



## **Narrative Based Medicine, Parents Pedagogy Methodology and International Classification of Functioning. A Multidisciplinary and Integrated Approach for People Care**

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### **Abstract**

*The educational therapeutic pact family-healthcare represents an important tool in order to share different kinds of knowledge of people involved in the care process: the knowledge which comes from family experiences, is not scientific but related to here and now, specific and personal, and healthcare professional workers knowledge which is scientific, standardized, based on statistical results, not personalized.*

*Materials and methods: narrative medicine and parents pedagogy are used as methodologies to collect the stories of people and families through the application of educational therapeutic pact family – healthcare. The ICF is an important tool to underline the personal factors which qualify the care and life process of the patients.*

*Conclusions: the patients and his/her family have need to be listened to and respected with dignity for what they are and what they do.*

*In 2011 a new project starts which aims to create a training path for the healthcare professional workers in order to acquire narrative knowledge for the definition of educational therapeutic pact. ([http://heppy.fadgradenigo.it/index.php?option=com\\_content&view=article&id=9&Itemid=105](http://heppy.fadgradenigo.it/index.php?option=com_content&view=article&id=9&Itemid=105)).*

### **Introduction**

The care continuity is the combination of all scientific, professional, educational, organizational, administrative and cultural initiatives which aim to protect the path of the "weak patient" from the territory to the hospital and from the hospital to territory creating synergies among the professional interventions and identifying the place of the care setting (e.g. home, homecare and territory services) which are more useful in that particular moment.

In order to guarantee an efficient and concrete care continuity, the communication needs to be developed, intensifying the services net, a mutual knowledge and the collaboration among the healthcare professional workers of the territory and the hospital. Also the quality of the diagnostic, therapeutic and assistential paths need to be improved using the territory and hospital resources in a more rational and adequate way.

To guarantee a care continuity suitable to the real needs of the patients in that particular moment, also his/her family needs to be involved in the chosen care path, they need to share it, to know how to listen to and to be ready to change it when it is necessary.

It's more and more important that the healthcare professional workers should have an holistic approach of the patients problems; they should be a reference point the patient could easily reach creating that trust relationship which is the bases of the educational and therapeutic pact.

We need to consider that each case is different, each person is different from another despite the same pathology, the same needs, the same interventions to operate.

The healthcare professional workers need to give a continuous care monitoring on the bases of their own different knowledge choosing the best care path for the "weak patients" considering the possibility to change it also in a drastic way in a short time, without making anybody guilty.

### **The Narrative Medicine**

In the growing technical and scientific development we can see in the care setting there is always an individual story of the person; the narrative medicine represents the recognition of the complexity of the person and of his/her story of being sick.

It stands for a paradigm to overcome the epistemological limits of the model of biomedical linear correlation, confirming again how the several humanistic approaches are important.



The narrative medicine aims to understand and to complement in the care pathway the stories and the experiences of the illness respecting the sick person involved. It is directed to the identification of physical, psychological and social suffering of the ill person with the aim to establish the priorities which could carry out with coherence the care and the support activities.

As new dimension of health care, the narrative medicine offers new perspectives to the health system now divided in several aspects, to become more efficient than in the past.

It offers to take care of the illness through the ability to know and to respect those who have been touched by the illness and also supporting those who take care of the sick people.

The descriptions of the illness provide how to become close to the problems in a global way and through the interpretation of the autobiographical story of the patient, simplify and guide therapeutic and diagnostic choices.

Moreover the illness stories a way to inform patients and healthcare professional workers and can also spread and enhance research hypothesis. Consequently the narrative medicine is not only a complementary approach to better understand the patient and his/her illness but it becomes a basis element for the care and diagnostic act; when the patient and the doctor get in contact according to the narrative based, together they build an illness story trying to discover all its aspects: the doctor and, more generally, the healthcare worker involves him/herself completely in order to deeply know the patient as a unique person.

The narrative paradigm takes a particular value getting in contact with a person affected by degenerative-chronic illnesses, where the patient and his/her family become protagonist of the care pathway.

The illness is first of all a human experience, beyond its causes, and the meanings it takes are linked to the personal story of the patient.

It is not possible to understand a human being without understanding his/her own world and his/her conceptual map he/she lives into. The words and the stories plots have an important role in the illness experience.

Listening to these stories it is possible to understand the complex reality which sometimes we can not only define according to the traditional biomedical prospective.

Deeply analyzing the story of the sick person we have to put together in a critical way all the elements that analysis method divide.

In conclusion the narrative medicine improves the care through paying attention and also, using in a therapeutic way, the patients, the doctors, nurses, and stakeholders stories giving a particular value to the prospective and the vision of the illness of the person and of his/her family

### **The Methodology “Parents Pedagogy”**

"Parent's Education", the enhancement of the educational skills and knowledge of families, was born in Turin as a result of activities that emphasize the leading role played by the citizens who commit themselves to being social workers in mental health in a dynamic of reciprocity, which is nourished by bringing forward interpersonal relationships. Some principles derive from the practice of the assemblies of Popular Therapeutic Activity, born in Modena and developed in Turin from 1978, in which parents take active part, speaking in public and talking about their educational pathways.

Because of the fruitfulness of the parents' desire of being active citizens and first connoisseurs of their children, they have been used as trainers in schools since 1995, date on which the Parent's Education principles and methodology were formalised.

### **From diagnostic approach to functional approach of ICF**

The increasing of disability, of the conditions of degenerative chronic diseases and consequently the necessity to improve the services of the care continuity require concrete tools which are able to better understand which are the assistential situations that can be the object of a care projects.

The publication by WHO of the International Classification of Functioning, Disability and Health has given great importance to that assistential care where the family, the patient and the healthcare professional workers take a position as cultural reciprocity.

As a matter of fact, the ICF is a tool which is open to all components of the care project, professional, non professional and family, where everybody can express him/herself.

The functional profile is the result of this interaction among healthcare professional workers, family and patient.



Whereas the clinic diagnosis which takes only care of the bio-medical aspect, obviously necessary to keep in good health the patient, the functional profile takes its origin from the holistic approach of the person and underlines the problems for example handicap (limited activities or restrictions of participations classified under the umbrella term "Disability").

The narrative medicine and parents pedagogy acting among patient, healthcare professional workers, family and parents represent two important strategies which allow to underline the personal factors ICF doesn't classify.

## Results

From the meeting of three methods a new working hypothesis has come out, creating a new project through the experience carried out by some experts.

A lot of scientific researches confirm that if the person and the family show resilience as an existential condition they can affect in a positive way the care results; on the other hand if they show resignation or if they don't cope, the results unfortunately will be negative.

The educational therapeutic pact of family health care is dedicated to the collecting of people stories transforming them into very useful information for the health, social and educational assistance.

The educational therapeutic pact has got the big strength to give dignity and respect back to people underlining the value of their culture, their habits and their beliefs.

The narrative medicine and parents' pedagogy are, therefore, strategies to build that dialogue going on between healthcare professional workers and citizens which can represent a mutual exchange of knowledge and where the active participation of the parts takes a valuable and important dimension (d'Ivernois, Gagnayre, Educare il paziente, 2009). We have consequently to operate a radical attitude change in the healthcare professional workers and citizens: the first one give up to their knowledge and responsibility about managing chronic disease, the second one take in charge their responsibility giving up a passive attitude.

Thanks to narrative medicine course carried on during these last years we have collected several experiences of the healthcare professional workers which allow us to deeply know human nature.

Here are some example:

- That woman has left in my heart a profound and unforgettable love and warmth sign and also a delicate soul sensitivity.
- 26 years old, my daughter's friend, prognosis one year of life. She has always managed the follow up and therapies herself. When the doctor of palliative treatment explains and asks her permission for sedation because of bad dyspnea she asks him the following question: "if you were me, what would you do? Will I be able to awaken?"
- The first time I got in her room I was really embarrassed, I wasn't feeling ready an adequate to face not the physical pain or the clinical aspect of her pathology but her emotional and psychological suffering. We almost feared to get in the room because, beside the pharmacologic answers we didn't know how to face to her despair. One morning she called me for hygienic purposes I got in her room I said hallo as usual and with my great surprise she answered "how nice of view to come, you always smile, you always talk to me and joke, I you listen to me you support me when I complain, you make me feel Laura and not a simple cancer patient". These beautiful words touched my deeply.

From the meeting of the experts of narrative description medicine, Parents pedagogy and ICF a new European project (HEPPY) has come out "Healthcare: parents pedagogy and functional profile" which aims to build a training path for the health professional workers in order to improve the narrative knowledge when they take in charge the patient and his/her family.

## Conclusions

This article puts the basis for the description of a different approach to the cares which comes from the integration of two methods and a classification tool.

To integrate the methods to take in charge the patient and his/her family in a holistic way represents a new challenge which, if it is well organized, will be able to obtain very positive results.

To introduce, as a working tool, the relatives, parents and patients' descriptions, who I was and who I am today, what I was doing and I am doing today etc allows the health professional workers to identify that type of care which is closer to the patient characteristics.

The empowerment of the patient is a clue word concerning several health politics and programs.



Our experience could represent one of the working methods even though we need to carry on other researches and direct experiences.

### References

- [1] A. Moletto, R. Zucchi (a cura di), Con i nostri occhi. Un itinerario di 'Pedagogia dei Genitori', Torino 2006 (Supplemento Rivista Handicap & Scuola), Torino 2006.
- [2] Bruner, J. (2002), La fabbrica delle storie. Diritto, letteratura, vita. Laterza, Roma-Bari.
- [3] Charon, R. (2004), "Narrative and medicine", In New England Journal of Medicine, 350, pp. 862-864
- [4] Charon, R. (2006), Narrative medicine - Honoring the Stories of Illness. Oxford University Press, New York.
- [5] D'Ivernois J., Gagnayre R., Educare il paziente. Un approccio pedagogico, McGrawHill, Milano 2009
- [6] Garrino L., La medicina narrativa nei luoghi di formazione e di cura, Edi.Ermes- divisione Centro Scientifico Editore, Milano 2010
- [7] Greenalgh T. Russel J. Swinglehurst D. (2005) Narrative methods in quality improvement research. Quality Safety Health Care 14:443-449.
- [8] Greenalgh, T. Hurwitz, B. (1998), Narrative Base Medicine. London: BMJ Books.
- [9] Harry B., Leaning Forward or Bending Over Backwards: Cultural Reciprocity in Working with families, Journal of Early Intervention, 21-1:62-72, 1997
- [10] Jeannie L Haggerty, Robert J Reid, George K Freeman, Barbara H Starfield, Carol E Adair and Rachael McKendry, Continuity of care: a multidisciplinary review, BMJ 2003;327;1219-1221
- [11] Moletto A. R. Zucchi, La Metodologia Pedagogia dei Genitori. Valorizzare il sapere dell'esperienza, Maggioli editore 2013
- [12] OMS, ICF Classificazione Internazionale del Funzionamento, della Disabilità e della Salute, Erickson: 2002
- [13] Zucchi R., Moletto A., Garrino L., La Metodologia della Pedagogia dei Genitori per la formazione alla relazione di cura, Tutor, vol. 12, Aprile 2012, pag. 7-15