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Barriers to Specialty Care and Specialty Referral Completion in the Community Health Center Setting

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Objective To assess the frequency of barriers to specialty care and to assess which barriers are associated with an incomplete specialty referral (not attending a specialty visit when referred by a primary care provider) among children seen in community health centers.

Study design Two months after their child's specialty referral, 341 parents completed telephone surveys assessing whether a specialty visit was completed and whether they experienced any of 10 barriers to care. Family/community barriers included difficulty leaving work, obtaining childcare, obtaining transportation, and inadequate insurance. Health care system barriers included getting appointments quickly, understanding doctors and nurses, communicating with doctors' offices, locating offices, accessing interpreters, and inconvenient office hours. We calculated barrier frequency and total barriers experienced. Using logistic regression, we assessed which barriers were associated with incomplete referral, and whether experiencing ≥4 barriers was associated with incomplete referral.

Results A total of 22.9% of families experienced incomplete referral. 42.0% of families encountered 1 or more barriers. The most frequent barriers were difficulty leaving work, obtaining childcare, and obtaining transportation. On multivariate analysis, difficulty getting appointments quickly, difficulty finding doctors' offices, and inconvenient office hours were associated with incomplete referral. Families experiencing ≥4 barriers were more likely than those experiencing ≤3 barriers to have incomplete referral.

Conclusion Barriers to specialty care were common and associated with incomplete referral. Families experiencing many barriers had greater risk of incomplete referral. Improving family/community factors may increase satisfaction with specialty care; however, improving health system factors may be the best way to reduce incomplete referrals. *(J Pediatr 2013;162:409-14)*.

Access to pediatric specialists has been cited by the American Academy of Pediatrics as an important measure of the Medical Home.[1] Unfortunately, many children do not have access to specialty care. Children from families who are poor, of black race/ethnicity, or uninsured use less specialty care, and minorities report more problems accessing specialty care.[2-4] One reason for low use of specialty care among underserved children may be an incomplete referral or not attending a pediatric specialty appointment when referred. Studies show that rates of incomplete referrals for children range from 14% to 20%,[5,6] and rates may be as high as 30% in the community health center setting.[7] Although the optimal rate of incomplete referral is not known,[8] high rates are of concern because they may lead to persistence or exacerbation of health problems. Reducing rates of incomplete referral could be advantageous to health care systems because incomplete referrals may lead to inefficient use of provider time, system waste, and decreased access to pediatric specialists. Studies have shown that patient demographic factors, referral characteristics, and parent/provider communication may contribute to high rates of incomplete referral.[7,9]

Determining which barriers to specialty care are most prevalent and which ones are most likely to prevent specialty visits from occurring may be an important way to improve health care quality and access for children. Sobo et al[10] have argued for a process-oriented model in approaching health care quality for underserved children. In this view, disparities in health care access arise in part because of barriers to care that moderate a child's journey through the health care system. Although sociodemographic risk factors may modulate the effects of barriers to care, ultimately it is through process barriers that health disparities play out.[10] As much of the navigation of health systems is done by parents, parents are in a good position to comment on the barriers that they face in attempting to access care for their children.[11,12]

In this study, we took a similar process-oriented approach in assessing barriers to specialty referral completion. Because barriers to care may be more pronounced in minority and underserved children,[13,14] we set our study in 2 com-

EHR	Electronic health record

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munity health centers that primarily served a safety-net population, with a large proportion of immigrant and racial/ethnic minority families. We surveyed parents of children who had received a primary care provider referral to a pediatric specialist at an affiliated tertiary medical center. Our primary study questions were as follows: (1) In this community health center population, which were the most common family, community, and health care system barriers to specialty care; and (2) which barriers were most strongly associated with incomplete specialty referral?

Methods

We carried out a study of pediatric referrals from 2 community health centers to a tertiary care center. Previous reports from this study have described the relationships of patient demographic factors, referral characteristics, and provider/parent communication on specialty referral completion.[7,9]

A sample of 501 referred children was created using referral tracking documents, which are generated for every referral for appointment scheduling and insurance purposes. We collected all referral documents on alternate weeks during the first 4 weeks of the survey period (June 17, 2008, through July 2, 2008), and then on consecutive weeks from July 3, 2008, through January 28, 2009. From these records, we included referrals from a pediatric primary care provider to the tertiary care center for consultation with a specialist in one of the following pediatric specialties: allergy/immunology, cardiology, dermatology, endocrinology, gastroenterology, genetics, hematology/oncology, infectious disease, nephrology, neurology, neurosurgery, ophthalmology, orthopedics, otolaryngology, general surgery, pulmonology, rheumatology, and urology. These represented all pediatric specialty clinics meeting at least weekly at the tertiary medical center, except for adolescent medicine and psychiatry, which we excluded for reasons of child confidentiality.

Because of difficulties in distinguishing follow-up referrals from insurance reauthorizations (which often did not involve a new medical concern), we only included new referrals (referrals to a specialty clinic not visited in the previous 5 years or since birth). If multiple referrals were made for an individual child, we randomly selected one referral for inclusion. We included only children younger than 18 years of age and included only one referral per household. We excluded households in which neither English nor Spanish was spoken. This study was approved by the Partners HealthCare and the Massachusetts Eye and Ear Infirmary Institutional Review Boards.

The survey focused on one referral episode for each child. The survey instrument used questions adapted from the US Census 2000,[15] a previous survey about barriers to cancer care performed in our health center,[16] and the 2003 National Survey of Children's Health.[17] We additionally performed key informant interviews with health care providers and clinic staff to assess their views of frequent barriers to care. The final barriers we studied were a composite of relevant barriers from prior study as well as those mentioned frequently by clinic staff. Barriers fell into 2 overall domains: Family and community barriers included difficulty leaving work, obtaining childcare, obtaining transportation, and inadequate insurance; Health care system barriers included getting appointments quickly, understanding doctors and nurses, communicating with doctors' offices, locating offices, accessing interpreters, and inconvenient office hours. Parents were asked how much they agreed with a statement about each barrier on a 4-part scale (eg, "It is hard to get out of work to go to appointments at [medical center]"). The text of each barrier item is shown in **Table I** (available at www.jpeds.com). The survey also collected demographic information about the parents and children. Parent demographic information included educational attainment, nativity, and race/ethnicity. Spanish translation for all written materials was performed by a certified translation specialist.

The survey sampling and fieldwork approaches were developed in a pilot study conducted in 2008. We used this approach to test accuracy of parent contact and language information as well as the number and mode of contacts needed to achieve adequate response rates. The parent survey was pilot-tested on a sample of 30 families. We modified survey items based on response patterns and feedback from interviewers.

Approximately 60 days after each referral, the referred child's parent or guardian was contacted by mail via a bilingual advance letter. We chose this interval on the basis of a preliminary review of medical records, which suggested that >90% of specialist visits were completed or missed within 60 days. However, in cases in which the specialty visit was scheduled more than 60 days after the referral, we waited until the visit was completed or missed before contacting the family. All subjects who did not opt out were contacted via telephone, 10 to 14 days after the initial mailing, by a bilingual interviewer trained on the survey instrument and study protocol. The interview was performed with the parent who "knew the most about the health and healthcare" of the child. The interview lasted approximately 15 minutes. All surveys were fielded between July, 2008 and June, 2009.

Extraction of Electronic Health Record (EHR) Data

Additional demographic information was extracted from EHR registration data. The tertiary care center obtains registration information by parent telephone interview and updates it at least yearly. Additional factors included child sex, age at referral, race/ethnicity (categorized as black, Hispanic, other race, and white non-Hispanic), and insurance status (categorized as publicly insured, privately insured, or uninsured).

Statistical Analyses

We used χ^2 tests to assess bivariate associations of each child and parent sociodemographic characteristic (child race/ethnicity, child sex, child age, insurance status, language of survey delivery, parent educational status, parent nativity, parent race/ethnicity) and each referral characteristic (medical versus surgical specialty, health center) with incomplete referral.

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