Obstacles which Patients with Type 2 Diabetes Meet while Adhering to the Therapeutic Regimen in Everyday Life: Qualitative Study

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Aim. To explore type 2 diabetic patients’ attitudes, thoughts, and fears connected with their illness; their expectations of the health care system; and the problems they encountered while adhering to the therapeutic regimen.

Method. Explanatory descriptive focus groups were held with 49 type 2 diabetic patients. Patients were recruited by their general/family practitioners and divided into seven focus groups. The group discussions were audio taped and transcribed, then analyzed to find emerging themes and sub-themes. Textual data were explored inductively using content analysis to generate categories and explanations. Hypotheses were derived from the qualitative content analysis.

Results. Eight major themes and explanatory models of patient’s perspective emerged out of the data: confronting the diagnosis, illness-related changes, treatment of illness, social context, relation to the health professionals, self-control, knowledge about the illness, and expectations from health professionals. Health beliefs, quality of the doctor-patient relationship, social environment of the family, workplace, health care system, and quality of the information they receive from health professionals and media were all important factors in patient adherence.

Conclusions. There were many obstacles for bettering patients adhering to the therapeutic regimen, as from the patients’ socio-economical aspect, and in the existing health system of Croatia as well. Providing of updated information about the disease, empathy and support of physicians can improve adherence to treatment.

Key words: communication; diabetes mellitus, type 2; family practice; patient compliance

Diabetes mellitus type 2 is a chronic illness and more than 95% of diabetes care is performed by the patient, so health professionals have very little control over how their patients manage their illness between office visits (1). To manage their illness appropriately, according to the Health Belief Model (2), patients must believe that their condition will not become more severe if they follow a set of health recommendations. Furthermore, the traditional approach to the doctor-patient interaction, in managing chronic diseases, which focuses on disease rather than the person with the disease, will not reduce total morbidity from these diseases. Indeed, it is increasingly evidence-based that patients should be considered as the doctor’s partner, and should make decisions about the treatment regimen after being appropriately informed together with the physician (3). Patients manage their diabetes on a daily basis within the context of their other goals, priorities, health issues, family demands, and other personal concerns that make up their lives; they have the right to set their own goals and decide on how they will manage their illness because it is they themselves that have to carry out those decisions and live with the consequences (1). Sharing the management of an illness between patient and physician is a model of patient-centered care and systematic reviews show that patient-centered care results in increased adherence to management protocols, reduced morbidity, and improved quality of life of the patients (4). There is growing evidence that medical outcomes may be improved substantially by changes in the process of care itself, including the physician-patient interaction (5). If we want to achieve better adherence to prescribed treatment, we should understand and distinguish factors that enable patients to adhere to it from those that do not. Defining the patient and physician behavior that contributes to the process of patient participation would assist the development of specific behavioral interventions (6).

There are a few studies (7-9) which explore the patient’s perspective and role in medical decision making and which critically examine the physician’s role. The aim of our study was to examine type 2 diabetic patients’ attitudes, thoughts, and fears connected with their illness, their expectations of the health care system, and the kinds of problems they encoun-
of the focus group discussions, patients were asked if they wanted to exclude parts of the conversation in case they had said something they wished not to be included. The duration of every focus group discussion was limited to 2 hours.

Focus Groups
Seven focus group discussions were conducted by a moderator and observed by a researcher. The participants were given a number of open-ended questions and statements (Table 2), about which they were completely free to express their personal views, thoughts, attitudes, and concerns. With 7 focus groups we certainly achieved content saturation.

Table 2. Questions asked during focus group discussions

1. How did you experience the diagnosis of diabetes? In what way did diabetes change your life?
2. Diabetes is a chronic illness treated by diet, lifestyle changes, oral medication or insulin. How do you feel about the treatment?
3. Your doctor probably decided on your therapeutic regimen. How did you feel about that?
4. Do you modify your treatment from time to time? How do you feel about this? Do you tell anyone about these decisions?

Data Analysis
The group discussions were audio taped and transcribed after the sessions. Two researchers performed the first analysis by reading the transcript independently and coding text fragments or words to build a code book. The coding process was guided by the research question. Textual data are, as described by Pope et al (11), typically explored inductively using content analysis to generate categories and explanations. In the first stage, the codes were attached to words or text fragments, in the second stage they were categorized to create themes and sub-themes, all leading to an explanation. We also considered the observer’s feedback since she was present at every focus group meeting, listening, and observing the discussions with full attention. As a result, her opinion proved to be invaluable in the process of analysis. The analyses resulted in 8 major themes and explanatory models of the patient’s perspective.

Results
Eight major themes and explanatory models emerged from the data: 1) confronting the diagnosis, 2) illness-related changes, 3) treatment of illness, 4) social context, 5) relation to the health professionals, 6) self-control, 7) knowledge about the illness, and 8) expectations.

Confronting the Diagnosis (Box 1)
The first news about diabetes was shocking and stressful for most patients, but they got used to it with time. Only a few patients, especially if they had already been suffering from another disease, described it as “nothing special,” and believed that they had no real medical problem, or even denied the seriousness of their diagnosis. Although most of them learned how to live with diabetes, many were still anxious.

Box 1
Confronting the diagnosis:

• 65 year old woman: “Sometimes I wake up at night and start thinking about my blood sugar and I get chills. I know that diabetes is a silent killer, so many things could happen to me and I cannot predict the consequences!”
• 50 year old woman: “…At first, when my physician told me the diagnosis I was in complete shock. I kept asking myself why this happened to me out of all people.”
• 57 year old man: “Living with diabetes is nothing special to me. One has to be disciplined and that’s it.”

Table 1. Demographical and clinical characteristics of patients in the study

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>No. of patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years):</td>
<td>male</td>
</tr>
<tr>
<td>40-50</td>
<td>2</td>
</tr>
<tr>
<td>51-60</td>
<td>5</td>
</tr>
<tr>
<td>61-70</td>
<td>7</td>
</tr>
<tr>
<td>71-80</td>
<td>5</td>
</tr>
<tr>
<td>80+</td>
<td>2</td>
</tr>
<tr>
<td>Marital status:</td>
<td></td>
</tr>
<tr>
<td>married</td>
<td>16</td>
</tr>
<tr>
<td>widowed</td>
<td>3</td>
</tr>
<tr>
<td>cohabitation</td>
<td>1</td>
</tr>
<tr>
<td>single</td>
<td>2</td>
</tr>
<tr>
<td>Employment:</td>
<td></td>
</tr>
<tr>
<td>not retired</td>
<td>8</td>
</tr>
<tr>
<td>retired</td>
<td>14</td>
</tr>
<tr>
<td>Duration of diabetes (years):</td>
<td></td>
</tr>
<tr>
<td>&lt;5</td>
<td>9</td>
</tr>
<tr>
<td>5-9</td>
<td>6</td>
</tr>
<tr>
<td>10-14</td>
<td>6</td>
</tr>
<tr>
<td>&gt;15</td>
<td>1</td>
</tr>
<tr>
<td>Diabetes mellitus treatment:</td>
<td></td>
</tr>
<tr>
<td>diet</td>
<td>4</td>
</tr>
<tr>
<td>diet + pills</td>
<td>10</td>
</tr>
<tr>
<td>diet + insulin</td>
<td>4</td>
</tr>
<tr>
<td>diet + insulin + pills</td>
<td>4</td>
</tr>
<tr>
<td>Follow up:</td>
<td></td>
</tr>
<tr>
<td>general/family practitioner only</td>
<td>7</td>
</tr>
<tr>
<td>general/family practitioner + community health nurse</td>
<td>6</td>
</tr>
<tr>
<td>general/family practitioner + hospital</td>
<td>7</td>
</tr>
<tr>
<td>hospital only</td>
<td>2</td>
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about different beliefs and facts connected with diabetes, such as possible complications of illness or hypoglycemia and insulin taking.

Illness-related Changes (Box 2)

For the majority of the patients, diabetes was an illness that dictated changes in lifestyle and habits. It was necessary to modify the diet (number of meals, quality and quantity of food) and to increase physical activity. It was even necessary to change the lifestyle of their family members, especially regarding eating habits.

Diabetic patients admitted that even in the situations where their family members tried to help them they did not always stick to the diet. They stated that the hardest change related to their illness was the relation to oneself, and the realization that they themselves, and not others, were the most responsible for their health status. That means that in time they started to realize that their everyday management of the illness would actually affect them. General/family practitioners can help patients come to this realization by offering their support and understanding.

<table>
<thead>
<tr>
<th>Box 2</th>
<th>Illness-related changes:</th>
</tr>
</thead>
<tbody>
<tr>
<td>62 year old woman: “...from the moment I found out that I suffered from diabetes everything started to revolve around me and my disease...”</td>
<td></td>
</tr>
<tr>
<td>48 year old woman: “I test my blood sugar more frequently. I am completely focused on my disease!”</td>
<td></td>
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<tr>
<td>60 year old man: “Many times I blamed my doctor for prescribing the wrong treatment. My sugar level was so high. We discussed it so many times. He told me that discipline is all about me, not about him! It took me a long time to realize that he was telling the truth. I remembered how many times I would go to the kitchen and steal my wife's cookies. Since then I don't cheat! And actually until then I was not cheating my physician or my family. I was cheating myself! I thought that I would have never achieved this without him giving me constant advice and support. And you know what, my blood sugar is almost perfect now!”</td>
<td></td>
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Treatment of Illness (Box 3)

Diabetic patients did not only stress the importance of dieting, but also their own inability or resistance to following it because of lack of willingness, motivation, and financial problems. They made individual adjustments as much as they could, but during various family celebrations they usually didn’t stick to them.

Most of the patients preferred taking pills because it is simpler. It is easier to take pills than to change eating habits and increase physical activity or take insulin. They also preferred taking pills to just modifying their diet, because they had a feeling that they could control their illness easier by themselves, which reassured them.

Attitudes about insulin taking differed in patients who had to take it from those who did not. Those who did not take insulin had pronounced anxiety about taking it. This attitude was the result of a belief that insulin taking is connected with a more severe form of disease, requiring further limitation of lifestyle, more everyday activities and more frequent blood sugar controls, the final stage of diabetes and their life. On the other hand, patients who were taking insulin were satisfied with it, concentrating on their ability to control their own lives and their glucose blood levels.

There were two extremes in relation to changing pill and insulin dosage prescribed by the physician. Some patients never changed the prescribed therapy and others changed it from time to time, depending on food quantity they consumed and physical activity they undertook. The patients who changed the dosage felt freer in their lives because of the ability to control their condition. Their general/family practitioners helped them to start taking and continue adjusting the dosage of their medications.

Although all 49 participants were well aware of the importance of physical activity, only few of them performed it regularly on a daily basis. Reasons given included lack of motivation and willpower, laziness, and time pressures.

Social Context (Box 4)

Absence of support in the social environment can create difficulties for diabetic patients when coping with the illness in everyday life.

Diabetic patients felt uncomfortable in front of their colleagues, felt less worthy, even admitted to hiding their disease because of the fear of losing their job. Furthermore, it was very difficult to follow the treatment regimen, especially the required diet, while working. Diabetic patients, compared to other colleagues, needed to undergo medical checkups more frequently, and renewed their drivers’ licenses more often. One patient even changed his job, others worked only during the day and never alone. Co-worker support varied: sometimes it was absent and sometimes present.
Diabetic patients usually received a lot of understanding and support from their friends. The majority of diabetic patients had supportive family members who got accustomed to the new diet regimen and who helped them follow the prescribed treatment. Only a few patients did not share the changes in their lifestyle with their family members.

**Relation to Health Professionals (Box 5)**

Physicians often patronized the patients, which resulted in their negative response. Still, the majority of diabetic patients felt support and closeness with the general/family practitioner and had complete trust in his or her suggestions and prescribed treatment. For mostly older patients (older than 75 years), the family doctor was the utmost authority. They appreciated the opportunities provided by general/family practitioners to learn about the self-regulation of medications according to the blood sugar level, different foods they ate, and activities they participated in. Since this made them feel more like partners than patients, diabetic patients were more thoughtful when managing their illness. Only a few patients had a bad relationship with their general/family practitioner, they experienced lack of understanding, even annoyance.

Diabetic patients considered that specialist intervention was reserved only for those patients treated with insulin and those with more severe diabetes with complications. Patients expressed criticism regarding long waits, bad communication, and narrow focus of specialists.

Only a few patients felt support and full understanding from a community nurse, yet most of them preferred her testing their blood sugar instead of doing it themselves.

**Self-control (Box 6)**

The management of diabetes mellitus, type 2 requires complex, continual, and demanding self-care, including dietary control, exercise, and frequent medication. Measuring of one’s own blood and urine glucose level was a matter of habit for mostly younger patients or those who took insulin.

Diabetic patients would have liked to test their own blood more frequently but they didn’t receive enough test-strips.

Only a few patients did not want to take their own blood because it was hard for them, while others feared their own blood test results.

**Knowledge about Illness (Box 7)**

Although all patients in our study were informed about the stage of their illness and its treatment, most of them showed incomplete and inaccurate knowledge not only of diabetes, but also of the occurring metabolic changes and possible complications.

Diabetic patients were not sufficiently aware of the importance of following a diet, and did not know how to prepare their meals, which food to choose for a proper diet, or how to carry out physical activities correctly.

Some patients even considered that diabetes was a common condition in older age, and therefore saw no need for it to be treated.
Diabetic patients expressed the need for more frequent physician checkups and for further education and constant refreshing of their knowledge about diabetes and its treatment. The mere fact that they were about to visit their general/family practitioner would force them to take better care of their treatment.

They explicitly stressed the need for meeting other people who suffer from the same illness (group therapy). Opportunities to share experiences with people who have similar problems would help them to learn from other people’s experiences, and to cope and live better with their illness.

They also wanted more written materials and pamphlets about diabetes designed for them, and TV shows to be shown at a more convenient time – in the evening.

**Box 8**

*Expectations:*
- 65 year old man: “I prefer more frequent checkups. When I know that my physician is going to see the results of my checkup I am more careful about the food I eat!”
- 63 year old man: “I would like to talk with people who have the same disease – it would be valuable to me to find out how other people manage diabetes while working. Maybe they could help me implement some changes in my diet, or give me some advice!”
- 53 year old woman: “I did not improve my blood sugar level until I started group therapy with other diabetic patients. I learned how to cope with many things which I couldn’t handle before. It is much easier when you talk to someone who has the same problems. We understand each other perfectly. And my blood sugar level is great now!”
- 60 year old woman: “If only I had watched TV shows on diabetes prevention before! I would have known that everybody could get diabetes! But they were on in the afternoon when I was working...”

**Discussion**

Our analysis resulted in 8 major themes and explanatory models of patient’s perspective: confronting the diagnosis, illness-related changes, treatment of illness, social context, relation to health professionals, self-control, knowledge about illness, and expectations.

Our study showed that diabetic patients have insufficient knowledge about the disease, particularly about the metabolic changes that occur, different treatment options, differences between various food staples, and the good ways of making physical activity a part of their lifestyle. Furthermore, diabetic patients fear their future and possible complications, but they do not know how these complications occur, and how to control or prevent them. They have scant information about diabetes, most of it from hearsay. This implies a deficient implementation of dietary measures, insufficient exercise and other lifestyle measures, or medical preventive actions. Speight et al (12) also identified knowledge deficits in many areas of diabetes management, e.g. prevention of hypoglycemia and avoidance of ketoacidosis. Furthermore, they found that 57% of patients thought that “fresh fruit can be eaten freely with little effect on blood glucose levels” and 75% of patients did not know that it is advisable to trim toenails to the shape of the toe. Ratzmann et al (13) reported similar trends, emphasizing that only 49% of all type 2 diabetes patients had adequate knowledge about hypoglycemia. In addition, Roossens et al (14) describe patients’ knowledge of diabetes and its complications, follow-up, surveillance, and dietary control as rather poor.

It is generally accepted that a diabetic patient should change his or her lifestyle and diet, increase physical activity, and take medication. We found that patients with health beliefs which included the idea that they were responsible for themselves, then they could adapt their lifestyle better and be more self-disciplined. To fully succeed in this, it is important for the patients to have time, self-control, and the physicians’ empathy and support.

Support from the health professionals for changing the diet and levels of physical activity was often found lacking. It appears that some physicians lost contact with their patients, limiting it to prescribing medicines. On the other hand, we found that closeness with the general/family practitioner and also his/her support and advice helped many patients in achieving better adherence to treatment. The length of their relationship and previous successful treatments that foster trust helped them to find strength to gradually try to control their treatment by themselves. Malý et al (15) showed that a simple patient-centered intervention, with the aim to facilitate information giving to patients with chronic medical conditions in the primary health care, can improve self-reported health, physical functioning, and satisfaction with care. Bodenheimer et al (16) expressed need for self-management education and patient-physician partnership. On the other hand, McDonald et al (17) came to the conclusion that diabetic patient education and support was not associated with any improvements in adherence, or clinical outcomes at all.

Physicians should educate patients how their health behavior affects their sugar levels. Most diabetic patients in our study felt that the physician’s supervision was very important because it gave them feedback on the treatment they were undertaking. O’Connor et al (18) also showed that diabetic patients require continuous supervision, direction, and education from their general/family practitioners.

Many diabetic patients felt a strong need for group therapy because they thought it might help them share experiences, resolve some dilemmas about their illness, and achieve success in carrying out lifestyle changes like following a dietary regimen and doing a physical activity on a daily basis.

In our study, general economic factors showed influence on the implementation of some of the required lifestyle adjustments. Diabetic patients in our study were socially endangered because they were not economically well off, they felt biologically less worthy, and did not receive the same treatment as an obese patient or smoker. Sometimes they had to conceal their illness in order to get a job and sometimes they even had to change their job.
Like other experimental studies (19), our study also showed a gap between the health care services intended to improve outcomes in chronic illness and the care that patients usually receive. The upholding public health service programs depend on the ability and will of an individual public health nurse and the general/family practitioner’s support and cooperation. Some patients in our study would have performed their own blood glucose tests more frequently but they did not receive enough test-strips. Patients asked for more written materials and specialized TV shows about diabetes. Practice guidelines and systems should be revised and developed within the larger strategy of chronic illness care. A recent meta-analysis (20) showed that different methods of education of healthcare providers were associated with improvements in their adherence to practice guidelines and disease control. On the other hand, obtaining health information through the public media is adequate (especially those concerning diet and physical activity), but not specific enough. Sometimes they tend to be sensationalistic, especially when informing about new drugs. Furthermore, people get susceptible to the media messages on good health behavior at an age (<50) when most habits and opinions are already defined. Therefore, health education through the media should start at school age.

Many studies explored patient compliance, but from a physician’s but not patient’s point of view (21). Noncompliance was considered as an irresponsible or even deviant behavior, and it was not considered as one of the choices available to the patient. On the other hand, Vermeire et al (3) emphasize the need for strengthening the model of patient-physician relationship – a concordance model in which the patient is a decision maker and the cornerstone is the doctor’s empathy. Furthermore, Funnel et al (1) share the same opinion and emphasize that physicians should recognize that it is the patients who are in charge of their own lives. Physicians can help patients achieve their goals by their support and medical expertise. Bauman et al (4) underline patient-centered care as an important and evidence-based concept for improving health outcomes in primary care practice for people with chronic diseases. The results of our study address the need for strengthening the doctor-patient partnership by recognizing a shared responsibility of both the doctor and the patient.

Our study had several limitations. One of weaknesses was the sampling of patients. We chose the individuals who were highly mobile and had low grade of complications, so we did not find out about the health beliefs of people with severe complications. Maybe that group of diabetic patients would have other ideas about the topics of the interview.

Furthermore, we took into account the patients who wanted to join the focus group, which excluded those who often avoid company, who are introverted, and do not want to talk about themselves.

The selected sample of the 49 assessed patients imposes limitations on the interpretation of results. This should be taken into account before transferring the conclusions to other contexts.

The aim of this study was to learn about the obstacles which patients with type 2 diabetes encounter while adhering to a therapeutic regimen in everyday life. Since there have not been many studies which included the patients’ point of view, we decided to explore and reveal the health beliefs of diabetic patients, the way they communicate about them, their expectations of the health care system, and the problems they encountered while adhering to the prescribed therapeutic regimen. Since low compliance has been quite a problem in chronic patient care, in our study we approached this important area of public health.

We used the method of focus groups because it induces the kind of discussion that can assist in the understanding of people’s personal beliefs, opinions, and attitudes. Furthermore, a focus group encourages interaction among the respondents and allows people to change their opinions after talking with others (22).

The focus group discussions were performed with careful adherence to the methodology as well as the analysis of our data. A certain criticism can be attributed to the fact that emerging themes have not been validated by the respondents in the original sample, nor in further focus groups. Nevertheless, the number of focus groups was sufficient to obtain content saturation, so we achieved good internal validity.

Recent qualitative studies have also identified important issues such as the need for improving the quality of the doctor-patient relationship and of patient health beliefs (23-25). They also emphasize the need for a change in the organization and delivery of health care services (26-27). Because adherence to treatment remains a major problem area, more studies are needed to assess various aspects of adherence-enhancing interventions.

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