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Review of Inpatient Admissions of Individuals With Autism Spectrum Disorders to a Specialized Dual Diagnosis Program

Anna M. Palucka and Yona Lunsky

Abstract

The treatment of challenging behaviour and psychiatric disorders in adults with autism spectrum disorder (ASD) is particularly difficult. Most severe presentation are especially stressful to caregivers in the community and may lead to hospitalization even though the resulting change in routine and loss of caregivers can be severely detrimental to the patient. This paper reports on the results of a review of all inpatient admissions of clients with ASD to a specialized Dual Diagnosis Program over a six year period. Demographic characteristics, information on reasons for referral, comorbid diagnoses, length of hospitalization, barriers to discharge and discharge placement as well as rates that hospitalization poses for this group of vulnerable clients.

Recent epidemiological studies estimate of rates for autism spectrum disorder (ASD) to be 6:1000 (Fombonne, 2003; Tidmarch & Volkmar, 2003), which is much higher than once thought. At the same time, there is limited research on adults with ASD and mental health problems and the actual prevalence rates for various psychiatric disorder in this population have not been determined (Tidmarch & Volkmar, 2003). It is known, however, that intellectual disability is present in 75% of individuals with ASD (Bradley & Lofchy, 2005) and a significant proportion of these individuals will have severe communication difficulties.

Several authors have recently examined predictive factors for inpatient hospital admission in the dual diagnosis population (e.g., Cowley at al., 2005; Xentidis et al., 2004), but none has considered the ASD subpopulation specifically. The purpose of the present study was to provide some preliminary information on the characteristics of individuals with ASD who required an inpatient admission to a specialized dual diagnosis program.

Method

All admission of clients with ASD to the inpatient Dual Diagnosis Program at the Centre for Addiction and Mental Health between October 1998 and October 2004 were reviewed with respect to: reason for admission, basic demographics, psychiatric diagnoses, length of hospitalization, barriers to discharge, placement at discharge, and re-admission rates.

Results

Characteristics of Clients

In total, 36% of (13 out of 36) of patients admitted during the study period had a diagnosis of ASD. Of these, the majority were male (69%). The mean age at admission was 28 years with the range from 17 to 52 years. Almost half (46%) of the patients were born outside Canada, and two were born in Canada to immigrant families.

Developmental Disorder Diagnoses

The most frequent diagnosis of the autism spectrum disorders was autistic disorder (69%), followed by Asperger's syndrome (15%) and pervasive developmental disorder NOS (15%). Almost 40% of patients had severe intellectual disability (ID). Fifteen percent of patients were at the moderate and mild level of ID each. Thirty–one percent functioned at the borderline level of intelligence.

Psychiatric Disorders

With regard to psychiatric diagnosis, almost half (46%) of the ASD patients had a confirmed or tentative diagnosis of a bipolar mood disorder. Psychotic spectrum disorders were diagnosed in three cases and involved schizophrenia (1) and psychosis NOS (2). There was one case where obsessive compulsive disorder needed to be ruled out. Twenty-three percent of patients had no co-morbid psychiatric diagnosis.

Reason for Admission

Serious physical aggression was identified as the reason for seeking inpatient admission in 77% of the sample. For the remaining patients, the reasons involved behaviours difficult to manage by parents (15%) and risk of self-harm/suicide (7.7%).

Hospitalization and Discharge

The length of hospitalization ranged from approximately two months to four years, with 295 days being the average length of stay. Following discharge, four individuals were re-admitted. Of those, two were re-admitted for a very brief stay during the transition process, whereas the other two were re-admitted following serious incidents of aggression and the subsequent break down of their community supports.

Locked seclusion rooms and/or mechanical restraints were used at some point during the hospitalization to manage incidents of aggression with 69% of the patients. PRN (*pro re nata*; as needed) medication for agitation and aggression were used with all except one patient. All patients received behavioural consultation and interventions as part of their treatment package.

Long length of stay was often related to the inability to discharge the patient back to the original primary care provider, who, in over 50% of cases, was the family. The majority (71%) of individuals who lived with their families prior to admission were not able to return home and were subsequently placed in group homes. In two cases, this was due to the death of one of the parents or a guardian. Two of the patients, who before coming to hospital lived in group homes for people with developmental disabilities, lost their residential placement as the agencies felt very strongly that they could no longer support the individuals due to the severity of their aggression. One of those individuals was eventually placed with a different community agency, and the other remains in hospital with no placement option yet identified.

Discussion

Individuals with ASD constituted a significant proportion (over one third) of all inpatient admissions to a specialized dual diagnosis program. In this group, the most frequent diagnosis was autistic disorder. Of comorbid psychiatric diagnoses, the most prevalent was a bipolar mood disorder, while almost a quarter had no psychiatric diagnosis besides the ASD. Serious physical aggression was the single most frequent reason for seeking inpatient admission in three quarters of the cases. Over one third of patients with ASD had a severe level of intellectual disability and associated severe communication difficulties. Almost half of the patients were born outside Canada.

Length of inpatient stay was related to placement difficulties due to severity of aggression or other challenging behaviours, particularly for individuals

who lived with parents prior to hospitalization and who required an alternative placement as the parents were no longer able to look after the individual at home. In extremely severe cases, when aggression involved injuries to staff, even the agencies refused to accept the individual back.

Findings reported here highlight the need for increased emphasis on supporting families and agencies prior to crisis to avoid the breakdown of support systems. While in some cases hospitalization may not be avoidable, it appears that in many cases it would not have been necessary had the planning for alternative accommodation started earlier before families and/or service producers became exhausted. Increased support in the community prior to hospitalization may also reduce the unnecessarily long hospital admissions reported here (see also Lunsky et al., in press). Prolonged inpatient admissions with all individuals with dual diagnosis but particularly individuals with ASD can have iatrogenic effects on the patient. By its very nature, hospitalization is a very disruptive event for the person with ASD as it leads to separation from significant others and disruption of routines — very significant stressors for individuals with ASD (Groden et al., 1994). In addition, characteristics of a hospital milieu, such as noise and limited space, limited food and recreation options, multiple care providers, and no direct access to an outside yard, make it a very restrictive environment compared to a community residence.

The finding that over half of the patients come from immigrant families requires further investigation to better understand the interplay between cultural factors and understanding of diagnosis, and family stress in families with individuals with ASD and aggressive behaviours. Our clinical observation is that the majority of these families had limited, late access to specialized services, combined with difficulty understanding the autism diagnosis and unrealistic treatment expectations (changing/curing autism). This often leads to an adversarial relationship with care providers as patients perceive the “failure” to treat autism as the system’s failure. The deeper understanding of these issues would help to inform development of appropriate culturally sensitive supports and services for these vulnerable families who are often disadvantaged because of language difficulties, lack of knowledge of existing services and resources, financial problems, and limited social support.

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Correspondence

Anna Palucka
Centre for Addiction and Mental Health
1001 Queen St. W.
Toronto, ON
M6J 1H4

Anna_Palucka@camh.net