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Normalizing Diabetes in Delhi: A Qualitative Study of Health and Health Care

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Abstract

The Type 2 diabetes epidemic in India poses challenges to the health system. Yet, little is known about how urban Indians view treatment and self-care. Such views are important within the pluralistic healthcare landscape of India, bringing together allopathic and non-allopathic (or traditional) paradigms and practices. We used in-depth qualitative interviews to examine how people living with diabetes in India selectively engage with allopathic and non-allopathic Indian care paradigms. We propose a ‘discourse marketplace’ model that demonstrates competing ways in which people frame diabetes care-seeking in India’s medical pluralism, which includes allopathic and traditional systems of care. Four major domains emerged from grounded theory analysis: 1) normalization of diabetes in social interactions; 2) stigma; 3) stress; and 4) decision-making with regard to diabetes treatment. We found that participants selectively engaged with aspects of allopathic and non-allopathic Indian illness paradigms to build personalized illness meanings and care plans that served psychological, physical, and social needs. Participants

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constructed illness narratives that emphasized the social-communal experience of diabetes and as a result, reported less stigma and stress due to diabetes. These data suggest that the pro-social construction of diabetes in India is both helpful and harmful for patients - it provides psychological comfort, but also lessens the impetus for prevention and self-care. Clarifying the social constructions of diabetes and chronic disease in India and other medically pluralistic contexts is a crucial first step to designing locally situated treatment schemes.

Keywords

type 2 diabetes; India; self-care; morality; stigma; medical anthropology

Introduction

India is the home of the second largest number of people living with Type 2 Diabetes (hereafter ‘diabetes’) globally (International Diabetes Federation, 2014). Studies project diabetes prevalence to be between 10–16% in Indian urban areas (Mohan, Sandeep, et al., 2007), which is considerably higher than the United States prevalence of 9.3% (American Diabetes Association, 2014), and between 2–6% prevalence in rural areas (Mohan, Sandeep, et al., 2007). These numbers are associated with social factors from rapid globalization of daily life, immigration to urban centers, social mobility through increased income, mechanization of everyday life, and sedentary jobs (Popkin, Adair, and Ng, 2012; Shetty, 2002). They are also associated with insufficiently explored biological reasons such as in-utero programming and early beta cell programming (Snehalatha et al., 1998; Victora et al 2008). The accumulation of these biological and lifestyle factors has created a ‘perfect storm’ for chronic diseases like diabetes to flourish in India (Ebrahim et al., 2010; Mohan, Jaydip, and Deepa, 2007; Shetty, 2002; Sullivan et al., 2011) and to overrun the country’s healthcare system (Mohan, Sandeep, et al., 2007). Yet, few studies investigate individual-level phenomena surrounding diabetes care.

We investigate individual-level beliefs and experiences to determine how people with diabetes in India engage with conflicting medical discourses surrounding the disease. In this way, we interrogate the concept of self-care, as one that requires individuals to renegotiate a sense of “self” and “care” in the context of diabetes (see Guell 2012). We argue that the existence of competing paradigms, or ‘discourses’, of suffering related to diabetes in India creates a radically different structure in which Indians reconfigure themselves as ‘diabetic’ when compared to how people in industrialized societies, where most research on diabetes has taken place, configure the diabetes identity (Leslie, 1998). Building upon seminal work in political science that uses the term “religious marketplace” to describe how people negotiate competing identities within a heterogeneous religious landscape (Chiswick and Chiswick, 2013; Gill, 2001; Grzymala-Busse, 2012), we propose a “discourse marketplace” to describe diabetes care in India.

A discourse marketplace is a space in which people choose from and navigate competing paradigms for health and healing to illustrate choices around health and healthcare. This discourse marketplace is situated within India’s collectivist paradigm, where people place the family or society above the individual. And while individuals navigate autonomously within this paradigm, especially as they age (Mines, 1988), this cultural backdrop also allows patients to create novel moral discourse(s) around diabetes that is less punitive than dominant biomedical discourses. This is built upon the growing body of research that illustrates how biomedical, or what we commonly refer to as allopathic, discourse around chronic diseases often places blame on the individual for failing to achieve health and prevent disease; for example, such research emphasizes how allopathic models place onus for dietary or physical activity regimens in diabetes care on individuals ‘compliance’ without addressing structural or social barriers (Browne, Ventura, Mosely, and Speight, 2013). This paper moves beyond structural analyses of diabetes treatment to elucidate how individuals navigate between illness discourses, or the socially constructed meanings of illness, as offered by a discourse marketplace.

Constructing Diabetes in India

Medical anthropologists have long argued that social, psychological, and physical aspects of disease interact with and create a powerful discourse about what illness means in individual lives (Kleinman, 1988; Becker 1999; Mendenhall, et al. 2010). Caregivers, healthcare workers, and systems collectively reinforce cultural values and social norms around illness that influence individual experiences (Kleinman, 1988; Conrad and Barker, 2010). For instance, western biomedical ideals of individualism foster a dominant discourse of patient autonomy and responsibility, pointing to individual responsibility and ‘self-control’ as proximate cause and cure for diseases (Browne et al, 2013; Schabert, Browne, Mosely, and Speight, 2013; Kleinman, 1988; Seligman, Mendenhall, Valdovinos, Fernandez, and Jacobs, 2014). One particularly influential aspect of the biomedical paradigm is its focus on ‘self-care’, which although often portrayed as an avenue for patient empowerment, oftentimes functions more as a source of moralistic control that constrains how individuals can and should define and attain ‘good health’ (Mishra, 2010). Browne and colleagues (2013) have argued that such a moralizing approach is common allopathic practice for diabetes care, placing blame upon the ill for becoming ‘diabetic’ and failing to prevent diabetes complications. Farmer (2001) identifies this as “exaggerated patient agency” and, as a result, people with diabetes often feel stigma imbued with moral blame, shame, and guilt (see Broom & Whittaker, 2004). This was documented in Australia where researchers found 84% of people with diabetes reported social stigma and personal (or self-perpetuated) stigma (Browne et al., 2013). A study of Mexican Americans with diabetes found that people develop burdensome feelings of stress and ‘moral blame’ (Seligman et al., 2014). A study of African Americans argued that racism had a negative impact on people’s perception of diabetes, self-care, and management (Wagner, et al., 2011). This stigma affects people living with diabetes in all aspects of life, from home to the workplace, and such emotions impact diabetes experiences (Schabert et al., 2013).

Yet, the biomedical framing of the ‘diabetic’ does not translate explicitly across cultures. In India, competing paradigms to the biomedical model of illness and treatment cultivate a medically pluralistic environment. We conceptualize these competing paradigms, which largely draw from, but do not exclusively situate themselves within, the AYUSH paradigm (Ayurvedic, Yoga, Unani, Sidda, and Homeopathy), as “non-allopathic” models. Just as the biomedical, or allopathic, paradigm is rooted in western individualism, indigenous frameworks for healing often emphasize interdependence rather than independence (Leslie and Young, 1992). This can be demonstrated by Ayurveda, one component of the AYUSH paradigm, which places the physical body and bodily ailments into an interrelated web of social relations and other basic cosmic elements, including earth, water, fire, air, and ether (vacuum). In this conception, illness results from imbalance between five elements, both intrinsically (within the body) and extrinsically (between the body and the universe) (Leslie, 1980; Leslie, 1998; Ministry of AYUSH, 2010). As such, the Cartesian dualism of western biomedicine, where the mind and body are perceived to be distinct entities, does not dominate the many traditional lineages that maintain the AYUSH paradigm. Thus, the AYUSH paradigm requires that physician and layperson understandings of disease etiology, diagnosis, and treatment weave together physical as well as spiritual, personal, social, and economic factors (Ministry of AYUSH, 2010).

India exists in a state of medical pluralism in which people with diabetes navigate personal or familial preference for non-allopathic and allopathic paradigms. Although allopathic medicine maintains the dominant source of diabetes care (Rao, Rao, Kumar, Chatterjee, and Sundararaman, 2011), non-allopathic paradigms hold cultural legitimacy as well as political legitimacy, as evidenced by the fact that there is a Ministry of AYUSH as well as Ministry of Health. Most research on medical pluralism attends to technical issues such as resource allocation (eg. Khan, 2006), relative physiological effectiveness of various treatments (Leslie, 1980; Naraindas, 2006; Sujatha, 2011), or patterns of patient consumer choice between allopathic and non-allopathic treatment options (Chacko, 2003; Chandra, 2011; Rao et al., 2011; Bhardwaj, 2010). For instance, research indicates that individuals use alternative therapies when allopathic options are perceived as bringing harsh side effects, being too invasive, or treating only symptoms rather than the cause of an illness (Bhardwaj, 2010). Others have demonstrated how imported biomedical models that were developed for and within the western context misalign with the needs of patients in low- and middle-income countries (Finkler, 2004). Thus, in this paper we move beyond technical analyses to elucidate how individuals navigate between and draw from allopathic and non-allopathic discourses around sickness and healing.

Discourse Marketplace for Diabetes in Delhi

We propose a Discourse Marketplace Model (Figure 1) to illustrate how Indians might navigate medical pluralism to give meaning to diabetes. This model builds upon previous scholarship relating marketplace analogies to immaterial phenomena such as Mill’s ‘marketplace of ideas’ concept (Mill, 1859), or the ‘currency of ideas’, concept that describes the powerful role of ideas in politics (McNamara 1999). We also draw from recent ‘political economy of religion’ scholarship that extends the marketplace to explain how religious patrons engage with religious paradigms as ‘consumers’ aiming to maximize benefits and minimize costs (Chiswick and Chiswick, 2013; Gill, 2001; Grzymala-Busse, 2012). A ‘discourse marketplace’ framework similarly casts people with diabetes as consumers to understand how urban Indians navigate medical pluralism to construct benefit-maximizing conceptions of chronic disease.

We return to Figure 1 in the discussion to synthesize options available to Indian patients and how they negotiate those options. The left column demonstrates a ‘monopolized’ marketplace of medical discourse, such as the United States, in which patients largely maintain biomedically oriented etiologies and patterns of healing. Individualism and priority of the self within the biomedical paradigm characterizes this model (identified by the blue). In this context, diabetes etiologies often prioritize personal blame and impose judgment for past digressions through treatment regimens. The right column illustrates India’s medically pluralistic marketplace in which neither allopathic nor non-allopathic paradigms holds a complete monopoly on how people understand or engage with diabetes. As exemplified by the yellow background, non-allopathic paradigms, including AYUSH, are situated within a larger cultural tradition of collectivism, placing family before the self. In the Indian context, allopathic options accompany traditional options, thereby juxtaposing how people define or interact with concepts of etiology, personal responsibility, and moral blame. People living with diabetes are therefore afforded the freedom to draw simultaneously from allopathic and non-allopathic discourses to construct and ‘consume’ a holistic, hybrid conception of diabetes that is most appetizing and appropriate for their pathway to healing, as exemplified by the hybrid green borders around sections in the non-allopathic context.

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. The first and third authors determined eligibility for the study by a rigorous screening process (EM and RS). We included only those who were older than 20 years-of-age, self-reported having type 2 diabetes, and who resided in one of three selected neighborhoods; these three neighborhoods were identified in order to provide views from people across socioeconomic strata, including one low income (*n*=20), middle-income (*n*=25), and high-income (*n*=14). We excluded individuals who did not meet our inclusion criteria or who had severely-disabling diabetes complications or cognitive impairment, active substance abuse, or psychosis severe enough to interfere with participation in the interview.

We conducted 59 in-depth qualitative interviews and depression inventories with equal numbers of men (*n*=30) and women (*n*=29) were purposively sampled. Each study participant was matched with a same-gender Hindi-speaking research assistant (RA) in order to prevent hesitation that a one might feel as a result of discussing sensitive subjects with the opposite sex. The gender-matched RAs introduced themselves, described the study on experiences and perceptions of living with 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) followed by the administration of a frequently used and Hindi-validated depression inventory. All interviews were audio-recorded in Hindi. Recruitment and interview administration occurred between December 2011 and February 2012.

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 within the formal healthcare sector. Each narrative interview began with: “Can you describe a typical day for me?” The interview then shifted to address the study participant’s experience with diabetes, including questions like “What caused your diabetes?”, “How did you feel when diagnosed with Diabetes”, “Has diabetes changed your life in any way?”, “Do you tell people about your diabetes? And if so how do they react?”, “Has diabetes affected your daily routine?” and “Does stress or tension affect your diabetes in any way?” (‘Tension’ is a term used interchangeably with ‘stress’ in India), “Can you tell me about how you care for your diabetes?”, and “Where do you seek diabetes care? And, how often?” Field notes were written immediately upon completion of each interview and quantitative data, including sociodemographic surveys and psychiatric inventories, were entered into excel spreadsheets.

Data Analysis

The qualitative interviews were transcribed into English from Hindi. Based on the literature, we used grounded theory (Strauss & Corbin 1998) to generate an understanding of how people with diabetes interpret the self within competing healthcare paradigms. Of the original 59 individuals interviewed, 53 were included in this study, due to six transcripts that did not contain enough information on participant views on the health system and disease self-care in order to be included in the analysis; four low-income, one middle-income, and one high-income study participants were dropped from analysis. We identified four major realms in which participants engaged with and experienced diabetes: 1) individual engagement in verbal, sociocultural construction of diabetes; 2) perception of social significance attached to diabetes; 3) personal and psychological experiences of living with diabetes; and 4) personal patterns of self-care behavior and care preferences in terms of allopathic versus non-allopathic practices. First, we asked individuals, “what caused your diabetes and how does it affect your everyday life?” Second, we identified how people communicated about their diabetes with family and community, including answers to questions such as: ‘Do you tell people about your diabetes?’ and ‘Do others act differently towards you because of your diabetes?’ Third, we evaluated how people described the social and psychological impact of living with diabetes based on the answers to questions such as: ‘Do you feel tension because of diabetes?’, ‘Has diabetes changed your life in any way?,” and ‘How did you feel when you were first diagnosed with diabetes?’. Lastly, we identified each individual’s self-care and treatment preferences based on answers to the question: ‘How do you manage your diabetes?’ as well as other narratives of engagement with allopathic or non-allopathic care.

Results

Table 1 shows that men and women were equally represented among study participants and were married, Hindu, and in their mid-fifties. Individuals from the lower income group completed less education and maintained lower incomes than those from middle- and high-income neighborhoods.

How Diabetes is Normalized in Everyday Life

In this section, we introduce how people described diabetes as "normalized" in everyday life, meaning that diabetes was a comfortable, non-foreign phenomena that had become part of the social fabric, not unlike the common cold. Most study participants reported learning about diabetes and diabetes care from the media, including television, newspapers, magazines, and books (n= 16), and friends (n = 12), underscoring the role of non-medical sources of knowledge in how people interpret and care for their diabetes. One-third of men (n=9) and two-thirds of women (n=15) normalized diabetes in their speech, stating things like "It's now common to everybody in Delhi. Children are getting it. They get it in the womb. Moreover, my father and brother had sugar." ('Sugar' is a term used interchangeably with 'diabetes' in India.) This open conversation about the increasing universality of diabetes is what we call 'discursive normalization' of diabetes and identified in the data in the following four ways: by identifying diabetes as "normal" (n=12), suggesting that diabetes is "not a disease" (n=2), saying "everyone has diabetes" and that it can "happen to anyone" (n=17), and that "this is just the way the world is" (n=3).

Many participants engaged in discursive normalization by offering expressly 'fatalistic' etiologies that removed personal blame for diabetes. In many cases, participants emphasized the 'inevitable' nature of diabetes, such as "It's a disease, anything can happen, anyone can suffer" and "it was my fate." In response to the question: why did you get diabetes?, some responded:

> "The world has these problems, people get them [diabetes] like that I also got it [diabetes]. What else?" – Low-income woman

> "This is actually no disease. This affects body, but this is no disease. If you eat less, have a controlled diet, then sugar will be controlled. This is no kind of disease. If you eat more, sugar will go up, then it is a disease […] These days kids have it. They are young kids, the environment is like that when the children are stressed and there is tension of the studies. It's the impact of the environment." - High-income woman

> "[Diabetes] is normal. Many people get it. I see children in the hospital suffering from it." –Low-income woman

Many participants stated that at the time of their diabetes diagnosis, their friends and family members comforted them by emphasizing that the disease was very common. When sharing her diabetes diagnosis with her family, a low-income woman was warmly received: "My elder daughter said that there is nothing to worry about, and it's normal these days." Others described it similarly:

> "First we [the family] thought that it is a big disease but now it has become very common, most of the people have diabetes, in every house." – Middle income man

> "I was with my office workers, the people with whom I talk about many things [when diagnosed with diabetes]. They encouraged me, told me that this happens with every third person in Delhi." – Low income man

As such, few people perceived diabetes as a source of social stigma or marginalization. Most (n = 37) stated that they did not feel any diabetes stigma and discrimination (Table 2) and many stated that they felt no need to hide their diabetes. Participants described feeling little or no need to conceal their condition from others:

> Interviewer: "Did you ever tell your relatives that you have sugar?"
>
> Low-income Woman: "Yes, they all know I have sugar […] one person has sugar in every house. So now they understand that it is very common. Also in hospitals there was a big line, which shows that not only I have this disease."
>
> Low-income Woman: "When they [family and friends] came to know that I had been diagnosed with diabetes they sympathized with me."
>
> Interviewer: "Did they ill-treat you?"
>
> Low-income Woman: "No, no. It's not that it is a contagious disease. Why would anyone do that?"

Similarly, participants rarely expressed feelings of self-blame or other forms of internalized stigma, and therefore avoided placing blame on the self.

> "I only think whatever happens is God's will. We always think good for others, we never wish anything wrong for anyone, so why blame ourselves?"-Low-income man

Tension, Stress, and Diabetes[1]

Few study respondents identified diabetes as a source of daily stress (Table 3). Nearly half of all study participants (n = 24) reported tension due to diabetes at any point (past or present), and one fifth (n= 10) reported feeling tension associated with diabetes at the time of the interview. Most felt distressed when first diagnosed, but tension reduced with time. In some cases, people described "acceptance", such as the following man: "Initially I used to get tensed [by my diabetes]. But I have accepted it." Similarly, many used normalizing discourse when speaking about stress and diabetes, as demonstrated in a woman's response to the inquiry if she gets tense because of sugar? She replied, "No I don't think about it much as I know that there are so many people in this world who have sugar." The following low-income woman who describes how stress related to illness reduced with time:

> Interviewer: Did you feel bad for having sugar?
>
> Woman: Yes I was worried - how I am going to handle all this?
>
> Interviewer: Do you still feel that way?
>
> Woman: No, now I think it is quite normal.

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[1] We published a more extensive discussion of the intersection of stress, mental health, and diabetes in *Social Science, and Medicine* in 2012.

> Interviewer: Don’t you feel scared when you think about it?
>
> Woman: No.

This normalizing discourse demonstrates how fear and worry go away with time. Even if diabetes was initially unfamiliar, many people, such as the following middle-income woman, described how diabetes becomes “part of one’s life”:

> “Now I have gotten used to it. In the beginning, I used to feel psychological pressure but not now. […] In the beginning I used to feel ‘what kind of disease do I have, one I’ve never heard of’. But now it doesn’t matter to me anymore. It’s become a part of my life. Now it will go with me.”

Most (n = 37) did not report any tension due to diabetes (instead, tension was related to social problems). Many participants expressed that they felt minimal tension due to diabetes and did not view the disease to be of major consequence, describing it as a “small problem” and “I don’t think it’s a big disease”. For many, they described not feeling stress associated with diabetes because they knew they could access treatment and attain some status of good health:

> Interviewer: “Due to diabetes do you feel that there are changes in your daily routine?”
>
> Middle-income Woman: “No I don’t think so. In old age everybody’s stamina gets weak, we can’t increase or decrease it. I hear from many people that they have diabetes, or blood pressure. I have both but I don’t feel any weakness.”
>
> “Those who don’t know, get panicked. But the treatment is there. It [diabetes] can be controlled, and you will have to take medicine for always. But with the course of time you get accustomed to it. So, why worry?”-Low-income man

Navigating Diabetes Treatment and Care

Self-care practices represent the tangible intersection between how people privately understand illness and how they act to engage with and address that illness win the public sphere (Guell, 2012). First, most people expressed engagement in self-care activities: most followed some form of a modified diabetic diet (n=33), half followed a walking regimen as part of their diabetes management program (n=27), and a fifth practiced yoga regularly (n=10). Approximately half of men (n=15) and half women (n=12) walked regularly, while markedly more women (n=7) than men (n=3) practiced yoga.

Second, a clear gender differential existed in terms of adherence to diabetes diet restrictions. We separated participants who described adherence to a diabetic diet into two categories: ‘strict’ and ‘relaxed’ adherence. ‘Strict’ diet adherence was defined as avoidance of several high-caloric foods including rice, potatoes, and sugary fruits. ‘Relaxed’ diet adherence was defined as avoidance of only direct sugar in the form of sweets or sweetened tea. Women (n=12) made up the majority participants who described adherence to a ‘strict’ diet regimen, whereas men (n=8) made up the majority of those who described a more ‘relaxed’ diet regimen. Overall, more than a third (n=20) of participants stated that they did not adhere to any diabetic diet, with men (n=13) comprising the majority of the non-diet group.

Third, diet and physical activity did not appear to be associated with where individuals sought diabetes care. The majority of respondents (n=31) chose to seek care for their diabetes in private hospitals, with many interviewees complaining about the long lines and poor quality of care at public institutions; those who sought diabetes care in public institutions were in the lowest income group. Most (n=25) seeking care at a private institution were satisfied with their care, as opposed to less than half (n=6) of those receiving care at a public hospital. However, where people sought medical care did not necessarily isolate them from deciding to seek other types of diabetes care, such as from non-allopathic care providers.

Fourth, in terms of allopathic versus non-allopathic treatment decision-making, most respondents (n=40) identified allopathic care as their main source of treatment for diabetes. One-quarter (n=14) of study participants perceived engaging with AYUSH treatment as an important, if not the primary component, of their care regimen; and most of these individuals (n = 11) were men. One-quarter (n = 14) of respondents stated that they did not use AYUSH treatments, but simultaneously reported using non-allopathic treatments such as fenugreek leaves and other medicinal plants; these respondents were nearly all women (n=12).

This finding emerged in extensive review of the narrative data, where women reported more frequently than men specific non-use of non-allopathic, alternative methods to control their diabetes; then, later in the interview women described adherence to non-allopathic therapies, including yoga and foods. For instance, when asked directly if one uses *churan* (powder) or Ayurvedic medicine to cure diabetes, a middle-income woman replied, “no.” But later in the interview her daughter-in-law (who was observing the interview) said, “She eats things, which are good for her health. We have a tree of Madagascar periwinkle and Sadabahar (Evergreen).” The woman then continued with, “I eat Sadabahar and also Neem leaves.” Similarly, a high-income woman said, “I don’t believe in homeopathy” and later in the interview explained, “I take fenugreek seeds and use them in food [when my sugar rises]. I feel better.” Others described using “seeds of java plum” such as the following low-income man:

> Interviewer: Have you taken Ayurveda medicine for this [diabetes]?
>
> Man: “No. I haven’t taken any other treatment except the English medicine. […] I took the powder of the seeds of java plum [pause] from the market it comes in a packet and costs 25 rupees. […] I believe that the herbs are most successful thing in this to bring bitterness in the blood. The seed of java plum is the best one. That totally cures it [diabetes].”

Similarly, the following low-income woman describes taking fenugreek seeds, which were a very common remedy:

> Interviewer: “Do you take any alternative therapy for your diabetes management?”
>
> Woman: “No, I don’t take anything. But I take fenugreek seeds. I ask my children to grind them. I take them directly. It helps in controlling my sugar.”

In contrast, most men directly reported AYUSH treatments as part of an overall care plan:

> Interviewer: “Do you get any treatment?”

Low-income Man: “Yes, medicine, homeopathy and physical classes are going on.”

Discussion

This paper describes how urban Indians with diabetes navigate north India’s discursive marketplace to selectively engage with multiple illness discourses. Within the space between allopathic and non-allopathic discourses, our interlocutors constructed personalized illness meanings and care plans to serve psychological, physical, and even social needs. Our data suggest that people engage with non-allopathic constructions of diabetes while also relying heavily upon biomedical treatments. This may result from non-allopathic constructions of diabetes that address psychological and social conditions, while allopathic treatments focus on the physiological. It may also result from the imprecise nature of biomedical rhetoric, which neither precisely identify a single cause, nor point to a doubtless cure (Mishra, 2011). Scholarship on Indian populations in India and the United Kingdom suggests that people construct illness narratives that move beyond individualistic notions of blame to place the cause of illness in the social world. Research in Delhi illustrated how many people with diabetes emphasize stress, significant life events, and even beliefs about fate or karma as causal to diabetes (Mendenhall, et al. 2012), a finding which is echoed within Indian immigrant populations in the U.K (Porqueddu, 2013) as well as elsewhere (Mendenhall, et al. 2010). Such research emphasizes the more universalizing non-allopathic discourse, such as Ayurvedic, as opposed to biomedical lifestyle factors. This paper goes further to show how our interlocutors identify diabetes as “normal”, thereby moving beyond physical aspects of suffering to focus on the social-communal experience of diabetes. This normalized construction of diabetes – something that “anyone can suffer” – may be in part why diabetes was reported to cause minimal tension. In what follows we deconstruct our key findings through the concept of the discourse marketplace.

We argue that the discursive marketplace through which people make meaning out of their diabetes experiences provides opportunities for people to shield themselves from biomedical frames of shame and stress in association with diabetes. This finding supports a recent study where women living with diabetes in Delhi displayed resilience against punitive biomedical discourse surrounding diabetes and as a result experienced lessened diabetes-related tension (Weaver, Worthman, DeCaro and Madhu, 2015). As such, we contend that cultural responses to social distress – which, in this case, quell potential stress through normalization of diabetes in everyday life – play an important role in reducing diabetes-related (dis)stress. This is not unlike what Seligman and Kirmayer (2008) call “bio-looping” (see Hacking 1995, 1998) where notions of distress are reinforced by or, as Lewis (2013) found, diminished by interaction in cultural spaces. Thus, our data suggest that the cultural space that draws from a pluralistic healthcare system works to normalize diabetes in social discourse, taking onus from the individual and recognizing diabetes as part of the social fabric, thereby diminishing self-blame.

Yet, many women and some men expressed unwillingness to report utilizing non-allopathic treatment modalities. We recognized this hesitation in the interviews because many women reported not seeking non-allopathic care when asked about it directly; however, they described non-allopathic practices in self-care indirectly (such as taking traditional fenugreek seeds). This suggests that social conventions are powerful mediators of how people conceive and engage with treatment modalities (regardless of their roles as ‘formal’ or ‘informal’ avenues of care). Moreover, women may have reported what they thought the interviewers *should* hear (that they prefer allopathic treatment paradigms) even though they off-handedly reported engaging in non-allopathic practices in their daily lives. Similarly, women seemed to comply with researcher expectations in describing much stricter adherence to diabetic diet regimens than men, and in doing so, may reveal that they are being “good” or “moral” patients by adhering to the allopathic paradigm. That women would be more likely to construct narratives that align with the perceived values of their audience than men is a reasonable expectation within the patriarchal system in which women hold less power in the public and private spheres in India (Sen, 2001), when compared to other nations, such as the United States. This finding builds upon previous studies that have found patients and physicians perceive people with diabetes to be “good” patients when their “good” blood sugar that reflects morally acceptable personal choices (Ferzacca 2004; Broom and Whitaker 2004). In contrast, we found that men were less likely to report adherence to diet restrictions proposed by allopathic physicians. This may result because men may more commonly rely upon and expect the family—and especially their wives—to cater to their diabetes-related needs (Weaver & Hadley, 2011), and with this increased support may feel more liberty to experiment with multiple latitudes of care and dietary choices, while women are more stringent with their self-care and dietary regimen due to lessened family support (Weaver, et al. 2015; Weaver and Hadley, 2011). It also may represent broader cultural phenomena where the flow of food and pleasure associated with it override latent concerns about the negative dietary excesses on long term health and chronic illness espoused by clinicians (see Wilson 2010).

The lack of moralizing discourse may play a role in poor diabetes control in India. Our interlocutors did not prescribe to moralizing discourse about diabetes, such as placing crippling blame on the self for their illness. Research from industrialized societies suggest that diabetes stigma can be, on the one hand, a deterrent to self-care in the public sphere (Thorne et al., 2003) or a motivator for self-care to shield oneself from blame or guilt if their condition worsens (Broom & Whittaker, 2004). However, our data suggest that the lack of diabetes stigma, while good for mental health, may pose the possibility of impeding good diabetes control. For example, previous research on the normalization of HIV/AIDS in everyday life shows that individuals are more likely to engage in risky self-care behavior if AIDS is socially normalized (eg. Wozniak, Prakash, Taylor, and Wild, 2007). With the normalization of diabetes, there are similar concerns that individuals will not feel pressures to manage blood sugars or even seek medical care for diabetes until their condition becomes severe (see Weaver, et al. 2015 and Bhojani, et al. 2013). Moreover, self-care practices may be further deterred by multiple other factors including personal resources in terms of money, time, convenience, gendered social roles and the built environment (Mishra, 2010). This paper does not seek to ignore the importance of such factors, but rather seeks to elucidate the relationship of a pluralistic healthcare system, social discourse around diabetes, stigma, and self-care in India.

Conclusion

The discourse marketplace model provides an analytic tool to interpret how individuals negotiate self-care within medically pluralistic societies. Biomedicine as practiced in India differs from biomedicine practiced in industrialized contexts because allopathic doctors are rooted in local sociocultural contexts and their clinical practice is wedged between cultural knowledge and medical training (Finkler, 2004). This dynamic creates an element of fluidity that is difficult to capture within the more two-dimensional space of the discourse marketplace. Similarly, the model does not reflect the ways in which individual engagement with allopathic or non-allopathic discourses may be influenced by cultural values or historically promoted by colonial and nationalist governments that promote modernity (Khan, 2006). Embedded within this model, therefore, are the more esoteric factors that influence how people pick and choose self-care practices that come from allopathic or non-allopathic paradigms. Indeed, advancing the fluidity of treatment paradigms may achieve greater health at the population level while empowering people navigating illness and achieving diabetes control.

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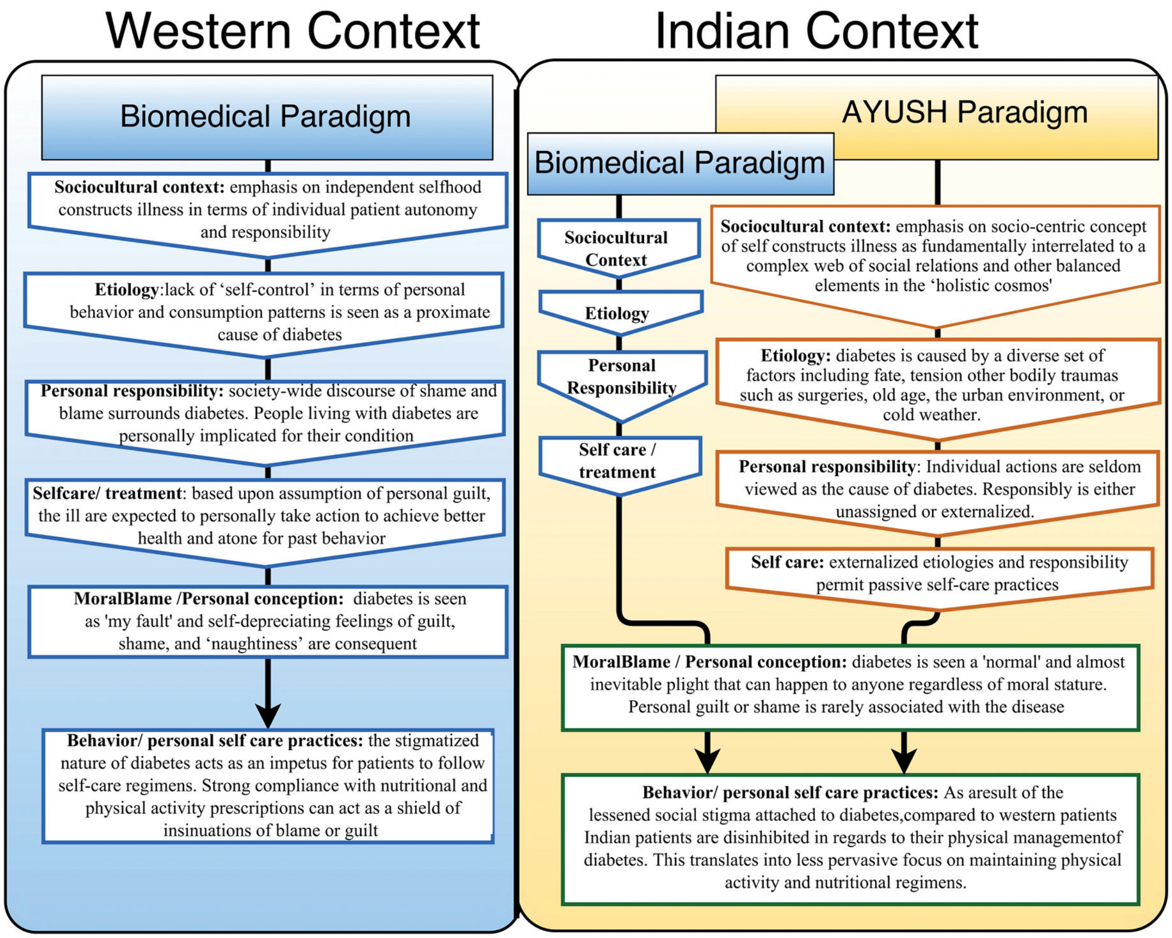

Sociocultural context: emphasis on independent selfhood constructs illness in terms of individual patient autonomy and responsibility

Etiology:lack of 'self-control' in terms of personal behavior and consumption patterns is seen as a proximate cause of diabetes

Personal responsibility: society-wide discourse of shame and blame surrounds diabetes. People living with diabetes are personally implicated for their condition

Selfcare/ treatment: based upon assumption of personal guilt, the ill are expected to personally take action to achieve better health and atone for past behavior

MoralBlame /Personal conception: diabetes is seen as 'my fault' and self-depreciating feelings of guilt, shame, and 'naughtiness' are consequent

Behavior/ personal self care practices: the stigmatized nature of diabetes acts as an impetus for patients to follow self-care regimens. Strong compliance with nutritional and physical activity prescriptions can act as a shield of insinuations of blame or guilt

Sociocultural context: emphasis on socio-centric concept of self constructs illness as fundamentally interrelated to a complex web of social relations and other balanced elements in the 'holistic cosmos'

Etiology: diabetes is caused by a diverse set of factors including fate, tension other bodily traumas such as surgeries, old age, the urban environment, or cold weather.

Personal responsibility: Individual actions are seldom viewed as the cause of diabetes. Responsibly is either unassigned or externalized.

Self care: externalized etiologies and responsibility permit passive self-care practices

MoralBlame / Personal conception: diabetes is seen a 'normal' and almost inevitable plight that can happen to anyone regardless of moral stature. Personal guilt or shame is rarely associated with the disease

Behavior/ personal self care practices: As aresult of the lessened social stigma attached to diabetes,compared to western patients Indian patients are disinhibited in regards to their physical managementof diabetes. This translates into less pervasive focus on maintaining physical activity and nutritional regimens.

Figure 1.

The Discourse Marketplace: Diabetes Care in India

Table 1

Sample Demographics

	Low Income (*n*=16)		**Middle Income (*n* =24)**		**High Income (*n* = 13)**		**Total (*n* = 53)**	
Women (*n*, %)	9	56 %	9	38 %	8	61 %	26	49 %
Men (*n*, %)	7	44 %	15	63 %	5	38 %	27	51 %
Age (mean, ±SD)	50	±9.2	58	±9.3	55	±10.7	54	±10.3
Born in Delhi (*n*, %)	2	12 %	8	33 %	6	46 %	16	30 %
Married (*n*, %)	15	94 %	21	87 %	11	85 %	47	89 %
Hindu (*n* %)	16	100 %	21	87 %	10	77 %	47	89 %
HbA1c (mean, ±SD)	8.8	±1.9	9.1	±1.9	8.5	±2.3	8.8	±2.0

Table 2

Perceived or Experienced Diabetes Stigma and Discrimination

	Male (n=27)		Female (n=26)		Total (n=53)	
	n	**%**	**n**	**%**	**n**	**%**
Expressed no overall felt discrimination	20	75	17	65	37	70
• No felt discrimination	20	74	11	42	31	58
• Readily disclose diabetes status	3	11	16	60	19	36
Expressed felt discrimination	1	4	2	8	3	6
Unclear	6	22	7	26	13	25

Table 3

Tension Regarding Diabetes

	Male (n=27)		Female (n=26)		Total (n=53)	
	n	**%**	**n**	**%**	**n**	**%**
Does not currently feel tension due to diabetes	21	78	16	60	37	68
• Don’t take tension because of sugar	18	67	15	57	33	62
• No change in daily life or tension due to diabetes	12	45	9	35	21	40
• Initial tension, but now diabetes is normal	6	22	8	30	14	25
• Diabetes is inevitable, so why take tension	6	22	7	26	13	25
Currently feels tension due to diabetes	4	19	5	19	10	19
Felt tension due to diabetes at any point (past or present)	11	40	13	50	24	45
Unclear	1	4	3	11	4	8