Research Article

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ClinicalPractice

Narrative medicine, a model of clinical governance: the experience of the Local Health Authority of Florence in Italy

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Aims: Modern medicine has recently faced the need to consider the existential qualities of patients during the process leading to diagnosis and choice of therapy, in addition to relying on technological progress. **Materials & methods:** Narrative medicine has gradually entered the routine of clinical work, aiming at improving patient–physician relationships and adherence to therapy and reducing direct and indirect health cost. **Results:** The Local Health Authority of Firenze (Italy) has launched an innovative process for the integration of narrative practices into the health services. This initiative's aim was to spread the culture of narrative-based medicine among health professionals and increase the quality and appropriateness of care (NaMe project). **Conclusion:** This article describes the experience through which a model of narrative medicine was implemented into the clinical practice.

Keywords: adherence • clinical practice • doctor–patient communication • health system • illness experience • narrative medicine • relationships

Qualitative approaches and narratives have been increasingly applied in health research in recent years. Stories and life experiences collection have been introduced as part of the clinical activity in the healthcare system. Despite recent technological progress in diagnosing and treating diseases, modern medicine, in fact, has been understanding the need to consider the existential qualities of patients, the "inner hurt, despair, hope, grief and moral pain that frequently accompany and often indeed constitute, the illnesses from which people suffer" [1]. Since the term narrative medicine was coined (deliberately distinct from evidence-based medicine), narratives and story-based knowledge have gradually entered into the routine of clinical work. Narrative-based medicine now represents an important cultural phenomenon [2–9]. Focusing on 'the singular and the particular in illness', narratives create a picture of illness from the inside and provide a way to explore how individuals make sense of their symptoms and illness, offering us the experience of 'living through, not simply knowing about'. Shortly, narratives provide the physician 'a possibility of understanding which cannot be arrived at by any other means' [1]. Furthermore, when included in the diagnostic and therapeutic process, narratives allow patients a greater integration in clinical decisions, with potential benefits in terms of patient engagement in self management and better patient outcomes [1,10,11].

Physicians who take part in this process leading to a patient-based medicine may perceive the need to understand deeply their patients' experiences and make an effort "to extend empathy toward those who suffer and to join honestly and courageously with patients in their illnesses" [12].

In this scenario, narrative medicine curricula are proliferating in several countries and the 'narrative competence' is increasingly foreseen in medical education. Patients' stories are collected and utilized by health professionals to illustrate and teach deeper empathy and compassion and "narrative writing by students and physicians has become a staple in many medical schools and hospitals

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to strengthen reflection, self-awareness and the adoption of patients' perspectives" [12]. In brief, narrative competence as a form of exploration and assimilation of illness stories, integrated in medicine practice, represents a model for human and effective medical practice [4,12–18].

In line with other countries, several activities based on narrative medicine have been recently realized in Italy. Hospitals and healthcare centers promote the use of narratives to help patients share illness experience among themselves, care givers and health professionals and universities incorporate narrative medicine in the curricula of clinical disciplines [19–23].

In this scenario, the Local Health Authority of Firenze has recently launched an innovative process for the integration of narrative practices into the health services, aimed at spreading the culture of narrative based medicine among health professionals and increasing the quality and appropriateness of care (NaMe project) [24,25]. The process started in 2004–2005 with a preliminary phase. Areas of interest were chosen among those where poor communication could be connected to a bad adherence to treatment. Training courses on narrative medicine designed for physicians, nurses and health workers were organized; afterward, patients referring to the oncology and cardiology departments and the Health Management Department (through the AIMA association) [26] were interviewed in order to collect information about their illness and identify critical issues. With the aim to improve doctor–patient relationships and to find out good or bad communication style practices, narrative medicine tools were adopted, such as focus groups, theater, poems, videotapes of conversations between the patient and doctor, in order to assess verbal and nonverbal behavior. At the end of this phase, a permanent Laboratory of Narrative Medicine has been established in the Local Health Authority offices. Later, the Laboratory was introduced in other Italian regions.

In this article, we describe the experience of the Local Health Authority 10 of Florence that implemented a model of narrative medicine into clinical practice.

Materials & methods

Preliminary workshops and training courses on narrative medicine were organized by the Local Health Authority 10 of Florence in 2004 and 2005. The laboratories – designed for doctors, nurses, health workers, social workers, hospital volunteers, psychoanalysts, therapists and specialists in human sciences – focused on tools and methods of narrative medicine and in particular on the importance of patient-centered orientation of cures to strengthen the therapeutic alliance.

The project's activities started in 2006 with collection of narratives with the objective to bring to light the history of disease and deeply comprehend the subjective experience of the patients. Subjects referring to the cardiology and oncology departments and to the Health Management Department were interviewed, after giving written consent. Interviews were conducted in hospital or at home by two trained sociologists not involved in the therapeutic process. During the interview, the history of the disease and the process of care (social network of patients, education level, risk factors, past health problems, onset of symptoms, medical consult, compliance requirements, the doctor–patient relationship, follow-up, side effects of drug therapies, quality of life) were investigated. The analysis of this activity will be the object of a future publication. All the interviews were audio-recorded, entirely transcribed and then discussed in the presence of multidisciplinary experts in order to highlight relevant aspects, in terms of a medical and a psychosocial point of view. Narratives were interpreted through a qualitative content analysis [27] in order to recreate patients' semantic system [28]. A second activity was launched with a special focus on the doctor–patient relationship, in particular in the field of heart diseases. The interactions between patients and doctors were video-recorded, in the perspective of observing practices and communication styles. In this way, it was possible to analyze verbal and nonverbal aspects of doctors' behavior. Concerning the verbal aspects of communication, attention was paid to the doctors' way to welcome a patient, to introduce themselves, to give information to patients and the use of appropriate language. In addition, the way doctors listen to a patient and how doctors establish and maintain a good relationship with a patient were considered. On the other hand, concerning nonverbal items, doctors' facial movements and expressions, head movements, body movements, posture, interpersonal distance, interpersonal touch and voice were evaluated.

Letters of complaint that patients had addressed the healthcare facility during 2009 were collected, in order to better assess the doctor–patient relationships. Each letter of complaint was read and analyzed by a multidisciplinary team (sociologist, psychologist, doctor) to identify causes of patient dissatisfaction, highlight the critical elements and reorient healthcare system quality. Furthermore, it was decided to advocate the narrative approach in a new area, the intensive care unit and to realize the passage from cure to care. Stories about illnesses were collected using qualitative interviews. Patients and caregivers were asked to narrate symptoms and their personal interpretation, the experience of having a critically ill family member admitted to an intensive care unit and the modalities of com-

Table 1. Cognitive map obtained from the interviews to patients affected by heart failure.

1. Symptom experience and perception of the problem	2. Patient role and problem interpretation	3. Professional help request	4. Patient role and adherence to therapy	5. Final outcome and efficacy evaluation
Early symptoms and given relevance	Types of evident symptoms	Diagnostic problems	Perceived quality of cures	Change of behavior at risk
Types of behaviors at risk	Types of lay explications	Role of the primary care physician	Problems with therapy	Evaluation of quality life
		Different health resource use	Types of day life changes	

Columns contain issues relevant to each area of the interview, as interpreted on the basis of semantics.

munication and relationship between caregivers and physicians.

As a final step, a narrative laboratory at Local Health Unit of Firenze was implemented, in order to recommend narrative approach in the clinical areas.

Results

During the preliminary training laboratories, over 70 professionals from the Local Health Authority 10 of Firenze were trained in methods and tools of narrative medicine. At the end of the training, the trainees were able to identify three significant chronic clinical fields where the activity of the laboratory could be more relevant: oncology; cardiology and neurological diseases (Alzheimer's disease).

The interviews program that followed the training was attended by 30 volunteers, ten subjects for each clinical setting: ten women with breast cancer; ten patients (male: nine, female: one) with heart failure; ten family members (male: two, female: eight) of patients with Alzheimer's disease. Cognitive maps were obtained from the interviews in each setting, showing the main issues identified in the area (Tables 1–3).

Despite the differences of experiences due to the different clinical settings, patients agreed that communication between patients and healthcare professionals was the most critical issue. In particular, in the cardiology setting, communication problems were encountered when diagnosis was communicated, during symptom examination and during the therapeutic phase after hospital discharge (Table 1). As an example, many patients found it difficult to understand that a stomach-ache or having shortness of breath while walking could be a symptom of heart problems. Moreover, many patients found it difficult to interpret the doctors' instructions about therapy and new lifestyle. For instance, at the time of the interview, some patients had not understood if running to catch a bus could be

Table 2. Cognitive map obtained from the interviews to patients affected by breast cancer.

1. Symptom experience and perception of the problem	2. Patient role and problem interpretation	3. Professional help request	4. Patient role and adherence to therapy	5. Progressive loss of autonomy	6. Final outcome and efficacy evaluation
Patient's abnormal behavior	Types of reactions and explications of the caregiver	Types of actions	Problems due to therapy	Types of disease progression	Perceived quality of therapy
		Role of the primary care physician		Problems with patient's management	Quality of life evaluation
		Diagnostic problems		Use of other care services	
		Problems with communication of diagnosis			

Columns contain issues relevant to each area of the interview, as interpreted on the basis of semantics.

Table 3. Cognitive map obtained from the interviews to patients affected by Alzheimer's disease.

1. Symptom experience and perception of the problem	2. Patient role and problem interpretation	3. Professional help request	4. Patient role and adherence to therapy	5. Progressive loss of autonomy	6. Final outcome and efficacy evaluation
Patient's abnormal behavior	Types of reactions and explications of the caregiver	Types of actions	Problems due to therapy	Types of disease progression	Perceived quality of therapy
		Role of the primary care physician		Problems with patient's management	Quality of life evaluation
		Diagnostic problems		Use of other care services	
		Problems with communication of diagnosis			

Columns contain issues relevant to each area of the interview, as interpreted on the basis of semantics.

dangerous or not; many patients did not practice sport because they were frightened; and the majority made use of medicines such as a 'magic tablet,' on demand in special situations such as a big meal and not on a daily basis.

Among oncologic patients, a critical communication gap emerged in the diagnostic process, resulting in patients' disorientation. In addition, organizational problems and perception of neglect were very common during the process of care and feelings of loneliness and anxiety were present at the end of the treatment period (Table 2). Everybody stated that the communication with doctors should be improved, in particular in the diagnostic phase, when doctors often break bad news hurtfully, and during the follow-up, when there are not many possibilities to get in touch or speak with doctors between the visits.

"The time in which you can contact them is quite short. Say: if you are sick or anything is wrong, you have one hour in the morning from Monday to Friday to call. This is not enough for me, I may be mad and feel sick at 5 pm. There is something wrong if you cannot talk to a doctor out of the office time, especially with certain diseases. You need a friendly voice, not only one hour a day!" (51 years old woman)

In neurology, the problems that emerged from the interviews with family members were mainly related to financial and organizational difficulties (Table 3). Caregivers of patients suffering from Alzheimer's, in fact, reported many unpleasant difficulties in handling with this pathology. First of all, they emphasized the confusion and the pain they felt when they discovered that their family member suffered from Alzheimer's. Then, they underlined the enormous economic and organizational problems connected to this disease. All caregivers complained about lack of structures for these patients, available therapy and rehabilitation, health visitors, economic support, communication between families, doctors and health workers and everybody claimed to feel abandoned.

"No help at all! It would be enough to have somewhere you can bring him to, one, two, three days! You pay and you bring him there. One day he will be bound to stay there forever, because I will be old. I cannot have a woman here, because how could I pay 1500 Euros a month? If I would send him to live in an institute I would not pay anything, but I would like to have him at home and send him to the institute from time to time, when I am tired out" (wife of a 77-year-old patient).

The 20 video-recorded interactions between doctors and patients were analyzed by a multidisciplinary panel of experts in order to analyze in depth the communication modalities. As a final result, it emerged that physicians' communication styles substantially fell into two categories: patient-oriented and duty-oriented, the former associated with higher performance scores.

Some critical elements emerged from the evaluation of 110 stories of complaints collected in the Internal Medicine Department in 2009. Data showed that patients used to complain mostly about the waiting time and the ineffectiveness of the healthcare system. In particular, they identified four main critical issues: a faulty appointments system with long waiting lists (72% of cases); a weak communicative relationship between the patient and the health service staff, in particular the operators of the Public Relations Office, characterized by poor information and lack of explanations (57% of cases); the bad/negative behavior of the health personnel, particularly the doctor when communicating with patients (48% of cases); the gap between citizens' and health operators' perception of urgency (36% of cases).

"I called, but they said it was impossible to book a medical examination."

"These are days in which I am wandering from hospital to hospital."

"The doctors did not provide any explanation."

Narratives clearly suggested that communication and relationship between medical staff and patients had to be improved, procedures simplified (reducing, e.g., the waiting lists) and information modalities changed.

In the final phase of the project, the interpretation of narratives collected in the intensive care department allowed operators to receive some relevant suggestions to make communication modalities more effective in their clinical practice: how to deliver bad news; how to behave with families; how to establish a good relationship with them; how the setting should be.

Discussion

In our experience, the utilization of narrative approaches allowed the identification, in each setting examined, of some areas for improvement of the overall management of the patient.

Moreover, narratives allowed patients to collect information for themselves and understand in depth their experience, which was often neglected in clinical settings.

Extensive staff training made it possible to increase all health professionals' sensitivity and also allowed the multidisciplinary team to improve the doctor–patient relationship.

Analyzes conducted on the complaints registered in 2009 led us to understand the areas of patients' dissatisfaction and therefore to pay more attention to some aspects of relationships between hospital medicine and the healthcare system in the area.

In addition, we underline that communication about chronic pain, particularly in cancer patients was little explored. In fact, pain is a subjective symptom and only with active listening doctors are able to understand the intensity, location, characteristics and many other parameters essential for the correct diagnosis.

Failing to listen to the patient means missing some key parameters that may be necessary in order to achieve a correct diagnosis and especially to set up a proper treatment or to review the therapeutic strategies in the event of medication failure. It also should be mentioned that the utilization of narratives exactly matches the fundamental principle that refers to informed consent. In fact, the process of informing the patient cannot be done without the patient involvement and, therefore, a good doctor–patient relationship. In this regard, it is estimated that in Italy 93% of the complaints are not caused by clinical errors, but can be traced back to poor patient–physician relationship.

The implementation of narrative medicine in intensive care allowed some proposals to be formulated: an intensive care unit opening to relatives for 24 h (in Italy it is not so frequent yet); a cozy, relaxing and colorful setting could be very supportive. Moreover, when doctors deliver bad news they should not forget caregivers' feelings and emotions: shock; incredulity; fury; aggressiveness; sadness; despondency and overall, the difficulty to accept their family members' serious conditions. So, doctors should pay particular attention to discuss with their colleagues before talking to caregivers and choose the most appropriate time and the best way to break bad news.

Conclusion

The term 'narrative-based medicine' was coined deliberately to mark its distinction from the 'evidence-based medicine,' aiming at overcoming the objective biomedical scientific approach, based on the doctors' judgements built on large scale randomized controlled trials and directing attention to an intuitive medical practice focused on the individual subjective dimension of illness experience.

The application of qualitative techniques and of a narrative approach had three advantages: it increased the ability of health professionals to share diagnostic and therapeutic strategies; enhanced the awareness of adhering to the prescribed therapies; improving the patient engagement in self-management and contributed to an improvement of the relationship between the citizen and the healthcare system, avoiding the waste of resources for conflict and optimizing resources.

However, if we want to strengthen the narrative medicine perspective, we need more and more evidence of successful experiences in applying this approach to the health sector. We hope that this article can contribute in this direction.

Future perspective

Application of narrative based medicine in the clinical practice should improve the ability of physicians to respond to patients needs, to direct efficiently therapeutic interventions, and to avoid unnecessary or even unwanted treatments.

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Ethical conduct of research

The authors state that they have obtained appropriate institutional review board approval or have followed the principles outlined in the Declaration of Helsinki for all human or animal experimental investigations. In addition, for investigations involving human subjects, informed consent has been obtained from the participants involved.

Practice points

- This article describes the experience through which a model of narrative medicine was implemented into the clinical practice.
- A permanent laboratory of narrative medicine has been created in the local health authority offices and now further effort is being made with the introduction of the laboratory in other Italian regions and, therefore, achieving the consolidation of narrative laboratories within the health services.
- In our experience, the utilization of narrative approaches allowed the identification of some areas for improvement of the overall management of the patient in each setting examined.
- Moreover, narratives allowed patients to collect information for themselves and understand in depth their experience, which is often neglected in clinical settings.
- Applying qualitative techniques/narrative approach leads to three advantages: it increases the degree of sharing diagnostic and therapeutic strategies; increases the degree of awareness of prescribed therapies; improves compliance and contributes to an improvement of the relationship between the citizen and the healthcare system, avoiding the waste of resources for conflict and optimizing resources.

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