Differences in Personal Models Among Latinos and European Americans

Implications for clinical care

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OBJECTIVE — To describe and contrast the personal models of type 2 diabetes in European Americans (EAs) and Latinos and to highlight differences that require a reorientation of clinical care.

RESEARCH DESIGN AND METHODS — A total of 116 EAs and 76 Latino individuals with type 2 diabetes were interviewed about their personal model of diabetes. Responses to open-ended questions about the perceived cause, nature, seriousness, course, and future course of diabetes and its impact on everyday life were analyzed using an iterative process, and categories of response were established. Responses were examined within ethnic group, and comparisons across ethnic groups were made for clinically significant differences.

RESULTS — Disease descriptions about the nature of the disease were categorized as experiential, biomedical, or psychosocial. Disease descriptions varied significantly by ethnicity ($\chi^2 = 35.92, 2$ df, $P < 0.001$), with more Latinos using an experiential model and more EAs using a biomedical model. Significant differences in life changes caused by the disease were found, with EAs reporting changes in exercise and spontaneity and Latinos in fatigue and mood. Individuals with diabetes from both ethnic groups gave comparable assessments about the cause, seriousness, and effectiveness of treatments for the disease.

CONCLUSIONS — Clinical practice that attends to the concerns and experiences of individuals with diabetes from diverse ethnic groups is warranted. Broad assessment of personal models in diverse ethnic groups is recommended.

Diabetes Care 23:1780–1785, 2000

The prevalence of type 2 diabetes is two to five times greater in Latinos than in European Americans (EAs) (1,2). Latinos report greater functional impairment with the disease (3), and their diabetes-specific mortality rates are higher than those of EAs and are increasing over time (4). Although greater morbidity and mortality from diabetes in Latinos cannot be clearly explained, culture, diet and exercise habits, economic status, genetics, language, and access to care each appear to make a contribution (5).

Diabetes is largely self-managed, and the changes required for careful control are dependent on the perceptions and understanding of individuals with the disease. Research attempting to understand approaches to self-management in individuals with diabetes have focused considerable attention on learning their understanding of the disease—what some have labeled a personal model of diabetes (5,6). Early work, conducted with predominantly EA samples, broadly examined the illness perceptions held by diabetic patients (7,8), whereas more recent reports have focused on aspects of their illness understanding, which have been found to correlate with or predict self-care practices (6,9,10). These include the diabetic patient's assessment of self-responsibility for causing the disease, seriousness of the disease, and treatment effectiveness.

Although the research on personal models has progressed quite substantially in the study of EAs, there is relatively little information about Latino experience with the disease. There have been several significant ethnographic and descriptive studies of Latinos, which are summarized below, but comparative studies of Latino and EA personal models are not available in the literature. Such comparisons are needed because, as Kleinman (11) and others (12) have shown, ideas about the body and illness can vary tremendously from culture to culture. Experience with any chronic illness, including the experience of symptoms and self-care, and advice-seeking from family or folk or biomedical health practitioners are influenced by culture. While it is unlikely that culture completely determines illness understanding (13), it logically forms a background for interpreting and reinterpreting experience with an illness (14,15).

In this study, we describe the personal models of individuals with type 2 diabetes in a bi-ethnic sample of diabetic patients who are in the early and middle stages of the disease. The central aim is to illuminate the commonalities and differences in illness understanding expressed by Latinos and EAs and to highlight differences that might require a reorientation of care for either ethnic group. We conceptualized personal models as an individuals complex sense of the disease, defined as the patient's notion of the cause, nature, and course of their diabetes (11,16).

Personal models of diabetes in Latinos

Descriptions of personal models of diabetes in EAs have been quite extensive and have...
recently been reviewed by Hampson (6). The few exploratory research projects examining the Latino experience have yielded inconsistent findings (17-22). Reports of Latino diabetic patients’ ideas about the cause, nature (including seriousness), and treatment of diabetes and the effects of the disease on their lives are reviewed here.

Reports of causal stories from Latinos yield contradictory information, with some studies reporting causes that match the biomedical story, including genetics, diet, and lifestyle factors (18,22), and others reporting that Latinos underappreciate the role of diet, exercise, or overweight in disease etiology (21). Some reports suggest that Latinos highlight emotional factors as causal (18,22).

A full study of Latino perceptions of the nature of diabetes has not been conducted. In a community survey of Latinos who knew about, but did not have, the disease (22), respondents described the disease in terms of symptoms such as thirst or frequent urination. In Latinos with diabetes, limited understanding of the disease itself or of the relationships between prescribed diet, exercise, and disease progression have been noted (21). An ethnography of Latinos with diabetes suggested that they revised their illness conceptions over time, based on experience with the disease and its regulation (18,19).

Studies of the effect of diabetes on the daily life of Latinos have emphasized lifestyle changes. Latinos noted difficulties in adapting their diet to the requirements of the disease in a family context because it required them to eat differently from the family and to give up traditional heavy foods (17,19). A desire to act and feel normal led Latinos to override self-care practices in favor of maintaining social roles. Women prioritized family responsibilities, such as childcare or cooking (17,19), and men prioritized socializing, eating, and drinking with friends over diabetes care (19). Cost was consistently reported as a barrier to self-management, including the expense of healthy foods, medications, and glucose strips (17,19).

Inconsistent reports about Latinos’ trust in and reliance upon biomedical treatments are evident in the literature. Hunt et al. (19) reported that Latinos believed so strongly in the ability of medication to manage the disease that they sometimes diminished their own self-management practices. In contrast, others reported that Caribbean Latinos distrusted biomedical treatments, particularly insulin, and held on instead to strong beliefs in traditional Latino remedies, such as herbs and bitter substances (21). Barriers to treatment included speaking a different language than the provider and unaffordable or unavailable health care (17,21). Reports about future concerns of Latinos were not found.

**RESEARCH DESIGN AND METHODS**

**Sample**

This research represents one aspect of a large multimethod study of personal, family, and provider influences on self-management and clinical outcomes in individuals with type 2 diabetes in a bi-ethnic sample of EAs and Latinos (23,24). Individuals who met the following inclusion criteria were recruited from 11 private and public health care facilities: patients diagnosed with diabetes for at least 1 but no more than 9 years; diabetic patients aged between 25 and 62 years with no major complications (proliferative retinopathy, cerebrovascular accident, or myocardial infarction within the last 12 months; renal insufficiency; amputations); diabetic patients and spouses or partner cohabiting for at least 3 continuous years; and diabetic patients and spouses self-identified as either EA or Latino (from Central America or Mexico). Sample criteria for the larger study were designed to support the development of interventions that target the early phase of the disease. The final sample was comprised of the 116 EAs and 76 Latino individuals with diabetes whose characteristics are described in Table 1.

**Methods**

This study reports on information obtained in the Personal Model Interview, which was adapted from the work of Kleinman (11) and the Personal Models of Diabetes Interview (9). Open-ended and fixed-choice questions addressed five aspects of personal models: cause, nature, seriousness, and effects of and future concerns about the disease. Interviewers encouraged personal rather than standard medical responses to questions. Additionally, interviewers elicited narratives about difficulties with diabetes and personal action responses. All interviewers were bilingual, and interviews were conducted in the informant’s preferred language (either English or Spanish).

**Cause.** Open-ended questions were used to assess each informant’s perception of what caused their diabetes, using probes for four potential causes: heredity, weight, diet, and stress.

**Nature of diabetes.** Informants were asked for a description of what diabetes was and how it worked. Additional questions were raised concerning differences in how their body worked before and after the diagnosis and differences in individuals with and without diabetes.

**Seriousness.** Informants were asked to rate the seriousness of diabetes on a five-point scale, with 1 equaling not at all serious and 5 equaling extremely serious.

**Effects of the diabetes.** Illness effects in everyday life were assessed by asking about any changes patients had noted in their lives since the diagnosis, e.g., changes in home life, family life, or work.

**Treatment effectiveness.** We conceptually divided management practices into two forms: standard, which included taking medications and observing diet, exercise, and glucose testing, and alternative, which included support from family, obtaining information about the disease, prayer, alternative self-treatments (e.g., herbs, teas), alternative treatment by others (e.g., acupuncture, massage), and advice from a dietitian (included as alternative because it was not a standard treatment for many patients we studied). Informants rated the helpfulness of each form of treatment on a five-point scale. Treatment effectiveness was calculated as two scores: the average helpfulness of the standard and of the alternative forms of care (nonuse was counted as being not at all helpful). The total number of forms of treatment used as part of standard and alternative care were also calculated.

**Future concerns.** Informants were asked in an unstructured way to name any concerns that they had for the future regarding their diabetes.

**Acculturation.** Acculturation was measured using a short acculturation scale (25) that provides an eight-item language-based acculturation measure (α = 0.94).

**Data analysis**

Responses to open-ended questions were analyzed using an iterative process to specify their nature and breadth. Three of the authors (C.A.C., M.M.S., R.J.B.) examined ~25 interviews to derive naturalistic codes for responses to each open-ended segment of the interview. Research assistants were trained in coding the interviews, and the codes were refined over time. After the codes were finalized, based on multiple cases reviewed, inter-rater reliability was established, unreliable items were dropped, and all previous interviews were recoded.
Two trained raters listened to the recorded interview and coded each item independently. Inter-rater agreement for four dimensions of personal models reported were as follows: cause (0.82), disease model (0.79), effects of diabetes on daily life (0.79), and future concerns (0.81); disease seriousness and treatment effectiveness were directly rated by patients.

RESULTS

Causal stories
When asked about any cause of diabetes and when they referred to complete answers on four potential causes (heredity, weight, diet, and stress), patients in both ethnic groups acknowledged all four causes at a relatively high rate. Heredity was named most often (72% of EAs and 67% of Latinos), followed by weight (73% and 60%), diet (58% and 59%), and stress (46% and 54%). In addition, when asked about the most important cause of the disease, both groups named heredity most often (35 and 32%).

Disease models
Informant understanding of what the disease comprised and how it worked in their bodies was classified as one of three identifiable disease models, which we distinguish from the more inclusive term, personal models. We define a disease model as an informant’s working ideas about the disease, gleaned from his or her encounters with providers, diabetes education, and disease management experience. Informants’ practical working ideas about diabetes, expressed in response to our open-ended questions, were classified as experiential, biologic, or psychosocial models.

In an experiential model, informants described diabetes in terms of symptoms or disease requirements, such as tender feet, fatigue, or increased irritability, without including an explanation of the biological mechanisms that might cause the symptoms or require care. Additionally, they emphasized the care practices required by the disease, such as taking medications or watching one’s diet. Despite repeated probes, informants with this disease model did not report a narrative about the biological mechanisms of the disease. Individuals who described their illness with an extremely simple account of diabetes that included only the explanation that one had too much sugar were included in this category (n = 15), as was the single informant who said he or she simply did not know what diabetes was or how it worked.

The two remaining disease models included some understanding of the underlying bodily changes involved in diabetes. Informants using a biological model included those who explained the disease as a pancreatic malfunction, insufficient insulin, or insulin resistance resulting in high blood glucose. The complexity of these biological disease models varied considerably, with some describing a very elementary grasp of the function of insulin and others demonstrating a complex and sophisticated understanding of the disease.

The final disease model, a psychosocial model, included biological, psychological, and/or social aspects of the disease. Informants who understood the disease in this way explicitly noted personal or social contextual factors that they believed were part of the disease process. For example, they described how stress on the job or interactions with family and friends might affect the disease process.

Disease descriptions varied significantly by ethnicity when data were analyzed using a two-by-two χ² analysis of ethnicity by disease (χ² = 35.92, 2 df, P < 0.0001). There were 14 EAs (12% of the total) and 39 Latinos (31%) who ascribed to an experiential model, 76 EAs (66%) and 30 Latinos (39%) who described a biological disease model, and 26 EAs (22%) and 7 Latinos (9%) who described the disease using a psychosocial model. In EAs, disease descriptions varied by sex, with women more likely to have a biopsychosocial understanding of the disease (χ² = 8.94, P < 0.01). Education level was significantly related to complexity of disease model when tested by a one-way analysis of variance [EAs: F(2, 113) = 4.68, P < 0.01; Latinos: F(2, 73) = 5.41, P < 0.01]. For Latinos, acculturation was related to increased education, and more acculturated Latinos were less likely to have experiential models of the disease.

Seriousness of the disease
Type of disease model was examined in relation to informant assessments of how serious the illness was. Patients rated their disease as fairly serious (mean 2.36–2.74), and there were no significant differences across ethnicity or disease models. Thus, both EAs and Latinos reported that the disease was fairly serious regardless of the complexity of their understanding of the disease.

Effects of diabetes on daily life
Reports by EAs and Latinos concerning the effect of diabetes on their lives and activities were strikingly different, with significantly more EAs reporting changes in self-care activities and significantly more Latinos reporting troubling symptoms of the disease. All changes reported by at least 25% of either sample are presented in Table 2. Diet changes were noted most frequently by patients from both ethnicities, although a significantly greater number of EA (93%) than Latino (83%) patients acknowledged any change in diet since the diagnosis. For EAs, exercise was the second most fre-

<table>
<thead>
<tr>
<th>Table 1—Characteristics of the sample</th>
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<tr>
<td>Latino</td>
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<tr>
<td>n</td>
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<tr>
<td>Sex (% M/F)</td>
</tr>
<tr>
<td>Age</td>
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<td>Income</td>
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<tr>
<td>Education</td>
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<td>Years married</td>
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<tr>
<td>Years since diagnosis</td>
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<tr>
<td>Medication (diet and exercise/oral medication/insulin)</td>
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<tr>
<td>HbA₁c</td>
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<td>Acculturation</td>
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Data for sex are based on the following ranges (values are given as percentages): 1 = 60–74; 2 = 75–89; 3 = 90–100. Data for education are based on the following ranges (values are given in years): 1 = 1–4.5; 2 = 4.6–5.9; 3 = 6.1–7.4; 4 = 7.5–8.8; 5 = 8.9–10.2; 6 = 10.3–11.6; 7 = 11.7–13.0; 8 = 13.1–15.4; 9 = ≥15.5. Data for income are based on the following ranges (values are given in dollars): 1 = 0–4,999; 2 = 5,000–9,999; 3 = 10,000–14,999; 4 = 15,000–19,999; 5 = 20,000–24,999; 6 = 25,000–29,999; 7 = 30,000–34,999; 8 = 35,000–39,999; 9 = ≥40,000. Data for health insurance are based on the following ranges (values are given as percentages): 1 = 0–24; 2 = 25–49; 3 = 50–74; 4 = 75–99; 5 = 100. Data for age are based on the following ranges (values are given in years): 1 = 18–24; 2 = 25–29; 3 = 30–34; 4 = 35–39; 5 = 40–44; 6 = 45–49; 7 = 50–54; 8 = 55–59; 9 = 60–64; 10 = 65–69; 11 = 70–74; 12 = ≥75.
Table 2—Life changes and future worries about diabetes for EA and Latino diabetic patients

<table>
<thead>
<tr>
<th>Life changes</th>
<th>Ethnicity</th>
<th>( \chi^2 )</th>
<th>( P )</th>
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<tbody>
<tr>
<td>Diet</td>
<td>EA (%)</td>
<td>Latino (%)</td>
<td></td>
</tr>
<tr>
<td>Exercise</td>
<td>45</td>
<td>21</td>
<td>11.35</td>
</tr>
<tr>
<td>Family relations</td>
<td>25</td>
<td>23</td>
<td>0.17</td>
</tr>
<tr>
<td>Social life</td>
<td>12</td>
<td>29</td>
<td>7.57</td>
</tr>
<tr>
<td>Decreased spontaneity</td>
<td>35</td>
<td>13</td>
<td>10.84</td>
</tr>
<tr>
<td>Fatigue/energy</td>
<td>35</td>
<td>65</td>
<td>16.61</td>
</tr>
<tr>
<td>Mood changes</td>
<td>24</td>
<td>47</td>
<td>10.26</td>
</tr>
<tr>
<td>Future worries</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical decline</td>
<td>91</td>
<td>88</td>
<td>1.29</td>
</tr>
<tr>
<td>Finances</td>
<td>16</td>
<td>42</td>
<td>16.08</td>
</tr>
<tr>
<td>Early death</td>
<td>24</td>
<td>29</td>
<td>0.55</td>
</tr>
<tr>
<td>Family becomes burdened/patient</td>
<td>28</td>
<td>32</td>
<td>0.22</td>
</tr>
<tr>
<td>dependency</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Children inherit disease</td>
<td>19</td>
<td>33</td>
<td>4.82</td>
</tr>
<tr>
<td>Ability to work</td>
<td>17</td>
<td>23</td>
<td>0.78</td>
</tr>
<tr>
<td>Patient will need insulin</td>
<td>24</td>
<td>13</td>
<td>3.49</td>
</tr>
<tr>
<td>Disease a threat to patient identity</td>
<td>16</td>
<td>13</td>
<td>0.21</td>
</tr>
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</table>

Assessment of treatment effectiveness

Similarities rather than differences stand out in EA and Latino ratings of the helpfulness of standard and alternative approaches to managing their diabetes. The only significant difference by ethnic group was that EAs reported using a significantly greater number of standard treatments (mean 4.72) than did Latinos (mean 4.22) \((t = 4.15, P = 0.0001)\). EA and Latino ratings of the average helpfulness of standard (EA: mean 3.96 out of a possible 5 and Latino: 3.95) and alternative (mean 3.76 and 3.79) treatments were quite similar. Diabetic patients from both ethnic groups reported using a greater number of standard treatments (mean 4.7 and 4.2) than alternative treatments (mean 2.8 and 3.0).

Future concerns

We were also interested in the content of informants’ concerns for the future. Some 91% of the EAs and 88% of the Latinos expressed concerns about the diabetic patient’s future physical decline (Table 2). Concerns about early death and dependency on the family were acknowledged by >25% of the diabetic patients from each ethnic group. Two concerns were mentioned significantly more frequently by Latinos than EAs: future financial worries, identified by 42% of the Latinos versus 16% of the EAs, and concerns that their children will inherit the disease, noted by 33% of the Latinos versus 19% of the EAs.

CONCLUSIONS — Using an open-ended comparative approach, differences between EAs and Latinos were found in their descriptions of the nature of type 2 diabetes and the effects of the disease on their lives. Diabetic patients from both ethnic groups gave comparable assessments of the illness and body, a distinction that may be less appreciated phenomenologically by Latinos. If Latinos experience their diabetes holistically, i.e., if the disease enters their lives as a relatively undifferentiated psychological, emotional, and biological process, then they may be less inclined to explain the disease as a distinctly biological phenomenon. In addition, Latino illness models may be strongly influenced by the health care systems from which they receive care. Some 43% of the Latinos in this sample, versus <1% of the EAs, were recruited from busy, oversubscribed, and under-resourced public health care systems. Perhaps less intense or comprehensive educational efforts about diabetes are available in public versus private settings and influence the relative ability of Latinos to describe the biological processes of diabetes. Finally, differences in socioeconomic status involve both limited material resources and greater daily stress. Given this social context, perhaps Latinos attend to those aspects of diabetes that require immediate attention: symptoms that interrupt daily life and demanding self-management requirements.

A second aspect of personal models that differs substantially between EAs and Latinos is the change they note in their lives since the diagnosis. EAs much more than Latinos note changes in exercise and spontaneity, suggesting that they experience the impact of the diabetes regimen, whereas Latinos note changes due to symptoms such as fatigue and irritability along with changes in their social lives.

The similarities in the causal stories and ratings of disease seriousness in EAs and Latinos in this sample parallel some earlier studies of Latino assessment of the illness (18,22), i.e., the causes named by Latinos match the biomedical story. When considered separately from the actual changes reported in their lives, Latinos and EAs assess the effectiveness of standard and alternative treatments for diabetes similarly.
The literature on trust of biomedical treatments by Latinos is equivocal, with reports of both over-reliance on and distrust of standard biomedical treatments for type 2 diabetes (19,21). It appears that in this sample, Latinos perceived commonly prescribed treatments to be effective and found no particular efficacy from traditional Latino treatments, such as Nopales or taking herbs or bitter substances, which would have been reported under alternative treatments.

**Implications**

We suggest that taking a broad look at the personal models of diabetic patients is crucial for the design of research and clinical interventions for diverse populations. Had we examined only those elements of patients’ illness understanding that are strongly related to self-care in EAs samples, we would have missed the significant differences found in the reports of a large and growing ethnic group. That is, EAs and Latinos do not differ in their assessments of the cause of the disease, its seriousness, or the efficacy of various treatments. Rather, they differ in how they understand the disease process and experience its impact on their daily lives.

Additionally, when investigating personal models in diverse groups, using an open-ended, as opposed to a more structured, approach may be important to identify dimensions of personal models that are unique to each group. Although, labor-intensive unstructured ethnographic approaches allow for the identification of disease aspects that have particular import for each group. The use of ethnographic approaches to complement the quantitative can provide invaluable information regarding the cultural sensitivity of standard measures.

This comparative study suggests points of reflection on clinical practice. Both Latinos and EAs in our sample have heterogeneous stories about diabetes and its impact on their lives, but there are also identifiable differences across groups. For whatever reason, be it culture, care systems, or life resources for learning about diabetes, about half of the Latino and a much smaller proportion of EA diabetic patients express their understanding of the disease at an experiential level. This suggests that education about type 2 diabetes for these diabetic patients needs to be meaningfully reconfigured to address the experience of living with diabetes. Such an educational approach would focus on the ways that diabetes is experienced in daily life and how it can be managed, both symptomatically and according to general behavioral guidelines. Taking such an approach requires health care providers to orient themselves to the pragmatic realities of living with diabetes, rather than simply explaining the biological mechanisms of the disease. This reorientation allows the practitioner better access to patient concerns and motivations for action and thus is an appropriate starting point for care.

A second finding that has implications for clinical care are the number of Latino patients reporting various negative symptoms like fatigue and irritability. Fatigue interferes with work, and work is both highly valued in Latino communities (13) and a necessary source of support in the low-income Latino sample we studied. Diabetes education that begins by pointing out the impact of tight glucose control on fatigue and the increased ease of work with lessened fatigue may be an extremely effective way to engage Latino diabetic patients in self-management. Similarly, substantial numbers of Latino diabetic patients note greater irritability since their diagnosis. Irritability can disrupt relationships with family and friends and thus can threaten self-control (ease in social relations) and self-management (expectations of self-control in social situations) (27). Again, clinical care that begins by linking these highly valued concerns with diabetes management may prove more effective in engaging Latinos in self-management than would a discussion of the biological mechanisms of the disease. Explicitly linking current care of diabetes to current patient concerns is a reasonable approach in any clinical care, but may be particularly effective with diabetic patients whose concerns with handling current discomforts and social expectations may overtake concerns about warding off future sequela of the disease.

**Acknowledgments** — This study was supported by a grant from the National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health (DK-49816).

The authors acknowledge the contributions of additional research team members, including co-investigators Catherine Gilliss, DNSc, Richard Kantor, MD, and Claudia Lutz, MPH, RD. The authors thank the following clinical settings: California Pacific Medical Center, Clinica de la Raza-Oakland, Brown and Toland Medical Group, Marin Community Clinic, Mills-Peninsula Medical Group, Northern California Kaiser Medical Centers, San Francisco General Hospital and Neighborhood Health Centers, and the University of California San Francisco Clinics and Collaborative Research Network.

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