

# Cultural and Family Challenges to Managing Type 2 Diabetes in Immigrant Chinese Americans

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**OBJECTIVE** — Although Asians demonstrate elevated levels of type 2 diabetes, little attention has been directed to their unique cultural beliefs and practices regarding diabetes. We describe cultural and family challenges to illness management in foreign-born Chinese American patients with type 2 diabetes and their spouses.

**RESEARCH DESIGN AND METHODS** — This was an interpretive comparative interview study with 20 foreign-born Chinese American couples ( $n = 40$ ) living with type 2 diabetes. Multiple (six to seven) semistructured interviews with each couple in individual, group, and couple settings elicited beliefs about diabetes and narratives of care within the family and community. Interpretive narrative and thematic analysis were completed. A separate respondent group of 19 patients and spouses who met the inclusion criteria reviewed and confirmed the themes developed from the initial couples.

**RESULTS** — Cultural and family challenges to diabetes management within foreign-born Chinese American families included how 1) diabetes symptoms challenged family harmony, 2) dietary prescriptions challenged food beliefs and practices, and 3) disease management requirements challenged established family role responsibilities.

**CONCLUSIONS** — Culturally nuanced care with immigrant Chinese Americans requires attentiveness to the social context of disease management. Patients' and families' disease management decisions are seldom made independent of their concerns for family well-being, family face, and the reciprocal responsibilities required by varied family roles. Framing disease recommendations to include cultural concerns for balance and significant food rituals are warranted.

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Increases in prevalence of type 2 diabetes in the U.S. are apparent in every age, sex, race, and socioeconomic group but are greatest in ethnic minorities (1). The prevalence of diabetes is also increasing in Asian and Pacific Islanders, who may comprise half the 300 million total cases anticipated worldwide by 2025, principally because of increased prevalence in India and China (2). Chinese Americans, the largest U.S. Asian ethnic group, are less likely to be obese than European Americans yet suffer up to twice the rate of impaired glucose tolerance and diabetes (2,3).

Asian Americans are among the fastest growing immigrant groups, with a growth rate of 48% from 1990 to 2000, outpacing the overall U.S. growth rate of 13% (4). Despite significant growth in numbers of Asian Americans and their exposure to acculturation and economic stressors, little data exists on their health practices. Descriptive research on ethnic health disparities has infrequently focused on Asian Americans, and intervention trials to improve health disparities in Asians are disproportionately few considering their numbers and demonstrated need (5). Although Asians comprise an

extremely diverse cultural group, research specific to cultural subgroups, such as Chinese Americans, is even less available.

The problem to be addressed is how cultural and family contextual issues make care of type 2 diabetes in immigrant Chinese unique or challenging. Available literature suggests the following. First, barriers to health care for Asians include language barriers, lack of provider awareness of cultural health preferences, and lack of culturally adapted programs (6). Health disparities in diabetes knowledge and glucose regulation due to language barriers have been noted in Chinese-specific samples (7). Second, family roles and relationships in type 2 diabetes are increasingly recognized as vital to effective management and quality of life (8,9). Family support, intimacy, relationship satisfaction (10), coherence beliefs, and conflict management (11,12) even in Chinese samples (13) have proven important to disease outcomes. Third, family relationships are likely more vital for Chinese Americans compared with European Americans because of a collectivistic social orientation and interdependent view of self (14). Well-being and stability of the family is often more highly esteemed than the well-being of the individual; family obligations and responsibilities similarly prevail over individual needs and wishes (14,15).

However, with few exceptions (16,17), detailed information on how Chinese couples and families adapt diabetes management to their cultural beliefs and background values is lacking. The aim of this article is to detail the cultural and family challenges to illness management identified by foreign-born Chinese American patients with type 2 diabetes and their spouses. Narratives of everyday disease management challenges noted by participants were analyzed for cultural themes. Articulating these challenges enables cultural adaptations of clinical approaches with this immigrant group.

## RESEARCH DESIGN AND METHODS

This was an interpretive comparative interview study with 20

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foreign-born Chinese American couples ( $n = 40$ ), in which one member was diagnosed with type 2 diabetes. Inclusion criteria included having a diabetes diagnosis for at least 1 year, being aged 35–75 years, having been married for a minimum of 1 year, self-identifying as Chinese American or Chinese, having immigrated to the U.S. from mainland China or Hong Kong, and having a spouse who would agree to participate. Exclusion criteria for patients included major diabetes complications (cerebrovascular accident or myocardial infarction within the last 12 months; proliferative retinopathy; renal insufficiency; or amputations) because our intent was to study patients who were early enough in the disease to benefit from behavioral and family interventions. A convenience sample was recruited from community clinics, community service organizations, and via public notices. Six semistructured interviews with couples in individual, couple, and group contexts focused on illness understandings, perceptions of diabetes care, acculturation histories, and concrete positive, negative, and memorable narratives of diabetes care. Couples narrated in each other's presence (two couple interviews) and in group interviews with those who shared their experience as a patient (two group interviews) or spouse (two group interviews). A subset of participants ( $n = 13$ ) was also interviewed individually if extra time was needed to complete interview questions or if nondisclosure in shared interview settings suggested that a private interview would yield more complete data. Interviews were conducted in Cantonese, and audiotaped text was simultaneously translated from Cantonese to English and transcribed verbatim by skilled bilingual staff. Each audiofile was then reviewed and checked for accuracy by a separate bilingual bicultural staff member who had conducted the interview.

Narrative and thematic analyses were conducted by a multicultural and multidisciplinary team of Chinese American and Caucasian nurses and psychologists (18,19). After all text was coded for thematic codes in Atlas-ti, codes were selected for review that identified challenging situations in diabetes management by patients and spouses. Complete text from three codes was examined: couple dynamics, conflict, and diabetes management. Both reflective discussions and narratives of positive, difficult, and meaningful aspects of care were analyzed. The

analyzed text comprised >450 pages of extracted text and represented a broad inclusive portion of narratives that were drawn from interviews conducted in all three contexts (couple, group, and individual interviews). Simultaneous to this thematic analysis, summaries for each couple were also constructed. Thus, text for this manuscript was analyzed in the context of the holistic analysis of each couple's dynamics.

To address generalizability, findings were presented to separate respondent groups of patients and spouses who met the same inclusion criteria as the original sample. Respondents ( $n = 19$ ) met in groups of patients or spouses for two separate 2-h interviews. They were asked to review themes presented in this manuscript for adequacy and to add personal variations to the presented themes.

**RESULTS**— The sample of informants was 20 foreign-born Chinese American couples ( $n = 40$ ), with one member with diabetes. On average, informants were (means  $\pm$  SD) age  $62 \pm 9.2$  years, married for  $34 \pm 13.4$  years, and had immigrated to the U.S.  $15 \pm 13.4$  years ago from mainland China (55%) or Hong Kong (45%). Patients were 40% male, had been diagnosed  $8.4 \pm 5.9$  years, were treated primarily with oral medications (85%), and had an average A1C of  $6.93 \pm 0.96\%$ .

Members of the respondent group ( $n = 19$ ; 13 patients, 6 spouses) representing 16 separate families were similar to the informant group on all measures. They were on average aged  $60 \pm 9.4$  years, married for  $32 \pm 12.1$  years, and had immigrated to the U.S.  $11.8 \pm 12$  years ago from mainland China (46%) and Hong Kong (54%). Patients in the respondent group were 54% male, had been diagnosed  $6.2 \pm 4.2$  years, and all were treated with oral medications; A1C was not collected with respondent group participants.

Cultural and family challenges to diabetes management within foreign-born Chinese American families included how 1) diabetes symptoms challenged family harmony, 2) dietary prescriptions challenged food beliefs and practices, and 3) disease management requirements challenged established family role responsibilities. Each theme is examined in depth with supportive text. In reporting findings, statements made by patients or spouses are identified as such, and state-

ments endorsed by both groups are identified as "participant" statements.

### Symptoms challenged family harmony

Increased irritability as a symptom of diabetes was frequently described as a challenge to family harmony. Participants noted that patients "get angry easily" and "easily throw a temper tantrum" particularly when their blood glucose was high. Emotional variability held particular resonance for Chinese immigrants because social ease, avoidance of overt expression of strong negative emotions, and accommodation of family members' expressed and unexpressed needs were culturally valued. Emotional fluctuations were most often attributed to the disease rather than to the person. Wife: "Before he was diagnosed, he wasn't like this. He was REALLY GOOD. After he was diagnosed, when he became upset, he would yell at his mother or whomever."

Participants noted situations when disease-related irritability contributed to family disagreements. In an illustrative narrative, a patient's husband went to buy cigarettes for a brother visiting from China. The brother requested a pack, but the husband bought a carton to save money and to demonstrate kindness. The patient became extremely angry when she learned of the purchase and sharply reprimanded her husband for supporting the brother's unhealthy habit. In a patient group interview, she attributed her outburst to diabetes ("diabetes destabilizes a person") but additionally expressed remorse at a comment that might "hurt him." This patient, like many in the study, believed immoderate anger posed harm to herself, by raising her blood glucose, and harm to her husband because he had to tolerate a strongly expressed negative emotion.

In this ethnic group, the social rather than physiological aspects of glucose regulation were highlighted. Participants seldom remarked upon the physiologic symptoms of glucose dysregulation, such as sweating or fatigue. Rather, their narratives suggested attunement to social and behavioral symptoms of glucose fluctuation and the social dilemmas these symptoms introduced. Patients felt called upon to contain their irritability to promote family harmony, while spouses reciprocally felt responsible to forgive patients' outbursts as a way of caring for patients.

### Prescribed diet challenged cultural beliefs and practices

Observing a biomedically prescribed diabetes regimen required Chinese American patients to distance themselves from familiar and shared cultural food habits and practices within the family and community. Participants found that culturally meaningful, familiar, and comforting foods had to be foregone or drastically reduced, new foods had to be accommodated, and food quantity became a source of concern. Additionally, social habits, such as eating out, sharing dim sum with family and friends, and easily participating in cultural celebrations and banquets were complicated by perceived disease restrictions.

Participants explicitly confirmed that the toughest challenge was diet: "Food. When to have it. What to have. Where to have it. I mean it's constantly. . . ." Another participant acknowledged, "The primary conflict is always in the diet." Disruptions in meaningful cultural food practices mentioned frequently included rice, restricting amounts of food, and changing the balance of various foods that were thought to be beneficial to general health.

The meaning of rice in the Chinese family diet was a culturally multifaceted and historically nuanced story about sustaining holistic health and well-being and partaking of a symbolically vital food. Patients and families were challenged by being asked to restrict rice and change from familiar white "fragrant" rice to foreign "chewy" and "tasteless" brown, red, or black rice. These challenges were persistently noted by participants who felt called upon to cope with this change in communal meals. The importance of rice was taken for granted in group discussions. Participants agreed that the amount of rice provided in institutional food settings like airplanes or hospitals was laughably small. The insufficiency was appreciated as an in-group issue, "a cultural thing" that Westerners were not likely to appreciate. When consumed in limited amounts as prescribed in a diabetic diet, rice was missed not just for its familiarity but as a requirement to health and perhaps survival. "If you don't eat rice can you sustain your daily living?" Additionally, participants expressed significant suffering because of restrictions on rice, a symbolically comforting food.

A central health metaphor expressed by most participants was the need for balance. Many found that disease-related

food restrictions disregarded cultural concerns for balancing foods (e.g., "hot" and "cold") understood to have specific medicinal properties according to traditional Chinese medicine (TCM). Even for those who did not specifically incorporate TCM in their diet management, the metaphor of balance was powerfully invoked. One spouse explained, "I feel that just purely eating like that with no oil or salt, you may be lacking certain nutrients. You are not balanced . . . and you would not be feeling very well." None of the participants received guidance from health care providers on balancing their diabetes food restrictions according to cultural concerns for balance, although many recommended foods raised concerns about creating such imbalances.

Participants additionally feared that diabetic food restrictions, if strictly followed, might lead to emotional imbalance and depression. Pleasurable food was generally appreciated as crucial to mental health and balance: "If I say every time, 'This and that you can't eat' some people would develop negative feelings and say, 'There's no meaning to life now.'"

Restricting food during illness is counterintuitive for many Chinese Americans (16,17). Rather, special foods and disease-specific medicinal foods should appropriately be provided for patients as both a means of supporting health and demonstrating family solicitude. Spouses were challenged by being asked to restrict patients' diets during illness and would have preferred providing abundant foods to comfort and fortify patients' health.

Diabetes diets also complicated shared social experiences of outings, meals, and celebrations with family and friends. Patients' difficulties in following an appropriate diet at Chinese restaurants led some to withdraw from socializing over meals. Spouse: "Now when I asked her to go to dim sum, she would say, 'I am not going. You can go.' I don't want to go alone, right? (Why?) It's meaningless to go by myself." For many Chinese participants, social interaction was an integral part of a meal. Attending dim sum or Chinese breakfast alone was meaningless because meals were sustaining only if shared.

Difficulties in managing the social elements of meals were intensified in ritual meals. Birthdays, weddings, or Chinese New Year's banquets, with multiple courses and desserts, were unavoidable, yet socially fraught: "Gee, I couldn't even

eat a bowl of sweet dessert soup! How miserable." The social context of ritual meals provided layered concerns for patients and families. The presence of family reminded patients of their responsibility to observe diabetes restrictions, as a duty to family. "Since they tell you, you don't dare do it. You are well aware that the bowl of sweet dessert soup may do you a lot of harm." Reciprocally, family members felt obliged to care for patients' disease and yet at the same time to create social ease and pleasure. A final social challenge was standing out socially, requiring special attention, or even stigmatized attention because of diabetes. As in earlier reports (16,17), patients varied in their willingness to disclose diabetes to friends, but most were distressed when diabetes was the focus of attention at social gatherings.

### Challenges to family roles and responsibilities

Living with diabetes challenged Chinese Americans to adapt their family roles to accommodate the disease. Beliefs varied about who in the family should be responsible to manage the disease, creating conflicts in negotiating differing role expectations. Many spouses believed that the family's role was to assist and encourage but that ultimately the patient had to be responsible: "He has to rely on himself. He is not a child anymore." Other spouses believed in and constructed a broader role, which included learning about the disease, assisting with disease management efforts, and offering ongoing advice and encouragement. Assistance with diet was most often cited, but help with all aspects of diabetes care were considered appropriate. Family role conflicts centered on who should create, observe, and enforce food restrictions; the degree of understanding each family member should have about the diabetes regimen; and whose philosophy of treatment should prevail.

Many spouses suggested that a communal diet should be respectful and accommodating of the patient's dietary restrictions. However, conflicts arose when the cook was over- or underresponsive to restrictions when cooking. For example, one patient asked her husband to cook more healthfully, but he "forgot" on a daily basis and continued to cook according to his own tastes. Conflicts also arose when a spouse cooked healthfully, but the patient felt unduly restricted: "It's

better to die. You restrict me like this and don't let me eat."

Disagreements arose about whether all family members should observe the patient's dietary restrictions. A few participants argued in favor of family restraint because the diabetic diet supported general health and observing restrictions demonstrated camaraderie with the patient. Participants also argued against such family restraint as unnecessarily restrictive. Longstanding couple and family dynamics were undoubtedly enacted in food arguments; diabetes provided a focus for these dynamics to be displayed. One couple, for example, reported a persistent, unresolved argument over the husband's wish to eat pork buns. He agreed to his wife's strict restrictions on family dinners but would not relinquish his breakfast pork buns.

Families were additionally challenged when patients and spouses held differing expectations about what family members should learn about the disease. Some patients felt neglected because spouses were "not very aware" of the risks and demands of the disease. These patients held that spouses had a reciprocal role responsibility to understand their condition and assist with its management. They expected spouses to intuitively understand, to be highly sensitive to, and to anticipate their diabetes management needs.

Differing spousal health philosophies and associated diabetes treatments led to ongoing challenges. Differences were apparent in the degree to which spouses believed in and relied upon Western biomedicine and TCM treatments and beliefs about the relative importance of treatment regimens, such as diet and exercise: "My wife doesn't quite accept the things of modern science . . . She's been using the method that her mother had taught her before . . . There is a 100% chance that she won't listen to you. So it's pretty hard to discuss this problem with her."

Patients role responsibilities encompassed managing diabetes well not only for health benefits but out of respect for their families. Reciprocal role responsibilities, or caring for diabetes in reciprocity for the family's care, reflected an interdependent self-construal and added emotional complexity to patients' responses to their disease. They may have been angry or upset at the disease requirements, but these responses had to be tempered to be responsive to the family's care. In addition to reciprocity, an interdepen-

dent norm of managing diabetes to protect the family's well-being was evident. Some patients addressed family members' worries by taking exceptional care of their diabetes. Patient: "This person by my side (husband) has to worry about me and watch my diet. How can I get mad? I feel apologetic, so I just eat these things that my husband wants."

Reciprocating care with filial children, those who perform their responsibility to care for a parent, also arose as a key concern for many patients. Patient: "My daughters (in China) are often concerned about me. 'Dad, you need to treasure your health. Don't eat sweets, don't eat fat, and don't eat salty food'" (chuckle). Interviewer: "How do you feel when they talk to you like this?" Patient: "This speaks to the family members' concern about me. So I should not disappoint them. I also need to be more conscientious."

Finally, some families believed the patient was weakened or made vulnerable by the disease. Some spouses doubted the patient's capacity to work at vigorous activity because restrictions on food or rice were thought to affect the patient's energy and stamina. Family sex roles shifted, with some wives shouldering greater financial support responsibilities to accommodate the perceived decrease in patient capabilities.

**CONCLUSIONS**— Foreign-born Chinese American patients and their spouses note multiple culturally nuanced dilemmas posed by type 2 diabetes. Their narratives suggest that Chinese families are integrally involved in interpreting symptoms and constructing disease management responses. Irritability in patients challenges tranquility and harmony in family life. Prescribed restrictions on symbolically vital foods and disruptions in valued family rituals and practices are sources of suffering and loss. Health prescriptions delivered in Western biomedical terms directly challenge cultural valuing of balance in emotional, social, and physical realms. Interdependencies and reciprocal role responsibilities additionally complicate disease management but differently for patients and spouses. Finally, overriding concerns for family well being frequently result in complex and layered decisions about disease management.

These data provide insight into the practical disease management of immigrant Chinese Americans whose per-

spectives have previously been poorly explored. Understanding these cultural and family obstacles to smooth management of diabetes deserves clinical attention. Clinical implications include a need for 1) concentrated attention regarding the social and family reverberations of diabetes symptoms, 2) consideration given to the central and pivotal role rice likely plays in Chinese patients' diets, 3) efforts to reframe diabetes guidelines as a way to increase balance rather than control, 4) care that incorporates an awareness that patients' disease management decisions are tempered by concerns for family well-being, family face, and the reciprocal role responsibilities.

Teaching foreign-born Chinese Americans about diabetes requires sensitivity to the social relevance of common symptoms, particularly irritability and emotional lability. Open expression of strong emotions, particularly negative emotions, is considered culturally inappropriate (14) given the potential to disrupt interpersonal harmony. Indirect, muted, and contained expressions of emotions are valued yet directly challenged by patients' perceived lack of control when symptomatic. Chinese Americans may experience emotional disregulation to be stressful and socially inappropriate and thus should be coached in advance about its possible occurrence.

The cultural challenges embedded in biomedical disease recommendations also deserve anticipatory guidance. Dietary restrictions on carbohydrates can be particularly challenging to a population that has historic, symbolic, and ritualized inclusion of rice in their daily diets. Recommended reductions in rice may be highly distressing and may challenge core beliefs about health maintenance. Stepwise approximations to an ideal diet may ease the transition and allow patients and families to explore healthy alternatives to highly processed white rice or rice noodles. Teaching patients about how rice affects blood glucose may dispel cultural myths. Consultation with dietitians who are familiar with Chinese food preferences and can offer culturally acceptable food substitutions is warranted. Helping Chinese families who may eat communally, with dietary guidance, will likely lead to greater observance of recommendations.

The central biomedical representation of ideal diabetes management is control or, optimally, intensive control (20). Prescriptions for a diabetic diet are per-



ceived by many foreign-born Chinese to be prescriptions to restrict, control, or limit what they eat. This framing challenges a cultural value of balance. Many foreign-born Chinese believe that balance and moderation in all things including diet (hot and cold, yin and yang), interpersonal relations, and environmental relations promotes health (21). When working with foreign-born Chinese Americans, greater success may be achieved by adapting the frame for diabetes management from limits or restrictions to balance. Actual prescriptions need not change tremendously, but prescribing a diet that balances new with old foods or rice with vegetables and proteins is more culturally suitable.

Appreciation of the socially embedded nature of health and health practices in immigrant Chinese Americans is necessary to provide culturally respectful care. Patients' and families' disease management decisions are seldom made independent of their concerns for family well-being, family face, and the reciprocal responsibilities required by varied family roles. Acknowledging the multiple and competing social concerns being managed by patients and families provides an opening for discussion and problem solving with the provider. Diet-related distress and family conflict are highly prevalent, and incorporating this social concern into diabetes management planning is warranted. Additionally, stress related to social concerns for family well-being and face are frequently factored into patient disease management decisions and should be part of patient-centered care with immigrant Chinese Americans (14,21).

Study strengths and weaknesses deserve mention. The sample size for an intensive interpretive study is robust, and participants who match the initial sample report in respondent groups that themes derived from the initial sample matched their lived realities. In interpretive work the investigator is the instrument, thus having a bicultural and bilingual team of interpreters strengthens the findings. Weaknesses of the study include the use of a convenience sample. Interviews were conducted only in Cantonese; therefore, cultural variations beyond Cantonese-speaking regions of Hong Kong and

China are not represented. Further research to confirm findings and to empirically test recommended clinical implications are needed.

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