

**DIABETES AND DIET:
MANAGING DIETARY BARRIERS**

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DIABETES AND DIET:
MANAGING DIETARY BARRIERS

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PROEFSCHRIFT

ter verkrijging van de graad van
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van de Landbouwwuniversiteit te Wageningen

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Het Diabetes Project waarvan de studies, die in dit proefschrift worden beschreven, deel uitmaken, werd financieel ondersteund door het Ministerie van Welzijn, Volksgezondheid en Cultuur en door de Landbouwuniversiteit Wageningen.

STELLINGEN

1. De uitspraak 'baat het niet, dan schaadt het niet' geldt niet voor restricties in een dieetadvies.
(Dit proefschrift)
2. Het verdient aanbeveling de stapgrootte in variatielijsten voor diabetes te vergroten tot 12 gram koolhydraten.
(Dit proefschrift)
3. De adviezen de suikerconsumptie te verlagen en de koolhydraatconsumptie te verhogen zijn strijdig.
McColl KA. The sugar-fat seesaw. Nutrition Bulletin 13;1114-118:1988.
4. Het advies gevarieerd te eten kan verschillend geïnterpreteerd worden. De enig juiste interpretatie is onbekend.
5. De toegenomen technische hulpmiddelen voor diabetes dienen niet alleen ingezet te worden om de regulatie van de diabetes te verbeteren, maar zeker ook om hen grotere flexibiliteit van leven te bieden.
6. If the patient was a furnace, or a chemical retort, and could passively accept any diet offered, there would be no problem.
Hinkle LE. Customs, Emotions, and Behaviour in the Dietary Treatment of Diabetes. J Am Diet Ass 1962;41:341-344.
7. De uitspraak dat 'De Islam' in zijn middeleeuwen zit, en dat 'wij' toen ook kruistochten hielden, suggereert ten onrechte een universeel ontwikkelingsmodel, namelijk het westerse.
8. Om de bijdrage van vet in de voeding omlaag te brengen verdient het aanbeveling koolhydraat houdende snacks op de markt te brengen, die effectief de 'hartige' trek stillen.

9. De uitspraak 'Thank God it is friday' is in essentie een creationistische uitspraak.
10. Adviezen over een gezond voedingspatroon worden door de consument doorgaans vertaald in geboden en verboden.
11. De consument wordt niet onmiddellijk beloond na vertoon van gezond eetgedrag. Dit is een fundamenteel probleem voor voedingsvoorlichters.
12. In tegenstelling tot voedingsvoorlichters kennen milieuvoorlichters wel een onmiddellijke beloning, in de vorm van de kick van rinkelend glas in een glaskak.
13. Het verdient aanbeveling om bij een bezoek aan De Efteling zelf een prop papier mee te nemen.

Stellingen behorend bij het proefschrift:

Diabetes and Diet: Managing Dietary Barriers, Roland D. Friele.

1 november 1989

Voor mijn ouders

ABSTRACT

DIABETES AND DIET: MANAGING DIETARY BARRIERS

THESIS, DEPARTMENT OF HUMAN NUTRITION,
WAGENINGEN AGRICULTURAL UNIVERSITY,
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This thesis reports on the barriers diabetic patients experience with their diet, and the ways they cope with these barriers. A dietary barrier is a hinderance to a person's well-being, induced by being advised a diet. First inventories were made of possible dietary barriers and ways of coping with them. Secondly the prevalence of these barriers and ways of coping with them were assessed among different diabetic populations. Most prevalent were barriers expressing physical discomfort and restrictions in food-use. Barriers with the highest prevalence were most often dealt with by non-compliance. The prevalence of barriers among recently diagnosed diabetics did not differ from prevalences after a follow-up period of one year. It was concluded that dietary barriers are not easily overcome by diabetic patients. Hardly any differences were found in barrier prevalence when comparing insulin-treated and non insulin-treated diabetic patients. Prevalence of barriers among diabetics with conventional insulin therapy was higher when compared to diabetics with continuous subcutaneous insulin infusion and a liberalized diet.

It is concluded that diets allowing for variability in energy-intake and meal-times will decrease prevalence of dietary barriers among diabetics. Also barrier prevalence could decrease when the diet is not perceived as consisting of forbidden foods. Diets leading to less dietary barriers are not only more pleasurable to live with, such diets also are more likely to be adhered to.

Key words: Diabetes, Diet, Patient Perspective, Dietary Barriers, Dietary Education, Coping Strategies

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VOORWOORD

Dit proefschrift gaat over onderzoek naar de moeilijkheden die diabeten ervaren met hun dieetadvies. Het onderzoek is in 1985 gestart op de vakgroep Humane Voeding van de Landbouwniversiteit te Wageningen en was mogelijk dankzij project-subsidies van het Ministerie van Welzijn, Volksgezondheid en Cultuur en de Landbouwniversiteit.

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In dit onderzoek heb ik het meest samengewerkt met Anja Niewind. Dit was meer dan de moeite waard. Door de discussies die wij voerden is het onderzoek uiteindelijk geworden tot wat het is. Ik heb grote bewondering voor haar vasthoudendheid en haar grondigheid en hoop dat hiervan iets bij mij is blijven hangen. Ik kijk terug op een gezellige tijd. Dank je wel.

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De Diabetes Vereniging Nederland (DVN) speelde een dubbelrol. Haar steun is onontbeerlijk geweest voor het benaderen van respondenten, terwijl ik de bestuursleden van de DVN in de regio Ede-Wageningen met name wil bedanken voor de tijd die zij vrij hebben gemaakt voor overleg over het onderzoek. Ook ben ik verschillende diëtisten erkentelijk voor hun medewerking bij het werven van respondenten. Bovenal wil ik de respondenten zelf bedanken. Zij hebben met hun zorgvuldige respons de enig mogelijke basis gelegd voor dit onderzoek.

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CHAPTER 1

INTRODUCTION

1.1. General

Influencing people's food choices in order to improve their food use is currently a major issue in preventive medicine. It is recognized that food choices are difficult to change (1-3).

In 1985 research was started in a diabetic population who were required to change their food choices for health-related reasons. The constraints these patients experience were expected to reveal the difficulties of changing food choices. Furthermore the results of this study could yield suggestions for alternative approaches to change food choices of the general public.

This research resulted in two different dissertations. One was published by Anja Niewind (4). The second is the one you are about to read. The focus of this thesis is presented in paragraph 1.6, whereas the outline is to be found in paragraph 1.8.

1.2. Diabetes Mellitus

Diabetes mellitus is a heterogeneous metabolic disease with profound nutritional implications. The incidence of diabetes mellitus is about 12 per 10.000 (5). The prevalence, derived from registration among family doctors, is about 125 per 10.000 (6). This would imply about 200.000 diabetic patients in the Netherlands. Diabetic patients have a deficit of insulin utilization. According to the degree of this deficit, two types of diabetes can be distinguished: insulin-dependent diabetes and non-insulin dependent diabetes. The two types of diabetes are differentiated by etiology, age of onset, prognosis and therapy. Insulin-dependent diabetes is characterized by a severe lack of insulin production, it starts at an early age, and affects the body for a long time. Non insulin-dependent diabetes usually starts at a later age, but its prevalence exceeds that of insulin-dependent diabetes (7). Untreated diabetes will cause blood glucose levels to increase well above 10 mmol/l, leading to ketoacidosis. Currently, diabetes management has progressed beyond merely surviving ketoacidosis. The emphasis now lies on increasing

longevity and preventing the long-term complications of diabetes, which especially affect the blood vessels and nerves. Metabolic derangements associated with poor glycemic control are a major determinant of the frequency and severity of these complications. This has been the rationale for current attempts to maintain near-normal glycemia in patients with diabetes (8,9). To acquire near-normal glycemia, consistency in the timing of meals and appropriate food choices together with regular activity and insulin injections are of paramount importance for insulin-dependent diabetics. For non insulin-dependent diabetic patients metabolic control may be achieved with proper food selection, weight loss and physical exercise, sometimes combined with the use of oral hypoglycemic agents or injecting insulin. In both types of diabetes the diet has been recognized as an essential element in both the management of diabetes and in minimizing the risk of developing long-term complications.

1.3. Dietary recommendations

Nutritional recommendations for diabetic patients are still controversial (10-16). It is agreed that the energy content of the diet should result in achieving and maintaining a desirable body weight. There is much controversy regarding the optimal carbohydrate intake (11), although the general consensus is that carbohydrates should make up 50% of the total energy intake (17,20). Although sucrose was forbidden in the diabetic diet for a long time, today it is recognized that modest amounts of sucrose (up to 50 grams a day) are acceptable, provided it is used in combination with other nutrients (18,19). Total fat intake should be restricted to about 30-35% of total energy intake, and cholesterol intake should not exceed 200-300 mg/day. Replacement of saturated fats with unsaturated fats may slow down the progression of atherosclerosis. The nutritional composition of the diabetic diet is similar to the diet advised for the general population by the Dutch government (20,21).

Currently, most insulin-treated diabetic patients have learned to use an exchange system, in which foods are exchanged on the basis of their carbohydrate content.

Compliance with the diabetic diet is low. It is suggested that only half of the diabetic patients comply with their dietary regimens, although measuring dietary compliance is very difficult (22-24).

Studies have pointed out the diet as a difficult aspect of the diabetic

regimen (25-30). Our own observations also demonstrated the diet to be a difficult aspect of the diabetic treatment (4,31). Furthermore the barriers reported by diabetic patients differed from the barriers reported by health care professionals (31), potentially causing a communication gap between diabetics and their physician or dietician.

1.4. Food choices

Until very recently, the study of food choices was mainly carried out by social anthropologists. In recent years sociologists have also displayed an interest in this subject. Both social anthropologists and sociologists went from the assumption that there is a cultural basis for food choices (32). Despite the structural approach in the 1970's (33) and the more practical or materialistic approach of the 1980's (34,35), there is little explicit theoretical discussion on the approach to be used by social scientists in the study of food choices.

Among nutritionists there is consensus that more knowledge is required about the factors influencing food choices in order to acquire desired changes in food habits. Nutritionists working in this field have been focusing more on doing research than on the development of a theoretical approach to investigate food choices. A fairly comprehensive theory on food choices based on empirical studies was developed by Krongl and co-workers (36,37). According to Krongl the basic requirement for food choices is an available food supply. In other words, there must be food accessibility, and this depends on a complex social system. Limited food access will reduce diversity in food use and decrease the chance of a nutritionally balanced diet. Food abundance will increase the risk of excessive use of some foods. Access to a food will allow a person the opportunity to taste, evaluate and then to accept or reject a food. This process of choosing foods precedes actual food consumption. Food choices are influenced by learned motives which are based on liking for a food, emotional response to the food or factual knowledge about it. Identified motives are: taste, perceived health, convenience, familiarity, prestige and tolerance. Taste and health have been shown to be the most important motives influencing food choices (36-41). Most studies by Krongl and co-workers were carried out among healthy and elderly populations, who were not restricted in their food choices.

The use of foods among healthy populations has also been studied by Shepherd and co-workers (42-45) and Tuorila and co-workers (46,47). They have used the

model of Fishbein and Ajzen (48) to explain the use of fatty foods and of salty foods. They found preferences for foods to be predictive for their use. Perceived social norms were found to be less predictive for food use.

1.5. Dietary barriers

Dietary barriers have been suggested as possible reasons for the lack of compliance with the diabetic diet (30). From this point of view a dietary barrier is a hinderance to dietary compliance. But the barriers that have been reported also impinge upon other area's of a person's well-being. Diabetics' dietary barriers are feelings of hunger, having to eat while other people do not eat or not being able to eat preferred foods (49,50). Therefore from a diabetic's point of view a dietary barrier not only may be a hinderance to dietary compliance, but a dietary barrier could also hinder a diabetic patient to feel physically well, to enjoy food or to enjoy their contacts with other people.

In this thesis the focus is on dietary barriers as experienced by diabetic patients. A dietary barrier is therefore defined as a hinderance to a person's well-being, because of being advised a diet.

1.6. Objectives and design of the study

The objective of the Diabetes Project was to study the difficulties diabetic patients experience when advised to change their food-use because of their diabetes. Niewind (4) studied the barriers insulin-treated diabetic patients experience with their diet, she studied the changes in food-use among insulin-treated diabetic patients before the diagnosis of their diabetes and recently after the diagnosis of their diabetes and she studied the influence of the perception of certain foods on food-use.

This thesis focusses upon the barriers diabetic patients experience with their diet. In appendix I an overview is given of the different studies presented in this thesis.

This thesis is founded on a qualitative inventory of possible dietary barriers among insulin-treated diabetics (4) and non insulin-treated diabetics (Study 1). Since dietary barriers are assumed to contribute to non-compliance (30), also the ways of coping with the different dietary barriers have been studied. A qualitative inventory of possible ways of coping with the different dietary barriers was made (Study 2). This study was followed by an inventory of

possible ways of coping with six specified dietary barriers (Study 3). It was assumed that recently diagnosed diabetic patients would experience many dietary barriers, because they were only recently required to make changes in their food use, and that later on the prevalence of dietary barriers would decrease. To test this assumption the prevalence of dietary barriers and the ways of coping with them was assessed among recently diagnosed diabetic patients with a follow-up after one year (Study 3). Since dietary barriers are caused by the diabetic diet it was assumed that diabetic patients with different diets would experience different dietary barriers. This assumption was tested by assessing barrier-prevalence and their ways of coping among insulin-treated diabetics and non insulin-treated diabetics (Study 4). Barrier prevalence was also assessed among insulin-treated diabetics on conventional insulin therapy and diabetics with continuous subcutaneous insulin infusion and a liberalized diet (Study 5).

1.7. Subjects

The selection of subjects presented us with several problems. First of all there is no registration of diabetic patients in the Netherlands. Sampling of patients through hospitals is dependent on the recruitment process carried out by the medical specialists and thus beyond our control.

In this study we recruited our subjects largely through the Dutch Diabetes Association. The Dutch Diabetes Association has 38,000 members, 80-90% of whom are insulin-treated (6). It is known that most patients who have been diagnosed as insulin-dependent, are being advised by medical personnel to join the organization. An increasing percentage of the patients cancel their memberships after a few years. This suggests that any particular member of the Dutch Diabetes Association may well be a relatively recently diagnosed diabetic. Patients joining the Dutch Diabetes Association may be more interested in their disease. It is known that members of the Dutch Diabetes Association have more knowledge about their disease, are better educated than non-members, and that female members outnumber males (51). In the light of the purpose of the Project, recruitment of insulin-dependent subjects through the Dutch Diabetes Association was considered the most appropriate.

The database of the Dutch Diabetes Association contains only a small fraction of the non insulin-dependent diabetic patients in the Netherlands. Therefore, non insulin-dependent diabetic patients were recruited from other sources.

1.8. Outline of the thesis

Chapter 2 of this thesis is a review of the literature on diabetics' dietary barriers. Chapters 3-7 present the results of our studies on dietary barriers (see appendix I). Chapter 3 is the report of a qualitative study on dietary barriers among non insulin-treated diabetic patients (Study 1). Chapter 4 presents a qualitative study on the ways of coping with dietary barriers among insulin-treated diabetic patients (study 2). Chapter 5 gives the results of an assessment of the change over time of prevalence in dietary barriers among 72 recently diagnosed insulin-treated diabetic patients (study 3), with the prevalence of ways to cope with different dietary barriers. Chapter 6 deals with the comparison of prevalence of dietary barriers and the ways of coping between 571 insulin-treated and 219 non insulin-treated diabetic patients (study 4). Chapter 7 discusses the prevalence of dietary barriers among 43 pair-matched insulin-treated diabetic patients with either conventional treatment or on continuous subcutaneous insulin infusion and a liberalized diet (study 5). Chapter 8 contains the general discussion of this thesis.

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CHAPTER 2

BARRIERS WITH THE DIABETIC DIET: A REVIEW

Extensive literature searches using DIMDI's Sociological, Psychological and Nutrition Abstracts and Medline provided us with only few titles on the subject of dietary barriers experienced by different types of patients. Virtually all of these titles that were found, dealt with dietary barriers experienced by diabetic patients.

The relevancy of dietary barriers to the management of diabetes has been stressed by Tunbridge (1). He stated that compliance with the diabetic diet was poor. He suggested as reasons for non-compliance the patient's failure to adjust to the requirements of a controlled diet, and the physician's failure to realize how difficult this is. He also found that the costs of the diabetic diet were higher than the costs of a commonly used diet and suggested these costs to be another reason for non-compliance. Furthermore he stated that the timetable of the diabetic diets may disagree with the timetable of other people in the social group, or with working and leisure activities, whereas certain foods that are advised may be unknown or disliked by a diabetic patient. Tunbridge based his opinions upon a study of the costs of the diabetic diet, some scattered literature and his own observations as a physician.

Hinkle (2) suggested that the major problem of dietary education was not what diabetic patients should eat. According to Hinkle the real issue was to get diabetic patients eat it. Hinkle based his notions on some remotely related studies and his own observations. Some of his observations are merely anecdotes: 'I have known boys with diabetes to drink half a dozen of 12-oz bottles of carbonated beverages in an afternoon'. Hinkle stated that the diet should satisfy the taste of a diabetic patient, should not disregard social and cultural values, should fit into the patient's routine and the routine of his family. But, most important the diet should satisfy feelings of hunger.

After this several publications stated compliance with the diet to be low, suggesting dietary barriers to be partially responsible for this low degree of compliance (3-5).

The first study, to our knowledge, where dietary barriers leading to dietary non-compliance were systematically assessed comes from Verdonk et al. (6,7). They studied 284 diabetic patients with different diabetic treatments and found that 85% of all respondents reported barriers related to their diet. Among these were financial barriers, psychosocial barriers, culinary barriers and feelings of hunger. A major difficulty in interpreting this study is the lack of a description of how the barriers were reported by the respondents and what method was used to categorize these barriers.

Broussard et al. (8) studied the reasons for dietary non-compliance among 90 non insulin-dependent (NIDDM) Cherokee Indians. Respondents were asked whether or not they followed the diet prescribed by the doctor. When the answer was negative, the interviewers asked for the reasons for non-compliance. The researchers independently categorized these reasons for dietary non-compliance. In a final joined session all barriers that had been differently categorized were discussed and finally categorized into three main-categories:

1. Barriers related to the clinician: feelings of hunger or dizziness, diet not individualized, no dietary instructions received, disagreement on prescribed weight loss and distrust of the medical staff (N=67).
2. Barriers related to the patient: failure to fulfill recognized psychological needs (like feeling distressed, but not able to eat to feel better), lack of support from family and friend, disinterest in the diet, striving for independence and economic reasons (N=40).
3. Barriers categorized as resulting from culturally embedded preferences for Indian foods (N=14).

The methods used in this study make the results more traceable than the results of Verdonk et al. (6,7). But still, it is not known how many reported barriers had to be discussed before agreement upon the final categorization was reached. Furthermore, the study population, Cherokee Indians, does not allow for generalization of the results to other populations.

Later studies were not limited to dietary barriers alone, but comprised the whole diabetic regimen. These studies demonstrated the dietary regimen to be the most difficult aspect of the diabetic regimen for most diabetic patients

(9-13).

Jenny (9,10) studied 245 diabetic patients, drawn from 3000 patient files of a diabetic day center. Data of these 245 patients were collected while they visited their physician. The study variables were based on the Health Belief Model; including beliefs about the barriers or costs associated with taking the recommended action. The study variables were contained in a self-report questionnaire. The research committee of the hospital and four nurse associates scrutinized an early version of the questionnaire for face validity. Also the questionnaire was tested in a pilot study among 35 diabetic subjects.

From the 66 variables assessed, eight were barriers that might affect compliance of the various aspects of the self-care regimen and nine were self-reported compliance variables. The barriers were: cost, time, difficulty, lack of planning, inconvenience, not important, not told, can't be bothered. In an analysis of these barriers between four age groups, Jenny found the diet to be considered the most problematic aspect of the regimen, except for the youngest group who identified urine/blood monitoring the most difficult, with diet coming second. The barriers mentioned most frequently were difficulty, inconvenience and lack of planning. The oldest group mentioned the costs most frequently (9). As the study of Jenny comprised all aspects of the diabetic regimen it was necessary to study those barriers that could be related to these different aspects of the regimen. Therefore these barriers could only be formulated in a very general way.

In the same period another research-group developed a 'Barriers to Adherence Questionnaire' (11,12). Schafer et al. (12) describe the procedure of developing this questionnaire. Six persons with insulin-dependent diabetes mellitus (IDDM) and two nurses specialized in diabetes were asked to generate as many problem situations as possible that occur for persons with IDDM. After eliminating redundant items 36 items remained of which the frequency of occurring and severity were assessed among these eight respondents. Items occurring infrequently or not problematic were eliminated, resulting in a list of 18 items. These items were administered to adolescents and adults attending meetings of the American Diabetic Association. Confusing items and items with no variation in frequency of occurrence or degree of severity were discarded. This resulted in a scale containing 15 items. These items together with variables on general family interaction and different adherence measures for different regimen aspects were administered to 34 campers (aged 12-14 years).

It was found that adherence to one area of the IDDM regimen was not highly related to adherence in an other area of the regimen. Barriers to adherence were found to be most predictive of following one's diet.

Glasgow et al. (12) also used this Barriers to Adherence Questionnaire. Out of the 15 items in the questionnaire four were related to the diet: 'It is easy to make mistakes on the number of food exchanges in a meal', 'After eating what I am allowed, I still feel hungry', 'I am in the middle of an activity with friends when I realize it is time for my afternoon snack' and 'It is embarrassing to eat when the people around me are not eating'. The questionnaire was administered to 65 persons (IDDM) who were recruited in various ways. Respondents were 12-65 years of age and not experiencing major medical problems besides diabetes. Also several adherence measures were assessed: closeness of following the diet, performance of glucose tests, exercise and insulin injections. The highest frequency of barriers was reported for barriers of dietary and exercise adherence. From the barriers related to the diet the highest prevalence was found for the barriers: 'It is easy to make mistakes on the number of food exchanges in a meal', 'After eating what I am allowed, I still feel hungry'. The social barriers had a lower prevalence.

Ary et al. (13) studied 208 diabetic persons (NIDDM and IDDM). They assessed regimen adherence and factors affecting adherence. Using open ended questions respondents were asked to state the two most common reasons for purposefully deciding not to adhere to the diabetic regimen and to state places or locations in which it was difficult to adhere to this regimen. The response was classified, and inter-rater agreement (14) was calculated as ranging from 0.75 to 0.81. Ary et al. (13) found the results for diabetic patients with IDDM and NIDDM to be generally quite similar. Eating out in restaurants and refusing inappropriate food offers from others, were the most frequently mentioned problematic reasons for dietary non-compliance.

When analyzing these studies, we found the most noticeable agreement in all studies to be that barriers are considered relevant to be studied, because such barriers may cause dietary non-compliance. No explicit remarks were found that dietary barriers may be undesirable irrespective of their effect of compliance. This is surprising. The barriers that were described imply that diabetic patients have to spend more money on the diet. They feel that they can not eat when or what other people eat, or they feel they have to eat foods

they dislike or can't eat foods they like. Also feelings of hunger have been reported as dietary barriers. Such barriers limit diabetic's options to enjoy food, keep up social relations, feel physically well or to they are limited to spend money on other things than foods required by the diet.

In those studies with a clear descriptions of the method, two fundamentally different methods to assess dietary barriers were used. One method (9-12) was to have 'experts' (researchers, research committee, nurses or some selected diabetics) create a list or approve of a list with possible dietary barriers. This list is tested in one or more pilot studies and adapted to make a final list with precoded response categories. The other method was to assess dietary barriers by asking a sample of diabetic respondents to indicate reasons for dietary non-compliance with open ended questions (8,13). The response is categorized, and frequencies of barriers in different categories are assessed. Such different methods may lead to different results, even in studies done by two related research-groups. Ary et al. (13) used open ended questions and categorized the response. They found social barriers to be systematically the most frequently mentioned reasons for dietary non-compliance. Glasgow et al. (11) applied a list with four possible dietary barriers and precoded response categories, and found social barriers to be lowest in frequency of occurrence.

2.3. Conclusions

From this review it is clear that the diet has to be considered as a difficult aspect of the diabetes regimen. This finding justifies paying specific attention to dietary barriers. There is no complete inventory of these barriers. Studies assessing the most difficult aspect of the diabetic diet should however be based on a complete inventory. Furthermore the different dietary barriers that have been identified demonstrate that studying dietary barriers may be relevant to understand why diabetic patients deviate from their diet. But, dietary barriers also limit diabetic's options to enjoy food, keep up social relations and feel physically well. Therefore studying dietary barriers should include all dietary barriers irrespective of their effect on dietary compliance. It remains to be studied to what degree these different dietary barriers may result in dietary non-compliance. Lastly it is evident that special attention should be paid to the method employed in a study on dietary barriers, since different methods lead to different conclusions.

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CHAPTER 3

DIETARY BARRIERS EXPERIENCED BY NON INSULIN-TREATED DIABETIC PATIENTS

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ABSTRACT

The aim of this study was to identify the barriers that non insulin-treated diabetic patients experience with their diet, and to compare these barriers with dietary barriers experienced by insulin-treated diabetic patients. Data were collected using a semi-structured questionnaire, in which 58 respondents described in their own words a total of 506 barriers they experienced with their diet. These were categorized into 10 categories with 30 sub-categories. Results demonstrate that dietary barriers are experienced because diabetics consider themselves restricted in foods to choose from. Barriers are experienced when eating in social situations and barriers are caused by the inconsistency between the diet and the physical functioning of a diabetic, leading to feelings of hunger and surfeit. The diet can also be incompatible with other diseases than diabetes. Diabetics experience it hard to have to eat regularly. They find their diet lacking of variety and they find it hard to cope with disruptions of their routine. Most of the barriers assessed in this study equally apply to insulin-treated as to non insulin-treated diabetics. However, some differences were found. It is discussed that a patients' perception of the diet may lead to unnecessary restrictions. Also, the advised diet can be unnecessarily restrictive. By modifying these restrictions the diet will be more pleasant to live with.

INTRODUCTION

Diabetic patients are advised a special diet to manage the possible complications of their diabetes. Among these complications are fluctuating blood-glucose levels possibly resulting in hypo- or hyperglycemia. For non insulin-treated diabetic patients these fluctuations can be managed by matching dietary intake with physical activities. Non insulin-treated diabetics can be prescribed oral hypoglycemic tablets. Dietary intake should be matched with taking such medication. Most of the non insulin-treated diabetic patients tend to be overweight. Successful weight-loss usually improves blood-glucose regulation (1-3). To decrease the increased risk on

cardiovascular diseases diabetic patients are advised a diet with one third of the total energy-intake coming from fat, of which one third should be poly-unsaturated (4). A sugar restriction has been a major aspect of the diabetic diet, but recently the consumption of sugar is considered acceptable. Only for diabetic patients that are overweight a sugar restriction may be relevant because of the contribution to the total energy intake from sugar (5).

For most diabetics the diet is a difficult aspect of the treatment (6-9). Although a systematic inventory of diabetics' dietary barriers is lacking, different barriers with the diet have been reported. These are: eating in social situations, feelings of hunger, inconvenience of the regimen, the financial costs of the diet, lack or difficulty of planning, lack of palatability of the diet and limited possibilities to eat preferred foods (7,9-13). These barriers hinder diabetics in their physical well-being, in living with other people or in enjoying food.

Compliance with the diabetic diet is low (10,14). Dietary barriers experienced by diabetic patient may partly be responsible for this low degree of compliance (15). In order to improve the effect of patient education, Bartlett (16) suggested that physicians should identify highly prevalent barriers that prevent patients from following their medical advice. Bartlett suggested modifying the regimen as a possible fruitful strategy for patient education. But, House et al. (7) showed that the physicians' perception of the difficult aspects of the diabetic treatment and the reasons for non-compliance differ essentially from the diabetics' perception of these. This makes it unlikely for physicians to address barriers that are really felt by diabetic patients. Therefore, we made a systematic inventory of possible dietary barriers experienced by diabetic patients. In a previous study (17) we made an inventory of the dietary barriers among 104 insulin-treated diabetic patients. This inventory yielded 10 categories with 37 different sub-categories of diabetics' dietary barriers. The dietary advice and the regimen for insulin-treated diabetic patients and non insulin-treated diabetics are different. Therefore in this study we made a systematic inventory of dietary barriers experienced by non insulin-treated diabetic patients.

METHODS

A qualitative cross-sectional study was carried out among non insulin-treated diabetic patients, of both sexes, varying in age and duration of diabetes. A qualitative method was used because such a method is suited to obtain an inventory of possible dietary-barriers.

Questionnaire

A self administered questionnaire was developed in which respondents could describe, in their own words, situations in which they had experienced barriers because of their diet. The questionnaire was semi-structured. The questionnaire contained suggestions with regard to situations where dietary barriers might be experienced, like situations at home, work, school, meetings, sports, parties, holidays and trips. We added suggestions as to certain foods that might cause barriers, or restricted amounts to eat, regularity of eating or feeling hungry, and we asked respondents to consider whether they had experienced barriers with their diet the week before the interview.

In a pretest we found that some respondents did not like to write down barriers. Instead, they preferred to be interviewed. To prevent any bias arising from this fact, we offered all respondents the choice between an oral interview and a mailed questionnaire. For the interview the same questionnaire was used. The interviewers used the phrasing of the questionnaire, only asking for clarification when the answers were unclear.

Population

In the Netherlands no general database with the names of non insulin-treated diabetic patients exists. Also the patients' file of the Dutch Diabetes Association (DDA) mainly contains insulin-treated diabetic patients. Therefore respondents were recruited by various ways. Our previous study in diabetics' dietary barriers, with respondents from the patients' file of the DDA, had provided us with six non insulin-treated respondents (17). These respondents were included in this study. Furthermore we put several advertisements in local newspapers and distributed these advertisements into waiting rooms of family physicians and dieticians. In the advertisements diabetics not injecting insulin were asked to participate in our study. Fifty-two non insulin-treated diabetic persons responded to these advertisements. This made the total number of respondents to be 58. Table 1 shows the respondents'

characteristics with a wide variation in age, duration of diabetes and with both sexes. Of the 58 respondents, 49 filled in the self-administered questionnaire and nine were interviewed. Before analysis all respondents' questionnaires were made anonymous.

TABLE 1. Respondents' characteristics, N=58 non insulin-treated diabetic patients.

GENDER (Number of respondents)	
Male	23
Female	32
Unknown	3
DURATION OF DIABETES (Years \pm sd)	
Range (Years)	5.3 \pm 5.0 0.2 - 20
AGE (Years \pm sd)	
Range (Years)	51.6 \pm 9.4 28 - 65
TREATMENT (Number of respondents)	
Only diet	26
Oral hypoglycemic medication	32

Data Analysis

All material received from the respondents was typed out. From this material the descriptions were selected of situations in which respondents had experienced barriers with their diet. To categorize these barriers a categorization system was developed. Our previous study among insulin-treated diabetic patients had produced a categorization system with 10 categories and 37 sub-categories (17). Initially these categories were used. Only when descriptions could not be categorized into the existing categories a new category was added. In the end empty categories were deleted or nearly empty categories were combined with closely related categories. The final categorization-system consisted of 10 main-categories and 30 sub-categories. This method is susceptible to subjective interpretation. Therefore two persons that were not involved in this study independently categorized the barriers into the categorization system. Their inter-coder agreement (18) for the categorization of the descriptions into the 30 sub-categories is 0.81, indicating that, after chance agreement is removed, 81% of the descriptions were categorized in the same way.

RESULTS

The total number of descriptions of dietary barriers was 506 (Table 2). The highest number of descriptions by one respondent was 39. Four respondents did not describe any barriers.

TABLE 2. Barriers Experienced with the Diabetic Diet (1).

Main Category	N
1. Restrictions in the amount and type of foods	79
2. Restrictions in using specific foods	64
3. Restrictions in using diabetic specialty foods	54
4. Reactions from others in social situations	46
5. Barriers with eating and drinking in social situations	59
6. Physical discomfort, feelings of hunger and surfeit	63
7. Barriers due to the required regularity of eating	43
8. Disruption of normal routine/special events	43
9. Lack of dietary variety	2
10. General barriers	53
	506 +

1) Response from 58 non insulin-treated diabetics

Descriptions of barriers were categorized into 10 main-categories (table 2). The first three main-categories relate to the restricted use of certain foods and cover 39% of all described barriers. In category 1 general feelings of being restricted in the use of foods were categorized such as: not being able to eat foods -as much as- one likes, finding it hard to assess how much to eat of a food, eating more than allowed of a certain food with possible subsequent feelings of discomfort or feeling obliged to eat certain foods. In category 2 barriers were placed that are felt because of the restricted use of specified foods. Such foods are high starch foods as pasta, rice, potatoes and pot-pies, vegetables or fruits, pulses or high fat foods. Category 3 relates to diabetic specialty foods that are considered to be bad-tasting, of a bad quality, hard to get or expensive. One fifth of all barriers was classified in the fourth and fifth categorie. These barriers relate to other people. Barriers are due to the reactions of other people, such as a complete disregard of the diabetic diet, or excessive considerations and remarks that also are considered troublesome (Category 4) or people regret that they can not eat what and when other people eat (Category 5). Category 6 contains 63 barriers expressing physical discomfort, feelings of hunger and surfeit. Patients

described that they can not eat while feeling hungry, or they report feelings of surfeit. The diet was also reported not to agree with the requirements set by other physical problems or diabetics describe that the diet makes them feel unwell. The defined quantities in the diet cause barriers because these do not always agree with the physical activities of a diabetic. Lastly barriers were reported because of the difficulty to lose weight. Category 7, with 43 barriers, relates to being required to eat regularly. In category 8, with 43 barriers, the difficulties to cope with routine disruptions or special events were categorized. Category 9, with two barriers, relates to a lack of variety in food intake due to the advised diet. The last category (10) comprises twelve general remarks on how troublesome having a diet can be. Furthermore, this category contains four barriers on the financial costs of the diet and twelve barriers expressing that having a diet is inconvenient for other people. Furthermore 25 barriers were categorized in this main-category where diabetics state that they find their diet unclear, or that they feel insecure because of their diet.

In our previous study among insulin-treated diabetic patients (17) 37 sub-categories were used to classify all information, whereas in this study 30 sub-categories were used. Differences between sub-categories used in this study and in the previous study patients are displayed in table 3.

DISCUSSION

Many barriers found in this study relate to the diabetics' perception of being restricted in foods to choose from. They considered sugar-containing foods or high fat foods forbidden, or they felt that they depend on less preferred diabetic specialty foods. As there are no forbidden foods for diabetic patients and as diabetics are not required to consume diabetic specialty foods these barriers are preventable.

The diet is meant to contribute to the physical well-being of diabetic patients. We found descriptions of barriers indicating that the diet can give rise to feelings of physical discomfort, like feeling hungry, surfeit or difficulties to manage the diet while having an additional disease. Reported feelings of hunger caused by an intended weight loss can not be prevented. But, the diet could provide the required energy needs if weight loss is not aimed at (13). Incidental feelings of hunger or surfeit may still be caused by the prevailing day to day variability of of required energy intake (19-21) and

TABLE 3. Differences in categories used to categorize barriers reported by insulin-treated and non insulin-treated diabetic patients.

MAIN CATEGORIES	Sub-categories uniquely used to categorize response among non insulin-treated diabetics	Sub-categories uniquely used to categorize the response of insulin-treated diabetics
CATEGORY 1. RESTRICTIONS IN AMOUNT AND TYPE OF FOODS		1.2. Being restricted in the use of special nutrients [11] 1.3. It's hard to assess how much to eat of a food [6]
CATEGORY 2. RESTRICTIONS IN USING SPECIFIC FOODS	2.8. Restrictions in the use of fatty foods [17]	2.7. Restrictions in the use of bread [0] 2.8. Restrictions in the use of fatty meats [2] 2.9. Restrictions in the use of butter or fatty sauces [6] 2.10. Restrictions in the use of fatty snacks [1]
CATEGORY 3. RESTRICTIONS IN USING DIABETIC SPECIALTY FOODS		3.1. Being restricted to diabetic specialty foods [2]
CATEGORY 4. REACTIONS FROM OTHERS IN SOCIAL SITUATION	4.1. Others don't consider my diet or they pay excessive attention to my diet [46]	4.1. Others don't consider my diet [4] 4.2. Others make remarks about my diet or pay excessive attention [24] 4.3. Other people buy me special foods [6] 4.4. Other people feel bad not to have bought special foods [4]
CATEGORY 6. PHYSICAL DISCOMFORT, HUNGER AND SURFEIT	6.3. The diet doesn't agree with other physical problems I have, because of the diet I feel sick [8] 6.4. The defined quantities in my diet do not agree with my activities [6] 6.5. It is hard to have to lose weight [13]	
CATEGORY 8. DISRUPTION OF NORMAL ROUTINE		8.2. It is inconvenient when things don't go the way they are planned [19]
CATEGORY 9. LACK OF DIETARY VARIETY		9.2. It is difficult to use exchange lists [7]
CATEGORY 10. GENERAL BARRIERS	10.4. The requirements of the diet are not clear, I feel insecure about the diet, it is hard to assess how much to eat of a food [31]	

Number between brackets [] indicates prevalence of these sub-categories in the respective studies. Total number of barriers in the study among non insulin-treated diabetics was 506, among insulin-treated diabetics 542.

a diet not allowing for such variability. The barriers of eating in social situations demonstrate that eating is not done in isolation. The diet may be incompatible with other peoples' food use, other peoples' food offers and with the variability in their time schedule.

From this study it is not possible to draw conclusions about the prevalence of the different barriers. The study population was self-selected and therefore not representative of the general non insulin-treated diabetic population. This study was a qualitative study, suited to obtain an inventory of possible dietary barriers. Most of the sub-categories used in this study and those used in our previous study among insulin-treated diabetics are the same. However, some new subcategories were added to describe the barriers experienced by non insulin-treated diabetic patients. These sub-categories demonstrate that for non insulin-treated diabetics their diet not always agrees with other physical problems or with their energy-needs. Also a new sub-category was added expressing that non insulin-treated diabetics feel insecure about their diet or experience their diet to be unclear. It remains to be studied whether these differences are really to be attributed to differences between insulin-treated and non insulin-treated diabetic patients.

This study shows the advised diet or the diabetic's perception of this diet to have different consequences. A diabetic patient may feel deprived from a favorite food, feel hungry or supersatiated or a diabetic may feel restricted in contact with other people. These - unintended - side-effects of the dietary treatment will make the diet hard to follow. A suggestion made by Bartlett (16) to improve patient education was to modify the regimen when it is hard to follow. From this study several barriers stand out that can be coped with by modifying the regimen or by modifying patients' perception of the regimen. Barriers arise because certain foods are considered forbidden whereas other foods are considered a must to eat. Such barriers can be prevented by stressing the non-existence of forbidden foods and by teaching diabetics how to include preferred foods in their diet. Other barriers require modifying the treatment, like the barriers due to unnecessary energy restrictions or inflexible diets, leading to feelings of hunger or surfeit. To prevent these barriers diets with flexibility in eating-times and amounts to eat are essential. Furthermore, when a diabetic patient has other diseases besides having diabetes special attention should be given to the requirements of the additional disease.

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CHAPTER 4

COPING WITH THE DIABETIC DIET: MANAGING MULTIPLE GOALS

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ABSTRACT

Diabetic patients look upon the diet as a problematic aspect of their treatment. This study analyses the ways diabetic patients cope with the barriers experienced with their diet. Data were collected using a semi-structured questionnaire, in which 104 insulin-treated diabetic respondents reported how they actually coped with barriers they experienced with their diet. 272 descriptions of ways to cope with a diet-related barrier were analyzed. In coping with these barriers a diabetic not only considers diet, but also physical well-being, social relations and food preferences. It is discussed that dietary education should provide diabetics with options to effectively manage existing incompatibilities between health, social relations, food preferences and the diet.

INTRODUCTION

In order to regulate blood glucose levels insulin-treated diabetic patients are required to adequately manage insulin use, physical activity and food intake. The short term effect of an impaired regulation is hypoglycemia or hyperglycemia. In the long run impaired regulation may result in more severe health complications. It is important that diabetics spread out their food intake over the course of the day, to avoid irregularities in blood glucose levels. Diabetics also are advised to limit their fat-intake to one third of the total energy intake in respect to their higher risk of cardiovascular diseases (1-4). Generally diabetic patients will receive a dietary advice with directions for distribution of meals over the course of the day, and for the nutritional composition of their meals.

Several studies have shown that diabetics find the dietary prescription the most difficult aspect of the treatment of their disease (5-10) and that the rate of compliance is low (11-13). House et al. (9) found that according to physicians lack of motivation is the prime reason for non-compliance. However,

in the same study many diabetics indicated environmental and somatic barriers as the prime reason for dietary non-compliance. Other authors who studied the reasons for dietary non-compliance, from the patient's perspective, conclude that dietary barriers play an important part. These barriers are: Eating in social situations, feelings of hunger, inconvenience of the regimen, lack or difficulty of planning, lack of palatability of the diet and limited possibilities to eat preferred food (6-9,11,14-16). These barriers impinge upon the ability to live a normal life. Therefore these barriers are relevant to the way in which diabetics manage their diet and try to lead a normal life. In a previous study an inventory was made of the barriers insulin-treated diabetics experience with their diet (17). The aim of this study is to subsequently analyze the possible ways insulin-treated diabetics cope with these barriers. We focus on what diabetics actually do in a situation in which they experience these dietary barriers.

METHODS

A qualitative cross-sectional study was carried out among insulin-treated diabetics of both sexes, varying in age and in duration of the diabetes. A qualitative method is particularly suited to obtain a complete inventory of possible coping strategies with dietary barriers. By including a wide range in age, duration of diabetes and both sexes, bias arising from selection of respondents was prevented.

Questionnaire

A questionnaire was developed in which respondents could describe in their own words, how they had actually coped with dietary barriers. First, respondents were asked to describe situations in which they had experienced such barriers. In the questionnaire we suggested a wide range of possible situations where barriers could be experienced, at home, work, school, meetings, sports, parties, holidays or trips. We added suggestions as to certain foods that might cause barriers, or the restricted amounts to eat, the regularity of eating or feelings of hunger, and asked respondents to consider whether they had experienced barriers with their diet the week before. Subsequently respondents were asked to describe what they had done about these barriers. In a pretest it had been found that some respondents do not like to write down barriers and their reactions. Instead, they preferred to be interviewed. To

prevent any bias arising from this fact, we offered all respondents the choice between an oral interview or a mailed questionnaire. For the interview, the interviewers used the phrasing of the questionnaire. For each dietary barrier they asked the respondent's reaction to that specific asked. Clarifications were asked only when the answer was not clear.

Subjects

Subjects were a random sample of 153 patient-members, aged between 20-65 years, of the Dutch Diabetes Association (DDA) living in the surrounding area of Wageningen, the Netherlands. There is no reason to assume that diabetics living in this area would cope differently with dietary barriers than diabetics living elsewhere. The DDA has 38,000 patient members, 80-90% of which are insulin-treated. The total number of insulin-treated diabetics in the Netherlands is estimated at about 100,000. The questionnaires were mailed by the mailing department of the DDA. In this way the anonymity of the respondents was guaranteed. In the mailing it was pointed out that an interview would be possible as an alternative to the writing down of answers. A pre-stamped envelope was enclosed for the return of either the questionnaire or the request for an interview. The first mailing was followed by four reminders, in order to increase response-rate (18). The final reminder was a reply card on which respondents could state the reasons why they did not want to participate in the study, or they could describe one or more barriers. Reactions were received from 137 out of 153 subjects (90%). Of these 137 subjects, 104 were insulin-treated diabetics all of whom were included in the study (68%). Of the other 33 subjects 8 were not included while they did not have diabetes or had non-insulin treated diabetes, 4 were too ill to participate, 3 had died and 2 could not be reached by mail, whereas 16 subjects were not able to participate in the study because they could not find the time. Table 1 shows the population with a wide variation in age, duration of diabetes and with both sexes. Of the 104 respondents, 19 were interviewed. From 63 respondents one or more descriptions of coping strategies were obtained.

TABLE 1. Subjects' characteristics.

	TOTAL POPULATION (N=104)	POPULATION DESCRIBING COPING STRATEGIES (N=63)
GENDER:		
males	50	25
females	53	38
unknown	1	-
TYPE OF RESPONSE:		
Questionnaire	75	44
Interview	19	19
Reply card	10	-
DURATION OF DIABETES (Years):		
Maximum	48	48
Minimum	0.8	0.8
Median	11	11
AGE (Years):		
Maximum	65	64
Minimum	19	19
Median	38	38

Data analysis

All material received from the respondents was typed out. From this material descriptions were selected of how the respondents had reacted when experiencing a barrier due to the diet. A system to categorize the response was developed. This resulted in a categorization system consisting two main categories and twelve sub-categories (Table 2).

This method is susceptible to subjective interpretation. Therefore two other persons, not involved in this study, were asked to independently categorize the coping strategies into the categorization system that was developed. Their inter-coder agreement (19) for classification of the descriptions into the twelve subcategories is 0.74, indicating that, after chance agreement is removed, the categorization-system adequately covers 74% of the described coping strategies. Each description was finally categorized by the two first authors. Whenever classification did not match, it was reconsidered until a final classification was agreed upon.

TABLE 2. Categorization of 273 descriptions of coping strategies with dietary barriers of the diabetic diet.

CATEGORIES		NUMBER OF DESCRIPTIONS
A	ADHERING TO THE RESTRICTIONS OF THE DIET.	
A1	Adhering to the restrictions of the diet	29
A2	Adhering to the restriction of the diet in special situations	32
A3	Avoidance of situations in which adherence to the diet may cause barriers	18
A4	Avoiding certain foods altogether	15
	Total	94
B	MODIFYING FOOD USE TO FULFIL OTHER GOALS BESIDES THE DIET.	
B1	Modifying food use to feel physical well	107
	- Modifying carbohydrate intake to feel physically well (47)	
	- Modifying food intake, without modifying carbohydrate intake, to feel physically well (5)	
	- Take food along, to feel physically well (26)	
	- Modifying insulin-dosage or measuring blood glucose levels, to feel physical well (13)	
	- Other people modify food use to make a diabetic feel physically well (16)	
B2	Modifying food use to play a desired social role	25
B3	Modifying food use to eat preferred foods, or to eat foods in preferred quantities	40
B4	Deviating from the restrictions of the diet	7
	Total	179

RESULTS

The total number of descriptions of coping strategies is 273 (Table 2). The highest number of descriptions for one respondent was 19. The descriptions were subdivided into two main categories (A and B).

The 94 descriptions in the first main category (A) aim at dietary adherence. In sub-category A1, 29 statements were classified which show that people will adhere to different aspects of the diet. These respondents take care that meals are prepared properly and they calculate the quantities to eat. They do not eat at times when they are not allowed to eat, even if they feel hungry. They do eat when they have to, even when feeling already satiated. In sub-category A2, 32 descriptions were classified of dietary adherence on special occasions, such as being out on vacations, eating with other people, parties or school. These respondents eat different foods than other people, they eat at different times or they refuse food offered by other people. The third category (A3) contains 18 descriptions by respondents who avoid situations where adherence to the diet may prove difficult. These situations mainly arise in the company of other people. The fourth category (A4) contains

15 descriptions of people who avoid certain foods altogether, such as sugar, pastas or drinking alcohol.

The second main-category (B) contains 179 descriptions concerning modifications of food use to fulfill other goals besides the diet. This main-category has four sub-categories. Descriptions in the first sub-category (B1) relate to coping with barriers of physical discomfort. Physical discomfort may consist of feelings of hunger and surfeit or of irregular and extreme blood-glucose levels. The descriptions show that these barriers can be the result of variability in physical activity or of changes in the weather. To feel physically well people change the amount of food they eat, they omit meals or eat extra sugar. Also we found descriptions of people not wanting to change their carbohydrate intake and therefore drinking water, eating cucumber, fibre rich food or fatty foods, to overcome feelings of hunger. People take food with them, to prevent low blood-glucose levels or to have something to eat while hungry. Diabetics measure blood glucose levels and change insulin dosage. They do so to manage a change in food intake or to manage unusual situations. Other people also assist in deciding when and which food to use for physical well-being. Sometimes this means that other people make the decision when and what to eat or where to go. The second sub-category (B2) describes how respondents modify food use for socially impelled reasons. They postpone meals, accept food from others, try to fit in, take care not to cause inconveniences to others or try not to draw attention. Descriptions in the third sub-category (B3) refer to the eating of preferred foods or eating of foods in preferred quantities. Foods mentioned here are cold cuts, sweet foods, vegetarian foods, ice-cream, alcoholic drinks, pork and cream cheese. Noteworthy are the efforts by some respondents to be able to eat certain dishes such as spaghetti, macaroni or hotchpotch in a quantity matching the quantity normally consumed by healthy people. The respondents include carbohydrate allowances from other elements of the meal, combine several adjacent meals or just eat more in order to eat these foods in the preferred quantities. All three sub-categories (B1,B2,B3) contain descriptions of coping strategies of respondents acknowledging the boundaries set by the regimen but also descriptions of people skipping meals, eating foods considered forbidden or overeating.

The final sub-category, B4, contains 7 statements of people just deviating from the diet. They state that they cannot afford the diet, or they state that they just do not wish to adhere to it.

DISCUSSION

The object of this study was to find out what diabetics do when experiencing dietary barriers. From this study it becomes clear that these barriers are coped with in different ways. They can be coped with by trying to comply with the diet, but also by modifying food use. When modifying food use, diabetics consider their physical well-being, social well-being and their food preference.

The ways diabetics manage their dietary advice have been studied using the concept of compliance (12,13,20). A compliant person is known to have followed the dietary advice. A non-compliant person is known not to have followed the dietary advice. Little is known about the alternatives chosen by this person instead (21,22). This study shows that coping strategies with dietary barriers which can not be classified as compliant are characterized by deliberate attempts to feel physically well, to play a desired social role or to enjoy food. Applying the concept of non-compliance to these coping strategies denies these attempts. Conrad states that from a patient's perspective the issue is one of self-regulation (23). This is especially relevant for diabetics. They themselves have to play an important role in managing their disease (24). Therefore using the concept of dietary compliance to study the ways diabetics manage their diet seems inadequate.

The coping strategies, found in this study demonstrate that it is not always possible to cope with the barriers of the diet in such a way that these barriers are really resolved. Several coping strategies demonstrate a necessity to choose between different objectives. Compliance with the diet may imply that a diabetic will feel hungry, or super-satiated, that he will have to refrain from eating preferred foods or stop seeing other people. On the other hand, yielding to the need for physical well-being, may imply a deviation from the diet. Yielding to the desire to eat preferred foods or to keep up relations with others may endanger somatic health. Such barriers will give rise to new situations which will again be appraised as problematic.

Diabetic patients should be able to self-manage the regulation of their blood-glucose levels by matching food choice, physical activity and insulin use. A dietary advice should enable diabetics to do so. The possible discrepancy that was found between dietary adherence and managing food intake to feel physically well is to be prevented. Furthermore, the diet is not

meant to restrict people in their enjoyment of food or keeping up relations with others. Still, the way to cope with certain barriers of the diet may require diabetics to choose between either the dietary advice or the enjoyment of food and social relations. Diabetics should be provided with realistic options to cope with the existing incompatibility between health, social relations and enjoying food on the one hand and the diet on the other hand.

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CHAPTER 5

DIABETICS' DIETARY BARRIERS: HARD TO OVERCOME

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ABSTRACT

In this study we investigated dietary barriers among 72 recently diagnosed insulin-dependent diabetics and the change in prevalence of these dietary barriers between recently after the diagnosis of diabetes and one year later. We also studied the ways diabetics cope with different dietary barriers. The most prevalent dietary barriers were feelings of physical discomfort (feeling unwell, feeling hungry), restrictions in food selection (restricted to small amounts of a food, wanting a food excluded by the diet) and the regularity of eating. Less prevalent were barriers related to eating in social situations. No change was found in prevalence of barriers after a one year follow-up. The barrier 'feeling hungry while not allowed to eat' is least often coped with by compliance to the diet. The barriers related to eating in social situations and regularity of eating are most often coped with by compliance. This study demonstrates that dietary barriers are not easily solved by diabetic patients themselves. Therefore, it is important that diets fit in with the irregularities of daily life, food preferences and social situations.

INTRODUCTION

The diagnosis of diabetes with the subsequent regimen requires major changes in life-style for most people. An insulin-dependent diabetic patient has to coordinate injected insulin, physical activity and food-intake. Furthermore the patient is advised to eat carbohydrate-rich foods with a low glycemic index (1), and to limit daily sucrose intake to a maximum of 50 g/day (2). The lifting of the complete ban on added sugar is relatively recent (3). A fat intake of 30% of total energy, a third of which may be saturated, is expected to limit the increased risk of coronary heart disease (1).

Compared to other aspects of the diabetic treatment compliance with the diabetic diet is low (4,5). Several studies report the diet to be the most difficult aspect of diabetic regimen (4,6-9). Among the dietary barriers reported are feelings of hunger and physical discomfort, limited opportunities to eat preferred foods, inconvenience of the regimen and lack or difficulty of

planning, eating in social situations and lack of palatability of the diet (4,9-15). Barriers resulting from the diabetic diet are suggested as an explanation for dietary non-compliance (16). Furthermore these barriers impinge upon some of the essential elements of human functioning such as physical well-being, the enjoyment of food and establishing and maintaining social relations. Identification of these barriers and of the prevalence of these barriers is a first step in the prevention of them.

In a qualitative study on the coping strategies with the barriers of the diabetic diet, it was found that these strategies are not always effective in overcoming the dietary barriers. Also it was found that dietary barriers will not necessarily lead to dietary non-compliance. The coping strategies with dietary barriers reflect diabetics' attempts to compromise between the restrictions of the diet on the one hand, and their desire to feel physically well, to keep up social relations and to enjoy food on the other hand (Chapter 4).

Little is known of the prevalence of dietary barriers among recently diagnosed diabetics, nor is it known whether the prevalence of these barriers would decrease after the first year of diabetes. Also it is not known whether certain dietary barriers are more frequently coped with by complying to the restrictions of the diet than other barriers. This study is an investigation into the prevalence of dietary barriers among recently diagnosed diabetic patients, and the change in prevalence after a follow-up period of one year. Furthermore we will assess the prevalence of specific ways of coping with specific dietary barriers.

METHODS

Design of the study

The design of the study is a cohort study. Diabetic patients were first interviewed shortly after the diagnosis of their diabetes (1987) followed one year later (1988) by a second interview.

Population

The study was carried out among insulin-dependent diabetic patients. The diagnosis of diabetes was limited to a maximum of 6 months prior to the study. For reasons of homogeneity of the population the age range was restricted from

20 to 40 years. Respondents were recruited from the new patient members of the Dutch Diabetes Association (DDA). This association has 38,000 patient members, of whom 80-90% are insulin-treated. Members of the DDA are known to be better informed about their diabetes, to be better educated, with female patients outnumbering male patients (17). From the DDA database we selected those members who had enlisted within a period of 4 months prior to the study and who were aged between 20-40 years (N=198). We excluded eleven people who lived in regions more than four hours of travelling away from the authors' residence. Through the mailing department of the DDA we sent 187 letters with the request to participate in the study. This letter was followed by a reminder. Altogether 174 persons responded (93%). Of these, two did not have diabetes, 16 did not use insulin and 64 had their diabetes diagnosed more than six months prior to the study. Thus 92 were found eligible for the study. Of these, six were not interested to participate in the study, two could not be contacted by telephone or after repeated mailings, leaving 84 respondents to start our study with. Of these four were found to be pregnant, their pregnancy concurring with the diagnosis of diabetes. They were excluded from the study. In the first year complete data-sets were obtained of 80 respondents. In the follow-up year respondents were contacted again. Four were not willing to participate in the study anymore, saying it was too time consuming, three persons could not be contacted and one was hospitalized at that time. Eventually data-sets for both years were obtained of 72 respondents.

Variables and questionnaire

In both years respondents first received a self-administered questionnaire followed within two weeks by an interview at the home or place of work of the respondent. During this interview the response on the self-administered questionnaire was examined, and if necessary, clarifications were asked for.

In this study we have used three sets of variables.

The first set of variables, subject's characteristics, consists of general characteristics, regimen characteristics, perceived most difficult aspect of the diabetic treatment and perceived health. These variables were assessed in the self-administered questionnaire. Respondents filled in date of birth, date of diagnosis of diabetes, height and weight. Educational level, gender, smoking behavior, regimen characteristics and perceived health status were assessed using precoded response categories. Height, weight, regimen

characteristics and perceived health were assessed in both years. The second set, dietary barriers, consists of 24 variables based on a qualitative inventory (10). The variables cover the following categories: 'Physical discomfort', 'Restricted food use', 'Regularity of eating', 'Reactions from others', 'Eating in social situations', 'Having to eat' and 'Lack of variety'. In both years dietary barriers were assessed in the self-administered questionnaire. Respondents indicated whether they had experienced any barriers in the month preceding the interview and subsequently they were asked to rate the severity of the barrier on a three-point scale (not bothersome, bothersome or very bothersome). Respondents were also asked to indicate the frequency of occurrence of these barriers. Glasgow et al. (9) found a high correlation between 'frequency' and 'severity' of barriers. Also in the present study a high inter-correlation between 'frequency' and 'severity' was found for both years. (For 85% of the barriers Kendall's tau B >0.75 and for 60% Kendall's tau B >0.85). The severity-ratings were used for further analysis.

The third set of variables consists of ways of coping with specific barriers. Six barriers were selected: 'Feeling hungry while not allowed to eat', 'Being allowed only small amounts of certain foods', 'Wanting a food excluded by the diet', 'Having to eat regularly', 'Having to turn down food offers' and 'Having to eat while others do not'. In the 1987 study respondents were asked to describe in their own words how they had coped with these six barriers. Their response was used to prepare a list with a full range of specific ways of coping for each barrier. Each list contained a way of coping only directed at compliance to the diet (CO) as well as a way of coping implying straightforward non-compliance (NC). In addition, intermediate ways of coping were included if possible (IC). In the 1988 study, respondents could indicate the use of these ways of coping on a four point scale (never, sometimes, almost always, always).

Data analysis

Data were analyzed using SPSS/PC+ (18). Barriers that were rated as 'bothersome' or 'very bothersome' were recoded as a 'perceived barrier'. For each respondent a total barrier-score was calculated by counting all perceived barriers. Dietary barriers were classified into the seven barrier-categories: 'Physical discomfort', 'Restricted food use', 'Regularity of eating', 'Reactions from others', 'Eating in social situations', 'Having to eat' and 'Lack of variety'. For each category the average prevalence of perceived

barriers was calculated (category-prevalence). For all variables a frequency distribution was made and, if applicable, means and standard deviation were assessed. To test differences we used non-parametric tests because normality could not be assumed for all variables and appropriate non-parametric alternatives were available. McNemar's test was used to test differences in prevalence of perceived barriers between both years. Wilcoxon's signed-ranks test, including zeros and correcting for ties (19), was used to test change in total barrier-score and category-prevalence between both years, and to test for differences in category-prevalence between the various categories for both years. To analyze the prevalence of ways of coping for the different dietary barriers the differences in scores on ways of coping primarily directed at compliance were compared for the different barriers. To test for differences we applied Wilcoxon's signed-ranks test, including zeros and correcting for ties (19). For all tests two-tailed probabilities were calculated.

RESULTS

Subjects' characteristics

General characteristics are displayed in Table 1. Of the 72 respondents 27 were female. The educational level was somewhat higher than that of the average Dutch population of that age (20). Their age was $29.3 \text{ years} \pm 5.6$ (mean \pm sd). The duration of diabetes at the start of the study was $4.1 \text{ months} \pm 2.1$ (mean \pm SD). Respondents were generally not overweight. BMI for 1987 was $22.3 \text{ kg/m}^2 \pm 2.4$ (mean \pm SD). For 1988 BMI was $22.6 \pm 2.2 \text{ kg/m}^2$ (mean \pm SD). Regimen characteristics, perceived most difficult aspect of the diet and perceived health are displayed in Table 2. Most of the respondents, about 80%, reported having been advised to eat at set times consuming set amounts of carbohydrates. In 1987, 18% and in 1988, 8% of the respondents reported to have been advised a diet without added sugar. In 1987 17%, and in 1988 14% of the respondents have been advised a carbohydrate limited diet. About 85% of the respondents considered an equal distribution of carbohydrates over the day the most important aspect of their diet. In 1987, 10% and in 1988 22% reported injecting insulin more than twice a day. In both years more than half of all respondents regarded the diet as the most difficult aspect of the diabetes regimen. About 80% of the respondents reported that they felt healthy.

TABLE 1. General characteristics of 72 recently diagnosed insulin-treated diabetic patients.

Gender (female/male; number)	27/45
Level of educational: (number of respondents) ^{a)}	
First level	3
Second level, first stage	23
Second level, second stage	28
Third level	18
Age (mean yr \pm sd)	29.3 \pm 5.6
Duration of diabetes (mean month \pm sd)	4.1 \pm 1.2
BMI 1987 (mean kg/m ² \pm sd)	22.3 \pm 2.4
BMI 1988 (mean kg/m ² \pm sd)	22.6 \pm 2.2

a) first level education = primary education; second level, first stage = general education, grades 1-3; second level, second stage = general education, grades 4-6 and senior vocational training; third level = vocational colleges, university education

Dietary barriers

Table 3 shows the prevalence of the perceived barriers with the diabetic diet ranging from 3% to 61%. The following four barriers had a prevalence of over 40%, for both years: 'Feeling ill because of irregular eating' (1.1), 'Feeling hungry while not allowed to eat' (1.2), 'Being allowed only small amounts of certain foods' (2.1) and 'Wanting a food excluded by the diet' (2.2).

A significant difference in prevalence between both years was found for only one barrier: 'Feeling ill because of irregular eating' (1.1) ($p < 0.05$).

In 1987 respondents reported an average of 6.3 dietary barriers out of 24 possible barriers, while a year later this average was 5.8. This difference was not statistically significant. Average prevalence of barriers for each category (category-prevalence) is displayed in Figure 1.

Significance of differences in category-prevalence was tested. In both years several clusters of barrier-categories could be identified differing significantly in prevalence ($p < 0.001$). For 1987 we identified the following 3 clusters, in order of descending prevalence. A: 'Physical discomfort', 'Restricted food use' and 'Regularity of eating'. B: 'Reactions from others', 'Eating in social situations' and 'Having to eat'. C: 'Having to eat' and 'Lack of variety'. For 1988 we found the following 4 clusters, in order of descending prevalence. A: 'Physical discomfort', 'Restricted food use' and 'Regularity of eating'. B: 'Regularity of eating', 'Reactions from others' and 'Eating in social situations'. C: 'Reactions from others', 'Eating in social situations'. D: 'Having to eat' and 'Lack of variety'.

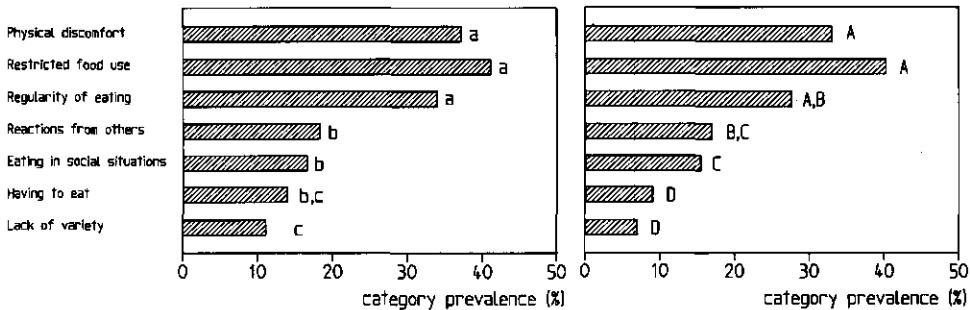


Figure 1. Average prevalence (%) of categorised dietary barriers, among insulin-treated diabetics, after 4 months of diabetes (left panel, 1987) and 16 months of diabetes (right panel, 1988).

Prevalence of categories with different letters differed significantly ($p < 0.001$). Prevalence of categories with the same letters did not differ significantly. Categories with two letters did not differ in prevalence from categories with either of these two letters.

Ways of coping

Table 4 presents the prevalence of different ways to cope with six dietary barriers in 1988. The most frequently mentioned way of coping was directed at compliance (CO). Exception was the barrier of feeling hungry while not allowed to eat. For this barrier the most frequently mentioned way of coping is to eat a carbohydrate free food. For each barrier the lowest prevalence was found for those ways of coping implying straightforward non-compliance (NC). The intermediate ways of coping (IC) were found to have an intermediate prevalence level. When comparing the prevalence of ways of coping directed at compliance between the different barriers it was found that the barrier 'feeling hungry while not allowed to eat' had the lowest prevalence of coping directed at compliance ($p < 0.01$).

The barriers of eating in social situations and the barrier of regularity of eating have the highest prevalence of coping directed at compliance ($p < 0.01$). The barriers of restricted food-use have an intermediate prevalence-level of coping directed at compliance. No differences were found in prevalence of ways of coping among respondents who reported a specific barrier to be bothersome or very bothersome or respondents not reporting this barrier to be bothersome.

TABLE 2. Regimen characteristics, perceived most difficult aspect of the diabetic treatment and perceived health (% of subjects) of 72 insulin-treated diabetic patients 4 months and 16 months after diagnosis of diabetes.

regimen characteristics	4 months	16 months
	% of respondents	
Dietary advice:		
Diet with set timing + amounts of carbohydrates	83	78
Diet with no added sugar	18	8
Carbohydrate limited	17	14
Energy restricted	6	0
No diet	0	4
Other	3	6
Another added diet	7	6
Perceived most important aspect of diet		
Equal distribution of carbohydrates	85	88
Equal distribution of calories	8	1
No sugar	6	3
Low fat	1	1
High fiber	0	1
Other	0	3
No answer	0	3
Frequency of insulin injections		
once a day	30	24
twice a day	61	54
more often than twice a day	10	22
Perceived most difficult aspect of treatment		
Diet	60	70
Insulin injections	21	14
Measuring blood-sugars or sugar in urine	10	11
No answer	10	6
Perceived health status		
Healthy	76	82
Sometimes healthy, sometimes unhealthy	18	14
Unhealthy	6	4

TABLE 3. Prevalence of perceived barriers with the diabetic diet among 72 insulin-treated diabetic patients 4 months and 16 months after the diagnosis of diabetes.

barriers	barrier prevalence	
	4 months	16 months
	% of respondents	
Category 1: physical discomfort		
1.1. Feeling ill because of irregular eating	61	47
1.2. Feeling hungry while not allowed to eat	47	43
1.3. Having to eat while not feeling hungry	36	40
1.4. Feeling thirsty while not allowed to drink	4	3
Category 2: restricted food use		
2.1. Being allowed only small amounts of certain foods	59	54
2.2. Wanting a food excluded by the diet	56	54
2.3. Not know how much to eat of certain foods	38	29
2.4. It is difficult to stay away from sweets	28	28
2.5. Eating more than allowed	26	35
Category 3: regularity of eating		
3.1. Having to eat regularly	42	32
3.2. Disruptions of daily routine makes it difficult to follow the diet	26	24
Category 4: reactions from others		
4.1. Others interfere with what I eat	29	29
4.2. Others forget to buy appropriate foods	21	11
4.3. Others buy special foods for me	18	19
4.4. Others disregard timing	17	15
4.5. Others do not consider that I am on a diet	7	10
Category 5: eating in social situations		
5.1. Having to turn down food offers	21	17
5.2. Having to eat while others don't	21	14
5.3. Being a bother for others	18	21
5.4. Can't eat with other people	11	17
5.5. Being an exception	11	10
Category 6: having to eat		
6.1. Having to eat lean or dietary foods	17	11
6.2. Having to eat much of a certain food	11	7
Category 7: lack of variety		
7.1. Eating is boring	11	7

TABLE 4. Prevalence of ways of coping with six dietary barriers among 72 insulin-treated diabetics 16 months after the diagnosis of diabetes.

Barriers	Ways of coping ^{b)}	Prevalence of ways of coping ^{a)} (%)
Category 1. physical discomfort		
1.2. Feeling hungry while not allowed to eat		
(IC)	I take something without carbohydrates	41
(CO)	I do not eat	29
(IC)	I smoke a cigarette	17 ^{c)}
(NC)	I eat something with carbohydrates	13
Category 2. restricted food use		
2.1. Being allowed only small amounts of certain foods		
(CO)	I do not eat more than allowed	67
(IC)	I eat something else, which I am allowed to eat	36
(IC)	I take as much as I want, and eat less other foods	18
(IC)	I do not eat these products anymore	17
(IC)	I inject extra insulin, and eat what I want	13
(NC)	I eat as much as I like	6
2.2. Not being able to eat preferred foods		
(CO)	I eat something else, which I am allowed to eat	56
(IC)	I eat a little of what I want to eat	15
(NC)	I eat what I want	11
Category 3. regularity of eating		
3.1. Having to eat regularly		
(CO)	I eat regularly	90
(NC)	I do not eat regularly	7
Category 5. eating in social situations		
5.1. Having to turn down peoples' food offers		
(CO)	I turn down people's food offers	79
(IC)	I explain I am diabetic, so that they understand that I have to refuse the food offered	44
(IC)	I inject extra insulin, so that I can accept the food	6
(NC)	I accept the food offered	1
5.2. Having to eat while others do not		
(CO)	I just eat	99
(IC)	I ask others to be considerate of my schedule	14
(NC)	I postpone eating	34

a) For reasons of tabulation, coping-scores were dichotomized. A way of coping was considered prevalent when scored 'always' or 'usually'.

b) Three types of ways of coping are distinguished: CO: Only directed at compliance; IC: Intermediate ways of coping; NC: Ways of coping implying non-compliance.

c) The prevalence of this way of coping among respondents who smoke is 30%.

DISCUSSION AND CONCLUSIONS

In this study the prevalence of dietary barriers was assessed among insulin-treated diabetic patients, an average of 4 months after the diagnosis of diabetes and one year later. This study confirms the findings of other studies that, from a diabetic's perspective, the diet is the most problematic aspect of the treatment of diabetes (4,6-9). For the insulin-treated diabetics participating in this study the most prevalent dietary barrier-categories turned out to be: feelings of physical discomfort, the restriction in food selection and the need for a regular eating-pattern. Barriers caused by others, barriers related to eating in social situations, barriers related to having to eat certain foods or amounts of food or finding eating boring, all have a lower prevalence. No relevant change in prevalence of barriers was found between 4 months and 16 months. This implies that the barriers that are caused by the diabetic diet are not solved by the diabetic patients after one year of having diabetes.

The prevalence of ways of coping directed at compliance differed for the different barriers. The barrier 'feeling hungry while not allowed to eat' was least often coped with by compliance. The barriers related to eating in social situations, and the barrier of regularity of eating were most often coped with by compliance. For the barriers of restricted food use this way of coping has an intermediate prevalence. Dietary barriers with a high prevalence are least often coped with by compliance.

Physical discomfort

The high prevalence, up to 61%, of the barriers in the categories physical discomfort and regularity of eating demonstrates how difficult it is for diabetic patients to coordinate irregularities of daily life with the required stability of food use. Diabetics feel hungry while not allowed to eat. They find it hard to eat regularly. They do not always manage to eat regularly with the result that they feel ill. Or they have to eat at times when they do not feel hungry. The most often mentioned way to cope with the barrier 'feeling hungry while not allowed to eat' is to eat a carbohydrate free food. In a previous qualitative study it was found that these products may be low in calories, such as cucumber or fibre rich food, but the diabetic patient may also decide to take fatty foods, such as cheese or sausage. One third of the smoking respondents, indicate that they smoke to cope with feeling hungry while not allowed to eat. Lean et al. (12) suggest that many diabetic

diets are too low in energy content and that a diabetic patient who feels hungry will use a fatty food when eating extra carbohydrates is not acceptable. For the population in this study, with a mean BMI of about 22.5, an energy restricted diet is not relevant. However it is not only a diet systematically low in energy that may cause feelings of hunger, ultimately leading to a higher fat-intake. Several studies showed a remarkable day to day variation in energy-intake among diabetic patients (21-23). Most of our respondents received a dietary advice with set times to eat set amounts of carbohydrates. According to these respondents the most important aspect of the diet is the equal distribution of carbohydrates over the day. Such diets are inadequate to cover the existing day to day variations in energy-intake. A diet with set times to eat set amounts of carbohydrates is unrealistic, in view of the fact that the energy intake of a diabetic patient varies a great deal from day to day. Such a diet gives rise to highly prevalent dietary barriers that are coped with in potentially unhealthy ways. Diets with set times to eat set amounts of carbohydrates should not be prescribed. It is essential to teach diabetics adequate ways how to vary their daily energy-intake in order to cope effectively with the irregularities of daily life. Studies have compared the impact of a measured versus an unmeasured diet for diabetic patients (24-27). These studies show no detrimental effects on diabetic control for the group of diabetics on the unmeasured diet. Based on our study the assumption can be made that with such diets the prevalence of dietary barriers will decrease.

Food preferences

Also high in prevalence, up to 58%, are those barriers where diabetics feel restricted in their food selection. Diabetics report that they can not eat the foods they like, that they do not know how much they are allowed to eat of a food, or find it problematic to be restricted to only small amounts of certain foods. The restrictions experienced apply to two food-groups: foods containing fat and foods containing sugar (10). The average level of fat intake in the Netherlands is 40% of the total energy intake, with more than one-third being saturated fat (29). To attain the recommended intake of only 30% of total energy, with a maximum of one-third saturated fat, dietary education could be directed at presenting well-tasting alternatives with modest amounts of saturated fats.

A complete restriction on added sugar for diabetic patients is not necessary, although many diabetics report to have been advised such a diet. The accepted

maximum of 50 grams of added sucrose is still well below the level of sucrose intake of the general Dutch population (28). A diet with a complete sugar restriction unnecessarily limits diabetics in the enjoyment of food. It is suggested that allowing sugar in the diet makes the diet more palatable (13). This might increase long-term compliance with important aspects of the diet, such as a low fat intake (2,29). Teaching diabetics how to include commonly used quantities of sucrose in their diet, will at least help making the diet easier to live with, without endangering somatic health.

Social barriers

The barriers where other people play an important role, have a lower prevalence than the afore-mentioned barriers. The relatively low prevalence of social barriers was quite unexpected. Ary et al. (4) state that diabetics should learn assertive refusal skills to cope with food offers. They expect such skills to be essential in attaining dietary adherence. Results from our study do not support this notion. Social barriers have a prevalence of up to 30%. Furthermore, social barriers are most often coped with by compliance. Barriers of physical discomfort and restricted food use have a higher prevalence and are less often coped with by compliance. Efforts should primarily be aimed at teaching diabetics adequate coping skills to manage the irregularities of daily life, to eat foods they like, including sugar containing foods. In this way the frequency with which food-offers need to be turned down may also diminish since many foods can be incorporated into the diabetic diet without endangering somatic health.

The answers we received on our questions on the ways of coping may have been influenced by the respondents' wish to give socially desirable answers demonstrating compliant behavior. Efforts were made to minimize this effect by not associating the research-project with the medical community and by absolutely refraining from value judgements while interviewing. Still, the absolute values of frequency of use of ways of coping should be interpreted with caution. Therefore we based our major conclusions on the relative comparison of the frequencies of ways of coping, and not on the absolute values.

Barriers: hard to overcome

The absence of change in prevalence of dietary barriers between four months and 16 months after the diagnosis suggests that dietary barriers are not easily overcome by diabetic patients. Furthermore, no difference was found in prevalence of ways of coping among respondents experiencing a certain barrier as bothersome or not. Differences would have been found, if effective ways of coping to overcome these dietary barriers had existed. This finding confirms the suggestion that those dietary barriers that we assessed are not easily solved. Dietary barriers occur when the rules of the diet are incompatible with the irregularities of daily life, food preferences or dislikes, food offers and social situations. It is essential to provide diabetic patients with diets that fit in with the irregularities of their daily lives, their food preferences or dislikes, offered foods and social situations.

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CHAPTER 6

DIABETICS' DIETARY BARRIERS: PREVALENCE AND COPING STRATEGIES

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ABSTRACT

In this study we investigated dietary barriers among 571 insulin-treated and 218 non insulin-treated diabetic patients. We also studied the prevalence of ways diabetic patients cope with different dietary barriers. Dietary barriers were categorized using factor-analysis. The most prevalent dietary barriers were the financial costs of the diet and feelings of physical discomfort as a result of the incompatibility between the required regularity of eating and the irregularities of daily life. Somewhat less prevalent were barriers which arise because of a restricted food use. Among the least prevalent were barriers related to eating in social situations. Dietary barriers with a high prevalence were least often coped with by compliance. The major results of this study apply to both insulin-treated and non insulin-treated diabetic patients. Dietary education directed at the prevention of dietary barriers will improve the quality of life of diabetic patients and will result in diets that are easier to be adhered to.

INTRODUCTION

Diabetic patients are advised a special diet in order to control the consequences of their diabetes. To decrease the increased risk on cardiovascular diseases the fat content of the diabetic diet should be one third of total energy-intake (Diabetes and Nutrition Study Group of the European Association for the Study of Diabetes-1988, 1988; Kissebah & Schectman, 1988). For many years a total ban on sugar has been a major aspect of the diabetic diet, but nowadays an intake of 50 grams of sucrose per day is considered to be acceptable (Mann, 1987). Insulin-treated diabetic patients need to balance insulin injections, dietary intake and physical activity (Skyler, 1982). Non insulin-treated diabetics tend to be overweight and therefore are advised to lose weight (Hansen, 1988; Wheeler, Delanthy & Wylie-Rosett, 1987; Wood & Bierman, 1986; Skyler 1982).

For most diabetics the diet is the most problematic part of the regimen (Lockwood et al., 1986; House, Pendleton & Parker, 1986; Glasgow, McCaul & Schafer, 1986; Jenny 1986). In a cross-sectional study among 540 insulin-treated diabetics it was found that 87% of the diabetics experienced one or more dietary barriers (Niewind, 1989). A study among recently diagnosed diabetics assessed differences in prevalence of categories of dietary barriers. Barriers were categorized according to common sense judgments. It was found that the most prevalent categories were those where diabetics experience physical discomfort or where they feel restricted in foods to choose from. Similarly high in prevalence were barriers due to the necessity to eat regularly. Less prevalent were categories related to eating in social situations (Chapter 5).

Dietary barriers impair the quality of life of diabetic patients since these barriers imply physical discomfort and limited possibilities to enjoy food or to keep up social relations (Ary, 1986; Nuttal, 1983). Therefore the prevention of dietary barriers will contribute to the improvement of the quality of life of a diabetic patient. Furthermore, several authors have suggested that dietary barriers can lead to dietary non-compliance (McCaul, Glasgow & Schafer, 1987; Glasgow et al., 1986; Ary et al., 1986; Jenny, 1986; Schafer et al., 1983; Broussard, Bass & Jackson, 1982). However, dietary barriers are coped with in different ways. In a qualitative study it was found that the way diabetics cope with dietary barriers range from compliance with the restrictions of the diet to deviations from the diet. Diabetic patients deviate from their diet to feel physically well, to be able to keep up social relations or they choose to eat preferred foods (Chapter 4). It was also found that highly prevalent dietary barriers are least often coped with by compliance, whereas compliance with dietary barriers with a lower prevalence proved to be more likely (Chapter 5).

Absence of dietary barriers improves the quality of life of diabetic patients. Preventing highly prevalent dietary barriers may make the diet easier to adhere to. Reliable identification of the prevalence of dietary barriers, and their related ways of coping, is a first step in the process of preventing such barriers. In this study we tested whether we could reproduce the finding of a relatively high prevalence of barriers expressing physical discomfort, restricted food use and regularity of eating in a study-population varying in duration of diabetes and age. Also we tested whether we could reproduce the finding that highly prevalent barriers are least likely to be coped with by

dietary compliance. Furthermore, we assessed the prevalence of dietary barriers and their related ways of coping among insulin-treated diabetic patients and non insulin-treated diabetic patients.

METHODS

Population

The study population consisted of insulin-treated and non insulin-treated diabetic patients, aged between 20-65 years. In the Netherlands there is no general database with all diabetic patients. The Dutch Diabetes Association (DDA) has the most complete data-base of diabetics patients. Non insulin-treated diabetics are under-represented in this data-base. From the DDA patient member file we selected those who had joined the DDA in the past five years. Nine hundred and four patient members were randomly selected. They were sent a questionnaire together with a letter explaining the study, and a prestamped envelope to return the questionnaire. To guarantee respondents' anonymity all mail was handled by the mailing department of the DDA. To increase response-rate we sent two reminders. Also the DDA announced in its newsletter the study urging its members to participate. Additional respondents were recruited via dieticians in three clinics and two home-based health care organizations.

Variables and questionnaire

Three sets of variables are used in this study.

The first set of variables are respondents' characteristics. Respondents gave their date of birth, date of diagnosis of diabetes, height and weight.

Educational level, gender, smoking behavior, regimen characteristics and perceived health were assessed using precoded response categories. Education was classified according to the International Standard Classification of Education by UNESCO, adapted to the Dutch educational system (Netherlands Central Bureau of Statistics, 1988).

The second set, dietary barriers, contains 22 variables. These variables are based on a qualitative study among insulin-treated diabetics assessing possible dietary barriers (Niewind, 1989), a replication of this qualitative study among non insulin-treated diabetic patients and our experiences with an earlier version of this set of variables (Chapter 3 & 5). From this last mentioned list we excluded redundant items, reworded unclear items and added

one item on the financial cost of the diet. This item had not been included in the previous study, since our purpose in that study was to assess the frequency with which dietary barriers were experienced as well as the degree of severity. Assessment of the frequency of encountering extra financial costs of the diet did not make sense. In a pretest the response format was tested. A three-point scale 'no barrier - a barrier - a major barrier' proved to be inadequate since respondents perceived the difference between the first two scale points to be far larger than the difference between the last two scale points. A scale was made with more equally distributed differences between the scale-points by adding one scale point, resulting in a four-point scale: 'No barrier - no barrier, but inconvenient - a barrier - a major barrier'. Assessing the frequency of barriers was omitted, since frequency-rating and severity-rating were found to be highly correlating (Glasgow et al., 1986; Chapter 5).

The third set of variables consists of barrier-related ways of coping. In a previous study we assessed possible barrier-related ways of coping with 6 dietary barriers (Chapter 5). From these, four barriers were selected for this study. These barriers are: 'Feeling hungry while not allowed to eat', 'Restricted to small amounts of a certain food', 'Having to eat while others do not' and 'Having to eat regularly'. Each list of barrier-related ways of coping contained a way of coping only directed at dietary compliance and a way of coping implying straightforward non-compliance. Whenever possible intermediate ways of coping were included. Respondents could indicate the use of these ways of coping on a four point scale (never -sometimes -almost always -always).

Data analysis

Analysis of data was done using SPSS/PC+ (Norusis, 1986). Frequencies and, if applicable, means were calculated for the respondents' characteristics. The total number of perceived barriers was calculated by adding up all perceived barriers (scored as 'a barrier' or 'a major barrier'). Common sense judgments were used to create barrier-categories in our previous study. In this study the population size suffices to base the categorization of barriers on the response. A principal components analysis was performed on the response on the 22 dietary barriers, followed by a varimax rotation. The barriers were categorized in agreement with the varimax-rotated components. The adequacy of applying the same categories to both populations was tested. For both

sub-populations two separate varimax-rotated six components solutions were assessed. The categorization of the 22 barriers for these sub-populations was compared to the categorization of these 22 barriers for the total population. Category-prevalence was calculated by averaging the prevalence of the perceived-barriers in one category. Statistical tests were performed using non-parametric statistics, since normality of all data could not be assumed and appropriate non-parametric tests are available. Differences between the scores on two different variables within a population were tested using Wilcoxon's signed-ranks test, including zero differences and correcting for ties (Marascuilo & McSweeney, 1977). Differences in the same variable, between two populations, were tested using Mann-Whitney's test, correcting for ties. For all tests two-way probabilities were assessed.

RESULTS

Respondents' characteristics

Out of 904 questionnaires that were sent to DDA-members, 730 (81%) were returned. From respondents that were recruited via dieticians 59 questionnaires were obtained. Total sample size of the study population amounted to 789. Of the 789 respondents 571 were insulin-treated (INS-population) and 218 were non insulin-treated (NINS-population). Of the NINS-population 74% were using oral hypoglycemic agents. Respondents' characteristics are displayed in Table 1. Of the INS-population 51% and 43% of the NINS-population were male. The level of education did not differ between both populations. Compared to the NINS-population the INS-population was younger, their duration of diabetes was longer and their BMI was lower. Of the INS-population 41% smoked with 27% of the NINS-population smoking. The majority of the INS-population (73%) reported having been advised to eat set amounts of carbohydrates at set times while 39% reported to having been advised not to eat sugar, 19% to limit carbohydrate intake and 10 % to restrict their energy intake. The majority of the NINS-population (71%) reported having been be advised not to eat sugar, 36% to eat set amounts of carbohydrates at set times, 34% to restrict energy-intake and 14% to restrict carbohydrate-intake. No difference in perceived health for both populations was found. About half of both populations considered themselves healthy or very healthy.

TABLE 1. Characteristics of the diabetic study population: Insulin-treated (INS, N=571), and non insulin-treated (NINS, N=218).

	INS	NINS	Difference ^{a)} (INS-NINS)
GENDER (% male)	51	43	*
EDUCATION (% of subjects) ^{b)}			
First level	20	24	NS
Second level, first stage	36	44	
Second level, second stage	29	21	
Third level	15	11	
AGE (mean yr \pm sd)	45.3 \pm 13.5	53.3 \pm 9.1	***
DURATION OF DIABETES (mean yr \pm sd)	8.2 \pm 8.6	4.6 \pm 4.7	***
BMI (Wt/Ht ² :Kg/m ² ; % of subjects)			
Low - < 20	8	4	***
>20 - < 25	59	36	
>25 - < 30	26	42	
\geq 30 - High	7	18	
SMOKING (% smokers)	41	27	--
DIETARY advice (% of subjects) ^{c)}			
Diet with set timing + quantities	73	36	--
Diet with no added sugar	39	71	
Carbohydrate limited	19	14	
Energy restricted	10	34	
Other diabetic-diet	6	13	
No diet	1	1	
PERCEIVED HEALTH STATUS (% of subjects)			
Feel very healthy	8	4	NS
Feel healthy	47	48	
Feel sometimes healthy/ sometimes unhealthy	39	41	
Feel unhealthy	5	7	
Feel very unhealthy	2	1	

a) NS, No significant difference between both populations was found
***, $p < 0.001$, Mann-Whitney's test. (—: Not tested)

b) first level education = primary education
second level, first stage = general education, grades 1-3
second level, second stage = general education, grades 4-6 and senior vocational training
third level = vocational colleges, university education

c) Due to multiple response, the total adds up to over 100%.

Dietary barriers

Table 2 shows the prevalence of the perceived dietary barriers ranging from 5% to 51%. The mean number of barriers for the INS-population is 4.9 and for the NINS-populations 5.2., the difference was not significant. For both populations the five barriers with the highest prevalence are: 'Disruption of the daily routine makes it difficult to follow the diet', 'Feeling ill because of irregular eating', 'Feeling hungry while not allowed to eat', 'Feeling ill because of eating more than allowed', 'Spending much money on food due to the diet'.

A solution with six principal components was selected from the possible solutions of the varimax rotated principal components on barrier-scores. This solution yielded the best interpretable set of components. The sixth component was the first with an eigenvalue below one. All variables loaded positively on these six components. The barrier 'spending much money on food' had a maximum load of 0.3 to 0.4 on three different components. No clear decision could be made where to categorize this barrier. Therefore this barrier was treated as a separate category. This resulted in a total of seven categories of dietary barriers: 'Physical discomfort and instability of eating pattern', 'Extra financial costs', 'Restricted food use', 'Inadequate food offers', 'Eating in social situations', 'Required regularity of eating' and 'Restricted food pattern'. For both sub-populations two separate varimax-rotated six components solutions were assessed. For the INS-population we found that the categorization of the 22 barriers was identical to the categorization of these 22 barriers for the total population. For the NINS-population we found the categorization of the 22 barriers to differ from the categorization of these 22 barriers for the total population: five barriers were categorized in an other category. To test whether these differences should be attributed to an essential difference in response between both sub-populations, we randomly selected 55 samples from the INS-population with 218 respondents. For these 55 samples we assessed 55 varimax-rotated six components solutions. We compared the categorization of barriers based on these six components solutions with the categorization based on the six components solution from the total population. The median number of barriers that were categorized in a different way was 5 (range: 1-8). These results show that a number of five barriers categorized in a different way is to be expected in a randomly drawn sample

TABLE 2. Prevalence of perceived dietary barriers (%) with the diabetic diet, of the diabetic study population: Insulin-treated (INS, N=571), and Non insulin-treated (NINS, N=218)^{a)}.

	Treatment ^{b)}		
	INS	NINS	Effect (INS-NINS)
CATEGORY 1: PHYSICAL DISCOMFORT AND INSTABILITY OF EATING-PATTERN.			
1.1. Disruption of the daily routine makes it difficult to follow the diet	45	51	NS
1.2. Feeling ill because of irregular eating	44	44	NS
1.3. Feeling hungry while not allowed to eat	37	42	NS
1.4. Feeling ill because of eating more than allowed	30	30	NS
CATEGORY 2: EXTRA FINANCIAL COSTS.			
2.1. Spending much money on food due to the diet	41	32	*
CATEGORY 3: RESTRICTED FOOD USE.			
3.1. Being allowed only small amounts of certain foods	26	30	NS
3.2. It is difficult to stay away from sweets	25	29	NS
3.3. Wanting a food excluded by the diet	24	26	NS
3.4. Having to eat lean foods	16	17	NS
3.5. Others eat foods I can't eat	15	20	NS
CATEGORY 4: INADEQUATE FOOD OFFERS.			
4.1. Others forget to buy appropriate foods	21	25	NS
4.2. Have to say no to food offers	18	22	NS
CATEGORY 5: EATING IN SOCIAL SITUATIONS.			
5.1. Others interfere with my eating	24	22	NS
5.2. Have to eat while others do not	18	20	NS
5.3. Having to explain the diet to others	12	18	NS
CATEGORY 6: REQUIRED REGULARITY OF EATING.			
6.1. Having to eat while not feeling hungry	25	15	**
6.2. Having to eat regularly	17	14	**
6.3. Having to take food along	16	11	**
6.4. Having to eat much of a certain food	7	5	*
CATEGORY 7: RESTRICTED FOOD PATTERN.			
7.1. Not know how much to eat of certain foods	19	31	**
7.2. Not able to enjoy food	16	23	**
7.3. Find eating boring	11	14	**
NUMBER OF PERCEIVED BARRIERS (Mean \pm SD)	4.9 (\pm 4.3)	5.2 (\pm 4.7)	NS

a) For reasons of clear display scores on the dietary barrier scale were dichotomised. A barrier was considered prevalent when scored as 'a barrier' or 'a great barrier'.

b) The effect of treatment (insulin-versus non-insulin) was tested using Mann-Whitney's test. Treatment effect was tested for each barrier using the original 4-point scale.

NS: no significant differences was found, * $p < 0.05$ ** $p < 0.01$.

from the INS-population. This number is equal to the five differently categorized barriers from the NINS-population. Therefore, we decided to apply the same categorization of barriers to both sub-populations.

The category-prevalence for the INS-population is displayed in Fig.1. The category-prevalence is highest for the categories 'Physical discomfort and instability of eating pattern' (38%) and 'Extra financial costs' (41%). Less prevalent is the category 'Restricted food use' (23%). This category is followed by the cluster of categories 'Inadequate food offers' (19%), 'Eating

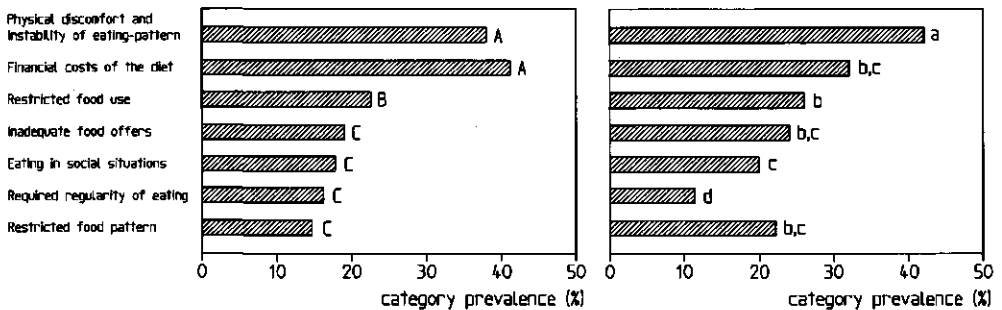


FIGURE 1. Average prevalence (%) of categorized dietary barriers among insulin-treated diabetic patients (left panel) and non-insulin treated diabetic patients (right panel). Prevalence of categories with different letters differed significantly ($p < 0.01$). Prevalence of categories with the same letters did not differ significantly. Categories with two letters did not differ in prevalence with either of these two letters.

in social situations' (18%), 'Required regularity of eating' (16%) and 'Restricted food pattern' (15%). For the NINS-population barrier-prevalence is also displayed in Fig. 1. The category 'Physical discomfort and instability of eating-pattern' (42%) has the highest prevalence. This category is followed by the cluster 'Extra financial costs' (32%), 'Restricted food use' (26%), 'Inadequate food offers' (24%) and 'Restricted food pattern' (22%). This cluster is overlapped in prevalence by the cluster of categories 'Extra financial costs' (32%), 'Inadequate food offers' (24%), 'Restricted food pattern' (22%) and 'Eating in social situations' (20%). The category 'Required regularity of eating' (11%) has the lowest prevalence.

Differences between both populations in barrier-prevalence as well as category-scores were found for three categories. These categories are: 'Extra financial costs' (INS-population higher; $p < 0.05$), 'Required regularity of

eating (INS-population higher; $p < 0.01$), and 'Restricted food pattern' (NINS-population higher; $p < 0.001$). Category-prevalence for the category 'Inadequate food offers' also differed significantly (NINS-population higher; $p < 0.05$). This latter category showed no significant difference for the two separate barriers contained in it. With study-populations significantly differing in gender we tested the effect of gender on the barrier-prevalence. A significant effect of gender was found for seven barriers. The treatment effect was separately tested among men and women for these seven barriers. The effect of treatment turned out to be similar for men and women just like for the total-population.

Barrier related ways of coping

The prevalence of the different ways of coping with the four dietary barriers is displayed in Table 3. The most frequently mentioned way of coping for three barriers is directed at compliance ($p < 0.001$). Ways of coping implying non-compliance were least frequently mentioned. One exception is the barrier 'feeling hungry while not allowed to eat'. For the INS-population the most frequently mentioned way of coping with this barrier is to take something without carbohydrates ($P < 0.01$). Two ways of coping with this barrier are most prevalent for the NINS-population: taking something without carbohydrates and taking something with carbohydrates ($P < 0.05$). For the smoking INS-respondents the most prevalent way of coping with this barrier is to smoke a cigarette ($P < 0.05$). For the smoking NINS-respondents to smoke a cigarette is more prevalent than not eating when feeling hungry while not allowed to eat ($P < 0.05$) and not different in prevalence from taking something with or without carbohydrates. The prevalence of the ways of coping only directed at compliance with the diet for the barrier 'feeling hungry while not allowed to eat' is significantly lowest ($p < 0.001$) when compared to the prevalence of such ways of coping with the other barriers. This applies to both populations. Compared to the barriers: 'having to eat while others do not' and 'having to eat regularly' the barrier 'being allowed only small amounts of a certain food' is significantly less often coped with by dietary compliance. Few differences between both populations in prevalence of barrier-related ways of coping were established. For the barrier 'having to eat while others do not', the NINS-populations shows a lower prevalence of the compliant and intermediate ways of coping.

TABLE 3. Prevalence (%) of ways of coping with four dietary barriers among Insulin-treated (INS, N=571) and Non insulin-treated diabetic patients (NINS, N=218)^{a)b)}.

barriers: ways of coping:	INS(%)	NINS(%)	treatment-effect (INS-NINS)
BARRIER 1.3:			
Feeling hungry while not allowed to eat.			
(IC) I take something without carbohydrates	32	26	NS
(CO) I do not eat	24	20	NS
(NC) I eat something with carbohydrates	23	24	NS
(IC) I take a cigarette	14 (32)	14 (47) ^{c)}	NS
BARRIER 3.1:			
Being allowed only small amounts of certain foods.			
(CO) I do not eat more than allowed	60	54	*
(IC) I take something else, that I am allowed to eat	30	31	NS
(IC) I do not eat these foods anymore	15	25	NS
(IC) I take as much as I want, and take less from others foods	12	13	NS
(NC) I eat as much as I like	6	9	NS
(IC) I inject extra insulin, and eat what I want	5	-	-
BARRIER 5.2:			
Having to eat while others do not			
(CO) I just eat	88	77	**
(IC) I ask others to consider my timing	40	30	***
(NC) I postpone eating	8	8	NS
BARRIER 6.2:			
Having to eat regularly			
(CO) I eat regularly	89	87	NS
(NC) I do not eat regularly	9	12	NS

a) Three types of ways of coping are distinguished

CO: Only directed at compliance

IC: Intermediate ways of coping

NC: Non-compliance.

b) For reasons of clear tabulations, coping scores were dichotomized. A way of coping was considered prevalent when scored as used 'always' or 'usually'. The treatment effect (insulin versus non-insulin) was tested with Mann-Whitney's test, using the original 4-point scale. NS: no significant difference was found, * $p < 0.05$ ** $p < 0.01$ *** $p < 0.001$.

c) Prevalence of this way of coping among those respondents that smoke.

DISCUSSION

The results of this study among a cross-section of diabetic patients are in agreement with the results of an earlier study among recently diagnosed insulin-treated diabetic patients (Chapter 5). The most prevalent barriers are barriers with 'physical discomfort and instability of eating-pattern' and the barrier 'spending much money on food due to the diet'. Less prevalent are barriers resulting from restricted food use. Among the least prevalent are barriers related to eating in social situations. Barriers with a high prevalence are least often coped with by compliance. This pattern applies almost equally to both insulin-treated and non insulin-treated diabetic patients.

This study's categorization of barriers is based on the response-characteristics of the respondents, using principal components analysis. This is a major difference in study-design compared to the earlier study (Chapter 5). Loadings of the barriers were positive on all components. Therefore, barriers in one category are relatively homogeneous.

The category 'physical discomfort and instability of eating pattern' contains barriers with a prevalence ranging from 30-50%. These barriers are characterized by the incompatibility between variability in when and how much a person wants to eat on the one hand and the required stability of food use on the other hand. This incompatibility leads to physical discomfort. This also applies to the barrier 'feeling hungry while not allowed to eat' categorized in this category. Among the insulin-treated respondents 67% has a BMI <25 with only ten percent having been advised an energy-restricted diet. In the earlier study (Chapter 5) the prevalence of this barrier exceeded 40%, with only few diabetic patients being overweight. Diets with set times to eat set amounts of carbohydrates do not agree with the documented reality of a variability in daily energy-intake among diabetic patients (Christensen et al., 1983; Henry et al., 1981; Tunbridge & Wetherill, 1970).

We assessed the prevalence of barrier-specific ways of coping for the barrier 'feeling hungry while not allowed to eat'. Respondents are equally likely to comply with the diet or to deviate from the diet when confronted with this barrier. This contrasts with the other barriers where compliance is the most likely way of coping. In addition the barrier 'feeling hungry while not allowed to eat' is least likely to be coped with by compliance. The most

likely way to cope with this barrier is to eat food without carbohydrates. From a patient's perspective this is a relevant way of coping when the total intake of carbohydrates is limited by the diet, as is the case for over 70% of the insulin-treated respondents. By eating food without carbohydrates diabetic patients avoid to eat extra carbohydrates and simultaneously they satisfy their feeling of hunger. Carbohydrate-free foods can be non-energy-containing foods or fat containing foods. In a qualitative study on the ways diabetic patients cope with their dietary barriers we found evidence for both options (Chapter 4). Lean & James (1986) suggest that diabetic patients will eat fatty foods, when feeling hungry while extra carbohydrate-intake not being an available option. In this way this barrier promotes a high fat intake. Smoking insulin-treated respondents are most likely to light a cigarette when feeling hungry while not allowed to eat. For these patients this barrier reinforces their smoking habit.

A diet with specified times to eat specified amounts of carbohydrates is based on the assumption that diabetic patients require a scheduled eating pattern with defined quantities to eat. Prospective studies have questioned this assumption. It was concluded that a diet without defined quantities to eat, without a time schedule of eating, does not endanger diabetic regulation (Chantelau et al., 1987; Gallagher, Abaira & Henderson, 1984). The necessity for diets with specified times to eat specified amounts is not proven. Such diets do not agree with the reality of variability in daily energy-intake. Ways to cope with a barrier resulting from such diets have a low degree of compliance. This type of diets should not be prescribed to insulin-treated diabetic patients, since such diets do not contribute to health.

Non insulin-treated diabetic patients tend to be overweight. A major goal of their diet is to have them lose weight (Wheeler, 1987; Mann, 1986; Skyler, 1982). Feeling hungry is inevitable. Among non insulin-treated diabetic patients the prevalence of barriers resulting from instability in eating pattern is equal to the prevalence among insulin-treated diabetic patients. It appears that both non insulin-treated and insulin-treated diabetic patients perceive a stable eating pattern equally essential for the control of their diabetes. The primary goal for most non insulin-treated diabetic patients is to loose weight and efforts should be directed at attaining this goal, which is hard enough (Hansen, 1988; Wheeler et al., 1987; Wood & Bierman, 1986).

Additional unnecessary restrictions should not be added to the diet, since it is demonstrated that additional restrictions lead to higher barrier-prevalence. (Niewind, 1989).

The barrier 'spending much money on food' proved to be highly prevalent. Buchenau et al. (1980) found the diabetic diet to be 20% more expensive than the average cost of a recommended normal diet. The difference was attributed to the fact that diabetic patients are required to eat plenty of fruits and salads, also out of season, and to eat low-fat foods which are usually more expensive. A study on the food-use frequency among recently diagnosed diabetic patients documented an increased intake of diabetic specialty foods and low-fat foods (Niewind, 1989). These foods are relatively expensive. It can be argued that the diabetic diet is 'just a healthy diet', without the need for specially required foods and therefore not more expensive than normal food. This position proves to be unsound from a patient's perspective. The required change in dietary intake does require extra money. Barrier prevalence will decrease only if extra attention is paid to low-cost alternatives for high-fat and high-sugar containing foods which are acceptable and tasting. To deny the extra financial cost of the diet, is not a productive strategy.

Barriers which present themselves due to restricted food use show a prevalence ranging from 15% to 30%. The liking of food is an important determinant in food use (Kronold, Coleman & Lewis, 1986; Sims & Shannon, 1989). An important tool in nutrition education is the use of exchange-lists (Franz et al., 1987; Luiten, 1986). A major goal of such lists is to enable diabetic patients to eat their favorite foods while still eating healthy. Even with the availability of exchange-lists it seems hard to prevent that the diabetic patient perceives the diabetic diet as a list of 'should nots' of favorite foods. The effectivity of such exchange lists is to be questioned seriously.

In this study we have compared insulin-treated and non insulin-treated diabetic patients. Both populations not only differed in the way they manage their blood-glucose levels. There were also differences in age, gender, duration of diabetes and BMI. We did not apply a correction for these variables. Differences in age, duration of diabetes and BMI are characteristic for the differences between both populations. Insulin-dependent diabetic patients become diabetic at a younger age. Therefore in a cross-sectional study they are likely to be younger than non insulin-dependent diabetic

patients, but they will also have been diabetic for a longer period of time. Furthermore, compared to non insulin-dependent diabetic patients, insulin-dependent diabetic patients usually are less often overweight. Any corrections for age, BMI or duration of diabetes, would have added artificiality. We tested the effect of gender on barrier prevalence and found it of no consequence to the treatment-effect.

For the two barrier-categories 'Required regularity of eating' and 'Restricted food pattern' the two populations demonstrated a significant difference in prevalence. Insulin-treated diabetic patients reported a higher prevalence, up to 25%, for barriers resulting from the requirement of having to eat regularly. Barriers in this category are comparable to barriers in the first category. The barrier 'Having to eat while not hungry' is the opposite of the barrier 'Feeling hungry while not allowed to eat'. Both barriers are caused by the incompatibility of a diet that stipulates set times to eat set a set amount of food and the reality of a variable daily energy-intake (Christensen et al., 1983; Henry et al., 1981; Tunbridge & Wetherill, 1970). Non insulin-treated diabetic patients report more often that they do not know how much they are allowed to eat of a certain food, or that they do not enjoy the food that they eat. Non insulin-treated diabetic patients in this study seem to have less pleasure in eating compared to insulin-treated diabetic patients. The study-population of non insulin-treated diabetic patients has a majority of diabetic patients using oral hypoglycemic agents. From this study it is not clear whether the conclusions apply equally to diabetic patients with oral hypoglycemic agents as to diabetic patients using only a diet.

The major results of this study apply almost equally to both populations, insulin and non insulin-treated. Both populations are faced with a different treatment and both populations differ significantly in BMI, age and duration of diabetes. From a patient's perspective it seems that the experienced dietary restrictions are not so different. Similarly Ary et al. (1986) found considerable consistency between type I and type II diabetic patients on self-reported factors affecting adherence.

The respondents' answers to the questions on the ways of coping may be influenced by their wish to give socially desirable answers: i.e. answers demonstrating compliant behavior. Efforts were made to minimize this effect by refraining from value judgments. Still, the absolute values of ways of coping should be interpreted with caution. Therefore our major conclusions have been based on the relative values of the ways of coping. Thus we were led to the

conclusion that the prevalence of dietary barriers is inversely proportional to the degree of compliance. This conclusion is in agreement with earlier findings among recently diagnosed insulin-treated diabetic patients (chapter 5) and comparable with the findings of Glasgow et al. (1986) who reported that highly prevalent barriers are related to low levels of adherence to the different components of the diabetic regimen.

Highly prevalent dietary barriers can be attributed to the difficulty to fit the rules on regularity of eating into daily life with its variability. Other highly prevalent barriers are caused by the need to lose weight for non insulin-treated diabetic patients, and the lack to enable diabetic patients to eat foods they enjoy. These barriers impair the quality of life for diabetic patients. Efforts directed at improving the quality of life by preventing highly prevalent dietary barriers, will result in diets that are more likely to be adhered to.

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CHAPTER 7

DIABETES AND DIET: THE EFFECT OF CONTINUOUS SUBCUTANEOUS INSULIN INFUSION (CSII) AND A LIBERALIZED DIET ON THE PREVALENCE OF DIETARY BARRIERS

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ABSTRACT

In this study we investigated whether diabetic patients treated with continuous subcutaneous insulin infusion (CSII) and a liberalized diet would experience less dietary barriers compared to diabetic patients with conventional insulin therapy. For this purpose we selected a group of 43 patients who were treated with CSII and a liberalized diet and a pair-matched group following a conventional therapy. We found that CSII-treated diabetic patients experience significantly less dietary barriers compared to diabetics treated with conventional insulin therapy. This difference is primarily explained by the greater flexibility CSII treated diabetic patients have in their decisions regarding when and how much they wish to eat. CSII-treated diabetic patients report less barriers with the cost of the diet. Both populations showed no difference in prevalence of barriers caused by restrictions in foods to choose from. It is discussed that CSII treatment with a liberalized diet, by improving glucose control but also by decreasing barrier prevalence, will contribute to the quality of life for the diabetic patient.

INTRODUCTION

Traditionally, the diet has been the most difficult aspect of the regimen of insulin-treated diabetic patients (1-4). In a pilot-study among 104 insulin-treated diabetic patients we made a systematic inventory of the possible barriers diabetic patients experience with their diets. The barriers we found were feelings of physical discomfort, the costs of the diet, barriers due to restrictions in foods to choose from, the required regularity of eating and social barriers (5).

A study of diabetic patients treated with long-term subcutaneous insulin infusion (CSII) reported positive health outcomes (6). The diet of these patients was relatively liberalized compared to their earlier conventional diets. A favorable significant decrease was found in mean HbA_{1c} -values from 7.7%(se = 0.1) before starting the CSII to 6.7%(se = 0.1) at follow up together with a favorable impact on the average hospitalization rates of patients.

It was suggested that liberalized diets might decrease the chance that dietary barriers will present themselves compared to caloric defined diets with set times to eat (7,8). In a recent editorial, Home (9) called for studies evaluating the effect of diabetic treatment on quality of life. In this study we address one aspect of the quality of life, which is quality of life associated with a free choice of foods and mealtime. A diabetic diet may be potentially harmful to the quality of life because it causes dietary barriers. These dietary barriers impinge upon aspects of the normal life of the diabetic patient, such as his physical well-being, his enjoyment of food and social relations.

In this study we assessed whether diabetics treated with a combination of CSII and a liberalized diet would experience less dietary barriers compared to diabetic patients on conventional insulin therapy.

METHODS

Subjects and diabetic regimen

Two populations were compared on the prevalence of experienced dietary barriers. The first population was a random sample of 50, drawn from a population of 125 CSII-treated diabetic patients with a liberalized diet and treated at the Department of Nutrition and Metabolism, University of Düsseldorf. CSII treatment was started at the request of patients already familiar with intensified insulin injection therapy (10) and willing to perform blood glucose self monitoring at least four times daily. CSII was initiated during a 5-day in-patient group teaching course (11) on the specific techniques of insulin pump therapy. Diet was liberalized to a certain extent: No caloric restrictions were given and weight maintenance was self-regulated. Patients were advised a diet in which fat, protein and carbohydrates contributed respectively 35%, 15% and 50% of total energy. Rapidly absorbed sugars were restricted except for correction of hypoglycemia. The carbohydrate

content of foods was assessed in 12-gram carbohydrate units which were to be balanced with boluses of regular insulin. No planned food-exchanges were provided. The patients were allowed variability of timing and number of meals (12).

The second population was a sample from a database with 540 randomly selected insulin treated diabetic patient members of the Dutch Diabetes Association (DDA). From this population respondents were matched to the CSII respondents as closely as possible on the variables: gender, educational level, age, duration of diabetes and body mass index (BMI).

Since the control-group was drawn from the files of the DDA, no information was available on the method of diabetes education, methods of self-control or dietary advice. However, self reported data were available. In the control-group for 31 respondents (72%) insulin therapy consisted of a maximum of two insulin injections per day. Thirty-seven respondents (86%) reported assessing blood-glucose values less than once a day. These figures show that the great majority of this population is on conventional insulin-therapy. The population will be referred to as diabetics on conventional treatment (CONV).

Variables

In this study we used two sets of variables. The first set consisted of general and regimen characteristics. These are gender, educational level, age, duration of diabetes, BMI, dietary advice, perceived most difficult aspect of the diabetic treatment and perceived health status. All variables were self-reported in a standardized questionnaire. BMI and HbA_{1c} values were retrieved from the patient files for the CSII respondents. HbA_{1c} was assessed as described earlier (6). Since the CONV-population was drawn from the files of the DDA, no HbA_{1c} values were available.

The second set of variables consisted of 21 dietary barriers. These barriers were derived from a qualitative inventory of possible dietary barriers among 104 insulin-treated diabetic patients (5). These barriers relate to different areas of human functioning that are affected by the prescription of a diet, and to different aspects of the diet causing these barriers. Areas of human functioning that are effected are feelings of bodily discomfort such as feeling hungry or sick and financial costs of the diet. Barriers are the result of restrictions in foods to choose from or barriers may present themselves because of the required regularity of eating. Social barriers are caused by inadequate food offers or social barriers occur while eating with

other people. The dietary barriers have been displayed in Table 2. The response format for the barriers was a four-point scale: No barrier / no barrier, but inconvenient / a barrier / a major barrier.

Statistical analysis

Data were analyzed using SPSS/PC+ (13). For the respondents' characteristics frequencies or if applicable means were calculated. Prevalence was calculated for each barrier. A barrier was considered prevalent when it was scored as 'a barrier' or 'a major barrier'. In addition the barriers were divided into seven categories. These categories were based on the categorization of the response on dietary barriers of 789 diabetic patients on which principal components analysis, followed by varimax-rotation was performed. For each of the seven categories the average prevalence of barriers was calculated in order to yield a category-prevalence.

The total dietary barrier score was calculated by adding all prevalent barriers for each respondent. We tested for differences using non-parametric statistics, since normality of the data could not be assumed and appropriate non-parametric tests are available. Differences in prevalence between both populations in respondents' characteristics, prevalence of dietary barriers, category prevalence and total dietary barrier score were tested using Wilcoxon's signed-ranks test, including zero differences and correcting for ties (14). Two tailed probabilities were assessed for testing differences in respondents' characteristics. The hypothesis of no difference between the prevalence of dietary barriers in both populations was tested against the alternative hypothesis of a lower barrier-prevalence among the CSII population. Therefore one-tailed probabilities were calculated.

RESULTS

We received questionnaires from 43 (86%) CSII respondents. Of these 26 were male, mean age was 33.5 (SD 9.4) years, mean duration of diabetes 15.8 (SD 7.2) years, mean BMI 23.4 (SD 2.0) kg/m^2 and mean HbA_{1c} 6.95% (SD 1.0) (normal 95% confidence interval: 4.07-6.03) (15). The CONV-group did not show differences regarding the matching variables: age, duration of diabetes, BMI, gender and educational level. Mean age was 34.4 years (SD 9.1), mean duration of diabetes was 14.8 years (SD 8.6) and mean BMI was 23.1 kg/m^2 (SD 2.2). Respondents' regimen characteristics are displayed in Table 1. Of the CSII

patients 31% reported being on a sugar-free diet, 25% reported to be on a carbohydrate-limited diet and 38% reported their diet to be a liberalized diet. Of the diabetic CONV-group 30% reported to be on a sugar-free diet while 19% reported to be advised a carbohydrate limited diet. Sixty-three percent reported their diet to prescribe set times to eat set amounts of carbohydrates. Several respondents of the control group mentioned more than one of these characteristics. The measuring of blood-sugars or sugar in urine

TABLE 1. Regimen characteristics and perceived health of diabetic patients with CSII treatment and a pair-matched diabetic population with conventional therapy (CONV) (N=2x43).

	CSII group	CONV group
Reported diet:		
Diet with set timing + quantities	0	63 ^{a)}
Diet with no added sugar	31	30
Carbohydrate limited	25	19
Energy restricted	3	2
Liberalized diet	38	0
Other	6	9
Perceived most difficult aspect of treatment:		
Measuring blood-sugars or sugar in urine	35	28
Insulin injections	9	14
Diet	19	51
Other	16	2
None of these	21	5
Perceived health status:		
Feel very healthy	14	7 ^{b)}
Feel healthy	58	49
Feel sometimes healthy, sometimes unhealthy	26	37
Feel unhealthy	2	5
Feel very unhealthy	0	2

a) due to multiple response the total may amount to >100%

b) No significant difference between both populations was found.

was felt to be the most difficult aspect of the regimen by 35% of the CSII population. Other aspects of the treatment were felt to be the most difficult aspect by fewer of the CSII-treated respondents. The diet was considered the most difficult aspect of the regimen by about half of the CONV-population, followed by measuring blood-sugars or sugar in urine for about one third of the population.

Both populations did not differ significantly in perceived health status: more than half of both populations considered themselves healthy or very healthy.

The mean number of experienced dietary barriers for the CSII-population was 2.6 (SD 2.9), which is significantly lower compared to the mean number of prevalent dietary barriers among the CONV-population: 5.5 (SD 4.3) (Table 2).

TABLE 2. Prevalence of perceived dietary barriers (%) with the diabetic diet among insulin treated diabetic patients, with CSII and a pair-matched group with conventional insulin therapy (CONV)

	Prevalence (%)	
	CSII group	CONV group
CATEGORY 1: BODILY DISCOMFORT AND INSTABILITY OF EATING PATTERN.		
1.1. Disruption of daily routine makes it difficult to follow the diet	28	51 *
1.2. Feeling ill because of irregular eating	14	38 ***
1.3. Feeling ill because of eating more than allowed	23	34 *
1.4. Feeling hungry while not allowed to eat	12	29 **
CATEGORY 2: FINANCIAL COSTS OF THE DIET.		
2.1. Spending much money on food due to the diet	9	45 **
CATEGORY 3: RESTRICTED FOOD USE.		
3.1. Wanting foods excluded by the diet	19	37 **
3.2. It is difficult to stay away from sweets	19	35 -
3.3. Being allowed only small amounts of certain foods	19	22 -
3.4. Having to eat lean foods	9	17 -
CATEGORY 4: INADEQUATE FOOD OFFERS.		
4.1. Have to say no to food offers	12	12 -
4.2. Others forget to buy appropriate foods	2	14 -
CATEGORY 5: EATING IN SOCIAL SITUATIONS.		
5.1. Others interfere with my eating	9	33 *
5.2. Have to eat while others don't	5	27 -
5.3. Having to explain the diet to others	9	19 -
CATEGORY 6: REQUIRED REGULARITY OF EATING.		
6.1. Having to eat regularly	19	31 *
6.2. Having to eat while not feeling hungry	21	27 -
6.3. Always having to take food along	19	27 -
6.4. Having to eat much of a certain food	2	5 -
CATEGORY 7: RESTRICTED FOOD PATTERN.		
7.1. Do not know how much to eat of certain foods	0	30 **
7.2. Not able to enjoy food	5	17 -
7.3. Find eating boring	5	15 *
Number of perceived barriers (Mean ± SD)	2.6 ± 2.9	5.5 ± 4.3**

For reasons of clear display scores on the dietary barrier scale were dichotomized. A barrier was considered prevalent when scored as 'a barrier' or 'a major barrier'. Tests were performed using the 4-point scale. * p<0.05 ** p<0.01 *** p<0.001 Wilcoxon's signed ranks test, one-tailed.

For the CSII treated population the three barriers with the highest prevalence were (Table 2):

- (1) 'Disruption of daily routine makes it difficult to follow the diet' (28%)
- (2) 'Feeling ill because of eating more than allowed' (23%)
- (3) 'Having to eat while not feeling hungry' (21%).

For the control-population the three most prevalent barriers were:

- (1) 'Disruption of daily routine makes it difficult to follow the diet' (51%)
- (2) 'Spending much money on food due to the diet' (45%)
- (3) 'Feeling ill because of irregular eating' (38%)

Barrier-prevalence for the CSII population was significantly lower for 10 barriers out of 21, when set against barrier-prevalence in the control-population ($p < 0.05$) (Table 2).

These barriers were:

- 'Disruption of daily routine makes it difficult to follow the diet'.
- 'Feeling ill because of irregular eating'.
- 'Feeling ill because of eating more than allowed'.
- 'Feeling hungry while not allowed to eat'.
- 'Spending much money on food due to the diet'.
- 'Wanting foods excluded by the diet'.
- 'Others interfere with my eating'.
- 'Having to eat regularly'.
- 'Do not know how much to eat of certain foods'.
- 'Find eating boring'.

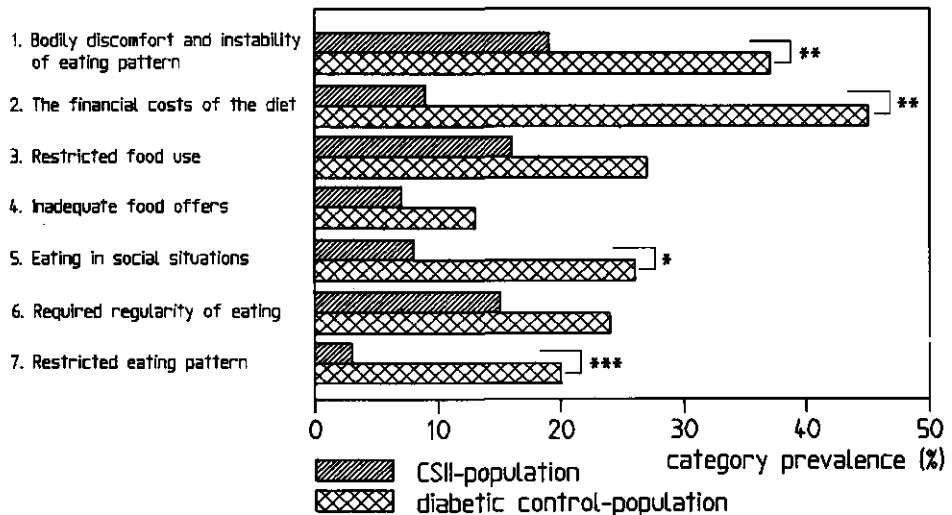


FIGURE 1. Mean prevalence of dietary barrier-categories (%) among insulin treated diabetic patients, with CSII and a pair-matched diabetic control population (N=2 x 43). Differences in category-prevalence were assessed with Wilcoxon's signed ranks test (one-tailed). For reasons of clear display category prevalence is printed as a mean percentage for each category. NS not significant, * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

Figure 1. displays the category-prevalence. Four out of seven categories showed a lower prevalence for the CSII-population.

These categories are:

- 'Bodily discomfort and instability of eating pattern'.
- 'The financial costs of the diet'.
- 'Eating in social situations'.
- 'Restricted eating pattern'.

DISCUSSION

In this study it was found that to CSII treated diabetic patients with a more or less liberalized diet, the diet is not the most difficult aspect of the treatment. This is in contrast with the finding among the population with conventional insulin therapy and earlier findings (1-4). Furthermore, CSII-treated diabetic patients with a liberalized diet experience fewer dietary barriers compared to diabetic patients with conventional insulin therapy matched on age, duration of diabetes, body mass index, gender and educational level. HbA_{1c} values of the sample of CSII-patients in this study are similar to the values reported by Chantelau et al. (6) demonstrating satisfactory blood-glucose regulation. Therefore it may be concluded that CSII in combination with a liberalized diet will lead to a decrease in prevalence of dietary barriers without endangering somatic health.

All barriers in category 1 showed a significant lower prevalence among the CSII-patient group. These barriers arise from the difficulty to combine the required stability of food use prescribed in the diet with the irregularities of daily life resulting in feelings of bodily discomfort (16-18). For the CSII-population combining the diet with the irregularities of daily life is less problematic compared to the CONV-group. The diet for the CSII population allows the patients to vary their timing and the number of meals. Two-thirds of the CONV-population reported to have been advised a diet with set times on which to eat set amounts of carbohydrates, whereas not one of the patients of the CSII-treated population reported such a diet. Greater meal-time flexibility for CSII treated diabetic patients was reported by Capper et al. (8). Lewis et al. (19) studied treatment satisfaction of diabetic patients who self-selected their treatment: CSII treatment, conventional insulin therapy or intensified insulin therapy. A comparison of these populations showed that CSII treated diabetic patients were more satisfied compared to the diabetic patients on a conventional insulin therapy or an intensified insulin therapy. A major factor contributing to this higher satisfaction was the perceived

improved compatibility of the CSII treatment and lifestyle. Greater flexibility of life style of CSII-treated patients results in experiencing fewer dietary barriers. In spite of this the three most prevalent dietary barriers among the CSII population turned out to be: 'Disruption of daily routine makes it difficult to follow the diet', 'Feeling ill because of eating more than allowed', and 'Having to eat while not feeling hungry'. This finding demonstrates that the required balance of insulin dosage and food use still is the major factor in contributing to the prevalence of dietary barriers for this population, although the prevalence of these barriers among the CSII-population is lower compared to the CONV-population.

Differences between both populations regarding barriers due to restrictions in foods to choose from (category 2 and 3) are less clear cut. The prevalence of the barrier related to the cost of the diet is significantly lower for the CSII population. Buchenau et al. (20) found the traditionally prescribed diabetic diet to be 20% more expensive than the average cost of a recommended normal diet. This difference was mainly attributable to the requirement for diabetic patients to eat plenty of fruits and salads and low-fat varieties of foods, which are usually more expensive. Therefore, the lower barrier-prevalence on the cost of the diet is to be explained by assuming that the CSII-treated patient is allowed more freedom in foods to choose from. On the other hand, the prevalence of category 3 (restricted food use) is similar in both populations. This fact contradicts last mentioned assumption. This lack of difference may be attributed to the continuing influence of the dietary pattern that had been adopted by the patients before CSII-treatment was started. The sugar restriction that was considered an essential element of the diet by one third of the CSII population can be the result of this continuing influence. This study is not conclusive about the fact whether or not CSII-treatment with a more or less liberalized diet will contribute to greater flexibility in foods to choose from.

Only one significant difference was found in barrier prevalence where others are concerned. This lack of differences may be partly due to the already low prevalence of such barriers among the CONV-population. Furthermore, the way others react toward a diabetic patient is not necessarily influenced by the kind of treatment, food offers can be equally inadequate.

This study relied on self reported data, this being the only way to assess dietary barriers experienced by diabetic patients in their daily lives. Such data can be subject to response-tendencies. The CSII-treated respondents in this study were self selected, with a special treatment and education. It is likely that these respondents appreciate their special regimen because of the special character of the treatment and therefore they may report less dietary barriers. This tendency may have influenced our results: we found a lower average barrier prevalence among the CSII-treated population. But not all results can be explained by such a tendency. A response-tendency is not likely to influence just one specific cluster of barriers. We found differences in category-prevalence between both populations for some categories, but not for all. We found major differences in barrier prevalence that could be attributed to a greater meal-time flexibility for CSII patients and a difference in barrier-prevalence on the costs of the diet. We found no difference in category prevalence of barriers related to restricted food use. Furthermore perceived health status did not differ between both populations. A supposed response tendency would most likely have lead to a better health evaluation among the CSII population, which we, however, did not find. Therefore, we conclude that, although some effect is to be expected from a response-tendency, the major differences in barrier prevalence are due to specific differences in diabetic regimen between the CSII-treated population and the CONV-population. The flexibility of CSII treatment together with a liberalized diet causes less dietary barriers for diabetic patients. CSII treatment with a liberalized diet contributes to the quality of life of diabetic patients not only by improving their health perspective but also by positively influencing the degree to which they experience dietary barriers.

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CHAPTER 8

DISCUSSION

This thesis deals with barriers diabetic patients experience with their diet, and the way they cope with these barriers. We considered that knowledge about these barriers would be a first step in preventing them. This may contribute to diets that are pleasurable to live with and easily adhered to, and it may contribute to dietary education leading to such diets. Furthermore we considered that knowledge of the barriers experienced would yield an insight into the constraints that the general public experience when advised to change their food-use by health messages.

This discussion is made up of four parts. Paragraph 8.1 describes the design of the study. Paragraph 8.2. is a discussion of the results, followed in paragraph 8.3 by a discussion of the consequences for dietary education for diabetic patients. In paragraph 8.4. the relevance of studying dietary barriers is contrasted against other studies on human food selection. The final paragraph (8.5) is reserved for the consequences of this study for nutrition education in general.

8.1. Study design

This project was designed to assess the prevalence of diabetics' dietary barriers and the ways of coping with these barriers. This project consists of different studies. These are displayed in Appendix 1.

It was started with qualitative inventories of possible dietary barriers among insulin-treated and non insulin-treated diabetics (Study 1). Also an inventory was made of the ways of coping with these barriers (Study 2; Study 3, Step 1). Such inventories were considered necessary as a basis for studies on prevalence.

Subsequently barrier prevalence and the prevalence of the ways of coping with different dietary barriers were assessed in Study 3 among recently diagnosed diabetic patients. To reproduce the findings from Study 3, barrier prevalence and the prevalence of ways to cope with them were assessed in a cross-sectional diabetic population, both insulin-treated and non

insulin-treated (Study 4), varying in age and duration of diabetes.

In Study 5 it was tested whether liberalization of a diet would lead to a decrease in barrier-prevalence.

In this paragraph (8.1.) three methodological issues will be discussed: questionnaire development, the study-population and the method of assessing barrier-prevalence.

8.1.1. Questionnaire development

First a qualitative study was carried out to make an inventory of possible dietary barriers in a group of 104 insulin-treated and a group of 58 non insulin-treated diabetic patients (Study 1) (1). This inventory was used to construct a questionnaire on dietary barriers experienced by diabetic patients (see Appendix 2). Using this questionnaire barrier prevalence was assessed among 72 insulin-treated diabetic patients, shortly after the diagnosis of their diabetes, and one year later (Study 3). In this study it was found that the questionnaire on dietary barriers needed some modification. These were made (see Appendix 3) and this revised questionnaire was applied in a large population of 571 insulin-treated and 218 non insulin-treated diabetic patients (Study 4). The same questionnaire was used to assess barrier prevalence among diabetics treated with Continuous Subcutaneous Insulin Infusion (CSII) in study 5. Only one item of this questionnaire had to be deleted from the analysis because of a translation error.

The study of ways of coping with dietary barriers was started by making an inventory of all possible ways of coping with them among a group of 104 insulin-treated diabetic patients (Study 2). Based on this study it was considered that the way diabetic patients cope with dietary barriers differs for different dietary barriers. Therefore, in the first step of Study 3 an inventory was made of possible ways to cope with six dietary barriers among 72 recently diagnosed diabetic patients. This inventory was used to construct a questionnaire on the ways of coping with six specific dietary barriers (see appendix 4). This questionnaire was used to study the ways to cope with these six barriers in the second step of Study 3 among 72 insulin-treated diabetic patients. In Study 4 the ways of coping with four dietary barriers were determined among 571 insulin-treated and 218 non insulin-treated diabetics, using the same questionnaire as used in study 3 (Appendix 5).

Questionnaires were constructed based on the results of qualitative inventories among relatively large populations of diabetic patients. This procedure has limited the risk of disregarding important barriers or ways of coping with them. The questionnaires can therefore be considered to reflect a full range of possible dietary barriers and ways of coping with six of these dietary barriers.

8.1.2. Study populations

Most of the insulin-treated respondents were recruited via the Dutch Diabetes Association (DDA). Only in Study 4, 31 additional insulin-treated diabetics were recruited via dietitians.

The DDA has the most complete database of insulin-treated diabetics in the Netherlands. However, some caution is required with regard to generalizing the conclusions to all insulin-treated diabetic patients in the Netherlands. Only one third of all insulin-treated diabetics is a DDA-member. Diabetics who had their diabetes diagnosed in recent years are better represented in DDA's database, since most newly diagnosed diabetics are advised to join the DDA. After a few year an increasing percentage of them cancels their membership. DDA-members are found to be better informed and more interested in their disease than non DDA members (2). This may have influenced barrier prevalence in two ways. They might have reported more barriers because of their greater interest in the disease, and subsequent higher awareness of their limitations. On the other hand they may also have succeeded in coping more effectively with their dietary barriers, resulting in a lower prevalence of these barriers.

Non insulin-treated respondents were recruited through the DDA, by an advertisement campaign in local newspapers and through dietitians.

The CSII-treated respondents were a random sample drawn from a self-selected population with CSII-treatment at a University clinic in Düsseldorf, FRG.

In the qualitative inventories (Study 1 + 2) respondents included both sexes, varied in age and duration of diabetes to prevent bias in barriers and ways of coping that might have come from a selected population.

The first study to quantify barrier-prevalence (Study 3) was done among recently diagnosed insulin-treated diabetics. Recently diagnosed diabetics were selected because for them the contrast between not being advised a diet and the advised diabetic diet would be most clear.

Subsequently a study was done among a cross-section of insulin-treated and non insulin-treated diabetics with both sexes, varying in age and duration of diabetes. This assorted population was selected to be able to generalize the

results of our study as much as possible within the constraints discussed earlier. Lastly diabetics with a liberalized diet were studied. These respondents were selected to be able to test whether diet-liberalization could be a possible strategy in preventing dietary barriers.

8.1.3. Assessing barrier-prevalence

In chapter two, the review of literature, we discussed the studies of Ary et al. (3) and Glasgow et al. (4). Ary et al. (3) reported that eating out in restaurants and food offers from others were the major reasons for dietary non-compliance. They based this conclusion on the response of 208 diabetics on open ended questions. Glasgow et al. (4) administered a questionnaire with 4 items on dietary barriers with precoded response categories among 65 diabetics. They found the most prevalent dietary barriers to be those that deal with the difficulty to eat the proper amounts of food and still feeling hungry while not being allowed to eat anymore. Social barriers came last. In chapter two we have attributed these different results to a different methodology: an open ended questionnaire versus questions with precoded response-categories.

In our study we employed both methods. To identify possible dietary barriers we used open ended questions in Study 1. In analogy with Ary et al. (3) we could have interpreted the response on these questions in terms of prevalence. The results would have suggested barriers due to restrictions in food use to be most prevalent, followed by social barriers. Barriers with physical discomfort would be less prevalent. Our results on barrier-prevalence in studies using precoded response-categories (Study 3+4) lead us to different conclusions. These studies show that barriers with physical discomfort are most prevalent while social barriers are less prevalent.

In our opinion conclusions about the prevalence of dietary barriers are best drawn on the results of studies 3 and 4. The method used in these studies allows for more control over the generation of the information and allows a more reliable comparison of the results between respondents (5). Furthermore the use of a four-point scale in study 4 allowed for more sophisticated statistical analysis.

8.2. Managing dietary barriers

8.2.1. General

The barriers that make the diet a difficult aspect of the diabetic regimen and their prevalence, the ways to cope with different dietary barriers, and the influence of duration of diabetes and different diabetic treatments on dietary barriers have been assessed in this study. The results will be discussed in this paragraph.

8.2.2. What is a dietary barrier

In chapter two we showed that dietary barriers were considered relevant to be studied because these may hinder dietary compliance. We considered that a dietary barrier encroaches upon a person's well-being regardless of its impact on compliance. Therefore it was decided to study dietary barriers whether or not they lead to dietary non-compliance. As a consequence a dietary barrier was defined as a hindrance to a person's well-being, induced by being advised a diet.

Analysis of the different dietary barriers that were identified shows two different elements that characterize a dietary barrier. The first element is a hindrance that is caused by being advised a diet. Such hindrances are: Restrictions in foods to choose from, the required regularity in the eating-pattern, restrictions in quantities to eat and hindrances caused by other people. The second element contains aspects of a person's well-being that are at stake because of these hindrances. These aspects are: physical well-being, well-being associated with enjoying food, well-being associated with feeling sure that one eats the right amount of foods, well-being associated with spending money on goods other than on food required by the diet and social well-being. In paragraph 8.2.3. to 8.2.6. the impact of the diet on these different aspects of a person's well-being will be discussed.

8.2.3. Physical discomfort

The prevalence of barriers expressing physical discomfort is among the highest as assessed in the Studies 4 and 5. This was an unexpected observation. The justification to ask diabetic patients to keep their diet lies in the assumed physical benefits that can be obtained from keeping the diet. From our results the validity of this justification is to be questioned.

The major explanation for the prevalence of barriers expressing physical discomfort is a caloric defined diet with set times to eat, that was advised to most of the insulin-treated diabetic patients in this study. Such a diet does not allow for variability in daily life nor for the day to day variability in energy-intake that has been found among insulin-treated diabetics (6-8).

We have shown that for the barrier: 'Feeling hungry while not allowed to eat' the most frequently used way to cope with this barrier was to eat carbohydrate-free foods, including fatty foods. Smoking respondents tended to light a cigarette when feeling hungry. These ways of coping are clear attempts to comply to the prescribed diet of no additional eating and certainly no additional carbohydrate-intake. These ways of coping can lead to an increased fat intake, or consolidate a smoking habit among diabetic patients.

A diet leading to feelings of physical discomfort whereas it is meant to contribute to a person's well-being is a paradox. Even more, attempts to comply with such a diet that prove not to contribute to a person's health perspective add to this paradox. This paradox is caused by caloric defined diets, that are inadequate. The desirability of advising such diets is therefore to be questioned.

8.2.4. Restrictions in foods to choose from

Barriers expressing restrictions in foods to choose from were found to be among those with the highest prevalence. These barriers restrict the possibility for diabetics to enjoy their food. These barriers also can be a cause for dietary non-compliance. It was found that these barriers have an intermediate rate of non-compliance. Furthermore, it was found that diabetic patients tend to reduce the number of foods they eat shortly after the diagnosis of their diabetes (1).

The barriers 'Wanting foods excluded by the diet', 'Finding it difficult to stay away from sweets', 'Having to eat lean foods' and 'Others eat foods I can't eat' demonstrate that many diabetic patients consider their diet to consist of forbidden foods or foods that should be eaten. For diabetics there are no forbidden foods. Therefore, this perception of the diet is to be a matter of concern for dietary educators.

One more barrier has to be mentioned under this heading: 'Not knowing how much to eat of a certain food'. Apart from feeling restricted in the use of certain foods, one fifth to one third of the diabetic patients have doubts about how much they can eat of a particular food and find this a barrier.

8.2.5. The financial costs of the diet

The barrier expressing that diabetic patients feel that they have to spend much money on food because of their diet was found to have a prevalence of 41% among insulin-treated diabetics and 32% among non insulin-treated diabetics. From the diabetic patient's point of view their diet is more than just a ordinary healthy diet. For them the advised diet requires extra money. This can be understood when considering that recently diagnosed diabetic patients exchange cheap high fat foods for more expensive lean foods and that they tend to eat diabetic specialty foods that are more expensive than their common alternative (1).

8.2.6. Social barriers

Social barriers were found to have a relatively low prevalence, ranging from 7% to 30%. Social barriers were least often coped with by dietary non-compliance. These findings could lead to the conclusion that social barriers, and with these the social function of food are not really to be bothered about when giving dietary advice. Such a conclusion would be premature. The barriers with physical discomfort are most felt. One can assume that social barriers will come up as major barriers when the barriers expressing physical discomfort are effectively resolved. On the other hand when advised diets allow for more flexibility in meal-times and when the exclusion of foods is not felt as being essential to the diet, the absolute prevalence of social barriers is also likely to decrease, because several of the social barriers are caused by fixed meal-times and considering foods to be forbidden.

8.2.7. The effect of duration of diabetes and different diets on dietary barriers

In study 3 no effect of duration of diabetes on barrier prevalence was found. Initially it was assumed that recently diagnosed diabetic patients would experience a great number of dietary barriers, whereas after having diabetes for one year the prevalence of barriers would have been decreased due to the increase of knowledge and daily experiences with the diet. These assumptions

proved to be wrong. It was concluded that the dietary barriers that were studied are not easily solved by diabetic patients themselves. The inventory of dietary barriers (Study 1) is based on the response of diabetic patients with a wide range of duration of diabetes. Barriers that could have been resolved within a year of having diabetes were therefore likely to go unnoticed. Therefore the dietary barriers in this study are those barriers that are not easily solved by diabetic patients themselves within one year. These barriers seem to be inherent to the advised diet. Differences in experienced barriers are to be expected with different advised diets.

It was subsequently studied whether insulin-treated or non insulin-treated diabetic patients experienced different dietary barriers (Study 4). In this study no great difference was found in barrier prevalence. Only for barriers in categories that were low in prevalence for both populations were differences found. This lack of difference was puzzling. The rationale behind the diet for insulin-treated and a non insulin-treated diabetic patients is different (9-11). Since we studied those barriers that were due to a diet, the lack of differing barrier prevalence, can imply that the advised diets were not so different after all. From this study it can not be concluded whether this suggestion is true or not. But if so, it would point to a lack of tailoring the diet to the requirements of the disease, thus causing unnecessary dietary barriers because of unnecessary restrictions.

To test whether a different diet would make any difference in barrier prevalence we selected a study population who were known to be advised on a different diet. In Study 5 it was tested whether CSII-treated diabetic patients with a liberalized diet would experience less dietary barriers than diabetic patients with conventional insulin therapy. Again a difference in barrier prevalence was expected, especially since the CSII-population were known to be explicitly taught a more liberalized diet. CSII-diabetics were found to experience less dietary barriers. Differences in barrier-prevalence could be attributed to the greater mealtime flexibility that is characteristic of CSII-treatment with a liberalized diet (12,13). It can be concluded that barriers that are caused by diets that do not allow for variability in daily life nor for the day to day variability in energy-intake can be prevented by creating greater mealtime flexibility.

8.2.8. Ways of coping with dietary barriers

The way to cope with different dietary barriers has also been studied in this thesis. In both Studies 3 and 4 an inverse relationship was found between barrier prevalence and prevalence of compliant ways of coping. Highly prevalent dietary barriers are major hindrances to the quality of life of diabetic patients. Highly prevalent barriers also are most often coped with by dietary non-compliance. Those dietary restrictions that make barriers highly prevalent also are most difficult to be adhered to. Aiming at reducing dietary barriers therefore is a fruitful strategy to both make the diet more pleasurable to live with and to make the diet more likely to be adhered to.

8.3. Preventing diabetics' dietary barriers

8.3.1. General

Dietary barriers are hindrances to a diabetic's well-being. The issue of how to prevent these barriers therefore is worth considering. Preventing dietary barriers will contribute to the quality of life of diabetic patients and to diets that are more likely to be adhered to. In this paragraph (8.3) the focus is on dietary education. The aim of dietary education should be to advise diets that contribute to a person's well-being. In this paragraph suggestions are made on how to prevent dietary barriers and thereby to contribute to a diabetic's well-being.

8.3.2. Advising diets that do not cause unnecessary dietary barriers

In Study 5, CSII-treated diabetic patients with a liberalized diet were found to experience less dietary barriers compared to diabetic patients with conventional insulin therapy. This finding demonstrated that dietary barriers can be prevented by advising diets that contain less restrictions. In Study 3 the lack of differences in prevalence of barriers among recently diagnosed diabetics patients compared to after a follow-up period of one year, demonstrated that it is hard for diabetic patients to overcome the dietary barriers caused by a given diet.

Studies have shown that non caloric defined diets are not detrimental to diabetic control for lean diabetics (14-17). Since caloric defined diets with set times to eat give rise to highly prevalent dietary barriers that are often coped with by dietary non-compliance, the desirability of advising caloric defined diets should be questioned.

Furthermore, to prevent dietary barriers, diets that suggest the exclusion of certain foods should not be advised. Exclusion of foods from the diet leads to highly prevalent dietary barriers. When confronted with these barriers the diet does not have a big chance of adherence.

8.3.3. Food exchange lists

Food exchange lists have been developed as an alternative for lists with foods that should be eaten and foods that should not be eaten (18). Exchange lists are meant to enable diabetic patients to eat a variety of foods while eating in a healthy way (19). Most insulin-treated diabetics are provided with an exchange list. The high prevalence of barriers that demonstrate diabetic patients to consider their advised diet to consist of foods that should or should not be eaten, questions the effectivity of these exchange lists. Ways to improve the effectivity of exchange lists to reduce barrier prevalence should be considered.

The principles of a food exchange list and the advised diet are strongly related. In our studies most insulin treated diabetics were advised a caloric defined diet with set times to eat. An exchange list could enable diabetic patients to adhere to such a diet, while eating a variety of foods. Constancy in energy-intake is not a requirement for lean diabetic patients. Therefore, an exchange list that enables them to adhere to such a diet is not needed. Instead, exchange lists can be used in a teaching process to provide diabetic patients with knowledge or a source of knowledge of the carbohydrate-content or energy-content of a food. With this knowledge they can adjust their insulin doses (20) to their energy intake and physical activity based on regular blood-glucose readings. This requires a new type of exchange lists.

The exchange list that was developed by the DDA contains classes of foods with equal carbohydrate contents. The class-width is 3.5 grams of carbohydrates. In this way this exchange-list enables diabetic patients to discriminate between foods that differ more than 3.5 grams of carbohydrates. Coefficients of day to day variation of carbohydrate-intake were reported to range from 7% to 24 % (8) for insulin-treated diabetics on a controlled diet, without this having a noticeable influence on diabetic regulation. Variation of 15% on a meal of, for instance 75 grams of carbohydrates, would imply a range of 64 grams to 86 grams of carbohydrates. This, realistic, range exceeds the precision of 3.5 grams in the exchange-lists by more than six times. The precision suggested by

using the exchange-list of the DDA does therefore not agree with the reality of the variability of energy-intake in daily life.

The CSII-patients on which we reported were taught to assess carbohydrate-contents of a food in 12 gram units (=one slice of bread) and to balance the estimated carbohydrate-contents or energy-contents of a meal with their insulin intake. Respondents from this study demonstrated satisfactory diabetic control. To effectively control blood-glucose values exchange lists can obviously do with a greater class-width. By increasing the class-width used in exchange lists the selection of a variety of foods is likely to be more easy to perform. Such exchange lists may best serve their aim: providing the possibilities for optimal food-variety.

8.3.4. Educating diabetic patients to cope with dietary barriers

Another strategy to prevent dietary barriers is to make these barriers the subject of a dietary consultation. Together with the diabetic patient the dietician can discuss the options to cope with a barrier that is encountered to prevent this barrier in the future (21). In a feasibility-study among 10 dieticians in 50 consultations we have tested whether such a strategy might work. The questionnaire with dietary barriers as displayed in appendix 3 was used to identify dietary barriers. According to eight out of ten of the dieticians the use of the questionnaire with subsequently making the reported dietary barriers the subject of a dietary consultation, is a feasible strategy.

8.4. The influence of dietary barriers on food use

8.4.1. The relationship between dietary barriers and food use

In chapter 1.5. the studies of Kronl and co-workers, Shepherd and co-workers and Tuorila and co-workers were presented as providing usefull theories on food choices. These authors have sought to explain the use of different foods from learned motives (22-24) or beliefs about these foods (25-30). All three groups studied populations in which dietary change was not especially urged.

In this thesis diabetic patients were studied, for whom dietary change was recommended. Many of the barriers diabetic patients experience with their diet, have in common that they are related to a specific situation. For instance the barrier 'Feeling hungry while not allowed to eat' is not experienced always or everywhere. The same goes for the other barriers in the

category of physical discomfort. Also the social barriers are situation specific. These barriers are experienced only when with other people. When confronted with a barrier in a certain situation a diabetic patient is required to do something. When feeling hungry but not allowed to eat the options are: 'not to eat', 'to take something without carbohydrates', 'to smoke a cigarette' or 'to take something with carbohydrates'. When someone offers a food that a diabetic considers best not to eat the options are: 'to refuse the food offered', 'to explain one is diabetic followed by a refusal of the food' or 'to accept the food'. For both situations either outcome has consequences for a person's food-use.

The studies of Kronl and co-workers, Shepherd and co-workers, Tuorila and co-workers provide an explanation of the respondent's preference for a certain food. But whether or not such a food is consumed in a certain situation also depends upon characteristics of this situation. Depending upon the options available in a specific situation, a food may or may not be consumed. Our study therefore adds to the models of Kronl, Shepherd and Tuorila the influence of a specific situation on food use. This influence is especially relevant when studying changes in food use influenced by an advised diet, because such an advised diet is likely to cause dietary barriers. Those barriers will subsequently influence food use, as e.g. shown in the way of coping when feeling hungry by eating fatty foods.

8.5. Nutrition education

This study was started to identify the constraints diabetic patients experience when trying to change their diet according to an advised diet. It was hoped that studying these constraints would yield some alternative approaches for dietary education of the general public.

Dietary education of the general public implies an advice to change dietary intake. The diabetic diet differs from the advice given to the general public. Most diabetic patients in this study were required to eat at set times and consume set amounts. Many of them considered that they were supposed not to eat sugar. But comparable to the general population, diabetic patients are advised to eat a healthy diet, with special attention to a reduction of (saturated) fat-consumption.

The degree to which the general public is likely to change their food-use is different from the degree to which diabetic patients are likely to change

their food-use. The general public will most likely make less efforts to change their diet since they lack an immediate feed-back like a change in blood-glucose values, nor do they have the close contacts with professional workers (physicians, dieticians) who stress the importance of a healthy diet. In spreading the message of a healthy diet to the general public the government takes a restrictive position to prevent themselves from mingling too much with the personal affairs of people (31). Within the boundaries of this restrictive position some suggestions are made, that could improve the effectivity of nutrition education.

Providing physiological feed-back

When trying to change their diet, the general public will experience dietary barriers. The possible positive feed back from for instance the decreased risk to a heart attack, by a decreased or modified fat-intake, is not immediately felt. However, negative feed-back is felt immediately: the extra costs involved in buying low-fat products or the exclusion of certain well-liked foods. This predominantly negative feed-back makes it hard for the general public to change their diet. It is therefore advisable to develop ways in which a short-term feed-back loop can be created. In high risk groups a regular check-up of cholesterol-levels may serve as a feed-back on the effect of a change in (saturated) fat consumption.

Providing behavioral feed-back

Closely related to the lack of positive physiological feed-back are the difficulties in evaluating whether one does or does not eat in a healthy way. When physiological feed-back is not possible it is important to enable people to evaluate what they are eating: is it healthy or not? When they find out their eating habits to be healthy, it may serve as a positive feed back to consolidate the dietary change.

The guidelines for a healthy diet as drawn up by the Nutrition Council (30) can not always clearly be evaluated. This applies especially to the advice on eating a variety of foods. No one really knows what 'a variety of foods' means. From other guidelines targets that are relevant for an individual can be formulated, like the guideline to reduce dietary fat to between 30% and 35% of total daily energy-intake. It is advisable to subsequently develop ways in which the general public can determine whether they are on the right track with their dietary change. They should be enabled to monitor a change in dietary intake, and evaluate the change in dietary intake against one of the

guidelines for a healthy diet.

Up to now such instruments to self-monitor changes in dietary intake are not available. Development of such instruments are therefore needed.

Set priorities

We have demonstrated that the more restrictions a diet contains, the more dietary barriers are to be expected. The more barriers the less the chance that the really important guidelines are followed. The Nutrition Council made a list of six dietary guidelines for the general population (32). It would be advisable to select one item from this list as most relevant for an education-campaign for the general public.

The respective barriers we identified in our study are all related to the diabetic diet. Not all of the identified barriers are of relevance to dietary education for the general public, but some are, like the financial costs of a dietary change and barriers caused by perceiving the diet as consisting of forbidden foods.

The costs of the diet

Many diabetic respondents in our study reported that they did spend more money on their diet. An important cause of the increased costs lies in the relative extra costs of low-fat-varieties of foods. The costs of these foods may also be a barrier to dietary change for the general public. It is advisable to include suggestions for low-cost low-fat foods in dietary education.

Forbidden foods

Many diabetics reported that they considered certain foods to be forbidden. Niewind (1) showed that the variety of foods used by recently diagnosed diabetic patients was decreased compared to the period before their diabetes was diagnosed. The perception of a diet as consisting of prohibited foods is not nutritionally sound: in nutritional theory no foods are bad in themselves. The idea that certain foods are prohibited leads to the exclusion of foods from the diet. The exclusion of foods from the diet is a barrier for many diabetic patients, often leading to dietary non-compliance. To prevent such barriers it is strongly advised to recommend favorable foods or favorable ways of preparing foods, rather than advising people to exclude certain 'bad' foods from their diets.

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APPENDIX I: Overview of the different studies

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- Study 1 Inventory of dietary barriers** (Niewind chapter 3, chapter 3)
Aim Inventory of barriers insulin-treated and non insulin-treated diabetic patients experience with their diet
Study 104 insulin-treated diabetics + 58 non insulin-treated population
Population diabetics. Variation in age and duration of diabetes, with both sexes
Method Qualitative inventory
- Study 2 Inventory of ways of coping** (chapter 4)
Aim Inventory of ways of coping with dietary barriers experienced by insulin-treated diabetic patients
Study 104 insulin-treated diabetics. Variation in age and duration
Population of diabetes, with both sexes
Method Qualitative inventory
- Study 3 Prevalence of Barriers and Ways of Coping among recently diagnosed diabetics** (chapter 5)
Aim - barrier prevalence among recently diagnosed diabetics
- change in barrier prevalence after follow-up of one year
- prevalence of ways of coping with different dietary barriers
Study 72 recently diagnosed insulin-treated diabetics. Age between
Population 20-40 years, initial duration of diabetes 6 months on average, with both sexes
Method Two steps: recently after diagnosis of diabetes and one year later. At both steps: Questionnaire on dietary barriers based on Study 1. At first step: Qualitative inventory of ways of coping with six dietary barriers. At second step: Questionnaire on ways of coping with six dietary barriers based on the qualitative inventory in the first step.
- Study 4 Prevalence of Barriers and Ways of Coping among insulin-treated and non insulin-treated diabetics** (chapter 6)
Aim - barrier prevalence among insulin-treated and non insulin-treated diabetics
- prevalence of ways of coping with different dietary barriers among insulin-treated and non insulin-treated diabetics
Study 571 insulin-treated + 218 non insulin-treated diabetics
Population population. Variation in age and duration of diabetes, with both sexes
Method Questionnaire on dietary barriers, adapted from Study 3
Questionnaire on ways of coping with four dietary barriers, adapted from Study 3
- Study 5 Barrier prevalence among CSII treated diabetics with a liberalized diet** (chapter 7)
Aim Compare barrier prevalence among diabetics with Continuous Subcutaneous Insulin Infusion (CSII) and a liberalized diet with barrier prevalence among diabetics with conventional insulin therapy
Study 43 CSII treated diabetics + pair matched diabetic population
Population group with conventional insulin therapy. Variation in age and duration of diabetes, with both sexes
Method Questionnaire on dietary barriers as in Study 4
-

Er zijn mensen met diabetes die vinden dat het hebben van een diabetesdieet wel eens vervelend is. Hieronder staan enkele uitspraken van mensen met diabetes over wat vervelend kan zijn aan het hebben van een dieetadvies:

Wilt u van iedere uitspraak aangeven

- of dit afgelopen maand een probleem voor u was?

- als het een probleem was, hoe vaak dit probleem voorkwam

- als het een probleem was, hoe moeilijk u het vond om met dit probleem om te gaan.

	Was dit een probleem?	Hoe vaak kwam dit voor?			Hoe hinderlijk vond u dit probleem?		
	nee/ja →	dage- lijks 1	weke- lijks 2	1 x deze maand 3	heel hinderlijk 1	hinderlijk 2	niet hinderlijk 3
1. Mensen bieden voedingsmiddelen aan die ik moet afslaan.	nee/ja →	1	2	3	1	2	3
2. Andere mensen vergeten iets te eten voor mij in huis te halen.	nee/ja →	1	2	3	1	2	3
3. Honger hebben en niet mogen eten.	nee/ja →	1	2	3	1	2	3
4. Ik eet meer dan voorgeschreven.	nee/ja →	1	2	3	1	2	3
5. Ik vind mijn eten saai.	nee/ja →	1	2	3	1	2	3
6. Andere mensen bemoeien zich met wat ik eet.	nee/ja →	1	2	3	1	2	3
7. Dorst hebben en niet mogen drinken	nee/ja →	1	2	3	1	2	3
8. Andere mensen houden er slecht rekening mee dat ik een dieet heb.	nee/ja →	1	2	3	1	2	3
9. Ik moet vetarme of dieetprodukten eten.	nee/ja →	1	2	3	1	2	3
10. In het bijzijn van anderen wat moeten eten.	nee/ja →	1	2	3	1	2	3
11. Geen zin in eten hebben en toch moeten eten.	nee/ja →	1	2	3	1	2	3
12. Ik weet niet altijd hoeveel ik van een bepaald produkt mag eten.	nee/ja →	1	2	3	1	2	3
13. Het is lastig voor andere mensen dat ik een dieet heb.	nee/ja →	1	2	3	1	2	3
14. Ik voel me niet lekker als ik niet regelmatig eet.	nee/ja →	1	2	3	1	2	3
15. Ik mag weinig eten van sommige voedingsmiddelen.	nee/ja →	1	2	3	1	2	3
16. Anderen houden slecht rekening met de tijdstippen waarop ik moet eten.	nee/ja →	1	2	3	1	2	3
17. Ik kan niet met anderen meeten.	nee/ja →	1	2	3	1	2	3
18. Alles loopt wat anders dan verwacht daardoor is het moeilijk het dieet te volgen.	nee/ja →	1	2	3	1	2	3
19. Ik voel me een uitzondering door het dieet.	nee/ja →	1	2	3	1	2	3
20. Andere mensen halen speciaal voor mij wat in huis.	nee/ja →	1	2	3	1	2	3
21. Ik kan moeilijk van zoetigheid afblijven.	nee/ja →	1	2	3	1	2	3
22. Ik kan niet eten waar ik zin in heb.	nee/ja →	1	2	3	1	2	3
23. Veel moeten eten van bepaalde produkten.	nee/ja →	1	2	3	1	2	3
24. Regelmatig moeten eten.	nee/ja →	1	2	3	1	2	3

Er zijn mensen met diabetes die vinden dat het hebben van een diabetesdieet wel eens lastig is. Hieronder volgen een aantal uitspraken van mensen met diabetes over wat lastig kan zijn aan het hebben van een dieetadvies.

Wilt u van elke uitspraak aangeven in hoeverre dit VOOR U een probleem is.

	een groot probleem	een probleem	geen probleem, wel lastig	geen probleem niet lastig
Ik wil iets eten wat ik niet mag eten.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik vind mijn eten saai.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Niet lekker kunnen eten.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik weet niet hoeveel ik van een voedingsmiddel kan eten.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In het bijzijn van anderen iets moeten eten terwijl de anderen niets eten.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Door het dieet ben ik veel geld kwijt aan mijn voeding.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anderen eten iets wat ik niet mag eten.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Honger hebben maar niet mogen eten.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik mag weinig eten van sommige voedingsmiddelen.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mensen bieden mij voedingsmiddelen aan die ik moet afslaan.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik moet vetarme produkten eten.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Als ik niet regelmatig eet, voel ik me niet lekker.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik moet veel eten van sommige voedingsmiddelen.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik moet uitleggen aan anderen dat ik een dieet heb.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anderen bemoeien zich met wat ik eet.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Altijd iets te eten bij me moeten hebben.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Geen trek in eten hebben en toch moeten eten.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In onverwachte situaties is het moeilijk het dieet te volgen.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Andere mensen vergeten iets voor mij in huis te halen.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Regelmatig moeten eten.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Moeilijk van zoetheid af kunnen blijven.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik krijg er last van wanneer ik meer eet dan ik mag eten.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Nu volgen enkele situaties die u misschien wel eens heeft meegemaakt. Over deze situatie stellen we een aantal vragen.

Situatie 1 Ik mag welnuig eten van sommige voedingsmiddelen

Nu volgen enkele manieren van reageren op deze situatie.

Kruis voor iedere mogelijkheid aan hoe vaak u zo reageert.

altijd meestal soms nooit

Ik eet niet meer dan ik mag eten.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik eet zoveel als ik wil en eet minder van andere producten.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik eet iets anders, waar ik wel meer van mag hebben.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik eet dit voedingsmiddel helemaal niet meer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik eet zoveel als ik wil en spuit insuline bij.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik eet zoveel als waar ik zin in heb.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Situatie 2 Het lastig vinden om regelmatig te moeten eten

Kruis voor beide mogelijkheden aan hoe vaak u zo reageert als deze situatie zich voordoet.

altijd meestal soms nooit

Ik eet onregelmatig.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik eet regelmatig	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Situatie 3 Niet kunnen eten waar u zin in heeft

Kruis voor iedere mogelijkheid aan hoe vaak u zo reageert als deze situatie zich voordoet.

altijd meestal soms nooit

Ik eet iets anders, wat ik zonder problemen kan eten.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik eet een beetje van waar ik zin in heb.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik eet waar ik zin in heb.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Situatie 4 In het bijzijn van anderen iets moeten eten, terwijl de anderen niet eten

Kruis voor iedere mogelijkheid aan hoe vaak u zo reageert als deze situatie zich voordoet.

altijd meestal soms nooit

Ik eet gewoon.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik stel het eten uit.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik vraag de anderen om rekening te houden met mijn etenstijden.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Situatie 5 Bonger hebben maar niet mogen eten

Kruis voor iedere mogelijkheid aan hoe vaak u zo reageert als deze situatie zich voordoet.

altijd meestal soms nooit

Ik eet iets met koolhydraten.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik steek een sigaret op.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Op zo'n moment eet ik niets.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik eet iets zonder koolhydraten.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Situatie 6 Mensen bieden u voedingsmiddelen aan die u moet afslaan

Kruis voor iedere mogelijkheid aan hoe vaak u zo reageert als deze situatie zich voordoet.

altijd meestal soms nooit

Ik leg uit dat ik diabetes heb, zodat ze begrijpen dat ik het niet kan eten.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik sla het af.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik eet het op.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik spuit extra insuline, zodat ik het wel kan eten.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Nu volgen enkele situaties die u misschien wel eens heeft meegemaakt. Over deze situaties stellen we een aantal vragen.

Situatie 1. Ik mag weinig eten van sommige voedingsmiddelen

Nu volgen enkele manieren van reageren op deze situatie. Kruis voor iedere mogelijkheid aan hoe vaak u zo reageert.

	altijd	meestal	soms	nooit
Ik eet niet meer dan ik mag eten	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik eet zoveel als ik wil en eet minder van andere produkten.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik eet iets anders, waar ik wel meer van mag hebben.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik eet dit voedingsmiddel helemaal niet meer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik eet zoveel als ik wil en spuit insuline bij.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik eet zoveel als waar ik zin in heb.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Situatie 2. Het lastig vinden om regelmatig te moeten eten

Kruis voor beide mogelijkheden aan hoe vaak u zo reageert als deze situatie zich voordoet.

	altijd	meestal	soms	nooit
Ik eet onregelmatig.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik eet regelmatig.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Situatie 3. In het bijzijn van anderen iets moeten eten, terwijl de anderen niet eten

Kruis voor iedere mogelijkheid aan hoe vaak u zo reageert als deze situatie zich voordoet.

	altijd	meestal	soms	nooit
Ik eet gewoon.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik stel het eten uit.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik vraag de anderen om rekening te houden met mijn etenstijden.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Situatie 4. Honger hebben maar niet mogen eten

Kruis voor iedere mogelijkheid aan hoe vaak u zo reageert als deze situatie zich voordoet.

	altijd	meestal	soms	nooit
Ik eet iets met koolhydraten.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik steek een sigaret op.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Op zo'n moment eet ik niets.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ik eet iets zonder koolhydraten.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SUMMARY

This is a study on the barriers that diabetic patients experience with their diet, and how they cope with them. The diet is a difficult aspect of the diabetic treatment (1-4). Dietary compliance is reported to be low (5,6). More knowledge on the dietary barriers that diabetic patients experience may contribute to diets that are easier to follow and more pleasurable to live with. For this reason a study on the dietary barriers experienced by diabetic patients was started.

Diabetes mellitus is a metabolic disease, with an impaired regulation of the blood glucose level. In The Netherlands there are at least 200.000 diabetics (7). Regulation of the blood glucose level is to be achieved by balancing dietary intake, physical activities and possibly insulin-injections or oral hypoglycemic agents. Most insulin-treated diabetic patients are advised a caloric defined diet with set times to eat. Non insulin-treated diabetics who are overweight are advised to lose weight. In general, diabetics are advised to eat a healthy diet (8). A sugar restriction is a major part of the diabetic diet, but for some time it has been known that sugar can be part of the diabetic diet (8,9).

Chapter 2 of this thesis is an overview of the literature on barriers diabetic patients experience with their diet. No reliable inventory of dietary barriers was found. It was concluded that such an inventory is a prerequisite for a study in diabetics' dietary barriers.

Chapter 3 is a description of an inventory of possible dietary barriers experienced by non insulin-treated diabetic patients. A similar inventory was made for insulin-treated diabetics (10). The results of both inventories are alike. Both show a great variety of possible barriers. Because of the dietary restrictions diabetics feel physically unwell or they regret that they can not eat foods they like. Social barriers were also reported. Having to eat regularly, spending much money on food or not knowing how much of a food to eat also are dietary barriers experienced by diabetics.

In chapter 4 an inventory is presented of the ways diabetic patients cope with the barriers they experience with their diet. Compliance with the advised diet

may imply that a diabetic will go on feeling hungry or feeling supersatiated, that a diabetic has to limit contacts with other people or not to eat certain foods. By not complying with the diet, a diabetic may eat preferred foods, meet other people or save money. Also non compliance may imply that a diabetic feels better. A paradox seems to exist between either compliance to the advised diet and feeling physically well.

In chapter 5 a study is presented on the prevalence of different dietary barriers and the ways to cope with them. The inventory on dietary barriers that was made earlier was used to construct a questionnaire with precoded response categories. In this way barrier-prevalence could be assessed. This study was carried out among insulin-dependent diabetics shortly after diagnosis, aged between 20 and 40. Physical discomfort, restrictions in food-use and the required regularity of eating are the categories of barriers most prevalent. After a follow-up period of one year barrier-prevalence was re-assessed. We had expected barrier-prevalence after one year of diabetes to be lower. However, this was not the case. It was therefore concluded that dietary barriers are not easily overcome by diabetic patients. It also became clear that those barriers with a high prevalence are mostly dealt with by non-compliance.

In chapter 6 a study on the prevalence of dietary barriers among 571 insulin-treated and 218 non insulin-treated diabetics is presented. The ways of coping with these barriers were also assessed. In this study it was tried to reproduce the findings of our first study on barrier-prevalence among an assorted diabetic study-population, varying in age and duration of diabetes. Again physical discomfort and restrictions in foods to use were found to be the most prevalent categories of dietary barriers. Once again barriers that were high in prevalence were most often dealt with by non-compliance. It was remarkable to notice the lack of differences in barrier-prevalence between the insulin-treated diabetics and the non insulin-treated diabetics. This finding could imply that the diets as perceived by both populations are not so different after all.

Chapter 7 is a description of a study that was done to find out whether diabetic patients with continuous subcutaneous insulin infusion and a liberalized diet (no caloric defined diet, not set times to eat) (11) would experience less dietary barriers when compared with diabetics with

conventional insulin therapy. This proved to be the case. It was concluded that liberalizing a diet will lead to diets causing less barriers.

Chapter 8 is a general discussion of the major results of this study. Barriers expressing physical discomfort are among the most prevalent. Such barriers give rise to dietary non-compliance and are mainly caused by diets with set eating-times and defined quantities (of carbohydrates) to eat. Such diets do not allow for the reality of variability in daily energy-intake (5,12). It was even found that diabetics consume fatty foods when feeling hungry while not allowed to eat, or smoke a cigarette if they are smokers. These are not healthy ways of dealing with such a barrier. The paradox of compliance with an advised diet leading to unhealthy behavior, and non-compliance being more health promoting is caused by a caloric defined diet with set times to eat. Such diets are not realistic. Many diabetics find that they are restricted in the use of certain foods. They consider their diet to consist of forbidden foods and this leads to the exclusion of certain foods from their diet (10). This makes their food pattern more boring, but not necessarily more healthy. For diabetics there are no forbidden foods. Dietary counseling can contribute to a decrease in barrier prevalence by preventing diabetics from perceiving their diet as consisting of foods they should not eat.

In chapter 8 it is concluded that diets that give rise to less dietary barriers will be more pleasurable to live with, and such diets will be easier to comply with. Also suggestions are made to improve the diabetic exchange-list to have it optimally contributing to dietary variety. It is furthermore suggested to organize a diabetic's consultation with a dietician based on the experienced dietary barriers. During such a consultation the dietician together with the diabetic patient can find ways to effectively overcome the barriers of the diabetic diet. The last paragraph of chapter 8 contains recommendations to improve nutrition education to the general public.

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SAMENVATTING

In deze studie zijn de moeilijkheden onderzocht die diabeten ervaren met hun dieetadvies en de manieren van reageren op deze moeilijkheden. Het dieetadvies is voor de meeste diabeten een bijzonder lastig aspect van hun behandeling (1-4). Ook wordt het dieetadvies slecht opgevolgd (5,6). Meer inzicht in de moeilijkheden die diabeten ervaren met hun dieetadvies kan bijdragen aan dieetadviezen die plezieriger zijn om mee te leven en makkelijker kunnen worden opgevolgd. Daarom is studie gemaakt van de moeilijkheden die diabeten ervaren met hun dieetadvies.

Diabetes mellitus is een stofwisselingsziekte, waarbij de regulatie van de bloedsuikers is verstoord. In Nederland zijn zeker 200.000 diabeten (7). Regulatie van de bloedsuikers is mogelijk door het op elkaar afstemmen van de voeding, lichamelijke activiteiten en eventuele insuline-injecties of het slikken van bloedsuiker verlagende tabletten. Aan de meeste diabeten die insuline spuiten wordt geadviseerd om regelmatig een vastgestelde hoeveelheid te eten. Niet insuline-sputende diabeten met overgewicht wordt geadviseerd gewicht te verliezen. Alle diabeten wordt geadviseerd een 'gezonde voeding' (8) te gebruiken. Een suikerverbod was jaren onderdeel van het diabetesdieet. Maar sinds enige tijd kan suiker een onderdeel zijn van de voeding van diabeten (8,9).

Hoofdstuk 2 van dit proefschrift is een overzicht van de literatuur over de moeilijkheden die diabeten ervaren met het dieetadvies. Er blijkt geen betrouwbare inventarisatie te zijn van deze moeilijkheden. Geconcludeerd wordt dat een betrouwbare inventarisatie een eerste stap moet zijn van een studie naar de moeilijkheden die diabeten ervaren met hun dieet.

In hoofdstuk 3 wordt beschreven welke moeilijkheden niet insuline-sputende diabeten met hun dieetadvies kunnen ervaren. Hetzelfde onderzoek is uitgevoerd onder insuline-sputende diabeten (10). De resultaten van deze studies verschillen weinig van elkaar. Beide studies tonen aan dat de moeilijkheden met het diabetesdieet divers van aard kan zijn. Door de beperkingen in het dieetadvies voelen diabeten zich niet lekker, of ze vinden het vervelend dat ze niet kunnen eten waar ze zin in hebben. Ook in het contact met andere mensen blijkt het dieetadvies lastig te kunnen zijn. Regelmatig moeten eten, veel geld kwijt zijn aan het eten of niet weten hoeveel je van een bepaald

voedingsmiddel kunt eten zijn andere moeilijkheden die voorkomen met het diabetesdieet.

Hoofdstuk 4 bevat een overzicht van de manieren waarop diabetes reageren op de moeilijkheden met het dieetadvies. Het dieet volgen kan inhouden dat een diabeet last houdt van een hongergevoel, van een gevoel van oververzadiging, dat het contact met andere mensen vermindert of dat bepaalde voedingsmiddelen niet meer gegeten kunnen worden. Door het dieetadvies niet op te volgen kan een diabeet zich lichamelijke prettiger voelen, eten waar hij of zij zin in heeft, niet teveel geld aan het eten kwijt zijn of kontakten met anderen onderhouden. Er lijkt een paradox te bestaan tussen het volgen van een dieetadvies en lichamenlijk welbevinden.

In hoofdstuk 5 wordt onderzoek beschreven naar de prevalentie van verschillende moeilijkheden met het diabetesdieet. Ook is bestudeerd hoe diabetes reageren op deze moeilijkheden. De eerder gemaakte inventarisatie van mogelijke moeilijkheden met het diabetesdieet is gebruikt om een gesloten vragenlijst te maken. Zo kon de prevalentie van de verschillende dieetmoeilijkheden gekwantificeerd worden. Dit onderzoek is uitgevoerd onder 72 insuline-sputende diabetes kort nadat hun diabetes was ontdekt tussen de 20 en 40 jaar oud. Lichamenlijke ongemakken, een beperkte voedselkeuze en de noodzaak om regelmatig te moeten eten waren de meest voorkomende moeilijkheden. Een jaar na de eerste meting werd weer vastgesteld welke moeilijkheden diabetes ervaren met hun dieet. We hadden verwacht dat diabetes na een jaar met diabetes minder moeilijkheden zouden ervaren. Dit bleek niet zo te zijn. Hieruit werd gekonkludeerd dat het voor diabetes niet makkelijk is de moeilijkheden met het diabetesdieet op te lossen. Uit deze studie bleek ook dat diabetes op de veel voorkomende problemen reageren door van het dieetadvies af te wijken.

In hoofdstuk 6 wordt onderzoek beschreven naar de prevalentie van moeilijkheden met het dieetadvies en de manieren van reageren hierop. In dit onderzoek is geprobeerd de conclusies van de vorige studie te toetsen in een breed samengestelde onderzoekspopulatie. Dit onderzoek is uitgevoerd onder 571 insuline-sputende en 218 niet insuline-sputende diabetes, variërend in leeftijd en duur van de diabetes. Ook nu bleken lichamenlijke ongemakken en de beperkte voedselkeuze de meest voorkomende moeilijkheden met het dieet te zijn en het bleek dat diabetes op de veel voorkomende problemen reageren door van

het dieetadvies af te wijken. Opmerkelijk was dat er geen grote verschillen waren tussen de twee onderzochte populaties in de moeilijkheden met het dieetadvies. Dit zou er op kunnen wijzen dat het beeld van het dieet weinig verschilt tussen beide populaties.

Hoofdstuk 7 is een beschrijving van onderzoek naar de vraag of diabetes met een insuline-pompje en een geliberaliseerd dieetadvies (geen vaste etenstijden en hoeveelheden) (11) minder moeilijkheden ervaren met het dieet dan diabetes met een conventionele behandeling. Dit bleek inderdaad het geval te zijn. Uit dit onderzoek werd geconcludeerd dat liberalisering van een dieetadvies leidt tot een dieet met minder moeilijkheden.

Hoofdstuk 8 bevat een algemene discussie van de onderzoeksresultaten. Lichamelijke ongemakken behoren tot de meest voorkomende dieetproblemen voor diabetes. Deze ongemakken geven het meest aanleiding om van het dieetadvies af te wijken. De oorzaak van deze ongemakken ligt vooral in diëten met het advies om op vaste tijden vaste hoeveelheden (koolhydraten) te eten. Dergelijke diëten gaan voorbij aan de normale dagelijkse variatie in energieopname (5,12). Het is zelfs zo dat diabetes vetrijke producten eten als zij honger hebben maar volgens het dieetadvies niet mogen eten, of een sigaret opsteken als ze roker zijn. Deze manieren van reageren dragen niet bij aan de gezondheid van een diabeet. De paradox die ontstaat doordat het volgen van het dieetadvies blijkt te kunnen leiden tot ongezond gedrag en dat afwijken van het dieetadvies een gezonde keuze kan zijn wordt veroorzaakt door een dieetadvies met vaste eettijden en voorgeschreven hoeveelheden. Een dergelijk dieetadvies is fysiologisch gezien niet realistisch.

Veel diabetes vinden het vervelend dat ze bepaalde producten niet, of maar in beperkte mate mogen gebruiken. Voor hen bestaat het dieetadvies uit een verbod op het gebruik van bepaalde voedingsmiddelen wat ertoe leidt dat zij bepaalde voedingsmiddelen niet meer eten (10). Hun voeding wordt hierdoor saaier, en niet noodzakelijkerwijs gezonder. Het idee dat het diabetesdieet bestaat uit verboden voedingsmiddelen is een onjuist idee. Begeleiding van diabetes die er op gericht is te voorkomen dat diabetes denken dat bepaalde producten verboden zijn kan bijdragen aan het verminderen van het problematische karakter van het dieet.

In hoofdstuk 8 wordt geconcludeerd dat dieetadviezen die weinig aanleiding geven tot moeilijkheden plezieriger zijn om mee te leven en tegelijkertijd makkelijker om op te volgen. Vervolgens worden er suggesties gedaan om de

diabetes-variatielijsten optimaal te laten bijdragen aan een zo groot mogelijke variatie in de voeding van diabeten. Ook wordt voorgesteld om consulten van diëtisten met diabeten te baseren op de moeilijkheden die diabeten ervaren met hun dieetadvies. Tijdens dit consult kan de diëtist met de diabeet zoeken naar effectieve manieren om deze moeilijkheden in de toekomst zoveel mogelijk te voorkomen. In de laatste paragraaf van hoofdstuk 8 worden enkele suggesties gedaan om de voedingsvoorlichting aan de Nederlandse bevolking te verbeteren.

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CURRICULUM VITEA

Roland Dingeman Friele werd geboren op 29 augustus 1957 te Pijnacker. Hij behaalde het Atheneum-B diploma op het Corderius College te Amersfoort in 1975. Hetzelfde jaar begon hij met zijn studie Voeding aan de Landbouwniversiteit te Wageningen. Zijn praktijktijd bracht hij door in India, met onderzoek naar erf-tuinen. In 1983 rondde hij zijn studie af met de hoofdvakken Voedingsleer en Voorlichtingskunde. Tijdens zijn studie was hij als cursusleider gezondheidsvoorlichting verbonden geweest aan het Instituut voor Toegepaste Voorlichtingskunde. Na zijn studie heeft hij op de vakgroep Humane Voeding gewerkt aan het voorstel voor onderzoek naar de hanteerbaarheid van het diabetesdieet. Vanaf augustus 1983 was hij docent Voorlichtingskunde en Onderzoekstechnieken bij de Hogere Landbouwschool te Deventer. Vanaf januari 1986 is hij als wetenschappelijk assistent verbonden aan de vakgroep Humane Voeding van de Landbouwniversiteit te Wageningen waar hij het in dit proefschrift beschreven onderzoek heeft gedaan.