Primary Care of Adults with Mental Retardation

Carl V. Tyler, Jr, MD, and Claire Bourguet, PhD
Cleveland and Rootstown, Ohio

BACKGROUND. There is a national trend to deinstitutionalize mentally retarded adults, placing them in community residential settings. As a result, community-based primary care physicians will assume responsibility for their medical care. Primary care physicians may have uncertainties regarding the medical care of this population. The purpose of this case series is to describe the medical care of a group of adults with mental retardation during their first year of community residence following deinstitutionalization, and to provide practical advice to family physicians who care for these adults.

METHODS. Medical diagnoses and medications at the time of deinstitutionalization of a series of 21 adults were abstracted from institutional records and transfer forms. Follow-up data were obtained from office medical records.

RESULTS. In the first year following deinstitutionalization, each patient averaged 6.6 office visits to a family physician. Newly identified major health impairments were: chronic persistent hepatitis due to hepatitis B, acid peptic disease, gastroesophageal reflux disease, dysphagia, primary degenerative dementia, absence seizures, bronchiectasis, and idiopathic iridocyclitis. Significant changes in pharmacotherapy included consolidation of multidrug anticonvulsant regimens and discontinuance of psychotropics and laxatives. Health maintenance practices included hepatitis B immunizations, cholesterol determinations, smoking cessation counseling, and calcium supplementation.

CONCLUSIONS. Newly deinstitutionalized patients require careful diagnostic and therapeutic reassessment. Family physicians assuming their care need to look for conditions common in this population, including dysphagia, seizure disorders, chronic hepatitis B, and sensory impairments. Previously neglected health maintenance practices need to be instituted. Pharmacotherapies, particularly anticonvulsants, psychotropics, and laxatives, may be amenable to dosage reduction or discontinuance.

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Over the past two decades, deinstitutionalization of persons with mental retardation has shifted the provision of their medical care from large institutions to community-based physicians. In 1977, nearly 150,000 adults with mental retardation were institutional residents; by 1992 their numbers had declined by 48% to just under 78,000.[1] Surprisingly, the decision in some states regarding who is deinstitutionalized may not be related to severity of mental retardation or types of comorbid conditions, but rather such factors as availability of community residential placements in the individual's county of birth. With few exceptions, such as the Morristown model in New Jersey,[2] most states have no organized community or regional medical services for the deinstitutionalized.

Along with deinstitutionalization, the emergence of managed care forms of health care delivery will require greater numbers of primary care physicians to provide care for adults with mental retardation. Deficiencies in the training of family physicians and internists in the health care needs of adults with mental retardation, impediments to specialist referrals, and disincentives to treat time-consuming patients will interfere with the quantity and quality of services provided. Birenbarum[3] warns, "There is

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From Fairview Health System, Department of Family Medicine, Case Western Reserve University School of Medicine, Cleveland (C.V.T.), and Division of Community Health Sciences, Northeastern Ohio Universities College of Medicine, Rootstown (C.B.), Ohio. Requests for reprints should be addressed to Carl V. Tyler, Jr, MD, Center for Family Medicine, 18200 Lorain Ave, Cleveland, OH 44111.

clear and substantial evidence that adults with mental retardation may become underserved as a result of the market changes in the health care system."

Community-based primary care physicians assuming the care of newly deinstitutionalized adults may have uncertainties regarding their health care needs. The purpose of this case series is to describe the medical care of a group of adults with mental retardation during their first year of community residence following deinstitutionalization. The discussion that follows is organized to provide practical advice to family physicians who care for community-dwelling adults with mental retardation.

METHODS

This study examined 21 adults with mental retardation who came under the care of the first author's private family practice in North Canton, Ohio, between 1987 and 1990. Over the course of 3 years, they were deinstitutionalized from developmental centers and nursing homes into small "group home" community residences.

Data were collected by reviewing the office record of each patient under study. Demographic data included age, sex, duration of institutionalization, degree of mental retardation, and when available, psychometric tests of intelligence and adaptive behavior. Available institutional records, including transfer forms, were reviewed to identify medical diagnoses and medications prescribed at the time of deinstitutionalization. The office records for the first year after deinstitutionalization were reviewed for each patient. Changes in diagnoses and pharmacotherapy, health maintenance practices, medical consultations, hospital emergency department and urgent care utilization, and office visit frequency and type were abstracted from the medical records.

RESULTS

Table 1 summarizes demographic and psychometric data regarding the study population. There was remarkably wide variation in age, ranging from 27 to 67 years, and duration of institutionalization, ranging from 3 to 46 years. Fourteen percent of the group were over 55 years old at the time of deinstitutionalization, an age that some researchers define as elderly for persons with mental retardation or developmental disabilities.[4] The preponderance of male patients shown on the table reflected that the group homes were segregated by sex, with only one of five homes devoted to female patients. Only one of the female patients in that home had been deinstitutionalized from a developmental center; the remainder had been living in private homes or other communi-

TABLE 1

Demographic and Psychometric Data of Study Population (N=21)

Characteristic	No. (%)
Age at deinstitutionalization, y	
25-39	11 (52)
40-54	7 (33)
≥55	3 (14)
Youngest	21
Oldest	67
Mean	42
Median	39
Race	
White	18 (86)
Black	3 (14)
Sex	
Male	20 (95)
Female	1 (5)
Duration of institutionalization, y	
0-10	2
11-20	6
21-30	8
31-40	2
41-50	1
Unknown	2
Range	3-46
Mean	22
Median	21
Intelligence testing	
Mild mental retardation	1 (11)
Moderate mental retardation	1 (11)
Severe mental retardation	4 (44)
Profound mental retardation	3 (33)
Mean IQ	30
Adaptive behavior scale	
Mild	0 (0)
Moderate	7 (78)
Severe	1 (11)
Profound	1 (11)
Degree of mental retardation	
Mild	1 (5)
Moderate	3 (14)
Severe	9 (43)
Profound	8 (38)
Type of institution	
Developmental center	17 (81)
Nursing home	4 (19)

ty residences and thus were not included in this study. Over 80% of the group were severely or profoundly mentally retarded. As occurs commonly in patients with mental retardation, the intelligence testing of our study population suggested slightly different degrees of mental retardation from those determined by adaptive behavior scales.

At the time of deinstitutionalization, each patient carried an average of 2.0 diagnoses related to chronic conditions for which an average of 2.1 long-term medications were prescribed . After 1 year of community residence, each patient bore an average of 2.9 diagnoses for which an average of 1.7 long-term medications were prescribed. Fifty percent of the diagnoses at 1 year were newly formulated.

Institutional diagnoses maintained during the first year of community residence included seizure disorder in six patients (28%) and various orthopedic diagnoses (talipes equinus, avascular necrosis of the hip, chronic dislocation of the patella, and hip contracture). At deinstitutionalization, seven (33%) carried causative diagnoses for their mental retardation, including Down syndrome, cerebral palsy, hypoxic encephalopathy, and post-traumatic encephalopathy. Only one of these diagnoses was subsequently revised. All four patients (19%) identified as hepatitis B carriers were reconfirmed as such in the community, although the degree of infectivity, severity of hepatic injury, and potential for treatment with interferon were determined after deinstitutionalization.

Table 2 lists major health impairments newly diagnosed in the first year of a community residence. This designation was coined by Decker et al[5] to identify a "chronic abnormality or set of related abnormalities of structure or function that imposed a distinct and significant handicap to health or performance." Additional new diagnoses included such diverse entities as thyroid-binding globulin deficiency, chronic rhinitis, benign prostatic hypertrophy, and chronic otitis externa. Many dermatologic conditions were identified, including dermatophytic infections, seborrhea, actinic keratoses, and rosacea.

Fully one third of patients suffering from chronic constipation while institutionalized no longer manifested this condition in the community. Other institutional diagnoses not confirmed following deinstitutionalization (in one patient each) were glaucoma, schizophrenia, dextrocardia, and cerebral palsy. One patient bearing the institutional diagnosis of cerebral palsy was found to have phenylketonuria instead.

TABLE 2

Newly Identified Major Health Impairments

Chronic persistent hepatitis due to hepatitis B
Dysphagia
Acid peptic disease
Gastroesophageal reflux disease
Absence seizures
Primary degenerative dementia
Bronchiectasis
Idiopathic iridocyclitis

Alterations in pharmacotherapy were most notable for the anticonvulsants, psychotropics, and laxatives. Initially, anticonvulsants were prescribed for five patients; two received triple-drug therapy, two received two-drug therapy, and one received monotherapy. One year later, with no worsening of seizure control, no patients required triple-drug therapy, two-drug therapy was prescribed for two patients, and monotherapy prescribed for three patients. Similarly, psychotic medication was prescribed for six patients in the institution. One year later, antipsychotics were administered to only one half of these, and none had destabilized psychiatrically. Of the 10 patients for whom laxatives were initially prescribed, only three patients still required them 1 year later.

After excluding short-term medications such as oral antibiotics and topical antifungals, monthly long-term medication costs were calculated. Average wholesale prices of generics were used (when available) for all products except Dilantin and Tegretol. Calculated monthly medication costs at deinstitutionalization were $727.51, compared with $1083.83 at 1 year later. The increased monthly medication costs were related to the relatively greater costs of H_2-blockers, prokinetic agents, and intranasal corticosteroids, in comparison with the savings provided by discontinuance of relatively inexpensive anticonvulsants, laxatives, psychotropics, and vitamin and mineral supplements.

At 1-year follow-up, none of the patients had returned to institutional settings. Although there were no comparative functional scales uniformly administered to each patient, many of them did manifest functional improvements in activities of daily living and instrumental activities of daily living. The most dramatic of these was a 38-year-old with cerebral palsy who was termed nonambulatory and

wheelchair-bound at the nursing home where he had resided. He gradually demonstrated ability to ambulate independently. He and other patients thought to have intractable urinary incontinence in the institution were continent after discharge.

The average weight gain in this group of patients was 8 lb during the first year of community residence, with a wide variation in individual weight change, from an 11-lb loss to a 34-lb gain. According to body mass indices, three of the group were underweight at entry into the community (BMI <20); after 1 year, two remained so. On the other end of the spectrum, only one patient was obese initially (BMI ≥30), but three were obese 1 year later. These weight changes occurred despite the discontinuance of all vitamin-mineral supplements.

In 1 year, each patient averaged 6.6 office visits to the family physician. By category, 30% of these were for intake and annual examinations; 31% for acute problems; 27% for chronic problems; and 12% for behavioral problems.

There were 20 consultations to medical or surgical specialists. Of these, 5 represented conditions typically associated with this population for which primary care physicians often seek specialist consultation. These are listed in Table 3.

Medical care included 21 emergency medical department or urgent care visits: 7 visits for injuries (3 lacerations, 3 fractures, and 1 human bite); 8 visits for infections (6 upper respiratory tract infections, 1 dermal abscess, and 1 exacerbation of chronic obstructive pulmonary disease); 3 visits for seizures; 2 visits for dermatologic conditions (eczema, tinea cruris); and 1 visit for rectal bleeding.

Issues relevant to preventive care included the lack of immunization records in 8 of the 21 patients (38%). Despite their identification as a group at high risk for hepatitis B infection, 4 patients (19%) were unprotected, as suggested by absence of hepatitis B surface antibody, and consequently received the hepatitis B vaccine series. There were no cholesterol determinations in five patients (24%). The one female patient taking estrogen replacement therapy was not receiving adequate dietary calcium and was thus prescribed the recommended 1500 mg of calcium daily.

TABLE 3

Indications for Referrals to Medical or Surgical Specialists

Gait evaluation in patient with cerebral palsy
Metabolic management of adult with phenylketonuria
Epilepsy management
Routine ophthalmologic examination for keratoconus
Evaluation of rumination
Evaluation of chronic hepatitis due to HBV

In the past, cigarettes were used as a reward for adults with mental retardation in behavioral programs and in workshop settings. Three of our group were cigarette smokers, and each suffered associated health consequences (severe COPD, peptic ulcer disease, and underweight). When smoking was identified by the physician as an issue of medical importance, one patient was convinced to discontinue cigarettes entirely and the other two halved their daily use.

DISCUSSION

This case series was limited to newly deinstitutionalized adults with mental retardation. We suspected that this group would likely demonstrate more diagnostic and therapeutic alterations over 1 year as compared with those persons with mental retardation who simply changed residence within the community. While the generalizability of this case series to other settings is uncertain, it raises clinical issues that family physicians commonly encounter in caring for all adults with mental retardation.

The process of relocating persons from developmental centers to community residences is ongoing. Additionally, community placements are changing their form from larger facilities, ie, those greater than 16-bed settings, to smaller residences, ie, 1-bed to 6-bed settings. Whether into or within the community, these residential changes are often associated with a change in the health care providers.

The following are several general principles relevant to the primary medical care of adults with mental retardation.

Attempt to Identify the Causes of Mental Retardation. Since the conditions responsible for the development of mental retardation may also cause additional health problems, initial assessment should include careful observation of physical features, behaviors, and family and social history that could lead to a specific diagnosis of the causes.[6] In the case of the phenylketonuric study patient, recog-

nition of hypopigmented hair and skin, and institutional documents referencing a brother with mental retardation, led to testing for this inborn error of metabolism. In another patient, recognition by workshop personnel of behavioral features frequently noted in fragile X syndrome, including tactile defensiveness, poor eye contact, and remarkable imitative skill,[7] prompted cytogenetic testing and confirmation of the diagnosis. (This occurred subsequent to the first-year anniversary of deinstitutionalization and thus was not included in our study findings.) Kurtz et al[8] screened 58 persons with idiopathic mental retardation and found that 8% demonstrated urinary organic acid abnormalities suggestive of specific genetic metabolic defects. *Diagnostic Dysmorphology*[9] and Smith's *Recognizable Patterns of Human Malformation*[10] are two excellent references that can assist family physicians in recognizing those patients most likely to benefit from selective referral to a dysmorphologist or geneticist. Efforts to identify causes should concentrate on the conditions that might have a meaningful impact on the future care of the patient or have genetic implications for family members.

As indicated above, identification of the biomedical causes of mental retardation allows the physician to individualize screening for medical and psychiatric comorbidities. For example, adults with Down syndrome require surveillance for hypothyroidism, auditory and visual impairments, mitral valve prolapse, dementia, and cervical myelopathy from atlantoaxial instability. These screening recommendations have been summarized in the Down Syndrome Preventive Medical Check List compiled by the Down Syndrome Medical Interest Group.[11]

Look for Conditions Commonly Seen in Persons with Mental Retardation. In our case series, all the newly identified major health impairments except for iridocyclitis were conditions known to occur more frequently in persons with mental retardation. All persons with mental retardation should be screened for chronic hepatitis B infection. If present, further evaluation to determine the severity of liver disease and the advisability of interferon therapy is warranted. Dysphagia with tracheal aspiration is recognized as a common cause of recurrent pulmonary disease in persons with developmental disabilities. Mealtime respiratory distress and chronic lung disease (chronic infiltrates on chest radiographs, recurrent pneumonias, pulmonary fibrosis, chronic obstructive pulmonary disease, bronchiectasis, asthma) should prompt consideration of dysphagia.[12] The prevalence of seizure disorders among persons with mental retardation without cerebral palsy is 21%. Among those persons with mental retardation and cerebral palsy, the prevalence is 50%. Seizures may manifest subtly, with eye deviations, aversions, and brief impairment of consciousness.[13]

Think of Geriatric Syndromes. Evaluation and management strategies developed for geriatric medicine can be applied to adults with mental retardation, regardless of age. The "geriatric syndromes," including incontinence, falls, immobility, functional impairment, cognitive decline, osteoporosis, and polypharmacy, may emerge before the 6th decade and require recognition and careful evaluation. In our study group, the diagnoses of actinic keratoses, benign prostatic hypertrophy, detrusor instability, primary degenerative dementia, and sensorineural hearing loss were all conditions associated with aging. Three of our study group (14%) were deinstitutionalized at ages over 55 years. Gambert et al[14] and Carlsen et al[15] suggest that comprehensive geriatric assessment programs are useful in the evaluation of these older community-dwelling individuals with mental retardation.

Identify and Treat Secondary Disabilities. Unfortunately, developmental disabilities have been conceptualized as static entities, leading physicians to ignore potentially remediable secondary conditions. Pope,[16] drawing on the Institute of Medicine report *Disability in America: Toward a National Agenda for Prevention*,[17] has outlined a model for preventing these secondary conditions, which requires physician knowledge of risk factors and potential interventions. For example, persons with cerebral palsy have the risk factor of poor positioning, which can lead to the secondary conditions of hip, knee, and spine deformities. Recommended interventions to limit the impact of these secondary conditions include range of motion exercises, positioning, and wheelchair selection. In our series, a patient with severe wrist deformity due to remote fracture was provided improved function of the hand through surgery.

Apply Medication Reduction Strategies. The ability to successfully consolidate multidrug anticonvulsant regimens seen in our case series is consistent with experience reported in the mental retardation literature. In a sample of 100 adult outpatients with mental retardation and seizures, Singh and Towle[18] reported that 60% were maintained on monotherapy with 90% of these seizure-free. They also found that individuals with varying degrees of mental retardation did not differ in their number of anticonvulsant medications or seizure control.

Similarly, there is widespread use of antipsychotic medication in this population, some of which appears unnecessary. Stone et al[19] reported the prevalence of psychotropic drug use in California developmental centers to be as high as 60% in the 1970s. Some investigators have described no deterioration in behavior with psychoactive medication withdrawal, as was the case in our study group, although Briggs[20] reported a need to reinitiate pharmacotherapy in 33%. Luchins et al[21] found that successful reduction in antipsychotic medication dosage was associated with the absence of a diagnosis of psychosis and with the use of alternative medications, such as carbamazepine, buspirone, lithium, and propranolol. Possible reactions induced by withdrawal of antipsychotic agents include reactivation of psychiatric disorder for which a medication was originally prescribed, or the emergence of a previously undiagnosed condition; anticholinergic withdrawal; tardive akathisia; and supersensitivity psychosis.[22] As Harper and Wadsworth[23] observed in their study of psychotropic and anticonvulsant medication use in older adults with mental retardation, "Medication usage may be more closely tied to factors within the residential setting (eg, staff tolerance and perceptions of problem behaviors, staff-client ratio, medical versus habilitative orientation, education level of staff, philosophy of attending physician) than to the type, frequency, and severity of residents' characteristics, problem behavior, or psychiatric diagnosis."

Although persons with mental retardation can manifest the full range of psychiatric disorders, their conditions tend to be misdiagnosed as psychotic disorders. With impaired communication skills and limited defense mechanisms, maladaptive behaviors arise that are easily misinterpreted as psychotic in nature. Physicians should view with suspicion any diagnosis of schizophrenia in this population. Psychiatric disorders typically manifest nonspecifically with aggression, self-injury, or repetitive behavior. In contrast to maladaptive learned behaviors, psychiatric disorders tend to be associated with changes in sleep, appetite, and sexual function, to occur in all or most environmental settings, and to fail to respond to behavioral interventions.

Psychoactive medication should be prescribed for specific psychiatric conditions, rather than for nonspecific symptoms such as self-injury or aggression. Psychotropic medication monitoring should be based on systematic behavioral records kept by staff, rather than subjective global impressions. *The Habilitative Mental Healthcare Newsletter* (Medford, Mass: Psych-Media) is an excellent resource for family physicians to learn more about diagnosis and treatment of mental illness in persons with mental retardation.

Institute Preventive Health Care Practices. Over 40% of persons with mental retardation will survive to the age of 60 years. Longer life expectancy is associated with the following features: female, milder severity of mental retardation, community residence, absence of Down syndrome, and ambulatory capability.[24] A study of cardiovascular risk factors in 329 adults with mental retardation[25] found their risk profiles to be similar to those of individuals without mental retardation in the Framingham Offspring Study. Cholesterol determinations, assistance with smoking cessation, and weight monitoring with dietary and activity recommendations should be provided to all persons with mental retardation. Promoting smoking cessation can be complicated by issues of residents' right to smoke, fellow residents and staff members' rights to a healthy living and working environment, and the uncertainty whether some persons with mental retardation can fully understand the health risks of smoking.

As in the population at large, obesity is a health concern among persons with mental retardation. One study of 364 adults with mental retardation living in a variety of settings found that 27% of the men and 58% of the women were obese. Persons with severe mental retardation had a 29% rate of obesity, compared with 53% and 46% among those with moderate and mild retardation, respectively. Those persons living in institutions had a 16% obesity rate, compared with a 50% rate in intermediate care facilities, a 50% rate in group homes, and a 55% rate in

natural family settings.[26] As seen in our case series, relocation to less restrictive settings appears to increase the risk for obesity.

Physicians should carefully evaluate the necessity of vitamin and mineral supplementation. In institutional populations, specific nutritional supplements may be prescribed for nonspecific indications, such as poor appetite or lethargy. As in our case series, vitamin and mineral supplements often can be discontinued without adverse effect.

Diagnostic variations between the institution and the community may reflect, in part, the development in the community setting of new conditions or sequelae of previously identified conditions. In addition, institutional limitations on the number of trained professional health care personnel may have required physicians and nurses to focus on the most immediately serious, potentially life-threatening problems. Specialist physicians may have been reluctant to evaluate residents in the institution, and there may have been logistical limitations in transporting residents off-site for diagnostic testing or specialist consultation. In the community, there are greater functional requirements placed on patients, and timely evaluation and treatment are needed for conditions that affect patients' ability to ambulate, to participate in workshop, and to meet the demands of a small-group residence.

Changes in pharmacotherapy reflect, in part, the diagnostic alterations between the institution and the community. Institutional formularies may be more restrictive than Medicaid guidelines applied in the community setting. Improved nutrition and increased activity levels in the community allowed successful discontinuance of laxatives in many of our patients. The greater functional demands placed on community-dwelling patients would render unacceptable those pharmacotherapies that diminish functional capabilities.

Our study group resembled institutional populations in age distribution and severity of mental retardation. This is congruent with a deinstitutionalization selection process based on administrative factors rather than patient characteristics. Overall, institutional residents represent a heterogeneous population in the severity and cause of their mental retardation and in their comorbid medical and psychiatric illness. Their transition to a community residence offers the family physician an important opportunity to carefully reappraise their medical care.

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