Examining the Characteristics of Persons with Intellectual Disability Receiving Hospital Services: Part 1 - Psychiatric Hospitals/Units

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Abstract

Closure of institutions designed for adults with intellectual disability (ID) has meant that those with more complex psychiatric and/or medical conditions have been admitted to health care settings designed for the general population of non-disabled adults. This paper describes the characteristics and service utilization of persons with ID receiving inpatient psychiatric care in Ontario, and compares them to patients without ID in the same setting. Results reveal that significant discrepancy exists between the identified needs and services offered to patients with ID, with most interventions focused on behaviour management, including use of psychotropic medication, seclusion rooms, and confinement to unit.

In Ontario, as in other jurisdictions in Canada and abroad, greater emphasis has been placed on the integration of persons with intellectual disability (ID) into mainstream society. Responsibility for services to persons with ID rests with the provincial Ministry of Community and Social Services (MCSS), which has closed thirteen of the sixteen institutions for persons with ID, and plans to close the last three by March 2009 (MCSS, 2004).

As a result of deinstitutionalization, the health and social service systems will experience an influx of adults with ID with complex care needs, many of whom will require long-term, mental health or home health care services. Though health care settings designed for the general population may not yet be equipped to deal with the needs of persons with ID, there is considerable urgency for this situation to change. The inability of community and long term care agencies to meet the needs of former psychiatric patients should serve as a cautionary tale in planning for the needs of persons leaving institutions.

This paper represents the first of two studies describing the characteristics of persons with ID receiving services in psychiatric and complex continuing care hospitals/units, and aims to improve our understanding of how they differ from patients without ID and to help determine what expertise needs to be developed as more adults with ID access these services. This paper focuses on psychiatric hospitals.

Psychopathology and ID

Persons with ID may experience the full range of psychiatric illnesses (Department of Health and Human Services, 2000) and are at increased risk of developing a psychopathology compared to the general population (Davidson, Prasher, & Janicki, 2003). Prevalence rates of psychiatric illnesses vary from 20% to 35% (Nezu, Nezu, & Gill-Weiss, 1992), making persons with ID up to five times more likely to develop a psychiatric illness (Borthwick-Duffy, 1994). Nevertheless, persons with ID are among the most under-serviced populations in terms of mental health services (Reed, 1997), and services provided are often limited to behaviour modification and social skills training (Baroff, 1986). There are very few studies evaluating the use psychological treatments for depression specifically (Arthur, 2003), and the presence of an ID has often been used to exclude individuals from outcome studies and therapeutic services in general (Keller, 1997).

Psychosis (Matson & Smiroldo, 1997), affective disorders (Crews, Bonaventura, & Rowe, 1994), and dementia (Cooper, 1997) are some of the most commonly diagnosed psychiatric conditions in this population. Between 5% and 10% of adults with ID have a diagnosed psychosis (Lunsky et al., 2003), and as many as three to four times more adults with than without ID have depression (Collacott, Cooper, & McGrother, 1992) and dementia (Cooper, 1997), respectively. Aggression is considered to be the most persistent, habitual and disruptive of challenging behaviours; it is observed with higher frequency in persons with ID (Gardner & Cole, 1993) and may lead to the harm of others, isolation, or placement into more restrictive environments (Bihm, Poindexter, & Warren, 1998). Prevalence rates typically fall between 9% and 24% (Jacobson, 1982), though some report rates as high as 45% in institutions (Eyman & Call, 1977) and 49% in community settings (Emerson et al., 2001).

Method

Measures

The RAI-MH was developed by a six-country research team working in collaboration with Ontario's Joint Planning and Policy Committee (JPPC) to help evaluate the needs of psychiatric patients (Hirdes et al. 1999), and its updated version (RAI-MH 2.0) has been mandated for use in all Ontario adult in-patient psychiatry beds. Hirdes et al. (2002) established the reliability (inter-rater and internal consistency) and convergent validity of the items and scales embedded in the RAI-MH among psychiatric inpatients, while Martin, Hirdes, Fries, and Smith (2006) demonstrated adequate to excellent internal consistency and criterion validity of these embedded scales among community-dwelling adults with ID.

Items in the RAI-MH. The RAI-MH consists of approximately 400 items measuring key life areas, including: mental state, substance use, harm to self and others, behaviour disturbance, cognition, self-care, communication, role functioning, social activity and support, physical health, stressors, medications, and service utilization. This paper will examine the relationship between ID and personal (age; sex; marital status; residence and living arrangement prior to admission), social (time since last contact with family/friends; presence of interpersonal conflict with family/friends, other patients, and staff; loneliness; and activity outside the facility), and clinical (medical and psychiatric diagnoses) characteristics, as well as service use (days of care from nurses and other professionals; interventions).

Embedded Scales. A series of measures are embedded in the interRAI instruments to help professionals understand the person's functioning in key areas, develop care plans, monitoring change, and evaluate interventions (Morris, Carpenter, Berg, & Jones, 2000).

a) The *Cognitive Performance Scale* (CPS) describes the individual's cognitive status using a predictive algorithm based on memory, decision-making, expression, and self-performance in eating. Scores ranges from intact (score=0) to very severely impaired (score=6).

b) The *Activities of Daily Living* (ADL) *Hierarchy Scale* measures self-performance of ADLs (i.e., personal hygiene, toilet use, mobility, and eating), classifying them according to the stages at which they can no longer be performed (to reflect the disablement process), resulting in an algorithm that yields scores ranging from independent (0) to full dependence (6).

c) The *Depression Rating Scale* (DRS) points to possible clinical depression based on the presence of negative statements, persistent anger, expressions of unrealistic fears, repetitive health-related and anxious complaints, facial expression, and crying or tearfulness over the last three days. Summary scores range from 0 to 14, where a score of 3 or more warrants further investigation into possible depression (Burrows, Morris, Simon, Hirdes, & Phillips, 2000).

d) The *Positive Symptoms Scale* (PSS) provides information psychosis, based on the presence of hallucinations, command hallucinations, delusions, and abnormal thought process/form over the last three days. The PSS is a summary scale with scores that range between 0 and 8; higher scores reflect a higher rate of positive symptoms.

e) The *Negative Symptoms Scale* (NSS) measures withdrawal based on the presence of anhedonia, withdrawal from activities, lack of motivation, and reduced social interaction over the last three days. The NSS is a summary scale with scores that range between 0 and 8; higher scores reflect a higher rate of withdrawal.

f) The *Aggressive Behaviour Scale* (ABS) indicates aggression exhibited within the last three days, based on verbal and physical abuse, socially inappropriate or disruptive behaviour, and resisting care; summary scores range from 0 to 12 (higher scores indicate more aggression).

Sample

Data from the 2000-2001 pilot implementation of the RAI-MH provides information on 3,717 patients in 34 in-patient psychiatric facilities in Ontario (*n=30*), Manitoba (*n=1*), and Alberta (*n=3*) who volunteered to implement the RAI-MH in select units for the duration of the study. The sample includes 129 individuals with ID (3.47%).

Staff (e.g., nurses, social workers, occupational therapists) in each of the participating facilities received a two-day training session on the completion of the RAI-MH and were given a *Users' Manual* that detailed the intent, definition, suggested process to obtain the information, and coding for every item in the instrument. Staff were encouraged to use their professional judgement and to use all sources of information available to complete the interRAI-MH. Assessors reported that by the end of the study they could complete the RAI-MH in about one hour.

Procedure

Logistic regression was used to evaluate the association between ID and personal, social, clinical, and service utilization variables. Characteristics significantly associated ($p<.05$) with ID are reported. The values of Cronbach's alpha are reported to demonstrate the internal consistency of embedded scales among persons with ID. However, as the CPS is based on a predictive algorithm that uses non-parallel items, Cronbach's alpha may not be calculated.

Results

Personal and Social Characteristics

Table 1 presents the results of analyses related to the association between ID and personal and social characteristics. ID was associated with increased odds of being single ($OR=6.98$), residence in a correctional ($OR=2.17$) or institutional ($OR=3.40$) setting prior to admission, living with an extended family member ($OR=1.73$) and non-relatives ($OR=6.31$), and decreased risk of having a spouse/partner ($OR=0.07$), separated or divorced ($OR=0.50$), and of living in the community ($OR=0.34$), alone ($OR=0.39$), with a spouse/partner ($OR=0.22$) or with others (0.04). ID was also related to increased odds of having seen family/friends more than one month ago ($OR=3.30$) and experiencing conflict with other patients ($OR=3.11$) and staff ($OR=2.24$), and with lesser odds of having contact with family/friends in the last week ($OR=0.46$) and feeling lonely ($OR=0.67$).

Diagnoses

Table 2 presents the results of analyses related to the relationship between ID and medical and psychiatric diagnoses. ID was associated with increased risk for neurological conditions ($OR=5.50$), organic disorders ($OR=2.22$), psychosis ($OR=2.04$), and medical comorbidity ($OR=4.50$), but with decreased risk for diagnosed anxiety ($OR=0.46$), mood ($OR=0.43$), or substance-related ($OR=0.62$) disorders.

Table 1. Relationship between ID and personal and social characteristics

	% Patients with ID (n=129)	% Patients without ID (n=3,588)	Odds ratio (95% CI)
Mean Age (SD)	43.1 (16.0)	44.9 (15.9)	0.83 (0.61-1.14)
Sex (male)	59.8	52.8	1.33 (0.93-1.90)
Marital status			
Single	83.6	42.3	6.98 (4.39-11.10)***
Married/Partner	3.1	31.5	0.07 (0.03-0.20)***
Widowed	2.3	6.1	0.38 (0.12-1.21)
Separated/Divorced	11.0	20.2	0.50 (0.29-0.88)*
Residence prior to admission			
Community	56.0	80.2	0.34 (0.24-0.49)***
Correctional	7.2	3.5	2.17 (1.08-4.37)*
Homeless	0.8	2.3	0.34 (0.05-2.45)
Institution	36.0	14.1	3.40 (2.34-4.95)***
Living arrangement prior to admission			
Alone	12.5	27.5	0.39 (0.23-0.67)**
With spouse/partner	3.9	16.2	0.22 (0.09-0.53)**
With spouse/partner/others	0.8	16.5	0.04 (0.01-0.30)*
With children (not spouse)	0.0	5.1	<.001 (<.001->1.00)
With other relatives	23.4	15.5	1.73 (1.14-2.62)*
With non-relatives	59.4	19.2	6.31 (4.40-9.05)***
Most recent contact with family/friends			
More than 30 days ago	35.7	15.0	3.30 (2.27-4.80)***
Within last 30 days	11.1	9.7	1.23 (0.70-2.17)
Within last 7 days	53.2	75.3	0.46 (0.33-0.66)***
Interpersonal conflict			
Patient hostile to family/friends	7.0	9.3	0.74 (0.37-1.46)
Patient hostile to other patients	14.0	5.0	3.11(1.85-5.23)***
Patient hostile to staff	15.5	7.6	2.24 (1.37-3.66)*
Family/friends hostile to patient	3.1	2.6	1.19 (0.43-3.29)
Loneliness	34.9	44.4	0.67 (0.47-0.97)*
Did an activity outside the facility in past 7 days	22.5	29.8	0.68 (0.45-1.04)

* p<.05   ** p<.001   *** p<.0001

Table 2: Relationship between ID and medical and psychiatric diagnoses

	% Patients with ID (n=129)	% Patients without ID (n=3,588)	Odds ratio (95% CI)
Medical diagnoses			
Gastrointestinal system	10.9	11.4	0.94 (0.54-1.66)
Heart/Circulation system	18.6	15.9	1.21 (0.77-1.90)
Infections	6.2	3.8	1.68 (0.80-3.50)
Musculoskeletal system	9.3	11.7	0.78 (0.43-1.42)
Neurological system	31.8	7.8	5.50 (3.73-8.13)***
Pulmonary system	15.5	11.9	1.36 (0.84-2.22)
Psychiatric diagnoses			
Adjustment disorder	7.0	6.5	1.09 (0.54-2.16)
Anxiety disorder	7.8	15.4	0.46 (0.24-0.88)*
Eating disorder	2.3	3.1	0.75 (0.23-2.38)
Mood disorder	23.3	41.4	0.43 (0.28-0.65)***
Organic disorder	12.4	6.0	2.22 (1.29-3.82)*
Personality disorder	14.0	15.3	0.90 (0.54-1.49)
Schizophrenia/Psychosis	40.3	24.8	2.04 (1.43-2.93)***
Substance-related disorder	17.8	25.9	0.62 (0.39-0.98)*
Mean (SD) Number of medical diagnoses	1.9 (1.5)	0.8 (1.2)	4.50 (3.29-6.17)***
Mean (SD Number of psychiatric diagnoses	1.3(1.1)	1.4 (1.0)	0.69 (0.51-1.02)

* p<.05   ** p<.001   *** p<.0001

Treatments and Interventions

Table 3 shows the results of analyses related to the association between ID and days of care from nurses and other professionals, while Table 4 shows the relationship between ID and interventions. ID was associated with more days of nursing care for crisis (OR=1.29) and medical (OR=1.76) interventions, physical assistance (OR=2.60), and from recreational therapists (OR=1.34).

ID was associated with increased odds of receiving behaviour management (OR=2.87), seclusion rooms (OR=3.09), confinement to the unit (1.89), constant observation (OR=1.85), neuroleptics/antipsychotics (OR=3.76), anxiolytics (OR=1.50), mood stabilizers (OR=1.77), and more medications overall (OR=2.06). Conversely, ID was associated with decreased risk of receiving alcohol/drug (OR=0.41) and smoking (OR=0.23) interventions, community reintegration (OR=0.50), antidepressants (OR=0.50), and hypnotics/sedatives (OR=0.65).

Table 3. Relationship between ID and days of care received from nurses and other professionals

	% Patients with ID (n=129)	% Patients without ID (n=3,588)	Odds ratio (95% CI)
Mean (SD)			
Days of nursing care			
in last 7 days for:			
Crisis intervention	1.0 (1.9)	0.6 (1.3)	1.29 (1.07-1.75)*
Family support	0.7 (1.3)	0.6 (1.3)	1.12 (0.76-1.65)
Medical interventions	2.5 (3.1)	1.4 (2.3)	1.76 (1.24-2.50)*
One-to-one counselling	3.2 (2.7)	3.2 (2.3)	0.51 (0.41-1.06)
Physical assistance	2.3 (3.1)	0.9 (2.1)	2.60 (1.82-3.72)***
Teaching	3.3 (3.0)	2.4 (2.4)	1.10 (0.76-1.60)
Mean (SD)			
Days of care in			
last 7 days from:			
Occupational therapist	0.5 (1.2)	0.4 (1.1)	1.58 (0.98-1.97)
Physician - last 7 days	1.1 (1.5)	1.2 (1.7)	1.12 (0.79-1.59)
Psychiatrist	2.1 (1.8)	2.1 (1.8)	1.21 (0.84-1.76)
Psychologist	0.3 (0.9)	0.2 (0.7)	1.20 (0.73-1.97)
Recreational therapist	1.5 (2.0)	1.0 (1.6)	1.34 (1.04-1.9)*
Social worker	0.9 (1.4)	0.9 (1.4)	1.03 (0.72-1.48)

* p<.05   ** p<.001   *** p<.0001

Table 4. Relationship between ID and interventions, observation, and psychotropic medications

	% Patients with ID (n=129)	% Patients without ID (n=3,588)	Odds ratio (95% CI)
Interventions			
Alcohol/Drug treatment	8.5	18.7	0.41 (0.22-0.76)*
Anger management	5.4	6.9	0.78 (0.36-1.68)
Behaviour management	7.8	2.8	2.87 (1.46-5.64)**
Community reintegration	7.0	13.0	0.50 (0.25-0.99)*
Respite care	3.9	3.5	1.12 (0.45-2.78)
Smoking cessation	2.3	9.4	0.23 (0.07-0.73)*
Vocational rehabilitation	7.0	4.5	1.61 (0.80-3.22)
Observation			
Seclusion room	12.4	4.4	3.09 (1.79-5.35)***
Confinement to room	7.0	4.0	1.81 (0.90-3.63)
Confinement to unit	60.5	44.7	1.89 (1.32-2.71)**
Close observation	31.8	26.3	1.31 (0.90-1.91)
Constant observation	11.6	6.6	1.85 (1.06-3.22)*

Table 4.   (cont'd)

	% Patients with ID (n=129)	% Patients without ID (n=3,588)	Odds ratio (95% CI)
Psychotropic medications			
Neuroleptic/Antipsychotic	79.1	50.1	3.76 (2.45-5.77)***
Anxiolytic	57.4	47.2	1.50 (1.05-2.14)*
Anti-depressant	31.0	47.3	0.50 (0.34-0.73)**
Mood stabilizer	27.9	17.9	1.77 (1.20-2.63)*
Hypnotic/Sedative	19.4	27.0	0.65 (0.42-0.99)*
Mean (SD)			
Number of medications	5.1 (3.0)	3.8 (3.1)	2.06 (1.52-2.81)***

* p<.05   ** p<.001   *** p<.0001

Embedded Scales

Acceptable levels of internal consistency (Cronbach's alpha) were reported for patients with and without ID for the ADL Hierarchy (0.90 for both), DRS (0.79 and 0.77, respectively), PSS (0.71 and 0.70, respectively), and NSS (0.83 and 0.85, respectively); weaker values were reported for patients with ID for the ABS (0.59 compared to 0.75 for patients without ID). Table 5 shows the results of analyses related to the relationship between ID and embedded scales.

With the exception of the NSS, where patients with ID were less likely to show any signs of withdrawal (*OR*=0.67), ID was related to increased risk of showing signs of impairment in cognition (6.12), impairment in ADLs (4.55), any positive symptoms (1.72), and any aggression (*OR*=3.32). Though the presence of an ID was not significantly related to the DRS cut-off score for possible depression (i.e., 3+), it was associated with the total DRS scale score. Specifically, for each point of its fourteen point range, the presence of an ID was associated with a 1.37 increase in the odds of showing depressive symptomology (95% CI=1.01-1.86, p<.05).

Table 5.   Relationship between the ID and embedded scale scores

		% Patients with ID (n=129)	% Patients without ID (n=3,588)	Odds ratio (95% CI)
Cognitive Performance Scale (CPS)				6.12 (4.45-8.40)***
Intact	(0)[1]	16.3	49.4	
Borderline Intact	(1)	15.5	24.6	
Mild impairment	(2)	3.9	6.3	
Moderate impairment	(3)	34.9	13.1	
Moderate-severe impairment	(4)	5.4	1.1	
Severe impairment	(5)	20.2	5.0	
Very severe impairment	(6)	3.9	0.6	
ADL Hierarchy Scale				4.55 (3.25-6.38)***
Independence	(0)	50.4	83.3	
Supervision	(1)	24.0	9.5	
Limited assistance	(2)	10.1	1.7	
Extensive assistance - level I	(3)	9.3	3.0	
Extensive assistance - level II	(4)	1.6	1.1	
Dependence	(5)	1.6	1.0	
Total dependence	(6)	3.1	0.4	
Depression Rating Scale (DRS)				1.15 (0.81-1.63)
% No signs of depression	(0-2)	49.6	53.1	
% Possible depression	(3+)	50.4	46.9	
Positive Symptoms Scale (PSS)				1.72 (1.21-2.44)*
No positive symptoms	(0)	51.2	64.2	
Any positive symptoms	(1+)	48.8	35.8	
Negative Symptoms Scale (NSS)				0.67 (0.47-0.95)*
No negative symptoms	(0)	51.9	41.9	
Any negative symptoms	(1+)	48.1	58.1	
Aggressive Behaviour Scale (ABS)				3.32 (2.35-4.68)***
No aggression	(0)	54.3	79.8	
Mild to moderate aggression	(1-5)	32.6	15.8	
Severe aggression	(6+)	13.2	4.4	

* p<.05   ** p<.001   *** p<.0001
[1] (n)=Category rating on the indicated scale

Discussion

This paper focused on evaluating the relationship between ID and various personal, social, and clinical characteristics, and service utilization in inpatient psychiatry. Patients with ID had experienced different living arrangements prior to admission, and currently had less contact with loved-

ones and more conflict with others in the facility compared to those without ID. Subsequent analyses (not shown) revealed that, though significant at the bivariate level, the addition of aggressive behaviour to models predicting interpersonal conflict with other patients and staff rendered the presence of an ID non-significant. This highlights the need for staff training in managing aggression among patients with ID.

Patients with ID exhibited three times the rate of severe aggressive behaviour, and over twice the rate of mild to moderate aggressive behaviour compared to patients without ID. Subsequent analyses (not shown) also showed that ID was associated with a five fold increase in the odds of impaired expressive communication and almost six times the risk for impaired receptive communication, which is consistent with the literature on increased behaviour disturbance among those persons with ID with limited communication skills (Emerson et al., 2001). Both types of communication skills were associated with increased risk of aggression; the presence of an ID remained significant in the model. Interventions aimed at improving communication may help to reduce aggressive behaviour in this population.

Patients with ID had higher rates of functional impairment, were more often diagnosed with an organic or psychotic disorder, in addition to having a higher rate of comorbid medical conditions. Though the literature is quite clear on the increased need for help with self-care and risk of medical comorbidity among persons with ID, it has been argued that psychosis is over-diagnosed in this population (Lunsky et al., 2003).

While less likely to have a diagnosed mood disorder, patients with ID exhibited higher rates of depressive symptomology than those without ID. It has been argued that current diagnostic criteria (i.e., ICD-10 or DSM IV-TR) may not be appropriate in diagnosing depression in adults with ID, and lead to a disproportionate number of false negatives (Davis, Judd, & Herrman, 1997), though professional bias is also thought to play a role (Balboni, Battagliese, & Pedrabissi, 2000; Bütz, Bowling, & Bliss, 2000). Despite much higher rates of depressive symptoms, patients with ID were seldom offered counselling or antidepressant medication. Consequently, depressive symptoms are recognized, but the underlying condition of depression remains largely undiagnosed and untreated.

The interventions received by patients with ID consisted mainly of behaviour management and use of psychotropic medication, seclusion rooms and confinement to unit. While this may be in line with elevated rates

of aggression, analyses (not shown) revealed that behaviour management and use of seclusion rooms remained less prevalent among patients without ID, even if exhibiting severe aggression. The fact that approximately 80% of patients with ID had received antipsychotic/neuroleptic medication is astonishing. Patients with ID remained two and a half times more likely to receive antipsychotics/neuroleptics even after controlling for the presence of aggression and diagnosed psychosis (analyses not shown). These findings warrant further investigation into the care provided to patients with ID in inpatient psychiatry. In particular, it would be useful to examine whether practice patterns differ based on the presence of a specialized dual diagnosis unit in the facility.

Given that impairment in self-care skills among patients with ID is recognized, the finding that they were less likely to receive interventions focused on community reintegration than patients without ID was surprising. Although the goal of care in psychiatric hospitals is to treat the specific issues currently affecting the individual, interventions aimed at helping the individual return to and remain in the community are necessary. That persons with ID had been in hospital approximately four times longer than those without ID and can be expected to be longer-stay patients should not diminish the importance of interventions focused on community reintegration.

There are some limitations to this study. First, the sample was based on entire units from volunteer hospitals that used the RAI-MH as part of normal practice for the duration of the study. Though it reflects the characteristics clinicians would expect to see, the sample may have some limitation in generalizability (Hirdes et al., 2002). Second, the study may also be limited by its conceptualization of ID. It remains unclear what specific types of conditions may fall into the broad categories of 'developmental disability' and 'developmental handicap', and conditions that involve intellectual impairment but where it is not the underlying characteristic (e.g., cerebral palsy) may have been included under this umbrella term. Further, the reliance on secondary analyses of the RAI-MH data meant that research questions were limited by the items available in the instrument. For example, the relationship between aggression and the severity of ID (i.e., borderline, mild, moderate, severe, and profound) could not be explored. Last, due to the small number of adults with ID in the sample, some statistical analyses were limited in scope. As a result, the paper focused only on the bivariate relationship between the presence of an ID and the variables of interest. Future studies should re-examine these models in larger samples of adults with ID and include other variables as well as interactions effects.

Conclusions

With such a low prevalence of persons with ID in inpatient psychiatry, it may not appear feasible to administration to promote expertise in caring for this population. However, given that the RAI-MH is now mandated in adult inpatient psychiatry, census data from those assessments can be used in the future to evaluate and monitor the needs, service utilization, and outcomes of psychiatric patients with ID.

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