

Convegno / Meeting

MEDICINA NARRATIVA E MALATTIE RARE

NARRATIVE - BASED MEDICINE AND RARE DISEASES

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Narrative-based medicine and counseling in general medicine

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The lived experience of patients who suffer from rare diseases may be a cause of painful feelings for those who listen to them, who treat them and who live through their suffering of anxiety, loneliness, existential vacuum and a deep sense of injustice.

There are three reasons why it happens:

1 The first reason is related to empathizing with the patient's pain caused by the disease - its specificity makes it even more difficult to find appropriate and adequate ways of expressing closeness.

2 The second reason is related to awareness of not being able to provide the patient with the necessary resources for the treatment not because of their shortage but due to the fact that the pharmaceutical market does not regard them as a good investment. Such a situation creates a general sense of guilt.

3 The third reason is related to the difficulty in understanding patient's particular suffering. It frequently appears to be unknown and difficult to interpret both due to physical pain and to restrictions that it sets on social life.

In these circumstances narrative-based medicine seems to be a crucial resource as it is practical criticism of the language of medicine which becomes enriched with the language of feelings and emotions expressed in disease stories. Narrative-based medicine fills another great void – the void of psychology of doctor-patient relationship. It is no coincidence that narrative-based medicine is in line with pedagogy, anthropology, sociology and counselling.

Driven by a very particular professional experience, I had searched the Web for many years, collected ideas and information from American websites and as a result, in 2004 I published the first volume in Italy on narrative-based medicine.

During my psychotherapy practice I had had some general practitioners with whom subsequently I started to cooperate working with their patients. I asked myself then about the intertwining stories of doctors' lives and the lives of patients who consulted me.

The experience of Porto Rosso group (a pseudonym which did not last for a long time but which I am not going to reveal because of my professional ethics) forced me to ask myself about the ways of linguistic expressions and narrative constructions of doctors' and their patients' stories.

The first question is: why did certain patients choose the doctor and not the other one even if they had various possibilities of changing them?

The answer: My doctors (and friends) had unequivocal ways of communicating:

1. Dr Giacomo was dynamically motivating, hot-tempered, energetic, integrated in community communication, an old-fashioned doctor, highly efficient with fragile and shy patients. I collected the stories of his patients' lives and they all focused on space and places. Space is usually emotional. It refers to places where the story is embedded and it reflects character's feelings (if sullen, they choose dark space, space at night etc.): the patients first described space and only then did they "come on stage". In their stories narrator's *point of view* focused on himself or was characterised by *zero focalization* (when the narrator was omniscient, knew everything and described characters in a complete way) or it was characterised by *internal focalization* (when the narrator was a part of the story, a character himself or a witness) or the narrator receded from the story and summarised it.

2. Dr Marcella was tolerant and open, pain-stricken because of being diabetic, sympathetic towards other people's suffering, humble and available. Her patients' stories were always focused on time. Time describes dynamics of *fabula* (chronological sequence), of *intertwining* (the way how it is narrated and presence of flashbacks and anticipation). Their narrations regarded the ways in which the story was suggested: some stories were filled with *stream of consciousness* (thoughts without interpretations and without any logic), *internal monologues*, real *soliloquies* or *dialogues* with long *digressions* which seemed to be creating *other stories* that drifted away from the main one. The stories were told in the subjunctive as its potentialities are extremely therapeutic but only for this group of patients.

3. Dr Romano – an intellectual informed about everything. His patients had some hang-ups. Their stories tried to create an image of themselves different from reality. Their stories were full of

conditional clauses: “If I were ... I would...”, of *rhetorical figures or devices* which were always symbolic, introduced by antitheses, contrapositions, similes, metaphors, allegories and analogies.

Where do these differences come from?

Everybody tries to find in their doctors what they miss. The doctor is chosen on the basis of his/ her relational style and the patient tells the story in line with the position that the doctor takes towards him/ her.

It is *speaker’s narrative disposition that makes the interlocutor available for an empathic disclosure*. Such a proposal may be a linguistic or non-linguistic act of communication or a simple relational position.

Empathy is usually discussed in relation to a subject that empathizes; the acknowledgement in literature of empathy that I discussed in other papers [cf. Masini:1993, 1996, 2000, 2004], after being under the influence of Edith Stein’s [1985] phenomenological considerations, has always regarded the speaker who empathizes with the experiences lived by the interlocutor. In this situation, however, a narrative suggestion comes into being as a proposal so that the patient can enter in contact with himself/ herself and with the speaker’s self.

In patient’s narration there are screams, wounds, liberations, silent and deep tears, there is weeping and crying. The narration of pain disintegrates the identity of the person who is able to listen. At this point, doctor’s and patient’s humane sides meet and a ‘prodigious spark’ comes into being: therapeutic intuition.

The narration introduces into diagnosis and therapy a new class of data which have been badly managed by the evidence-based approach and which need to be collected in a system of communicative processes, linguistic acts and relational models which intervene in the correlation between doctors and between doctors and patients.

Social process	Linguistic act	Communicative process	Relational models	Neuropsychological processes
Interactive	Illocutionary	Persuasive	Dynamics	Activation
Symbolic	Perlocutionary	Heuristic suggestive	Cognitive empathy	Control
Relational	Locutionary	Expressive	Affective empathy	Arousal

An **interactive process** is an objectivizing social action which concentrates on the role and is based on illocutionary linguistic acts (ordering, commanding, asking, persuading). Words in an illocutionary act are used to state, value, give orders, ask, promise, thank and apologise. After the illocutionary act has taken place, the confirmation of message reception follows by means of conventional signs or by eliciting a response. Generally, in Italian they are expressed in first person-present tense active voice and indicative mood (“Listen to my suggestions!”, “I order you to leave!”, “I assure you that it works!”, “Take this medicine!”). The interactive process creates a dynamic relation that imprints an impulse in addressee’s mind modifying their lived experience and state of mind through a process of activation. The dynamic-interactive social process appears in the acts which communicate reproach, encouragement, satisfaction and it is based on ‘taking turns’ in conversation and on maximizing communicative profits of speaker’s predominance in turn-taking in conversation.

The aim of communication is persuasive and assertive and it gives the speaker a superior position. The model of conversational sequence is as follows: Question, Response, Comment and subsequently, a new Question etc.

A **symbolic process**, on the other hand, makes use of symbols and is more reserved and neutral on the communication level. Communication refers to something else that is already known or that has already been said or something that the participants of the communicative act have already agreed or are trying to agree on. The process of tendential symbol sharing which has the aim of creating an agreement is expressed in Italian by means of linguistic acts in the subjunctive: “Se le dicessi che..”, “Qualora sperimentasse effetti...” (“If I told you...”, “If only you tried out...”). As far as the narration is concerned, the collection of disease stories implies the recognition of alternatives and creates “narrations in the subjunctive” or “exploration of possible meanings”. The discursive process increases personal control over meanings and an opening into cognitive empathy by means of which the categorisation of meanings used by the interlocutor and projective identification of their symbolic world are investigated. These communicative forms are strategic because they tend to make people do something by conveying a message. The success of symbol sharing makes it possible for the communication process to become suggestive and assertive determining changes in interlocutor’s point of view and actions. Conversational sequence that best describes this process is as follows: Question – Response – New Question, which only at the end of the sequence can finish the illocutionary or locutionary act. The most common communicative forms are responsabilisation, giving information, teaching and tranquillizing.

A **relational process** is based on exchanging statements without reciprocal characterisations during which the social role of the participants of the communication process is of less importance. It

creates an anticipatory process of emotional or affective empathy. The speaker is open and ready to receive the emotional experience of the others; the speaker “feels” it and moves to identification of feeling and ends with objectivation or with reflexion on the meaning of what the interlocutor goes through. In relational processes with empathic background there is a constant anticipation of the speaker because he/ she is emotionally with the interlocutor. The narrative disposition extends its potentiality as the possibility of interlocutor’s expression through narration depends on the speaker’s behaviour and on his/ her empathic readiness. The development of arousal, that is the somatic perception of emotions, is the most characteristic sign of empathization. The communicative sequence typical of this relational narration is Anticipation of the lived experience – Response – Affirmation or Question. Such a model appears in communication of support and emotive involvement.

On the basis of these three models I have tried to analyse doctors’ communication.

Communicative disposition of doctors

The question regarding relational and communicative models among doctors in Porto Rosso group and their patients has initialized a research into relational and communicative styles of 130 general practitioners and has been conducted by means of a short questionnaire composed of 35 items that were to identify predominant communicative behaviour of doctors. These items originated from patients’ stories of their lived experience of disease collected from their doctors.

Choices of social and communicative acts made by the doctors are as follows:

Communicating:	Number of items	Percentage
responsibilization	236	24,48133
encouragement	200	20,74689
involvement	168	17,42739
support	112	11,61826
gratification	108	11,20332
information	80	8,298755
tranquillization	60	6,224066

Doctors’ communicative inclinations show that those who are in the responsibilization group choose a number of answers which seem to assume symbolic communicative models, doctors in the encouragement group choose a number of answers which appear to assume dynamic

communicative models etc. The variations of communicative styles are the expression of the characteristics of doctors' personality.

Do communicative styles vary in relation to the patient?

Unfortunately not. Having verified communicative styles, some video recordings with simulations of relational climate (misunderstanding, impatience, avoidance, incomprehension, pain, attrition, disappointment) have been shown in order to understand the communicative style of every doctor exposed to patient's narrations.

Correlations between the style of response and the type of patient show that doctors try to communicate information and social acts to the patient in their personal way. Unfortunately they do not choose the most suitable communicative style. The chosen communicative style "reflects" the patient's personality or he/ she belongs to the same communicative style as the speaker. Contrarily to what intuition should say, the doctor does not adopt therapeutic communicative position. In front of an anxious patient the doctor should adopt a tranquillizing communicative style but in contrast, he/she tries to repress anxiety using active and dynamic communicative style as if he wanted to overwhelm patient's experience in an authoritarian way to make it stronger than anxiety. In front of a resigned patient doctors comply with the narration participating in it without activating cognition or symbols that could lead the patient to change his/her position; in front of a voluble and unreliable patient they try to give explanations, information and examples without conveying any emotions which could make the patient feel responsible (f.ex. by trying to make them afraid of the consequences of their behaviour).

Correlation between the style of response in a given situation and the type of patient

Style of response	Type of patient	Correlation
dynamic	anxious patient	1
dynamic	resigned patient	-0,25115
dynamic	voluble patient	-0,57637
narrative	resigned patient	0,827843
narrative	voluble patient	-0,31329
narrative	anxious patient	-0,42825
symbolic	voluble patient	0,894649
symbolic	resigned patient	-0,50646
symbolic	anxious patient	-0,5447

Narrations from doctors and medical counselling

Narrative-based medicine can teach doctors how to develop appropriate instruments of medical counselling.

The possibility of narrative writing done by doctors really develops their awareness. In their stories I noticed doubts, awareness of their limitations, denials, psychological projections, internal dilemmas created as a result of having been in contact with their patients' lived experience of disease.

Using the practice of narrations, emotions become feelings and symbols they use become real and concrete as they are freed from traditional defence mechanisms.

By means of narrative exercises, the experiences are revised and a possibility of new communicative forms adequate for patient's lived experience comes into being.

The stories that are written and told provide doctors with instruments necessary for facing their own projections and the projections of others as well as denials and internal dilemmas.

Projection (i.e. a transfer of personal experiences on the others aimed at defending oneself from the sense of guilt) can be contained even in its most acute implications like anger or anxiety and can be spread by listening and releasing internal tensions. "I understand you!" is a central statement of medical counselling in front of projective processes.

Denial which is a process of avoiding unpleasant aspects of reality as if they did not exist or the repression (exclusion of negative experiences from one's consciousness) with its typical forms of shutting oneself from the outside world, excessive resignation reaching panic, can be overturned by means of consolations. In order to be able to console somebody, it is necessary to have something to say. "I once had a patient who was ill just like you and he managed..."

Internal dilemma is a split between feelings and behaviour but it is also a way of distancing yourself from your feelings and a loss of normal integration of memories, perceptions, identity and consciousness. It appears as a consequence of an intolerable internal conflict which forces the mind to separate from incompatible and unacceptable information and feelings.

In case of internal dilemmas it is necessary to contain mental confusion by regenerating patient's contact with himself/ herself. "You are a person who ... do you remember when ...". This communicative model reorganizes patient's mind. Stories are also a storage of identity.

Applying this simple scheme when training GPs on doctor-patient relationships, it is possible to continue the experience of collecting stories so as to make communicative disposition of doctors more efficient.

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