PATIENTS' ADHERENCE TO TREATMENT OF DIABETES MELLITUS

BOLNIKOVO SODELOVANJE PRI ZDRAVLJENJU SLADKORNE BOLEZNI

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Abstract

Objectives: Diabetes is a chronic disease where patient's ability for self management is very important. Patients are every day taking decisions how to integrate treatment recommendations into their lives without impacting the quality of life. The aim of this study was to explore participants' perceived barriers to adherence to treatment. **Methods:** A qualitative study with five focus groups of patients with Type 2 diabetes and one group of experts on diabetes mellitus was performed in the central area of Slovenia. The transcribed text was independently analysed by principles of grounded theory with codes merging into themes and categories.

Results: Time changes patients' attitudes toward disease. Good education about the disease and their own experience with the disease help patients to adapt to different life situations and to regain control in their life. Family and friends are not always supportive to diabetes treatment. Some patients deny having disease in social encounters because they feel stigmatised. Diabetes also challenges patient's working ability and financial welfare. Patients also emphasise that mutual trust with physician and his true interest in patients' problems is very important for good results of medical care. They refuse universal advice and expect that the doctor helps them to develop self-management skills and coping with the disease. Additional prerequisites for good self management are also adequate organisation of life and adequate personal characteristics of the patients.

Discussion: This study offers additional insights into patients' views of the barriers to adherence. Patients feel empowered for occasional departure from recommended treatment in some social and life situations. Better medical care could be the result of good balance between social expectations of the patients, treatment and working demands on one side and individualised support of the physician with patients' own capacity to rearrange life on the other side.

Key words: adherence to treatment, primary care, self management, qualitative research, diabetes care

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Izvleček

Izhodišče: Za uspešno zdravljenje diabetesa je zelo pomembna bolnikova sposobnost za samooskrbo. Bolniki vsakodnevno sprejemajo odločitve, kako vključiti priporočila zdravljenja_v svoje življenje, ne da bi pri tem trpela kakovost njihovega življenja. Raziskava predstavlja, kakšne ovire v sodelovanju pri zdravljenju občutijo sladkorni bolniki.

Metode: Uporabljena je bila kvalitativna metodologija s petimi fokusnimi skupinami bolnikov in eno skupino strokovnjakov z osrednjega področja Slovenije. Prepis posnetka je bil dvojno neodvisno analiziran z uporabo metode bazalne teorije z določitvijo kod kot osnovnih analiznih enot in združevanjem kod v teme in kategorije. **Rezultati:** Bolnikova stališča do bolezni se po postavitvi diagnoze sčasoma spreminjajo. K prilagoditvi na drugačne življenjske okoliščine in k ponovnemu obvladovanju življenja pripomorejo znanje o bolezni in lastne izkušnje v zvezi z boleznijo. Prijatelji in družina ne podpirajo vedno zdravljenja sladkorne bolezni. Nekateri bolniki v družbi

zanikajo bolezen, ker jo čutijo kot stigmo. Sladkorna tudi vpliva na bolnikovo delovno sposobnost in finančno blagostanje. Pri premagovanju ovir je zelo pomembno vzajemno zaupanje z zdravnikom in zdravnikovo iskreno zanimanje za težave bolnika. Bolniki odklanjajo presplošne nasvete in pričakujejo, da jim bo zdravnik pomagal razviti sposobnost samooskrbe in obvladovanje bolezni. Na sposobnost samooskrbe pa vplivajo tudi dobra organiziranost bolnikovega življenja in njegove osebnostne lastnosti.

Razprava: Raziskava predstavlja ovire za bolnikovo zavzetost za zdravljenje, kot jih doživlja bolnik. Bolniki čutijo pravico do občasne opustitve priporočenega zdravljenja, posebej v določenih družabnih in življenjskih okoliščinah. Ravnovesje med željami bolnika, delovnimi zahtevami in priporočili za zdravljenje na eni strani ter k bolniku usmerjena individualna podpora zdravnika ob bolnikovi prilagoditveni sposobnosti na drugi strani lahko izboljša zdravstveno oskrbo.

Ključne besede: zavzetost za zdravljenje, osnovno zdravstvo, samooskrba, kvalitativna metodologija, sladkorna bolezen

Introduction

Patients' adherence to doctor's advice on medical interventions influences clinical outcomes of medical care, improves the quality of care and has measurable economic benefits [1-4]. Adherence to long term diabetes care is known to be low [5-8]. Diabetes is an example of a chronic disease which requires many changes in a patient's life. Patients are taking decisions about adjustments of treatment on daily basis to achieve a balance in living with diabetes [9,10]. How to integrate the advised, complex medical regimen into a patient's day to day life without overly impacting the quality of their life is a challenge for patients and for health care providers. Patients' ability to take prompt and sound decisions and capacity for problem-solving are very important for the quality of self management of the disease [11,12]. By including the psychological and social circumstances of patients' situations, this moves beyond simple adherence to treatment [13]. Besides patient's own adjustment of disease management to his personal needs [14-16] and his personal willingness to take more or less active position in the partnership with his doctor [17-24], several factors that could influence adherence have been studied, practice teamwork and organisation of service being one of them [5,8,25-31].

Diabetes is a model of chronic illness which demands many life style changes from patients and also their active role in the management. As such, the voice from patients is very important. People acquire experience with their disease over time and cope with it in different ways. They often need to prioritise their life goals and social life apart from Type 2 diabetes and its treatment. As of now, we don't have any national data on the experiences of people living with type 2 diabetes and we can only assume that there are no

cultural differences and that experience of living with diabetes is similar to other countries. We conducted a qualitative study involving focus groups (FG) to explore patients' experience of managing the disease and the obstacles to adhering to treatment..

Methods

Participants and settings

Patients from the central area of Slovenia were invited to participate by their family physicians. The sampling was purposive and convenient to include patients with variety of sociodemografic characteristics, different duration of diabetes mellitus type 2, presence or absence of chronic complications, different methods of treatment and diabetes health care providers.

Data collection and analysis

The approval of the ethics committee was obtained. We arranged five focus groups of diabetes patients, each with 6-8 participants, and one focus group of experts in the research topic for the purpose of validating the themes of the patients' focus groups. Each focus group met once.

The discussion was moderated by open-ended questions, prepared in advance, asking about patients' feelings on the diagnosis of their disease, their thoughts on their doctor's decisions on how to treat their disease and their decisions or thoughts about changing the treatment by themselves. The moderator was a final-year medical student with previous extensive training in qualitative research. The main researcher was an observer at each focus group meeting and conducted the discussion of the expert group. After each focus group the moderator and the observer met to discuss the course of the focus group, the new issues that were noticed and made conclusions in the field notes regarding future

discussion points. The analysis of the the transcript of audiotape followed the principle of grounded theory after each focus group - the breaking down of the text into meaningful units (marking of important citations), along with the coding and emergence of themes [32]. These themes were discussed with other members of the research team. By using a network of concepts to represent the relations between the codes, we identified the analytical categories that emerged from the data that were not previously defined. The procedure was repeated many times until no additional new codes could be found. The analysis of the expert group followed the same principle. After that, we gathered the results of the expert group along with the results of the patient focus groups. We looked for connections in the analytical themes and categories and for matches of the context.

Quality control

The study's validity was achieved through the careful transcriptions by a professional with additional control to ensure the correct typing process, the presence of an observer in each focus group, and through several triangulation methods. During the study we organised regular peer debriefings between the moderator, observer and expert in the qualitative research. Two analysts conducted an independent analysis of the data and a discussion leading to a consensus was made in each case of a different coding. The degree of agreement between the two analysts was high and a consensus-achieving meeting was held after the first set of coding. Finally, we organised one meeting of the expert group, which provided further help in the interpretational process and served to validate the themes. The eight invited experts were medical professionals (a diabetologist, a family physician, a representative of the Medical Chamber, a nurse educator), a representative of the national insurance company, a representative of the National Diabetes Association, and a patient with diabetes. One invited expert could not attend the meeting. The experts received the results of the focus group analysis several days before their meeting. The organisation of the expert group followed the rules of the focus groups but involved different questions based on the results of the patient focus groups. They were asked to comment on each category.

Reliability was achieved by carefully following a qualitative methodology [33,34], including the demand for data saturation which was achieved after fifth focus group. The analysis was performed by using ATLAS.ti programme version 4.2. For the purposes of this article,

the quotes were translated from the Slovenian to the English language and retranslated for the linguistic validity.

Results

Focus groups of patients

34 patients with type 2 diabetes participated in the study, among them 17 were women. Majority of the patients (27) were from the age group between 50 and 69 years. Mean duration of diabetes was 8,2 years. 7 participants were on diet only, 21 on diet and were taking pills, 4 participants on diet, pills and insulin and 2 on diet and insulin. 12 patients were employed, others retired.

The analysis of the transcript from patient groups yielded 667 citations representing 921 codes. The codes were organised into 45 code groups. The code groups could be gathered around 17 themes, which could fit within 5 categories.

The explanation of the five categories is as follows:

Category 1: Emotional reactions to the disease:

They ranged between indifference and negative feelings. Diabetes patients wondered if their illness is important for them.

Most of these themes related to the feelings immediately after being diagnosed as a diabetic patient. Patients experienced a range of feelings, ranging from shock and fear to carelessness. Eventually, the progression of the disease itself changed their feelings, especially when chronic complications occurred or additional treatment became necessary. Patients also admitted that the knowledge about the disease and education modified their attitudes. Some participants succeeded to manage the demands of their own diabetes care well, adjusted their lifestyles and regained the feeling of being in control. Others were frustrated and afraid of management demands and felt that their quality of life has dropped.

The exemplar quotes from participants in category 1: I was afraid I wouldn't be the main (financial) provider anymore, and that others would be disappointed of me.

At this point, I have the feeling that I can cope with it (diabetes).

You are listed diabetic until your death. A dog on a leash.

You have to resign from everything good.

Category 2: Social environment: Changes in social life and a need for understanding.

This category covered themes about interpersonal relationships including the family. Diabetes patients seek support within their families but, at the same time, they know they cannot expect too much of adaptation from their family members. The family does not always adjust to the new circumstances, especially when diet is concerned. The same problem appears in other areas of social life. Diabetes patients perceive their illness as a stigma. At work, patients face many difficulties, especially in following the dietary advice. The disease can also have a negative influence on their careers: it interferes with ability to work and switching to a less demanding job brings economic disadvantages. Patients feel the need to prioritise between diabetes control and financial welfare.

The exemplar quotes from participants in category 2: The whole family has to agree. But you can't expect that they would subordinate to you.

It took us one year, then my husband said – if it's good for you, then it won't do any harm to me if I eat what you eat. So we don't cook extra – the same for both. Diabetes is not understood as a disease when you need help. But it is a disease which limits your professional ability.

To be 10 or 14 hours on a business trip, keeping your diet, insulin. I could have said – I'm not doing this anymore – and stay at home. But I had three children, a wife; we had to make a living.

In the business world you must not tell that you have diabetes, you are immediately written off in the business. There you have to be perfect and healthy.

Category 3: Medical care: The issue is mutual trust and doctor's interest in patients

This category included the role of medical services. Patients emphasised the importance of good communication with one's doctor. Besides expert advice from the doctor they expect also his interest in their disease management, who should take them seriously. There should be a mutual trust in the relationship between the patient and the doctor. Some patients were emphasising their need for paternalistic approach from the doctor. The nurse was seen as a person for kind, personal contact. Patients' anticipation regarding the organisation of services especially pointed to good practice organisation, shorter waiting time in the waiting room. They don't want that diabetes management takes them too much time in life.

The exemplar quotes from participants in category 3: I trust them (doctors) and do what they ask me to. I have to be disciplined, of course. They know best. The doctor trusted me so I tried with insulin at home.

We didn't discuss other things. Just: from the doctor's point of view – eat pills, you have diabetes, that's all. At the beginning she (doctor) didn't take me seriously.

Something isn't right with this organisation of care. In fact, I have said many times this is a disease for a retired person, they have time for themselves, and this is an "occupation" where they can arrange things for their lives.

Category 4: Diabetes management: Overcoming personal barriers

This category included the themes about the problems of everyday management of the disease and shows attitudes and ways of patients' adaptation. The changes to one's life style and daily routine are much more difficult than simply taking oral medication. If used as a method of treatment, diet is perceived as the most difficult to follow. On the other hand, it is also perceived as a management of a mild stage disease, braking diet rules being harmless and understandable. Many themes were connected to problems with adherence to the diet: lack of motivation, poor self-discipline, feelings of constant renunciation, overeating habits and different taste of diet food.

Diabetic pills can be taken regularly, after the patient has accepted the need for management of the disease by pills as treatment regimen and organises his schedule to take them as prescribed.

Physical activity is also based on personal characteristics, one's motivation for exercise and external factors like the weather, lack of time and comorbidity.

Treatment with insulin is in the eyes of patients a sign of serious disease and they emphasized the importance of expert advice from a doctor they can trust. Starting insulin treatment represents important point in a diabetic patient's life. People have fears from insulin therapy but, after they adopt it, they believe in its positive effects. They perceive insulin as especially stigmatic therapy.

The exemplar quotes from participants in category 4: I really enjoy eating so that I have difficulty to refuse some items.

Now I have balanced myself so that after my lunch at work, at 6 o'clock when I come home, I eat something small or nothing. And I feel quite fine.

...and also I started again to climb mountains, I reactivated myself.

I was very scared of pills. She (the doctor) wanted to give me them immediately... I was starving just to avoid the pills.

You get used to it (insulin), when you realise that it's better for you and if they (doctors) tell you that.

When I go on business trip my colleagues are afraid that I will fall into hypo(glycaemia) and don't want to stay in the same room with me.

It is very good if you test your sugar (self-control), as you test yourself actually...

Category 5: Education: The same for everybody? This category included the themes about sources of education. Patients cited sources of self-education, materials from the media and information from other people. They were aware that education brings about the change in attitude about the disease that is considered more serious. Critics of current education were missing an accurate and individualised approach to the treatment of patients, tailored to their more or less active lives.

The exemplar quotes from participants in category 5: ... It's too technically written.

Too late, we get information too late, what this is and what the consequences can be.

They told me only that I am 7 kilograms overweight, and to diet. Being 10 hours on a (business) trip... and they advise a diet!

First, I wasn't very shocked, I probably didn't take it seriously. Then I went to the lectures and I was told about the consequences of the disease, what can happen. Then I started to think that it's not as simple as I thought.

Expert group

This group interpreted the categories identified from the focus groups of patients. Their discussions yielded 13 themes.

Category A: The problems of patients

Experts were aware of the problems patients experience at work and regarding their work disability, but they have also critically emphasized the high social security level of those patients.

The exemplar quotes regarding Category A:

It is difficult to have a very successful career and adjust the need for discipline during the treatment with one's own career demands.

Social security is so high that it doesn't have any match with other countries. The length of sick leave is unlimited in our country, unlike elsewhere in Europe.

Category B: Education

The experts were discussing the purpose of health education which has to be made clearer for patients, adjusted to the patient needs and should be continuous. It should start with healthy people. It should assist in behavioural change and not only educate in the sense of giving the right information. There is a lack of nurse-educators.

The exemplar quotes regarding Category B:

Patients are right to expect more precise, adequate instructions.

Individual advice has to be emphasised in education. It has to be included in every check-up.

We change, assist, help him cook, change his life style.

Discussion

Previous studies [17,35] and ours show that the chronic nature of diabetes has an important influence on patients' lives. The integration of the illness in everyday life takes time. Many studies confirm time factor in progression from passive compliance of the patient toward taking personal control [35]. Patients are seeking trade offs between adherence to recommended treatment and their other interests, goals and needs in everyday life [16,36-38]. Several studies found balancing all the demands as a predominant patients' goal [10]. Time factor – providing opportunity to get information and to gain experience with the disease – is a bridge between first emotional response and adaptation, adjustment, or the opposite – maladaptive feelings of constant burden and frustration.

Social support is important to the patient's ability for self-management and it can be either positive or negative [20,25,39]. The family is not always supportive. Many persons with diabetes do not expect support from their family because they do not want to put this burden on to family members. In social encounters, patients did not want to reveal their needs, especially if they perceived their disease as a stigma. It is surprising that a disease with high and still increasing prevalence is perceived as a stigma by patients.

The patients felt the disease was difficult to reconcile with their jobs. The diet recommendations seemed very rigid, individually unadjusted and uniform to them. They felt the right for autonomy and taking breaks from diabetic diet in many social aspects of nutrition, such as social activity and pleasure but on the other hand they blamed themselves to have weak personality for not resisting food temptations [10,40]. Increasing

sense for the right of autonomy of the patients is a fact that providers will need to address in the future [41]. Diabetes is regarded as a public health issue, which was especially emphasized by the experts. Society needs to co-operate and seek solutions together with the health care system – the public and media should be more interested in the disease, public education is important. Social security of the patients in the case of limited working ability is very important. The social security of patients has been mentioned by patients and experts, but was perceived in the opposite ways. It seemed that diabetic care is quite well organised at the legislative level, but at the personal level patients encounter many problems.

Similar to others our study clearly shows that patients expect personalised care [42]. Care providers should not just give universal advice but should help patients to cope with diabetes in their everyday life [43]. Patients expect flexibility in communication styles, empathic interest of the doctor in their illness and specific situation and are critical to superficial, unconvincing general advices provided. The demands toward physicians are increasing beyond plain expert advice on management diabetes.

Each new stage of treatment is accompanied with patient's reluctance for change. Patients need time to accept pharmacological treatment and also starting insulin is an important decision for them. At these important turning points in the disease progression they need to trust the doctor and value his support [44-46]. Despite being aware of several problems regarding adherence, patients also felt that they have adjusted to the management plan and they developed capacities of self-management.

Comprehensive information on the disease is a cornerstone of good adherence and the best way to gain it is systematic patient education [47,48]. Education through active involvement of the patient is the best method to overcome a patient's refusal of therapy. Teaching self-management skills and including trial and error, testing, listening for the body's responses should be provided as part of the teachinglearning process [17,21,22]. This has been proven by the Gillibrandt study [49]. Patient education was often mentioned in the experts' discussion. Patients did not feel there was a lack of education provision by the medical service, although they felt that they had not been given enough information at the beginning of the disease. In some management areas, like physical activity, education has been proven to be insufficient and should include other professionals. Patients are also very interested in other sources of information,

such as friends, acquaintances, and the mass media, which they do not assess critically for the quality of the information. According to the similar results with other studies [9,10], the problems of diabetes management are perceived by patients on individual level while health care professionals are seeing the opportunity in society to improve diabetes care.

Limitations of the study: We tried to include a variety of diabetes patients in the study, but patients from nursing homes and those in home care were not represented. However, majority of those is managed more thoroughly by the health care personnel. We used several control qualitative methods to reduce the subjectivity of the data, with the expert group as a benchmark being the most important. As the discussion of the participants of the study was conducted in the native spoken language, the translation of the quotations presented some dilemmas. To avoid subjectivity in translation, we retranslated the text and compared the meaning of the retranslation with the original.

Conclusion

We presented the results of the first national study how patients with a chronic disease are coping with treatment demands in everyday life. This study offers additional insights into patients' views of the barriers to adherence. The possibility for occasional departure from recommended treatment in certain social and life situations is an important dilemma for patients. The trade-offs between social expectations, working demands, their own capacity to re-organise life on one side and individualised support of the physician with patients' increasing knowledge and experience could lead to better adherence and results of the treatment.

Considering the results, our suggestions for improvement of chronic care management are: better organisation of appointments and medical care, constant long-term psychological support, increased empathy of doctors for the patients' problems in coping with the disease, individualised approach to patients, assistance to behavioural change and empowerment of patients.

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