

# Expectations held by type 1 and 2 diabetes mellitus patients and their relatives: the importance of facilitating the health-care process

María J. Escudero-Carretero,\* M<sup>a</sup> Ángeles Prieto-Rodríguez,† Isabel Fernández-Fernández MD‡ and Joan Carles March-Cerdá MD§

\*Doctor in Sociology, Consultant, Andalusian Public Healthcare School, Granada, †Sociologist and nurse, Lecturer at the Andalusian Public Healthcare School, Granada, ‡Family Doctor, Associated lecturer at the Medicine Department, University of Seville, and Directorate, Comprehensive Diabetes Plan for Andalusia, Andalusian Public Healthcare System, Seville and §Doctor in Medicine, Lecturer and Consultant, Public Healthcare School, Granada, Spain

## Abstract

### Correspondence

María J. Escudero-Carretero  
Doctor in Sociology, Consultant  
Escuela Andaluza de Salud Pública  
Cuesta del Observatorio  
4. Campus Universitario de Cartuja  
Ap. Correos 2070  
Granada 18080  
Spain  
E-mail: maria.escudero.easp@  
juntadeandalucia.es

### Accepted for publication

4 April 2007

**Keywords:** diabetes mellitus 1 & 2, informal care, patient expectations, patient views, patient-centred care, qualitative design

**Aim** To understand the expectations held by type 1 and 2 diabetes mellitus (DM 1 & 2) patients and their relatives regarding the health-care provided to them.

**Design** Qualitative. Focus groups.

**Setting and participants** Andalusia. A theoretical sample that includes the most characteristic profiles. Thirty-one subjects with DM. Segmentation characteristics: receiving health-care for DM in Primary or Specialized care, living in urban and rural areas, men and women, age, varying diagnosis times, DM course and consequences. Subjects were recruited by health-care professionals at reference care centres.

**Results** Patients expect their health-care professionals to be understanding, to treat them with kindness and respect, to have good communication skills, to provide information in a non-authoritarian manner while fully acknowledging patients' know-how. Regarding the health-care system, their expectations focus on the system's ability to respond when required to do so, through a relevant professional, along with readily available equipment for treatment. The expectations of people affected by DM1 focus on leading a normal life and not having their educational, labour, social and family opportunities limited by the disease. Expectations in people with DM2 tend towards avoiding what they know has happened to other patients.

**Conclusions** 'Facilitating', is a key word. Both the health-care system and its professionals must pay keener attention to the emotional aspects of the disease and its process, adopting a comprehensive approach to care. It is vital that health-care professionals take an active interest in the course of their patient's disease, promoting accessibility and an atmosphere of trust and flexibility.

## Introduction

Diabetic patients in Andalusia are treated at Primary Care Health Centres by professional doctors and nurses. These health-care centres do the follow-up of the process and provide medicine and equipment required for the treatment. There is also a consultation scheme with different specialists, usually working in different specialized hospitals or clinics. The Andalusian Public Health System covers all the expenses for health-care: retired people have their whole medicine bill paid, and the rest of the population has 60% paid for them. Since 2002, this disease has been tackled through a comprehensive management-process model in the whole region. In Andalusia, the prevalence of this disease is around 6–9% of the total population, of which 80–90% is in treatment.<sup>1</sup>

In many cases, diabetic patients' care programmes have only focused on treating the physiological aspects of the disease, relegating to a secondary place; or not considering as a clinical entity at all, the psycho-social and emotional aspects suffered by diabetic patients<sup>2–4</sup>.

At present, this trend is gradually changing because of health-care service models which are becoming more patient-centred (*patient-centred care*)<sup>5–7</sup> allowing care and services to be geared to patients' needs and expectations. A number of reasons underpin this change: ethical issues, the widely held view that health-care users are clients, attempts to make services more democratic and the influence of the Total Quality<sup>5</sup> paradigm in management of care services. Patients' contribution to their own health process is essential; in fact, in overall terms, health-care professionals only account for 12% of the total time devoted to health-care each year in Spain; the remaining 88% is time devoted by relatives and care-givers, and time spent on self-care.<sup>8</sup> On the other hand, a number of reports point to a correlation between unmet expectations and diminished patient satisfaction, which leads to lower degrees of treatment compliance and hence to worse health outcomes, and poor quality of care.<sup>9</sup>

Patients verbalize their expectations on the basis of their beliefs and views on what the

health services should involve, in the hope that they will be provided with the health-care they need.<sup>6</sup>

The goal of this study was to pinpoint, understand and describe the normative expectations held by type 1 and 2 diabetes mellitus (DM 1 & 2) patients and their relatives. Consistent with the definition adopted by Thompson and Suñol,<sup>10</sup> we consider normative expectations as those that express beliefs about what health-care should entail, and the bare minimum that patients believe they should expect from the health-care system and its professionals.

## Participants and methods

### Design

Qualitative and based on focus groups. This methodology allows a deep understanding of interviewees' opinions and priorities<sup>11,12</sup> to be ascertained. Focus groups allow individuals with a broad range of stances and experiences to come together as a group, thereby fostering dialogue and group dynamics which encourage participation and a free voicing of views. The study was keen to analyse how group discourse and a collective vision are constructed, together with context.<sup>13,14</sup> All groups were chaired by the same person, an independent researcher not belonging to the health-care system, with research experience in the field of health-care and who is acquainted with the use of this sort of techniques. These skills and experience are crucial in qualitative research.<sup>15</sup>

Four focus groups were formed in two different areas of Andalusia, namely the cities of Granada and Seville. A guide including topics and questions (Table 1) was produced for group steering. To do so, a group of experts was summoned (people in charge of the DM care-giving process in Andalusia, nursing staff, patients and relatives), which proposed subject areas to be later included in the script. From this starting point, the research team drafted a series of questions according to the comprehension and neutrality criteria of the interviewer, which were previously tested. Sessions were recorded

**Table 1** Interview script

---

Please summarize how your health-care process has proceeded from the onset of initial symptoms to date – which health-care professional you visited first, consultations since then, referrals to other services, where has follow-up been conducted and how frequent are your appointments. When you were diagnosed, how did you feel about the news? How do you cope with your disease and treatment?

Which parts of your treatment are you more at ease with and which cause more hassle?

In what ways did your life change before and after diagnosis?

How were you told about your condition? What information were you given at the time?

What background information have you been given? Do you really understand what's going on?

Have you got any questions? What would you like to know and do not? What do you do when in doubt? Who do you resort to? How are your concerns addressed?

How have you been treated?

Do you feel that health-care professionals are sympathetic?

Have you felt supported by health-care professionals? Have you received psychological support at any time? Have you ever needed it?

What would you change in the health-care assistance provided? What would you rather keep?

How would you define your relationship with health-care professionals? What sort of relationship would you prefer?

---

and transcribed verbatim. The sessions were conducted in a pleasant atmosphere and were not hindered by the disparate backgrounds of those recruited to take part.

### Sample and participants

A prior definition of the most typical profiles of subjects with DM1 & 2<sup>14,16</sup> was carried out, designed from the bibliography on the subject and the contribution of clinical experts. Using these profiles, the patients were selected through a two-stage theoretical sampling (*systematic non-probabilistic sampling*).<sup>17</sup>

1. Selection of health centres, guaranteeing that in the study people receiving care in different health centres, from different city areas and different areas from the two provinces (Granada and Seville) will participate.
2. Selection of participants. In each of the selected health centres, we were assisted by the nursing staff which provided a list of all the patients that complied with the defined profiles. Using this list, the participants were selected randomly. The components of this sample are given in Table 2.

A study such as this does not seek statistical representation, but rather as a 'representation' of the array of possible discourses in the population under study.<sup>11</sup> In all cases, participants were

receiving care delivered by the Andalusian Public Health-care System: they periodically visited their health centres, their specialists at the designated hospitals, occasionally the emergency services, and in some cases, had visited a private specialist. The aim of this study was also to achieve intra-group heterogeneity. All the participants were briefed on the aim of the meetings, asked for their consent and were guaranteed full confidentiality.

### Data analysis

Data analysis was conducted using the Nudist VIVO program. The perspective of the analysis was developed in three stages: descriptive, analytical (identifying the expectations and basic relationships) and interpretative (seeing the explanation and comprehension of the compiled information).<sup>18</sup> First, a tree of codes was produced from the different dimensions reflected in the interview script and the data were compiled from the groups (Table 3). transcripts were read, assigning the codes to each text. The outcomes were described for each of the categories of analysis, trying to identify shared opinions and experiences, as well as particular ones. Finally, the results were explained in relation to the studied profiles (type of diabetes, age group, gender, length of time with the disease, attitude and clinical condition).

**Table 2** Structural sample composition

Focus group	Number of people and gender	Age (years)	Profession <sup>1</sup>	Time with the disease/ time within the process (years)	Clinical condition
Group 1: DM1 Granada	4 women	16–65	Women:	2 people < 2	4 people well controlled and without any complications
	3 men		1 housewife	2 people between 2 and 5	
			1 untrained worker	2 people between 5 and 10	
			1 full-time employee (service sector)	1 person > 10	
			1 liberal professional (education)		
Group 2: DM2 Granada	4 women	50–80	Men:	2 people < 2	4 people well controlled and without any complications
	4 men		1 student	2 people between 2 and 10	
			1 full time employee (service sector)	2 people between 10 and 15	
			1 liberal professional (business man)	2 people > 15	
			Women:		
			2 housewives		
			1 full-time employee (service sector), retired		
			1 liberal professional (civil servant) Men:		
			2 untrained workers, retired		
			1 full-time employee (service sector)		
Group 3 DM1 Seville	4 women	18–65	1 liberal professional (business man)	2 people < 2	4 people well controlled and without any complications
	4 men		Women:	2 people between 2 and 5	
			1 housewife	2 people between 5 and 10	
			1 untrained worker	2 people > 10	
			1 full-time employee (service sector)		
			1 liberal professional (business woman) Men:		
			1 student		
			1 untrained worker (construction)		
			1 full-time employee (service sector)		
			1 liberal professional (business man)		

**Table 2** (Continued)

Focus group	Number of people and gender	Age (years)	Profession <sup>1</sup>	Time with the disease / time within the process (years)	Clinical condition
Group 4: DM2 Seville	4 women 4 men	50–80	Women: 2 housewives 1 full-time employee (service sector) 1 liberal professional (civil servant), retired Men: 1 untrained worker 2 full-time employee (service sector) 1 liberal professional (business man), retired	2 people < 2 2 people between 2 and 10 2 people between 10 and 15 2 people > 15	3 people well controlled and without any complications 3 people with difficulties in controlling their condition but without complications 2 people with difficulties in controlling their condition and presenting the first complications

<sup>1</sup>Considering the profession as an indicator of social class, as identified by the Clasificación Nacional de Ocupaciones [Spanish National Occupational Classification] (Álvarez Dardet C, Alonso J, Domingo A, Regidor E. La medición de la clase social en ciencias de la salud. Barcelona [The measuring of social class in health sciences]; SG Editores, 1995).

**Table 3** Analysis categories

Health-care process
Lived experience with disease and emotional issues
Changes to quality of life
Delivery of diagnosis
Information – communication
Queries
Manners in dealing with patients
Understanding
Support

To guarantee reliability and validity of the data collection and analysis process, the research team designed a triangulation process for discussion and comparison of outcomes, thus enhancing the study’s reliability and enabling the group chairperson to take part in data analysis as well, thereby guaranteeing correct interpretation of the data.

## Results

### Experience and emotional aspects

The emotional path of DM is a difficult process, starting with diagnosis of the condition, patients having to learn how to live with diabetes, how to control their symptoms until they manage to ‘co-exist’ normally with this chronic disease. However, the way patients face the disease varies greatly; young children and their parents, or young adults and the elderly adopt different attitudes. Within the groups, different experiences are manifested according to age group and the role of the participants.

*Girls and boys* learn over time, what suffering from ‘diabetes’ means. They are not overly concerned, but do rebel against the restrictions imposed by treatment. They feel ‘special’ because they cannot lead the life their peers do, and shift the burden of responsibility of care on to their parents, who feel terribly overburdened:

“Children can be so cruel to their parents; they say “of course, you don’t have to have injections, you can eat whatever you fancy...” (Mother of young girl with DM1)

The expression “I feel like the whole world’s collapsing around me” is repeated by the *parents*

in the groups. Mothers acknowledge that their life has changed in order to take care of their children and control their disease. This is manifested by all women independently of their occupation, more frequently than their partners. They live with the constant worry that their young ones may not be properly controlled, with the fear that their blood sugar levels may be unbalanced, the fear of the unforeseen and the hope that once they grow up they will become more responsible for their condition and that a scientific discovery may improve their quality of life. Parents live in anguish of the fact that the disease would hinder the life expectations (at educational, social, emotional level, as well as quality of life) of their children:

“Sleepless nights, with controls at 12, at 6... There’s no respite, no weekends or holidays...”  
(Mother, DM1)

When diabetes arises during *teenage years*, attitudes range from total responsibility to total denial of the problem. Some of the young people interviewed talk about their condition with a mixture of contempt, self-importance and defiance. They want to show that although the disease did raise anxiety about their future, they have learnt to live with it and are no longer concerned. They claim to know enough about their condition to take care of themselves and emphasize that their relation with health-care centres is indirect in nature – through their mothers who act as ‘intermediaries and messengers’. Regarding treatment, they understand clearly that treatment has to adapt to their lifestyle and not the other way around, and amidst the process to gain some sort of ‘normality’, in general, they do not feel supported by health-care professionals:

“What doctors study in theory is very different to what happens in real life...One day you can’t keep to your time-table, because you’re eating out; you know you’ll never become the best athlete in history; you know very well that if you go out clubbing one night, you won’t be getting up early in the morning...” (Teenager with DM1)

*Elderly people with DM2* face diabetes in a very different way. The majority express a crippling fear in terms of the possible consequences

of the disease, in most cases because they have seen its effects in close friends, relatives who died young, suffered amputation of the limbs, or are visually impaired or blind as a result of diabetes...

“My mother had her two legs amputated, so I don’t need anyone to tell me that I’m going to die – I know”. (Male, DM2)

On the other hand, they experience treatment demands as a form of ‘slavery’ which governs their daily routine, jeopardizing their lives and relationships:

“The disease doesn’t hurt; it simply turns you into a walking clock”. (Female, DM2)

The emotional experience of the disease as well as the needs it triggers both exert a profound influence on the expectations that emerge with regard to the health-care system and its professionals.

#### Expectations regarding health-care professionals

*Understanding: “I want them to be understanding and sympathetic”*

In every group, the participants manifested the need that the health professionals treating them show a genuine interest in their lives and how they experience the disease, and not that they centre solely on the figures emerging from diagnostic tests. They need them to be capable of customizing their recommendations and advice to each particular case. They think that the health-care staff should be able to ‘put themselves in their place’ and understand the patients’ personal circumstances. These opinions are more critical among the youngsters and mothers of children with DM1. Adults with DM2 appear, in principle, to be more satisfied with the health professionals, although when they listen to the above concerns within their focal groups, they share them:

“The doctor said, listen I don’t care what you say, I don’t care if the weather’s bad, it’s really not my problem; if it’s raining just put on a raincoat and wellies, but she’s got to exercise. A child with diabetes cannot lie in after eight in the morning”.  
(Mother of young girl with DM1)

“They throw the numbers at you: 120 – Oh, that’s awful! They never ask what happened that day, if you lost your job or something...” (Young man with DM1)

“You visit your endocrinologist, you get weighed, measured, you’re given your test results and told you’ve got to lose weight – lose weight and that’s it, end of story”. (Female with DM2)

*Treatment and communication capacity: “I want to be treated with courtesy, to be reassured and be able to talk about my treatment and concerns”*

Patients must be treated with respect and courtesy. This is manifested in all the groups and by all the participants:

“This chap’s great with my granny; he’s really kind. When I call him he comes over to the house to see her straight away. I want them to treat me with kindness and courtesy; that’s what we all want, more so if we’re talking about an older person; I want doctors and nurses to understand... it’s a mixture of many things”. (Female carer of elderly female patient with DM2)

The interviewees, young, adults or elderly, patients or care-givers, all acknowledge that a pleasant atmosphere should be encouraged during consultations, with no hurrying, nurturing trust so that patients are able to share their concerns and fears with health professionals, to manifest their doubts and ask for the advice they need. This will contribute to overcoming fear of the disease and build the basis of a positive and therapeutic relationship. Brusque manners will only inhibit and restrict patients. Patients with DM1, the younger ones, and those with liberal professions seem to be the more demanding ones:

“If we could simply tell them how we feel, it would make things easier for us”. (Male with DM1)

“I’m distressed, I’m scared, I feel sad... but I never tell them about it. You don’t discuss your feelings with the doctor”. (Female, DM2)

They demand a constructive relationship which would seek options and alternatives. When the monitoring and control of the disease is based on revisiting diagnostic test results, and on scare-tactics, as a way to motivate patients,

interviewees say that their reaction is to distance themselves from health-care professionals, to lie or rebel against the treatment. This is what usually happens with young, adult and elderly patients who do not perceive the complications brought by the disease. Some of the participants have changed doctor because of this and have attended private specialists:

“You go along, get your test results, they tell you more or less how things are progressing, and you get an ear bashing because you’re not keeping strictly to your treatment”. (Young male with DM1)

In every group, they coincided in the need that professionals had the capacity for listening actively to talk about their difficulties in following the treatment, and that they were able to explain how to adapt it to their lives by conveying positive messages, giving them support so that their quality of life can be as good as possible. In this regard, self-help groups are also seen as a necessary option.

They want open communication, direct, where they are looked straight in the eye. As regards this, it is revealing how computers are pointed out as obstacles to achieving it, as something that separates them from their doctors:

“You go to see the doctor, but he doesn’t see you. All he sees is his computer, and says: “show me your tongue, or you’ve got to do this or that; or let’s see, tell me where it hurts?” It used to be different; there were no computers in consultation rooms, and doctors used to take their time to have a good look at you and they’d say: “well, I think you’ve got this or that; you can do this about it, can’t do that”. Nowadays, they’ve only got time for their computers. (Male, DM2)

*Information: “More information in order to control my diabetes”*

Information about their disease and its process is considered a key aspect to controlling diabetes and improving their quality of life:

“It should be improved with more information, more information to people with diabetes .Just that would be an achievement, knowing what it is and dealing properly with the three aspects, since it isn’t that dangerous”. (Elderly man DM2)

Parents of children with DM1 (specially mothers as main care-givers) particularly manifest the need for more information on how to deal with any problems that could occur. They acknowledge that the information provided by the health centres, in most of the cases, is not enough to clarify any doubts. Meeting other people with similar experiences, in particular through associations, frequently becomes a source of additional information.

Teenagers' opinions compiled in the groups show that they believe they have enough information, most of it from the Internet, which for them is an accessible (more than health-professionals) source as well as reliable (as good as the best one).

Adult patients, with either DM1 or DM2, who took part in the groups believed they had good information, although it had been obtained over a long period of time and by various means. The main source of information is the family doctor, followed by the endocrinologist, friends and relatives, mass media, books or encyclopaedias and Internet. These patients complete this information with the consultations they obtained by other means:

"I bought a book on diabetes in that stall at the book fair; of course I was interested because I had it. I've read several books on the subject. I'm well informed. Here they explained things to me, they explained a few things, didn't they?, 'you have to eat this, have to do that, you ought to...'; but after that book I've learnt a lot" (Adult man DM2).

Older patients with DM2 are those who voice fewer expectations about improvements on this issue, as they consider that they have sufficient information from the health-care professionals, who are their main source of information along with TV programmes. Both sources are considered as reliable.

In general, all the groups expected to receive enough information about the disease, treatment, care and a prognosis, transmitted in straightforward language, easy to understand and sensitive to the emotional repercussion it can produce:

"They should explain to you, for example, what is more or less harmful for you, for example: 4 of the so called sugar-free pastries or a small slice of a normal cake?" (Elder man DM2)

They particularly demand sensitiveness when the diagnose is given to the patient, taking into account the reactions that might occur, to be encouraged and reassured, and to be informed about the risks of having the disease gradually, in 'small doses'. These expectations are primarily manifested by the younger group and parents of children with DM1, but are shared by all the participants:

"At the beginning, when you haven't a clue about diabetes and they tell you that your child could lose his sight, that he could go into a coma and die, it's really heartbreaking. What's the point of going to the doctor? Instead of coming to see them for help and encouragement, all these visits do is cause dreadful distress. (Father of child with DM1)

"I was told: "there you are, you are diabetic, take this and don't eat or drink those ones, and so on" (Male Adult, DM2)

"At hospital (...) they'd tell you about diet, how to swap ingredients, they'd say you could lead a normal life, OK! You'd have to exercise and keep to a strict diet and insulin regimen... They say "if you get these three things right, you'll be fine" and they'd really make you feel good about it". (Young female with DM1)

*Recognition: "I want them to acknowledge my know-how on diabetes"*

Patients, who control and take care of their diabetes, each and every day, become great experts on the disease. They know how to adapt their treatment; they understand what the signs and symptoms mean; they learn how to control critical episodes. However, they feel that physicians tend to dismiss their knowledge. So, they call for full acknowledgement of their expertise, and hope that they will be listened to when visiting a health-care centre. Regardless of their occupation, people who manifest these expectations in the groups are fundamentally those patients who have been living with DM1 and DM2 for a long time:



“I’ve got to be my best doctor because I’m going to have to live with this every day”. (Young male with DM1)

“That man came in here saying I had no idea of what diabetes is all about. Come on, I’ve been dealing with it for five years, how can he even suggest that I don’t know what I’m talking about? When I came to the Children’s Hospital and told him my daughter takes X number of centimetres, he said “hey, you must be mad, that’s completely wrong!” How can he say that sort of thing? (Mother of young girl with DM1)

### Expectations regarding health-care centres

*Regarding primary care consultation: “I want to be seen regularly by a professional who knows about diabetes”*

Patients with DM2 voice their need for a specific consultation for diabetes at their health-care centre, manned by expert professionals. They also demand continuity of care on the part of their GP who they see as a ‘safe haven’ providing safe and customized care, their main carer, who carries out regular follow-up and helps them keep their disease in check, has complete medical records of their disease, and knows them personally. Someone they can trust. This makes them feel more secure:

“I think there should be a specific consultation for diabetes at each health centre”. (Male, DM2)

“What I like most about the treatment is my doctor’s follow-up – she’s got my medical records, and I might lose track of something, but it doesn’t bother me because I know she’s got it all under control”. (Female, DM2)

“I’ve had four GPs over the last year, and each one has changed my treatment and the diagnosis. They’re driving me mad”. (Male, DM2)

*Regarding specialized care consultation: “I want to be seen by the right professional every time”*

Patients with DM1 expect to always be treated by endocrinology specialists and not GPs with less experience in the disease. They expect their endocrinologist to see them whenever they need

him/her, so they request more channels to be established – for personal or telephone access – to tackle crises or unforeseen events (e.g. a 24-h hotline). They also call for specialists in endocrinology to be present at hospital emergency admissions. They expect the public health-care system to provide a swift and efficient response in the face of a crisis:

“I went in for a check-up today, after three months. I’ve been told to change my insulin to a different acting one, and I’ve been told to come back in 4 to 6 months time. What if this type of insulin doesn’t work for me? What do I do? Do I go back to the one I had before? What dosage should I use – more or less? I could also ask for an appointment, but when would I get it? With insulin, you inject it and immediately get a reaction...” (Young male with DM1)

“I take my daughter in to see the endocrinologist every four months. I think it’s absurd, because she’s had hypoglycaemias over that period of time, she’s poorly controlled and I’ve got nowhere to go. If I take her in through emergency admissions, all I get is a paediatric doctor with no experience with diabetic children; there are no specialists, so all they say is “go and see your endocrinologist tomorrow”. But then, I call him and he can’t see me because his diary’s full of appointments”. (Mother of young girl with DM1)

Patients with DM1 and DM2 request that the specialists they have to resort to for follow-up of their condition – ophthalmology, cardiology, podiatry, and others – should give them timely check-up appointments, with no waiting-list related delays:

“I feel I’m gradually losing my eye-sight. I’m diabetic, so it’s not the same as someone who doesn’t have this disease because diabetes damages your eye-sight. But I’ve got to wait regardless, and in four months time, I might be almost blind, because I can tell that I’m gradually seeing less and less”. (Female, DM2)

“He had a problem in his foot. That was way back in December. He was given an appointment for March... a child with diabetes, can you believe it? I had to see a private podiatrist and it turned out to be a papilloma, and he’s got another fifteen more. What would have happened if I’d waited till March?... (Mother of young boy with DM1)

*Regarding the necessary material and tools for treatment: "I want to be provided with all that I need"*

Good control of diabetes requires daily use of a series of tools – syringes, lancets, reactive strips and others – as well as the relevant medication. As chronic patients, they expect the public health-care system to assist them by helping them obtain the material they need to control blood sugar levels, and the necessary treatment dosage. How? By streamlining access to the health-care system, by implementing improvements to the organization and by reducing red-tape and the necessary paper work and waiting times. Patients call for mechanisms to be put in place such as long-term treatment cards, and other measures to facilitate access and reduce the inconveniences and delays involved in obtaining inspection clearance:

“Well I had to go in one day to get an appointment, the next day to see the doctor and get a prescription. Then yet another queue to see the inspector, and another visit the day after to collect it” (Mother of young girl with DM1) “The problem is that this is for life. We aren’t going to be told we needn’t take any more medication in a month’s time. We’re going to be doing the same thing next month, and next year. So they should make our treatment easier”. (Young female with DM1)

## Discussion and conclusions

The use of a qualitative methodology in this study allowed us to implement a deep and comprehensive analysis with our informants, the same as in some articles we have referred to.<sup>7,12,19,20</sup> Grasping a deep understanding of the reasons that underpin patients’ responses and the reasons underlying their behaviour and attitudes is the core value of qualitative methods and the reason why they have been used so extensively over the last few years in the field of health-care. ‘To unravel what other methods cannot’<sup>13</sup> and ‘to reach a profound understanding of what appears to be obvious’<sup>15</sup> are, at present, the fundamental challenges for health-care professionals and managers alike. The heterogeneity of patients that have taken part in the

study has been very positive and has contributed meaningfully and with a broad perspective to the outcome.<sup>13</sup> On the other hand, one of the shortcomings of the study is that the personal opinions of each profile are not very saturated, and so we shall continue our research along this line.

The fact that DM is a chronic disease, together with the variety and complexity of the risks it poses, determine the expectations held by patients and their relatives, and their own views.<sup>21,22</sup> In every group, we devoted a great deal of time to researching the experiences of each of the interviewees and their emotional response to the disease. Their perception and reaction to the diagnosis, the concerns the disease causes, the fear of the most negative consequences that might occur, nervousness about the future, the changes their lives have to undergo to control diabetes, among others, are some of the aspects that give shape to the emotional experience of the problem. These are aspects that have a decisive influence on their beliefs about the disease, on how they face it, which is not usually considered in its treatment.<sup>7,12,23</sup>

Patients and relatives voice expectations that would improve their health and life standards; expectations that have been classified, fundamentally, along two lines: the health-care professionals who treat them, and the health-care system and its management.

Regarding the health-care professionals, they overtly demand understanding of their situation and flexibility or customized treatment; good manners, i.e. kind and considerate; communication skills and abilities in terms of listening, time for expressing concerns; building up an atmosphere of confidence in the consultations which could encourage asking questions or clarifying concerns, talking about concerns and fears; sufficient, clear and meaningful information, expressed in a clear way, and acknowledging their know-how in treating their own diabetes.

The outcomes coincide with those obtained by other studies which argue that relational aspects

are crucial in the course and outcome of the disease, and also in terms of patients' assessment of the care they receive.<sup>7,19,20,24</sup> The study conducted by Frank<sup>2</sup> reported that what irritates the patients most are short, very technical consultations which ignore the psycho-social aspects of the disease, and where no interest is shown in their views about their condition.<sup>2</sup>

The ideal relationship and communication style between professionals and patients should facilitate agreement and pacts<sup>7,21</sup>, in clear, easy-to-understand language,<sup>21,24,25</sup> where patients are invited to ask questions and voice their concerns,<sup>12,26,27</sup> taking into account emotional issues,<sup>12,28</sup> proposing positive alternatives, while offering innovative, useful and non-repetitive information. Participants who reported satisfactory experiences with health-care professionals, invariably give more priority to the fact that they are treated as human beings, with skills and feelings or emotions, and not solely as diabetic patients.<sup>12,19</sup>

Patients call for a more intimate and humane relationship<sup>29</sup> that adopts a participatory and inclusive health-care model, in turn focused on achieving an increasingly therapeutic and flexible relationship that concentrates on the individual and his or her circumstances,<sup>24,28,30</sup> taking full account of each patient's lifestyle and priorities.<sup>12</sup>

In chronic diseases like diabetes, where patients are required to control their treatment on a daily bases, they become experts in their own disease and wish this could be acknowledged.<sup>6,23,25,31</sup>

We have not found any studies that compare both the needs and expectations of patients with DM1 and DM2 and the relationship with health-care professionals. It would be interesting to advance along this research line and compare them to the outcomes of this study.

Regarding health centres, accessibility and response capacity are two dimensions of quality that are considered as essential. All the interviewees demand that care be delivered by qualified staff with some experience in treating diabetes.<sup>12</sup> However, there is a difference, patients with DM2 wish that reference pro-

fessional could be their family doctor (as long as he or she had enough knowledge about diabetes), while patients with DM1 prefer to have consultations with endocrinologists. Both groups coincide in the need for easy and regular follow-up consultations with other specialists to monitor the effects of diabetes. These outcomes from patients with DM2 coincide with the studies by Lawton *et al.* and Naithani *et al.*<sup>19,32</sup>. Facilitating access to services – particularly check-up and follow-up appointments, and to tackle crises or respond to queries – while providing continuity of health-care are both seen as key points in achieving greater efficiency of the health-care services<sup>12,19,31</sup>. Flexibility, and 'being there' for patients, showing a keen interest and solving their problems as and when they arise, are fundamental issues that are much appreciated by all patients<sup>12,19</sup>. To achieve these targets, the study also proposes the use of various communication channels (e.g. telephone or internet), to make health-care centres more efficient, optimizing the time available and avoiding unnecessary visits. In addition, one of patients' essential demands is that health-care should be provided out of 'normal hours' such as nights and weekends.<sup>12</sup>

Regarding both professional health-care workers and health centres, one key expectation is receiving support. When facing a chronic disease such as DM, patients place great emphasis on the need to receive as much support as possible, both in terms of the material resources required for treatment and control of the disease, and in terms of the emotional aspects involved.<sup>7,20,24,28,29,33–35</sup> With greater support, patients find it easier to make progress and to change their lifestyles and habits.<sup>30</sup> Learning to face their chronic condition optimistically, feeling that they are being motivated, while believing and placing their trust in self-efficacy, has a positive impact on patients' mental state and on their ability to control their disease, thus paving the way to a better quality of life, even when suffering from other diseases.<sup>6,20,34,36</sup> Support is requested in terms of the following:

1. Shared responsibility regarding control and treatment.<sup>20,26,30</sup>
2. Helping patients to accept and take full responsibility for their disease.<sup>32</sup>
3. Training patients and caregivers in the daily routine of care, and in how to face any unforeseen events that may emerge during the course of disease control.<sup>12,30,34,37</sup>

## Conclusions

It is of utmost importance to take into account patients and caregivers' expectations and needs in the design and management of health services. In the case of DM1 & 2, a communication style that facilitates agreements and pacts, in clear, easy to understand language, where patients find room to ask questions and voice their concerns, emotional issues are taken into account, positive alternatives are presented and useful and up-to-date information is offered becomes appropriate. Patients call for a more intimate and humane relationship that would lead towards a more participatory and inclusive health-care model, in turn focused on achieving a relationship based on the individual and his or her circumstances, taking full account of each patients' lifestyle and priorities, through on-going, transparent and truthful information. Facilitating the access to services, with follow-up consultations and flexibility, is regarded as a key element in efficacy of health-care services. It is considered necessary to streamline the organization and necessary paper work, to make time-tables and access to physicians more flexible, and to curb waiting times. Necessary support is demanded from various perspectives such as sharing the responsibility of control and treatment or helping patients to accept their diabetes and training patients and caregivers in tasks related to care. There is a clear trend towards patient-based health-care models.

The expectations held by diabetic patients all focus on a shared priority: that their life and treatment be made easier. Thus, 'facilitating' becomes a key word. On the one hand it involves the health-care system 'facilitating' or providing health-care assistance and treatment, and on the

other, it entails professionals who are required to 'take care of the emotional face' of the disease.

## References

- 1 Consejería de Salud, Junta de Andalucía. *Plan Integral de Diabetes de Andalucía 2003–2007*. Sevilla: Consejería de Salud, 2003.
- 2 Frank R. Homeopath and patient – a dyad of harmony? *Social Science and Medicine*, 2002; **55**: 1285–1296.
- 3 Dijkstra R, Braspenning J, Grol R. Empowering patients: how to implement a diabetes passport in hospital care. *Patient Education and Counseling*, 2002; **47**: 173–177.
- 4 Laing A. Meeting patient expectations: healthcare professionals and service re-engineering. *Health Services Management Research*, 2002; **15**: 165–172.
- 5 Lewis JR. Patient views on quality care in general practice: literature review. *Social Science and Medicine*, 1994; **39**: 655–670.
- 6 Winkelman WJ, Wei Ch. Provider-sponsored virtual communities for chronic patients: improving health outcomes through organizational patient-centred knowledge management. *Health expectations*, 2003; **6**: 352–358.
- 7 Bolaños E, Sarriá-Santamera A. Perspectiva de los pacientes sobre la diabetes tipo 2 y relación con los profesionales sanitarios de atención primaria: un estudio cualitativo. *Atencion Primaria*, 2003; **32**: 195–202.
- 8 Durán MA. Las demandas sanitarias de las familias. *Gaceta Sanitaria*, 2004; **1**: 195–200.
- 9 Jackson J.L., Kroenke K. The effect of unmet expectations among adults presenting with physical symptoms. *Annals of Internal Medicine*, 2001; **134**: 8889–8897.
- 10 Thompson AGH, Suñol R. Las expectativas como factores determinantes en la satisfacción de los pacientes: conceptos, teoría y pruebas. *Revista Española de Calidad Asistencial*, 1996; **11**: 74–86.
- 11 March JC, Prieto MA, Hernán M, Solas O. Técnicas cualitativas en salud pública y gestión de servicios de salud: algo más que otro tipo de técnicas. *Gaceta Sanitaria*, 1999; **13**: 312–319.
- 12 Hiscock J, Legard R, Snape D. *Listening to Diabetes Service Users: Qualitative Findings for the Diabetes National Service Framework*. London: Department of Health (Diabetes National Service Framework), 2001.
- 13 Kitzinger J. Qualitative research: introducing focus groups. *BMJ*, 1995; **7000**: 299–302.
- 14 Prieto Rodríguez MA, March Cerdá JC. Paso a paso en el diseño de un estudio mediante grupos focales. *Atencion Primaria*, 2002; **29**: 343–347.

- 15 Hurley RE. La investigación cualitativa y el profundo entendimiento de lo obvio. *HSR: Health Services Research*, 1999; **34**(5 part II): 1119–1136.
- 16 Mercado FJ, Alcántara Hernández E, Lara Flores N, Sánchez A, Tejada Tayabas LM. La atención médica a la enfermedad crónica: reflexiones sobre los procedimientos metodológicos de un estudio cualitativo. *Revista Española Salud Pública*, 2002; **76**: 461–471.
- 17 Mays N., Pope C. Rigour and qualitative research. *BMJ*, 1995; **311**: 109–112.
- 18 Wolcott H. *Transforming Qualitative Data: Description, Analysis and Interpretation*. London: Thousand Oaks Sage, 1994.
- 19 Naithani S, Gulliford M, Morgan M. Patients' perceptions and experiences of continuity of care' in diabetes. *Health Expectations*, 2006; **9**: 118–129.
- 20 Johnson M, Newton P, Jiwa M, Goyder E. Meeting the educational needs of people at risk of diabetes-related amputation: a vignette study with patients and professionals. *Health Expectations*, 2005; **8**: 324–333.
- 21 Fernández-Fernández I. Atención sanitaria centrada en el paciente con diabetes: necesitamos incorporar las perspectivas/expectativas de los pacientes. *Atención Primaria*, 2002; **32**: 195–202.
- 22 Hart HE, Bilo HJG, Redekop WK, Stolk RP, Assink JH, Meyboom de Jong B. Quality of life of patients with type I diabetes mellitus. *Quality of Life Research*, 2003; **12**: 1089–1097.
- 23 Escudero-Carretero MJ, Prieto-Rodríguez MA, Fernández-Fernández I, March-Cerdá JC. La relación médico-paciente en el tratamiento de la diabetes mellitus tipo 1. Un estudio cualitativo. *Atención Primaria*, 2006; **38**: 8–18.
- 24 Epstein R, Alper B, Quill T. Communicating Evidence for participatory decision making. *JAMA*, 2004; **291**: 2359–2366.
- 25 Curtis K, Liabo K, Roberts H, Barker M. Consulted but not heard: a qualitative study of young people's views of their local health service. *Health Expectations*, 2004; **7**: 149–156.
- 26 Jadad A, Rizo CA, Enkin MW. I am a good patient believe it or not. *BMJ*, 2003; **326**: 1293–1294.
- 27 Stevenson FA, Cox K, Britten N, Dundar Y. A systematic review of the research on communication between patients and health-care professionals about medicines: the consequences for concordance. *Health Expectations*, 2004; **7**: 235–245.
- 28 Peralta G, Figuerola D. Aspectos psicosociales de la diabetes. *Revista de Endocrinología y Nutrición*, 2003; **50**: 280–285.
- 29 Szabó-Kallai K, Gyimesi A, Iványi J. Role of emotional factors in diabetes. *Acta Diabetologica*, 1990; **27**: 23–29.
- 30 Ruiz Moral R, Rodríguez JJ, Epstein R. ¿Qué estilo de consulta debería emplear con mis pacientes?: reflexiones prácticas sobre la relación médico-paciente. *Atención Primaria*, 2003; **32**: 594–602.
- 31 Kennedy I. Patients are experts in their own field. *BMJ*, 2003; **326**: 1276.
- 32 Lawton J, Parry O, Peel E, Douglas M. Diabetes service provision: a qualitative study of newly diagnosed Type 2 diabetes patients' experiences and views. *Diabetic Medicine*, 2005; **22**: 1246–1251.
- 33 Cramer JA. A systematic Review of adherence with medications for diabetes. *Diabetes Care*, 2004; **27**: 1218–1224.
- 34 Rose M, Fliege H, Hildebrandt M, Schirop T, Klapp B. The network of psychological variables in patients with diabetes and their importance for quality of life and metabolic control. *Diabetes Care*, 2002; **25**: 35–42.
- 35 Wens J, Vermeire E, Royen PV, Sabbe B, Denekens J. GPs' perspectives of type 2 diabetes patients' adherence treatment: a qualitative analysis of barriers and solutions. *BMC Family Practice*, 2005; **6**: 20.
- 36 Prueksaritanond S, Tubtimtes S, Asavanich K, Tiewtranon V. Type 2 diabetic patient-centered care. *Journal of the Medical Association of Thailand*, 2004; **87**: 345–352.
- 37 Zúñiga González S, Islas Andrade S. Educación del paciente diabético. Un problema ancestral. *Revista Médica del IMSS*, 2000; **38**: 187–191.