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The Political Economy of Tardive Dyskinesia: Asymmetries in Power and Responsibility

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Tardive dyskinesia is a serious, well publicized adverse effect resulting from long-term neuroleptic drug use. However, little progress has been made during the last two decades in ensuring that these drugs are prescribed with necessary caution. Incentives and constraints operating on the major participants (patients, families, physicians, institutions, drug companies, society) in the decision-making process leading to the prescription of neuroleptics increase the likelihood that the benefits of drugs will be exaggerated and their adverse effects minimized. When combined with imbalances of power, these factors ensure that persons having little power and information to make the decision to prescribe will bear most costs of that decision. This points to the operation of an inefficient system which can be expected to yield sub-optimal results. We suggest ways to make the decision process more efficient by more closely aligning responsibility with cost. If those who hold power in the decision process are held accountable for the unwanted risks they impose upon others, both the use of neuroleptics and its inevitable iatrogenesis would probably be reduced.

Tardive dyskinesia (TD), a movement disorder induced by neuroleptic drugs and first described in 1957, has been a most controversial subject in psychiatry – extensively studied, discussed and debated since the early 1970s. Although there is no effective method to treat TD, and despite the fact that it is irreversible in many cases, the current practice of maintaining disturbing and disturbed people indefinitely on neuroleptics has only assured, as Mosher and Burti (1989) put it, the growth of a new species, the "tardive dyskinesic,

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stigmatized by the impossible-to-hide, cosmetic disfigurement of tardive dyskinesia" (p. 3). According to one estimate, up to 625,000 people per year in the United States exhibit signs of TD (Dewan and Koss, 1989).

In response to rising concern about this public health problem, the American Psychiatric Association (APA) in 1979 and 1985 offered guidelines to prevent and manage TD (APA, 1985; Baldessarini, Cole, Davis, Gardos, Preskorn, Simpson, and Tarsy, 1979). These included using neuroleptics at minimum doses, monitoring for side effects, discussing side effects with patients and families, and reducing or withdrawing drugs if TD appears. Moreover, in a dozen well-publicized court cases between 1980 and 1988, patients filed civil suits for damages for injury suffered as a result of TD (Slaw and Kalachnik, 1988). Courts ruled that to prescribe drugs without monitoring the patient, that failure to diagnose TD accurately, that failure to react appropriately to signs of TD, and that failure to inform the patient of the risks of TD were instances of negligent practice (see summaries and commentaries by Gualitieri, Sprague, and Cole, 1986; Mills and Eth, 1987; Mills, Norquist, Shelton, Gelenberg, and Van Putten, 1986; Slaw and Kalachnik, 1985). In the largest verdict, *Hedin v. United States* (1984), the plaintiff was awarded over $2,000,000. In 1982, Pirodsky summarized the emerging consensus on the prevention of TD: "the best way to deal with tardive dyskinesia right now is primary prevention. This means using less medication or perhaps not using it at all" (p. 170).

Unfortunately, a decade later, we see no indication that the incidence of TD is about to decline. Although outpatient prescriptions of neuroleptics in the United States have decreased about one percent a year between 1976–1985 (from 21 to 19 million) [Wysowsky and Baum, 1989], this trend is accompanied by switches to more potent drugs (such as haloperidol) which are prescribed in much higher chlorpromazine-equivalent doses than the previously popular phenothiazines. Reardon, Rifkin, Schwartz, Myerson, and Siris (1989) confirm this trend, showing that mean daily chlorpromazine-equivalent doses of neuroleptics prescribed in institutional and community settings have doubled between 1973 and 1982. Mosher and Burti (1989) remark that "it is especially painful to us that, in spite of a nearly 5% annual incidence in T.D. (i.e., in four years 20% of neuroleptic-maintained patients will have developed it), it has become difficult to even raise the question of withdrawal or decreased neuroleptic dosage with psychiatrists presently in the public system" (p. 3). At the same time, nine times out of ten, TD is misdiagnosed, even by well-trained clinicians (Dixon, Weiden, Frances, and Rapkin, 1989; Weiden, Mann, Haas, Mattson, and Frances, 1987). In addition, "few institutions have adopted the APA guidelines, and in those that have, many professionals try to circumvent them. Even when informed consent about psychiatric treatment is seriously pursued, patients are provided little information

about side effects. When side effects are mentioned, tardive dyskinesia is frequently not among those named" (Wolf and Brown, 1988, p. 284, references omitted). These puzzling facts might be explained by dynamics in the decisions to administer neuroleptics that do not fully take into consideration the balance of costs and benefits ensuing from the use of neuroleptics.

TD is a complex problem because it results from decisions made by several parties, not just those of patients who might be physically afflicted by this disease. Furthermore, the costs and benefits of neuroleptic drug use may not be distributed in accordance with the relative power of the parties involved in the decisions to prescribe neuroleptics. For example, a voluntary mental patient not fully informed by the prescribing physician of the risks of TD, or an involuntary patient forcibly medicated, or an elderly nursing home resident who has not been told that neuroleptics were prescribed, may develop TD. Patients having little power and information available to make a decision concerning prescription often end up bearing most of the costs resulting from that decision. Disregarding the issue of moral responsibility for the production of TD, analysis of these facts from a purely economic perspective points to the operation of an inefficient system of decision-making which can be expected to yield sub-optimal results.

In this paper we discuss some of the incentives that operate on various parties (patients, families, medical and other professionals, institutions, drug companies, society) involved in the decision-making process leading to the prescription of neuroleptic drugs, and some of the constraints that limit these actors' freedom to make decisions. The structural biases in this process increase the likelihood that participants in the decision will opt in favor of using neuroleptics, will downplay their risks, and will exaggerate their benefits. These biases, when combined with imbalances of power and responsibility, result in behaviour which is inefficient in the sense that most costs are borne by participants who do not have the incentive nor the power to impose these costs.

In a number of areas linked to neuroleptic prescription and its consequences, including informed consent to treatment, civil litigation for compensation for TD, and drug information provided to prescribers, we suggest ways to make decision-making more efficient by more closely aligning responsibility with cost. If those who have the power in the decision to treat using neuroleptics are informed of and held accountable for the risks they impose, the use of neuroleptics would be reduced, with a concomitant reduction in neuroleptic-induced iatrogenesis.

Therapeutic and Iatrogenic Effects of Neuroleptics

After thirty-five years of use, the limitations of neuroleptic drugs have become acutely apparent and the subject of much debate. Some authors ques-

tion whether the term "therapeutic," as applied to neuroleptic effects, has any meaning (Breggin, 1983; Cohen, 1988, 1989; Fisher and Greenberg, 1989; Lidz, 1987); some criticize psychiatry's overreliance on drugs to control "schizophrenic" patients and its systematic avoidance of psychosocial alternatives (Easton and Link, 1987; Haley, 1989; Karon, 1989; Kiesler and Sibulkin, 1987, pp. 245–248; Mosher and Burti, 1989); while others detail the visible and hidden costs of adverse effects (Dewan and Koss, 1989; Van Putten and Marder, 1987). According to Doggett and Mercurio (1989), if "schizophrenia" were less debilitating, neuroleptics "would probably be withdrawn on grounds of toxicity" (p. 121). Neurological effects alone include parkinsonism, akathisia, dystonic reactions, the potentially fatal neuroleptic malignant syndrome, supersensitivity psychosis upon drug withdrawal, tardive dementia, and tardive dyskinesia. As many as 75% to 95% of patients develop extrapyramidal symptoms during the course of treatment (Casey, 1989, p. 47).

Roughly one-fifth of patients on long-term neuroleptic treatment exhibit symptoms of TD (Gerlach and Casey, 1988), with the majority of cases rated as mild (Baldessarini et al., 1979). Among the aged and institutionalized, prevalence may be about 40% (Yassa, Nastase, Camille, and Belzile, 1988). Dewan and Koss (1989, pp. 218–219) estimate – using the figure of two million adults prescribed neuroleptics annually in the United States – that somewhere between 90,000 and 625,000 people suffer irreversible TD in a given year. Their figure does not include nursing home residents and the mentally retarded, the two most medicated groups in society (Aman and Singh, 1988; Cluxton and Hurford, 1987); hence it seems likely that more than a million Americans are suffering persistent TD today. It is difficult to estimate accurately the prevalence of TD because neuroleptics also *mask* TD: abnormal movements may emerge only during dose reduction or drug withdrawal. It is now recognized that some physicians do not reduce neuroleptic dosage because they fear that abnormal movements will emerge as a result (Bélanger, 1990).

Other physicians are reluctant to discontinue neuroleptics because of medical complications caused by TD even though they suspect or know that TD is present. Chouinard (1986) states that "a considerable number of patients, particularly those over 65 years of age, would die of complications relating to swallowing or breathing if the neuroleptic medication is withdrawn" (p. 3). Still, some authors suggest that too many discussions of TD are "alarmist" or "overreactions" (Munetz and Schultz, 1986).

Despite the known risks of neuroleptics, most psychiatrists continue to prescribe these drugs because they believe that "the unique therapeutic benefits of neuroleptics are striking and well proved . . . while the effectiveness of alternative treatments remains unproved" (Baldessarini and Cohen, 1986, p. 750). However, considerable evidence from controlled, random-assignment studies clearly shows that, *given the proper social environment*, most newly iden-

tified "schizophrenics" can be treated successfully with little or no psychotropic medication. Moreover, open studies demonstrate consistently that these types of social environments can be successfully adapted for use with veteran clients (see extensive reviews and discussions by Karon, 1989, and Mosher and Burti, 1989, pp. 109–168; see also Elizur and Minuchin, 1989).

The "striking" and "unique" benefits of neuroleptics are these drugs' unusual ability to quickly quiet down very excited persons without inducing sleep. Karon (1989) describes this short-term effect and its implications:

> Patients usually become less frightened and frightening. They also generally become less angry. They may lose some of their dramatic "positive" symptoms, like hallucinations. . . . In other cases, the hallucinations and delusions remain, but the patients are not as troubled by them. They take orders better, and comply with other people's demands better. . . . Violent patients usually become manageable, although sometimes only by dosage levels that leave the patient barely awake. The ward staff, treating physician, and family do not feel powerless. Patients are spared some of the destructive things that other people, out of fear, often used to do to schizophrenic patients, both in and out of hospitals. (p. 145)

In longer-term use, the advantages of neuroleptics are more difficult to discern. Regardless of whether patients are maintained on oral or injected neuroleptics, where compliance is ensured, two-year relapse rates in random assignment double-blind studies run about 70–80% for placebo-treated patients and 40–50% for neuroleptic-maintained patients. Combined with a 5% annual incidence of tardive dyskinesia in the latter group, the risk/benefit ratio does *not* seem to favor long-term maintenance (Mosher and Burti, 1989, p. 44). Easton and Link (1987) state that they "have been making long-term observations of patients who do and do not relapse – with high doses, low doses or no doses, and clinically, there has not appeared to be any particular relationship between neuroleptic intake and relapse diminution" (p. 49). Long-term outcome in "schizophrenia" is no better today than it was before the introduction of neuroleptics, when two-thirds of "schizophrenics" recovered without drugs (see Haley, 1989; Mosher and Burti, 1989, p. 3).

We therefore find plausible Karon's (1989) conclusion at the end of his own detailed review of psychosocial treatments for "schizophrenics," that "unfortunately, political and economic factors and a concentration on short-term cost-effectiveness, rather than the scientific findings, currently seem to dictate the type of treatment" (p. 146). One may question the logic and practice of maintaining "schizophrenics" on indefinite maintenance treatment with neuroleptics and exposing them to the known toxicities of these chemicals. Nevertheless, inadequacies in the structure of the mental health system continue to suppress honest appraisals and implementations of alternatives to drug treatments. Drugs are easy to administer – initiating and maintaining supportive, well-staffed social environments is difficult and expensive.

The use of neuroleptic drugs generates difficult dilemmas which patients, physicians, families and other parties face continually. Allocating responsibility for TD and compensating its victims are problems that these participants – and the rest of society – will have to address soon (Appelbaum, Schaffner, and Meisel, 1985).

The Ideal Prescribing Situation

One ethical assumption underlies our analysis: that a person does not have the right to interfere in another person's decisions if these decisions do not affect the first person tangibly.[1] Given this principle, we would not consider the production of drug-induced diseases problematic on a social level if the conditions implicit in Adam Smith's welfare-maximizing free market (Smith, 1924, p. 400) were to exist. These conditions are as follows: individuals are "rational," in that they will attempt to maximize their welfare; all persons have equal access to all available information on the drugs; all persons have an equal ability to understand this information and its implications; no externalities arise from a person's decision to use or not use a neuroleptic, that is to say, this decision has a tangible impact – positive or negative – only on that person[2]; and finally, all citizens have equal access to the drug at a free market price. If all these conditions were met, this would result in a situation where no intermediaries need be involved in the decision to use neuroleptics. Hence, in this situation, responsibility for the consequences of drug use lies with the individual who alone possesses power to decide to take the drug. On a societal level, this abstract situation could not be improved upon by policy intervention.

In reality, of course, these conditions do not hold fully. The decision to use neuroleptics is made in different contexts with varying degrees of adherence to the above "ideal" conditions. We examine some typical contexts in which neuroleptics are used, assess the extent to which participants in the decision to prescribe neuroleptics impose externalities on others, and suggest how these variations from the "ideal" result in sub-optimal consequences. The ensuing

[1]We do not attempt the difficult task of defining explicitly what qualifies objectively as a "tangible" interest other than to note that it inevitably involves some further ethical assumptions about what interests are invalid. For example, do persons who are offended because their neighbor sits on his or her porch in pajamas have a *valid* interest in that particular behavior, even if such behavior might affect their property values? (We think not.)

[2]Meade (cited in Cornes and Sandler, 1986, p. 29) has offered the following definition of externality which fits this context well: "an event which confers an appreciable benefit (inflicts an appreciable damage) on the decision or decisions which led directly or indirectly to the event in question." The existence of an externality implies transaction costs and/or imperfect information resulting in a sub-optimal allocation of resources relative to what could be achieved with a change in institutional/government policies (see Dahlman, 1988).

policy recommendations are designed to render the decision-making process more efficient, that is, more likely to yield benefits exceeding costs.

We avoid directly addressing the moral issues inherent in the decision-making process leading to use or avoidance of neuroleptics as moral issues per se, concentrating instead on an efficiency criterion.[3] We do not ignore the difference between a moral problem and a technical problem, but we believe it may be very difficult indeed to arrive at a consensus about moral responsibility for TD. We also find that most technical discussions of socio-legal implications of TD fail to address technical issues that might illuminate some of the moral dilemmas (but see Appelbaum et al., 1985; Breggin, 1983; Brown and Funk, 1986; Crane, 1982; Wolf and Brown, 1988).

We use a "political economy" approach in explaining the circumstances under which neuroleptics are prescribed; economic in the sense that actions and transactions by individuals are assumed comprehensible given identified interests (security, money, power, status, etc.), political in recognizing that individuals and groups act to influence the setting of rules which alter the incentive and constraint structure within which the decisions of concern are made. The two terms are put together in recognition that the *same* people act in the political and economic spheres, and that there exists a dynamic relationship between the two spheres. The foregoing is essentially how Buchanan (1972) described the "theory of public choice," a new field whose practitioners frequently term their approach as "political economy," using a broader and more traditional sense of the term than that used by Marxist authors who adopt a class structure analysis.

Power, Information and Incentives in the Prescription of Neuroleptic Drugs

Neuroleptic drugs are prescribed to members of two broad and overlapping categories which can be loosely characterized as "psychiatric patients" and "the institutionalized dependent." The first category contains persons diagnosed with acute or chronic psychotic disorders, for whom neuroleptics are officially indicated (included in this category are those diagnosed with manic-depression; between 1976–1985, there was a nine-fold increase in the number of neuroleptic prescriptions for this subgroup of patients [Wysowsky and Baum, 1989]). The second category contains more or less helpless and

[3]"Efficiency" becomes a less clear-cut concept when combined with considerations of power allocations (see Turk, 1983). Economics typically considers power as a given, and the efficiency criterion that of Pareto-optimality, a situation where no one could improve without someone else becoming worse off. Policy recommendations that result in redistributions of initial power could result in a violation of the Pareto-optimality criterion. Our notion of efficiency is modified Pareto-optimality which allows for redistribution of power endowments in accordance with our above-stated ethical assumption regarding non-interference by a person without a tangible interest.

institutionalized persons, with or without psychiatric diagnoses, such as the elderly in nursing homes, the mentally disadvantaged in community residential facilities and the indigent ex-patients in board and care homes. Today, after nearly three decades of psychiatric transinstitutionalization, most persons prescribed neuroleptics fall within the second category.

In this section we describe – using as examples psychiatric patients and nursing home residents – the situations in which neuroleptic drugs are prescribed, with attention to attributes of power/constraints, information, and incentives with respect to the major participants in the medication process (e.g., patients, doctors, institutions and their staff, families, drug companies, society/government). Our arguments would also apply to other groups receiving neuroleptics, but with some modifications. For example, although the level of neuroleptic use among residents of facilities for the mentally disadvantaged is very high (Buck and Sprague, 1989), this level appears to have dropped significantly during the last decade (see analyses by Aman and Singh, 1988; Beyer, 1988; Schroeder, 1988).[4]

Neuroleptics for Psychiatric Patients

Patients. Over 90% of hospitalized persons with a diagnosis of schizophrenia are prescribed neuroleptic drugs (Ban, Guy, and Wilson, 1984). For what reasons are they given drugs? Diamond (1985) mentions that drugs relieve some of patients' pain and suffering, protect patients from unbearable stresses, help patients to sleep or to work, and help patients to shut out unpleasant thoughts. A few first-person accounts of the benefits provided by neuroleptic drugs have been published. For example, Bockes (1985), a graduate student diagnosed as schizophrenic, first resisted taking drugs, but later accepted medication after several hospitalizations. Periodically she experiences hallucinations, but knows when these are coming and uses neuroleptics "before things get out of hand" (p. 489). In sum, neuroleptic drugs, like other drugs, are sought after by certain people who have learned to derive distinct benefits from their use.

Other patients take neuroleptics not because they appreciate their psychophysical benefits but because drugs come with a role these individuals must assume to buttress a claim of disability (perhaps one of the few career options they have). Still other patients do not particularly wish to take neuroleptics,

[4]This may be the result of several interacting factors, such as the fact that one of the first tardive dyskinesia lawsuits involved a mentally disadvantaged resident of a residential facility; the entrenched advocacy movement on behalf of the institutionalized mentally disadvantaged; the focus on objective behavioral criteria to justify medication; the increasing application of medication-reducing and medication-monitoring programs in these facilities; and – compared to nursing homes – a greater involvement of trained professionals in the care offered to the mentally disadvantaged.

but feel they must because of implicit or explicit threats. These patients may be threatened with new or prolonged incarceration, with loss of financial benefits (some welfare agencies will dispense funds only upon proof that neuroleptics have been injected), with eviction from one's lodgings, with removal of family affection, with the belief that they will forever remain "mentally ill." There is also an undetermined number of veteran patients who cannot be weaned off neuroleptics either "because their dopamine receptors are starved or because of a real addiction-like withdrawal syndrome which includes what *looks like* the beginning of an exacerbation of psychosis" (Mosher and Burti, 1989, p. 47; see also Breggin, 1989). Finally, some psychiatric patients refuse to take neuroleptic drugs. Professionals often assert that these patients are "delusional" or "deny their illness," though when the patients themselves are given a forum to express their reasons, they usually cite the unpleasantness of adverse effects (Burstow and Weitz, 1988; Van Putten, 1974).[5] It is difficult to estimate how many persons on neuroleptics do not wish to take them. We do know that in 1980, 26% of inpatient psychiatric admissions in the United States were classified as involuntary (cited in Roth, 1989). This statistic is, of course, misleading, since many other less formal but equally effective degrees of coercion of patients co-exist in the mental health system as a whole.

Families. Families of patients have numerous incentives to encourage the use of neuroleptic drugs. Families may support drug use because they seek to support a claim of disability and thus formally enlist the help of the state in supporting their relative/patient. Many patients are "failures," in that they lack basic work and educational skills. In another vein, family members have strong and obvious interests in suppressing the outward signs of psychosis in one of their own, especially if this member lives with them, is dependent on them, and disturbs them with angry, withdrawn, or unpredictable behaviour. The stigma, embarrassment, stresses and sorrows of being related to someone who acts incomprehensibly or erratically are extremely difficult to bear (Lefley, 1989).

Families also come to believe what they are told about their relatives, that they suffer from a brain disease which responds to treatment with neuroleptic drugs (see Johnson, 1989; Rose, 1988). Drug treatment is therefore seen as an enlightened, loving response to psychological distress. In the past, psycho-social formulations of the "causes" of "schizophrenia" implicitly or explicitly blamed families for producing behaviour then labelled "schizo-

[5]It is astonishing to note the paucity of published professional discussions envisaging TD from the patient's point of view. Dearing's (1982) short piece is an exception. Accounts from patients themselves appear in Skov (1985) and Steinman (1979), the latter a magazine article on neuroleptics. Finally, TD patients presented their stories in the CBS Evening News programs of November 21–23, 1983.

phrenic." It is well-accepted today that the main reason families of persons with mental illness hold as a central tenet that "schizophrenia" is a brain disease is that this view places no blame on the family (Buie, 1989; Johnson, 1989). Perhaps the most vocal, well-organized and influential lobby group in mental health is the National Alliance for the Mentally Ill (NAMI), an organization of nearly 80,000 relatives of psychiatric patients, which has successfully oriented publicly-funded research toward defining "schizophrenia" as a disease of the brain (see McLean, 1990). For the fiscal year 1990, NAMI is actively lobbying for "at least a $500 million budget for NIMH, with a special emphasis on brain research" (Buie, 1989, p. 26).

Society. The definition and management of misbehaviour and unhappiness as mental health problems constitute an important characteristic of our society. This is reflected in, among other things, monopoly licensing of medical practitioners to diagnose and treat various conditions classified by these practitioners as illnesses. From a societal perspective, drug treatment appears much less costly than any other alternative, cheaper perhaps than even funding *research* into alternatives. Some policy advantages of using drugs are the simplicity of the policy itself and the ease with which it can be communicated to decision makers and the public, the existence of a large network of prescribers, and the ease of training these prescribers (see Kiesler and Sibulkin, 1987, p. 246).

Brown and Cooksey (1989) and Morreim (1990) have discussed two major trends in the new economics of psychiatry and mental health in the United States: the growth of corporate entrepeneurial activities which aim to raise revenues by expanding one's products, services, and clienteles; and reciprocal pressures to contain costs. "The economic pressure to fill beds translates into a commensurate pressure on the profession to expand the concept of psychiatric illness, and with it the criteria for hospitalization and other extensive (revenue-producing) care. . . . Conversely, [with] cost-containment . . . psychiatrists may be pressured to emphasize only those forms of care that are easiest to document and cheapest to deliver" (Morreim, 1990, p. 98).

To the extent that government and third parties pay the cost of health care, they are justified in influencing the decision whether or not to treat with drugs. However, governments are often short-sighted, failing to consider in their policy decisions some of the longer-term costs of neuroleptic treatment should TD develop in substantial numbers of patients. Clearly, neuroleptic treatment in the short run saves the costs of institutionalization, professional services, and policing deviance, but in the longer run such costs may still have to be paid. Severe TD implies severe disability, mental and physical (Engle, Whall, Dimond, and Bobel, 1985; Gardos, Cole, Salomon, and Schneilbock, 1987), including possibly tardive psychosis and tardive dementia. This, in turn, implies institutionalization or extensive home care

support. Discussions on the short- and long-term costs of neuroleptic use are rare (but see Dewan and Koss, 1989), and these costs remain unexplored despite the numbers of TD cases.

The paucity of discussions on long-term costs may reflect the belief that drugs are justified because of the medical nature of the problems drugs are said to treat. This belief – roughly translated as "the medical model" – constitutes one of the ideological underpinnings of our modern age and necessarily shapes possible responses to TD. For example, Munetz and Schultz (1986), who claim to adopt a balanced, rational approach to TD, state that the proposition "schizophrenia is a serious brain disease," "need[s] to be accepted before TD can be responded to objectively" (p. 168). Similarly, Rose (1988, p. 1) believes that only "a change in the way schizophrenia is perceived in America will help to make antipsychotic medicine more acceptable." This is an unusual assertion, since prescribers, families, institutions, drug companies, and society widely praise, endorse, use, advertise and accept neuroleptics. If anyone needs to accept neuroleptics more than at present, patients themselves appear to be the prime candidates.

Not unexpectedly, patients are the least represented parties in public policy debates and lobbying. This is partly a result of the "free rider" problem, which increases as group size increases (i.e., people are individually likely to invest fewer resources in lobbying the more dispersed are the benefits arising from such lobbying). Therefore, by virtue of numbers alone, we cannot expect patient advocacy groups to enjoy an advantage over competing groups with smaller membership (Katz, Nitzan, and Rosenberg, 1990). The drug industry has less of a free rider problem than patient groups since the relatively few firms benefit directly from investing to influence public perceptions and government policies. Psychiatric associations, for their part, have defeated the free rider problem among their members by enforcing membership (with legal sanction); the group as a whole has the power to levy members for contributions for lobbying purposes. While families have a free rider problem similar to that of patients, family associations have been very successful in inducing families to join their lobby groups and to make a membership contribution. Some of their success, relative to that of patient groups, can be attributed to patients' limited socio-political skills, education, and access to financial resources.

Groups representing patients' interests are very small, loosely organized and receive, at best, haphazard funding. On Our Own, an association of current and ex-psychiatric patients in Toronto, constitutes the only such group in Canada to consistently offer guidelines for the use of biological treatments in psychiatry. However, their magazine, *Phoenix Rising*, is regularly threatened with dissolution due to underfunding. The privation of patient groups weakens their ability to participate in public policy debates and leaves a greater

role to the other parties involved. Two former On Our Own activists put it this way: "Those who have experienced [neuroleptics] rarely have the resources to combat the propaganda churned out by the medical establishment and its allies – they can't launch an advertising campaign to counter the deceptive schizophrenia posters found on the Toronto Transit Commission vehicles" (Burstow and Weitz, 1990, p. 8). Mental patients, as with other relatively helpless and unempowered people, thus often must rely on *others* to protect their public interests. It is natural to think that families are best-suited for this role, but there is no reason to assume that the interests of patients and the interests of families coincide. On the contrary, common sense suggests that patient and family concerns may conflict – and personal observation confirms that they usually do. This simple fact is rarely acknowledged, which helps explain why so few concerned persons press to ensure that points of view unique to patients are reflected in public debates.

Physicians. The most powerful incentive for psychiatrists to prescribe neuroleptics derives from their professional identity as physicians. For most practicing psychiatrists, "functional" psychoses are soon-to-be-discovered brain diseases or the symptoms of such diseases. Though practitioners recognize the importance of social, psychological and environmental factors on the causes, courses and outcomes of many conditions they treat, their practice relies almost exclusively on psychotropic drugs. According to Mosher and Burti (1989), "the drug treatment of schizophrenia seems to be subject to the greatest intensity of dogmatism. . . . [W]ithdrawing neuroleptics from persons with this label is extraordinarily difficult. . . . The party line that schizophrenia is a chronic illness treatable only with medication has the field firmly in its grasp" (p. 40).

Brown and Funk (1986) have also pointed out the importance of physician-patient differences in the perception of medication efficacy: "Physicians usually perceive medication in terms of symptom reduction and/or illness cure, whereas patients typically are more concerned about its effects on daily living routines. . . ." These authors believe physician concern "with narrow medical issues rather than broader sociomedical ones . . . demonstrates some important shortcomings of [medical] training," notably, an "emphasis on individual pathology without regard for social components of the experience of illness" (pp. 126–127).

In a similar vein, Szasz (1977) pointed out that psychiatrists do not give money to their poor patients or friendship to the lonely. Today, the only visible sign of their power to heal is the drug and the regimen with which the drug is prescribed (Montagne, 1988). It is not difficult to see why, as Munetz (1985) suggested, it is psychologically painful for a clinician to recognize that medication he or she has prescribed may cause severe or irreversible harm.

Yet, even if such recognition occurs, what is an ordinary, well-intentioned

physician schooled in the medical model to do? Well-organized psychosocial healing contexts are so rare or inaccessible as not even to rate as a viable alternative (Elizur and Minuchin, 1989).[6] At the present time, aside from hospitalization and neuroleptic drugs, the only real option in the treatment of a "schizophrenic" patient is to do nothing. Yet, to do nothing or to remove neuroleptics, even in a research project, may leave the physician exposed to charges of unethical practice (Engstrom, 1988). Even expressing views concerning the danger of neuroleptics may lead to serious repercussions. "When a psychiatrist (Dr. Peter Breggin) acknowledged on a television interview . . . that patients' concerns about [TD] were justified, that this was a serious problem, and that patients should seek out professionals who are interested in helping the patients understand themselves, and not professionals who are interested in only medicating, an attempt was made to silence him" (Karon, 1989, p. 107). NAMI, assisted by the American Psychiatric Association, filed charges with the medical licensing board of Maryland to revoke Dr. Breggin's medical license (the charges were eventually dismissed).

Thus, every general bias that we are able to identify in the practitioner increases the likelihood of prescribing drugs. Moreover, if – in the doctor's mind – information given to the patient about drug risks leads to the patient's refusal to take the drug, then the doctor also has an incentive *not* to inform. Benson (1984) reported that one-third of psychiatrists disclosed risks for significant adverse effects and TD to patients on neuroleptics, and one-tenth thought it better not to discuss this with patients. One recent trend, however, represents a potential incentive to prevent TD: the threat of malpractice litigation. Recent, well-publicized cases have set precedents and – in theory at least – have constrained psychiatric practice. Yet, as we have seen, established guidelines such as APA's "have been honored more in the breach than the keeping" (Gualtieri et al., 1986, p. 206).

Generally, doctors are assumed to act "in the best interests" of their patients. In our view, this should mean acting *as the patient would act* if fully competent and possessing the knowledge possessed by the doctor. The doctor, however, brings in more than his or her knowledge in reaching the decision. The doctor also brings in his or her own values, which may or may not correspond with the patient's, including values attached to the medical model – a model which constitutes more than a theory but which may be

[6]It is beyond the scope of this paper to analyze why "community mental health," which was seen as a viable alternative by many physicians in the 1960s and early 1970s, has greatly declined and why choice of treatment is now posed as a simple dichotomy of drug/no drug. Suffice it to say that this change may be due to the strong rightward trend of American politics during this period, a trend characterized in the field of mental health by the application of narrow perspectives to larger social problems and by the downplaying of real and potential fears about the effects of psychotechnology expressed by target populations and other critics (see analyses by Brown, 1985; Mosher and Burti, 1989).

in fact a self-serving attitude/paradigm for the profession [see Engel, 1977]).

Drug companies. Drug companies profit from drug sales and cannot be expected to have incentives other than aiming for increased consumption of their products. The symbiotic relationship between drug companies, medical associations and regulatory bodies has been extensively discussed (Silverman and Lee, 1974). Drug companies are directly involved in the decision to prescribe drugs via the information they provide to doctors and the funds they contribute to professional psychiatric associations. This information includes advertisements in psychiatric journals, package inserts, and other forms of labeling and promotion. In the standard by which most investigators judge the quality of prescription practices, the *Physicians' Desk Reference*, listings themselves – which must be approved by the Food and Drug Administration (FDA) – are forms of labeling *and* promotion, or a form of paid advertising distributed freely to physicians (Silverman, 1976). A recent example of drug promotion is an unprecendented ten-page advertisement by Sandoz Pharmaceuticals Corporation for the neuroleptic clozapine (Clozaril) – used for a decade in Europe and recently introduced into the United States – in the January 1990 issue of the *American Journal of Psychiatry* and other journals. The ad, which resembles a newspaper insert, comes complete with the Statue of Liberty announcing "A beacon of hope for thousands of problem schizophrenic patients and their psychiatrists" (clozapine is thought to be superior than typical neuroleptics for nonresponders and almost free of extrapyramidal symptoms). The amount of money multinational drug companies can spend on advertising creates an imbalance in the sort of information physicians are exposed to. Simply, information provided by independent observers and anti-drug advocates does not get nearly as much publicity (see also McDonnell, 1986; Mintz, 1985).

Neuroleptics for Elderly Nursing Home Residents

The staple use of neuroleptics in nursing homes is well-documented (Bishop, 1989; Cluxton and Hurford, 1987). In a recent study of all 33,351 Illinois long-term adult nursing home residents who are Medicaid recipients, Buck (1988) found that 45% received neuroleptic drugs. Most neuroleptics had mean lengths of administration of six months or more, "implying that once individuals are placed on such medications, they continue to receive them" (p. 417). If we estimate a conservative 20% prevalence rate of neuroleptic use in nursing homes, approximately 400,000 institutionalized elderly in the United States are receiving these drugs.

Most experts agree that neuroleptics are administered to nursing home residents because the drugs effectively control disruptive and agitated behaviour (Fauteux, 1988). On a daily basis, one-fifth of elderly nursing home residents

may exhibit "problem behaviours," such as disorientation, aggression, wandering, noisiness (Rockwood, Stolee, and Robertson, 1989). One study found that neuroleptics were prescribed more frequently to "physically incapacitated people together with wandering and aggressive ones" (Nygaard, Bakke, and Breivik, 1990, p. 170). To what extent is this practice justified? It is well to remember that few persons are officially committed to nursing homes and treatment is thus ostensibly on a "voluntary" basis for most residents. Thus, in only a few situations might there exist some legal controls that would apply to compensate for the general helplessness of the resident.

Residents. Many residents of nursing homes – perhaps even the typical resident – have less than full mental capacity, and many incompetent patients receive neuroleptic drugs without recognition of their incompetency by a court of law (Hoffman, 1989). It is reasonable to assume that most of these persons do not have any incentives to take neuroleptics. We cannot imagine that neuroleptics make them feel better physically. Generally, we do not see the possibility that neuroleptics present any benefits for these individuals. However, neuroleptics have a cost: the onset of TD – of which increasing age is the single most widely accepted risk factor (Gerlach and Casey, 1988). The available evidence clearly supports the conclusion that nursing home residents are usually not informed of the risks of drugs and that the rationale offered for prescribing the drugs – if one is offered – is simplistic or misleading. The investigators in one study – which attempted to determine how prescribers obtained informed consent from their nursing home patients – summarized part of their findings as follows: "The results indicate that physicians in nursing homes do not inform their patients of the risks of neuroleptics, do not seek consent, and do not consider competency to be even an issue" (Gurian, Baker, Jacobson, Lagerbom, and Watts, 1990, p. 37).

Institutions. By 1980, 81% of nursing homes in the United States were privately owned (Hawes and Phillips, 1986). These facilities operate in a highly competitive market, increasingly dominated by large proprietary chains. Possibly the strongest incentive for these institutions to remain competitive is to keep their costs as low as is legally possible (see Grimaldi, 1985, pp. 80–81). Service competition is restricted to the few elite homes which charge more than the competitive minimum to clients or families who are relatively wealthy. However, over 50% of nursing home expenditures in the United States are financed by direct or indirect government funding (Eckholm, 1990). For these institutions most revenues are legally fixed and profit lies in cutting costs.

Third-party payers can be expected to be less concerned about service than the client but more concerned about price. Therefore, it may be the rare institution that will maintain staff and standards beyond the minimum legal requirements. There is a very high patient-staff ratio, and minimum standards in fact operate as *average* standards of care (Waxman, Klein, and Carner,

1985). A recent study estimates that there are only 1.5 licensed nursing staff per 100 patients in United States nursing homes, compared to one registered nurse for 4.5 patients in acute care ("Hospitalization," 1989).

According to Waxman et al. (1985), "psychotropic drugs are used less for the treatment of ailing patients than for the treatment of an ailing institution – the long-term care industry" (p. 886). Pay is low, physical conditions are often poor, work is demanding, frequently degrading. Nursing home staff are consequently less qualified than those in other health care settings. Physicians are usually not present. More than 90% of the patient care in nursing homes is actually delivered by nurses' aides, who, in terms of education and wages, fall at the bottom of the nursing home hierarchy; job turnover among aides averages nearly 40% annually in the United States (pp. 886–887). Under these conditions, "it is not difficult to understand how psychotropic drugs, particularly [neuroleptics], are quite effective in reducing the burden on the staff. Patients who are drowsy, asleep, or slowed down are simply less of a management problem" (p. 887). According to other studies, overdrugging of residents is especially common on weekends, when homes are apt to be short-staffed (Bishop, 1989; see also Lempinen, 1987).

How do staff responsibilities correlate with staff knowledge of psychotropic drugs? Avorn, Dreyer, Connelly, and Soumerai (1989), in a survey of 55 rest homes in Massachusetts, assessed staff competence and found a low level of comprehension of the purpose and side effects of commonly used psychotropics. The neuroleptic chlorpromazine (Thorazine, Largactil) was identified as a minor tranquilizer by 47% and as an antidepressant by 12%, while 19% did not know its purpose. In response to a straightforward clinical vignette, nearly half the respondents failed to recognize the primary manifestation of TD, attributing the symptoms to a stroke (15 percent), mental illness (11 percent), a heart condition (6 percent), or blood pressure problems (3 percent), or gave no response (12 percent). Among the residents with movement disorders noted on examination by surveyors, only 17% had any mention of TD in their records.

Engle et al. (1985) showed that among residents in foster care homes on neuroleptics, as the number of TD symptoms increase, there is a corresponding decrease in the ability to perform activities. This suggests that medicating nursing home residents in order to reduce the time it takes to care for them is an option that may not be fully balanced by information concerning the increased disability of these residents, and thus the increased efforts to minister to them.

Physicians may be paid by the resident, institution, a government agency, families, or insurance companies, but they are hired by the institution. It is unlikely that residents of nursing homes have much say concerning who their doctor will be. Much of the information the physician receives about

the residents will come by necessity from the staff. The power of nurses and other staff is considerable: Avorn et al. (1989) found nearly half of prescriptions for neuroleptics to be written "as needed," thereby placing the decision to administer in the hands of the nurses. Ray, Blazer, Schaffner, and Federspiel (1987) – reporting on the failure of an educational visit aiming to reduce neuroleptic prescriptions by nursing home physicians – concluded that "in the nursing home, nursing staff may have a key part in therapeutic decisions. Alternate methods of behavior management can require increased commitment of time by nurses and physicians or resources by the facility, a commitment which may be difficult to make in the present-day nursing home environment" (p. 1449).

As noted, many people who enter nursing homes have limited capacity, a condition magnified further by residing in an institution. It is easy for physicians in such a situation to treat the consent process lightly, and that appears to be the reality in most nursing homes. Their own biases, as noted earlier, in addition to the institutional pressures, would militate against disclosing risks such as TD or explaining why a neuroleptic is needed. The fear of malpractice would be much lower than in more supervised settings, and when TD symptoms emerge, these might be attributed by staff to the resident's generally disabled condition.

Institutional pressures, delegation of health care responsibilities to facility staff, and an insufficient recognition of the risk of TD lead us to the conclusion that the effect of physicians' neuroleptic prescription practices in nursing homes reflects more the interests of institutions than of residents. In the short term at least, the decision to use neuroleptics in a nursing home imposes a cost to the resident and a benefit to the institution. The latter is often funded by third parties, supposedly acting on behalf of the resident, to provide shelter, care, and supervision. Such funding does not justify the *modification* of the resident through the administration of neuroleptics. Unfortunately, an institution that does not encourage the indiscriminate use of neuroleptics may believe itself to be at a competitive disadvantage to an institution that does, since the latter practice may cut costs and may be more attractive to potential payers. However, if neuroleptic use were drastically curtailed and all institutions changed their practices, costs would be increased equitably for all. Hence, regulating the administration of neuroleptics might not face institutional opposition – as long as regulations are enforced and institutions are compensated for increased care costs.

Policy Recommendations

Our brief examination of the contexts within which neuroleptic drugs are prescribed reveals systematic pressures, constraints, and biases leading parti-

cipants to opt for neuroleptics without sufficient attention to the costs imposed by their use. In our view, this situation calls for countervailing pressures and policy interventions.

The Medical Model

There is a pressing need for public debate about the legitimacy of the medical model (i.e., that the phenomena termed "mental illnesses" are actual diseases requiring eradication or management by mental health professionals [Engel, 1977]). In our view, society can best represent its interests if it becomes more aware of the controversy surrounding issues of definition of misbehaviour, and if it attempts to critically rethink the claims of biological psychiatry (see Fisher and Greenberg, 1989). To that end, we suggest, as a first step, that patients and patient advocate groups receive far greater assistance to represent and present their points of view to the general public. Such assistance would help to counterbalance the advantages enjoyed by groups with competing perspectives, particularly by professional associations, who have reduced their free-rider problem due to government regulation sanctioning professional monopolies (see, for example, Kilbane and Beck, 1990).

Standard of Care

The incentives facing institutions and doctors are such that, by itself, *information on TD is not sufficient to produce major changes in neuroleptic prescription practices.* Unquestionably, adherence to the American Psychiatric Association's 1979 guidelines would reduce the incidence and prevalence of TD and other adverse effects. Fewer persons would be treated with neuroleptics, and fewer persons on neuroleptics would receive high doses. Constant monitoring for TD through periodic dose reduction or drug withdrawal would uncover early signs and lead to proper management and prevention of the condition. The results of litigation thus far have established little in the way of judicially created standards for the administration of neuroleptics. We believe the American Psychiatric Association guidelines should immediately form the basis for such standard. In our view, not adhering to these guidelines without valid reason constitutes grounds for malpractice action. Specific regulations should be considered regarding certain aspects of neuroleptic use: for example, if "as needed" prescriptions are not banned altogether, time restrictions must be imposed on them. The APA should yearly re-issue its guidelines with a warning that contravenors could be liable to disciplinary action (e.g., license suspension or revocation, fine, re-education, removal of prescription privileges) if a complaint is substantiated. All persons – particularly nursing

home staff and aides – who have a role in prescribing and administering the drugs should have a role in monitoring for TD.

Informed Consent

Informed consent remains at the heart of ethical medical practice. In our view, consent, not the presence of illness, constitutes the only morally justifiable basis for medical treatment. If a patient appears incompetent, it is incumbent upon the health professional not to treat and to obtain a court order to do so.

For a condition as severe as TD, a signed consent form should be a minimum requirement. A consent form may in some instances serve to cover up the failure to obtain true informed consent, but a consent form need not simply explain risks and benefits of neuroleptics. A consent form should specify the physician's duties as given in the APA guidelines, and it should be signed by the prescriber. The consent form should also indicate that the prescriber's professional actions are suitably monitored, and be signed by the administrator (see, for example, Kalachnik and Slaw's [1986, p. 5] discussion of written informed consent policy variables). Failure to abide by the conditions of consent forms would constitute, in the absence of mitigating circumstances, sufficient grounds for courts to find malpractice.

Civil Litigation

Civil litigation is a means of reducing externalities so that those who impose unwanted costs on others are made to compensate the affected persons. In this context it means that physicians and institutions who improperly impose or maintain neuroleptic treatments, for example, without the patient's full informed consent, should compensate the patient who develops TD as a result. However, since litigation is available to a very few, court decisions have a limited impact. On the other hand, court decisions inform patients and families of the risks of TD and warn physicians and administrators of the risks *they* may face if the patient develops TD.

Some observers of the judicial process, while supporting the concept of malpractice litigation, decry "excessive" awards to plaintiffs. In any individual case such awards may be excessive, but overall they amount to a minute fraction of what "justifiably" would be awarded if all aggrieved TD sufferers were to litigate. Malpractice awards are paid for by professionals' insurance companies and are reflected in the fees for insurance. To the extent that these fees approach the cost of TD borne by patients who were not properly treated or informed, doctors and administrators can be expected to moderate their use of neuroleptics. Since the vast majority of potentially successful litigants

will never go to court, individual awards should more than compensate successful litigants for all identifiable costs, including loss of earnings, loss of enjoyment of life, loss of companionship borne by the victim and by family members. In cases of negligence, a punitive award should also be levied. If anything, such litigation should be encouraged, including using existing government funding mechanisms, such as provision of legal aid and/or justice department funding to monitor relevant court cases and help provide precedents to aspiring litigants.

Drug Information

Professional medical and psychiatric associations should recognize the flagrant conflict of interest in accepting paid advertisements for drugs in their official journals as well as in the practice of financial support of their professional and scientific activities. While any individual practitioner might with good conscience deny the impact of such drug company subsidies in their own practice, these subsidies, combined with the high rate of psychotropic drug prescription by physicians, create a clear impression of at least systematic or unconscious bias.

Physicans are subject to extremely large quantities of information (in the form of advertisements, samples, brochures, and other promotional material) from drug companies operating with a purely financial incentive. Should not physicians also receive information from the naysayers? By means of voluntary compliance or regulation, drug company information should be made more balanced by inclusion of references to controversies regarding therapeutic and adverse effects of neuroleptics.

Conclusion

Although we believe that our recommendations, if implemented, will help reduce the problems we have outlined in this paper, we realize that decision-makers are likely to consider them only in a social and economic environment which reflects a commitment to scientific and professional responsibility, and to individual autonomy (see Mosher and Burti, 1989). Thus, as long as psychosocial alternatives to drug treatment of "schizophrenics" do not exist widely, drug treatment is inevitable. As long as non-medical health professionals continue to defer to physicians when medication decisions are contemplated and avoid learning more about the documented values and limitations of drug treatment, prescription abuses will persist. As long as mental health interventions continue to be dominated by mental hospitalization, the preservation of personal power of patients will be eroded and will lead to further dependency and iatrogenic injury.

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