Decoding the Type 2 Diabetes Epidemic in Rural India

Matthew Little, Sally Humphries, Kirit Patel & Cate Dewey

Submit your article to this journal ↗

Article views: 372

View related articles ↗

View Crossmark data ↗

Decoding the Type 2 Diabetes Epidemic in Rural India

Matthew Little [ID][a], Sally Humphries[b], Kirit Patel[c], and Cate Dewey[a]

[a]Department of Population Medicine, University of Guelph, Guelph, Ontario, Canada; [b]Department of Sociology and Anthropology, University of Guelph, Ontario, Canada; [c]International Development Studies Program, Menno Simmons College, A College of Canadian Mennonite University, Affiliated with the University of Winnipeg, Winnipeg, Manitoba, Canada

ABSTRACT

Type 2 diabetes mellitus is an escalating public health problem in India, associated with genetic susceptibility, dietary shift, and rapid lifestyle changes. Historically a disease of the urban elite, quantitative studies have recently confirmed rising prevalence rates among marginalized populations in rural India. To analyze the role of cultural and sociopolitical factors in diabetes onset and management, we employed in-depth interviews and focus groups within a rural community of Tamil Nadu. The objectives of the study were to understand sources and extent of health knowledge, diabetes explanatory models, and the impact of illness on individual, social, and familial roles. Several cultural, socioeconomic, and political factors appear to contribute to diabetes in rural regions of India, highlighting the need to address structural inequities and empower individuals to pursue health and well-being on their own terms.

Type 2 diabetes mellitus (hereafter diabetes) is rapidly emerging as a major threat to global human health (Zimmet, Alberti, and Shaw 2001). As of 2014, 8.3% of the world's adult population suffered from diabetes (International Diabetes Federation 2014), with low-income countries in Africa and Asia bearing the brunt of this burden. India's prevalence of diabetes is 7.8% and rising, and some areas are experiencing prevalence rates as high as 18% (Ramachandran et al. 2008). Further, while typically considered a problem of the urban affluent, diabetes has become a serious concern among rural populations and is contributing to widening health gaps (Shetty 2002). A review of studies in rural India conducted by Misra and colleagues (2011) found that prevalence increased from 1.9% in 1994 to upwards of 12% in 2009. In addition, rural prevalence rates of impaired glucose tolerance (IGT, a form of pre-diabetes) range from 5.5% to 7.2% (Ramachandran et al. 2004). Such figures are concerning, especially considering 72.2% of the Indian population live in rural areas characterized by poverty, isolation, and poor access to health services (Government of India 2011).

Diabetes is a complex disease of multifactorial origin. Epidemiological and biomedical discourse and research on the Indian diabetes epidemic tend to focus on proximate individual-level factors such as lifestyle, diet, and exercise, and overlook the roles of distal social, cultural, and political-economic forces (Mendenhall et al. 2010; Rock 2003). The literature also emphasizes genetic factors as a contributing cause of disease for Indian ethnic groups (Ferreira and Lang 2005; Mohan 2004). The result is 'individualization of risk,' such that diabetes is perceived by epidemiologists as individually or ethnically determined, rather than a result of sociopolitical environment (Diez-Roux 1998). Ultimately, this may place blame on patients' "out-of-control" behavior (Broom and Whittaker 2004: 2371) and makes individuals responsible for preventing and managing the disease, rather than inspiring systemic change that alters the course of the epidemic at the population level. Efforts to prevent further rises in diabetes

prevalence therefore require the examination of the social, political, and economic structures in which diabetes emerges and is sustained (*Lancet* 2010).

Qualitative inquiry is often used to generate knowledge about lay perceptions and social experiences, which can offer insight into micro-level health effects of macro-level politics and economics (Brown et al. 2009) and into cultural beliefs, which may play an important role in illness management (Greenhalgh, Helman, and Chodhury 1998; Mendenhall et al. 2012; Stone et al. 2005). While a growing body of research explores the anthropology of diabetes in urban India (Mendenhall et al. 2012; Weaver and Hadley 2011), very few studies focus on rural diabetes. With this in mind, we sought to determine how a rural population understands and experiences diabetes in an area of northwest Tamil Nadu, India. After describing the research methods, we first identify and explore perceptions and knowledge about diabetes—specifically, perceived factors that result in diabetes onset and act as challenges to illness management. Second, we examine illness narratives and present a summary of participants' illness narratives, which include reactions to diagnosis, perceptions of appropriate diabetes management, and the impact of diabetes on normative societal and individual roles (Williams 2004). Overall, our findings contribute to an understanding of diabetes morbidity and mortality in the rural Indian population.

Methods

Research setting and participants

The study took place in 14 villages across two *panchayats* (townships) in Krishnagiri District, northwest Tamil Nadu, in February–April 2013. After receiving ethics approval from the Research Ethics Board at the University of Guelph, we recruited a convenience sample of individuals with diabetes (n = 54). One third of participants were recruited over three days at a local government clinic, with additional participants recruited by approaching community leaders and requesting contact with individuals with diabetes who lived locally. We screened all potential participants for eligibility before asking them to participate in the study. We only included those who were older than 20 years, could prove their diabetes status with medical records, and resided in the study region. Response rate was 100%. After participants provided informed consent, interviews were scheduled for a later date.

In-depth interviews

The interview guide was written in English, translated into both Kannada and Tamil, and then back-translated to check for accuracy. Interviews were conducted by trained research assistants in the participant's first language, and lasted between 60 and 100 minutes. Each interview began by collecting basic descriptive information, and then collected the following: (1) An illness 'free narrative' (Williams 2004);(2) open-ended questions regarding patient history and experiences with diabetes, as well as perceptions about causes and treatment; (3) a 24-hour dietary recall (Cupples et al. 1992); and (4) interactive exercises, including construction of a genogram (family health tree) (Greenhalgh et al. 1998) and food picture pile sorting into 'healthy,' 'unhealthy,' and 'neither healthy nor unhealthy' categories (Tolley, Robinson, and Ulin 2005; Weller and Romney 1988).

Supplementary methods

We randomly selected 18 individuals from the initial study to participate in a secondary phase of data collection intended to confirm initial findings and gather further information. Methods were as follows:

   (1) A structured vignette (10 participants), in which we read participants a standardized story about a fictional character, Rajapandian, who had been diagnosed with diabetes (adapted

from Greenhalgh et al. 1998). The story included 24 different statements relating to Rajapandian's beliefs and perceptions about his new disease and treatment seeking. After each of these statements, the participant was asked whether they agreed or disagreed with the story's protagonist, and was encouraged to expand on his or her beliefs.

(2) Two gender-segregated focus groups (four participants each, eight participants total) were conducted, in which four men and four women separately discussed diabetes and associated topics. Focus groups were conducted in Tamil and facilitated by a trained facilitator. The facilitator used prompts and questions to encourage discussion around issues such as gender and health, stigma, and social constraints (Green and Thorogood 2005).

Data analysis

Questionnaires were analyzed for basic descriptive characteristics using Microsoft Excel 14.1. Interviews and focus groups were audio-recorded, then translated to English and transcribed within 12 hours. Transcripts were processed separately in NVivo 10 (QSR International 2012) using a thematic content analysis framework developed by Braun and Clarke (2006). First, text was coded using 59 distinct codes. Related codes were amalgamated into themes and each coded passage of text was re-examined for consistency with its overlying theme. Themes were then validated with information from the structured vignette and focus groups and collapsed or expanded if necessary.

Results and discussion

Men and women were equally represented in the study. Eleven percent of participants were ≤ 40 years, 54% aged 41–60 years, and 35% ≥ 61 years. The majority were subsistence farmers and laborers, of whom 66% owned land; of these, 78% claimed agriculture or livestock was their principal livelihood strategy. Seventeen percent owned a small shop or local business, and one person was employed in a multi-employee business. All participants were classified as 'below poverty line' (BPL) or 'ultra-poor' (UP). The population had low formal education: 91% of participants including all women had six or fewer years of schooling.

General perceptions of diabetes

All participants believed that diabetes was a 'new' health problem and that prevalence was rising in the study region. One woman told us, "Thirty years ago, nobody had diabetes. We were healthier. Now, it seems that many people are affected, even some young people" (Balagowramma, 69). Understandings of diabetes were rooted in traditional health beliefs, personal experience, and information provided by health care providers. Patients viewed doctors as the most important source of knowledge about diabetes. In the structured vignette sessions, most participants (90%) agreed with the statement, "Rajapandian thinks that the best way to learn about his diabetes is to speak to doctors." However, doctor-patient interactions are often unproductive and short. One participant told us, "The doctor barely speaks to me. I go in, he checks my blood sugar, my heart[rate] and BP [blood pressure], then writes me a prescription and sends me away" (Nagaraju, 38). According to participants, the mean length of a health check-up with a health care provider was three and a half minutes. Focus group participants confirmed that the check-ups were never longer than five minutes.

General awareness of diabetes appeared to be low among the local population; more than two thirds of participants were unaware of diabetes until diagnosis. One participant told us, "I had never heard of the disease before. … I didn't have any family with diabetes … the doctor didn't tell me about it until he tested me and diagnosed me" (Puttamma, 56). Short, unproductive doctor-patient interactions and little access to education materials maintained poor biomedical understandings of diabetes, its pathophysiology, and potential complications among participants. When we asked, "What happens inside your body

when you get sick with diabetes?," 96% of participants said, "I don't know." The remaining few stated that diabetes increased their blood sugar, but could not provide further detail. All participants were unaware of the pancreas and its role in insulin secretion and metabolism. While several participants expressed fear of infected lesions and subsequent amputations, none were aware that diabetes could affect their hearts, kidneys, or eyes. Further, participants tended to blame any postdiagnosis health problem on their diabetes, even those likely unrelated, such as cancers and respiratory illnesses. Many participants appeared to lack interest in their disease. Only 44.4% said "yes" when asked if they would like to learn more about their condition, and even fewer (41%) said they would attend an education session if it were offered for free. As one woman stated, "I don't really care to learn about diabetes. It's no use … the rest of my family has diabetes, so I was always going to get diabetes. There is no use in learning about something when it's inevitable" (Maariyamma, 55).

Explanatory models

Perceived causes of the diabetes epidemic were varied (Table 1 When we asked participants, "What causes diabetes?," the most common response was "poor diet." Often, participants blamed dietary change—specifically, the increasing consumption of "new" or "city" foods like soft drinks, potato chips, sweets, and rice. These products are rapidly the replacing the traditional food basket, comprised mainly of small millets and pulses (Praduman Kumar and Dev 2007). Sugar was implicated in many cases—indeed, the local terms for diabetes were *sacre kaila* in Kannada and *sacre noi* in Tamil, which translate to 'sugar disease.' As one participant stated, "I think [diabetes] is caused by diet. I think that drinking too much tea with sugar will cause it. I used to drink so much tea—maybe 10 cups of tea every day, with lots of sugar. For that reason, I got diabetes" (Vediyappan, 56).

Drivers of dietary change

Participants identified three primary factors that have catalyzed dietary changes leading to rising prevalence of diabetes. First was the increasing presence and influence of "government shops," the local term for state-mandated fair price shops operated through the Public Distribution System (PDS). Second was as increasing availability of 'new' foods at low prices at local food stalls and shops. And third was a shift in agricultural patterns due to the financial incentives of commercial crop production. We will now explore these three drivers as explained to us by participants.

The PDS is a large-scale food-rationing scheme that provides below BPL and UP families in Tamil Nadu with 20 kilograms and 35 kilograms per month of polished white rice, respectively, as well as

Table 1. Causal models of diabetes among a sample of 53 rural individuals with diabetes[1].

Cited Cause	No. of Participants that Implicated Factor in General (Percent)	No. of Participants that Implicated Factor in Their Diabetes (Percent)
Poor diet	24 (44.4)	9 (12.9)
• "New foods" (e.g., soft drinks, chips)	30 (37)	4 (7.3)
• Sugar	18 (33.3)	5 (9.3)
• Rice	4 (7.4)	2 (3.7)
• Other carbohydrates	2 (3.7)	0 (0)
Tension	19 (35.2)	14 (25.9)
Don't know	15 (27.8)	24 (44.4)
Family History	10 (18.5)	8 (14.8)
Lack of exercise	3 (5.6)	0 (0)
Fate	3 (5.6)	2 (3.7)
Drinking	2 (3.7)	2 (3.7)
Other	3 (5.6)	3 (5.6)

[1]Several patients cited multiple causes of type 2 diabetes.

subsidized wheat, sugar, palm oil, pulses, and kerosene (Ramakrishnan 2011; Mooij 1998). Rations are distributed through fair price shops, which are ubiquitous throughout the research site. One woman explained her experiences with the PDS,

> The government shop is … about one km away, and is open one day every month. A man comes … and he opens the shop, and we line up, sometimes for hours, to receive our rations. They have big bags of rice, and sugar, oil, kerosene, and sometimes pulses. My family has a BPL card, and I'm supposed to get 20 kilograms of rice for my family, and some of the UP people get more. Some people will bribe the government official and get more than their quota. Even some rich people, they have two or three ration cards, and they come with trucks and take away their quotas to sell them. Sometimes there isn't enough food for us and we get less than our quota, but usually it is fine. But the products are not good quality. Once in a while there are even rocks or insects in the rice! But we still go every month, because we need the food and it is cheap and everyone uses the scheme. (Channamma, 48)

The PDS has altered the subsistence relationship that farming families have with the food they produce and has catalyzed a shift away from traditional diets. Consider the following, told by a former subsistence farmer and the head of his household:

> We grow *ragi* [finger millet], *cholam* [sorghum], *avarai* and *thobarai* [pulses], as well as some vegetables. We also have a tamarind tree that produces fruit. I keep some millet and some pulses, but mostly I sell my food. I get free rice and cheap oil and sugar through the government shop [fair price shop], and I get a good price for my crops. So why wouldn't I sell the food I grow? That way I can have some money. It isn't much money, but what choice do I have? (Muniyappan, 52)

This quote suggests that the PDS has fostered an environment in which farmers opt to forego traditional staples in favor of products distributed by the PDS. Detrimental dietary changes in rural regions of India are well studied (e.g., Deaton and Drèze 2009; Deshpande and Rao 2004) yet little published literature has examined the role of the PDS in this trend (Kochar 2005). However, participants identified potential connections between PDS and their illness, as one woman explained: "The government rice is not hygienic. It sometimes has rocks in it and it is bad for our bodies … maybe it causes diabetes. But we must eat it, because it is free" (Balagowramma, 69). The association of the consumption of sugar and polished white rice with increased risk of diabetes exists in both biomedical and folk models (Grams et al. 1996; Greenhalgh et al. 1998; Naemiratch and Manderson 2007; Poss and Jezewski 2002). A major oversight of the PDS is that it emphasizes caloric quantity rather than nutritional quality by distributing calorie-dense but nutritionally inferior food products (Deaton and Drèze 2009; Sen 2005). Polished white rice has low fiber content, a high glycemic index, and a poor micronutrient profile (Qi Sun et al. 2010). If consumed in excess, polished rice increases risk of diabetes and reduces glycemic control among individuals with diabetes (Radhika et al. 2009). In addition, the distribution of refined sugar and palm oil encourages increased consumption of these foods. Consequently, despite operating as a social welfare program intended to improve nutritional health, the PDS may indeed be contributing to rising obesity and diabetes.

The PDS is a viable alternative source of staple foods, thus reducing the necessity for subsistence farming and catalyzing a shift towards commercial agriculture, which in turn increases the local dependency on the PDS and purchased food. Participants identified agricultural changes as a second driver of dietary shift. Previously, agriculture in the research site was characterized by diverse cereal and pulses production; however, market liberalization and expansion encouraged farmers to shift from subsistence to commercial production, often reducing crop diversity (Pingali 1997). As one farmer stated, "We used to produce and eat … *samai* [little millet], *varagu* [kodo millet], *arca* [barnyard millet], *cholam* [sorghum], and *thenai* [foxtail millet]. But we stopped growing [these crops] because they were more difficult to grow … we switched to *ragi* [finger millet], which is less work … ragi is easy to sell … we keep some but we sell most of it" (Narayanappa, 70). Other farmers had shifted their entire production system to cash cropping and grew tomatoes, groundnuts, bananas, coconuts, or other products with market value. In some cases, farmers signed supply contracts with large food outlets (see also Pingali and Khwaja 2004). Hence most participants

were partially or fully immersed in the cash economy, with food for household consumption obtained outside the home.

A third driver of dietary change is the availability of commercial processed foods. One participant, who lived the largest of the sampled villages, told us, "Thirty years ago, there was only one shop in our village. In that shop, they sold tea, ragi, rice, pulses, some root vegetables, and some supplies. But now, there are many shops, and they sell new foods, like sodas, crisps, and sweets. There is even a bakery! They have cakes, pastries, and northern [i.e., north Indian] sweets like gulab" (Lakshmi, 64). These comments provide evidence that the study region is experiencing similar trends to those seen at the state level, which include increased availability and intake of sugar sweetened beverages, oily snacks, and sugar (Government of India 2012; Praduman Kumar and Dev 2007; Shetty 2002). Increased availability of processed foods is rooted in recent historical political and economic processes, including market liberalization through structural adjustment programs (see World Bank 2012), which lowered restrictions on food imports and encouraged expansion of processed food distribution into rural regions (Government of India 2014; Vepa 2004; World Bank 2012). Often, participants implicated 'new' foods in explanatory models of diabetes. Participants also claimed that taste preferences of young people are shifting to favor high-fat and high-sugar foods, which Kessler (2007: 44) called "hyperpalatable" (Pingali and Khwaja 2004). One woman told us, "My children refuse to eat ragi. They only want rice dishes and sweets. All the young people are like this" (Chinnthayi, 46).

The role of 'tension.'

Some 35% of participants implicated 'tension' in onset of diabetes and as an ongoing challenge to diabetes management. 'Tension' is an expression adopted from English into many Indian languages, including Kannada and Tamil, and encompasses feelings of stress, grief, depression, and anxiety (Mendenhall et al. 2012; Halliburton 2005; Pereira et al. 2007). Most participants related a personal story about a stressful event that led to diabetes onset. For example, one woman told us, "My son died in a motorcycle accident. From this I had a lot of tension; I cried for two months, I didn't work, my husband got frustrated with me and was very angry. Only a year after, the doctor told me I had diabetes. I think the family troubles caused the diabetes to emerge" (Rajamma, 65). Hunt, Valenzuela, and Pugh (1998: 961) referred to disease-inducing traumatic events as "provoking factors," and noted that immigrant patients in the United States perceived diabetes as an inherent characteristic of everyone, but that provoking factors caused the illness to "come out." Likewise, several participants viewed diabetes as a latent illness that was 'exposed' by sudden tension, often related to modernization (e.g., vehicle travel, migration of children for work or school) or more traditional stressors (e.g., poverty and low social status) (Mendenhall et al. 2012). Familial stressors such as intergenerational conflicts were also common, as one woman explained: "My sons are working in Bangalore, and I'm worried about them. There is nobody here to work on our land, and I'm getting older. I don't know how I'll care for my remaining children as I get older, so it has caused me tension in the past few years. I think that this tension caused my diabetes" (Prabarvathy, 65).

Tension was not only a perceived cause of diabetes, but also a common outcome or symptom, which corresponds with a growing body of research showing that comorbid depression is a serious public health issue in India and around the world (Ali et al. 2006; Mendenhall et al. 2012). Tension impeded participants' ability to manage their disease (Schoenberg et al. 2005). Several participants described how stress compromised their capacity to practice optimal self-care. Fear of injury and infection reduced participants' willingness to travel to healthcare facilities or participate in physical activity, which is counter-productive to treatment goals. One man told us: "Diabetes controls my life now. I want to work on the land, but diabetes makes me faint and fall down. I want to do things, but I'm scared of getting a small cut that become [s] infected. I get shaking, like fits [seizures], and a lack of strength. I can barely work. It gives me tension ... there are a lot that I would like to do but cannot" (Nagaraju, 38).

'Tradition.'

Ten participants (18.5%) implicated 'tradition' in diabetes onset, a term that is used locally to imply family history. Many participants directly witnessed tradition, as they identified family members with diabetes in their genograms and believed this increased their risk of developing the disease apart from diet and lifestyle factors. One woman summarized her views by stating: "There is no use trying to prevent diabetes. My father had diabetes, my uncle had diabetes, and my brother had diabetes. I was always going to get it. I am telling my oldest son to get tested, because he is getting up every night to pee, and maybe he has it, too" (Rajamma, 65). Another participant told us, "... my mother and father both have diabetes, so I got diabetes. It didn't matter what I ate or what I did, diabetes was always in my blood." (Nagaraju, 38). The concept of heredity as "shared blood" has been previously documented amongst south Asian populations (Greenhalgh et al. 1998: 980), although it is unclear whether such perceptions originate from traditional belief systems or have been introduced by biomedical experts promoting ideas of genetic predisposition.

The impact of diabetes

Reactions to diagnosis

When asked, "What were your initial thoughts when you were diagnosed with diabetes?," most participants responded 'tension' or 'fear.' Fear of deterioration and death were common. Many believed that diabetes was imminently fatal and equated diagnosis with a 'death sentence'—"When I was first diagnosed, I was worried about my health. I was scared that I was going to die, that the diabetes would kill me soon. It hasn't killed me yet, but it does get worse year by year" (Geetha, 49). Participants also feared for their ability to maintain a livelihood and support a family while their health deteriorated. Participants lacked social and economic safety nets, so illness was often associated with money problems. As one man explained: "I'm the only one [in my family] who makes any income, and we don't have any lands or cattle to sell in case of an emergency, so I know if I get sick or die, my family will have money problems" (Raju, 39).

Diabetes was viewed as a life altering, debilitating diagnosis. Actual symptoms, as well as fear of worsening symptoms, affected participants' lives in a variety of ways. Many had witnessed (in others) or experienced (themselves) fainting, infections, amputations, and death as a result of diabetes. Such experiences increased tension and inhibited individuals from working, travelling, and taking on normative community and familial responsibilities. Several women expressed a fear of pregnancy, as explained next. Eleven (21%) participants were mostly bedridden and could not work.

Managing diabetes

Most participants (91%) had taken steps to manage their diabetes, either through diet, medication, insulin, or a combination of these methods (Table 2). Two-thirds insisted that pharmaceutical medication (tablets or insulin, locally called 'Anglo-medicine') was the most effective way to treat diabetes. However, participants often reported sporadic use of medication, for various reasons. Some believed that medication should only be used to treat bothersome symptoms and ceased pharmaceutical regimens when their diabetes was not "acting up." One man admitted, "I took medicine until about 20 days ago. I haven't been bothered by symptoms in three months, so I decided to stop taking

Table 2. Diabetes management preferences of a group of individuals from a community of rural south India.

Treatment	Men (Percent)	Women (Percent)
Nothing	1 (4)	1 (4)
Ayurvedic treatment only	1 (4)	2 (7)
Diet only	3 (11)	0 (0)
Pharmaceutical Tablets (PT) only	6 (22)	7 (26)
Diet + PT	15 (56)	13 (48)
Diet + PT + Insulin	1 (4)	4 (15)

medicines. I think the diabetes is controlled" (Raju, 39). Others did not perceive diabetes as a chronic illness, but "bouts" of the same illness, intermittent with periods of being "cured," and thus justified only occasional use of medicines. One woman told us: "My uncle was cured [of diabetes] for a long time by an ayurvedic doctor in [town 40 km away]. When I feel the diabetes causing problems, I go there to get treated. The doctor gives me tablets and dried plants to take, and tells me that I might be cured if I follow his instructions." (Rajamma, 65). Many also perceived the high cost of medicine as a barrier to treatment. The average monthly expenditure for diabetes treatment was 569.30 rupees (~US $9.29). Due to the subsistence livelihoods of most participants, we were unable to ascertain accurate monthly income figures and thus cannot express treatment expenses as a percentage of earnings. However, most participants viewed treatment as prohibitively expensive. Many individuals sought loans or employed emergency measures (e.g., selling cattle or land) to cover their health care costs, especially when unforeseen complications arise, as Krishnan (44) related: "I had a very bad infection in my toe from working in my land. I was hospitalized for one month in Bangalore so they could amputate the toe. I spent 500,000 rupees (US ~$8163.82) for the treatment. I couldn't pay so I had to sell 3.5 acres of my 4 acres of land." Very few participants trusted alternative medicines for managing their diabetes, and only three participants used natural or *ayurvedic* medicines and found them effective. Most participants considered such practices to be obsolete and futile. Since diabetes was a 'modern' phenomenon, they suggested, it must be treated with 'modern' medication.

Diabetes management through diet was recognized as important. Two thirds exercised dietary control, largely by avoiding sweet items and reducing their intake of refined carbohydrates such as rice and wheat products, as recommended by their doctors. Many participants, however, stated that they "should be doing more" to control food consumption, citing difficulties related to food access and palatability, and a desire to "eat what everyone else in the family was eating." During the pile-sorting exercises, most participants acknowledged the health benefits of vegetables; although 24-hour dietary recall data suggest that the consumption of these items was low, averaging less than one serving per day. In addition, very few participants avoided high-fat items. Oil (usually groundnut oil or palm oil) was readily consumed by patients and was identified as 'healthy' by more than two-thirds of participants during the sorting exercise.

While most participants (85%) admitted that their doctor had recommended physical activity, only two exercised apart from their normal work duties. Participants reported difficulty incorporating physical activity into their normal routines for various reasons. Most commonly, participants regarded themselves as very busy and cited a lack of free time. One woman told us: "I wake up early, make food for my children, go to work all day, come home, make dinner, and take care of my children. Where is the time to exercise? I must fulfill my responsibilities. … I do labor work all day, I cook for my family, I am tired, and then the doctor says 'you need to walk an hour a day'!" (Saroja, 38). This quote also suggests that exercise is perceived to detract from work and family duties, and may be considered selfish or irresponsible. Other participants, particularly elderly participants, viewed themselves as incapacitated by diabetes or other health problems and therefore unable to exercise. Some recognized this as a negative cycle: "The doctor says I must exercise to feel better, but I have pain in my feet, so I can't exercise, and so the diabetes gets worse. It's no use" (Narayanappa, 70). During focus groups, it became apparent that exercise for health or leisure had little cultural importance or acceptance, and was often met with fears of appearing 'abnormal.' One man, who worked a sedentary job at a bank, stated, "I don't have time for exercise. I need to relax in the evenings because my job is stressful. If I just go out and walk around, my friends might say, 'what is he doing, walking in circles? Has he gone mad?'" (Pachiyappan, 42).

Stigma

Several participants identified potential sources of stigma (see also Bajaj et al. 2013; Gopichandran et al. 2012). Many expressed a prediagnosis belief that diabetes was infectious, or explained that nondiabetic acquaintances misperceive diabetes as infectious. As one woman explained, when she was initially diagnosed, "I thought, 'oh, we [my family] are going to die' so that's why I was afraid. Because I'd never heard of the disease before and I thought it was very serious and that my whole

family would get it" (Puttamma, 56). Another man explained his experiences with social exclusion due to his diabetes, "I used to be the village Chairperson [local leader that represents the village at the district level], but when I was diagnosed with diabetes, I couldn't continue working. Now nobody comes to see me, they avoid me … because they don't want diabetes. Even my family can stay away sometimes" (Chinu, 60). Another source of stigma relates to the notion that women with diabetes are at increased risk of developing complications during pregnancy, and therefore are less desirable spouses (Bajaj et al. 2013). Several women withheld their diagnosis from spouses (or potential spouses), and expressed a postdiagnosis fear of pregnancy. As one woman explained, "I was diagnosed with diabetes young—maybe around age 25. I had two daughters then, but wanted a son. The doctor told me I might have difficulty with pregnancy … but I didn't want to disappoint my husband, so I didn't tell him about the diabetes. … I didn't tell anyone. He [my husband] didn't know about it for more than eight years" (Geetha, 49). These stigmas serve as a further source of tension and exacerbate the difficulties of living with diabetes.

Control, autonomy, and empowerment

Many participants felt that diabetes infringed on their sense of autonomy by forcing them to become subservient to doctors, caretakers, and family members. Diagnosis was felt to reverse the authoritative relationship an individual had with his or her own health—from *being in control* of one's well-being to *being controlled* by disease, resulting in a sense of lost autonomy and empowerment (Clark and Anderson 1980; Naemiratch and Manderson 2006). To mitigate this loss, patients attempted to regain some control by perceiving themselves as unique from the 'typical' diseased individual, and therefore abided by a 'different' set of rules that was personally relevant (Ferzacca 2000). This perception, and subsequent actions, manifested in a number of different ways. First, participants were unwilling to accept culpability for their illness, and therefore appeared to feel little personal guilt. When asked, "What causes diabetes?" (general causes) and "What caused *your* diabetes?" (personal causes), answers were often different. While diet was implicated by more than 44% of participants as a general cause of diabetes, only 12.9% blamed diet for their own illness. Similarly, "lack of exercise" and "tension" were less commonly cited as personal causes. Indeed, when asked about the cause of *their own* diabetes, most participants claimed that they did not know. One participant elucidated his views by telling us, "I know that diabetes is caused by poor diet, eating too many sweets, drinking too much tea, whatever. … But I only ragi and rice, and maybe a little tea … every day. I'm poor, I don't have enough food. I don't know why I got diabetes" (Raju, 39). Many participants displayed similar attitudes that diabetes was something that "just happened" to them, thus alleviating personal responsibility and perhaps removing themselves from having participated in the poor behavior implicit in general causal models (see also Broom and Whittaker 2004). As a result, diabetes onset was often presented as beyond the control of the participant, and in many cases, inevitable. Removal of guilt may be an attempt by participants to reduce their burden of tension.

Another way in which patients exert autonomy is during treatment. Patients may challenge their subservient role in the doctor/patient relationship by refusing to obey doctors' orders and instead creating a treatment regimen that is personally relevant and therefore empowering (Ferzacca 2000). For example, against doctors' recommendations, participants rarely exercised since physical activity has little personal and cultural value. In addition, as elucidated, patients often refrained from their prescribed pharmaceutical regimens if and when they felt their diabetes wasn't "acting up." While this behavior may be rooted in necessity (e.g., lack of mobility, financial woes) and is viewed as noncompliant behavior by clinicians, some patients explained their actions as an attempt to regain control. One man told us, "I think many of us [farmers] are stubborn. We disagree with the doctor, maybe not in words, but in actions. He says 'do this, do that,' and when I go to the hospital, I tell him, 'yes sir, I'm avoiding sugar. Yes sir, I'm taking tablets. I'm exercising.' But I don't want him to control my life. I think the best way to treat an illness is to just live like it isn't there" (Ramu, 49). Patients may therefore use noncompliance to assert control over their disease and thus recuperate some autonomy lost through diagnosis.

Limitations and conclusion

While type 2 diabetes in India has been explored in many epidemiology and clinical studies, comparatively few have studied the anthropology of diabetes in India, and none have focused on rural regions. In the study on which this article is based, we used a range of qualitative and semi-quantitative methods to examine the perceptions and experiences of a group that is widely representative of the population in the region, since it included 50% women, a wide age range (32–82 years), and participants were recruited in several different contexts. The study does, however, have some limitations. We selected a convenience sample of 54 individuals in a small geographic area, so data may not reflect experiences amongst other populations in India. We did not assess any measure of diabetes control, and thus were unable to correlate perceptions and experiences with how well individuals were managing their illness. The research team was exclusively male, which may have influenced the emergent narrative during interviews, particularly when discussing sensitive topics such as pregnancy and stigmas. Little research has scrutinized the dynamic resulting from men interviewing women in a social science research context, so it is difficult to determine how gender incongruences may have influenced results (Broom, Hand, and Tovey 2009; Manderson, Bennett, and Andajani-Sutjahjo 2006).

Diabetes is a growing public health concern in India and disadvantaged rural areas are increasingly affected. Although a number of studies draw attention to the prevalence and epidemiology of diabetes in rural regions (see Misra et al. 2011 for a systematic review), none provide qualitative data on perceptions and experiences of people with diabetes. Epidemiology and biomedical literature often blame ethnic predisposition and the 'nutrition transition' (characterized by increased sedentarism, urbanization, and consumption of calorie-dense foods) for India's diabetes epidemic (Mohan 2004; Popkin et al. 2001). Such rhetoric often emphasizes *individual choices and factors* that perpetuate the nutrition transition, such as rural-to-urban migration (Ebrahim et al. 2010), wealth (Corsi and Subramanian 2012), dietary intake (Mohan et al. 2009), and low physical activity (Little et al. 2016; Ramachandran et al. 2001), an approach that overlooks and eclipses the importance of structural social, economic, and political processes in perpetuating the nutrition transition and, subsequently, the diabetes epidemic. Qualitative data are therefore crucial, not only to understand the impact of diabetes on lives and livelihoods but also to identify perceived structural factors contributing to the diabetes epidemic.

Participants perceived shifting dietary patterns as the primary driver of the diabetes epidemic and identified a number of processes that influenced food intake in recent years. Specifically, participants perceived the increasing presence of the PDS, which subsidizes rice, sugar, and cooking oil, as having an impact on the consumption of the products it provides. In addition, participants acknowledged the role of commercialization of agriculture in reducing the local availability of healthy traditional staples and creating a dependency on foods obtained outside the household. Finally, improved access to 'new' packaged and/or processed foods (such as sodas, candies, baked goods, etc.) due to the expansion of the food processing sector and aggressive rural marketing, has increased consumption of high-fat and high-sugar foods. Therefore, if policymakers wish to combat the nutrition transition and the diabetes epidemic in rural regions of India, it would be prudent to examine these three political/economic drivers and identify opportunities to promote foods with higher fiber content and lower glycemic indices, while simultaneously reducing availability and consumption of 'hyperpalatable' foods.

A common theme underlying perceived causes of diabetes and barriers to illness management was poverty. Participants often cited "tension" as a cause of diabetes, and "financial problems" were a common source of tension. Many other tensions were indirectly associated with poverty, such as infant mortality, injuries and infectious illness, and "family problems" induced by financial deficits, migrant labor, or other socioeconomic difficulties. Poverty was also considered a serious barrier to proper diabetes management due to the high costs associated with regular health check-ups, medication, and dietary control. Finally, diabetes management often served to exacerbate poverty, as many participants were required to sell possessions or seek loans to pay for medical treatment of diabetes or associated

complications. Thus, while diabetes is often considered a "disease of the affluent" (Mendenhall et al. 2012) in low-income countries, it is increasingly impacting the rural poor (Anjana et al. 2011), and serves to exacerbate the financial difficulties of already-marginalized populations.

While large-scale changes in political and socioeconomic processes may be required to alleviate the risks factors of diabetes in rural regions of India, culturally sensitive public health education and clinical practices remain important for prevention and proper illness management. Health education that acknowledges patients' illness perceptions is more likely to lead to positive behavior changes (Airhihenbuwa et al. 1990). Given that the participants in this study trusted health professionals as their primary source of health information, we think that clinical check-ups are an opportunity to share appropriate information and advice with patients. The current study is therefore important for elucidating relevant cultural 'constructs' that can be used to develop public health programming and doctor-patient relationships that concord with patients' beliefs. These constructs include 'tradition' as an explanatory model; the lack of cultural acceptability of physical activity outside of work duties; stigmas associated with diabetes; perceived loss of autonomy upon diagnosis; ready acceptance of pharmaceutical regimens; and perceived redundancy of medication when diabetes is 'controlled.' The importance of tension among participants suggests that health professionals may need to address the mental health dimensions of diabetes, both prior to and following diagnosis (Mendenhall et al. 2012).

Over the course of this article, we have elucidated socioeconomic and political structures that contribute to diabetes onset and act as barriers to management. We have also identified a number of cultural factors that are relevant to future efforts to halt rising diabetes prevalence rates and improve the capacity of individuals with diabetes to properly manage their illness. Future research and action must continue to emphasize reducing structural inequities and empowering individuals to improve their quality of life by addressing social, physical, and mental aspects of health.

Notes on contributors

Matthew Little is a PhD candidate in the collaborative Population Medicine and International Development program at the University of Guelph. His interests in food security and chronic disease epidemiology have brought him to Guatemala and India to research policy, nutrition, obesity, and type 2 diabetes.

Sally Humphries is an associate professor in the Department of Sociology and Anthropology at the University of Guelph. Her expertise lies in the area of small farmer development, especially farmer participatory research and gender empowerment.

Kirit Patel is an assistant professor, International Development Studies Program, Menno Simons College affiliated with the University of Winnipeg and Canadian Mennonite University, Winnipeg. Dr. Patel has extensive experience as an academic, development policy analyst, and community development practitioner.

Cate Dewey is a department chair and professor of Epidemiology and Ecosystem Approaches to Global Health in the Department of Population Medicine at the University of Guelph. She has been conducting observational field studies since 1985. Beginning in 2006, she has worked with rural and smallholder farmers in several countries researching animal and human health.

ORCID

Matthew Little http://orcid.org/0000-0001-6644-2336

References

Airhihenbuwa, C. O.
  1990   A conceptual model for culturally appropriate health education programs in developing countries. International Quarterly of Community Health Education 11(1):53–62.
Ali, S., M. A. Stone, J. L. Peters, M. J. Davies, and K. Khunti
  2006   The prevalence of co-morbid depression in adults with type 2 diabetes: A systematic review and meta-analysis. Diabetic Medicine 23(11):1165–1173.
Anjana R. M., R. Pradeepa, M. Deepa, M. Datta, V. Sudha, R. Unnikrishnan, A. Bhansali, et al.
  2011   Prevalence of diabetes and prediabetes (impaired fasting glucose and/or impaired glucose tolerance in urban and rural India: Phase I results of the Indian Council of Medical Research—India DIABetes (ICMR-INDIAB) study. Diabetologia 54(12):3022–3027.
Bajaj, S., F. Jawad, N. Islam, H. Mahtab, J. Bhattarai, D. Shrestha, C. Wijeyaratne, et al.
  2013   South Asian women with diabetes: Psychosocial challenges and management: Consensus statement. Endocrinology and Gender 17(4):548–562.
Braun, V. and V. Clarke
  2006   Using thematic analysis in psychology. Qualitative Research in Psychology 3:77–101.
Broom, A., K. Hand, and P. Tovey
  2009   The role of gender, environment, and individual biography in shaping qualitative interview data. International Journal of Social Research Methodology 12(1):51–65.
Broom, D. and A. Whittaker
  2004   Controlling diabetes, controlling diabetics: Moral language and the management of diabetes type 2. Social Science & Medicine 58(11):2371–2382.
Brown, R. A., J. Kuzara, W. E. Copland, E. J. Costello, A. Angold, and C. M. Worthman
  2009   Moving from ethnography to epidemiology: Lessons learned in Appalachia. Annals of Human Biology 36:248–260.
Clark, M. and B. G. Anderson
  1980   Culture and aging: An anthropological study of older Americans. New York: Arno Press.
Corsi, D. J. and S. V. Subramanian
  2012   Association between socioeconomic status and self-reported diabetes in India: A cross-sectional multilevel analysis. BMJ Open 2(4):1–12.
Cupples, J. L., E. S. Cobb, D. R. Miller, and R. B. D'Agostino
  1992   Comparison of techniques for estimating nutrient intake: The Framingham Study. Epidemiology 3(2):171–177.
Deaton, A. and J. Drèze
  2009   Food and nutrition in India: Facts and interpretations. Economic and Political Weekly 44(7):42–65.
Deshpande, R. S. and V. M. Rao
  2004   Coarse cereals in a drought-prone region: A study in Karnataka. Institute for Social and Economic Change. http://www.isec.ac.in/Monograph%202.pdf.
Diez-Roux, A. V.
  1998   Bringing context back into epidemiology: Variables and fallacies in multilevel analysis. American Journal of Public Health 88(2):216–222.
Ebrahim, S., S. Kinra, L. Bowen, E. Anderson, Y. Ben-Shlomo, T. Lyngdoh, and L. Ramakrishnan
  2010   The effect of rural-to-urban migration on obesity and diabetes in India: A cross-sectional study. PLoS Medicine 7(4):1–12.
Ferreira, M. L. and G. C. Lang
  2005   Indigenous Peoples and Diabetes: Empowering Community Wellness. Durham, NC: Carolina Academic Press.

Ferzacca, S.
   2000   "Actually, I don't feel that bad": Managing diabetes and the clinical encounter. Medical Anthropology Quarterly 14(1):28–50.
Gopichandran, V., S. Lyndon, M. K. Angel, B. P. Manayalil, K. R. Blessy, R. G. Alex, V. Kumaran, and V. Balraj
   2012   Diabetes self-care activities: A community-based survey in urban southern India. The National Medical Journal of India 25(1):14–17.
Government of India
   2011   SRS Statistical Report 2011. http://www.censusindia.gov.in/2011-common/vitalstatistics.html.
——.
   2012   Household consumption of goods and services in India. NSS 66th Round, National Statistical Organization. http://mospi.nic.in/Mospi_New/site/home.aspx.
——.
   2014   Data on economic parameters of the food processing sector. http://www.mofpi.nic.in.
Grams, G., C. Herbert, C. Heffernan, M. A. Calam, B. Wilson, and S. Grzybowski
   1996   Haida perspectives on living with non-insulin-dependent diabetes. Journal of The Canadian Medical Association 155:1563–1568.
Green, J. and N. Thorogood
   2005   Qualitative Methods for Health Research. Thousand Oaks, CA: Sage.
Greenhalgh, T., C. Helman, and A. Chodhury
   1998   Health beliefs and folk models of diabetes in British Bangladeshis. British Medical Journal 316(7136):978–983.
Halliburton, M.
   2005   "Just some spirits": The erosion of spirit possession and the rise of "tension" in South India. Medical Anthropology: Cross-Cultural Studies in Health and Illness 24(2):111–144.
Hunt, L., M. A. Valenzuela, and J. A. Pugh
   1998   Porque me tocó a mi? Mexican American diabetes patients' causal stories and their relationship to treatment behaviors. Social Science & Medicine 46:959–969.
International Diabetes Federation
   2014   IDF Diabetes Atlas. https://www.idf.org/sites/default/files/Atlas-poster-2014_EN.pdf.
Kessler, D. A.
   2010   The End of Overeating: Taking Control of the Insatiable American Appetite. New York: Rodale Books.
Kochar, A.
   2005   Can targeted food programs improve nutrition? An empirical analysis of India's Public Distribution System. Economic Development and Cultural Change 54(1):203–235.
Lancet
   2010   Type 2 diabetes: Time to change our approach. Lancet 375:2193–2195.
Little, M., S. Humphries, K. Patel, W. Dodd, and C. Dewey
   2016   Factors associated with glucose tolerance, pre-diabetes, and type 2 diabetes in a rural community of south India: A cross-sectional study. Diabetology and Metabolic Syndrome 8(21). doi:10.1186/s13098-016-0135-7
Manderson, L., E. Bennett, and S. Andajani-Sutjahjo
   2006   The social dynamics of the interview: Age, class, and gender. Qualitative Health Research 16(10):1317–1334.
Mendenhall, E., R. S. Seligman, A. Fernandez, and E. A. Jacobs
   2010   Speaking through diabetes: Rethinking the significance of lay discourses on diabetes. Medical Anthropology Quarterly 24(2):220–239.
Mendenhall, E., R. Shivashankar, N. Tandon, M. K. Ali, K. M. Venkat Narayan, and D. Prabhakaran
   2012   Stress and diabetes in socioeconomic context: A qualitative study of urban Indians. Social Science & Medicine 75:2522–2529.
Misra, P., R. P. Upadhyay, A. Misra and K. Anand
   2011   A review of the epidemiology of diabetes in rural India. Diabetes Research and Clinical Practice 92:303–311.
Mohan, V.
   2004   Why are Indians more prone to diabetes? Journal of Applied Physicians of India 52: 468–474.
Mohan, V., G. Radhika, R. M. Sathya, S. R. Tamil, A. Ganesan, and V. Sudha
   2009   Dietary carbohydrates, glycaemic load, food groups and newly detected type 2 diabetes among urban Asian Indian population in Chennai, India (Chennai Urban Rural Epidemiology Study 59). British Journal of Nutrition 102:1498–1506.
Mooij, J.
   1998   The political economy of the Public Distribution System in India. Journal of Peasant Studies 25(2):1–22.
Naemiratch, B. and L. Manderson
   2006   Control and adherence: Living with diabetes in Bangkok, Thailand. Social Science & Medicine 63:1147–1157.
———.
   2007   Lay explanations of type 2 diabetes in Bangkok, Thailand. Anthropology & Medicine 14(1):83–94.

Pereira, B., G. Andrew, S. Pednekar, R. Pai, P. Pelto, and B. Patel
2007   The explanatory models of depression in low income countries: Listening to women in India. Journal of Affective Disorders 102:209–218.
Pingali, P.
1997   From subsistence to commercial production systems: The transformation of Asian agriculture. American Agricultural Economics 79:628–634.
Pingali, P. and Y. Khwaja
2004   Globalisation of Indian diets and the transformation of food supply systems. Inaugural keynote address, 17th Annual Conference of the Indian Society of Agricultural Marketing. http://www.eldis.org/vfile/upload/1/document/0708/doc15357.pdf.
Popkin, B. M., S. Horton, S. Kim, A. Mahal and J. Shuigao
2001   Trends in diet, nutritional status, and diet-related noncommunicable diseases in China and India: The economic costs of the nutrition transition. Nutrition Reviews 59(12):379–390.
Poss, J. and M. A. Jezewski
2002   Mexican Americans' explanatory models of type 2 diabetes. Western Journal of Nursing Research 24(8):840–858.
Praduman Kumar, M. M., and M. M. Dev
2007   Long-term changes in Indian food basket and nutrition. Economic and Political Weekly 42(35):3567–3572.
Qi Sun, P., D. Spiegelman, R. M. van Dam, M. D. Holmes, V. S. Malik, W. C. Willett, and F. B. Hu
2010   White rice, brown rice, and risk of type 2 diabetes in US men and women. Archives of Internal Medicine 170(11):961–969.
Radhika, G., R. M. Van Dam, V. Sudha, A. Ganesan, and V. Mohan
2009   Refined grain consumption and the metabolic syndrome in urban Asian Indians (Chennai Urban Rural Epidemiology Study 57). Metabolism—Clinical and Experimental 58:675–681.
Ramakrishnan, R.
2011   Free rice distribution scheme in Tamil Nadu from June 1. The Hindu, May 18. http://www.thehindu.com/news/states/tamil-nadu/article2027215.ece.
Ramachandran, A., S. Mary, A. Yamuna, N. Murugesan, and C. Snehalatha
2008   High prevalence of diabetes and cardiovascular risk factors associated with urbanization in India. Diabetes Care 31(5):893–898.
Ramachandran, A., C. Snehalatha, A. D. S. Baskar, S. Mary, C. K. Sathish Kumar, and S. Selvam
2004   Temporal changes in prevalence of diabetes and impaired glucose tolerance associated with lifestyle transition occurring in the rural population in India. Diabetologia 47(5):860–865.
Ramachandran, A., C. Snehalatha, A. Kapur, V. Vijary, V. Mohan, A. K. Das, P. C. Rao, et al.
2001   High prevalence of diabetes and impaired glucose tolerance in India: National Urban Diabetes Survey. Diabetologia 44(9):1094–1101.
Rock, M.
2003   Sweet blood and social suffering: Rethinking cause–effect relationships in diabetes, distress and duress. Medical Anthropology 22(2):131–174.
Schoenberg, N. E., E. M. Drew, E. P. Stoller, and C. S. Kart
2005   Situating stress: Lessons from lay discourses on diabetes. Medical Anthropology Quarterly 19(2):171–193.
Sen, P.
2005   Of calories and things: Reflections on nutritional norms, poverty, and consumption behaviour in India. Economic and Political Weekly 40(43):4611–4618.
Shetty, P. S.
2002   Nutrition Transition in India. Public Health Nutrition 5(1A):175–182.
Stone, M., E. Pound, A. Pahcnoli, A. Farooqi, and K. Khunti
2005   Empowering patients with diabetes: A qualitative primary care study focusing on South Asians in Leicester, UK. Family Practice 22(6):647–652.
Tolley, E. E., E. T. Robinson, and P. R. Ulin
2005   Qualitative Methods in Public Health: A Field Guide for Applied Research. San Francisco, CA: Jossey Bass.
Vepa, S. S.
2004   Impact of globalization on the food consumption of urban India. In: Globalization of food systems in developing countries: impact on food security and nutrition. Pp. 215–230. Rome: FAO
Weaver, L. J. and C. Hadley
2011   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 39:211–225.
Weller, S. C. and A. K. Romney
1988   Systematic Data Collection. Newbury Park, CA: Sage Publications.

Williams, G.
  2004   Narratives of health inequality: Interpreting the determinants of health. Paper presented at the Annual Meeting of Sociology, San Francisco, CA.
World Bank
  2012   Structural adjustment in India. http://lnweb90.worldbank.org/oed/oeddoclib.nsf/DocUNIDViewForJavaSearch/0586CC45A28A2749852567F5005D8C89
Zimmet P., K. G. Alberti, and J. Shaw.
  2001   Global and societal implications of the diabetes epidemic. Nature 13; 414(6865):782–787.