Rice Today, Roti Tomorrow: Diets and Diabetes in Urban Indian Households

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ABSTRACT
In India, where diabetes is a growing concern and approximately 69 million are affected, we investigate the factors that influence diet management, a critical component of living with the disease. Taking the middle-income diabetes-affected household as our unit of analysis, we use a combination of semi-structured interviews and a design probe to understand if and how diets are monitored, tailored, and balanced. We research the various information-seeking behaviors of our participants and their culturally situated approaches to food and eating. Our findings illuminate how contextual nuances shape individuals' beliefs around dealing with diabetes and the ways in which family, friends, and broader social networks influence dietary decisions. We conclude by offering a framework of *Learning-Being-Doing* to inform the holistic design of technologies for managing diets and diabetes.

Author Keywords
Diabetes; Diets; India; Qualitative Methods

ACM Classification Keywords
H.5.m. Information Interfaces and Presentation (e.g. HCI): Miscellaneous

INTRODUCTION
The incidence of chronic, non-communicable diseases has been on the rise worldwide. Diabetes, in particular, is a major public health concern that is considered to be approaching epidemic proportions across the globe. According to the International Diabetes Federation, as of 2014, the number of diabetics in India alone is calculated to be approximately 69 million [25]. In other words, roughly 17% of people with diabetes in the world live in India. To manage this ailment, patients are prescribed a regulated diet management, exercise management, and self-monitoring regime. Although a multitude of technological approaches have been aimed at addressing diabetes management in the U.S. [1, 31, 34], there is a paucity of research that examines the incidence of diabetes in India, the factors that drive its prevalence in the country, and ways in which the disease might be managed by those affected.

Diet is a major component of diabetes management; many existing mobile solutions for those with diabetes target healthier diets [13, 14, 18, 38]. These tools, however, lack an understanding of lifestyles, cooking styles, dietary preferences, and eating practices that are typical of Indian households. The cultural specificity extends beyond cooking and eating practices. Research shows that Indians are used to an approach to medicine with different roots from those of the West and a different style of doctor-patient interactions [7, 47]. Medical and dietary consultations are irregular and infrequent, often expensive, and not always helpful. Given that the incidence of diabetes in India is among the highest in the world and growing rapidly [25, 45], it is critical that we also investigate and address concerns around diabetes management for the Indian populace.

Our research presents a qualitative investigation of how diet is managed in urban, middle-income Indian households affected by diabetes. Taking the household as our unit of analysis, we use a combination of semi-structured interviews and a design probe to understand how persons with diabetes (PWDs) monitor, tailor, and balance their diet. We examine various information-seeking behaviors related to food and eating, the roles friends and family play in providing care and assistance for managing diet, and actions taken to effect lifestyle dietary changes. Based on the insights gleaned from our findings, we present a framework of *Learning-Being-Doing* to inform the holistic design of technologies for the management of diet and diabetes.

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RELATED WORK

The rising incidence of diabetes across the world, including in India, has led to its recognition as a major public health concern. Our research examines those affected by Type 2 Diabetes, a disease that affects a person's ability to produce insulin and properly control their concentration of blood glucose [19]. To avoid short- and long-term complications of the disease, medical management is critical; however, a high degree of self-management around diet and physical activity levels is also required [2].

Diet Management and Food as Medicine

Lifestyle changes around diet and exercise form the mainstay of the treatment of diabetes [30]. Diet modification is regarded as the first line of therapy [24]. Studies have shown that diet modifications alone can achieve up to one third of glycemic control [19] and lead to significant reduction in overall morbidity and mortality [37].

Dietary preferences are highly contextualized and culturally entrenched, and should be investigated as such [12]. Contextual nuances including local folklore shape beliefs related to diet, disease, and treatment. Apart from the formal biomedical system, the culture in India draws heavily on multiple systems of medicine including Ayurveda, Siddha, Unani, Homeopathy, and Naturopathy. These systems of medicine differ in their conceptualization of disease and treatment, and take varying approaches to etiology, diet, drugs, and treatment protocols [47]. Most of these systems emphasize the importance of food in disease. In Ayurveda, for example, food is regarded as medicine itself [47]. These dimensions suggest that an exploration of the relationship between diet and diabetes in India must recognize these diverse viewpoints and conceptualizations.

Behavior Change for Health

Lifestyle modifications such as diet alterations entail adjustment of preferences and behaviors that are deeply entrenched in individuals' lives [5]. Adherence to recommendations regarding change of diet and lifestyle has thus been shown to be poor among diabetes patients [3, 40]. People newly diagnosed with diabetes may have difficulty adapting recommended behavior changes due to well-established habits, insufficient knowledge about healthy lifestyles, or lack of motivation [5]. Stress-related overeating, inability to resist unhealthy food, old age, and lower education levels have also been shown to relate to non-adherence [26, 36, 49].

Factors related to healthcare providers can often affect compliance with recommended behavior changes as well. Daly et al. [11] found that patients who reported better physician-patient communication had better blood glucose control. Nurse practitioners interviewed by Jansink et al. [26] reported that adherence can also be affected by healthcare providers' inadequate counseling skills or lack of time. Confusing vocabulary used by dieticians and doctors along with impractical suggestions regarding the quantity of diet also present challenges for PWDs [49] in following recommendations. In addition, it has been found that there is no consensus regarding dietary management in diabetes, and therefore advice from doctors is frequently inconsistent [46]. Hale et al. [22] conducted a study of guideline repositories, diabetes organization websites, and literature for protocols regarding treatment of diabetes. They observed that clinical practice recommendations were more patient-focused and consistent compared to nutrition-specific guidelines, which showed a high degree of inconsistency.

Care and social influences also play a critical role within the diabetes-affected household. Lack of family or social support can be a critical barrier to lifestyle changes for PWDs [2, 49], and social influence can be a key determiner of success in behavior change [28]. Therefore, members of the greater care network surrounding an individual must be taken into account when designing health applications and services promoting behavior change [10, 15, 39]. Abowd [1] describes how affected individuals are typically "considered the most important link in the care network" and usually serve as primary caregivers, but we seek to analyze how nuances in the Indian context challenge this notion. We aim to understand the larger environments in which people live and eat, and the collective needs and attitudes of all household actors involved in diet and disease management.

HCI for Diabetes and Chronic Disease Management

HCI research efforts have long explored chronic disease management, and have typically focused on analyzing and designing for settings in the Western world. Work on managing chronic conditions has investigated how people collect and make sense of data about their health-related behaviors, set health goals and track progress, and share health information via social networks. Projects in recent years have examined a range of topics, including routines and preferences around sharing chronic disease-related information with geographically distributed family members [42], web-based in-home treatment options for those without access to services in-person [48], ways to encourage increased physical activity to combat disease [9], as well as support for patients in self-management after being discharged from the hospital [43].

Within the realm of chronic disease management, HCI has recently seen a growing focus on diabetes in particular. Several themes have emerged from this body of work regarding the effective design of tools for individuals living with the disease. The work of Mamykina et al [34] and Mamykina and Mynatt [33] analyzes how people living with diabetes manage their health, highlighting the incessant struggle to find balance between short-term pleasures and long-term health goals. As individuals cater health management routines to their own unique conditions and circumstances, trial and error become an inherent part of coping with diabetes. A substantial part of this experimentation lies in critically reflecting on and analyzing one's experiences, "one of the most critical skills in the management of such diseases as diabetes" [32]. Self-reflection has thus evolved as a major component in many tools designed for people with the disease, serving as a mode of sense-making and a promoter of behavior change [8, 32, 33, 41]. Involving the family and/or broader care network in the reflective process has also been demonstrated to help people look beyond their biases [1] and create a shared memory of behaviors and routines [21].

In addition to their immediate circles, many people living with diabetes engage with communities on the web for information, advice, and support as they seek to manage their conditions and identities. The MAHI platform [31], for example, provides free-form inputs to individuals to help improve their disease management skills through rich expressions of identity that serve purposes beyond those that are purely utilitarian. Zhou et al. [50] analyze how a grassroots online diabetes forum in China called *Sweet Home* provides information and helps individuals to construct their identities, focusing on cultural factors that influence people's understanding and interactions. Beyond identity, Mamykina et al. [35] explore community engagement in "collective sensemaking" of health information contributed to online forums.

These and related works highlight several principles of design relevant to our analysis. Many articulate the need to explicitly connect information presented to individuals with outcomes related to behavior change efforts. Simply outputting or visualizing data without providing context and specific directions or action points does not effectively promote behavior change in most cases, as it may just reinforce existing biases or prove difficult to mentally process [27]. Others pinpoint the importance of intricately integrating conceptions of time into designs. Individuals with diabetes must constantly balance their immediate needs and desires with their long-term health goals, and should be able to reflect on their past successes and failures to consistently improve their self-management practices. Beyond incorporating factors related to short- and long-term considerations into designs, realistically evaluating a solution's effectiveness in behavior change requires analysis that takes place over a substantial period of time [28].

While some existing models of behavior change leveraged in HCI research such as the transtheoretical model [44] and self-efficacy theory [4] pose certain limitations related to measurement, fragmentation, and inability to account for a majority of variance in behavior change [23], frameworks such as BJ Fogg's functional triad [17] provide valuable foundations for analyzing persuasive technologies. We seek to extend these and related works on behavior change in HCI by taking the household rather than the individual as our unit of analysis. Given that food is frequently a family affair and not merely an individual activity in the Indian context, it becomes imperative for us to examine how food habits are adjusted and co-created in our target households.

METHODOLOGY

Our research, approved by our institutional review board, took place in three distinct phases that we categorize and describe below as (1) formative work, (2) semi-structured interviews, and (3) EatingRight, our design probe.

Formative Work

In October 2015, we attended a weekend-long hackathon in Hyderabad, India that included participants who worked across India and internationally on matters concerning diabetes management. To identify an area of need that could benefit from a technology-based solution in this domain, we were provided with a carefully researched list of challenges compiled by the organizers. Addressing diet management for those with an Indian palate and lifestyle was the challenge we decided to investigate. At the hackathon, we had the opportunity to do a rapid but extensive needs assessment of our problem space. We surveyed, brainstormed with, and sought feedback from 20-25 domain experts who were present, including endocrinologists, dietitians, physicians, and public health professionals. In November, we conducted a short survey with approximately 75 individuals with diabetes at an endocrinology clinic in Ahmedabad. The purpose of this survey was to gain a preliminary understanding of prevalent beliefs and practices regarding dietary guidelines and restrictions for those with diabetes. We used survey findings to design our interview approach for the next stage of data collection. In addition, the endocrinologist who has runs this clinic for more than 20 years gave us valuable inputs and feedback throughout our study.

Semi-Structured Interviews

The next stage of data collection began in May 2016 and involved 36 semi-structured interviews with individuals in diabetes-affected households. Interviews were conducted by four authors in five cities across India: Ahmedabad, Bangalore, New Delhi, Kolkata, and Ramagundam. We chose multiple cities in order to obtain a rich understanding of how food practices varied across the Indian geography. We chose these cities in particular because the authors collecting data had strong local ties and were able to gain access to households with relative ease. Within these cities, we recruited participants using a combination of purposive and snowball sampling [20]. We targeted PWDs from middle-class households; all participants were well-educated and reasonably familiar with technology. In India, households often include others beyond the immediate nuclear family, such as grandparents or adult siblings and their children. Since we wished to understand diet management behaviors and concerns in the context of household dynamics, we strongly encouraged the presence of other members of the household or larger care network of the PWD, including extended family and close friends. This was challenging to enforce for various unavoidable reasons; thus, on a few occasions, we only interviewed the PWD or caregiver. The details of our participants are indicated in Table 1. All interviews took place in person at participants' homes and lasted 45-60 minutes on average.

Though we made a concerted effort to achieve gender balance, 27 out of 36 PWDs in our sample were male. In one interview, a participant promised to introduce us to women in his apartment building who had diabetes, but after several follow-ups informed us that the women were simply not comfortable talking about their ailment. Many male participants were also of the view that it was mostly men who had diabetes. Since scientific data does not support this view, we conjectured that it was mainly because, culturally speaking, the women were not as open in talking about their condition.

In our interviews, we first asked participants more general questions, such as how they had discovered that they had diabetes, whether there was family history of the disease, what advice and recommendations they received from their doctors

to manage it, and what behavior change they had put into effect thus far. We then asked more focused questions around eating practices of the PWDs, their efforts to manage diet, and the role of their friends and family in supporting diet management. All interviews were audio-recorded, but because some took place at short notice or were in noisier settings, we also took extensive notes.

Our interviewing stage involved almost daily check-ins among authors to discuss findings, compare notes, and iterate on our interview protocol. Interview transcripts were translated to English (since they were otherwise in multiple different Indian languages) and analyzed along with our notes. We subjected our interview data to thematic analysis as outlined in [6]. This process was primarily driven by the first author, but all interviewers participated and we iterated through the findings as a group. Our coding entailed a rigorous categorization of data as we identified patterns and arrived at appropriate themes. We began with manually conducting open coding. First-level codes were carefully linked to our data, *e.g.,* "experimentation with dark chocolate," "thinks video is too long," and "tip learned from Facebook." After multiple rounds of coding, we condensed the codes into larger themes such as "trial and error" and "information-seeking practices."

EatingRight

Based on the data collected above, and in an effort to understand how technology could ease the challenges of diet management for diabetes-affected households by providing relevant, friendly, constructive, and medically correct recommendations, we designed a probe called *EatingRight* (see Fig. 1). Our process was highly iterative and began with the hackathon, evolving as we obtained insights, advice, and feedback from health and diet experts as well as our survey and interview participants. We developed *EatingRight* in the form of a mobile application prototype, with its interface centered around presenting users with new recipes appropriate for people with diabetes through videos featuring a dietitian, endocrinologist, and female chef. Five videos shot in the format of popular Indian cooking shows were factored into the design. Our goal was to target the "kitchen manager," most often the woman/women of the house, by delivering recipes that were diabetes-friendly and tasty (unlike doctors' usual suggestions) in a format that was familiar and engaging. EatingRight was chiefly used in our interviews to determine participants' level of interest in learning new recipes through the mobile medium and glean what nature of content is seen as most beneficial. It provided an opening for discussions regarding who is seen as a credible source, how willing people are to experiment with new recipes in their families, and what formats and channels they prefer to use for finding and sharing information related to diets for people with diabetes. This exercise allowed us to make more effective design recommendations, as outlined in our discussion section.

Researcher Backgrounds and Biases

We are a team of six researchers, coming from a combination of backgrounds. Five have background and training in HCI, two are designers, and two have researched public health concerns in India for a sum total of 13 years. Four of us are

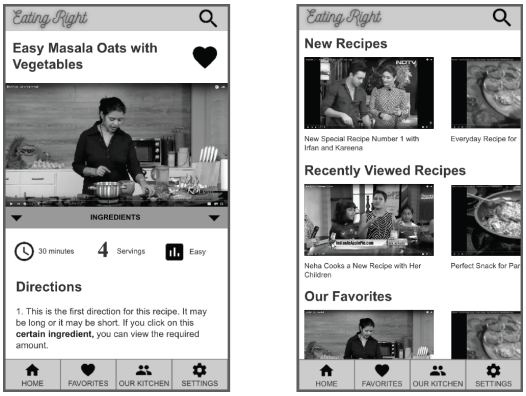


Figure 1. An early iteration of EatingRight

of Indian origin while a fifth has done fieldwork in India. All interviews were conducted in languages that respondents (and interviewers) were fluent and comfortable in, including Hindi, Kannada, English, Gujarati, Bengali, and Telugu. We acknowledge that while it was helpful that we were intimately familiar with Indian culture and the diverse health and medical practices it engenders, this may also have introduced a biased perspective and we ask that our paper be read as such. In addition, we clarify that although we heard many different approaches to health and medicine, we are not equipped to and have no desire to take a correctness stand regarding any of the "cures" and/or "treatments" shared by our participants.

FINDINGS

We now present our findings with particular attention to how PWDs learn about "eating right" for diabetes, the roles played by different members of their immediate social networks in this regard, and how they put changes into effect.

Learning to "Eat Right" for Diabetes

Our interviews indicated that the ways in which participants learned about diabetes and the recommended changes to diets were multiple and diverse. We lay them out below, highlighting the roles that "ambient" knowledge, trusted doctors, family and friends, and additional sources played in generating their understanding of the ailment.

"Ambient" Knowledge

Most participants were familiar with the disease long before being diagnosed with it. One man explained:

> *"My father, his father, his father's father, my uncle, his older brother, everyone has had diabetes. So I knew I was also going to get it."* – P23

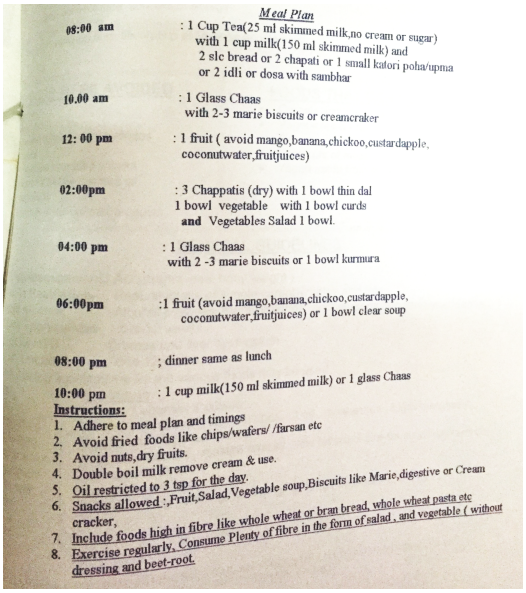
Like in P23's case, many participants were already familiar with the lifestyle recommended by doctors because they had seen a parent, sibling, or other extended family member grapple with the disease. This also meant that they considered themselves to be equipped with necessary knowledge regarding the ailment, without having made an active effort to seek this out.

Household	Location	Years with Diabetes	Present in Interview
1	Ahmedabad	1.5	PWD
2	Ahmedabad	7	PWD, wife
3	Ahmedabad	7	PWD, wife
4	Ahmedabad	5	PWD, daughter
5	Ahmedabad	12	PWD, father
6	Ahmedabad	14	son, daughter-in-law
7	Ahmedabad	4	PWD, husband
8	Ahmedabad	16	son
9	Bangalore	15	PWD, wife, daughter
10	Bangalore	10	PWD, wife
11	Bangalore	5	PWD, wife
12	Bangalore	15	PWD, wife
13	Bangalore	30	PWD
14	Bangalore	2	PWD, wife
15	Bangalore	12	PWD, wife
16	Bangalore	23	PWD, wife
17	Bangalore	22	PWD
18	Bangalore	8	son, daughter-in-law
19	Delhi	6	PWD
20	Delhi	29	PWD, wife, 2 friends
21	Delhi	18	PWD, wife, daughter, cousin
22	Delhi	7	PWD, extended family
23	Delhi	15	PWD, close friends
24	Delhi	3	PWD, close friends
25	Delhi	8	PWD, family
26	Delhi	2	PWD, family
27	Delhi	6	PWD, husband
28	Kolkata	10-15	PWD, family
29	Kolkata	8	PWD, friends
30	Kolkata	10-15	PWD, friends
31	Ramagundam	8	PWD, husband
32	Ramagundam	10	PWD, wife
33	Ramagundam	9	PWD
34	Ramagundam	15	son, daughter-in-law
35	Ramagundam	9	PWD, wife
36	Ramagundam	18	PWD, wife

Table 1. Participant Demographics

"Less of this, less of that"

On first being diagnosed, PWDs are given a diet chart from their doctors (as seen in Fig. 2). Doctors serve as an important, credible, and trusted source about good food habits, particularly for newly diagnosed patients. While the doctor's advice was generally taken to heart, it was also viewed by participants as being impossible to follow. As shown in the chart above, doctors list out meal times and options that are starkly divergent from patients' existing dietary regimens. This contrast is sufficient to deter many from making concerted efforts towards changing their diet. Further, advice from doctors tends to place emphasis on foods to avoid rather than foods to include in one's diet. Our participants complained that the doctor's advice was always in the form of "less of this, less of that" as opposed to "do this" or "do more of that." This may be especially relevant in the Indian context where the food has a high proportion of carbohydrates and sweets, which are particularly diabetes-unfriendly. One PWD remarked:


Meal Plan

08:00 am : 1 Cup Tea(25 ml skimmed milk,no cream or sugar) with 1 cup milk(150 ml skimmed milk) and 2 slc bread or 2 chapati or 1 small katori poha/upma or 2 idli or dosa with sambhar

10.00 am : 1 Glass Chaas with 2-3 marie biscuits or creamcraker

12: 00 pm : 1 fruit (avoid mango,banana,chickoo,custardapple, coconutwater,fruitjuices)

02:00pm : 3 Chappatis (dry) with 1 bowl thin dal 1 bowl vegetable with 1 bowl curds and Vegetables Salad 1 bowl.

04:00 pm : 1 Glass Chaas with 2 -3 marie biscuits or 1 bowl kurmura

06:00pm :1 fruit (avoid mango,banana,chickoo,custardapple, coconutwater,fruitjuices) or 1 bowl clear soup

08:00 pm ; dinner same as lunch

10:00 pm : 1 cup milk(150 ml skimmed milk) or 1 glass Chaas

Instructions:
1. Adhere to meal plan and timings
2. Avoid fried foods like chips/wafers/ /farsan etc
3. Avoid nuts,dry fruits.
4. Double boil milk remove cream & use.
5. Oil restricted to 3 tsp for the day.
6. Snacks allowed :,Fruit,Salad,Vegetable soup,Biscuits like Marie,digestive or Cream cracker,
7. Include foods high in fibre like whole wheat or bran bread, whole wheat pasta etc
8. Exercise regularly, Consume Plenty of fibre in the form of salad , and vegetable (without dressing and beet-root.

Figure 2. A recommended diabetes-friendly diet regimen

> *"My doctor emphasizes on what not to eat such as extra sugar, sweet dishes, ice creams, colas…"* – P21

Accurate and fitting as these recommendations may be, they leave patients at a loss for changes they feel they can realistically introduce into their diets. Beyond recommendations being seen as overly idealistic, patients only touch base with their doctors at the time of diagnosis and at checkups that happen once every several months at most for a majority. Conversations with doctors only take place in person as far as we could tell, so their suggestions are not reinforced on a consistent or regular basis.

"I saw it on the Facebook"

Far more frequently than with doctors, information exchanges take place with family members, friends, and wider social circles through in-person conversations or via mobile communication applications such as WhatsApp. Information is also encountered on television, social media platforms, and other web-based sources. Face-to-face discussions we observed were invariably centered around food, whether with friends, family members, or extended social networks. Participants related to foods in ways that demonstrated their love for eating and experimenting, even outside of the constraints of diabetes.

We did not find that our participants made particular efforts to search for diabetes-related information, but several mentioned that they had encountered relevant advice on social media that had piqued their curiosity (see Fig. 3). For example, when asked about dietary changes, one participant shared that she had started using *vijaysaar* (a tree). She would soak pieces of the vijaysaar bark overnight and in the morning drink the water in which it soaked. She followed this practice daily, and over time felt it had improved her diabetes. When we asked how she had learned to do this, she responded:

Figure 3. Image forwarded through WhatsApp

"I saw it on the Facebook." – P27

Images, videos, and messages received via social media appeared to be willingly embraced and adopted. Our participants felt that if this information was being circulated so widely, there must be a modicum of truth to it. Since our participants were generally older, virality and social media are still somewhat novel for them, and this may be why they were more receptive to these "forwards" than younger users more adept at social networking might be. We also witnessed a pervasive culture of relying on and turning to alternative and/or home remedies for health, which we touch upon next.

Alternative Remedies

Unlike most Western contexts, India has a rich tradition of folklore and Complementary and Alternative Medicine (CAM) related to diseases and their management, such as Ayurveda and Naturopathy [47]. We found our participants to be most willing to embrace knowledge about food based on these forms of CAM. One reason often cited was that allopathic forms of therapy would entail lifelong treatment through pills/injections without any possibility of cure. CAM, on the other hand, presented no known side effects and was, in fact, a familiar and trusted alternative. One PWD emphasized:

> *"I was advised to have soaked fenugreek seeds every morning on an empty stomach to control diabetes. These home remedies are very effective. Most important, they don't have any side effects like the English medicines."* – P27

There was a resounding sense that, as long as there is no harm, it is okay and even advisable to try home remedies. One PWD shared that four years ago, his friend had suggested he go to a healer in Delhi who prescribed "drops" for PWDs. When we asked what kind of drops they were, he said:

> *"I asked him what was in the drops. He did not tell me. He said, 'if you want them take them otherwise don't.' I did not have any better options at my disposal, so I did."* – P20

We heard several stories such as this, illustrating the willingness of participants to adopt unknown and unfamiliar remedies even if they could not fully understand them.

The examples above and several others we heard naturally raise the question of credibility; that is, when can advice received from non-experts be relied upon? We found that our participants ascribed high credibility to a variety of information sources other than doctors. Although doctors may be considered the final authorities on disease-related matters, participants were also influenced by the prospect of having to swallow pills for life. One endocrinologist we spoke with during our formative research described the challenge of communicating with patients who regularly consult a multitude of information sources with varying credibility:

> *"Many times, patients come with typical queries. Can diabetes be cured with bitter gourd? Some of these remedies have scientific basis and have been proven as agents for enhancing control, but they perceive that these are curing agents. On the other hand, some patients will come with weird solutions like eating rotten tomatoes. It is a task to convince them that not all messages are reliable."* – Endocrinologist (Ahmedabad)

Participants asserted that remedies stemming from CAM sources rarely come from doctors; rather, they are learned primarily through family, friends, and broader social networks. While some participants expressed slight disavowal towards Ayurvedic medicine, citing unreliability of results and slow speed of effectiveness, many more conveyed doubts about the effectiveness of allopathy. Most participants expressed great optimism that Ayurvedic solutions and home remedies can improve or cure their disease, even if the information comes from unknown sources or is somewhat eccentric. One couple described the husband's endeavor to seek out organic chickens with *pittha* (a black growth on the liver) that is said to stop diabetes if eaten by the affected person:

> *Wife: "He's gone to his village and tried with about 10 chickens!"*
>
> *Husband: "I never found one with the black spot. You get it in those fighter cocks… you have to swallow that part… if you take that every 6 months thrice, it's supposedly enough and it stops the disease altogether."* –H12

The husband has not yet found an instance of this black spot, but was adamant to continue his search.

Do Videos Work?

By employing the *EatingRight* mobile application prototype in our interviews, we were able to investigate questions around how people consume and share information related to diabetes management and whether videos are effective for disseminating this. We quickly learned that men did not find the idea of cooking videos engaging at all, not contrary to what we expected. Many women we spoke with watched cooking shows on television, but did so more out of curiosity or for entertainment than a desire to try the recipes they saw. They explained that most recipes from the shows are hard to remember, too complicated, and too divergent from normal

meal routines to be worth trying. When these women viewed the 5 to 7 minute long *EatingRight* videos they would be engaged at first but soon lose interest. Feedback indicated that the videos were too long and the recipes were good but did not generate enough interest.

Challenges Within and Outside the Home

Within our sample, the special needs of people with diabetes typically permeate dietary practices at the household level. This was an initial insight that led to a more elaborate focus on our part, also deciding our interview strategy to examine households and not individuals alone. As a result, we were able to perceive the care and attention that goes into home-cooked meals for those with diabetes. We also repeatedly heard how eating meals outside of the home exponentially increases the complexity of managing one's diet and sticking to a regimen of any kind. Dishes specifically catered to people with diabetes are likely to be scarce or unavailable in most cases, and avoiding the temptation to eat "forbidden foods" proves tremendously difficult for most PWDs.

Gender and Kitchen Management

The Indian diet consists largely of meals eaten at home, most often prepared by a woman, typically the wife or daughter-in-law of the house. Consequently, a woman may control the diet of everyone in the household a majority of the time. Even if a husband, child, father-in-law, or some other member of the household has the disease but she does not, the woman managing the kitchen often actively seeks out information about appropriate foods and implementing changes in the family's meals through in-person conversations and various digital channels. In one interview, the wife and caretaker of a PWD spoke of a female friend of hers whose husband had diabetes. This friend, as she said, cooked special diabetes-friendly meals for her husband on a daily basis. She went on to explain:

> *"She is not very educated, you see, so she mostly busies herself with cooking."* – C20

Gender roles are deeply entrenched and we found that diet management becomes a family affair, involving more than just the individual with the disease. This contrasts with contexts where an individual with diabetes may be solely responsible for his/her dietary intake and handles meals more independently. The care network immediately becomes relevant, with family members and friends playing a key role.

Although kitchen managers regularly go out of their way to learn about appropriate food preparations for PWDs, advice given to diabetes patients by doctors occurs in a clinical setup where the doctor and patient interact with each other on a one-on-one basis. In many cases, this leaves the woman who controls the kitchen out of the conversation when she is not the PWD. As one male participant remarked:

> *"I go to the physician who tells me about the dietary modifications... No special counseling is given to my wife, who controls the food and kitchen in my house."* – P22

In almost all households we interacted with, taking steps to consciously control diabetes is a process taken on by a husband and wife together when it is the male member with the disease. However, when the woman herself had diabetes, she would manage it on her own without directly seeking help from her husband or others at home. In our interview with H28, we asked the husband of the woman with diabetes whether he knew what his wife ate daily. He immediately responded by saying that she knew what she was doing and did not need him to *"interfere."*

Balancing Household Needs and Preferences

Mealtime for diabetes-affected households can quickly become a balancing act. We found that most households sit down to eat their meals together and share the same dishes, so foods are rarely prepared separately for the person with diabetes. Beyond consciously preparing appropriate meals and adjusting amounts of specific ingredients such as salt, kitchen managers strive to keep food preferences of the whole family in mind. Attempting to entirely omit ingredients like rice that are staples of the diet in many regions in India can prove to be not just difficult but nearly impossible, since family members have been accustomed to eating these regularly over the course of their entire lives. Some participants claimed their families were entirely averse to trying new meals or even new mealtimes (because they were so aligned with television-watching schedules), making the risk of such attempts essentially not worthy of the effort required. We found this often led to experimentation with small substitutions of particular ingredients or cooking familiar ingredients in new ways to maintain variety in meals.

Social Occasions

During social occasions outside the home, all bets are off about what food might be available in any given situation. In India, it is generally considered downright impolite to turn down more helpings of food or decline when offered dessert. Many interviewees mentioned the intense social pressure they face during social occasions to eat sweets or consume larger portions than they would at home. The PWD from H22 shared that because it was *shaadi* season (the season for weddings), it had become impossible to control his meals. Another brought religion into the conversation, describing a time someone had brought him *prasad* (a religious offering in the form of a sweet) from the temple:

> *"When you say something is prasad (blessing from god) can you not have? They'll get one laddoo from Tirupati... can I not eat that?"* – P12

Participants expressed how this added layer of social pressures often far outweighs the benefits of controlling one's diet in such situations, and leads most of them to indulge even when they know they should not.

Atithi Devo Bhava or "Guest is God"

In addition to challenges with meals outside of the home, we found that similar constraints arise when families host visitors in their homes. In India, where "the guest is god," food is an integral part of showing hospitality and a special meal is often prepared for visitors. Sweets are an essential part of an

Indian meal, and the eating experience is said to be complete if it ends with a sweet or dessert. The post-meal sweet is, therefore, especially important for demonstrating hospitality. Participants explained how social pressures and reduced control over avoiding temptation again come into play in these scenarios. After the interview in H21, the participants insisted that the author stay for dinner. The male PWD shared that he was happy she had done so, because it meant he would get to partake of the fancier food items as well.

Striving for Control

While practices around managing diabetes are influenced by the larger context in which they exist, the disease is physically only experienced by the individual. One caregiver said:

> *"Only the one with the sugar (diabetes) can understand what is happening to them."* – C15

This highlights the extent of self-awareness, self-monitoring, and self-control required to manage the disease. Participants shared that they had become so attuned to their body that they knew when their sugar levels were high and needed attention. One PWD mentioned that every time she developed a skin rash, it was because of high sugar. Thus we note that both group and individual perspectives are critical to consider.

Trial and Error with Food

Effecting a balance between food, exercise, and medicine presents an endless challenge for any diabetes-affected household, regardless of context. In India, where home-cooked meals are an integral part of everyday life, diet management is especially challenging. Participants explained how altering a family's diet to address the needs of a PWD is typically done by controlling the ingredients used in meals, the quantities of food consumed, and the frequency with which meals take place. Households tended to skew more towards substituting ingredients or making minor alterations to dishes they are used to consuming instead of seeking out entirely new recipes to try. We found some families to have a higher tolerance for experimenting with new recipes, but need several factors to come together: open-mindedness on part of all members of the household to try something new, willpower of the person managing the kitchen to learn and attempt a new recipe, and procurement of possibly unfamiliar ingredients.

While PWDs expressed great reverence for medical professionals, most also cited difficulties in following their advice. Some people expressed an interest in learning through experimentation what helps or does not help in controlling their sugar levels. P26, for example, shared that he had conducted a two-week long experiment last year. In one week, he ate a piece of dark chocolate daily and measured his sugar levels at the end of the week. In the next week, he did not eat this dark chocolate and measured sugar levels at the week's end. He concluded that dark chocolate helped his diabetes, the hypothesis he was out to test, and this led him to eat dark chocolate without guilt thereafter.

In general, participants found it hard to give up their favorite foods, even if they understand the risks. One participant explained how he had just returned to Delhi from his home town, Varanasi. Since it was mango season, there was a particular kind of sweet made of mango and cream that he could not possibly miss out on. He ate several sweets a day, and described the effects upon his return home to Delhi:

> *"I was in terrible shape. It took me three days to recover. And for those three days, I just did not know what to do with myself. But now I am fine. . . ."* – P21

This pattern of "crime and punishment" [16] was common across the board. Participants would indulge and then roll back their diet for a few days until they found an opportunity to indulge again. Cutting back on ingredients, or eliminating foods from their diet altogether, was difficult. Most Indian dishes made at home use one or more staple grains, vegetables, and spices. In South India, for example, rice is a staple food present in meals served throughout the day. Asking a resident of this region who is accustomed to eating rice every day to simply cut it out of his or her diet is no simple request. Instead, we found that people seek to lessen their consumption of foods they know to be detrimental for their health.

Participants mentioned cutting back quantities of rice they ate or attempting to stop eating it altogether by replacing it with alternative grain-based foods such as *roti* (whole wheat flat bread), *ragi* (finger millet), *idli* (fermented lentil and rice cakes), *dosa* (fermented lentil and rice pancakes), *bajra* (pearl millet), or *rava* (semolina). They discussed consuming less sweets, fruits, spice, meats, and oily/deep fried foods. Some described a need to increase their intake of vegetables and greens, particularly bitter gourd, slimy greens, and fenugreek greens. Participants also claimed they were better able to control sugar levels by eating less frequently and less overall.

'Fixing' Indulgence with Other Forms of Control

Those dealing with diabetes must find ways to balance their desires for certain foods with their health requirements, and often press their limits in doing so. We found that as people gain more experience experimenting with combinations of food, medicine, and exercise, they become more in tune with how to stabilize their condition after making dietary choices that are not ideal. One PWD described:

> *"If you increase your activity and you eat then it is not a problem. If activity is less, you should not eat."* – P9

Overall, there was a general sense that one must never completely give up foods that bring great happiness and satisfaction, but instead manage consumption and restore balance when lines are crossed. Beyond managing food intake, participants widely claimed to control their diabetes through exercise. Walking was brought up in nearly every interview as a critical method of control. Some claimed walking after a meal would counteract the effects of bad dietary choices and stabilize their condition. In addition to controlling food and walking, managing stress–typically referred to as "tension" in India–was also seen as critical. One couple explained:

> *"You shouldn't take it too seriously. . . if you do dieting and all that you will become weak. . . then your diseases will increase. Just be tension free."* – P10

The relationship between tension and *sugar*–a term often used in India instead of diabetes–was mentioned by several participants, some of whom believed that they had contracted diabetes because of stress that they suffered on account of their jobs. One participant explained:

"If you get tension, you get sugar." – P9

Participants hinted at a balance between exercising great control over their habits and keeping a relaxed attitude for fear of exacerbating the effects of the disease. They expressed concern that being too worrisome or neurotic would increase stress and and make their sugar levels even harder to control.

DISCUSSION

Having studied diets and eating behaviors of middle-income diabetes-affected urban Indian households, we now discuss takeaways from our findings. To understand how the beast of diet management might be addressed, we highlight factors to be considered in designing technology for this goal. Our analysis drove the creation of a framework centered on three important aspects that must be addressed for a holistic approach: *Learning* factors, how one seeks and gains information regarding diet management; *Being* factors, how one is situated within his or her surroundings (such as one's household, family, and friends); and *Doing* factors, how one is willing and able to take action. We elaborate on these below.

Learning

To understand *learning* is to understand the different sources individuals and caregivers are willing and able to turn to for information and their receptivity towards varied sources. Doctors might be the trusted, authoritative figures we expect to view them as, and they may be the ones our participants turned to if they were in discomfort or unease. However, the day-to-day routines recommended by doctors were considered by participants to be impractical and unrealistic. Doctors provide dietary advice to patients in a clinical setup and specifically address the patient rather than the person who controls the kitchen, mostly the woman of the house. Furthermore, the advice emphasizes strict "don'ts" and avoiding high carbohydrate foods which are normally abundant in the Indian diet. Following a regimented lifestyle appeared too challenging, except for one participant who said he was okay with strict regimens probably because he had been in the army.

More than doctors' advice, participants relied on "ambient" knowledge, or the knowledge that "everyone" had, shared, and disseminated. These real-life behavior patterns found their way onto social media behaviors as well, as participants reported that their friends, family, and broader networks "knew" how to deal with diabetes, and generously shared and disseminated new tips and tricks they came across using WhatsApp and Facebook. To receive this information, participants neither had to look hard for it, nor engage very deeply with it. Photos, images, and even short videos were viewed and assimilated without much reflection. It was the introduction of our 5-7 minute videos to participants, in fact, that made them visibly uncomfortable.

Finally, the openness to alternative remedies or CAM also conditioned participants to be accepting of information from varied sources. While this may be particular to India, it is worthwhile to consider what kinds of information are viewed as meaningful and/or acceptable and why others are rejected or overlooked. This proposed focus on how learning takes place also draws on insights from Lave and Wenger, who emphasize the importance of situatedness [29].

Being

The *being* aspect of our framework alludes to the ways in which people and their behaviors are shaped by their intimate surroundings and beyond. By taking the household as our unit of analysis, we learned that disease in the context of our study was not managed solely by an individual. It was a collective effort, with the spouse, children, children-in-law, and even neighbors contributing to the management of this disease. Participants were often able to follow their diet plan because their spouse assisted them in doing so. Alternatively, they were sometimes unable to stick to their regimen because they found themselves in unfamiliar surroundings where this care was missing, such as in their daughter's home, where the spouse would focus on cooking for the daughter and son-in-law instead of the husband with diabetes.

Gender roles are important to consider when examining social contexts, especially in our scenario where it is considered understandable that women who are not very educated like to cook for those around them. More holistically, however, we might consider what care networks look like and how power relationships are negotiated to influence the lifestyle and disease management behavior of the one with the disease.

Doing

As highlighted above, our first observation with regards to *doing* was that our participants found it difficult to *not* do. In the doctor's chart we shared, there were more "don'ts" than "dos". We also heard from most participants that a doctor's advice is structured more around what is *not* recommended rather than what *is* recommended. Participants were looking to find constructive suggestions for steps they could take, and not doing something did not seem like solution enough. This meant that they were very willing to try out new things, as long as they did not view it as potentially harmful. The high reliance on CAM and on folklore was instrumental in the trial and error behavior adopted by the patients. We also found that participants were very open to self-experimentation, trying different things to figure out what would reduce their sugar levels even if doctors said that there were no cures for the disease. Additionally, "bad" behavior with respect to food consumption was frequently balanced by "good" behavior elsewhere. Trying to understand these mental checks and balances and how they manifest should be a critical aspect of designing for contexts like those we studied.

Implications for Design

Based on the *Learning-Being-Doing* framework, we make recommendations for designing technologies for engaging diabetes-affected Indian households in diet management.

Towards Informed Decision-Making

Our analysis indicated that members of diabetes-affected households in India seek out and receive information about the disease from numerous sources but often have limited insight into its credibility. While recommendations from health care professionals are always taken as medically sound, fear of adverse side affects and the necessity of sticking to a strict regimen makes some hesitant to follow the advice. On the other hand, CAM approaches are viewed as more innocuous to adopt, but inspire less confidence than hope regarding the results. Designers of technologies that present patients with dietary recommendations could consider integrating indicators of credibility such as "stamps of approval" from medical professionals, reviews from patients who have tried a particular approach, or testimonials from well-known figures. We could further support members of these households in effectively evaluating treatment options from diverse schools of thought by providing socially sourced information regarding potential side effects, perceived effectiveness, how a treatment was derived, combinations with other treatments, or limitations for certain groups (*e.g.,* pregnant women).

Towards Holistic Understandings

The immense influence gender and family roles have on disease management in this context came up repeatedly in our analysis. Established gender roles mean that women, while subject to patriarchal pressures, also control the household diet and prepare foods for the family members with diabetes. This tension between agency and patriarchy that our research uncovered deserves greater attention. Information disconnects often arise in cases where the patient is not the kitchen manager, as generally only the patient is present when medical professionals provide dietary advice. Designers can facilitate better joint decision-making around meals by creating systems where these kitchen managers can more easily access dietary information provided to patients by doctors. Because the needs of the PWD typically permeate household dietary practices, we can also support kitchen managers by creating technologies that help them balance these needs with preferences of all their family members. Technologies might facilitate group communication about food choices or consider providing ideas or recommendations in a range of formats preferred by cooks and caregivers.

Towards Actionable Recommendations

To be seen as plausible alternatives to current options and deemed worth sharing on their social networks, participants described how dietary recommendations must be easy to implement in their family's everyday life. A majority were open to experimentation, but primarily interested in tweaking familiar dishes or substituting certain ingredients rather than attempting to try entirely new recipes. We propose that designers focus on helping people make small changes rather than overhauling their recipe repertoires. Beyond promoting simple, easy to remember, and regionally-specific content, mobile application or web-based interfaces might do this by integrating refined functionality for searching, sorting, or filtering by ingredients or geographical regions, helping users explore and analyze appropriate substitutions for ingredients in a robust manner, or supporting discussion among users about how to tweak and personalize dishes. Most importantly, designers should prioritize presenting recommendations in a highly adaptable format over providing a larger quantity of them.

We could also contribute to positive dietary changes by supporting the practice of "checks and balances" that many participants described as part of their daily decision-making. Patients who have significant experience living with the disease gradually become more adept at restoring balance to their condition through medicine, exercise, or other foods after consciously making detrimental dietary choices. Technologies we design for newly-diagnosed patients, in particular, could promote more rapid acquisition of these skills by visualizing which approaches help them achieve their desired balance in the healthiest way and suggesting similar alternatives that they might try.

Limitations and Directions for Future Work

Our work presents a first look into behaviors associated with diet management for diabetes in an urban Indian context. Our sample was limited to middle-income households and did not include enough women with diabetes. Future work could examine the challenges of addressing diet management across diverse socioeconomic strata and among women with the ailment. Although our research offers a deeper understanding of the different information sources that PWDs and caregivers rely on, future work might also examine which sources are more successful in effecting behavior change and/or which result in greater spread. Lessons learned from EatingRight could be leveraged towards further pursuit of technology design for diet management. Finally, our research finds that in the Indian context where health infrastructures may be underequipped to ensure chronic disease management, care networks are rich and could be examined and leveraged suitably for other ailments as well.

CONCLUSION

We investigated the ways in which middle-class diabetes-affected households in urban India experiment with and adopt certain dietary practices to manage the disease. Our research highlights nuances in information-seeking behaviors and challenges to diet management specific to the Indian context. We present a framework of *Learning-Being-Doing* to highlight important contextual factors that should be considered when taking a holistic approach to designing tools for diet management for diabetes. Finally, we discuss design guidelines for future applications intended to support households dealing with diabetes management.

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