



ELSEVIER

available at [www.sciencedirect.com](http://www.sciencedirect.com)journal homepage: <http://www.intl.elsevierhealth.com/journals/pcd/>

# Obstacles to adherence in living with type-2 diabetes: An international qualitative study using meta-ethnography (EUROBSTACLE)

Etienne Vermeire<sup>a,\*</sup>, Hilary Hearnshaw<sup>b</sup>, Anneli Rätsep<sup>c</sup>, Gwenola Levasseur<sup>d</sup>,  
Davorina Petek<sup>e</sup>, Henk van Dam<sup>f</sup>, Frans van der Horst<sup>f</sup>, Nevenka Vinter-Repalust<sup>g</sup>,  
Johan Wens<sup>a</sup>, Jeremy Dale<sup>b</sup>, Paul Van Royen<sup>a</sup>

<sup>a</sup> Department of General Practice, University of Antwerp, Belgium

<sup>b</sup> Warwick Medical School, University of Warwick, UK

<sup>c</sup> Department of General Practice, University of Tartu, Estonia

<sup>d</sup> Department of General Practice, University of Rennes, France

<sup>e</sup> Department of General Practice, University of Ljubljana, Slovenia

<sup>f</sup> Department of General Practice, University of Maastricht, Netherlands

<sup>g</sup> Department of General Practice, University of Zagreb, Croatia

## ARTICLE INFO

### Article history:

Received 25 April 2006

Received in revised form

18 July 2006

Accepted 24 July 2006

Published on line 19 December 2006

### Keywords:

Europe

Diabetes type-2

Adherence

Qualitative

Meta-ethnography

Meta-analysis

## ABSTRACT

Quantitative studies failed to determine variables which consistently explain adherence or non-adherence to treatment recommendations. Qualitative studies identified issues such as the quality of the health provider–health receiver relationship and the patient's health beliefs. According to these findings, 39 focus groups of 246 people living with type-2 diabetes were conducted in seven European countries, assessing health beliefs, communication with caregivers and problems encountered in adhering to treatment regimens. Meta-ethnography was later applied to make a qualitative meta-analysis. Obstacles to adherence are common across countries, and seem to be related less to issues of the health-care system and more to patient's knowledge about diabetes, beliefs and attitudes and the relationship with health-care professionals. The resulting key themes are course of diabetes, information, person and context, body awareness and relationship with the health care provider. Meta-ethnography is a feasible tool for the meta-analysis of multilingual qualitative data and leads to a richer account.

© 2006 Published by Elsevier Ltd on behalf of Primary Care Diabetes Europe.

## 1. Introduction

Low adherence to prescribed medical interventions is an ever-present and complex problem, especially for people with a chronic illness. Low adherence is a growing concern, seriously undermining the benefits of current medical care. Therefore,

medical non-adherence has been identified as a major public health problem. The enormous amount of quantitative research, ~9000 articles, undertaken since 1975 was of variable methodological quality, with no gold standard for the measurement of adherence so that it often was not clear which type of non-adherence was being studied. Many authors did

\* Corresponding author.

E-mail address: [etienne.vermeire@ua.ac.be](mailto:etienne.vermeire@ua.ac.be) (E. Vermeire).

1751-9918/\$ – see front matter © 2006 Published by Elsevier Ltd on behalf of Primary Care Diabetes Europe.

doi:10.1016/j.pcd.2006.07.002

not feel even the need to define 'adherence'. Often absent in this research was the patient, although the concordance model [1] points at the importance of the patient's agreement and harmony in the doctor-patient relationship. The backbone of the concordance model is the patient as a decision maker and a cornerstone is professional empathy. Some qualitative studies in the 1990s have identified important issues such as the quality of the health provider-health receiver relationship and the patient's health beliefs in this context [1,2].

Diabetes requires complicated treatments and lifestyle changes and is, therefore, a useful model of self-management as a necessary component of care [3-5]. One aspect of effectiveness is the adherence to the prescribed medication, monitoring or lifestyle advice, by people who have diabetes. Evidence indicates that improved adherence to medication and lifestyle advice improves metabolic control: thereby leading to a reduction in the risk of complications, an increase in life expectancy and a reduction of morbidity in people living with type-2 diabetes [6-10]. Furthermore, successful management of diabetes, including adherence to treatment and advice, can also improve the quality of life for people living with diabetes [11].

According to these findings, qualitative studies using focus groups were conducted in seven European countries to assess health beliefs and obstacles to treatment recommendation adherence. The objective of the meta-ethnography study presented was to make a synthesis of these seven studies.

Our research aimed to answer three questions. First, what are the differences and similarities of the obstacles to adherence for people living with type-2 diabetes in each country? Second, are these obstacles the same in countries with different health-care systems? Third, can the data from parallel, international, multilingual qualitative studies be synthesised to answer the first two questions?

## 2. Methods

A first study using focus groups [12] was conducted in Flanders (Belgium) to assess the health beliefs of people living with type-2 diabetes in relation to their illness, their communication with caregivers and the problems encountered in adhering to treatment regimens [13].

The findings were that health beliefs, the quality of the doctor-patient communication, and the quality of the infor-

### Box 1: The questions or statements posed to the focus group participants.

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 did you experience the treatment?
3. Probably, your doctor chose the treatment regime for you. How do 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 this decision?

mation patients receive are important factors for patient adherence to treatment recommendations. Possible explanatory models for adherence emerged, relating to knowledge of the illness, body awareness and the doctor-patient relationship [13].

These results were presented at a European General Practice Research Network (EGPRN) meeting [14] and generated a collaborative study in six more European countries: Croatia, Estonia, France, The Netherlands, Slovenia and the UK. This was the EUROBSTACLE study. The same data gathering technique, namely focus groups, was used as in Flanders, including the same questions posed to the participants (Box 1).

In each country the focus groups were conducted according to Krueger's technique [12]. Some information about the national samples are shown in Table 1. More details about ethic committee's approval and sampling have been reported exhaustively in the published national studies. The data was first analysed using grounded theory [15] to derive themes, generating a primary level interpretation in the native language. The researchers from each country then met and presented their primary data to each other. Many of the studies had been published [13,16-18]. In attempting to combine the data from each country, the research group was confronted with a number of problems: six different languages, different cultures, the translation of codes and themes into a common language, English, which might lose some of the valuable content and context, and seven reports and accounts on the primary analysis in each country. It was

**Table 1 – Participants in each country**

Country	Number of focus groups	Number of participants	Males/females	Mean age (range)	Duration of diabetes (mean)
Belgium	6	46	21/25	64 (<50-80)	8 (1-21)
Croatia	7	49	22/27	64 (40-80)	11 (2-22)
Estonia	5	21	9/12	66 (<50-79)	12 (1-22)
France	6	44	24/20	64 (<50-74)	9.8 (2-21)
Netherlands	5	33	20/13	64 (41-80)	10.2 (2-21)
Slovenia	5	34	17/17	59 (<50-79)	9.8 (2-21)
UK	5	19	9/10	65 (<50-75)	11 (1-22)
Total	39	246	41%male	63.8 (40-80)	10.2 (1-22)

confirmed, as was expected beforehand, that a simple aggregation of data would be insufficient to capture the depth and the variety of the findings. This supported the decision to use a synthesis, a more structured meta-analysis as the most appropriate method to seek common key themes and ensure transferability between countries. The main goal of this research, reported here, was not simply aggregating the findings into a summary list of themes emerging from the primary analyses, but seeking a deeper insight and reaching a conceptual development that was richer than the individual studies. For this qualitative meta-analysis, techniques from the method of meta-ethnography developed by Noblit and Hare which was first published in 1988 [19], were borrowed and adapted. Meta-ethnography offers on the one hand the opportunity to make a comparative analysis of qualitative findings, for instance from different settings, but enables researchers on the other hand to treat their data in a cumulative and synthetic way [19]. Unlike the meta-analysis of quantitative studies, meta-analysis of qualitative studies is interpretive rather than aggregative, requiring the researchers to compare and analyse reports, creating new interpretations in the process. The process involves inductive analysis of data generated from research studies, development of hypotheses, and testing of hypothetical relationships [20]. Noblit and Hare offer a stepwise programme (Box 2) that guides the researcher to find similarities in a series of qualitative studies (reciprocal translation), to detect differences (refutation) or to reflect on the totality (a problem, an organisation or a culture), thus making a synthesis (lines of argument synthesis). Several British researchers have used the technique successfully [21,22] suggesting its appropriateness for our purposes.

The themes derived from each study were entered into a table based on the list of key themes identified in the initial Flanders study [13]. This was discussed by the researchers until agreement was reached on how far the concepts relating

#### Box 2: Steps in Noblit and Hare's meta-ethnography.

1. Getting started: the meta-ethnographer identifies an intellectual interest that qualitative research might inform.
2. Deciding what is relevant to the initial interests. The meta-ethnographer decides what is relevant to initial interests, including what studies to include.
3. Reading the studies. This is not a one-time event; as the synthesis develops, studies are read and reread to check the relevant metaphors and interpretations.
4. Determining how the studies are related. Lists of key metaphors, phrases, ideas, and/or concepts and their relationships are made for each study and juxtaposed with those of other studies. This phase is complete when the initial assumption about the relationship between the studies can be made.
5. Translation. Translating involves treating the accounts as analogies. An adequate translation maintains the central metaphors and/or concepts of each account in their relationship to other metaphors or concepts in account while comparing them to the relevant metaphors and concepts in other accounts.
6. Synthesising translations. Translations are the first level of a meta-ethnographic synthesis. The various translations can be compared with one another to determine if some metaphors and/or concepts are able to encompass those of other accounts. If so, a second level of synthesis is possible: analysing types of competing interpretations and translating them into each other.
7. Expressing the synthesis. A meta-ethnography must be 'translated' into 'language' of the intended audience. This involves using the forms and metaphors appropriate for that audience.

#### Qualitative synthesis

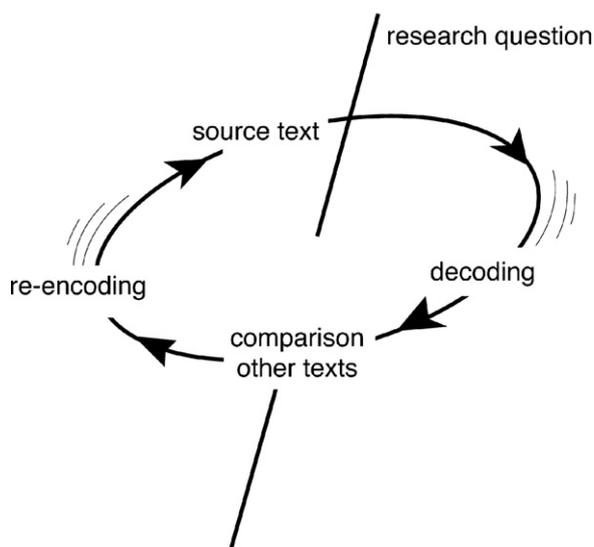


Fig. 1 – The axial translation process [23].

to the themes could, in fact, be translated from one study into another, and whether this led to richer explanations. This process required returning repeatedly to the original data from each country to either verify, contradict, or enrich interpretations: it is an axial process [23] of coding and re-coding in the context of the different studies guided by the research questions (Fig. 1).

This process aimed to ensure that the newly created narrative not only accounted for the original metaphors and interpretations but also went beyond them to describe broader phenomena that were operating in the studies. A systematic search was undertaken for either the presence or absence of these concepts in the individual studies.

A supplementary difficulty in drawing lists of codes or key concepts was to verify and clarify the exact meanings. The comparability of the translation was cross-checked, verifying whether the English word covered the native meaning and the expressed nuances. At the same time it was checked whether the translation process had not forced the researchers to go too far in abstraction or to use abstruse terminology.

**Table 2 – Key themes and second-order interpretations of patients' perceived obstacles to adherence**

Key theme	Belgium	Croatia	Estonia	France	Netherlands	Slovenia	United Kingdom
Course of diabetes—diagnosis onwards	The evolution of complications is imperceptible	The fear of complications	It is not a life threatening disease	Illness is denied until complications arrive	You feel good, so why change your life?	Relative indifference at first, which changes as the disease progresses	Mild diabetes is a problem, a risk factor, the silent killer. True diabetes is the disease with complications or when treated with insulin
Information	Patients: poor knowledge of disease. Physicians: incomplete and even conflicting information. Uncertainty about physician's adherence to management guidelines. Need for tailored information	Ignorance. Even leaflets unavailable. Information not adapted to education level	It is better not to talk about diabetes. Those who are indifferent or even negligent perhaps need more information than others	Satisfying information provided in specialised hospital departments. There are many reliable sources available, though	Coping depends on how serious you consider the condition is Patients' knowledge of diabetes enhances as times goes on. Limited, conflicting information especially about the treatment	The lack of knowledge is very variable, depending on which aspect of the disease	Information is complex, and non-transparent
Person and context	Social context is 'harmful' for dietary adherence	Lack of understanding Hiding diagnosis. Career? Support and control by family	Health beliefs and feelings usually not expressed	There are many reasons and occasions to adapt the recommended treatment	Being adherent means thinking of the disease all the time, which makes people nervous and as a result non-adherent. Coping strategies and adherence depend on how seriously the individual condition is being considered	National food is forbidden for diabetics	Patients shocked by the diagnosis need the most support. People without a healthy life-style encounter more problems. It means being able to live with the condition and not deny it. Support leads to better confidence. Own creative solutions are allowed. There is a negative effect of continuous social encouragement: being nagged
Body awareness	Imperceptible treatment effects. Self-regulation is keeping in touch with own body. Observation of body's functioning with or without treatment				Why change your life-style when feeling good?		
Relationship with health care provider	Blaming patients for bad outcomes. Not enough time to listen to patients. Patients' health beliefs not assessed. Treatment tailored to patient's personal situation? Better and more appropriate communication with nurses. Physicians 'lose their conviction', their efforts fade	Physicians do not understand patients' difficulties. Specialist care: only when insulin treatment or complications: waiting lists. Nurses are more supporting for patients, giving more understanding and sympathy	It is physicians' role to decide on the treatment. Not enough technical investigations, more referrals desired. Limited time of consultations	GPs are not concerned about diabetics. Specialists are competent and listen to patients at least	Insufficient encouragement from physicians	From trustful to authoritarian	'Postcode lottery': referral to specialist care depends on the city you live in

**Table 3 – Synthesis, including key themes and third-order interpretations**

Key concepts	Third-order interpretations
The course of diabetes	Diabetes is a 'problem' until there are complications, then becoming a 'disease'
Information	Non-adherence is to a large extent determined by the lack or un-transparent information
Person and context	Coping with diabetes depends on social support, personal attitude towards a healthy life-style and health beliefs
Health care provider	Does not assess health beliefs, does not tailor recommended treatment
Body awareness	Imperceptible treatment effects. Self-regulation is keeping in touch with the body, to see how it functions with or without recommended regimen

We then aimed to follow Britten and co-workers [21,22] in developing second- and third-order interpretations from the first-order ones. The first-order interpretation related to the participants' everyday understanding and is represented by specific and representative text fragments. The second-order interpretations were constructed when translating studies into one another by the researchers taking into account the context of the first-order interpretations (Table 2). As the EUROSTACLE studies were all similar to the initial Flanders study, a line of argument could then be developed, as the third order interpretation, based on the second-order interpretations as the constituent parts (Table 3).

### 3. Results

Thirty-nine focus groups with 246 participants were conducted in seven European countries. The key themes and second-order interpretations of the data from each country are shown in Box 2. The synthesis with key themes and third-order interpretations is presented in Table 3. The resulting key themes were: course of diabetes, information, person and context, body awareness and relationship with the health-care provider.

#### 3.1. Course of diabetes

The progression of the condition is difficult to appreciate, especially if there are no symptoms. People felt they were often not given enough warning of the risk of development of complications, even though they agreed they had been told at the beginning. There was a feeling of the silent, unnoticed effects having bad outcomes, but not being given enough 'weapons' to prevent them. The condition was not perceived as serious, by either the person with diabetes or the health-care professionals, until after complications had arrived. There was often no feeling of being ill and so the diagnosis could be a great shock. This concurs with Bury's description of chronic illness as a biographical disruption [24]. The following are typical quotations from people with diabetes:

*"Diabetes type 2 is not a 'real' disease. It is difficult to consider oneself ill and thus to follow the treatment or diet."* [France]

*"I have had diabetes for almost 20 years. I take a pill in the morning and one in the evening. Food, well less sugar. That's what they told me, and I don't feel any trouble."* [Belgium]

*"Diabetes is not serious. I've always said that diabetes wasn't the end of the world."* [France]

*"My first feelings were—why me? Then if the disease doesn't progress too quickly, you just live with it. The problem appears if the disease progresses quickly."* [Slovenia]

*"It's an illness that can't be felt, or that can be denied until there are serious complications, and that's easily treated."* [UK]

Course of change of the disease and change of lifestyle and behaviour is often not accepted because the effects of current treatment are not fully understood.

*"The discovery of diabetes is difficult as it means losing weight, being careful, fixing limits, going on a diet, not eating like everyone else."* [France]

*"Sometimes I am threatened when I need to start injecting insulin. I used to take 5 tablets a day. I can't say I have cheated recently, but this is 11 [blood glucose level in mmol/l] again, with 5 tablets!"* [Estonia]

*"I feel good, so why lose weight? If I did lose weight, I might feel bad and become ill, and then what?"* [Netherlands]

#### 3.2. Information

There was a problem in that people were not aware of how ignorant they were. There was much information presented to them, but not all of it was understandable or memorable, and often the information was given at inappropriate times. It is also clear that explanations could clash, or contradict existing lay knowledge [25].

*"Diabetes: it's a matter for the specialist. The major problem with GPs is that they know far less than we do. We get information, we read and keep informed."* [UK]

There were many examples of incomplete, conflicting or misunderstood information and the person's concern about this.

*"Diabetes in older people requires no treatment."* [Croatia]

*"I feel that I am not properly informed on new diabetes care developments, i.e. new drugs, by providers. I want this information. Perhaps the internet might help."* [Netherlands]

*"Several doctors and nurses explained to me what to do or what not to do on different occasions. It seems to me as if everyone has their own diabetes theory."* [Belgium]

*"Information and explanation about the treatment is often not provided. When I get this, it lowers my fears and worries, and I find it positive."* [Netherlands]

These findings confirm those reported by Barber et al. [26] from patients starting new medication, expressing need for more and better information, in order to improve adherence. They felt that adherence to the professional's advice is not always the best action for a patient, which the EUROSTACLE participants also suggest.

### 3.3. Person and context

Belief in the seriousness of the condition is essential as a motivation for making those adaptations and sustaining them [27]. Belief in the effectiveness of self-management behaviours is essential in order to attempt the adaptations [28].

Having to adapt every aspect of life to include diabetes was difficult. Social events were perceived as being difficult (e.g. pressure to eat sweet cake at a family wedding) or being expected to cook different meals for your husband because he did not want to follow your diet. The common feeling was of being different from the rest of society and the reactions that this difference induced from other people in social and work contexts.

*"I do without everything. I dread evenings like New Year's Eve. You're not free with insulin, you have to do it at a regular time, eat straight away. You're not at all like the others."* [UK]

*"They make fun of my diet, bawling at me."* [France]

*"I cheat when my children visit me, I suppose because I bake for them. I add little sugar but then my youngest son complains that I made a sour cake again. But when I am alone I don't cheat."* [Estonia]

*"When people from my social circle intrude into my food habits, or show no understanding of my diet, then I perceive their help as negative or nagging."* [Netherlands]

It is also considered a stigma in business for the same reasons:

*"All of us, people with diabetes, are hiding our disease. In the business world it's forbidden to say that you have diabetes. You are out of business immediately. In business you have to be healthy and perfect."* [Slovenia]

*"You live with that. You have to synchronise everything. I still work and I didn't take a single day of sick leave because of diabetes. In a way, it is good; because you have to follow a certain order. I never had breakfast before, now I do. I eat a piece of bread, take my pill and go to work."* [Slovenia]

The influence on the rest of the family of the diet followed by the person with diabetes varied from total change to no change. In the 'no change' situation, the desire to fit in with usual family habits of others overrides the individual's own need to adapt the eating for diabetes.

*"Every family member has changed their eating habits."* [Croatia]

*"Illness has not influenced my family in any special way. I cook different kinds of meals for them and for myself."* [Croatia]

*"My wife is a wonderful wife, but only after she became a diabetic did we start with diet food at home."* [Slovenia]

*"I don't think about it [diet] extensively. I don't reckon myself as a diabetic."* [Estonia]

*"I eat like every one else. I just have a small aperitif, a few chips and a small! piece of cake for my daughter's sake."* [France]

### 3.4. Body awareness

As people learn how their body reacts to different foods, activities and medications, they can also develop ways to manage their diabetes. As each person reacts differently, people need to learn this for themselves. This is a proactive role for the patient and possibly means a change in the relationship between the patient and the professional advisor.

The adaptations that people make may be major but are based on their own judgement of what is appropriate for them as an individual, with their own limitations:

*"I frequently change the dosage based on my own physical activity, diet and sugar levels."* [Croatia]

*"You keep thinking about when you'll give yourself a shot and when you'll eat. You can't eat when it suits you."* [Croatia]

*"It's an illness that puts one in charge of one's own illness."* [France]

*"And it is complicated. . ."* [UK]. *"It is complicated but we are real technicians."* [France]

*"I can do without a lot of things but not bread; a baguette every morning; I used to eat a bar of chocolate every evening with my wife, now I just have two squares. I just have 125 g of butter, half in the morning and the other half for tea."* [France]

*"I don't consciously recognise hyperglycaemia. Physically you don't feel anything. This limits my motivation for regular tablet taking, more physical activity, food adaptations or more insulin."* [Netherlands]

### 3.5. Relationship to the health care provider

Many doctors were perceived as not liking overweight patients with diabetes. The patients were blamed for being, and staying, overweight. In turn, the people here suggested the doctor also had some responsibility:

*"I think that doctors should insist more and be more authoritative to persuade the patients that being overweight is very harmful. They should put more effort into this job."* [Slovenia]

*"They don't like fat people. . . It hurts when you're told there weren't any fat people in the concentration camps."* [UK]

The way the diagnosis was given was often carelessly casual, with no regard to the feelings of the person receiving this diagnosis. It was surmised that this was a result of the doctor delivering a frequent and depressing diagnosis. Doctors are seen to lose interest or belief in the treatment they offer.

*"Last year I went to the endocrinologist again, and then she said I could stop taking the tablets. I used them for a year or so and then I stopped taking them. My general practitioner does not pay any attention, and then I have to ask because my friend is a*

**Table 4 – Provision of diabetes care in seven European countries**

Question	Answers	Be	Cro	Est	Fr	NL	Sl	UK
How does a patient first see a specialist?	Referred by a GP		✓	✓	✓	✓	✓	✓
	Patient can go direct	✓			✓			
Who provides the routine care?	GP mainly	✓		✓				
	Primary healthcare team		✓			✓	✓	✓
	GP and specialist				✓		✓	
How is the provider paid?	Fee for service	✓			✓			
	Capitation		✓					
	Salary						✓	
	Mixture			✓		✓		✓
The patient pays for . . .	Every consultation	✓	✓		✓			
	Diabetes medication			✓				
	Laboratory tests	✓	✓					
	Self testing materials	✓	✓				✓	
How often are routine check-ups?	More often than 6 m	✓	✓	✓	✓	✓		
	Every 6 m						✓	✓
Difficulties for patients in getting education materials	No difficulties		✓		✓	✓		✓
	Not enough available	✓		✓				
	Cost						✓	
Difficulties for patients in getting medications	No difficulties	✓			✓	✓	✓	✓
	Not enough available		✓					
	Cost			✓				
Difficulties for patients in getting testing materials	No difficulties				✓			✓
	Not enough available							
	Cost	✓	✓	✓		✓	✓	

B, Belgium; Cro, Croatia; Est, Estonia; Fr, France; NL, Netherlands; Sl, Slovenia; UK, United Kingdom.

cardiologist and she asked how could I let it be, not taking the tablets? Am I supposed to ask then? The doctor should advise me." [Estonia]

Health-care professionals were thought to have very little understanding or acceptance of the real difficulties patients have to face when living with diabetes:

"Some doctors don't allow discussion of details of the treatment. For me, not being allowed to speak freely is the biggest problem." [Netherlands]

"GPs talk about it like for smoking: 'you should stop'. It's hard because of my weight. The GPs are unkind." [UK]

"Doctors do not understand what it means to live with diabetes for 365 days a year." [Belgium]

Nevertheless, many people have complete trust in their doctor and the prescribed treatment:

"My doctor decided on my treatment plan and she made a good decision." [Croatia]

"I have no complaint with my GP. He explained things clearly. When I got upset he told me not to get in such a state. We are comfortable with him. It's easier to ask him than the specialist we don't know well." [France]

"To decide about treatment is the doctor's role. I really do as the doctor said." [Estonia]

"My doctor knows me. He is a good fellow. When I phone him to know my sugar, he usually says 'You are doing fine', even if the

sugar is still too high. But sometimes he sounds angry when he's saying that." [Belgium]

### 3.6. Care provision for diabetes

The data about diabetes care service provision in each country are summarised in Table 4. There is no item that is present in every country, so there is variation across the countries in every aspect. In particular, there are difficulties for patients getting medication in Croatia because of a lack of availability. There are difficulties in getting glucose testing materials in Belgium, Croatia, Estonia, Netherlands, and Slovenia also because of the high costs. In Slovenia, costs are covered by insurance for those on insulin, but not for others. There are difficulties in getting education materials in Belgium and Estonia, because there are not enough available, and in Croatia because of cost. Thus, costs and lack of materials would seem to be candidate reasons for obstacles to adherence for patients in these countries.

## 4. Discussion

The research questions were answered. The data from seven, parallel, qualitative studies was synthesised successfully to provide these answers. The results of this synthesis of qualitative studies using meta-ethnography show that the obstacles to adhering to treatment recommendations for people living with type-2 diabetes comes to an number of explanatory models: the course of diabetes, information, person and context,

body awareness, and the relationship with the health-care provider. These are common to people living with type-2 diabetes in Belgium, Croatia, Estonia, France, Netherlands, Slovenia, and the UK. Though the health-care systems in these seven countries vary substantially in structures and processes as shown in Table 3, the obstacles to adherence, however, vary much less. This suggests that the health-care system is not a major factor in influencing the adherence to treatment and lifestyle advice, except in providing materials and resources. The major factors affecting adherence come from the themes identified. These themes are transferable between the seven countries.

The amalgamation of qualitative data was completed successfully. Because there are no precise guidelines on how to conduct qualitative evidence synthesis, we followed methods from different experts and researchers doing pioneer work such as Noblit and Hare [19] and Britten et al. [21]. Our process of synthesis of data was different from a straightforward secondary analysis of pooled cases. The secondary analyses were carried out by the researchers who completed the original (first-order) studies, which is a novel factor. This method allowed a closer involvement with the content and context of the data that were to be synthesised. It also helped to overcome the difficulties of synthesising studies that were carried out in six different languages. The purpose of our synthesis was not to confirm or validate data but to create a richer and deeper reading of the interpretations in the individual studies by increasing the range of data sources using different countries, health-care systems and cultures. Qualitative evidence synthesis is less about the reduction of data than the amplification of data and interpretive innovation [29,30].

In this article a line of argument synthesis is presented that highlight concepts that encompass all studies. In this work all researchers used similar theoretical perspectives when conducting focus-group interviews and used grounded theory, thus without using any particular theoretical framework when analysing their data, making the studies directly comparable as reciprocal translations.

Although the samples in each country were small, they were homogeneous and when combined they provide a more-than-adequate sample for qualitative research, making us confident in the synthesised results [22]. Further reasons for confidence in the findings include the rigorous data analysis and the adoption of a standardised protocol that had been previously used and tested. The ease with which the focus group participants generated discussion and relevant data confirm the concept validity of the topic of the focus groups and the relevance to people who live with diabetes. The meta-analysis presented here gives more confidence to the interpretations than would be possible for the interpretation of the data from any one individual country.

The potential audiences for these findings include researchers, health-care providers, commissioners of research, and health policymakers. Key themes and interpretations are presented that could enhance greatly our understanding of the sources of obstacles to adherence.

Though very time-consuming, as is also the case for the meta-analysis of quantitative studies, meta-ethnography revealed itself as a very feasible technique for the synthesis of qualitative data. Prerequisites for the successful realisation of

this technique is being familiar with qualitative research and the analysis of qualitative data for meta-ethnography makes a synthesis of interpretations, which are the core of qualitative inquiry. We cannot imagine alternative methodologies that would have been helpful in answering these research objectives. The axial and interactive way of doing meta-ethnography also helped enormously in overcoming problems arising from this multilingual and international collaborative research project. Meta-ethnography may be considered a feasible tool for the synthesis of qualitative data and data from research using diverse study designs, with which researchers will be confronted with more frequently in the future. The added value lies in a deeper and richer account and the broader context than can be obtained than from the individual studies alone.

Having identified the obstacles to adherence, and ascertained that these are common across many different countries and health-care services, future research should be conducted into discovering how these obstacles affect the outcomes of care. Such research could also question the effects that local circumstances or contexts affect the utilisation of services. These will not only be geographical and physical aspects of access but may also show financial and cultural aspects.

If the obstacles to adherence to treatment are independent of the health-care system, the suggestion is that guidelines for high quality diabetes care could also similarly be independent of the health care system. The implication is that guidelines may be more global than previously imagined, and rather than needing guidelines to be adapted separately for each country or health-care system, a universal version may be feasible.

Finally, it is important to place our work in the context of previous research. There is a large body of literature about adherence to treatment recommendations that mainly reports quantitative studies. Evidence published from 1975 until recently suggests that no variables could be determined which consistently explain either adherence or non-adherence [1,2]. At the end of the 1990s, it became clear to the researchers accepting the quantitative paradigm that factors such as health beliefs, patient decision making, patient participation, and the sharing of power in the medical encounter may play an important role in patient adherence to treatment recommendations [13,31-35]. The narrative line of this research project is in line with that recent body of evidence. The primary studies in seven European countries confirm the themes arising from similar work and the meta-ethnography confirms the transcultural value of these findings. Obstacles to adherence are merely not related to quantifiable variables, but to health beliefs, context and relationships, which are qualitative data. Qualitative studies assessing non-adherence in other chronic conditions, such as asthma, point in a similar direction [36].

This lends more credibility to the conclusion that obstacles to adherence to treatment recommendations in type-2 diabetes seem to be related less to the type of health-care system than to the person's knowledge about diabetes and its progression, their beliefs and attitudes to themselves and their social context, and their relationship with their health-care professionals. It is striking that so many of the obstacles found in seven countries relate to the issues concerned with communication between the health-care provider and the person living with diabetes.

## Conflict of interest statement

The authors declare that they have no conflict of interest.

## Acknowledgements

The authors thank the Executive and Research Committees of the European General Practice Research Network for encouraging this research project and for funding. The Departments of General Practice of the universities of Antwerp, Ljubljana, Maastricht, Rennes, Tartu, Warwick and Zagreb are thanked for their miscellaneous support.

## REFERENCES

- [1] M. Marinker, From compliance to concordance, in: *Achieving Shared Goals in Medicine Taking*, Royal Pharmaceutical Society of Great Britain, London, 1997.
- [2] E. Vermeire, H. Hearnshaw, P. Van Royen, J. Denekens, Patient adherence to treatment: three decades of research. A comprehensive review, *J. Clin. Pharm. Ther.* 26 (2001) 331-342.
- [3] International Diabetes Federation (IDF), 2004, facts and figures available at: <http://www.idf.org/home/index.cfm?node=6>.
- [4] A.F. Amos, D.J. McCarty, P. Zimmet, The rising global burden of diabetes and its complications: estimates and projections to the year 2010, *Diab. Med.* 14 (Supp 15) (1997) S1-S85.
- [5] Audit Commission, *Testing Times: A review of Diabetes Services in England and Wales*, London, 2001.
- [6] J.M. Schectman, M.M. Nadkarni, J.D. Voss, The association between diabetes metabolism control and drug adherence in an indigent population, *Diab. Care* 25 (2002) 1015-1021.
- [7] A.L. Kinmonth, S. Griffin, N.J. Wareham, Implications of the United Kingdom prospective diabetes study for general practice care of type 2 diabetes, *Br. J. Gen. Pract.* (1999) 692-694.
- [8] UK Prospective Diabetes Study (UKPDS) Group, Intensive blood-glucose control with sulphonylureas or insulin compared with conventional treatment and risk of complications in patients with type 2 diabetes (UKPDS 33), *Lancet* 352 (1998) 837-853.
- [9] UK Prospective Diabetes Study (UKPDS) Group, Effect of intensive blood-glucose control with metformin on complications in overweight patients with type 2 diabetes (UKPDS 34), *Lancet* 352 (1998) 854-865.
- [10] UK Prospective Diabetes Study (UKPDS) Group, Tight blood pressure control and risk of macrovascular and microvascular complications in type 2 diabetes: UKPDS 38, *BMJ* 314 (1998) 703-713.
- [11] National Institute of Clinical Excellence, *Management of type 2 Diabetes: Blood Glucose (Guideline G)*, London, NICE, 2002.
- [12] R.A. Krueger, *Focus Groups: A Practical Guide for Applied Research*, Sage Publications, Newbury Park, Calif., 1988.
- [13] E. Vermeire, P. Van Royen, S. Coenen, J. Wens, J. Denekens, The adherence of type 2 diabetes patients to their therapeutic regimen: a qualitative study from the patient's perspective, *Pract. Diab. Int.* 20 (6) (2003) 209-214.
- [14] European General Practice Research Network, available at <http://www.egprn.org/info.htm>.
- [15] J.W. Creswell, *Qualitative Inquiry and Research Design*, Sage, Thousand Oaks, California, 1988.
- [16] D. Petek, Attitudes and adherence to treatment of patients with diabetes mellitus, master's thesis, University of Ljubljana, Slovenia, 2004.
- [17] A. Rätsep, Teist tüüpi diabeediga haitege ravikuulekust mojutavad parsiendipoosed tegurid—kvalitatiivne uuring, *Eesti Arst* 5 (2003) 353-356.
- [18] N. Vinter-Repalust, G. Petriček, K. Milica, Obstacles which patients with type 2 diabetes meet while adhering to the therapeutic regimen in everyday life: qualitative study, *Croat. Med. J.* 45 (5) (2004) 630-638.
- [19] G.W. Noblit, R.D. Hare, *Meta-Ethnography: Synthesising Qualitative Studies*, Sage, Newbury Park, 1988.
- [20] B. Paterson, Myth of empowerment in chronic illness, *J. Adv. Nurs.* (2001) 574-581.
- [21] N. Britten, R. Campbell, C. Pope, J. Donovan, M. Morgan, R. Pill, Using meta-ethnography to synthesise qualitative research: a worked example, *J. Health Serv. Res. Pol.* 7 (4) (2002) 209-215.
- [22] P. Campbell, P. Pound, C. Pope, N. Britten, R. Pill, M. Morgan, J. Donovan, Evaluating meta-ethnography: a synthesis of qualitative research on lay experiences of diabetes care, *Soc. Sci. Med.* 56 (2003) 671-684.
- [23] E. Vermeire, The study of research evidence synthesis, applied to adherence to treatment recommendations in people living with type 2 diabetes, Doctoral thesis, Faculty of Medicine, University of Antwerp, Belgium, 2005.
- [24] M. Bury, Chronic illness as a biographical disruption, *Sociol. Health Illness* IV (2) (1982).
- [25] M. Blaxter, The causes of disease: women talking, *Soc. Sci. Med.* 18 (1983) 59-69.
- [26] N. Barber, J. Parsons, S. Clofford, R. Darracott, R. Horne, Differences in treatment regimes, consultation frequency and referral patterns of diabetes mellitus in general practice in five European countries, *Fam. Pract.* 21 (2004) 362-369.
- [27] E. Goffman, *Les rites d'interaction*, Paris: Les Editions de Minuit, 1998.
- [28] A. Bandura, Self-efficacy: toward a unifying theory of behavioural change, *Psych. Rev.* 84 (1977) 191-215.
- [29] M. Sandelowski, J. Barroso, Toward a meta-synthesis of qualitative findings on motherhood in HIV-positive women, *Res. Nurs. Health* 26 (2) (2003) 153-170.
- [30] M. Sandelowski, S. Docherty, C. Emden, Qualitative metasynthesis: issues and techniques, *Res. Nurs. Health* 20 (1997) 365-371.
- [31] J.L. Donovan, Patient decision making. The missing ingredient in compliance research, *Int. J. Technol. Assess. Health Care* 11 (1995) 443-455.
- [32] L.S. Morris, R.M. Schulz, Patient compliance: an overview, *J. Clin. Pharm. Ther.* 17 (1992) 283-295.
- [33] C.E. Golin, M.R. DiMatteo, L. Gelberg, The role of patient participation in the doctor visit. Implications for adherence to diabetes care, *Diab. Care* 19 (1996) 1153-1164.
- [34] E.C. McCord, C. Brandenburg, Beliefs and attitudes of persons with diabetes, *Fam. Med.* 27 (1995) 267-271.
- [35] B.L. Paterson, J. Sloan, A phenomenological study of the decision-making experience of individuals with long-standing diabetes, *Can. J. Diab. Care* 18 (1994) 10-19.
- [36] S. Walsh, T. Hagan, D. Gamsu, Rescuer and rescued: applying a cognitive analytical perspective to explore the 'mis-management' of asthma, *Br. J. Med. Psych.* 73 (2000) 151-168.