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A National Study of Prescribed
Drugs in Institutions and Community
Residential Facilities for Mentally
Retarded People

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Abstract

Several studies conducted during the past 15 years have reported that high proportions of mentally retarded persons in institutions receive prescribed drugs. Widespread use of psychotropic drugs has been considered to be unnecessary or unwarranted chemical restraint.

Despite increased use of drug reviews, behavioral observation, improved record keeping, and transfers of relatively large numbers of residents from institutions to community residential facilities, the proportion of residents receiving drugs has not been reported to have declined appreciably. The present interview study of 2271 residents in 75 institutions and 161 private community based residential facilities indicated that in 1978-1979 75.8% of institutionalized residents received at least one prescribed drug; 39.7% received a psychotropic drug, a decrease from 51.1% ten years earlier. In community residences 54.3% of residents received at least one drug; 25.4% a psychotropic drug.

A National Study of Prescribed Drugs
in Institutions and Community Residential Facilities
for Mentally Retarded People

For many years there has been concern about the large proportion of institutionalized mentally retarded people who routinely receive a variety of drugs. The seriousness of the problem has been evidenced by a number of court cases in which irregularities in the use of medication with retarded people in residential facilities has been an issue.¹ Of main concern has been the delivery and evaluation of psychotropic drugs (drugs which alter behavior, mood, or thought processes) and the effects of psychotropic drugs on non-drug habilitative treatment strategies.^{2,3}

There have been many reviews on the use of psychotropic drugs with handicapped people.^{1,4,5} Most drug studies involving mentally retarded people have been criticized for lack of adequate controls, lack of appropriate outcome criteria or sound statistical analysis.^{1,5,6,7} Although it is agreed that psychotropic drugs suppress certain behaviors, there is little evidence that they promote the acquisition or development of other skills. Most studies that have specifically examined the effect of psychotropic drugs on behavioral intervention have found no beneficial effect.⁸⁻¹²

Several previous studies have reported on the use of prescribed medication drugs in public institutions for mentally retarded persons. In 1968 Lipman surveyed 100 public and 9 private institutions housing 148,000 retarded people, and found that 51.1% of all residents received some type of psychotropic

medication, including 39.2% who received major tranquilizers, 8.1% minor tranquilizers, and 3.8% antidepressants or energizers.¹³

More recent studies included smaller samples of one to five residential facilities, and are somewhat difficult to compare because of problems in differentiating drugs by usage. Antiepilepsy medications frequently include phenobarbital, which is also prescribed as a sedative for residents without epilepsy. Some antianxiety drugs such as benzodiazepam (Valium) may also be prescribed for seizure control. Since 1968 reports of psychotropic drug use in institutions, usually excluding drugs prescribed for epilepsy, range from 35% to 65%, indicating no clear decline.¹⁴⁻¹⁶ Females, mentally ill retarded residents, and residents of smaller institutions may be more likely to receive psychotropic medication.¹⁷ No relationship between drug use and age or severity of retardation has been found after controlling for other variables.

Antiepilepsy drugs such as diphenylhydantoin (Dilantin) are prescribed for 20 - 40% of all mentally retarded institutionalized residents.¹⁴⁻¹⁶ A study that included non-psychotropic and non-anticonvulsant drugs, reported that 56.2% of the residents in one institution received at least one prescribed medicine regularly over a three month period.¹⁸

There is limited information about the use of psychotropic drugs in the community or in special education classes. Among 3,306 trainable mentally retarded students in a public school system, most of whom lived at home with parents, 10.0% received medication for seizure disorders (6.9% phenytoin, 6.2%

phenobarbital); 4.9% were medicated for a behavior disorder (2.7% methylphenidate, 1.5% thioridazine, and 1.4% diazepam); including 1.8% of all students who were medicated for both reasons.¹⁸

A study that examined the prevalence of drug prescription for mentally retarded people in community residential facilities such as group homes included 3,496 randomly selected mentally retarded residents in four states, and reported that 74% of all mentally retarded residents were receiving one or more of a combination of antianxiety, antiepilepsy, antidepressant, antimanic, antipsychotic, or stimulant drugs; 57.6% received an antipsychotic drug and 46.4% received an antiepilepsy drug. Mildly retarded and profoundly retarded residents were most likely to receive drugs; mildly retarded residents most frequently received antipsychotic and antianxiety agents (mildly retarded people are often placed in residential care because of behavior problems) and profoundly retarded residents most often received antiepilepsy drugs.¹⁹

The purpose of the present report is to present data on all medication prescribed for mentally retarded residents of institutions and community residential facilities throughout the United States in 1978-1979. These data were gathered as part of a comprehensive national interview study of the characteristics of residential facilities and their residents.²⁰

MethodSample

The study included 2,271 retarded individuals in 236 residential facilities, selected through a two-stage probability sample design developed in cooperation with the Survey Research Center at the University of Michigan's Institute for Social Research. A sample of facilities was selected in such a way that the probability of a facility's selection was proportionate to its size (number of residents) and so that the distribution of sample facilities across census regions and size classes was in close agreement with the distribution of the national resident population. The following criteria were used to define facilities:

A community residential facility is any community-based living quarter(s) which provides 24-hour, 7 days-a-week responsibility for room, board, and supervision of mentally retarded persons as of June 30, 1977, with the exception of: (a) single family homes providing services to a relative; (b) nursing homes, boarding homes, and foster homes that are not formally state licensed or contracted as mental retardation service providers; and (c) independent living (apartment) programs which have no staff residing in the same facility.

A public residential facility (institution) is any state sponsored and administered facility which offers comprehensive programming on a 24-hour, 7 days-a-week basis.

Public facilities were sampled from a 1977 list maintained by the National Association of Superintendents of Public Residential Facilities. Community facilities were sampled from among 4,427 facilities that participated in a 1977 national mail questionnaire survey.²¹

Within each sampled facility a random sample of residents was selected so that the total sample size would be approximately 1000 public institution and 1000 community facility residents. This design was intended to provide an unbiased representation of all mentally retarded residents in public and community residential facilities in the United States in 1978. Only one of six community residential facilities in the United States that had more than 400 residents participated in the study. Therefore, community facilities with more than 400 residents are underrepresented.

No adjustment was made for non-response of individual residents or non-response on individual questionnaire items because it was not felt that the limited number of non-responses was biased in a particular direction. A weight adjustment of resident data was made for facility non-response and for disproportionate sampling. This adjustment, although minor, assured that each resident represented the appropriate proportion of residents in the residential population as a whole.

Procedure

Interviews at the 236 facilities were conducted between September 1978, and April 1979. At each facility trained interviewers selected a predetermined number of mentally retarded residents according to a random sampling procedure. Demographic

information about individual residents, including date of birth, date of admission, previous type of residential placement, age, height, weight, diagnosed degree of retardation, and diagnosis of epilepsy, autism, or mental illness was obtained from each resident's records. The staff person most familiar with each resident was then identified and interviewed about the resident. Each interview, which lasted approximately one hour, covered topics such as program plans, day programs, leisure time activities, family and social contact, specialized services, characteristics of the residential environment, and physical, health, and behavioral characteristics of each resident.

Care persons were asked whether and for what purpose drugs were prescribed for each resident. If a drug was prescribed for "overactive behavior" or if its purpose was unknown, the name of the drug was recorded. Care persons sometimes consulted records, but were not required to do so.

Because the care person interviewed had been nominated as being most responsible for the resident's day-to-day care, was likely to be familiar with any treatment and medical or nursing consultation, and often was trained to administer medications, the underestimation of incidence of prescribed medications was expected to be minimal, and similar for institutions and community residence samples.

Results

As indicated in Table 1, 76% of institutionalized residents and 54% of community facility residents were reported to be receiving at least one type of regularly prescribed medication. Percentages for specific drug types should be considered minimums, limited by the study's methodology. Drugs not named, but reported to be prescribed for a chronic health condition, epilepsy, a psychiatric problem, for sleeping, or for birth control were listed with "other" within tentative categories. The validity of this classification cannot be tested directly, but was supported by the linear regression analyses that follow.

Table 1 about here

Multiple regression was used to examine the relationships among drug use and several resident and facility characteristics listed in Table 2. A separate analysis was run for each drug category.²² Partially because of the study's large sample size, all resulting regression equations were significant ($P < .001$) although relatively small proportions of variance in drug use were explained. Dependent variables were coded 0 (does not receive) or 1 (receives). Standardized regression coefficients (Betas) obtained in the analysis of dichotomous dependent variables are equivalent to standardized variable weights yielded by discriminant analysis.

Table 2 about here

Table 3 summarizes the results regression analyses for four drug categories. Because the direct regression method was used,

the part r^2 for each independent variable represents the variance it explains after controlling for every other independent variable. Only variables with significant Betas ($p < .01$; $df=1,1539$) are listed in Table 3 although each analysis included all 16 independent variables.

Table 3 about here

Drugs reported to be prescribed for chronic health problems were most frequently used by older, non-ambulatory residents who had health problems. Likewise, use of antiepilepsy drugs was most closely associated with a history of seizures. In the present study 25.3% of community facility residents had a recorded mention of epilepsy, 21.5% were medicated at the time of the interview, and 12.9% had been observed to have a seizure within the previous 12 months. In institutions these proportions were 42.8%, 36.3%, and 22.2%, respectively. Only 1.3% of community facility residents and 1.6% of institutionalized residents whose records did not document epilepsy were reported to be receiving antiepilepsy drugs.

Psychotropic drugs were most often prescribed for residents with behavior problems or for those with a recorded mention of mental illness or autism. Older, heavier and more severely retarded residents were also more likely to receive psychotropic drugs.

Birth control medications (for age 12 or older) was predicted by sex, age, ability and minority status. Younger and less retarded women were more likely to receive birth control

medication, as were minorities, even after controlling for other variables. Part correlations were very small, although statistically significant.

Direct-care staff ratio is expressed in this paper as the number of residents per direct-care staff person at home on a typical weekday evening. A larger number of residents per staff was associated with health related and psychotropic drugs, but antiepilepsy drugs were associated with fewer residents per staff.

Variables that did not predict drug use (after controlling for others) included facility size, ICF-MR certification, salaried facility medical staff, paid consulting medical staff, or state vs. private ownership.

Discussion

The majority of mentally retarded residents in both community residential facilities and state institutions regularly received at least one type of prescribed medication. Drugs were more common in institutions not because of the institutions' large sizes, but because institutionalized residents were more severely retarded, more likely to have epilepsy and more likely to have behavior problems. Although the proportion of institutionalized residents reported to have had chronic health problems, (20.1%) was not significantly different than the proportion of community facility residents (17.5%), institutionalized residents were more likely to be medicated for this reason, largely as a result of prescribed laxatives.

The use of psychotropic drugs in institutions appears to have declined in the last decade, from 51% of residents in 1968

to 38% of all residents in 1978-79. Although deinstitutionalization has caused the release of better adjusted residents and the readmission of residents exhibiting maladaptive behavior, a decrease in psychotropic drug use is not surprising, given many recent court ordered restrictions on psychotropic medications in institutions and less general emphasis on a medical model.²³ Perhaps somewhat more surprising is the relatively common use of psychotropic drugs in community facilities.

Whereas the correlation between health problems and medication for health problems, epilepsy and antiepilepsy medication, and fertility and birth control appear to have an objective basis, it is less apparent whether behavior problems distinct from mental illness should be an indication for psychotropic medication. Sprague and Baxley, commenting upon safeguards to overuse of psychotropic medication stated that

Current requirements in some states for prescription evaluations every 30 days are laudable. But the lack of meaningful behavioral monitoring, the tendency to use cryptic or trite phrases to describe behavior, and the focus on symptom suppression lead us to the conclusion that such a requirement for routine evaluation is inadequate.¹ (p. 116).

Community residences are often subject to fewer controls than institutions are. The relatively high incidence of psychotropic drug use with residents who are not mentally ill suggests the need for continuing attention to this issue. In recent years, as persons for whom life-long institutionalization was

once the norm have been placed in community settings, the population of community residential facilities has become more physically and behaviorally impaired. Physicians in the community need to be aware of alternatives to medications for a retarded person with behavior problems. Residential facility staff and foster parents need training in behavior management skills and in teaching alternative adaptive behaviors.

The overall rate of drug use in institutions, including non-psychotropic drugs, remains quite high. Although results of the present study indicate expected relationships between health problems and drugs for health problems, epilepsy and drugs for epilepsy, etc., there also appears to be a pattern of drug use that relates to age, ability, and to facility staff ratio -- factors not amenable to change by drug intervention.

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Table 1
Percent of Residents Receiving Prescribed Drugs

Reason/Drug	Community facilities (N=962)	Institutions (N=992)
Health related		
anti-diabetic	0.0%	0.2%
cardiovascular	1.2	1.8
diuretic	0.2	0.5
antihistamine/allergy	1.5	1.7
antibiotic/antiinfective	0.3	0.5
hormones/thyroid	0.6	0.8
laxatives/softeners	2.5	11.4
dermatologicals	2.0	4.4
aspirin/tylenol	0.3	0.6
demerol/codiene	0.1	0.3
other or not specified	<u>6.7</u>	<u>5.2</u>
total	14.7%	24.4%
Epilepsy		
drug not specified	21.5%	36.3%
Psychotropic drugs		
anti-psychotics		
phenothiazines (Thorazine)	13.5%	23.6%
butyrophenones (Haldol)	1.9	3.5
thioxanthenes (Navane)	0.4	0.7
rauwolfia alk. (Reserpine)	0.1	0.0
"psychiatric problem"	<u>5.2</u>	<u>2.9</u>
total	20.5%	29.9%
anti-anxiety		
benzodiazepine (Valium)	3.2	4.2
hydroxyzines (Atarax)	0.3	1.1
other or not specified	<u>0.4</u>	<u>0.1</u>
total	3.8%	5.4%
sedative		
chloral derivative	0.0%	0.2%
barbiturate*	0.7	0.7
"problem sleeping"	<u>3.2</u>	<u>6.4</u>
total	4.0%	7.3%
stimulant		
amphetamines	0.1%	0.0%
benzylpiperadines (Ritalin)	0.9	0.3
other or not specified	<u>0.0</u>	<u>0.1</u>
total	1.0%	0.4%

(table 1 cont.)

antidepressant/antimanic		
tricyclics	1.2%	1.1%
lithium salts	0.2	0.6
other or not specified	0.1	0.0
total	1.6%	1.7%
total psychotropics	25.9%	37.9%
Anti-parkinsonian	4.2%	3.3%
Birth control	3.5%	2.7%
Other or not specified	1.8%	2.4%
Total one drug or more	54.3%	75.8%

*excluding residents with epilepsy

Table 2
Independent Variables in Regression Analysis

Variable	Mean	SD	Description
SEIZURE	.37	.48	Records indicate, or staff have have observed seizures
ABILITY	29.36	19.01	A measure of adaptive behavior (M=29;SD=19)
HEALTH	.19	.39	Presence (1) or absence (0) of one or more physical health problems
AGE	354.67	180.33	Resident's age in months
FEMALE	.43	.50	Female (1) or male (0)
MI/AUT	.12	.33	Records mention mental illness or autistic traits
NONAMB	.16	.37	Non-ambulatory (1) or ambulatory (0)
BPROB	1.23	1.53	1-8 behavior problem categories evidenced by resident
MINORITY	.17	.37	Non-white or hispanic (1) white (0)
SIZE	550.07	647.02	Number of residents per facility
ICFMR	.62	.48	ICF-MR certified (1)
MEDSTAFF	.75	.43	One or more full or part-time doctor, nurse or pharmacists on facility payroll (1)
CMEDSTAFF	.03	.17	No salaried medical staff, but regular consulting medical staff (1=presence of consulting staff)
WEIGHT	121.61	37.30	Resident's weight in pounds
PRIV/PUB	.47	.50	Private (1) public institution (0)
RES/STAFF	7.08	5.96	Number of residents per direct care staff at home on a typical work- day evening

Table 3
Summary of Direct Multiple Regression Analysis

Drug group	Independent variable	Beta	Part r ²	Simple r ²
Health related r ² =.17 F=19.09 p<.001	HEALTH	.31	.113	.34
	NONAMB	.11	.010	.13
	AGE	.09	.006	.16
	RES/STAFF	.09	.010	.10
Anti-epilepsy r ² =.65 F=175.03 p<.001	SEIZURE	.78	.639	.80
	RES/STAFF	-.05	.003	-.09
Psychotropic r ² =.18 F=21.57 p<.001	BPROB	.28	.083	.33
	MI/AUT	.17	.050	.22
	ABILITY	-.14	.011	-.07
	AGE	.09	.006	.09
	WEIGHT	.10	.005	.11
	RES/STAFF	.08	.002	.05
Birth control r ² =.10 F=9.16 p<.001	FEMALE	.25	.054	.23
	ABILITY	.12	.009	.14
	AGE	.10	.006	.07
	MINORITY	.08	.009	.09

Note. Independent variables listed had F to enter with p<.01 (1,1539 df).
Overall (16,1539 df).
Regression for birth control included only age 12+
N=1446; (16,1429 df)