

# The narrative interview in therapeutic education. The diabetic patients' point of view

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**Abstract.** *Introduction:* Due to the rise of the average age, chronic-degenerative diseases, including diabetes, are in constant increase, resulting in high complications, in terms of social-economical costs and of the quality of life of the people affected by it. For these reasons, adherence to therapeutic prescriptions becomes essential. Through the implementation of motivation, clear information and follow-up, health professionals can help patients with diabetes to increase therapeutic adherence and maintain healthy lifestyles. *Aims:* The aims of this study were to explore the diabetic patient's adherence and their illness perceptions and the role of the Case-Care Manager in improving the empowerment of patients. *Method:* For this purpose, a semi-structured interview was used, and submitted by 30 patients (19 males; age range: 20-65; mean age: 49.9) belonging to two diabetological centres of Emilia-Romagna (Italy). *Results:* In the both contexts, knowledge of diabetes is limited and 2/3 of patients found out about diabetes almost by chance. As for the correct lifestyle (diet and physical activity), patients have initially started to change but the behaviour was not maintained and not perceived as an important part of the disease management. It emerged that a health specialist could help them keep a healthy lifestyle. *Conclusions and discussion:* The CCM, in particular, can effectively intervene on the poor knowledge of the disease, on difficulty in getting used to the new lifestyle and on the lack of motivation. In fact, The CCM deals specifically with information and education of the patient, promoting self-care and monitoring the patients' paths and outcomes.

**Key words:** interview, chronicity, diabetes, therapeutic education, Case-Care Manager

## 1. Introduction

The therapeutic education is the combination of educational activities for specific categories of people. It covers transmission of knowledge and training, in order to get the necessary skills and promote habit changes.

The therapeutic education is also based on values

like autonomy, freedom and responsibility; in other words, the ethic component of the care approach (1).

The therapeutic education is a complex action, because it is not only prevention-aimed, but it is also cure-aimed. It will create a patient/caregiver who is competent and able to apply the theory of *knowing*, *knowing what to do* and *knowing what to be* (2).

The therapeutic education carried out by expert and trained staff should lead the patients to adopt an appropriate lifestyle. For example, the changes in the lifestyle (body weight reduction of 5/7%, exercise for at least 150 minutes per week) have been more effective than dosing one drug (metformin) in pre-diabetic patients. (3). In order to reach a correct lifestyle, the therapeutic education is extremely vital.

However the healthcare professionals interrupt patients on average every 23 seconds during a consultation; in this way not only significant information risks to be lost, thus compromising the diagnostic accuracy, but the patients end up feeling poorly listened and not adequately understood (4).

“For the practitioners it is advisable to establish an educational dialogue, which is “bi-directional”, by starting with a careful listening and carefully choosing the language and the “timing” of communication. Through the educational dialogue, the professionals have the opportunity to bring to the surface the real knowledge and conjectures about illness and treatment” (5).

Moreover, the narration should help those with a chronic disease to make order, to give a sense to their experiences and to place them on a space-time level, thus becoming a therapeutic mechanism (6).

In the last few years in the clinical-care field, there has been an increasing multi-professional interest in the adoption of the narrative approach, both in the clinical and the educational/ethical context, to which medicine and all the health sciences are related (7).

“Narrative medicine” is substantially an alternative and innovative medicine, an expressive form through which health concerns are structured and conveyed by patients, relatives and friends, as well as by medical staff, in conversations, presentations and reports of specific cases (8).

The tool mainly used by narrative medicine is the narrative interview, which is based not only on the analysis of the cultural meanings of the disease, but above all on their production, being aimed at the active participation of the patients in the process of elaborating a sense to their events (9).

More and more professionals recognize the importance of using narrative approaches in medicine, by emphasizing the value of a “patient-centered educational approach”.

This approach, based on holistic understanding, hermeneutical dialogues and a high degree of narrative ability, produces different ways of offering care and assistance.

The benefits deriving from the use of this methodology are different; for example, a better understanding of the needs, resources and perspectives of the patient by creating positive effects on the care results (10).

In a recent qualitative study conducted on diabetic adults in Japan (11) a perception of impotence experienced in relation to their condition was detected through structured interviews, meetings, analysis of clinical documentation. The state of impotence is not only an emotional condition but also a combination of sensations, perceptions and thoughts; therefore, it is important to understand the stories that the patients tell. The results suggested improving the nursing approach; firstly, by listening carefully to the patients as they tell about themselves; secondly, by grasping the signs of inadequacy in order to create situations in which they can express themselves freely, talking about their stories, personal thoughts and difficulties.

Depression is another condition that is frequently found in diabetic patients. It can negatively affect the ability to keep the disease under control with diet, exercise and any insulin injections. The reasons why many diabetics are prone to depression are not clear. Perhaps diabetes causes biochemical changes that can induce depression. In any case, from a meta-analysis (12), it emerges that the subjects with diabetes were twice as likely to show symptoms related to anxiety and depression compared to the healthy population; this probability was higher among women than among men, 28% against 18%.

A recent study conducted in Nepal (13). showed a strong relationship between the disease and the perception of depressive symptoms among diabetic patients. Furthermore, the knowledge of the disease made patients implement an active coping behaviour that led them to prevent depressive symptoms and to better control diabetes

## 2. Aim

This main goal was to study in depth, through a qualitative and exploratory methodology, the efficacy

of the narrative interview as an instrument that allows to plan a personalized assistance for diabetes mellitus type 2 patients. The aims were to explore the diabetic patient's adherence, their illness perceptions, and the role of the Case-Care Manager in improving their empowerment.

### 3. Method

For this purpose, a qualitative and explorative methodology based on interviews was chosen.

#### 3.1 Setting

The chosen organizational context was the Diabetes Center.

According to a convenience sampling, two organizational-sanitary ambulatory contexts in North Italy, and in Emilia-Romagna (Italy) have been examined.

The first one is the Diabetological Center of Reggio Emilia, which is endowed with its own resources and functional autonomy. Approximately 11,200 patients are treated here.

The second one is the Diabetological Center of Guastalla, which is endowed with its own resources and functional autonomy. Approximately 11,900 patients are treated here.

The target of chronicity, which is typical of the outpatient care, has made it possible to analyse the diabetic path during the not acute phase.

#### 3.2 Participants

##### *Exclusion criteria*

Patients who were in the acute phase of their disease, or in new diagnosis and pregnant women because of a lack of chronicity were excluded.

Children were excluded, too, since they usually suffer from diabetes type I, as well as elderly people, who are often patients with different diseases.

##### *Inclusion criteria*

Patients suffering from diabetes type II, aged 18-65 and in chronic stage.

Finally, 30 patients were randomly recruited (15 for each context).

#### 3.3. Instrument

Patients have been interviewed with open questions about the stages of the disease:

- **Pre-Diagnosis:** data about the disease, how the diagnosis was formulated (through specific exams or symptoms) and the lifestyle of the patients (diet and physical activity).

The questions were, for instance: "How did you find out you had diabetes?", "Did you have any important symptoms before?", "How was your lifestyle before the disease?"

- **Diagnosis:** data related with emotional consequences of having a chronic disease, with fears linked to the new life condition, with the information given through the diagnosis were appropriate and if patients know who they can rely on in times of need.

The questions were, for instance, "How has your lifestyle been affected after discovering the disease?"; "How has your mood been affected after discovering the disease?" "Did any professionals help and take care of you during the first stages of the disease?"

- **Post-Diagnosis:** we have analysed if the interviewed patients agree with the idea of having a professional following them from the diagnosis onwards.

The questions were, for instance, "What has your chronic disease changed in your lifestyle?", "What do you fear most about your illness?", "What do you think if there was a professional following you throughout this new life condition?", and "what would you like to say to this professional?"

#### 3.3 Data Analysis

This study has analysed the level of acceptance of the disease; the changes in the patient's lifestyle; the level of adherence during treatment; the skills gained by the patients in managing their own state of health autonomously and the importance of a guide who is with them during the "chronic disease" phase. Each macro-area illustrated below was accompanied by some significant patient quotes

## 4. Results

### 4.1 Pre-Diagnosis

#### *Knowledge Area*

It has been analyzed the awareness of the interviewed patients of the diabetes before diagnosis was confirmed, what they knew about the disease and where they had taken the relevant information.

In Reggio Emilia, 2/3 of the interviewed patients did not have or had a little information about diabetes, even though this is one of the most widespread diseases; the patients aware of it (4/15) knew about diabetes as friends or relatives were diabetic.

*"I didn't know about diabetes so much; I had only heard about it before"* (Patient 5).

*"I had almost no information about it"* (Patient 10).

In Guastalla, 9/15 patients did not know anything about diabetes, 4 knew a little and the 2 knew about it because they had one or more relatives with diabetes.

*"I had absolutely no knowledge of it before"* (Patient 14).

*"I knew something about it as my aunt who lived with me had diabetes. As a consequence, I knew what to do more or less."* (Patient 12).

#### *How diabetes was diagnosed*

It has been analyzed how patients were diagnosed with type II mellitus diabetes.

The purpose was to understand if patients had had specific tests after recognising some symptoms or they had been diagnosed accidentally.

According to our data, in Reggio Emilia the diagnosis is mostly accidental (7 /15), thanks to exams and tests like routine check-up or for surgeries or pregnancy. In almost half of the interviews patients the diagnosis is linked to symptoms they had had for long but seemed not to be alarming.

*"I found it out by accident, after having a traditional blood test"* (Patient 15).

*"I was tired, my legs hurt, and I wasn't able to do some actions"* (Patient 8).

In Guastalla, the patients were diagnosed after some tests they had done by chance; relevant symp-

toms were in few of them (2 / 15) and were not recognised as symptoms of a disease.

*"...by having a test, I usually have a test twice a year"* (Patient 13).

*"It was a friend of mine who alarmed me: I came home from a transfer and I was very thirsty, even if it was in winter"* (Patient 2).

#### *Lifestyle area: diet and physical activity*

##### *Diet*

The patients' diet both before and after the diagnosis has been analysed. The purpose was to understand how the diagnosed disease would affect the patients' diet and nutrition. Before the diagnosis, patients used to eat irregularly and a lot, especially carbohydrates.

In Reggio Emilia, 2/15 patients said they did not make any changes in their diet, while the other 13 have changed it, partially or completely. These changes, yet, were only temporary, undermining the results obtained.

*"To be honest, I'm not a model patient. I try to find a compromise between curing myself and having a social life so that I don't feel lonely or excluded...very often I don't eat much in the evenings, but it's a constant struggle with myself"* (Patient 5).

*"Now I'm trying to be careful with what I eat, but I am not able to...actually, at all"* (Patient 4).

In Guastalla, all the patients had a irregular an irregular or too abundant diet. Most of them had obesity issues. 13/ 15 patients started a proper diet suggested by the Diabetes Centre and dietician and, over the time, 6 of them adhere to the prescription; other 6 followed the diet irregularly and 1 decided to interrupt it. 2 instead, never accepted to follow the prescriptions.

The interviewed patients who accepted to change their usual diet were more aware of the mistakes made in their previous diet. They also realised that a change would lead them to a better and healthier life, with less fear of the future and of the complications. Changes occurred in the patients who were treated with insulin therapy.

*"If I only think of going on a diet, I just go crazy"* (Patient 8).

*"I have been on a diet for years and now I'm used to it"* (Patient 14).

### Physical Activity

In the Reggio Emilia, 9/15 patients started some physical activity and 6 did not; however, only 2 out of 9 who started doing physical activity, kept on doing it.

*"I have no time for me, so also time for physical activity is zero"* (Patient 1).

*"I do no physical activity, which is a bad thing"* (Patient 8).

In Guastalla, even though the nursing staff has dealt in depth with the physical activity of the patients and all the patients think that physical activity is very important, the majority of them have not put their awareness into practice, have not even started a physical activity or undervalued it and stopped after a while (only 8 of them continued some physical activity).

The few patients who started with physical activity and declare they know about the correlation between physical activity and their glycaemia keep the suggested physical activity (6 are constant while 2 have quit).

*"I have a bad knee due to arthritis, my bunion hurts and so do my legs and I am not able to walk"* (Patient 8).

*"At the beginning I pretended my back hurt, but then I started and now I walk a little bit everyday and I am feeling well."* (Patient 12).

Data shown that physical activity is not constantly done even if this affects some achievements, such as weight loss, reduction of blood levels of glycosylated hemoglobin and nutrition control.

In sum, the patients know that the physical activity is important, but it is also difficult to keep on doing it, since it affects their consolidated habits.

## 4.2 Diagnosis Phase

### Emotional Aspects

In Reggio Emilia, 10/15 patients had shown feelings of fear related above all to the complications, to the change of life quality. For one patient, the fear is linked to the possibility of passing the disease on to his own children. The remaining 5 declared they have no fears.

*"I tell you the truth: I, considering that diabetes causes no pain.. I, at the moment, I have no fears".* (Patient 5)

*"But it knows how to die first because we do know that diabetes is a bastard".*

In Guastalla, 9/15 patients had declared to have fear. In the specific, they have talked about physical pain, complications (above all ulcers in lower limbs, eyes problems, amputations) and fear of the insulin therapy and of the diet. 4 patients declared they have no fears and some of them are convinced they can control the disease following the provided prescriptions. 2 patients stated they felt a lot of anger.

*"Well undoubtedly yes, some mothers of my friends have had their foot cut off"* (Patient 6).

*"I'm angry... I just needed that"* (Patient 8).

### Informative Support

This area explores if the information provided by the team of doctors has been complete at the diagnosis phase, referring in particular to the lifestyle. In Reggio Emilia almost the majority of the patients were satisfied with the instructions received, only one patient reported some circumstances where he didn't feel really supported. 2 patients revealed that the first information received was too much to elaborate and internalize.

*"The doctor was very clear about the important things to do in order to feel good and live with this problem, then also the nurses of the centre, when I go checking, ask me what's my lifestyle, how much I move..."* (Patient 15).

*"But... I was told many things! The doctor told me I have to be careful and to take care of myself otherwise I need the insulin"* (Patient 9).

Among the patients interviewed in Guastalla, 12 report they have been satisfactorily informed about how to be on the best behaviour.

*"The centre has given me enough information"* (Patient 1).

For 2 of them the prescriptions were too much, while 1 patient has mostly compared his situation with acquaintances who have the same disease in order to know how to behave.

*"There are always some doubts because then you feel dazed by all the things you are told... especially the first time"* (Patient 13).



### Points of Reference

In Reggio Emilia, for 8 patients the most important person is the Case-Care Manager of the Diabetes Center; for 5 of them is the Case-Care Manager plus the Center in its entirety, besides the Case-Care Manager of the Diabetes Center, who is certainly the prevailing person, 2 patients considered the possibility of activating an emergency number (SOS DIABETES, Reggio Emilia's telephone number available from Saturday afternoon to Monday morning, and public holidays during the week).

*"The doctor gave me her telephone number, if the glycaemic indexes increase, I'll call her right away"* (Patient 9).

*"At the diabetes ward, they are were good at their job"* (Patient 6).

In Guastalla 10 interviewed patients declared that the professional reference is the Diabetes Center and for 5 of them is the Case-Care Manager. Among those that said the Diabetes Center, 1 out of these 10 also stated to have a go-to person that can be a friend, a relative (cousin), 1 patient also searches for news on the web.

*"The Center has always been my sanitary reference image"* (Patient 7).

*"I'm with my primary care physician, at the Center they always change doctors..."* (Patient 9).

### 4.3 Post-Diagnosis Phase

The last area investigated if, in patient's opinion, it could be beneficial to have a professional as a point of reference during their pathway.

In Reggio Emilia, for 8 patients it wasn't necessary, since they felt already protected by the staff that has been following them. 1 patient was unsure about this opportunity, considering that it could be "interfering. 6 patients would be in favour of this opportunity because it might help them to follow the therapeutic prescriptions and to increase their motivation and their the information in a more efficient way.

*"No, in my case I already have a doctor who monitors me..."* (Patient 13).

*"Well, I'd probably live it as interfering, if somebody called me and asked me "How's your glycaemia?" perhaps,*

*I'd feel controlled. But, at the same, it could be good for me keeping the attention alive. Let's say that it always depends on how a person would do this"* (Patient 11).

In Guastalla 12/15 patients have declared that it would be a positive thing to have only one reference sanitary manager, while 3 of them did not feel the need to have more continuity service than that they've been receiving until now.

*"I've already asked for it, I go to the Case-Care Manager and I only want to go there, she already knows my name, so together we are reaching a goal"* (Patient 4).

*"I feel a little bit more protected, you have a different approach, you know that he already knows your story, if you have something that changes you say it"* (Patient 15).

### Conclusions and discussions

Qualitative strategies are an important care instrument whose aim is not only gathering standard information about the disease, but also about the emotions, about the illness.

The main objective of the study was to examine the importance of the narrative talk as a tool of investigation for the health professionals with educational and managerial functions in order to plan a personalized assistance of the patient who accesses the diabetic clinic. The goal of the study was to understand if all this can be an effective guide in the context of chronic disease and in particular, if it could be considered a construction tool within the aid relationship. In this perspective, it emerged from this study that the narration should help those patients who have a disease to make it clear, to give a sense to their experiences and to put them on a space-time level, in order to turn them into a therapeutic mechanism.

According to this model, this work is based on the narrative nursing perspective. It is in fact focused on the person and the feeling about illness and sickness, and what could possibly mean starting a treatment path together with its own therapist or a reference sanitary group of care. It was proved a valid instrument for the promotion of the current educational paradigm that is centred on the engagement of patient and the caregiver in their own path of care (16). The Integrated Narrative Nursing Model (INNM) is based on such

an approach and it integrates the qualitative with the quantitative methodology. This model has been successfully applied in valuating chronic patients (15) and recently applied in the phase of education (Integrated Narrative Nursing Education, INNE).

The narration becomes an efficient instrument during the therapeutic education, thanks to which the patient can retrace his disease path and reinsert, relocate, also the contents provided by the Case - Care Manager.

At the Diabetes Center in Reggio Emilia we noticed that, the knowledge related to the diabetes disease was always very poor, and in certain cases null. After the diagnosis, the patients held an unhealthy lifestyle, had wrong food habits and used to live sedentary lives.

After the diagnosis, almost all the patients interviewed tried to change their daily habits but none of them succeeded in keeping them in the time.

The prevailing emotional state that has been told by the patients interviewed was that of fears for complications and fears of dealing with the changes in their lifestyle.

Almost all the patients consider themselves satisfied with the information received at the moment of diagnosis and they find in the image of the Care manager of the Diabetes Center the reference sanitary image. The Case/Care Manager allows to plan a care path and to give the opportunity to observe also the patient's behaviour and its way of taking in charge, by using the account of the experience of the disease, provided by the patient, through all the different stages.

It is probably for this reason that more than a half of the patients don't consider necessary the presence of another professional who follows them during all the stages of their treatment path.

At the Diabetes Center in Guastalla as well, fear for complications related to the disease and the anger are the emotions reported, felt at the moment of the diagnosis. All the patients interviewed had a sedentary lifestyle, with wrong food habits, but this habits were all modified by the patients after the diagnosis of diabetes, succeeding in keeping a correct lifestyle.

The Diabetes Center is the reference sanitary image for the majority of patients interviewed, even if they did not specify a precise professional inside the Center. They reported they would like to have a sani-

tary professional to go and speak to and that follows them during the entire treatment path, establishing a relationship based on trust.

During all the interviews, all the participants, even the most skeptical ones, told their life, their story, and made us live through their own words all the difficulties they found. They also re-evaluated their actions and their approach with the disease, increasing the awareness of their knowledge, their uncertainties and weaknesses. The use of qualitative strategies appeared, therefore, an efficient help for reading and understanding the difficulties met by patients daily, providing directions for improving the performance in the working environment.

In a historic moment where the gap between technical dimension and human dimension is always more evident, the qualitative strategy allows the patient to be closer with the professionals becoming an efficient tool also during the therapeutic education. The risk of failing the care's goals comes in fact from the probable misalignment of meaning between the healthcare professional and its patient.

An integrated-type approach requires the use of qualified human resources from health organizations, opportunely trained and motivated to learn, to always improve.

Such process, inevitably, increases costs, but it increases patients and their families' satisfaction, improving the quality of care and services.

In conclusion, we cite the thought of Arthur W. Frank's book, *The renewal of generosity*, (17) in which the author offers the sense of the above expressed:

"As doctors and people that take care of other human beings, we inevitably become characters of their stories; the most important thing we can do then is to become some characters that can help them telling their stories in the best way".

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