Published in final edited form as:

Psychiatr Serv. 2017 April 01; 68(4): 411–414. doi:10.1176/appi.ps.201600111.

# Parent burden in accessing outpatient psychiatric services for adolescent depression in a large state system

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### **Abstract**

**Objective**—To examine barriers facing parents of adolescents with depression seeking outpatient psychiatric care in a large state system.

**Methods**—264 outpatient facilities licensed to treat youths in New York were contacted using a mystery shopper methodology. Callers tracked the number of call attempts, in-person appointments and other steps required prior to seeing a psychiatrist.

**Results**—Fewer than two thirds of parents were able to make a psychiatry, therapy, or intake appointment. 19% of those who could not make an appointment received no referrals. Most callers made at least 2 call attempts and spoke with at least two people before initiating scheduling. Virtually all clinics required intake and/or therapy appointment(s) before a psychiatry appointment. The level of parental burden did not differ by region, urbanicity, clinic type, seasonality (Spring or Summer) or insurance status.

**Conclusions**—Families of youth with mental health needs face considerable burden in accessing treatments in a timely manner.

# Introduction

Despite the prevalence and impairment of mental disorders in adolescence, and despite effective existing treatments for mental disorders, the vast majority of adolescents who need mental health services do not receive any services. Many barriers to mental health care exist, such as stigma, finite resources, policy constraints, disjointed services, and unequal access. For youth, parent burden plays a significant role. In addition to long wait times, 7 parents can face financial and logistical barriers to secure even initial psychiatry appointments for adolescents. Notably, a recent study of wait times for adolescent psychiatrists in New York State revealed that only two-thirds of callers to clinics could schedule a psychiatry appointment, with a median 6-week wait for a psychiatrist appointment and 3 weeks for a therapy appointment. Corollary to wait times for services, little has been documented about the specific obstacles parents may encounter while trying to access psychiatric care for adolescents.

The present study utilized mystery shopper methodology to understand the barriers parents of adolescents face when seeking outpatient psychiatric care for their adolescents' depression in a large state system. We further examined whether barriers to access differ by geographic region, urbanicity, clinic type, seasonality and insurance. We hypothesized that burden would be higher in non-metro vs. metro clinics; in the summer vs. spring (when clinician vacation time may tax available clinical hours); and among those with Medicaid vs. commercial insurance.

## Method

The study population included the 340 New York State Office of Mental Health (NYS OMH) outpatient mental health clinics licensed to serve children and adolescents that were in operation since October 2012 and at the time of data collection (Spring/Summer 2014). As the outpatient hospital and state-run facilities represent 17% and 5% of the eligible population, respectively, all of these clinics were sampled with certainty (n=75). Approximately 70% of the 265 community clinics were selected via stratified random sampling by region (New York City, Long Island, Hudson, Central, and Western) and urbanicity (metropolitan vs. non-metropolitan county). All selected clinics were randomly assigned to season (clinic contacted in the spring vs. summer) and insurance condition (Medicaid vs. commercial). This study was a quality improvement project approved by the NYS OMH and hence exempt from review by the Institutional Review Board.

The study utilized a mystery shopper study design. As described elsewhere, <sup>8</sup> using a standardized script, 4 trained callers contacted clinics posing as English-speaking mothers seeking psychiatry appointments for their 14-year-old daughters after a recent relocation. The "mother" explained to clinic staff that her adolescent was previously prescribed antidepressant medication, but her symptoms were worsening and she needed a psychiatrist appointment for a potential medication adjustment. In addition to requesting a psychiatry appointment, the "mother" also discussed scheduling a therapy appointment and inquired about whether Cognitive Behavioral Therapy (CBT) was available.

Callers made five separate call attempts at each clinic to schedule an appointment when there was some initial contact with the clinic (e.g., the caller spoke to a receptionist but was waiting to hear back from intake personnel). Callers left detailed voicemail messages that included their name, phone number, and their primary reason for calling, and waited 48 hours before a subsequent call attempt if the clinic did not return their call. If the caller was unable to speak with anyone at the clinic, three separate call attempts were made.

## Pre-call and call experience

To parallel a real world referral, callers were provided with only the name and address of the clinics. The pre-call experience was the total amount of time required to find accurate clinic contact information, including number of call attempts, minutes on the phone, and number of people to whom the caller spoke.

## Steps prior to psychiatry appointment

All steps required before the psychiatry visit were systematically recorded: pre-intake steps (i.e., insurance pre-authorization; phone screen/intake; parent, school, and/or PCP paperwork, other primary care/MD visit or referral, or other pre-intake appointment), minimum and maximum number of intake appointments, and required therapy appointments.

The analyses focused on three measures of parent burden: number of call attempts; minimum number of in-person appointments required prior to seeing a psychiatrist; and minimum number of steps (e.g., paperwork, intake appointment, therapy appointment) required prior to seeing a psychiatrist. Sample weights were created to account for the unequal probability of selection of clinics. Unweighted counts and weighted percentages were used to summarize categorical variables. Weighted Poisson mixed effects regression models with a random effect for agency (to account for the within-agency correlation; 21% of agencies had multiple clinics) were fitted to examine whether measures of parent burden varied by region, urbanicity, clinic type, season and insurance. The data were analyzed using SAS version 9.39and Stata/SE version 14.0.10

# Results

The analytic sample consisted of 264 clinics (*n*=57 hospitals, *n*=17 state-run facilities and *n*=190 community clinics). About half (43%) of the clinics were located in New York City, and 86% of clinics were in metropolitan areas. Callers were able to discuss scheduling a psychiatry appointment at 94% of the clinics. Most callers spent 2 or more minutes finding the correct contact information and had to make at least 2 call attempts, and 40% spoke with at least 3 people (Table 1). The number of call attempts did not vary by region, urbanicity, clinic type, season, or insurance (results not shown).

At the 248 clinics where callers were able to discuss scheduling, 63% of callers were able to schedule an intake or screening appointment, and 67% were able to schedule a therapy appointment (CBT was available in 74% of these clinics). Callers were unable to schedule any appointments at 79 (37%) of the clinics because the clinic was at capacity (n=34); the adolescent did not meet the clinic's criteria (n=31; e.g., adolescent was too young);

insurance reasons (n=9 did not accept BCBS insurance or self-pay; n=1 did not accept Medicaid; n=2 required verification of insurance coverage); a referral was needed from an emergency department or primary care physician (n=2). Nineteen percent of callers who could not schedule any appointments were unable to obtain a referral to another clinic.

Of the 146 clinics that provided the caller with an actual or estimated date of the psychiatry appointment, 99% required at least one in-person appointment (e.g., an intake appointment or a therapy session) prior to the psychiatry appointment; 27% required a minimum of 2 appointments and 21% required a minimum of 3–5 appointments (Table 1). Forty-two percent of clinics required at least one therapy appointment prior to the psychiatry appointment, and 15% of clinics required multiple therapy appointments. The majority of parents and/or adolescents had to complete more than one step prior to the psychiatry appointment: 42% of clinics required only one step (e.g., an intake appointment), 26% required 2 steps (e.g., paperwork and an intake appointment), and 32% required 3 or more steps (e.g., paperwork, intake appointment, and a referral). There were no significant differences in the minimum number of pre-psychiatrist in-person appointments or number of steps required by region, urbanicity, clinic type, season or insurance (results not shown).

## **Discussion**

Most youth needing mental health services do not receive care. Existing research points to disparities in availability of services based on geography, insurance status, and family income. This study examined barriers faced by parents of adolescents seeking outpatient psychiatric care for their adolescents' depression in a large state system, using a mystery shopper methodology.

In the current study, two thirds (146/264) of callers were able to make a psychiatry appointment, a therapy appointment, or an intake appointment, and 19% of those who could not make an appointment were not provided a referral. Parents were often subjected to several levels of hurdles before being able to consult with a psychiatrist. These hurdles included: Multiple attempts to reach a person(at least 2 call attempts before reaching someone, speaking with at least two people before initiating scheduling); administrative paperwork (e.g., insurance) and recommendations from other informants (e.g., school). If scheduling was possible, virtually all clinics required one in-person intake/therapy appointment before a psychiatry appointment. This level of burden was quite typical across the state, and the level of parental burden did not differ by geographic region, urbanicity, clinic type, seasonality or insurance. These null findings may be explained by the fact that these state licensed clinics likely operate under similar regulations for care provision. For example, the state has invested in workforce training in evidence-based care. In accordance with current evidence-based guidelines of care for youth (http://www.aacap.org/AACAP/ Resources for Primary Care/Practice Parameters and Resource Centers/ Practice\_Parameters.aspx), clinics often required an initial trial of a psychosocial intervention before allowing a psychiatrist appointment. However, such rigid adherence may actually be counterproductive; requiring an adolescent who is already on medication to undergo the same procedures as a treatment naïve adolescent may lead to less effective avenues of care. For example, a parent may instead seek care for her child with her primary

care doctor, or even the local emergency department, to secure her prescription. A more efficient strategy may be to tailor intake procedures to youth needs; bypassing burdensome procedures for psychiatry appointments in cases of medication adjustment may alleviate some of the clinic service burden.

Our findings focus only on parent burden in situations where psychiatric care could be accessed; for a sizable proportion of calls (about 40%), a psychiatry appointment could not be made. Our callers were trained English-speaking research assistants, who may be savvier than a layperson in accessing services, and without language barriers that may pose additional hurdles for some parents. Consequently, their experience may have led to practice effects and hence quicker and more effective ways to contact to clinics. Moreover, in a real-life situation, parents may not be as persistent after not receiving a response from the clinic. Therefore, the current data likely underestimate the actual burden and difficulty scheduling an appointment faced by real families. Moreover, this study focused specifically on experiences seeking services for adolescent depression, which may not reflect parents' experiences seeking services for other types mental disorders.

Our findings across the state are sobering, especially in conjunction with epidemiologic data. Kessler et al. 11 found that half of adults who have mental disorders show signs of illness by age 14; yet, on average, individuals suffer a median delay of 10 years after disease onset and first treatment contact. 12 Families of youth with unmet need often face considerable burden in providing care and accessing needed treatments, usually at high personal financial, emotional and social costs. Strategies to improve and facilitate timely access to treatments are urgently needed; in youth with psychiatric disorders, the role of the family and hence parent burden is key.

# **Acknowledgments**

This project was supported by grants P30 MH090322 from the National Institute of Mental Health.

Funding Source: NIMH P30 MH09 0322 and the CHIPRA Subcontract Sponsor #1U18HS020503 supported this research

# References

- 1. Kataoka SH, Zhang L, Wells KB. Unmet need for mental health care among US children: Variation by ethnicity and insurance status. American Journal of Psychiatry. 2002; 159:1548–1555. [PubMed: 12202276]
- Merikangas KR, He J-p, Burstein M, et al. Lifetime prevalence of mental disorders in U.S. adolescents: Results from the National Comorbidity Survey Replication

  –Adolescent Supplement (NCS-A). Journal of the American Academy of Child & Adolescent Psychiatry. 2010; 49:980

  –989. [PubMed: 20855043]
- 3. Wells KB, Miranda J, Bauer MS, et al. Overcoming barriers to reducing the burden of affective disorders. Biological Psychiatry. 2002; 52:655–675. [PubMed: 12361673]
- 4. Stiffman AR, Stelk W, Horwitz SM, et al. A public health approach to children's mental health services: Possible solutions to current service inadequacies. Administration and Policy in Mental Health and Mental Health Services Research. 2010; 37:120–124. [PubMed: 20039117]
- 5. Horwitz S, Hoagwood K. Children and adolescents. Mental Health Services Research. 2002; 4:239–243. [PubMed: 12558010]

6. Children's Health Council: Children with special health care needs enrolled in HUSKY Part A: Survey to assess access to care and satisfaction. Hartford, Connecticut Voices for Children. 2000. Available at http://www.ctvoices.org/publications/children-special-health-care-needs-enrolled-husky-part-survey-assess-access-care-and-sa

- 7. Glied S, Hoven CW, Moore RE, et al. Children's access to mental health care: does insurance matter? Health Affairs. 1997; 16:167–174.
- 8. Olin S, O'Connor B, Storfer-Isser A, et al. Access to pediatric specialty mental health care in a state public health system: A simulated patient approach. Journal of the American Academy of Child & Adolescent Psychiatry. 2016; 55:392–399. [PubMed: 27126853]
- 9. SAS Institute Inc. Base SAS® 9.3 Procedures Guide. Cary, NC: SAS Institute Inc; 2011.
- 10. StataCorp. Stata Statistical Software: Release 14. College Station, TX: StataCorp LP; 2015.
- Kessler RC, Berglund P, Demler O, et al. Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the National Comorbidity Survey Replication. Archives of General Psychiatry. 2005; 62:593–602. [PubMed: 15939837]
- 12. Wang PS, Berglund PA, Olfson M, et al. Delays in initial treatment contact after first onset of a mental disorder. Health Services Research. 2004; 39:393–416. [PubMed: 15032961]

Table 1

Pre-Call Experience, Call Experience, and Requirements Prior to Psychiatry Appointment

	N	Wtd %
Pre-Call Experience: All Clinics (N=264)		
Minutes to find correct phone number/contact information (N=264)		
1 minute	69	27
2 minutes	96	37
3–5 minutes	85	32
6–10 minutes	10	3
11–21 minutes	4	1
Number of call attempts (N=264)		
1	128	49
2	69	26
3	36	13
4 or 5	31	12
Call Experience: Clinics Where Callers Were Able to Discuss Scheduling (n=248)		
Number of people spoke with(n=248)		
1	105	43
2	50	21
3	32	12
4	22	8
5+	39	16
Number of minutes on phone (n=248)		
<5 minutes	33	13
5–9 minutes	96	40
10–14 minutes	66	26
15–29 minutes	53	21
Requirements Prior to Psychiatry Appointment: Callers Who Were Given an Actual or Estimated Psychiatry Appointment Date (N=146)		
Pre-intake steps required		
Insurance pre-authorization	7	5
Phone screen/phone intake	7	4
Parent paperwork	8	5
School paperwork	4	2
PCP paperwork/referral	9	6
Other primary care/MD visit	1	1
Pre-intake appointment (screening, registration, triage, parents only)	6	4
Minimum number of in person appointments required (N=146)		
None	1	1
One	75	50

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N Wtd % 39 28 Two Three 20 14 11 7 Four or Five Minimum number of therapy appointments required (N=146) 87 58 None One 38 38 7 5 Two Three or Four 14 10 Requirements Prior to Psychiatry Appointment: Callers Who Were Given an Actual or Estimated Psychiatry Appointment Date (N=146) Minimum number of steps required (N=146) 0 0 None One 62 43 Two 38 26 22 31 Three 11 6 Four 4 3 Five or Six

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