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When Family Comes First:

Diabetes, Social Roles, and Coping among Women in Urban North India

by

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Doctor of Philosophy in Anthropology

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Lesley Jo Weaver

Ph.D., Emory University, 2014

Co-advisors: Peter J. Brown, Ph.D., Craig Hadley, Ph.D.

An abstract of
A dissertation submitted to the Faculty of the Graduate School
of Emory University in partial fulfillment
of the requirements for the degree of
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Abstract

Why is it so hard for us to do what is best for our health, and why do we often feel compelled to do things that are harmful for our bodies? The research described in this dissertation sought to respond to this persistent human problem by exploring health choices among a group of people with magnified self-care needs: women with type 2 diabetes in New Delhi, India. The general theme of the research was how type 2 diabetic women balance their mental health, social health, and physical health in this rapidly developing part of the world.

Between 2009 and 2011, the research engaged over 400 diabetic and non-diabetic women recruited from public, private, and charitable clinics in New Delhi. Using mixed methods, it investigated women's perceptions of appropriate gendered social roles, their ability or disability to participate in these roles, their mental health status using both locally derived and standard screeners, health management choices, and actual physical health outcomes (measured using anthropometrics and blood biomarkers).

The research found that women experience significant psychosocial and practical conflicts living with diabetes, an illness requiring a great deal of self-care, in a cultural context where gender roles strongly emphasize women's service to others. This tension can be conceptualized as a choice between self-care for the sake of one's physical health and other-care for the sake of one's social health (and, of course, for others' benefit). In this calculus, the care of others usually wins out. The vast majority of women in my study do not attain good diabetes control, but do report

good mental health, unlike many people with diabetes in other parts of the world. I suggest that this anomalous result is partially due to the possibility that by choosing the care of others over self-care, women preserve a crucial ability to participate in social roles that shape their identities and confer social status in powerful ways. This, however, comes at the expense of their physical health, and as such I emphasize the centrality of women's service-oriented gendered roles in shaping their health choices. I consider the theoretical implications of this scenario for anthropology, and also address the practical implications of these findings for diabetic women's health. The dissertation concludes with recommendations for practitioners engaged in global health policy and programming about culturally viable ways to improve women's adherence to self-care regimens for diabetes and other chronic illnesses.

The dissertation chapters are structured in a loosely chronological manner meant to reflect the progression an individual might experience from an initial diabetes diagnosis, integration of the illness in her everyday life, and eventual experience of vulnerability to health complications or resilience against them. It consists of five body chapters bracketed by an introduction, a conclusion, and a methods appendix. The five chapters address the following topics:

1. Women's diagnosis experiences and perceptions of the causes of their diabetes
2. Mental health in North India generally and among women in my study specifically
3. Everyday experiences of living with diabetes

4. Characteristics related to vulnerability among women in the study who are not faring well physically, mentally, or both
5. Characteristics related to resiliency among women who are faring well physically, mentally, or both

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In the USA, I want to extend sincere thanks to my doctoral dissertation committee, chaired by Peter J. Brown and Craig Hadley, with members Ron Barrett, Joyce Flueckiger, and Carol Worthman. Each has provided extraordinary mentorship and support on research grant proposals, methods and project design, fieldwork troubleshooting, article drafts, chapter drafts, and the larger project of developing a career in academia. In particular, I have benefited greatly from Peter Brown's sage advice and have been inspired by Craig Hadley's energy and intelligence. The research presented here is as much a product of their expertise as it is of my work. I also want to thank other Emory faculty for the formative influences of their research

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LIST OF CASE STUDIES BY CHAPTER

Chapter 2

Indu is a lower-middle-class Hindu homemaker with a high school education. She is 40 years old. Unlike most women in India, she has only one child, a son, because, according to her, "a small family is a happy family" (which, uncoincidentally, is also the government's population control slogan). She is short and somewhat stocky, with a large tummy that stretches her fitted *salwar-kameez* when she sits down. Indu lives in a joint family with her husband, her son, and her frail father-in-law, for whom she cares every day. She also does various kinds of work out of her home to earn a bit of additional income, such as tutoring and selling handicrafts. Diagnosed with diabetes 10 years ago, Indu is remarkably knowledgeable about the illness, its causes, and its potential consequences. This knowledge comes largely from her own reading and research about diabetes, which she conducted for years even prior to her diagnosis because diabetes runs in her family, and she knew she was at risk of developing the illness. She goes on daily walks with other diabetic women in her neighborhood, gets checkups monthly, and follows a diabetic diet. Her knowledge about diabetes, proactive self-care, and positive attitude add up to excellent diabetes control and good overall health.

Rita is a middle-class, conservative Hindu woman with no formal education. Her family runs a successful neighborhood general store out of the bottom floor of their house. In her nuclear family household are her two unmarried adult sons, her teenaged daughter, and her husband. Now 40 years old, she was diagnosed with type 2 diabetes at the young age of 30. She is of average height and weight, but she does not exercise, nor does she proactively care for her health. She loves white rice, for instance, and her husband reports that she goes into the pantry to eat it in secret. More than once, Rita has been admitted to the hospital and nearly died from high blood sugar. Part of Rita's hesitation to care for herself stems from the fact that female members of her caste are prohibited from going out alone. Yet, on top of that, she and her teenaged daughter both report that she has been more withdrawn, increasingly timid, and less interested in social activity since getting diabetes. These symptoms, along with significant reduced daily function and a marked complacence about her own health, are consistent with a potential sub-clinical case of depression, even though she did not report enough symptoms on the depression screener to qualify as "depressed."

Manpreet is a devout 50-year-old Sikh woman with a high school education who lives in a traditional joint family with her husband, her oldest son, his wife, and their child. Both members of the younger couple work full time, leaving

Manpreet to manage the household. She and her husband are financially dependent on their working son and daughter-in-law, a fact that she resents because she must ask her husband or son for money every time she has to go to the doctor for a checkup. Their criticism of her spending habits means that Manpreet feels compelled to attend a charitable clinic instead of a private one, where she believes she would receive higher quality care. Diagnosed with diabetes a year ago, she is managing her diabetes fairly well but has not attained the ideal standards of blood sugar control that her doctor recommends. Her main sources of social, emotional, and illness support are her natal family members, including her father, who has had diabetes for many years and counsels Manpreet on its management; and her daughter, who lives nearby and visits frequently. Her mental health is generally good.

Chapter 3

Shila is a 54-year-old, lower-middle-class Hindu woman who was diagnosed with diabetes 12 years ago. She wears many of the markers of a traditional Hindu woman, with a sari covering her head, a bindi (dot between eyebrows), sindoor (vermilion powder in her hair part), a nose ring, and long hair parted in the middle and braided neatly down her back. She is obese. Although she lives in Calcutta, Shila comes to Delhi regularly for diabetes care because she does not trust the diabetes physicians in Calcutta, and because her oldest daughter lives there. Shila and her daughter believe that she developed diabetes directly as a result of conflicts with her younger daughter's parents-in-law, who would not allow Shila and her other family members to see the daughter for several years after her marriage. Even now, Shila is dissatisfied with the family's control over her younger daughter and feels that this ongoing "tension" exacerbates her diabetes. Despite this “tension,” Shila does not report clinically significant levels of depression or anxiety symptoms.

Chapter 4

Manjot is an obese, 62-year-old, wealthy widow with a pronounced anxiety and depression disorders. Manjot is highly educated, holding two M.A. degrees, and attends a well known private physician for her diabetes care. She was diagnosed with diabetes 12 years ago and also suffers from hypertension and sleep apnea. As she has aged and her health has declined, Manjot has withdrawn from activities and social roles she once participated in, including managing an NGO and entertaining regularly. She is insulin-dependent but dreads giving herself daily injections and checking her blood sugar multiple times a day; she describes her blood sugar as "my biggest enemy." Indeed, her diabetes is quite poorly controlled, a fact that makes her extremely angry because she feels that she works so hard to adhere to her medication and diet regimes. Manjot's daughter says that her blood sugar stays high because she remains constantly "stressed out," a possibility that Manjot herself acknowledges.

Sita is an extremely thin, dark-skinned woman with no formal education. She is in her early 40s, although she looks much younger. Because she and her husband are both orphans, they have no extended family in New Delhi, and therefore live alone with their two children in a one-room servant quarter provided by Sita's employer for her family. Sita works full time as a maid, and has a hectic schedule that requires her to walk the 15 minutes between her quarter and the house multiple times a day. This high level of activity, combined with Sita's very uncontrolled diabetes, are probably responsible for her extreme thinness. Sita's main problem is that the demands of her family and her employer leave her virtually no time to care for herself. As a result, she often eats nothing until mid-afternoon. Because of the family's poverty, she eats whatever they can afford, rather than diabetes-specific foods, and cannot always afford to buy her diabetes medications. She reports severe depression, feels tired all the time, and has trouble completing her work with the efficiency she used to.

Kalpana (far left) is an elderly Sikh woman who lives comfortably in a large extended family consisting of her sons, their wives and children, and her oldest grandson's wife (far right), whose main job is to act as Kalpana's companion and helper. Now 78, she was diagnosed with diabetes 10 years ago, and her blood sugar is well managed. This is thanks largely to the efforts of her sons and her granddaughter-in-law, who administer her medications, check her blood sugar pre- and post-meal every day, and take her to the doctor. She also has a servant who makes and serves foods that agree with her constitution and her diabetic diet. Kalpana has a simple daily routine involving prayer, walking, watching TV, a visit to the local Gurdwara, and a midday nap. She has excellent mental health, reporting little life "tension" and no clinically significant levels of depression or anxiety symptoms.

Indu, who was introduced in Chapter 2, is further discussed in this chapter. This section of her illness narrative focuses on identifying the characteristics that help Indu maintain good health.

Chapter 5

Rita, who was introduced in Chapter 2, is further discussed in this chapter. This section of her illness narrative focuses on the role of crisis in her diabetes experience.

Maya is a young, timid widow whose 35 years do not show on her youthful face. She only appears tired and shy. She was married as a child of seven to her husband, who died suddenly from an aneurism five years ago. In the wake of that tragedy, Maya has been forced to continue living with her in-laws because she has no education that would allow her to work, and she needs to be home to care for her two young sons. The in-laws provide housing and financial support for her and the children but extract an exhausting toll from Maya that includes managing the household, caring for them (her mother-in-law is diabetic), and enduring poor treatment. Six months after her husband's sudden death, Maya was diagnosed with pre-diabetes, but has not once had the opportunity to follow up with the doctor about her condition in the intervening four-and-a-half years. Her blood sugar is poorly controlled, she takes no medications, and she reports severe depression and anxiety symptoms. Because Maya has never consulted the doctor for her condition, she is not aware of precautions she should take and therefore continues to do things like participate in religious fasts, a dangerous practice for people with diabetes.

Ankita is a bespectacled 42-year-old professional woman who works full-time for an international organization in Delhi and speaks fluent English. Diagnosed with diabetes a year ago, she maintains excellent blood sugar control but has poor mental health, with clinically significant levels of both anxiety and depression symptoms. This pattern is unusual among the women in my study, who more often had good mental health but poorly controlled blood sugar. Ankita even uses the English word "depression" to talk about her mental state, and cites the extremely stressful nature of her job as the main culprit. Specifically, her efforts to maintain long working hours, spend time with her family, and help keep the house running even when she is not home (by directing their maid over the phone from work, for instance) make her feel that she is pulled in too many directions at once. Ankita reports that her efforts to manage her diabetes add "another layer" of stress to her life. Even though she adheres most of the time to a diabetic diet and takes her medications exactly as instructed, she worries that she is not doing enough to take care of her health because she so rarely finds the time to exercise.

Chapter 6

Sudesh is a 35-year-old impoverished mother of three whose husband has not been able to hold a job in the last year because of debilitating body pain following a severe case of dengue fever. Sudesh has contemplated working, but she worries that with her 10th grade education she would only be qualified to do poorly paid, low-status work. Diagnosed with diabetes only six months ago, Sudesh relies on Ayurvedic treatments to control her blood sugar, but it remains high. Despite her family's difficulties, she maintains a positive attitude because, as she explains, her husband's serious illness reminded her that life is more important than money. After her diabetes diagnosis, Sudesh initially found it difficult to give up sweets, which she has always loved. When I visited her several months later, however, she said it had become habit. Although her blood sugar is not in good control, she reports feeling significantly better than she did before she began treatment. She reports no depression or anxiety.

Krishna is a deeply religious Hindu woman who was diagnosed with diabetes 10 years ago. Now 55, she lives in a joint family with her husband, son, daughter-in-law, and young grandson. Krishna is obese, but she rarely worries about her diabetes or her concurrent hypertension because her strong faith keeps her mind "tension-free." Indeed, she reports no depression or anxiety. Her daughter-in-law, who does the family's cooking, tries to convince Krishna to allow her to reduce the amount of oil in their vegetable dishes for the sake of Krishna's health, but she likes them on the oilier side. Krishna takes oral diabetes medications regularly but adjusts the dosage and frequency to suit her needs, because she feels shaky if she takes full doses. Her diabetes is relatively well controlled, though her blood sugar remains above ideal levels.

Sarita is a youthful looking upper-class woman of 63, whose children and grandchildren live abroad and whose husband was a high-ranking government official prior to his retirement. She is slim, fashionably depressed, and speaks in a British-accented English about her husband's recent health crisis, through which she persevered in a remarkable manner. Sarita was diagnosed with diabetes 14 years ago but has never had a bout of ill health related to her illness, even during her husband's crisis. She is insulin dependent, adheres to a strict diet, exercises regularly, and checks her blood sugar at home. Because she is wealthy, Sarita is able to attend one of the most comprehensive diabetes care centers in Delhi, which offers annual package programs that include regular checkups, diabetes lifestyle education, and dietician consultations. She has very good mental health as well. Her excellent self-care contrasts markedly with that of her husband's aunt, whom she watched suffer and eventually die from diabetes complications.

Nirmala is a 40-year-old lower middle class woman whose husband is a low-ranking government official. A Delhi native, she rarely sees her parents or siblings because she remains busy caring for her three teenaged children and for the house. She is soft-spoken, wears traditional markers of North Indian womanhood, such as a long braid down her back and a bindi, and is an excellent and cheerful conversationalist. Yet, she is no stranger to suffering; during her children's youth, her husband worked in a different city, supporting her financially but leaving her alone to raise the three babies. During this time she was diagnosed with depression as well as diabetes, and even now their relationship remains strained because of lingering resentment she feels toward her husband for leaving her during this difficult time. This long period of aloneness might contribute to her present selfsufficiency regarding her diabetes care, which she maintains despite a lack of support from her family members. She demonstrates similar self-motivation regarding her mental health, forcing herself to go out and be social when she begins feeling down because she knows this will ultimately make her feel better. She reports no clinically significant levels of anxiety or depression symptoms, although her anxiety symptoms are approaching significant levels.

PREFACE

This dissertation is an ethnographic and epidemiological study of type 2 diabetes, family life, and mental health among women living in New Delhi, India.

At the dawn of 2010, India held the dubious distinction of being not only the world's second most populous country, but also its "diabetes capital," with more diabetic individuals than any other country (International Diabetes Federation 2011). Home to a mind-boggling 61 million diabetic people comprising over 8 percent of the total population, India is already in the midst of a public health crisis that its underdeveloped healthcare system is ill equipped to handle. The collision of the country's demographics, diabetes burden, and weak public health infrastructure is, in many ways, a "perfect storm" setting India up for serious economic losses that are much needed to help improve basic living conditions for the country's still large, desperately poor sectors.

This catastrophizing discourse will be familiar to anyone who reads world news, and it certainly holds grains of truth. Yet, the story of diabetes in India is much more complex than this discourse would suggest. Just as not every child in India suffers from severe undernutrition—a stereotype promoted by global media in the 1980s and 1990s that many people in America still believe to be true—not every diabetic person in India is struggling to stay healthy.

This dissertation is about the variety of experiences among people (specifically women) with type 2 diabetes in India's capital, New Delhi, and about what can be done to help them face the challenges of managing their illnesses for a lifetime. A careful comparison of women's personal and medical experiences can illuminate not only who is doing well, by *why* they are doing well. Conversely, it can also help us identify why others are not doing as well.

Some of these women need little, if any, help managing their illness. They usually have several advantages that help them stay healthy, such as plenty of money, enough education to understand their doctors' instructions, personal autonomy, good mental health, or family support. Others face personal health crises that fit the damning discourse of popular media and public health. These women often face structural and personal challenges that make it virtually impossible for them to manage their type 2 diabetes well. These challenges include, among many others, poverty, illiteracy, poor mental health, and heavy domestic responsibilities that afford them no personal time.

Women are an especially important focus for me, as a social scientist interested in health, because they still bear the vast majority of responsibilities to home and family in India's largely patriarchal and rapidly developing societies. This means that they face special challenges managing their health and personal needs that men in India, or women in less patriarchal societies, do not. In addition, many women's life stories remain untold and undervalued in the global arena, despite valiant efforts to correct this long-standing imbalance. By listening closely and paying attention to women's voices and bodies, we can surely learn new things about what it means to be someone with a chronic disease in a developing country.

This fundamental question—what it means to be someone with a chronic disease in urban India—drives the dissertation. While this question might at first seem overly specific and perhaps not so important to those of us outside the developing world, this is not the case. As global development continues to change power and economic relations between countries, an ever-increasing portion of the world's population will be living with chronic diseases, and we need to understand how they impact individual lives. Furthermore, blurred national boundaries resulting from global movements of migration and media mean that over time, more and more of us will be drawing from and contributing to the same healthcare systems through our healthcare needs and our taxpayer dollars. Already, over 75 percent of the USA's national public and private health expenditures go to chronic disease treatment (Centers for Disease Control and Prevention 2011). This study of type 2 diabetes, women, and social life helps us understand how and why chronic diseases are becoming such a global challenge, what can be done, and why it should matter for everyone.

Exploring women's lives around the focal topic of type 2 diabetes helps us understand much more than their physical health, however. As a point of entry into a whole social world, type 2 diabetes can tell us about family life; individual and group values; cultural norms, expectations, and conflicts facing urban Indian women in the 21st century; and much more. It gives us windows into the lives of others—one of the fundamental goals of anthropology as a discipline. In this way, the question, "What does it mean to be someone with a chronic disease in urban India?" resonates far beyond the immediate concerns of health, teaching us about development, gender, family, and what matters from day to day in the lives of a large portion of the world.

When I began talking with women in India about type 2 diabetes, two things surprised me. First was the fact that virtually every woman I met either had diabetes herself, or had a close friend or relative with the illness. Second, and even more interesting to me, was the degree to which diabetes shaped these women's lives. For many, diabetes was not only a physical syndrome, but an emotional and social one as well. Particularly important, it seemed, were negative emotions such as stress and grief. Women often told me that they first got diabetes during a period of "tension"[1] in their lives, such as the death or serious illness of a loved one. Likewise, they often told me that diabetes caused more "tension" by placing extra demands on their already busy schedules, which were usually dominated by childcare, household cleaning, cooking, care of elderly parents-in-law, and sometimes a career as well. This dissertation will explore the complicated webs of how diabetes is both created out of, and creates, stress in women's lives.

Chapter 1, "Introduction," introduces readers to the megacity of New Delhi and the social, political, and economic situations of women living there today. It also introduces several key theoretical concepts that drive the subsequent chapters and provides a brief overview of how the study was conducted. Chapter 2, "One Only Goes to the Doctor When One's Health is Bad" explores how women come to be diagnosed with type 2 diabetes, with a particular focus on their healthcare-seeking behaviors. It also examines women's own understandings of the causes of their illnesses. Chapter 3, "Tension Happens," explores the most common cause women mentioned for their diabetes, "tension," and considers its meaning both in general usage and with specific reference to diabetes. By way of this conversation, Chapter 3 also discusses the role of

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[1] A common idiom among Hindi speakers, the English word "tension" is a general term that denotes stress or agitation. It may, however, also be used to indicate more serious and persistent negative feelings associated with clinical depression or anxiety disorders. Chapter 3 deals specifically with the concept of "tension" and its relationship to diabetes.

mental health in diabetes. Chapter 4, “Domesticity and Disability,” presents the case studies of four women to illustrate how diabetes management intersects with everyday life, especially in the domestic sphere where most women I worked with spend most of their time. In Chapter 5, “Vulnerability,” I consider what cultural and personal factors make some women vulnerable to diabetes complications. Chapter 6, “Resilience,” is the companion to Chapter 5, and explores the cases of women who have good mental health, good diabetes control, or both. Finally, Chapter 7, “Conclusions,” synthesizes the findings of the dissertation and distills them into targeted recommendations that could be used to improve diabetes management in India and all over the world.

Over the course of these chapters, we will explore several key questions:

- Why is type 2 diabetes becoming such a significant health problem in urban north India today? What is missing from biomedical models of this “epidemic”?
- What is it like to live as a woman with type 2 diabetes in urban north India? What personal, social, and emotional roles are at stake in these chronically ill women’s lives? Where do conflicts arise?
- How are type 2 diabetes and mental health related in this cultural context?
- How does New Delhi’s medical system work for people with chronic illnesses?
- Why do some women fare well, while others suffer serious complications? What resources (or lack thereof), personal characteristics, and situations are involved in creating this difference?
- How do these differences play out in women’s everyday lives, in their relationships to their own bodies, and in their bodies themselves?

- And finally, can this information help women with diabetes in urban North India manage their health better, and perhaps help others avoid getting diabetes at all?

CHAPTER 1: INTRODUCTION

DECEMBER 31, 2010

It was a balmy evening in Orchha, a small town in India's central-most state, Madhya Pradesh. Bats were flitting in and out of the open archways of the small town's famous Mughal architecture. The town was abuzz not only with mosquitos, but with young people from outlying areas who came on this New Year's Eve to see and be seen in this, the most urban area for miles around. As guests began to gather and enjoy appetizers in the courtyard of my hotel, three musicians in pink turbans and long tunic-style *salwar kurta* sat cross-legged on a carpet covering a low stage and began to play and sing Betwa folk songs. Their songs, passed down by generations of bards before them, told the stories of love and loss, of right and wrong, of gods and demons. The melodious *tabla* drums laid down a beat, while the *sarod* player strummed and the singer expertly slid his voice between notes. Meanwhile, not 20 feet away, young men in jeans and tee shirts began setting up a portable disco floor with light-up tiles, a smoke machine, and two speaker towers. Before long, the speakers began emitting American and Indian pop music remixed with techno beats. The volume crept up until the guests could not converse unless they shouted, and the Betwa musicians became entirely inaudible. I moved closer to the stage and tried to encourage them by nodding agreeably to the *tabla* player's ever-more imperceptible beat. Finally, they gave up. Shaking their heads in resignation, they began to put their instruments away. I must have looked disappointed, for the singer and harmonium player addressed me. "Ah, madam," he sighed, "nobody wants this *purana-wurana* music anymore. What to do?" I shook my head along with them, and did not linger long, but returned to my room. Soon, a pumped-up version of a Michael Jackson song echoed into my dreams.

The competing musicians—the folk singers who did not stand a chance against the international pop music—are to me an evocative metaphor for the colossal cultural changes occurring in North India today. Since the country's economic liberalization in the early 1990s, traditional lifeways are being progressively supplanted by modern desires for wealth, technology, development, and independence. Yet, many Indians still identify deeply with those traditional values, which pulse in the undercurrents of their lives like the beat of the *tabla* player at the New Year's Eve party. Like generations before them, their mothers and aunts raised them to believe in the centrality of family, duty to others, and recognition of the interconnections that run deep between us. Despite urban North India's rapid modernization in the last two decades, the vast majority of women in North India continue to work exclusively inside the home, teaching children these values, keeping house, and encouraging religious piety. Yet they, too, feel the pull of modern desires and ways of being.

This mode of living in dual spheres, at once traditional and modern, defines life for many women in India. The fundamental tension between tradition and modernity, though not always harmful, creates conflict that has real implications for how women in New Delhi live their lives.

This dissertation is about how women negotiate these changing cultural norms in the context of their own health. It centers primarily around a group of women with type 2 diabetes, a chronic disease that requires a great deal of self-management at home. Type 2 diabetes is a chronic disease resulting from the body's reduced production of, and/or sensitivity to, the hormone insulin, which is produced by the pancreas. Insulin instructs the body's muscle, liver, and fat cells to absorb glucose, or sugar, which enters the blood when we eat and digest food. It is therefore a key player in the process of digestion and uptake of food energy.

Diabetes in any form is caused by problems with insulin. The key difference between type 2 and other types of diabetes is what creates the insulin problem. People with type 1 diabetes, for instance, have a physiological problem that prevents the pancreas from producing enough insulin. When a person has type 2 diabetes, in contrast, insulin is present, but the body's cells begin to "ignore" insulin's "instructions" to absorb glucose.[2] The result, in either case, is abnormal levels of blood glucose, often too high but sometimes too low. Over time, this abnormal blood sugar causes damage to organs receiving the high-glucose blood and to the circulatory system.

Treatment of diabetes generally involves getting regular exercise, taking medications and/or injecting insulin, eating a restricted diet that excludes foods high in sugar and carbohydrates, and monitoring one's blood sugar regularly at home using a machine called a glucometer, which reads blood sugar from a drop of blood.

There is a balance that women around the world with type 2 diabetes must negotiate between their diabetes self-care and their other roles. I found that decisions about how to attain this balance are complicated for women in New Delhi because of

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[2] One process leading the body's cells to "ignore" insulin, a condition called *reduced insulin sensitivity*, involves stress hormones like adrenaline. In stressful situations, adrenaline blocks insulin's action for the purpose of keeping sugar available in the blood in case we need a sudden burst of energy to escape from a stressor. When the body is chronically stressed (by stressful lifestyles, obesity, or other illnesses), this mechanism remains chronically activated, leading to unhealthily high blood sugar levels that are never dispelled by sudden bursts of energy.

competing traditional and modern priorities that inform how they choose to live their lives. After 14 months of work in New Delhi, I concluded that women with diabetes[3] often prioritize the care of others over the care of themselves. This service to others takes a unique form in India, where it is so deeply engrained in cultural expectations of what women should do that it hardly makes sense to use the language of "personal choice" to talk about how prioritize self-care and other-care. This service is also unique, in that it is typically oriented around the husband and in-laws, rather than one's children or one's own aging parents. Though women are, of course, expected to serve their children very attentively, it is almost taken as a "given" that they will do so. The superlative service to parents-in-law on top of one's childcare duties is an especially powerful way of measuring middle-class women's devotion to family in North India specifically.

One result of this heavy cultural emphasis on the care of others is extremely high rates of uncontrolled diabetes. Yet, despite having poor blood sugar control, the women with whom I worked generally maintained excellent mental health, no different than their non-diabetic peers. This may be in part because they preserve important social relationships and sources of cultural integratedness by continuing to participate in valued family roles. If this is the case, *not* adhering to diabetes control standards may actually be "good" for women's health (socially, though not physically).

This notion led me to several conclusions that will be elaborated throughout the dissertation. Firstly, social roles sometimes matter more than one's physical health. The teenager who smokes cigarettes or uses drugs under peer pressure knows this, but so does the overweight father who spends time with his children instead of going for a jog. At many junctures in life, our physical health is not our first priority, and that is not

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[3] From here on, "diabetes" is used as shorthand for "type 2 diabetes."

necessarily a bad thing. Unfortunately, medical discourses surrounding diabetes control often cast people with poor control as weak-willed hedonists, generating some degree of stigma (especially in Western countries) around those who are unable to take care of their own health.

Secondly, as we will see, this study suggests that biomedicine ought to rethink its criteria for success or failure of diabetes management. Most physicians judge their patients' diabetes control as acceptable or unacceptable based on whether or not their blood sugar falls below internationally recognized thresholds set by the American Diabetes Association. However, those who do not meet these thresholds may still lead fulfilling and happy lives for many years. For some, the promise of years of life added is not as valuable as the freedom to live as one chooses in the present, even with the knowledge that poor blood sugar control will lead to health complications later on and, ultimately, an earlier death.

Finally, the women in this study illustrate that a lack of "good" chronic disease control is not necessarily an indicator of hedonism, weakness, or self-indulgence. Rather, it may be the product of an alternative values system that recognizes the primacy of social relationships and their importance to quality of life over the preservation of physical health at any cost. It may also be an indicator of the enormous amount of pressure on women in this cultural context to meet social expectations that involve caring for others. Either way, the "choice" to prioritize others over oneself is a much more complex tradeoff than medicine's discourse of victim-blame allows us to see.

This dissertation grew from a very simple initial observation, followed by a question, which became a multi-year project whose many twists and turns sometimes took me toward topics I anticipated, and other times did not. The beauty of anthropology, the social science dealing with all aspects of the study of humans, is its flexibility. Perhaps the field grew to be this way because of its capricious subject matter. After all, we as a species often act unpredictably, irrationally, and sometimes counter-intuitively.

This research began with the observation that many women I knew in North India were either suffering from diabetes themselves, or knew someone who was. It was striking how often "sugar"[4] came up in everyday conversation. In addition, the North Indian woman with whom I was living at the time suffered from what I suspected, after many days of sharing the same space, to be severe depression. She was a modern, educated woman who held a Ph.D. in English literature and was one of the few divorcees I had met in India, but she lived alone, with only one son who had emigrated to America and never returned. Cohabitating with her sensitized me to the problem of undiagnosed depression among older women in India and illustrated in a very concrete sense how depression and rapid modernization could be linked for women in urban North India.

When I began reading the literature on diabetes, it quickly became apparent that a major concern from a medical, a public health, and a personal perspective was quality of life. The many tasks involved in diabetes management may interfere with people's lifestyles, while fluctuating blood sugar may affect not only physical health, but also mood. A key problem associated with quality of life in diabetes is mental health, but most studies documenting the association between diabetes and poor mental health have been

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[4] Most of the people I worked with used the English word "sugar" to colloquially refer to diabetes, even though they spoke Hindi. It is common for Hindi speakers to insert English words into their speech, especially in New Delhi. The English word "sugar" is the most frequently used colloquial name for diabetes among those with whom I worked. Another variant found among the less educated groups is *chini ki bimari*, a Hindi phrase meaning "sugar sickness."

conducted among Western populations. I accordingly decided to focus my work around questions of diabetes and mental health among women in North India.

As often occurs in field research, two unexpected themes arose organically, and they are the focus of many of the following chapters. Firstly, women used the English word “tension” to talk about all kinds of stresses in life all the time. This struck me as odd, firstly because they actually used the English word “tension” (rather than the Hindi word *tanav*), and secondly because I, as an outsider, could not determine where the blurry boundaries of the concept of “tension” were located. Given my interest in mental health and its effects on chronic disease management, I pursued a detailed study of how women defined, used, and understood the construct of “tension,” both in relation to diabetes and more generally. The findings of this portion of the study are the subject of Chapter 3.

A second unexpected finding was that while diabetes control was generally poor among diabetic women, mental health was good. This was surprising because it disagreed with the established literature documenting associations between diabetes and depression. Trying to deduce why this might be the case ended up occupying much of my research time. Ultimately, I concluded that a crucial part of women’s trouble managing their diabetes is the conflict that arises between the intensive self-care required for good diabetes control, and traditional gender roles in North India, which teach women to emphasize the care of others. To preserve their identities, their significant social roles, and perhaps their own mental health, women prioritize the care of others over the care of themselves with striking regularity, one outcome of which is poor blood sugar control. This tells us something about what matters most in North Indian society, but it also tells us something clinically relevant about why women have trouble controlling their diabetes in this cultural context.

Theoretical Orientation

The research presented here aims to contribute to critical medical anthropology, a specific school of thought within medical anthropology that critiques the assumptions underlying biomedicine. Critical medical anthropology departs from the observation that biomedical models of disease and treatment are grounded in the 16th and 17th century European scientific revolution, which privileged the superiority of reason over religion and superstition. Although biomedicine presents itself as an objective, impartial, and "truth"-based system supposedly free of moral or religious underpinnings, it in fact involves many ideologies specific to Western Europe and North America, such as a Cartesian separation between body and mind, a Fordist conception of the body-as-machine, and an emphasis on preserving life using highly interventionist technologies, to name just a few. As biomedicine becomes increasingly dominant around the world via "medical colonization" (Guerra 1963), it can be easy to forget that it is only one of many systems humans have developed to deal with illness. This is where critical medical anthropology steps in, working to expose the imperfections and the biases implicit in the values-laden system of biomedicine (Baer, Singer, and Johnsen 1983; Lock 2001; Scheper-Hughes and Lock 1987). In particular, critical medical anthropologists have drawn attention to the political-economic causes of unequal health between class, race, ethnic, and gender groups and have sought to apply these findings to improve health equity by interfacing with global health (*cf.* Farmer 2001; Greene 2004; Packard et al. 2004; Pfeiffer and Nichter 2008; Singer 2009).

In this dissertation, I will draw on critical medical anthropology to show how the values inherent to biomedical management of diabetes—specifically, ideals surrounding control, preventative care, and self-care—conflict with dominant cultural values specific to women in North India. One of the main things I hope to show is that such cultural conflicts are partially responsible for the high rate of poor diabetes management in North India in general (Venkataraman, Kannan, and Mohan 2009), and in my study group specifically. This conclusion gives us insight into the fundamental causes (Link and Phelan 1995) of women's poor diabetes health in India, and it also suggests that individuals should not bear the full onus of blame for the difficulties they face with their self-care. Structural conditions, rather, are often at least partially responsible for women's inability to care effectively for their diabetes. This conclusion, too, stands in direct contrast to most biomedical models of chronic disease and blame, which tend to focus responsibility for success or failure in illness management on the individual (Ferzacca 2004).

This dissertation also will employ the distinction often used in medical anthropology between "disease," "illness," and "sickness" (Helman 1981; Kleinman 1988; Young 1982), a cornerstone of medical anthropology. According to Kleinman (1988), a "disease" is the technical dysfunction that a physician has been trained to diagnose using observable symptoms; "illness," on the other hand, is the totality of how a sick person and his/her social network "perceive, live with, and respond to symptoms and disability" (3). "Sickness" refers to the social and political-economic production of ill health through forces such as unequal power relations, poverty, and discrimination (Young 1982). Together, these three concepts help explain how two people with the same physical symptoms might have very different illness experiences, depending on factors like their social networks, the type and quality of medical care they receive, their social and economic position, and attributes of their own personalities.

As Chapters 5 and 6 will show, women may suffer from the “disease” of diabetes but not the “illness” or the “sickness,” or vice-versa. Women who have the disease of diabetes but not the illness are aware of the biological fact of their diabetes but live life as before, thus limiting or even completely avoiding the social complications often associated with diabetes (such as reduced functioning in important social roles). Those who live without the “sickness” are usually privileged individuals who are exempt from the political and economic subordination that creates the preconditions for poor diabetes health among individuals in impoverished groups. Those with the illness but not the disease, however, experience biological levels of blood sugar that resemble those of a person without diabetes (that is, they have excellent diabetes control), but still face social ramifications of diabetes. Then, of course, there are some who experience all three of these entities together, and these tend to be the poorest, least-healthy individuals. People who experience none of these comprise the non-diabetic group of 97 women who serve as the baseline against which I compare the diabetic group’s mental health and other indicators.

As this elaborated distinction between illness, disease, and sickness suggests, medical anthropologists have, for decades, been keenly interested in the degree to which the perception of health and illness shapes our actual experiences. In particular, medical anthropologists have focused on what illness narratives—or the stories we tell about the illnesses[5] we have—can reveal about human health, illness, perception of what matters in life, and even about life more generally (Kleinman 1988). The words we choose, the trajectories we describe, the details we leave in or out, the reasons we think we got sick in the first place—these are not mere technicalities, but are the traces many medical anthropologists follow to gain deeper understanding into the ways illnesses shape our lives and our identities (Mattingly 1994).

One way of conceptualizing the relationships between illnesses and identity is to take stock of their effects over time, since indeed the uniting feature of chronic diseases is their *chronicity*, or long duration. Originating from medical anthropological studies of schizophrenia in the 1990s, chronicity is often poorly defined in contemporary usage but essentially refers to the progressive, cumulative takeover of an individual's identity that can occur with chronic illness. According to Estroff (1993), "Western notions of the nature of schizophrenia (and perhaps other chronic, debilitating conditions) combine with Western notions of the self and identity to produce 'I am' illnesses, a fusion of self with sickness, of diagnosis with identity—in consequence, chronicity " (257). Diabetes may precipitate a similar "engulfment of the person" as an individual transforms from "a person with diabetes" into "a diabetic" whose activities are constrained by the disease, and whose identity revolves around the illness. For instance, the need for constant self-monitoring of blood glucose, diet, and exercise may limit one's ability to enjoy hobbies (Ferzacca 2004) and may result in the avoidance of social situations involving foods not

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[5] Here and throughout most of the dissertation, I use the distinction often made in medical anthropology between "disease" and "illness." While "disease" refers to a biological malfunction, "illness" refers to the social conditions and responses that surround such a malfunction (Kleinman 1980).

allowed by a diabetic diet (Broom and Whittaker 2003). The accumulation of these small changes over time may result in significant narrowing of social worlds and identity loss resembling that seen in people with other chronic diseases (Charmaz 1991; Crooks 2007).

Indeed, the accumulated effects of illnesses are what make them most difficult: the long-term toleration of pains or medication routines or the progressive loss of function, which may require increasing withdrawal from former life routines. Although I met the women in this study at only one point in their lives, they had been living with illness for different periods of time and therefore represented different "stages" in the chronicity of diabetes. Some were diagnosed the day I met them, while others had had diabetes for decades.

More important than the temporal duration of women's illnesses, however, is the way they *perceive* the duration and severity of their illnesses. Consider the fact that a woman who has had diabetes for a short time may nevertheless feel heavily burdened by her illness, while a woman who has had diabetes for a long time may experience few problems related to her illness and live much as she did before. This variation depends on the point when she was diagnosed, on her physical health before diagnosis, on her attitude, her access to medications and to doctors, her family support, her other responsibilities, and myriad other factors.

The ultimate point of chronicity and other medical anthropological theories, such as the distinction between illness and disease, is that individual perceptions of illness matter for one's wellbeing. They matter just as much for wellbeing as do actual physical states, and therefore, in the view of many medical anthropologists, deserve just as much attention. The fact that they rarely receive that kind of attention from doctors is one of medicine’s biggest shortcomings.

Gender, Health, and Development in India

Work by social scientists in India has done an excellent job of characterizing the nature of women’s domestic roles. This body of work, coming mostly from anthropology and gender studies, has explored how urbanization, class mobility, and labor force participation are shaping expectations and roles for women in urban centers such as Delhi and Calcutta (*cf.* Dickey 2002; Donner 2008; Standing 1991). Faced with new opportunities, women are becoming more educated, marrying later, and in many cases having careers, but they still desire and are expected to produce families for whom they must care in a deeply self-sacrificial manner (Donner 2008). Thinking of her working sister-in-law, for example, one woman in my study explained,

> Because of her children she couldn't advance as quickly as she would have otherwise, but still she's come into a good position now. After she cleared her officer exam, the first two years were really difficult for her. Within those two years she had her daughter, and she would come home from the office at nine or ten at night, there was so much work. She had to look after her job, her daughter, and the household. It was very tough. Then she thought that she should stay with her children till they became a little more independent, then she could think about her future more.

As this quote suggests, particularly important is women’s role as the primary perpetuators and elevators of the family’s social status through bearing and raising children (especially sons) according to traditional values that emphasize piety, study, and family devotion. These studies quite rightly note that although South Asia is becoming an ever more active participant in global economies, it is not seamlessly assimilating the Western values that often come along with such socioeconomic transformation. Instead, this meeting of values systems is messy, partial, and inconsistent.

The result is that while modern ways of life are highly sought after, traditional family practices are still the norm for many women. About half of the women in this study lived in nuclear families, while the other half lived in the more traditional patrilocal joint family setting.[6] The vast majority were stay-at-home mothers, wives, and grandmothers. Almost all had arranged marriages. While these family arrangements confer many benefits, including strong social support networks, they also place a heavy burden of responsibility on women. Some traditional practices growing out of this domestic model subordinate women in extreme ways. National newspapers regularly print stories chronicling crimes against women such as child marriage and "dowry deaths" (young brides being murdered by their in-laws' families for not bringing enough dowry to the marriage). The India Census has documented a steadily worsening sex ratio since at least the 1960s, which was likely initiated by selective female infanticide and structural factors predisposing female infants to lower survival. It has been exacerbated in recent years by the increasing availability of prenatal sex determination technology and selective female abortion.[7] The most recent census revealed that sex ratios have been worsening in urban areas and especially among wealthier and more educated groups,

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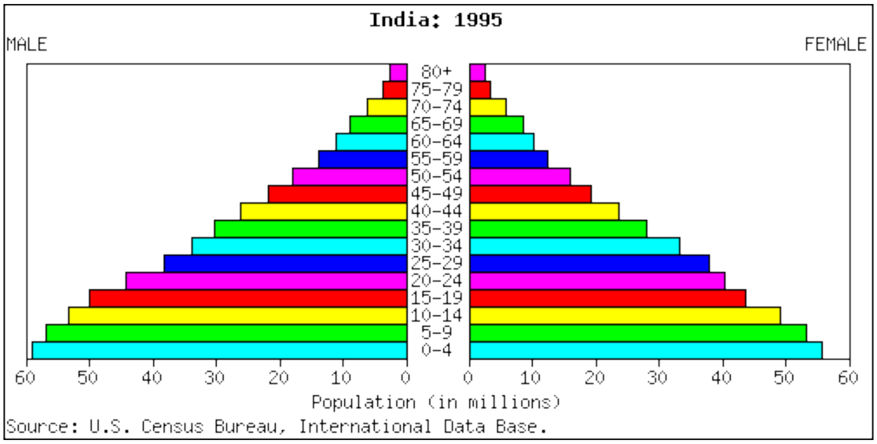
[6] In most Indian societies, a bride traditionally moves in with her husband's family after their marriage, a pattern of settlement referred to as "patrilocal." Her family roles involve bearing and caring for children, but also caring for her parents-in-law as they age. Ideally, from the mother-in-law's perspective, the arrival of a bride in the household should allow her to "retire" from her domestic roles. If there is more than one son in the household, the daughters-in-law work together sharing these domestic responsibilities.

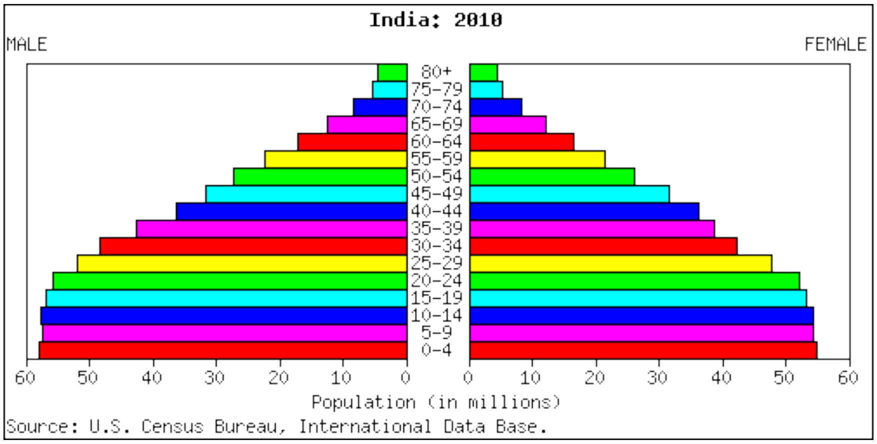
[7] Prenatal sex determination was outlawed in 1994 by India's Pre-Conception and Pre-Natal Diagnostic Techniques Act, but is still available in many places. Anecdotally, there also appears to be a growing trend of wealthy families crossing international borders to seek sex determination ultrasounds.

including in Delhi (Jha et al. 2011). Such practices remain part of the national consciousness about women and their value to society because they are so widely covered by the media.

The situation of women is also complicated in contemporary India by the fact that the nation's population is currently in the midst of what is known as a "demographic transition" from a high birth rate and high mortality rate (characteristic of poorer populations) to a lower birth rate and lower mortality rate characteristic of more economically developed groups with better access to healthcare (Caldwell 2006). A main driver of this demographic shift comes from an "epidemiological transition" (Omran 1971), where people increasingly die from chronic and degenerative diseases of old age (e.g., cancer, diabetes) instead of dying earlier in life from acute infectious diseases (e.g., cholera). As a result, the population ages rapidly, with a growing proportion of elderly and frail individuals and a shrinking proportion of productive adults to support them.


India: 1995

Source: U.S. Census Bureau, International Data Base.



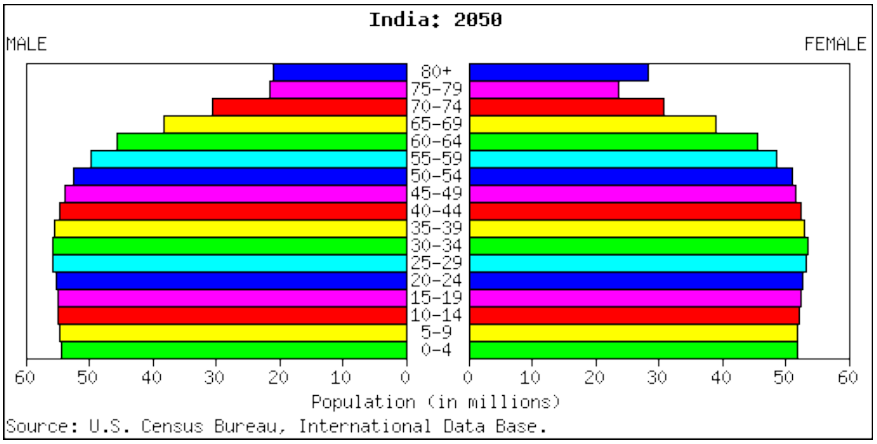


Figure 1. India's changing population structure. In 1995, the largest population groups were the youngest groups (top). This pyramidal structure is typical of courtiers in the early stages of development and reflects high birth and high infant and child death rates. In 2010, with decreases in birth rates and increasing survivorship of infants and children, young adult groups were becoming proportionally larger (middle). By 2050, India's largest age group is projected to be middle-aged adults, while, as life expectancy increases, elderly and frail adults will comprise a much larger proportion of the population than they did in 2010 or 1995 (bottom).

These large-scale demographic changes have important implications for Indian women's tasks and roles, especially in the context of the observations made earlier that expectations for women are staying largely the same, despite other social changes. As populations age and families become smaller, the so-called "sandwich generation" of women face heavier burdens than they once did, because they are simultaneously responsible for the care of their children and of their increasingly frail parents-in-law, who are generally living longer but not necessarily living healthier. The vast majority of elder care in the country still occurs in the home, with elder care centers being quite uncommon (Bali 2001). Furthermore, because people are having fewer children, families are getting smaller, and women are therefore less likely to have sisters-in-law or older daughters in the household with whom to share domestic responsibilities.

Against this backdrop of cultural norms that are both changing and static, management of an illness like type 2 diabetes can be complicated. This is especially true when the individual suffers from a concurrent mental health condition, such as depression, which is a common diabetes comorbidity. Biomedical and epidemiological research has demonstrated how type 2 diabetes affects quality of life, including mental health. People with diabetes have a significantly higher prevalence of depression than their non-diabetic counterparts (Almawi et al. 2008; Anderson et al. 2001; Egede et al. 2002). In some cases, depression is higher among people treated for diabetes than among those untreated (Golden et al. 2008), suggesting a depression-inducing effect of diabetes treatment programs. There appears to be a bidirectional relationship between diabetes and depression; that is, people who are depressed are more likely to get diabetes later on, but people who have diabetes are also more likely to develop depression (Egede and Ellis 2010; Golden et al. 2008; Mezuk et al. 2008; Pan et al. 2010; Talbot and Nouwen 2000).

This comorbidity has serious consequences for health and wellbeing (Katon and Ciechanowski 2002) including increased risk of retinopathy and neuropathy (DeGroot et al. 2001), reduced adherence to treatment (Ciechanowski, Katon, and Russo 2000;

Lerman et al. 2009), increased healthcare expenditure (Egede, Zheng, and Simpson 2002), lower perceived quality of life (Goldney et al. 2004), and higher mortality (Katon et al. 2005).

Women around the world have about the same rates of diabetes as men, but above age 60, the prevalence of diabetes among women increases more rapidly than men's (Wild et al. 2004). Limited data from India suggest that this pattern also holds there (Ramachandran et al. 2001), but relatively little work has considered how women in India experience health and illness (Kielmann 2002), particularly outside the context of reproductive health. Some research suggests that Indian diabetic women report lower quality of life and fewer coping abilities than diabetic men (Sridhar and Madhu 2001). Complicating the health picture for Indian women is what one physician in this study referred to as a ''widespread ethos of quiet suffering'': women frequently conceal symptoms of ill health to avoid generating concern or incurring expenses, delaying treatment until serious complications arise (Basu 1990; Conrad and Pacquiao 2005). This pattern is shaped by gender-based inequalities and beliefs about appropriate timing and methods of care seeking (Amin and Bentley 2002).

Only a handful of medical social scientists have studied diabetes, and even fewer have done so in India (but see Mendenhall et al. 2012). For this reason among others, the research presented in this dissertation is unique. It provides new information about a large group of people, one whose numbers are expected to grow significantly in coming years.

The Setting

This study took place in New Delhi, India's capital and its second-largest city, with a population of over 17 million. Like many parts of India, Delhi's very infrastructure embodies the clash of tradition and modernity that I introduced above. Multi-lane highways ring the city, yet until recently, cows blocked their traffic. The city boasts one of the newest, most extensive metro systems in the world, yet lacks basic infrastructure such as municipal trash collection. People die on its busy streets from tuberculosis and hunger, yet the country is home to some of the wealthiest people in the world. It is often said that India is a country where contradiction is embraced, and it appears that this extends to its infrastructure as well.

Although referred to officially as "New Delhi," the city in fact consists of two distinct parts: New Delhi and Old Delhi. Old Delhi, occupying the north-central part of the city, was originally constructed by 17th-century Mughal Emperor Shah Jahan, also responsible for the construction of the Taj Mahal. New Delhi, occupying the southern part of the city, was inaugurated in the early 20th century by two British architects during the colonial period, and is still home to Delhi's wealthier groups. New and Old Delhi are surrounded by miles of sprawl that now extend to other cities of the National Capitol Region, such as Gurgaon and Noida, which are known for their high density of international call centers and software companies.

This rapidly developing information technology industry draws migrants from all over the country and the world, typically into relatively high-paying and sedentary occupations. Delhi's per-capita income is twice the national average (India Brand Equity Foundation 2008). Mechanized transport is necessary to negotiate the city's urban sprawl; thus, as per-capita income increases and public transport infrastructure improves, the population's activity level is decreasing. This emerging affluent and sedentary lifestyle is an important risk factor for type 2 diabetes and other chronic diseases, and many researchers attribute India's skyrocketing diabetes problem to the development-related changes exemplified by Delhi's growing middle and upper class (Mohan et al. 2003; Popkin 2002, Ramachandran 2008). Patterns of rural-to-urban migration are also associated with increased life stress and poor mental health in developing countries (Desjarlais et al. 1996; Harpham 1994). A recent population-based study in urban South India has documented levels of depression around 15 percent (Poongothai et al. 2009), comparable to levels in countries such as Brazil, the Netherlands, and the UK, and slightly above the global average of about 10 percent (World Health Organization 2001).

While the country-wide prevalence of diabetes in India is around eight percent, similar to that in developed countries such as the USA, India is home to the second-largest population of people with diabetes in the world, totaling over 61 million individuals (International Diabetes Federation 2012).[8] This number is expected to nearly double by 2030 (*Ibid*.). Moreover, if we focus on urban areas only, the prevalence of diabetes is about 15 percent (Misra et al. 2011; Mohan et al. 2006). As one of my informants explained, "Nowadays everyone has diabetes; it's become some kind of fashion. Those who don't have it are out of fashion!" she exclaimed only half-jokingly, laughing. "In the morning when I go for a walk, eight out of 10 ladies [at the park] have diabetes. We tell each other to do this, do that, eat this, eat that." Awareness of diabetes in the general population is increasing, thanks to government campaigns on television, public transport, and other major media outlets, but people with diabetes in India

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[8] This is in contrast to China, the world's most populous country, which has a larger total population than India's but a lower prevalence of diabetes.

generally still go undiagnosed for longer than their Western counterparts, and still have poorer blood sugar management (Venkataraman, Kannan, and Mohan 2009).

Figure 2. An illuminated sign in one of Delhi's metro stations sponsored by the Ministry of Health and Family Welfare.

Study recruitment and the health system

India's health system consists of dual public and private sectors. Most people who can afford to do so attend private clinics for both routine and specialized care, although any Indian citizen is eligible for free or low-cost treatment at government hospitals. The unpleasant conditions, lack of amenities, interminable waiting times, and extreme overcrowding in these hospitals make them an unattractive option for anyone who can afford to go elsewhere, however.

Figure 3. Patients and doctors crowd the hallway of a public hospital in Delhi.

It was an intentional part of the study design to try to capture a microcosm of Delhi's socioeconomic groups, so as to speak to the broadest range of experiences possible. Instead of using the traditional method in epidemiological studies of producing representative samples by random sampling within a specific population, which was beyond the scope of the study, I recruited women from a range of clinical settings to gain access to different socioeconomic groups. Ultimately I recruited women from 10 centers, including a public hospital that caters mostly to poor patients who receive free care; several charitable clinics operated by physicians with private practices and/or by private institutions, also geared toward low-income patients; and several private clinics or institutions ranging from a nice clinic run out of a doctor's home, to a clinic with valet parking and guards in uniform who open doors for patients. This last category of clinics primarily serves the middle and upper socioeconomic classes. These centers were mostly clustered in the southern part of New Delhi. Some were general health clinics, while others were endocrinology-specific. This recruitment strategy ensured that I gained access to a wide range of socioeconomic groups while minimizing long commutes. Details of the recruitment process are provided in the Appendix.

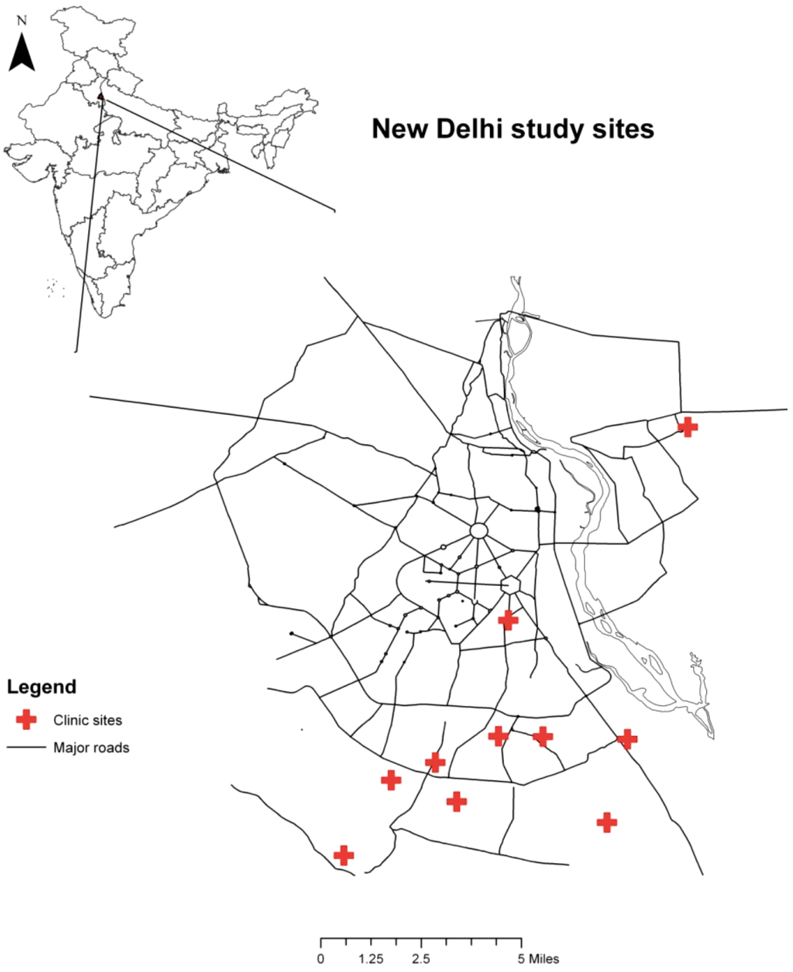

Figure 4. Map of New Delhi showing locations of the 10 clinics from which women were recruited to participate in this study.

The services available in each clinic ranged widely. Some, especially the charitable clinics, were general health clinics for the poor where a diabetes physician volunteered his time a few days a week. Most people at such clinics were there for coughs and colds, prenatal checkups, or routine dental work. Those who came for diabetes were lucky to catch the diabetes doctor in his office, and when they did so, they could expect to receive a momentary exam, a written prescription, and low-cost oral medications on site. By contrast, people attending private clinics often spent 15 minutes or more with the doctor, paid dearly for this time, and frequently received complicated prescriptions involving not only oral medications, but also dietary modifications, exercise instructions, and sometimes a prescription for injectable insulin. The most advanced centers had full-time diabetes lifestyle educators and dieticians on staff to “train” patients on the proper administration of their medicines and on proper dietary guidelines. These services were provided at no extra charge to patients in private clinics, who in any case were paying large sums for their consultations. Patients at the most expensive private clinics were paying up to 100 times the fees of patients at charitable clinics (up to 2,000 INR, or about 50 USD, as opposed to about 20 INR, or 0.50 USD).

I met women who agreed to participate in this study by going to these 10 clinics on random days and asking individuals if they would participate while waiting to see the doctor. Although I did not collect data on the response rate, the vast majority of women who were asked to participate agreed to do so. Accompanied by my research assistant, I would then take them to a private room in the clinic (which each doctor provided for my work) and explain the nature of the study. After obtaining their oral consent to participate, we would ask them a series of questions about their personal background, general health, daily activities, experiences with diabetes, and mental health. I also performed a finger-stick blood test to measure women's diabetes control and stress biomarkers, and recorded each woman's height, weight, and waist-to-hip ratio. Both diabetic and non-diabetic women were recruited in this way, so as to maintain as much similarity as possible between the two groups. During this phase of the research, we interviewed nearly 300 women.

We then asked each diabetic woman if she might be willing to participate in a second interview several months later, and recorded the contact information of those who agreed. These eventually became the 30 case studies, many of which are presented in the dissertation.

Almost all interviews in both stages took place in Hindi, and were recorded for later transcription and translation. This is the source of all direct quotes from participants that are included in the dissertation. I and my native-Hindi-speaking research assistant translated the interviews together. A more detailed description of the recruitment methods, procedures, and analyses used in this study is provided in the Appendix.

A Note on Methods

This is a mixed-method study employing ethnography, health and personal questionnaires, body measurements, and blood tests to measure diabetes control, mental health, and other important indicators of general health. As already noted, the detailed methods used in the study are outlined in the Appendix. Here I want to briefly explain why this methodological approach was chosen.

As a biocultural anthropologist, or an anthropologist who believes that both culture and biology are central to human experience, I consider individual perceptions of illness only one part of the puzzle of illness experience. Studying how those illness experiences impact human biology is another important piece that we miss if we focus solely on individual perceptions. For this reason, I have not only collected the stories of women who have diabetes. I have also measured several biomarkers in their blood, taken body measurements such as height and weight, and administered a questionnaire about demographics, daily life, and mental health. This overlapping data collection procedure furnishes a fuller understanding of individual experiences by facilitating comparison of information from different sources.

For instance, a woman who tells me anecdotally that she feels stressed may or may not have symptoms of poor mental health. Assessing her mental health through a questionnaire helps me determine the extent to which this stress is affecting her long-term mental health. The same woman may or may not have distress serious and chronic enough to actually change her biology. Her blood levels of Epstein-Barr virus antibodies and C-reactive protein will tell me to what extent this distress is causing hormonal cascades that increase her body's inflammation and immune response. Sometimes women complain of stress but have low biomarkers and few symptoms of mental health problems. Others do not complain of distress but have high levels of mental health symptoms and biomarkers. Having all three pieces of the puzzle helps me understand more fully what is going on with women mentally, physically, and socially. Although these may seem like disparate ways of gathering information, they can enrich and complement each other (Worthman and Costello 2009).

The ultimate goal of this research approach is to trace disease processes from their broad socioeconomic origins to their specific outcomes in individual lives and bodies.

Limitations

Like all studies, this one is limited in its scope and generalizability. By explicitly focusing on biomedical clinics, I aim to address the biomedical mode of treatment that is becoming increasingly dominant in India. This focus means that the dissertation largely overlooks the rich histories of nonbiomedical systems in India, which people often use in parallel with biomedicine or instead of it. Ayurveda, Unani medicine, faith healing, homeopathy—all have a prominent place in contemporary Indian healthcare. The absence of detailed exploration of nonbiomedical approaches to these illnesses may be noticed, for instance, in Chapter 3, where mental health and healthcare in India are discussed. For example, I note in this chapter that very few psychiatrists are available in India. Readers should keep in mind that nonbiomedical healthcare providers are more widely available, especially in rural India where there are virtually no psychiatrists or other specialized healthcare providers. These providers frequently offer efficacious treatments. In some cases, nonbiomedical providers may even link up directly with biomedical providers, referring their patients when needed (Flueckiger 2012, personal communication). In short, a lack of biomedical providers does not mean a total lack of healthcare providers. Readers should keep in mind that nonbiomedical systems thrive in India and coexist, interact, and act in parallel with the biomedical system that is the primary focus of this dissertation. The great potential for fruitful linkages between biomedical and nonbiomedical health systems are discussed in the "Recommendations" section of the concluding chapter.

Another limitation arises from this study's cross-sectional design, meaning it assessed women's health and lives at one point in time. Although this is a common practice in research, it leaves me unable to speculate about the long-term relationships between the topics I study, and also makes it impossible to draw conclusions about the directionality of the statistical relationships I notice. For instance, my data cannot determine whether women who have concurrent diabetes and depression got diabetes first, or got depression first. A longitudinal study design, which might follow women over the course of multiple years, could better address questions about the changing nature of these relationships over time.

Third, the topic and setting of the study created some challenges that are unique to urban anthropology. Although I made every effort to become familiar with the women who participated in this study, my research was by no means a "traditional" ethnography in the sense that I came to live with a specific, small group of people and insinuate myself into their lives as much as possible. Women with diabetes in New Delhi are not a cohesive group who live together or know each other, for the most part, so my research relied primarily on single, or at most three- or four-time meetings, with informants. Although I was able to work with a large group of informants because the amount of time I spent with each one was limited, I did not experience the long-term, in-depth relationships that characterized traditional cultural anthropological fieldwork.

Fourth, the fact that diabetic women in New Delhi are a dispersed group necessitated that I find them in the one place they might all go: medical clinics. This was a convenient recruitment strategy, but it has important implications. First, it means that my study group is self-selected to be more biomedically oriented and more proactive about their own health than the average diabetic woman might be. The simple fact that each woman I worked with presented herself at a medical clinic suggested that this is so, since there are many women with diabetes in India who never go to clinics or do not even know that they are diabetic. Second, this clinic-based recruitment strategy means that women in the study often viewed me, the researcher, as a peri-medical professional. Especially in the charitable or government clinics, where many informants were unfamiliar with the concept of research, it became difficult to explain to people that I was not a medical professional who could help them. This invariably changed the nature of our interactions by introducing power dynamics. There are, to my knowledge, no other diabetes-specific organizations in Delhi at present (such as support groups, special stores, etc.) where I might have recruited women in a reasonably efficient manner, but readers should bear in mind that this strategy introduces some biases into the study.

Fifth, although the larger study sample reflects a ratio of religious groups that roughly mirrors larger patterns in India, none of the in-depth case studies were conducted with Muslim women. Muslims are the largest religious minority in India, comprising over 10 percent of the population. We did make consistent efforts to contact Muslim women for home visits, but none were successful. This challenge stems partially from the fact that many Muslim women practice *purdah*, or female seclusion, meaning that they rarely go out or receive visitors. Muslim women might also have been reluctant to meet with me because I am clearly not Muslim based on my appearance and foreignness, and my research assistant was a high-caste Hindu woman. This means that the present study cannot speak to the unique experiences of diabetes, daily life, and family relationships that might differ for Muslim women as compared to their Hindu or Sikh counterparts. These differences could be significant, as Muslim women's diets and activities tend to differ from Hindu women's; as do their opportunities for exercise, clinic visits, and trips to the market; as do their family relationships.

Finally, as in all anthropological studies, my presence likely changed women's reports of their experiences in subtle ways. As a Hindi-speaking foreigner, I was quite a curiosity. My strangeness amused some women and intrigued others, but also caught some off guard or even made them visibly uncomfortable. This was especially true among my impoverished informants, most of whom had never spoken with a foreigner before and who viewed me as an authority figure because they were meeting me in a clinical setting. In such scenarios, women might have responded to my questions with what they imagined I wanted to hear, rather than what they actually believed or experienced. It is nearly impossible to control for this kind of response bias, but readers should keep this and the other limitations of the study in mind as they proceed.

Description of the Participants and Overview of Trends in the Data

Women who participated in my study ranged widely in terms of their socioeconomic backgrounds, ages, education levels, caste and ethnicity, and family structures. The carefully chosen combination of research sites provided access to a wide range of groups. I worked with women who were forced to seek intermittent wages by carrying bricks on their heads at construction sites, and who did not know if they would have the money to buy food for an evening meal. I worked with women who had so many servants that they barely ever lifted a finger and dined on imported caviar. I worked with Christians, Hindus, Muslims, Sikhs, agnostics, Buddhists, and Jains; Punjabis, Biharis, Assamese, Orissans, Rajasthanis, U.P.ites, Keralans. I met women who had never set foot in a classroom and women with Ph.D.s.; women who had no children, others who had 12; women in their 20s and women approaching their 80s. Some women I worked with were dangerously underweight, while others were morbidly obese. While I cannot claim that these women accurately represent the entire population of women in Delhi with diabetes, they do illustrate the broadness of that range.

On random days, a local research assistant and I visited each clinic and interviewed consenting patients as they waited to see the physician. Non-diabetic women, who were usually at the clinic accompanying friends, family members, or consulting the doctor themselves for a non-diabetes related health issue, were recruited in the same way. Women under the age of 27, who were pregnant, who had thyroid or other endocrine disorders, or who were unable to complete the interview because of physical or mental illnesses were excluded. The cutoff age of 27 was chosen because this was the age of the youngest type 2 diabetic woman who participated in my study.

In terms of most basic characteristics, the diabetic and non-diabetic groups were similar. This similarity is at least partially a result of the recruitment process, which sourced diabetic and non-diabetic women from the same places. The diabetic and non-diabetic groups had similar educational levels, family structures, religious and caste compositions. Both groups were overweight, exceeding the WHO recommendation that South Asians' body mass index (BMI) should remain below 23.0 (World Health Organization 2004), but the diabetic group was somewhat more overweight than the non-diabetic group, probably reflecting the fact that diabetes, body fat, and weight gain are related (Colditz et al. 1995; see below).

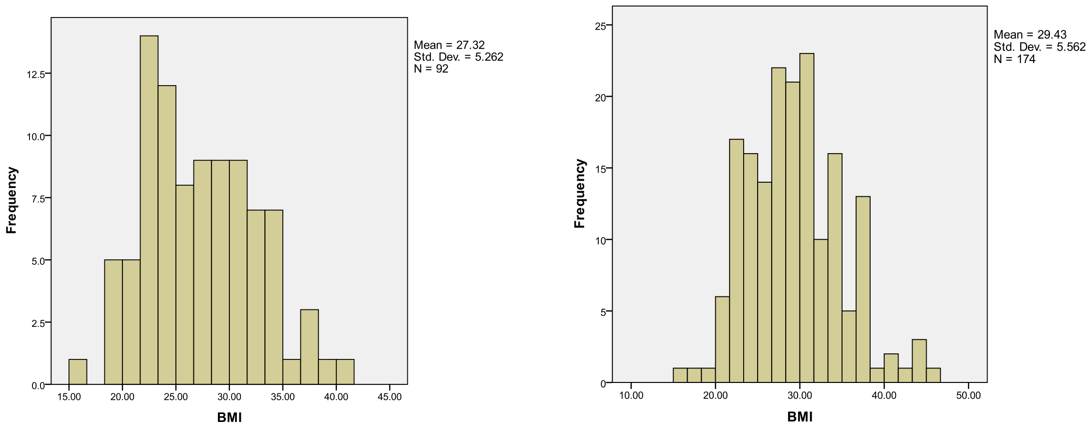

Figure 5. Body mass index of the non-diabetic (left) and diabetic (right) groups.

The diabetic group was also generally more wealthy than the non-diabetic group, with a lower percentage of poor women and slightly higher percentages of middle- and upper-class women. Furthermore, the diabetic women in this study were, on average, seven years older than the non-diabetic women. This is unsurprising because diabetes is usually diagnosed among older adults and, although it may set in earlier, usually does not cause complications that would lead one to a diagnosis for some years. The diabetic women also had slightly more children than the non-diabetic women. This observation is probably also related to the age and SES differences between the two groups, since in India today, younger generations and wealthier groups are having fewer children than older generations or less wealthy groups do. Indeed, age is significantly correlated with number of children in this group ($r=0.33$, $p<0.01$), and this association persists when we control for diabetes status ($r=0.32$, $p<0.01$).

Table 1. Selected characteristics of diabetic and non-diabetic women.

Characteristic	**Diabetic** n=184	**Non-diabetic** n=96	**Range**
Age (avg)*	54.0	47.3	27.0-78.0
% with HS degree	52.2	56.1	
% living in a joint family	47.3	44.8	
No. children ever born*	2.9	2.7	
Socioeconomic status			
% low	17.9	26.0	
% middle	57.7	58.4	
% high	23.4	14.6	
% undetermined	1.0	1.0	
Religion			
% Hindu	81.5	83.3	
% other	18.5	16.7	
Caste			
% Brahmin	14.1	16.7	
% Kshatriya	15.2	15.6	
% Vaishya	16.3	21.9	
% Shudra	12.5	16.7	
% n/a or other	41.3	29.2	
Body mass index (avg)†	28.1	26.2	16.0-59.2
Body fat percent (avg)†	35.6	33.1	5.5-51.0
Waist-to-hip ratio (avg)	0.8	0.8	0.7-1.0
HSCL anxiety % symptomatic	26.6	26.0	
HSCL depression % symptomatic	18.8	17.9	
Tension score (avg)*	1.0	0.7	0.0-2.0
Stressful life events in past year (avg)	2.9	3.0	0.0-11.0
C-reactive protein (avg)	1.8	1.9	0.0-6.9

CRP >7 (n, %)	3, 2.1%	7, 7.4%	
Epstein-Barr antibodies (avg)	128.5	125.8	31.0-267.3
EBV <30 (n, %)*	29, 15.9%	5, 6.8%	

*Difference in means is statistically significant at a 0.05 level. This is the standard by which results are typically judged as statistically significant or otherwise.

†Difference in means is statistically significant at a 0.10 level. This is a slightly more liberal standard for judging statistical significance and indicates a "marginally significant" result.

One central question of this research was how type 2 diabetes and mental health are related among women in New Delhi. The study was designed to compare the common mental disorders (CMD) of depression and anxiety in a diabetic group and a non-diabetic group, as well as the prevalence of "tension" in their lives. The English word "tension" is a common expression for stress in North India and is associated with depression and anxiety among both the diabetic and non-diabetic groups. Its range of uses and meanings will be discussed at length in Chapter 3. I expected to discover a higher prevalence of common mental disorders in the diabetic group as compared to the non-diabetic group.

Surprisingly, however, mental health and ill health patterns were similar between the diabetic and non-diabetic groups. Levels of depression and anxiety in both groups ranged between 8 and 16 percent, approximating larger trends in urban India (Poongothai et al. 2009) and around the world, where many population-based studies find a prevalence of common mental disorders around 15 percent (Andrande et al. 2000; Patel et al. 1999; Ustun et al. 2004). In fact, non-diabetic women reported marginally more depression and anxiety than the diabetic group, but not enough to create statistically significant differences. While both diabetic and non-diabetic women reported moderate levels of "tension", diabetic women's average "tension" score was significantly higher than the non-diabetic group's. Possible explanations for these curious findings will be addressed throughout the dissertation, but especially in Chapter 3. Again, some of this similarity between groups may be a result of the way in which they were recruited for the study.

When we focus on the diabetic women only, some important within-group differences emerge. One key area of difference between the 184 diabetic women included in this study is the length of time they have lived with diabetes. The average duration of the illness is seven years, but there was a wide range in this variable. Some women were diagnosed several months before I interviewed them or even at the time of the interview. Others have been living with diabetes for decades, and in fact most of the women have been living with the illness for somewhere between 5 and 15 years (Figure 8, below). The normal curve superimposed on the data in this figure illustrates that the duration of diabetes in this sample is not symmetrically distributed. Instead, it is right-skewed; that is, a high proportion of women have had diabetes for a relatively short time (0 to 5 years). The mean duration of diabetes at 7 years masks large differences in the sample; many women have had diabetes a shorter time, but the few women who have had the illness for 20 years or more bring this average value up.

Based on this wide range of diabetes duration, I further divided the diabetic group into short-term diabetic women (having been diagnosed less than two years before we met) and long-term diabetic women (who were diagnosed two or more years before we met) for the purpose of comparing the two groups' basic characteristics.

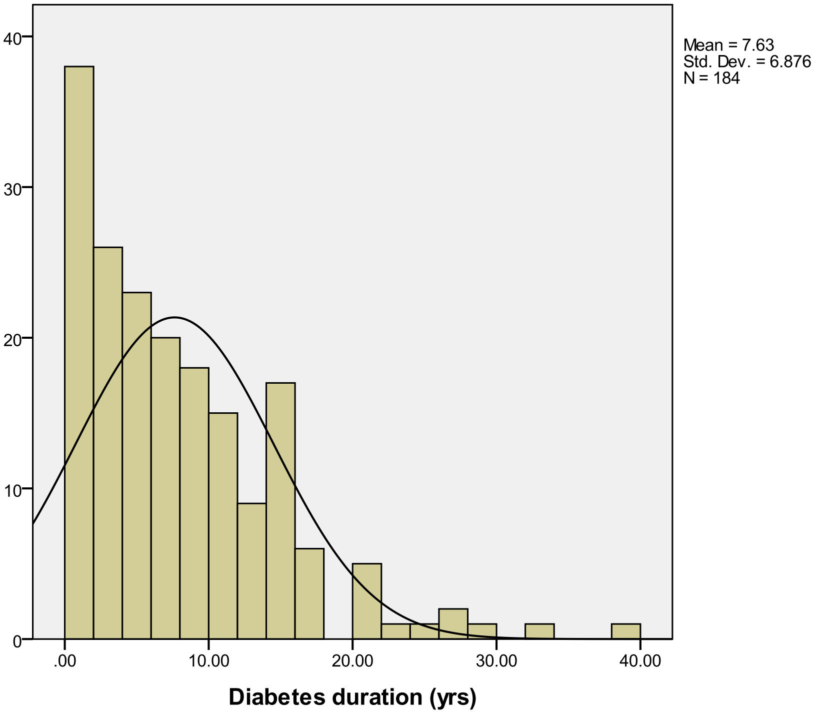

Figure 6. Duration of diabetes among the 184 diabetic women in this study with a normal curve superimposed on the data. The curve demonstrates that the duration of diabetes among the women in this study is skewed toward more recently diagnosed groups.

Although they are similar in most respects (Table 2, below), including education, family type, and number of children born, the long-term and short-term diabetic women differ in their socioeconomic status. The long-term diabetic women are substantially wealthier than the short-term women. This difference is partially due to the fact that wealthier groups have better access to medical care and therefore are more likely to receive an early diagnosis than their less wealthy peers, but it also likely reflects the fact that wealthier women with diabetes live longer and attend clinics for regular checkups more frequently than poorer women, meaning they would be represented to a larger extent in my clinic-based study than others.

The long-term and short-term diabetic groups also differ on some key health indicators, including distress. While women who have lived with diabetes for more than two years are no more depressed than those who have lived with diabetes for a shorter time, but those women diagnosed with diabetes more recently report more “tension” on average, and a significantly higher proportion of newly-diagnosed women report anxiety ($p=0.047$). Perhaps women diagnosed more recently with diabetes have “tension” and anxiety about their new illness, or perhaps life “tensions” and anxieties precipitated the onset of their diabetes. Regardless of the explanation for this trend, long-term diabetic women appear to have, on average, better mental health than short-term diabetic women. This, too, will be explored in Chapter 3. Although differences between the two groups’ HbA1c and blood glucose levels are not statistically significant, it is worth noting that both groups’ HbA1c levels far exceed the cutoff value of 7.0 recommended for good diabetes control, and the short-term group has slightly higher HbA1c and blood glucose values. Finally, C-reactive protein blood levels, which indicate generalized body inflammation and are often used to predict risk of cardiovascular disease, are slightly higher among the long-term than the short-term diabetic women. This is unsurprising, first, because those who have had diabetes for longer time are likely to have more body inflammation resulting from the cumulative damage that diabetes inflicts on the body over time. Second, the long-term diabetic women tend to be older and heavier than the short-term diabetic women, and CRP is associated with body mass index (Frohlich et al. 2000). This result suggests that long-term diabetic women are at higher risk of cardiovascular disease than those who have not had diabetes for as long. Diabetic women's Epstein-Barr virus antibody levels do not differ significantly between short- and long-term groups, however, suggesting that the long-term group is no more immune-stressed than the short-term group.

Table 2. Demographic, mental health, and diabetes management indicators for women diagnosed with diabetes two or more years ago (n=146), versus less than two years ago (n=38).

Characteristic	**Diabetic 2 years or more**	**Diabetic less than 2 yrs**	**Range**
Age (avg)*	55.3	47.8	27.0-78.0
Education			
% with HS degree	54.4	44.7	
Living in joint family	47.3	47.4	
No. children ever born	3.0	2.8	
Socioeconomic status			
% low	16.4	28.9	
% middle	55.5	65.8	
% high	28.1	5.3	
% undetermined	0		
Religion			
% Hindu	83.6	73.7	
% other			
Caste			
% Brahmin	15.1	13.2	
% Kshatriya	17.1	7.9	
% Vaishya	16.4	15.8	
% Shudra	13.0	10.5	
% n/a or other	38.3	52.7	
Body mass index (avg)†	28.4	26.5	16.0-59.2
Body fat percent (avg)†	35.6	33.8	5.5-51.0
Waist-to-hip ratio (avg)	0.8	0.8	0.7-1.0

% insulin-dependent*	33.6	-	
Random blood glucose (avg)	158.2	173.3	0.0-468.0
HbA1c (avg)	8.4	8.8	5.6- >13.0
C-reactive protein (avg)†	3.8	3.6	0.0-6.9
Epstein-Barr antibodies (avg)	130.1	124.7	31.0-267.3
HSCL anxiety* % symptomatic	23.3	39.5	
HSCL depression % symptomatic	17.8	18.4	
Tension score (avg)*	0.7	0.8	0.0-2.0
Stressful life events in past year (avg)	3.0	2.9	0.0-11.0
Disability score*	6.0	1.1	0.0-14.0

*Difference in means or proportions is statistically significant at a 0.05 level.

†Difference in means is statistically significant at a 0.10 level.

As a whole, the diabetic women’s blood sugar management does not meet the standards their physicians would prefer. Most diabetes physicians I worked with adhere to the American Diabetes Association’s (2001) recommendations for blood sugar management, which state that glucose should remain between a low threshold of 70 mg/dL before a meal and a high of 180 mg/dL after a meal, while HbA1c should not exceed 7.0 percent. The more important of the two measures for assessing long-term diabetes control is HbA1c, since it indicates overall fluctuations in blood sugar in the preceding three months. While the diabetic women's average blood sugar is about 170 mg/dL, falling within an acceptable range, the average HbA1c is 8.5 percent, much higher than it should be according to the ADA's accepted standards. This is true despite the fact that almost 30 percent of the diabetic women are on injectable insulin therapy, which is often an effective way of managing blood sugar.

Table 3. Diabetes indicators among the diabetic sample (n=184).

Characteristic	**Value**	**Range**
Diabetes duration (yrs, avg)	7.7	0-39
% insulin-dependent	27.7	-
Random blood glucose (avg)	169.6	63-468
HbA1c (avg)	8.5	5.6- >13.0

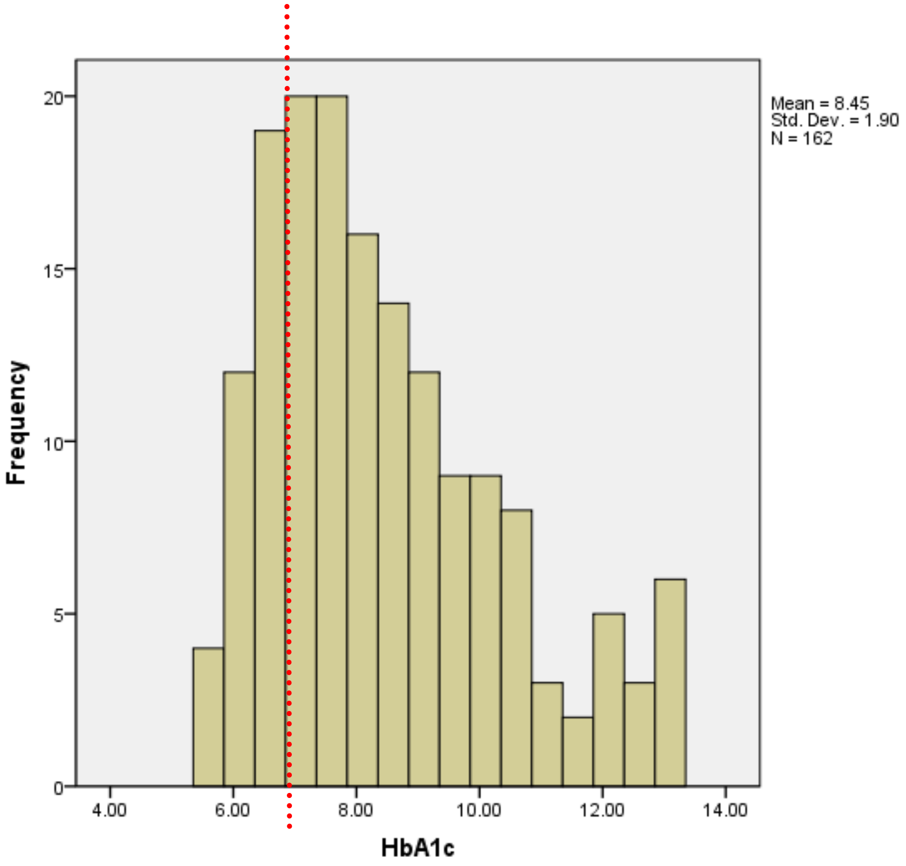

Figure 7. Over 70 percent of the sample has HbA1c levels falling above the cutoff recommended by the American Diabetes Association of 7.0 percent.

While long-term diabetic women appear to have better mental health than women more recently diagnosed with diabetes, they do not appear to be learning more effective strategies for managing their physical health over time. When we compare women diagnosed with diabetes recently with those diagnosed longer ago, there is no significant difference in their glucose or HbA1c levels, although, as noted above, the newly-diagnosed group's diabetes indicators are slightly higher. Women who have had diabetes for a longer time appear to be in worse general health than the short-term diabetic women, based on health indicators such as body mass index and body fat percentage. Long-term diabetic women tend to be heavier and to have more body fat, and they also report significantly more disability in daily life than short-term diabetic women. This might be related to the fact that the long-term women are older, and weight and body fat increase with age (Hughes et al. 2002). Body weight also tends to increase when people with diabetes take insulin (United Kingdom PDSG 1998), and a much higher percentage of the long-term diabetic women are insulin-dependent as compared to the shorter-term diabetic women. This is not particularly surprising, since oral diabetic medicines are usually prescribed as first-line therapy before moving on to insulin, but it does suggest another reason why the long-term diabetic women might be heavier than the short-term diabetic women. It also suggests that the longer-term diabetic women were not achieving healthy blood sugars on oral hypoglycemic drugs alone.

These within-group comparisons suggest a couple of interesting things. First, even though they are more likely to use insulin and be overweight, the long-term diabetic women report less life “tension” than the short-term diabetic women. This is surprising, in part, because injecting oneself regularly with insulin and living longer with a chronic, degenerative illness are two potential sources of life stress to which the long-term diabetic women exclusively are exposed, and this is especially true for the injection of insulin in a cultural context where needle self-injection is stigmatized. The longer-term diabetic women may be less stressed partially because they are older, and in general, older women are taken care of by younger family members in India’s joint family system. However, about half of the group lives in nuclear families, so family care cannot entirely explain the lower distress of longer-term diabetic women. Perhaps, instead, the stresses surrounding diabetes diagnosis decrease over time as one becomes accustomed to the idea, and to the everyday experience, of living with diabetes. The use of insulin is a good example: although many women in my study expressed a fear of *the idea* of being on insulin therapy, those who actually take it do not report more life "tension" than those who do not. Perhaps, in some cases, the reality (of having diabetes, of finding creative ways to accomplish work tasks while accommodating its symptoms, of taking insulin, etc.) is less scary than the anticipation of that reality.[9]

These comparisons also underscore the fact that the relationship between diabetes control and mental health is not monolithic, but rather that women experience the interaction between these factors in a wide range of ways. This should come as no surprise, as their personal and health backgrounds range widely. Some women, for instance, have poor diabetes control and poor mental health. These women are vulnerable to both physical and mental health sequelae associated with comorbid chronic diseases and mental ill health. For the purposes of this dissertation, I define these women as "vulnerable," and their situation will be explored in Chapter 5. Some women suffer from depression or anxiety but are able to maintain good diabetes control. Other women have poor diabetes control but good mental health, and I define these women as "resilient" against the complications of diabetes. Finally, some women have good diabetes control and good mental health, and I define these women as "resilient" in terms of both physical and mental health. These differences can be conceptualized as follows:

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[9] These time-related speculations are made by comparing women who have had diabetes for a long time against women who have had diabetes for a short time. The best way to study time-related questions about health management is to follow individuals longitudinally (over time), but because that was impossible in the present study, this comparison method is used as a proxy.

Table 4: Categorization of vulnerability and resiliency categories based on diabetes control and mental health indicators, and, below, the spread of the sample of diabetic women (n=162 with all relevant data) across these categories.

	No depression or anxiety	**Depression or anxiety**
Good diabetes control	Resilient physically and mentally	Mentally vulnerable
Poor diabetes control	Resilient mentally	Physically and mentally vulnerable

	No depression or anxiety	**Depression or anxiety**
Good diabetes control	25	17
Poor diabetes control	88	32

Of the 184 diabetic women who participated in this study, the majority were what I define as “resilient mentally.” They had poor diabetes control, yet they did not report clinically significant levels of depression or anxiety symptoms. Their experiences will be discussed in Chapter 6. The second largest group following these women was the group I refer to as “vulnerable”: those with poor mental health and poorly controlled diabetes. Their experiences are discussed in Chapter 5. Fewer still reported good mental health and good diabetes control, or what I refer to as "resilient physically and mentally," and these, too, are explored in Chapter 6. Finally, very few women (6 out of 184) had poor mental health but good diabetes control, suggesting that good diabetes control does not always yield good mental health. I refer to these women as "vulnerable mentally" and briefly consider their cases in Chapter 5.

Conclusion

This introduction was intended to give readers a feel for the social and cultural setting in which this study took place, the relevant background literature, as well as to introduce the methods used in the study and the major characteristics of the participants. The analyses presented here touch on a wide variety of topics quite superficially, but each one will be elaborated in the chapters that follow.

Like the musicians on that warm winter evening in Orchha, India is juggling disparate sources of information about its developmental trajectory. While people feel enthusiastically about some aspects of the country's openness to globalizing forces, others prefer to maintain traditional identities and values. In reality, most fall somewhere in between, picking and choosing what values "work" for them—metaphorically speaking, listening to the Hindi pop remixes while still keeping an ear to the ground for the beat of the *tabla*. The result is hybrid values systems which are not always entirely cohesive, but which are chosen for good reasons.

These hybrid values systems extend to health. As the chapters to come will illustrate, women value some aspects of wellbeing at a higher premium than others. Although they sometimes make healthcare choices which may not be in the best interest of their physical health, these choices are usually made with clear ideas about what constitute the most important priorities in their lives. The most important point that readers can take away from this dissertation, and indeed from anthropology more generally, is that if one pauses long enough to give full consideration to the competing priorities that inform people's decisions in any context, there is usually a logic underlying these decisions that must be respected even if one does not agree with the choices they make.

CHAPTER 2: "ONE ONLY GOES TO THE DOCTOR WHEN ONE'S HEALTH IS BAD"

BUILDING AN UNDERSTANDING OF DIABETES DIAGNOSIS EXPERIENCES, WOMEN'S HEALTHCARE-SEEKING BEHAVIORS, AND EXPLANATORY MODELS OF DIABETES

Rita[10] is not feeling well. For months, she has been getting unusually tired during her daily routine of laundry, cooking, cleaning, caring for her two children, and helping in the family's colorful, brightly lit general store. This general feeling of "weakness," as she describes it, is now making it hard for her to catch her breath as she climbs up and down the stairs between the ground-floor store and the bathroom in their apartment, which she is feeling the need to do more and more frequently. Perhaps she is pregnant, she thinks, but she has lost weight rather than gained it. One day, she feels so horrible that she cannot even get up in the morning and, to her embarrassment, urinates in bed. With these strange symptoms that can no longer be ignored, she finally sees a doctor, who tests her blood sugar and finds it over 400 mg/dL.[11]

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[10] All names appearing in this dissertation are pseudonyms.

[11] Blood glucose is the most frequently used parameter to monitor diabetes management on a daily basis. It can be measured when fasting before breakfast, post-prandially (after a meal), or at a random time, and can be done at home using a hand-held glucometer and a finger stick blood test. Consistently high blood sugar levels can lead to diabetes complications like nerve damage, while very low blood sugar levels can cause people to fall into a coma or even die. According to the American Diabetes Association, blood glucose should remain between 70 mg/dL and the high of180 mg/dL at all times. People with diabetes who receive management counseling are taught to monitor their blood sugar before and after eating, sometimes multiple times a day, to make sure it stays within the recommended range.

This chapter “begins at the beginning” of diabetes experience by exploring women’s diabetes diagnosis stories and the related topic of healthcare seeking behaviors. It proceeds in a loosely chronological manner that mirrors the early processes an individual might go through upon getting a diabetes diagnosis, and beginning to make sense of this diagnosis for their lives. We begin with the reception of the diagnosis and women’s range of reactions to it; secondly, we explore what factors influence women’s care-seeking behaviors and thus their diagnosis experiences; thirdly, we finish with women’s reflections on why they think they got diabetes in the first place.

Individual experiences with chronic illnesses range widely, but as I mentioned in the introduction to this dissertation, they all have one thing in common: their “chronicity,” or the long duration of time across which those illness experiences accumulate (Estroff 1993). A chronic illness diagnosis may at first cause abrupt disjunctures, as people learn to overcome the shock of a diagnosis and incorporate new illness identities into their regular lives. Whether or not it is expected, the diagnosis of a chronic disease can cause both physical and existential quandaries, as an individual interrogates her past and her future, looking retrospectively for causes and wondering about the impending consequences of a newly-diagnosed chronic condition. Becker (1997) uses the concept of “disrupted lives” to explore how a chronic disease diagnosis, and its sequelae of symptom flare-ups and remissions, causes life interruptions. These interruptions can occur on a “micro” level, as in having one’s routine disturbed by the need to take medications at certain times during the day, or on a “macro” level, by changing the way one imagines her larger life trajectory in the future.

With time, especially if the disease is a degenerative one whose symptoms increase in severity over weeks or years, physical symptoms and psychological effects of the illness may accumulate. The life disruptions created by worsening symptoms may accumulate as well, to the point that an individual must build a new sense of normalcy by refiguring social relationships, daily routines, and a sense of self to make space for chronic illness. This is one sense of the term “chronicity” (Estroff 1993). This reinterpretation of one’s identity through the lens of chronic illness can, and often does, change the way an individual thinks about herself and the way others perceive her as well (Estroff 1993; Murphy 1987).

According to Charmaz (1991), author of an evocative auto-ethnography about her personal experiences with a degenerative chronic pain disorder, people experience chronic illnesses along a continuum ranging from a temporary interruption in life, to significant intrusion into one’s lifestyle, and finally to a stage she calls “immersion,” or the total engulfment of the person by her condition. The speed of this progression and the ultimate degree of immersion along this continuum depend upon many factors relating to the individual, her social milieu, and the severity of the illness itself.

The deeper the immersion, the harder it becomes to rebuild a sense of normalcy in life (Becker 1997), and the more the illness begins to dominate one’s identity and sense of self. In some cases, the illness identity may come to be the foremost attribute by which one identifies oneself, and by which others identify him or her. Erving Goffman’s (1963) classic work on social stigma uses the term “master status” to describe a personal attribute that overrides all others, becoming the one by which we are first known to others. We can think of immersion in illness as an internalized form of “master status;”

that is, as a cognitive shift whereby one goes from thinking of oneself as someone with an “I have” illness to someone with an “I am” illness (Becker 1997). The simple linguistic shift from “I have diabetes” to “I am a diabetic,” for instance, is more significant than it may appear on first glance, as it can symbolize profound changes that take place in one’s identity as one comes to identify more and more with a long-term chronic illness or disability.

The range of experience among women in this study when confronted with a diabetes diagnosis fits well with Estroff’s (1993) concept of chronicity, Becker’s (1997) concept of lives disrupted by “I have” vs. “I am” illnesses, Goffman’s (1963) concept of “master status,” and Charmaz’s (1991) continuum model of immersion in illness. Collectively, these ideas help us develop models for understanding how people experience chronic illnesses over time, and how these illnesses may come to invade, intertwine with, and sometimes overcome other aspects of personality.

Some women were unsurprised to be diagnosed by type 2 diabetes, continue to live a normal lifestyle now, and insist that they “don’t think of it as a disease.” Others were shocked by their diagnosis, and, even years later, still felt a keen sense of injustice that they got the illness despite a healthy lifestyle or a lack of family history. Whether or not their diagnosis came as a surprise, many have subsequently felt challenged by the lifestyle changes that their diabetes demands. Some have experienced such poor physical or mental health along with their diabetes that their previous activities have been severely restricted. This range of disability experience will be addressed in detail in Chapter 4. For now, we will begin where most of the women begin their journeys with diabetes: at the time of diagnosis.

How and When Does Diagnosis Happen? Culture and Care-Seeking Behaviors

For most women in this study, the diabetes diagnosis was unexpected. Although almost everyone had heard of diabetes, many felt no symptoms at first and described a sense of invincibility, as if diabetes was something that happens to “other people.” Many such women only discovered their diabetes by chance during routine blood tests preceding a gallbladder removal, a hysterectomy, or other non-diabetes-related surgery. Even among women educated about the symptoms of diabetes, the diagnosis was often surprising. “It *did* come as a surprise,” verified one highly educated woman, for instance. “I started losing weight last year in January, and it continued for about three, four months, till I went for some other kind of test, and then I was [feeling unwell], but I have a long history of other ailments, so [I didn't know it might be diabetes].” Many women experienced telltale symptoms of diabetes before they received their diagnosis, such as fatigue or frequent urination, but did not realize that these could indicate diabetes. Such was the case with Rita, the woman introduced at the beginning of the chapter, whom we will encounter again below. The threshold at which women began to recognize their symptoms, consider them worthy of professional attention, and actually seek that attention varies widely between individuals.

While almost everyone has heard of diabetes, or “sugar,” as it is colloquially called among Hindi speakers, concerted efforts by the government and public health agencies to raise awareness about common diabetes symptoms have only recently been inaugurated. The two largest-circulating newspapers in India, the *Times of India* and the *Hindustan Times*, now regularly run articles with titles like “Please take the stairs” (*Times* *of India*, 25 March 2011), “Health care for diabetes management” (*Hindustan Times*, 3 September 2011) and “Living with sugar” (*Hindustan Times*, 14 November 2011), and advertise free seminars hosted by private hospitals on managing diabetes.[12] Unsurprisingly, those with lower literacy and less access to media, such as some of the low-socioeconomic-status women in my study who came from rural areas for treatment in Delhi, less frequently realized that their ill health might be due to diabetes. Even after diagnosis, one-third of the women I worked with had no idea what might have caused them to get diabetes.[13]

The question of awareness about diabetes symptoms is important because it shapes how and when women recognize symptoms as sufficiently serious to warrant professional attention. Some women in this study went to the doctor right away when they began having diabetes symptoms, but many did not. Because early detection of diabetes can help prevent or delay the onset of complications (Marshall and Flyvbjerg 2006), it is important to understand *why* some women’s diabetes is detected early, while others’ is not. Here we will explore the diagnosis stories of three diabetic women who attend the same charitable clinic but live in different neighborhoods of Delhi to illustrate some of the factors that influence their healthcare-seeking behaviors. Both receive free healthcare at the clinic and have access to free or low-cost medications.

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[12] Newspapers are notorious for their use of a rarified form of Hindi heavily influenced by Sanskritic words that can make comprehension difficult or impossible for those with basic literacy.

[13] See the next section for an extended discussion on perceived causes of diabetes.

Indu, age 50, diagnosed 1 year ago, glucose 117 mg/dL,[14] *HbA1c 6.9%*[15]*, CRP 2.9 Mg/L*[16]*, EBV 83.0 ELISA units*[17]

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[14] The blood glucose values presented here and throughout the rest of the dissertation are random blood glucose values, meaning that they were not measured at a specific, consistent time before or after eating. They were taken whenever interviews were done. This means that some women may have eaten just before the glucose test, and some may not have eaten anything at all. Still, this test is useful for approximating overall glucose control. Recall that a healthy blood glucose level should remain between a low boundary of 70 mg/dL when fasting and a high boundary of 180 mg/dL after a meal. Indu's random blood sugar of 117 mg/dL is within the healthy range, but Rita's, presented below, is well below the low boundary for healthy blood glucose.

[15] HbA1c indicates average blood sugar fluctuations in the previous 3 months. It should ideally not exceed 7.0% in people with diabetes. The measure takes into account both highs and lows in blood sugar, which are equally dangerous for health. People with diabetes who receive management counseling are taught to work toward keeping their blood sugar relatively constant. Indu's value of 6.9% is just within ideal limits, suggesting she is keeping her blood sugar well controlled.

[16] CRP, or C-reactive protein, is an acute-phase protein synthesized by the liver whose levels rise in the blood in response to inflammatory processes in the body, such as immune system activity. Because it is chronically elevated among people with chronic diseases, CRP is often used clinically to estimate risk of developing cardiovascular disease, hypertension, and diabetes. It is used in this study as an indicator of overall body stress. Indu's value of 2.9 mg/L is not particularly high compared with the other diabetic women in this study, suggesting that her cardiovascular health is not at unusually high risk.

[17] EBV, or Epstein-Barr virus p18-VCA antibodies, measure immune stress. Epstein-Barr virus, a member of the herpesvirus family, is one of the most common human viruses and is responsible for mononucleosis (known colloquially in the USA as "mono"). Once infected, the virus remains in the body permanently and may flare up when the body is stressed. Generally, as a result, people who experience more stress have higher levels of EBV antibodies in their blood, and EBV antibodies have been associated with social stressors such as socioeconomic status and adverse life events (McDade et al. 2000; Worthman and Panter-Brick 2008). In this study, EBV antibodies are used along with CRP as an indicator of overall body stress, but also as a measurable index associated with the experience of psychosocial stress and social inequality. Indu's value of 83 ELISA units is low compared to other diabetic women in this study. This suggests Indu faces less stress than others in the study. See below for a table of acceptable cutoff or reference values for each biomarker reported here.

Biomarker	**"Healthy" value or relevant cutoff**
Blood glucose	Should remain between 70-180 mg/dL
HbA1c	Should be < 7.0%
C-reactive protein (CRP)	"High" is above 3.2 mg/L (highest quartile)
Epstein-Barr virus antibodies (EBV)	"High" is above 178.9 ELISA units (highest quartile)

Indu, a tall woman with strong arms, a square jaw, and long black hair pulled tightly back, pops her head out of her wrought-iron screen door to invite me into her apartment. She is a naturally poised woman, with a dignified face entirely free of makeup and a dry brow despite the July monsoon heat. A lower-middle-class homemaker with a high school education, Indu was diagnosed with diabetes the year before we met. As we sit in her combination living room and dining room with water-stained white walls and trinkets lining the windowsill, she explains, "I used to get tested for sugar every six months. No one in my family had it, but …I just felt like I might have sugar, because I was thirsty a lot and had to urinate a lot. These things happen from diabetes. I am educated; I read books and I keep reading about diabetes. Articles come in the paper about it all the time. It comes on TV too." Upon noticing these symptoms, Indu went promptly to the charitable health clinic nearby her house, as she had predicted, was diagnosed with diabetes. "I don't know why I got this disease!" she laughs, shaking her head. She and I are both surprised, considering her high level of awareness about the causes and prevention of diabetes years before she was actually diagnosed.

In between taking care of her small household, which consists of her only son, her husband, and her ailing father-in-law, Indu continues to attend the clinic every month for checkups, often going with her diabetic friends in the neighborhood for company. She takes her medicines, watches her diet, and goes on daily walks with other women in her neighborhood. She also makes time in her daily routine to do some sewing work to earn extra income. She reports no significant life stress and has good blood sugar control, although her blood test results suggest that she is at elevated risk of developing cardiovascular disease (CRP).

Rita, age 40, diagnosed 10 years ago, glucose 29 mg/dL, HbA1c 8.3%, CRP 7.5 mg/L, EBV 165.0 ELISA units

Rita looks flustered when I arrive at her apartment door, which is accessible through a narrow passageway and a staircase leading above their family's large, well-organized, and brightly lit neighborhood general store. Still wearing her night dress and with hair uncombed, she seems tired and somewhat discombobulated even though it is late morning. A middle-class woman with no formal education, Rita was diagnosed with diabetes in her early 30s. She explains, "When I was at the shop standing up a lot, I was feeling weaker and weaker. I had to go to the bathroom a lot." This continued for about a year before it reached a serious state. "One day I was really sick, and I urinated in bed by accident. Then I went to the doctor and asked him what could be wrong with me. He tested my sugar, and it was 405." Now, Rita rarely goes to the doctor for regular checkups even though she lives nearby the clinic because, as her husband explains, "There's no time. If one's health stays okay, then no one goes to the doctor. One only goes to the doctor when one's health is bad. Her health doesn't go that bad; she stays 100 percent okay. She just has leg pain, that's all. That always happens to sugar patients." Rita does not feel comfortable going to the doctor alone or going to market alone to buy medicines, but her husband and children are so busy running the shop that no one has time to go with her. The last time Rita sought healthcare was when she fell into a diabetic coma for several days, nearly died, and had to remain in the ICU for over two weeks. Rita's daughter feels that after her diagnosis with diabetes, her mother's personality changed. Her daughter says that she has lost confidence, now refuses to go out to the market alone, and resists participation in social functions. When I test Rita's blood sugar during the interview, it is dangerously low. She does not regularly monitor her blood sugar at home. Furthermore, her extremely elevated CRP result suggest that her poor diabetes control and her distress are taking a toll on her body, stressing her immune system and putting her at high risk of developing cardiovascular disease.

Manpreet, Age 50, diagnosed 1 year ago, glucose 103 mg/dL, HbA1c 7.6%, CRP 3.2 mg/L, EBV 140.9 ELISA units

As a devout Sikh, Manpreet dresses simply, wears little jewelry or makeup, and has long hair pulled low and tight into a bun. Although she has a family history of diabetes, Manpreet never expected to get it herself. She explains how her diabetes was discovered by accident:

> My papa actually has had it for seven years, but I never thought I would get it myself. I never tested myself during all that time. Actually, my father's glucometer wasn't working right. My brother told me to take it to a chemist and get it fixed. There was nobody to test it on nearby, so he asked me to give a drop of blood to test out the machine, and I volunteered to do it. I never

> dreamed that I could possibly have sugar. Actually, my schedule was such that I would get up at 6:00 in the morning and start feeling sleepy by 7:30. I had no idea that this could be a symptom of sugar.

Having had diabetes for only a year, Manpreet is not terribly strict with her diet, exercise, and regular checkups. She remains active in household management because her daughter-in-law does very little household work, but this routine tires her out too much to go walking for exercise on a regular basis. She and her retired husband live with their adult son and his wife, on whom they depend for support. Today, however, none of them are home. Instead, we sit on her doily-clad sofa with her mother, her daughter, and her granddaughter (who are visiting from their nearby households) and discuss their family-related frustrations, which come pouring out when I ask about their families. Manpreet's diabetic father, who lives nearby, is her main source of support. With his many years of experience with diabetes, he counsels her on management and calls her if he finds out that her sugar is running high. "My father is very caring toward me," she reflects affectionately. Manpreet's son and husband are, unfortunately, not so supportive. She gets her diabetes care from a monthly charitable clinic that she attends only intermittently because her husband and son will not give her adequate money for her medicines and consultations.

> If I need to go to the doctor, I think twice about it because you have to pay 500 for the consultation. If I ask my son for 1000 for the fees, he says, "Why do you need so much?" These days 1000 isn't that much. So I have to come to these clinics. Last time, I waited for hours and the doctor showed up, talked with some relative of his, and then left without seeing me. I was really upset about it. If we had more money, I could go somewhere else for a consultation. But I have to come to these clinics and wait. My husband and my son always tell me that they don't have change if I ask for money. He spends so many thousands on his wife, going on trips, eating out.

This is only one of Manpreet’s many family-related frustrations, but it impacts her health significantly. Her HbA1c and blood glucose suggest acceptable overall blood sugar control, although her HbA1c is slightly elevated. Her C-reactive protein values are slightly elevated, indicating that she has body inflammation that puts her at risk of developing cardiovascular disease.

Indu’s and Rita’s diabetes diagnosis stories represent two extremes along the continuum of healthcare-seeking behaviors, while Manpreet’s story falls somewhere in between. Not coincidentally, their blood biomarker levels also conform to this pattern; Indu’s most closely approximate official guidelines, Manpreet’s are moderate, while Rita’s are well above recommended levels. Indu was diagnosed with diabetes shortly after noticing symptoms of ill health. She makes sure to attend regular checkups and follows her doctor’s health management guidelines. Her blood glucose and HbA1c test results show that her diabetes is in good control, and she has never had a health crisis related to it. Her EBV and CRP blood tests further confirm that her general body stress is low. She has many household responsibilities but is able to manage them by herself, since her family is unusually small, and even has free time to do some paid work. In contrast, Rita and her family members share a heavy burden of responsibilities to the household and the general store, such that neither she nor her relatives have free time to go to the doctor or monitor her medication. As a result, Rita’s diabetes went undiagnosed until it reached an acute state, and her visits to the doctor are usually limited to hospitalizations for health crises, some of which have been nearly fatal. Rita does not engage in any form of preventative care for her diabetes, such as regular health checkups. Instead, her approach to healthcare resembles the “revolving door” phenomenon, a phrase originally coined to describe rapid, sequential hospital readmissions among the chronic mentally ill (Haywood et al. 1995). Manpreet’s story represents the way many women in my study were diagnosed—purely by accident, and without any noticeable symptoms. Although she has more household responsibility than she believes is appropriate for a woman of her age with a daughter-in-law, she is able to do most of what she did before getting diabetes and has not had a major health crisis related to it. Yet, her sugar goes low more often than it should, she does not exercise, and she is not always able to go for her monthly checkups because of money and health issues. This is reflected in her somewhat elevated levels of CRP, which suggests she is at risk of cardiovascular disease.

These three diabetes diagnosis experiences illustrate women’s varying thresholds for care seeking. Indu has a low threshold for care-seeking. She received her diabetes diagnosis shortly after noticing symptoms and now consults her doctor regularly. Rita, however, has a very high threshold for care-seeking, not going to the doctor until her symptoms intrude so much in her life that she cannot carry on. Manpreet’s diabetes care-seeking patterns fall somewhere in the middle: she does not go to the doctor as regularly as she should, but at the same time, she has never had a diabetes health crisis and tries to go for checkups when she can.

Social support, financial autonomy, and individual mobility are important here. Among other factors, Indu’s and Manpreet’s mobility outside of home and social support contribute to their ability to manage their diabetes. Both women feel comfortable going out alone for checkups and have peers or family members with diabetes who help them stay on track. Additionally, Indu’s small amount of financial independence, which she gets from her sewing work, allows her to obtain her medicines without causing family strain. Manpreet's lack of financial independence clearly affects her care-seeking behaviors, forcing her to attend a charitable clinic where she is dissatisfied with the treatment she receives. Rita's situation is even more difficult; she lacks support, autonomy, and mobility. Her family is largely unable to be involved in her care because they have such limited time, as evidenced by her husband's comment, "There's no time. If one's health stays okay, then no one goes to the doctor. One only goes to the doctor when one's health is bad." Although they have adequate money to pay for her treatment, Rita does not feel comfortable going out alone, so does not take the initiative to seek care for her diabetes.

The majority of the women who participated in this study have life circumstances that most closely resemble Manpreet's. In general, the middle-class diabetic women with whom I worked are, like Manpreet, not financially independent. Many, like Rita, do not feel comfortable going out alone because of ill health, religious restrictions, or because of a well-founded belief that it is unsafe for women to travel alone in Delhi. Before seeking care at a clinic, women like these must secure money to pay for transport and treatment, and arrange for someone to accompany them. These barriers are often enough to discourage women from going to a clinic at all.

But this lack of healthcare seeking among many women cannot be attributed entirely to factors like social support, financial autonomy, and mobility. There is another force that influences the time to diagnosis and subsequent healthcare usage among women in Delhi: the highly valued cultural norm that women should prioritize care of others over self-care. This cultural emphasis on caring for others is ubiquitous in North

India (see Chapter 5), and it first came to my attention as an important factor influencing women's diabetes care choices during my discussions with diabetes physicians. For example, Dr. Gupta, a high-profile diabetes physician who treats wealthy clients in Delhi, refers to this phenomenon among his female patients as a "widespread ethos of quiet suffering" (Weaver and Hadley 2011) and considers it a major challenge in his work with diabetic women.

This cultural value of "quiet suffering" among women is a widely shared norm, evident in the way Rita prioritizes her family's busy schedules over her own health needs. This norm leads to reduced use of healthcare services by Indian women, especially women with lower autonomy or lower family status based on age and gender hierarchies (Basu 1990; Conrad and Pacquiao 2005; Roy and Chaudhury 2008). Rita's case provides an extreme example of this tendency to avoid acting on ill health until it becomes unavoidable.

The forces that shape Indian women's care-seeking behaviors are myriad, but here we have highlighted three factors that seem to play key roles in Indu's, Rita's, and Manpreet's diabetes diagnosis and care-seeking experiences. The first factor is autonomy, in terms of economic independence and mobility outside the home. Having access to some disposable income and being able to travel alone remove some of the barriers to women's care-seeking and compliance to medication regimes, as in Indu's case. A second factor is having access to a supportive peer group. Indu has friends with diabetes in her neighborhood with whom she goes on regular walks and to clinics for checkups, while Manpreet's diabetic father gives her advice and checks up on her when he hears her blood sugar is out of control. Rita has no such group and therefore has no alternative source of support when her family is unavailable. The hassles associated with obtaining money, accompaniment, and transport for healthcare mean that Rita avoids disclosing her symptoms until her health is seriously compromised, a behavioral trend reported in studies among other South Asian women with low autonomy (Basu 1990; Conrad and Pacquiao 2005; Kielmann and Bentley 2002; Shaikh, Haran, and Hatcher 2008).

A third factor that influences care-seeking behaviors among the women in my study is a deeply entrenched cultural emphasis on women's selflessness. This ethos encourages women like Rita to prioritize their families' needs over their own health needs, such that "they are not being looked after well, even by themselves," as Rita's and Indu's doctor explained. The continuum model of immersion in illness (Charmaz 1991) that I introduced at the beginning of this chapter can also apply here, to situations where women subscribe so extensively to this social role that comes to have significant negative effects on their health. Immersion in the social role contributes to immersion in illness for women like Rita, who become unable to supervise their own health because they are preoccupied with the care of others. Because such other-oriented perspectives are such a key factor shaping diabetic women's health in North India, we will revisit this topic in greater detail in Chapter 5.

For now, it is sufficient to note that personal and cultural factors like women's financial dependence, restrictions on mobility, lack of peer support, and valuation of women's quiet suffering lead to delayed diagnosis of diabetes, and often mean that women who do have diabetes are not attending regular checkups, a cornerstone of diabetes care. The ultimate source of the differences in each woman's healthcare seeking behaviors is gender-based structural inequality that manifests in family relationships, restrictions on women's activities, and beliefs about appropriate timing and method of care seeking (Basu 1990; Conrad and Pacquiao 2005; Kielmann and Bentley 2002).

What Causes Diabetes?

After discussing with women the process that led them to their diabetes diagnosis, my second question was usually, "In your opinion, what caused your diabetes?" Women's perceptions of the causes of their illnesses provide insights into the cosmologies women draw on to understand the bodily symptoms they experience because of diabetes. These cosmologies draw heavily on biomedicine but also make use of non-biomedical and religious systems of meaning to make sense of diabetes.

Diabetic women's responses to this question—"What caused your diabetes?"—can be grouped into seven distinct categories. They are shown below with the number of respondents who mentioned each category listed at the top of each bar. Some women volunteered more than one cause for their diabetes, but only the first two causes mentioned by each woman were included in the tabulations for this figure.

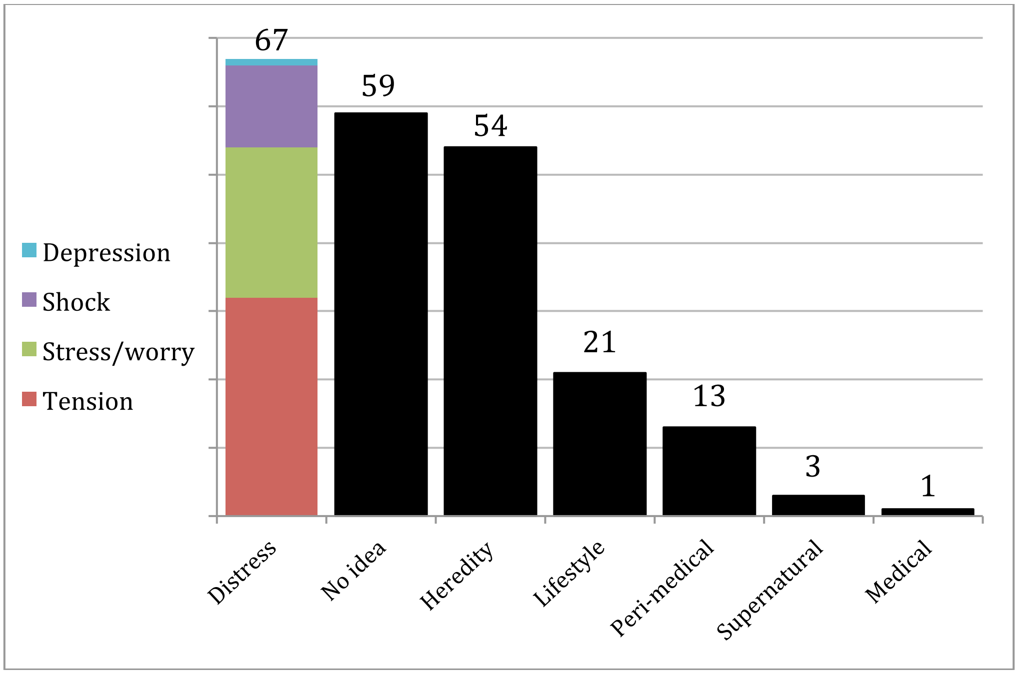

Figure 8. Women's self-reported causes of diabetes. The numbers above each column represent the number of people who mentioned each cause. "Distress," the most commonly mentioned causal category, is further disaggregated into four sub-categories labeled in the legend on the left.

Broom and Whittaker (2003) found that in the face of dominant discourses of control and individual responsibility associated with diabetes etiology and management, diabetic men and women in Australia tended to name causes for their illness that deflected blame away from themselves. The majority of women I worked with also name external causes for their diabetes. Factors like distress (n=67) and heredity (n=54), over which one is presumed to have little if any control, are the most commonly mentioned (see Figure 10, above). That this pattern holds cross-culturally suggests that it is a reaction to dominant biomedical models of diabetes causality, which characterize diabetes as a self-induced "lifestyle" condition brought about by overindulgence. The 21 women who mentioned lifestyle as a cause of their diabetes usually self-consciously described themselves as “lazy” and reported a habit of overindulging in food, especially sweets. Several of these women also mentioned undesirable aspects of urban life, such as pollution, sedentism, and confinement. This explanatory model deserves pause because a growing body of research on rural-to-urban migration around the world, and in India specifically, suggests that the lifestyle changes associated with urban areas put urban migrants and dwellers at risk for developing chronic diseases (Chadha, Gopinath, and Shekawat 1997; Ebrahim et al. 2010; Shetty 2002; Sobngwi et al. 2004; Ruel and Haddad 1999; Torun et al. 2002). Factors like mechanized transport, unwalkable street environments, and office-based employment foster sedentism, while reduced access to fresh foods and increasing consumption of processed and packaged foods encourages unhealthy dietary habits (*Ibid*.). As one rural-to-urban migrant woman explained, “Before I used to live in a village, but since coming to the city I don't work like I did there. I stay sitting in one place making *bindis* [adhesive decorations worn on the forehead], and sometimes I get gas from sitting so much. Maybe for this reason [I got diabetes].”

Thirteen women mentioned what I refer to in the figure above as “peri-medical” causes for their diabetes. This group felt that their diabetes had been caused by the latent side effects of medical procedures they had undergone earlier in life, such as a surgery or a long course of antibiotic treatment for tuberculosis. As one woman explained,

> I had—what do you call it? Gallstones. I had the stones removed, and after that I had a bit of a lung infection, so I was taking anti-tuberculosis medication. I think the side effects of this medicine caused [diabetes], that's what it seems to me. …I had to take these expensive medicines on an empty stomach [for TB] and then I got jaundice because I was working in a school in a village, and at home potable water wasn't available. Those medicines were really strong. It [TB] got better, but then this [diabetes] happened.

Because she lacked any family or personal history with diabetes, this woman felt confident that the onset of her diabetes after her gallstones and the course of anti-tuberculosis medications must have been related to the weakening effects of both, especially the TB medications. That women like this one locate disease-causing elements in biomedical treatments suggest a degree of distrust of biomedicine, which was common among my informants. They were particularly concerned with loss of blood during operations or injuries, and the destructive heating properties of certain "strong" medications they had taken in the past—two powerful modes of bodily harm according to Ayurveda,[18] one of India's most common non-biomedical systems, and one that informs popular understandings of the body and illness in North India.

As a result of concerns about biomedical treatments, medical pluralism was common among the women I worked with. The concurrent use of treatments from different medical systems is extremely common in India, where Ayurveda, Unani, religious ritual healing, and homeopathy treatments are widely used in addition to biomedical ones for all types of health problems (Flueckiger 2006; Gupta et al. 2002; Shafiq et al. 2003; Tandon, Prabhakar, and Pandi 2002). Often, medical pluralism was motivated by concerns about the side effects of pharmaceuticals. "She gets hot from taking all the medicines, so she has trouble," explains one respondent's son. "She'd like to take some medicine that would create less heat in her stomach." The respondent then clarified, "I'm taking homeopathy along with the pills. The homeopathic doctor told me to take one medicine and gradually reduce my allopathic medicines until I feel better." Many women engaged in some degree of complementary medicine use or dietary

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[18] According to Ayurveda, antibiotics generate heat in the body that can harm the internal organs and disrupt the body's balance.

alteration prescribed by a non-biomedical treatment system, such as regularly drinking bitter gourd (*karela*) juice along with their oral diabetes medications. [19]

Finally, a few women (n=3) understood their diabetes partially or entirely as a supernatural phenomenon. This kind of explanation was rare among my informants, partially because my method of locating them through biomedical physicians self-selected a group of women exposed to medical explanations for diabetes. In other parts of India or among groups who do not seek treatment from biomedical doctors, such explanations would likely be much more common. Manjot, a wealthy widow whose story we will explore in detail in Chapter 4, said, “It's not because of your negligence; it is destiny. It's your destiny. Because He wants you to suffer, you have to suffer. I've made a lot of mistakes in my life.” Manjot evokes the foundational Hindu concept of *karma*—a Hindi term derived from Sanskrit and meaning “action”—which holds that a person’s virtuous and non-virtuous actions in life produce good and bad consequences that shape the future. In her understanding, diabetes is a punishment for the “mistakes” she has made, and it is meant to make her suffer. Another recently-diagnosed woman views her diabetes as a trial of her faith. “I don’t know why He has given me this disease; what did he want to see? God gives you trouble because He wants to check if you still trust him or not.” That this group is so small, however, suggests that biomedical or peri-medical explanations of diabetes permeate understandings of illness to a great extent in this primarily urban-dwelling sample.

Lack of Awareness about the Causes of Diabetes

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[19] In Ayurveda, bitter substances are prescribed to treat diabetes. Karela, or bitter gourd (*Momordica charantia*), is one of the most widely-known of such treatments, and does have potent hypoglycemic properties (Yeh et al. 2003).

Although many women had clear ideas about the causes of their diabetes, over one-third of the group (n=59) stated that they had no idea what caused it. Many of these individuals were diagnosed years or decades ago in clinics or hospitals, but either did not receive or did not remember information from their healthcare providers about why they might have gotten the illness. This is unsurprising, as many medical practitioners in India, especially those working in understaffed government hospitals, simply do not have the time to educate each patient about the causes and complications associated with an illness as multi-faceted as diabetes. One diabetes physician who volunteers twice a week at a rural medical center on the outskirts of Delhi complained with a sigh and a shrug of the shoulders, “There's just no time. I have to see 70 patients in two hours, so there are only two or three minutes for a patient. What to do? If I take too much time, the outside people will start shouting. Pressure!—and you have to deliver. You have to work within your means and circumstances.” A female patient at one of the busy charitable clinics where I worked only obtained minimal information from her doctor about warning signs of dangerously low blood sugar. She explained, “I don't have any problems because of sugar, and I don't know what can happen from it. Doctor-sir hasn't told me. I just know that if your sugar goes low, then you'll feel dizzy and giddy, but that has never happened to me.” Only the women attending the private clinics, where consultations cost up to Rs. 1200 (about USD 25, and 60 times the cost of a consultation at a charitable clinic), were given more than a few minutes to consult with their physicians. In addition to time with their physicians, patients at private clinics often had access to dieticians, physiotherapists, and diabetes educators as part of their regular care, but such amenities were less available or absent at the charitable and government-subsidized clinics. The extreme cost difference between public and private sectors is a key source of unequal healthcare access in India (Sengupta and Nundy 2005).

A second factor contributing to reduced awareness about the causes of diabetes among women is the hierarchical nature of North Indian societies (Beteille 1990; Derne 1995; Dumont 1966; Liddle and Joshi 1991; Marriott and Inden 1977; Ray and Qayum 2009) and the high status of physicians in this hierarchy. Because physicians are considered authority figures, patients are not encouraged to ask questions, lest their questions be perceived as doubting the physician's good judgment. Several women told me that they avoid asking questions for fear of being reprimanded. One patient of an especially strict male doctor explains,

> He yells at the people whose sugar is not in control. Everyone who comes here is scared of him. They can't speak in front of him. He gets very angry. If he says something and you bring up something else then he gets very angry and says, "If you're a doctor then why did you come to me?" Like, if he suggests one medicine for me and I say I've heard of some other medication, he says, "Well, go sit at home and write your own prescriptions!" He's a good doctor [but] you can't interrupt or contradict him. You have to say, "Yes, yes, sir."

This hierarchy is reinforced in everyday doctor-patient interactions, where doctors often refer to their patients using informal word for "you" (*tum*), while patients invariably refer to their doctors using the honorific "you" (*aap*) or using the English titles "Sir" or "Madam."

Such dynamics—a clear status differential, listening without questioning to the expert's words—mirror the language employed in other hierarchical social relationships, such as guru-disciple, father-child, and those based on caste, age, and gender that serve as templates for how superiors and inferiors should interact (Vaidyanathan 1989). As a corollary of this deferential attitude toward physicians, many women seemed content to leave the knowledge about the causes of their diabetes in their doctors' hands. This is true, in my observation, for patients of both biomedical and non-biomedical physicians.

It should be noted, however, that women frequently exercise agency about their own healthcare when their doctors are not looking. Although women generally approach their physicians with respect and deference, they do not necessarily follow the guidelines their doctors give them when they return to the privacy of their own homes. Sometimes they do not understand the guidelines, or the guidelines are simply too difficult to follow, or medications or dietary changes are unpleasant to follow. Other times, as we saw earlier in this chapter, the duty to care for family members "trumps" an authority figure's injunctions to perform self-care.

Another possible explanation for the lack of awareness about the causes of diabetes among women in North India is the fact that because the majority of Indian physicians (especially diabetes physicians) are male, there is often a gendered element of authority that shapes question-asking and disclosure of symptoms between female patients and their male doctors. Many women were reluctant to share questions about gynecological problems, for instance. One young, very thin, pregnant non-diabetic woman who was accompanying her husband to a charitable clinic where I worked said, "I come here for my own checkups as well, but I'm only able to talk to Lalita [the receptionist], not anyone else. I feel shame. I am only able to tell you this because you are a girl." As it turned out, this young woman was taking no prenatal vitamins and having severe morning sickness, but she felt it was inappropriate to talk to her male doctor about her symptoms because pregnancy is seen as exclusively a women's issue. This is a significant concern for diabetes management because gestational diabetes is very common in India (Seshiah et al. 2004).

Finally, it might be that women who said they did not know why they got diabetes were simply uncomfortable making guesses about this question in my presence. Many women could have ideas about its causes, but since most assumed I was a diabetes “expert,” might be reluctant to express views that are “incorrect.” Women’s view of me as a quasi-medical-professional (a natural reaction to my foreignness and to meeting me in a clinical setting) could have influenced them to say “I don’t know” more frequently than they might have said to someone they perceived as a non-expert.

Wrapping Up

This chapter covered a lot of ground. We began by exploring women’s experiences of diabetes diagnosis through Indu’s, Rita’s, and Manpreet’s case studies, which led us into a discussion of women’s healthcare seeking behaviors and the cultural and personal factors that shape them. Along the way, we investigated the factors that shape women’s paths to a diagnosis of diabetes, and compared women’s and their physicians’ perceptions of its causes.

As discussed in the opening section of this chapter, chronic diseases, by virtue of their duration and their fluctuating symptoms over time, create varying levels of disruption in individuals’ lives (Becker 1997). Our exploration of women’s care-seeking behaviors at the time of their diabetes diagnosis and beyond illustrates the range of life disruptions that North Indian women endure in the name of chronic diseases. Some women seek care regularly to help manage their diabetes; these women may be wealthy, educated, or independent, like Indu, and are able to maintain relatively uninterrupted life routines. Others, like Rita, avoid going to the doctor for financial or interpersonal reasons until their ill health simply cannot be ignored because it is endangering their very lives. Still others face some structural inequalities that impact their health-seeking behaviors, such as lack of financial autonomy, but manage to maintain intermittent diabetes care regimens, like Manpreet.

Gendered cultural norms surrounding women's behavior also shape the extent to which they are willing and able to express physical symptoms of diabetes and psychological symptoms of distress. Gendered hierarchies between male physicians and female patients make it difficult for some women to discuss their physical and mental health with the one person to whom they should be disclosing these issues. The pervasive idea that women should suffer silently in a martyr-like fashion, placing the care of their family members ahead of their own self-care, also makes it difficult for some women to justify seeking physical or mental healthcare until they are in severe need of it. This cultural norm has such profound effects on women's healthcare behaviors that it will be revisited later with its own chapter.

We have not yet addressed in depth the most common perceived cause of diabetes among the women with whom I worked: stress. The relationship between distress and diabetes has received much attention in the medical literature and, to an increasing extent, in the work of medical social scientists as well. In my experience, distress is one of the most common perceived causes of diabetes in North India. Because it is so commonly mentioned, the relationship between distress and diabetes will be dissected in the next chapter.

CHAPTER 3: "TENSION HAPPENS"

DIABETES, DISTRESS, AND MENTAL HEALTH

An air of gloom hung around Shila, a traditional Hindu middle-aged woman visiting her daughter in Delhi from Calcutta. The two generations of women might have been happy, as a lower-middle-class family reuniting on holiday and enjoying each other's company. Yet, Shila was dissatisfied. The reason came to light early on in our interview, when I asked her about why she thought she had gotten diabetes. "Oh, I don't know anything," she said, waving her hand dismissively, in a mix of Hindi and English. Yet, before I could open my mouth to encourage her to share her thoughts, she went on, "Well, my other daughter's mother-in-law is bad." "Yes," interjected her daughter. "*Veh hammein bahut* tension *detein hein* [They give us a lot of tension]. They don't let us meet her." "My younger daughter's mother-in-law, she doesn't let us come or let her go. This has totally impacted my mind. She didn't allow her to meet me for two or three years!" exclaimed Shila. "*Usi din se usko* sugar *pakar liye* [From that very day she got sugar (literally, "*sugar got hold of her*")]," explained her daughter. "She kept on crying." "Mmmm hmmm," Shila agreed, "*Chinta karte-karte, sugar ho gya* [with all this worrying, sugar happened to me].”[20] At this point, I couldn’t have stopped them from talking if I had tried. Her daughter went on, “Mommy kept brooding about why they wouldn't let her come, why can't she meet her? If we went to meet her, even then [the mother-in-law] wouldn't allow her to talk to us, only let us see her. She's really bad.” Sighing, Shila recalled, “Just after this, my health went bad.” “Yes,” said her daughter in quick succession, “just after [my sister’s] marriage, sugar got hold of my mom. ...Now she comes to visit after a year or two, but she leaves quickly. I mean, her in-laws aren't alright, her husband isn't alright, either. He doesn't help her arrange to see us.” When I asked what could possibly be motivating the daughter’s in-laws to act so controllingly, Shila shook her head, saying resignedly, “I don't know. Everyone has their own different mentality.”

The concept of “tension” figures prominently in Shila’s narrative of family discord, distress, and diabetes. E.E. Evans-Pritchard, one of social anthropology’s founding fathers, once wrote, “The most difficult task in social anthropological fieldwork is to determine the meaning of a few key words, upon an understanding of which the success of the whole investigation depends” (2004 [1951]: 80). One of the most common expressions I encountered in my fieldwork among Hindi-speaking women was the English word “tension” inserted into a Hindi sentence (as Shila’s daughter says above, “*Ve hammein bahut* tension *detein hein* [They give us a lot of tension”]). Women used

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[20] The use of passive voice to talk about getting an illness (in this case, “Sugar happened to me” or “Sugar got hold of her,” instead of “I got sugar”) is a common construct in Hindi and is used to talk about most illnesses as well as both negative and positive feelings like irritation, happiness, and tiredness.

"tension" to talk about all kinds of distress, and more than any other potential cause of diabetes, it was the one most commonly mentioned. Among the 184 diabetic women interviewed in this study, over a third (67 women; 36 percent) reported that distress was the major cause of their diabetes, and almost half of these (32 women; 48 percent) specifically used the term "tension" to talk about this distress (refer back to Figure 10, Chapter 2). It was the most common cause women mentioned for their diabetes, a finding corroborated by the recent work of Mendenhall and colleagues (2012) in this same cultural context. To understand women's experiences and perceptions of diabetes, we must therefore also understand women's experiences and perceptions of "tension."

The rarely-studied but widely-used construct of "tension" as a colloquial expression for stress in North India is a key aspect of women's models of diabetes, and for this reason, "tension" is the subject of this chapter. As Evans-Pritchard predicted, it became a key concept around which much of my work, and especially my understanding of women's mental health, revolved. Below, we will explore the general meanings and uses of "tension." In particular, we will tease apart how this concept compares to the common mental disorders (CMD) of clinical depression and anxiety, which are common ways of understanding distress in the US. We will then explore how women with diabetes understand "tension" as part of their physical health and use it to express their distress.

"Tension," Stress, and Mental Health in North India: Measuring Distress Cross-Culturally

The term “tension” is found among Hindi speakers and other Indian linguistic groups, including Malayalam speakers in Kerala and Konkani speakers in Goa (Halliburton 2005; Pereira et al. 2007). Halliburton (2005) has noted the use of “tension” in Kerala as a “popular psychological term” (113), or what he describes as a modern way to talk about psychiatric problems. In Halliburton’s view, when Western terms like “tension” supplant the expression of distress through the more “traditional” medium of spirit possession, a sort of cultural homogenization occurs. Here Halliburton and I disagree, for I view “tension” as its own culturally specific form of expression. Although the word itself is Western English in origin, my informants have appropriated it for their own unique usage in both Hindi and Indian English. Like Pereira et al’s (2007) informants in Goa, the women I worked with use “tension” both to express distress and to explain why they have distress.

The insertion of English words into conversational Hindi is common in North India, especially in urban areas like Delhi. This bilingual “code-switching,” as it is called in linguistic anthropology (Gumperz 1982), not only demonstrates the extent to which English has been adopted in India, but it also suggests how the adoption of new modes of self-expression, like “tension,” are both foreign and local at the same time (Liechty 2003). The term “tension” is foreign in the sense that it is an English word, yet local because it is used widely and specifically in Indian English. Because there is a Hindi term that means “tension” (*tanav*), the use of the English word may denote an underlying construct that is not captured by *tanav*. Here we will explore the various ways women in my study use the expression of “tension,” and below, we will explore how “tension” specifically interacts with diabetes.

Much like the concept of “stress” in American English (e.g., “I’m so stressed out”), “tension” is used in an extremely wide range of contexts and can denote anything from everyday irritations to more serious forms of distress such as severe poverty or lack of sufficient food. In conversation, women used it to describe both episodic and chronic stress. There is a widely-held perception that urban, modern lifestyles are more fraught with “tension” than more traditional lifestyles, and a general agreement among the women with whom I worked that “tension” is increasing in modern times. In some ways, then, “tension” is analogous to a “disease of modernity.” One older man, the husband of one of my informants, explained it this way:

> God could have created the sexes the same, but he made two of them, he made them differently. Tell me, why is there so much depression in America? By all measures the standard of living is higher. The rural women in India are oppressed, but still they don't get depression, even though they are treated very badly. Maybe women there [USA] are too independent. With independence the element of aggression comes out; the competition between the sexes creates tension. It creates clashes. You tell me if I am saying anything wrong. In Delhi and Bombay it is also happening. It used to be that we would open doors for ladies and speak politely to them. I thought it was very nice. Nowadays who opens the door for them? If you open a door for a lady she will get offended: “You think I can't open the door for myself?” But in rural areas, he does his work and she does her work. There is no clash, so the stress is less. Even though they are oppressed, they stay happy.

This statement is clearly plagued by a lack of sensitivity to the plight of rural South Asian women, among whom mental health problems can in fact be very common and in some cases are increasing (Mumford et al. 1997; Nandi et al. 2000). Yet, that fact aside, this man’s statement encapsulates a common explanation for increasing levels of depression and “tension” in urban India as the product of development (and, specifically for him, in the changing configurations of gender roles in contemporary Indian society). A young psychologist agreed that mental health problems seem to be increasing in India,

> …because our society is in a huge transitional state. We're leaving behind a lot of things that are supposed to be our cultural values, and we're not very sure if we want to accept the new values or the new belief systems that are coming from different parts of the world. …But while we want to hold on to whatever we believe is our heritage, is our culture, there is a very strong need--and I'm not just talking about a 16-year-old, but I'm also talking about the 40 year olds and 45 year olds--to look at the other exciting ideas that are coming from different parts of the world. So there is a huge state of flux, and I think that is necessarily leading to a lot of problems.

This perspective, echoed in public opinion as well as in medical and academic discourses, locates increasing levels of "tension," depression, and other mental health concerns in the conflicts surrounding development and changing values systems in India.

"Tension," like "stress," is a word borrowed from physics, and therefore its colloquial use involves a physical referent, whether or not users realize this. While "stress" refers to the forces that occur when an external load is applied to an object (as when an object is placed on top of another), "tension" refers to the pulling forces that a rope, chain, or other solid object exerts on another object, which tend to stretch or elongate it (as in a rope being pulled in opposite directions). This physical metaphor is relevant for the kinds of "tension" women most often experienced in my study; "tension" usually involved social relationships and included a sense of being pulled between competing responsibilities. This form of distress, I believe, is subtly distinct from American conceptions of "stress," which often involve a sense of being "weighed down" or "having the weight of the world on your shoulders," as opposed to being stretched between poles.

Indeed, the causes women most often mentioned for "tension" were based in relationships. The specifics of these causes, however, varied by socioeconomic class and by life stage. Younger, middle-class or upper-class women often worried about young children's success in school, about finding appropriate marriage partners for older children, or for older women, perhaps about the fact that children and their spouses lived far away or were hard to be in touch with, as in Shila's case. Other common sources of "tension" that spanned socioeconomic groups included a relative's substance abuse, an overload of domestic responsibilities, or frequent arguments with one's spouse. As one non-diabetic woman explained, "I get tension because my husband drinks so much. I'm sure I've got a BP problem because of it. Yes, I have a lot of tension, and it seems to me that I've developed a BP problem because of it. I also get dizzy sometimes. He drinks a lot, since our marriage. I've tried, I've tried [to stop him]."

For impoverished women, a common cause of "tension" was financial worry, which was often spurred by the high costs of daughters' marriages. [21] For Manpreet, the Sikh woman we met in Chapter 2, major healthcare costs around the time of her daughter's marriage created so much "tension" that she feels sure it triggered her diabetes:

> Those days I had a lot of tension. I was arranging to get my daughter married, and I had a lot of tension because two and a half months after my [hysterectomy] operation, her wedding was scheduled. I wanted to have the operation after the wedding, but I had to get it done sooner because it could burst from inside my uterus if I waited. After the operation I was tired out; I was worried about my daughter's wedding. The money that was supposed to be for her wedding had to be spent on my operation, and we weren't in that good of a financial condition at the time. I was so tensed about it that for two and a half months I didn't sleep. I was that tense. And I had tension even more because two months after the wedding my daughter's husband got ill. My tension got even worse, I couldn't talk to anyone, I couldn't tell anyone these tensions. So this is why it [diabetes]

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[21] Although the practice of dowry—property or money brought by a bride to the groom's family on their marriage—was outlawed in India in 1961, it is still common in act if not in name. Grooms' families often make it known, implicitly or explicitly, that they expect a certain amount of money or costly gifts such as vehicles or household appliances. Refusal to give these "gifts" can have serious consequences. Even in the present, news media occasionally report "dowry deaths," or the murder of brides committed by the groom's family because they did not receive the expected dowry.

> happened to me; because my tension kept increasing. I don't take an [excessive] diet, it's not like I eat all day."

Thus, "tension" appears to be primarily a social phenomenon. Unlike common mental disorders such as clinical depression or anxiety, "tension" does not usually include elements of existential angst or generalized anxiety, which are "individual"-oriented characteristics. Instead, women usually understand "tension" as arising from interpersonal problems related to family and marriage.

The degree to which "tension" intrudes in women's lives conforms to the continuum model of immersion in illness that was introduced at the beginning of Chapter 2 (Charmaz 1991). "Tension" can be chronic or episodic. Manjot, a wealthy woman whose story we will explore more thoroughly in Chapter 4, explains, "*Yeh diabetes mere haath mein aa nahin rahi hein* [I can't get a hold of this diabetes]. I don't have tension, but I do. I take tension habitually." Her daughter agrees, "She is hypersensitive and she takes stress a lot. Since my birth I have seen her taking stress only. That is why it's [sugar] not going down."

For some women, "tension" is more episodic and is minimal enough that they can overcome it by staying busy with activities they enjoy. As one respondent explained, "Normally I keep myself happy with *satsang* or *bhajan* [religious singing groups], and I make food. As long as I stay busy, I stay happy." For this woman, "tension" seems to signal nothing more than day-to-day stress over small incidents. This kind of "tension" is a simple fact of life, one we all must face. As another woman succinctly stated, "Tension happens! I mean, what good does it do us to think about it all the time?" This type of "tension" creates small interruptions in daily life, but is not enough to derail a woman's larger routines and lifestyles (Charmaz 1991).

"Tension" is a more dominating force in other women's lives, however, from which everyday distractions offer no relief. A lower-middle-class middle-aged woman who operates a successful lunch supply business out of her home explained candidly, "I always have a little tension and worry at my house. I have to get my daughters married, and I want to have my own house built. Whenever this thought comes to mind, I dwell on it all day. There are no arguments or fights at home, just this tension." This kind of "tension" corresponds to a moderate level of Charmaz's (1991) symptom severity continuum, where symptoms intrude into life but do not entirely take it over. Although this woman was preoccupied by her "tension," it was confined to specific spheres of life (building a home and marrying her daughters) and did not impede her daily routines, such as the operation of her business.

In some cases, "tension" indicates a serious level of mental disturbance. Much like Charmaz's (1991) concept of immersion, "tension" comes to dominate the way some people frame their larger life stories, including this young, recently widowed poor woman:

> I do get sad. It's not [that I am suicidal], but I do feel sometimes like, "What kind of a life is this?" There's so much struggle. I have two girls to educate and raise by myself. Everything is my responsibility. Because of this I feel tension. I've had this tension from the beginning because my husband's health was poor since our marriage.

Supporting one's daughters is a potent stressor for women with limited economic resources, particularly because of the enormous costs associated with weddings and the dowries that typically accompany them. Another respondent who was poor and anxious about paying for her daughters' marriages associated her "tension" with morbid thoughts: "Sometimes I even feel like dying when I'm in tension. ...I have a lot of tension, just tension." For these women, "tension" is much more than mundane stress, and in fact seems to signal serious disenchantment with life. The first woman's rhetorical question—"What kind of life is this?"—and the second woman's statement that she "even feel[s] like dying" speak volumes about the severity of despair that each woman endures under the name of "tension."

But why is "tension" such a ubiquitous expression? I suggest that for women who experience serious distress, "tension" can serve as an effective way of expressing unhappiness without reverting to terms with negative, stigmatizing connotations. In such cases, "tension" is useful because it can be tactically used to both reveal and conceal information—for instance, revealing that a difficult personal event is taking place, while concealing the specific nature of that event. In many cases, women seemed to be using "tension" in our conversations as a blanket term to signal distress but avoid discussing specific personal concerns. One such woman explained, "You know, tension, it happens. I mean," she paused, "after marriage, one's life changes." Given the strong cultural emphasis on family harmony in North India and on women as the creators and maintainers of that harmony (Donner 2008; Standing 1991; Trawick 1992; Wadley 2008[1977]), it is not surprising that this respondent hesitated to talk openly about household discord, especially in an interview setting. Still, she was able to communicate to me the general nature of her problems (family discord) and the reason (marital conflict) indirectly using the word "tension." This use of the "tension" idiom to communicate underlying distress is reminiscent of psychiatrist Arthur Kleinman's

(1988a) work in post-Cultural-Revolution China, where the relatively innocuous and extremely common diagnosis of neurasthenia, a physical illness, seemed to act as a somatized substitute for the less culturally appropriate diagnosis of depression or other mental illnesses.

I suspect that there are two main reasons motivating women to communicate distress indirectly. First is the "ethos of quiet suffering" mentioned earlier in this chapter, which mandates that women avoid complaining. "Tension," an innocuous and vague term, allows women to disclose stress in a culturally acceptable way without going into great detail or appearing to be "complaining." Besides, "tension" often arises from interpersonal conflicts that women may not want publicized, in case they might reflect poorly on the family.

A second reason for the use of euphemistic terms like "tension" to discuss serious distress is the fact that in India today, like China in the 1980s (Kleinman 1988a), there is a relatively low level of awareness about biomedical mental health problems, with the result that stigma persists around them (Conrad and Pacquiao 2005; Desjarlais et al. 1996; Raguram et al. 1996). Although "tension" is different than clinical depression or anxiety, it seems that the expression is sometimes used to disclose severe distress that could be related to depression or anxiety. According to one of the physicians I worked with, however, psychiatrists and psychologists in North India are popularly known as *paglon ki docteron* ("crazy-person doctors"). Another physician explained,

> It's a stigma! My goodness, in this country going to a psychiatrist is—mad, mad! You have to be, you know, really funny in the head. If you are living in a joint family, and you have a mother in law and father in law, and if they get to know that the daughter-in-law—even if the daughter-in-law is 56 or 60 [years old]—is going to a psychiatrist, she might have a tough time. That's the biggest problem,

> really, the stigma that, 'Oh my God, what will they say, now that I'm going to a psychiatrist?'

One cause for a strong family reaction to a relative seeking psychiatric care is the "courtesy stigma" (Goffman 1963) that often attaches to them as relatives of someone with a mental disorder. "Depression," for instance, implies an intrinsic defect in the individual that could extend to other family members and must be medically treated, thus tainting the family and making the sufferer into "a mental patient," a highly stigmatized category. This constitutes a great risk in a society like North India's, where family reputation is a key criterion on which the marriageability of young adults is judged. An endocrinologist I worked with explained,

> If you ask [female patients] if they're depressed, they say, 'No, why should I be? My husband's great, kids are great, blah blah blah.' If you tell them they have depression, they'll hate you. You have to do it delicately. If you say, 'You seem to have a lot of tension,' they love that. It's because of the stigma. If it's depression, then you are a patient. If it's tension, then it's something somebody else has done to you.

The stigma surrounding mental health care has real clinical implications, as diabetes physicians often feel compelled to treat comorbid mental health disorders themselves, either because mental healthcare is unavailable to their patients, or because patients resist going to a mental health professional. *All* of the diabetes physicians I worked with prescribe antidepressants or tranquilizers for their patients who have mild depression or anxiety disorders, fearing that they will lose patients if they try to refer them out to a psychiatrist. "It's almost impossible to refer them to a psychiatrist or a psychologist. They don't want to be seen sitting in a psychiatrist hospital or a clinic. They just don't want to be seen," explains one doctor. Another claims that when he refers patients to a psychiatrist, "Nine out of 10 don't [go]. So I say, 'Look, I think you need to do some yoga, do some meditation, and I'll give you something to calm you down. If it doesn't help then I will send you to a friend who will take care of you, but let's try this first.' I never send them to the psychiatrist on the first go, even though it's obvious that they need help, because they'll never go. They'll never come back [to me], either. So I prescribe a mild antidepressant sometimes."

Unsurprisingly, given this stigma, women very rarely used the word "depression" to talk about themselves; only 10 out of 306 women I spoke with over the entire course of the research talked about "feeling depressed" or "having depression," and they belonged exclusively to wealthier English-speaking groups. When they mentioned depression, they invariably used the English word. Below are a few examples:

> "I had depression a year ago, but now I'm controlling myself."
> --upper middle class homemaker, age 61, diabetic

> "The thing is, I have a little depression. I know. But now I have taken myself out of this depression."
> --wealthy socialite, age 60, diabetic

> "I used to have giddiness and restlessness. Around the time of my daughters' marriages, my health was bad for a whole month. I fell into depression because of tension. I couldn't sleep then, but now I'm fine."
> --upper middle class homemaker, age 50, diabetic

Each of these women made specific efforts to clarify that their depression was a thing of the past, something they had pulled themselves out of by sheer force of will or self-control. This tendency suggests the extent to which "depression" carries a connotation of responsibility, personal flaw, and a formality of clinical diagnosis. The implication is that depression is a form of inappropriate self-indulgence that can be remedied if one learns to "control myself" or "take myself out of this." The implied locus of causality outside the individual likely makes "tension" a more appealing way to talk about distress, but the emotions women reference when they say they have "tension" or "depression," based on ethnographic context, do not differ dramatically.

In an effort to systematically capture what women mean when they say they have "tension" and how this might relate to depression and anxiety, I asked a group of 62 diabetic and non-diabetic women to list words or feelings they associated with "tension" (Weaver and Hadley 2011). Among the 62 women polled, twenty items were mentioned independently by at least 2 women and included emotional (e.g., anger), behavioral (e.g. crying), and physical (e.g. weakness, headaches) symptoms. Of these 20 items, 11 are very similar to items in the Hopkins Symptoms Checklist-25, a standard instrument for detecting clinical depression and anxiety and the one used in this study to assess mental health (see Table 5, below). These findings led me to further hypothesize that "tension" can be used to talk about symptoms of depression and anxiety.

Table 5. Comparison of items in the Hopkins Symptoms Checklist-25 and the 20-item locally derived "tension" scale developed in this study.

Hopkins Symptoms Checklist-25	**"Tension" assessment checklist**
1. Suddenly scared for no reason	Feeling angry
2. Feeling fearful	Feeling troubled or upset
3. Faintness, dizziness or weakness	Frequent mood swings
4. Nervousness or shakiness inside	Feeling disappointed due to unmet expectations
5. Heart pounding or racing	Being irritable
6. Trembling	Feeling oversensitive
7. Feeling tense or keyed up†	Feeling stressed out, tense†
8. Headaches†	Headaches/migraines†
9. Spell of terror or panic	Feeling like hitting someone or becoming physically violent
10. Feeling restless or can't sit still†	Feeling restless†
11. Feeling low in energy, slowed down†	Feeling weak or tired out†

12. Blaming yourself for things†	Blaming others or taking out anger on them†
13. Crying easily†	Crying†
14. Loss of sexual interest or pleasure	Stomach pain, gas, or digestive problems
15. Poor appetite†	Loss of appetite†
16. Difficulty falling asleep, staying asleep†	Problems sleeping†
17. Feeling hopeless about future†	Feeling hopeless†
18. Feeling blue†	Feeling bad for no particular reason†
19. Feeling lonely	Negative thinking
20. Thought of ending your life	
21. Feeling of being trapped or caught	
22. Worry too much about things	
23. Feeling no interest in things†	Not feeling like doing anything at all†
24. Feeling everything is an effort	
25. Feeling of worthlessness	

† Similar items are arranged adjacent to each other.

Based on the words women associated with "tension" most frequently, I created a questionnaire to measure "tension" and assessed its validity and reliability using the methods detailed in the Appendix. The purpose of this step was to try to address the potential relationships between "tension" and clinical depression and anxiety not only ethnographically, but also quantitatively. Using this questionnaire, I collected quantitative data on "tension" and depression and anxiety among the sample of 280 diabetic and non-diabetic women.

One way to understand the relationship between "tension" and common mental disorders like clinical depression and anxiety is the distinction in psychology between "states" and "traits." Originally proposed by Cattell and Scheier (1961), the distinction is meant to differentiate between transitory emotions and chronic patterns of thought or behavior. Distress is considered a "state" when it is temporary, linked to specific events or circumstances, and resolved with the alleviation of the distressing circumstance. When it is chronic, however, distress can become integrated into one's personality as a "trait," much harder-to-treat because it is integrated as an aspect of one's personality. Words like "depression" carry a "trait" connotation in India, suggesting an intrinsic defect, while words like "tension" evoke temporary negative "states" that suggest a quick recovery (even if recovery is not actually imminent, and even if that "tension" is experienced as a state).

"Tension" and Diabetes: Building Ethnophysiological Models through Patient, Family, and Doctor Perspectives

As noted earlier in this chapter, "tension" is often implicated in women's causal models of their diabetes. Many women reported being diagnosed with diabetes during a period in their lives when they were experiencing an unusually high level of "tension." For some, this "tension" was linked to a specific and stressful event, such as the sudden death of a close family member, an illness, or a child's marriage. A recently widowed 54-year-old Punjabi woman explained, "Why did [diabetes] happen? It happened because of tension. When one's husband dies, then it happens." This linkage of "tension" with diabetes was extremely common (refer back to Figure 10, first column).

As I noted in the Introduction, there is a significant medical and epidemiological literature linking psychosocial distress and diabetes (Egede and Ellis 2010; Golden et al. 2008; Mezuk et al. 2008; Renn, Feliciano, and Segal 2011). The association appears to be bidirectional; people with depression are more likely to develop diabetes, and people with diabetes are more likely to develop depression. The predominant direction of the association between the two conditions is not clear, and in reality, they are likely cyclically related. Of greater concern than a debate about the directionality of this relationship is the fact that each epidemic illness generates positive feedback for the other, in a “syndemic” fashion that interacts with social conditions and ultimately augments the reach and severity of both (Singer 2009).

The perception among the lay community that stress is causally related to chronic diseases like hypertension, diabetes, and heart disease is common here in the US, in India, and around the world. Work in the 1980s and early 1990s by medical anthropologists such as Dan Blumhagen (1980), Linda Garro (1988) and Suzanne Huertin-Roberts (1993) established ethnophysiologies of hypertension among various American groups that all incorporated notions of life stress. Blumhagen’s (1980) informants, for example, understood hypertension as “hyper-tension,” that is, as too much tension. In this scenario “tension” meant both physical overexertion and an excess of worry.

Women in the North Indian context often conceptualized this relationship as the residual physical effects of embodied stress they experienced earlier in life, which they believed to linger in the body and eventually cause diabetes. A 51-year-old woman who was diagnosed with diabetes at age 43 states, “People on my in-laws' side have it, but neither my mother nor father had it. It seems to me it's from tension. The environment at my in-laws' place was stressful at the time of my marriage [19 years ago]. Maybe it happened for this reason.” This conception of the relationship between diabetes and “tension” closely mirrors biomedical models of diabetes causality that emphasize the role of psychological stress in precipitating the onset of the disease, including the allostatic load model (Geronimus et al. 2006; Juster et al. 2010; McEwen 1998; McEwen and Seeman 1999).[22]

Family members of diabetic women also perceived a connection between women's distress and their blood sugar. They often described cumulative life stress or "tension" as an obstacle that physiologically obstructs women's blood sugar from decreasing, despite their adherence to diabetic medication routines. Shila's daughter comments, for instance, "She is hypersensitive and she takes stress a lot. Since my birth I have seen her taking stress only. That is why [her blood glucose] is not going down." Similarly, one woman's husband told me, "I am only concerned about one thing, and that is these mood swings, this temper, *et cetera*. I know that it definitely obstructs the bringing down of her sugar level. She has to control her temper, she has to control herself, and then automatically this sugar also will come down. Because medication is one way of bringing down…metabolism and all that, but psyche also plays a role."

This model of "tension" is congruent with models of Indian personhood termed "intersubstantial" in classic anthropological literature on the subject. "Intersubstantial" personhood describes a system in which the physical self is believed to be constituted out of the exchange of visible or invisible substances (through food, touching, sex, or even a glance) between people (Dumont, 1966; Lamb 2000; Marriott & Inden, 1977; Ramanujan, 1989). This "intersubstantial" model of personhood is closely tied to caste and notions of purity, impurity, and exchange. It underlies the way many women in my study talk about stress as a force entering their bodies and causing an imbalance that

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[22] "Allostatic load" refers to the cumulative effects of chronic stress on the physical body, including overactivation of the hormonal fight-or-flight response, which is hypothesized to lead over time to body inflammation, insulin resistance, and illnesses like diabetes.

leads to depression, diabetes, hypertension, and other stress-related illnesses over the life course (not just in the present or recent past). An important feature of locally relevant models of diabetes is the role of "tension" in precipitating the onset of diabetes by causing physiological damage, and in preventing good blood sugar control by blocking the effects of diabetes medications. "Tension" is conceptualized as a health-demoting force that accumulates and lingers in the body, creating complications that may be immediate or delayed, sometimes by decades.

The comorbidity between distress and diabetes is unusual because lay, medical, and biomedical explanatory models converge upon a shared conclusion: that stress is causally related to diabetes. The physiological pathways that lay and biomedical explanatory models draw on to understand this comorbidity differ, however, and are not always clear. I found that women, their families, and their healthcare providers were unsure about the ordering of the diabetes-tension dyad and imagined the pathways connecting the two differently. Women conceived of "tension" as a physically destructive force whose consequences linger in the body and, over time, cause degeneration leading to diabetes. Biomedically-oriented healthcare providers usually described hormonal stress pathways leading to insulin insensitivity as the main link between diabetes and distress. Non-biomedical healthcare providers had their own explanations, which sometimes referenced portions of the biomedical model, but departed in significant ways as well.

What we have here appears to be a series of hybrid local and global etiologies of diabetes and distress, in which elements of biomedicine appear and disappear as we toggle between perspectives. As Garro (1988) notes, "A central component of individual models is an intersubjectively shared cultural model for the illness…[which] consists of both cultural knowledge specific to a given illness as well as knowledge about illness in general" (98). In other words, individual explanations for illness are hybrid creatures, consisting of shared models—often multiple models—and individual knowledge. These models may arise from idiosyncratic experiences, popular belief, and expert systems of knowledge, and usually consist of information from all of these sources (Blumhagen 1980).

"Tension" is not only conceived of as a *cause* of diabetes; it can also be an *outcome*. "Now I have tension in my mind because of diabetes. They've given me so many medicines. Because of these medicines I have to urinate frequently, and it makes me feel weak," says one recently diagnosed 65-year-old woman. Other women felt that the alterations they experienced in their physiology due to diabetes (specifically, low blood sugar) created moods they associated with "tension." For instance, one diabetic woman said, "I don't know why, but when I have a low-glucose feeling I have all these [mood] problems. When my sugar goes low, everything goes low." A psychologist who often works with diabetic women explained that diabetes creates additional distress for women who are already stressed by family responsibilities. "They would be like, 'First it was just my husband, then my in-laws, then my children, and I knew it was taking a toll on me, but I didn't know that it would lead to something like this. I didn't realize that I had compromised so badly on my health, and now here I am with a lifelong illness.' They tend to feel that the diagnosis of something like diabetes, or let's say a heart ailment, puts them even more down and out. They're like, 'Oh, that's the last straw.'" Thus, women understand "tension" as a cause of diabetes, but also as an outcome of diabetes.

All nine of the diabetes physicians I worked with noted “tension,” anxiety, and depressive symptoms among the majority of their female diabetic patients; some estimated that as many as 80 percent of their female patients suffered from some degree of depression or anxiety disorder. “They may not vocalize it,” explained one particularly sensitive diabetologist. “They will not say that this is the problem, but you can sense it.” As this physician and others observed, mental health problems among their diabetic female patients were rarely overt and almost never discussed directly. Diabetes sometimes served as a starting point, allowing women to open up to some extent about their stresses. Like Mendenhall and colleagues’ diabetic immigrant informants in America, some physicians observed that women patients “speak through diabetes” (Mendenhall et al. 2010), using the illness as a framework for understanding and expressing underlying psychosocial distress which may not be directly related to diabetes itself. “Avery high proportion has complaints that have nothing to do with their physical ailments, or they've somatized their [distress]. It’s really amazing how common that is. There is a degree of anxiety, or in India they say ‘tension’ and ‘stress,’ that is *really,* really high. I think dealing with chronic disease is a big stress for most people. It's like using chronic disease as a peg to hang all of your problems on.”

The conflation of symptoms that this physician describes as “using chronic disease as a peg to hang all your problems on” is one way in which diabetes and common mental health disorders like depression and anxiety can comingle in individual lives. But from a clinical perspective, there are other important ways in which diabetes and mental health problems interact as well. Diabetes frequently exacerbates mental health problems, and mental health problems reduce compliance to diabetes management routines. People with diabetes have a significantly higher prevalence of depression than their non-diabetic counterparts (Anderson et al. 2001; Egede, Zheng, and Simpson 2002). In my study, higher blood glucose was significantly associated with more symptoms of depression, anxiety, and "tension" when controlling for other factors (see statistical analyses, below). For some physicians, a consistent lack of compliance serves as a "red flag" indicating that a patient may be experiencing significant psychosocial distress. "When we see poor control and lack of discipline over months, we ask a leading question: Is there something that is stopping you from doing your control? By circumventing the issue, sometimes they come to the point and tell us."

Several physicians noted that one of the first realms of life to be affected by depression is their patients' diabetes control behaviors. As these deteriorate, physical and mental health are affected, creating a syndemic positive feedback cycle that augments the seriousness of both conditions (Singer 2009). "The first thing that is affected is diet and exercise discipline, and that triggers poor control. Poor control further worsens the cognitive function a bit, and [triggers] some somatic symptoms. When the somatic symptoms are added with those, the level of mood is further down," observes one diabetologist. This cyclical relationship between diabetes and distress has serious consequences for health and wellbeing (Ciechanowski, Katon, and Russo 2000; DeGroot et al. 2001; Egede, Zheng, and Simpson 2002; Goldney et al. 2004; Katon and Ciechanowski 2002; Katon et al. 2005; Lerman et al. 2009).

In some extreme cases, the treatment for one ailment becomes the tool of the other. Insulin injections oral medications, normally used to treat diabetes, may be strategically deployed by severely depressed women as a method of attempting suicide.

"They know—they have been told—if you take too much insulin or take too much [medication] and don't eat, you can have a diabetic coma, you can have a hypoglycemic coma," explains one senior cardiologist and diabetologist. "Three, four times a year [I see this]. They have a tool with them. They inject 100 units, take 10 sleeping pills, and, actually, that is enough unless somebody intervenes. …If you sort them out, it's very rewarding, but we need the help of antidepressants pretty often. The addition of antidepressants has become much more common in the last few years." Like most other diabetologists with whom I spoke, this physician reported that he often prescribes antidepressants for patients who seem to have intractable compliance problems. He usually finds that the addition of an antidepressant improves his patients' self-care, even if they never disclosed a depression problem. Based on such observations, he assumes (probably correctly) that depression was one key factor impeding their ability to perform diabetes self-care.

Clearly, the relationships between mental health and diabetes are complicated. Both women and their physicians perceived the importance of these relationships for overall health and wellbeing, but they described them somewhat differently. Women considered "tension" and life stress a key cause of their diabetes, and sometimes report that diabetes has increased the "tension" in their lives. Physicians, unsurprisingly, were more concerned with the effects of "tension" and distress on women's lives post-diagnosis, especially on their ability to effectively manage their diabetes.

Diabetes, "tension," and common mental disorders in quantitative perspective

A statistical analysis of mental health trends among the diabetic and non-diabetic study sample helps us explore relationships between “tension,” depression and anxiety, and diabetes. About 45 percent of the total group of 280 diabetic and non-diabetic women reported clinically significant levels of *either* depression or anxiety symptoms, with 26.4 percent (74 individuals) reporting anxiety and 18.2 percent (51 individuals) reporting depression, and 13.6 percent (38 individuals) reporting concurrent clinically significant levels of anxiety and depression symptoms. These levels are somewhat higher than general prevalences of common mental disorders reported for urban populations in India and other parts of the world (Andrande et al. 2000; Patel et al. 1999; Poongothai et al. 2009; Ustun et al. 2004), which tend to range between 10 and 15 percent, although the epidemiological literature on common mental disorders in India is very scant.

Women with more depression or anxiety symptoms consistently reported more “tension” in their lives. This association remained when I separately analyzed the diabetic ($r=0.8$ for depression and $r=0.7$ for anxiety; both $p<0.01$) and non-diabetic ($r=0.7$ for depression and $r=0.8$ for anxiety; both $p<0.01$) groups (Table 6, below). In other words, the idiom of “tension” seemed to behave in women’s lives similarly to depression and anxiety: women who reported more symptoms of “tension” also experienced more symptoms of depression and anxiety.

Table 6. Bivariate correlations between standard depression and anxiety screener scores and “tension” scores for the diabetic and non-diabetic groups.

	Depression	Anxiety
Tension (diabetic)	0.760**	0.727**

Tension (non-diabetic)	0.707**	0.789**

**=p<0.01

Next, I used t-tests to examine the difference in mean scores on the Hopkins Symptoms Checklist (HSCL) depression and anxiety screeners between groups of individuals who endorse or do not endorse a single item on the “tension” scale. All 14 items in the “tension” scale were discriminant in relation to the HSCL anxiety and depression scores; in other words, those who endorsed no experience of a given item on the “tension” scale uniformly scored significantly lower on the HSCL depression measure and the HSCL anxiety measure than those who endorsed the item. The fact that this was true both for the depression and anxiety components of the HSCL suggests that “tension” resembles depression and anxiety equally strongly; as such, “tension” may be a catch-all term that indexes distress experiences that span the sometimes artificial distinction made in clinical psychiatry between depression and anxiety.

Most studies conducted on diabetes and mental health find higher levels of depression among people with diabetes than among the general population (Egede and Ellis 2010; Golden et al. 2008; Mezuk et al. 2008; Renn, Feliciano, and Segal 2011), but this was not the case for the women in my study. Although they did report significantly more symptoms of “tension” than the non-diabetic women, there was no statistically significant difference in levels of depression and anxiety symptoms between the diabetic and non-diabetic groups. In fact, the non-diabetic group consistently reported slightly *higher* levels of anxiety and depression symptoms than the diabetic group (see Table 7, below).

There are several possible explanations for the lack of difference in depression and anxiety between the diabetic and non-diabetic groups. First, it is possible that my depression and anxiety measurement tools did not work properly, although every effort was made during pilot research to ensure their validity and reliability in this cultural and linguistic context (see Appendix). This result might also reflect my sampling methods, which involved recruitment from outpatient clinics where diabetic and non-diabetic groups closely resemble one another on demographic and other variables, perhaps including their mental health status. Third, some women may have intentionally under-reported mental health concerns when they were aware that they were being assessed by a questionnaire, but felt more comfortable discussing distress in an unstructured way. There is ethnographic evidence to support this possibility, as several women expressed discomfort when I conducted formal mental health assessments. One woman stated immediately when I mentioned after the interview that I had done a depression and anxiety screening, "No, no, no, no, nonono, I am not part of that group. I am okay," when in fact she did report clinically significant levels of anxiety. As we saw above, physicians reported that their patients denied having clinical syndromes like depression or anxiety, but at the same time reported serious life stress, often using the word "tension."

Table 7. Comparison of mean mental health scores and proportions of women with clinically significant mental health scores for diabetic and non-diabetic groups.

Mental Health Measures	Mean scores (standard deviation)	
	Diabetic (n=184)	Non-Diabetic (n=96)
HSCL anxiety score	0.86 (0.79)	0.90 (0.72)
HSCL depression score	0.78 (0.64)	0.81 (0.82)

Tension score	0.74 (0.51)	1.0 (1.47)**
Proportion with clinically significant scores		
HSCL anxiety	26.6	26.0
HSCL depression	17.9	18.8
Tension	-	-

**Statistically significant difference between the two groups determined by independent samples t-tests for differences in means; $p<0.05$.

To gain some further insight into the quantitative relationships between diabetes, depression, anxiety, and “tension,” I performed multivariate linear regression analyses. First, an analysis of the entire study group revealed an important differential effect of socioeconomic status on depression for diabetic versus non-diabetic women. The model below (Table 8) accounts for 21.2 percent of the total variance in depression scores among the women in this study, as demonstrated by the r-squared value (also sometimes referred to as the “coefficient of determination”). The adjusted beta values indicate the amount of change we would expect in depression score for every one-unit increase in the given predictor when other variables in the model are held constant. For instance, for every additional stressful life event a woman reports, this model predicts that her depression score would increase by 0.264 points, while every additional child she has would increase her depression score by 0.167 points. Higher socioeconomic status (SES) and education, meanwhile, are protective against depression; a woman belonging to the higher-SES group is expected to have a depression score 0.272 points lower than a woman belonging to the lower-SES group, while a woman with a college degree or higher is expected to have a depression score 0.226 points lower than a woman with less education, when controlling for other factors. Although seemingly small, these differences are relatively large in relation to the narrow range of depression scores, which fall between 0 and 4.8 points. The p values in the table indicate that each of the predictor variables is statistically significant; that is, the relationship observed between the predictor variable and the outcome variable is very unlikely due to chance.

These findings agree with the established literature that demonstrates higher depression in low-SES groups (Lorant et al. 2003), and higher depression among people who have experienced a greater number of stressful life events (Cochrane and Robertson 1973). with lower-SES women being more likely to have depression than higher-SES women. This SES effect could be due to the reduced availability of financial, educational, and social resources to help women maintain resilience against stressful life events in low-SES groups as opposed to their higher-SES counterparts. This finding points to the crucial role of SES in shaping mental health, and suggests that, in this group, depression may be linked to SES through a reduced ability to cope with adversity. Similarly and somewhat paradoxically, having diabetes appears to be protective against depression based on the negative beta value of the diabetes coefficient in the model. This result could be an artifact of the differences between the diabetic and non-diabetic groups; the diabetic group is higher-SES on average.

Table 8. Linear regression model predicting depression for the entire sample of diabetic and non-diabetic women together (n=277).

Predictor Variables	Standardized Beta Coefficients	P-Values
Diabetes Status	-.156	.046
Life Events	.264	.000
Children	.167	.005
SES	-.272	.008
Education	-.226	.001

SES*Diabetes Status	.249	.027

a. Outcome variable=depression score
b. Model adjusted R-squared value=0.212
c. Other predictors considered for inclusion in the model: Religion, age, BMI, body fat percentage, waist-to-hip ratio, blood glucose, years married, family type (joint vs. nuclear), SESxlife events interaction

Indeed, SES is related to mental health in important ways. This model shows that being diabetic differentially impacts a woman's depression score depending on whether she is wealthy or poor, as demonstrated by the statistical significance of an interaction term between socioeconomic status and diabetes status. Figure 11, below, depicts this interaction graphically. As a woman moves from being non-diabetic (0 on the X axis) to diabetic (1 on the X axis), her predicted depression score increases if she belongs to a high-SES group, as shown by the positive slope of the small dashed line toward the bottom of the figure. If she belongs to a low-SES group, however, her predicted depression score *decreases* as she moves from being non-diabetic to being diabetic, as shown by the negative slope of the larger dashed line toward the top of the figure.

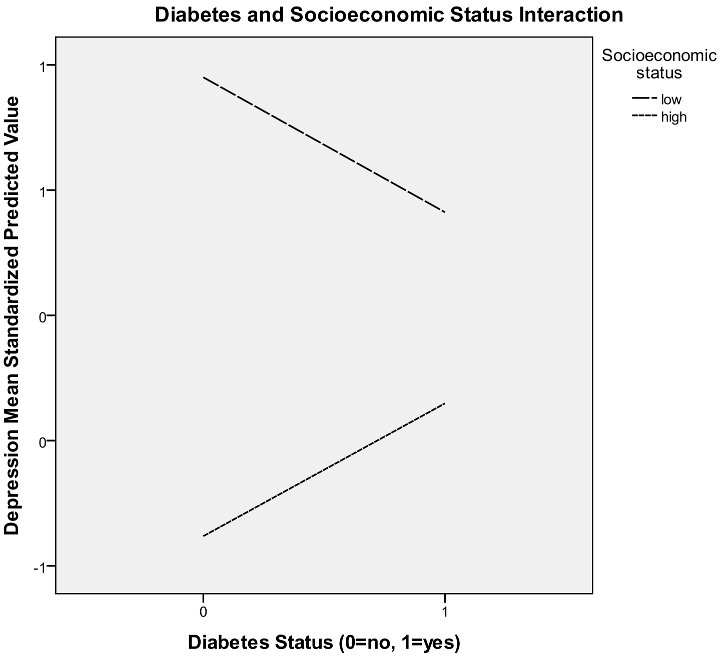

Figure 9. Graph of the relationships between predicted depression score, diabetes status, and socioeconomic status based on a regression model designed to predict depression.

The statistically significant SES variable in the regression model, above, suggests that the difference visible in the slopes of the two lines in Figure 11 is large enough to make SES a significant predictor of depression. An analysis of depression scores by SES group shows that the two extreme groups, the poorest and the richest, have mean depression scores that are significantly different, but the two middle groups, lower-middle-class and upper-middle-class, have similar mean depression scores (Table 9, below). Thus, socioeconomic status appears to matter for depression, but it seems to matter more when we compare the two extreme SES groups (highest and lowest) than it does for the two middle-class groups. This should not be surprising, as we would expect a larger difference between the richest and poorest individuals on most indicators than we would expect between the two more socioeconomically similar middle-class groups.

Table 9. Mean depression scores for the four individual socioeconomic status groups (low, mid-low, mid-high, and high) and t-test results for the differences between the mean depression scores of the lowest versus highest SES groups, and the mid-low versus mid-high groups.

SES Group	N	Mean Depression Score	Std. Deviation	T-test Statistics
Low	59	1.1335	.71659	} F=5.54
High	57	.5486	.54224	p=.020
Mid-low	65	.8786	.80236	} F=1.521
Mid-high	96	.6549	.61600	p=.219

Next, I performed linear regression analyses on data from the diabetic and non-diabetic groups separately. For each group, I constructed three models, one designed to predict depression, one to predict anxiety, and one to predict "tension." These analyses help elucidate which personal characteristics, life circumstances, and physical health outcomes are consistently related to distress among each of the two groups, and are presented in Tables 10 and 11, below. All possible variables were considered for inclusion in each model, but, as in the model above, only significant predictor variables are presented in the final models to facilitate the simplest interpretation possible.

Table 10. Linear regressions predicting depression, anxiety, and "tension" among diabetic women (n=184).

Predictor Variables	Standardized Beta Coefficients	P-Values

Glucose	.151	.010
Disability	.583	.000
Life events	.146	.015
Diabetes Duration	-.217	.000

a. Outcome variable=depression score
b. Model adjusted R-squared value=0.391

Predictor Variables	Standardized Beta Coefficients	P-Values
Glucose	.177	.008
Disability	.410	.000
Age	-.160	.018

a. Outcome variable=anxiety score
b. Model adjusted R-squared value=0.193

Predictor Variables	Standardized Beta Coefficients	P-Values
Glucose	.193	.004
Disability	.440	.000

a. Outcome variable=”tension” score
b. Model adjusted R-squared value=0.218
c. Other predictors considered for inclusion in the models: Religion, age, BMI, body fat percentage, waist-to-hip ratio, years married, family type (joint vs. nuclear), insulin dependent, SESxdisability interaction, SESxlife events interaction.

Notice that blood glucose and disability due to diabetes are significant predictors of all three mental health outcomes among diabetic women, while in addition, life events and diabetes duration predict depression, and age predicts anxiety.

First I will discuss the trends that hold across all three regression models. Women with higher blood glucose values are likely to report more symptoms of depression, anxiety, or “tension,” as are women who report more disability in daily life. Blood sugar and disability are two markers of diabetes control and severity. These findings agree with the established literature demonstrating that diabetic people with less controlled or more advanced diabetes have greater prevalence, or risk of developing, depression (Almawi et al. 2008; Anderson et al. 2001; Egede and Ellis 2010; Egede et al. 2002; Golden et al. 2008; Mezuk et al. 2008; Pan et al. 2010; Talbot and Nouwen 2000). The findings presented here also augment the existing literature by demonstrating that in addition to depression, other forms of distress (in this case, anxiety and “tension”) are related to diabetes severity in a dose-response manner. This is an important insight because depression is only one of many ways in which an individual may experience distress, yet studies of comorbid diabetes and mental ill health have almost exclusively focused on depression.

Now we will examine the predictors that are inconsistently related to mental health outcomes across all three regression models. The model predicting depression, for instance, shows that for every additional stressful life event a diabetic woman reported in the last year, her depression score is expected to increase by 0.146 points. This observed association is consistent with literature that demonstrates higher depression among people who have recently experienced stressful life events (Cochrane and Robertson 1973).

Diabetes duration is also related to depression, but not in the direction one might anticipate. Although one might expect risk of depression to increase with diabetes duration, in this study, women diagnosed with diabetes more recently are more likely to report depression symptoms than those who have had diabetes for a longer time, as evidenced by the negative beta coefficient for diabetes duration in the model. This could reflect the strains associated with the initial shock of a chronic disease diagnosis. Ethnographic work on chronic diseases supports the idea that recently-diagnosed chronic disease sufferers, while perhaps less heavily burdened by physical complications associated with long-term illness, must cope with a front-loaded burden of emotional, identity, and illness work (Corbin and Strauss 1985). This work involves, among other things, learning to manage the illness on an everyday basis, refiguring one's identity and social roles surrounding the diagnosis, and adjusting to strong emotional responses to the illness (Becker 1997; Charmaz 1991; Corbin and Strauss 1985; Crooks 2007; Estroff 1993; Murphy 1987). The qualitative results of this chapter also demonstrated that women report high levels of "tension" around the time of their diabetes diagnosis.

When we further disaggregate the diabetic group into women diagnosed with diabetes two or more years prior to their participation in the study versus women diagnosed less than two years ago, there are significant differences in anxiety and "tension" scores between the two groups (refer back to Table 2, Introduction). Nearly 40 percent of newly diagnosed women report clinically significant levels of anxiety symptoms, while about 23 percent of those diagnosed longer ago report such levels. This early-stage emotional upheaval thus seems to manifest in symptoms of depression, anxiety, and tension, depending on the way the population is divided and on the analyses used.

In addition, younger diabetic women generally reported more anxiety; the regression model predicting anxiety shows that for every year a woman ages, her anxiety score should decrease by approximately 0.16 points. Younger diabetic women are more likely to have been diagnosed recently than are older diabetic women, so this result may simply be reflecting the early-stage distress discussed above. Yet younger adulthood—which, in my sample of adults, would mean being in one's late 20s, 30s, or 40s, as opposed to one's 50s or 60s—is indeed a stressful phase of life for many Indian women. During this period, women are often adjusting to the demands of living with their in-laws after marriage, raising young children of their own, as well as caring for their aging parents-in-law and managing a household with or without domestic help. Older age, in contrast, is a more restful time for many women, especially those belonging to the middle and upper classes, whose daughters-in-law traditionally take over household maintenance, allowing them to "retire" in a sense (Lamb 2000; Shrinivas 1989; Vatuk 1990, 1995).

The relationship between age and anxiety did not hold for non-diabetic women, however, suggesting that stressful life events may be especially difficult for younger women to cope with *on top of having diabetes*.

In general, the models predicting mental ill health among diabetic women illustrate that common mental disorders are related to diabetes control and duration of diabetes, as well as to other (non-diabetes-related) stressful life events.

Table 11. Linear regressions predicting depression, anxiety, and "tension" among non-diabetic women (n=96).

Predictor Variables	Standardized Beta Coefficients	P-Values
Life events	.286	.002
Education	-.492	.000

a. Outcome variable=depression score
b. Model adjusted R-squared value=0.287

Predictor Variables	Standardized Beta Coefficients	P-Values
Life Events	.268	.001
Education	-.460	.000
No. children	.197	.032
Body Fat	-.197	.018

a. Outcome variable=anxiety score
b. Model adjusted R-squared value=0.394

Predictor Variables	Standardized Beta Coefficients	P-Values
Body Fat	-.420	.001
WHR	.321	.008
Age	-.233	.017

a. Outcome variable="tension" score
b. Model adjusted R-squared value=0.160
c. Other predictors considered for inclusion in the models: Religion, BMI, years married, family type (joint vs. nuclear), SES*life events interaction

Among non-diabetic women, there were no consistent trends that held across all mental health outcomes, but there was more similarity between depression and anxiety models than there were between the others. Depression and anxiety models shared two common predictors: level of education and stressful life events. As was the case with diabetic women, greater occurrence of stressful life events was related to greater depression or anxiety among non-diabetic women, and to a similar magnitude. In each case, every additional stressful life event predicted an approximate 0.30-point increase in depression or anxiety score. In contrast, education was protective against anxiety or depression, in both models predicting a decrease of nearly 0.50 points on the mental health outcome for women holding a B.A. degree or above. This finding is somewhat concordant with the literature that demonstrates higher depression in low-SES groups (Lorant et al. 2003), since SES is intimately related with education in North India. It is, however, also surprising in this particular cultural context because women higher levels of education are more likely to be exposed to biomedical diagnostic categories like anxiety and depression, which are just beginning to become part of public knowledge in North India. While the wealthier women were certainly the only ones in my study who voluntarily mentioned words like “depression” in their discussions with me (as noted above), these statistical analyses suggest that the lower-SES groups are the ones who actually suffer from higher levels of anxiety and depression. As a result of the low number of psychiatrists in North India and inequitable access to healthcare, however, the poorer groups are least likely to seek or receive treatment for these common mental health disorders.

The model predicting anxiety includes two other significant predictors. First, women with more children were more likely to have anxiety, with a predicted 0.197-point increase in anxiety score for every additional child. This should not be surprising, since each additional child represents a set of long-term responsibilities which a woman must juggle. It may also be true that women with more children specifically have more *daughters*, since many couples continue having children until they bear a son in this cultural context, which highly values having sons. The widespread practice of dowry, and its astronomical associated costs, means that multiple daughters can create serious financial strain on a family.

Second, non-diabetic women with higher body fat percentages reported fewer symptoms of anxiety and less life “tension.” Higher body fat appears to be especially protective against “tension,” generating a 0.420-point decrease in “tension” score for each additional percentage point of body fat as opposed to a 0.197-point decrease for anxiety. This protective effect could be partially related to socioeconomic and educational status, which in my sample tended to be higher among heavier women. Waist-hip ratio, however, predicted higher “tension” scores, suggesting that a larger accumulation of abdominal fat specifically is related to more life “tension,” even when overall body fat is not. Well-established literature suggests that stress hormones such as cortisol and adrenaline trigger the preferential storage of abdominal fat in the body (Bjorntorp 2001; Rosmond 2007); this mechanism could underlay the association observed in this study between waist-hip ratio and “tension.”

The three models predicting mental ill health among non-diabetic women were more heterogeneous than the models for diabetic women, possibly reflecting the greater presumed differences between members of the general population as opposed to members of a subgroup with a particular illness, who are likely to share some characteristics.

To summarize the results of these seven regression models, socioeconomic status appears to matter for mental health among North Indian women, but only through the intermediary of diabetes, and only specifically for depression outcomes (not for anxiety or "tension"). When the diabetic and non-diabetic groups are analyzed together, there is a significant interaction between diabetes status and socioeconomic status that predicts depression (refer back to Figure 11). This indicates that low-SES women are expected to experience increased depression as they move from non-diabetic to diabetic groups, while the reverse is true for higher-SES women.

When the diabetic and non-diabetic groups are analyzed separately, SES is not independently related to any mental health outcome. Instead, education matters for non-diabetic women's levels of depression and anxiety. As I noted above, SES and education are intimately related in North India as they are in many parts of the world, so for the non-diabetic group, education may be serving roughly the same predictive "function" as SES might in other models. It is noteworthy, however, that both education and SES were considered for inclusion in each model, and only education emerged as a significant predictor of mental health; and that too only among non-diabetic groups.

Additionally, it should be noted that all of the statistical models presented above are limited. While the two models predicting depression among diabetic women and anxiety among non-diabetic women explained about 40 percent of the total variance in the outcome variables, most of the other models explained no more than 20 percent.[23] These relatively low R-squared values are not uncommon for ecological studies such as this one, but they do suggest that there are significant sources of variation in mental health not accounted for by these models. This fact underscores the limitations of statistical analysis, lending support to my and other mixed-methods social scientists' claims that statistical work should be complemented with careful ethnography to help identify variables not measured quantitatively. For instance, family relationships and stigma surrounding mental illness appear to be very important factors shaping women's identification, experience, and management of common mental health disorders based on the qualitative work presented in the first half of this chapter. It was not possible to measure these variables quantitatively in the present study, so their influences are missing from the statistical models.

Equally important in these regression models are variables measured but not found to be significantly related to mental health. These "negative" results supply information about the relationships in question. For instance, duration of diabetes, education, family type (joint or nuclear), religion, and insulin dependence were all considered for inclusion in each model, but did not have statistically significant predictive power for the mental health outcomes, so were not included in the final models. I also looked for possible interaction effects between socioeconomic status and life events, SES and disability, and SES and diabetes status, none of which were significant. The lack of significant SES interactions suggests that the variables in question affect all socioeconomic groups with diabetes roughly equally; stressful life

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[23] The adjusted R-squared value for each model provides this information.

events are no “more” distressing for a lower-class diabetic woman than for an upper-class diabetic woman in this study. The fact that diabetes control (glucose or HbA1c) was inconsistently and often weakly related to mental health, but that women’s ability to function in important roles (“disability”) was a consistent and strong predictor of mental health status, supports the ethnographic observations made earlier in this chapter that suggest that the most relevant measure of diabetes’ impact on women’s lives is not their blood sugar numbers, but is their ability or inability to perform important daily functions.

Conclusion: Distress and Diabetes

This chapter investigated women’s perceptions of the relationship between distress and diabetes. As we saw in Chapter 2, distress was the single most common cause women perceived for their diabetes, and they often used the expression “tension” to describe this distress. Over a third of the women in this study reported developing diabetes during a period of unusually high levels of “tension” surrounding the death of a family member, a difficult life transition, or another similar event. On the heels of that observation, this chapter explored the meanings and uses of “tension” in North India, especially as it compares to biomedical depression and anxiety. In addition to a general exploration of its function, it examined women’s and physicians’ perceptions of the relationships between diabetes, “tension,” and mental health using both ethnographic and quantitative data. I concluded that “tension” appears to be related both to depression and anxiety, and represents a “blended” syndrome consisting of symptoms of both.

The exceedingly common use of the euphemistic term “tension” to communicate distress and to explain physical illnesses like diabetes underscores how it functions as a culturally-acceptable way of discussing distress in North India. It also, however, suggests a degree of culturally-sanctioned ambivalence about expressing distress, which is likely related to the stigma surrounding mental disorders in India and the widely-held belief that women should not complain. Because the language of depression is not a culturally-appropriate way for North Indian women to talk about distress, “tension” seems to function as one non-stigmatizing alternative. Psychological anthropologists have named this kind of expression an “idiom of distress” (Nichter 1981). Women may tactically communicate in this way because they desire to leave some protective ambiguity surrounding their distress and its causes, but at the same time, words like “tension” allow them to disclose some minimal information about distress.

The causes and consequences of “tension” in women’s lives are so diverse that it is a nearly impossible, and would be reductionistic, to isolate a single operational definition of the expression. Instead, Charmaz’s (1991) continuum model, introduced in Chapter 2, is a more appropriate way to conceive of “tension.” Women use “tension” to talk about a continuum of distressing emotions, ranging from irritation over everyday hassles to serious, long-term depression or anxiety. In statistical analyses, however, women’s “tension” was strongly associated with clinical depression and anxiety, as well as with their blood sugar. This suggests that we can consider “tension” an important indicator of mental health as well as physical health for women with diabetes. This finding substantiates what the physicians I worked with already know—that a patient’s mention of “tension” may have far-reaching consequences for their physical and mental health, and should not be taken lightly.

Although women with diabetes did not report statistically *more* depression or anxiety than women without diabetes, they did report more "tension." Furthermore, diabetic women who reported more "tension" had higher blood glucose levels, indicating poorer diabetes management among distressed individuals. This suggests that even low-to-moderate levels of distress resembling those in a general population may adversely affect diabetic women's health. Diabetes physicians, too, agree that women's distress significantly impairs their ability to manage their chronic diseases.

Socioeconomic status also seems to be an important mediator of the relationships between mental health and diabetes. Low-SES women who get diabetes are much more likely to suffer from depression than high-SES women who get diabetes, according to the predictions made by a depression regression model for the entire sample. This finding could also explain why, as a whole, the diabetic group in this study does not display more signs of mental ill health, on average, than the non-diabetic group, since the diabetic sub-sample was generally wealthier.

This chapter has accomplished two things. First, it has illustrated the breadth and depth of one particular expression of distress in North India, "tension." Second, it has examined how that expression—used almost exclusively to talk about mental distress—becomes implicated not only in women's explanatory models of their physical health problems, but also gets reflected in measurable health outcomes, such as blood sugar and depression symptoms. Overall, these findings underscore the importance of paying close attention to indirect ways of expressing distress, both for clinical purposes and for academic investigations of cross-cultural psychiatry.

CHAPTER 4: DOMESTICITY AND DISABILITY

DIABETES MANAGEMENT AND DAILY LIFE

Sita awakens at 6:00 every morning and gulps a cup of hot, milky-sweet chai before walking to her employers' large house to begin her domestic workday. Several times a day, she makes the 15-minute walk between her one-room servant quarters and her employers' house. She must leave extra early because in between her morning duties, she must also prepare breakfast and lunch for her husband and children before they leave home, and walk back to give it to them. She does not finish her workday until after her employers have eaten dinner and she has cleaned it up, around 9:00 in the evening. Although she is thin, frail, and exhausted from her uncontrolled blood sugar, Sita has no time to eat properly or get adequate sleep. She keeps drinking sweet tea throughout the day to maintain her energy, often skipping lunch because she is so busy with house work that she does not find the time to sit down and have a meal. Sita avoids going to the doctor even when she is sick because her family and her employers cannot manage without her. For example, she reflected on a two-week bout of illness so severe that it left her bedridden, "I didn't want to go to the doctor; if I went to the hospital they would admit me. Then who would do the housework? Who would be there for my children, to make their breakfast before school? I make our food in the *kothi* kitchen because we don't have our own kitchen, but my children aren't allowed inside. I have to go there to make food for them, to make everything they need." She suffers from severe depression and "tension," to the point that she sometimes contemplates suicide because she sees no other way out of the burden of responsibility she bears for both her and her employers' families.

More than almost any other chronic disease, type 2 diabetes requires intensive management, which frequently interferes with other responsibilities and life routines. This chapter is about what Indian women with diabetes do and do not do to manage their illness on a daily basis, what motivates these decisions, and how these illness management activities interface with the rest of their lives. Specifically, we will focus on the extent to which diabetes does or does not impinge on women's daily routines, and what personal characteristics and management efforts are associated with being able or unable to continue a daily routine unaffected by diabetes.

Diabetes management differs for every individual based on the severity of their illness, the types of medication they are taking (oral medicines, versus injected insulin), their age, weight, other illnesses, and so on. However, there are similarities across all cases. Globally accepted diabetes management standards recommend that individuals regularly monitor their blood sugar at home using a hand-held glucometer device that accepts a small drop of blood from a fingertip stick. Some people are instructed to monitor their glucose multiple times every day, as is usually recommended in the USA, while some women in my study were instructed to do so only once a week or even less frequently. People with diabetes are also expected to attend regular health checkups to monitor their HbA1c, lipids, urine ketones, and other parameters, usually every three months. Most people with diabetes take medications at least once a day, though usually more frequently, and some inject insulin one or more times per day as well. Guidelines further recommend that people with diabetes reduce or eliminate sweets, simple carbohydrates, fats, and some fruits from their diets, and in some cases restrict calories to avoid gaining weight or to lose weight. Finally, people with diabetes should get daily exercise.

Self-management of a chronic illness requires a lot of work. Corbin and Strauss (1985), in a landmark publication, identified “three lines of work” associated with the management of chronic illnesses at home. These include illness work, biographical work, and everyday life work. Illness work refers to tasks involved in management and prevention of symptoms, such as adherence to medication and exercise routines, dietary control, getting proper sleep, and making sure to refill medication prescriptions before they run out. Biographical work refers to the emotional and logistical work surrounding the rebuilding of identity, regaining a sense of everyday normalcy, and imagining and preparing for an altered future that often comes with a chronic disease diagnosis. Finally, everyday life work is everything involved in keeping a household going, such as housecleaning, childcare, eating and food preparation, marital and sentimental work. In North India and many other parts of the world, the majority of this everyday life work is performed by one individual, usually a junior (but adult) female. This is increasingly true as urban Indian families transform from a joint family to a nuclear family arrangement. When such an individual receives a chronic illness diagnosis, she must suddenly add illness work and biographical work to her already heavy burden of everyday life work. Corbin and Strauss (1985) point out how changes in any one stream of work have a reciprocal impact in the other streams, but everyday life work is rarely redistributed when a woman receives a type 2 diabetes diagnosis, unless she has the financial resources to hire household help. The resulting tension can be imagined as a "tug-of-war between the requisites of [illness] trajectory management and those of everyday life and biography" (Corbin and Strauss 1985: 233), a tension that is very salient for the women in this study.

Studies conducted at various sites in India suggest that a large percentage of diabetic Indians do not maintain good blood sugar control (Bjork et al. 2003; Joshi et al. 2008; Nagpal and Bhartia 2006; Raheja et al. 2001; Rayappa et al. 1999; Venkataraman, Kannan, and Mohan 2009), but many women I spoke with kept their blood sugar in check and were able to live lives minimally affected by the disease. Others did indeed maintain poor glucose control and felt that their diabetes had interfered with, or even ruined, their lives. This chapter explores both extremes and asks what predisposes an individual toward one path or the other. It sets the stage for Chapters 5 and 6, which will explore in detail what cultural and personal characteristics are associated with vulnerability to diabetes complications.

The concept of control and its associated moral judgments of "good" versus "bad" behavior—in terms of diet choices, time management, exercise, and blood sugar itself—looms large in biomedical models of diabetes care (Broom and Whittaker 2003; Ferzacca 2000; Feudtner 2003; Naemiratch and Manderson 2006). Moralistic approaches to diabetes control have been deeply entrenched in biomedicine since the paradigmatic work of Elliot Joslin, a pioneer in diabetes care who began his work in America at the turn of the 20th century (Feudtner 2003). The biological fact that blood sugar is extremely sensitive to daily, hourly, and moment-to-moment physiological changes creates challenges specific to people with diabetes. One key challenge is reconciling the need to maintain blood sugar control with the desire to lead a relatively normal lifestyle. Unlike those suffering from heart diseases or other chronic health conditions, people with diabetes bear the heavy responsibility of perpetually monitoring their diets, medications, and exercise to attain good blood sugar control.

Dr. Gupta, a diabetes physician who has devoted his career to innovative treatment strategies for Indians with chronic diseases, once asked me, “Why would a perfectly intelligent, aware, educated person not follow things when he knows that *not* following them is gonna harm him?” He answered his own question, “It's not out of real [hedonistic] pleasure. I think it is about the feeling of restriction that the disease brings. It's a feeling that I'm being told what to do, and I have to control it. That’s very irritating for people.” As Dr. Gupta’s statement implies, people’s health maintenance choices are often interpreted through the moral discourse of choosing to “cheat” (or not) on guidelines. Ironically, as he points out, people may sometimes choose to exercise autonomy and self-control over their lives by *not* controlling diabetes. He suggests, as an alternative, that instead of judging behaviors as “good” or “bad,” we have to dig deeper to understand why it is so difficult to follow diabetes management guidelines when the consequences of letting them lapse are potentially so grave.

Judgment about what constitutes “good” versus “bad” blood sugar in diabetes originates primarily from biomedicine, which establishes blood sugar control guidelines and characterizes chronic diseases as self-induced “lifestyle” diseases. Categories of “bad blood” are also often thought to be responsible illnesses with moral and stigmatizing connotations, such as leprosy (Barkataki, Kumar, and Rao 2006; Barrett 2005). As we saw in Chapter 2, people with diabetes in India and in other parts of the world may consciously or unconsciously resist this dominant discourse of blame by preferentially naming causes for their illnesses that deflect blame away from themselves (Broom and Whittaker 2003). This morally-charged attitude toward diabetes management gets transferred by physicians to their diabetic patients when they talk about their illness management, but it also permeates lay conceptions of chronic diseases, diet, and activity patterns (Broom and Whittaker 2003; Ferzacca 2004).

Some of the healthcare providers with whom I worked in Delhi use blame strategically to encourage better blood sugar control among their patients, threatening them with the complications that might ensue if they fail to adhere to their diets, exercise, and medication routines. However, this strategy often has unintended negative consequences. Several women I worked with reported putting off their regular diabetes health checkups when they had not been adhering to their diets because they did not want to be "shouted at" by their doctors. Similar phenomena have been noted by other medical anthropologists, whose diabetic informants avoid checkups, or manipulate their medication or diets to improve outcomes just prior to checkups to avoid being chastised by their healthcare providers (Broom and Whittaker 2003).

The idea of "scaring" patients into better compliance, although often ineffective, is a defensible action, in light of the potential seriousness of diabetes complications. If "good"[24] blood sugar control is maintained, the payoff may be large; people with well-managed diabetes can delay or completely prevent most complications associated with

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[24] Here and throughout this chapter I borrow the biomedical definition of "good" blood sugar control, which is understood to be "better" the closer it resembles levels seen in non-diabetic individuals.

the illness. On the other hand, people with chronically “bad”[25] blood sugar control can face serious, disabling complications including loss of feeling in the hands and feet due to nerve damage (neuropathy), wounds that will not heal, weak vision and eventual blindness, the loss of limbs due to infections, kidney damage (nephropathy), and diabetic coma, which may be fatal. Underpinning much of the moralized discourse of “good” and “bad” diabetes control is the fundamental dichotomy of life (good) versus death (bad), a key tenet of the biomedical values system, and one that casts illness as a form of social deviance to be corrected by medical intervention (Parsons 1951; Sontag 1978; Williams 1993). This moral dichotomy also runs deep in many Indian societies, where Hindu moralities of good and bad actions determine one’s path after death and are believed to drive a good or bad rebirth.

These stark dichotomies between good and bad, life and death, and social compliance versus social deviance do not represent how women experience diabetes on a daily basis. Nor do they accurately reflect how women perceive and manage risk surrounding their illness (Morden, Jinks, and Ong 2011). Sometimes the choices women make to compromise their health are indeed motivated by “bad” (i.e., noncompliant) desires to indulge in prohibited foods or engage in health-harming behaviors they feel entitled to by force of habit. But for many, a lack of compliance comes about because nonnegotiable responsibilities outside or inside the home interfere with diabetes management, and vice versa: diabetes management interferes with people’s other duties. Like tobacco use, the delayed and often invisible consequences of poor diabetes management make it difficult for people to cognitively link cause and effect (Odum,

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[25] I also borrow the biomedical definition of “bad” blood sugar control, which is understood to be “worse” the more it exceeds low and high boundaries seen in non-diabetic individuals.

Madden, and Bickel 2002). Under such conditions, the expectation of compliance to major lifestyle changes is perhaps unrealistic; it is simply too easy to forget that the larger struggle for a healthy life underpins mundane behavioral choices about food and exercise. Chris Feudtner, a critical medical scholar, asks, "How should we think or feel about a remarkable medical achievement that gives with one hand and, years later, takes away with the other?" (2003: 195). Physicians' use of blame, guilt, and accusatory discourses of self-indulgence to encourage compliance falls on fallow ground in such cases, especially when women lack the freedom to refigure their larger responsibilities around their health needs.

"Bad" Diabetes Management and Daily Life: Two Case Studies

Manjot, age 62, diagnosed 12 years ago, glucose 243 mg/dL, HbA1c 10.0%,[26]*CRP 12.4 mg/L, EBV 224.7 ELISA units*

Manjot, a wealthy Punjabi widow, is furious. She insists that she follows her diabetes management guidelines strictly, yet her blood sugar remains inexplicably high. It causes her serious anxiety. "Look, I am highly educated," she begins, underscoring that she is not suffering with her diabetes due to lack of awareness about its seriousness.

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[26] Recall the relevant cutoffs for blood biomarkers:

Biomarker	"Healthy" value or relevant cutoff
Blood glucose	Should remain between 70-180 mg/dL
HbA1c	Should be < 7.0%
C-reactive protein (CRP)	"High" is above 3.2 mg/L (highest quartile)
Epstein-Barr virus antibodies (EBV)	"High" is above 178.9 ELISA units (highest quartile)

“My sugar is always high, and every day I feel that maybe this is the last day I will live.” Manjot’s HbA1c blood test was 10.0 percent, indicating that in the previous three months her blood sugar had fluctuated well beyond healthy levels. Her CRP and EBV levels are both extremely elevated, speaking to the high degree of chronic physical and psychosocial stress she experiences. She describes a rigid schedule which, much to her frustration, does not translate into rigidly controlled blood sugar, and in fact her frustration itself probably contributes to her elevated stress biomarkers. When I ask her about her daily routine, she says in well-polished English,

> I get up, do meditation, and remember my God who has given me life. I supervise the gardener who comes. I roam around the lawn for an hour or an hour and a half. Then I come back to my room, I take a cup of milk and one slice [of bread]. After that I take so many medicines, and insulin. My latest fear is whenever I put my blood in the glucometer; my heart beats fast. I am more scared of it than anything else in my life because I don't know what to do. I get depressed when I see my fasting glucose. What do I eat in the evening? One *chappati* [flat bread], then 3 tablets, and how can my sugar go so high? It comes so high, and I can't ignore it being so high right in front of me like that. I try to divert myself by listening to music, singing, or watching TV. Then, when I call my daughter to check my blood sugar, she asks me why it's so high. …She says, what did I eat? And she starts fighting with me about it. …She starts shouting at me, like what did I eat? Am I the enemy of myself? I don't want my blood sugar to be so alarmingly high. I feel bad that my youngest child is so stressed because of me. I'm tired of this illness! In the morning I get up and say to God, "You've made such a big world, you've made everything. But I don't want this illness." I get very angry.

Manjot works hard in this statement to make it clear that she is not to blame for her poor diabetes control by emphasizing how little she eats and how much medicine she takes. Her defensive stance suggests that this is a sensitive subject for her, and it is clearly one that has created conflict in her family. It also creates existential conflicts for her; she describes feeling that both God and her own body have betrayed her. These strains contribute to her clinically significant levels of depression and anxiety symptoms, which are quite significant (HSCL depression=1.6; anxiety=2.5). Her depression and anxiety themselves likely exacerbate her blood sugar through biochemical pathways that link stress and the body's reactivity to insulin (Bjorntorp, Holm, and Rosmond 1999; Lustman and Clouse 2007; Talbot and Nouwen 2000). In fact, Manjot's distress could be the primary cause of her inexplicably uncontrolled blood sugar despite her adherence to her diabetes management routines. She and her daughter both suspect that this is the case.

Manjot's lifeworld has shrunk as her efforts to attain control of her diabetes have grown. What medical anthropologist Valerie Crooks (2007) refers to as Manjot's "daily geography"—that is, the extent to which she ventures out of her house over both space and time—has diminished until it is confined primarily to her house and the small yard surrounding it. Such spatial shrinking is also common among Crooks's informants with fibromyalgia, who were sometimes forced to quit jobs and give up activities they loved because of their chronic pain. Similarly, although Manjot used to work in an office as the head of an NGO that provided marriage counseling, children's education, and conflict resolution to disadvantaged groups in the surrounding area, she slowly reduced her participation in that organization as her health deteriorated, until she no longer went there at all. She avoids social functions because she feels that they exhaust her already weak body. Although she walked for exercise in the past, Manjot can no longer manage any exercise besides "roaming around" her garden in the morning because of knee problems; as a result, she remains very obese (BMI: 35). Although she is certainly not the only person I worked with who limited her activities after getting diabetes, Manjot's extreme isolation was unusual among my informants, many of whom lived in extended families and maintained social relationships despite having diabetes.

Manjot's life has clearly been deeply disrupted by chronic illnesses. Her disjointed description of her daily routine alternates between a list-like account of her morning activities (supervising the gardener, etc.) and an emotionally-charged statement about her fears surrounding her blood sugar, returns to a dispassionate enumeration of the activities she engages in to entertain herself over the course of the day (music, TV, etc.), and finally ends with another emotional expression of frustration over the conflicts that diabetes creates with her daughter and with God. The interweaving of dispassionate description and emotional outpouring is, as I learned after meeting her several times, part of Manjot's general style of communication, but based on the severity of her anxiety symptoms, I also believe that it hints at the depth of distress she experiences because of her uncontrolled diabetes. The disjointed nature of Manjot's narrative speaks to the larger disruptions that chronic diseases have created in her life, both in the short-term and in the bigger picture of what she can expect from life as she ages (Becker 1997; Charmaz 1991).

The relationship between sociality and health is not unidirectional, but rather cyclical; Manjot's daily geography has become confined both as a cause and a consequence of her diabetes, its symptoms, and her concurrent anxiety. She has isolated herself more as her health declines, with the result that she has gained weight, felt sicker, had more trouble controlling her diabetes, and thus experienced increasingly severe symptoms of anxiety. In response to her anxiety and physical illness, she has further isolated herself until she has reached the point where she rarely leaves home at all. But what happens when a woman with uncontrolled diabetes lacks the financial security to hire domestic workers to take care of her household and office workers to take care of her job outside the home?

Sita, age 40, diagnosed 8 years ago, glucose 280 mg/dL, HbA1c >13.0%, CRP 0.30 mg/L, EBV 72.1 ELISA units

Sita, whose daily routine opened this chapter, was orphaned as a young girl in the state of Orissa, where some of India's lowest-paid migrant workers originate. Just after her parents' death in a vehicle accident, a goods trader came from a nearby town, took Sita and her infant sister out of the village, and enrolled them in a Christian missionary orphanage in the state capitol. Sita's sister died shortly thereafter from severe jaundice, but Sita studied at the orphanage until the fifth class and was eventually transferred to the main branch in New Delhi. When she was 19, the orphanage arranged her marriage to a young man who was also their ward, and within five years they had a son and a daughter.

Now 40 years old, Sita is an extremely thin (BMI 18.9), wiry woman whose colorful polyester saris practically hang off of her. She works full-time as a cook and maid in a large *kothi*, or wealthy estate, in central New Delhi. Her husband is also employed at the *kothi*, and the owners give her family a small room to live in along with a meager salary. Although they would like to find more lucrative jobs, Sita worries about losing their servant quarter in expensive New Delhi, and besides, her husband has been working there since he was a child. Their finances are especially stretched by the high cost of the after-school tuitions that her children attend, like many others in urban India, in order to excel in the country's increasingly competitive educational and employment systems.

Sita's financially insecure family depends on her income as a domestic worker. Despite her physical illness, Sita maintains the work schedule that was described at the start of this chapter. Sita feels the strain of the dual dependence of her family and her employers' family, and told me, crying, that she just wants to die sometimes. She reports very high levels of "tension" and her scores on the depression and anxiety questionnaire indicate a very significant level of depression (HSCL depression=2.4). However, her CRP and EBV levels are lower than I expected based on her life stress and poor diabetes control, and in fact fall within normal range. This suggests that, at least until this point, she does not face elevated risk of cardiovascular diseases or an overly stressed immune system.

Because Sita bears the dual responsibility of managing her own family and her employers' family, her schedule has no slack to accommodate her diabetes management. A determined woman, Sita describes the single-minded focus with which she attends to her work in the *kothi*. "When I'm working, I don't pay attention to the time, so I don't eat on time. Sometimes I don't eat anything till 4. When I'm free, then I eat. …I don't think about [my health]. I just want a house, nothing else, so that my children can be well settled." Sita considers this dream of obtaining secure housing for her children the primary purpose of her life, and this serious need understandably detracts from the attention she pays to her own health. Sita's poorly controlled blood sugar (HbA1c >13%, so high that it exceeded the capacity of my measurement device) interferes with her daily routines and makes the completion of her job difficult because she feels so unwell most of the time. She explains,

> As I did it [house cleaning] before, I can't do anymore. I don't feel like getting up in the morning. After 2005 I couldn't even lift [my left arm] up to comb my hair. I did some exercises and then my blood sugar went down and I was able to move it a little more. Then after two more years, the same thing happened to my other arm. ...At that time I had a lot of trouble doing laundry because of diabetes and these hand problems. ...[Nowadays] After I do some work, I have to sit down for a little while. I did everything before, but now I don't feel like doing anything. Everything I do, I have to force myself to do.

We began this case study by asking how a diabetic woman with poor illness management copes when she lacks resources like Manjot's to compensate for the work she cannot do herself. Based on Sita's experience and similar ones among other women, including Rita, the middle class woman we met in the previous chapter, the answer seems to be that one simply makes do. In an effort to fulfill social roles expected of them as wives and mothers, Rita, Sita, and others like her engage in "quiet suffering," prioritizing the care of others over their own self-care. Sita simply does not have the option of delegating household work to other people, as Manjot has. Adjustments like slowing the pace of work and enlisting another family member to help with household upkeep compensate partially for the disability such women experience because of diabetes, but these adjustments take a toll on other family members and on these women's ability to participate in work roles that they and their cohabitants expect of them.

The theme of control is much less prominent in Sita's narrative than in Manjot's. With her limited finances, limited time, and limited health resources, Sita cannot maintain control of her blood sugar and in fact makes very little explicit effort to do so. While Manjot attends a well-reputed private diabetes clinics in Delhi, where she pays Rs.

500 per consultation and receives one-on-one instruction about diabetes management from her doctor, Sita goes to a charitable clinic where she pays Rs. 20 for a consultation, which affords her very little time to talk to the doctor, much less obtain diabetes education. Lines at the charitable clinic are often long, requiring her to wait for an hour or more and taking important time away from her family and her job. As a result, Sita takes medicines only when she can afford them, does not eat at regular times, avoids the doctor, does not monitor her blood sugar, and does not take time off of work unless she is physically unable to get out of bed. It is almost as if she has resigned herself to the impossibility of managing her health along with her other responsibilities. Although she has to "force herself" to do everything, she maintains an active life motivated by her desire to buy a house for her children. This theme recurs throughout Sita's life story and serves as an overarching explanatory model for most of her daily activities.

As we saw earlier, Manjot makes many efforts to manage her diabetes, including following a diabetic diet, taking pills and insulin religiously, and monitoring her blood sugar at home. She is largely consumed by these efforts, which frame the way she describes her daily routine. Much like Sita's dream of buying a house, Manjot's efforts to control her diabetes frame her narrative and provide the impetus for many of her daily activities. Despite maintaining a time- and space-controlled daily routine, blood sugar control eludes Manjot and creates major frustration in her life. Her sugar is nearly as uncontrolled as Sita's (recall that Manjot's HbA1c is 10.0 percent, while Sita's is >13.0 percent). Both women have experienced serious episodes of ill health because of diabetes, as well as complications such as neuropathy and body pain.

Manjot and Sita report high levels of disability in their daily routines, which they attribute to their diabetes, but their equally high symptoms of anxiety and depression (respectively) also likely contribute to their disability. Manjot is able to compensate for the work she cannot do herself by hiring others, but she still suffers from significant anxiety. Sita is less able to compensate for the work she does not feel capable of doing, and she suffers from depression equally as significant as Manjot's anxiety.

Manjot and Sita have "bad" blood sugar control. Biomedicine would situate the locus of blame on Manjot and Sita themselves for their uncontrolled sugar, but a closer analysis of their life circumstances suggests that each woman may be suffering with diabetes, in part, because reasons out of her control. Manjot's clinically significant level of anxiety symptoms[27] likely contributes to her high blood sugar, and this anxiety combined with her physical disability makes it difficult for her to get exercise. Sita's clinically significant levels of depression symptoms, financial and housing insecurity, and heavy burden of family and work responsibilities prevent her from accessing the resources that might help her maintain her health, such as time with a doctor to learn about her illness, money to buy medicines, and the ability to rest when she is not feeling well. That these women are grappling with poor diabetes control is not entirely their responsibility, although structural factors that limit health management are rarely acknowledged in biomedical models of diseases (Farmer et al. 2006).

"Good" Diabetes Management and Daily Life: Two Case Studies

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[27] Based on standard scoring methods for the depression and anxiety screening tool I used, the Hopkins Symptoms Checklist.

Manjot's and Sita's stories provide clear examples of poorly controlled diabetes with co-occurring mental health concerns in two distinct socioeconomic settings, and they suggest that the biomedical system's assignment of blame to individuals with poor blood sugar control is often unjustified. However, for every woman like Manjot or Sita who did not maintain diabetes control, there was at least one woman in my study who did maintain control and experienced little or no disability in her daily life as a result of diabetes. In what follows, we will explore the life stories of two women with well-controlled diabetes and see what factors allow them to attain this control.

Kalpana, age 78, diagnosed 10 years ago, glucose 98 mg/dL, HbA1c 7.1% (CRP and EBV not available)

Kalpana, on the far left of this picture, is one of the oldest women who participated in my study. She suffers from both type 2 diabetes and heart disease. At 78, she is somewhat frail and walks slowly, but prides herself on the fact that she hand-washes her own clothes and is able to serve me a beverage when I visit her upper-middle-class home. Kalpana and her husband immigrated penniless to India as young adults during Partition and over time accumulated wealth running a well-known tailoring business in central Delhi. Now a widow, Kalpana lives in a large extended family consisting of her two sons and their wives, two grandsons and their wives, and three great-grandchildren, one of whom is pictured here. She has no formal education.

Kalpana spied her oldest granddaughter-in-law, Roopa, at the local Gurdwara [Sikh temple] one day and began inquiring with her family about arranging a marriage with her grandson. Although Roopa, pictured at the far right, has a B.A. in fine arts, her husband has requested from the start that she not work outside the home and instead take care of Kalpana full-time. Roopa accordingly accompanies Kalpana to all medical checkups, gives her insulin injections daily, and takes her out at 5:00 every evening for a walk to the Gurdwara. As Roopa explains, "Nowadays there is no one to care for the older family members, and they tend to get more ill and depressed. …We're here, so of course we help her, because it's good to have an elder in the household as a guide." "My servant takes good care of me too," Kalpana adds. "He makes light food for me and knows that *urad dal* [a type of lentil] gives me gas." Kalpana's son also eats breakfast with her every morning and monitors her fasting and post-prandial glucose before and after the meal. She shows us a slip of paper titled "Mummy Sugar" where her son has jotted down her fasting and post-prandial glucose for the last several days.

Kalpana's daily routine is simple. "I get up at 6:00 and pray. I pray for an hour, then my son comes and sits with me. We sit and watch the news. Then the servant gives me tea, and I have breakfast. Cornflakes with a spoonful of nuts…. At 2:00 the servant comes downstairs and makes lunch. [I eat lunch] at 2:30. I go to the temple in the evening. For lunch I don't eat too much. I have light food, like *moong dal* or *malke dal* [types of lentils], and they make *karela* [bitter gourd, believed to be anti-diabetic] for me. I have very thin *rotis* [flat breads]. I eat one and a half and give the rest to the birds. It's always been my custom to take God's name and give foods to them." In between meals and prayer, Kalpana naps, watches TV serials, or reads religious texts.

Although not perfect, Kalpana's blood sugar is relatively well controlled, with an HbA1c of 7.1 percent. Kalpana does not herself understand the meanings of her glucose and HbA1c reports, but she is aware of the potential complications of diabetes. "Sugar-related problems happen like this—the kidneys go bad, you become bedridden. …I don't understand it all. I just know that I don't want to become bedridden, that's all. My son tells me if it's okay."

Key to Kalpana's diabetes management is the family support she receives from her granddaughter-in-law, her son, and her servant. Her health is intensively managed by this "team," who monitors her blood glucose, medications, and exercise, and tell her "if it's okay." This home-based care system is quite common in contemporary India and is grounded in cultural values such as long-term reciprocity and extended family living, which we see reflected in Roopa's statement, "Of course we help her because it's good to have an elder in the household as a guide."[28] Under this model of reciprocity, later-life care is considered a repayment for the sacrifices parents made when raising their children (Bali 2001; Vatuk 1990). When this system works as intended, the service of younger family members grants elders the freedom to rest and pursue their own interests, as Kalpana is able to do with her daily routine of praying, going to the Gurdwara, watching TV serials, and taking a nap. Kalpana's family in many ways represents the traditional ideal in India, where elders are respected and cared for. Fears and narratives about modernity often center on uncared-for elderly as alarming signs of cultural disintegration (Cohen 2000; Lamb 2000). Roopa's comment that "nowadays there is no one to care for

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[28] In 2007, the Maintenance and Welfare of Parents and Senior Citizens Act established this custom as a legal right. Under this act, senior citizens, parents, and grandparents can claim maintenance from their children (or the heir to their property if they have no children) when they are unable to maintain themselves on their own income.

the elderly family members" speaks to the importance of elder care in this particular family's cosmology.

Kalpana's description of her daily routine also mirrors the dominant model of age-appropriate activities described in Hindu religious texts, which is familiar to most Indians and endorsed even among non-Hindu groups (Shrinivas 1989). This "stages-of-life" model states that elders should withdraw from worldly attachments in preparation for death by increasing religious activities, eating simpler foods, and turning major decision-making roles over to younger family members (Lamb 2000; Shrinivas 1989; Vatuk 1990, 1995). Kalpana has not only withdrawn from major family decisions, but has turned control of her personal health over to others. In this and other senses, Kalpana's narrative reproduces an archetypical Indian model of a good old age, made possible by her family's adherence to traditional elder-care roles. This freedom contrasts markedly with the lifestyles of less fortunate elders, such as an elderly diabetic woman who must work alongside her husband as a day laborer, despite her tremors and weakness. "We're old, we do one thing or another [to make ends meet]," she explains. "When you're hungry, you have to do something to get food. I work in construction sometimes, mixing and carrying concrete. I don't know how to do any other work."

Kalpana, in contrast, unsurprisingly reports little disability related to diabetes and reports no significant levels of "tension," depression, or anxiety. Ethnography among older North Indians suggests that many women experience old age as a pleasurable and restful time of life, in which they are allowed to pursue their own interests and move outside the house in ways they were never before able to do. This pleasurable state depends, however, upon the diligent service of younger family members and upon a harmonious household atmosphere (Vatuk 1995). The freedom Kalpana enjoys is a function of her age, socioeconomic status, and most importantly, the remarkably high level of social support she receives from her dedicated family.

Indu, age 50, diagnosed 1 year ago, glucose 117 mg/dL, HbA1c 6.9%, CRP 2.9 Mg/L, EBV 83.0 ELISA units

Indu, the lower-middle-class homemaker we met in Chapter 2, quips, "A small family is a happy family," when I ask her about her only child, repeating the government's well-known population control slogan. Born in Punjab as one of 10 siblings, she came to Delhi in 1986 after her marriage and now lives in a dark ground-floor apartment with her husband, son, and ailing father-in-law. When I ask her about her daily routine, she says, "I do all the household work. I get up at 6:00 and make *chai* [sweet, milky black tea], then I go out to get milk and vegetables. I come home and cook them, have *chai*, and wash the dishes. Then I do the sweeping and mopping, bathe, make breakfast, serve it to my family, and eat it myself. In the afternoon I make one vegetable dish that's enough for dinner too." She watches two or three television serials every day, goes on a walk, and pursues some home-based sewing work, which, she says, "Helps me pass the time, and also gives me some money." In addition, she looks after her very elderly father-in-law. Her routine thus includes a lot of household work but also affords her leisure time, and she reports no depression or anxiety.

With her high school degree, Indu has an average level of education compared to the other women in my study, but she knows more about diabetes than almost any other woman I met. She receives her diabetes care at a charitable clinic much like the one Sita goes to, where consultation fees are minimal but time with the doctor is very limited; most of her diabetes knowledge is self-acquired. As we saw when we first met Indu in Chapter 2, she regularly reads books and newspaper articles about diabetes, watches programs about it on TV, and has clear opinions about its larger societal causes. “The atmosphere these days, like our diets, the pollution and smoke, this illness has started happening to everyone,” she opines. “And look, everyone has heart disease, blood pressure, and cancer too. It's happening to everyone.” Indu is very much in control of her illness, with glucose and HbA1c levels resembling levels among people with normal pancreatic function.

Indu reports only mild symptoms of diabetes that do not interfere with her daily tasks. She explains, “I just have a little weakness because of diabetes. I never used to get tired out before. Now I have some pain in my feet, too. Still, I just do work the same way I used to. In a week I only use the washing machine once, just to wash the sheets and towels. I wash the rest by hand every day. I also go out and get the vegetables myself, or go out with my husband.” Despite the fact that she is rather new at managing her diabetes, having only been diagnosed a year ago, she says, “I've never had a low sugar problem. I keep having a little bit of sweets so that my sugar doesn't go too low. I know that low sugar is the most dangerous thing.” She and her diabetic neighbors go together to get their blood sugar checked when free screenings are offered in their area, and they often walk together in the evenings.

Indu lacks many characteristics that we might expect to be associated with good diabetes management. She is neither wealthy, nor educated to a great extent. She lives in a small joint family with a seriously ill father-in-law and has no domestic worker to help her with household duties. She attends a charitable diabetes clinic where she gets little one-on-one time with the doctor, and was only recently diagnosed with diabetes. Despite these facts, her blood sugar is exceptionally well controlled, and she demonstrates an unusual level of knowledge about the causes, complications, and management of diabetes.

There are a few key characteristics that might contribute to Kalpana's and Indu's good diabetes management. These include autonomy; social support from family, friends, and neighbors; and lack of life stress. Each of these factors creates pathways that lead to better health. First is Indu's autonomy and its relationship to her health. Her Sikh family observes no restrictions on women's mobility, allowing her to build exercise into her daily routine by going on walks in her neighborhood park and doing the family's marketing on foot. Although this is not especially unusual in modern New Delhi, there are still many groups, including some Hindu and Muslim groups, who do not allow women to go out alone. Indu's sewing work also grants her a degree of financial autonomy, which eliminates financial pressure her family might otherwise feel about the costs of managing her illness. Although many women in her situation would not maintain control of this income, Indu says, "It gives me a little extra money." Finally, Indu's reference to the population control slogan suggests that she and her husband had only one child *intentionally*, a choice that has certainly lessened her burden of domestic work. The fact that they seem to have used birth control and that she had the opportunity to choose to have only one child suggests a greater degree of autonomy than many of the other women in this study.

In addition to allowing Indu to engage in health-preserving behaviors like walking, Indu's autonomy seems to grant her a feeling of self-efficacy that translates into proactivity toward her health. She states confidently, "It's a very dangerous illness, this. I'm not afraid for myself; I keep in control." Although she did not have a family history of diabetes, she felt concerned from the start that she might develop diabetes, and therefore got herself tested every six months. When she did develop the illness, she recognized the symptoms herself and immediately went to the doctor. She now goes for regular health checkups, even when she is feeling well, and has taught herself a great deal about diabetes management. She even makes a point of doing most of her family's laundry by hand despite the fact that they own a washing machine in order to build extra exercise into her daily routine. She controls her diet and seems unperturbed about having to give up certain foods, such as rice and sweets. Indu is also open about her health, telling friends and neighbors without reservation that she has diabetes so that they do not offer her foods that are prohibited in her diabetic diet.

The second factor that contributes to Kalpana's and Indu's successful diabetes self-care is social support, although this support comes from different places for each woman. The two women's families are strikingly different. Kalpana lives in a large, traditional joint family, while Indu has an unusually small one. In Kalpana's case, social support from family members contributes directly to her diabetes control, as they perform health monitoring activities on her behalf. Although her family is smaller than most because she has only a single unmarried child, Indu has many friends in her neighborhood, particularly diabetic women friends. They attend free diabetes health events together and meet in the local park in the evenings for walks. Most of them know each other primarily as neighbors and secondarily as fellow women with diabetes; many were acquainted before their diagnoses because they have all lived in the same neighborhood for many years. According to Indu, they often discuss tips and tricks for diabetes management, especially foods. She learned from her diabetic friends, for example, that crepes made out of chickpea flour are a diabetic-friendly substitute for the usual wheat-based flatbreads that constitute a key part of North Indian diets. These social relationships provide practical advice, motivation to attend clinics, and emotional support for Indu, filling the niche that a larger family might otherwise do. Other medical anthropologists working with diabetic women have also found that social support improves their ability to manage and cope with their diabetes on their own (Kokanovic and Manderson 2006).

A third reason why Kalpana and Indu are so successful in their diabetes management is that they lack stress about their diabetes, and about life more generally. Kalpana has renounced most family responsibilities as part of her transition to old age, and therefore is free to pursue relaxing activities such as prayer, watching TV, and napping. Indu has a relatively busy day but still has time every day to relax. Indu seems to take comfort in her knowledge about the management of diabetes. Although she is well aware of the dangers of diabetes, too, having seen two neighbors die of extremely high or low blood sugar and another have his leg amputated recently, she feels confident that she will be all right because she knows what she needs to do to take care of herself.

These four case studies give us a solid ethnographic foundation from which to explore the personal and interpersonal factors that shape women's day-to-day management of diabetes and its concomitant symptoms. They suggest that one's ability to control one’s glucose is not random or unpredictable, but rather that key elements of women’s lives appear to vary along with their control over their glucose levels, including women’s levels of autonomy, social support, and life stress. A statistical analysis of the relationships between diabetes control, disability in daily life, and personal characteristics using data from the sample of 184 diabetic women can provide a clearer overview of the broad trends in these variables.

Another Point of View: Statistical Analyses

My statistical analyses provide a counterpoint to the ethnographic analyses presented thus far. In order to quantitatively measure women’s experiences of disability in daily life, I used a three-step process to build a locally relevant questionnaire that would measure disability. First, I asked 62 diabetic and non-diabetic women what tasks women like themselves should perform to care for themselves, their families, and their communities on a daily basis (Bolton and Tang 2002; Weaver and Hadley 2011). The purpose of this step was to identify important women’s activities for this specific population. Second, I converted activities that were mentioned independently by three or more women into items on a questionnaire asking about whether or not women experience any trouble doing important daily tasks because of diabetes, and validated it using the methods described in the Appendix. Using this questionnaire within a larger questionnaire about diabetes, demographics, and mental health (reproduced in the Appendix), I collected quantitative data on disability in daily tasks among the sample of 184 diabetic women. Each diabetic woman was assigned a “disability score” based on the number of tasks she reported having trouble with, and the severity of that trouble. This score was then used in quantitative analyses.

A linear regression predicting the amount of disability that diabetic women experience due to diabetes reveals that both demographic characteristics (number of children) and health characteristics (depression score) are the most important factors predicting disability in daily tasks (Table 12, below). As the regression model's r-squared value demonstrates, almost 36 percent of the total variance in women's levels of disability in daily life (the outcome variable) can be accounted for by the two predictor variables.

Table 12. Linear regression predicting disability in daily life among diabetic women (n=184).

Predictor Variables	Standardized Beta Coefficients	P-Values
No. of Children	.190	.001
Depression Score	.561	.000

a. Outcome variable=disability
b. Model adjusted R-squared value=.356
c. Other variables considered for inclusion in the model: Age, education, socioeconomic status, religion, years married, joint family, "tension," HSCL anxiety, glucose, diabetes duration, HbA1c, body mass index and body fat percent, insulin dependency, stressful life events.

As the beta-values of each predictor variable demonstrate, for every additional child a woman has, we would expect a 0.19 point increase in her disability score; while for every one-point increase in depression score, we can expect a 0.56 point increase in disability. The observed association between disability and having more children may be related to the fact that women who have more children are more likely to have help around the house, and therefore to be able to "afford" to forego some activities when they feel unwell. Teenaged daughters, for instance, often help with household chores and cooking. Alternatively, women with more children may simply have more responsibilities than those with fewer children, leading to a higher likelihood that they will experience some degree of disability in those responsibilities.

It is also unsurprising that women who report more symptoms of depression are more likely to experience disability in important roles. Depression, like diabetes, can be a debilitating and chronic condition; it is well-established that depression frequently interferes with daily function (Broadhead et al. 1990). This result is further supported by the ethnographic observation that women like Manjot and Sita, who suffer from acute mental distress, experience greater disability in their daily lives. This disability is likely due to the distress itself, as well as the interaction that occurs between this distress and diabetes control. It is noteworthy that neither anxiety nor "tension" was related to disability as depression was. This suggests that clinical depression may be more debilitating for the diabetic women in my study than other mental health problems.

In a second linear regression predicting diabetes control, I measured diabetes control using blood HbA1c, which reflects long-term trends in women's blood sugar levels. The analysis (see Table 13, below) shows that in general, women who are more educated and who report more depression symptoms also have better diabetes control as measured by HbA1c. Those who were diagnosed with diabetes longer ago, who are insulin dependent, or who experience more disability related to diabetes have poorer blood sugar control as measured by HbA1c. The model explains about 19 percent of the total variance in HbA1c among the women I studied, suggesting that while the predictors in this model matter, there are other important forces at work that were not measured in the study.

Table 13. Linear regression predicting blood HbA1c among diabetic women (n=184).

Predictor Variables	Standardized Beta Coefficients	P-Values
Diabetes duration	.169	.028
Disability	.220	.002
Insulin dependent	.140	.054
Education (B.A.+)	-.152	.015
HSCL depression	-.144	.036

[1]Model adjusted r-squared value=.193

In this analysis, holding a B.A. degree or higher is related to better blood sugar control. Those with a B.A. or higher degree have, on average, HbA1c values 0.152 percentage points lower than women with less than a B.A. A simple correlation analysis also illustrates a weak relationship between education and lower blood sugar ($r=-0.2$, $p<0.01$), implying a small trend of better diabetes control and lower likelihood of developing disabling symptoms. This association might be explained by the fact that more educated women are likely better able to understand their illness and its management requirements, and they tend to be wealthier.

Surprisingly, this model demonstrates that women with *more* symptoms of depression have slightly *better* blood sugar control. The adjusted beta value of the depression variable in the regression model demonstrates that for every one-point increase in the HSCL depression scale, HbA1c drops by 0.144 percentage points. Although this might seem counterintuitive, other studies have found similar results, and they suggest that the maintenance of tight diabetes control is itself depressing (Golden et al. 2008). Chapter 5 will introduce Ankita, a woman whose diabetes experience illustrates the ways in which diabetes control can act as a depressing force in itself.

Finally, the regression demonstrates that women who were diagnosed with diabetes longer ago, who are insulin dependent, or who report more disability in their lives due to diabetes are likely to have higher HbA1c values. This should come as no surprise, since insulin dependence and disability are two markers of diabetes severity. The fact that women who have had diabetes for a longer time are more likely to experience poor blood sugar control is not particularly surprising, but it also does not necessarily have to be this way. Not everyone in my study who had had diabetes for a long time experienced poorer blood sugar control, and in fact some of those with the best blood sugar control were the ones who had lived the longest with the disease. Women like Sarita, a woman diagnosed with diabetes 14 years ago, who will be introduced in Chapter 6, have had time to practice and perfect diabetes self care.

Overall, the two statistical models presented here show that blood sugar control, depression, disability, and duration of diabetes are related in significant ways. They also suggest that some of the trends represented in the four case studies hold across the entire study sample, implying that the case studies are not merely anecdotal, but legitimately illustrate some typical aspects of diabetes experiences among women in Delhi. This concordance between ethnographic and quantitative data strengthens the case for the validity of both approaches, and is a reassuring finding for medical anthropologists who work with mixed methods.

The statistical finding that disability is related to more symptoms of depression is illustrated by Manjot and Sita, the two women from this chapter with uncontrolled blood sugar, who report high levels of distress. Their mental health problems interact synergistically with their diabetes and produce impairment in their daily lives. Kalpana and Indu, by contrast, have controlled blood sugar, report no significant mental health problems, and do not experience impairment in their daily lives. However, the two-by-two table presented in the Introduction (Table 4) suggests that Kalpana's and Indu's cases are exceptions rather than the norm—out of 162 diabetic women with relevant data, only 25 fell into their category. Both women have good diabetes control and good mental health, but this is likely at least partially a result of the buffering effects that their unusually strong family- and friend-based social support groups provide. Not all women who maintain good blood sugar control can expect better mental health; and in fact, the opposite may be true. This forces us to question whether strict blood sugar control is in fact "worth" the mental distress that efforts to attain it might cause. Although this question is only being introduced briefly here, it will be revisited in greater detail in subsequent chapters.

Conclusion: Blame, work, and diabetes self-management

At the beginning of this chapter, we discussed three kinds of work associated with managing chronic illnesses at home: illness work, everyday life work, and biographical work (Corbin and Strauss 1985). Self-managed illnesses like diabetes demand a high level of "illness work," which we saw in the cases of Indu and Manjot, who devote significant time to learning about diabetes, self-monitoring their blood sugar, making special foods, exercising, and attending checkups. Similarly, women like Indu and Kalpana perform "biographical work" when they express a fear of increasing dependency as they imagine their futures with diabetes. Although it is perfectly socially acceptable for adults to receive long-term care from their sons and daughters-in-law at home as Kalpana does, many women nevertheless feel concerned about over-burdening their children (Lamb 2000; Vatuk 1995). Notably, Indu and Kalpana state their worries using exactly the same phrase—"I just don't want to become bedridden, that's all"—as if to say that they are prepared to accept many diabetes-related complications, but need to maintain a bottom line of functionality. Finally, each woman performs varying "everyday life work" tasks. People like Kalpana and Manjot, who are looked after by family members or servants, have lower burdens of everyday life work than those like Sita and Indu, who are the primary caretakers of their households.

This chapter has corroborated Corbin and Strauss's (1985) original assertion that an unusually high burden of work in any one realm may detract from one's ability to perform the other types of work. In Sita's case, for example, the "everyday life work" associated with her heavy domestic responsibilities both at home and at her job limit her ability to perform the "illness work" that might help her care for her own illness.

To this qualifying statement about the three types of work, I would also add the observation that *the amount of work one performs is not necessarily related to the degree of diabetes control one attains*. Indu's "illness work" translates into good diabetes control, while Sita's lack of "illness work" contributes to her poor diabetes control. Manjot, however, spends more time thinking about her diabetes than any of the other women introduced in this chapter, yet her health status is the worst, judging from her numbers. Likewise, Kalpana performs almost no "illness work" but has excellent diabetes control because her family members perform it for her. The relationship between management effort and diabetes control does not always resemble what one might expect.

The question about why some people are able to manage their diabetes while others are not, and where the onus of blame should fall, is essentially a variant of the longstanding debate in anthropology over the roles of structure versus agency in determining human behavior. Prominent social theorists such as Claude Levi-Strauss, Karl Marx, Michel Foucault, and Pierre Bourdieu have grappled with this question for decades (Ortner 1984). Throughout this chapter, I have taken a critical approach to each woman's story, drawing attention to the importance of the social circumstances in which each story is played out. I have, for instance, suggested that Manjot and Sita suffer from poorly managed diabetes at least partially because of factors out of their control such as depression, poverty, and heavy family responsibilities. A critical look at the factors that make Kalpana's and Indu's diabetes control possible suggests that their success is as much a product of their life circumstances—including autonomy, small families, and strong family support—as it is of their individual efforts. While people, of course, make individual choices that affect their health, the range of choices available to them and the route they are likely to choose are influenced by these larger structural factors. Diabetic women's freedom to choose how they divide their attention between their illness, biographical, and everyday life work is constrained by their personal circumstances. This is perhaps clearest in the case of Sita, whose lifelong poverty and social disadvantage make it nearly impossible for her to care for herself effectively.

When we take a step back from the qualitative and quantitative analyses presented in this chapter, there are several lessons to be learned about how Indian women manage their diabetes on a daily basis. At stake in biomedical models of diabetes management are moral judgments of "good" and "bad" control (Broom and Whittaker 2003; Feudtner 2003; Ferzacca 2000; Naemiratch and Manderson 2006), which in the cases we have explored here, transfer directly into "good" (i.e., less disruptive to life) or "bad" (i.e., more disruptive to life) experiences with the illness. Assigning blame to individuals for poor diabetes control is neither useful for encouraging compliance, nor is it necessarily an accurate reflection of the reasons why some individuals are unable to maintain diabetes control while others are successful. The four narratives presented here show that factors leading to poor management include mental health problems and financial insecurity, while factors leading to good management include autonomy, social support, and lack of life stress. From a theoretical perspective, this is interesting because it highlights how illness experiences are shaped in part by external forces that may differ across class, community, culture, and other contextual factors—a theme we will explore in more detail in the next chapter. As we will see, "good" or "bad" control is not always predictive of "good" or "bad" illness experiences, and it is important to problematize this assumption.

This is especially true because this dichotomy serves as the basis of most biomedical models of diabetes management.

The women in my study experience varying levels of life disruption as a result of their diabetes. Such experiences of disjuncture are common among people with chronic illnesses (Becker 1997; Charmaz 1991). For women like Manjot and Sita, "bad" illness control transfers into "bad" experiences with diabetes characterized by life disruptions and disability. These disruptions often extend beyond the individual to affect family members, friends, and other social contacts. Manjot's narrative is punctuated with strong emotional statements that hint at the depth of this life disruption for her (e.g., "My sugar is always high, and every day I feel that maybe this is the last day I will live"). Manjot's life disruption not only limits her activities, but also intrudes into her family relationships, her religious beliefs, and her understanding of her own body. Sita works hard to avoid the intrusion of diabetes into her family life and work as a domestic servant, but there are times when her illness flares up to the extent that she has to remain in bed. When this happens, she has to inform her employers that she cannot come to work, but she avoids going to the hospital because she has neither the time nor the money to afford being admitted. She knows that if she misses work too frequently, she will be fired, and her family will lose the servants' quarter in which they've lived for over a decade. This would also make her dream of eventually buying a flat for her children impossible. Each woman's mental health problems interacted cyclically with her diabetes symptoms, ultimately worsening her quality of life and her physical health as well.

For Kalpana and Indu, by contrast, "good" blood sugar control transfers directly into "good" diabetes experiences characterized by a lack of disability and less intrusive life disruptions. The family support that Kalpana receives from her son, her granddaughter-in-law, and her servant is the key factor that determines her diabetes management success and allows her to lead a relaxing lifestyle in her old age. Indu lacks extended family support, but she maintains relationships with a network of diabetic women in her neighborhood who essentially function as a self-built support group. In addition, Indu's personal and financial autonomy and proactivity about her own health are unusual among the women in my study and likely contribute to the blood sugar control she maintains despite a full schedule of domestic responsibilities. Other scholars have noted a positive relationship between autonomy and diabetes control (Peyrot and Rubin 1994). For both Kalpana and Indu, a low-stress approach to life in general, and to their diabetes in particular, helps them maintain good mental health, which in turn helps them manage their diabetes. Ironically, although they both possess diabetes control, the metaphor of control appears very little in either woman's narrative.

The statistical analyses, however, suggest that Kalpana's and Indu's good diabetes control and lack of distress may, in fact, be atypical. A regression model predicting blood sugar control demonstrated that women with the best blood sugar suffer from more symptoms of depression than those with poorer blood sugar results. Although this result might seem surprising, it has been noted in other studies of diabetes control and mental health (Golden et al. 2008) and might reflect the strains associated with strict maintenance of blood sugar control. This unexpected finding will be discussed in greater detail.

Overall, this analysis is not intended to suggest that Manjot, Sita, Kalpana, and Indu have no say in their own health-related behaviors, but rather is intended to emphasize how we must give due consideration to factors outside their control that affect their diabetes outcomes. This kind of analysis attempts to correct for biomedicine's failure to account for external factors that shape individual vulnerability to illnesses. Paul Farmer, a medical anthropologist, physician, and health equity advocate famous for his work in rural Haiti, applies the term "structural violence" to describe these forces that so profoundly shape differential health outcomes, yet are left out of medical models. They are "social structures—economic, political, legal, religious, and cultural—that stop individuals, groups, and societies from reaching their full potential" (Farmer et al. 2006: 1686). Structural violence in the form of unequal access to resources, political power of one group over another, lack of education, unequal access to healthcare, or barriers to legal standing, constrains one's ability to act in one's own best interest (Farmer 2004). Women like Manjot, Sita, Kalpana, and Indu do indeed play an active role in their diabetes control, but they are also subject to different sources of structural advantage and disadvantage that either enhance or jeopardize their ability to control their diabetes. These factors include a lack of access to mental healthcare (a problem throughout India, where there are very few trained psychiatrists, yet where increasingly common biomedical diagnoses of mental health problems are creating greater demand for their services) and, in Sita's case, poverty and lack of autonomy. Acknowledging these external factors is especially important when we are considering a chronic disease like diabetes, which has been characterized by biomedicine as an illness that is entirely self-induced. Such "victim-blaming" rarely reflects reality, and almost never results in a positive change in behavior for someone with diabetes.

CHAPTER 5: VULNERABILITY

"A WIDESPREAD ETHOS OF QUIET SUFFERING" AND GENDERED IDEALS AT THE INTERSECTION OF DIABETIC WOMEN'S HEALTH

In Chapter 4, we explored what happens in the daily lives of women who have "good" and "bad" diabetes management practices, as defined by biomedical models. Close analysis of Manjot's and Sita's case studies suggested some proximal causes of their vulnerability to poor diabetes control, including poor mental health and financial insecurity. In contrast, Kalpana's and Indu's cases illustrated that proximal factors such as autonomy, social support, and good mental health boosted their resilience against the challenges of diabetes. All of these causes are "proximal" in the sense that they are close to the individual; that is, they are individual characteristics. I noted that many of these proximal characteristics are outside the control of individuals even though they "belong" to individuals, and we began to discuss how illness experiences are shaped in part by external forces that differ across class, community, and other cultural contexts.

In contrast, this chapter characterizes the specific features of the larger cultural contexts in which North Indian women's diabetes experiences are embedded. Other medical anthropologists have examined how structure shapes diabetes experience. Much work by medical anthropologists on diabetes has focused on indigenous, especially Native American, groups because they have some of the highest prevalences of diabetes in the world (*c.f.* the volume edited by Ferreira and Lang 2006; Kozak 1997; Smith-Morris 2005, 2006, 2010). Many of these authors conclude that high rates of diabetes among indigenous groups are due to structural conditions brought about by colonialism, such as dietary changes and sedentism that came with the introduction of wage economies in place of labor-heavy lifestyles such as subsistence agriculture or hunting and gathering (Omran 1971; Popkin 1999). Similarly, in North India, British colonization from the early 19th century to the 1950s radically changed economic and social structures in ways that still echo in the present and shape the health profile of India's vast population. During the last two decades, with India's rapid modernization following its economic liberalization in 1991, chronic and noncommunicable illnesses like heart disease and type 2 diabetes have become the leading causes of death in the country (World Health Organization 2011). Yet, evidence from Vedic medical texts suggests that diabetes has been present in Indian populations at some level for millennia (Weaver and Narayan 2008). When I talk about the larger contextual or "distal" factors that shape diabetes in North India, I am referring not to the historic and ongoing influences of colonialism, but rather to how cultural and social norms *in the present* shape individual diabetes experiences.

This conversation is not necessarily specific to women with diabetes, but the lens of diabetes is helpful because it amplifies the amount of self-care women must do, therefore throwing into sharp relief the tensions that can arise when self-care conflicts with overarching cultural norms. The contextual features this chapter will address are "distal" to the individual, in the sense that they are not personal characteristics belonging to individuals, but are rather overarching norms, values, and systems in which women's diabetes self-care occurs. In other words, they are fundamental causes of illness, or factors that put people “at risk of [health] risks” (Link and Phelan 1995).

The chapter begins by examining the stories of two diabetic women, Rita and Maya, paying special attention to the role of crisis in their narratives and the factors that make them vulnerable to these crises. Both women profiled in this chapter belong to the sub-group of about 34 women (out of the total group of 184 diabetic women) identified in the Introduction as “physically and mentally vulnerable,” as they have poor diabetes control *and* poor mental health along with it. I then present the case of a third woman, Ankita, who represents the smaller sub-group of six women identified in the Introduction as “mentally vulnerable,” in the sense that she has good diabetes control but poor mental health. Her story provides a window into the strains associated with maintaining adherence to diabetes management regimes, and the ways in which this effort to maintain good physical health can, paradoxically, open one up to vulnerabilities in other areas of health and wellbeing.

Together, the three cases illustrate both types of vulnerability women in this study experienced (that is, physical and mental vulnerability versus mental vulnerability only), but Rita’s and Maya’s cases are also intended to impress upon readers how fear, uncertainty, and urgency can be as much a part of diabetes experience as the daily drudgery of management tasks we see in Ankita’s case. The small but growing body of work by medical anthropologists on various aspects of diabetes often overlooks the role of crisis in the illness (*c.f.* Broom and Whittaker 2003; Cabassa et al. 2008; Cohen et al. 1994; Daniulaityte 2004; Ferzacca 2000, 2004; Garcia de Alba Garcia et al. 2007; Hunt, Valenzuela, and Pugh 1998; Loewe and Freeman 2000; Kokanovic and Manderson 2006;

Lang 1989; Mendenhall et al. 2010; Mendenhall and Jacobs 2012; Naemiratch and Manderson 2006; Poss and Jezewski 2002; Rock 2003; Scheder 1988; Smith-Morris 2005, 2006; Weller et al. 1999). Confronting this gap in the social sciences literature on diabetes will help us better understand women's illness experiences in North India, and will give voice to acute experiences not always discussed in chronic disease research. These case studies also bring to life the "cultural context" that shapes women's vulnerability to diabetes crises and complications. Identifying specific cultural causes of diabetes helps clarify what is particularly "Indian" about the illness experiences of the women in this study, and corrects the tendency in medical research to gloss over cultural contextual factors. Quantitative health research tends to invoke "cultural context" as an important factor contributing to health, without specifying what this context means either in theory or in practice (Hruschka and Hadley 2008; Kohrt, Hadley, and Hruschka 2009). The analysis presented in this chapter will facilitate a critical examination of what is missing from biomedical models of diabetes etiology and management, a key goal of this dissertation. This lays the foundations for designing tools that measure contextual factors in a locally-relevant manner.

Mental and Physical Vulnerability to Diabetes: Two Case Studies

Rita, age 40, diagnosed 10 years ago, glucose 29 mg/dL, HbA1c 8.3%[29]*, CRP 7.5 mg/L, EBV 165.0 ELISA units*

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[29] Recall relevant cutoff values for these biomarkers:

Biomarker	"Healthy" value or relevant cutoff
Blood glucose	Should remain between 70-180 mg/dL
HbA1c	Should be < 7.0%
C-reactive protein (CRP)	"High" is above 3.2 mg/L (highest quartile)

Rita, the middle-class woman we met in Chapter 2 whose husband runs a general store, has been admitted to the ICU several times for diabetes-related crises. While she looks expressionlessly at the floor, as if she hardly registers what he is saying, her husband recounts in detail the most recent of these health crises, which occurred the month before I visited their family at their home. Here, at length, is his account of this dramatic event. He began by describing the inconsistent nature of her healthcare in general, and especially during this period when they were traveling:

> Only once every year or two she goes for a checkup. Like in March, she was admitted in the ICU for 15 days. We had gone to Bihar [state]. She left her medicines behind, and when we got there her health went bad. There aren't any good doctors there. We did consult one, and he gave her a glucose drip [because he assumed she was suffering from hypoglycemia without checking her blood sugar]. This made her health even worse. It was some doctor in Gaya. There's a famous doctor there with so many patients; we saw him next. He sent me to a nursing home [small hospital], and there I saw so many people that I thought, "This will take so long that she'll die while we're waiting!"

Finally, he says, he gave up and decided to return to Delhi. But when he arrived, his wife's case was so dire that he had trouble finding a doctor who would take her on:

> So we caught a train, and while we were sitting her tongue protruded out of her mouth. It was totally dry and black. The way back was so long, it took 48 hours. When we finally reached Delhi her sugar had reached 800, then it crossed 1000. When we got here, I took her to Apollo hospital but they wouldn't admit her. They told us there was no hope for her case. I said, "Doctor-sir, I've brought her from Bihar. Please admit her, I've brought her so far." I called up another doctor whom I trust, and he said, "Brother, this isn't a matter of trust. If anything happens to her, I'll be mixed up in it. So you have to sign a document that it's your own responsibility to admit her here."

After he signed the disclaimer, the doctor finally agreed to admit her.

Epstein-Barr virus antibodies (EBV)	"High" is above 178.9 ELISA units (highest quartile)

> They put her on a stretcher and attached 15 or 16 machines to her. The doctor said, “For the next 36 hours it's your responsibility what happens to her. If she's still alive after 36 hours, then she'll be my responsibility.” After 8 days she regained consciousness. They weren't allowing me inside, but I insisted, “Let me in. If she hears my voice, she'll surely respond in some way.”

His account of her reawakening, and his confidence in her ability to bounce back from the crisis, are moving:

> When I went inside and talked and tapped her hand, tears started coming down her cheeks. The doctor said, “She's no longer in a coma. She's hearing what you say.” Then he said, “Now her case is clear. She'll respond positively by tomorrow.” After two or three hours, she opened her eyes. The doctor called me in and they asked her if she recognized me. She started crying and said, “Yes.” Her entire body was so dry, like a *papad* [dry, crispy wafer]. The doctor said, “She may have trouble speaking in the future or have a stammer.” I said, “Doctor, she'll be fine. Don't you worry a bit.”

She did indeed improve rapidly, and suffered no permanent complications from the coma. But her health deteriorated again just after she came home from the hospital.

> After two or three more days I started slowly getting her to speak. I brought her home and she got sick again, even though we were continuing her treatment. I had to take her back to the hospital and the doctor admitted her in the ICU again. Then after four or five hours she regained consciousness, and I said, “Doctor, please discharge us. I will take responsibility for whatever happens to her.” At that time she started on Lantus® [insulin]. The doctor said, “Give her this injection and you won't have to bring her to the hospital again.”

This story was especially striking because the health crisis was so severe and had occurred so recently, in the brief span of time between my first meeting with Rita at the doctor’s office and my subsequent visit to her home. Also strikingly, Rita’s account of diabetes crises expanded after her husband left the room, when she and her bright, talkative teenage daughter discussed an incident that happened last week:

> Daughter: Sometimes she forgets her regular routine. Sometimes she forgets to take her [insulin] injection at night and takes it the next morning instead.

> Rita: When it's hectic, I sometimes can't manage it. I know I need to take it before eating. Actually, I go to *satsang* [religious singing group, where women usually fast]. So last Sunday, I took my injection [without eating] and went. When I came out at 11:30, my sugar was very low. I felt like I should eat something; it was difficult even to walk. Then my husband started scolding me, “You shouldn't come along with me, your health is always bad and it creates a problem. We'll get some Lantus® on the way home.” Walking between the temple and the chemist my sugar went so low—
>
> Daughter: This is her biggest weakness. She'll never do that [carry something sweet to guard against hypoglycemia].
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> Rita: Just after I told the chemist I needed Lantus®, I asked for a toffee because my sugar was down. He took out a toffee, opened it, and told me to eat it right away. I was sweating a lot. I could barely stand up. Then he went into his house and brought me back some glucose solution he had mixed up. He told me, “Sit down here for a minute or two. Your health is too bad, just sit down.” Even after drinking the glucose I didn't get better because my sugar had gone so low.
>
> Daughter: You should make a separate rack for yourself with all the things that you need when you go out.
>
> Rita: When my health got so bad, it seemed to me that I shouldn't have gone out at all.

Almost incredibly at this point, Rita’s crisis narrative expanded even further in real time during our discussion. Rita was getting more quiet and withdrawn over the course of the interview. Thinking that this might be a reaction to her husband’s and daughter’s critical comments about her diabetes self-management, I noted it and let it pass. After an hour and a half of conversation, I finally asked her what was wrong, and she responded, “My sugar is going down. It's not such a big issue.” Upon checking, her sugar was 29 mg/dL, dangerously outside the low boundary of 70 mg/dL recommended by the American Diabetes Association for people with diabetes. Rita’s daughter went immediately downstairs to the general store and got her a small chocolate bar. When I asked her why she didn’t say something to me she responded, “Oh, look, I don't pay enough attention, but I know I should eat something every three-and-a-half hours. I didn't know that my sugar would go down at this time, otherwise I would have made some food and eaten a little something."

Rita's diabetes experience is imbued with crisis—in the months, weeks, and even moments surrounding our conversation. Yet, strangely to me as an outsider, neither Rita nor her husband seems to feel that these incidents constitute a worrisome pattern in the larger story of her health management. On the heels of his account of his wife's life-threatening crisis, Rita's husband made the comment already quoted in Chapter 4, "Her health stays 100 percent okay." The contrast between her crises and her husband's gloss on the situation is curious and suggests that perhaps neither she nor her husband is willing to admit to the seriousness of her situation.

Only Rita's daughter urges her to maintain her health during our discussion, with specific complaints about the effects diabetes had had on their family. Rita's daughter explains candidly, "If she uses up her [insulin] injections, she'll only say once, 'My injections are finished.' She thinks that if we're busy all the time and she asks us to do even more than we're already doing, we will get irritated. If one is busy working all day in the heat, then one can't keep track of all these things [so she needs to remind us]. Then she won't take the injections again until she ends up in the ICU." Her daughter also suggests specific strategies Rita could use to cope better (i.e., "Make a separate rack for yourself," and her comments, above, about Rita needing to take responsibility for her medications). I left our interview with the impression that if anyone could convince Rita to be more careful about her health, it would be her daughter.

It is not difficult to recognize the crisis nature of Rita's illness experience; as such, it provides a clear and poignant example of the serious disruptions that diabetes can create in people's lives. However, not all health-related crises are so obvious. Sometimes they exist but remain largely concealed, as in Maya's case, below.

Maya, age 35, diagnosed 4½ years ago, glucose 119 mg/dL, HbA1c 6.7%, CRP 0.4 mg/L, EBV 107.0 ELISA units

Married at the age of seven[30] to a man who passed away five years ago from an aneurism, Maya is a slight, youthful widow who self-consciously covers her head with her *dupatta* [long scarf worn over the head or shoulders] whenever her mother-in-law or father-in-law enters the room. She had to ask permission from her father-in-law for me to visit her house that day, and her mother-in-law hovers in an unfriendly manner during most of our brief interview, as if she wants to make sure she knows what Maya was telling us. Maya seems nervous around her, but because she has no education and cannot support her two sons on her own, Maya is forced to live with her in-laws, for whom she manages all of the household work in exchange for their support. They do not get along, and Maya is very depressed. Their small household offers no sisters-in-law or other peer family members with whom she might commiserate. "I am sad all the time, but I don't express it to anyone else. I only speak to God about it. ...I've

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[30] Although child marriage was outlawed by India's Parliament in 1978 with the Child Marriage Restraint Act, and even earlier under British rule with the 1929 Child Marriage Prevention Act, it is still a relatively frequent occurrence in present-day India, especially in rural areas. Poor families sometimes marry more than one daughter in a single ceremony to save money on wedding costs; Maya was married along with her older sister.

lost the zest for life." She has visible bruises on her forearms in the shape of finger prints but laughs nervously, looks away, and says "no" when I ask her if she is being physically abused. The dark circles under Maya's eyes hint at tiredness; she reports a reduced appetite and often has trouble getting up in the morning because she feels faint and has severe headaches.

I met Maya by chance one day at a private diabetes clinic, where she was accompanying her diabetic mother-in-law for a checkup. Maya herself did not get checked by the doctor, and in fact has not been to him for any diabetes-related care since her diagnosis with borderline diabetes four-and-a-half years ago. Maya believes her pre-diabetes was caused by the tensions she experienced surrounding her husband's sudden death. "Nobody had [diabetes] in my family, I just had a lot of tension at that time. That's why I got diabetes," she said. When her mother-in-law leaves the room briefly, she continues in a lowered voice, leaning in toward me, "Family tension—I'll tell you now. My husband passed away five years ago. You're asking me, so as a friend I am telling you this. My mother in law was here, so...The tension, like you said, happens to me sometimes, but for the children I try to adjust." She is still plagued by guilt about the fact that her husband died when she was away visiting her parents, so she could not be with him.

Maya goes on a daily walk, but does not control her diet and does not take medications. When I visited her at home, she was participating in the *Navratra* fast [nine days fast], during which she only had sweetened *chai*, fruit, and milk products during the day, and a small dish of pumpkin with yogurt in the evening. Her headaches had worsened and she had started experiencing more dizziness since I first met her at the clinic. “The thing is, I'm feeling very weak these days. The dizziness I was telling you about that day [when we first met], it's been happening to me in between. I'm okay today, but the day before yesterday I was dizzy.” Maya’s two children do not know that she is pre-diabetic, and she avoids telling people in general.

On first glance, Maya’s story may not seem to fit in with a discussion about diabetes-related crises, and in fact her blood biomarkers, as a whole, are relatively normal (with the exception of HbA1c, which is elevated, suggesting she is having too many blood sugar highs and lows). The symptoms Maya describes, along with her reports that she eats very little, suggest that she suffers from frequent episodes of hypoglycemia, or low blood sugar, which is indeed a very dangerous condition for people with diabetes, especially if it is prolonged. Maya’s ongoing symptoms of hypoglycemia and lack of self-care suggest a significant potential for advancement of her pre-diabetes to full-blown diabetes, and a potential for future complications. Compounding these worrisome tendencies are her apparently abusive living situation, her family responsibilities, and her severe depression and anxiety symptoms (HSCL depression=2.5; HSCL anxiety=2.1), which prevent her from taking care of herself.

Concealment is a key theme in Maya’s narrative. She conceals her unhappiness about the family situation from her in-laws and her children, conceals her pre-diabetes from her children and others, conceals what appears to be physical abuse from me, and, as she says, shares her problems only with God. Her blood tests even conceal what could be a dangerous trend of chronic hypoglycemia, judging from the symptoms she reports. Keeping her problems to herself is an important part of Maya’s performance of her role as a mother and a daughter-in-law, as well as a reflection of dominant cultural norms of self-sacrifice, but it also results in significant physical and mental suffering that might be addressed at least partially if she were able to share it. Maya's "quiet suffering" in action may not be as obvious as Rita's full-blown crises, but it is every bit as severe, if not more so, because of its concealed nature.

Maya's crises do not look like Rita's; they are not readily visible and do not precipitate urgent action, nor are they reflected in abnormally high blood biomarker levels. Instead, they stay dormant under the surface of her daily life in the form of constant uncontrolled pre-diabetes, mental health problems, and family struggles. Maya's story serves as a good reminder that heath-related crises are not always evident on first glance, but may indeed be there under the surface.

Mental Vulnerability to Diabetes: Ankita's Unusual Case

Ankita, age 42, diagnosed 1 year ago, glucose 88 mg/dL, HbA1c 5.6%, EBV 267.2 mg/L, CRP 7.3 ELISA units

A modern woman who holds multiple Master's degrees, wears glasses, and has a bobbed hairstyle, Ankita greets me at her office in Central Delhi, where she works for a large international non-profit organization. As we sit down at a modern-style wood-and-chrome table, she snaps her fingers imperiously to summon the *chai* boy to bring us a coffee. Ankita's elegant yet nontraditional burnt orange *salwar-kameez* looks as if it were purchased at one of Delhi's popular upscale fusion boutiques, which combine traditional handicraft techniques such as vegetable dying and hand weaving with modern-style cuts and tailoring. Like most Indian women who can afford to do so, she wears jewelry: a gold chain and small stud earrings and several rings on her fingers. Otherwise, she lacks the more traditional markers of North Indian womanhood, such as a *bindi* (dot between the eyebrows), *sindoor* (a stripe of vermillion in the part of her hair), sari, or nose ring. Ankita's self-presentation reflects her larger life position, which is deeply grounded in her Indian identity, yet departs from its more traditional aspects.

Ankita was diagnosed with type 2 diabetes a year ago, which was unsurprising to her because she had had gestational diabetes during her second pregnancy and knew that this put her at risk for developing type 2 diabetes later on. Although she was adhering very carefully to a diet and exercise regimen directly after her diagnosis, when she started her present job about seven months ago, this self-care fell by the wayside. Still, she estimates that she maintains a diabetic diet "about 75 percent of the time."

Ankita's story is, in many ways, representative of the struggles that many career women face all over the world, and especially in urban India. She battles city traffic to drive herself to work every day (unusual for most women in Delhi), feels torn between family and career, and describes herself as feeling exhausted most of the time. She copes with these multiple responsibilities in creative ways, for instance by directing their maid over the phone while she is at her office, but many things simply do not get done, including her exercise routine. Ankita rarely arrives home from work before 7:30 PM, she tells me with a weary sigh and a shake of the head, by which time it is too late to go on a walk. Still, Ankita does what she can to take care of herself at work, and this mostly centers around food and medication management. "I have things kind of chalked out, that I have to eat this right now and this right now, so...there's no option to feel that, y'know, I'm very hungry, or I missed out a meal and I need to eat. It's only when you miss one of those..."

Although this diet control seems to be working—Ankita's blood sugar and HbA1c levels are excellent, resembling those of someone without diabetes—she reports symptoms such as body and joint pain, lack of energy, and major mood swings. Pausing introspectively, she reflects that these symptoms may be more a result of her lifestyle and mental state than of her diabetes. When I ask how her health is in general, she says, "Not so good. Stress, work stress…The work pressure here is enough to—" she says, trailing off. Unlike the vast majority of women in this study, she even uses the English word "depression" to talk about distress. "Mood swings, oh God! ...The sudden burst of anger is very intense [since getting diabetes]. Irritated? It's the feeling of depression that comes on. That's part of the depression, that feeling of depression."

Despite her good blood sugar control, Ankita is deeply distressed and reports levels of depression and anxiety symptoms suggesting clinically significant disorders (HSCL depression 1.7; HSCL anxiety 1.6). She is not simply tired out, but tired of life. For instance, she has given up having houseguests and running errands because it tires her to such an extent that she feels she needs days to recover afterward. She reports feeling lonely "even in a crowd of ten people," lacking interest in former activities, and feeling trapped by her hectic life routine. "Sometimes you *do* feel trapped," she concedes, "but I don't know. Everybody feels that way sometimes. When things are going fine, it's like everything is nice and well, but the moment you are—you feel trapped, somewhat. Anyways, that's part of…" This persistent habit of allowing emotionally-charged sentences to trail off left me with the distinct impression that Ankita was leaving unsaid much more than she was saying.

Ankita's struggle to manage her diabetes, her career, and her family appears to have taken a significant toll on her mental health. While her diabetes health is excellent, her mental health is not good, and in fact her effort to manage diabetes creates what she refers to as "another layer of complication" in her already complicated life. The intensive self-monitoring required for successful diabetes management such as Ankita's might also be linked to increased vigilance, self-rumination, and potentially increase vulnerability to depression in this way. Along with the handful of other women participating in my study who had good diabetes control but poor mental health, Ankita seems to be suffering mentally in part because of the stress associated with maintaining good diabetes management in an already busy life. Other studies suggest a potential depression-inducing effect of diabetes management routines (Golden et al. 2008), and it appears that Ankita's stress about not being able to fulfill her diabetes management responsibilities adds another source of feelings of disappointment, stress, and guilt to her life. While her diabetes management struggles are certainly not the sole cause of her depression, they do not help.

Cultural Sources of Women's Self-Sacrificial Attitudes in North India

Rita's and Maya's narratives are very different, but they share an embedded self-dismissive attitude represented by statements such as Rita's, "My sugar is going down. It's not such a big issue," and Maya's, "For the children I try to adjust." Ankita, too, attempts to downplay her distress with statements such as, "Everybody feels that way sometimes." This kind of self-effacement is quite prevalent among the women with whom I work, is in fact often normalized by them, and manifests in various ways, including concealment of symptoms of diabetes or mental health problems. For example, a spirited middle-class woman who runs a catering business out of her home states that she will prepare healthy breakfasts for her husband but not for herself. "I'll make [oat porridge] for him with milk for breakfast. But I don't care about myself. One day I'll have to die. …I don't take care of myself, I don't think about anything, I just work with all my effort."

This sentiment—"I don't care about myself"—was echoed again and again in the narratives of the women with whom I worked, and seemed to have significant impacts on their physical and mental health. For many women I interviewed, especially those with more traditional lifestyles, beliefs, and values, the idea of self-care seemed almost anathema. Even their physicians recognized this attitude as a major barrier to good self-care. Recall from Chapter 2 that Dr. Gupta referred to this self-sacrificing phenomenon as "a widespread ethos of quiet suffering" among his patients.

During early phases of the research, I asked both diabetic and non-diabetic women three questions: "What should a woman do every day to care for her family? Her community? Herself?" Although women had no trouble generating long lists of domestic responsibilities they felt women should fulfill on behalf of their families and communities, many found it difficult to come up with even one self-care activity that women should perform regularly. They often seemed embarrassed by this question, looking down and giggling or glancing to another person in the room for suggestions about how they ought to respond. Pausing briefly to think, one woman stated, "Actually, the thought never occurred to me." Others said, "I don't have time to think of myself. God does that" and "Responsibilities to myself? I don't think much about myself." "See," explained a fourth woman, "we must always put our families first. Women are normally seen as the builder of the family, the heart of the family."

This ethos of self-sacrifice on behalf of the family and community is deeply grounded in Indian religions, popular culture, and history. The value placed on women's self-sacrifice shapes how women are expected to act and constitutes a key criterion for judgments about their goodness and appropriateness in this largely patriarchal, conservative society.

The concept of *majboori* is relevant for understanding women's attitudes toward domestic responsibilities and care of others. In North India, the word *majboori* (helplessness, compulsion) is used to differentiate forced work, or intrinsic responsibility, from work that is partially or entirely voluntary. Surrogate mothers in India, for instance, often describe their choice to become surrogates as not really a choice at all, but a *majboori* undertaken out of desperate poverty (Pande 2010; Unnithan 2010). The same is often true of women's domestic work, which may be construed as a nonnegotiable fact of social roles, one that women cannot and should not try to evade.

Dharma, a closely-related concept first elaborated in Vedic texts, refers to duties or appropriate behaviors which are life-stage-specific, while *stridharma* is a term referring specifically to women's duties. Although *dharma* and *stridharma* are most closely linked with Hinduism and Buddhism, they maintain relevance for how women of all faiths in India understand their duties to others as an intrinsic part of their lives. Having strong ideas about self-care in this duty-oriented schema implies a culturally inappropriate self-centeredness, a lack of attention to one's *stridharma* that moves dangerously close to a moral shortcoming. As such, it is no surprise that this attitude of self-sacrifice crops up again and again in my conversations with women. The result is a cultural de-emphasis on complaining, which extends to all realms of life for women, including health. Hence the "widespread ethos of quiet suffering," as Dr. Gupta calls it.

This idea that women should care for others and avoid complaining is not unique to India; in many parts of the world, women occupy self-sacrificial roles. The Jewish American mother stereotype in North America, for instance, is an overly loving, self-sacrificial nurturer. The difference here is that this stereotypical Jewish mother leverages her own self-sacrifice to instill guilt and obedience in her children, while the stereotypical Indian woman ideally should not call attention to her sacrificial activities. What is distinct about the kind of self-sacrifice that exists in North India, however, is first the degree to which it is embedded in Indian conceptions of personhood; second, the way it becomes implicated in nationalist and religious discourses; and third, the recipients to whom that care is most likely directed—not necessarily toward one's children, but toward one's husband's family.

The social sciences literature on personhood and caste in North India can also help us better understand the extent to which the values of "quiet suffering" is embedded in North Indian societies, and can also illuminate how women become "immersed" (Charmaz 1991) in this role. Scholarship on India has, for decades, asserted that Indians conceive of personhood in a manner that is distinct from Western conceptions of personhood, where an emphasis on individualism and independence is paramount (Dumont 1966; Marriott and Inden 1977; Ramanujan 1989). Instead, Indian societies espouse a “collectivist” conception of personhood characterized by tight social bonds, strong emphases on hierarchy, and an intense sense of belonging within one’s caste, gender, and family groups (Hofstede 1980). In this kind of a collectivist society, people’s identities and even physical selves are conceptualized with reference to other people to a much greater extent than they would be in individualist-oriented societies (Beidelman 1959; Raheja 1988). Marriott and Inden (1977) introduced the term “dividual” (as opposed to “individual”) to illustrate the concept that Indian identity is defined through relationships and exchanges with others.

The social and political landscape of India has changed radically since most of these authors were writing, but a tendency to ground one’s identity in relation to others—especially in family relationships—lingers in North India today. That this ideal is linked with notions of tradition and propriety in India is evident in the fact that discussions about the problems of modernity often center on the family conflicts that arise when a woman is working (Donner 2008), as in the case of Ankita, above. An educated stay-at-home mother who chose not to work in a job feels that the choice to work is a selfish one. She explained it to me this way: “If one is working outside, it's good for them, but it's not good for the other family members.” Other scholars have documented how members of the younger generation are judged as “good” or “bad” people based not on their personal achievements, but on the degree to which they care for elder family members (Cohen 2000; Vatuk 1990).

Unequal gender relations in North India are intimately connected to notions of tradition, family, and “dividual” personhood. Because middle- and upper-class women traditionally have not worked outside the home, the primary relationships that define these groups' identities have been, and continue to be, family relationships. Social scientists working in India observe that family-based practices such as arranged marriages at young ages (though illegal, child marriage does still occur), marital power dynamics, and patrilocality put women at risk of subordination, making the family a potentially crucial site of self-perpetuating oppression (Derne 1995; Krishnan et al. 2010; Liddle and Joshi 1989; Ray and Qayum 2009; Wadley 2002). Among socially mobile middle-class groups, the gendered behavior and movement of women both inside and outside the home is a crucial index of family status and propriety (Mandelbaum 1988; Mankekar 1999). This highlights a unique feature of India's modernizing process, which in addition to familiar features such as increased education, urban migration, and employment, also sometimes includes expectations that as families become more prosperous, women should behave in a *more* traditional manner. The result is a renewed emphasis with increasing development on conservative roles and expectations for women, especially among the rising middle classes who occupy a tenuous position between poverty and success (Derne 1995; Donner 2008). This is at least partially due to the fact that women are viewed as the guardians of "Indian culture" and "propriety," which people fear are waning with increasing Westernization (Liddle and Joshi 1989; Mankekar 1999). The tenuously-positioned middle classes often depend on women to raise their children in a manner consistent with "traditional" values, yet also to help elevate the family status by bearing sons and preparing their children to be successful in India's increasingly competitive educational system (*Ibid.*).

The result of these complex interactions between collectivist identity, development, and gender is a double standard for middle-class women that pivots on the fact that their activities shape and are shaped by the status of their household members. The result is that women often receive fewer of the development-associated dividends that their other family members may enjoy. Rita and Maya, both members of relatively financially-secure middle class families who came from poor backgrounds, do not seem to benefit from the social mobility that their families have won in urban Delhi; neither woman has any formal education, and both suffer from unaddressed mental disorders. Both women's main responsibility is household management, which limits their social and physical mobility. Rita feels uncomfortable going to market alone because her caste group traditionally does not allow women to go unchaperoned in public, and Maya has to ask permission from her overbearing in-laws to have a visitor in her home. Both women's vulnerability to diabetes complications is almost certainly related to their family roles. The centrality of women's activities to family honor and the collectivist nature of North Indian societies ensure that women are consistently taught to place family-care ahead of self-care. They are enculturated, in short, to shape their daily lives around the collectivist, "dividual" ideal of personhood. When they are not able to attain this ideal, as in Ankita's situation, significant stress can result.

Another major source of the cultural emphasis on women's self-sacrifice is Hindu morality, which reenacts this sacrificial ethos through fasting and symbolic sacrifices to the gods that women perform on a daily, weekly, and monthly basis on behalf of their families. Sacrifice by women on behalf of others also plays a key role in the Hindu epics *Mahabharata* and *Ramayana*, told and retold at festivals and in two wildly popular television series aired in the late 1980s on Doordarshan, India's largest public television station (Mankekar 1999). Both epics feature self-sacrificing female protagonists.

Briefly, the Mahabharata tells the story of the five good Pandava brothers, who lose their kingdom and finally their polygynous wife Draupadi to two evil brothers in a wager. The evil brothers insist on publicly disrobing Draupadi to demonstrate their power over the Pandava clan. Because of her extreme piety, the god Krishna hears Draupadi's prayers for help and rescues her from this injustice by making her sari never-ending, so that it cannot be unwound to reveal her nakedness. Mankekar's (1993, 1999) ethnographic work among viewers of the Mahabharata television serial demonstrates how Draupadi was intentionally depicted by the producers as a symbol of Indian womanhood and nationalism, but interpreted by female viewers as a symbol of the injustices Indian women bear at the hands of men. This woman-as-sacrifice depiction of Draupadi feeds directly into ideas that equate sacrificial women with piety and virtue.

Similarly, a pivotal event in the Ramayana, the other major Hindu epic, is the heroine Sita's abduction by Ravana, the demon king who wants the beautiful Sita for his queen. Before Ram, Sita's husband, accepts her back as his wife, he demands that she prove that her honor has not been compromised by Ravana during her kidnapping. Sita accordingly throws herself on a blazing fire, praying to the fire god, Agni, to protect her if she is "pure." Agni delivers her unharmed into the arms of Rama. This episode evokes *sati*, a highly praised act of self-sacrifice in Hindu religious history in which a widow commits suicide by throwing herself on her husband's burning funeral pyre out of devotion. It also is a larger-than-life representation of more mundane fire sacrifices to the gods, a key component of everyday Hindu ritual, with woman-as-sacrifice.

But the values portrayed in these epics are not only relevant for India's Hindu majority. The ideal of women's sacrifice depicted in the Mahabharata and Ramayana permeates notions of righteous and patriotic womanhood even among non-Hindu groups. Non-Hindus are generally familiar with the stories of the Ramayana and the Mahabharata, and many followed the television serials when they were aired (Mankekar 1993, 1999). As part of the Hindu revivalism that continues into the present, Hindu morals have become conflated with ideals of Indian patriotism, womanhood, and propriety (*Ibid*.). Although the values of women's sacrifice may be Hindu in origin, they have been adopted as part of Indian nationalist rhetoric and constitute a powerful driver of the contemporary emphasis on women's self-sacrifice as an expression of devotion to both family and nation (Mankekar 1993).

India's popular media is yet another force promoting the reinscription of the self-sacrificial archetype for women in North India. Perhaps the most well-known contemporary example of this archetype can be found in the epic 1957 film *Mother India*, one of Bollywood's most successful films of all time, which is said to occupy a cultural space similar to *Gone with the Wind* in the United States. The film tells the story of Radha, a long-suffering village woman who struggles to raise her sons with a strong moral compass despite the machinations of a dishonest moneylender. She endures loss after loss with stoicism, including the moneylender's repeated insults of her honor and chastity, while working to exhaustion to support her sons. In both character and visual depiction, Radha appears almost goddess-like in her self-sacrifice and represents a pervasive cultural model of the ideal Indian woman (Thomas 1989).

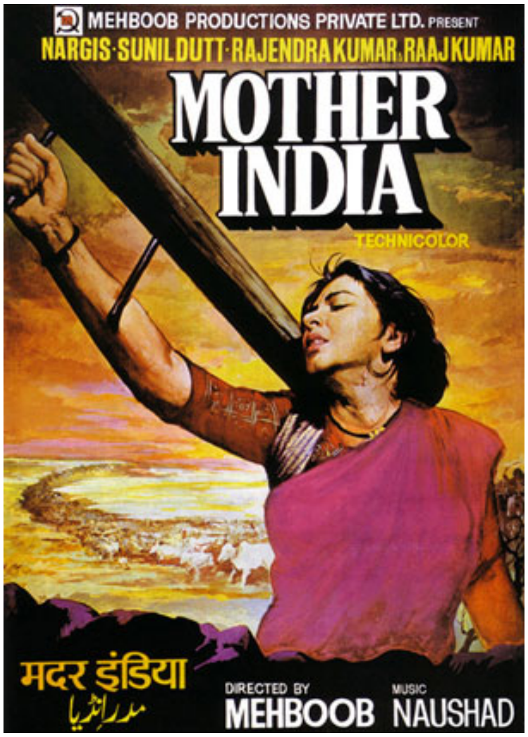


Figure 10. Film poster from *Mother India* (Mehboob Studios 1957) depicting the long-suffering heroin, Radha.

This cultural ideal persists in media portrayals of Indian women, where newspapers regularly lionize Bollywood actresses who place family responsibilities ahead of their careers with headlines like “Marriage is my first priority,” and “’I am not ambitious’” (Hindustan Times, 9 and 12 October 2011). The former article, reproduced in Figure 13, below, quotes actress Shilpa Shetty saying that she misses her acting work but has “learnt to prioritize things” and “obviously” places her marriage first. This headline runs alongside a photo of Shetty projecting an internationally appealing ideal of beauty—thin, wearing revealing Western-style clothes, hair long and unbound, and light-skinned—that does not at all resemble a traditional Indian woman.

Marriage is my first priority: Shilpa

Actor **Shilpa Shetty** (right), who is returning to the big screen after four years with the Sino-Indian venture, The Desire, says she missed being on the celluloid, but has learnt to priorities her life with time.

"I miss being on the silver screen, but I have learnt to priorities things and my marriage is obviously my first priority," says the 36-year old actor, who wants to focus on her personal life and business.

"I have taken a backseat from showbiz purely out of choice because I am really enjoying what I am doing. I've been there and done that," said Shetty, who married Britain-based Indian businessman Raj Kundra in 2009.

IANS

Figure 11. An article published in the Hindustan Times, India's largest-circulating newspaper, on October 9, 2011 reports on Shilpa Shetty's choice to stop acting after her marriage.

The juxtaposition between Shetty's modern appearance and her traditional statement is a striking reminder of the difficult negotiations women are making between tradition and modernity in North India. While women like Shetty seek to project a modern, Westernized persona through their appearance, they simultaneously make efforts to publicize traditional life choices that their Indian women fans may identify with, such as "obviously" prioritizing marriage over one's career or declaring oneself "not ambitious." This incongruence is at once a reflection of the value placed on family over individual priorities in North India's collectivist societies (choosing family over career, for example), an indicator of women's partial movement away from this value. The pull between modernity and tradition puts women all over India in the difficult position of conforming to new standards of productivity and beauty, while still maintaining traditional obligations to family and home.

A Habitus of Self-Sacrifice

This survey of Indian historic, religious, and popular culture demonstrates how pervasive the figure of the self-sacrificial woman is in North India. But how and why do women continue to conform to this ideal, when it seemingly encourages them to ignore their own health needs? According to social theorist Pierre Bourdieu, people's actions are guided by implicit social inequalities that are "inscribed in the most apparently insignificant aspects of the things, situations, and practices of everyday life" (Bourdieu 1991: 51). Collectively called "habitus," these mundane practices of everyday life create inequalities that are deeply embedded, unconsciously produced and reproduced by both the dominators and the dominated. People are so "immersed," to borrow Charmaz's (1991) term, in these omnipresent modes of being that it becomes difficult to recognize them. Existing somewhere between complicity and freedom, *habitus* is comprised of unremarkable dispositions, preferences, and forms of knowledge that "function below the level of consciousness and language, beyond the reach of introspective scrutiny or control by the will" (Bourdieu 1984: 466, cited in Kontos 2004).

I suggest that the pervasive North Indian cultural emphasis on women's self-sacrifice amounts to a *habitus of self-sacrifice*, and that this habitus interacts meaningfully with women's efforts to control their diabetes. North Indian social structures of interdependent family and patriarchy dictate that women should prioritize others over themselves, and the internalization of these cultural expectations increases vulnerability to diabetes complications for women like Rita and Maya, and vulnerability to poor mental health for women like Ankita. Like all forms of habitus, this habitus of self-sacrifice is forged from multiple cultural processes and structures, including those we explored above: 1) historic relations between caste, gender, and exchange, exemplified by lingering conceptions of personhood in North India that pivot on interpersonal relationships rather than individual traits and qualities; 2) women's sacrificial activities as a key part of Hindu religious morality, exemplified by religious rituals and female characters in Hindu epics; and 3) popular media representations of ideal Indian womanhood that include the quiet endurance of suffering, exemplified by the classic film *Mother India*, and which praise women for leaving careers to focus on family, exemplified by the newspaper article about Shilpa Shetty. The habitus of self-sacrifice is comprised of the many everyday actions and interactions that arise from these features of contemporary North Indian society. As we will see in the next section, it jeopardizes good diabetes control among North Indian women by predisposing them toward low levels of diabetes self-care.

Self-Sacrifice in Action: Health Behaviors among Diabetic Women

In a mix of Hindi and English that is common among Delhi's middle classes, a youthful homemaker wearing fashionable Western clothes with her three-year-old son perched on her lap explained to me, "*Apne bare mein zyada nahin sochna* [I don't think too much about myself], you know? The family comes first. If there is *baki* [extra] time, then I read a book or something."

The attitude exemplified by this woman’s statement, “I don’t think too much about myself” can at times be harmless, but it often gets translated into women’s denial of their own suffering, lack of healthcare seeking, and concealment of ill health. Unsurprisingly, when such a habitus of self-sacrifice intersects with a chronic disease like diabetes that requires significant self-care, conflicts can arise. Women’s denial of their own suffering creates and exacerbates physical and mental illness, sometimes to the point that it seriously endangers their wellbeing.

Rita’s and Maya’s health crises, presented above, provide clear examples of this cultural norm in action. When I asked Rita if diabetes had affected her household, she responded, “Yes, it has. I can't do all the work myself and take care of the house in a proper way. When things are scattered around the house, I want it to be tidy. I want the house to be okay, I want to look after the shop, and I want to cook for the family, but my body doesn't let me.” Her husband agrees: “There's a lot of household work. If she eats rice, then she'll get leg pain, and she'll create conflict because she can't do any work.” Rita’s impairment has also affected her teenage daughter, who is studying in the 10th class and hopes to go to medical school someday. She explains, “I don't know where my childhood has gone. I'm now 16 years old, but I have no idea how I got here. It's been four or five years since I've been looking after the household, since Mommy got diabetes. I make the food and do the cleaning.” Under normal circumstances, Rita would be expected to manage the household and all of the cooking.

Rita experiences significant psychosocial conflict about the fact that she is unable to participate in her former domestic roles, and this impacts her mental health. Rita’s husband and daughter do not blame her for her impairment, yet they do express frustration about the extra burden it places on them. Rita herself recognizes the importance of her role as household manager and laments the fact that she simply cannot do it all. She seems to feel compelled to justify her incapacity by emphasizing that although she'd like to do the work, her body "doesn't let me." This guilt is a prominent source of strain in Rita's family life, one that likely contributes to her suffering mental health. Paradoxically, Ankita's well-controlled diabetes is *also* a source of strain in her life, adding "another layer" of stress that impacts her mental health.

Rita's and Ankita's stories differ with regard to how this diabetes-related stress does or does not become embodied in poor physical health. Ankita keeps her physical health in check despite distress, while psychosocial conflict over Rita's disability perpetuates her physical health problems. Because domestic roles are no longer available to her, the main route through which Rita can demonstrate culturally appropriate self-sacrifice is to minimize her poor health. Rita comes to embody the norm of self-sacrifice by avoiding asking for help when she needs it. When she runs out of medication, Rita allows her very real need for insulin to go unfulfilled because she is worried about irritating her busy family members. Instead, she engages in "quiet suffering" until her health reaches a state that can no longer be ignored. Rita's concealment of ill health is a clear example of the tendency documented by other scholars working among Indian women to delay treatment until their health reaches a crisis state (Basu 1990; Conrad and Pacquiao 2005; Kielmann and Bentley 2002). It is also a product and an expression of a habitus of self-sacrifice. Most importantly, Rita's delay in care-seeking has seriously endangered her health more than once.

Ankita, meanwhile, strives to fulfill family-oriented tasks such as directing the maid's housework, entertaining, and running errands for the household, all while working and juggling her diabetes management. She concedes that she has had to swear off some of these activities after seeing how strongly they impacted her physical health since she got diabetes a year ago. Unlike Rita, Ankita lets the activities go in a bid to preserve her health, and it seems to be working—at least physically. Her mental health, on the other hand, is suffering significantly more so than Rita's, according to their comparative scores on the depression and anxiety questionnaire (Ankita's HSCL depression and anxiety scores are 1.7 and 1.6, respectively, while Rita's are 0.7 and 1.0, respectively. A score of 1.75 or above is considered clinically significant, so only Ankita has depression and anxiety scores approaching levels suggesting diagnosable disorders.)

Maya, a younger woman with early-stage diabetes, also displays self-sacrificing tendencies that portend a worrisome future health trajectory. Her crises remain largely undetected and unaddressed, however, since they have not yet created an acute bout of ill health. They also remain undetected because Maya is careful to keep her problems to herself. A close look at Maya's physical and mental health symptoms reveals much about her adverse social situation, which has become embodied in many ways. Noting how surprised people are to learn that she is pre-diabetic at such a young age when no one else in her family has the illness, she attributes it to the "tension" she experienced when her husband died suddenly. Her illness itself thus functions a relic of the trauma of her husband's death. She reports severe depression, anxiety, and tension connected directly to her conflicts with her in-laws, the strains of which are visible in her tired-looking face. Finally, the bruises on Maya's arms hint at family conflicts she experiences as a woman indebted to her parents-in-law for supporting her after their son's death. Maya's case illustrates how social inequalities and traumatic events become embodied, that is, how her experiences of disadvantage literally "gets under the skin" to shape her biological processes (Worthman & Costello 2009). It also demonstrates the quiet power that a habitus of self-sacrifice can exert over both mind and body.

Before moving on, it is important underscore once more that self-sacrificial norms not only affect physical health; they also affect mental health through complex pathways. One such pathway is the conflict women like Rita and Ankita feel about not being able to participate fully in domestic roles that legitimate their status as "good women." These include domestic tasks such as house cleaning, food preparation, and childcare. Rita's guilt about task-shifting household responsibilities onto her daughter and husband, for instance, takes away crucial opportunities for her to participate in the self-sacrificial role that is such a key part of North Indian conceptions of good womanhood. Ankita's struggle to manage her diabetes health with other responsibilities is working out in terms of her physical health, but is wreaking havoc on her mental health.

A second pathway through which self-sacrificial norms impact mental health is the concealment of suffering in an effort to preserve "good womanliness" by not complaining. All three women whose stories were presented in this chapter engage in this kind of self-effacement. Rita holds onto quiet suffering as one of the few remaining performances of self-sacrifice available to her in her physically disabled state. Likewise, the young widow Maya attempts to accommodate her in-laws' expectations by remaining isolated in her home, where she has neither access to friends nor to healthcare providers with whom she could discuss some of her sorrows. Instead, she says, she tells them only to God, and in particular tries to conceal her sadness from her children. Ankita dismisses her extraordinary distress as something that "everybody feels" sometimes. While a habitus of self-sacrifice is harmful for physical health by impeding women's care-seeking, it is equally if not more harmful for mental health because it sets up expectations that may become unattainable if a woman has diabetes or another chronic disease.

Self-Sacrifice and Patient Care: Physicians' Perspectives

Women's self-sacrifice has important clinical implications for diabetic women's health, a fact that their physicians often commented upon. Many of the nine physicians with whom I worked specifically identified self-sacrifice as a key barrier to their female patients' diabetes management.

All the physicians involved in my study are senior consultants at public and private hospitals in Delhi, belong to an organization called the Research Society for the Study of Diabetes in India, and completed their medical training during or before the early- to mid-1980s. Many specialized in cardiology, the only specialization available in India at the time, but gradually shifted their practice toward endocrinology or cardio-diabetes through continuing education, residency programs, fellowships abroad, and clinical experience. All but one are men. In our interviews, I asked about the general trends and obstacles they noticed in their female patients' physical and mental health management (see Appendix for the full list of physician interview prompts), but did not ask specifically about self-sacrificial tendencies. Still, they came up frequently. As Dr. Uppal, a general physician working in Delhi's public hospital system, remarked, "There has been a tradition in India that ladies eat last at the meals. The possible explanation for this could be, like suppose you fall short—then the lady adjusts. She won't cook for herself. So this kind of sacrifice for the family is done by the ladies. More or less, more or less that has been the culture."

I often began interviews with physicians by asking how their female patients were doing with diabetes control. Although the vast majority of physicians in India, and especially diabetologists, are men, they were often sensitive to the unique struggles that their women patients face. Dr. Patel, a former head of diabetes care in two well-known hospitals who now operates a private practice, commented, "Most of them have lots of trouble. Females in Indian society, all said and done, are still ignoring their own selves because of family compulsions and male dominance. Of course the scenario is changing, but that is only with the younger class. The 40-plus classes are still behaving the same, ignoring the females in the family, male-centric." Dr. Saxena, a meticulous cardio-diabetologist who has worked for over 30 years at one of India's leading cardiac hospitals, agreed that diabetic women's health control is generally "still very far behind the gentlemen. Still!" he exclaims, throwing up his hands in a gesture of disbelief. "Most of the time, the reason is that this lady is a housewife. She's not working, so when she's not working she's doing everything [at home]. So the attention that she gets is less, and the attention that she gives to herself is less." In short, he finishes, "They are not being looked after well, even by themselves."

These male physicians' perceptiveness is a product of decades of working around—and sometimes against—the restrictions on self-care that accompany women's traditional roles as homemakers. Yet, although they understand very well the physical health impacts of the conflict between women's self-care and their "family compulsions," as Dr. Patel describes them, diabetologists sometimes miss the effects on mental health that arise from this tension.

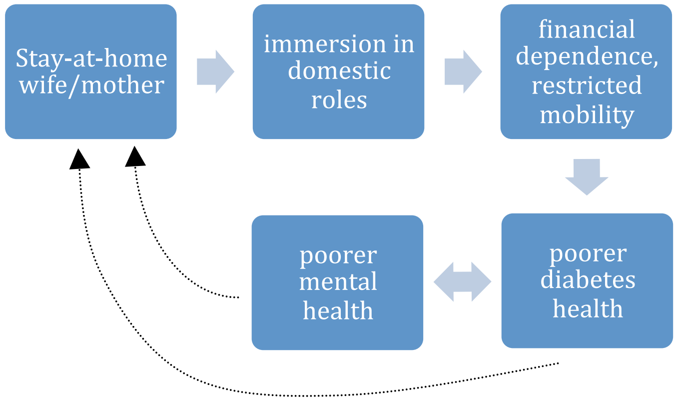
Dr. Nair, a young female psychologist with a budding research career, feels that women's conflicting family roles are a key source of stress. She explains that women feel torn by the multiple roles of caring for children, home, and their own work. The scenario she outlines bears an uncanny resemblance to Ankita's situation. "Again" she says, "the multiple roles stuff. Typically, their mental and physical health is last on their priority list. That's why women come in [to clinics] less—not because I think they have less [*sic*] disorders or less problems, but simply because they don't place their mental health or their physical health at priority. Neither do their families, nor do the women themselves." It is not just a lack of time, however, that prevents women from taking care of themselves. Prevailing patriarchal attitudes also train women to direct their time and energy toward others, so that even when they *do* have extra time, they are unlikely to devote it to themselves.

Take, for example, the issue of household food preparation. Dr. Sharma, the only woman diabetes physician I worked with (and in fact one of the only female diabetologists in Delhi) explained her female patients' conundrum this way: "If the man has diabetes, the whole family changes. If the woman has diabetes, nobody changes except her. The husband is certainly not going to change." Dr. Sharma continues, "The woman is not going to cook a separate meal for herself. You know, you cook for the whole family, and then you should say, 'I've gotta cook something different for me.' It's just not possible." Dr. Gupta, one of Delhi's top diabetologists who sees elite patients from all over India, points out the classed element of food struggles. "There's a certain class of patients I see where no one has ever entered a kitchen. They have an army of servants doing everything, and they are able to manage better, actually, because everyone can have different food every meal. That [separate food] is the biggest challenge in a regular middle-class family, that's a big challenge." Although it certainly is not the only source of conflict for women with diabetes, the preparation of food is important because it is loaded with the symbolism of family caste, financial status, regional identity, and nurturance (Donner 2008; Liddle and Joshi 1989; Smith 1990). Therefore it is perhaps the domestic task *par excellence* for most stay-at-home women, and any kind of change in this realm involves significant inertia. Even if they do have the time to cook separate food for themselves, most women cooking for their families will make food as per their husbands', children's, and in-laws' tastes and preferences.

Doctors agree that women's financial dependence is a major contributing factor to their self-sacrificing behaviors. "The *whole thing* boils down to whether it's a working lady or a housewife," intones the meticulous Dr. Saxena, with a sharp slap on his desk for emphasis. He elaborates, "Mostly in these families, the males are the head of the family and the earning member, so they have access to all the funds, while the funds kept aside for the lady are much less. …There is an unwritten rule that the least money should be spent on her treatment." Indeed, literature on healthcare spending patterns in India suggests that from childhood onward, less money is spent on girls' and women's healthcare as compared to their men's (Pandey et al. 2002; Ramakrishnan et al. 2011). In this and many other ways, a habitus of self-sacrifice is shaped from birth. Dr. Saxena explains how this comes about: "See, if she starts spending five or 6,000 rupees on every visit, it's not liked. So she goes to a GP who charges 50 rupees, and in 50 rupees she only gets a prescription. No counseling, no advice, no monitoring of the diet and exercise on every visit, and even the prescription is not backed by evidence-based medicine. The GP will just say, '[Take] sugar medicine, one morning, one evening' because he's going to give her five minutes for his 50 rupees." By not paying for specialized care, according to Dr. Saxena, women compromise on their own health. Yet, they are pushed toward seeking cheaper care (or in some cases, no care) because of family pressure.

Some doctors feel that the solution to nonworking women's self-sacrificial behaviors is to get women working in formal jobs. Although working outside the home brings its own stresses, many of the physicians agree that their working patients fare better than their stay-at-home counterparts. Working gives women some financial autonomy. Dr. Saxena explains: "Because they are working, they don't have to borrow money from their spouses. They are mobile; they have vehicles, so they can go to the hospital to have a test, laboratory. So they are more empowered." As a result, he claims, "You've got business ladies, executive ladies, absolutely finely controlled." Dr. Sharma, the female diabetologist, agreed that working women seemed to fare better than nonworking women, but she believes this is because of limited opportunities for grazing in offices, as opposed to at home. "I would think probably the people who work—I mean, we haven't done any studies on this—but they are probably a little better off because if you stay at home, you snack here, you snack there. You graze when you're at home. At work, it's specified. You can't keep eating all the time."

The physicians outline a conceptual framework that would look something like the following two models:



VERSUS

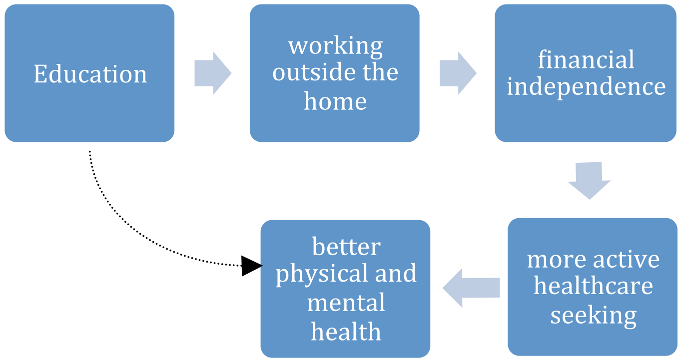


Figure 12. Two conceptual models depicting physicians' perceptions of the relationships between patients' employment status, education, and health.

The relationships between education, traditional roles, financial autonomy and health are likely more complicated than these pathways suggest, and are probably reciprocal to some extent. I have attempted to indicate these subtleties using dashed and double-headed arrows in the models above. For instance, we know that poor mental health and diabetes interact (illustrated by the double-headed arrow in the first conceptual model). Women with poor mental and physical health may also be more likely to remain in stay-at-home roles than their healthier counterparts, who would have more of the physical and mental energy required, should they decide to take a course or seek employment.

It is also important, however, to acknowledge that a working woman is not necessarily a financially independent woman, a fact that the doctors rarely noted. Dr. Saxena's working patients who are "absolutely finely controlled" are professional women in powerful executive positions, not those working in the informal sector as domestic help, day laborers, or selling street food. Women I met who worked in the informal sector (like Sita, the orphaned domestic worker from Orissa whom we met in the previous chapter) almost invariably had poor diabetes control. Of the 29 diabetic women included in my study who work in the informal sector, I saw only one with good diabetes control, a maid who lived with and worked for one of my diabetes physicians and benefited from his informal health guidance.

Furthermore, although health benefits are sometimes linked to economic status, they do not necessarily come easily. As noted earlier in this chapter, women with more education sometimes paradoxically face additional domestic responsibilities such as tutoring their children which curtail their ability to act independently in the interest of their own health (Derne 1995; Donner 2008; Seymour 1999). Similarly, having access to money does not necessarily translate into economic independence. Being the wife of a wealthy man, for example, may mean a high standard of living but does not guarantee economic freedom that then translates into better diabetes control. Dr. Gupta, the physician with elite patients from all over the world, explains, "Even in Delhi, even in the kind of patients I see, these kinds of things [diabetes control problems] are linked to economic dependence." It seems that the women who reap noticeable health benefits from their economic situation are both highly educated and working in the formal sector, while those with family money or those who work in the informal sector benefit much less directly, if at all, from their financial status.

And finally, as Ankita's story demonstrates, a working woman is not always a happy woman. While the doctors acknowledge that working comes with "its own stresses," they tend to underestimate the degree of stress that can be associated with the efforts to balance household and parenting roles, work roles, and diabetes self-care. Although Ankita's diabetes is well controlled, she is vulnerable to poor mental health, and this seriously impacts the quality of her life. Her elevated levels of Epstein-Barr Virus antibodies and C-reactive protein indicate that despite good blood sugar control, Ankita's more general physical health is at risk. Her immune system appears to be compromised, and her elevated C-reactive protein suggests that she is at risk of cardiovascular diseases despite having controlled blood sugar. These elevated blood levels are probably partially related to her chronic depression.

To recap, physicians and other healthcare providers agreed that women's self-sacrificial attitudes contribute to poor diabetes self-care and to untreated mental health problems. Several also asserted that financial dependence is the main cause perpetuating this self-sacrificial behavior. Although the clarity of this idea is appealing, the reality is perhaps more complicated. In addition to financial status and other personal characteristics, as the earlier sections of this chapter suggested, there are larger cultural and social forces at work that influence the choices women make, and the range of choices that are available to them in the first place, when most are working as primary family caretakers. Most prominent among these, based on my work with North Indian women, is a habitus of self-sacrifice.

Conclusions: Vulnerability, Quiet Suffering, and Society

This chapter explored North Indian women's diabetes crises and the ultimate sociocultural sources of their vulnerability to these crises. I suggested that a culturally inculcated and valued habitus of self-sacrifice jeopardizes diabetic women's ability to manage their health in this North Indian cultural context. Grounded in historic relations between caste, gender, and family, notions of Hindu morality, and popular representations of ideal womanhood, the cultural ideal of women's "quiet suffering" is deeply entrenched in North India. This habitus of self-sacrifice can be thought of as a fundamental cause of ill health, and it appears to affect diabetic women's physical and mental health at least as much as proximal factors (like individual levels of education, working status, or socioeconomic status) do.

The cases presented in this chapter illustrate that a habitus of self-sacrifice shapes women's health-related behaviors in important ways. According to this norm, women should prioritize care for family members over self-care, and as a part of this duty, should avoid complaining. There is a fundamental clash between this cultural norm and the intensive self-care required to manage a chronic disease like diabetes. Women like Rita and Maya internalize the cultural emphasis on self-sacrifice in their own lives by concealing symptoms of ill health until they reach a crisis state. Meanwhile, Ankita takes care of her physical health but appears to experience extraordinarily high levels of mental distress partially as a result of her inability to fulfill these self-sacrificial norms. Rita was apologetic about her disability, and reluctant to ask family members to obtain her diabetes medicines for fear of inconveniencing them further. This hesitation caused her health to deteriorate until she was admitted to the ICU. Maya, in contrast, concealed her fatigue, dizziness, headaches, potential physical abuse, and mental health problems. She had never been to the doctor for a diabetes checkup, although she regularly accompanied her mother-in-law to the endocrinologist who diagnosed her with pre-diabetes. This low healthcare utilization means that women like Rita and Maya endure significant physical suffering that could be prevented, or at least ameliorated.

In addition to its implications for physical health, a habitus of self-sacrifice among North Indian women affects mental health as well. The expectation that women should place family responsibilities first creates psychological conflict by causing women like Ankita and Rita to feel stressed when they cannot fulfill expected gender roles. In addition, the expectation that women should avoid complaining causes women like Maya and Ankita to conceal depressive or anxiety symptoms, lest they be perceived as excessively self-involved. As Maya says, she feels that she can only share her problems with God. Ankita dismisses her distress as “normal,” and consequently does not seek mental healthcare, although her high levels of depression and anxiety symptoms suggest that she should.

Indeed, the cost of *not* fulfilling self-sacrificial social roles is often one's mental health in cultural context. For women like Ankita who cannot adhere to self-sacrificial norms because of career responsibilities and efforts to maintain blood sugar control, stress and depression can override any improved quality of life they might otherwise gain by being more autonomous than the average North Indian woman. The habitus of self-sacrifice thus creates an impasse for many women with diabetes, where adherence often means sacrificing diabetes control, while lack of adherence may mean sacrificing mental health.

Among the nine physicians who participated in this study, doctors Uppal, Patel, Saxena, Sharma, and Gupta commented at length about how women's traditional domestic roles contribute to their vulnerability in diabetes. Without prompting from me, they also identified self-sacrificial tendencies as a key source of conflict for women's diabetes control. In particular, they reported that their patients struggle with dietary recommendations because their family members' food preferences usually take precedence, and women do not have the time to make separate meals for themselves. The expense of good diabetes care was also a realm of conflict. Although they acknowledged that working is stressful in its own ways, the doctors agreed that their female patients who work in the formal sector fare better with diabetes than non-working women or women working in the informal sector, because they are more educated, financially more independent, and have access to informational resources such as the Internet and educated co-workers. The pathways laid out by the physicians linking education to health may be oversimplified, as some of my findings and the other literature on South Asia suggests, but they hold a grain of truth as well.

Ultimately, many women's self-sacrifice is embodied, and reinforced, through their experiences with poor diabetes control, but poor diabetes control may reciprocally cause women to further embody and reinforce self-sacrifice as well. Pausing thoughtfully during our interview, Dr. Patel, the physician who trained in Australia, commented, "You know, it is an odd thing in Indian society: to suffer makes you great in your own eyes or something." This concept of "noble suffering" suggests that in some ways, poor health can act as an embodied signal of successful fulfillment of self-sacrificial roles for Indian women. While diabetic women do not, of course, consciously sabotage their own health in a bid to appear virtuous, there are cultural incentives associated with embodying the image of the woman who is so busy caring for her family that she cannot manage her own health. The fact that this role exists in shared cultural understandings of *what women should do* or *how women should be* paves the way for women to slip into it without the intention of doing so. For some diabetic women, therefore, poor health may serve as an index of womanly morality and righteousness.

Perhaps it is easier to understand this phenomenon if we explore the reverse. There is *not* a culturally shared role of a self-nurturing female in North India's shared social consciousness. Therefore, diabetic women like Ankita who are inclined toward self-nurturance do not receive culturally endorsed reinforcement for their self-care behaviors. Although they may enjoy better physical health, they receive no cultural currency for their self-caring actions and therefore may experience significant stress. In contrast, because there *is* a culturally-shared role of a self-sacrificial female household member in North India, diabetic women who are inclined toward self-sacrifice receive cultural reinforcement for these self-sacrificing behaviors.

The cultural emphasis on women's self sacrifice in North India means that many women who become diabetic were predisposed toward self-sacrificing behaviors before their diabetes ever set in. Although their health suffers with diabetes, they receive cultural currency for their self-sacrificial actions, not only "making you great in your own eyes," as Dr. Patel commented, but also elevating their status by meeting deeply held expectations of what women should do. Self-worth and self-image therefore emerge as more important than self-care in this context. Vulnerability to diabetes complications is a key arena in which a habitus of self-sacrifice becomes reinscribed in the bodies of women. In the next chapter, we will examine the cases of women who depart from this trend and explore ways that the cultural conflict between gendered family care roles and diabetes self-care may be eased to improve diabetic women's health.

CHAPTER 6: RESILIENCE

LIVING WELL WITH DIABETES

This chapter is about women with diabetes who fare well despite their illnesses and other life adversities. It shifts our emphasis away from the illness problems that were the focus of the last chapter, and instead focuses on the experiences of women who are doing well with diabetes, mental health, or both.

Growing out of positive psychology, resilience theory has become an increasingly popular framework for the study of health-related behaviors that promises to help us understand what allows some people to thrive with adversity (in our case, a chronic illness), while others flounder. The umbrella concept of resilience has been defined as a "self-righting mechanism" (Werner and Smith 1992: 202) possessed by all people to some degree. One's level of resilience depends on personal and environmental characteristics, including things like optimism, self-esteem, humor, communication skills, planning skills, and good memory; as well as social support from family and peers, and recent stressful events (Benson et al. 1997; Garmezy 1991; Garmezy, Masten and Tellegen 1984; Richardson 2002; Werner and Smith 1992).

Resiliency's orientation toward human strengths is a relatively new approach in psychology, medicine, and allied health fields, which have traditionally been dominated by a problem-focused approach that seeks to correct things that are wrong (Richardson 2002). This problem orientation has dominated medical anthropology as well, according to Obrist (2003), who observes that “health is a neglected topic in anthropology” (275). Instead, its inverse, illness, has dominated medical anthropological research, including much of the present study. Exceptions include my exploration of cases such as Kalpana and Indu from Chapter 4, who thrived in spite of heavy family responsibilities and lack of formal education. Still, the diversity of resilient women’s experiences in this study deserves greater analysis than this dissertation has yet accomplished.

How does resilience work in real life? Richardson and colleagues’ (1990) resilience process model suggests that people generally maintain a state of emotional and functional homeostasis, which can be disrupted by life events. Following a disruption, people reintegrate into “normal” life in one of the following fashions: 1) Individuals may recover resiliently, having gained new knowledge, self-understanding, or increased strength of resilient qualities and having returned to a state of wellbeing comparable or superlative to their original level; 2) They may recover from the disruption, but only return to previous homeostasis; 3) They may recover from the disruption with loss of a motivation or hope; or 4) They may recover with dysfunction, using self-destructive behaviors, such as substance misuse, to cope with the challenge (Richardson et al. 1990).

A large body of research links resilience with better health. Resilience in these studies must be defined some way, but they all do so differently. The concept is often operationalized as one or more measurable qualities, including *health locus of control* (Wallston, Wallston, and DeVellis 1978; Wallston 1992), *self-efficacy* (Bandura 1977), *self-esteem* (Rosenberg 1965), and *self-mastery* (Marshall 1991). Scholarship on these qualities seeks to understand how people’s health-related behaviors are shaped by their beliefs about the amount of control they have over their own health and the amount of self-worth they possess. Unsurprisingly, people with a stronger sense of control over their health and higher self-esteem generally have better health. Although they are often treated as distinct, some of these constructs, like self-efficacy and locus of control, have significant semantic overlap (Judge et al. 2002). With the emergence of resilience theory, they have been reconceptualized as components of resilience and folded into resiliency studies.

Health locus of control, self-esteem, self-mastery, and self-efficacy have been used to explore the self-care behaviors of people with diabetes (Alogna 1980; Anderson et al. 2000; Bradshaw et al. 2007; Hurley and Shea 1992; Perfect and Jaramillo 2012; Peyrot and Rubin 1994; Schlenk and Hart 1984; Tillotson and Smith 1996; Yi et al. 2008; Yi-Frazier et al. 2010). Collectively, these studies agree that those who believe they have control over their diabetes and have high self-esteem have better compliance to diabetes care regimens and better use of health-promoting coping strategies. A high level of resilience, however, is not consistently associated with better blood sugar control in ecological studies among people with diabetes. Only some studies (Perfect and Jaramillo 2012; Yi et al. 2008) find that resilience, as measured by individual qualities such as self-esteem, self-efficacy, self-mastery and optimism, is associated with better blood sugar control. Barring these exceptions, most studies of diabetes and resilience find that although resilience improves compliance, it does not have significant effects on blood glucose or HbA1c. One study, for instance, used a resiliency training program to help people with type 2 diabetes in the USA cope with the stresses of illness management (Bradshaw, Richardson, and Kulkarni 2007; Bradshaw et al. 2007). Although this training intervention improved diabetic people’s self-reported quality of life and levels of physical activity, it did not improve their physical health as measured by HbA1c and waist circumference (Bradshaw et al. 2007). One can therefore conclude from the literature that factors like self-efficacy, an internal health locus of control, and resilience matter for diabetic people's quality of life, ability to cope with the stresses of illness management, and ability to consistently perform self-care activities mandated by diabetes management routines. However, these factors are not necessarily related to better physical health outcomes. This is similar to the findings of this research, which suggest that women who report doing well are not necessarily those attaining good diabetes management.

What personal and environmental characteristics facilitate resilience among women in this North Indian context? What does resilience "look like" in the realms of diabetic women's mental and physical health? Do women with mental health resilience also have physical health resilience, and vice-versa? Chapter 4 demonstrated that good blood sugar control was generally associated with enhanced ability to participate fully on one's work and family roles. Social support, autonomy, and good mental health helped women like Kalpana and Indu excel in their physical health management despite lacking other factors likely to promote good health, such as a high level of education. Indu's statement, "It's a very dangerous illness, this. I'm not afraid for myself; I keep in control" exemplifies a sense of self-efficacy; she feels confident that her diabetes management activities will protect her from the complications she has seen among others in her community who have died or had amputations as a result of uncontrolled diabetes.

Although many of the women in my study exhibited resilient qualities, they generally had poor blood glucose control. Of the 184 diabetic women interviewed, 162 agreed to have their HbA1c tested. Of the 162 women tested, only 18 women (11.1 percent) had an HbA1c blood test at or below the American Diabetes Association's recommended threshold of 7.0 percent for good diabetes control. In other words, the majority of the diabetic women with whom I worked were not achieving good blood sugar control as defined by biomedicine.

Furthermore, a majority of women attributed their diabetes to "tension," suggesting that distress would play a major role in their lives. Despite this fact, I was surprised to learn that the diabetic women in my study generally reported good mental health. Recall from Chapter 3 that the diabetic women did not report quantitatively more depression or anxiety than the non-diabetic women I interviewed. In fact, non-diabetic women report slightly *higher* mean symptoms of depression and anxiety than diabetic women, as measured by the Hopkins Symptoms Checklist (HSCL) for depression and anxiety, and a slightly higher percentage of people with clinically significant levels of anxiety and depression symptoms (refer to Table 1, Chapter 2). These findings are unusual among studies exploring type 2 diabetes and mental health, which typically conclude that people with diabetes have more symptoms of mental health problems than those without diabetes, or develop more symptoms of mental health problems post-diagnosis than they had before (Anderson et al. 2001; Golden et al. 2008; Knol et al.2006, 2007; Mezuk et al. 2008; Nouwen et al. 2010; Talbot and Nouwen 2000).

What is going on here? The fact that the diabetic women experience "tension," get diabetes, and yet appear to be no more anxious or depressed than the non-diabetic women is surprising. One possible explanation for this finding is that this group of women is self-selected to be more care-oriented than others, a result of the fact that they were recruited from medical clinics. Such women might be more proactive about guarding their mental health than those who do not actively seek care at medical clinics. This form of selection bias most likely affects my study results, but it does not adequately explain what happens to the "tension" women experience preceding their diabetes diagnoses in later years. A second possibility is that these women simply have a high level of resilience against the physical and mental health problems that often accompany diabetes. The various forms that this resilience might take are the focus of the rest of this chapter.

Below, I present four ethnographic case studies. The first two cases explore resilience among women who have undergone ordeals in the recent past and have come away from them with physical and mental health intact. This was unusual among the diabetic women with whom I worked; as the statistical analyses in Chapter 4 demonstrated, the number of stressful life events women had experienced in the previous year predicted HbA1c levels in a dose-response manner. Because many women in my study lived well with diabetes yet had poor blood sugar control, the second two cases will explore an alternative form of resilience among women who have poor diabetes control but good mental health and good quality of life. These four cases, taken together, shed light on the experiences of the many women in my study who led normal lives and had excellent mental health despite their diabetes.

In the Introduction, I presented a two-by-two table (Table 4) that categorized the diabetic women in my study as resilient or vulnerable based on their diabetes control and mental health scores. The majority of them (88, or 56 percent) fell into the category of being "resilient mentally;" that is, they had excellent mental health but poor diabetes control. Sixteen women fell into the category of being "resilient physically and mentally," meaning that they had good diabetes control and good mental health. Below, I will present four case studies. The first two illustrate the most common scenario in my study, where women had poor diabetes control but good mental health, while the final two represent the unusual case of having good physical and mental health. Comparison of these four cases will demonstrate the characteristics and resources that allow women to attain these two types of resiliency.

Mental Resilience: Two Case Studies

"Being resilient" can mean many different things. The resilience-oriented approach used in this chapter can provide insights into the experiences of women who do not have good diabetes control, but who still maintain good mental health. I referred to these women as "resilient mentally" in Chapter 1. Such women may experience a high quality of life despite their illness, with few or no symptoms of diabetes. Although biomedicine might dismiss these as noncompliant cases who will suffer diabetes complications later in life (and this may be true), the fact that many women with diabetes go through this stage of quiescence at some point, and may remain in it for years, suggests that it deserves full consideration as a part of illness experience in a exploration of the lived experience of diabetes. The same would be true for any illness whose early-stage symptoms are minimal and whose effects (in terms of poor health) are delayed.

From a theoretical standpoint, these cases are interesting because they "have" diabetes physiologically, but not socially or personally. The distinction I introduced in the introduction between disease, illness, and sickness is relevant here. Although they are very aware that they have diabetes, such women do not *seem* diabetic, in that there appear to be no functional consequences to their diseases. In other words, these women have the physical disease of diabetes but not the illness. This raises important questions about what diabetes really is: the physiology or the experience? Moreover, the two cases presented below force us to consider what is, and what should be, the ultimate goal of biomedical models for managing this chronic disease.

Sudesh, age 35, diagnosed 6 months ago, glucose 93 mg/dL, HbA1c 9.8%, CRP 3.0 mg/L, EBV 50.2 ELISA units[31]

Sudesh is tall and heavy (with a body mass index of 27.6, which is just below the cutoff for obesity in South Asian Populations; World Health Organization 2004), with a red streak of henna-dyed hair framing her face and a sparkly nose ring. Originally from India's poorest state, Bihar, Sudesh was married at 18 and migrated to Delhi thereafter. She and her husband's families still live in Bihar, where they support themselves by farming and running a pharmaceutical supply business.

Sudesh was recently diagnosed with diabetes, after complaining to her doctor of debilitating foot pain and dizziness. This diagnosis came at the end of a stressful year during which her husband had been unemployed because of a severe case of dengue

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[31] Recall relevant cutoff values for the blood biomarkers presented here:

Biomarker	"Healthy" value or relevant cutoff
Blood glucose	Should remain between 70-180 mg/dL
HbA1c	Should be < 7.0%
C-reactive protein (CRP)	"High" is above 3.2 mg/L (highest quartile)
Epstein-Barr virus antibodies (EBV)	"High" is above 178.9 ELISA units (highest quartile)

fever, and she attributes the onset of her diabetes to the “tension” she endured through that year. Her husband had recovered enough to get a job as a service man for a mobile phone company the month before we met, and this has resolved most of her stress. She now reports virtually no symptoms of clinical depression or anxiety (HSCL anxiety=0.17, HSCL depression=0.07). Her main source of irritation now, she says, is her new dietary requirements. “I can't eat anything, so I get sad. Sadness happens, doesn't it? Because I loved sweets, and now I've had to cut them out completely.” Sudesh’s very high HbA1c level of 9.8 percent suggests that her blood sugar is not under good control, but her relatively normal CRP and EBV levels indicate that this poor diabetes control is not unduly compromising her overall health, at least not yet.

Five months later, I arrive late at Sudesh’s small apartment after wandering through a warren of dark alleys too narrow for cars, populated instead by motorcycles and dogs. Her husband is once again unemployed, she tells me over the din of a television and the whir of an air cooler as she dashes out of the tiny front room to check on a pot of rice. He had to leave his job because his dengue-related body pain made it impossible for him to drive long distances on a motorcycle. When I remark that this must be hard for her, she disagrees. “Money is always coming and going, but the main thing for us is that their father almost died [last year]. The doctor said that it would be very hard to save him. Whether there's money or not is a small thing. Life is more precious.” Sudesh herself has considered working outside the home to generate some income, but she feels doubtful about the type of work she could get with her 10th grade education, and besides, she needs to remain home to look after her children and the household. These activities consume the vast majority of her time.

Sudesh's main diabetes management activities are diet control and intermittent walking. Although she still misses sweets sometimes, she has acclimated to her new diet in the five months between our encounters. Since it is mango season, she has been eating mangoes lately, but she has completely eliminated *chai* from her diet and eats rice and potatoes in limited amounts. Sudesh says that making these changes was not so difficult after all, reports that she feels physically much better, and seems to be getting on with life. She attributes this to her unique mentality:

> I'll tell you one thing: Actually, I don't take anything too personally. My mind is a little different. What's happened has happened; it makes no difference to me. People complain, 'Oh, I'm ill, I'm this, I'm that.' It's your thinking that makes your body feel sick. It's all in the mind. See, three days ago I had a fever. I didn't have the strength even to get up, but I took some medicine and felt a little better so I washed the dishes, did the laundry, and did the sweeping and mopping. I keep myself active. Like if I get some time, I go to the park at 6:00. I take water along because I get thirsty. I'll take five or six rounds in the park, then sit beneath a *neem* tree and eat some of its leaves. Then I get up again, and come back and do the housework. There are several people in the neighborhood who have sugar, like the Sardar's wife. She sits around brooding about her illness and acting so sick, just sitting there quietly. I'm not like this; I can go anyplace.

Sudesh takes no allopathic medicines for her diabetes but relies on Ayurvedic medicine, which she gets for free as a low-income patient from a well-known private hospital in Delhi. She prefers Ayurveda because the allopathic medicines gave her stomach acidity, and on several occasions when she had to skip her medicines for a few days because she did not have the money to refill her prescription, her symptoms would return immediately. She finds that the Ayurvedic treatment does not have these side effects, and otherwise prefers it because she is able to direct her own care to some extent. "I try to take care of myself with whatever herbal medicine knowledge I have. I take it according to my own desires. I take the things which I know about. I watch the Care-One [health] channel." Although Sudesh does not monitor her own blood sugar, she reports that it stays in control. Now five months into her treatment, she says she has no disability whatsoever ("I can do everything") because her leg pain has been completely resolved. She only complains of a little skin irritation on her feet that has not healed well since she got diabetes.

Krishna, age 55, diagnosed 10 years ago, glucose 167 mg/dL, HbA1c 7.7%, CRP 4.4 mg/L, EBV 35.9 ELISA units

Born in Delhi, Krishna leans back on her overstuffed, doily-clad couch as she explains to me that she was initially diagnosed with diabetes when she complained of severe leg pain more than a decade ago. She also suffers from hypertension. Krishna wears a light mustard-colored *salwar kameez* with red embroidery and sequins along the border, and metal bangles that cut into her plump wrists. Her body mass index classifies her as high risk (BMI 28.9) based on South Asian body mass cutoffs (WHO 2004). She and her husband live with their son, his wife, and their grandson in a shady upper-middle-class neighborhood of Delhi.

A deeply religious Hindu woman, Krishna does *pooja* (worship) twice daily and regularly attends *kirtan* (religious singing) at her local temple. Her faith mitigates any concerns about health that she might otherwise have. She explains, "I don't have any tension, my mind is free! God has given birth to us and written our fate, so we have to live through it. No one else can do it for us. If illness is written on our body, then we have to suffer it. This is why I'm never afraid that I have sugar or BP [hypertension]. When we have to die, we have to die."

Krishna has a relaxed attitude toward her diabetes medications, which she is supposed to take three times a day. She started feeling shaky and dizzy when she took them as her doctor prescribed, so she "decided to take them according to my own wishes." She elaborates, "I'm only taking it twice. I take the morning one, then I take the mid-day one in the evening. My sugar is coming out totally fine now. The doctor is away these days, so I haven't told him, but I've started feeling better since doing this." She self-regulates her medications based on her symptoms.

Krishna also adheres only partially to a diabetic diet, a fact that worries her daughter-in-law. This was the topic of a somewhat heated discussion during our interview:

> Daughter-in-law: I try to make as many things as possible boiled or with less oil. Mommy, there's a lot of oil in our food at this household. We don't eat as much at my parents' place. I don't like it, how much oil we add. Oil makes your sugar go up, no?
>
> Krishna: I don't eat that many vegetables anyway. I just eat a little bit of whatever is made. We don't add so much oil that the vegetables float around in it, just according to our preference.
>
> DIL: If we made it with less oil, it would be better. I mean, a lot—
>
> K: Hey, if we make our vegetables totally dry, then it seems like there's nothing in it. Look, we don't put extra *ghee* [clarified butter] on top. Just once in a while if someone makes me *parathas* in the morning they'll put a little light ghee on them. [To me] These people don't give me food! They give me the right amount to eat, and they tell me that I shouldn't put too much oil in the vegetables. Eesh! Everyone says I put too much oil in the vegetables.

Krishna gets up at 6:00 every morning to prepare her husband’s tea, but she delays her own breakfast until 9:00, after her morning *pooja* is complete, in accordance with the Hindu custom of worshipping before eating. Although her doctor instructed her not to eat sweets and most fruits, Krishna confides, “I won’t lie—I go to temple, so I'll eat a little *prasad* [devotional offering of fruit or sweets].” Like most Hindu women, Krishna also fasts regularly. During the upcoming *Navratra* (nine-nights) festival, for instance, she will eat only fasting foods during the day, such as fruit and fried potatoes, and will only take her diabetes medicines at night when the fast is opened. She has never had a problem with this kind of routine. “I stay totally fit, I'm telling you the truth. My body feels as light as a flower. Lord Durga allows me to keep the fast. If she didn't want me to, she would make it impossible for me.” Anyway, she concludes, “It's all in God's hands. We can't do anything.”

Although they differ in terms of age, duration of diabetes, and socioeconomic status, Sudesh and Krishna exhibit a form of resilience that was common among the women with whom I worked. It is distinctive because it results in good mental health, but does *not* transfer into good blood sugar control. In fact, part of what makes Sudesh and Krishna resilient is their ability to function healthily both physically and psychologically *despite* poor blood sugar control. In other words, blood sugar functions as an obstacle over which Sudesh and Krishna exhibit resilience.

In order to face life resiliently, Sudesh and Krishna draw on sources of psychological strength that they describe as crucial to their ways of understanding the world. For Sudesh, this mentality is partially comprised of her refusal to “take anything too personally" in life, and partially comprised of the new perspective she has gained in the wake of her husband's recent near-death: the realization that their money troubles (and other similar concerns) are "a small thing" compared to the catastrophe they would have endured had he actually died. Krishna's main source of psychological strength is her strong faith and daily religious practice, which keeps her mind free of worries about her diabetes or hypertension. Scholars studying resilience among people with diabetes have come to similar conclusions about the importance of religiosity for coping with diabetes among white and African Americans (Samuel-Hodge et al. 2008; Schlenk and Hart 1984). Sudesh and Krishna's carefree attitudes toward life allow them to respond to and deal with stress effectively.

Sudesh and Krishna also actualize resilience by actively working to balance their quality of life against their physical health. Chris Feudtner, an American physician and critical medical historian who writes about the history of diabetes care, describes this as "the chronically ill patient's archetypal dilemma: how to reconcile the pursuit of control over a disease with the pursuit of living well with that disease" (2003: 212). While it is a biological fact that people with diabetes will eventually develop physical complications if their blood sugar remains uncontrolled, the time it takes for complications to set in is quite variable between individuals and depends on a multitude of factors, such as how long they had diabetes before being diagnosed and how poorly controlled their blood sugar remains. Neither woman suffers with her high blood sugar at present, and although Sudesh has only been aware of her diabetes for six months, Krishna has remained in this state of quiescence for a decade. They may have a disease, but they do not act or feel particularly ill.

Sudesh and Krishna adapt their lives to their diabetes, and adapt their diabetes to their lives, compromising a little on each side. The choices they make may not be the most medically advisable from their doctors' perspectives, but Sudesh and Krishna apply commendable ingenuity to make their diabetes care routines work for them. Krishna's comment, "Eesh! These people don't give me food!" suggests that she feels harassed by the requirements of her diabetes management, and her own dietary modifications (e.g., adding oil to the vegetables, taking *prasad*) are motivated by her need to address these feelings of being constrained while keeping her blood sugar within a reasonable range—in other words, trying to balance the "archetypical dilemma" that Feudtner refers to above. Both have made efforts to change their habits after getting diabetes, especially their diets, but both have also altered their prescribed management routines to meet their own needs. Each woman eats foods that she has been told not to from time to time, Sudesh as a way to enjoy the short mango season, and Krishna as part of her religious practice. Each woman also alters her medications as she sees fit; Krishna takes less medicine than her doctor instructs her to do, while Sudesh alters her Ayurvedic medicines according to what she learns on TV.

As part of their modified approaches to diabetes, each woman also chooses an alternative rubric for monitoring her diabetes health. Instead of monitoring their blood sugar using a glucometer at home, a cornerstone of biomedical diabetes management, each woman judges the appropriateness of her food and medication routines by her body's response to them; after substituting Ayurvedic medicines for allopathic ones, Sudesh no longer has stomach acidity, while Krishna no longer feels dizzy after changing the quantity and timing of her medications. The method of monitoring they choose—how they feel physically—is intuitive and experience-near, not technocratic or removed from their own bodies, as blood glucose monitoring can be.

Again, the distinction between the disease of diabetes and its illness-inducing effects on life is important here. Medical anthropologists have been grappling with this distinction for decades, differentiating “disease” (the physiological dysfunction that a physician has been trained to diagnose using observable symptoms) from “illness” (the totality of how a sick person and his/her social network grapple with symptoms and disability resulting from that physiological malfunction) (Helman 1981; Kleinman 1988b). Neither Sudesh nor Krishna “acts” sick; as Sudesh explains, “sickness is all in the mind. …I keep myself active.” Although they have the physical disease of diabetes, they do not experience the social “illness” that often goes along with it, such as the loss of social roles or disability in daily activities that were demonstrated in Chapter 5. Sudesh and Krishna are resilient against the socially-mediated illness of their diabetes, even though they have the physical disease.

Furthermore, Sudesh and Krishna’s symptoms of “disease” are mild. Sudesh has some lingering skin problems that were present at the time of her diagnosis, and Krishna sometimes feels dizzy or fatigued if she eats lunch later than usual. Although these symptoms might give them legitimate reason to adopt a “sick role” that would exempt them from some responsibilities and roles (Parsons 1951), Sudesh and Krishna reject this role by refusing to allow their symptoms to impinge on their lifestyles and activities. If and when they do experience complications related to their uncontrolled blood sugar in the future, their resilient attitudes will likely help them adapt to maintain as active a life as they are able to. While long-term physical prognosis might be poor for Sudesh and

Krishna because their blood sugar remains uncontrolled, their "social prognosis" is good, and might to some extent attenuate the physical complications we would expect from long-term uncontrolled blood glucose.[32]

Are Sudesh and Krishna taking unnecessary risks with their future health by modifying their diabetes management routines, or are they making rational choices? Biomedicine has made tremendous advances that now give people with diabetes hope for a relatively normal life where once there was none, but this hope comes with a heavy burden: the intensive work involved in maintaining constant vigilance over one's blood sugar control, and the associated worry about potential complications. This work and worry is itself a form of suffering that has replaced the more immediate physical suffering a diabetic person would experience without biomedical management (Feudtner 2003). In light of the heavy tradeoffs associated with maintaining optimal blood sugar control, is not surprising that people like Sudesh and Krishna feel ambivalent about adhering to an intensive diabetes regimen, and sometimes choose to prioritize their present quality of life over an abstract and indefinite set of possible future complications.

The fact that Sudesh, Krishna, and many others like them live well with diabetes for long periods of time despite their lack of medical compliance forces us to consider what the ultimate goal of medical treatment for diabetes should be. If the goal of diabetes management is perfectly controlled blood sugar, then Sudesh and Krishna are failing. If,

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[32] Presumably, the biological mechanism involved in this effect would be neuroendocrine pathways, where reduced psychosocial stress leads to reduced activation of the hypothalamic-pituitary-adrenal (HPA) axis, and thus encourages effective regulation of the body's insulin sensitivity (Bjorntorp, Holm, and Rosmond 1999; Bjorntorp 2001; Golden 2007; Kiecolt-Glaser and Glaser 2002; Knol et al. 2006).

however, the goal is to maintain the best possible quality of life with the disease, then they are succeeding quite well, thanks in large part to the modifications they make to their prescribed management routines.

Physical and Mental Resilience: Two Case Studies

In contrast to Sudesh's and Krishna's apparently dissonant good mental health and poor diabetes control (dissonant in the sense that one might expect good mental health to come along with good diabetes control, and poor mental health to come along with poor diabetes control), several women (16, or 8.7 percent of the total diabetic sample) experienced consonant good mental health and good diabetes control. As such, they represent the "ideal" situation that most diabetes physicians and diabetes management programs seek to promote, but they were few and far between in my work.

Sarita, age 63, diagnosed 14 years ago, glucose 153 mg/dL, HbA1c 7.0%, CRP 1.5 mg/L, EBV 115.6 ELISA units

Sarita's combination of jeans, a red *kurti* (short tunic), shoulder-length salt-and-pepper hair pulled back loosely, and modern glasses with thick black temples mark her as a stylish, cosmopolitan woman as she walks into Dr. Sharma's private diabetes clinic. The wife of a retired chief of India's Central Intelligence Agency, Sarita has long been accustomed to high-class socializing at parties and banquets. Although she once worked as a nursery school teacher, Sarita gave up her job long ago when her husband's work took them for long periods to London and Paris. Now that they are both retired, Sarita describes herself as a "lady of leisure" who enjoys tea in bed every morning while she reads the newspaper. In retirement, her husband is a prominent columnist who publishes regularly in India's largest-circulating newspaper. Their recently built house in a wealthy suburb is filled with photographs of their two children and four grandchildren who all live abroad. Their life is generally low-stress and happy. Sarita reports not a single symptom of clinical depression or anxiety (HSCL depression=0; HSCL anxiety=0).

Sarita is conscientious about her blood sugar management, has good diabetes control, and has never experienced an episode of hypoglycemia in her 14 years with the illness. She describes a practical approach to her diabetes that involves regular walks, eating light "continental" [non-Indian] food for dinner, and making sure she eats and takes her medications on a regular schedule. Partially, she has learned this approach by watching a relative with diabetes who did not do well. "[My husband]'s aunt used to be diabetic, and her blood sugar used to go up to 500 then come down to 20. She was careless like that, and she went into diabetic coma a couple of times. Her grandkids used to come back from school at 2:30, so they waited to have lunch with them at 3:00. What nonsense! I mean, I wouldn't. You have to be sensible! You can sit with your kids, but the gap between breakfast and lunch becomes too long [if you wait to eat with them]."

When I first met her, it seemed that Sarita had no troubles against which she would need to be "resilient." Yet, during the few months between our initial meeting at the clinic and my follow-up visit to Sarita's home, their family went through a serious crisis that threatened to destroy not only her good diabetes management routine, but also their happy life. After what she calls a "hectic week of partying," Sarita's husband was having some persistent stomach upset, so they went to the nearby private hospital for a consultation. Routine tests revealed some minor arterial blockage that the doctor treated aggressively with unnecessary stents and arterial puncturing, causing so much internal bleeding that Sarita's husband went into cardiac shock, multiple organ failure, and nearly died. He had to remain in the hospital on life support for over two months, during which time it was unclear if he would survive or if he had suffered severe brain damage.

The shock of this severe crisis in an otherwise smooth life hit Sarita like a tidal wave, but she recovered from it amazingly quickly and was able to step back and view it coolly even as it was going on. "I did have two big bouts of self-pity and crying—I have to admit that the tears came. Not self-pity, I think, frustration. But I think it was legitimate to feel sorry for myself also." Part of her ability to cope, Sarita says, came from her supportive friends and family. Her children and other relatives visited more than once from France and the USA and called every day to check in when they were away. People called her so frequently that she eventually stopped answering the phone. "All I told them was, 'Pray for [my husband]. Pray for me. Pray for us.' And all of their collective prayers worked!" Now that their lives are returning to normal, Sarita can hardly believe that they went through this ordeal and came away more or less unscathed. She reflects, "It was a very tough time, a very tough time, but you can see I am smiling again. I took him to see a movie yesterday, and today I am taking him out for lunch."

Sarita claims that her fortitude during this time was born of necessity. "People tell me, 'You were so brave, you were so brave!' And I say to them, 'Did I have a choice?'" Even if she had no choice, Sarita is proud of her self-care during this time of upheaval. "I had some palpitations… but I was standing, and my diabetes was under control. I'm the first one to faint, but in all this two and a half months, I'm so proud of myself—I didn't faint, and I ate well because I felt that I needed to conserve my energy, I needed to feel strong. So instead of somebody telling me, I took the pains to do it myself," she explains. Once during the early part of her husband's hospitalization, Sarita noticed her sugars going up and called her diabetologist, Dr. Sharma, who instructed her to increase her insulin dosage for some time. Toward the end of her husband's hospitalization, Sarita went for a diabetes checkup and Dr. Sharma was surprised to see that her HbA1c was only 6.9, having remained under control during the family crisis. When we met, all of her blood biomarkers fell within a normal range.

Nirmala, age 40, diagnosed 4 years ago, glucose 132 mg/dL, HbA1c 7.1%, CRP 1.7 mg/L, EBV 220.8 ELISA units

An unusually tall woman with a strong but slim build, precisely groomed eyebrows with a small red *bindi* between them, and a long, thick braid trailing down the back of her pink *salwar kameez*, Nirmala is a Delhi native who moved to a neighborhood of uniform, off-white government housing blocks after her arranged marriage at age 21 to a civil servant. Their small, dark, ground-floor apartment has peeling paint and water stains on the concrete walls, marking their home as a lower-middle-class one. A poised woman who looks as if she just stepped out of a beauty parlor, Nirmala explains laconically that she does all of the household work, cooking, and cleaning for her nuclear family. Since her three children are at school most of the day and her husband is at work, she spends much of her day alone at home. Her oldest daughter is about to finish high school, and Nirmala is deeply invested in making sure her daughter chooses a college major that will play to her academic strengths and ensure her a job later on. We spend a long time talking about her daughter's various options for studies in social versus biological sciences.

Nirmala was initially diagnosed with diabetes during a prolonged period of stress, when her husband's work transferred him to Shimla for nine or ten years. She acutely felt the weight of being the sole caretaker for the household and her three young children, but her husband was unsupportive. They began having marital conflicts during this time which were still going on when I met her. "I needed emotional support but he didn't give it to me. He said, 'The whole world stays alone, so what's your problem?' Other people appreciate how I managed all alone, but instead of showing me some emotional support just harshly said this to me, that everyone stays alone." Nirmala believes her diagnosis during this time was the direct result of "that tension, tension, tension, maybe. I was alone; I had to manage everything alone." In addition, Nirmala fell into what she calls a deep "depression" (using the English word) during this time. "I had a lot of tension at that time, but now I'm feeling better. In those days when I was really depressed, then I felt [suicidal]," she explains.

Nirmala still reports "tension" in her daily life, primarily due to her ongoing marital conflicts and concerns about her children's education, but she clearly distinguishes these worries from her depression of previous years. She is aware of some lingering depressive tendencies and tries to cope with them proactively. "At times I still feel sort of depressed. When that happens I don't feel like going out. But when I feel depression, I make an effort to go out and see a good friend, then I feel fresh. …I try to make a change. I read a book or visit my parents." She now reports no clinically significant levels of symptoms of depression or anxiety (HSCL depression=0.4; HSCL anxiety=1.1). Furthermore, her stress biomarkers suggest that she does not experience elevated body inflammation (as measured by CRP), but that she does have very high immune system load (EBV). This could be the result of a recent infection, but it more likely reflects the chronic stress she experiences.

Nirmala makes consistent efforts to manage her diabetes and does indeed keep her blood sugar in good control. She gets regular checkups and has educated herself about her blood tests. "I do understand superficially [what my tests mean], and I do some reading about it in books. The doctor told me to check my fasting sugar and get my HbA1c tested every three months. They always come out normal." Nirmala maintains this diabetes control with little support from her family, especially from her husband, who "doesn't compromise all that much on food," she explains. Instead, she adapts. For instance, when her family requests foods that are prohibited for her, such as *poori* [fried bread], she makes them but does not eat them. Shrugging slightly when I ask if this is difficult for her, she responds, "No, it has become a habit." She also goes on regular walks with women in her neighborhood, "and that also for my own mental satisfaction" as much as for her health. She estimates that about half of her female friends have diabetes.

Nirmala thinks about her diabetes, but she describes it as a peripheral concern in her life compared with other worries, such as her daughter's impending transition to college. It was not always this way, however. Having grown up watching her father suffer with kidney problems due to his diabetes, she was initially very upset by her diagnosis. As she explains, “I saw that my papa had kidney problems because of diabetes, and since I got it at such a young age I felt scared that such things might happen to me too . …It's not difficult now, but the doctor has told me not to eat this, not to eat that. At the beginning it really bothered me, but now it's normal.”

What allowed Sarita and Nirmala to persevere in their self-care through adversity? Some structural factors helped them both. Firstly, they had family or friends nearby, and both were capable of calling upon them for help in times of need. Sarita additionally had household servants. Secondly, and perhaps most notable by its absence, neither woman mentioned any money-related stresses. Though Nirmala’s family is much less well-off than Sarita’s, she was able to get her diabetes care at a private clinic and never reported any financial burden associated with it. Sarita’s excellent health insurance allowed them to pay for her husband’s multiple months of hospitalizations without going into any debt. These financial and interpersonal resources laid the groundwork for Nirmala’s and Sarita’s ability to “bounce back” after difficult life events, and maintain good health throughout.

Yet, there is more to the story; personal characteristics specific to each woman also contributed to their resiliency. Perhaps the most important personal factor helping Sarita maintain her physical health was her common-sense approach to her own diabetes care, which was cemented long prior to her husband’s health crisis. This approach involves a willingness to sacrifice some behaviors indicative of family fidelity in order to maintain her diabetes self-care. Sarita's ability to recognize that she could not care for her husband unless she cared for herself is also key. As she explained it, "Instead of somebody telling me, I took the pains to do it myself." This choice to prioritize self-care is indicative of what Bandura (1977) refers to as "self-efficacy" in action. For her, this health maintenance was not a "decision," but a simple necessity; as she said, "Did I have a choice?"

Sarita's narrative also demonstrates a self-affirming approach to strong negative emotions, which helped her remain mentally resilient. She reported breaking down in "bouts of self-pity" only once or twice, but at the same time acknowledged how legitimate it was to feel sorry for herself under the circumstances. Granting herself permission to feel negatively for brief periods provided Sarita a controlled emotional outlet from which she was able to recover quickly, rather than remaining in a chronic state of severe distress.

Nirmala's life crisis was more prolonged than Sarita's, involving her husband's transfer far away from Delhi and the subsequent deterioration of her physical and mental health. Yet, like Sarita, Nirmala demonstrated remarkable proactivity toward maintaining her health. She educated herself about diabetes by reading, and she and diabetic neighbors went on regular walks together. Although Nirmala initially worried about her diagnosis, by the time I met her, she demonstrated a strong sense of mastery over her self-care needs and described her diabetes control efforts as "normal" and "habit," despite lacking family support.

Likewise, Nirmala actively worked to manage her mental health by using self-initiated coping strategies she learned during her previous period of depression, such as going out to visit friends or family, reading a book—trying to “make a change” when she felt depressed. Nirmala’s present-day lack of depression, anxiety, or “tension” suggests that these strategies have worked. It is certainly possible that Nirmala intentionally under-reported symptoms of distress, but her willingness to talk openly about her history with mental health problems and her current life stresses suggested that she would feel comfortable responding honestly.

The key source of resilience that emerges from both women’s narratives is that hard-to-pin-down trait discussed in the introduction to this chapter, which has been variously named “self-efficacy” (Bandura 1977), “health locus of control” (Wallston, Wallston, and DeVellis 1978; Wallston 1992), and “self-mastery” (Marshall 1991). This trait involves both a *desire* and an *ability* to take care of oneself, which seem to stem from internal motivation and an awareness of self-worth. Motivation and self-worth, in turn, can come from many sources. For Sarita and Nirmala, motivation appears to arise from an awareness of their responsibilities to others and a desire to remain capable of fulfilling them, as well as from witnessing the health complications endured by a family member who did not take care of him- or herself. Self-worth is likely related to Sarita’s and Nirmala’s education, their upbringing, their socially active lives, and economic stability, among other factors. As the conceptual model below illustrates, this self-efficacy (or what have you) transfers ultimately into an ability to maintain good physical and mental health.

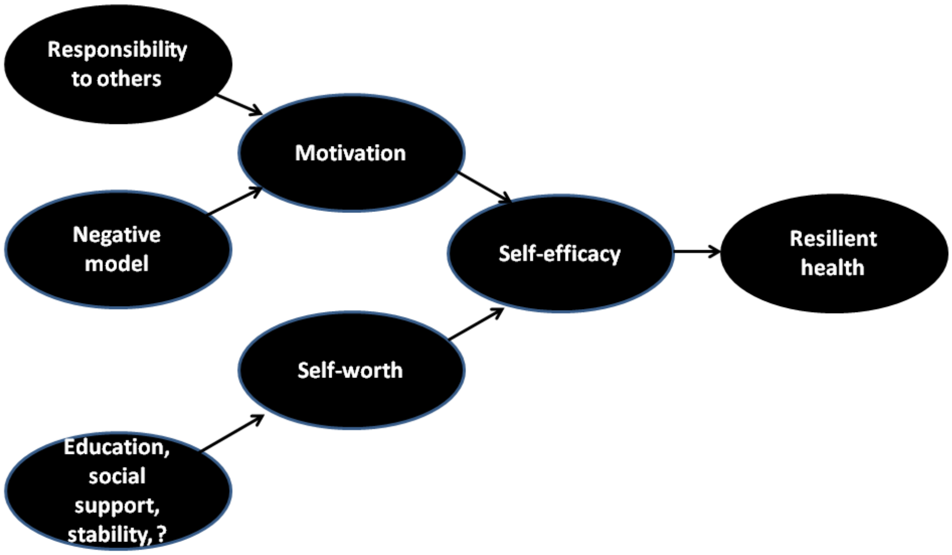

Figure 13. A conceptual model illustrating some factors that help Sarita and Nirmala maintain good physical and mental health in spite of life adversity. Feeling a sense of personal responsibility to others and having a family member or friend who has poorly managed diabetes (“negative model”) seem to generate in both women a sense of motivation to perform self-care. Other factors, including education, social support (and a host of other unnamed possibilities not included in the women’s narratives, such as upbringing and personal disposition) contribute to their feelings of self-worth, which again results in better self-care.

While poor blood sugar acted as an obstacle over which women like Sudesh and Krishna were resilient, good blood sugar for Sarita and Nirmala serves as a kind of “proof” of their resilience, particularly in the face of adverse life events.

Conclusions: Questioning the Assumptions Underlying Biomedical Diabetes Management, and Developing Culturally-Sensitive Diabetes Management Programs

In this chapter we have explored the cases of four diabetic women who exhibit different forms of resilience to their illnesses. They are meant to represent the large proportion of women in my study who report good mental health and relatively little disability due to their diabetes, despite having poor blood sugar control. The fact that psychologists have spent decades developing various scales for measuring resilience and its associated personality traits (such as self-efficacy and health locus of control) is a testament to the complexity of this construct and the diversity of its meanings. Resilience may mean responding to adversity with preserved or improved physical health, mental health, ability to function normally, or all of these. The women we have met in this chapter contrast with those we met in Chapter 5, who have difficulty managing their illness in part because of cultural conflicts between their family responsibilities and the demands of diabetes self-care.

The case studies presented here have illustrated two forms of resilience in the context of diabetes: one demonstrated by Sudesh and Krishna, in which women balance the rigors of controlling their physical health against their mental health and quality of life, and one demonstrated by Sarita and Nirmala, in which women preserve good physical and mental health despite stressful life events. The first set of cases illustrated how some women are resilient against diabetes itself—that is, they have poor blood sugar control but nevertheless maintain good mental health and a good quality of life. The second set of cases illustrated how resilient characteristics help some women manage their diabetes and their mental health effectively through life crises such as the near-death of a loved one or long periods of family separation. The women in this chapter are resilient because, in different ways, they all strike a balance between the need to care for others and the need to care for themselves.

It is worth noting that the life crises of three of the four women in this chapter center around their husbands. Sita's was the hospitalization of her husband, Nirmala's was her husband's work transfer away from Delhi, and Sudesh's was the near-death of her husband due to dengue. This fact serves as a reminder of the importance of family and the extent of women's financial and emotional dependence on their husbands in this cultural context. It also highlights the fact that social relationships have the potential to be both supportive and stressful. In the context of the patriarchal social structures of North Indian societies, which were discussed at length in Chapter 5 as a source of women's vulnerability to ill physical and mental health, it is even more remarkable that the women in this chapter are able to prioritize self-care.

The fact that many women I worked with have poor diabetes control yet still live well with their diabetes, like Sudesh and Krishna, led us into a critical discussion of what it means to "have" diabetes, what it means to live well with the condition, and what is (and what should be) the ultimate goal of biomedical treatment for diabetes. While Sudesh and Krishna are not succeeding in managing their diabetes well by biomedical standards, they are succeeding in maximizing their quality of life and making their diabetes management routines fit in with the other demands, expectations, and desires that shape their lives.

This observation demands a critical look at biomedical standards for diabetes management. In the first half of the 20th century, biomedicine transformed diabetes from a relatively brief and fatal diagnosis to a life-long chronic condition. This transformation essentially created a new disease, with a new trajectory, new complications, and new management requirements (Feudtner 2003). While it has prolonged millions of lives, biomedical management of diabetes exerts its own tyranny over the lives of sufferers by introducing new worries and new complications. Understanding why some women do not comply with routines that will manifestly help preserve their long-term health requires that we acknowledge the day-by-day difficulties these routines present. Considered from this perspective, one should not be surprised that some women elect to modify or ignore portions of their management routines; and indeed, a careful look at their ways of making these choices reveals that they are working to strike a balance between their physical healthcare and their quality of life, both at present and in the future.

If women who subscribe to a habitus of self-sacrifice have trouble managing their diabetes, as we saw in Chapter 5, it seems that the women profiled in this chapter succeed in managing their health and their quality of life in part because of their ability to act autonomously. To varying extents, all four women introduced in this chapter display independence toward their diabetes self-care that contradicts the traditional emphasis in North Indian societies on women's self-sacrifice. Nirmala, for instance, devotes her day to the care of her family and quietly bears a lot of sorrow caused by her unsympathetic husband. Yet, when it comes to her diabetes self-care behaviors, she acts autonomously by taking the initiative to eat differently than the rest of her family, get regular exercise, and go for checkups. Sudesh's case is another example; when it comes to her own health, she acts individualistically. However, when it comes to her everyday life activities and her understanding of her own responsibilities, she prioritizes the care of others—not looking for a job, for instance, because she feels that someone needs to stay home to look after the house and the children.

The biomedical system of diabetes management is predicated on ideals of self-care and self-nurturance that are rooted in Western conceptions of selfhood. An important factor influencing an individual's ability to access this motivation for self-care is a conception of personhood that views the individual and her body as the primary functional unit. Although we cannot necessarily determine how they come by it, the women introduced in this chapter demonstrate a foundational understanding of a valuable "self" who *needs* caring, and whose care deserves to be prioritized. Sarita's case is especially illustrative of this tendency; although her husband is gravely ill in the hospital and their lives are in crisis, she makes sure to take care of herself so she can "feel strong." There is a high level of congruence between a biomedical treatment system built on individualism and the four women in this chapter who successfully manage their diabetes with individualistic characteristics.

In contrast, there is potential incongruence between the individual-oriented ideology of biomedicine and women who do not approach their diabetes with such an individualistic attitude. Women who subscribe fully to the habitus of self-sacrifice we explored in Chapter 5, for instance, may be less able to access a motivation for self-care and actualize it according to the requirements of the biomedical model than the women in this chapter are able to do. Being self-motivated with respect to one's healthcare and being oriented toward the care of others are not mutually exclusive possibilities, as we saw in the cases of Nirmala and Sudesh, who accomplish both. However, these priorities do sometimes compete. As we saw in Chapter 5, women sometimes demonstrate their commitment to other-care through self-neglect. It may be unfair for biomedicine to expect patients to adopt entirely new notions of self-care when they get a chronic illness, but most diabetes treatment models hinge to a great extent upon an assumption that people want to, have the freedom to, and have the cultural endorsement to, act in an individualistic manner that prioritizes their self-care.

This chapter and the previous one have touched upon some of the fundamental questions in medical anthropology: What makes an illness experience? Biology, behavior, or both? What are the values and limitations of biomedical disease models and their treatments? What cultural assumptions underlay biomedicine? What tradeoffs are associated with adherence to biomedical models of disease and treatment, and what alternatives are available? The seven women, nine physicians, multiple media sources, and cultural and historic frameworks introduced in Chapters 5 and 6 illustrate that biomedicine is a culturally-shaped system informed by specific conceptions of personhood and moral values, despite its claim to objectivity. In the case of type 2 diabetes, biomedical conceptions of disease and its management may be incongruent with dominant values systems and conceptions of personhood in non-Western cultural contexts. These cultural clashes may make it difficult or even impossible for some women in North India to effectively manage their diabetes while striving to attain culturally appropriate gendered roles that involve heavy family responsibilities.

CHAPTER 7: CONCLUSIONS

In December 2012, the brutal gang rape and murder of a 23-year-old college student on a moving bus in New Delhi sparked massive popular protests that have drawn global attention to the plight of Indian women. Much of the rhetoric surrounding this incident engages the comment made by Mohan Rao Bhagwat, the head of the conservative Hindu nationalist group Rashtriya Swayamsevak Sangh (RSS), in which he observed, "Such crimes hardly take place in 'Bharat' but occur frequently in 'India.'" This notion of two Indias—the traditional, idyllic *Bharat* (the Hindi word for India) versus the modern, corrupt India—is an often-cited distinction in discussion of India's uneven socioeconomic development (Macdonald 2006).

In many ways, like the Orchha musicians with whom I opened the introduction to this dissertation, the women whose experiences comprised study are straddling these "two Indias." These urban-dwelling, mostly middle-aged and middle-class, educated individuals have plenty of exposure to modern modes of economic consumption and consumer desires associated with India's increasing participation in global markets. Many have the financial means to attain some of these ideals. Most, however, do not work outside the home and still respond in their everyday lives to engrained expectations that they serve as the upholders of family and tradition. As part of this duty, they focus their energies on the care of others to a large extent.

One of the most important underlying factors shaping women's health and illness in urban India today is, in fact, one of the most important factors shaping their lives in general: the tension between tradition and modernity. The story of the battling musicians with which I began the introduction to this dissertation is symbolic of this tension. The intervening chapters introduced women whose personal circumstances ranged dramatically. Although such variation exists the world over, the spread of that range is especially characteristic of India's ethnically diverse and highly socially stratified societies. So, too, is the intensity with which women are socialized to prioritize the care of others over the care of themselves, and the rapidity with which they are being confronted with new, alternative values systems that emphasize individualistic identity.

The young clinical psychologist I quoted in Chapter 3, who sees many women patients with diabetes and is herself a modern, educated woman, explained it this way: "See, India's typically known as a 'collectivist society,' and we seem to be taking more and more from whatever's understood as an 'individualistic society,' and that's a major negotiation that I think large parts of Indian society is making." This negotiation, she feels, is one of the root causes of mental health problems and general life stresses among the women she sees. "So what was an impossibility [before]—for example, moving out of the parents' home, either before or after you get married, unless and until you have to work in a different city—it was an impossibility. It was not heard of. You don't do it. You just don't do it. And that is part of the collectivist society." Yet, she continued, she could name three young couples off the top of her head from her group of friends who had gotten divorced within the last year, bucking another of India's collectivist-oriented traditions. "A large part of Indian society is negotiating with those [new] values. So I think that's it; that would be the most important structure that we are trying to break down but that we are also trying to hold onto.” As I quoted her in Chapter 3, “while we want to hold on to whatever we believe is our heritage, is our culture, there is a very strong need…to look at the other exciting ideas that are coming from different parts of the world… so we’re in a state of flux.” Although she struck me as someone so modern, so professional, that she herself must have transcended these conflicting values, I found out later that she too was immersed in this “state of flux.” Having recently married and moved in with her parents-in-law, she was facing pressure to reduce her work hours.

The large-scale modernization of India involves social, economic, political, and ethical components that reach into the interstices of everyday lives. Yet, women’s personal circumstances and individual choices also shape their diabetes experiences, and vice-versa, in many ways. The case studies presented in this dissertation show how personal circumstances and diabetes intersect in both positive and negative ways, sometimes simultaneously. There was Sita, whose domestic labor in a wealthy household makes it nearly impossible for her to care for herself; Manjot with her large servant staff and anxiety about checking her blood sugar; Sarita, who kept herself healthy despite her husband’s protracted illness; Rita, who refused to ask her busy family at the general store for help managing her diabetes and consequently kept ending up in the ICU; Krishna, who altered her medications as per her own preferences and felt good despite a decade of poorly-controlled blood sugar; Indu, who kept herself in good health almost entirely by her own self-education and self-care efforts; young Maya who associated her early-onset diabetes with the shock of her husband’s sudden death, and who had practically become an indentured servant for her in-laws following her widowhood; and others.[33] It should be clear by now that no two women's experiences with diabetes are quite the same, and in fact, that their outcomes are often quite different than we might expect based on their physical health status. Some women, for example, live well with diabetes despite many years of sub-optimal blood sugar control. Others, like Ankita, have good blood sugar control but are unhappy.

In addition to illustrating the range of experiences women have with diabetes, a second priority of this dissertation was to explore how a mixture of quantitative and qualitative methods could facilitate a better understanding of women's health and illness experiences. As a biocultural anthropologist, I believe that context, behavior, and biology contribute equally to human experience. Hence the triangulation in this research of various kinds of measurements, including quantitative information about biology (height, weight, blood tests), other kinds of quantitative information about illness management and demographic characteristics (age, education, SES), and qualitative information about illness experience. These investigations were designed to address the overall theme of what it is like to be a person with a chronic disease in a developing country. The pairing of quantitative and qualitative methods allows for a complementary analysis, just as the combination of personal stories and biological measurements helps us see what is at stake for diabetic women from various angles.

A third goal of this dissertation was to begin to identify some of the "fundamental causes" (Link and Phelan 1995) leading this group of women to face difficulties with their diabetes. As a critical medical anthropologist, I believe that context plays an

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[33] Refer back to the front matter for a list of all case studies introduced in the manuscript.

important role in shaping the *realm of possibilities* in which behavior and biology are enacted, or as Link and Phelan phrase it, the degree to which one is “at risk of risks” (1995: 80). This dissertation has addressed how the context of North India—a patriarchal society characterized by traditional women’s roles that revolve almost exclusively around the service of home and family—puts women at risk of specific challenges regarding their self-care behaviors and also their biological outcomes. One key fundamental cause was the “habitus of self-sacrifice” I introduced in Chapter 4, a part of North India’s dominant values system that teaches women to prioritize the care of others over all else. For an educated woman living in a nuclear family, perhaps working outside the home, a new diabetes self-care routine may or may not create great contention. But for a full-time homemaker whose daily routine revolves around activities that demonstrate her devotion to others, the dietary and exercise regimes of diabetes management can amount to a change in a woman’s fundamental identity roles. Through this culturally-reinterpreted lens, it is perhaps unrealistic to expect women to adhere to the lifestyle changes demanded by biomedical diabetes management, especially in the name of a disease whose effects may not manifest for years to come.

The “tensions” of life in general may contribute to diabetes, but the stresses created by trying to manage these almost irreconcilable sets of responsibilities toward self and other may also erode women’s mental health. Biomedicine’s general lack of attention to the role of cultural variables in personal health decisions is a fatal flaw in its crusade against lifestyle-managed diseases such as diabetes, cardiovascular diseases, and hypertension. Among the women with whom I worked in North India, medicine’s lack of attention to these cultural variables means that there is no viable alternative for women attempting to cope with the disjuncture they experience between what their doctors tell them they are supposed to do and the imperatives of their gendered social roles. Either they do what their doctors say and neglect important roles, or they maintain their roles and ignore their doctors. There seems to be very little behavior that falls between these two extremes.

Perhaps one reason why this conflict continues to be relevant despite India's rapid development is the fact that while most of the women I worked with were raised and live in a cultural context particular to North India, the biomedical clinics where they receive their diabetes management are essentially sociocultural "transplants." Medical anthropologists have long noted that biomedicine, though claiming to be an objective and values-free scientific system, is in fact steeped in cultural biases particular to the Western European context in which it evolved. The values inherent in biomedical care—the idea of control, the association of self-restraint with moral virtue, the perception of the body as a machine which must be adjusted to keep it running smoothly, the idea that the body and the mind are distinct entities, and the very idea of the individual as the base unit of society, to name just a few—are not necessarily the values most relevant for North Indian women. And while cultural diffusion has generated a significant amount of overlap between North Indian and Western European values since the time of British colonization, there are still some important distinctions that may have real impacts for women's health.

One such distinction shaping women's diabetes health, for example, is whether or not her immediate family members embrace the idea of preventative care. Preventative care is crucial for avoiding acute illness episodes in diabetes, but it is also a very Western and very biomedical concept. As Rita's husband said, "One only goes to the doctor when one is sick," and indeed that model of medical care-seeking is still very prominent in India, where until recently, acute infectious diseases were the dominant health concerns. Most health insurance programs provide for routine health checkups (and in fact encourage their holders to get checkups because early detection of illnesses saves them money), but the low level of access to health insurance in North India means that most people are not receiving this external motivation. When family members do not understand a woman's need to see a doctor regularly for blood sugar monitoring and medication management, conflicts can arise. This is especially true if she, like most women I worked with, must pay each time she sees the doctor, and must obtain the money for such payments from a male family member.

As this example suggests, and indeed as I have emphasized throughout the dissertation, women's diabetes experiences are intimately related to the ways in which they and their social worlds interpret and respond to the everyday challenges that the illness presents. Crucial to many women's success in coping with diabetes are social factors such as family support, especially support from children. When family members, friends, and other social contacts are able to provide support (whether in the form of accompanying a woman to the doctor, buying her medicines for her, reminding her to check her blood sugar, being willing to accept a modified diet, encouraging her to visit the doctor regularly, accompanying her on daily walks, and so forth), women seem to fare better. But women's ability to live well with diabetes is contingent on much more than just individual-to-individual relationships, central though they may be.

Three Levels of Causation

The stories and statistics presented in this dissertation have demonstrated that other, equally intangible factors contribute to a woman's ability to actively care for herself. These include agency, which I define in this study as the ability to act in the world as one chooses; a sense of self-worth; and resiliency in the face of life difficulties. Also important is mental health and one's larger position in the life course, which dictates social relationships and expected social roles. Of course, the degree to which one subscribes to the traditional gender roles and expectations also shapes self-care behaviors.[34] And then there are the more directly-observable matters, such as one's level of education, wealth, employment status, and access to modes of transport, which all affect the extent to which a woman can seek and understand guidance about her health. Indeed, these demographic characteristics are inexorably related to the more intangible ones such as self-worth and the degree to which one adheres to traditional roles.

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[34] Some of the wealthiest women in this study grew up either abroad or in American or European missionary schools, were highly educated, and did not have arranged marriages; these women generally did not subscribe to traditional middle-class Indian family roles and therefore had different (and usually easier) experiences with diabetes self-care.

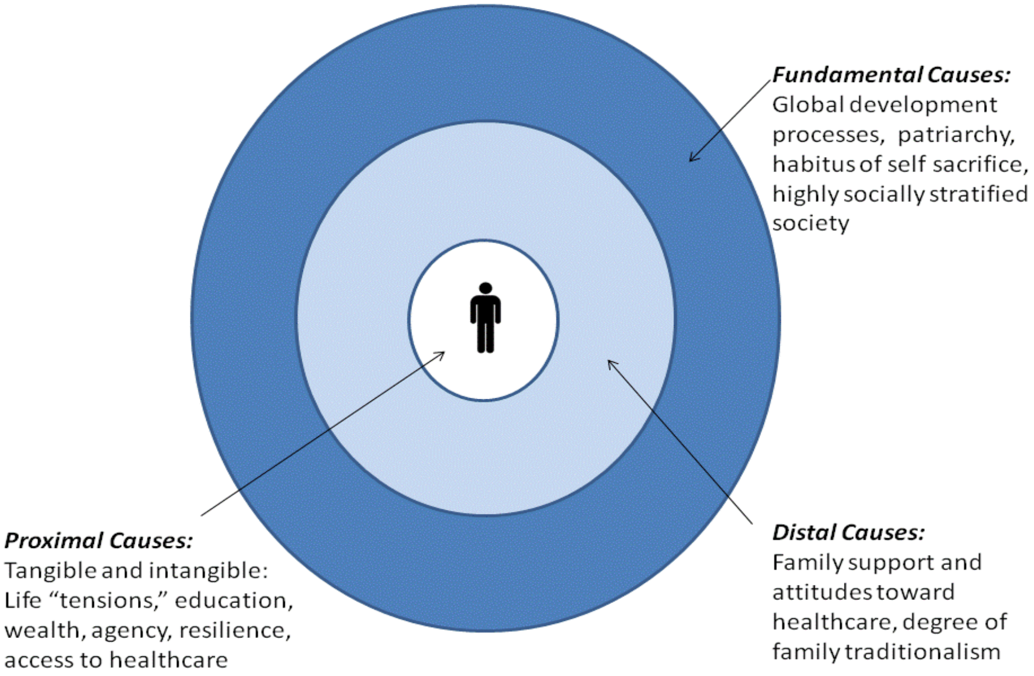

Figure 14. Conceptual model of the relationships among fundamental, distal, and proximal factors shaping diabetic women's health outcomes in North India.

The causes of diabetes discussed in this dissertation can be conceptualized as a series of concentric circles with an individual at the center, as pictured in the figure above. The outermost circle consists of "fundamental causes" (Link and Phelan 1995) that are conceptually "far" from the individual because they consist of population- or even global-level influences that shape the realm of possibilities in which people live their daily lives. These might include, in North India, both cultural and economic factors such as a tradition of patriarchy and patrilocality; a highly socially stratified society (stratified along class, gender, and caste lines); a habitus of self-sacrifice which encourages women to serve others; and the socioeconomic development processes that are bringing North India's traditional systems into contact with systems from other parts of the world. Such large-scale "causes" of disease are often referred to in medical anthropology and public health as *the social determinants of health* and are key foci in the critical medical anthropological tradition, which critiques social causes of unequal ill health between groups.

The second circle in this conceptual model consists of what I described as "distal" causes of illness at the beginning of Chapter 5. These causes of illness are "distal" because they are not qualities belonging to individuals, yet they are also not features shared at a society- or worldwide level. For the women in this study, distal factors affecting diabetes health were usually located in the family, the primary source of identity and social roles for most participants. Family support for a woman (Does her mother-in-law expect to have all household work done for her by her daughter-in-law? Do family members inquire about a woman's health or offer to help by picking up medications or reminding her not to eat certain foods?) depends on the dispositions and life stages of her other family members, but also hinges on the degree to which the family does or does not subscribe to traditional middle-class social roles that call upon women to serve others. Also important here might be caste-, religion-, or ethnicity-based norms that differentially allow women more or less freedom outside the home, access to education or lack thereof, and permission or prohibition of the use of birth control.

Finally, the innermost circle in this conceptual model consists of factors I called "proximal causes" of illness in Chapter 5. These are "proximal" in the sense that they belong to individuals; they are features that one might use to describe a person. Height, weight, education level, socioeconomic status, access to healthcare, and resilience are some of the innumerable proximal factors shaping women's health and illness. Some are directly observable (height, weight), while others can be partially inferred from physical appearance (socioeconomic status) or asked about (age, education level). These are the kinds of characteristics for which one tries to determine statistical effects in regression models. And although these are characteristics of individuals, they are not characteristics over which the individual always (or even often) has control. This is where the interactions between the fundamental, distal, and proximal causes of illness become relevant. Fundamental causes of illness predispose individuals toward down-stream risk factors, as in the case of global marketing of sweetened soft drinks (a fundamental cause, economic and political process) creating increased risk for higher body mass index and insulin resistence (proximal causes) in communities around the world. The degree to which sodas affect individual health might be mediated by community-level access to healthcare (a distal cause), which is, in turn, shaped by fundamental political and economic factors that shape government and NGO healthcare spending.

A Generalizable Model of Physical, Mental, and Social Health in Diabetes

Collectively, the experiences of the women involved in this study led me to develop a second conceptual model that depicts the relationships between women's diabetes health status, their mental health status, and their social and everyday functionality.

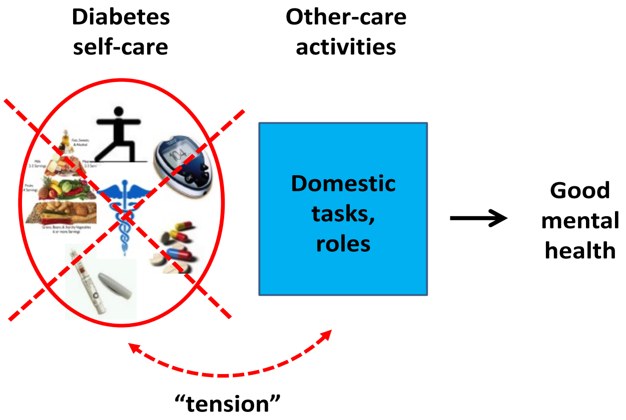

Figure 15. Conceptual model linking diabetes self-care, women's gendered social roles, and their mental health.

This model suggests that diabetes self-care (represented in the figure above by the circle containing a food pyramid, figure of someone exercising, a home blood sugar testing machine, oral and injectable medications, and a medical symbol) is often compromised by efforts to maintain culturally important gendered roles that emphasize other-care (the blue box in the figure above). This tradeoff results in better-than-expected mental health for the diabetic women in the study because it allows women to maintain important social roles and functions that have the potential to be compromised by a chronic illness like diabetes. But this tradeoff also has costs; it appears to generate worse-than-expected diabetes control among women because they do not adhere to diabetes self-care guidelines. The result is that the vast majority of the diabetic women I worked with had good mental health, reported little disability related to their diabetes, but had poor blood sugar control.

Further, women appeared to be aware of the conflict between their other-oriented gender roles and their self-oriented diabetes needs, and for some, this conflict manifested as increased “tension,” as shown by the hashed two-headed arrow in the figure above. “Tension” (refer back to Chapter 3) is a local expression that refers to generalized stress and shares some features with biomedical depression and anxiety, but is not equivalent to either. Women almost always view “tension” as being caused by social phenomena, such as worries about one’s children, a disagreement in the household, or other conflicts related to relationships.

This model is only one of many ways to conceptualize the relationships between diabetic women’s physical, mental, and social health, but it is supported by the quantitative analyses presented in the study, which demonstrated that most women had good mental health, little disability, but poor diabetes control. This model also aligns with the qualitative work conducted by me as part of this study and by other scholars working among women in India (c.f. Dickey 2002; Donner 2008; Standing 1991; Ray and Qayum 2009; Trawick 1992; Wadley 2008[1977]), which suggest that family roles are the main source of middle-class women’s identity and are therefore extremely central to their lives. Therefore, women are likely to hold onto these roles, even at great expense to themselves.

This model suggests that diabetic women who live in societies where their service to others is a less central aspect of identity might be able to achieve better diabetes management but might experience poorer mental health than the women in this study. First, adherence to diabetes management routines can be depressing (Golden et al. 2008). Second, in places where women’s identity is less fully intertwined with the identities of others, they may receive less social support doing times of illness, leading to poorer mental health. This poor mental health could loop back to affect women’s hypothetically better diabetes control in sociocultural contexts outside of North India; a large body of literature indicates that poor mental health strongly impacts diabetes management (Ciechanowski, Katon, and Russo 2000; DeGroot et al. 2001; Goldney et al. 2004; Katon and Ciechanowski 2002; Katon et al. 2005; Lerman et al. 2009). Alternatively, women's better diabetes control in such a hypothetical scenario might protect them against depression from the outset. These various predictions could be tested in cultural contexts where women's domestic responsibilities and family relationships are less central to their identities, to help confirm or refute the tentative findings of this dissertation.

Recommendations

Unsurprisingly, it is impossible to distill this complex web of social and individual factors into a single statement about what is going on among women in India with diabetes. To even attempt to do so would vastly oversimplify the picture. However, these women's experiences share some common elements that suggest inroads to improvement of their quality of life. The dissertation concludes below with a discussion of recommendations for improving women's healthcare and quality of life in India. Although some of these recommendations are obvious yet so broad that they would be extremely difficult to attain—such as "improve mental healthcare in India"—I mention them below because they are directly related to my research findings.

1. Encourage physicians to think critically about how diabetes management "success" should be defined.

As the many women in my study who have poor blood sugar control but live without diabetes complications demonstrate (at least for some time, and often for a long time), the relative importance of meeting blood sugar control guidelines must be balanced against the concern of maintaining a quality of life acceptable to the patient. The American Diabetes Association, the source of most official guidelines about how strictly blood sugar should be controlled, views as its duty the delay or prevention of diabetes-associated complications. Such complications can indeed be traumatic or life-threatening. They include, among others, neuropathy, or the loss of feeling in the extremities, which can lead to unnoticed infections that sometimes result in amputation; eventual blindness due to retinopathy; skin problems; heart disease and hypertension; kidney failure; and diabetic coma from extremely high or extremely low blood sugar, which can result in death. The ADA crafts its recommendations based on the findings of longitudinal research, which determines the blood sugar thresholds below which the fewest or complications occur. As such, ADA recommendations actually represent a "best-case scenario" of optimal blood sugar control; they do not necessarily consider the burden that attaining this ideal might place on a person with diabetes. And in fact, this burden will differ from person to person based on life circumstances and personal attributes. A 70-year-old woman who has terminal cancer in addition to diabetes, as an extreme example, would probably not need to focus on maintaining tight blood sugar control, but would instead focus on maximizing quality of life before her impending death. A 27-year-old woman with early-onset diabetes, however, might be more concerned about maintaining tight blood sugar control because she knows that she will live with the illness for a much longer time, and further, that she will do so during her most productive years. The point of these examples is that what is most important, and what constitutes an acceptable quality of life, differ for each individual. The conversation about what is at stake in diabetes should occur with each doctor-patient pair so that they can make informed decisions about how best to approach her care, and how best to integrate it with the other priorities in her life. Further, this conversation should be revisited periodically as women's priorities shift over the life course.

2. Improve early detection of diabetes. This effort could include educating non-biomedical healthcare providers and the general public about the causes and consequences of diabetes, implementing a diabetes screener, and increasing healthcare spending in India.

An important aspect of improving diabetes care in India will be facilitating earlier diagnosis and preventative programs among affected individuals (Patel et al. 2011). This would not only reduce the suffering that women experience before being diagnosed with diabetes, which as we saw in Rita's case can be severe, but might also help improve diabetes outcomes by providing individuals with opportunities to start diabetes management routines before the illness reaches an advanced stage. The best way to accomplish this goal would probably be a diabetes screening campaign, but the expense of screening India's enormous at-risk population and the logistical difficulty of bringing this kind of program to rural areas have thwarted efforts to develop a national screening program (Ali, Narayan, and Mohan 2009). Such an effort would require major government investment in healthcare in India. India's government currently spends less than four percent of its total GDP on health, as opposed to 18 percent in the USA (World Health Organization 2013).

Alternatively, diabetes education programs could be provided to nonbiomedical practitioners who often see people with diabetes, including Ayurvedic, Unani, and Homeopathic doctors, faith healers, and bone setters. Such healers often occupy central social positions in villages or urban neighborhoods, and serve as gathering points for large groups of people from surrounding areas (Flueckiger 2006). They also frequently refer patients to biomedical doctors (Flueckiger 2012, personal communication). Involving healthcare providers from India's well developed nonbiomedical systems would broaden the influence of diabetes education and help it reach people who might otherwise not get it because they might not regularly attend biomedical doctors.

3. Develop better biomedical mental healthcare programs in India.

A key way to improve healthcare in India generally, and especially among women, would be to develop better mental healthcare programs and decrease stigma surrounding mental illness. As the young female psychologist told me, "There are not enough good mental health practitioners. I can count the number of good mental health professionals on my fingers in Delhi—good ones, trained ones. Which means that around India, it's pretty sad." The District Mental Health Program, a subsidiary of the National Mental Health program, was conceived some 20 years ago to begin to fill this gap in mental healthcare. It was tasked with the development of regional mental health centers in about 20 percent of India's 640 districts, yet virtually no programs exist to date in these districts (National Mental Health Task Force, personal communication, 18

November 2011). Instead, the money allocated for these centers has either been siphoned off by corrupt government officials, or simply left unused. A new task force has been convened by the Ministry of Health and Social Welfare to ameliorate the problem, but at the time of this writing they were only in the investigation and planning stages. They face many obstacles; even basic epidemiological data about the prevalence of mental health disorders in India does not exist. Psychiatrists in Delhi estimate that common mental disorders like depression and anxiety occur in 5 to 10 percent of the urban population, but no survey has been conducted in Delhi to corroborate these figures (*Ibid*.).

The fact that women and physicians involved in this study link mental health so closely with their diabetes suggests that improving mental healthcare in India would have "double returns"; that is, it would not only address mental health problems like depression and anxiety, but would also help improve physical health, which individuals are better able to manage when their mental health is good. The diabetes physicians and mental healthcare providers I worked with agreed that treatment for depression often helps their patients manage their diabetes better, and vice-versa. This is consistent with my finding that women with high bloods sugar tend to report more "tension" and symptoms of anxiety than those with better controlled diabetes. It is also consistent with the published literature demonstrating that mental health problems and diabetes interact synergistically (Egede and Ellis 2010; Golden et al. 2008; Mezuk et al. 2008; Renn, Feliciano, and Segal 2011).

This is another juncture where collaborations between biomedical and nonbiomedical providers could be fruitful. Nonbiomedical providers in North India tend to attract large numbers of people with long-term illnesses that have no obvious cause, no easily apparent treatment, and where biomedicine can offer no cure. Diabetes is one such illness, but so are infertility, recurrent pregnancy loss, and most mental disorders. It is likely that nonbiomedical providers administer the majority of mental healthcare in India at present, especially when we consider how few biomedical mental healthcare providers there are in the country (especially in rural areas), and the strength of the stigma surrounding those who do exist. Integrating the strong networks of patients and providers who already operate outside the biomedical system will likely be crucial for improving India's mental illness detection and treatment.

4. Encourage women with diabetes to engage in stress-reducing activities as part of their self care.

The vast majority of women included in this study were women of strong religious faith who regularly attended temples, prayed at home, and sometimes practiced meditation and yoga. These practices are extremely beneficial for both social and mental health, and could be easily encouraged among people with diabetes in India because they are already quite familiar activities.

Dr. Kaur, a deeply religious Punjabi Sikh cardiologist, recommends that all of his chronically ill patients incorporate meditation and prayer into their lives explicitly as part of their illness management routine. While adjusting his turban he explained to me in a slow, thoughtful manner,

> I stress on the patients to meditate according to their own religious belief. When you are meditating, your body secretes endorphins, relaxing the mind. And the endorphin is equivalent to morphine. Your own hormones are secreted, your body is at peace, where you can fight disease, anxiety, and tension in a better way. …Then you can look after your body in a better way. You clean your body properly. You don't smoke, you don't take alcohol, you don't chew tobacco.

> …[This is] so whether you follow the Bible or the Koran or the Gita or Buddha, or any good spiritual religion.

Dr. Kaur's observation that religious practice improves his patients' physical and mental health is supported by a large body of literature demonstrating the positive effects of religious participation on health outcomes and behaviors in different parts of the world (Aukst-Margetic and Margetic 2005; Ellison 1998; Seybold and Hill 2001). There are many potential pathways linking religious involvement and health, including the physiological and behavior-modifying ones that Dr. Kaur outlines in his explanation above. Another important pathway linking religiosity and improved health may be the social support that people receive from religious groups (Ellison 1998), therefore providing further evidence for the importance of social support for health among diabetic women. Unfortunately, this study included no data on religiosity, so differences in diabetes control between those who were more or less religiously active could not be explored. Still, it is likely that encouraging patients to take comfort in their religious practice, as Dr. Kaur does, would be beneficial.

5. Empower women to be proactive about their own health by addressing root causes, such as autonomy and social support.

Delivering healthcare programs like the regional mental health centers in the previous paragraph is a great challenge. An alternative approach, instead of bringing healthcare campaigns to individuals, is to foster the conditions that enable individuals to seek out healthcare themselves. The case studies of Indu and Rita suggest a few potential approaches for improving women's healthcare seeking behaviors when a chronic disease like diabetes is involved. One way is to encourage women's mobility outside the home and financial independence, which could enhance their ability to seek healthcare and purchase medicines without having to ask for money or accompaniment from a relative.

Although mobility and financial independence are not values traditionally consistent with middle-class North India female roles, efforts to augment these qualities could be folded within existing social structures to some extent. For example, women's informal neighborhood social groups could organize trips to diabetes clinics, as Indu's friends do, or could accompany each other to purchase medicines. As for financial autonomy, it is not unheard of for middle-class women in North India to engage in home-based work, such as selling handicrafts or offering tutoring, for extra income. A bigger challenge would be to find a way of ensuring that women maintain control over the earnings resulting from such activities. Still, there are several culturally appropriate starting points which could be built upon to address norms that impede women's ability to seek their own healthcare, such as mobility and financial restrictions, without demanding major cultural changes.

The findings presented in this dissertation about why women have trouble managing their health are compelling, in part, because they suggest that factors usually assumed to be associated with better health, such as formal education and wealth, may not, in fact, be the "magic bullets" for chronic diseases that they have been for infectious diseases. They are certainly associated with better health at a population level, but most studies documenting these associations have been conducted among Western populations and/or use infectious diseases as health outcomes (*c.f.* Adler and Ostrove 1999; Ross and Wu 1995). Further, the specific pathways through which these variables exert their effects on health are difficult to pinpoint because their planes of action in life are so broad. My research suggests that although education and socioeconomic status are important for women's health, other factors have the potential to make lasting improvements in health.

Autonomy, social support, and good mental health may be some of the pivotal factors that enable Indian women to manage their diabetes effectively. As Indu's case demonstrates and as another group of scholars working among Indians with diabetes has recently found (Venkataraman et al. 2011), autonomy and good mental health encourage an attitude of proactive self-efficacy, facilitate the development of social support networks with fellow diabetes sufferers, and enable women to generate some income to help support their healthcare. One diabetes physician agrees, "Yes, yes, yes. People whose HbA1c's are 6.5 or 7, I haven't seen them feeling stressed. You know, I think it just gives them a good feeling, that 'I'm on top of it, I can do it,' and they're able to cope with everything else too." Programs that aim to boost feelings of self-efficacy among people with diabetes through social support groups and income-generating activities that increase financial autonomy might be able to address both diabetes and mental health concerns together, thus helping people in India manage or prevent diabetes in the long term.

6. Develop healthcare programs that work with, rather than against, the culturally valued ideal of women's self-sacrifice.

The "habitus of self-sacrifice" among women in North India often translates into the idea that women should prioritize care of their families over self-care. At present, most diabetes physicians recommend programs of treatment that actively oppose this orientation toward other-care. Instead of working directly against cultural norms, programs to promote diabetes self-care could leverage this conflict by emphasizing how women's diabetes self-management is a "family value" because it ensures that they will be able to continue providing high quality care to their families. For Sarita, from Chapter 6, the notion that she had to take care of herself in order to be there for her critically ill husband was a powerful motivator to perform self-care, and this type of motivation could be harnessed on a larger scale.

Like the suggestions mentioned in recommendation number four, this approach is useful because it works within the existing system of cultural beliefs, rather than attempting to run against it. It could be a crucial yet simple point of intervention for culturally sensitive programs designed to improve diabetic women's health in India.

7. Reduce stigma surrounding diabetes and mental health problems by restructuring medical discourses of blame.

An important part of improved diabetes care worldwide, as well as in India, will be a shift in mindset on the part of physicians, patients, and the public regarding diabetes and blame. If structural factors are indeed partially responsible for individuals' diabetes outcomes, as I have suggested in this dissertation, then blaming individuals for poor diabetes control is unlikely to improve it. Likewise, using fear as a tool to engender fear (and thus, presumably, compliance) in patients is unlikely to be effective, because patients' level of concern about their health is only one factor that motivates their health choices. As we have seen, equally if not more significant barriers to diabetes control for women in Delhi are lack of autonomy, unaddressed mental health problems, and lack of social support for self-care within the family. Dr. Saxena, a cardiologist and diabetes physician with over 30 years' experience treating diabetes in Delhi, describes how he and his colleagues gradually became aware that fear-based treatment was not working: "In the 80s and 90s, physicians all over the world, including me, were in the business of scaring their patients. By the turn of the century, we all realized it didn't help. 'Hope' became a watchword for diabetes in 1999, the same year that the HOPE study came out.[35] We have to rethink strategies, and one of them is that instead of fear, we have to give them hope. It works better."

8. Listen to, and learn from, physicians in India who are already implementing creative diabetes management strategies for their patients.

Exposing the fundamental causes of health problems is illuminating but sometimes discouraging, because most health systems are ill equipped to address health problems stemming from global economic processes and engrained cultural roles that de-emphasize self care, and in fact they should not necessarily seek do so. As one man commented when I asked his wife what a woman should do to care for herself on a daily basis, "Actually, what you are asking is a revolution! Women here are not taught to think about themselves; they are only for their families, their husbands and children." Although a "revolution" may be beyond the scope of most healthcare providers and health workers interested in improving women's self-care behaviors in India, I want to briefly highlight

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[35] The Heart Outcomes Prevention Evaluation (HOPE) Study was a large, randomized clinical trial testing the effects of various drugs for preventing heart attacks and diabetes complications among people with heart disease. Based in Canada, it was funded by large national health organizations and major pharmaceutical corporations.

some of the strategies that physicians I worked with have developed for coping with or compensating for women's difficulties managing diabetes. They illustrate that diabetes management routines could be altered in minor ways to better accommodate women's needs and priorities in North India's specific cultural contexts, while still allowing them to maintain socially important roles.

Dr. Saxena, the cardio-diabetologist we met in Chapter 4, offered a parsimonious solution to his female patients' management problems that helps ease the difficulty women face at home with their diabetes. "We insist that they should not come to the clinic alone," he explained.

> So, we have a family member here. We tell them, "This diet is not for a person who has become diabetic; this is also a diet for a person who does not *want to* become a diabetic," and that catches their attention: "Oh, ho! We'll also catch diabetes, so we might as well take some care." Then the lady gets strengthened, because if we tell her to reduce the fat intake to a half liter per person per month, she has to cook the meal. If she reduces the oil content at the source, they all start disliking the food, and they blame her: "It is you who have to take this, why are you making us? Put more oil for us." So we have to tell them that less oil will prevent diabetes for you, or will prevent hypertension for you. The answer is, one family member should accompany, and that solves it.

Dr. Gupta, the diabetologist with international clients whom we also met in Chapter 4, agrees that enlisting a family member can be a great help for diabetic women. "I've found that especially the children, in dietary modifications—especially daughters—are far more supportive than spouses, who are often busy and have never looked at food in that sense, who don't want to be bothered by all that. 'You take care of your food'—you know, that kind of thing. The children are big supporters in families, I see that." Two other physicians also specifically mentioned that children and grandchildren are reliable, but largely untapped, sources of support for women with diabetes, and they also encouraged their patients to choose one person, perhaps a child or grandchild, to accompany them regularly to consultations. "Luckily, this middle and upper-middle class is having one good thing: that the youngsters who are growing up right now in the families are very much aware. We will call their children with them [to appointments]. Daughters and concerned sons—if you take them into confidence, then things go at a faster pace. Spouses, 50-50. Not as much." People in India very rarely go to doctors alone, but emphasizing that they should always be accompanied by the *same person* introduces consistency and increases the chances that the companion will be able to become involved in the patient's home care.

Dr. Gupta's diabetes specialty center has recently introduced an email and mobile phone reminder system to help patients remember to monitor their blood sugar and come in for regular checkups. Soon, the system will be expanded so that patients can respond directly to reminder emails or text messages with their blood sugar readings, which will be entered into a computer that charts their blood sugar over time, allowing him to monitor his patients' blood sugar fluctuations continuously. Recently, he added a psychiatrist and a psychologist to his diabetes management team in hopes of giving his patients greater opportunity to work through home-based stresses that contribute to their diabetes vulnerability. "You know, we were trained to think about the chronic care patient, that your job is to advise them, and if they don't follow it, it's their problem. If the guy doesn't follow it, what do you do?" asks Dr. Gupta. "But over the years I've come to realize that that's only half the job. We've gotta do more." For Dr. Gupta, who has significant resources at his disposal in the private diabetes clinic where he is the head physician, this means providing free or low-cost reminders to patients to perform self-care activities between visits, and encouraging them to involve family members in their health maintenance.

Although such innovations are emerging in private healthcare and are therefore not yet available widely, they suggest that physicians in India are beginning to take steps to ease the struggles that women face in diabetes care. These initial steps are encouraging because they represent some of the first practice-based efforts to acknowledge and accommodate the unique cultural contexts that shape their patients' diabetes self-care behaviors in India. The findings of Chapters 5 and 6 together suggest that if such efforts can be elaborated and expanded into the public sector, they could improve diabetes care in India significantly.

Final Thoughts

Arthur Kleinman, a prominent psychiatrist and anthropologist, once wrote, "The study of the experience of illness has something fundamental to teach each of us about the human condition, with its universal suffering and death. Nothing so concentrates experience and clarifies the central conditions of living as serious illness" (1988: xiii). The illness experiences that comprised this study demonstrate, as Kleinman suggests, something fundamental to the life stories of this slice of Indian society. At the heart of many women's troubles managing their illnesses are fundamental conflicts between self and other, modernity and tradition, liberalism and conservatism. Furthermore, the expressions women use to discuss their diabetes-related problems are the very same expressions they use to express troubles of any kind in everyday life. Through these and other routes, the experience of living with diabetes becomes, in many ways, the experience of life itself.

Diabetes is an odd thing. Once an acute disease that resulted in relatively quick death, it is now a manageable condition that may last for decades or even most of a lifetime. This is thanks to the advent of medical technologies including insulin therapy, oral hypoglycemic drugs, and now continuous insulin monitoring and insulin pumps, which mimic normal pancreatic function via a mechanical device worn outside the body. Yet, the trade-off for longer years of life comes with a high price. Physician Chris Feutner writes, "Never has medical care offered more yet demanded so much" (2003: xiv), promising years of life “poised against all the ramifications of living with a chronic, often debilitating disease" (2003: 10). Indeed, perhaps one of the hardest and most unfair aspects of diabetes is the fact that it puts the sufferer in the position of having to weigh these mixed consequences and continually—every time she puts something in her mouth, every time she does any physical movement—make micro-decisions about what to put first: self, or other? And if the answer is to prioritize oneself, what matters most: immediate gratification versus the long-term pursuit of optimal diabetes control?

Over time, the burden of making these decisions again and again can wear away at the quality of life of people with diabetes. In light of such burdens, it should come as no surprise that some people decide to enjoy the life they have in the style they choose, rather than maintaining strict adherence to regimes that limit their activities. Such individuals put off the worry of complications until those complications actually occur, and in fact they comprised most of the women I worked with. Others, especially physicians and a small group of women themselves, feel compelled to do whatever they can to prolong the duration and quality of their lives. This motivation comes both from a sense of duty to others which is highly valued in North Indian societies, and from a well-founded fear about the suffering such women might face if serious diabetes complications set in.

Of course, these decisions need not be so black-and-white, and it is my hope that those who read this dissertation will see that there are many routes to living well with diabetes. Some of these routes look very much like what a physician would prescribe, while others do not. Likewise, there are many routes to living poorly with diabetes, and these are not always the ones we might envision. Ultimately, the decision about how to manage diabetes ought to be treated as carefully as the decision about how to live one's life, for they are in fact one and the same thing.

APPENDIX

METHODS IN DETAIL

This appendix provides details on the methods used to conduct the research reported in this dissertation. The research consisted of three basic phases: a pilot phase in 2009, when I developed and tested locally-derived scales for measuring disability in daily tasks and "tension" among pilot samples of diabetic and non-diabetic women; a clinic-based phase in early 2011, when I conducted structured interviews, took body measurements, and did blood tests with women; and a home-based phase in later 2011, when I followed up with a sub-sample women from the clinical phase for in-depth, ethnographic interviews. At this time I also interviewed 12 healthcare providers.

In each case, I spoke with participants in a private room to maintain confidentiality. All interview materials were translated into Hindi and back-translated into English prior to the interviews, which were conducted in Hindi, or, if participants preferred, in English. Most interviews took under one hour, with the exception of some case study interviews that continued for two or even three hours.

All participants gave informed consent, and no identifying information was retained in the data. All study procedures were pre-approved by the Internal Review Board of Emory University. The study procedures carried out in 2011 were also pre-approved by the Ethical Review Board of the University College of Medical Sciences, New Delhi, and the Indian Council of Medical Research.

Phase 1: 2009 pilot research[36]

Two separate samples consisting of 62 diabetic and non-diabetic women (n=37 diabetic) and 30 diabetic-only women were recruited from 14 private clinics throughout New Delhi. On random days, a local research assistant and I visited each clinic and interviewed consenting patients as they waited to see the physician.

We conducted semistructured interviews with 62 diabetic and non-diabetic women using freelisting techniques (Borgatti 1999) to collect baseline information about important women's roles and perceptions of diabetes and "tension." Freelisting involves asking open-ended questions and requesting that respondents state as many answers as they can think of.

In the first freelist, we sought to identify locally salient gender-specific roles and responsibilities so that we could later assess whether diabetes impinges on these activities. We relied on freelisting because of our interest in tasks and roles pertaining specifically to women in the same population as the women with diabetes participating in this study. Because diabetic women may not be engaging in some normative activities due to illness, we interviewed both diabetic and non-diabetic women about tasks that women like themselves should perform to care for themselves, their families, and their communities (Bolton and Tang 2002).

Secondly, we were interested in women's perceptions regarding symptoms of diabetes (are they conceived of in entirely physical terms, or are affective symptoms also a part of women's perceptions?). We asked both diabetic and non-diabetic women in the second freelist to name all the symptoms of diabetes that they knew. Thirdly, we asked

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[36] This section is a modified excerpt from Weaver and Hadley 2011.

women to name as many synonyms or symptoms of “tension” as they could. We interviewed both diabetic and non-diabetic women to capture a general (nondiabetes-specific) conception of “tension.” We also collected basic demographic information.

Results of the freelist interviews were handled as follows: Items mentioned by more than two (or in the case of the daily activities freelist, three) out of the total 62 women were retained for further study. Twenty-three daily activities, 21 diabetes symptoms, and 20 symptoms of “tension” were included. From these frequently mentioned items in the three freelist exercises, we created three checklists about daily function, diabetes symptoms, and “tension.” For instance, 11 of the 62 women mentioned anger as a synonym for tension. We converted “anger” into an item in the “tension” checklist by adding “feeling angry” under the question “Since getting diabetes, do you feel any of the following mood-related items more, less, or the same as before?” with the response categories “much more,” “somewhat more,” “no change,” or “n/a or no answer.” Additional items in this checklist were derived from other synonyms of tension nominated by multiple women, such as “feeling troubled” and “feeling weak or tired.” Similarly, the daily function items were aggregated under the heading, “Below is a list of tasks that women do regularly. Since getting diabetes, have you had a lot more trouble, some more, or no more trouble doing these tasks?” Finally, we created an inventory for physical diabetes symptoms under the heading, “Which of the following physical problems have you experienced due to diabetes?” We included here only symptoms mentioned by women (rather than using a standard medical interview) because we were interested in learning how women’s experiences of diabetes map onto others’ expectations of the symptoms one would have, and because women's lists of symptoms closely resembled a standard clinical interview.

The three freelist-derived checklists comprised part of a questionnaire about women's experiences with diabetes, difficulties with gender-specific social roles and responsibilities, and "tension." We also included in this questionnaire demographic questions, sections about religiosity, autonomy, perceptions of the causes of one's diabetes, opinions on the best ways to prevent diabetes, general health and health-seeking behaviors, and a Hindi-translated version of the Hopkins Symptoms Checklist-25 (Mollica et al. 2004). The first 10 questions of the HSCL assess anxiety; the latter 15 questions assess depression. The purpose of including a standard mental health assessment was to compare whether diabetic women who perceived more "tension" in their lives also reported more symptoms of depression or anxiety. In this questionnaire we also collected demographic information. This questionnaire is reproduced in below.

We administered the questionnaire to a novel sample of 33 diabetic women. The resulting quantitative data were analyzed using SPSS 18 to validate and assess the psychometric properties of the "tension" scale and the Hindi version of the HSCL for future use. Both the HSCL and the tension scale had excellent internal validity; the HSCL had a Cronbach's alpha of 0.92 and the tension scale had a Cronbach's alpha of 0.93. The anxiety component of the HSCL (questions 1-10) had a Cronbach's alpha of 0.81, and the depression component (questions 11-25) had a Cronbach's alpha of 0.89. These values are all well above the cutoff value of 0.70 suggested by Nunnally and Bernstein (1994). A factor analysis revealed one dominant factor in the tension scale, which explained 40 percent of the variance, and two dominant factors in the HSCL, explaining 31 percent and

15 percent of the variance and representing depression and anxiety, respectively. These analyses suggest that the tension scale assesses one major underlying construct, whereas the HSCL measures two (in this case, judging from the analysis, anxiety and depression).

Phase 2: 2011 clinic-based interviews and quantitative analyses

A sample consisting of 306 diabetic and non-diabetic women (n=184 diabetic, 96 non-diabetic) were recruited from seven private clinics, a public hospital, and two charitable clinics dispersed throughout Delhi but centered primarily around the southern half of the city to reduce commute time. On random days, a local research assistant and I visited each clinic and interviewed consenting patients as they waited to see the physician. These interviews were voice recorded for later transcription and translation, and a photograph was taken of the participant when she permitted it. Women under the age of 27, who were pregnant, who had thyroid or other endocrine disorders, or who were unable to complete the interview because of physical or mental illnesses were excluded. Women were classified as diabetic based on self report. In the few cases where there was a doubt, they were classified as diabetic or non-diabetic based on their HbA1c blood test result during the interview. If a woman's random blood glucose was found to be high but her HbA1c was within a normal range, she was classified as non-diabetic. Conversely, if a woman's random blood glucose was within a normal range but her HbA1c was high, then she was classified as diabetic. Standard ranges for normal and abnormal blood glucose and HbA1c were used in this determination (American Diabetes Association 2011).

We administered a questionnaire similar to the one developed and tested in the pilot phase of research, with a few modifications to improve accuracy of the Hindi translations, focus the questionnaire around a single topic, and reduce respondent fatigue. First, the “tension” scale was reduced to 14 items from the original 20 to eliminate some of the redundancies between it and the HSCL. The item on the HSCL that asks about sexual dysfunction was eliminated due to respondent discomfort in the previous round of research, meaning that the total number of depression-related questions on the HSCL was reduced from 15 to 14. The questions about disability in daily tasks were condensed from 22 to 18 items. The diabetes symptoms section of the questionnaire was eliminated, along with the questions about religiosity, autonomy, and opinions on the best ways to prevent diabetes. The section on perceptions of the causes of one’s diabetes was changed from a multi-item questionnaire to a single open-ended question, as was the section on self-rated health and health seeking behaviors. Some Hindi translations were modified from the previous version of the questionnaire based on feedback from native Hindi speakers. The questionnaire is reproduced in below. Finally, I added a life events inventory to help control for stressful events in women’s lives over the preceding year, specifically designed for Indian populations (Singh, Kaur, and Kaur 1984).

After administering the questionnaire, we measured each woman’s height in meters using a Seca 201 body measuring tape against a wall, weight in kilograms and body fat percentage using a Tanita UM-061 floor scale and bioelectrical impedance device, and waist-to-hip ratio using the same Seca 201 tape. Bioelectrical impedence and waist-to-hip ratio have historically been used in studies of body composition among people with diabetes (Leiter et al. 1994). After cleaning the finger with a disposable alcohol pad, we pricked it with a BD Micro-Fine Contact-Activated disposable lancet (#366594) and tested each woman's random blood glucose using the Bayer Contour glucometer and HbA1c using the Bayer A1cNOW test kit, a relatively new instrument which allows point-of-care testing of HbA1c levels from a finger-stick blood test. Such technology has been shown to produce reliable HbA1c results (Wiwanitkit 2012). Finally, we collected four spots of blood on Whatman Protein Saver blood spot filter paper (#903) and allowed them to dry completely before storing them with desiccant in a -80 C freezer for later laboratory analysis of C-reactive protein and Epstein-Barr virus p18-VCA antibodies. The blood spots were transported to and analyzed at Emory University's Laboratory for Comparative Human Biology following protocols for handling, storage, and analysis described in McDade and colleagues' paper (2000), and an article by Worthman and Stallings (1997).

Of the 306 women interviewed in this phase, 280 had complete questionnaire data and were eligible to be included in the quantitative analysis sample based on the study's exclusion criteria. Some women declined to do the blood tests but consented to the interview. Of the 280 women, 231 had complete data for both the questionnaire and the blood tests. The questionnaire data were entered into Microsoft Excel 2007. The following variables were calculated and made categorical or binomial as follows:

<u>Education</u> was divided into four categories: less than high school graduation, high school graduation, undergraduate degree, and Master's degree or higher. For the regression analyses, education was dichotomized as less than an undergraduate degree versus an undergraduate degree or higher. It was also dichotomized as less than an Master's versus

a Master's or higher to test my suspicion that the cutoff point at which additional education begins to "matter" for women's health would be very high; that is, only women with very high levels of education would benefit health-wise from that exposure. In the end, the cutoff point using an undergraduate degree had more predictive power for women's health, so this division was used in the analyses.

Socioeconomic status was estimated qualitatively for each case because women during the 2009 pilot phase of research were either uncomfortable answering the question "What is your approximate monthly household income?" or did not know the answer. This is not unusual in India, since households often consist of multiple earners from different generations, and male heads of household are usually responsible for collecting and redistributing family income. We estimated SES using an algorithm comprised of each woman's education, caste, employment status (and, if working, the type of job), presence or absence of a maid in the household, and style of dress. I and the research assistant independently rated each case as lower class, lower-middle class, upper-middle class, or upper class. Our ratings agreed 75 percent of the time, suggesting that this algorithm is relatively reliable. The research assistant's SES ratings were used in the final analyses because, as a long-time resident of New Delhi, her ratings are likely to be more accurate than my own.

Body mass index was calculated by dividing each woman's mass in kilograms by her height in meters squared.

A body composition variable was calculated for the purpose of linear regression by combining each woman's body mass index score with her body fat percentage. This summary score was created to avoid multicollinearity in the regression analysis because BMI and body fat measures were highly correlated.

"Tension" symptoms were summed for each woman. Because there are no standardized cutoffs for our "tension" scale, we divided the respondents' "tension" scores into three groups to represent low, medium, and high numbers of symptoms. Individuals with "tension" scores in the highest tertile were considered to have high scores compared to the others.

Depression/anxiety symptoms were calculated by summing all HSCL scores and dividing by the total number of questions on the HSCL to obtain an overall depression–anxiety score. Scores of 1.3 or above were considered symptomatic. This cutoff was determined based on clinically relevant cutoffs for the HSCL published by Mollica and colleagues (2004), but the actual threshold is different in this study (1.3 as opposed to Mollica's 1.75) because my scoring methods were different (I used a Likert scale ranging from zero (not at all) to two (severe), while Mollica and colleagues used a scale ranging from 1 to 3). The total HSCL score indicates the average severity of each symptom on the Likert scale.

Depression symptoms were dichotomized by summing HSCL items 12-25 and dividing by 14. Scores of 1.3 or above were considered symptomatic.

Anxiety symptoms were dichotomized by summing HSCL items 1-10 and dividing by 10. Scores of 1.3 or above were considered symptomatic.

Stressful life events reported in the previous year on the stressful life events questionnaire were summed for each case.

Joint family was coded as 0 (nuclear) if two generations or fewer lived in the household and as 1 (joint) if three or more generations lived in the household.

For the diabetic women in the sample, allopathic treatment was categorized as none, oral medications only, insulin only, or oral medications and insulin concurrently.

Each respondent's religion was categorized as Hindu, Muslim, Sikh, Christian, or other. In the regression analyses, religion was treated as a dichotomous variable (Hindu versus non-Hindu) and was also tested using dummy variables for Hindu and Muslim groups, the two predominating religions in the sample.

Women with C-reactive protein (CRP) values above 7.0 were considered actively infected with an acute illness and excluded from the analyses to avoid skewing the data. After this exclusion, women with CRP values falling in the highest quartile were considered to have "high" CRP.

Women with Epstein-Barr virus p18-VCA antibodies lower than 30.0 ELISA units were considered seronegative for Epstein-Barr virus and excluded from analyses. After this exclusion, women with EBV values falling in the highest quartile were considered to have "high" EBV.

We also collected data on each respondent's age, caste, number of years married, number of children ever born, employment status, self-reported duration of diabetes, self-reported general health at the time of the interview, height, weight, body fat percentage, random blood glucose, HbA1c (see description of equipment and methods for blood tests, above).

Quantitative analyses were performed using SPSS 18. The sample of 280 cases with complete data were used for analysis of the questionnaire data. Analyses involving the blood biomarker data and anthropometric data used the sub-sample of 231 women with complete data for these variables.

After checking the distributions of the data to verify normality, I conducted univariate, bivariate, and multivariate statistical analyses. Univariate and bivariate analyses were primarily exploratory and included means, ranges, correlations, scatter plots, independent samples t-tests, and cross-tabulations. Multivariate analyses included partial correlations and hierarchical linear regression.

Phase 3: Home-based ethnographic interviews and interviews with healthcare providers

In this third and final phase of research, I and/or the research assistant contacted diabetic women from Phase 2 by phone and asked them if they would be willing to let us visit them at a time and place of their convenience for a follow-up interview. We proceeded through the contact list until we had conducted follow-up interviews with approximately 10 percent of the 280 women whose data was retained for analysis in Phase 2. Some women were included or excluded purposively to maximize variety in religion, age, and socioeconomic background. In total, 25 women completed these in-depth interviews. With two exceptions, all of the women opted to be interviewed in their homes.

These interviews followed an interview guide designed to elicit illness narratives, originally developed by Kleinman (1988) and refined for use specifically with diabetic populations by Liburd and colleagues (2004). Each question included in the interview guide was worked into conversation rather than asked in sequence in order to avoid interrupting the respondent's train of thought and keep the interview atmosphere relaxed. All interviews were voice recorded. See below for the questionnaire.

When additional family members such as husbands, children, and daughters-in-law were available and willing to participate in the interview as well, we asked them if they perceived any difference in their family routines or in their diabetic family member's behaviors since her diagnosis.

Finally, in this phase of research I conducted semi-structured interviews with most of the physicians from whose clinics I recruited women during Phase 2. I also interviewed one homeopathic doctor, one Ayurvedic physician, a Hindu faith healer, and a Unani physician. All interviews were voice recorded. The interview guide used for these interviews is reproduced below.

Qualitative analyses

All of the voice-recorded interviews from Phases 2 and 3 were translated, and relevant portions were transcribed using Express Scribe 5.06 transcription software by myself and the research assistant. Interview transcripts were coded in MaxQDA 10 textual analysis software using an iterative approach similar to that outlined in Strauss and Corbin's (1990) work on grounded theory. Rather than applying *a priori* categories of analysis to a dataset, the grounded theory approach allows categories to emerge as the researcher reads over the data and engages in constant comparison of the materials. I used open coding and axial coding procedures (Strauss and Corbin 1990) to identify concepts and sub-concepts in the qualitative data, with one exception: any mention of the word "tension" was coded outright using a simple keywords-in-context search and autocode function in MaxQDA 10 because this was an important target concept in my research. The coding taxonomy eventually developed using this method is as follows:

Diagnosis stories
Insulin
Education or employment—regrets, concerns
TV
Aging
Urban life, modern life
Marriage and joint family
Comorbidities
    a. General symptoms (not diabetes-specific)
    b. Blood pressure
Compliance
Illness narrative snippets
Patients and doctors
Crises related to diabetes

Crying
Indian characteristics/religiosity/traditional beliefs
Anxiety/depression/negative emotions
    a. Optimistic attitude
Domestic/family responsibilities
Perceived causes of diabetes
Relatives or self abroad
Diabetes management efforts
Alternative healing
Diabetes symptoms
Tension
    a. Family tensions—children, money, spouse
Class characteristics
Costs of care
Medical system
Disability/challenges
Attitudes toward chronic diseases
Tradition versus modernity

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