

Narrative medicine in diabetes care: Report from FEND Conference Munich 2016[†]

Natalia Piana

Healthy Lifestyle Institute, University of Perugia, Perugia, Italy

Introduction

Several theoretical, philosophical, pedagogical, scientific premises can help understand the pivotal importance of Narrative Medicine (NM) in the field of diabetes care.

Let us start from the most recognizable premise. The scientific one. Which means considering data, numbers, evidence.

The latest IDF Atlas report¹ mentions several hundred millions of people affected by diabetes and shows that diabetes is impacting every country, every age group and every economy across the world. This prevalence data show up an ever increasing paradox: on the one hand an ever more advanced technological and specialized medicine able to deliver the best care possible; on the other hand people who are not sensitive to prevention, who find difficulties in managing their disease and are often unaware of the disease itself and of the possible consequences if it is not well controlled.

What is the problem? What is it that we are not able to understand? Why cannot we reverse this phenomenon?

Our traditional approaches to care are no longer effective, or rather, are not enough, and require reflection and different answers on our part. For a long time the scientific literature has shown that correct information and knowledge about the disease are not enough to motivate people to look after themselves and change their habits, as long as diabetes and other chronic diseases are concerned.

A personal account of NM in Diabetes — my Narrative

As we all well know, diabetes is a complex disease. It is the disease of technical skills and psychological barriers. It is the disease of family, work and social relationships. It is the disease of ignorance and discrimination. It is the disease of lifestyle change, which is today for us, as carers, one of the most difficult challenges to face up to. Diabetes is a chronic disease. This means, quoting a patient, that 'it never goes on holiday'. With its irreversible advance, its chronic nature and the constant implications that it brings to a person's daily life, diabetes emphasizes that we need to change our approach looking at the problem from a different wider perspective, in order to understand its complexity.

As professionals, however, we are not capable of doing so, because we have grown up in a 'culture of dissociation' which, in the last two centuries, has led to a separation between the scientific and humanistic components of knowledge, not allowing us to have a comprehensive vision of the reality, the human being, the disease. In fact, until today, education has not provided us with the right cognitive and emotional skills to cope with it. We come from an approach to knowledge aimed at controlling reality, a structure of thought that proceeds by induction and deduction (our usual scientific way of understanding the world). As if we had chosen not to be programmed for the unforeseeable or the uncertain, the undefinable, the unknown, the mysterious or the subjective. We have been educated in a simplified and reductive way of thought which for these various reasons risks not to be relevant. And even to mutilate. But, as the Greek playwright Euripides² wrote in his maxim 'The expected never happens, a God opens the way to the unexpected'.

To learn to live with this complexity, to be able to receive and recognize the 'unexpected', we have to start again by listening. Listening to ourselves, to others, to where the current is taking us, to the direction humanity is moving in, to the needs and questions of care that we are no longer able to recognize or answer. Understanding is among the main responsibilities required by the paradigm of care. Living means continually needing to understand and to be understood.

Our age of advanced communication is not an age of understanding. For all our lives, both as individuals and as professionals, we risk incomprehension: by others of ourselves, and of others by ourselves. Understanding can only happen in the relationship, where the stories and the expertise of both provider and patient are brought to the interaction.

Unfortunately, however, 'the skills of listening to, appreciating and interpreting stories are only rarely upheld as core clinical skills in medical curriculum. As its most arid, modern medicine lacks metric for existential qualities such as the inner hurt, despair, hope, grief, and moral pain that frequently accompany, and often indeed constitute, the illnesses from which people suffer'.³

In her article entitled 'The power of relationship',⁴ Riva Greenberg, a woman with Type 1 diabetes who is changing the way of thinking and approaching diabetes thanks to her flourishing perspective, writes that by

[†]This is a summary of Natali Piana's lecture given at the FEND conference in Munich in September 2016.

merely being human, we know the need we have for, and the power of relationships in our life. We know how the good ones make you better, stronger, more complete, more confident and comfort you in times of need. They also make you healthier. Being social, states psychology, is primal and it is a key driver behind much of our behaviour.⁵ The power of relationship influences the quality of our everyday visits with our patients. As well as what someone with a chronic illness decides to do, or not to do, when leaving our office.

To be effective in our care, we need to become expert of listening, understanding and of the relationship where the different worlds of patients and health professionals meet. A life 'obstinately refuses to be reduced just to the object of scientific research; instead, it forces the researchers to act in the opposite direction'.⁶ The introduction of NM in healthcare accompanied an evolution in the way of thinking about the care of ill people. The dominant scientific paradigm of knowledge based on quantitative approach, is then integrated by a new paradigm, the narrative one, that enables us to interpret complexity and to deeply understand the human being. Human beings 'are storytelling animals, and narrative is the most compelling form by which we recount our reality, understand events, and through which we make sense of our experiences and ourselves'.⁷ According to Widdershoven's words, 'we dream in narrative, daydream in narrative, remember, anticipate, hope, despair, believe, doubt, plan, revise, criticise, construct, gossip, learn, hate and love by narrative'.⁸ Originated at the Columbia University in 2000, NM is a growing and deepening field of healthcare that equips clinicians with capacities of attentive listening and deep recognition of patient and self, situating medicine between the humanities and the sciences. This medical approach recognizes the value of people's narratives in clinical practice, research and education as a way to promote healing.

Clinicians spend their lives in the midst of narrative: listening to story fragments, interpreting words sequences, observing gestures, deciphering symptoms, ascribing causes and suggesting treatments.⁹ When doctors take a medical history they inevitably act as ethnographers, historians and biographers, required to understand aspects of personhood, personality, social and psychological functioning and biological and physical phenomena.¹⁰ The official definition of NM is given by Rita Charon, Professor of Medicine, Founder and Executive Director of the Program in Narrative Medicine at Columbia University College of Physician and Surgeons in New York City. Charon states that 'the effective practice of medicine requires narrative competence, that is, the ability to acknowledge, absorb, interpret, and act on the stories and plights of others. Medicine practiced with narrative competence, called narrative medicine, is proposed as a model for humane and effective medical practice'.¹¹

I met Rita Charon in New York in 2013. I wanted to meet the person who for many years had been an

important reference point for me and my work. It was an intense and meaningful meeting. Rita Charon involved me in two training seminars aimed at teaching clinicians the skills of close reading, reflective writing and slow 'looking', as means to attune oneself to what is seen, heard, or read. She used Medical Humanities, a methodological approach to develop a better understanding of self and others, particularly through the use of literature (poetry), music and self-writing. From the humanities physicians can learn how to implement the narrative aspect of their practice with new effectiveness. In the first seminar, sitting together around a table, Prof. Charon gave us a copy of a fragment from a novel by Denis Johnson called 'Train Dreams'. She asked us to read it together and to comment and analyze the text, to take in the sense of the story, the emotions and the context. Then, she selected one sentence 'The ground about was healing' and asked us to write about ourselves and our stories starting from the suggestion 'Write about a time when a ground about was healing'. Each of us wrote about ourselves, then she asked us questions: Where did you go?, How did you start? What text reference did you use? And then everyone read their story to the others with emotion, sense of nearness, accepting comments and reactions on what we had written.

She said goodbye, leaving me still completely involved in the words I had heard, in the emotions that came out from my writing and from what I had heard from the others. She gave an appointment for a private chat so that I could tell her my impressions of what I had just experienced and for the second seminar. Sitting around the table again in the afternoon, Rita Charon asked us to work on the poem by W.B. Yeats 'When you are old'. Textual analysis, description of the atmosphere and of the images depicted, giving shape to what was said and left unsaid. And then we were invited to write about us and our lives again, starting from the suggestion 'When you are old'. And again reading, sharing, the others offering you a view of your story and coming delicately into your world. This is the meaning of NM in medical education. Starting from personal and professional narratives, health care professionals experience the power of narrating and sharing stories and emotions as a way to self-awareness and relational skills' acquisition. As a nurse wrote at the end of a training course in NM:

speaking, writing and listening to colleagues about our work with sick people was a different way of exploring myself, looking at our methods of drawing closer to sickness and suffering.¹²

The narrative provides meaning, context and perspective for the patient's predicament.

It defines how, why, and in what way he or she is ill.³ It offers an understanding that cannot be arrived at by any other means and can give the health professional access

to the lived experience of their patients. As another nurse wrote:

the life history of those I meet is, for me, the only map that shows the way to start travelling together.

Through narratives carers see their roles in terms of facilitating alternative stories that make sense from the patient's point of view³ and can be assisted in formulating more appropriate diagnostic and treatment options.

Rita Charon identifies three specific different movements¹³ within clinical telling and listening. The first movement is *Attention*, and it is defined as the most pivotal skill with which to endow a health professional who wants to be a healer. Attention requires the ability 'to empty the self or at least suspend the self so as to become a receptive vessel for the language and experience of another'. The second movement, *Representation*, consists in representing what is heard and witnessed, by writing it down. When writing, clinicians discover aspects of the experience that, until the writing, were not evident to them. Representing these events enables one to experience them. Attention and representation together spiral towards the third movement of *Affiliation*. 'Finally, attention and representation, we believe, can enable us to know in earthy, rich detail that we are affiliated as humans, all of us humble in the face of time, ready to suffer our portion, and brave enough to help one another on our shared journeys'.¹³ I am grateful to Rita Charon for having generously welcome me into her world.

Also I am profoundly grateful to Prof. Aldo Maldonato, who asked me in 2003 to introduce NM in the Training of Health Care Professionals and in Therapeutic Patient Education.^{14–16} In my personal approach I have chosen to use mainly self-writing, both as an effective tool for training health care professionals in the understanding of the interpersonal relationship, and as a therapeutic tool for patients. Here are some writings collected during medical training aimed to experience *representation* and *affiliation*, which happen when I recognize in the other a part of me and of my humanity:

Sometimes I try to imagine how I would behave if I were the person in front of me: I realise that I would probably be much less conscientious in coming to appointments, in following a course of treatment or in keeping the record of blood glucose levels. When I manage to see some of my children's behaviour from the outside, I often think "and if they were diabetic?" And so I can understand certain parents' anger, their feelings of guilt, their anxiety and the huge effort they make to allow their diabetic children simply to live their adolescence like others. I understand the superficiality of some young people regarding the disease, I understand the reason for the "instability" of their diabetes, I understand their reactions of escape, their not taking insulin. And when things go well I really

admire them and feel respect for them and a little envy for the parents of such responsible children. Me and diabetes: yes, diabetes is an opportunity, but it's an opportunity for me. For me it's a lesson in life and humanity...

In my professional experience I applied NM to patients' care too, with children, adolescents, adults with diabetes and their family members. What benefits does telling a story bring to the patients?

There are infinite reasons to tell, narrate and write a story when becoming ill. They come both from evidences and experiences. In a narrative perspective, the disease is not solely a biological problem, it is a breakdown that imposes changes in day-to-day life and poses questions regarding the sense of the existence of the individual. To accept, cope, react and live with the new problem, it is necessary for the person to understand this new experience, finding and giving a meaning to the new condition. As in psychoanalysis, in all of medical practice the narrating of the patient's story is a therapeutically central act, because to find the words to contain the disorder and its attendant worries gives shape to and control over the chaos of illness.¹⁷ Telling and writing a story when becoming ill, allows one to put back together all pieces of one's life broken down by the irruption of the disease and to give voice to pain and suffering, finding and giving a new meaning to the condition and so coming to terms with it:

I'm helping myself. With pen in hand in front of a blank sheet of paper, I want to try to find myself again...What have I learnt from my illness, what has it taught me? Above all that life is wonderful, that there are hundreds and thousands of ways we can go and, even more, I have learnt and I'm still learning to develop, enjoying my senses. My illness became mine the moment I gave it my personal sense and meaning. My feelings are here, with me, at the desk, where I spend hours writing. After a period of intense pain, my illness created in me an awareness of the importance of writing about myself as an essential therapy.

Telling and writing a story leads to re-experience feelings and emotions linked to events, in particular, those which were painful and traumatic and to help one fully overcome them and go on with one's life:

The day I discovered Diabetes, I didn't want to admit to myself what had happened to me. The confirmation, the harsh and sad reality came all of a sudden; maybe I wasn't ready, it arrived when I had to give myself my first injection. And then I didn't cry anymore, nor I relieved my feelings, I kept all the sorrow inside of me. Accepting it straightaway was forced, I had to! But inside of me, this acceptance has never been full. I can smile when I talk about it, I can say I accept it, but I lie when I do, not to myself though, but to

the others. I can't feel like people who don't have diabetes, society itself sets us limits. I can't either consider diabetes a friend, talking is easy for those who are not in our situation. You choose your friends, friends don't set you limits.

Telling and writing a story leads to a better self-comprehension and to share one's own life with others overcoming loneliness, it represents an opportunity for the patients to acquire knowledge and attitudes regarding the management of their illness, and to educate the wider world to what diabetes is.

Finally, telling and writing a story, may change one 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; from death in life, to a full life.

Concluding comments

I want to write some of my thoughts on a piece of white paper because I want you to understand by means of this little letter how well I felt with you and how much I brought home. As soon as I got home I immediately thought again of how much I had learned in that week spent with you. You managed to make me weep and then free myself of a weight that I did not know I had inside. This happened often after the activities of writing when I went to my room to get ready for supper, and while I was in the bathroom I looked at myself in the mirror and thought how much I was managing to come to terms with Diabetes. Thanks to writing I have clarified certain things. I will never forget you and I wish you all a world of goodness. (written by a teenager with DM1 after a camp)

At long last in 2015 NM has obtained in Italy an official recognition by the Ministry for Health as a personalized clinical practice, recommended in the field of prevention, patient education and care of rare and of chronic diseases, and in the training of health care professionals.¹⁸ According to each setting, to local resources and to the actual condition of the different health systems in different countries, several different approaches may be adopted to implement NM, thus enhancing healthcare professionals' effectiveness in the field of diabetes.

Starting with just an improvement of sensitivity, good manners and respect for the patient, NM leads then to better communicative skills, such as the ability to listen to the others, to recognize their needs, difficulties and expectations, and to understand them. Consequently, it

can also enhance the awareness of the importance of contexts and of nonverbal communication (with patients and colleagues) while managing the care relationship. The final step allows to improve the entire process of attention, representation, affiliation, leading to care and change.

When applied to patients' care, in my professional experience groups and residential camps have represented the ideal context for a therapeutic approach based on NM for children, adolescents, adults with diabetes and family members:

- As a self-care tool for the patient
- In doctor–nurse/patient relationship (a diary rather than simply a blood-glucose log-book)
- In patient education groups at the hospital
- In summer camps /educational week-ends
- In research projects

I very much hope you find this overview helpful in considering how you work to support people with diabetes.

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