South Asian Stories: Firsthand Client Perspectives on Barriers to Accessing Speech-Language Pathology Services

Nidhi Mahendra

California State University East Bay
Hayward, CA

This article details the experience of two South Asian individuals with family members who had communication disorders. I provide information on intrinsic and extrinsic barriers reported by these clients in responses to a survey and during individual ethnographic interviews. These data are part of a larger study and provide empirical support of cultural and linguistic barriers that may impede timely access to and utilization of speech-language pathology (SLP) services.

The purpose of this article is to shed light on barriers and facilitators that influence South Asian clients' access to SLP services. I provide and briefly analyze two case vignettes to provide readers a phenomenological perspective on client experiences. Data about barriers limiting access to SLP services were obtained via client surveys and individual interviews. These two clients' data were extracted from a larger study (Mahendra, Scullion, Hamerschlag, Cooper, & La, 2011) in which 52 racially/ethnically diverse clients participated. Survey items and interview questions were designed to elicit information about client experiences when accessing SLP services. Results reveal specific intrinsic and extrinsic barriers that affected two South Asian clients' access to SLP services and have important implications for all providers.

South Asians are among the fastest growing ethnic groups in the United States today (see Faroqi-Shah, this issue). The population of South Asians grew from approximately 1.6 million in the year 2000 to over 2.8 million in 2010 (United States Census Bureau, 2010a). The four largest South Asian groups in the United States trace their origin to India, Pakistan, Bangladesh, and Sri Lanka. The top two metropolitan areas in the United States with the highest numbers of South Asian individuals are New York/New Jersey and the San Francisco Bay area (South Asian Americans Leading Together [SAALT], 2011). With a population of over 37 million people, the state of California is the most populous state of the United States (United States Census Bureau, 2010b) and is home to roughly 20% of the nation's minority residents. In California, Asian Americans represent approximately 13% of the state's over 37 million residents, and South Asians account for approximately 11% of this Asian population (United States Census Bureau, 2010a).

Faroqi-Shah (2007) previously discussed the status of South Asians in the United States with regard to their significant education and income level, compared to the national average. She also highlighted the cultural and linguistic heterogeneity within this population, as well as vulnerability to specific health conditions (e.g., cardiovascular disease, diabetes). In this study, the particular focus was on client awareness about communication disorders and scope of speech pathology and audiology services, client perceptions of the experience of accessing and receiving services, and reflections on clinician behaviors that made clients more or less comfortable.

Cultural and Linguistic Diversity: Impact on Health-Care Access

Access has been described as "the timely use of personal health services to achieve the best possible health outcomes" (Millman, 1993, p. 33). It is well established that racially and ethnically diverse clients generally face barriers to accessing health-care services and frequently receive lower levels of care (Institute of Medicine, 2002). Such barriers to access directly and indirectly contribute to health disparities. Although minority clients' access to general medical services has been previously studied, two limitations characterize most published research on this topic. First, minority clients' access to and utilization of specialized services, such as speech-language pathology (SLP) and audiology services, has not been systematically studied. Second, in most published studies, the focus is on financial barriers (e.g., lack of or inadequate health insurance) and not on specific cultural and linguistic barriers to access (Barr & Wanat, 2005). Many barriers faced by diverse clients may result from cultural factors (e.g., limited knowledge about SLP, different beliefs about causes of communication disorders, varying perceptions about the most appropriate intervention/provider) and linguistic factors (e.g., limited access to information in non-English languages), even when clients are educated and have middle to high socioeconomic status.

The data presented here are part of a larger empirical study (Mahendra, Schoneman, & Engineer, 2009; Mahendra et al., 2011) that was motivated by the mostly anecdotal and limited empirical evidence on cultural and linguistic barriers that may influence minority clients' access to SLP services. Two descriptive case studies are presented in this article as salient examples of the experience of South Asian clients while accessing and receiving SLP services. We specifically apply grounded theory (Glaser & Strauss, 1967) and formal qualitative data analysis (Saldaña, 2009) to highlight the "lived experience" of two South Asian clients: a mother (Suma*) of a child diagnosed with autism spectrum disorders and the wife (Jiya*) of a man with post-stroke anomic aphasia and acquired alexia. (*Pseudonyms used to protect client confidentiality.)

Method

Participants responded to a flyer describing the study and a subsequent personalized letter of invitation. Signed, informed consent was obtained from participants, followed by completion of a detailed, 25-item survey in English and participation in individual, ethnographic interview. Of the 25 items on the survey, 10 were about demographic data (e.g., respondent age, city of residence, education, annual household income, race/ethnicity, and generational status as immigrants [if applicable]). Twelve items pertained to data about the type of communicative disorder, clinical setting where therapy was obtained, duration and type of services received, and status of insurance payment for services. Three survey items were open-ended questions about level of satisfaction with services received and self-report of challenges and facilitators encountered when accessing speech therapy services.

Interview questions were developed in close collaboration with a researcher with expertise in the use of ethnographic interviews for persons with aphasia and a sociologist with substantial experience in conducting focus groups with minority and low-income patients in a community setting. Fourteen hierarchically organized questions (see Krueger, 1998, for a detailed discussion of question types) were developed and categorized as one opening question, two introductory questions, three transition questions, five key questions, and three ending questions. Table 1 provides a brief description of the purpose of each type of question, with one specific example from our interview protocol.

Table 1. Types of Interview Questions and Representative Examples

Type of Question	Example
Opening question: The purpose of an opening question is not to get detailed information but just to encourage respondents to be comfortable and begin talking.	*Please tell us your name and where you live in the Bay area.*
Introductory question: These questions are designed to introduce the topic of discussion and to help persons think about their connection to the topic.	*What would be an ideal result of therapy for you or your family member?*
Transition question: These questions move the conversation into the primary questions that drive the research.	*When you were first referred for speech therapy or audiology services, what did you know about speech pathology or audiology?*
Key questions: These are central to the research being conducted and require the most careful and thorough analysis.	*What were some challenges to finding a speech therapist?* *What are some things speech-language pathologists that you like, do or say that make you more comfortable?* *What are some things speech language pathologists that you did not like do or say that made you less comfortable?*
Ending questions: These questions bring closure to the discussion topic and allow participants to reflect on prior comments.	*If you could give some advice to speech pathologists and audiologists about working with diverse clients like yourself, what would you like to share?*

Responses to interview questions were audiotaped and subsequently transcribed. Interview transcripts of the two participants presented here were manually analyzed for first impressions and key themes, followed by classification of ideas into categories by the author and a second coder. Responses to these open-ended questions were analyzed qualitatively by coding key themes (Boyatzis, 1998; Saldaña, 2009) and also quantitatively by counting the number of times similar themes came up across participants.

Case Study 1: Child With Autism

Background and Referral History

Suma was a 37-year-old South Asian mother of a 4-year-old child diagnosed with communicative and social delays secondary to a diagnosis of autism spectrum disorders (ASD). This participant was a first-generation immigrant from India who had lived in California for 5 years when she was interviewed. She lived with her husband and one additional younger child; was college educated; and was fluent in English, Hindi, and Punjabi. She socialized primarily with other South Asian families, living close to her own home. Her son had received 4 months of early intervention (EI) services until he turned 3 years old and was currently receiving individual therapy at a private practice clinic, close to her home.

Observations and Responses During the Interview

Suma was candid about her experiences and emotions during the interview. She expressed gratitude for the opportunity to share her thoughts and hoped that "I [she] can help other parents." After analyzing her responses, we learned that she had been appropriately concerned about her son's speech and language development when he was about 18 months old and expressed these concerns to his pediatrician. This pediatrician did not act on these concerns, despite multiple self-reported requests and expressed anxiety by Suma. Eventually, she switched pediatricians (see Table 2) and requested a referral to an audiologist, by which

time her son was 2.5 years old. The audiologist referred her to an SLP, and her son began receiving EI services when he was 2 years and 7 months old. She was emphatic that the first pediatrician was responsible for delaying her son's referral (see Table 2) and expressed anguish that her son's outcomes would have been superior if she had been (a) more assertive with her pediatrician, (b) knowledgeable about the type/nature of EI services (and that they were offered free of cost), and (c) aware of the signs and symptoms of ASD and the specific role of SLPs in working with children with ASD.

When asked about challenges experienced, she elaborated on her frustrating encounter with two pediatricians and tearfully expressed the frustration of being Asian Indian with a child with ASD and accompanying social and communicative deficits. It was noteworthy that she mentioned feeling "isolated and sidelined" by several educated, accomplished South Asian parents in her social network. According to her, these parents had high aspirations for their children's academic and social achievement and also were hugely unaware of the condition of autism and its effects on development. Suma perceived that as her son's deficits worsened, she was not always welcome in select social circles nor invited to play dates and parties. She expressed sadness about being alone in the United States, away from her parents and extended family, stating, "I feel so much pressure to do the best for my son, but to do it all myself." She described this as "making me [her] feel desperate" because she did not feel equipped with important information and resources to make sound decisions for her child. Table 2 shows an excerpt from her response to a transition question with a simple illustration of thematic coding.

Table 2. Thematic Coding of Participant Response to Transition Question

Transition question	Response	Key themes identified
When you were first referred for speech therapy or audiology services, what did you know about speech pathology or audiology?	"I knew very little.[1] I was very dependent on our pediatrician[2] . . . which was a mistake. The pediatrician was unusually relaxed[3] and very cool . . . kept on saying to wait until he is 3[4] years old. I kept pushing the pediatrician but she wasn't really open or listening to our concerns.[5] Then I was reading a pamphlet in the waiting room about hearing testing.[6] . . . and started wondering what if my son has a hearing loss? By this time, I got frustrated with our pediatrician . . . I changed pediatricians[7] and first asked for a referral to an audiologist[8] and showed her the pamphlet I had. I just feel so terrible[9] that so much time was wasted[10] because of the pediatrician's lack of knowledge.[11] . . . shouldn't they know better? For us, being referred late[12] has made us put double, triple the effort[13] than what our son could have achieved if his speech delay was caught early. I guess it is better late than never.[14] . . . but its been very sad and heartbreaking as a parent."[15]	1. Acknowledgment of limited knowledge about professions: Idea 1. 2. Role of pediatrician and adverse impact on outcomes: Ideas 2–7, 11–12. 3. Link between resources (pamphlet) and positive action (e.g., requesting referral): Ideas 6, 8. 4. Negative feelings about delayed referral: Ideas 9, 10, 12, 14, 15. 5. Consequence of delayed referral-huge parental effort: Idea 13.

Case Study 2: Adult Male With Aphasia

Background and Referral History

Jiya was a 54-year-old South Asian wife of a 61-year-old man who had a stroke 2 years prior to the interview. He sustained a left hemisphere ischemic cerebrovascular accident during planned cardiac surgery and presented post-surgically with right hemiparesis, anomic aphasia, and acquired alexia. He was not present during the interview, as Jiya wanted to "talk freely what I think [she thinks], but without hurting his feelings." Jiya worked as a bank teller, and her husband had been a certified public accountant, prior to his stroke. She and her husband immigrated to the United States from Fiji in 1991 and had never lived in India. They had a son in college, who was completing an undergraduate degree in business administration. They had lived in the Bay area for 13 years. Jiya was fluent in English (specifically, the Fijian English dialect) and Gujarati. They socialized with an ethnically diverse group of close friends, most of whom they had known for about 2 decades.

Observations and Responses During the Interview

Jiya was a more stoic and reserved participant than Suma, described earlier. She frequently requested questions to be repeated or paraphrased and thought silently (with an averted gaze) for a while before responding. She frequently asked the interviewer if her responses were appropriate and second-guessed her own instinctive response (e.g., "I don't know if this is helping you. Is it making sense?"). Overall, she was satisfied with the SLP services she was receiving and reported that her spouse had made significant gains in 1 year, following a combination of individual and group therapy at a local university clinic. When asked about challenges, she revealed that her greatest difficulty was at the point of initial referral to speech pathology (see Table 3) and that she felt lost without specific resources to identify providers in the Bay area. She reported that she did not know anyone who had experienced a stroke. Next, physical access to services played a prominent role in her narrative as she detailed her difficulty with navigating poorly connected local public transit systems (see Table 3) and unreliable paratransit services and her need to maintain her employment for income and health benefits. This made her unable to drive her husband to therapy. She described this as placing stress on her relationship with him, because she felt that he wanted her to do so. She expressed anxiety that their pre-stroke, more traditional gender roles had substantially changed, with her now having to make key decisions and handle all financial, social, parental, and caregiving responsibilities. She was guarded but expressed that "sometimes it is too much to handle everything." She described feeling emotionally well supported by her son, two neighbors, and multiple close friends who lived near her home. It is interesting to note that she pointed out ("I think I should tell you one last thing") that she never did home program activities with her spouse that required her to give him explicit feedback about errors or to correct him repeatedly (e.g., during a naming task or conversational coaching activity). When asked why, she responded that it made her uncomfortable "being his teacher," and her husband often got agitated when she tried. This perception may reflect the more traditional, rigid gender roles often observed among immigrant South Asian couples, particularly those in Jiya's generation.

Table 3. Thematic Coding of Excerpts From BA's Responses

Transition question	Response	Key themes identified
When you were first referred for speech therapy or audiology services, what did you know about speech pathology or audiology?	"I did not know anything at all.[1] At the hospital, I was told there is this support group for people with a stroke.[2] There I met several caregivers[3] who then referred me to the Cal State clinic."[4]	1. Acknowledgment of no knowledge about the professions: Idea 1. 2. Impact of resources: Idea 2 (support group), 3 (other caregivers), and 4 (local university clinic).
Key question *What were some challenges to finding a speech pathologist or audiologist?*	"I just was not aware of what was out there in the Bay area,[1] and where to look for resources.[2] You feel like you are on your own.[3] I talked to friends and people at work,[4] did some research,[5] and found a friend whose son had a brain injury.[6] That gave me some information and one doctor[7] we met was very knowledgeable. Private speech therapy was very expensive[8] and I had no information about affordable options[9] for speech therapy. Then we found one program,[10] for which he took the light rail, then paratransit from the train station, and it was taking 2.5 to 3 hours one way to get there. He was not able to handle the travel.[11] Another very big struggle was that he was 61 when he had his stroke and not eligible for Medicare.[12] His insurance only paid for evaluations, but not for therapy."[13]	1. Acknowledgment of no awareness of local resources: Ideas 1, 2, 9. 2. Feelings associated with no awareness of resources: Idea 3. 3. Resources: Ideas 4 (friends/coworkers), 5 (research), 6 (friend), 7 (doctor). 4. Challenges: Idea 8 (cost of private therapy), 10–11 (physical access, logistics), 12 (non-eligibility for Medicare), 13 (limited reimbursement).

Summary of Reported Barriers

Whereas extensive responses from interviews done with Suma and Jiya cannot be presented here given space limitations, it is evident that both encountered some barriers in accessing SLP services. Initial access barriers for Suma were her pediatrician's lack of knowledge and responsiveness to her concerns, her own limited understanding of autism, and confusion about the nature and duration of EI services. Secondary barriers after beginning speech therapy included limited parent training provided by SLPs, her persistent lack of clarity on how/when to use therapeutic techniques with her son at home, inability to observe therapy sessions in real time (at the clinic her son attended), high cost of services in a private clinic (given their single-income household in an area known for high cost of living), limited knowledge of alternate options for SLP services in the Bay area, disconnection from extended family in India, and self-reported attitudes and awareness levels of other South Asians in her social milieu.

Jiya experienced similar initial access barriers regarding her own lack of knowledge about the professions and local resources. However, hospital-based providers, other caregivers, and her friends facilitated her access to SLP services. Secondary barriers and challenges reported by Jiya included physical access limitations, ineligibility for Medicare benefits, limited

insurance reimbursement for SLP services, and altered gender roles post-stroke that affected her relationship with her husband and her participation in home program exercises.

Conclusions and Clinical Implications

Ethnographic interviews allow clinicians and researchers to listen to client perspectives and learn from their rich, individual experiences of a phenomenon. A central assumption in using such interviews is that individuals are valuable sources of information and are capable of expressing their own feelings and behaviors. Qualitative and quantitative data obtained from these two South Asian clients reveal that they encountered both intrinsic and extrinsic barriers when accessing SLP services. Examples of intrinsic barriers were limited personal knowledge about communicative disorders and the role of SLPs, little knowledge about the U.S. health-care/educational system (e.g., federal mandates for EI services), and cultural differences in communication style (e.g., more indirect, less assertive, deferential to authority of medical providers, impact of traditional gender roles). Significant extrinsic barriers were medical providers with limited knowledge, lack of adequate print/online/personnel resources to assist with locating SLP services, extended family not being nearby, and attitudes among other South Asians toward persons with a communication disorder (e.g., Suma's case).

Obtaining such data is critical to better prepare SLPs to serve diverse clients competently and ethically. Further, these data provide insights about South Asian clients' encounters with health-care providers, agencies, and SLPs themselves. Some best practice implications for SLPs, apparent from these emerging data, are that clinicians should

1. Speak with a South Asian cultural informant to develop an understanding of expected knowledge or attitudes about the professions and communicative disorders among South Asians (see Shah, 2007 for an excellent review).
2. Ask a client about his/her general understanding of how/what SLPs and audiologists do, as well as of specific techniques/strategies used in therapy.
3. Obtain information about language/dialect acquisition history and patterns of current language use.
4. Offer support and resources to help understand federal/legal mandates for services and age limits (e.g., for EI services) and provide answers to questions about eligibility and reimbursement policies or procedures.
5. Provide direct print/online resources about low-cost (e.g., university clinics) and alternate options/contexts for receiving SLP services.
6. Encourage parents of clients/families to provide ongoing feedback about services received and any unmet needs.
7. Suggest that clients participate in online or face-to-face support groups (e.g., Parents Helping Parents, http://php.com/) to address possible social isolation from routine social networks.

In summary, such data have compelling implications for designing future studies, using ethnographic interview protocols, and developing evidence-based community outreach and consumer education practices. Forthcoming work will present results from clients of varying cultural and linguistic backgrounds, discuss the impact of this research on reducing disparities in access to health services, and provide a close look at SLP behaviors and competencies that affect minority clients' participation in speech and language therapy.

Acknowledgments

Chancellor's Office. The author acknowledges the invaluable contributions of Dr. Jan Avent at CSUEB and Dr. Stanley Wanat at Stanford University.

Nidhi Mahendra is an associate professor in the Department of Communicative Sciences and Disorders at California State University East Bay. She is a certified bilingual speech-language pathologist with expertise in adult neurogenic language disorders and diversity issues that affect service delivery in speech-language pathology. She is past Chair of ASHA's Multicultural Issues Board and the Diversity Issue Committee of the California Speech-Language-Hearing Association (CSHA).

References

Barr, D. A., & Wanat, S. F. (2005). Listening to patients: Cultural and linguistic barriers to health care access. *Clinical Research and Methods, 37*(3), 199–204.

Boyatzis, R. E. (1998). *Transforming qualitative information: Thematic analysis and code development.* Thousand Oaks, CA: Sage.

Faroqi-Shah, Y. (2007). Cultural diversity: The Asian Indian contribution. *Perspectives on Issues in Higher Education, 10*(2), 14–17.

Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research.* Chicago, IL: Aldine Transaction.

Institute of Medicine. (2002). *Unequal treatment: What health care providers need to know about racial and ethnic disparities in health care.* Washington, DC: National Academy of Sciences.

Krueger, R. A. (1998). *Developing questions for focus groups.* Thousand Oaks, CA: Sage.

Mahendra, N., Schoneman, K., Engineer, N. (2009, November). *Barriers influencing minority clients' access to speech language pathology services.* Paper presented at the Annual Convention of the American Speech-Language-Hearing Association, New Orleans, LA.

Mahendra, N., Scullion, A., Hamerschlag, C., Cooper, S., & La, J. (2011, March). *Barriers influencing minority patients' access to speech pathology and audiology services.* Paper presented at the Annual Convention of the California Speech-Language-Hearing Association, Los Angeles, CA.

Millman, M. (1993). *Access to health care in America.* Washington, D.C.: National Academies Press.

Saldaña, J. (2009). *The coding manual for qualitative researchers.* Los Angeles, CA: Sage.

Shah, A. P. (2007). Cultural issues in clinical context with Asian Indian patients. In B. Uzzell, M. Ponton, & A. Ardila (Eds). *International handbook of cross-cultural clinical neuropsychology* (pp. 303–317). London, UK: Lawrence Erlbaum Associates.

South Asian Americans Leading Together. (2011). *About the South Asian Community.* Retrieved from www.saalt.org/pages/About-the-South-Asian-Community.html

United States Census Bureau. (2010a). *2010 census data.* Retrieved from http://2010.census.gov/2010census/data/

United States Census Bureau. (2010b). *Population distribution and change: 2000–2010.* Retrieved from www.census.gov/prod/cen2010/briefs/c2010br-01.pdf