The Problem: How Many Patients Live in Residential Care Facilities?

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As a result of the depopulation of state hospitals in the 1960s, hundreds of thousands of patients were released into the community. In a relatively short period a new system of residential community care emerged for persons who would have otherwise had to spend a major part of their lives in an institution. Many of these patients were transferred to transitional residential facilities, where they received support and assistance. The goal of these facilities was to assist these patients so they would be able to live independently. This system included halfway houses, three-quarter-way houses, cooperative apartments, crisis lodge facilities, specialized hotels, and residential care facilities (RCFs).

Residential care facilities

RCFs are also known as board-and-care homes, adult residential facilities, adult foster homes, adult homes, community care homes, supervisory care homes, sheltered care facilities, continuing care facilities, transitional living facilities, group homes, domiciliary care homes, personal care homes, family care homes, and rest homes, among others. This diversity of names has created a problem in that it has discouraged national statistical categorizations.

Generally speaking, these facilities provide room and board, supervise medication use, and offer assistance with activities of daily living for patients who have chronic mental illness or who are developmentally disabled. RCFs are sometimes confused with nursing homes but are quite different in that the purpose of an RCF is to provide nonmedical personal care and to supervise medication use. Nursing homes, on the other hand, provide essential nursing care at a level somewhat lower than that found in hospitals.

In a sense RCFs are long-term-care facilities. For many persons long-term care connotes a facility for persons who are elderly, but, in fact, many chronic psychotic patients spend much of their young and middle years in facilities that are designed for nongeriatric persons. Many patients with chronic schizophrenia spend most of their lives in an RCF, and, in that sense, the long-term care that is provided by these facilities is probably longer in duration than that provided by facilities for geriatric patients.

As chronically ill psychotic patients get older, they eventually qualify for placement in a geriatric long-term-care facility. However, although much has been written about the treatment of geriatric patients—both psychiatric and nonpsychiatric—in long-term-care facilities, very little has been written about the treatment of nongeriatric psychiatric patients in other types of long-term-care facilities. One exception is a book that addresses the problems that are involved in the on-site treatment of patients with mental illness in residential care facilities and that discusses the topics of this column in greater depth (1).

Because of the multiplicity of names, it is difficult to determine how many chronically ill psychotic patients are living in nongeriatric long-term-care facilities in the nation. Perhaps the least ambiguous descriptive name to define the function of these RCFs is "long-term-care facilities for nongeriatric persons who are mentally ill," but this name has its disadvantages in that it is somewhat cumbersome and does not lend itself to easily articulated acronyms that trip off the tip of the tongue. Besides, if residents of these RCFs are in reasonably good health, they may under certain circumstances remain in the RCF rather than be transferred to a geriatric facility. To make matters even more confusing, many nonpsychotic residents who are developmentally disabled also live in these RCFs.

The problem of data collection

Data collection for RCF patients is complicated by the fact that it is difficult to distinguish the RCF population from the population of other community-based domiciles for long-term patients, such as nursing homes. The reason that data collection is difficult is that states have different licensing laws and some states do not clearly delineate the distinction between nursing homes and RCFs.

In 1987 a national survey of state licensing agencies was conducted by the National Association of Residential Care Facilities, which represents RCF owners and operators (2). The survey reported a total of 41,381 homes with 562,837 beds. Of this total, approximately 10,000 homes with about 264,000 beds were identified as being primarily geriatric, with the rest serving persons who were developmentally disabled or mentally ill.

The association stated that its estimates were incomplete because of

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the wide variety of definitions that are included in licensing and because some states were still in the process of licensing homes. Confusion about the size of the RCF population is not new. During congressional hearings in 1981 the Department of Health and Human Services estimated that the boarding home population was between 500,000 and 1.5 million (3). However, the survey did not sufficiently categorize residents in RCFs as being elderly, developmentally disabled, or mentally ill. Also, the department acknowledged that the bottom-line estimate of 500,000 was an undercount because of the lack of information on the number of unlicensed facilities. Some facilities were unlicensed, whereas other homes were able to meet criteria but remained unlicensed because of a lack of enforcement efforts. Thus there was and is no nationwide information on the number of unlicensed homes. Nor is there clear nationwide information on the number of licensed homes.

However, in California the picture is somewhat clearer in that we have statistics for the number of licensed RCFs in the state and a breakdown as to which of these homes are populated by persons who are aged, mentally ill, or developmentally disabled. We also know the number of nursing home patients nationwide as well as the number of nursing home patients in each state. Because of this information, we are able calculate the ratio of RCF beds in California for persons with mental illness to the number of nursing home beds in California. We are then able to apply this ratio to the number of nursing home patients nationwide to obtain an estimate of the number of RCF beds for persons with mental illness in the nation.

California had a total of 4,639 licensed nongeriatric RCFs with a bed capacity of 37,985 in the year 2000 (personal communication, Levenson-Palmer G, California Department of Social Services, 2004). These facilities are categorized as RCFs by the Department of Social Services and are occupied by persons who are mentally ill or developmentally disabled. A total of 26,590 of the RCF beds (70 percent) were occupied by residents who were developmentally disabled, and 11,395 RCF beds were occupied by patients who were mentally ill (30 percent) (personal communication, Levenson-Palmer G, 2004).

In September 2000 the total number of California nursing home patients was estimated to be 107,084 (4). Using the data on RCFs from 2000, we can calculate a ratio of RCF occupants with mental illness to nursing home patients of 11,395 to 107,084, or 10.6 percent, in California. We can label the 11.13 percent as the California ratio. It is possible to use this ratio to estimate the nationwide population of RCF residents with mental illness as follows. According to statistics from the agency then known as the Health Care Financing Administration, the total number of nursing home beds in the nation in 2000 was 1,490,155 (4). We can estimate the total number of RCF beds for persons with mental illness by multiplying the number of nursing home beds in the nation by the California ratio (10.6 percent), which produces a value of 157,956.

It can be argued that such an extrapolation is unwarranted, because California has a higher incidence of mental illness than the rest of the country. Although this inference may appear to be true from observing the pedestrian traffic at certain intersections in San Francisco, it is not true of the state as whole. There may be no way to prove that California is typical of the rest of the country, but the fact is that California accounts for one-eighth of the national population, which provides a sufficiently large sample so as to make it unlikely that California-derived statistics are seriously unrepresentative.

However, it is probable that many more persons who are mentally ill occupy RCF beds in the United States than the estimate of 157,956. In the first place, the California statistics for the RCF population are based on licensed homes. The number of residents in unlicensed California facilities is unknown. Second, and even more important, many residents who are mentally ill are frequently transferred to geriatric RCFs after age 60. These patients continue to be mentally ill, but they no longer occupy recognized beds for persons with mental illness. From the statistical point of view these patients have literally disappeared.

This problem is building in importance, because an increasing number of patients with schizophrenia are attaining geriatric status and are thus in danger of disappearing statistically. Patients with schizophrenia are now living longer, because many of them are being effectively treated for concurrent medical diseases, such as arthritis, diabetes, heart disease, hypertension, hypercholesterolemia, and the various forms of chronic obstructive pulmonary diseases—to name only a few. To make matters somewhat more complicated, many geriatric patients who do not have a history of mental illness develop psychopathology during their residency in geriatric facilities. When these factors are considered, it is highly probable that the nation has many more persons with mental illness who are staying in RCFs than our estimate of 157,956 persons.

However, this is not to say that 157,956 patients are residing in licensed RCFs nationwide. The fact is that some states may not have RCFs or their equivalents. Some states have substituted other facilities, such as specialized hotels, to fulfill the functions that would otherwise have been delegated to RCFs. These considerations give some indication of the scope of the population that is in need of the services that these types of facilities provide.

Another uncounted population consists of geriatric patients with schizophrenia who are too disabled to reside in geriatric RCFs and who currently occupy beds in nursing homes. In many instances the nursing home has replaced the state hospital as the repository for the severely disabled geriatric patient with schizophrenia. In fact, statistics for nursing homes are much more accurate with respect to mental illness than are statistics for geriatric RCFs. Thus in 1999 it was estimated that the U.S. psychiatric population of nursing homes—which mainly consisted of persons with schizophrenia—accounted for 14.5 percent of the total nursing home population, or 216,072 of 1,490,155

(5). If we add this number to the estimate of 157,956 psychotic patients who live in RCFs or their equivalent, it is apparent that more than 370,000 patients with mental illness are living in nursing homes or RCFs. This number does not include patients with mental illness who would benefit from placement in such facilities but are unable to use them because the number of facilities is inadequate, such as homeless persons with mental illness—defined as persons lacking fixed nighttime domiciles and experiencing clinically diagnosable psychiatric disorders.

Many homeless persons with mental illness would have been the chronic residents of state hospitals—for better or worse—but they are now left to the tides of fate and chance wherein they drift across the intersections of urban America with shopping carts full of pitiful belongings. More than 700,000 individuals in the United States are estimated to be homeless, and at least one-quarter of these persons are mentally ill (6).

Conclusions

Although there was a great deal of initial optimism that returning chronically hospitalized patients with mental illness to community settings would facilitate rehabilitation, it became apparent over the course of time that many of these patients—mostly patients with chronic schizophrenia—were unable to achieve their hoped-for independence because of the persistence of illness and the irretrievable loss of job skills. Consequently, many of the community residences that were originally conceived of as transitional became permanent.

The existence of persons with mental illness who require long-term care has created new systems of care and new problems for psychiatrists who have been long accustomed to treating patients in their offices, in clinics, or in hospitals. Psychiatrists are now faced with the option of treating patients with mental illness in places where these patients congregate—in psychiatric offices, clinics, or hospitals—or where these patients live—in the aforementioned RCFs. Because of the difficulties in obtaining reliable statistics, little research has been done on the population of persons with mental illness who require long-term care, and the most effective modalities of treatment have yet to be determined. ♦

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