

Published in final edited form as:

Soc Sci Med. 2012 December ; 75(12): 2522–2529. doi:10.1016/j.socscimed.2012.09.040.

Stress and Diabetes in Socioeconomic Context: A Qualitative Study of Urban Indians

Emily Mendenhall^{1,2}, Roopa Shivashankar^{3,4}, Nikhil Tandon^{4,5}, Mohammed K. Ali^{2,6}, K.M. Venkat Narayan^{2,6}, and Dorairaj Prabhakaran^{2,3,4}

¹MRC/Wits Developmental Pathways for Health Research Unit, Faculty of Health Sciences, University of Witwatersrand, Johannesburg, South Africa

²NIH Fogarty International Center, Bethesda, MD, USA

³COE-CARRS, Public Health Foundation of India, New Delhi, India

⁴Centre for Chronic Disease Control, New Delhi, India

⁵All Indian Institute of Medical Research, New Delhi, India

⁶Rollins School of Public Health, Emory University, Atlanta, GA, USA

Abstract

Type 2 diabetes has escalated in urban India in the past two decades. Historically a disease of the affluent, recent epidemiological evidence indicates rising diabetes incidence and prevalence in urban India's middle class and working poor. Although there is substantial qualitative data about people with diabetes from high-income countries, scant resources provide insight into diabetes experiences among those in India, and lower-income groups specifically. In this article, we use individual-level analysis of illness narratives to understand how people experience and understand diabetes across income groups in Delhi, India. We conducted in-depth qualitative interviews and administered the Hopkins Symptoms Check-List (HSCL-25) to evaluate depression among 59 people with diabetes in northeast Delhi between December 2011 and February 2012. We analyzed their responses to: 1) what caused your diabetes?; 2) what do you find most stressful in your daily life?; and 3) where do you seek diabetes care? We found few people held diabetes beliefs that were congruent with socio-spiritual or biomedical explanatory models, and higher income participants commonly cited "tension" as a contributor to diabetes. Stress associated with children's futures, financial security, and family dynamics were most commonly reported, but how these subjective stresses were realized in people's lives varied across income groups. Depression was most common among the poorest income group (55%) but was also reported among middle- (38%) and high-income (29%) participants. One-quarter of respondents reported diabetes distress, but only those from the low-income community reported co-occurring depression and these respondents often revealed poor access to diabetes care. These data suggest that lower-income populations not only have higher rates of depression but also may be more likely to delay health care and therefore develop diabetes complications. This research has many implications for public health care in India as diabetes prevalence shifts to affect lower income groups who concurrently experience higher rates of depression and poorer access to medical care.

© 2012 Elsevier Ltd. All rights reserved.

Corresponding Author: Emily Mendenhall, emily.mendenhall@gmail.com.

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Keywords

Social Distress; Depression; Type 2 Diabetes; Qualitative Interviews; Urban Health; India

Introduction

Originally from Punjab, Kamala moved to Delhi to settle with her husband's family soon after marriage. In her late 50s, Kamala reflected on the chronic stress of the past thirty years spurred by tensions of joint-family conflicts, worries about the success and economic mobility of her children, and diabetes. She reported mild depression in addition to poor diabetes control. Kamala often would forgo medical treatment because of overcrowding in government hospitals and the expense of private hospitals. Therefore, she managed diabetes with her diet and relied on friends for social support, a television show for information, and Ayurvedic medicines to manage her glucose. Rarely did she find time or opportunities for physical activity, as the only physical work she once did was housework, and these tasks had been taken over by her daughter-in-law.

Historically type 2 diabetes (hereafter, "diabetes") in India was considered a disease of the elite. But in tandem with escalating diabetes incidence in India, diabetes is shifting to afflict people like Kamala who represent the growing urban middle class and working poor (Popkin et al., 2012). With an estimated 11 to 16% diabetes prevalence within mega-cities, such as Delhi and Chennai, these increases are significant (Ajay et al., 2008; Ebrahim et al., 2010; Gupta and Misra, 2007; Patel et al., 2011a) and a documented socioeconomic reversal of diabetes distribution (Deepa et al., 2011; Reddy et al., 2007) produces new public health challenges. Specifically, as diabetes increases among lower income groups, the stress-diabetes interface will become a central part of the diabetes problem as a result of increased exposure to stressful experiences, economic insecurity, co-morbid depression, and poor access to health care.

Heretofore, a small body of research attends to the social and cultural factors that shape diabetes onset and management in India (Sarkar and Mukhopadhyay 2008; Shobhana et al., 2003; Sridhar et al., 2000, 2002, 2007; Weaver and Hadley 2011). Weaver and Hadley (2011) published an extensive list of tensions reported by women with diabetes and discussed how these stressors result from and contribute to social roles and mental distress. Sridhar and Madhu (2002) found that men more commonly than women relied on their spouses to manage their diets and were less likely to seek their support with regard to emotional states or medication adherence. Others suggest that men's reliance on women was one reason for men having fewer diabetes complications than women (Shobhana et al., 2003; Sridhar et al., 2007) and that women's feelings of stress and guilt associated with diabetes might be a contributor to diabetes problems (Sridhar et al., 2007). Few studies have considered the role of economic security in the social experiences or psychological burden of urban Indians with diabetes.

In addition to everyday stresses that may facilitate diabetes onset or impede one's ability to manage their disease, co-morbid depression plays an important role in diabetes management among people with diabetes. Studies from high-income countries identify depression as both a cause and consequence of diabetes and a growing body of research emphasizes bi-directionality between the two chronic conditions (Egede and Ellis, 2010; Golden et al., 2008; Golden et al., 2007; Knol et al., 2006; Mezuk et al., 2008). A recent population-based study in metropolitan India found 20% of people with newly diagnosed diabetes had co-occurring depression (Poongothai et al., 2010). Another study of a clinical population of

urban Indians with diabetes found that depression was estimated at 41% (Raval et al., 2010). Indeed, the urgency for understanding the role of social and psychological distress in diabetes, particularly among poorer Indians with limited health care access, is underscored by the strong association of depression with poor self-care practices and poor glycemic control (Katon et al., 2010), which, in turn, can increase the likelihood of diabetes-related complications and consequently mortality (deGroot et al., 2001; Lin et al., 2009).

In this article, we use individual-level analyses of illness narratives to understand how people across income groups experience and understand diabetes in Delhi, India. This article is the first in depth qualitative study to examine socioeconomic variation in knowledge about diabetes, common stressors that people with diabetes report, and problems regarding health care access that lower income groups face in diabetes care in the urban Indian context. In addition, we use a mixed-methods approach to inventory depression in order to explore psychological morbidity across socioeconomic groups. We differentiate study participants by income group to evaluate how social and economic resources may shape knowledge about and experiences with diabetes, social stress, and access to health care.

Background

Anthropologists and social epidemiologists describe diabetes as a disease of “modernization” because of its strong relationship with economic development and urbanization (McGarvey et al., 1989; Zimmet, Alberti, and Shaw 2001; Lieberman 2003). Elsewhere we have argued that rapid socioeconomic and demographic changes as a result of such processes may contribute to increased incidence and prevalence of diabetes and depression in two fundamental ways (Mendenhall et al., 2012). First, significant changes in quality, quantity, and source of food consumption and physical activity patterns in the past decade have facilitated the escalation of overweight, obesity, and diabetes in India (Popkin et al., 2012). Rapidly improving socioeconomic status has been associated with increased diabetes, particularly among the affluent (Ramachandram 2007), and the subsequent rise in diabetes incidence among middle- and low-income groups (Deepa et al 2011; Reddy et al 2007). Thus, we are beginning to see a shift in the distribution of diabetes that represents a shift previously observed in high-income countries, such as the U.S., where much of the diabetes burden afflicts the socially disadvantaged.

Second, extremely high rates of depression (15%) exist in the urban Indian population (Poongothai et al., 2009), and are observed largely among people who are older, lower socioeconomic status, women, divorced or widowed, and in poorer physical health (Patel et al., 1998; Poongothai et al., 2009). Epidemiological studies indicate that these high rates of depression may be attributable to discrimination, unemployment, and living through rapid and unpredictable social change (Patel and Kleinman 2003). Other social factors associated with modernization that play an important role in depression and, indirectly, diabetes, may include, but are not limited to, rural to urban migration, changing family structures, social integration, intergenerational conflicts, and changing value systems (see Kielmann 2002). Such experiences are embedded within larger political-economic and social changes that shape not only how people live and interact, but also diabetes and depression epidemiology.

Medical anthropologists traditionally have drawn from lay perspectives to generate understanding of social experiences and cultural beliefs that may function as conduits of these epidemiological trends (Kirmayer and Young 1998; Kleinman 1980; Brown et al., 2009). For example, diabetes research in the United States has documented the importance of understanding the role of folk beliefs and social stress in diabetes onset and management among low-income Mexican immigrants (Poss and Jezewski 2002; Hunt et al., 1998;

Mendenhall et al., 2010). While a growing number of studies address diabetes epidemiology in India, very few attend to social experiences and cultural beliefs.

We may glean some insight into such beliefs from Dalal's (2000) finding that people often implicate karma, God, and fate in their experiences with health and illness. In addition, many people maintain a traditional understanding of self-care and healing with regard to their diabetes problems (Rai and Kishore 2009). These cultural beliefs may shape the way in which people understand and experience their diabetes, and therefore function as a critical aspect in diabetes self-care and social understandings of the disease more generally. Moreover, an examination of such beliefs may inform how people conceive of diabetes, and therefore provide information regarding diabetes knowledge in the general population and congruence of lay beliefs with messages from biomedicine.

As diabetes transitions from affluent to lower-income groups, more research is necessary to understand what social and health problems might come to bear. In this article, we address three themes from our qualitative data in order to portray the cultural, social, and psychological domains within the lives of people with diabetes in Delhi. First, we explore people's beliefs about diabetes causality. Second, we investigate the major social stressors reported in people's lives and evaluate depression across income groups. Finally, we present people's health care experiences and consider the role of socioeconomic status in how people seek care for diabetes. In doing so, we believe our qualitative findings will provide insights into what forms of prevention and treatment strategies will be most meaningful to combat diabetes morbidity and mortality in the coming decade as poorer groups comprise a greater proportion of those with diabetes and who are dually compromised by stress, depression, and unmet needs for medical care.

Methods

Data Source

We recruited a convenience sample of individuals ($n=59$) who were enrolled in the broader Center for cArdio-metabolic Risk Reduction in South Asia (CARRS) Study (see Nair et al., 2012). We employed a rigorous screening process conducted by the second author (RS) to identify eligible study participants before we invited them to partake in the study. We included only those who were older than 20 years-of-age, self-reported having type 2 diabetes, and resided in one of three neighborhoods that we selected: 1) we identified low-income participants ($n=20$) from those living in a resettlement community, or government housing allocated for people who previously resided in Delhi slums; 2) our high-income group ($n=14$) included individuals residing in a gated community where the upper echelons of Delhi society reside; and 3) those in the middle-income group ($n=25$) lived in neither a slum, resettlement community, or gated community and resided in a neighborhood commonly referred to as "middle-class." We designed the cross-sectional study to include around 20 individuals in each of the three income groups to provide sufficient numbers for saturation of intra-group themes and comparison of inter-group variation (Bernard 1998). We excluded individuals who did not meet our inclusion criteria or who had severely disabling diabetes complications or cognitive impairment, active substance abusers, or psychosis severe enough to interfere with participation in the interview.

The study took place in northern Delhi between 2011 and 2012. One hundred eligible study participants in the CARRS parent study were initially identified and 59 took part in the interview. Fewer than five eligible study participants declined to participate in the study, and many were not home or unavailable. A field-team member involved in recruitment for the CARRS Study introduced a gender-matched, Hindi-speaking research assistant (RA) to each study participant. We purposively sampled equal numbers of men and women and gender-

matched RAs and respondents in order to prevent hesitation that one might feel as a result of discussing sensitive subjects with the opposite sex. The gender-matched RAs introduced themselves, described the study as focused on stress and diabetes, and scheduled an interview for a later date. After providing informed consent, study participants were interviewed for around one hour (between 50 and 90 minutes) and a frequently used and Hindi-validated depression inventory was then administered. All interviews were audio-recorded in Hindi. The Institutional Review Boards at the Public Health Foundation of India and Emory University approved the study.

Data Collection

The qualitative interview guide was written in English, translated into Hindi, and back-translated into English. We organized the interview guide into five domains: 1) routine daily activities; 2) general questions about stress; 3) social relationships; 4) beliefs and experiences regarding diabetes; and 5) experiences of health care. Each narrative interview began with: “Can you describe a typical day for me?” The interview then shifted to address the study participant’s understanding of and experiences with stress, including questions like “What does stress mean to you?” and “Have you experienced a stressful situation in the past 30 days? Can you describe it? What aspects of your life cause you the most tension?” Since the English term “tension” is a common term utilized to express stressful experiences in India (Weaver and Hadley 2011), we often probed using the terms tension and stress interchangeably. We also asked targeted questions about social relationships, including family and community tensions or support systems. We spent the last half of the interview discussing issues associated with diabetes, including questions like “What caused your diabetes?”, “Has diabetes changed your life in any way?”, “Has diabetes affected your daily routine?” and “Does stress or tension affect your diabetes in any way?” And, finally, we asked a number of questions about diabetes management, such as “Can you tell me about how you care for your diabetes?”, “Who makes decisions about your diabetes care?” and “Where do you seek diabetes care? And, how often?”

Following the in-depth interview, we conducted the Hopkins Symptoms Check-List (HSCL-25), a 25-item questionnaire in which respondents are asked to score each mood-related item on a scale ranging from 0 (“not at all”) to 3 (“extremely”) (Mollica et al., 2004). The HSCL-25 has been validated in Hindi (Weaver and Hadley, 2011), and the second author, a medical doctor, oversaw the implementation of this depression inventory. The depression component of the HSCL (questions 11–25) was averaged over the number of items and a score greater than 1.75 was considered a clinically significant level of depression. The HSCL-25 had excellent internal validity; the standard cutoff for validity using a Cronbach’s alpha statistic is 0.70 or above (Nunnally and Bernstein 1994) and the HSCL had a Cronbach’s alpha of 0.83.

Data Analysis

The qualitative interviews were transcribed into English from Hindi. Based on the literature, we employed a deductive approach and used content-analysis to evaluate three overarching themes that we predicted would be central to participant stories: beliefs about diabetes causality, social stressors, and health care experiences. First, we identified eight common “diabetes beliefs” reported in response to the question (Table 2): What caused your diabetes? Second, we identified twelve major social stressors described across the dataset in response to questions such as “Have you experienced stress or tension in the past 30 days? What aspects of your life cause you the most tension?” Through axial-coding we found five sub-codes that more explicitly defined the nuances of these social stress reported by our sample (Table 3). Finally, we recorded what people identified to be their major source of health care and found key patterns across income groups corresponding with seeking care,

delaying care, and attending private versus public clinic services. The first (EM) and second (RS) authors coded each of these themes and discrepancies in the data were discussed in order to reach consensus; a bilingual research assistant also coded the social stressors domain. Patterns in these data are reported in Table 2 and 3 and exemplar quotations of each category were excerpted to provide in depth understanding of people's responses.

We present measures of depression as descriptive data in conjunction with demographic information that was retrieved from the parent CARRS Study (collected within the previous one year) (Table 1). We also provide additional information in the text in order to describe concordance between depression and experiencing specific forms of social stress reported in qualitative interviews; we present these data only to provide insight into concordance between social stress and depression, as opposed to correlation or causation.

Results

Table 1 presents descriptive data of the sample's characteristics. Men and women were equally represented in this group and tended to be married, Hindu, and forty years-of-age or older. Individuals from the resettlement community completed less education and maintained lower incomes than those from middle- and high-income neighborhoods. Co-morbid depression was higher among the lowest-income group (55%). This was higher than the overall occurrence of depression (41%) in addition to high-income (29%) and middle-income (38%) groups. Fifty-five percent of low-income participants reported that they were diagnosed with diabetes ten or more years before the interview compared to 76% and 79% of those in middle-income and high-income groups, respectively.

Diabetes Beliefs

We asked our study participants: What caused your diabetes? Table 2 shows that the response "I don't know" (49%) was most common and stress or "tension" (24%), eating habits (17%), and heredity (14%) were frequent responses. Other causal models included: karma, fate, physical inactivity, and obesity. In most cases, study participants stated only one cause of diabetes, but several incorporated more than one contributor thereby relegating causal reasoning to multiple factors. For example, one middle-income man said, "contaminated food items, pollution, and tension" caused his diabetes.

Half of the study participants stated: "I don't know what caused my diabetes" (Table 2). Three-quarters of those living in the resettlement community provided this response compared to around one quarter of those living in the middle- or high-income neighborhoods. Seven of these 29 study participants stated, "I don't know, but..." which was followed by a description of what might cause diabetes generally. In these cases, study participants stated that they knew what might cause diabetes for other people and in doing so dissociated this explanation from their personal causal model.

"I don't know. But people say it is due to eating sugar." (Low-income man)

"I don't know why I got diabetes. It might be that my earlier diet contributed to my sugar diagnosis but I don't know exactly. As far as my lifestyle is concerned, in terms of daily activities, I was very active and did a lot of household work."
(Middle-income woman)

Surprisingly few study participants implicated biomedical causes into their diabetes explanatory models. The following quote illustrates how some respondents reported heredity, eating habits, and physical inactivity in their diabetes beliefs:

"People used to work hard and so they did not conceive of diabetes – it was so uncommon. Now because of automated machines people become more prone to

disease. Earlier people would walk and now they use vehicles. Earlier they used hand pumps and wells to get water and now they use taps. So this modern, high-tech era has had some bad effects on our health. I guess if people would go back 25–30 [years] then they would not have any tension or health issues. I guess automated advanced age is the biggest source of any kind of diseases.” (Middle-income man)

Similarly, few people incorporated socio-spiritual beliefs, such as fate, karma, or God into their diabetes etiologies. This belief is demonstrated by the following quote:

“I think [diabetes] happened because it was in my fate.” (Low-income woman) One in four study participants implicated a stressful situation or “tension” in diabetes onset (Table 2). Those who reported this causal model were primarily from the middle- and high-income groups. In many cases, this belief was associated with a stressful experience or period in one’s life, as described by the following narrative excerpts:

“I got diabetes because of tension only. It’s not because of food habits or lifestyle.” (Middle-income man)

“I got it [diabetes] from tension after my husband’s death. I remained normal when I was not so stressed.” (High-income woman)

Stress and Diabetes

We asked our study participants to describe what caused stress in their lives. Most people reported between two and five major stressors, with an average of 3.4 (SD \pm 1.5) stressors across the sample, including stress related to children’s future, family conflict, personal health, financial security, a job, family health, loss of a family member, old age, diabetes, interpersonal abuse, loneliness, and an alcoholic spouse (see Table 3).

The most commonly reported stressor was worrying about their children’s future (Table 3). Fifty-five percent of the sample worried about children’s schooling, potential for wealth accumulation, preparing for a child’s marriage, and saving for dowry, as described by the following:

“I want to make a good future for my children. Sometimes I get tension when children don’t follow my words and I just worry about their future.” (Middle-income man)

We found variation across income groups in what types of stress were caused by worry over their children’s future and the co-occurrence of that stress with depression. Just over half of those from the resettlement community (53%) who reported this stressor also had co-occurring depression, and this was true particularly for stress associated with child’s marriage (50%) and saving for a daughter’s dowry (67%):

“I am tensed about my children’s marriage. We have been searching for a good match for my daughters for two years. We are not getting our choice in grooms. We want our daughters to be happy after marriage. We cannot afford a big dowry.” (Low-income woman)

One in two respondents described family conflict to be a major source of stress (Table 3). But axial-coding revealed that family stress was experienced and expressed differently according to socioeconomic group. Those who were low-income were more likely to report general family stress, such as interpersonal conflicts or concern for a family member’s well-being, and 50% of these individuals were also depressed:

“My son is being pursued legally by some neighbor. So the legal case is going on. This is giving a lot of tension.” (Low-income man)

Those stratified by higher incomes reported family stress differently, often related to conflict with a mother-in-law or daughter-in-law (Table 3). These individuals were exclusively women and many had co-occurring depression. These disputes often stemmed from differing opinions about raising children and keeping the home.

“My in-laws were not reasonable people. They were biased for one thing or another. They scolded me all the time. [...] She [mother-in-law] never let me leave; all the time I was busy with housework.” (High-income woman)

Personal health concern was reported by almost half the sample (47%). This stressor included diabetes and other health problems such as heart disease, stroke, and tuberculosis. It also included explicit mention of mental health and substance abuse (tobacco, alcohol, and other drugs). Although a larger percentage of people in the higher income group reported concern for personal health (71%), around one-third of those who reported this stressor across income groups were concurrently depressed.

One-quarter of respondents specifically reported diabetes distress:

“The biggest problem I face is I’m diabetic. [...] I feel physical weakness because of diabetes. For everything you do needs power; if power is not there you can’t do anything. So because of that I can’t do any physical work. And the second one is that for every work you need eyes. I’m fond of reading, but I’m not able to do it [because of reduced eyesight as a result of diabetes].” (High-income man)

Despite the fact that diabetes distress was reported across income groups, only those from the resettlement community had co-occurring depression and diabetes distress (57%).

One in two study participants reported financial stress to be a major problem, which co-occurred with depression most frequently among lower (43%) and middle-income (36%) respondents. This might be a reflection of the fact that financial stress was expressed differently across income groups. One-third of the resettlement community respondents described the stress of financial insecurity.

“I don’t have my own house, we are living in a government flat. How are my children going to live [in the future]?” (Low-income woman)

People with higher incomes were more likely to complain of financial stress in a less direct way, often describing stress associated with sustaining one’s living standard or keeping up with a modern lifestyle.

“The major reason for tension in today’s world is the status factor: we need to have a car, a bungalow, so much money to survive. I guess people are running behind [in status] and [they believe that] if you don’t have all this, you would not be respected in society.” (Middle-income man)

In addition to stress related to their children’s futures, family conflict, personal health, and finances, less frequently reported social stressors reveal important differences across socioeconomic groups, as well (Table 3). One-third of the sample reported work-related or “job” stress—from managing work-family time to coping with work expectations and interpersonal conflict; men exclusively reported this theme.

“The tensions of business are of a different nature. It’s like you wanted to get something and then you can’t get it. Like you wanted to earn 100 rupees and you got only 25 rupees, so the rest is loss. Expectations never end. It’s not actually

loss of 75 rupees; it's all about how much assurance you can give yourself and feel satisfied. This is what happens most of the time.” (Middle-income man)

Twenty-nine percent of the sample reported a family member's health and 19% reported that caring for family members caused stress. Low- and middle-income respondents identified these stressors more frequently. In a similar vein, one in four study participants described the loss of a family member to cause much strain; this included not only recent loss but also losing a loved one many years in the past.

Table 3 also shows that old age (25%), interpersonal abuse (19%), loneliness (19%), and living with alcoholic husbands (8%) were significant stressors. These stressors co-occurred with depression among low- and middle-income groups, and women in particular.

“My husband abused me and hit me whenever he drank. He was an unhappy person.” (Middle-income woman)

Seeking Support for Diabetes

Two key themes emerged from people's descriptions of diabetes care seeking. First, few people sought routine medical care for their diabetes, and many sought care only when they perceived a medical problem.

“Since there is no problem [with my diabetes] that is why I do not visit the doctor.” (Middle-income man)

“Generally doctors recommend me to get tested every time I visit the doctors. But due to some reason it has not been possible for me [to visit the doctor] for the past few months.” (Middle-income woman)

Second, higher-income respondents commonly described seeking medical care in private clinics while those from the resettlement community reported spending less money on health care by not going to the doctor and avoiding tests and medicines due to cost.

“See, I don't have much money, why should I lie to you? Earlier my [private] doctor took Rs 60 for tests. Now he has increased it to Rs 80. The private doctor charges you when you have consultation from him so I don't go. Actually what my earlier doctor gave to me [in terms of care] was not an advantage to me. If my reports are normal I don't consult the doctor. But if there is some problem then I go to the government hospital for consultation.” (Low-income woman)

The delay in care might be, in some part, due to mistrust of government facilities, and external barriers to care, such as transport and distance from a health center:

“These government hospitals are not providing proper facilities. There are no facilities for old people whereas in foreign countries, a vehicle will come to pick them up if they want to go to a bank or somewhere. Or an ambulance will come to pick them up if anybody is ill, all they have to do is to call 911. Hospitals have to provide the proper facilities to people.” (Middle-income woman)

In contrast, most middle- and high-income respondents reported visiting a private hospital, but many sought care at both private and public hospitals:

“I: Where do you receive diabetes care?”

P: First I went to [Private Hospital A], then [Private Hospital B], then [A Government Teaching Hospital] and now [Private Hospital C].” (High-income man)

And, many of these respondents reported having an ongoing relationship with a particular doctor for general health and diabetes care.

“I visit a private doctor. He is our family doctor. I have problem of blood pressure since last 35–36 years and experiencing diabetes since 20 years. There are plenty of problem in government hospitals. Therefore, I prefer going to the private doctors.”
(Middle-income woman)

However, this study participant also stated:

“I can’t afford doctors’ fees. I have not been tested for diabetes since last five to six months.”

Discussion and Conclusion

To the best of our knowledge, this is the first study to examine the social experiences of men and women with diabetes across income groups in urban India. The data confirm several expectations, but bring to light other issues that better elucidate the relationship of diabetes with social, psychological, and cultural domains across income groups in Delhi. First, we found few people held diabetes beliefs that were congruent with socio-spiritual or biomedical explanatory models, and many people dissociated their own diabetes from general knowledge about causative factors for diabetes. Second, social stressors associated with meeting expectations regarding children’s future, financial security, and family were the most commonly reported social stressors, but how these subjective stresses were realized in people’s lives varied across income groups. Third, one-quarter of respondents reported diabetes distress, but only those from the low-income community reported co-occurring depression and these respondents often revealed a diabetes complication. As do our qualitative findings around health care access, these data suggest that lower-income populations may be more likely to delay health care and therefore might experience higher rates of diabetes complications.

There were important findings revealed by middle- and high-income groups that expose nuances in their knowledge about and experience with diabetes. While one-third of these interlocutors revealed that they did not know why their diabetes precipitated, they more commonly endorsed an alternative explanation, including socio-spiritual beliefs (karma specifically), biomedical beliefs (such as eating habits), and stress or tension, than did low income respondents. By recognizing social stress as causal to diabetes, these individuals revealed the belief that the social world may function as a contributor to their physical health, thereby making connections between social-biological domains. The common belief that stress or tension contributes to diabetes onset also might reflect a cultural nuance in which mind-body connections are integral to the ways in which people in India think about health and healing. Moreover, consideration of the role of social stress in diabetes onset and complications may be more salient in “doctor talk” among Indian clinicians as opposed to those in societies like the United States that maintain a western-biomedical understanding of diabetes (Finkler, 2004; Loewe et al., 1998). Thus, more frequent endorsement of tension or stress as causal to diabetes among middle- and high-income groups also might be a reflection of their better and more consistent access to diabetes care.

In addition, middle- and high-income groups reported distinctive social stressors that bring to light the important role of social and economic changes in subjective social stress (McDade, 2002) and depression (Patel and Kleinman, 2003). In contrast to those from the resettlement community who fretted about preparing their children’s marriages and saving for dowry, higher-income respondents revealed subjective stress associated with maintaining or elevating social status, and expressed concern for children’s demands for “gadgets,” which mismatched with their own beliefs and behaviors. Intergenerational conflicts

expressed by women in higher economic echelons also point to dissatisfaction with living in a traditional joint family. This finding reflects an important aspect of culture change because, in a relational country such as India, where family is the center of many people's lives, family discord is a major contributor to mental distress (Chokkanathan, 2009). It also reveals a critical dimension of subjective social stress within the higher socioeconomic echelons that will only continue to escalate in tandem with modernization within the urban Indian context. Fast-paced uptake of social change among young people may continue to foster intergenerational conflict, and this conflict, in addition to changes in physical activity as a result of mechanization, might play a fundamental role in diabetes management through social isolation and lack of family support that traditionally has been so important for Indian families.

Perhaps the most significant finding was that diabetes beliefs, salient social stressors, and health care access among those with diabetes who resided in the resettlement community were notably different than those living in middle- and high-income neighborhoods. Three-fourths of the low-income respondents indicated that they did not know what caused their diabetes, and only a few reported socio-spiritual beliefs, such as fate, or biomedical beliefs, such as heredity or obesity, which suggests that there is very low social awareness of the disease within this income group. It also suggests that these individuals might have very little interaction with biomedical care.

Indeed, one-third of respondents in the lowest income group identified diabetes to be a major stressor in their lives, but other forms of social stress were even more common. Concern for their children's future was most common, including the stress of arranging a child's marriage and paying for a daughter's dowry. Family conflict was also a major concern for more than half of those living in the resettlement community, in addition to concern for a family member's health, personal health, and finances. Gender played a specific role in social stressors reported, in addition to income groups; low- and middle-income women revealed concerns regarding interpersonal abuse, loneliness, and living with an alcoholic spouse (and it is likely that these were underreported—see Chokkanathan, 2009), and many of these women reported co-occurring depression. Such findings bring the light the unique stressors that affect lower income participants, and may be at the root of higher rates of depression within this group.

The fact that one-quarter of respondents across socioeconomic groups reported diabetes distress, but only those from the resettlement community reported co-occurring depression, brings to light an interesting question that attends to the data around health care access. Are lower income respondents who report diabetes problems more likely to be distressed because they have lower overall knowledge about the disease, or because they have less interaction with diabetes care? The fact that more study participants from the resettlement group learned about their diabetes only in the last ten years, compared to higher-income groups, also may be a reflection of reduced access to health care over the life course (Table 1). Reduced access to medical care among those from the resettlement community might result from poor facilities in government hospitals, mistrust in these facilities, and higher costs for private practice. Such findings are congruent with data from high-income countries that suggest that economically disadvantaged groups experience higher rates of diabetes-related morbidity and mortality as a result of chronic, untreated depression and poor health care access (deGroot et al., 2006). Indeed, this is an important area for further research and mental health intervention.

Finally, these data have relevance for public health and clinical practice in urban India for two reasons. First, although the indigent poor within India are still largely unaffected by diabetes, the escalating number of middle-class and working poor with diabetes eventually

may overburden the fragile health care system. This poses problems not only for diabetologists, endocrinologists, and general medical practitioners, but also for mental health professionals (who are extremely limited in India) (see Patel et al., 2011a). The limitations of the existing health infrastructure will likely play a major role in increasing diabetes mortality among poorer groups as an increasing proportion of lower-income Indians become affected by diabetes (Patel et al., 2011a). Second, increasing rates of diabetes among lower income groups bring to light the importance of task-shifting responsibilities to mid-level health professionals (such as specialist nurses) in order to provide comprehensive medical care. Collaborative-care models have proven successful for improving mental health (Patel et al., 2011b; Patel et al., 2010) and diabetes (Renders et al., 2001) outcomes by task-shifting responsibilities from physicians to lay health workers. The importance of integrated models of health care for patients with diabetes and depression is underscored by the strong relationship of depression with poor diabetes control (Lustman et al., 2000) and increased diabetes complications (deGroot et al., 2001), and vice versa.

This study is not without limitations. We interviewed a convenience sample of people with diabetes participating in a cohort-modeled surveillance study so these findings might not reflect the experiences of people seeking care at primary health care settings. However, we also see this as a strength as our findings provide insight into experiences of those who less frequently seek routine diabetes care – a population that requires further attention as diabetes continues to increase among urban Indians. As with all research that requires memory work around subjective experiences, there is also a possibility of recall bias that must be considered as a limitation. Moreover, this is a cross-sectional mixed qualitative and survey study so we are unable to assign causality between stressors and depression. Even more, we are unable to say that the social experiences or cultural beliefs held by our sample are those maintained solely by those diagnosed with diabetes, and future studies must examine a comparative group of people without diabetes. That said, our study reveals important overlaps between social stressors and depression that require further investigation at the population-level to better understand variation between men and women and socioeconomic groups.

Our study highlights the confluence of increased social distress and depression, lower diabetes knowledge, and poor access to health care that will likely become a problem as diabetes incidence increases among lower-income Indians. Health care reform currently is underway in urban India and our data suggest that policy-makers need to recognize the importance of an integrated health-care system for mitigating the stress-diabetes interface. More qualitative and context-specific data is needed to understand what forms of stress affect the health and social well-being of Indians with diabetes due to the extraordinary diversity found within the Indian context. Interventions targeting the stress-diabetes interface will likely differ according to sociodemographic characteristics of the populations they serve, which will require population-centered programs that attend to the needs of their communities.

Acknowledgments

We are grateful to the study participants who shared their time and personal experiences with us. Thank you to John Millhauser and Sara Lewis for reviewing the manuscript. The first author (EM) was supported by the Fogarty International Center of the National Institutes of Health through the International Clinical Research Fellows Program at Vanderbilt University (R24 TW007988) and the American Relief and Recovery Act. The second author (RS) was supported by a D43 Fellowship through the Fogarty International Center of the National Institutes of Health.

References

- Ajay V, Prabhakaran D, Jeemon P, Thankappan K, Mohan V, Ramakrishnan L, Joshi P, Ahmed F, Mohan B, Chaturvedi V, Mukherjee R, Reddy K. Prevalence and determinants of diabetes mellitus in the Indian industrial population. *Diabetic Medicine*. 2008; 25:1187–1194. [PubMed: 19046197]
- Bernard, HR. *Research Methods in Cultural Anthropology*. Newbury Park, CA: Sage; 1988.
- Brown RA, Kuzara J, Copland WE, Costello EJ, Angold A, Worthman CM. Moving from ethnography to epidemiology: lessons learned in Appalachia. *Annals of Human Biology*. 2009; 36:248–260.
- Chokkanathan S. Resources, stressors and psychological distress among older adults in Chennai, India. *Social Science and Medicine*. 2009; 68:243–250. [PubMed: 19026479]
- Dalal AK. *Living with a Chronic Disease: Healing and Psychological Adjustment in Indian Society*. *Psychology and Developing Societies*. 2000; 12:67–81.
- Deepa M, Anjana R, Manjula D, Narayan K, Mohan V. Convergence of prevalence rates of diabetes and cardiometabolic risk factors in middle and low income groups in urban India: 10-year follow-up of the Chennai Urban Population Study. *Journal of Diabetes Science and Technology*. 2011; 5:918–927. [PubMed: 21880235]
- de Groot M, Pinkerman B, Wagner J, Hockman E. Depression treatment and satisfaction in a multicultural sample of type 1 and type 2 diabetic patients. *Diabetes Care*. 2006; 29:549–553. [PubMed: 16505504]
- de Groot M, Anderson RJ, Freedland KE, Clouse RE, Lustman PJ. Association of Depression and Diabetes Complications: A Meta-Analysis. *Psychosomatic Medicine*. 2001; 63:619–630. [PubMed: 11485116]
- Ebrahim S, Kinra S, Bowen L, Andersen E, Ben-Shlomo Y, Lyngdoh T, Ramakrishnan L, Ahuja RC, Joshi P, Das SM, Mohan M, Smith GD, Prabhakaran D, Reddy KS, group IMS. The Effect of Rural-to-Urban Migration on Obesity and Diabetes in India: A Cross-Sectional Study. *PLoS Medicine*. 2010; 7:e1000268. [PubMed: 20436961]
- Egede L, Ellis C. Diabetes and Depression: Global Perspectives. *Diabetes Research and Clinical Practice*. 2010; 87:302–312. [PubMed: 20181405]
- Finkler K. Biomedicine globalized and localized: western medical practices in an outpatient clinic of a Mexican hospital. *Social Science and Medicine*. 2004; 59:2037–2051. [PubMed: 15351471]
- Golden S, Lazo M, Carnethon M, Bertoni A, Schreiner P, Roux A, Lee H, Lyketsos C. Examining a bidirectional association between depressive symptoms and diabetes. *Journal of the American Medical Association*. 2008; 299:2751–2759. [PubMed: 18560002]
- Golden SH, Chang BLH, Schreiner PJ, Roux AD, Fitzpatrick AL, Szklo M, Lyketsos C. Depression and Type 2 Diabetes Mellitus: The Multiethnic Study of Atherosclerosis. *Psychosomatic Medicine*. 2007; 69:529–536. [PubMed: 17636146]
- Gupta R, Misra A. Type 2 diabetes in India: regional disparities. *British Journal of Diabetes and Vascular Disease*. 2007; 7:12–16.
- Hunt L, Valenzuela M, et al. Porque me tocó a mi? Mexican American diabetes patients' causal stories and their relationship to treatment behaviors. *Social Science and Medicine*. 1998; 46:959–969. [PubMed: 9579748]
- Kielmann K. Theorizing health in the context of transition: The dynamics of perceived morbidity among women in Peri-Urban Maharashtra, India. *Medical Anthropology*. 2002; 21:157–205. [PubMed: 12126274]
- Kirmayer LJ, Young A. Culture and Somatization: Clinical, Epidemiological, and Ethnographic Perspectives. *Psychosomatic Medicine*. 1998; 3:343–367.
- Kleinman, A. *Patients and Healers in the Context of Culture: An Exploration of the Borderland between Anthropology, Medicine, and Psychiatry*. Berkeley: University of California Press; 1980.
- Knol M, Twisk J, Beekman A, Heine R, Snoek F, Pouwer F. Depression as a risk factor for the onset of type 2 diabetes mellitus. A meta-analysis. *Diabetologia*. 2006; 49:837–845. [PubMed: 16520921]
- Lieberman LS. Dietary, evolutionary, and modernizing influences on the prevalence of type 2 diabetes. *Annual Review of Nutrition*. 2003; 23:345–377.

- Lin E, Heckbert S, Rutter C, Katon W, Ciechanowski P, Ludman E, Oliver M, Young B, McCulloch D, Korff MV. Depression and increased mortality in diabetes: unexpected causes of death. *Annals of Family Medicine*. 2009; 7:414–421. [PubMed: 19752469]
- Loewe R, Schwartzman J, Freeman J, Quinn L, Zuckerman S. Doctor Talk and Diabetes: Towards an Analysis of the Clinical Construction of Chronic Illness. *Social Science and Medicine*. 1998; 47:1267–1276. [PubMed: 9783869]
- Lustman PJ, deGroot M, Anderson RJ, Carney RM, Freedland KE, Clouse RE. Depression and Poor Glycemic Control. *Diabetes Care*. 2000; 23:934–942. [PubMed: 10895843]
- McDade TW. Status Incongruity in Samoan Youth: A Biocultural Analysis of Culture Change, Stress, and Immune Function. *Medical Anthropology Quarterly*. 2002; 16:123–150. [PubMed: 12087626]
- McGarvey, ST.; Bindon, JR.; Crews, DE.; Schendel, DE. Modernization and adiposity: Causes and consequences. In: Little, M.; Haas, J., editors. In *Human Population Biology*. London: Oxford University Press; 1989. p. 263-280.
- Mendenhall E, Seligman R, et al. Speaking through Diabetes: Rethinking the Significance of Lay Discourses on Diabetes. *Medical Anthropology Quarterly*. 2010; 24:220–239. [PubMed: 20550094]
- Mendenhall E, Narayanan G, Prabhakaran D. Depression and Diabetes in India: Perspectives and Recommendations. *Diabetic Medicine*. 2012; 29(9):e308–e311. [PubMed: 22587494]
- Mezuk B, Eaton W, Albrecht S, Golden S. Depression and type 2 diabetes over the lifespan: a meta-analysis. *Diabetes Care*. 2008; 31:2383–2390. [PubMed: 19033418]
- Mollica, RF.; McDonald, LS.; Massagli, MP.; Silove, DM. *Measuring Trauma, Measuring Torture*. Cambridge, MA: Harvard Program in Refugee Trauma; 2004.
- Nair M, Ali MK, Ajay VS, Shivashankar R, Mohan V, Pradeepa R, Deepa M, Khan HM, Kadir MK, Fatmi ZA, Reddy KS, Tandon N, Narayan KMV, Prabhakaran D. CARRS Surveillance study: design and methods to assess burdens from multiple perspective. *BMC Public Health*. 2012; 12:701. [PubMed: 22928740]
- Nunnally, JC.; Bernstein, IH. *Psychometric Theory*. New York: McGraw-Hill; 1994.
- Patel V, Pereira J, Coutinho L, Fernandes R, Fernandes J, Mann. Poverty, psychological disorder, and disability in primary care attenders in Goa, India. *British Journal of Psychiatry*. 1998; 172:533–536. [PubMed: 9828996]
- Patel V, Kleinman A. Poverty and common mental disorders in developing countries. *Bulletin of the World Health Organization*. 2003; 81:609e–615e. [PubMed: 14576893]
- Patel V, Weiss H, Chowdhary N, Naik S, Pednekar S, Chatterjee S, Silva MD, Bhat B, Araya R, King M, Simon G, Verdeli H, Kirkwood B. Effectiveness of an intervention led by lay health counsellors for depressive and anxiety disorders in primary care in Goa, India (MANAS): a cluster randomised controlled trial. *Lancet*. 2010; 376:2086–2095. [PubMed: 21159375]
- Patel V, Chatterji S, Chisholm D, Ebrahim S, Golapkrishna G, Mathers C, Mohan V, Prabhakaran D, Ravindram RD, Reddy KS. Chronic diseases and injuries in India. *Lancet*. 2011a; 377:413–428. [PubMed: 21227486]
- Patel V, Weiss HA, Chowdhary N, Naik S, Pednekar S, Chatterjee S, Bhat B, Araya R, King M, Simon G, Verdeli H, Kirkwood BR. Lay health worker led intervention for depressive and anxiety disorders in India: impact on clinical and disability outcomes over 12 months. *The British Journal of Psychiatry*. 2011b; 199:459–466. [PubMed: 22130747]
- Poongothai S, Pradeepa R, Ganesan A, Mohan V. Prevalence of Depression in a Large Urban South Indian Population -- The Chennai Urban Rural Epidemiology Study (CURES-70). *PLoS ONE*. 2009; 4:e7185. [PubMed: 19784380]
- Poongothai S, Anjana R, Pradeepa R, Ganesan A, Umapathy N, Mohan V. Prevalence of depression in relation to glucose intolerance in urban south Indians-the Chennai Urban Rural Epidemiology Study (CURES-76). *Diabetes Technology and Therapeutics*. 2010; 12:989–994. [PubMed: 21128845]
- Popkin BM, Adair LS, Ng SW. Global nutrition transition and the pandemic of obesity in developing countries. *Nutrition Reviews*. 2012; 70:3–21. [PubMed: 22221213]
- Poss J, Jezewski MA. The role and meaning of susto in Mexican Americans' explanatory model of type 2 diabetes. *Medical Anthropology Quarterly*. 2002; 16:360–377. [PubMed: 12227261]

- Rai M, Kishore J. Myths about diabetes and its treatment in North Indian population. *International Journal of Diabetes in Developing Countries*. 2009; 29:129–132. [PubMed: 20165650]
- Ramachandram, A. *Epidemiology of diabetes in India*. New Delhi: Jaypee; 2007.
- Raval A, Dhanaraj E, Bhansali A, Grover S, Tiwari P. Prevalence & determinants of depression in type 2 diabetes patients in a tertiary care centre. *Indian Journal of Medical Research*. 2010; 132:195–200. [PubMed: 20716820]
- Reddy KS, Prabhakaran D, Jeemon P, Thankappan KR, Joshi P, Chaturvedi V, Ramakrishnan L, Ahmed F. Educational status and cardiovascular risk profile in Indians. *PNAS*. 2007; 104:16263–16268. [PubMed: 17923677]
- Renders C, Valk G, Griffin S, Wagner E, Eijk J, Assendelft W. Interventions to improve the management of diabetes in primary care, outpatient, and community settlements: a systematic review. *Diabetes Care*. 2001; 24:1821–1833. [PubMed: 11574449]
- Shobhana R, Rao PR, Lavanya A, Padma C, Vijay V, Ramachandran A. Quality of Life and Diabetes Integration among Subjects with Type 2 Diabetes. *Journal of the Association of Physicians of India*. 2003; 51:363–365. [PubMed: 12723650]
- Sridhar G, Madhu K. Psychosocial and cultural issues in diabetes mellitus. *Current Science*. 2002; 83:1556–1564.
- Sridhar G, Madhu K, Veena S, Madhavi R, Sangeetha B, Rani A. Living with diabetes: Indian experience. *Diabetes and Metabolic Syndrome*. 2007; 1:181–187.
- Weaver LJ, Hadley C. Social Pathways in the Comorbidity between Type 2 Diabetes and Mental Health: Concerns in a Pilot Study of Urban Middle- and Upper-Class Indian Women. *Ethos*. 2011; 39:211–225.
- Zimmet P, Alberti KGMM, Shaw J. Global and societal implications of the diabetes epidemic. *Nature*. 2001; 414:782–787. [PubMed: 11742409]

Research Highlights

1. Provides analysis of personal experiences and beliefs of people with type 2 diabetes in urban India
2. Describes common beliefs people hold about diabetes causality
3. Compares common social stressors reported by people with diabetes across income groups
4. Compares depression reported among people with diabetes across income groups
5. Describes challenges in health care access for people with diabetes across income groups

Table 1

Demographics of the Study Sample

	Low Income (n=20)	Middle Income (n=25)	High Income (n=14)	Total (n=59)
Women (n, %)	11 55%	10 40%	8 57%	29 49%
Age (mean, +/-SD)	49 +/- 9.2	58 +/- 9.3	56 +/- 10.7	55 +/- 10.3
Born in Delhi (n, %)	6 30%	9 36%	7 50%	20 34%
Married (n, %)	19 95%	22 88%	12 86%	53 90%
Hindu (n, %)	20 100%	22 88%	11 79%	53 90%
Years of School (mean, +/-SD)	8 +/- 3.9	11 +/- 3.7	13 +/- 2.4	10 +/- 3.9
<Rs 10,000 per month (n, %)	13 65%	7 28%	0 0%	20 34%
Depressed (n, %)	11 55%	9 36%	4 29%	24 41%
10+ years diagnosed with diabetes (n, %)	11 55%	19 76%	11 79%	41 69%

Table 2

Diabetes Beliefs by Income Group

What caused your diabetes?	Low Income (n=20)		Middle Income (n=25)		High Income (n=14)		Total (n=59)	
	n	%	n	%	n	%	n	%
I don't know	15	75%	9	36%	5	36%	29	49%
Karma	0	0%	3	12%	0	0%	3	5%
Fate	2	10%	0	0%	1	7%	3	5%
Hereditry	2	10%	4	16%	2	14%	8	14%
Eating habits	0	0%	7	28%	3	21%	10	17%
Exercise	1	5%	2	8%	1	7%	4	7%
Obesity	2	10%	1	4%	0	0%	3	5%
Tension	1	5%	8	32%	5	36%	14	24%

Table 3

Social Stress Reported by Income Group

	Low Income (n=20)		Middle Income (n=25)		High Income (n=14)		Total (n=59)	
	n	%	n	%	n	%	n	%
Children's Future	15	75%	12	48%	6	43%	33	56%
Child's Marriage	8	40%	2	8%	1	7%	11	19%
Dowry	3	15%	1	4%	0	0%	4	7%
Family Conflict	12	60%	12	48%	6	43%	30	51%
Joint Family Stress	3	15%	9	36%	4	29%	16	27%
Mother or Daughter-in-law stress	0	0%	5	20%	2	14%	7	12%
Personal Health Concern	7	35%	11	44%	10	71%	28	47%
Financial Stress	7	35%	11	44%	10	71%	28	47%
Job Stress	5	25%	9	36%	5	36%	19	32%
Family Health Concern	9	45%	7	28%	1	7%	17	29%
Burden of Family Care	5	25%	5	20%	1	7%	11	19%
Loss of Family Member	2	10%	6	24%	7	50%	15	25%
Old Age	3	15%	6	24%	6	43%	15	25%
Diabetes Distress	7	35%	4	16%	4	29%	15	25%
Interpersonal Abuse	2	10%	6	24%	3	21%	11	19%
Loneliness	4	20%	6	24%	1	7%	11	19%
Alcoholic Husband	1	5%	3	12%	1	7%	5	8%