

The narrative- autobiographical approach to education and care in diabetes

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Very often people with diabetes, particularly in certain age groups, do not adopt healthy behaviours, despite education (Norris et al, 2001). Telling one's story and sharing it with others who suffer from the same condition may stimulate self-reflection and allow individuals to build up a new personal and collective awareness of their condition that brings changes in their attitudes. Listening to and sharing patients' stories may help health professionals to better understand them and manage a better relationship. In this article, the authors describe a narrative-autobiographical approach used in diabetes camps in order to help people become aware of the needs and feelings they were experiencing related to their diabetes.

From a pedagogic perspective, the introduction of the narrative approach into medicine in the 1960s prompted a change in the way healthcare professionals think about education and care of people with chronic conditions (see glossary on page 383 for an explanation of selected terms).

The narrative approach is a model that helps us to understand and explain reality by considering the external world as a complex text that can better be described and understood starting from each person's subjective interpretations of reality.

From an evidence-based medical perspective, the narrative model was defined by Rita Charon (2001) as the ability to acknowledge, absorb, interpret and act on the stories and plights of others and was proposed as a model for humane and effective medical practice.

The autobiographical approach

Within the narrative model, the autobiographical approach represents an effective way of helping people to reveal needs and feelings related to their condition (DasGupta and Charon, 2004). In it autobiography becomes a tool through which individuals' life histories can be discovered, explored and interpreted by thinking about their life history and recalling episodes and experiences that are part of their identity. From this perspective, an autobiography represents a very effective technique in aiding the development of self-awareness, self-training and the continued discovery of one's innermost feelings.

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Article points

1. The narrative approach is a model that helps us to understand and explain reality by considering the external world as a complex text that can better be described and understood starting from each person's subjective interpretations of reality.
2. The autobiographical approach represents an effective way of helping people to reveal needs and feelings related to their condition.
3. By inviting people to write about themselves and their perception of their diabetes, health professionals can help them to give voice to their problems.

Key words

- Narrative-autobiographical approach
- Diabetes camps
- Patient education

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Page points

1. When dealing with chronic conditions such as diabetes, autobiographical illness stories pave the way for a management strategy that is no longer only a transference of knowledge and techniques, but a chance for the individual to grow and make changes.
2. Since 2004 the authors have been using the narrative-autobiographical approach with teenagers and adults with type 1 or type 2 diabetes.

but a chance for the individual to grow and make changes (Aronson, 2000). This means that patient education and care, as complex phenomena, cannot be reduced to universally valid predefined procedures and programmes. Therapeutic patient education becomes a process through which, by using a narrative-autobiographical model, people can gain awareness of their own condition and understand the real meanings they give to themselves, to others, to the external world and to diabetes.

Autobiographical approach in diabetes camps

Since 2004 the authors have been using the narrative-autobiographical approach with teenagers and adults with type 1 or type 2 diabetes during 3 or 9 day residential camps, in order for them to take advantage of the emotional benefits of self-writing and anonymously sharing this with peers. At these camps, along with the traditional training on the practicalities of how to handle their diabetes, every day for two hours the attendees, who volunteered through their local diabetes associations, are invited to write about themselves and their experiences. This is in an effort to deal not only with the biological consequences of diabetes, but also with the deeper meanings people attach to their everyday life and medical history. Those who were unable to write are offered help with the writing. See *Box 1* for a selection of the suggested writing prompts. The following quotes are from writings by two people with type 1 diabetes concerning the important topic 'The day when I first discovered I had diabetes'.

'Like a bolt of lightning out of a clear sky, fear entered my life, tears (a rare occurrence) flowed plentifully, happiness abandoned me, my mother's forcefully optimistic words, the doctors' encouragements, friends' warmth, a nurse's touching smile, the forced cohabitation with insulin – like a marriage – or even better, a new life made of responsibilities that emerge, the hope that diabetes is like the flu, resignation, then hope again but with the sour consciousness of reality. My first day with diabetes is like

this, I haven't yet taken it in, I am calm: I go to the doctor and an hour later I find myself lying on a bed with a drip, I clear my mind and new thoughts, remote and never thought before, get incessantly stuck in my mind, going through the mind to the heart, where they will stay for God-only-knows how long...'

'I stopped believing in Father Christmas at the age of 8. At 15 I accepted the fact that I did not own a perfect body. Sometimes I think I understand the meaning of life, though this enlightenment only lasts a fraction of a second. I don't remember ever saying "I accept being ill". Diabetes is an old childhood friend. One of those friends that your parents introduced you to when you were very young and that walk along with you for a long time: you do not remember how you met, you only know it has always been there. I did not accept it, I absorbed it.'

After the 2004 and 2005 summer camps with teenagers, the authors investigated the educational and therapeutic impact of the autobiographical approach (Piana, 2006). This was achieved by analysing the reflections and experiences of young people aged 13–18 years through non-structured questionnaires and open-ended questions submitted to participants one year after the camp; these were answered by 70% of the teenagers who attended (see *Box 2*) – none said they had not benefitted from the camps. The narrative material was analysed qualitatively according to the Grounded Theory method (Glaser and Strauss, 1967). This method consists of extracting semantic units from the writings through a process called *conceptual labelling* and grouping the units into various categories by a process of understanding and interpretation.

In the author's opinion, one of the most important results that emerged from the questionnaire was the change reported by teenagers in the meaning and perception of themselves and their condition; and, consequently, in self-care behaviours, as shown in *Box 3*. The results of the questionnaire have been published as a doctoral thesis (Piana, 2006).

Below are examples of writings by health professionals, written at the end of a 9-day course, where they had witnessed and experienced the use of the narrative-autobiographical approach themselves.

'I confess that my first impact was traumatic: the new approach to diabetes destroyed my certitudes, which had been carefully put together in so many years of professional activity. I felt as a child from whom the bicycle stabilisers have been taken away... Today, thanks to this camp, I look at those who have diabetes with new eyes, aware that behind this condition there is a boy, a child, an adult, with thousands of facets (joy, anxiety, pain, fears, inspirations, loneliness). All things that up to now I had just overlooked when meeting the patient in the formal routine of the daily management of diabetes.'

'The camp gave me the opportunity to live a different "diabetes". The opportunity for new reflections, new knowledge, distinct spheres. Patients made me dig deeper and see what I perhaps did not want to see: their tiredness of living within predefined schemes... our schemes.

Am I now capable of modifying my attitudes? Will I be able to recall what I have experienced?

Will I be able to accept?

I think I will – thinking of them.

I think I will – thinking of their voices, their reactions, their spoken and unspoken feelings, their eyes.'

Discussion

Nowadays the narrative-autobiographical approach in therapeutic patient education is being increasingly appreciated and introduced in the care of people with diabetes; not only as a self-care tool for the person with diabetes, but also in nurse–patient relationships and in patient education groups at the hospital.

By inviting people to write about themselves and their perception of their diabetes, health professionals can help them to give voice to their

Box 1. Some of the writing prompts for camp attendees.

- One word for diabetes.
- From one word to a story: my diabetes and I.
- Describe the time when...
 - I discovered I had diabetes.
 - I took care of myself.
 - I felt I was being taken care of.
 - I overcame a difficulty.
- My diabetes and others (parents, friends, girlfriend/boyfriend, teachers, school-friends, relations, doctors and society in general).
- Diabetes: a need, a difficulty, a question, a fear, a hope, a resource.
- My diabetes and my body.
- My relationship with food.
- A message in a bottle (SOS).

problems, to reach a better self-comprehension and to share, through the reading of writings, their own life experience with others.

The narrative-autobiographical approach makes the change from being alone to being one of a crowd, from silence to speaking, from needs to aspirations, from knowledge of experience to experience of knowledge and from death in life to a full life. ■

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Glossary of terms

Conceptual labelling. The writings are initially broken down by asking simple questions such as what, where, how, when. Subsequently, these data are compared and similar events are grouped together and given the same conceptual label.

Pedagogy. The method and practice of teaching, especially as an academic subject or theoretical concept.

Semantic units. The properties of an entity as a quantifiable unit.

Box 2. The questionnaire sent to teenagers after the camps in 2003 and 2004.

- What are your most significant memories of your experiences at the summer camp in Sardinia and why?
- From the several proposals suggested at the camp, which are now the most significant for you and why?
- Do you remember any of the feelings and emotions that you experienced while you were writing at the camp?
- In what way do you think that by using the autobiographical approach your way of living and thinking and your perception of your life history has been influenced?
- Do you feel changed by your experience at the camp and, if so, in what way?
- Because of your experience at the camp has anything changed in your relationships with others?
- Have you written anything more about yourself following the experience of the autobiographical exercises at the camp?
- Has anything changed since the camp in your relationship with your diabetes?
- If we ask you again now for one word or an image to describe your diabetes, what would be your answer?
- Has anything changed since the camp in the self-management of your diabetes?
- When you have to make a decision concerning the self-management of your diabetes, can you recognise any lasting influence from the camp – if so, what?
- What are your hopes for the future?
- Do you have anything to tell us not covered by our questions or do you have any comments or suggestions for future camps?

Box 3. Examples of results of the qualitative analysis of questionnaires, dealing with the conceptual labelling relating to change.

Change in perception of oneself

Self-esteem and confidence

- 'It helped me to be more secure about myself'.
- 'It let me acquire more trust in myself, in particular when socialising with others'.
- 'The most important thing is that I think this experience has changed not just my way of living with diabetes but also many aspects of my life. It has made me think in a more positive way'.

Change in relationship with diabetes

- 'It changed my relationship with diabetes: before it was a battle, afterwards more peaceful'.
- 'It changed my way of accepting diabetes'.
- 'Now it is a part of me, I don't pretend not to have it anymore'.
- 'I now feel that diabetes is a part of me. Before the camp I truly didn't think this'.
- 'I have a more peaceful relationship with diabetes, now it is a part of me. Before I said, "I have diabetes," now I say, "I am diabetic": it is an aspect of my identity, part of my existence that I don't deny. In fact I am almost proud of it'.
- 'Diabetes is *my own*'.
- 'In Sardinia I began to consider diabetes not just as a disease, but as if it were my life'.
- 'It changed it from a disease to part of me and if I were cured today, it would be like an amputation'.

Change in relationship with others

- 'When I returned from the summer camp I decided to tell others I had diabetes'.
- 'Now I don't have any more problems telling a boy or my friends that I am a diabetic, I tell them this quite happily. Basically, why be ashamed of it? It's nothing!'
- 'I have changed because now I'm ready to talk about my illness'.
- 'I'm no longer embarrassed taking insulin in front of others, I'm not embarrassed when taking the sugar sachet out of my pocket when I have hypoglycaemia. I'm now not ashamed to speak to people about diabetes, I say quite easily and simply and without complexes, I am a *diabetic*'.