

Physician/Patient Relationship in Diabetes Mellitus Type I Treatment. A Qualitative Study

María J. Escudero-Carretero,^a M. Ángeles Prieto-Rodríguez,^a Isabel Fernández-Fernández,^b and Joan Carles March-Cerdà^a

Objectives. To know the experiences and expectations of diabetes mellitus type 1 (DM1) patients and their relatives as regards the relationships established with doctors, and the impact of

such relationships on their strategies to cope with the disease and treatment.

Design. Qualitative design based on focus groups conducted in 2001.

Location. Several health care centres in Granada and Seville, Spain.

Participants. DM1 patients and their relatives and/or carers.

Method. Theory-based sampling including the most representative profiles. Qualitative analysis procedure: text coding, triangulation and interpretation of results.

Results. Doctor/patient relationship highly influences the emotional experience of disease and the way patients gain control over it. Interviewed patients said that the relationship with doctors is focused on disease signs and symptoms, leaving emotional aspects aside. Very often, provider communication is built on recrimination and threat. Treatment is imposed rather than agreed, with scarce opportunities for participating in clinical decisions. Patients develop strategies to take their own decisions and adapting treatment to their daily life.

Conclusions. Patients value a relationship model whereby providers listen and empathise with their situation, understand their difficulties in treatment compliance, encourage them, and adapt recommendations to the personal and emotional circumstances of each patient. They prefer doctors combining professional competence—including relational skills—with humanity and kindness, as well as being capable of assuming their co-responsibility in treatment success.

Key words: Doctor/patient relationship. Diabetes mellitus type 1. Treatment compliance. Qualitative study. Patient needs and expectations. Communication.

LA RELACIÓN MÉDICO-PACIENTE EN EL TRATAMIENTO DE LA DIABETES TIPO 1. UN ESTUDIO CUALITATIVO

Objetivos. Conocer las experiencias y las expectativas de pacientes con diabetes tipo 1 (DM1) y sus familiares sobre la relación que establecen con sus médicos y su influencia en la forma de afrontar la enfermedad y el tratamiento.

Diseño. Diseño cualitativo a través de grupos focales realizado en 2001.

Emplazamiento. Distintos centros sanitarios de Granada y Sevilla.

Participantes. Pacientes con DM1, familiares y/o cuidadores.

Método. Muestreo teórico con representación de los perfiles más característicos. Procedimiento de análisis cualitativo: asignación de códigos al texto, triangulación e interpretación de resultados.

Resultados. La relación médico-paciente influye decisivamente en la vivencia emocional de la enfermedad y en la manera en que los pacientes asumen el control. Los pacientes entrevistados aseguran que la relación con sus médicos está centrada en los signos y los síntomas de la enfermedad, y que el aspecto emocional se deja de lado. Es frecuente que los profesionales basen su comunicación en la reprimenda y en la amenaza. Los tratamientos se imponen más que se consensúan, y las posibilidades de participación en las decisiones clínicas son escasas. En consecuencia, los pacientes desarrollan estrategias para tomar sus propias decisiones sobre el tratamiento adaptándolo a su vida.

Conclusiones. Desean un modelo de relación con sus médicos en el que los escuchen, empaticen con su situación, comprendan los problemas que enfrentan para seguir el tratamiento, les transmitan ánimos y adapten sus recomendaciones a las circunstancias vitales y emocionales de cada paciente. Se prefiere a los profesionales que combinan la competencia técnica (incluida la dimensión relacional) con la humanidad y la amabilidad, y que asumen su corresponsabilidad en el éxito del tratamiento.

Palabras clave: Relación médico-paciente. Diabetes tipo 1. Cumplimiento del tratamiento. Estudio cualitativo. Necesidades y expectativas de pacientes. Comunicación.

Spanish version available at

www.atencionprimaria.com/169.144

A commentary follow this article (pág. 16)

^aAndalucía School of Public Health, Granada, Spain.

^bAndalusian Management of the Integral Diabetes Plan, Andalusian Health Service, Seville, Spain.

Correspondence:
 M.J. Escudero Carretero.
 Escuela Andaluza de Salud Pública.
 Cuesta del Observatorio, 4.
 Campus Universitario de Cartuja.
 Apdo. de Correos 2.070. 18080 Granada. España.
 E-mail:
 maria.escudero.easp@juntadeandalucia.es

Manuscript received April 11, 2005.

Manuscript accepted for publication September 5, 2005.

This study has been financed by the Department of Quality, Research and Management of Knowledge of the Autonomous Andalusian Health Ministry.

Introduction

Insulin diabetes tipe 1 (DM1) is a chronic process which has an enormous social and health impact. Its prevalence in the adult population is estimated to be 2%-6%¹⁻³ and a significant increase is forecast in the coming years, resulting from the increase in life expectancy of the population, and the unhealthy life habits and increasing rates of obesity.⁴

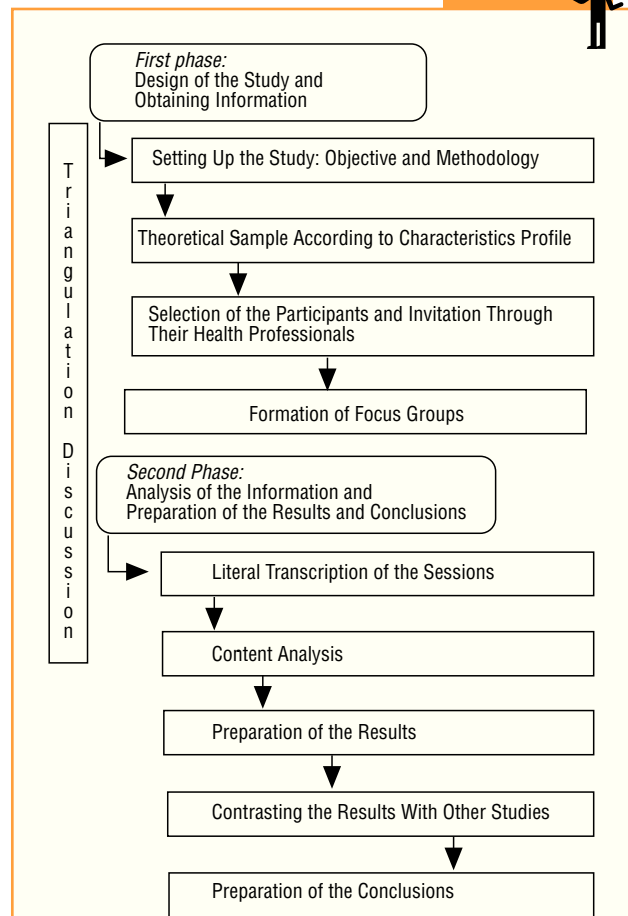
To have good diabetes control delays the appearance of complications and secondary diseases, as well as improving the quality of life.^{1,5} Control of the disease fundamentally depends on having good treatment, which is supported by 3 basic pillars: diet, exercise, and the administration of insulin.^{1,6,7} It is a way of life which assumes certain self-sacrifices, particularly harsh for young people^{6,8} and which, in the short term, the great benefits are not appreciated, which makes its follow up even more difficult.^{1,9} This is one of the reasons why there is relatively frequent non-compliance of treatment, one of the most important problems in chronic diseases, which decreases the efficacy, the effectiveness and efficiency of the treatment.⁷ Around 50% of people with diabetes do not comply adequately with their therapy.⁷

In the specialist literature different factors are pointed out which influence compliance with the treatment: sociodemographics, relationships with the disease, with the therapy itself, and with the doctor-patient relationship.^{1,7} Of all of them, the doctor-patient relationship is the factor with a stronger predictive power.⁷ Numerous studies conclude that the relationship that doctors establish with their patients is often superficial and is centred more on purely systematic and physiological aspects, without taking into account their expectations, and making unilateral decisions, depending on their experience.⁹⁻¹¹ However, it is established that this focus centred on the disease and the interests of the health institutions are no longer valid, and that these days, the actions need to be centred on the person and not only on their diseases, thus providing integrated care.^{5,12-13} The problems of communication is a barrier to the effective treatment of diabetes.¹⁰

The aim of this article is to fet to know, in depth, how people with DM1 perceive their relationships with their doctors and to evaluate its influence in confronting the disease and its implications on the treatment.

It was decided to use qualitative methodology, centred on the focus group technique, as this allows looking in depth into the experiences and make up of the patients, placing them in their social context and, in this case, health context, by interaction between members of the group.^{14,15}

Material and methods



General Scheme of the Study

Qualitative design, based on focus groups from a theoretical sample represented by patients and families with the most characteristic profiles.

Subjects and Methods

Design

A qualitative design based on focus groups. Two focus groups were formed in 2 different areas of Andalusia, in the cities of Granada and Seville. The participants in the 2 groups had similar profiles, looking for discourse saturation. Young people with diabetes and parents of other young people with the same disease, without there being any relationship between them, participated in each group. This strategy pursued the opinions of some and provoked similar arguments and perceptions of family life, but in context of freedom, since the participants did not know each other. Both groups were moderated by the same person (research profile, not related to the health centres). A guide of topics and questions to lead the group was prepared (Table 1). The sessions were recorded and transcribed literally.

Although one of the limitations of focus groups is that they can inhibit some of the participants from freely expressing their

TABLE 1 Interview plan

Care process: they should give a short description of their care process, since the first symptoms were noticed, until now, to which professional they were sent to in the first place, what consultations have they gone through, where they were referred to, where they have their follow up, how often do they have appointments, etc
Their experience on receiving the diagnosis and how they live with the disease and treatment, how they cope with it
Which aspects of the treatment do they find difficult and those they cope with better
Changes in their quality of life: before and after
Communication of the diagnosis: How were they told? What information were they given at that time?
What information have they been given in general? Do they really know what is happening to them?
Doubts. Do they have doubts? What would they like to know and not know? What do they do when they have doubts? Who do they go to? How are they resolved?
Treatment. How has the treatment been?
Understanding. Do they feel understanding in the health professionals?
Support. Have they received support from the professionals? Have they had psychological support at any time? Have they needed it?
Health care. What aspects of care would they change? Which would they keep?
Relationships with the professionals. How would they define the relationship with the professionals? What type of relationship would they prefer?

opinion,¹⁵ they can also have the opposite effect and create an atmosphere to freely express themselves under the protection of the group, that it helps people to state their own opinion and argue it and, as Kitzinger said “reaching where other methods do not reach.”¹⁴ In this case, the group interaction worked in this way. The heterogeneity of the people invited into each group was not an obstacle for its development but, on the contrary, there was a pleasant atmosphere under a climate of confidence. The

groups met in places associated with the health context. However, this did not inhibit the people participating from expressing critical opinions.

Sample and Participants

People with DM1 and parents of diabetic children were selected by theoretical sampling.^{15,16} The profiles most characteristic of these patients are represented in the sample, as regards, age, time of living with diabetes, continuing relationship with the health centre (they periodically attend established check ups) and attitude to the disease (positive and accepting: they want to have the necessary knowledge and skills to be able to have self-control; negative and rejection: they delegate the control of the disease to their parents). These profiles were prepared from the literature consulted and from the experience of the professionals who treat them. Heterogeneity was also looked for as regards other variables, such as place of residence, level of studies and occupation. In all these cases, the participants received care in health centres, went there regularly for check ups and periodically to the endocrinology clinics, according to that indicated in the care process (Table 2). The invited participants were taken from a list of candidates, who fitted the desired profiles, or proposed by their doctors and nurses. The objective of the meeting was explained to them and they were guaranteed confidentiality.

Analysis

The information was analysed by means of content analysis, using the following steps:

- Preparation of a code tree (Table 3 and Figure 1).
- Reading the transcriptions and assigning codes to fragments of text.
- Analysis and relationship of the information contained in each code.
- Description of the results.

Parallel to the whole process of collection and analysis of the data, the research team developed a process of triangulation, discussion and contrast of the results, which increases the reliability of the study. Likewise, the moderator of the groups also worked

TABLE 2 Profiles of the Participants and Composition of the Focus Groups (Total Participants: 15 People)

	Focus Group 1	Focus Group 2
Place carried out	Seville	Granada
Gender	4 males and 3 females	4 males and 4 females
Relationship with the disease	5 patients, 1 father and 1 mother	4 patients, 1 father and 3 others
Age	Patients (young people between 15 and 25 years), fathers and mothers of children with diabetes (between 30 and 45 years)	
Geographical location	2 rural and 5 urban	2 rural and 6 urban
Parents education (of the patients and education of the participating parents)	Average (5) and higher (2)	Average (7) and higher (1)
Time since the diagnosis	3 cases between 1 and 5 years 4 cases between 6 and 17 years	4 cases between 1 and 5 years 4 cases between 6 and 10 years
Attitude towards the disease	Positive, acceptance 5 cases Negative, rejection 2 cases	Positive, acceptance 6 cases Negative, rejection 2 cases
Continued relationship with the health centre	All go periodically to the check ups at the health centre (the patients themselves or their parents)	

TABLE 3 Expectations on the Doctor-Patient Relationship*The communication of bad news: "it's diabetes"*

"At first, when you have no idea what is diabetes and they tell you, well, that it makes the child go blind, that he can go into a coma and the child could die...later you are content, they make you so angry, educating you, what happens is they demoralise me and this has happened to us more than once..." (father of a diabetic child)

"They said to: "take this, you are diabetic, take this and don't eat and don't drink this and this" (young male with insulin dependent diabetes)

"Viruses and bacteria" in doctor-patient communication

"He told me: look, it doesn't matter what you say to me, it doesn't matter to me if you have a bad time, I couldn't care less, if you have a bad time put on a crash helmet, but the child has to walk outside and a diabetic child cannot be in bed at 8 o'clock in the morning" (mother of a child with insulin dependent diabetes)

"I arrive there, he separates us and he says to the child: you, come here, why?, explain that to me, because it is terrible..." (mother of a child with insulin dependent diabetes)

"They look at the numbers: ooh!, bad! They don't ask you what happened to you that day, if they fired you from work..." (young male with insulin dependent diabetes)

"Adapt the disease to your life, not your life to the disease"

"Now you think, why am I going?, as instead of encouraging you, educating you, what happens is they demoralise me and this has happened to us more than once."
"I control myself, why am I going?, to put up with the barrage, or the nice words? (young male with insulin dependent diabetes)

"Afterwards, life is totally different to what they tell you at the clinic, because there are times when you can't comply with the insulin times, because there are times when you can't eat because you are out, because there are hundreds of things, circumstances, because one day I took part in sport more than I should have, because one day I took more insulin and later he told me off for doing that activity" (young male with insulin dependent diabetes)

"First rejection, later, you start to take information and you inject yourself once and you do it to the letter, you go from one extreme "nothing matters" to controlling yourself to the maximum: because it is me who is going to go blind or not, if I get up tomorrow...but, in the end, you remember that you have to adapt the disease to your life, not your life to the disease" (young male with insulin dependent diabetes)

"The doctors, they want me to become the best sportsman in history, not just to wake up at half-past 8 in the morning to inject my insulin to have breakfast at nine, and this makes you think and you say: it's why I can't work, I can't go out...it is why you can't take it according to the instructions like the doctor says, it is impossible" (young male with insulin dependent diabetes)

The doctor-patient relationship: responsibility and making decisions

"And my doctor told me: You, if that happens to you again, the only thing you have to do is check the glucose every 20 minutes and eat. You know that after six hours the child is going to be alright. You, why did you take her to hospital? While the child is not in a coma, you don't have to go to the hospital at all" (mother of a child with insulin dependent diabetes)

"I have to be my best doctor because I am going to be here every day" (young male with insulin dependent diabetes)

"I have now decided, for example, to inject myself at midday. Me, in 4 months, I have been able to change 40 things and I told this to the specialist: Aah! Well you have done very well!" (mother of a child with insulin dependent diabetes)

"They admitted me to hospital once, I was 3 days in a coma due to the doctors' fault, not my fault. My mother was saying it was a very big drop and they didn't notice it. And, in the end, it was the sugar" (young male with insulin dependent diabetes)

"I have been doing it for 5 years. And I had to go to the hospital and he told me: "That my daughter has got fatter", "Ooh! You are crazy! That shouldn't happen" (mother of a child with insulin dependent diabetes)

"I don't talk to the doctor about these things. It has never occurred to me...he hasn't asked me either" (young women)

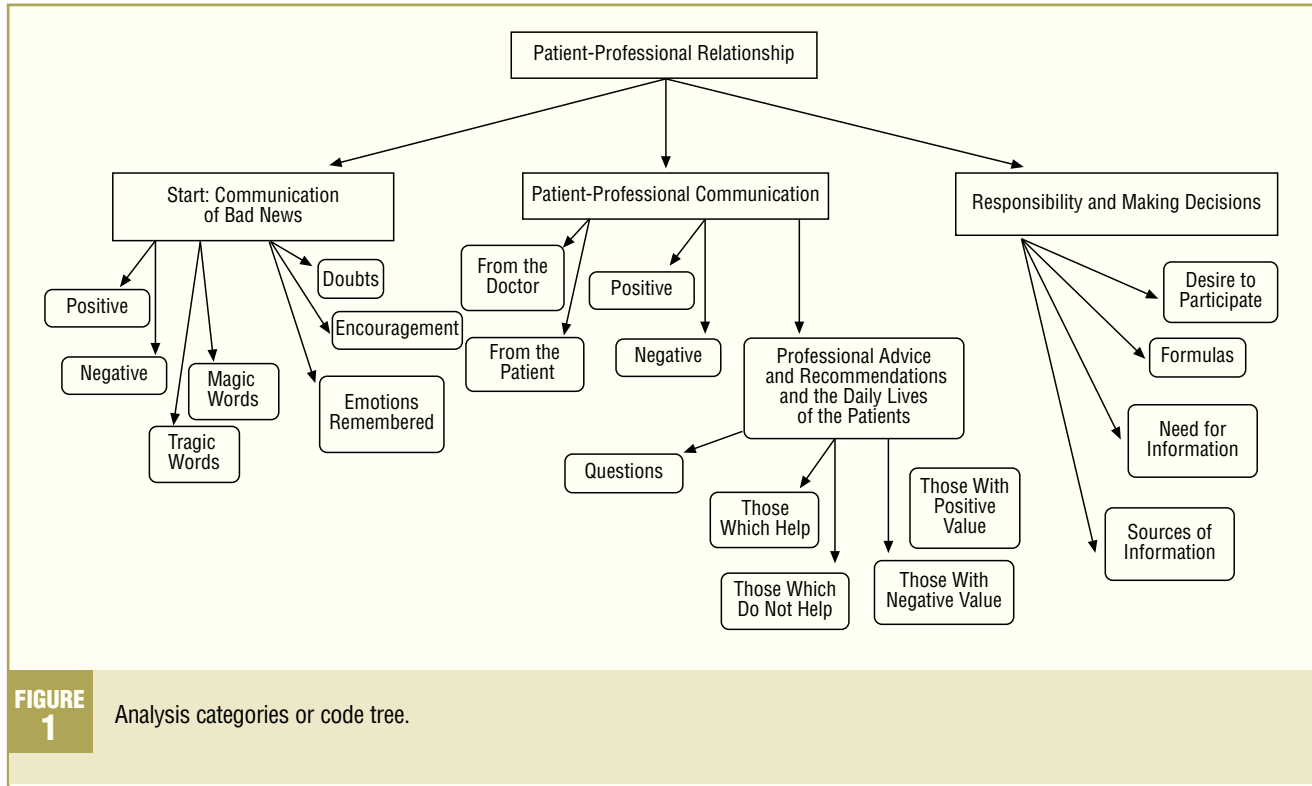
on the analysis of the information, which guaranteed that the interpretations were as faithful as possible to the original feeling. The contrast of our results with the available literature also constituted a test of validity and rigour, and the level of consistency is very high, as will be seen in the discussion of the results.

Results

The Communication of Bad News: "It's Diabetes"

In the experience of the people interviewed, the communication of the diagnosis is a determining factor in the way the disease is confronted and lived with. In many cases it was made abruptly and their condition was pointed out as "incurable" and were informed of the negative consequences of poor control. In the majority of cases, the diabetes was diagnosed in primary care. The patients said

they did not ask much at that consultation and the doubts came later. The doctors provided them with a lot of information, but they admitted they were "blocked." The emotions they remembered at that first visit are: fear, denial, doubts on a possible error and disheartened. In both groups, the parents remembered the communication of the "news" in a more negative way and were sure it would be difficult for them to get over its impact. The young people said that their parents were "more frightened." Some positive experiences were also recorded on the communication of the diagnosis. In these cases, the patients said that their doctors stressed that they could lead a "normal life" and that the treatment was "easy." They were asked about their doubts and feelings in view of the news and were informed that in the following visits they were going to explain more about the disease to them.



The information they remembered most was the drawing and graphic support.

"Viruses and Bacteria" in Doctor-Patient Communication

In the control and follow up visits, the patients reported that the medical care centred on reviewing the self-monitoring data and it was normal "to reprimand" if the results were not good. This seems more evident with the endocrinologists and nursing consultation in health centres. According to the patients, they said that the clinical interview is centred on the results of the monitoring and in the "interrogation" of the patient to discover "what they have done wrong." The patients considered it "very difficult to do everything well." These opinions are stronger in people of both groups with negative or denial attitudes towards the disease. Few patients recorded that their doctors or nurses positively reinforced them. When they arrived at the review they had the feeling that "they were going to be discovered." This promoted "childish" attitudes, both in the patients and in their carers: they "hide" information or they lie to the professional to look for approval and to avoid the "telling-offs." The communication becomes partial, centred only on what "the doctor wants to hear" without sharing their feelings, their fears or their worries with the professionals, or to comment on the strategies that they develop to adapt the treatment to their lives, the "tricks" they use to carry on with the most "normal" life possible or how they have learned to get round the limitations that their disease has imposed on them. The major-

ity of young people interviewed, particularly those with a more negative attitude towards their disease, stated not feeling understanding in the professionals. In general, the young people as well as the parents interviewed are more critical about the communication skills and the capacity of the endocrinologists to empathise, than they are of the family doctors. Few opinions were expressed on the nurses and the nurse clinics in the health centres.

"Adapt the Disease to Your Life, Not Your Life to the Disease"

Some young people interviewed declared that they had stopped going to the health centre and preferred to control the disease themselves. They "used" their mothers and other family members so that they could act as mediators with the health system. The emotions that these people describe as regards the treatment vary from rebellious, non-conformist, invulnerability and anxiety. They are those whom we have characterised with a negative attitude. The interviewees assured that, to live with diabetes and maintain social relationships and a "normal" daily life, they had to give up and learn to adapt their life to the treatment and to their disease and learn to make its demands more flexible and point to the incompatibility, on many occasions, between the recommendations of their doctors and their life circumstances. They learn to self-regulate the treatment in accordance with their activities by the method of trial and error. In view of these opinions, the parents recognise that their children also go through periods of refusing the treatment. They also express that

Discussion
Key points

What Is Known About the Subject

- To have good control in diabetes delays the appearance of secondary complications and diseases, at the same time it improves the quality of life.
- Approximately 50% of diabetic patients do not comply with the treatment adequately.
- The problems of communication in the clinic is a barrier to the effective treatment of diabetes.

What This Study Contributes

- The communication of the diagnosis is remembered positively when the doctors emphasised that they could have a “normal life” and that the treatment was “easy,” they were asked about their doubts and feelings on hearing the news and when they were informed about the disease and the treatment gradually in several visits, and taking into account the emotional impact.
- The style based on threats and control promotes attitudes of “concealment” or lying to the professionals to seek approval and avoiding the “tellings-off,” without sharing their feelings, fears or anxieties with the professionals, or commenting on the strategies being developed to adapt the treatment to their lives, their “tricks.”
- The majority of young people interviewed would like to be able to exchange information with their doctor, to jointly decide their life plan and even discuss the hypothetical risks linked to the decisions.

they feel impotent to convince them to the contrary. They would like the health system to provide help on this subject and that psychological care be included in the menu of services.

Many interviewees during the working of the focus group expressed that they often felt worried and anxious when faced with these questions: “What jobs will I not be able to do?,” “Will they discriminate against me?,” “Will it be more difficult to find a partner?,” “Will I be able to have healthy children?,” and “Will my children inherit my diabetes?”...

The Doctor–Patient Relationship: Responsibility and Making Decisions

By controlling themselves, these people are “experts” in their own disease. They learn to know it, how to act in a

crisis and they make decisions on changes in treatment. They state that their doctors and nurses encourage this assuming of responsibility for their self-care and treatment. However, they do not feel they participate in the decisions on their health and would like to do so. The majority of interviewees say that their doctors do not ask for their opinion, they do not recognise their “expertise” and after listening, the professional decides “the best for him/her.” The majority of young interviewees would like to be able to exchange information with their doctor (e.g., information they find on the Internet), to jointly decide a life plan and even share hypothetical risks linked to the decisions. In the case of the parents, their attitudes are more oriented towards a less active model of participation, although always informed of decisions. The principal source of information is the family doctor, followed by the endocrinologist, friends and family, the media, books or encyclopaedias and the Internet.

Discussion

Qualitative methodology allows a holistic approach to the daily life of the participants, with which the wealth of information on their intentions, experiences and opinions,^{13,15,17-19} aspects which are difficult to achieve by quantitative methods.^{7,20} This method allows us to explore, describe and understand the perspectives, the experiences and the emotions of the reality which we are investigating^{15,21} and identify conclusions that, although they are not generalised probabilistically, they are from a logical point of view.^{16,22} Also, the qualitative method, by using few interventions or no structures, does not determine the results themselves.¹⁸ In fact, the emotional reaction and distress with which some people spoke to us about their diabetes, as well as the problem of communication with their health professionals was somewhat of a “surprise.”

This study has been centred on patients with DM1 to guarantee that the participants shared the same disease. This strategy, recommended in the designs of qualitative research,¹⁴ expects that, on talking about subjects in common, group discussions can go deeper into the experiences of the participants. The number of groups formed, 2, enable reaching a high saturation level of information, which was redundant in both groups for all the dimensions of the study. The different geographic locations of the groups (Granada and Seville) attempted to obtain varied experiences about the health care received. However, it should be pointed out that the services on offer described by the participants were very similar.

The presence of young people and the parents of other young people in the same group did not inhibit the participation of any of those present, which was expressed with spontaneity and interest in both focus groups.

The experience of diabetes and its treatment and its complications is a harsh experience and, in many cases, produces a strong emotional shock and is a source of stress^{1,5,8,13} which will influence the course of the disease.¹² However, the level of acceptance and the expectations which are generated on its future will depend to a great extent on the confrontation and communication style of health professionals. The results of this study show that a cold, managerial style and lack of empathy has negative consequences on the progress of the patients. The question which arises is: How can we intervene and improve these interactions? The answer is in the needs expressed by the patients and in the research available. Some key points which should be included in the care of patients with DM1 are:

1. The relationship has to be taken care of. In this and other studies it is established that patients with DM1 demand a closer relationship with their health professionals.^{9,12,13} To improve the doctor-patient relationship improves therapeutic compliance⁷ and the manner of coming to terms and confronting the disorder,²³ and it is one of the most determining elements of patient satisfaction.²⁴ It is important that health professionals should show interest in the situation, the process and progress of the patient, and an open mind and not judgemental on the attitudes, behaviour and needs,^{7,19} which should be listened to without hurry^{2,9,13} and that they should learn to be flexible with treatment depending on the circumstances and individual preferences.

2. There has to be support. The health professionals must understand the psychological impact that a serious health problem can have¹³ and offer emotional support throughout the whole process.^{1,8,12,25} For this, two essential points: the emotional state and the circumstances of the patients and their families must be known,^{12,27} to know the person, not only the disease, and the capacity to empathise with the patients must be developed and put into practice. It is an exercise in understanding the feelings and situations of the patients and showing them this understanding.^{5,13,19}

3. There must be effective communication. The way the diagnosis and other information is communicated influences the response.¹³ If an emotional reaction is triggered, such as anxiety, on conveying the message, counter-productive effects can be achieved, such as block or denial. The communication of news must be prepared and consider that one of its objectives will be to calm down and soothe.¹³ Messages must provoke an attention reaction and will always be accompanied by recommendations perceived as effective and by alternatives, endeavouring not to always repeat the same messages and adapting the conversation depending on the characteristics of who receives it.²⁶ For example, when the diagnosis is communicated, it is essential to give emotional support and show an empathetic attitude.^{5,9,13} It has to be transmitted in the most

encouraging way possible, without moving on to all the adverse consequences of the disease in the first moments and allowing the expression of feelings and the emotional outburst.⁵ The information must be provided gradually, in small doses and requesting feedback to assess the level of comprehension,^{13,27} using understandable language¹⁹ and allowing the expression of doubts or questions at all times.^{13,25}

4. There must be motivation. The information and the knowledge of the seriousness of a disorder are not sufficient to promote therapeutic compliance in a chronic disease⁵; the patient also has to believe and perceive that the follow up of the treatment will produce benefits for him/her.¹ In this disorder, which involves such a conditioning therapeutic regime for the patients, making them feel “different,” “special,” and “slaves” of their routine, it is particularly necessary to motivate them to achieve good therapeutic compliance. On the other hand, if a patient confronts a disease with an optimistic attitude and a strong belief in his self-sufficiency, it is more likely that he/she will obtain a better quality of life.^{23,28}

5. There has to be training. Diabetes training is fundamental to increase compliance with the treatment¹ and has to be linked to the whole care process,¹¹ whether it is in person or by telephone or by other means.^{4,29} It is not only training in skills and knowledge, but training in minimising the damage of unfavourable behaviour,¹³ in helping patients to accept their DM1, in increasing a responsible and critical attitude, and to achieve more independence and participation of the patients.¹¹

6. The responsibilities must be shared. Good compliance to treatment can only be achieved if the patient actively participates in the process and is continually involved in the making of decisions.³⁰ There are studies that demonstrate that an active style of confrontation correlates with better blood glucose regulation.²³ But it is not enough just to inform the patient what has to be done; it is important to understand that the responsibility in the success of the treatment is shared. Interaction and exchange are the key words. Consensus agreements have to be reached^{7,9} in which the problems, the possible solutions and the most relevant decisions with clear objectives are defined.⁷

To improve health care and its results, to promote patient participation in their own health processes and to maintain quality communication with the patients not only improves compliance to treatment and its effectiveness and efficiency,¹⁰ it also increases patient satisfaction.^{25,30,31} And the increase in satisfaction, at the same time, increases compliance to the treatment.²⁴

Conclusions

The future of health clinics is moving towards the “empowering” of the patients and by the collaboration and

exchange between doctors and patients.¹⁰ The health system as well as every one of its professionals must establish the need to treat patients in an integrated manner, paying particular attention to 2 key aspects of care, the treatment and communication, which have a direct bearing on the efficacy of the treatments and their therapeutic compliance.

This is a descriptive and exploratory study which has allowed us to approach a part of a reality frequently ignored by the health services, the experience and the qualitative perception of its users. We can generalise its conclusions, by the validity and rigour of the investigation as well as by the agreement with other studies. However, considering the limited sample, it would be interesting to carry out a wider study along this line, as well as investigating, by means of qualitative methodology, the perception of health professionals on their communication and their relationships with their patients and their problems in facing up to them.

A primary and consistent practical implication of the study is the need for training in communication and health of some health professionals.

References

1. Heredia Galán MV. ¿Qué influye en la adherencia al tratamiento de la diabetes? Rol de Enfermería. 2004;27:57-60.
2. Consejería de Salud Junta de Andalucía. Diabetes Mellitus tipo 1. Proceso asistencial integrado. Sevilla: Consejería de Salud; 2002.
3. Consejería de Salud Junta de Andalucía. Plan Integral de Diabetes de Andalucía 2003-2007. Sevilla: Consejería de Salud; 2003.
4. Koenigsberg MR, Bartlett D, Cramer JS. Facilitating treatment adherence with lifestyle changes in Diabetes. *American Family Physician*. 2004;69:309-16.
5. Peralta G, Figuerola D. Aspectos psicosociales de la diabetes. *Endocrinol Nutr*. 2003;50:280-5.
6. Zúñiga González S, Islas Andrade S. Educación del paciente diabético. Un problema ancestral. *Revista Médica del IMSS*. 2000;38:187-91.
7. Carratalá Munuera C, Orozco Beltrán D, Gil Guillén V, Merino Sánchez J. Factores en el cumplimiento terapéutico y diabetes. In: Gil Guillén V, Merino Sánchez J, Palop Larrea V, editors. *El cumplimiento factor clave en el control de las enfermedades*. Valencia: SVMFIC Societat Valenciana de Medicina Familiar i Comunitaria; 2003. p. 133-42.
8. Lucio Gómez-Maqueo E, Alcántara-Rodríguez Y, Tapia-Hernández B, Durán-Patiño C, Calzada-León R. Personalidad y autoestima del adolescente que padece diabetes mellitus insulino-dependiente. *Bol Med Hosp Infant Mex*. 2003;60:173-83.
9. Fernández Fernández I. Atención sanitaria centrada en el paciente con diabetes: necesitamos incorporar las perspectivas/expectativas de los pacientes. *Aten Primaria*. 2002;32:195-202.
10. Dijkstra R, Braspenning J, Grol R. Empowering patients: how to implement a diabetes passport in hospital care. *Patient Education and Counseling*. 2002;47:173-7.
11. Isla P, López C, Valls R. Diabetes mellitus. Expectativas de futuro en la educación sanitaria. Rol de Enfermería. 1997;224:51-3.
12. Szabó-Kallai K, Gyimesi A, Iványi J. Role of emotional factors in diabetes. *Acta Diabetol*. 1990;27:23-9.
13. Hiscock J, Legard R, Snape D. Listening to diabetes service users: qualitative findings for the Diabetes National Service Framework, UK; 2001.
14. Kitzinger J. Qualitative research: introducing focus groups. *BMJ*. 1995;311:299-302.
15. 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. *Rev Esp Salud Pública*. 2002;76:461-71.
16. Prieto Rodríguez MA, March Cerdá JC. Paso a paso en el diseño de un estudio mediante grupos focales. *Aten Primaria*. 2002;29:343-7.
17. Pope C, Mays N. Qualitative research: reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *BMJ*. 1995;311:42-5.
18. Hurley RE. La investigación cualitativa y el profundo entendimiento de lo obvio. *HSR: Health Services Research*. 1999;34:1119-36.
19. Nuño Gutiérrez BL, Canales Muñoz JL, Madrigal de León EA, Villaseñor Farias M, San Martín AH. Motivos y expectativas de los adolescentes sobre la utilización de servicios de salud. *Revista Médica del IMSS*. 1998;36:13-21.
20. Muntaner C, Gómez MB. Qualitative and quantitative research in social epidemiology: is complementarity the only issue? *Gac Sanit*. 2003;17:53-7.
21. 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. *Gac Sanit*. 1999;13:312-19.
22. Popay J. Qualitative research and the epidemiological imagination: a vital relationship. *Gac Sanit*. 2003;17:58-63.
23. 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.
24. Mira JJ, Vitaller J, Aranaz J, Herrero JF, Buil JA. La satisfacción del paciente: concepto y aspectos metodológicos. *Revista de Psicología de la Salud*. 1992;4:89-116.
25. Clark CH, Snyder J, Meek R, Stutz L, Parkin CH. A systematic approach to risk stratification and intervention within a managed care environment improves diabetes outcomes and patient satisfaction. *Diabetes Care*. 2001;24:1079-86.
26. Epstein R, Alper B, Quill T. Communicating Evidence for participatory decision making. *JAMA*. 2004;291:2359-66.
27. Ordoñana Martín JR, Gómez Amor J, Galván Olivares F. El uso del miedo en los mensajes de salud. *Gaceta Sanitaria*. 2000;14 Supl 3:45-59.
28. Hart HE, Bilo HJG, Redekop WK, Stolk RP, Assink JH, Meyboom de Jong B. Quality of life of patients with type I diabetes mellitus. *Qual Lyfe Res*. 2003;12:1089-97.
29. Izquierdo R, Knudson P, Meyer S, Kearns J, Plutz-Snyder R, Weinstock R. A comparison of diabetes education administered through telemedicine versus in person. *Diabetes Care*. 2003; 26:1002-7.
30. Gross R, Tabenkin H, Porath A, Heymann A, Greenstein M, Porter B, Matzliach R. The relationship between primary care physicians' adherence to guidelines for the treatment of diabetes and patient satisfaction: findings from a pilot study. *Family Practice*. 2003;20:563-9.
31. Wellbery C. Active role in diabetes care improves patient satisfaction. *American Family Physician*. 2003;67:877.

COMMENTARY

Chronic Diseases: Why Are We Still Waiting for Godot?

Javier Júdez and M. Teresa Martínez Ros

Murcia Region Foundation for Health Training and Research, Murcia, Spain.

The article by Escudero-Carretero et al,¹ which presents a qualitative study on the clinical relationship in the context of insulin-dependent diabetes mellitus (DM), is timely and a guide to the direction that must be taken in the present and the future in the care of chronic diseases. Timely, because it directs us to a health problem which determines the life of those affected and their families and which does not fit well with functional clinical model, centred on the “technique,” with risks of lack of continuity in care, or with a health system based on the “on demand” consultation, on the acute episode, on the doctor or on the hospital. A guide because it highlights facets centred on the patient and the carer (expectations, needs, opinions, emotions) and, therefore, value laden.

This study ratifies and confirms the urgency and the need to change the health care, both from the professional and institutional perspective, to take it more centred on the patient than a team, coordinated and in a process of continual improvement. A care which might incorporate and specify values which might promote coherent life styles and which is oriented towards self-care, to the self-management of the body and health. A care where the decision making is based on confidence and updated assessment which attempts to avoid uncertainty. In short, an integrated care which calls for, among its demands, that of rethinking and reformulating the therapeutic vehicle par excellence: interaction and clinical relationship.

Indeed, DM in general is a model of what chronic diseases signify for health care and society. DM is, without a doubt, a chronic, important and costly and disease which is reaching epidemic proportions. It is estimated that there are currently 194 million people in the world who have DM, which is 5.1% of the adult population, and this figure will increase 333 million (6.3%) by the year 2052. In a recent study carried out in the Autonomous Community of the Murcia Region³ indicated that an estimated 11% of the population ≥ 20 years had DM. The total prevalence of DM in the Murcia Region adjusted for the standard world population (30–64 years) is 7.6% (10.2% in males and 5.2% in females). Insulin dependent DM makes up between 5% and 10% of the cases diagnosed, and the age most affected is between 10–14 years. In Spain, the ap-

Key Points

- Chronic diseases in general and diabetes in particular require treatments and changes in life style every day and for all their lives.
- Health professionals have to adapt relationship models centred on the patient which include physical, emotional, values, family and social dimensions with the aim of improving the care given and the satisfaction of the patients and the professionals.
- The professionals as well as the health organisations must make progress in the redesigning of the care processes for chronic diseases, such as diabetes, from an integrated perspective.

proximate incidence is 10–17 new cases/100 000 inhabitants/year.

Thus, DM is shown as a problem of considerable dimensions, particularly if we take into account its relationship with the increase in cardiovascular risk, the morbidity and the complications in the short and long term which it involves. To have good control and treatment of the disease delays and reduces the appearance of these complications. The treatment of DM is one of the most complex, given that the patients have to combine medication, diet and exercise, throughout the day, dynamically and day in day out, permanently, for all their lives. To the drastic changes in the patients' routine, is added the most common ways of administering the treatments and carrying out controls: the daily lacerations in the form of injections or pricks. All this very often means that therapeutic compliance is a challenge of the first magnitude. And this is even greater in the young patients, since the complexity and chronic nature of the treatment, added to the biological-social changes that occur during adolescence, makes it a very important challenge to the competence of the adolescent with DM, which

means that around 50% do not comply completely with their treatment.⁴

Despite all this being basically known by any primary care doctor, it is shocking that studies like that of Escudero et al continues to show the persistence of a care model which clearly does not help to confront the challenges which are involved in a disease like DM. Once again (how many times more do we need?), the “Godot” for which this is designed, is largely, our system of health care and for which, to a large extent, they prepare us in pre-grade and resident training, is not going to come. If the classic mid-XX century work of Samuel Becket, Nobel prize winner of Irish origin, characteristic of the theatre of the absurd, shows the futility of a chimeric wait and without direction, is it not equally inappropriate that health professionals should expect some rewards from some interventions which are weakly going to favour that which they ostensibly pursue? We cannot ignore this reality, if we have a vision and some sketchy performances in a much more complex process and which requires us to work in various dimensions, between those which are unavoidable and that which incorporates the expectations of the patients and in relationship-communication context that is established with them and their care environments.

The psychologists Salvador and Melgarejo⁵ grouped the principal factors which can influence therapeutic compliance into 6 categories: factors associated with the disease (chronic nature, severity, stigma), with the treatment (administration, dosing regime), with the patient (age, belief, motivations, self-efficiency), with the doctor (empathy, communication strategy, values), with the patient-doctor interaction (type of relationship, control, making decisions, contact-empathy) and with the environment (family support and care environment). These same authors remind us that therapeutic non-compliance and its associated factors constitute a paradigmatic example of the failure of the traditional biomedical model to take into account the process of the disease and its impact in those affected by it. Timely and, as we said, in one of the suitable directions, Escudero et al confirm this insufficiency, which can be applied not only to the care of the insulin-dependent DM patient, but to all patients with chronic diseases. The participants in the mentioned study claimed something so “outrageous,” like it should take them into account, that the health professional should centred on them as a person, in all their dimensions (physical emotional, intellectual and spiritual) and not simply a glucose value and the physical signs and symptoms. They demand health personnel who can empathise with their emotions, with their day to day difficulties to carry on with a “normal” life, that they are an emotional support throughout time, that they have the ability to communicate efficiently and therapeutically, that they teach them and motivate them, that they do not “tell us off” or threaten us, and that they recognise that they are experts, to a large extent, of

their own disease and in the management of their own body.

How is it that, all too often, as health professionals as well as the health care system, we are inherently incapable of systematically integrating these so logical and so reasonable demands? How have we produced a health system which often shields us and prevents us from taking advantage of these “opportunities” which gives us the dynamics of a chronic disease extended throughout time? What else can emerge from the new Training Program of the Family and Community Medicine Speciality, which includes as essential competences, care communication and bioethics, together with the acquisition of clinical reasoning and care management?

Doctor-patient interaction is the principal determining factor of a wide range of factors associated with health intervention: information obtained in the interview, accuracy of the diagnosis, effectiveness of the consultation, compliance, the understanding of problems on the part of the patient and the satisfaction of the patient with the consultation, as well as that of the doctor too. However, the group of skills needed to improve this relationship, is not taught or practiced adequately in pre-grade, in resident training, or in continued education, which can have clear repercussions on patient care and on the job satisfaction of the doctor.

Twenty years ago, Jay Katz spoke of the paradoxical “silent world (or lack of communication) of the clinical relationship” as something that had to be reversed. All in all, things are changing. Today, after the pioneering efforts of the Communication and Health Group of semFYC (Family and Community Medicine) and numerous professionals from other fields and disciplines, it now cannot be said that there are no training (and to a lesser degree research) in aspects of communication and clinical relationships. Perhaps, that is not sufficiently generalised.

There also increasing initiatives in practical training in clinical bioethics such as, for example, that promoted by Bioethics Project for Clinical Practitioners of the Sciences and Health Foundation, led by Diego Gracia.

The focus on the essential competencies of the family doctor of the previously mentioned new training programme is welcome. But there is still much to do. It is good that some approaches are permeating little by little and at least they may become familiar: for example, the biopsychosocial model which George Engel pointed out almost thirty years ago, or “medicine centred on the patient” developed by McWhinney and Stewart, among others.

However, general systematic care practice, the “informal culture” of the organisation, is still a long way from moving into these parameters. These practices have still not been “automated”, apart from those politically and healthily correct. For that reason, it is necessary not to give up on this line of work which Escudero et al point out. For that reason, it has to go deeper to confront the challenges

TABLE 1 Examples for Benchmarking of the Care and Investigation Approach of Chronic Diseases, Like Diabetes. More Than the Mere “Medical Technique” on the Disease, the Reorganisation of the Care Conception

Project	Information Found on the Web
Trends in research by Trisha Greenhalgh (University College of London)	Series of articles in the <i>British Medical Journal</i> http://bmj.bmjournals.com/) + Evidenced based medicine (Series “how to read an article on...,” 1997 + Medicine based on the narrative, 1999 + Complexity in health care, 2001 + Research action in the field of diabetes, young people, minors, immigrants, 2004-2006
“Improving Chronic Illness Care” (ICIC), “Assessment of Chronic Illness Care” (ACIC), Institute for Healthcare Improvement initiatives “Patient Assessment of Chronic Illness Care” (PACIC)	http://www.improvingchroniccare.org/research/index.html Program sponsored by the Robert Wood Johnson Foundation “Chronic Care Model” developed by Ed Wagner http://www.ihl.org/IHI/Topics/ChronicConditions/ Application to diabetes: Research by the RE Glasgow group in Kaiser Permanente Colorado (<i>Med Care.</i> 2005; 43:436-44; <i>Diabetes Care.</i> 2005; 28:2655-61)
Observations on health care in chronic diseases (WHO)	http://www.who.int/chronic_conditions/en/
Collaborative Spanish web site on type 1 DM	http://www.diabetesjuvenil.com

that the chronic diseases create, from a professional as well as an interdisciplinary and institutional perspective, as regards care, but also in training and research.

We cannot ignore the path which is being opened up with examples (Table 1) like those of Trisha Greenhalgh of medicine based, at the same time and indissociable, on the “evidence” and on the narrative (quantitative and qualitative), which approaches the increasing complexity and what comes out of the health institution headquarters to go to the population. Or like the initiatives for improving the care of chronic diseases picked up by the Institute of Healthcare Improvement, driving force for the improvement of quality in the United States. Or like the initiative of the World Health Organisation which promotes the Chronic Care Model (CCM). With all these new work tools and new lines of investigation are emerging, not only descriptive, but of action, establishing, health services, such as the Assessment of Chronic Illness Care (ACIC) or the Patient Assessment of Chronic Illness Care (PACIC). In this sense, it is very illustrative and encouraging to go on the Internet and look at the quantity and quality in some cases, of the information it has on DM. The possibilities of the new technologies, far from “displacing” the professionals should be an opportunity to promote more and better informed patients. The health professionals have to be aware of this situation, in the extent of our possibilities, and orientate or patients towards using these resources. Some diabetic patients, experts in other areas of knowledge, have made this knowledge available to everybody and have created Web pages or computer programs which help in the control of the disease and provide information and support.⁶

We have, therefore an exciting path ahead to walk in the improvement in the care of chronic diseases in general, and DM in particular. A path to walk, but not to waste time in futile, and often, self-destruction (professional erosion), waiting like the protagonists Vladimir and Estragón, waiting in vain for Godot, but for both the professional and the institution to walk together. We have to continue along this path with good walking companions such as Escudero et al, who spread the example.

References

1. Escudero-Carretero MJ, Prieto-Rodríguez MA, Fernández-Fernández I, March-Cerdà JC. La relación médico/a en el tratamiento de la diabetes tipo 1. Un estudio cualitativo. *Aten Primaria.* 2006;38:8-15.
2. International Diabetes Federation: Diabetes Atlas 2000. Bruselas: International Diabetes Federation; 2000.
3. Cerezo J, Torno MJ, Navarro C, Rodríguez-Barranco M, Marco R, Egea JM, et al. Diabetes y obesidad en la población adulta de la Región de Murcia. Murcia: Consejería de Sanidad. Dirección General de Salud Pública. Serie Informes n.º 40; 2005.
4. Ortiz M, Ortiz E. Adherencia al tratamiento en adolescentes diabéticos tipo 1 chilenos: una aproximación psicológica. *Rev Med Chile.* 2005;133:307-13.
5. Carulla LS, Melgarejo Ochoa M. Cumplimiento terapéutico. El gran reto de la medicina del siglo XXI. Barcelona: Stm editores; 2002.
6. Fernández Fernández I, Ortega Millán C, Martín Manzano JL, Rodríguez Pappalardo V, Vázquez Ortega C, Costa Mestanza CS. La diabetes en Internet. *Aten Primaria.* 2002;29:443-51.