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Population and service characteristics of youth with schizophrenia-spectrum diagnoses in the Hawaii system of care

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Background: Population and service characteristics were compared for youth (age 0–18 years) with and without schizophrenia-spectrum disorders, who received public mental health services in Hawaii's comprehensive system of care between July 1, 2000 and June 30, 2001. **Methods:** Electronic records of youth with a diagnosis in the schizophrenia-spectrum ($n = 71$) were compared to all other youth ($n = 13{,}904$) who received services with respect to age, gender, ethnicity, comorbidity, type of service, and service cost. **Results:** The schizophrenia-spectrum group had higher Asian representation, greater comorbidity, and was more likely to receive restrictive services for a higher average annual expense. When restrictive services were provided, they were of similar duration and intensity across groups. Almost all youth received less intensive services, but the schizophrenia-spectrum group received a higher frequency or longer duration of such services. **Conclusions:** Although youth with schizophrenia-spectrum disorders were uncommon, collectively they represented a distinct population with above average service consumption. Future monitoring of interventions and outcomes may help develop systematic and effective treatment strategies for youth with schizophrenia-spectrum disorders. **Keywords:** Schizophrenia spectrum, services, demographics.

Schizophrenia-spectrum disorders among young people are devastating and costly mental illnesses. Despite growing interest, research on schizophrenia among children and adolescents is limited (Asarnow & Asarnow, 2003). Factors such as basic demographics, services received, and cost of services remain areas of relative mystery. Increased knowledge of the population portrait and services provided to these youth may increase understanding of both early- and adult-onset schizophrenia-spectrum disorders, and have implications for mental health care provision.

Several studies have described rates of schizophrenia among youth in the general population. Generally, prevalence estimates range from 1:10,000 to 1:100,000 and vary greatly by age (Evans & Acton, 1972; Gillberg & Steffenburg, 1987; Remschmidt et al., 1994; Thomsen, 1996). Asarnow and Asarnow (2003) concluded, 'prevalence figures must be viewed as highly tentative until more representative data become available' (p. 461).

No community-based study to date has investigated youth served in non-hospital settings, and most studies do not include use of a broad diagnostic definition that incorporates the schizophrenia spectrum. Given trends towards least restrictive care in the United States, many children and adolescents with schizophrenia and related conditions likely receive treatment outside of hospitals. Spectrum disorders may be of particular interest due to genetic linking with schizophrenia (Tienari et al., 2003), and to more common diagnosis in young people to avoid the more stigmatic label of full schizophrenia (Thomsen, 1996). Although no comprehensive community-based care studies are available for this population, Gillberg and colleagues (1986) investigated subtypes of psychoses in a population-based survey. Non-schizophrenia psychotic groups defined in their study consisted of disorders not typically considered in the schizophrenia spectrum (e.g., substance-induced psychosis, major affective disorders with psychotic features), and the study was limited to individuals receiving inpatient care. Assessing children and adolescents more broadly (e.g., including schizophrenia-spectrum diagnoses and a comprehensive hospital and community service array) promises a more complete representation of early schizophrenia-spectrum conditions.

Current study

This study presents population and service summaries for youth who received public mental health services from the Hawaii Department of Health's Child and Adolescent Mental Health Division (CAMHD) between July 1, 2000 and June 30, 2001. We describe age, gender, ethnicity, comorbid diagnoses, level of service, and cost per youth, and compare these variables for youth with and without schizophrenia-spectrum disorders.

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Methods

Participants

Participants for this study were all youth 18 years of age and under registered with CAMHD between July 1, 2000 and June 30, 2001 (see Daleiden, 2003 for additional background information). The total sample ($N = 13,975$) was divided into groups with or without a schizophrenia-spectrum disorder. Schizophrenia-spectrum disorders included schizophrenia, schizophreniform, schizotypal personality disorder, schizoaffective disorder, delusional disorder, paranoid personality disorder, brief psychotic disorder, and psychotic disorder not otherwise specified. This grouping was based on familial research suggesting genetic links between these disorders (Baron et al., 1985; Tienari et al., 2003). The spectrum group was liberally defined to address potential conservatism in diagnosis to avoid stigma among youth, but did not include schizoid personality, avoidant personality, or affective psychoses. Seventy-one youth (.5% of all youth) received a primary ($N = 52$) or comorbid ($N = 19$) schizophrenia-spectrum diagnosis during their most recent assessment, and no youth received multiple schizophrenia-spectrum diagnoses. The remaining 13,904 youth without schizophrenia-spectrum diagnoses were included as a comparison group (Table 1).

We included youth with missing primary diagnostic information ($n = 3,879$) in the non-schizophrenia-spectrum group. If the overall diagnostic distribution was comparable in this group with missing data, then 20 youth in the missing group would have a schizophrenia-spectrum diagnosis. Such contamination decreased the likelihood of finding group differences, but the large size of the comparison group mitigated this tendency so erroneously classified cases would have a minimal overall effect. The alternative of listwise deletion of 3,879 cases (3,859 without a schizophrenia-spectrum diagnosis) would likely cause a larger overall bias and restrict the representativeness of the sample to the total system.

Table 1 Qualifying diagnosis of participants in the schizophrenia-spectrum group and primary diagnosis of participants in the comparison group

	N	% of group
Schizophrenia-spectrum group		
Psychotic disorder NOS	37	52.1
Schizophrenia	13	18.3
Schizoaffective	8	11.3
Schizophreniform	4	5.6
Delusional disorder	4	5.6
Paranoid personality	2	2.8
Schizotypal personality	2	2.8
Brief psychotic disorder	1	1.4
Group total	*71*	
Non-spectrum group		
Attentional disorders	3,244	23.3
Disruptive behavior	1,688	12.1
Mood disorders	1,419	10.2
Adjustment disorders	1,320	9.5
Anxiety	852	6.1
Pervasive developmental	651	4.7
Other disorders[1]	851	6.1
Missing diagnosis	3,879	27.9
Group total	*13,904*	
Study total	*13,975*	

[1]'Other disorders' primarily consisted of learning disorders, relational problems, academic problems or intellectual/cognitive disorders, child abuse or neglect, enuresis, and attachment disorders.

Measures

The primary data source for this report was the Child and Adolescent Mental Health Management Information System (CAMHMIS). CAMHMIS information was gathered and entered through standard procedures of the regional Family Guidance Centers, and included age, gender, ethnicity, diagnosis, service type, and service cost.

Diagnoses were based on DSM-IV (American Psychiatric Association, 1994) codes. Youth received diagnostic evaluations from the Department of Education (DOE), contracted providers, or CAMHD clinical staff. Assessment performance standards require inclusion of a five-axis DSM-IV diagnosis in their report. All diagnoses on axes I and II were studied and comorbidity was defined at the disorder category rather than diagnostic code level.

Practice guidelines state that 'clinicians are encouraged to use structured or semi-structured clinical interviews to arrive at a clinical diagnosis' (p. 160), but do not mandate an interview protocol. To explore diagnostic reliability, 326 cases were identified with a new assessment within one year. Consistent with other register-based reliability analyses (e.g., $k = .52$; McConville & Walker, 2000), group assignment was moderately reliable ($k = .56$) across assessments.

Analyses

Group comparisons were performed using chi-square tests with frequency count variables (e.g., gender, service receipt, etc.) and analysis of variance (ANOVA) with ratio-scaled variables (i.e., age, number of diagnoses, and total expenditures). An alpha of .05 was used for all analyses unless otherwise indicated. Additional alpha correction was not performed because tests were generally expected to be somewhat conservative due to the inclusion of cases with missing primary diagnostic information in the comparison group.

Results

Population findings

Demographics. The first set of analyses compared groups on age, gender, and ethnicity. The schizophrenia-spectrum and non-spectrum groups did not significantly differ in gender (70% male; 30% female), but did differ in age and ethnicity. The schizophrenia-spectrum youth, $M = 14.6$ years, $SD = 2.9$, were significantly older than the non-spectrum youth, $M = 12.0$ years, $SD = 3.8$, $F(1, 13,973) = 33.37$, $p < .001$.

The schizophrenia-spectrum group had significantly greater Asian representation than the non-spectrum group, χ^2 (1, $N = 6,566$) = 4.16, $p = .041$

(Table 2). This was balanced by a non-significant tendency for the spectrum group to include fewer Native Hawaiian or Pacific Islander youth, χ^2 (1, N = 6,566) = 2.84, p = .092.

Comorbidity. The spectrum group experienced a higher rate of comorbidity. Specifically, 62.0% of the spectrum group (49.8% of non-spectrum) received comorbid diagnoses, χ^2 (1, N = 10,096) = 4.18, p = .041, and the spectrum group averaged 2.0 diagnoses (1.7 for non-spectrum), F(1, 10,094) = 11.61, p = .001. The spectrum and non-spectrum groups did not significantly differ in the proportion of youth in the other, mood, anxiety, pervasive developmental, or substance-related disorder categories. The spectrum group was significantly *less* likely to receive diagnoses of attentional (14.1% vs. 42.6%, χ^2 (1, N = 10,096) = 23.52, p < .001), disruptive behavior (15.5% vs. 30.2%, χ^2 (1, N = 10,096) = 7.21, p = .007), and adjustment disorders (7.0% vs. 17.1%, χ^2 (1, N = 10,096) = 5.08, p = .024), and *more* likely to receive a diagnosis of mental retardation (9.9% vs. 3.1%, χ^2 (1, N = 10,096) = 10.68, p = .001).

Service findings

Type of services. A higher proportion of youth in the spectrum group (87.3%) than in the non-spectrum group (77.2%) had at least one service procured, χ^2 (1, N = 13,975) = 4.12, p = .042. The groups did not significantly differ in the proportion receiving less intensive services, χ^2 (1, N = 10,795) = .01, p = .942, but a higher proportion of youth in the schizophrenia-spectrum group received out-of-home, χ^2 (1, N = 10,795) = 21.93, p < .001, intensive-home-and-community, χ^2 (1, N = 10,795) = 4.61, p = .032, and flex or respite services, χ^2 (1, N = 10,795) = 30.33, p < .001, than the non-spectrum group (Table 3).

Cost of services. The average annual cost of services in the spectrum group ($16,240 per youth) was significantly higher than in the non-spectrum group ($8,931 per youth), χ^2 (1, N = 10,787) = 8.30, p = .004. Thus, youth with schizophrenia-spectrum disorders consumed more financial resources in the form of services provided at a greater level of intensity, duration, or restrictiveness. To distinguish the restrictiveness from intensity and duration cost drivers, analyses were repeated by type of service. The average annual cost per youth for out-of-home, intensive-home-and-community, and flex or respite services did not significantly differ between groups. The average annual expenditure per youth for less intensive services was greater in the spectrum ($5,103) than the non-spectrum ($3,123) group, χ^2 (1, N = 10,249) = 5.52, p = .019.

Altogether, these findings indicated that a higher proportion of youth with schizophrenia-spectrum disorders received out-of-home, intensive-home-and-community-based, and flex or respite services, but when provided, these services were of similar duration and intensity across groups. Conversely, almost all youth (95%) across groups received less intensive services, but the schizophrenia-spectrum group received such treatment at a higher intensity or longer duration than the non-spectrum group.

Additional analyses

Due to observed group differences, we further examined age and comorbidity as potential confounding variables. Comparison of comorbid cases across groups and single disorder cases across groups generally replicated the pattern of primary results. Within the spectrum group, few significant differences were evident between those with and without a comorbid diagnosis (e.g., age, gender, ethnicity, and cost did not significantly differ). Within the non-spectrum group, comorbid cases were older, used more intensive services, and were more expensive than non-comorbid cases. Age emerged as a significant covariate in ANCOVA analyses, but the pattern of primary findings was unaffected. Thus, we concluded that age and comorbidity were significant factors in understanding demogra-

Table 2 Ethnic distribution of youth with and without schizophrenia-spectrum disorders

	Spectrum		Non-spectrum	
Ethnicity	*n*	% of available	*n*	% of available
American Indian or Alaska Native	0	.0	30	.5
Asian[a]	13	30.2	1,186	18.2
Black or African American	2	4.7	161	2.5
Hispanic	0	.0	127	1.9
Multiethnic	15	34.9	1,921	29.4
Native Hawaiian or Pacific Islander[b]	6	14.0	1,639	25.1
White	7	16.3	1,459	22.4

Note: [a]p < .05, [b]p < .10; spectrum n = 43 available, non-spectrum n = 6, 523 available.

Table 3 Summary of the type of services received by youth with and without schizophrenia-spectrum disorders in terms of the number and proportion of youth with services procured

	Spectrum		Non-spectrum	
Service category	*n*	% of procured	*n*	% of procured
Out-of-home[a]	14	22.6	766	7.1
Intensive home & community[a]	31	50.0	3,951	36.8
Less intensive	59	95.2	10,192	95.0
Flex or respite[a]	19	30.6	1,045	9.7

Note: [a]p < .05; youth may have received more than one type of service; spectrum group n = 62 with services procured, non-spectrum group n = 10,733 with services procured.

phic and service patterns, but were not sufficient to explain differences between the schizophrenia spectrum and non-spectrum groups.

Finally, we tested for significant differences within the schizophrenia-spectrum. Analyses comparing the psychotic disorder NOS to the schizophrenia group, and comparing the psychotic disorder NOS group to all other spectrum disorders did not reveal significant differences in age, gender, ethnicity, services received, or cost of services.

Discussion

The current study found that youth with a schizophrenia-spectrum disorder registered for mental health services with the Hawaii Department of Health in 2000–2001 showed a unique demographic and service-utilization profile relative to other registered youth. Specifically, youth with schizophrenia-spectrum disorders were more likely of Asian descent; more likely diagnosed with mental retardation; less likely diagnosed with disruptive behavior, attentional, or adjustment disorders; more likely to receive out-of-home, intensive-home-and-community-based, and flex or respite services; and more financially expensive per youth.

Participants

The observed prevalence (.5%) of schizophrenia-spectrum disorders was not a precise estimate of the true population value. This rate was conservative relative to the true value in the service-seeking population as diagnostic information was missing for a sizable proportion of registered youth. Nevertheless, the rate in our comprehensive services sample was lower than that reported in a psychiatric inpatient population (Thomsen, 1996).

This study provided novel findings regarding ethnicity among schizophrenia-spectrum youth. Asian youth accounted for a larger proportion of the spectrum disorder group (30.2%) and approximated the proportion in the general Hawaii population (29.9%; US Census Bureau, 2000). In contrast, within the non-spectrum group, Asian youth (18.2%) were underrepresented, a common pattern at CAMHD across recent years (Daleiden, 2003). The source of such underutilization is unclear, but cultural factors may partially account for this finding (e.g., Leong, 1994; Sue & Morishima, 1982). The severity of spectrum disorders or a perception that spectrum disorders have a physical health basis may contribute to the increased likelihood that Asian youth with spectrum disorders seek mental health services.

Youth with spectrum disorders from our sample typically had multiple diagnoses. Disruptive behaviors and attentional problems were the most frequently diagnosed comorbid conditions for youth both with and without spectrum disorders, but the comorbidity rate for these problems was lower in the schizophrenia-spectrum group. Youth with spectrum disorders were more likely to have a diagnosis of mental retardation (9.9%) than non-spectrum youth (3.1%). Although consistent with previous reports, this rate delineates a relatively small group for whom mental retardation might serve as a premorbid feature and relate to the course of the illness (Aylward, Walker, & Bettes, 1984).

Services

This study makes a unique contribution through analysis of a comprehensive system of care. The greater use of more restrictive levels of care may reflect that youth with schizophrenia-spectrum disorders suffered from severe and complex problems that tax resources and increase risks to child safety. However, approximately four out of five youth with schizophrenia-spectrum disorders were managed exclusively in their home or community. Nearly all received less intensive community treatment while intensive-home-and-community services, flexibly funded customized services, and respite services were used to provide more extensive community-based supports. Thus, a variety of community treatment options across the system of care were employed and only a small minority of youth accessed hospital-based services.

Despite the use of less expensive community treatments, the average annual cost per youth with a schizophrenia-spectrum disorder was nearly double the comparison group cost. This finding adds to a host of research reporting that schizophrenia in adulthood is an expensive illness (Cuffel et al., 1996; King, Singh, & Shepherd, 2000; Rothbard, Metraux, & Blank, 2003; Smith, Shah, Wright, & Lewis, 1995).

Additional community research is needed to inform decision making beyond inpatient settings. Little is known about effective treatments for early onset schizophrenia (Asarnow & Asarnow, 2003). However, Rund and colleagues (1994) reported that youth with schizophrenia benefited from a family-centered psychoeducational treatment relative to standard care. This promising result and the frequent utilization of community treatment options highlight the need for development of evidence-based interventions for managing schizophrenia-spectrum disorders in home and community settings.

Limitations

As noted, assigning youth with the missing diagnostic information to the comparison group would tend to underestimate the size of schizophrenia-spectrum group and restrict group differences. Additionally, clinical standards require DSM diagnoses and practice guidelines recommend use of structured interviews, but electronic records do not identify which diagnostic data resulted from structured versus

unstructured approaches. Although some providers use structured interviews, some do not, and this may introduce unreliability into case assignment. Our current analysis revealed moderate diagnostic reliability within one year, a result similar to other community register-based studies. This sample was clinic referred and was representative of CAMHD, but not the general population. These results provide general guidance to the prevalence of these disorders within a specific public mental health system, but should *not* be used as valid population estimates.

Conclusion

Youth with schizophrenia-spectrum disorders were uncommon, but represented a distinct population with above average service consumption. Many youth with schizophrenia-spectrum disorders were served exclusively in community settings. More information is needed regarding the clinical outcomes of these youth and effective treatment options. Prospective monitoring may help establish treatment guidelines, clarify the course of these disorders, and predict needs in transition to adulthood.

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