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Examining the Characteristics of Persons with Intellectual Disability Receiving Hospital Services: Part 2 - Complex Continuing Care 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 all persons with ID receiving care in Ontario's complex continuing care hospitals, and compares them to patients without ID in the same setting. Overall, patients with ID appeared to be more clinically complex given their higher rates of functional impairment and aggressive behaviour, despite exhibiting less medical complexity.However, interventions mostly focused on behaviour management.

Improved medical technologies and quality of life of adults with intellectual disability (ID) has meant that a larger number of individuals have survived past infancy and well into adulthood (Janicki, Dalton, Henderson, & Davidson, 1999). The gap between the life expectancy of adults with and without ID has narrowed over the last few decades, and will inevitably continue to do so. Just as in the aging population, adults with ID will become at risk of developing age-related health conditions resulting in the need for formal services.

While the creation of community living services, along with educational, vocational, and recreational opportunities have allowed adults with ID to become a part of mainstream society, it appears that they still struggle to fit into the current health care system (Ouellette-Kuntz, 2005).

This is the second of two papers describing the characteristics of adults with ID receiving hospital-based health care services in Ontario. The first paper focused on inpatient psychiatry, while the results presented here depict persons in complex continuing care (CCC) hospitals/units.

Physical Health, Aging, and Intellectual Disability

Though adults with ID experience many of the same health conditions as in the general population, they have been described as a group with specific disability-linked comorbidity not found to the same extent in the general population (Janicki et al., 2002); complications associated with their ID put them at additional risk for health problems (Lunsky et al., 2003). Eight bodily areas or systems have been identified as being especially problematic in this population, including the gastrointestinal (van Schrojenstein Lantman-deValk et al., 1997), endocrine (van Schrojenstein Lantman-de Valk, Haveman, & Crebolder, 1996), genitourinary, respiratory, musculoskeletal (Cheetham, 2003), and central nervous (Matson, Bamburg, Mayville, & Khan, 1999) systems, as well as skin (Cheetham, 2003) and the head and neck area (Evenhuis, Mul, Lemaire, & de Wijs, 1997). The risk for problems in many of these areas has been found to increase with age, and severity and etiology of ID (Matson et al., 1999).

Communication deficits, atypical presentation of symptoms, inadequate management of treatable conditions, and lack of systematic and regular health examination have led to inadequate medical care in this population (Cheetham, 2003). For example, Béange, McElduff, and Baker (1995) identified 95% of adults with ID in their sample as having a health problem using a simple medical exam; 40% were afflicted by six or more health problems and 42% had health conditions that were previously unnoticed. Regular physical examination is important not only for health monitoring, but also for early identification of conditions that may otherwise go undetected (Cooper, 1998).

As in the general population, the physical changes associated with aging may have an impact on both the self-care skills of persons with ID and the ability of their informal network to continue providing support. In 2005, the Ontario Partnership on Aging and Developmental Disabilities (OPADD) developed a guide to assist persons with ID and their families plan for the transition into old age, pointing to long-term care as an appropriate setting for those with more complex care needs. The combination of medical comorbidity, population aging, and community integration has imposed some urgency on the formal health care system to better appreciate the needs of adults with ID.

Method

Measures

The *Resident Assessment Instrument* (RAI) was developed to evaluate the needs of elderly nursing home residents (Hawes et al., 1997), and has been mandated in all US nursing homes since 1995. There exists a wide body of evidence demonstrating the psychometric properties of the RAI 2.0 (Morris et al., 1990; Hawes et al., 1997).

Items in the RAI 2.0. The RAI 2.0 consists of approximately 400 items that measure the person's status in key domains (cognition, communication, senses, mood and behaviour, psychosocial well-being, self-care, continence, medical diagnoses, physical health, activities, service utilization). This paper will examine the relationship between ID and personal (age; sex; marital status; residence and living arrangement prior to admission), social (absence of contact with family/friends; interpersonal conflict with family/friends and staff; unhappiness with roommate and other residents; involvement in life of facility; time spent in activities), and clinical (medical and psychiatric diagnoses) characteristics, as well as service use (days of nurse training and care from other professionals; special programs; restraints; psychotropic medication).

Embedded scales. As in the RAI-MH, a series of measures are embedded in the RAI 2.0 to help professionals understand the person's status in key areas. Scales measuring cognition (*Cognitive Performance Scale*, CPS), self-care skills (*ADL Hierarchy Scale*), depression (DRS), and aggression (ABS) described in the first part of this paper will again be used here. Further, scores on the *Changes in Health, End-stage disease, and Signs and Symptoms* (CHESS) scale will be examined. The CHESS represents a calculation of health instability, based on the presence of cognitive decline, ADL decline, shortness of breath, dehydration or insufficient fluid, edema, vomiting, weight loss, and decrease in amount of food or fluid usually consumed; scores range from 0 (Not at all unstable) to 4 (Highly unstable). The psychometric properties of this scale have been demonstrated in long-term care settings (Hirdes, Frijters, & Teare, 2003).

Sample

In 1996, the Ontario Ministry of Health and Long Term Care (MoH-LTC) mandated the use of the RAI 2.0 in all its complex continuing care (CCC) hospitals/units, with the requirement that facilities submit data to the Canadian Institute for Health Information's Ontario Chronic Care Patient System (OCCPS) (Hirdes et al., 1999). The OCCPS provides information on all 86,663 patients assessed between 1996 and 2003, including 753 patients with ID (0.9%).

Procedure

Logistic regression was used to evaluate the association between ID and various personal, social, clinical, and service utilization variables; only those significantly associated ($p<.05$) with ID are reported. The internal consistency of embedded scales is reported for all but the CPS and CHESS, for which Cronbach's alpha may not be calculated (both are based on predictive algorithms that uses non-parallel items).

Results

Personal and Social Characteristics

Table 1 shows the results of analyses related to the relationship between ID and personal and social characteristics. ID was related to increased odds of being younger (*OR*=0.88), never married (*OR*=16.95), having resided in the community prior to admission (*OR*=1.84), having no contact with family or friends (*OR*=2.37), experiencing conflict with family or friends (*OR*=1.37), and being unhappy with other residents (*OR*=1.67), though it was associated with a decreased risk of being married (*OR*=0.30) or widowed (*OR*=0.22), having been admitted from another active treatment hospital (*OR*=0.56), having lived alone prior to admission (*OR*=0.36), and pursuing involvement in facility life (*OR*=0.70).

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 (SD) Age	55.3 (22.1)	76.9 (12.5)	0.88 (0.71-0.92)***
Sex (female)	56.7	57.8	0.96 (0.83-1.11)
Marital status			
Single	60.6	8.3	16.95 (14.61-19.65)***
Married	16.9	40.3	0.30 (0.25-0.36)***
Widowed	13.0	41.1	0.22 (0.17-0.27)***
Separated/Divorced	5.8	6.3	0.91 (0.67-1.24)
Residence prior to admission			
Community	21.7	13.0	1.84 (1.55-2.19)***
Long-term care	4.3	3.3	1.31 (0.91-1.86)
Hospital setting	74.0	83.7	0.56 (0.47-0.66)***
Lived alone prior to admission	11.3	26.0	0.36 (0.29-0.45)***
Absence of contact with family/friends	15.5	7.2	2.37 (1.94-2.89)***
Interpersonal conflict			
Conflict with family or friends	10.2	7.7	1.37 (1.08-1.74)*
Unhappy with roommate	5.1	4.5	1.14 (0.82-1.58)
Unhappy with other residents	4.3	2.6	1.67 (1.17-2.39)*
Conflict or criticism of staff	6.8	5.6	1.23 (0.92-1.63)
Pursues involvement in life of facility	13.9	18.9	0.70 (0.57-0.85)**
Average time involved in activities			
Most	18.9	17.7	1.08 (0.90-1.30)
Some	27.4	30.0	0.88 (0.75-1.03)
Little	52.1	51.0	1.05 (0.91-1.21)

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

Diagnoses

Table 2 shows the results of analyses related to the relationship between ID and medical and psychiatric diagnoses. ID was associated with increased risk of neurological disorders (*OR*=2.36), bipolar disorder (*OR*=4.68), dementia (*OR*=1.41), schizophrenia (*OR*=8.95), and psychiatric comorbidity (*OR*=1.50), but with decreased risk of cardiac/circulatory (*OR*=0.31), musculoskeletal (*OR*=0.46), pulmonary (*OR*=0.51), sensory (*OR*=0.44), and mood (*OR*=0.77) disorders, as well as medical comorbity (*OR*=0.51).

Table 2. Relationship between ID and medical and psychiatric diagnoses

	% Patients with ID (n=753)	% Patients without ID (n=85,910)	Odds ratio (95% CI)
Medical diagnoses			
Heart/Circulation	26.0	53.5	0.31 (0.26-0.36)***
Musculoskeletal	21.0	36.6	0.46 (0.39-0.55)***
Neurological	70.3	50.0	2.36 (2.02-2.76)***
Pulmonary	9.0	16.2	0.51 (0.40-0.66)***
Sensory	5.2	11.0	0.44 (0.32-0.61)***
Psychiatric diagnoses			
Anxiety	6.4	5.1	1.28 (0.95-1.72)
Depression	12.2	15.3	0.77 (0.62-0.96)*
Bipolar	4.1	0.9	4.68 (3.24-6.75)***
Dementia	27.4	21.1	1.41 (1.20-1.66)***
Schizophrenia	7.7	0.9	8.95 (6.78-11.80)***
Mean (SD) Number of medical diagnoses	2.6 (1.9)	3.4 (2.2)	0.51 (0.45-0.58)***
Mean (SD) Number of psychiatric diagnoses	0.6 (0.7)	0.4 (0.7)	1.50 (1.30-1.72)***

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

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 its relationship to interventions. ID was associated with decreased odds of receiving nursing care for training in bed mobility (*OR*=0.63), transfer (*OR*=0.59), walking (*OR*=0.48), and dressing/grooming (*OR*=0.67), as well as fewer days of care from occupational therapists (*OR*=0.65), physical therapists (*OR*=0.46) and physicians (*OR*=0.62). However, ID was related to increased odds of having received respiratory therapy (*OR*=1.48).

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

	% Patients with ID (n=753)	% Patients without ID (n=85,910)	Odds ratio (95% CI)
Mean (SD) Days of nurse training in last 7 days for:			
Bed mobility	1.3 (2.7)	1.9 (3.1)	0.63 (0.52-0.75)***
Transfer	1.9 (3.0)	2.7 (3.3)	0.59 (0.51-0.69)***
Walking	1.2 (2.6)	2.2 (3.1)	0.48 (0.40-0.57)***
Dressing/Grooming	1.8 (3.0)	2.4 (3.3)	0.67 (0.57-0.79)***
Eating/Swallowing	1.2 (2.6)	1.2 (2.6)	1.07 (0.89-1.29)
Communication	1.1 (2.5)	1.0 (2.4)	0.56 (0.25-1.24)
Mean (SD) Days of care in last 7 days from:			
Mental health professional	0.2 (0.6)	0.2 (0.7)	1.07 (0.82-1.38)
Occupational therapist	0.8 (1.4)	1.1 (1.6)	0.65 (0.56-0.76)***
Physical therapist	1.4 (1.9)	2.2 (2.1)	0.46 (0.40-0.53)***
Physician (in last 14 days)	3.3 (2.7)	4.1 (3.1)	0.62 (0.49-0.78)***
Respiratory therapist	0.3 (1.3)	0.2 (1.2)	1.48 (1.11-1.97)**
Speech therapist	0.2 (0.6)	0.2 (0.7)	0.87 (0.67-1.15)

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

ID was related to a higher probability of receiving treatment in an Alzheimer's or dementia unit (*OR*=2.45), respite (*OR*=3.78), restraints involving trunk (*OR*=1.95), limb (*OR*=2.99), and chairs that prevent rising (*OR*=2.85), and antipsychotic medication (*OR*=1.86). Conversely, ID was associated with decreased probability of receiving hospice care (*OR*=0.41), nurse training in community reintegration skills (*OR*=0.42), and multiple medications (*OR*=0.54).

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

	% Patients with ID (n=753)	% Patients without ID (n=85,910)	Odds ratio (95% CI)
Special programs in last 14 days			
Alzheimer's/Dementia unit	11.2	4.9	2.45 (1.95-3.07)***
Hospice care	4.9	11.3	0.41 (0.29)***
Respite care	14.6	4.3	3.78 (3.08-4.65)***
Community reintegration skills	11.2	22.9	0.42 (0.34-0.53)***

(continued)

Table 4. (cont'd)

	% Patients with ID (n=753)	% Patients without ID (n=85,910)	Odds ratio (95% CI)
Restraint use in last 7 days			
Trunk restraint	19.9	11.3	1.95 (1.63-2.33)***
Limb restraint	3.1	1.0	2.99 (1.96-4.55)***
Chair prevents rising	28.0	12.0	2.85 (2.43-3.35)***
Psychotropic medications in last 7 days			
Antipsychotic	25.5	15.5	1.86 (1.58-2.20)***
Antianxiety	31.7	32.0	0.99 (0.85-1.15)
Anti-depressant	19.8	22.3	0.86 (0.72-1.03)
Hypnotic	13.3	12.4	1.09 (0.88-1.34)
Mean (SD) Number of medications	7.5 (4.3)	9.1 (5.3)	0.54 (0.47-0.61)***

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

Embedded Scales

Good to excellent levels of internal consistency (Cronbach's alpha) were reported for patients with and without ID, respectively, for the ADL Hierarchy Scale (0.85 and 0.86), DRS (0.78 and 0.74) and ABS (0.93 and 0.95).

Table 5 shows results related to the association between ID and embedded scales. With the exception of the CHESS, where ID was related to decreased risk of showing any signs of health instability (*OR*==0.45), ID was significantly associated with increased risk of cognitive impairment (*OR*==3.92), impairment in ADLs (*OR*==2.13), possible depression (*OR*==1.44), and any signs of aggression (*OR*==2.28).

Table 5. Relationship between ID and embedded scale scores

		% Patients with ID (n=753)	% Patients without ID (n=85,910)	Odds ratio (95% CI)
Cognitive Performance Scale (CPS)				3.92 (3.45-4.45)***
Intact	(0)[1]	5.8	26.1	
Borderline Intact	(1)	11.6	17.0	
Mild impairment	(2)	8.2	12.5	

(continued)

Table 5. (cont'd)

		% Patients with ID (n=753)	% Patients without ID (n=85,910)	Odds ratio (95% CI)
Moderate impairment	(3)	19.5	20.3	
Moderate-severe impairment	(4)	6.4	5.2	
Severe impairment	(5)	15.3	8.0	
Very severe impairment	(6)	33.2	11.0	
ADL Hierarchy Scale				2.13 (1.87-2.43)***
Independence	(0)	3.7	8.1	
Supervision	(1)	6.0	7.6	
Limited assistance	(2)	7.4	14.2	
Extensive assistance - level I	(3)	15.8	13.5	
Extensive assistance - level II	(4)	7.4	8.3	
Dependence	(5)	21.9	30.8	
Total dependence	(6)	37.7	17.5	
				0.45 (0.40-0.51)***
No instability	(0)	40.2	28.0	
Any instability	(1+)	59.8	72.0	
Depression Rating Scale (DRS)				1.44 (1.22-1.69)***
% No signs of depression	(0-2)	72.1	78.8	
% Possible depression	(3+)	27.9	21.2	
Aggressive Behaviour Scale (ABS)				2.28 (1.98-2.63)***
No aggression	(0)	58.8	76.4	
Mild to moderate aggression	(1-5)	32.0	19.6	
Severe aggression	(6+)	9.2	4.0	

**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 use in CCC hospitals. Patients with ID tended to be younger, male, more socially isolated, and more functionally impaired, though they had less medical comorbidity and health instability than patients without ID. The latter finding was somewhat, but not altogether surprising, given the body of literature describing the increased risk for both medical comorbidity and unrecognized/untreated health problems.

Patients with ID exhibited more signs of depression, though they were less likely to have a diagnosis of depression, and equally likely to receive antidepressant medication or to have seen a mental health professional. Education is needed to help staff recognize not only the symptoms, but the underlying syndrome of depression as well.

Patients with ID exhibited twice the rate of aggression and more frequently indicated unhappiness with other residents in the facility. However, subsequent analyses (not shown) revealed that aggression was more important in predicting unhappiness with other residents than was the presence of an ID. Higher rates of restraint and antipsychotic medication use were noted for patients with ID, which may be in response to elevated levels of aggressive behaviour (e.g., to prevent injury to the patient or others) or functional impairment (e.g., to prevent the patient from falling out of a chair). However, subsequent analyses (not shown) demonstrated that, even when controlling for cognitive and ADL impairment, health instability, and aggression, patients with ID remained at higher risk for being in chairs that prevent rising compared to patients without ID. Controlling for presence of aggression and a diagnosis of schizophrenia, patients with ID remained at increased risk for use of antipsychotic medication (analyses not shown). The combination of ID, dependency, and psychopathology may have lead to an overall higher level of care complexity than staff were accustomed to, or equipped for; education to help staff understand and manage aggressive behaviour among persons with ID is needed. The circumstances surrounding use of restraints and antipsychotic medication in this population also merits attention.

Despite having recognized impairment in self-care skills, patients with ID were less likely to receive interventions aimed at improving ADL self-performance or community reintegration. Though the majority of all patients had been hospitalized for less than one year, almost four times as many patients with ID had been hospitalized for over one year (2.3% compared to 0.6%, respectively). The fact that persons with ID are often longer-stay patients should not diminish their access to interventions aimed at improving independence, but rather provides the opportunity for more intensive intervention focused on improving these skills.

Persons with ID had over twice the rate of problems with chewing and swallowing, but were just as likely to receive training from a nurse in eating/swallowing as patients without ID; they were also less likely to receive interventions focused on communication or speech therapy, despite being at much higher risk for impaired expressive and receptive communication (analyses not shown). These finding further illustrates how easily identifiable problems (such as feeding and communication) remain under-detected and untreated in this population.

There are some limitations to this study. Reliance on secondary analyses meant that research questions were limited by the items available in the RAI 2.0. For example, the relationship between aggression and the severity of ID could not be assessed, and the presence of positive and negative symptoms could not be determined. Though sample size would have permitted more sophisticated models, (i.e., multivariate models), these were made to be consistent with Part 1 of this study. As the RAI-MH is now mandated, the research team will soon have access to census-data on all persons receiving inpatient psychiatric services in Ontario; at that time, multivariate models will be developed.

Conclusion

As in psychiatric hospital settings, the prevalence of persons with ID in CCC is low, making it difficult to promote adequate and focused care standards for this population. Even with the mandated use of an assessment instrument capable of identifying patient-specific needs, there remains a discrepancy between recognized needs and interventions received by patients with an ID – this undoubtedly deserves further attention.

Final Comments

In both hospital settings, interventions for patients with ID focused primarily on controlling behaviour, rather than promoting self-care skills or addressing other clearly identified physical and mental health problems. Research that further delves into the reasons underlying the discrepancies between identified needs and interventions, as well as the tendency for higher use of restraints, control, and psychotropic medication among patients with ID is certainly warranted, and necessary if the health care system intends to provide appropriate care to its patients with ID. In light of the forthcoming relocation of approximately 1,000 institutionalized Ontarians with ID into the community, and the growing and aging population of persons with ID, there is some urgency for this to happen.

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