse and intended effects of these drugs. Individuals who take psychotropic drugs are quite familiar with the effects on their bodies and minds. While they may not appreciate the full extent of toxic effects that may occur in the future, they experience current effects more acutely than anyone else. With access to laboratory data, they could also familiarize themselves with those side-effects that are not perceptible (i.e. lower blood cell counts, subtle changes in liver enzymes, and thyroid function). Nevertheless, most persons who take psychotropic drugs regularly are not aware of their long-term risks, including tardive dyskinesia (McPherson, 1993).

Risks:

It is a legal requirement for prescribing physicians to obtain "informed consent" from any patient about to enter treatment or undergo a medical procedure. This means that the physician must disclose all relevant information and assure that the patient appreciates the risk-benefit relationship for each drug or combination of drugs (see Lidz et al., 1984). In psychiatry, this requirement is far from universally accepted (Hoge and Appelbaum, 1992). The impact of such disclosure can be quite dramatic, predicting an up to 100% chance of suffering side-effects at some point. These range from mild, barely noticeable tardive dyskinesia, to severe, disfiguring movement disorders and death by choking, heart attack, kidney failure and suicide. Clearly, more serious side effects are rarer than less serious ones, requiring a risk assessment not unlike those associated with invasive medical procedures. In psychotropic drugs however, the risk-benefit ratio is considerably more complicated than in other medical procedures. People are frequently confronted with a choice of taking drugs "for the rest of their life." This is rather rare among medical treatments. Furthermore, to decide taking a drug designed to have major effects on thinking, feeling and interpersonal relations, may merit a different assessment than other types of medical procedures.

It goes beyond the scope of this paper to even outline the seemingly interminable list of ubiquitous, common and rarer side-effects encountered with psychotropic medications. The reader is referred to a voluminous literature, including some recent comprehensive works cited earlier (Kane & Lieberman; Keshavan & Kennedy). Here I merely emphasize some of the lesser known, but wide-spread negative effects of these drugs. For example, it has become clear that the majority of persons receiving neuroleptics are still benefiting from brain development. Weinberger, et al. (1987) summarized this research and the potentially detrimental effects of neuroleptics on the frontal lobe-limbic system connections. These reports lend credence to statements about "lobotomizing" effects of these drugs, interfering with a persons ability to experience emotions, take charge of their life and

develop their personal identity (Martenson, 1988).

While there are extensive reports on drug-induced sexual dysfunction in men, women have received much less attention, even though its prevalence among them (25-30%) is considerable (Sullivan and Lukoff, 1990). Women are more at risk for tardive dyskinesia, especially if they are older (American Psychiatric Association, 1992). Older individuals, particularly nursing home residents, suffer from polypharmacy and persistent high dosages, contributing to a shortening of their life-expectancy (Peabody, et al., 1987).

Toxicity and therapeutic dose ranges are also different across ethnic groups (Lin, et al., 1986). For example, the incidence of extrapyramidal side-effects from neuroleptics is much higher among Asian-Americans than Caucasian and Black controls (Binder and Levy, 1981).

Benefits:

In spite of this overwhelming evidence and personal experience with side-effects of psychotropic drugs, a considerable number of informed consumers opt for taking them regularly or intermittently. Some of their reasons are: fear of relapse, overcompliance with doctor's orders (Lesser and Freedman, 1980), a reduction of distressing and destructive thoughts and perceptions, and the prevention of outside forceful intervention. While this position receives enthusiastic support from the psychiatric field and family advocates, very few consumers embrace their medication without reservation (Gelman, 1993). Only 12% of consumers in Campbell and Schraiber's (1989) study reported being free of side-effects.

Freedom to Choose

The consumer's right to refuse and the freedom to choose psychotropic medications are certainly the two most hotly debated issues in this field. In spite of efforts conducted by N.I.M.H. we are far from achieving consensus in this area (N.I.M.H., 1992). Legally, the right to refuse has been firmly established for persons deemed competent (Appelbaum, 1988). However, the right to make affirmative choices about treatment options, including psychotropic regimes, has not been granted. It has been demonstrated that a positive subjective response to the type and dosage of a drug predicts better long-term outcome (Van Putten, et al., 1984). Most consumers feel that their right to refuse psychotropics is inalienable and should never be compromised (e.g. Thompson, 1992). Those few who report positive results from being coerced have the option of making advance provisions for future treatment through "health proxies" or "living wills" (Rogers and Centifanti, 1991; Rosenson and Kasten, 1991). In my experience at a major state psychiatric institution, I found that outside clinical review could lead to non-coercive alternatives in all applications for court-order to medicate over objection.

In addition to the research findings often supported by the pharmaceutical industry I suggest that each person should consider their personal experience when making such a decision. Most mental health professionals recommend maintenance drug regimes for virtually all major psychiatric problems. This is partially due to the fact, that the search for successful therapies in psychiatry seems somehow limited by psychopharmacological "tunnel-vision". Less toxic interventions are not included in the research agenda (N.I.M.H., 1992a). Therefore, each person should carefully monitor medication effects to evaluate any positive and negative results. Research findings should be subjected to a rigorous review by everyone offered psychotropic medications.

Less Toxic Alternatives

The concept of the "least toxic alternative" (Campbell, 1993) suggests a hierarchy of treatments ranging from the completely harmless to massive toxicity. It includes non-pharmacological and pharmacological interventions, which should be tried in an ascending order of harmfulness. This goes along with the Hippocratic principle of "primum non nocere" - first do no harm.

Early Prevention of Drug-Induced Problems

An important and neglected issue is the use of drugs during the initial "onset of symptoms." The first experience of altered states of mind or serious conflict, tension, questions about life and oneself, often leads down irreversible career paths of mental patients. Damage is inflicted almost immediately when a person seeks help from psychiatry. Not only does the usual psychopharmacological response suppress attempts to understand one's difficulties and find ways to solve problems, it forces the person to enter a

course shaped by the dilemma of drugs versus no drugs. Much damage can be prevented early on by using psychotherapeutic and psychosocial alternatives (Ciompi, 1987).

Non-Pharmacological Alternatives

Successful avoidance of psychotropics depends on the availability and suitability of alternate medical and non-medical methods of healing. Meditation, relaxation techniques, vitamins and other nutrients, acupuncture, homeopathy, cognitive rehabilitation and interpersonal therapies have largely been neglected by the endorsers of the medical model, but may offer alternatives to traditional prescribing practices, while providing much sought relief of symptoms. In addition, such "holistic" approaches offer a non-medical framework for interpreting altered states of the mind.

Soteria House was the best-known non-medical alternative to hospitalization (Mosher and Menn, 1979). It showed that persons can be supported through extreme emotional crises with favorable outcome and minimal use of psychotropics. The replication of this model has been thwarted by the psychiatric and insurance field (Mosher and Menn, 1983).

The Windhorse Project, described by Podvoll (1990), has shown highly promising results applying a Buddhist healing philosophy, while helping people wean themselves off psychotropics. Other examples of comprehensive non-medical alternatives include Birch House in Massachusetts and the Arbor Society in London, England, both based on a Laingian "antipsychiatry" model.

Self-help and self-rehabilitation have emerged as important avenues for recovery within and outside the mental health system. Unfortunately, there are no studies assessing the effectiveness of self-help methods as alternatives to psychotropics. Such studies are long overdue, given the rapid expansion of the consumer/survivor movement. A forthcoming book edited by Peter Lehmann (1993) will outline a range of anti-psychiatric practices.

Less Toxic Drugs

Recent research shows that certain drugs, such as benzodiazepines, may provide better short term alternatives with less toxicity even for "psychotic" symptoms (Neppe, 1989). The fear of addiction may be less warranted when compared with the side-effects of neuroleptics and mood-stabilizing drugs.

After a prolonged honeymoon, mood-stabilizing drugs, in particular Lithium have become under increasing scrutiny (Breggin, 1988). They were initially viewed as a relatively benign method to relieve and prevent mood disturbances. Some consumers still feel that they have less debilitating effects than neuroleptics.

Recently there has been considerable publicity about Clozaril, which is being marketed as a "safe" drug for "non-responders" (Time, 1992). While this drug may indeed not cause tardive dyskinesia or other neuromuscular side-effects, it has other, some times lethal side effects. While there are a few European long-term studies showing advantages over other neuroleptics, "miraculous" responses claimed by some U.S. psychiatrists are exceedingly rare (Kane, 1992).

Intermittent and Low-Dose Regimes

For those who cannot avoid psychotropics, there are a number of ways to minimize their risk. Intermittent use is advocated by some psychiatrists (e.g. Herz, 1982), recommending that persons utilize their subjective "prodromal (warning) signs" to ward off a full blown "psychotic episode". Early intervention and short-term use may prevent long-term dependency on these drugs (Hirsch, 1987). Another alternative is the ongoing ingestion of neuroleptics at the lowest effective dosage. Those who have attempted to detoxify from these drugs only to experience an uncontrollable resurgence of distressing or unproductive thoughts and perceptions, might choose to remain on these drugs, in spite of their proven toxicity. In that case it is essential to ascertain the lowest possible dosage which averts withdrawal or other emergent symptoms. This could be as low as 0.5mg Haloperidol or 10 mg chlorpromazine per day. The impact of very low dosages is similar and often better than the popular moderate to high dosages, which damaged three generations of institutionalized persons (Rifkin and Kane, 1983).

Drug Dependency and Withdrawal

On "maintenance medication" the choices are considerably more limited. A form of dependency develops, fostered by prescribing physicians. This makes cessation virtually impossible. In clinical practice, reemergence of distressing "symptoms" is generally seen as proof for the ongoing need for drugs, rather than an effect of withdrawal. An irreversible transformation of brain receptors has set in, which compounds the original problem.

Based on clinical experience I recommend that everyone, no matter how late in their course, be given the opportunity to withdraw from psychotropic drugs. Effects of such withdrawal could be evaluated. Benefits and problems should be documented. This process is complicated and its success depends on many largely unknown factors. The life-time and daily dosage of neuroleptic may effect the likely success of withdrawal and subsequent control of psychotic symptoms (Lohr, 1992). In other words, having taken more drugs, may make it more difficult to withdraw. This could relate to the same drug-induced "supersensitivity" at the synaptic level which is thought to cause tardive dyskinesia. Some researchers suggest that this supersensitivity induces a "withdrawal psychosis" upon discontinuation of neuroleptics (Chouinard, 1978; Meyerhoff & Lieberman, 1992). Rate and speed of drug withdrawal is also an important variable. "Dr. Caligari" (Richman, 1984) proposes a weekly reduction of 10%. Others, including myself, recommend much slower schedules, extending for one year or longer.

In any case, such withdrawal will confront the person increasingly with drug-free states of mind. There may be emergent feelings or experiences that one may not be prepared to confront without the use of drugs. Unfortunately, there are few supportive environments in which one can engage in a self-evaluation process untainted by drugs.

Implications:

Prescribing practices in psychiatry are intimately tied to the medical illness model and the dream to find biological cures. After 50 years of modern psychopharmacology it is clear that this dream is far from being realized. To the contrary, a lot of damage was done along the way and many opportunities for non-pharmacological healing were missed. In order to revert this trend one might foster the development of an alternate culture of healing in a humanistic system of care. Consumers and survivors of psychiatry who are sensitive to each other's needs must play a major role in such a system (e.g. Fisher, 1992). A new kind of collaborative partnership between consumers and psychiatrists must be established to buttress the essential role of the "patient" in the recovery process (Strauss, et al., 1987; Stastny, 1993).

In addition, it would be well advised to develop a greater understanding of the irrational use of drugs in various cultures, as recommended by the International Network for the Rational Use of Drugs (Ross-Degnan, et al., 1992). Economic strategies, such as "making those who hold power in the decision process accountable for the unwanted risks they impose", might cause a radical shift in psychotropic prescribing practices (Cohen and McCubbin, 1990). Combined with a major effort to disseminate proven non-pharmacological alternatives, these approaches would surely lead to a better system of care.

Conclusions:

1. Major emphasis must placed on developing and evaluating non-toxic alternative therapies useful to the majority of persons suffering from psychiatric disabilities.
2. This is particularly important during the early phases of the problem, when significant drug-induced dysfunction can still be avoided.
3. Anyone who feels they cannot get by without taking psychotropic medication must be offered the "least toxic alternative" in choice and dosage of drug.
4. Researchers, clinicians and potential consumers should work closely together in developing and disseminating a shared knowledge base on the impact of psychotropic medications.
5. Only in the context of such a collaborative relationship can we ensure that consumers are empowered to make truly informed decisions about these drugs.

The author is Associate Professor of Psychiatry at Albert Einstein College of Medicine and has been involved in rehabilitation research and program development for 15 years. He has collaborated extensively with consumers/survivors in developing and evaluating consumer-run programs. In addition, he has provided consultation on medication issues to survivors of psychiatric institutions and other mental health consumers.

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Quality of Life Outcome Measures for Three Case Management Models: Psychiatric Rehabilitation, Broker, and Traditional".

by Ruth O. Ralph, Ph.D.,
Bruce B. Clary, Ph.D.,

Quality of life has become a way to conceptualize a person's well-being (Lehman, 1988). It is defined in a variety of ways, but most often includes variables that relate to a person's living situation, family and social relations, work environment, leisure time, health status and personal safety. (Zautra and Goodhart, 1979). "At a minimum 'quality of life' covers persons' sense of well-being; often it also includes how they are doing (functional status) and what they have (access to resources and opportunities)." (Lehman, 1991).

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