The Chronic Mentally Ill

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Historical Background

The care and treatment of the chronic mentally ill date back to the founding of America. From the early Colonial period, there are reports of families who were distressed by the conduct and behavior of their kin and requested the court's permission to build outhouse-like cells in which to house their mentally ill relatives. Later, jails, workhouses, and almshouses housed the chronic mentally ill. An early precursor of "dumping" occurred in some Massachusetts communities when mentally ill persons were transported over county or town lines in order to shift the responsibility for their care to another community.

In the mid-1800s, Dorothea Dix, appalled by the shabby treatment and dismal surroundings which localities provided for the severely and chronically mentally ill, successfully crusaded to have the states assume the burden for their care and treatment. These institutions were intended to provide the best available treatment and care of the mentally ill, known at that time as "moral treatment." Moral treatment followed Pinel's example in Paris of "striking off the chains" and was also modeled on Tuke's establishment, the York Retreat in England, which emphasized a humane,

familial-like atmosphere and pleasant, open settings, with a minimum of physical restraint and a maximum of structured activity.

The numbers of the chronic mentally ill in America soon grew larger than the institutions' capacity to provide humane housing. This situation was due to increasing immigration from Europe, the impersonality of the industrial era, and the "aging-into" chronicity of the seriously mentally ill. Ultimately, state hospitals provoked scandals similar to those that motivated Dorothea Dix to agitate for elimination of local community responsibility for care of the mentally ill.

As America entered the twentieth century, society was ripe for experimentation with new methods in the care and treatment of the mentally ill. The combined efforts of dedicated individuals, such as Clifford Beers, accompanied by the establishment of alternative treatment settings (psychopathic hospitals, child guidance clinics, outpatient clinics, general psychiatric units) facilitated the shift from a single-sited service system into a pluralistic one. But inherent in this development was one of the major problems of the chronic mentally ill—the fragmentation of responsibility for providing the services needed by these patients. While the state hospital was overcrowded, understaffed, and inhumane, it did provide the services needed by the severely and chronically mentally ill, such as psychiatric and medical treatment, social and vocational rehabilitation, and custodial services,

including food and lodging. However, with the establishment of multiple institutions and services, there was no longer any single institution responsible for the severely and chronically mentally ill population.

The foundation blocks for the movement known as community psychiatry began to be laid during the first half of the twentieth century. These included: preventive psychiatry; group, family, and systems treatment; home care; walk-in clinics; and emergency room services. In addition, the philosophic basis of community psychiatry began to be articulated—that it was better to treat persons in the community than in hospitals, that community care was cheaper, and that communities would respond to the challenge to provide the necessary services.

With the introduction of phenothiazines in the mid-1950s, American psychiatrists finally had the technological tool that enabled them to begin to move severely and chronically mentally ill persons from institutional to community settings, and to control psychotic symptoms in newly discovered cases, thus obviating long-term hospitalization and resultant institutionalization.

Two other developments hastened this shift from the institution to the community. First, the federal government's assumption of funding for the poor and aged under Medicaid and Medicare, as well as funding for daily

needs of the disabled indigent under Supplementary Security Income (SSI); and second, the pressure from judicial, legislative, and regulatory bodies to treat patients in the "least restrictive setting," to make involuntary admissions to mental hospitals increasingly difficult, to broaden the concept of informed consent, and to ensure the patient's right to refuse treatment. These economic and legal pressures, combined with the previously mentioned technological and philosophic developments, led to the beginning of the movement now known as deinstitutionalization.

Deinstitutionalization is commonly defined as having two parts: first, shifting the locus of care from institutions to community settings; and second, blocking the admission of new patients into institutions. The result of this movement was awesome. In 1955, with the patient population at an all-time high in the nation, state hospitals housed 560,000 patients. By 1978, this figure had dropped to less than 150,000.

Where did all these people go? Many went to live in shabby welfare hotels, flophouses, and single-room occupancy dwellings, wandering the nearby streets during the day. Many died, both in the hospital and in transition from hospital to community, and, in the earliest days of deinstitutionalization, many returned home.

While it is generally recognized that state hospitals have reduced their

populations by over two-thirds and that numerous chronically mentally ill persons now walk aimlessly in America's cities, it is disconcerting to learn that the percentage of Americans housed in institutions has not changed at all since 195°. While state hospitals have shrunk by two-thirds and tuberculosis sanitaria have disappeared, nursing home populations have tripled. Thus the movement is more accurately described as trans-institutionalization than as deinstitutionalization.

Definitions

Up to this point, I have used the term "chronic mentally ill" without defining it. The conceptualization of this segment of the population did not occur until after the deinstitutionalization movement had begun. Before that, we referred either to the mentally ill as a single entity or to specific diagnostic groups (schizophrenics, neurotics, and the like), whether acutely or chronically ill. The deinstitutionalization movement, however, demonstrated that we needed to be concerned with a subset of the mentally ill—individuals with many diagnoses and levels of disability. The features that bound them together were their inability to survive unassisted in the community, their tendency toward episodic or chronic mental illness, and the fact that in earlier times they would probably have been housed in state mental hospitals. It was this feature that prompted Bachrach to define the population as "those individuals who are, have been, or might have been, but for the

deinstitutionalization movement, on the rolls of long-term mental institutions, especially state hospitals." Such persons may or may not currently be in mental hospitals. They are of all ages, including children, and their illnesses have received a variety of diagnoses, but primarily they suffer from the major psychoses (for example, chronic schizophrenia), chronic recurrent affective disorders, and severe character disorders. Such patients must be distinguished from those persons who may be in long-term psychotherapy, but who do not have chronic disability.

Chronic is a modifier that is usually defined as occurring for "a long time" or over "a long duration." Most states define chronicity of illness as one or two years of hospitalization. The chronic disabled, however, can be easily defined as those meeting federal eligibility standards for Supplemental Security Income (SSI).

The terms "chronic mental illness," "chronic mentally ill," and "chronic mental patient" are stigmatizing and simplistic and are, unfortunately, interpreted by some as synonymous with hopelessness, deterioration, and regression. While "long-term patient" and "those in need of long-term continuing care and rehabilitation" have been suggested as preferred alternatives, the terms "chronic mentally ill" and "chronic mental patient" will be used here because they are descriptive, universally understood, and generally employed by those in the field.

Characteristics of the Patient Population

Bachrach has demonstrated that there are five subgroups among the chronic mentally ill. In the community, there are those who have been hospitalized in state hospitals and there are those who have never been institutionalized. In the hospital, there are those who are long-stay patients (almost half of state hospital residents have been there for more than five years); those who are recent admissions and who will soon be released to the community; and the new long-stay patients (some 10 to 15 percent of new admissions) who will continue to need some kind of "highly structured care." How many persons are encompassed in these five groups?

An epidemiological reconstruction must be attempted to ascertain how many patients would be in state hospitals were it not for the deinstitutionalization movement. Minkoff estimates that there are a total of 1,100,000 schizophrenics in the United States, of whom, 900,000 are in the community and 200,000 are in institutions (primarily nursing homes, state hospitals, and prisons). He also suggests that there are between 600,000 and 800,000 depressives, almost all of whom are in the community. Further, almost 1,000,000 elderly persons are in institutions (nursing homes and state hospitals) and between 600,000 and 1,250,000 of the elderly living in the community are psychotic. Finally, assessing the numbers of mentally disabled individuals, Minkoff states that there are 1,762,000 institutionalized severely

disabled (those who have been in an institution more than thirty days) and 225,000 severely disabled individuals living in the community (who receive SSI for mental illness). Thus, while the groups designated are not always separate (for example, there are elderly schizophrenics who are severely mentally disabled), at a minimum there are about 1 to 2 million, at a maximum 5 to 7 million chronically mentally ill in the United States.

The problems and needs of this population are complex. As articulated by the Conference on the Chronic Mental Patient, their problems include: "extreme dependency needs, high vulnerability to stress, and difficulty coping with the demands of everyday living, resulting in difficulty securing adequate income and housing and holding down a job." The needs of the chronic mentally ill include medical and psychiatric treatment, social and vocational rehabilitation, and the components of everyday survival (housing, food, clothes, heat, and the like). As was stated earlier, in previous eras all these needs were filled, however poorly, by the state hospital; now they must be met by various sources in the community, through a method described by some as a "scrounging system."

Where the chronic mentally ill are housed is now moderately well known. In the early days of deinstitutionalization, 70 to 80 percent returned to their own or relatives' homes, and only 20 to 25 percent left institutions to live alone or in boarding homes. Now, however, the percentages are reversed,

and only 20 to 23 percent return home; the rest go to suboptimal locations (38 percent to hotels, 11 percent to nursing homes, 28 percent to undetermined locations). In one study in California, almost 50 percent of patients discharged five years earlier were now residing in board and care homes.

There are considerable differences among the states in the degree of deinstitutionalization. While all states have experienced a reduction in their state hospital censuses, the speed with which the process took place has varied. In retrospect, Minkoff concluded that states that did better jobs of caring for the chronic mentally ill, had a "moderate population density, and availability of resources and living accommodations for the discharged patients."

How well the chronic mentally ill function in the community is dependent on several variables: readmission due to relapse, symptomatology, vocational history, socialization, and aftercare involvement. The single best predictor of readmission is the number of previous hospital admissions. Prior to deinstitutionalization, fewer than 25 percent of admissions were readmissions, whereas today the rate exceeds 60 percent in many states. Both continuation on medication and the number of aftercare visits can help to decrease readmission rates. However, a major problem results from the lack of provision of both these services to the chronic mentally ill. Studies have

shown that 38 percent of discharged patients receive no aftercare referral and only 35 percent of schizophrenics applying for treatment receive it. In addition, compliance is a barrier to continuity of treatment—in one study, only 10 percent of patients from a state hospital that closed contacted the outpatient facility. Minkoff has concluded that fewer than 25 percent of discharged patients continue in regular aftercare programs and fewer than 50 percent continue to take their medications.

It is not surprising, therefore, to discover that two-thirds of the chronic mentally ill living in the community have mild to moderate symptomatology, while only one-third are asymptomatic. The socialization of the chronically ill is similar—only 25 percent are fairly socially active—approximately three-fourths live isolated lives.

Finally, the work history of discharged patients reveals the true ravages of serious and chronic mental illness. Only 30 to 50 percent of discharged patients are employed within the first six months following discharge, and this percentage drops to 20 to 30 percent at the end of a year. While previous employment (as with hospitalization and all other functional predictors) is the best predictor of future employability, the fact that half of those working before admission do not return to work and that 70 percent of those who do work, return to less-skilled jobs, indicates the effects of these illnesses in marketplace terms.

Economic Issues Regarding the Chronically III

The economic factors relevant to the care and treatment of the chronic mentally ill have an enormous impact on individual patient care as well as on deinstitutionalization policies. Sharfstein, Turner, and Clark have analyzed two of the most important economic issues: the costs of chronic mental illness and the cost-benefit analyses of treatment and care in institutional versus community settings.

In fiscal year 1977, health care in this country accounted for 9 percent of the gross national product (GNP). Of that, 15 percent was allocated to mental health care. Forty percent of the nation's health care is now paid for with federal dollars, through Medicaid and Medicare, and over a billion dollars is spent by the federal government on public assistance to the chronic mentally ill through SSI.

The direct costs of mental illness, those incurred by provision of psychiatric services, were 14.5 billion dollars in 1974—over 1 percent of the gross national product. Over one-half of these monies went toward institutional services—30 percent to nursing homes and 23 percent to state and county mental hospitals. Those sectors of the mental health system providing the care and treatment for the vast majority of the severely and chronically mentally ill consume much smaller portions of our expenditures: general hospitals, 12 percent; private psychiatrists, 9 percent; drugs, 5

percent; freestanding Out Patient Clinics (OPDs), 5 percent; community mental health centers, 4 percent; general medical services and halfway houses, 3 percent; private mental hospitals, 3 percent; and private psychologists, 1 percent. It is abundantly clear from this, that money is not going where the patients are. Current funding patterns direct monies toward institutional facilities rather than toward community resources, and the problem of underfunding may be more correctly described as maldistribution rather than inadequacy of funds.

The indirect costs of mental illness in 1974 were estimated to be even greater than the direct costs—almost 20 billion dollars. These costs are allocated for loss of labor and loss of production due to mental illness. In all, the mental health bill in 1974 is estimated to have approached 37 billion dollars—of which 87 percent can be earmarked as having been spent on the care and treatment of the chronic mentally ill. Thus the myth that America spends its mental health dollars on the "walking well" and on long-term intensive psychotherapy seems to be refuted. Again, with 32 billion dollars going toward the care and treatment of the chronically ill, the issue does not seem to be that insufficient funds are being expended on this population, but that they are not being allocated to the right institutions, services, and programs.

Several recently published studies have explored the issue of whether it

is cheaper to treat patients in community or in institutional settings. Because state hospitals provide a variety of services (housing, food, heat, medical and psychiatric treatment, and so forth) under one roof, it has been easier to calculate the cost of institutional services. When these services are provided in the community, they are both more difficult for patients to acquire and more difficult to cost out. Despite the lack of accurate cost comparisons, state policy makers and community mental health advocates promoted the concept of deinstitutionalization in part because it would save money. Is this claim true?

Sharfstein and Nafziger figured the costs of treatment for one patient over a fifteen-year period, comparing institutional to community care. They found that the costs were roughly the same for the first three years, but that after that, community care cost 10 percent less than hospital treatment.

Murphy and Datel studied fifty-two patients and found that for their twelve stratified groups, all but one cost more in the hospital than in the community. On an average, the yearly saving to the U.S. economy for community care was 25 percent over that of institutional care. However, it should be noted that all persons whose costs were calculated were judged to be "successfully" deinstitutionalized, that one-third were mentally retarded, that recidivists were dropped from the study, and that the data were extrapolated from figures used after persons had been deinstitutionalized an

average of only 8.5 months. For the state government, however, the saving in deinstitutionalizing these more intact patients was between 65 and 80 percent, since care in the community becomes a higher federal expense.

In another cost-benefit analysis, Weisbrod, Test, and Stein examined the cost of their program in community care versus hospitalization and traditional aftercare. They found that the cost of both exceeded \$7,200 per patient a year, although less than half of this expense could be attributed to direct treatment services. While the community program had both additional costs and additional benefits for the patients, it was shown that community care resulted in a 5 percent savings for the total package of care and treatment. It should be noted that the increased costs of community care derived from the added treatment services provided and the added benefits were paid for by the outpatients, whose income was double that of the hospital patients.

In sum, these controlled studies demonstrate a 5 to 10 percent costeffectiveness advantage for community care; a 25 percent cost reduction for selected populations of healthier patients and mentally retarded persons; and a 65 to 80 percent saving for the state resulting from the discharge of more intact persons previously housed in institutions. The latter finding, however, points to one of the problems our funding system has encouraged. By allowing state governments to effect substantial savings by deinstitutionalizing patients, the federal government covertly encourages deinstitutionalization, and in the absence of adequate community services and funding of programs, poorer care and treatment frequently result.

In addition, while it may be cheaper for the United States to have an exclusively community-based care system, the institutional system is still in place at the present time, and adequate funding of both systems has become less feasible during periods of economic recession.

The Problems of the Chronic Mentally III

The principal concern regarding the chronic mentally ill is their continued poor care and treatment. Most professionals would agree, that in the twenty years since deinstitutionalization began, whether in community or institutional settings, the quality of the patient's care has not improved. The media have described vividly the consequences of moving hundreds of thousands of discharged mental patients into communities where they are ill-equipped to survive. The media also continue to publicize the poor conditions found in most of our public mental hospitals. For the public, the problems of the chronically ill appear in the form of shabbily dressed, bizarre, or demented-looking ex-patients wandering the cities' streets or crowded into mental patient ghettos; for professionals the problems continue to center on the inadequacy of care and treatment for this population. There are many

reasons for this publicly visible problem and for this professional concern. To assess the opinions of psychiatrists about the problems posed by and facing the chronic mentally ill, Talbott conducted a survey in 1975 and found the following:

The most commonly mentioned problems were:

- The failure of deinstitutionalization to provide patients in either hospital or community settings with good treatment and care
- The inadequacy, maldistribution and discrimination in funding for this population
- The absence of a continuum of community care and housing facilities
- The lack of a model service system
- The inadequate number of housing and job opportunities, as well as rehabilitation services
- The negative attitudes about the chronic mentally ill held by legislators, the public, and mental health professionals
- The lack of definition of the role of psychiatrists and others in caring for this group
- The lack of adequately trained professionals to treat the chronic

mentally ill

- The lack of involvement of families in the treatment of the population
- The lack of adequate descriptions of effective programs for the chronically ill
- The lack of continuity of care
- The paucity of community care facilities
- The problems of long-term use of psychopharmacological agents
- The lack of knowledge as to which patients should be treated at what level of care and in what facilities
- The lack of responsibility for coordination of the delivery of care
- The absence of a single, responsible person to make sure care is provided to those in need

From this list, it is apparent that several different but related areas contribute to the basic problem of inadequate care and treatment of the chronically mentally ill. These can be grouped into problems in treatment, community care, governmental responsibility, and societal and professional attitudes.

Treatment

It is clear that despite the introduction of phenothiazines in the 1950s, the treatment of the chronic mentally ill in either institutional or community settings has not met with success. The quality of state mental hospitals seems to have fallen, and their original goal of providing humane custodial care in asylum settings seems unachievable today. The resistance of patients, families, and third-party re-imbursers to insure continuing long-term care is also a significant problem, as is the lack of respite facilities and emergency care for the chronically ill.

Too few professionals have received appropriate training in the care and treatment of this population and there is too little interchange between academic settings, wherein much expertise lies, and public sectors, in which most chronic patients receive their care. The roles of all mental health professionals, especially those of psychiatrists and non-psychiatric physicians, need clarification. In addition, research should be accelerated into what works, for whom, and in what setting; what prevents, maintains, or encourages chronicity; and what constitutes effective service delivery.

Community Care

Supportive services that enable patients to survive in the community are woefully lacking. There is a need for adequate housing, employment, transportation, socialization, vocational rehabilitation, and social services, as

well as for an appropriate range of each type of service. The current options of a state hospital, nursing home, or aftercare clinic for the care and treatment of the chronically ill are clearly inadequate. In addition, the lack of continuity of care, aggressive outreach, and vigilant monitoring present formidable barriers to effective care and treatment.

Government Responsibility

Dozens of federal, state, and local governmental agencies have programs and funding for the chronic mentally ill. At the federal level, many of these (Medicaid, Medicare, SSI), are based in the Department of Health, Education and Welfare (HEW), but others are in the departments of Housing and Urban Development (HUD), Labor, Transportation, and so forth. Each program has its own standards, target populations, eligibility for funding, and regulations. As a result, patients do not have ready access to these funds to provide for their needs. In addition, there is a continuing discrimination against long-term care, less restrictive alternatives to hospitalization, and chronic illness. Indeed, there is not only no effective service system for delivering care and treatment to the chronic mentally ill, there seems to be no mental health system at all.

Attitudes

There are significant negative attitudes about the chronic mentally ill on

the part of patients, families, legislators, and mental health professionals. In addition to the stigma suffered by all mentally ill persons, the chronically ill, with few articulate family members to advocate for them, fewer ego assets, and little empathy-evoking abilities, have less political clout, less lobbying ability, and less social presence than any group of have-nots now in need of services.

Treatment of the Chronic Mentally III

Treatment of chronic mentally ill patients is complex and involves many modes of intervention. One must not only take into consideration the medical and psychiatric elements of treatment, but the social and rehabilitative components (housing, socialization, vocational rehabilitation, and so forth) as well. Since, as May, and Hogarty and associates have amply demonstrated, the additive effects of medication and talking therapy are considerable, one must not rely on only one modality of treatment (drugs or psychotherapy). In this section, the individual elements in the care and treatment of the chronic mentally ill will be reviewed, with the caution that the reader must assume that no one mode stands alone in the provision of effective treatment.

Medication

Experts have considered psychopharmacological agents as the single

most important ingredient in the care and treatment of the chronic mentally ill. The only consistent finding among the studies of relapse among the chronically ill is that medication is the best preventer of relapse, in both schizophrenia and the affective disorders. The fact that only 50 percent of patients discharged from mental hospitals continue to take their medication, makes patient cooperation and compliance a critical issue for this population. Much of the discontinuity in treatment occurs at interfaces in the system, and there is a high rate of patient dropout and lack of follow through after hospital discharge. A recent study demonstrated that only 22 percent of discharged patients follow through with aftercare if simply told to call the mental health center when problems arise, but that the percentage goes up to 68 percent if a specific appointment is made, and to 75 percent if both an appointment and pre-discharge contact is made. Recidivism rates are decreased 50 percent by such simple measures.

Hansell has spelled out a comprehensive yet common-sense approach to consideration of pharmacotherapy with the chronic mentally ill. He lists five steps: efficacy, necessity, surveillance, cooperation, and emergency. With patients suffering from either schizophrenia or the major affective disorders, he cautions the physician to review whether the drug is indeed efficacious and necessary—suggesting a methodology for reducing the medication to a minimum; providing drug holidays; and instructing the patient in how to recognize effectiveness, side-effects, and early warning signs of recurrence.

He cautions the physician to be vigilant, but with the patient's full understanding and cooperation. Finally, he suggests that the ability to respond to emergencies and exacerbations is facilitated by the therapeutic relationship, counseling, and crisis management.

Johansen, a psychiatric pharmacist, has further stressed the requirement of drug monitoring and its importance with the chronically ill. She advocates a sophisticated, comprehensive program, involving the collaboration of both the patient and his physician, which includes drug education, historical review of drug use and response, and drug monitoring (especially regarding side effects which may prompt the patient to discontinue the medication). The knowledge that patients who neither possess insight about nor perceive benefits from their medication will not continue that medication, demands that the physician ensure that patients do see the value of their medication.

Several authors have raised the point that while antipsychotic drugs are of inestimable value in the treatment of acute schizophrenia, their usefulness in the treatment of the chronic state is less certain. Hansell insists, therefore, that the physician be sure that he is dealing with chronicity and not continue medication when it is not needed. Segal and Aviram go further. In their recent study, they demonstrate the anti-therapeutic effects of medication when prescribed to less disturbed patients who were attempting to reenter society,

resocialize, and so forth. The same caution about ensuring the existence of a chronic or episodic process applies to the affective disorders. In view of the increasing evidence of the detrimental effects of lithium on the kidney, consideration should always be given to prescribing tricyclics rather than lithium to those patients requiring continuing medication.

Finally, several treatment issues require reemphasis. First, there are few indications for the prescription of multiple medications (polypharmacy) for the chronic mentally ill. Second, seeking consent of the patient is sensible when prescribing long-term medications that have possible detrimental effects (such as tardive dyskinesia or renal damage). And third, non-responders may not be absorbing adequate medication and determination of blood levels should be attempted.

Psychotherapy

Most recent discussion of the use of psychotherapy for the chronic mentally ill focuses not so much on psychoanalytically-oriented, individual psychotherapy, as that of a broader amalgam of supportive and directive therapy. In fact, much effective psychotherapy with this population involves groups, activities, and what many psychiatrists may regard as social or vocational rehabilitation.

May reviewed the studies on the effectiveness of psychotherapy with

the chronically ill and noted that seven studies demonstrated its effectiveness. He concluded that outpatient group therapy was probably more effective than individual psychotherapy, that medication alone was insufficient to prevent relapses, and that while psychotherapy added little to drug treatment of inpatients, it was helpful with outpatients.

Lamb suggests that there are several critical elements in the psychotherapy of the chronically ill that merit special attention. He lists these as: increasing the patient's sense of mastery; focusing on the healthy part of the patient's life and personality; problem-solving in the here-and-now; insight into the patient's symptoms rather than psychodynamics; taking sides with the patient against his harsh superego; and "putting the family in perspective."

Talbott recently reviewed many aspects of the psychotherapy of the chronic mentally ill and enumerated several critical areas: therapeutic issues, therapeutic techniques, therapist attitudes and behavior, and content of therapy. Among the therapeutic issues that must be addressed by both patient and physician, he listed: establishing a correct working diagnosis; collaborating in setting the treatment plan; setting of clear goals; establishing a working relationship, involving the patient's family and social system; understanding the patient's communications, behavior, and thinking; titering the patient's affect so that it is not overwhelming; attending to nonverbal

cues; utilizing psychodynamics without necessarily interpreting them; focusing on the here-and-now; and avoiding regression.

The therapeutic techniques employed are

- those used with sicker patients and at the commencement of treatment (support, advice-giving, and establishment of the "real" relationship);
- 2. those employed much of the time (labeling, reality testing, and problem solving);
- 3. those used in times of relative health (exploration) and regression (suppression); and
- 4. those used relatively infrequently, or when the patient becomes more "neurotic" (clarification, interpretation, and abreaction)

The attitudes and behaviors of the therapist are highly important to the success of the therapeutic relationship with the chronically ill. While no one psychiatrist can embody all the features he considers important, his knowledge of what is critical may help guide his behavior. The attitudes and behavior considered important include a positive attitude about the patient and chronic mental illness, honesty without being pseudo-honest or cruel, flexibility and resilience, a caring attitude without patronization, tolerance of uncertainty and dependency, an active role in therapy, a gift for intuitive

thinking, and patience, persistence, dependability, and consistency.

Finally, Talbott enumerated several issues in the content of treatment which he felt must be addressed during the treatment of each chronic mentally ill patient. These were: identifying the precipitating stress; delineating the defenses and coping patterns; exploring the patient's fear of intimacy, his harsh conscience, and flooding by impulses; defining his ability to function in the real world; and understanding and alleviating the patient's emotional dyscontrol. He also concluded that the attitude toward termination must be open-ended, with the understanding that the patient may return at times of regression, crisis, or destabilization.

Housing

Residential care programs constitute an essential ingredient in the total program of care and treatment of the chronic mentally ill. Optimally, there should be an adequate range of graded facilities offering an individual patient the opportunity to progress step by step from total dependence (hospitalization) to total independence (independent living), while also allowing him the option of staying for indefinite periods at any one stage when his maximum level of functioning has been achieved. Budson has written a comprehensive guide to community residential care programs, and the range of options he describes will be summarized here starting from the

most structured and dividing the facilities into those with staffing, those offering independent living, and finally those operated under proprietary ownership.

Those facilities that have staffing include nursing homes, quarter-way settings, halfway houses, Fairweather Lodges, and long-term group residences. Nursing homes are the most highly structured, highly staffed, and restrictive settings. Because they were designed for medically ill patients, those with physical or multiple handicaps, and the elderly, nursing homes may prevent growth, be antitherapeutic, and not allow younger, chronic mentally ill persons to progress to higher levels of functioning. Quarter-way settings tend to be wards, with fewer staff than normal, established in mental hospitals to encourage skills in everyday living (such as cooking, shopping, laundering clothes, banking) and promote return to more independent settings. Halfway houses are one step further removed from the hospital. They are located in the community, have on-site staff and programs, and serve a younger, more vocationally able patient who has retained his ties with the community. Despite the hope that hundreds of such houses would be instituted across the country, as of 1973, there were only 200 in the United States with a capacity of 9,000 persons. Their success rate in preventing recidivism, however, is admirable. Rog and Raush showed that only 20 percent of patients seen in halfway houses are readmitted, while 58 percent are living independently, and 55 percent are employed or in school.

Fairweather Lodges¹ represent a more comprehensive attempt to move persons from hospital to community settings. Their basic premise is that groups of patients, taught the skills of everyday living and survival in an interdependent fashion, can move from hospital to lodge to group living. Integral to the program is the utilization of sheltered work.

A forty-month follow-up of persons using the lodge program demonstrated that they spent only 20 percent of their time in hospital while controls spent 80 percent. The last type of staffed facility is the long-term group residence. Staffed more richly than halfway houses, these units are best suited for persons who may stay longer than a year, as opposed to those who use halfway facilities as transitional living arrangements.

Those facilities that do not have onsite staff range from semi-independent to totally independent ones. Cooperative apartments represent the first step in this series. Compared to halfway house residents, patients in these settings tend to be older, more chronic, and have fewer vocational skills and community ties. Cooperative apartments are either leased by the mental health agency or a related nonprofit corporation, and/or their leases shared with the patients, who live in groups of two to five. They pay their own rent, share in household chores, and have professional supervision with crisis intervention readily available. Work camps in rural environments serve patients who cannot yet survive in independent rural housing, but do not

need the structure offered by an institution. They function as a working farm, with daily chores and work activities, and supervision and care is available as needed. Foster care represents another concept altogether. Based on a centuries-old program in Gheel, Belgium, such placements are run by a non-clinical caretaker, who provides housing for one to four persons, often elderly or mentally retarded. Other necessary services are provided in the nearby community. A problem with foster care, despite its attractiveness, is that the caretaker may offer nothing more stimulating than custodial care, and no growth for the patient is possible if he does not successfully pursue outside programs.

Totally independent living, in individual apartments or homes, is provided by some programs. While such satellite housing or apartments may be found or initially leased by the program, the ex-patient assumes responsibility for the lease and upkeep of the housing, as well as the attendance at social programs and psychiatric/medical services. One other innovative service should be described, despite the fact that to date there has been only one of its kind and apparently it no longer functions. It is the crisis hostel—a community residence located near a psychiatric facility, where patients go for respite housing as an alternative to inpatient admission. The hostel is supervised by a nonclinical houseparent, and patients receive medication from a nurse and participate in programs at the hospital.

The last large category of housing options is that of the private (proprietary) facilities. Whether designed as hotels (welfare or single-room occupancy) or homes for adults (PPHAs), they usually provide neither relief from social isolation, despite their size, nor appropriate rehabilitation or treatment. Board and care homes, California's proliferating alternative to hospitalization, carry the same hazard of fostering regression and inhibiting growth.

There are several programs that offer a range of treatment options under one umbrella. Transitional Services, Inc. (TSI) has a four-step program: assessment centers which are medium-sized group homes with maximum supervision; learning centers which have six to twelve units with moderate supervision; semi-independent apartments with minimal supervision; and independent apartments where services are not provided unless asked for. TSI is not a mental health service, but views itself as a housing/living agency that tries to build continuation of aftercare into ex-patients' lives.

Test and Stein have provided a conceptualization of the decision-making process in selection of the correct housing alternative for each patient. They suggest that the appropriate environment should ensure that the patient's needs are met, but not meet needs that the individual can manage by himself.

Despite the growth of housing options in the past few decades, there is

still a dearth of adequate alternatives. This is due to several factors. First, community resistance to establishment of such services continues to be considerable. This forces patients and staffs to seek housing in rundown or undesirable areas, creating ex-patient ghettos. Second, funding to develop these alternatives continues to be extremely limited. Under the 1978 HUD initiative, 18 million dollars were allocated for housing for the chronic mentally ill. Part of this fund was to subsidize loans for group homes, apartments, and halfway houses and part to provide rental subsidies to allow for repayment of the loans. But 18 million dollars represents only a start. Third, regulations for obtaining funding and establishing housing alternatives remain exceedingly cumbersome. At one time, in New York State, there were more than forty-seven steps in the process, and the need to gain approval from more and more community bodies extends the length of the process. And lastly, as deinstitutionalization proceeds, there is no provision for those who will continue to need an asylum setting that provides adequate custodial care. The development of community asylum settings or domiciliary care institutions is imperative.

Social Rehabilitation

While social and vocational rehabilitation are usually conceptualized, referred to, and indeed delivered together, they really constitute two separate modes of intervention for psychiatric patients and will be presented

separately. In addition, while some consider treatment and rehabilitation to be separate and some consider them synonymous, others, including the author, think that rehabilitation is one portion of the total treatment. In any case, the boundaries are not sharp. However, rehabilitation does stress disability rather than disease, focuses on assets not deficits, and aims at restoration of functioning rather than relief of symptoms.

Skills in everyday living are critical to survival in the community for the chronic mentally ill. One glaring fault of deinstitutionalization, especially in its earliest days, was its failure to anticipate the degree of social ineptness of discharged patients. While the armed forces have elaborate programs to reorient servicemen, who retire after twenty to thirty years from a peculiar form of dependent living, state hospitals apparently expected patients hospitalized for decades and without such preparation to somehow negotiate complex and ill-marked transit systems, maintain budgets and handle money wisely, and select and prepare nutritious food. In retrospect, this failure to teach skills necessary to survive in our complex, urbanized, twentieth-century American environment was a catastrophic omission.

The skills of everyday living—banking, money management, and budget-planning; shopping, cooking, and serving food; learning and using transportation systems; grooming, buying clothes, and dressing appropriately; attending to personal hygiene; and using leisure time wisely—

are critical to every patient's life. Any program of merit for the chronically ill now stresses the teaching of these skills. An exemplary program in Philadelphia, the Enablers Program, uses indigenous members from the patient's community to teach these survival skills others take for granted. This approach increases a patient's chance of returning to full functioning in his particular community.

In addition, it is critical to provide persons with chronic mental illness the opportunity to gain or regain the ability to get along with others, to participate in social activities, and to communicate effectively and directly their thoughts and needs to others. Structured programs, such as activity groups, therapeutic groups, therapeutic milieus, individual counseling, and training, all contribute to acquisition of these abilities.

In the 1930s, Joshua Bierer recognized the need for ex-patients to participate in many different social activities, structured and unstructured, and to benefit from professional guidance and planning. In his Marlborough Experiment, he pioneered in the establishment of patient-run social clubs; day, night, and weekend hospitals; rehabilitative aftercare; community hostels; and patient self-help groups (Neurotics Nomine).

More recently in this country, we have seen the gradual emergence of numerous psychosocial rehabilitation centers, which combine housing, socialization, and vocational rehabilitation. Programs such as Fountain House, Horizon House, Thresholds, and so forth, concentrate on putting together in one setting all the ingredients necessary for successful rehabilitation to full community life.

Given the early onset of some mental illness (for example, schizophrenia), habilitation—the learning of new skills to enable persons to reach levels of functioning they have never achieved before—may be more pertinent than rehabilitation. Another aspect, mentioned by Lamb, is the thin line that separates patients' high but realistic expectations from unrealistic goals. Patients who attempt to attain unrealistic levels of functioning become frustrated and often regress, while patients with low-level goals may stagnate.

Vocational Rehabilitation

The primary goal of vocational rehabilitation is to evaluate the past and current work capacity of the patient and return him to his highest possible level of functioning. Again, in many cases habilitation, not rehabilitation, is meant, and the level of functioning that is aimed for may actually be higher than that previously achieved by the patient. It is important that the physician not assume that because of the severity of either the patient's diagnosis or illness, his work capacity is similarly deficient. Many chronic schizophrenics work successfully throughout their lifetimes in special settings (such as the

post office), while other neurotic patients (for example, with severe compulsions) cannot work at all.

Vocational rehabilitation consists of several discrete sub-entities: prevocational assessment, counseling, and remuneration in a variety of settings; sheltered workshops; transitional placements; placement services; and long-term or terminal vocational settings. Prevocational assessment and counseling consists of a functional assessment of the patient's particular work skills and his ability to work in various settings, under various conditions. Also included is an evaluation of his attitudes, behaviors, and expectations about work. These assessments are usually conducted in health settings (hospitals, community agencies, or psychosocial rehabilitation centers) by use of formal interest and aptitude testing and work samples, but some agencies (for example, Council House in Pittsburgh, Pennsylvania) conduct assessments at the job site.

Sheltered workshops are work settings where real work is performed by patients, side by side with staff, with professionally trained supervisors or foremen as well as clinically trained counselors. Because most employers feel that they can train motivated employees to do a particular type of work, prevocational programs and sheltered workshops often teach patients about work (interest, neatness, responsibility); behavior related to work (promptness, care, courteousness); and expectations about work (as

demeaning or grandiose, offering rapid advancement without a track record, and the like) rather than the particular skills (typing, lens-grinding, and so forth). Rather than impart specialized skills, they attempt to alter maladaptive behavior so the patient can succeed in the marketplace.

Transitional placement consists of placements in industry where a certain number of patients can try out genuine employment. Patients in transitional placements are able to begin regular work, have a sense of reality of the work world, and assume permanent employment when they feel comfortable in doing so. Many programs, private and governmental, offer placement services to facilitate the patient's search for regular employment. One other service that is a necessary element in the range of vocational services needed by the chronic mentally ill is that of long-term or terminal vocational settings or sheltered workshops. Partly because of government's reluctance to continue a long-term maintenance situation without the guarantee of "cure" or "rehabilitation," and partly because of society and psychiatry's reluctance to admit that certain patients will never return to full community life—we have too few of these placements and too little funding for existing programs.

There are several programs connected with vocational rehabilitation that are worth noting. First, given a national unemployment rate in recent years of 5 to 12 percent and regional variations of these figures (over 25

percent for young blacks), the availability of jobs for marginal persons is often insufficient. Second, some patients are unwilling to work, and their resistance and reluctance may frustrate the well-meaning professional. Third, SSI has an inherent disincentive built into the resumption of paid employment— one which must be addressed from a policy standpoint if we intend to return many of our chronic mentally ill to the work force. Finally, there is a great need for part-time employment opportunities for those chronic mentally ill who cannot return to full-time employment.

Case Management

Two problems have become glaringly apparent as the process of deinstitutionalization has progressed. First, ensuring that discharged patients have access to and obtain all the services they did in an institution (food, shelter, socialization, medical and psychiatric treatment) is a difficult task. Second, finding a single point of responsibility for the total care and treatment of the chronic mentally ill has proved difficult. Case management seeks to remedy these problems by making sure that one person, team, or agency is responsible for the patient to ensure that he receives all the services he needs and that at least one person is in contact with all elements in the complex system of care and treatment.

The tasks of case management have been defined as including

assessment of needs, planning for service provision, linking the patient up with needed services, monitoring the provision of services, advocating for services, reviewing and updating the treatment plan, developing additional resources, providing direct services (from psychotherapy to escort services), integrating services, and expediting them.

Who should perform these various tasks has been a matter of dispute. Ideally, an intact family can often be the best case management resource, but many blood relatives of the severely and chronically mentally ill are themselves impaired. Traditionally, social workers have performed many of these tasks, but in the past few decades, the profession of social work has turned away from case work and direct service provision toward the practice of psychotherapy. In truth, most physicians perform the role without knowing it, and may indeed be the most capable of doing so, as long as they recognize the need for a broader array of services, comprehend the necessity of a community support approach, and have the time and interest. The paucity of intact available family members, the decreasing numbers of interested social workers, and the insufficient number of psychiatrists in the country, have, however, led some planners to call for a new profession or paraprofession of case managers to assume this role. Whether this new paraprofession is the answer is problematic, given the history of other paraprofessional efforts in the mental health field.

Certainly, there remain several critical unanswered questions about case management. Is it best performed by the person who has the most information about the patient, such as the psychotherapist? Is it best performed by a team rather than an individual? Is it best performed by a professional or paraprofessional? These and other questions will have to be answered in the next few years if these case management services are to be provided more expeditiously.

Effective Program and Service Systems

In the 200 years of organized mental health care of the chronic mentally ill, neither hospital nor community programs have demonstrated impressive effectiveness in treating the severely and chronically mentally ill.

However, recently there have been a number of program and service systems that combine the treatment and care described in the preceding sections. While still isolated and experimental, such systems have been described in detail and scientifically based evaluation studies have been conducted, allowing others to attempt their replication.

Programs for the chronic mentally ill are basically of two types: institutional programs attempting to return patients successfully to community life; and community programs that try to keep chronic mentally ill persons functioning at an effective level in their communities. The best

description of the former is by Paul and Lentz. They described their four-and-a-half-year program, which teaches state hospital patients skills necessary to everyday living through a resocialization-relearning program oriented along behavioral modification lines. On outcome, their study group had a readmission rate of less than 10 percent over the year-and-a-half period following discharge, while the control group treated with milieu therapy had a readmission rate of 30 percent, and those treated with "traditional" state hospital treatment, 50 percent.

The program that best exemplifies the community approach to treatment of the chronic mentally ill is that described by Stein and Test. Their Training in Community Living Program (TCL) takes randomly selected patients who otherwise would have been admitted to a state hospital. Employing retrained staff from a state hospital ward and concentrating on skills in everyday living, providing linkage with essential services, and ensuring medical and psychiatric treatment, their program also sharply decreased the amount of time spent in hospital compared to their hospital-treated controls. In addition, they discovered that the group they treated had less symptomatology than their controls, the burden to the patients' families and communities was no greater than that of the controls, their self-esteem levels were the same, and the quality of life of both groups was the same.

Two recent publications provide further descriptions of apparently

successful programs for the chronic mentally ill. While often touted as "model" programs, these descriptions do not so much offer models as examples of programs that seem to work in certain areas (for example, rural, urban, nonindustrial), with certain populations (first-break schizophrenics, multiply admitted chronic patients, children, the aged), from certain institutional bases (nursing homes; state, general, and private hospitals; CMHCs; and freestanding community agencies). As Bachrach has noted, rather than replicable models, they offer examples to others who must then adapt their own programs to local exigencies and conditions.

There are certain characteristics that seem to typify the newer and more successful programs for the chronic mentally ill. Barter notes that such programs have leaders who understand chronic illness and know what they are doing; have effective outreach, advocacy and monitoring systems; provide highly individualized treatment; show appreciation of small progress in their patient populations; have sound vertical and horizontal administration; and have effective accountability and responsibility systems. Bachrach also notes that they assign top priority to the most severely impaired, link their programs with other resources, provide patients with a range of needed services, individually tailor treatment, adapt programs to meet local needs, utilize specially trained staff, have accessible liaisons with hospital units, and provide good internal evaluation of their operations. Talbott concludes that there are several more important characteristics of successful programs: their

ability to conceptualize and win necessary community support; their concentration on the factors known to help survival in the community, such as medication and skills in everyday living; and their effective use of a case management approach.

It should be emphasized, however, that despite impressive progress in beginning to understand what works and what doesn't for the chronic mentally ill, there is a long way to go. The programs described require continued appraisal, replication, and comparison. The process of teasing out exactly what it is in each program that works needs to be continued.

When it comes to looking at the larger picture—that of the state, regional, or national mental health systems—the situation is even more tentative. While several states have begun to deal with the problem of the chronically ill on a statewide or systems level, and while the National Institute of Mental Health has initiated a community-support program to fund new programs for the chronically ill, nationally there remain a huge number of formidable tasks to be accomplished if effective care and treatment of the chronic mentally ill is ever to be realized.

The Future

In its "Call to Action on The Chronic Mental Patient," the American Psychiatric Association spelled out the magnitude of the problem and the multiplicity of solutions needed if the current situation were to be remedied. These included changes in:

- the funding of services to the chronic mentally ill, so that discrimination against long-term care and maintenance in the community would be eliminated and funding could follow patients from institutional to community settings;
- 2. the attitudes all Americans hold about the chronic mentally ill;
- 3. the role of the psychiatrist (who has been leaving the field of public psychiatry), making him more involved in planning, implementation, and monitoring of services to the chronically ill;
- 4. the current administrative structure, which fragments funding, program planning, and service provision;
- 5. research efforts to provide increased understanding of epidemiology, prevention of chronicity, evaluation of what treatment works for which patients, and the like;
- 6. training priorities so that medical students, psychiatric residents, and practicing physicians, who all receive too little training in the care and treatment of chronic patients, understand more about effective modern programs; and
- 7. legislation that discriminates against the chronically ill.

It is clear that no single or simple solution will solve the multitude of

problems posed by and encountered by the chronic mentally ill. Many small steps must be taken in research, training, and service delivery if the current deplorable situation is to change.

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Notes

<u>1</u> Fairweather Lodges, developed by George Fairweather, are intermediary facilities between hospital settings and community living. They are group residences, where the staff is available for training patients in the skills of everyday living and where patients can learn to live interdependently.