Health perceptions of diabetic patients in the REDIA study

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SUMMARY
Aim: To explore the beliefs and perceptions of type 2 diabetic patients in La Réunion where the disease is highly prevalent (17.5% among 30-69 yr old subjects) with a strong link to the metabolic syndrome and nutritional habits.
Methods: Two sets of data were analysed. An 80-item questionnaire explored the perceptions of causal factors, knowledge of complications and therapeutic issues in 331 known diabetic patients included in the REDIA study. The data were completed by semi-structured interviews of 40 diabetic patients in a hospital setting.
Results: Perceived causal factors of diabetes are mainly sugar excess, heredity and stress or life events. Weight excess and lack of physical activity are virtually never mentioned as causes. Diabetes is predominantly perceived as potentially acute, with risk of coma and death. Its chronic and progressive nature is not appreciated, and chronic complications are not well understood, especially in poorly educated people. Only 33% of males and 42% of females are willing to change their nutritional habits and the role of fats is largely underestimated (30.2%) although 90% consider physical activity as an effective course of action. Most patients are tardy in the way that they adopt medical recommendations and treatment in the course of the disease.
Conclusion: These results highlight the discrepancy between medical knowledge and patients’ perceptions, especially concerning etiological issues and complications. Lifestyle and therapeutic recommendations are not well understood. Educational activities need to consider the knowledge issues and understanding by patients early in the course of chronic diseases like diabetes.

Key-words: Diabetes · Health perceptions · Chronic diseases · Knowledge · REDIA study.

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RÉSUMÉ
Perceptions de santé des patients diabétiques : l’étude REDIA
Objectif : Explorer les perceptions des patients diabétiques de type 2 à la Réunion, dans un contexte de prévalence élevée (17.5 % chez les 30-69 ans) avec une liaison forte au syndrome métabolique et aux pratiques alimentaires.
Méthodes : Deux sources de données sont analysées : 331 questionnaires (80 items : causes, conséquences et traitement du diabète) soumis aux patients diabétiques connus de l’étude REDIA et 40 entretiens semi-directifs auprès de patients diabétiques hospitalisés.
Résultats : Les causes rapportées les plus fréquentes sont l’excès de sucre, l’hérédité, et le « stress » ou événements de vie. Le surpoids et l’inactivité ne sont pratiquement pas mis en cause. Le diabète est perçu avant tout comme une maladie menaçante avec risque de coma et de mort. Sa nature chronique n’est pas mise en avant. Les complications sont mal comprises, surtout dans les niveaux de sociabilité faible. Une volonté de modification des habitudes alimentaires n’est exprimée que par 33 % des hommes et 42 % des femmes. Le rôle des lipides est largement sous-estimé (30.2 %), tandis que 90 % considèrent l’activité physique comme efficace. Les recommandations médicales sont prises en compte tardivement par les patients.
Conclusion : Ces résultats montrent le décalage persistant entre les connaissances médicales et les perceptions des patients, notamment en ce qui concerne les modèles étiologiques et évolutifs de la maladie. Les ressources thérapeutiques sont mal comprises, intégrées tardivement par les patients. Les actions d’éducation doivent tenir compte de ces faits pour une action précoce dans l’histoire de la maladie chronique.

Mots-clés : Diabète sucré · Perceptions de santé · Maladies chroniques · Connaissances · Étude REDIA.

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Introduction

Diabetes is associated with a major increase in the risk of cardiovascular and renal disease and is the leading cause of non-traumatic amputations of the lower limbs. An important issue in research is to identify factors which contribute to promotion of weight loss, healthy eating with physical activity, and appropriate therapies to prevent diabetes and its complications [1,2]. Attitudes to health and behaviour are complex and are the result of various factors such as medical information and the relationship with health care providers, personal experience, perceptions, knowledge and understanding of the disease. In order to evaluate the adequacy of preventive actions it is essential to assess the perceptions and beliefs about diabetes as determinants of care [3]. Reunion Island is located in the Indian Ocean, close to Mauritius and Madagascar. A multi-ethnic background characterises the population of La Réunion, with a wide cultural and religious diversity. It is a French overseas “department”, with access to modern Western lifestyle as in any other French metropolitan area. Diabetes is considered by the national health insurance system as a lifelong disease with 100% reimbursement. Prevalence of type 2 diabetes mellitus in Reunion Island is high, up to 17.5%, amongst the population aged 30-69, with frequent, early and severe complications [4-7]. The age of diagnosis is lower than in Metropolitan France [8], and 25% of Type 2 diabetic patients are on insulin treatment. Secondary health care settings and specialists are unable to face the burden of diabetes. Consequently, most type 2 diabetic patients are almost exclusively managed by GPs. A strong link with intra-abdominal fat was found [4], and decreased physical activity as well as high-energy intake, have been shown in local surveys [9].

The purpose of this study was to explore the perceptions and attitudes of Reunion Island diabetic patients about their disease, its causal factors, perceived risks and treatments, in the context of the implementation of educational policies.

Patients and methods

The REDIA (REunion DIAbète) epidemiological study [4] was aimed primarily at assessing the prevalence, risk factors and clinical forms of diabetes mellitus in Reunion Island. Briefly, a representative sample of 3600 subjects (aged 30-69) from randomised blocks of houses in 3 geographical regions of the island (communes of Le Tampon, Saint-Pierre and Saint-André) was studied. According to WHO criteria, 17.5% IC95% = [16.5%; 19.0%] of the subjects were diagnosed with diabetes. One third were unaware of their status, which was discovered during REDIA. The socio-cultural study was conducted among the 430 subjects (11.2%), already known to be diabetics, and of these 331 (77.0%; 129 M, 202 F) answered the questionnaire, including 80 items in the French language. Data were collected on perceptions of diabetes and its causal factors, knowledge of complications and treatment, diet and physical activity. Questionnaires were completed at home with oral translation into the Creole language if necessary, from May 1999 to March 2001, 6 to 12 months after the first screening visit by REDIA investigators.

Data were completed by the analyses of 40 semi-structured interviews conducted by an anthropologist (MR). Patients were randomly recruited amongst those hospitalised in the department of Diabetology of the Centre Hospitalier Départemental (Saint-Denis). In order to elicit information on patients’ perspectives on their health status, diabetes, causal factors, consequences, and therapeutic issues, open-ended questions were drafted as a structured interview. Face to face interviews were conducted in hospital settings (n=36) or at home (n=4). All interviews were recorded, and later transcribed verbatim. The same anthropologist (MR) carried out the 40 interviews and performed the analysis in order to identify emerging themes. The process was iterative, each new data set being used to verify all interpretations and to evaluate the gap between common and medical perspectives.

Results (table I)

Characteristics of the population studied

The 331 respondent patients of the socio-cultural questionnaire were comprised of 61% females and 39% males. The mean age was 54.7 ± 6.0 yrs (30-69), with a mean duration of diabetes of 9 yrs (Table I). The mean HbA1c was 8.4 ± 0.1%, BMI 27.3 ± 0.3 kg/m², waist circumference 96.5 ± 0.6 cm, and systolic blood pressure 142.1 ± 1.2 mmHg. Proteinuria > 1.0 g/l was present in 18.1% of patients. Non-respondent patients were slightly younger (51.3 ± 0.8 yrs; P < 0.004), with more males (52.5%; P < 0.02). Other data (geographical location, clinical and biological data) were not different, except for a tendency to a poorer level of control of hypertension in respondents. Patients were mostly from low socio-economic groups and low educational level. Literacy was not assessed.

The 40 interviewed type 2 diabetes patients were 25 females/15 males, native from Reunion Island and aged 30-75 yrs. They were on oral (n = 30) or insulin treatment (n = 10). Fifteen were active (8M, 7F), 11 did housework (11F), 4 were unemployed (2M, 2F) and 10 retired (5M, 5F).

Causal factors

Three groups of reported causal factors emerge: heredity, sugar intake, and stress or daily life concerns. Heredity is quoted as a causal factor of diabetes by 36% of males and 29% of females, less with longer duration of diabetes (19%...
in females > 10 yrs duration). Sugar is linked to diabetes in 38% of cases. Very few individuals link diabetes to excess weight (3.2%), inactivity (0.6%), or to cultural/ethnic origin (1%). Females, with a long duration of diabetes mostly refer to life events, such as stress, accidents and misfortune as other causes. Items relating to the causal factors of diseases in general, beyond diabetes, most frequently included internal causes, lack of care (38%), heredity (34%) and “weak temperament” (21%), as opposed to physical unbalance (6%). Among external factors, every day troubles and concerns are considered direct causes of disease for 22% males and 24% females.

The analysis of interviews confirms these findings. It revealed, however, that heredity is self-assessed and unsubstantiated. Food is easily incriminated, especially when recurrently invoked by medical staff. Modern society junk food is considered by many to be a responsible factor; but some concepts, such as the cultural significance of rice and of fatty and spicy food, and food excess as part of local customs (mostly with respect to cane sugar) still prevail. Traditional habits (cane sugar) are replaced by sweet drinks to reinforce the positive cultural role of sugar in Reunion Island. Amongst older inhabitants, food sufficiency is regarded as a fair compensation after periods of deprivation. Finally, beliefs such as magic and religious convictions, or personal build-ups after life events, are still significant and predominantly quoted. The high proportion of external causes claimed is closely interconnected with internal causes, related to the biomedical, the individual or the popular model. The semantic relationship between language and beliefs can be organized into 3 overlapping areas for the construction of personal profiles: (i) common sense (causal factors arising from collective and social talk, and considered as possibly related), (ii) individual experience (which structure representations since they require personal causal factors in order to make sense), and (iii) medical talk (in which the relationship is primarily excluded from a public point of view). The frequently mentioned causes consistent with the biomedical model could be due to the location of the interviews (hospital settings), and to the frequent and recent contact with health care system. Care needs to be taken when interpreting the data on the basis of prevalent causality conforming to the biomedical model, which could simply be a result of “medical talk”.

### Consequences of the disease

The perceived consequences have been assessed in the socio-cultural questionnaire as risk for health and daily life. The life-threatening aspect is a major concern for many. The predominant cited risk is coma and handicap (60%), whereas death is cited by 50% and no risk by 20%. The chronic and progressive nature of the disease is underestimated, and diabetes complications are not well-known (unknown 25%, and ≥ 3 known complications 25%). These results are roughly similar whatever the duration of diabetes. People who did not attend school cite complications less frequently, but these are accurate when quoted. Unemployment and work difficulties are of great concern (71.3% males; 46.3% females), but many subjects report that there are no or few constraints (23.8% males; 42.2% females) due to diabetes. The interviews revealed that persons with diabetes generally do not consider themselves sick until pain or complications actually occur. The notion of disease as a medical concept does not conform with the condition of diabetes. Diabetes is not really considered to be a disease like others: it is a long-lasting and silent illness, potentially serious but hard to understand and describe. Despite its seriousness, it is very slow to be taken into consideration. In fact, the individual progress from diagnosis to patent disease and complications is remote from the biomedical process. Once the physician states the diagnosis of diabetes, the “patient” looks for an explanation for the disease in order to understand it.

### Table I

Socio-demographic and disease characteristics of the 331 subjects with known diabetes mellitus. Results of the REDIA study.

<table>
<thead>
<tr>
<th></th>
<th>Males (n = 129)</th>
<th>Females (n = 202)</th>
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</thead>
<tbody>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(33-69)</td>
<td>54.7 ± 0.8</td>
<td>54.8 ± 0.7</td>
</tr>
<tr>
<td>(0-40)</td>
<td>8.9 ± 0.7</td>
<td>9.0 ± 0.5</td>
</tr>
<tr>
<td><strong>Disease duration (years)</strong></td>
<td></td>
<td></td>
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<tr>
<td>(0-39)</td>
<td></td>
<td></td>
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<tr>
<td><strong>Treatment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>10.8%</td>
<td>4.0%</td>
</tr>
<tr>
<td>Diet only</td>
<td>7.0%</td>
<td>6.9%</td>
</tr>
<tr>
<td>Oral</td>
<td>62.8%</td>
<td>60.9%</td>
</tr>
<tr>
<td>Insulin</td>
<td>19.4%</td>
<td>28.2%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>25.6%</td>
<td>22.8%</td>
</tr>
<tr>
<td>Primary school</td>
<td>50.4%</td>
<td>58.4%</td>
</tr>
<tr>
<td>High school</td>
<td>24.0%</td>
<td>18.8%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td><strong>Occupation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Active</td>
<td>25.6%</td>
<td>10.9%</td>
</tr>
<tr>
<td>Unemployed</td>
<td>27.1%</td>
<td>21.8%</td>
</tr>
<tr>
<td>Housework</td>
<td>0.8%</td>
<td>37.6%</td>
</tr>
<tr>
<td>Invalidity</td>
<td>12.4%</td>
<td>7.4%</td>
</tr>
<tr>
<td>Retired</td>
<td>31.8%</td>
<td>21.3%</td>
</tr>
<tr>
<td>Other</td>
<td>2.3%</td>
<td>1.0%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

Results are expressed as: mean ± SE or percentage.
interpretation has to first come from personal experience in order to make sense. The subject has to re-build his identity, and seek for assistance, before assuming his therapeutic choices. All these stages are necessary before an adequate realisation is reached. This usually occurs in advanced stages of the disease, when discomfort and disabling complications are already present.

Therapeutic issues

Diet

Effective willingness to change nutritional habits is not frequent, found in 33% of men and 42% of women (obese women: 50%). Diet is addressed late with patients: 67% never underwent a diet review and weight assessment is not an issue (none: 18%; at home: 27%; by physician: 55%). The role of fat and meat is somewhat underestimated: 30.2% cite fat and 8.3% cite meat as the first foodstuff, and 25.3% fat and 17.8% meat as the second form of nutrition to be reduced. A low level of education seems to be associated with a greater tendency to underestimate the role of fat, but not the role of meat products. On the other hand, the role of rice is overestimated, especially in women (50% females; 33% males, as the first nutrient to be reduced), independently of the educational level. Among the patients interviewed a majority reported having received information on diet from health professionals. Finally, the study revealed the persistent high proportion of self-production of food (59.5% versus 29.6% local market and 10.9% supermarket). Ninety seven percent of patients reported the positive effect of physical activity.

Interviews indicate that diet is the last item to be considered by patients as a therapeutic resource, even though lifestyle recommendations are generally well known [9]. This mostly occurs when symptoms, suffering, or life consequences are actually present. On the other side, physical activity is perceived as beneficial, since it prevents stresses from turning over in one’s mind. It is important to note that medical knowledge about the efficiency of physical activity differs from conceptions prevailing in the diabetic subjects themselves.

Medical treatment

Patients use plants as a treatment in 49% cases. The perception of insulin is negative in 67% of cases (useless 2%, dangerous 13%, uneasy 14%, constraining 38%). Insulin is perceived as useful in 33% of cases. Amongst insulin-treated patients, self-management is effective in only 27% of cases, while 52% refuse all self-management (eye involvement, low literacy, fear of injection, dosage hazard and lack of self confidence).

In interviews diet and insulin are primarily rejected, and oral anti-diabetic treatment is perceived in the correct way. Only medicinal plants are commonly accepted as the first therapeutic choice. Diet and oral hypoglycaemic agents are incompatible with medicinal plants from the popular point of view. Insulin is perceived mainly as a dangerous drug (alienating remedy, drug, poison, dosage hazard, life-long dependency, weight concern...), which cannot be stopped once initiated. Moreover, insulin treatment means to them seriousness of a disease at a late stage. However, insulin-treated patients have a more informed opinion about their therapy, since the treatment is well tolerated and considered as a guarantee of good medical care.

Discussion

The present qualitative study explores health perceptions held by diabetic patients in La Réunion. To our knowledge, no or few data have previously been published in France or French territories [10-13]. Mauritius, close to La Réunion, is characterized by a similar trend in diabetes prevalence in a multi-ethnic background [14], but no such qualitative data are available. The questionnaire study provides useful information for the implementation of educational policies, and access to the qualitative data originating from interviews brings a better understanding of effective knowledge and perceptions about causes, consequences and treatments. On the one hand, the perceived reported causes are primarily sugar excess, heredity and stress and/or life events, and the role of fat, excess weight and physical inactivity are largely neglected. On the other hand, this study emphasises the persistent awareness of diabetes as an acute, potentially life-threatening disease, regardless of its progressive and chronic aspect as depicted by the medical community. The first therapeutic choices of patients (medicinal plants) are not consistent with those of the health professionals and patients adhere to treatment late into the course of their disease.

Data concerning beliefs about the causal factors of the disease are consistent with those in other diverse populations [15-18]. External factors such as emotional or social events, personal accident, accident or death of a close relative, fright, conflict, are all perceived causes for the disease [17-20]. Unawareness of excess weight and physical inactivity as potential triggers of the disease is noteworthy. These factors have been highlighted in another study in the US, among women > 65 yrs [21]. The findings concerning nutritional and diet issues are striking. The overestimation of the role of rice is correlated with the overestimation of the role of carbohydrates observed in French patients [10]. However, the role of fat consumption is largely neglected as a causal factor and as a therapeutic issue. Eighty seven percent of patients in the questionnaire study received information and recommendations on diet from medical staff. Hence, we may suspect inadequate messages given by GPs, or patients misunderstanding and difficulty in relating fat and weight to diabetes.
Most subjects with non-complicated type 2 diabetes are unaware of the potential seriousness of the diabetic state. Chronic complications such as cardiovascular, renal, retinal, or foot lesions are not frequently mentioned. In a prior study conducted in France, nearly half of the patients were unable to cite one complication of diabetes in an open questionnaire [10]. Patients, even after receiving education, often still don’t share the medical view that diabetes is a chronic, progressive and potentially serious disease [22]. Furthermore, even if the seriousness of the disease is not denied, patients may perceive themselves as being personally immune to its complications [23].

These present results have to be seen in the local context of La Réunion. The social and cultural significance of food habits are of importance in relation to Creole history and identity [24]. La Réunion, from a colonial society based on intensive culture of sugar cane and slavery until mid 19th century, evolved rapidly after 1946 to a modern lifestyle, although the local population was originally largely rural and living in poverty with a low life expectancy. Inhabitants are characterised by a high rate of interbreeding on the basis of 4 main ethnic groups (European, African, southern Indian, and northern Indian ascendency) and 2 minor groups (Asiatic and Metropolitan French). Melted imprinting from these numerous sources constitutes cultural, and especially food, habits. We have to consider too the strong social disparity with unemployment and the low social level of many inhabitants. However, many notions may be relevant to other populations and have to be considered when dealing with health educational activities, especially in France or French territories. Perceptions arising from cultural and traditional beliefs are still present in the background, but mixed with information coming from various forms of the media, healthcare professionals, and individual experience [25]. The individuals’ understanding of risk progresses by assimilating improved information within their own mental models [21]. Other studies have highlighted the usual gap between patients’ perceptions and scientific (medical) knowledge [26–29]. Patients’ “misperceptions” regarding the potential seriousness of the disease, and differences between their understanding and that of medical professionals, have been implicated in the poor adherence to treatment [21,26,27]. As seen here, patients emphasised social difficulties (inability to work, familial concerns) more than chronic complications of the disease. Health professionals primarily consider diabetes as a pathophysiological problem with physical impact on the patient, while patients focus more on social issues with impact on their own lives [28]. Subjects need to develop self-awareness of concepts and knowledge on the disease, and to make sense of it. Without such individual awareness and exposure to knowledge the usual process leads to personal interpretations of mechanisms and causes [30]. Furthermore, in the absence of correct understanding of the disease, patients tend to rely heavily and passively on physicians.

In conclusion, sugar excess and stress are the main perceived causes of diabetes, whereas medical science points to the role of being overweight, excess fat consumption and lack of physical activity. Complications are not well understood and diabetes is not considered as a chronic disease, at least until complications are actually present. These data are of importance in the context of La Réunion as educational issues, but most may also be relevant in other places. Instead of outlining the usual distance between healthcare professionals and patients, it is necessary to consider knowledge as a more complex concept, integrating both biomedic and common knowledge and beliefs as cores to the self-care process.

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