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My interest in diabetes was sparked by my grandmother, who lived in India and had the disease for over 30 years. I had anecdotal evidence that diabetes self-management is approached quite differently in India than in the United States, and that people often didn't know much more about diabetes than that they had to limit sugar in their diets. After digging a little deeper, I learned that this lack of information affects populations across the country. I also noticed a lack of studies exploring health beliefs, attitudes and knowledge, and how they relate to diabetes self-management and adherence. I set out to Pune, India, to collect this data firsthand.

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Karina Javalkar

EXPLORING DIABETES HEALTH BELIEFS, BEHAVIORS, AND KNOWLEDGE IN INDIA

I came to India with a set of questions I wanted to ask, with previous literature, statistical analyses and a thousand questions buzzing around in my head. I had practiced how to administer my surveys, how to obtain consent, how to thank someone for participating. In general, I would speak to each patient for about 40 minutes administering a variety of scales that had questions such as, “Which of the following foods is highest in carbohydrates?” and “How important do you think it is to get a medical checkup even when you feel ok?” However, within my first week in India, I replaced several of the questions with things I became more interested in. I learned what questions would garner what responses—including those that would



get anything from mild confusion to outrage, such as asking some women about their alcohol consumption. Because I was doing these surveys at a doctor's office, I had to be extra patient and build the trust of whomever I was speaking with, to ensure that that person was answering honestly and not just saying things they thought they ought to say.

The Sanjeevani Cardiac Care Centre, where I conducted my research for most of the summer, was the perfect place for me. It was in the very heart of the city, and so drew in patients from all over. I got to talk to 115 patients there, including an auto-rickshaw driver, a health care professional, a couple from far outside the city, and even some people that didn't believe they had diabetes, or that it was going to go away soon. Each person brought in a new perspective, and a new story, and most were more than happy to share. Each

of these stories was eye-opening. For instance, it felt unbelievable for me to be asking someone if they exercised after they had just told me that they worked 18 hours per day, or that they didn't have space around their house to walk. There was no such thing as a cookie-cutter individual with diabetes. It is easy when doing research or reading literature to think of diabetes as a statistic—that it is something about 65,000,000 Indians have. But talking to this small sample of them gave me unique insights into how very different each of these people are and therefore how very differently self-management is for each. It reminded me of how much more there is to treating a chronic illness than just science and medicine. When I didn't have a patient to occupy my time in clinic, I got to shadow doctor's visits, observe in the clinical lab, and get to know the clinic staff. The staff at this clinic was crucial to the success of my project, because they not only helped me identify patients eligible for my study but discussed some background about each patient, helping me know what to expect. Throughout this experience, I was thankful to my parents for ensuring that I was fluent in Marathi. That was a huge factor in building trust with the patients and in building friendships with the clinic staff.

After reaching my recruitment goal, I headed to a diabetes specialty clinic in Trivandrum (in the state of Kerala) for a week. There, I knew, the patients had constant access to diabetes educators, so their degree of knowledge was not of interest to me. Instead, I wanted to pinpoint how the people here got their information outside of the doctor's office—whether it was from booklets, television, the Internet, etc. I talked to 38 patients in Trivandrum and gained valuable insight. Additionally, I was able to tour the clinic as well as shadow the physicians, diabetes educators, and dietitians. I arrived back in Pune with a wealth of information and a desire to



do something with it. So I examined the data I had collected, and decided to make a booklet highlighting things that people had the least knowledge and the most questions about: food, diabetes-related complications, and how to recognize conditions such as hypoglycemia. I wrote this in Marathi, with colorful pictures to ensure accessibility to those with limited literacy. Simultaneously, I began to discuss the data with the physicians and medical students at Sanjeevani.

In addition to my research this summer, I was able to make the most of my time in India by travelling and spending time with my grandmother. Overall, my Burch fellowship gave me the opportunity not only to explore medicine and public health, but to explore the cultural aspects of it, and to interact with an amazing and inspirational group of patients, physicians, peers and allied health professionals. They helped me grow as a researcher, a student and person by forcing me to think on my feet, conceptualize new questions every day, work in a completely unfamiliar professional setting, and identify with and respond to over a hundred unique individuals with unique stories. The data I collected during my summer will serve my academic pursuits in the short term. But I will be able to carry the lessons I have learned and the skills I have gained with me forever.

