

The Clinical Profile and Service Needs of Hospitalized Adults With Mental Retardation and a Psychiatric Diagnosis

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Objective: This study compared patients with both mental retardation and a psychiatric diagnosis with patients who did not have co-occurring mental retardation who were served in Ontario's tertiary mental health care system in terms of demographic characteristics, symptom profile, strengths and resources, and clinical service needs. **Methods:** A secondary analysis of data from the Colorado Client Assessment Record (CCAR) that were collected between 1999 and 2003 from all tertiary psychiatric hospitals in Ontario, Canada, was completed for a random sample of 3,927 cases, representing 12,470 patients receiving psychiatric services. **Results:** Patients with both mental retardation and a psychiatric diagnosis differed from those who did not have mental retardation in terms of demographic characteristics, diagnostic and symptom profile, resources, and recommended level of care. More specifically, patients with both mental retardation and a psychiatric diagnosis had significantly worse ratings across nearly all CCAR functional domains and were assessed as requiring more than the recommended levels of care compared with other patients. **Conclusions:** Patients who have both mental retardation and a psychiatric diagnosis constitute a sizeable subgroup of an already underserved psychiatric hospital population. Greater attention is required to meet the unique clinical and service needs of this challenging group. (*Psychiatric Services* 57:77-83, 2006)

In Canada and other parts of the world, psychiatric services for persons with mental retardation, as defined in *DSM-IV-TR*, were once provided through institutions. In the 1970s, plans to downsize and close

these institutions were initiated, and, since then, persons with mental retardation have been directed to the generic mental health system for their psychiatric needs (1). Little information is available about how patients

with both mental retardation and a psychiatric disorder differ from those who do not have intellectual impairments in terms of their demographic characteristics, symptom profile, and clinical needs. Such information is critical to delivering effective mental health services to these patients (2).

A small number of studies have compared persons with and without co-occurring mental retardation who are receiving psychiatric services (3-8). These studies have shown that the patients with mental retardation are typically younger, are more likely to live in dependent living settings (with family or in group homes), and are less likely to be married or have children. With regard to symptom profile, they tend to have higher rates of comorbid medical conditions, more problems with aggression, and lower rates of substance abuse compared with other patients. In terms of aggression, patients with mental retardation have been reported to display more assaultive behavior and to receive more chemical and physical seclusion and restraint than other patients (4,6,9,10).

Lohrer and associates (6) and Saeed and colleagues (4) reported a longer stay for inpatients who had both mental retardation and a psychiatric diagnosis than for patients who did not have mental retardation. Several researchers have commented on the intensive clinical needs of this patient group and the high level of care required if they are to be supported outside the hospital

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(4,11–15). However, no studies have directly compared the level of services required by patients who have mental retardation and a comorbid psychiatric illness with the levels required by other groups of patients.

The study reported here compared the clinical profile and service needs of patients with both mental retardation and a psychiatric diagnosis with those of other patients receiving tertiary-level mental health care in Ontario. The goals of the study were to determine the prevalence of co-occurring mental retardation within the tertiary care psychiatric hospital system, to examine the patient characteristics and symptom profile of the group with both mental retardation and a psychiatric diagnosis compared with those of other patients receiving tertiary mental health care, and to calculate and compare the recommended level of care for those with and without mental retardation.

Methods



Sample and data collection

Patients were drawn from all nine provincial psychiatric hospitals responsible for providing tertiary inpatient and outpatient mental health services to urban, semiurban, and rural communities in Ontario, Canada, between 1999 and 2003. Tertiary inpatient programs provide mental health beds for persons with complex or chronic conditions for the purpose of specialized assessment and treatment. Such programs provide the highest level of care in the mental health service continuum in Ontario. Tertiary outpatient programs also target patients who have more complex conditions and represent the middle ground between specialized inpatient and community-based mental health care. All programs included in this study serve persons aged 16 years or older with severe and persistent mental illness.

For each hospital facility, all individuals receiving inpatient services on a specified census day were assessed. It was believed that this approach would yield a stable estimate of which patients received inpatient services, because these patients tend to be admitted for chronic conditions. In fact, patients' average length of stay was 3.65 years, and only 13 percent of in-

patients were in the hospital for less than one month at the time of the survey. For the outpatient population, the sampling frame included all individuals who were using outpatient services during a three-month period.

The sample was drawn by using random selection, stratifying by clinical program. Sampling rates varied between 10 percent and 100 percent, with the aim of obtaining a minimum sample of 30 patients per program. For the purpose of generating population estimates, individual cases were then assigned weights based on the


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sampling rate per program. For example, if ten patients were assessed out of a total of 40, each patient would be given a weight of 4. Given that all inpatients were assessed, each inpatient case was given a weight of 1. The final study database comprised 3,927 cases, weighted to represent 2,218 inpatients and 10,323 outpatients, for a total of 12,541 patients (16). Institutional review board approval for conducting secondary analyses to compare patients with and without co-occurring mental retardation was obtained.

For all selected cases, standardized

assessments were completed by trained staff who were familiar with the patients who were being rated (17). An interview was not required. For each patient, staff indicated the presence or absence of a developmental disability. (In Ontario, the term "developmental disability" is equivalent to the term "mental retardation" in *DSM-IV-TR*). Staff also reported any psychiatric diagnoses, including mental retardation. A patient was identified as having co-occurring mental retardation if he or she was recorded as having a developmental disability or a mental retardation diagnosis in addition to a psychiatric diagnosis (18). Using these criteria, we excluded a small number of cases ($N=71$, weighted) for which there was a designation of developmental disability or a diagnosis of mental retardation, but a precise psychiatric diagnosis was unknown or unavailable. This approach resulted in a final weighted total of 12,470 patients for analysis.

Measure

The assessment included completion of the Colorado Client Assessment Record (CCAR). The CCAR is a standardized tool for conducting a comprehensive assessment of patient functioning (19,20). Staff record basic patient information, such as current diagnosis and history of illness; legal, marital, employment, and educational status; and residential stability. Also, on the basis of his or her knowledge of the patient, input from other staff, and program records and charts, staff assess patient impairments and strengths across 25 domains and two global ratings. Each domain is rated on a 9-point scale from 1 (high functioning, no special problem) to 9 (low functioning, extreme problem of difficulty). Information from the CCAR is used to calculate a "recommended level of care" for each patient. The CCAR has been found to be both reliable and valid in the United States and in Ontario (17,21,22).

Level-of-care assessment

A level-of-care template was developed to provide a systematic approach for matching an individual to a particular level of care on the basis of need. The template is intended to

support needs-based service planning for various patient groups.

An individual's recommended level of care is calculated through use of an algorithm based on ratings from six CCAR domains: security or management risk, overall problem severity, self-care and basic needs, overall lack of resources, danger to self, and danger to others. Patients were assigned to one of five recommended levels of care (Table 1) ranging from self-management (level 1) to specialized inpatient care (level 5) on the basis of their ratings on each of these six domains. Validity testing has supported the ability of the template to map patients who have more complex conditions into a higher recommended level of care (17).

Analyses

For patients with and without co-occurring mental retardation, frequencies of demographic characteristics, diagnoses, and recommended level of care were compared by using the chi square statistic and odds ratios. Symptom and resource ratings organized under three headings—adaptive behavior and cognition, challenging behavior, and lack of resources—were contrasted with analyses of variance (ANOVAs) for weighted data. To achieve an overall alpha level

Table 1

Recommended level-of-care template for patients with both mental retardation and a psychiatric diagnosis

Level	Description
1	Self-management with intermittent use of core community services and supports
2	Individualized support on a weekly basis; psychiatric care provided through regular contact with a psychiatrist or mental health nurse in an outpatient setting
3	Community living with intensive integrated treatment and support (daily with 24-hour access); usually associated with assertive community treatment
4	Residential treatment with a strong rehabilitation component; this level is appropriate for persons whose behaviors make it difficult for them to live independently and who at times need a secure environment
5	Tertiary inpatient care

of .05, Bonferroni corrections were applied, which lowered the significance level for individual tests to .0016 (based on 31 comparisons in total). Analyses were performed with SPSS version 11 (23) and STATA (24) software (ANOVAs for weighted data).

Results

Prevalence of comorbid mental retardation

Of the final weighted sample of 12,470, which included 2,196 inpatients and 10,274 outpatients, 1,665 patients (13.4 percent)—394 inpa-

tients, or 17.9 percent, and 1,271 outpatients, or 12.4 percent—were classified as having co-occurring mental retardation. Inpatients were significantly more likely to have both mental retardation and a psychiatric diagnosis than outpatients ($\chi^2 = 48.05$, $p < .001$). Initial analyses indicated that the pattern of differences between patients with and without co-occurring mental retardation was virtually identical across the inpatient and outpatient samples. Accordingly, we present findings for the combined group of inpatients and outpatients.

Table 2

Comparison of patient characteristics and psychiatric diagnoses among patients with both mental retardation and a psychiatric diagnosis and patients without co-occurring mental retardation

Category	Co-occurring mental retardation				χ^2 [†]	p ^a	OR	95% CI
	Yes		No					
	N	%	N	%				
Patient characteristics								
Gender, male	894	54	5,696	53	.28	.598	1.03	.93–1.14
Not married	1,511	92	8,424	79	146.05	<.001	2.91	2.43–3.48
Unemployed	1,404	86	8,606	80	25.00	<.001	1.45	1.26–1.68
Psychotropic medication	1,378	92	8,465	90	5.52	.023	1.27	1.04–1.55
Comorbid medical condition	667	50	3,577	38	63.33	<.001	1.60	1.42–1.79
Legal problems	188	12	1,414	13	2.91	.088	.87	.74–1.02
Psychiatric diagnoses ^b								
Mood disorder	339	20	3,944	37	164.31	<.001	.45	.39–.51
Anxiety disorder	136	8	1,357	13	25.62	<.001	.62	.51–.75
Substance abuse	98	6	1,467	14	76.38	<.001	.40	.32–.49
Psychotic disorder	902	54	5,853	54	.01	.922	1.01	.91–1.12
Personality disorder	238	14	1,414	13	1.85	.174	1.11	.96–1.29
Organic disorder	121	7	781	7	<.001	.970	1.01	.84–1.03

^a $p < .0016$ was considered statistically significant to achieve an overall alpha level of .05 with Bonferroni correction for multiple comparisons applied.

^b Patients could receive more than one diagnosis.

[†] df=1

Table 3

Mean problem severity and resources among patients with both mental retardation and a psychiatric diagnosis and among patients without co-occurring mental retardation

CCAR domain ^a	Co-occurring mental retardation				F	df ^b	p ^c
	Yes		No				
	Mean	SD	Mean	SD			
Adaptive behavior and cognition							
Attention problems	4.78	5.53	3.78	2.31	62.84	1, 3,859	<.001
Cognitive problems	4.64	5.75	3.45	2.34	76.10	1, 3,503	<.001
Role performance (work or school)	5.88	8.57	4.65	3.45	36.50	1, 3,809	<.001
Self care and basic needs	5.65	6.52	3.71	2.85	155.80	1, 3,863	<.001
Challenging behavior							
Aggressiveness	3.62	6.76	2.50	2.28	55.97	1, 3,853	<.001
Antisocial behavior	2.87	6.21	2.10	2.03	31.96	1, 3,787	<.001
Legal issues	1.62	4.73	1.54	1.69	.76	1, 3,756	.38
Resistiveness	4.02	5.76	3.57	2.38	11.91	1, 3,823	<.001
Security and management risk	4.01	6.24	2.95	2.51	56.69	1, 3,860	<.001
Suicide and danger to self	2.40	5.64	2.04	1.88	9.67	1, 3,818	.0019
Violence and danger to others	2.88	6.27	1.97	1.94	49.42	1, 3,775	<.001
Lack of resources							
Lack of educational and social resources	7.90	4.34	5.72	2.42	339.65	1, 3,129	<.001
Lack of economic resources	6.23	6.33	5.51	2.40	22.79	1, 3,130	<.001
Lack of person resources (social support)	6.30	6.36	5.56	2.39	21.69	1, 3,113	<.001
Lack of personal strengths	6.90	5.00	5.45	2.20	121.67	1, 3,121	<.001
Global rating of problem severity	5.54	4.32	4.99	1.77	30.17	1, 3,837	<.001
Global rating of lack of resources	6.78	4.82	5.54	2.04	116.93	1, 3,841	<.001

^a Colorado Client Assessment Record; rated on a scale of 1 to 9, where 1 represents high functioning and no special problem and 9 represents low functioning and extreme problem or difficulty

^b The overall sample size varied because of missing information; some variables were not collected at all sites.

^c $p < .0016$ was considered statistically significant to achieve an overall alpha level of .05 with Bonferroni correction for multiple comparisons applied.

Patient characteristics and symptom profile

Patients with and without co-occurring mental retardation were compared in terms of their characteristics and psychiatric diagnoses (Table 2). Although patients with co-occurring mental retardation were slightly younger (mean age of 46 compared with 49 years), this age difference was not statistically significant once the Bonferroni correction for multiple comparisons was applied ($F=7.06$, $df=1$, 3824, $p=.008$). Inpatients with co-occurring mental retardation had significantly longer admissions than did those who did not have mental retardation (an average of 6.6 years compared with 3.0 years, $F=85.95$, $df=1$, 2123, $p<.001$). As indicated in Table 2, patients with both diagnoses were more likely to be unmarried, to be unemployed, and to have more comorbid medical conditions than those who did not have co-occurring mental retardation. Regarding psychiatric diagnoses, patients who had co-occurring mental retardation were less likely to have a

mood, anxiety, or substance use disorder than those without mental retardation but were equally likely to receive a diagnosis of a psychotic, personality, or organic disorder.

Table 3 compares patients with and without co-occurring mental retardation on several CCAR domains, summarized under three relevant headings: adaptive behavior and cognition, challenging behavior, and lack of resources. Patients with co-occurring mental retardation were given a higher severity rating on almost every domain under these three headings compared with patients who did not have mental retardation. This pattern was also reflected in higher global ratings on problem severity and lack of strengths for those with both mental retardation and a psychiatric diagnosis than for other patients.

Recommended level of care

As can be seen from Table 4, a larger proportion of individuals with co-occurring mental retardation were recommended for level 3 care (42.8 per-

cent compared with 31.9 percent) or level 4 care (27.3 percent compared with 15.1 percent), and significantly fewer were rated as being able to manage with less intensive supports (25.8 percent compared with 50.8 percent for levels 1 and 2 combined). Patients who had both mental retardation and a psychiatric diagnosis had a different distribution of levels of care than those without mental retardation ($\chi^2=385.3$, $df=4$, $p<.001$). However, the percentage of patients with recommended level-of-care ratings of 5 (tertiary inpatient care) was very low for both groups (4.0 percent and 2.2 percent). Thus patients with both diagnoses were not determined to be in greater need of tertiary-level inpatient care but were in greater need of more intensive outpatient supports than other patients.

Discussion

This study was conducted to determine the patient characteristics and clinical needs of persons with both mental retardation and a psychiatric

Table 4

Recommended level of care for patients with both mental retardation and a psychiatric diagnosis and for patients without co-occurring mental retardation

Recommended level of care	Co-occurring mental retardation			
	Yes		No	
	N	%	N	%
1 (self-management)	108	6.6	1,716	16.6
2 (weekly individual support)	313	19.2	3,542	34.2
3 (intensive outpatient treatment)	699	42.8	3,305	31.9
4 (residential treatment facility)	446	27.3	1,572	15.1
5 (tertiary inpatient care)	66	4.0	225	2.2

diagnosis who were currently being served by the tertiary care psychiatric hospital system in Ontario. The results of the study provide important information for those planning services for this population. As many as one in eight individuals (13.4 percent) served by the tertiary mental health care system in Ontario have co-occurring mental retardation. Patients with both diagnoses differed from patients who did not have mental retardation with regard to demographic characteristics and tended to have a more severe diagnostic and symptom profile, a greater lack of resources, and a higher recommended level of care. Despite their more severe profiles, only a small percentage of patients with co-occurring mental retardation were rated as requiring long-term inpatient care (level 5). A majority were rated as requiring either intensive outpatient support (level 3) or residential treatment (level 4).

In terms of patient profiles, patients who had both mental retardation and a psychiatric diagnosis were more likely to be single, to be unemployed, to have comorbid medical conditions, and to have a longer stay than patients who did not have mental retardation. This presentation matches the profile reported by Saeed and associates (4), Hurley and colleagues (5), and Lohrer and colleagues (6) in their studies of patients in acute care settings. The patients with both diagnoses had lower rates of substance abuse, which has been reported elsewhere (6,8) and may be partly explained by the fact that persons with mental retardation have

limited access to substances because of their supervised lifestyle (25).

The patients with co-occurring mental retardation who were included in the study reported here were found to have lower rates of mood and anxiety disorders than other patients. This finding is inconsistent with the general finding that persons with mental retardation have an increased risk of affective disorders (26). One explanation for our finding is that clinicians who do not have specialized training can underdiagnose or misdiagnose mood and anxiety disorders among persons with mental retardation (5,27). The lower rates may also reflect the fact that individuals with mental retardation and mood or anxiety disorders do not tend to receive the attention of tertiary-level services. Rather, it is those who have challenging behaviors, such as aggression, who receive such services (28,29).

In terms of patient profiles, the results of this study suggest that persons who have both mental retardation and a psychiatric diagnosis are disadvantaged as a result of adaptive behavior and cognitive limitations, challenging or aggressive behavior, and lack of resources. Adaptive limitations (poor attention and cognitive dysfunction) make it more difficult for patients who have co-occurring mental retardation to participate in treatments that have been developed for the "typical" patient (30,31). Compounding these functional limitations are problems with aggression to self and to others, referred to in the literature as "challenging behavior." Often, it is this challenging be-

havior rather than psychiatric symptoms that receives clinical attention (29,32) and jeopardizes community placements (13). Finally, persons with co-occurring mental retardation lack internal and external resources, which makes it difficult for them to obtain appropriate services, to maintain gains made in therapy, and to avoid regressing without extensive professional supports.

An important finding of this study from a service delivery perspective is that the recommended level of care for patients with co-occurring mental retardation is higher than for other patients. However, only a few patients in this study who had co-occurring mental retardation were deemed to require the highest level of support—inpatient tertiary care (level 5). This finding implies that a large percentage of individuals who were receiving level 5 care at the time of the study were deemed to require a lower recommended level of care. In other words, level 3 and 4 supports would be more appropriate for many of these individuals. Level 4 supports (highly staffed community residences with a strong therapeutic component) and level 3 supports (intensive case management services, such as specialized assertive community treatment teams) have evidenced some benefit for persons with lower functioning (33–35). Perhaps the longer stay among patients with co-occurring mental retardation in this study is in part a reflection of the shortage of level 3 and level 4 supports and the reluctance of agencies that provide intensive outpatient services to ac-

cept these more challenging, higher-need individuals. This question has been discussed by others in Ontario (4), the United States (13), and the United Kingdom (15).

An important caveat should be kept in mind in the interpretation of this study's findings. In this study, the patients with co-occurring mental retardation were defined as those who had a clinical diagnosis of mental retardation and a psychiatric disorder. Accurate psychiatric assessment of low-functioning individuals requires assessment from a psychiatrist or a psychologist who is specifically trained in making this type of dual diagnosis. Unfortunately, such specialist diagnostic skills have historically been limited in tertiary mental health services. Thus it is likely that a portion of our sample may have appeared clinically to have mental retardation but without correctly meeting *DSM-IV* criteria for mental retardation (IQ below 70, adaptive behavior deficits, and onset before age 18) (11). Similarly, it is likely that a number of patients in the group of patients with both diagnoses had been given a misdiagnosis—for example, psychotic-like behaviors may have led to diagnosis of psychosis when in fact the behaviors were related to another underlying cause (27,36).

This study had several limitations, which should be taken into consideration in interpreting its findings. First, data reported here are based on secondary analyses of data developed for another purpose. Issues such as accuracy of diagnoses of mental retardation or developmental disability and psychiatric diagnoses cannot be addressed by using this database, only through further research. Also, numbers reported here are estimates based on inpatients who were sampled on a given census day; not every outpatient was surveyed. Second, findings are based on the subgroup of persons with co-occurring mental retardation who were being served by Ontario's tertiary-level psychiatric hospitals. The study did not address the needs of patients obtaining services outside the tertiary care system or not receiving any services. Third, the findings may be

unique to Ontario and not generalizable to other jurisdictions. Only comparable research in other places will address this issue. Finally, the level-of-care algorithm has demonstrated good concurrent validity, yet it is still relatively new and would benefit from further testing, especially in psychiatric populations with complex conditions.

Conclusions

One in eight patients served by Ontario's tertiary care psychiatric system were identified as having both mental retardation and a psychiatric disorder. These patients differed from patients who did not have co-occurring mental retardation in terms of demographic characteristics and tended to have a more severe diagnostic and symptom profile, a greater lack of resources, and a higher recommended level of care. Therefore, intensive services that match the greater needs of these patients (for example, care levels 3 and 4) must be made available to them. In addition, staff in the tertiary mental health care system would benefit from further training to better provide such services. The unique needs of patients with co-occurring mental retardation must be taken into consideration as part of mental health reform.

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***Psychiatric Services* Invites Short Descriptions of Novel Programs**

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Text should be 350 to 750 words. A maximum of three authors, including the contact person, can be listed; one author is preferred. References, tables, and figures are not used. Any statements about program effectiveness must be accompanied by supporting data within the text.

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