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First international congress
Narrative medicine and rare diseases



Istituto Superiore di Sanità
Rome, June 4, 2012



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PROCEEDINGS

Edited by
I. Luzi, A. E. Gentile
and D. Taruscio

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ISTITUTO SUPERIORE DI SANITÀ

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Edited by
Ilaria Luzi (a), Amalia Egle Gentile (b) and Domenica Taruscio (b)
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(b) Centro Nazionale Malattie Rare

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First international congress “Narrative medicine and rare diseases”. Istituto Superiore di Sanità. Rome, June 4, 2012. Proceedings.

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2013, 68 p. Rapporti ISTISAN 13/13

The First international congress “Narrative medicine and rare diseases” has been organized by the Italian National Centre for Rare Diseases (CNMR) at the Istituto Superiore di Sanità (the National Institute of Health in Italy). The objectives were to understand and disseminate narrative medicine application, particularly on rare diseases, among health and social operators, persons with rare diseases and their families and associations of patients. Rare diseases are defined by low prevalence in the population ($\leq 5:10,000$ in the European Union). These disorders are mainly characterized by being severe, chronic and invalidating. They are difficult to diagnose and with few decisive therapeutic options. Narrative medicine may also contribute to reduce the distance from the clinical knowledge (“disease”) of medical doctors and health professionals and the patient’s subjective experience (“illness”). The present report collects the authors’ contributions to the Congress through invited lecture, oral communications and posters.

Key words: Rare diseases; Narrative medicine; Narration; Narrative ethics

Istituto Superiore di Sanità

Primo convegno internazionale “Medicina narrativa e malattie rare”. Istituto Superiore di Sanità. Roma, 4 giugno 2012. Atti.

A cura di Ilaria Luzi, Amalia Egle Gentile e Domenica Taruscio

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Il Primo convegno internazionale “Medicina narrativa e malattie rare” è stato organizzato dal Centro Nazionale Malattie Rare dell’Istituto Superiore di Sanità. L’evento è stato volto a conoscere e diffondere anche la medicina narrativa applicazione, in particolare sulle malattie rare, tra operatori sanitari e sociali, persone con malattie rare e loro familiari e Associazioni di pazienti. Le malattie rare sono definite dalla bassa prevalenza nella popolazione ($\leq 5:10,000$ nell’Unione Europea). Queste patologie sono principalmente caratterizzate dall’essere gravi, croniche e invalidanti. Sono difficili da diagnosticare e con poche opzioni terapeutiche decisive. In tale contesto, la medicina narrativa può anche contribuire a ridurre la distanza dalla conoscenza clinica (“diseases”) di medici e operatori sanitari e l’esperienza soggettiva del paziente (“illness”). Il presente volume raccoglie i contributi di coloro che hanno partecipato al convegno attraverso letture magistrali, comunicazioni orali e poster.

Parole chiave: Malattie rare; Medicina narrativa; Narrazione; Etica

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Session I

Chairpersons

Roberto Lala, Domenica Taruscio

INTRODUCTION

Domenica Taruscio

Centro Nazionale Malattie Rare, Istituto Superiore di Sanità, Rome

The Centro Nazionale Malattie Rare (CNMR, the Italian National Centre for Rare Diseases) organized the First International Congress “Narrative Medicine and Rare Diseases” which took place in Rome on June 4, 2012.

The CNMR has engaged since several years in studying the application of narrative medicine, especially in the field of Rare Diseases (RDs). RDs are a large group of diseases (7-8,000) characterised by low prevalence in the population ($\leq 5:10\ 000$ in the European Union) and represent an important public health challenge. RDs are often severe, chronic, disabling and life-threatening conditions and cause a significant decrease of the patients’ quality of life. Whereas RDs can be largely different, their social and health impact share diverse common features such as difficult diagnosis and scarce availability of etiologic therapeutic options. People with RDs and their families are often suffering from isolation, frustration, depression, abandonment; often, health and social operators dealing with Rds have these same feelings.

What approach is carried out by the CNMR? Since 2000, the Rare Diseases Unit at the Istituto Superiore di Sanità (ISS, the National Institute of Health in Italy) has been developing national and international initiatives on RDs. Finally, the CNMR was established by law at the ISS in 2008. Its mission is research, surveillance and information on RDs and orphan drugs, with the intent to support prevention, diagnosis, treatment and surveillance of these disorders. A large range of scientific and technical expertise is engaged in the several activities of the CNMR which, furthermore, participates in national and international networks for the development of a multidisciplinary integrated approach to RD issues.

The narrative medicine, widespread since some years in Italy, pays attention to the study of the stories and direct experiences of illness in order to place and understand the people involved (patients, family members, health workers) in their specific context. Furthermore, it is a tool that helps to highlight not only the needs but also new strategies for intervention on public health problems. The collection of “narrative evidence” is an opportunity to contextualize the clinical data and identify many unfulfilled needs. The narrative of personal experience should play a significant role in relations of care (especially in RDs) in order to tell and explain the real-life suffering, make it shareable and transform it into a resource.

The laboratory “Rare diseases and narrative medicine” of the CNMR aims to promote a culture of participation and the knowledge of narrative medicine among health/social professionals, patients with RDs and their families. The activities of the laboratory are:

- research: reviewing scientific literature (“D-Space”, an open source database); collection and analysis of “life stories” (available online at www.iss.it/cnmr), specific projects in collaboration with health/social professionals, Patients Associations, etc.;
- training to health/social professionals, patients with RDs and their families;
- information: newsletter “Nar-rare”, an online tool to share and disseminate knowledge in the field of narrative medicine through publications, studies, researches and events.

The First International Congress “Narrative Medicine and Rare Diseases” is the 4th consecutive event organized by the CNMR on this subject, different from the previous ones because it has been open to international experiences, including the major contribution by an international Scientific Committee with the participation of: Brian Hurwitz, professor of

Medicine & the Arts at the King's College London, with the invited lecture "Watching & walking the streets of Georgian London. James Parkinson & the art of observation"; and Rita Charon, Director of the Program in Narrative Medicine at the Columbia University College of Physicians and Surgeon.

Finally, I would conclude this introduction with Gianni Bonadonna's words, Emeritus Head of Oncology (National Cancer Institute, Milan) and guest of the event:

Negli atenei si insegna troppo la tecnica e poco l'umanità. Il medico deve imparare a pensare come un malato. Bisogna avere l'umiltà di imparare da chi soffre. Date a un malato la possibilità di sentirsi vivo, di uscire dalla gabbia del dolore. E ascoltate i suoi sogni; ce ne sono di incredibili.

(Bonadonna G, Schiavi G. *Medici umani, pazienti guerrieri. La cura è questa*; 2008)

WATCHING & WALKING THE STREETS OF GEORGIAN LONDON. JAMES PARKINSON AND THE ART OF OBSERVATION

Brian Hurwitz
School of Arts & Humanities, King's College London, London

In his 1817 *Essay on the Shaking Palsy*, James Parkinson supplemented the existing clinical classification of C18th European nosologists with a highly pictorial, literary depiction of a slowly progressive disorder involving trembling and abnormalities of posture and gait.

In a closely observed description of altered bodily functions, the *Essay* delineated a cluster of evolving signs and symptoms whose onset in a single limb, or in the head, was so very slight as initially to be virtually unnoticeable. To Parkinson the condition appeared almost always to be fatal and he charted its deterioration chronologically, not only in loss of movement and function, but also in semi-biographical terms: as weakness, trembling and a failure of the limbs “to answer with exactness to the dictates of the will”; in difficulties eating and swallowing; in the propensities of sufferers to “walk on the fore part of the[ir] feet and toes”, to move unwillingly from a walking to running pace; in attempts by sufferers to avoid falling over by use of a stick; and in efforts to stop the shaking by effecting sudden changes in posture.

The *Essay* featured six case reports, rich in individual detail, and precisely, economically and delicately described, concerning people seen in varied circumstances, across widely differing intervals of time. Parkinson had noticed that tremor, bowed posture and festinant gait could sometimes co-occur together in sufferers whom Parkinson clearly knew well from his Hoxton apothecary's shop, whom he had followed for over a decade, and strangers he had seen only fleetingly, from afar, on London streets. He brought together these case narratives to form a composite “natural history”, redolent of sentiment and with a string moral atmosphere, creating, thereby, a picture of a disease that is pungent and memorable, and which has proved remarkably durable.

Parkinson (1755-1824) worked from Hoxton Square, then in a green suburb under construction to the north east of the City of London. He was the first born of the three children of John and Mary Parkinson, who ran a medical household at number 1 Hoxton Square.

His father, John, worked as an apothecary and was a member of the Surgeons Company, the forerunner of the Royal College of Surgeons of England. In due course, James joined his father as an apprentice and, in 1776, spent 6-months as a dresser at the newly established London Hospital at Whitechapel, East London. In April 1784, Parkinson, too, became a member of the Surgeons Company and the following year attended the lectures of the renowned surgeon, experimenter, collector and fossilist, John Hunter. His notes of Hunter's presentations, taken down in shorthand and published posthumously, reveal that James's interest in shaking could have arisen during Hunter's lectures, as he noted brief details of a 72 year old woman who was thought to suffer from “a universal palsy...every part of the body shook which was not fully supported. The muscles of respiration were so affected, that respiration was with difficulty effected; but in sleep the vibratory motions of the muscles ceased, and the respiration was performed more equably: any endeavor of the will to alter these morbid actions increased them”, he wrote.

There is no doubt Parkinson had an acute and lively mind. When only 22, he was awarded the Silver Medal of the Royal Humane Society, for the resuscitation of Brian Maxey, a local

East London man whom he'd found to be without a pulse after hanging himself. He observed, treated and wrote-up the effects of lightning strikes on a patient whose extremities he noticed first went black and then turned white after death; another man he attended after a lightning strike suffered blindness but survived. He wrote case reports on what he thought was rabies in a 28 year-old servant and a 10-year old boy and, with his son, he published a report of a child with appendicitis that resulted in peritonitis from perforated appendix.

In 1805, he published *Observations on the Nature and Cure of the Gout*, a book that discussed his own and his father's gout, in which he reviewed ancient and contemporary accounts of the condition, including recent work on its clinico-pathological nature published in the *Philosophical Transactions* of the Royal Society.

By the time James Parkinson took over his father's practice in the 1770s, a "literature of urban spectatorship" regarding street life and human movement on city pavements, was well established. Compared to country folk, city dwellers were thought brisk, animated and hyper-alert, which was thought to account for their agility on busy streets and their ability to dodge traffic. Eighteenth century growth in population, density and in the complexity of cities, led to contemplation of *difference* between the manners and movements of people in the town and in the countryside, a difference that depicted in late C18th and early C19th novels, engravings, in sketches of London streets, and in poetry about town life. Parkinson's case descriptions partook of this wider culture of Georgian urban spectatorship an art of street observation that is also found in the later urban literature of Henry Mayhew and Charles Dickens.

Soon after the essay was published, it was hailed a landmark of clinical description. It was cited in the early pages of *The Lancet* and the *British Medical Journal*, by the German physician, Moritz Romberg in his *Manual of The Nervous Disease* (1851), by the French physician, Armand Trousseau, in his 1861 *Lectures*, and later still by J-M Charcot, who recognized the condition and suggested it be named *Maladie de Parkinson*. Charcot was so impressed with the work that he advised students at the Salpêtrière to translate the essay: "it will provide you", he said, "with the satisfaction and knowledge that one always gleans from a direct clinical description made by an honest and careful observer".

In embedding clinical observation in narrative form, James Parkinson *Essay* set out the features of a newly recognised condition with great accuracy and sensitivity.

References

- Charcot J-M. Policlinique du Mardi 12 Juin, 1888. In: Charcot J-M. *Leçons du mardi à la Salpêtrière*. Tome 2. Paris: La Bibliothèque des Introuvables; 2002. p. 123-140. (In English: Goetz CG. *Charcot the clinician*. New York: Raven Press; 1987).
- Charcot J-M. Policlinique du Mardi 31 Janvier, 1888. In: Charcot J-M. *Leçons du mardi à la Salpêtrière*. Tome 1. Paris: La Bibliothèque des Introuvables; 2002. p. 199-220.
- Currier RD. Did John Hunter give James Parkinson an idea? *Arch Neurol* 1996;53:377-8.
- Elliotson J. Clinical lecture. *Lancet* 1830;15:119-24.
- Goetz CG, Bonduelle M, Gelfand T. *Charcot. Constructing neurology*. Oxford: Oxford University Press; 1995.
- Horowski R, Horowski L, Vogel S, Poewe W, Kielhorn FW. An essay on Wilhelm von Humboldt and the shaking palsy: first comprehensive description of Parkinson's disease by a patient. *Neurology* 1995;45:565-8.
- Kempster P, Hurwitz B, Lees A. A new look at James Parkinson's Essay on the Shaking Palsy. *Neurology* 2007;69:482-5.

- McMenemey WH. James Parkinson (1755–1824). A biographical essay. In: Critchley M. (Ed.) *James Parkinson (1755–1824)*. London: MacMillan & Co.; 1955. p. 1-143.
- Morris AD. *James Parkinson. His life and times*. Boston: Birkhäuser; 1989.
- Parkinson J. *An essay on the shaking palsy*. London: Sherwood, Neely and Jones; 1817. Reprinted in: Neuropsychiatric classics. *J Neuropsychiatry Clin Neurosci* 2002;14:223-36.
- Parkinson J. Hydrophobia. 1814. In: Morris AD. *James Parkinson. His life and times*. Boston: Birkhäuser; 1989. p. 73-73.
- Parkinson JWK. *Hunterian reminiscences*. London: Sherwood, Gilbert and Piper; 1833.
- Porter R. *Enlightenment*. London: Penguin Books Ltd.; 2000.
- Roberts S. *James Parkinson (1755–1824)*. London: The Royal Society of Medicine Press; 1977.
- Rowntree LG. James Parkinson. *Bull Johns Hopkins Hospital* 1912;23:33-45.
- Weightman G, Humphries S. *The making of modern London 1815–1914*. London: Sidgwick and Jackson; 1983.
- Winter J. *London's teeming streets 1830–1914*. London: Routledge; 1983

WRITING AS THERAPY

Elaine Benton

Patient, Kadima, Israel

I was born with Gaucher disease, a rare disorder, caused by a genetic mutation from both my parents, resulting in a deficiency of a specific enzyme (glucocerebrosidase) in the body. The missing enzyme affects many organs such as the liver, spleen, bone marrow, severe bone pain, bone deterioration in particular damaging joints, and various additional symptoms such as bleeding and anaemia.

I was diagnosed at the age of 5; little was known about this disease back then, and the prognosis looked grim. The only way of testing for Gaucher in those days was a painful sternum puncture performed under general anaesthetic. As I was coming around from the aesthetic, I could hear doctors standing around my bed talking about me. As anyone would in such circumstances, I remained silent, keeping my eyes tightly closed I listened carefully, and overheard a doctor saying that a child with Gaucher in my condition with an enlarged spleen would not live much past puberty. I kept this information to myself; a secret I thought only I knew. It wasn't till I was in my late twenties, that I found out the doctors had told the same thing to my mother. *Both of us knew, but neither had said a word about this to the other during all those years!*

I started writing stories and poems when I was quite young, expressing myself on paper, which I now realise, was therapeutic, but at the time I simply enjoyed it.

I grew up, finished school, started working, fell in love and married a wonderful man. I became pregnant and after a normal uneventful pregnancy, I gave birth by caesarean section to a healthy baby girl. I am now 49 years old; I guess those doctors who stood around the bed of a five year old little girl with Gaucher disease in 1968 were very wrong. The information I secretly carried with me for years had a distinct effect on me, moulding me into the person you see before you today. I was never afraid of dying, and believing I didn't have very long to live, I was given the ability to enjoy every moment I have, no matter where I am, or what I am doing. I grab life with both hands and make the most of it.

Twenty two years ago, I met Prof. Ari Zimran who specializes in Gaucher disease and it was an unforgettable moment. Just seeing the small simple sign that said "Gaucher Clinic" was an extraordinary feeling.

For the first time in my life, I sat before someone who knew about Gaucher disease, understood what I had been through, had advice and information to offer; finally I had a place to go, and a knowledgeable doctor who would competently take care of me. After years of feeling isolated, no treatment or information, no support group, left in the hands of people who had never heard of Gaucher disease, I can't express enough, the gratitude I feel towards Prof. Zimran for deciding to make this rare disease his life's work. I fondly refer to the hospital where I am taken care of, as "my second home". It's probably hard for others who have not been in my shoes to understand how I feel. As soon as I walk through those hospital doors, I immediately relax, feeling calm and confidently knowing I am in the best possible hands.

Twenty-one years ago, when the first medicine became available, I started enzyme replacement therapy by infusions, initially at the hospital. Thankfully, "home treatment" was eventually put in place improving the patient's quality of life, by not spending countless hours in hospital on a regular basis.

As if suffering a rare chronic disease was not enough, five years ago, at the age of 44, I was diagnosed with Parkinson's disease. My life became very difficult indeed now struggling with two diseases.

I have taken part in a number of clinical trials, and one particular story sticks in my mind. After meeting various doctors involved in this trial, they were all extremely puzzled by my attitude, for they had never come across a happy smiling patient suffering two chronic diseases. In their eyes, they felt something was very wrong, and eventually sent me to a psychiatrist. Although I didn't want to go; felt it unnecessary, I couldn't refuse, for fear it would confirm their thoughts, and so I merrily walked into the psychiatrist's office, smiling as I always do, I asked him "*how are you?*" His bemused expression made me aware that he too had not come across a patient like me. He asked if I understood what Gaucher and Parkinson's disease were and if I realised the serious prognosis. Seeing his face, it suddenly occurred to me that these doctors did not understand me at all, and believed me to either be in denial, uninformed or crazy! I removed the smile from my face and explained in great length and detail about Gaucher and Parkinson's disease, the treatments, and my prognosis. Satisfied, the psychiatrist wrote down that I had an unusually healthy mental attitude and a great sense of humour! Having a good sense of humour is very important.

When I visit a doctor, I often go with a list. At first they would smile as I would hold my list ready to report as if I'd been out on assignment. Making a list of new symptoms, questions or concerns helps me get the most out of an appointment, and gives the doctor a clear picture with the maximum of information. Doctor and patient working together as a team, have the best results.

A year ago, I wrote a book of poems about living with Gaucher and Parkinson's. For me it was very therapeutic in a cathartic sense, but what was even more astounding; I found others suffering chronic disease could relate to my poems. From personal experience I've written with stark honesty and humour, something that neither patients nor doctors have read before which has captured attention world-wide. I have poured my heart and soul into this book, giving a fresh perspective from the patient's view.

My book gives doctors the opportunity to understand completely a patient's story, not merely medical facts but the emotional side of suffering a rare disease; how patients really feel. Today we realise there is a link between physical medical issues and the emotional attitude. What started as merely a few poems has spiraled into an entire project, resulting in me writing a blog on wide-ranging topics sufferers can relate to, letting them know they're not alone in their daily struggles. People around the world are reading my blog and contacting me, and I reply personally to each one. I have been speaking at various organisations, groups and to student doctors, for I believe there is need for education and greater awareness heard directly from patients.

This project has given my life purpose, keeping busy, making me feel I have something of value to contribute which is highly important in sustaining me; probably the best medicine I could have received. My book could revolutionise how doctors interact with patients, encouraging empathy and understanding better those who suffer rare diseases, which ultimately benefits both doctor and patient.

I consider myself very lucky to receive such good medical care, and have met many wonderful dedicated doctors and nurses over the years. I am grateful to be in good hands, and although it's not easy suffering Gaucher and Parkinson's, there is a silver lining to everything in life. *You've just got to know how to see it!* No matter what rare disease a patient may have, it's the state of mind that counts. It's very easy to fall into depression and wallow in self-pity, but I advise being cheerful and putting a smile on your face, making the best out of a bad situation.

I hope that more doctors adopt narrative medicine as an additional valuable tool, helping patients cope better with ill health and that it becomes an integral part of medical care.

I was very glad to be part of this “First International Congress Narrative Medicine and Rare Diseases” and thank you for inviting me.

Session II

Chairpersons
Guido Giarelli, Paola De Castro

REPRESENTATIONS AND PRACTICES ABOUT COMPLEX DISEASES IN PAEDIATRIC PATIENTS: NARRATIVE AS A RESEARCH TOOL

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Background

Childhood as social construction

During the last years, many historical, philosophical, sociological and anthropological studies have explored the concept of "childhood" and have considered it as a socio-cultural construction that emerged in "Western" countries in a specific historical period. Censi (1994) places its emergence in XVII century: since that period a peculiar planning has been dedicated to children; social structures, cultural processes and inter-subjective attitudes arose from it. Today, we still reserve such socio-cultural dynamics to childhood, in medical field too: for this reason analysing the birth of this concept is fundamental in order to understand how paediatric patients relate to health, to disease and to the other subjects involved in health-care (professionals, care givers, etc.).

Anthropological studies show that peculiar features are generally attached to children and distinguish them from adults: children are considered irrational, unhistorical, evolving, unaware, dependent, incompetent, incomplete, while adults would reach a kind of "completeness", being rational, cultivated, static, aware, autonomous and competent people. By assuming that, it seems that the child's goal is the physical, moral and intellectual completeness set for the adult age. Such a pattern implied the comparison between the child and an ideal type of adult, obviously created by the point of view of the adult itself.

Some scholars suggested to reverse the perspective; they refuse to consider children as imperfect adults: Harris claims that "a child's goal is not to become a successful adult [...] is to be a successful child. Children are not incompetent members of adults' society, they are competent members of their own society" (1998). Therefore, children are going to be considered as subjects able to develop a symbolic thinking, to attach and modify the function of the objects, to negotiate the socio-cultural worlds created for them by other people. Indeed, they role as social actors is dynamic: the difference between them and the adults is the power they have for negotiating their own goals (Hardman, 2001; Hirschfeld, 2002; Van der Geest, 1996; Bluebond-Langner & Korbin, 2007).

The child as moral subject

How should we treat children – also in the medical sense of the word? As moral subjects, or as objects? Moral agents, or patients? Competent or incompetent individuals?

If the children are considered competent, they are moral subjects. They can express understanding of their wellness and decide for themselves. If they are considered incompetent, they cannot decide for themselves. They cannot evaluate costs versus benefits, they are dependent on someone else's decisions, and they deserve protection to develop their own wellness. In this context, beneficence (someone else deciding in the child's best interest) is the criteria of reference (Beauchamp & Childress 1979-1999). Competence, instead, consists of the entire set of skills which are deemed necessary to be considered a moral subject, capable of responsible choices and decisions.

In a medical sense, competence is the basis for granting a subject freedom of self-determination. Competence enables the subject to sign an informed consent form: a competent individual is in the best position to determine which treatments are appropriate for him/herself (Kleinman, 1991). A subject is considered competent if able to participate in a diagnosis or in deciding a therapy in clinical practice.

Criteria for decision-making capacity for consent to treatment incorporate the abilities to communicate a choice; to understand the relevant information; to appreciate the medical consequences of the situation; and to reason about treatment choices (Appelbaum, 2007).

A moral subject is someone who takes responsibility for his/her own choices and actions, and for their predictable consequences. Many children are capable of making well-pondered judgments. Children start early on to attribute meaning to what is happening, to show preferences, and to accept the responsibility on some of their choices.

Moreover, "contingencies such as experience and ability can be more salient than age to a child's competence" (Alderson, 2007). The Gillick ruling established a direct relationship between capacity for informed consent and "individual ability" (also defined as direct social individual experience) rather than physical development (Gillick, 1985, 3, All ER 423). The competent child "achieves a sufficient understanding and intelligence to enable him/her to understand fully what is proposed", and has "sufficient discretion to enable him/her to make a wise choice in his/her own interests".

Therefore, the child can be a competent and a moral subject.

The context: clinical encounter

Clinical encounter, relevant in every experience of chronic illness, is very illustrative about the difference of power between children and adults. Firstly, it implies a differential power between the physician and the patient: indeed, the first one owns expert knowledge, which is believed to objectively describe reality; the latter is considered incompetent about that. Actually, every subject works out his/her personal representations about his/her health/disease: such representations are selected by physicians during clinical encounter, where the experience is re-interpreted in biomedical terms. Moreover, in children cases, their parents select some elements in order to submit them to the further selection of the doctors.

This should be interpreted as an expression of the unequal power relationships in which the subjects are involved, rather than a demonstration of children's and adolescents' incompetence.

Complex pathologies and narratives

In recent years, the number of patients with complex diseases is increasing in Western countries; presently, the treatment of paediatric complex diseases is challenged by inadequate responses.

The care of children with complex diseases requires competences, resources and specific organization different from those provided to adults: these children and their families express physical, psychological, social and spiritual needs which can be faced only by a holistic approach.

A project for the participation of paediatrics patients in care decisions

The “Study of representations and practices about ‘health’ and ‘disease’ aiming to participation of paediatrics patients in care decisions. An interdisciplinary pilot project conducted with children and adolescents with complex diseases” arose from the above mentioned assumptions. It aims to more actively involve children and adolescents with complex conditions in clinical encounters and to provide them the opportunity of expressing their own points of view.

Objectives

The project had theoretical objectives:

- to investigate the representations elaborated by children and adolescents about their experience of health and disease;
- to understand how they relate their own representations to the enacted practices;
- to consider the opportunity and the moral legitimacy of their participation in health-care decisions.

The practical objectives were:

- to encourage the negotiation among children/adolescents, their families and the professionals;
- to conceive health-care practices centered on pediatric patients.

Materials and methods

The project consists of:

- Creation of an interdisciplinary team consisting of:
 - 1 paediatric endocrinologist trained in rare diseases;
 - 1 anthropologist;
 - 1 bioethicist.
- Involvement of 13 children/adolescents with chronic disease and their families. Such sample encloses six girls, six boys and a subject with gender dysphoria. In the sample, there are two couples of twins. All the subjects are affected by complex pathologies that are those affecting neonates, children and young adults with multi-organ, systemic, chronic, disabling, life-threatening conditions.
- Participant observations during clinical consultations.
- Semi-structured interviews, separately performed to the children/teens and to their families.
- Analysis of the collected narratives through:
 - bioethics (analytical method);

- anthropology (interpretivist method);
- synthesis of biomedical, bioethical and anthropological perspectives through dialogic narratives within the team.

Analytical method

The analytical method consists of:

- determination of bioethical issues emerging from language usage;
- systematic definition (an explanation of the meaning) of used terms in arguments;
- distinction between empirical, verbal and conceptual questions;
- distinction between: facts and values;
- identification of fallacy, doubts or ambiguity that originate from improper use of the language and are based on faulty use of inference.

Interpretivist method

The anthropological analysis makes use of the interpretivist method, which allows a qualitative approach to the research. Such a method does not examine the averages, while it explores the socio-cultural elements that emerge from the subject's way of thinking, which is inter-subjective and public.

In this way a sharp demarcation between universal and particular vanishes: indeed, if the particular is always socio-culturally built, then the historical dynamics, the economic processes and the moral systems settle together in that particular. Moreover, interpretivism assumes that knowledge (also the scientific one) arises by historical and political dynamics, so it can give just an interpretation of the reality, rather than an objective description of it. Therefore, the analysis of the interviews does not aim to catch the reality, but to explore the representations, the relationships and the behaviours that cropped out during the research process. So, a "falsification" of interviewed people is not considered, because even if their narrations did not correspond to the actual enacted practices, the focus is on the meanings dialogically elaborated together with the researcher.

Dialogical narrations among biomedicine, bioethics and anthropology

As we saw, the analytical technique isolates and describes the moral aspects of the care setting (the development of specific moralities, motivations, justifications) implied in individual choices; while the interpretivist method deconstructs the socio-cultural aspects that are given for granted and clears the way for new possibilities of conceiving and understanding the inter-subjective and clinical dynamics. Lastly, clinical practice, consisting in the encounter among the physician, the children/adolescents and their families entails the application of scientific knowledge bound to the moral assessment and the interpretation of the context. Dialogical narration among the members of the team who used these different approaches consisted in the mutual exchange of different kinds of knowledge about the clinical experiences lived during the research process.

This is fundamental in the management of complex diseases, because such diseases imply experiences of extreme uncertainty: the crisis of the being-in-the-world¹, the dissolution of the

¹ The concept refers to the phenomenological philosophy, then reclaimed by Bourdieu. This sociologist describes the continuous exchanges between the subjective experience and the external world; particularly, he underlines the process through which the body assumes some attitudes coming from the external world; it is structured by those attitudes and it contributes to modify them with its own actions.

self and of one's socio-cultural context. Since narrative allows to reassemble shared meanings and to introduce new thoughts and interpretations, then Narrative Based Medicine stimulates new care strategies in multiple "fields of possibility" outside the well-defined Evidence Based Medicine. It allows the individualization of practices and the increasing of awareness about risks, doubts and uncertainties of clinical action, starting from different points of view.

Results

Anthropological results

These are some results emerged from the anthropological analysis:

- The hypothesis that children creatively work out their own representations about health and disease is confirmed. Such representations often contribute to positively re-mean their being-in the world. An example was purposed by a boy suffering from a rare genetic disease, who assimilates himself to an X-Man². He exalts his own strength and relates it to the lack of calcium: "I am... am... I have always been relatively strong. I don't know if it depends on the lack of calcium... maybe... who knows... Anyway... I am... proportionally healthy.... I am... according to my friends I am very strong. In my arms, above all. Also... in my legs, yes". Also very young children show a similar creative ability, even though it rather emerges from the analysis of their enacted practices: a 4 years old child with rickets made an handstand after the interview, as if he reacted to the weakness of his legs.
- Most of the children and of their parents consider biomedical knowledge as objective and, then, little disputable. They do not take into account the idea of negotiating with doctors their own representations, that are relegated to the private field and that are not narrated elsewhere. Some children told that they studied issues about health and disease at school "when we do the human body"; anyway, their personal experiences are never told because they are considered useless in order to produce knowledge.
- Because of this situation, in patients' and their parents' opinion free choices in the therapeutic area are not expected: the right decision is already established and an open negotiation is not taken into account. So, the father of a 23 years old daughter told that, since they are "laypersons", they have to totally entrust in physicians: "As we are laypersons in biomedical field we cannot... We must trust with our lives". A similar idea is also claimed by the mother of 15 years old boy twin; moreover, in one of her sentences the woman also underlined her presumptions about the hierarchy among the involved subjects: "I think that if a doctor says that a thing must be done, it must be done. Without any argument. We ourselves [MOTHER AND FATHER] do not argue, all we need is for him [THE SON] to start arguing!". The children themselves state that "if drugs must be taken, you take them" (15 years old boy) or that "I always agreed" (14 years old boy).
- Such a situation also underlines the process of infantilization to which the patients are subjected when they are deprived of competences, decision power and voices.

² X-Men are heroes of movies and comics who are characterized by some genetic mutations that gave them superpowers, which subject them to marginalization, ghettoization and to persecutions enacted by the "humans".

In this process, parents and physicians emphasize the children's attitudes of acceptance and tolerance, more than those of independence, creation and autonomy. The mother of a 10 years old girl specifically related her daughter's strength to her ability for accepting the therapies: "She faced everything with great strength, that is without complaining".

- The personal representations, and the subsequent practices that some children try to purpose are generally obstructed, forbidden and suppressed, if they do not accord with those of biomedicine and public opinion. This is possible right because of their supposed incompetence. A clear example is the story of a girl/boy with a "gender disphoria" diagnosis: s/he told that s/he frequently fought against the assumption of psychotropic drugs during her/his long therapeutic itinerary, but s/he has always had little results: "when I said that to the doctor [that I suffered when taking the drug], she told me that it was not true. That's why I didn't like her: everything I said should have confirmed her idea, otherwise it was not true [...] That drug: I didn't understand why I had to take it [...] But she knew everything. She was too snooty".
- Therefore, in order to negotiate their goals the children use non verbal and indirect strategies, for example hidden transcripts³: generally, they apparently acquiesce to legitimated behaviours, while they express critics and resistance against biomedical practices by means of actions for which they cannot be blamed, both because they are not considered responsible for them (i.e. they "forget" to assume drugs: "... sometimes I forget things... maybe because my mind automatically refuses things") or because their own intentionality in those actions is not recognized by adults (i.e. non-verbal practices that are usually considered related to their pathologies: "[during the interview] the boy does not show the desire to stand up, he never tries to do it, while before, in the doctor's room, he seemed not to be able to pay attention, nor to maintain his position, even for a very short period").

Bioethical results

The initial questions, aimed at determining the actual level of involvement of pediatric patients in health care practice were:

- Are children with chronic disease involved in their health care process? How?
- Would they like to be more involved?
- Do they show any understanding of their wellness?
- And, from "is" to "ought" (Hume, 1739) – going from what is to what should be, from factual description to moral evaluation – should they be more involved?

Survey results showed the link between the developing of individual morality and chronic pathology. Individual morality is elaborated through body experience: children's and adolescents' experiences are conditioned by their state of health, that influences their judgment and their evaluation about what is right and good for them.

Although "adversity may increase knowledge, skills and courage when children cope with disability or illness in ways that more fortunate people may not imagine" (Alderson, 1990), the children and adolescents from our pilot project who suffered from complex ailments were less autonomous in their conception of morality: what they consider "good" is what is prescribed to

³ Scott defines the "hidden transcript" the "discourse that takes place off 'stage', beyond direct observation by powerholders. Hidden transcript is thus derivative, in the sense that it consists of those offstage speeches, gestures, and practices that confirm, contradict, or inflect what appears in the public transcript"; while public transcript is "the open interactions between subordinates and those who dominate" (Scott, 1990).

them. They do not question procedures, raise questions, move for claims, want to know anything more. They consider “good” what is considered so by the adults relevant for them. Very few teens seemed to have any drive towards moral autonomy, which according to Jean Piaget clicks in around age 7.

To develop their morality, children who suffered from complex ailments showed the need to feel their fragility protected. Moreover, they showed more dependence on their parents and were less confident and friendly with their peers.

Medical environment does not encourage children and adolescents to make their own choices: neither parents or medical staff encourage them.

In this survey children and adolescents don't seem to experience the will to be involved in the choices about their health and their bodies. They do not realize to have title, competence and right to manage their own care.

With these assumptions, from an ethical point of view, what should be done to improve clinical practice?

If “enhance their [children's] choices and their [children's] control over their lives” (WHO, 2007) is considered a valid moral rule, then, for their best interest, children should be educated to become decisional agents, moral subjects, whose wills need to be respected. Children and adolescents should be involved in decisional processes about their body and their care.

The experimental project have demonstrated that children and teens do not have this requirement. Children and adolescents probably do not feel this need because familiar and care contexts have never encouraged them to participate in decision-making process. The consideration that they do not manifest any need of autonomy, does not mean that the autonomy would not be beneficial for them. It is required a cultural change of clinical practice, a paradigmatic shift (Kuhn, 1962; Mori, 2012) in the scientific community that takes care to children.

Conclusions

Children and adolescents with complex diseases are infantilized, made incompetent and disempowered by the adults during the care process. The practices of negotiation that children and adolescents enact match the description of “hidden transcripts”, that is those strategies usually activated by subordinate groups aiming to resist to the dominant groups. An open involvement of children and adolescents in the decision making process should be enacted, by recognizing their competences and reducing the differential power between them and the adults, implied in the clinical encounter.

References

- Alderson, P. *Choosing for children: parents' consent to surgery*. Oxford: Oxford University Press; 1990.
- Alderson P. Competent children? Minors' consent to health care treatment and research. *Social Science & Medicine* 2007;65:2272-83.
- Appelbaum PS. Assessment of patients' competence to consent to treatment. *N Engl J Med* 2007;357:1834-40.
- Beauchamp TL, Childress JF. *Principles of biomedical ethics*. Oxford: Oxford University Press; 1979. Trad. it. *Principi di etica biomedical*. Firenze: Le Lettere; 1999.

- Bluebond-Langner M, Korbin J. Challenges and opportunities in the anthropology of childhoods: an introduction to 'children, childhoods and childhood studies'. *American Anthropologist* 2007;109(2):241-6.
- Censi A. *La costruzione sociale dell'infanzia*. Milano Franco: Angeli; 1994.
- Hardman C. Can there be an anthropology of children? *Childhood* 2001;8(4):501-17.
- Harris JR. *The nurture assumption: why children turn out the way they do*. New York: Free Press; 1998.
- Hirschfeld LA. Why don't anthropologists like children. *American Anthropologist* 2002;104(2):611-27.
- Hume D. *Treatise of human nature (1739-40)*. Trad. it. Trattato sulla natura umana. In: *Opere filosofiche*. Vol. I. Roma-Bari: Laterza; 2004.
- Kleinman I. The right to refuse treatment: ethical considerations for the competent patient. *Can Med Assoc J* 1991;144:1219-26.
- Kuhn TS. *The structure of scientific revolutions*. Chicago: Chicago Un. Press; 1962-1970. Trad. it. *La struttura delle rivoluzioni scientifiche*. Torino: Einaudi; 2009.
- Mori M. *Introduzione alla bioetica*. Torino: Espress; 2012.
- Scott JC. *Domination and the art of resistance: hidden transcripts*. New Haven, CT-London: Yale University Press; 1990.
- Van der Geest S. Grasping the children's point of view? An anthropological reflection. In: Bush P, et al. (Ed.) *Children, medicines & cultures*. New York-London: Pharmaceutical Products Press (Haworth); 1996. p. 337-47.
- World Health Organization. *International classification of functioning, disability, and health. Children & Youth Version (ICF-CY)*. Geneva: WHO; 2007.

IBSEN'S *GHOSTS*: AN ALTERNATIVE MODEL FOR LEARNING ABOUT RARE DISEASES

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“It may perhaps seem to you as though our theories are a kind of mythology, and, in the present case, not even an agreeable one. But does not every science come in the end to a kind of mythology like this? Cannot the same be said to-day of your own Physics?”
(*Why war?* Sigmund Freud and Albert Einstein, 1964).

“To say that all human thinking is essentially of two kinds – reasoning on the one hand, and narrative, descriptive, contemplative thinking on the other – is to say only what every reader’s experience will corroborate.”
(William James, 1983)

According to the historian Hayden White (1987), “narrative” is a word derived from two Latin words: *gnarus*, an adjective that stands for “knowing” or “skillful” and *narro*, a verb meaning “to tell”. The root, however, originated from the Sanskrit *gna* – “to know”. If we ponder on it, *knowledge* is what lies at the very root of narrative, not only when we think of narrative as a linguistic sign, a word, but also when we reflect on it in terms of narrative theory, and beyond. Thus, narrative could, and should, be understood as a *model* through which we pass and gain certain knowledge. This thought, of course, is not new. Without relying on etymology, French philosopher Jean-François Lyotard (1984) had expressed it well when he defined the narrative act as the “quintessential form of customary knowledge”.

Even though narrative approaches have become an acknowledged and influential practice during the last decades, the disciplines affected by them could be traced within the range of human sciences. It wasn’t until the field of narrative medicine had appeared on the horizon that narrative approach found its way into a field close to, and often identified with, physical sciences – healthcare science (Hunter, 2009). However reasonable this may have seemed, given that physicians are, in fact, confronted with narratives on which they rely in more ways than one, it was at the same time quite surprising.

As Hunter noted, clinical medicine:

shares its methods of knowing with history, law, economics, anthropology, and other human sciences less certain and more concerned with meaning than the physical sciences. But unlike those disciplines, it does not explicitly recognize its interpretive character or the rules it uses to negotiate meaning.

(Hunter 1996, cited in Greenhalgh & Hurwitz, 1999).

The part of the clinical practice that was most affected by the epistemological turn Hunter made was the part that most has to do with knowing and knowledge: the diagnostic practice. Ideally, the diagnostic practice would entail the narrative model of communication that involves three participants: a narrator, a narrative message and a narratee, the one to whom the narrative

message is addressed. Nevertheless, because of the specificity of the diagnostic communicative situation, the participants of the model take a certain form. The narrator, in this case, is a patient¹ who selects events and narrates about them from a perspective that *a priori* determines the range of information he is able to provide. The product of his narrative activity is the narrative discourse, which represents an encoded narrative message. In this instance, the narrative message is hermeneutically encoded, which means that it has a hermeneutical gap in the story that requires filling-in. The range of these information gaps can vary both in number and importance in a narrative discourse, but in a medical narrative there is one permanent gap in the story that is the focal point of the diagnostic process: *What is the diagnosis?* (Rimmon-Kenan, 2002). This means that the physician is never just a narratee, but also a reader. However, in order to become a reader, the physician first needs to place himself in the position of a narratee, in order to create an environment that enables the narrative act. Being appropriately appealing is the first and the most important factor for this.

Why have I used the word “reader”? Reading is a process that, in many ways, is analogous with the diagnostic process. Reading has two aspects – the integration of the data and the filling-in of gaps.

Making sense of a text requires an integration of its elements with each other; an integration that involves an appeal to various familiar models of coherence. The assimilation of the text into *déjà-vu* models is called “naturalization” by Culler: “to naturalize a text is to bring it into relation with a type of discourse or model which is already, in some sense, natural and legible.

(Rimmon-Kenan, 2002)

These “models of coherence” (Rimmon-Kenan, 1983), “codes” (Barthes, 1974), or “frames of reference” (Hrushovsky, 1976) form the basis of what has already been read, seen, done and experienced (Barthes, 1974). They are structures and concepts to which the readers refer in order to decode, or, in other words, to integrate a narrative message and make it intelligible.

When the narrative message is hermeneutically encoded, the role of the reader becomes central and information divulgence depends solely on the reader’s *knowledge* and *competence*. If the central information is omitted, the purpose of the reading act is to fill in the gap upon which, and because of which, a narrative is constructed. In that case, the integration of the existing information happens simultaneously with the construction of hypotheses.

What is more, the reading process follows a specific pattern that involves these reading activities:

1. detecting a gap;
2. searching for clues;
3. forming hypotheses;
4. trying to choose among them;
5. constructing one finalized hypothesis.

However, it is important to bear in mind that hypotheses are always grounded in *déjà-vu* models of coherence; that they are, in other words, formed by reference to them (Rimmon-Kenan, 2002).

¹ Not necessarily, of course. Difference should be made between the patient’s narrative discourse and narrative discourse of a person other than the patient because they significantly differ in point of view. A research on limits of both is perhaps equally as important as a research on their interplay, particularly regarding counter-narratives

Therefore,

dynamics of reading can be seen not only as a formation, development, modification and replacement of hypotheses but also as the construction of frames, their transformation, and dismantling

(Rimmon-Kenan, 2002).

If we now think about the diagnostic process (Figure 1) in light of these facts, we can conclude that decoding the patient's narrative message entails two steps: 1) the reconstruction and the abstraction of the story, understood as a non-verbal chronological sequence of events, from the narrative discourse²; 2) the selection between them on the basis of familiar models of coherence acquired through medical education and clinical practice and drawing a map of possible plots by marking possible causal connections³.

However, a fact that is often neglected is that the story is approachable only through the narrative discourse. The narrative discourse, on the other hand, is also encoded and its decoding requires models of coherence as well.⁴

² There are several distinctions that should be made here for the sake of the argument. The first is the difference that narratologists make regarding the notions of narrative discourse and story. As Abbott, following the structuralists, fairly points out, "narrative is the representation of events consisting of a story and narrative discourse; story is the event or sequence of events (the action), and narrative discourse is those events as represented" (Abbott, 2002). Therefore, story refers to what is told and discourse to how it is told. Narratologists have however shown that elements of narrative discourse largely determine not only how a story is going to be told but also what story is going to be told.

³ The other important distinction, not so much for literary works as for this particular analysis of medical narrative, is the one Forster made between story and plot: "We have defined story as a narrative of events arranged in time-sequence. A plot is also a narrative of events, the emphasis falling on causality. 'The king died *and then* (cursive mine) died the queen' is a story. 'The king died and then died the queen died *of* (cursive mine) grief' is a plot." (Forster, 1963). However, as Chatman noted, even in the first sentence, where there is no overt indication of causation, readers will supply the causal nexus (Chatman, 1978), that is, they will naturalize the sentence by narrativizing it (Abbott, 2002). Given that the complex issue of causation exceeds the length of this paper and note, I will limit myself to a few remarks. If we take a look at the model of communication, we can say that "The king died and then the queen died of grief" is narrative discourse. The narrator may in this case be, for example, someone close to the queen telling this to a doctor. Therefore, it is important to note that plotting can be, and often is, a part of narrative discourse. What a doctor in this instance does is he breaks the causal link present in the narrative discourse, and extracts the story: The king died and then died the queen. Those are the facts. "Are these two events related, and if they are, then how?" is what he will probably ask himself next. The king could have had some infectious disease, for example. Also, a good doctor will keep in mind the narrator's plotting (p) even though he won't accept it as the cause (C). The fact that the queen was grieving for the late king may also serve as an indication. Grief might have caused (c), triggered, the queen to poison herself (see Chekhov's story *The Examining Magistrate*) and the narrator may not be aware of this event. Not less important, plotting (p) is also a valuable source of medical knowledge. For example, hereditary angioedema plot (P) is that C1-INH deficiency (C) causes episodes of edema. Nevertheless, what triggers HAE attacks is known only on the basis of patients' narratives, their plotting (p), why emotional stress is believed to be one of common attack triggers (The Physician's Guide to HAE, 2010). Thus, as should be noted, patients' plotting already forms part of medical knowledge, especially with regard to rare diseases (Mancini, 2011).

⁴ "We are always called upon to be active participants in the narrative, because receiving the story depends on how we construct it from narrative" (Abbott, 2002).

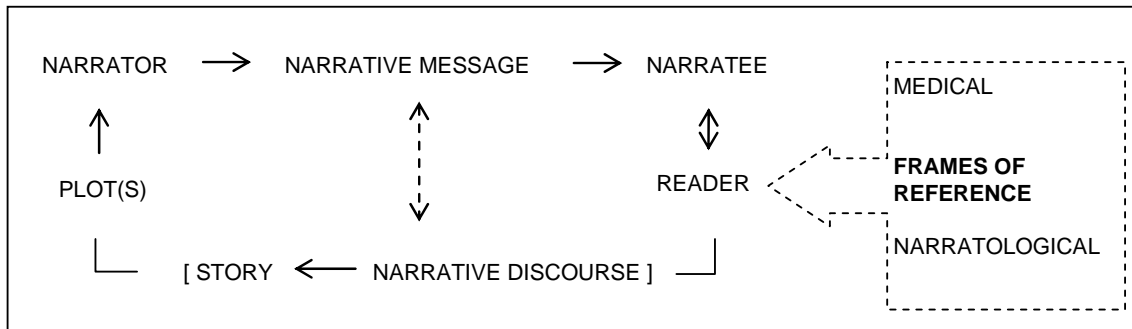


Figure 1. The diagnostic (narrative) model of communication

Therefore, a narrative message of this type is always at least double coded and the omission of these narratological models of coherence in the diagnostic practice would be unacceptable. The selection is a part of narration just as it is of the interpretation, which means that while a permanent “gap in the story entails a gap in the narrative discourse, a gap in the narrative discourse need not entail a corresponding gap in the story” (Rimmon-Kenan, 2002). Both the selection and the construction of events depend on the narrator and his particular narrative situation. Therefore, it is my opinion that it is important to examine and give a description of the prevalent narrative situation and narrative modes in the medical communication on the grounds of the theory of narrative. That would, of course, entail the creation of a research field within the narrative medicine that would focus on narrative discourse in the medical context, that is, on *medical narratology*.

Although these theoretical frames of reference are irreplaceable - after all, knowledge encompassed by these frames is what draws a distinction between professionals and lay people - I wish to emphasize the fact that I am not arguing for the implementation of an additional decontextualized set of frames to those already present in medical academic curriculum. Narratological knowledge can be acquired in a different manner.

It is my profound belief that learning is never just a simple assimilation of denotative knowledge. How we learn is perhaps equally as important as the knowledge we receive. The way we learn shapes our mind and forms our patterns of thinking, thus creating something comparable to a net that we later cast on whatever preoccupies our mind. It is not surprising that diagnostic practice takes the form of interrogation more often than does listening. Consequently, patients report more than they narrate, reciting their symptoms as if they are reading from a medical textbook. The very root of this *circulus vitiosus* lies, in my opinion, at the taxonomic method of learning as the only learning paradigm. Some professors may indeed repeat to their students: “Listen to the patient: he is telling you the diagnosis” (Hunter, 2009), but the model of learning repeats otherwise.

The question that naturally arises is how can the right form of listening and the adequate thinking pattern be learned? The answer is that they cannot, in the traditional sense of the word learning, since they are acquired skills. As such, they are acquired through practice. But as I have previously shown, the model of learning shapes the model of practice. Therefore, it is necessary to pose the following question: What alternative model of learning would be able to provide a vicarious experience that would encourage the formation of the appropriate behavioral model and that would at the same time employ both medical and narratological frames of reference and foster a proper pattern of thinking?

The Norwegian playwright Ibsen supplied the answer to this question when he wrote *Ghosts*. Ibsen's play is encoded with many different gaps. Whereas some of them are filled-in by the text upon the completion of reading, some were left open for readers to fill in. One of the permanent hermeneutical gaps, and in my opinion perhaps the central one, is medicinal in nature: What is one of the main characters, Oswald Alving, suffering from? As we can see, Ibsen employed double-coding when writing *Ghosts*. As a result, he created an intriguing work of art that speaks to two different audiences in two different ways. Literary scholars and physicians were both intrigued, but while the first studied Ibsen's broad repertoire of dramatic techniques, the second discussed the possible diagnosis. The idea that prevailed was that Oswald Alving suffered from a rare disease (Hoening, 2009).

I propose that Ibsen's play be used as a structural model for the creation of texts that would be collected and issued as a medical workbook and to be implemented in the medical academic curriculum. Additionally, I consider that the gap should entail a rare disease diagnosis, for two reasons, since rare diseases are difficult to diagnose. Firstly because they are deceiving and can easily be mistaken for other, more frequent medical conditions. For example, hereditary angioedema may easily be mistaken for allergies or appendicitis. Rare diseases produce a variety of misleading plots, making them diagnostically challenging and perhaps methodologically very adequate for acquisition of diagnostic proficiency. Secondly, because they are rare, diagnosis is very unlikely if the physician hasn't already treated a case and early diagnosis is uppermost in treating rare diseases. Thus, it is my belief that imaginative experience that would be provided by this workbook would compensate for the lack of real clinical experience.

Each story in the workbook would be about one rare disease. There would be a team for each story that would consist of a literary scholar and a physician, a writer and the patients suffering from that disease. A qualified writer would be writing an encoded story on the basis of patients' experience, with the literary scholar and the physician helping him to encode the story. Following the completion of the project, I propose that the texts are discussed and taught in class from all of the aspects they encompass – both medical and narrative – because only if taught together will future physicians come to realize how inextricably related they in fact are. The main idea is that students practice to diagnose the patient using only the information disseminated across the text.

It is my belief that in this way future physicians will not only acquire the needed diagnostic proficiency by learning to use their medical and narratological knowledge in a certain way, which will make them more proficient “readers” of real patients' narratives, but that this way of learning will also enable long-term retention of rare disease knowledge that will be the first step toward resolving the problem of early detection of rare diseases.

References

- Abbott HP. *The Cambridge introduction to narrative*. Cambridge: Cambridge University Press; 2002.
- Barthes R. *S/Z*. Translated by Miller R. New York: Hill and Wang; 1974.
- Chatman S. *Story and discourse: narrative structure in fiction and film*. Ithaca, NY: Cornell University Press; 1978.
- Forster EM. *Aspects of the novel*. Harmondsworth: Penguin; 1963.
- Greenhalgh T, Hurwitz B. Narrative-based medicine: Why study narrative? *British Medical Journal* 1999;318(7175):48-50.
- James W. *Brute and human intellect. Essays in psychology*. Cambridge, MA: Harvard University Press; 1983.

- Hoening LJ. Congenital neurosyphilis as portrayed in Henrik Ibsen's *Ghosts*. *Dermanities* 2009;6(1).
- Hunter K. Thinking about thinking: implications for patient safety. *Healthcare Quarterly* 2009;12(Special Issue):191-4.
- Lyotard JF. *The postmodern condition: a report on knowledge*. Translated by Bennington G and Massumi, B. Minneapolis: University of Minnesota Press & Manchester: University of Manchester Press; 1984.
- Mancini E. Glossario. In: Taranto M, Taruscio D (Ed.). *Controvento*. Roma: Istituto Superiore di Sanità; 2011.
- National Organization for Rare Disorders. *The physician's guide. Hereditary angioedema (HAE)*. Danbury, CT: NORD; 2010. (Nord Guides for Physicians #10). Available from: http://www.rarediseases.org/docs/HAE_3_8.pdf; last visited 18/3/13.
- Rimmon-Kenan S. *Narrative fiction: contemporary poetics*. Ithaca, NY: Routledge; 2002.
- Freud S. *The standard edition of the complete psychological works of Sigmund Freud*. Translated from the German under the general editorship of James Strachey. Vol. 22. London: Hogarth Press; 1964.
- White H. *The content of the form: narrative discourse and historical representation*. Baltimore: The John Hopkins University Press; 1987.

Session III

Chairpersons
Stefania Polvani, Mirella Taranto

LITERARY AND FILM REPRESENTATIONS OF BREAST CANCER

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The purpose of this presentation is to illustrate and analyse representations of breast cancer in young women, in contemporary literary and film production. The present brief paper is the first stage in a more ambitious research project in progress, due to be developed in the future. As such, it should be considered as provisional.

In particular, my analysis will focus on the short novel *The Dying Animal* (2001) by the American writer Philip Roth and the film adaptation of this novel by the Spanish director Isabel Coixet, under the title *Elegy* (2008).

Before looking closely at these two works, some crucial arguments have to be considered, as they may serve not only as an introduction but also as critical suggestions for debate.

To my knowledge – I am not a specialist – data on the incidence of breast cancer in women under 40 is debatable, but it is clear that numbers are growing. In a recent radio interview, an oncologist declared that young women affected by breast cancer are rare exceptions. This tells us that we have here a sensitive aspect worth investigating and clarifying.

The growing number of young women affected by breast cancer sparks off not only the need to find models in literature and in cinema, but also an urge to narrate personal experiences of illness. Through personal accounts, these young women are inspired to give voice to a variety of conflicting feelings and concerns. Having said that, we need to identify different kinds of narratives.

To begin with, there is a fundamental distinction to be made between the autobiographical narratives written by women who have had to battle breast cancer and the narratives written by other (not directly affected) authors who depict the illness. These accounts display both similar and different features. There are three evident dissimilarities, one being the different degree of personal involvement, the second the different genre chosen to describe this disease; and the third related to points of view: the insider's and the outsider's. On the other hand, crucially, the two kinds of narrative have several points in common, in other words they share common features. If in the autobiographical narratives (as Rita Charon points out by reference to post-modern theory) "the identity is both declared and created with narrative" (Charon, 2006, p. 73), it is also true that narratives contribute to creating the language and the images through which we build our own identities. These narratives, for instance, share a set of imagery and metaphors; both are influenced by the predominant representations of illness spread by media, literature and cinema. It seems that all these narratives show the dichotomy between mind and body rooted in Western cultures and societies.

This presentation focuses on the second kind of narrative. *The Dying Animal* is the last book of a trilogy portraying the life of a fictional professor, David Kepesh. The books that precede it are entitled *The Breast* (1972) and *The Professor of Desire* (1977).

The novel focuses on the professor's life, but the most important character is Consuela Castillo, a young Cuban student of his with whom he had a passionate love affair. Cutting to the chase, we may say that Philip Roth's recurrent topics are sex, body, narcissism, fear of getting old, fear of getting ill, illness itself and fear of dying, or – if you prefer – death. In his books, *The Dying Animal* included, he comes close to pornography in his descriptions of sexual details

and fetishisms. David Kepesh's particular fetish is "breasts" – in fact in the novel entitled *The Breast* the professor turns, through a Kafkaesque metamorphosis, into a female breast. It is clear that in this novel breast cancer is regarded from a male perspective or, to put it better, through the male gaze.

Following the approach of the feminist scholar, Zillah Eisenstein, author of *Manmade Breast Cancer* (2001), *The Dying Animal* is a strikingly masculine cultural product. Indeed, in her book she writes: "In order to see how breast cancer is manmade, its various environments must be uncovered as a part of the setting for science. Masculinist fantasies equate the body with its breasts and ovaries. One sees this in sculpture from prehistoric times. Breasts distinguish the female. They are the outer symbol of femininity. As one explores Pablo Picasso's art one looks for the breast to find the woman. [...] The symbolic breast infiltrates the flesh and becomes as cultural as it is biological" (p.110).

This quotation illustrates the influence of art representations in the perception of breasts both by women and men. In the novel, Consuela sends a postcard to David Kepesh with a Modigliani nude from the MOMA: this nude is the alter ego of Consuela, as we can read in the following passage:

By the trademark Modigliani nude, the accessible, elongated dream girl he ritualistically painted and that Consuela had chosen to send, so immodestly, through the U.S. mail. A nude whose breasts, full and canting a bit to the side, might well have been modelled on her own. A nude represented with her eyes closed, defended, like Consuela, by nothing other than her erotic power, at once, like Consuela, elemental and elegant. A golden-skinned nude inexplicably asleep over a velvety black abyss that, in my mood, I associated with the grave. One long, undulating line, she lies there awaiting you, still as death. (p. 98)

The professor describes Consuela's beauty always referring to her breasts and it seems that Consuela is her own breast. This metonymy reduces Consuela to a part of her anatomy. David Kepesh declares: "There are two things you notice about Consuela's body. In the first place, the breasts. The most gorgeous breasts I have ever seen – and I was born, remember, in 1930: I have seen quite a few breasts by now. These were round, full, perfect etc." (p. 28).

The novel may be divided into two parts: the latter part is devoted to the description of Consuela's illness and the reactions of her former lover to her illness.

The relationship between the 60-year-old professor and 24-year-old student lasts one year and a half. After eight years, Consuela goes to visit him on New Year's Eve. She arrives at Kepesh's place with a hat and when he asks her about the hat she answers she doesn't want to take it off because she is very ill. Consuela is concerned about her physical appearance and says: "You've seen my body at its most glorious. So I wanted you to see it before it is ruined by what the doctors are going to do" (p. 131). Consuela is shocked, devastated at the idea of losing her beauty and her youth and she wants Kepesh to take some photos of her breasts before they are transformed by medical treatments.

Below have been gathered a number of passages from the novel that poignantly describe Consuela's feelings and her fears. They may be seen to symbolize or reflect the fears and feelings of any young woman in similar circumstances:

1. "My doctor's trying everything to keep the surgery minimal. She's humane. She is wonderful. She is not a butcher. She is not a heartless machine" (p. 132).
2. "[Consuela] no longer measures time like the young, marking backward to when you started. Time for the young is always made up of what is past, but for Consuela time is now how much future she has left, and she doesn't believe there is any. Now she measures time counting forward, continuing time by the closeness of death. The illusion has been broken, the metronomic illusion, the comforting thought that, tick tock,

everything happens in its proper time. Her sense of time is now the same as mine, speeded up and more forlorn even than mine. She, in fact, has overtaken me” (p. 148).

3. “Terrible, terrible longing. And that’s what I have. But it’s for myself. It’s for my life. I feel myself, I feel my body with my hands, I think, this is my body! It can’t go away! This can’t be real! This can’t be happening! How can it go away? I don’t want to die! David, I am afraid to die!” (p. 150).
4. “In every calm and reasonable person there is a hidden second person scared witless about death, but for some thirty-two the time between Now and Then is ordinarily so vast, so boundless, that it’s no more than maybe than a couple of times a year, and then only for a moment or two and late at night, that one comes anywhere near encountering that second person and in the state of madness that is the second person’s everyday life” (p. 153-154).
5. “I experienced at that moment not only as a shock but as a betrayal. A betrayal of Consuela for my having so rapidly absorbed the shock and made this accounting. The traumatic moment was upon us when the change occurs, when you discover that the other person’s expectations can no longer resemble yours and that no matter how appropriately you may be acting and you may continue to act, he or she will leave before you do – if you’re lucky, well before” (p. 155).
6. “She’s thirty-two, and she thinks she’s now exiled from everything, experiencing each experience for the very last time” (p. 155).

These passages encapsulate the most important issues about illness and youth. Philip Roth describes this experience in a raw, violent and cruel way insisting on some horrible aspects and ending the novel with a gloomy, unclear conclusion.

Now let us look at the film. The filmmaker Isabel Coixet remoulds Roth’s material into a softer and more acceptable version, probably also because the film is intended for a wider audience. In *Elegy*, Consuela’s nudity and breasts are not morbidly depicted as in *The Dying Animal*. Consuela doesn’t appear with a hat or bald; the only hint seems to be her short hair and professor Kepesh seems to be more compassionate and less selfish than he is in the novel. In fact, he goes to see Consuela at the hospital after surgery (the end of the novel is not clear about that). He tries to cheer her up by narrating the myth of Hippolyta, the Amazon queen, and reassures her about his presence.

In conclusion, if we compare these representations of breast cancer in young women with some autobiographical narratives, we find a lot of points in common. Cancer puts patients suddenly and abruptly in a marginal space where they are exposed with their bodies to violent therapies, to loss and death. Because of that, these patients often feel dispossessed of themselves. Thus, their autobiographical narratives become an instrument to recover their former identities and to process and acquire new ones. “Perhaps” – as the American philosopher Judith Butler argues – “we can say that grief contains the possibility of apprehending a mode of dispossession that is fundamental to who I am” (Butler, 2004, p. 28).

The closeness of death and the undesirable body changes seem to compel young patients to transform their own private pain into something public. Cancer brings vulnerability, which is common to all human kind, to the surface. These patients want to communicate fears and their sense of loss, which Western societies have labelled as inconvenient and uncomfortable to discuss.

References

- Bert G. *Medicina narrativa. Storie e parole nella relazione di cura*. Roma: Pensiero Scientifico Editore; 2007.
- Biasini G. *Come una funambola. Dieci anni in equilibrio sul cancro*. Roma: Ilmiolibro; 2011.
- Butler J. *Antigone's claim*. New York: Columbia University Press; 2000.
- Butler J. *Precarious life*. London-New York: Verso; 2004.
- Butler J. *Giving an account of oneself*. New York: Fordham University Press; 2005.
- Charon R. *Narrative medicine: honoring the stories of illness*. New York: Oxford University Press; 2006.
- Marzano M. *La filosofia del corpo*. Genova: Il Melangolo; 2010.
- Russo AL. *Toglietemi tutto ma non il sorriso*. Milano: Mondadori; 2012.
- Deshazer MK. *Fractured borders. Reading women's cancer literature*. Ann Arbor, MI: University of Michigan Press; 2005.
- Roth P. *The dying animal*. London: Vintage; 2002.
- Roth P. *The breast*. New York: Holt, Rinehart and Winston; 1972.
- Roth P. *The Professor of desire*. New York: Farrar, Straus and Giroux; 1977.
- Sontag S. *Illness as metaphor and Aids and its metaphors*. New York: Picador; 1977.
- Sontag S. *Regarding the pain of others*. New York: Picador; 2003.
- Eisenstein Z. *Manmade breast cancer*. Ithaca, NY: Cornell University Press; 2001.

RELEVANCE OF ILLNESS EXPERIENCES ON TRUST AND HELP RELATIONSHIP BETWEEN NURSE AND PATIENT WITH THALASSEMIA

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In caring patient with thalassemia, the nurse worries to create an open relationship, an exchange, a report, but above to establish a climate of trust.

The trust is the basis of the human relation: it is present in the emotional relationships (as the friendship). It is less emotional in relationships as those between citizen and institutions.

The trust can be represented symbolically as a scale that the nurse has to go, ranging from listening, empathy, support, arriving at the final result (the trust).

The trust relaxes the tension between present and future, where there are the uncertainty and the risk is not known. Space and time are enclosed in the helping relationship between nurse and patient, but space and time are not enough to trust each other. The security is given by the known risk and it excludes makes useless trust. Trust means risk.

One who trusts in another, he forces to behave in a precise way: all that that time will be, it will be measured to define if trust placed in him was well spent: why not trust?... Naïve.

The trust has the connotation of a responsible action choice: you decide to live using rationality in order to have a certain amount of serenity.

The helping relationship is defined as a “proper interpersonal communication process that promotes quality contact between health professional and a person in need of treatment” (Marchi, 1993)”. It promotes mutual understanding between two people and raises the therapeutic relationship between nurse and patient. The nurses offer help: this is their job; thanks to the communication, they promote interaction with the patient, encouraging the emergence of feelings, thoughts and values. Thanks to the variable help, communication becomes more effective, even in the most difficult relationships.

The nurses job satisfaction is a variable for an effective helping relationship: today there is a correlation between the satisfaction of the health professional and that of the patient, in the new vision of health services quality.

By nature, the processes of production and supply of health and social services are not passive, but active, because performance is a person who produces.

The new Code of Ethics of Italian Nurses (2009) states that communication between nurse and patient is of interactive type (art. 20).

The patient living with the rare disease thalassemia, which imposes itself by force and intensity as to fundamentally alter the relationship with oneself and with others, involved a keen sense of treat and uncertainty because of the connotations of chronicity and disability. In his life the patient constantly challenge his role: the personal, family, social and affective relationships are often compromised by problems related to pathology. In fact, sometimes the presence of hypogonadism and infertility reinforce mechanisms of defence, closing at interpersonal relationships.

The chronic condition affects the thalassaemic patient’s social role; he feels the need to leave totally or reduce the work because of her body image that changes with the passage of time. Exceed the continuous regret and comparison of the previous condition that has been altered, for example, from the teeth and cheeks or more protruding from the onset of infection. Negative

events such as insomnia, irritability, mood swings are to be interpreted as indices of adaptation and not as psychiatric symptoms.

The characteristics of thalassemia define the patient expert: he is not only a great expert on the disease in all its features but also on the applicable law and on their rights. The patient with thalassemia is rightly angry and more combative than others, for the connotation of “rare disease” who has placed the thalassemia in a condition of discrimination compared with other diseases. This condition made it too often the victim of poor health policies.

Good management of chronic disease can improve the quality of life of the thalassemic patient: the new oral iron chelation therapy; the ability to get compensation for viruses (AIDS, hepatitis) contracts in the past during blood transfusions. The realization of maternity and paternity more real with medical progress: more opportunities for work and social level. Step by adaptation to death than of life, which today is one year long.

A phenomenological qualitative research was carried out on experiences, emotions and feelings of thalassemic patients between twenty-nine and fifty-six years, in a day hospital in a Health Centre in Rome. The central theme of the study is the relationship established between nurse and patient through the contribution of nursing narrative by focusing on the relationship of patient care by the trust and support of the nurse. Analysis of study consists of reaction to the interview, the common traits, the significant phrases and study the words. The tools used were narrative interviews, recorded live with the written consent of the patient, and direct administration. It consists of areas of investigation together with a observational description sheet concerning each patient:

- general attitude;
- body language;
- verbal communication;
- nonverbal communication.

The results showed that:

- the patients' reaction to the interview were:
 - kind;
 - quiet;
 - genuine;
 - proactive;
- the common traits present in patients were:
 - presence of holistic pain;
 - anxiety and fear for the future;
 - feeling of sympathy;
 - social integration;
 - respect and discretion by operators;
 - great desire to speak.

Significant phrases that have given rise to emotions and feelings:

- “The attitude of nurses is positive”;
- “Nurses are responsible”;
- “For me are like a second family”;
- “Tend to meet you as much as possible”.

The study of words permits the evidence of the many traits of experienced psychological and emotional. The terms which emerge have been:

- Contact-empathy: approach, attend, resemble, belonging;
- Affectivity: be patient, give hope, feel protected, advice;
- Denial: judge, reject, isolate, fight.

In conclusion, the narrative in the Health Centre for Thalassemia:

- highlighted the proactive approach and desire to communicate with the patient;
- underlined the demand for a greater emotional of nurses in the care process;
- noted the manifestation of positive and negative experiences in the experience of illness.

The idea of a feeling of trust placed in nurse is reinforced: in a score from 1 to 10, the degree of confidence is higher than 8.

The nursing profession has, as a starting point, the constant reference to human and the values it carries within. For several decades there has been an opposition between the technology-oriented medicine and the medicine that humanized the disease, patient-oriented, that values listening narration and the experiences of the disease of people...because the disease itself does not exist: it is related to the human.

In this new scientific perspective and social condition of the patient, you put the path, in the last decade, of the nursing profession which reached great intellectual an educational target, accompanied by a high sense of responsibility. The New Code of Practice Nurse is part of this path:

“Nurse understands the importance of the dialogue with the other” (art. 8).

“Nurse helps and supports the client and adjusting the communication personal abilities of the patient” (art. 24).

“The Human Person and his true good is the measure of the Authenticity of every action and progress. What is good and evil coincides with what is truly human and what is not.” (Spinsanti, 2000).

References

Marchi R. *La comunicazione terapeutica: interazione infermiere-paziente*. Milano: Edizioni Sorbona; 1993.

Federazione Nazionale Collegi Infermieri. *Nuovo Codice Deontologico degli Infermieri Italiani*. Roma: IPASVI; 2009. Available from: <http://www.ipasvi.it/norme-e-codici/deontologia/il-codice-deontologico.htm>; last visited 18/3/13.

Spinsanti S. *Curare e prendersi cura*. Roma: Edizioni CIDAS; 2000.

THE ILLNESS EXPERIENCE IN AN INTERREGIONAL REFERENCE CENTRE FOR RARE DISEASES: NARRATIVES OF PATIENTS AND HEALTH PROFESSIONALS

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The project “Pathways of care focused on people with rare diseases to improve the quality of care through narrative method” began with the joint cooperation of various different institutions and was carried out through the collaboration of Local Health Unit TO2, the Interregional Reference Centre for Rare Diseases (*Centro Multidisciplinare di Ricerche di Immunopatologia e Documentazione su Malattie Rare*, CMID), the Centre’s Nursing Services and the Master program in nursing and obstetrics sciences of the University of Turin.

The shared objective was to respond to the call by the European Community recommendations to improve our understanding of rare diseases, exploring this little known area by fostering awareness of such illnesses, the care provided to patients, and the training needs of health professionals working with these patients.

The idea was to give voice to persons with rare illnesses by eliciting narratives on their experiences and problems in coping with the illness, as well as involving health professionals to delineate their perspective on caring for patients with such diseases.

The study was conducted from 2009 to 2011 and was funded by the Region of Piedmont in the framework of targeted research projects.

The objectives were:

- to explore the experiences of illness in patients with a rare disease and the experience of the health professionals caring for them;
- to compare the salient elements that emerged from the interviews, with a view to highlight the positive and critical aspects of health services.

The study population was persons with a rare disease, as defined by the European Union in 2005: diseases with an incidence ≤ 5 cases per 10,000 EU residents. Additional criteria were: at least one contact with a day hospital service and currently in active follow-up. The study population of the health professionals included: doctors, nurses and nursing assistants who had been working at the Centre for at least 6 months prior to the beginning of the study. The data were collected through audio recording of semi-structured interviews. Participation in the study was on a volunteer basis. All subjects were informed of the purpose of the study and gave their informed consent.

The study team designed two sets of question forms, one for the patients and the other for the health professionals, which listed topics that would stimulate dialogue and reflection as an aid to reconstructing the illness experience or the management of care for patients with a rare illness.

The interviews were transcribed and presented in a feedback session to validate the content of the transcriptions.

The texts were analyzed using a phenomenological approach according to the Colaizzi method by three different researchers who then reached a consensus on their interpretation of the study results.

A pilot study with 8 interviews was conducted between May and September 2010. During this work phase, the interview items were refined, selecting open questions on specific topics that would stimulate reflection on several issues that had emerged as relevant during the interviews.

Between May 2010 and January 2011, 22 interviews were conducted with persons with a rare disease and 12 interviews with health professionals.

The analysis of the recorded interviews revealed five topics that were important for the patients and four topics for the health professionals. The patient-related topics were: illness unwinding; living with the disease; living with everyday life; relationships with others and relationships with health professionals. The health professional-related topics were: dealing with the disease; handling expectations; building relationships; and being operators in the context.

The patients focused their attention on the difficulty of coping with the illness in everyday life. The major elements were the sense of uncertainty and precariousness linked to an illness that is initially difficult to recognize (the common problem of delayed diagnosis) and the alternating phases of stabilization and relapse of the illness. They also described the profound changes they had to face: altered body image; new routines; giving up their occupation.

Rather than being specific to rare diseases, numerous issues were common to those associated with chronic-degenerative conditions.

Many of the patients said they had devised coping strategies that enabled them to maintain self-autonomy as far and as practical as possible. Adapting to the condition also meant learning about the disease, seeking information about it and available treatment options.

In most cases, the patient's family played a pivotal role in providing support. Finally, the patients felt strongly about having a reference center for obtaining care: one place where they can go for visits, treatments, examinations and controls. Attending a single center helps them feel looked after and recognized. The patients expressed a positive opinion of the CMID, appreciating the attention they receive and the openness of the health professionals with whom they are able to build a trusting relationship. The criticalities were the frequent turnover of doctors, which generates a sense of disorientation, and the perception of not receiving enough time for communication and imparting of information, which patients may not considered sufficient or comprehensible.

The health professionals demonstrated they were particularly sensitive to the stress and difficulties their patients experienced. They recognized the suffering caused by the impact of the disease and stressed the need to approach the patients attending the Centre with appropriate delicacy and openness. They reported that, because of the long-term relationships that develop, becoming overinvolved is often inevitable. The health professionals reported to have trouble finding specific elements that could summarily describe patients with very different illnesses. Nonetheless, such illnesses create problems similar to those of chronic-degenerative conditions and require regular monitoring to check for possible worsening of the illness. The health professionals also mentioned the difficulty in meeting patients' expectations of receiving prompt diagnosis and therapy; this sometimes leads to frustration and disappointment. They also stated that the relationship with patients highly informed about their illness can be a challenge. In some cases, it may be an opportunity to share and negotiate the decision process; in other instances, they see their role as mediator and filter of information patients have gleaned from other sources.

With regard to the Centre, the health professionals identified the multidisciplinary approach as a strength, since it involves various different specialists working together to find the best treatment options possible. However, achieving effective integration of specialists in continuity of care is not always easy.

The study enabled us to explore a little known area of health care and to shed light on the personal stories, fragility, and stress persons with rare diseases experience.

The study also uncovered certain often overlooked aspects of illness, as well as the uncertainty, difficulty, and daily stress the health professionals themselves often experience when dealing with such patients. For all participants, the study provided a context that fostered reflection and rethinking of their experiences and gave them sense and meaning.

By comparing their illness narratives, the participants were able to identify strengths and weakness in the Centre's services, laying the basis for implementing actions to improve the care pathways. Finally, the participants demonstrated willingness and openness to dialogue, a sure sign for a common way forward to improve the Centre's services.

Poster session

POSTER PRESENTATION

Amalia Egle Gentile (a), Ilaria Luzi (b)

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The Centro Nazionale Malattie Rare (CNMR, the Italian National Centre for Rare Diseases) of the Istituto Superiore di Sanità (ISS, the National Institute of Health in Italy) has been organizing the Italian national congress “Narrative medicine and rare diseases” every year, since 2009. In 2012, instead, it organized the First International Congress “Narrative medicine and rare diseases”.

This Congress aimed to promote narrative medicine applied to rare diseases among health practitioners and patients and to stimulate, know and share new theoretical approaches and practical applications, at international level.

Through the call for abstract, persons busied in the field of rare diseases (physicians, nurses, psychologists, patients’ associations, etc.) were invited to present, in English language, abstracts based on any of the following topic areas about narrative medicine, with a particular attention to the rare diseases:

- research;
- education;
- quality of life;
- ethics, cinema and literature.

A total number of 31 abstracts has been submitted. Among these, the International Scientific Committee of the Congress selected 22 contributes for the poster session, distributed on the indicated topics as showed in Figure 1. The most contributes are in the “Research” area.

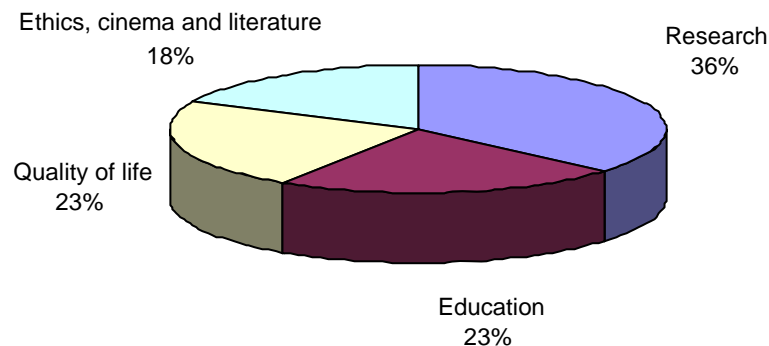


Figure 1. Posters by topic area

The 57% of the submitted works is focused on projects, studies or experiences about rare diseases (Figure 2).

Furthermore, it is worth noting that the contributes are dedicated equally enough to “health care practitioners” (35%), “patients” (35%) and “relatives” of ill persons (30%) (Figure 3).

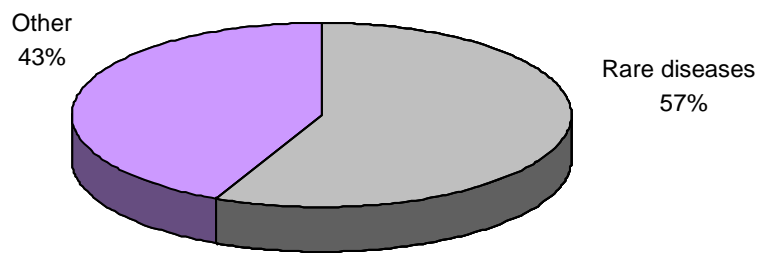


Figure 2. Posters by pathology

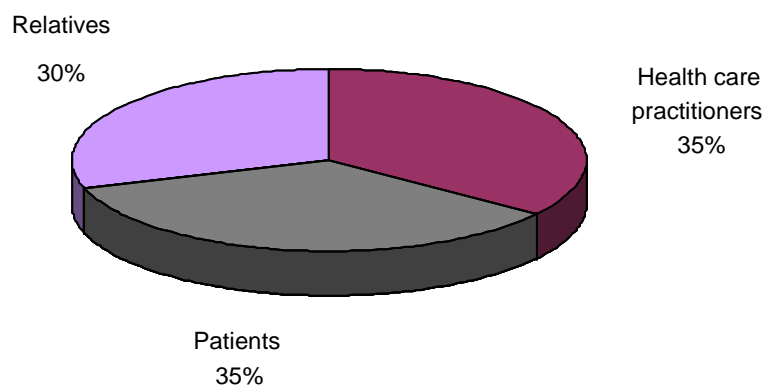


Figure 3. Posters by addressed target

Finally, we analyzed the methodology used by posters' authors in their works (Figure 4).

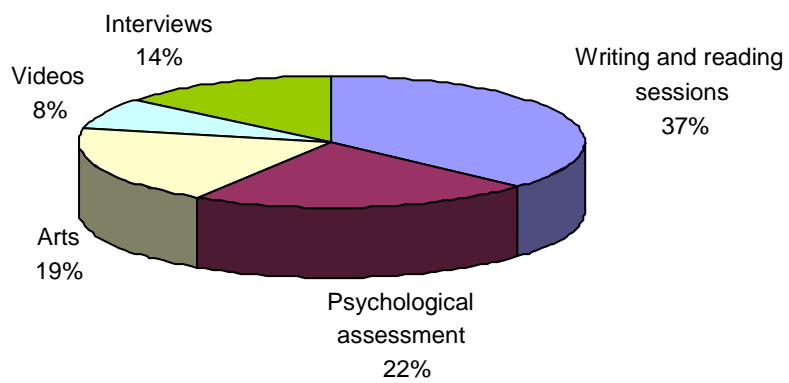


Figure 4. Posters by methodology

The most of these is focused on projects which have planned writing and reading sessions: writing about the own experiences, reading (others' experiences or also classics in the literature) and listening to stories of disease can facilitate the comprehension of what patients feel and, also important, the feelings of health practitioners about their role and the work's quality they are doing with their patients.

The Poster session is an excellent occasion for authors to show their works in an interactive setting: it allows authors and participants to get together and to talk and go into more depth on the showed works. Posters are useful to present practical experiences or to introduce innovative methods.

The posters are presented in alphabetical order of the first author.

P PSYCHOLOGICAL FACTORS' INFLUENCE IN THE ETIOPATHOGENESIS OF HEREDITARY ANGIOEDEMA'S ATTACKS IN CHILDREN AND ADOLESCENTS

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Background. Hereditary Angioedema (HAE) is a genetic and rare disease characterized by recurrent and transient edema, responsible for bloating and abdominal pain. Patients who are affected may show edemas recurring with variable frequency. Edema may be facial, laryngeal or genital, or acute abdominal pain's episodes resulting from intra-abdominal edema. In most cases HAE is caused by a defective gene that controls a blood protein called C1 esterase inhibitor (C1-INH), however is still considered a disease that also stress or emotional and physical traumas can have a significance, but there aren't still researches interested to investigate specifically this aspect. Actually, literature's examination has shown the absence of specific studies on the influence of psychological factors in patients with HAE in the age of development.

Objectives. Our study's aim is to assess how the possible presence of psychopathological problems is associated to the disease's manifestations and to observe the interaction among occurrence, frequency and quality of the attacks of HAE and stressful life events in children and adolescents, affected by this disease.

Methodology. It will be involved patients aged between 4 and 18 years, suffering from HAE, relating to the "Centro Interdipartimentale di Ricerca in Scienze Immunologiche di base e cliniche", together with the respective parents. A semi-structured interview with these last will be used as tool to explore through narrative history of their son's disease which associations and mental representations individuals relate with disease's manifestations. After, CBCL (Child Behaviour CheckList) will be administered to parents and the Diary of symptoms will be required to filled for the following year. After a year, the child/teenager will be contacted for the administration of CLES (Coddington Life Events Scales) in order to assess whether the previous year changes of life have been experimented, both positive and negative, which could be considered source of stress.

Expected results. Study's results are a greater understanding of the causes and manifestations of disease, specially from direct experience that patient do and from the sense that he attribute to it, in order to improve the assistance to children and adolescents, in the context of a global management that considers the biological dimension and psychological and social.

P THE WORKSHOP OF NARRATIVE NURSING: AN EXPERIENCE WITH STUDENTS OF THE FIRST DEGREE COURSE

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Introduction. Into university's curricula, the narrative is effective in order to acquire new competences and to facilitate a change of the psycho-relational behaviour, especially in the nursing profession, which requires the ability of manage events of an high emotional impact. In order to change the nurse's formative process it's necessary to intervene into the informal dimension of the education and to understand the hidden aspects of the training. These aspects are important because they can influence the construction of a professional identity. This is the reason why a new project of a workshop of Nursing Narrative has been planned for three years and it has been tested for the first- year students.

Objectives.

- To develop the narrative competence, the skills of listening, observation and communication through the identification of the clinical and narrative aspects of the patient's history.
- To sensitize to the "narratology" to understand the way how the patient lives the illness and the suffering, especially in the more complicated and stigmatizing diseases.

Materials and methods. Frontal classes, teamwork, role playing. The used materials, literary passages, movies and pictures, highlight all the aspects of the illness. They also help the comprehension and the management of the emotions. The construction of reading forms for the used materials create a good method to acquire the relational skills.

Results. The students can recognize the importance of the listening as a fundamental element of the mutual understanding. They can also relate personal experiences and they are able to observe attitudes and behaviours through the knowledge of verbal, no-verbal and paraverbal communication. They can also interpret the sub-message by literary, pictorial and movies works in order to implement the evaluation of the lived, emotions and the feelings of the patient, to overcome stereotyped and prejudiced observations. The students have proved to be deeply active and interested. The alternative method to be into the relationship has increased the professional motivation and the interest for deepening. The workshop has reported deeply positive evaluations.

Discussion and conclusions. The experimentation of analyze capacity from both clinical and narrative point of view has offered to the students the possibility of building a more complete professional competence and allowed to acquire the outsourced awareness of illness, in fact, the narrative creates a passage from a passive to an active cultural conception. The class-group is perceived as practical community, a competence that can be used in the working world.

P THE LITERARY DIMENSION OF DISEASE

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Introduction and objectives. Everyone's life takes place in a real dimension and one that we can call "literary" in which we become characters of a story like a novel. Only the patient's story told slowly with own language reveals the literary dimension. This dimension is inscribed in our lives and is part of our being. In neurology there are diseases that put doctors face to face with new ethical problems as in amyotrophic lateral sclerosis and dementia. The literary dimension gives back to patients their identity and allows us not to lose ours. The result is a humanized diagnostic process. The objective is to reevaluate the relationship with the patient in a literary sense.

Materials and methods. The team is composed of one neurologist, one neuropsychologist and three psychologists. The theory at the base is the biospsychosocial model of G. Engel (1977). Every patient undergoes a neuropsychological exam. A psychologist conducts the first clinical interview with the caregiver for the patient history and administers scales such as Caregiver Burden Inventory (CBI), Neuropsychiatric Inventory (NPI), Instrumental Activities of Daily Living (IADL) (Lawton & Brody, 1969), Activities of Daily Living (ADL) (Katz *et al.*, 1970). Then the caregiver is contacted again to be informed of the findings from the evaluation and be informed about the possibility of having a psychological support if necessary. Ten meetings are proposed, five individual informative and five with the patient to implement practical strategies of problem solving. The technique adopted is that of cognitive therapy.

Results. Until now we are treating three patients with corticobasal degeneration, one young patient with frontotemporal dementia, one patient with early Alzheimer, one patient with frontal post-traumatic syndrome, the wife of one patient dead with limbic paraneoplastic encephalitis. The result is to carefully listen to patients and their families in order to redefine the subjective meaning attributed to the disease in a context that takes care of their interpersonal relationships and reduces conflicts.

Discussion and conclusions. Giving the patient a "literary dignity" means to value listening and dialogue which, in present day medicine, are reduced to the minimum and employed exclusively for diagnostic aims.

References

- Engel GL. The need for a new medical model: a challenge for biomedicine. *Science* 1977;196(4286):129-36.
- Katz S, Downs TD, Cash HR. Progress in the development of the index of ADL. *Gerontologist* 1970;10(1):20-30.
- Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. *Gerontologist* 1969;9(3):179-186.

P ONE OVER ONE THOUSANDS

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Sorry, I have used the expression “one over one thousands” because it sounds well for a title, though it is not correct. More correctly, it would have to be one on 3000-3500: the incidence of the new born affected by neurofibromatosis.

My wife and I are the parents of a girl of nearly seven years, and from six years we know of the disease.

We started with medical tests on a cavernous angioma on the left cheek (now in phase of regression), we got in the mystery of the milk and coffee spots (the paediatrician mentioned the spots to us, but refused to provide further details) then after a dermatological control we got the unexpected and pitiless diagnosis. The world collapses. Moreover the doctor asked to remove the shirt in order to control personally if we had spots or little tumours and that disappointed could not find any.

The best step is learning more of the disease and the first think that you find are the apocalyptic and hopeless images from internet. We begin a life similar to the inhabitants of Los Angeles waiting for the “Big One”, the catastrophic earthquake that will destroy one day California.

We begin with the controls to the sight and those of the hearing and the control to carpet of the cute of the child waiting for the development of the tumors. It cannot be made nothing, be only waited for and not augured worse. Neurofibromatosis is a hereditary disease. Unfortunately nobody for generations in the families of my wife and mine has never suffered of this disease. You wonder if the cause is a genetic mutation at the moment of the conception or that unfortunately my wife and I have awakened Jurassic evil gene.

It is hard to think of her future. We decided that we have to make our best to make our daughter hard, in order to face a hostile and myopic world, where beauty and perfection are a must. In the meantime, for a paradox, we also believe that the obsession of perfection could be useful in order to find a way to cancel possible sings on her skin, if needed one day in the future.

We keep hoping that the damage is only aesthetic and that, at the end, she accepts her status and nothing worse happens. The mind goes back to the apocalyptic and hopeless images that you have seen on internet. The logo of a very active Italian association of the patients affected by neurofibromatosis makes you think: it is a pineapple. It comes from the Italian acronym of the association, but you think that in the best of the cases this is the final outcome of the face of my daughter.

There is no cure, but only observation like in a sort of Bastian fortress waiting for the Tartars like in a famous Italian novel by Dino Buzzati: *The desert of the Tartars*. Waiting for that your daughter's skin becomes more and more similar to a geographic paper with a lot of mount chains, in the best one of the hypotheses. While the time passes and begins the questions of the relatives on the spots. In the meantime, the child begins to react to her condition. She would want to tear the spots from her skin, wishing that the spots will go away after the bath. Also the plan of my wife and mine to have another child remains in stand due to the fear of having the same problem.

Then the school begins and we discover that our child is slower of the others, she takes more time compared to the others to make the things and she does not run as fast as the other

children. She returns home and says to us “I do not make us”. And you feel yourself to die, but you must however spur it and give them a hand. Despite the pain that takes you and let you wake up at early morning or in the middle of the night and does not give you any chance to fall asleep again, you must go ahead go and give her the force in order to accept and to face all which she will have to face in the future. We treat her severely when it is necessary, but we make her live as much as possible moments of joy, happiness and relax when it is possible.

We go to the oculist doctor that says that at the moment there are no problems to the optical nerve, but she lacks 5 degrees of astigmatism.

We would like to talk of the disease with the teacher, the same who told you that the child is a little slow, but in the meantime we thought that was opportune a dialogue among the teacher and the doctor. After a while since the dialogue does not take place we told the teacher the entire story, leaving her shocked. Nobody knows this disease, unfortunately. It is rare.

The teacher also tells us that she has the impression that the child does not hear well, and also at home she asks us to repeat again the phrases. The child makes an audiometric control and on purpose cheats it, says that she hears something even when there is no sound. We hope that is the mucus. She has a lot of mucus and it might create problems to the eardrum, otherwise could be something worse.

Next month we will another audiometric examination and a Magnetic Resonance Imaging (MRI). We made another MRI one year ago to the left leg where we felt something and thinking of a tumours (neurofibroma) we made tests, discovering that it was just a deep angioma. I have made the MRI with her, since the child did not want to be alone in the room. I told her stories and sang songs to cover the noises of the machine and recommending her not to move and repeating her was almost over every time she told me “I am tired, I want to exit”.

We cannot make anything, only wait and wish for the best.

P PARENTS' NARRATIVES AS BRIDGE BETWEEN DISEASE AND ILLNESS IN A FAMILY WITH A CHILD AFFECTED BY A RARE DISEASE. PILOT STUDY

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An ill child means an affected family. The parents' illness narratives could represent the best way to put in the right light the multiple relational dimensions of being affected by a disease.

Following the experiences matured in HIV/AIDS and Rheumatic Disease Narrative Based Medicine research (+300 hours of films), in order to evaluate the potential of this approach also in rare disease (RD) focusing in parents narratives, a semi-structured interview video was proposed to 4 parents of children affected by Dermatomyositis, attending Paediatric Unit of Panico Hospital in Tricase (Lecce). The aim of this interview was to test the frame and to evaluate the most important aspects for families related to the disease (biological aspects), the illness (child and parents perception) or the sickness (society perception).

Dermatomyositis is an idiopathic inflammatory myopathy, with characteristic coetaneous findings, a systemic disorder that most frequently affects the skin and muscles, but may also affect the joints, the oesophagus, and some organs. The frame of the interview was focused on the diagnosis impact (time and procedures), the chasing for meaning of the illness experience; Medical Doctor-family relationship; the impact of the care system on the family daily life; the treatment experience (drug adherence, side-effects); the disease burden in terms of social disruption (for the child: school, daily life at home, hospitalization; for the parents: employment, social assurance); the importance of the name of the disease; the disease impact on the couple relations.

The main important reported areas of interest were: parents homogeneously reported a positive impact of available care close to their home. Most of them reported uncertainties for the future and showed difficulty to abandon the idea that their children will be to be affected again by the disease. Worries were expressed about the long term toxicity of the treatments. A significative gap among parents, physician and society perception of RD was observed. On the other hand, all the parents underlined the importance of having a "name" of the disease in order to have clear against what they have to fight. Extended family is perceived as a crucial tool in order to reduce the disease burden on the core family. The child's disease has an impact on the couple relation between parents. Information obtained through this narrative-based medicine approach are an useful instrument to identify strategies for the improvement of family-physician communication and of quality of overall care in families/people with RD.

P DESIGNING PROJECTS OF NARRATIVE AND COMMUNICATION IN HEALTHCARE

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Who we are and how we work. H.story is a no profit association designed to promote social communication tools and strategies to be included in the realities of healthcare, to improve the relationship dynamics between patients and medical staff, and between medical staff and familiars. H.story is supporter and promoter of Narrative Medicine within Italian hospitals and support groups to diseases. The H.story blog is an important repository in which we put out all the projects related to Narrative Medicine and Medical Humanities.

Our methods are based on communication rules and process. For each project we follow with accuracy all these steps: preliminary analysis, design (of strategy and tools), management and study results.

The association works always with many other professionals that actively participate during all the project design. H.story develops and offers advice to introduce communication principles and the Narrative Medicine in hospital wards: developing strategies and designing customized tools for each type of facility and department.

Our projects. These are our most important projects:

1. *H.story in rianimazione* (from 2009): a project of Narrative Medicine at the ICU of the San Giovanni Bosco (Turin) with the support of dr. Giuseppe Naretto and the nursing-medical staff. The core of the project is the H.story diary for familiars and friends;
2. *H.story per OctopusMed* (from 2008): we proposed for OctopusMed (an association for the revention of diseases related to smoking) a path of Narrative Medicine to support those who want to quit smoking, supported by dr. Enzo Soresi;
3. *H.story per le future mamme* (from 2008 to 2010): within the department of Obstetrics and Gynecology of the Macedonio Melloni Hospital (Milan) we designed a crossing diary in order to support pregnant women in that period of radical changes.

Currently we are working on other projects that will be adopted in various healthcare facilities with the support of valued professionals.

Our results and conclusions. In these last three years we have discovered a lot of organizations and people that everyday work on Narrative Medicine, persons that are often unaware of doing it. Developing our projects, taking some conferences and talking to Medical Humanities professional, we have reached our goal: spreading the Narrative Medicine discipline and helping people who are going through important, and often dramatic, moments of their lives.

P NARRATIVE MEDICINE AND ICF ROLE IN THE DEFINITION OF ALS REHABILITATION PROJECT

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Introduction. Narrative Medicine is a new approach to understanding the illness of patients with Amyotrophic Lateral Sclerosis (ALS). The purpose of this study is to highlight the functional and psychological effects that ALS has on the life of patients and to identify the most critical areas of rehabilitation, using the narration through ICF (International Classification of Functioning, Disability and Health), to create a targeted rehabilitation project.

Materials and methods. We recruited patients resident in Umbria, Italy, living in their own home with a diagnosis of ALS who were monitored from March to September 2011. The following factors were considered: age, gender, type of illness and time to diagnosis. For each patient we spent about 1 hour and half collecting the narration of illness using ICF items. The areas evaluated were: communication, travel, personal care, interaction with people, daily activities and social life. To assess the functioning of patients we used 19 ICF items taken from the questionnaire WHO DAS 2 2000, assigning a score from 0 to 4 for capacity and performance, when these were completed a statistical analysis of the collected data was carried out.

Results. We recruited 20 patients with ALS (12 males and 8 females), with a median age of 65 years (range 42-80 years) with different ALS forms at various stages of the disease. The follow up time was 1291.75 days (range 60-5170). The disability areas were: "Remunerative employment" and "doing housework" (mean score 3.85), "dressing" and "washing" (average score 3.6). The items performance using facilitators were: "wash"(100%), "dress"(100%), "sit down"(80%), "move around the house" (70%), "eating" (60%), "move to different locations" (60%), while performance was essentially unchanged in the items: "paid employment" (5%), "economic life" (5%), "managing tension" (10%), "life in the community" (25%), "doing housework" (25%).

Discussion. Different types of narrative were identified. Narrative interviews allow an understanding of living with ALS and highlight the most critical problems that need solving in order to live life as well as possible through keeping active and engaged in life.

Conclusions. The facilitators make a difference in the areas of movement and personal care while performance is lower in daily activities and social life. Narrative Medicine and ICF can highlight the critical issues, which will need more attention with a targeted rehabilitation project.

P FILM ARCHIVE FOR MEDICAL EDUCATION

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Introduction and motivations. The creation of this Archive (February 2012) is part of a broader research Program that has as its focus the innovation in medical education, through the reconfiguration of the identity of health care professionals as “reflective practitioners”.

The hypothesis of the Program is to enable training courses (including through the Cinema) capable of building forms of “usual” reflective learning and observation with its own thoughts, to help the health care professionals to “better understand” mode of action, choices and directions of their professionalism. From this premise, the Film Archive for Medical Education (www.laboratoriodimedicaleducation-unifi.it) collects and sorts, in an appropriate and justified manner based on the design and methodology, short video sequences (called “scenes”) from different types of audiovisual products (films, documentaries, student developed, TV series) that were chosen and combined systematically in relation to specific thematic clusters (called “keywords”) considered a priority in the training of health care professionals (called “professional fields”). Access to the Archive is free, takes place by means of recording and its use is solely for educational aims.

Objectives.

1. Contribute to help health care professionals to re-organize their knowledge and their learning style revealing the mechanisms of construction, the automatic and habitual cognitive patterns.
2. Encourage future health care professionals (especially students) to experience the practice of self-reflection as a tool of personal knowledge and recognition of its work.
3. Helping to put at the center of the medical listening (through visual examples) stories of patients, the enhancement of human relationships (not only technical) between doctor and patient, an approach to the disease capable of understanding the cultural dynamics (models) and historical relations.
4. Contribute to help patients and their families to be able to understand the point of view of the physician and the operator in relation to their expectations and needs, and respect its implicit reference models.
5. Create an on-line database which is:
 - accessible through registration, but clear and easy to use;
 - structured around specific themes;
 - free;
 - implementable;
 - open to the contribution of individual users.

Target.

- Health care professionals;
- Teachers and university researchers;
- University students;
- Sick people and their relatives.

P PUPPIES HYENA

Gianni del Corral (a), Giulio Benna (b)

(a) *filmdirector, Collegno (TO)*

(b) *Neuropsichiatria Infantile Ovest, Ospedale Martini, ASL Torino 1, Turin*

The project stems from the Laboratory of Cinema KLICCA PLAY ON, aimed at able bodied and disabled children.

The workshop is an initiative of the Baby-Xitter, first in Italy babysitting service specialist for children with disabilities (www.baby-xitter.org).

The project was conceived by Hyena Cubs and managed by the Turin director Gianni del Corral (www.filmdirectorworks.com) in collaboration with dr. Giulio Benna, M.D. It has been filmed episode zero.

The guys, dressed as “hyena”, will address the issue of disability. They will apply directly to institutions, schools and various characters, because they are not complied with certain laws, it creates some discomfort and a thousand other reason. But will also like to thank those who have demonstrated sensitivity to these less fortunate children.

The intention of the authors and the children themselves, is to make however many episodes to be broadcast on the Internet.

The Hyena Cubs are now 6 guys. Two will present the theme from “Headquarters of the hyena cubs”: Marco, 18 years old, with a brain tumor and Stefano, 15 years, with impaired ocular fibrosis and a congenital bone disease. Also from the same place, will take Beatrice, 17 years normodotata and Edoardo, 11 years old, with Klinefelter’s Syndrome. While on the field, with the role of reporters: Gaia, 11 years with Fragile X Syndrome and Roberto, 14 years old with attention deficit and learning problems.

The project objectives are various:

- to learn to communicate through images;
- the integration;
- the game;
- to use the image as a health tool for to overcome some difficulties deriving from their syndromes (this technique, called MOVIECARE™, is used by the director Gianni del Corral for some time with success);
- total acceptance and awareness of its current limitations;
- the discovery of its resources;
- to raise awareness on disability;
- to complain directly to a system that is the “real sick”!

P A STORY OF FRAGILITY

Gioia Di Biagio (a), Ilaria Di Biagio (b)

(a) *Patient, Florence*

(b) *Photographer, Florence*

The project is a collaboration between two sisters, one is a patient and the other a photographer.

Gioia has the EDS (Ehlers Danlos Syndrome), a rare connective tissue disorder due to a defect in the synthesis of protein collagen. It involves mainly the skin, which is hyper-elastic, fragile, tending to break and it is difficult to heal. The joints and especially the spine often cause suffering. She calls herself a “woman of glass”.

Gioia has lived in and out of hospitals for years. The two sisters have constantly had to fight with doctors, trying to explain them what this rare syndrome was and what the dangers were. They are orphan since 10 years and it brought them to have an unique friendship.

EDS is not well known and often people who are affected by it, are considered hypochondriacs. The “sick” person is not able to describe the pain experienced. Le Breton writes: “the expressed pain, is never the pain you actually feel” and gives an example: “To know how much it hurts the fire, you have to burn yourself. But it remains the inability to know how great is the suffering of another who burns”. That is why chronic pain produces new forms of expressive imagination, focusing on the metaphor, which helps to express the suffering to the rest of the world.

The project aims is to describe, through texts and photos, not only Gioia’s medical experience but also it gives prominence to her personality, her enthusiasm and how she relates to her body and the world around.

Thanks to this work, it has been possible to learn more about the EDS: associations, specialized centres, doctors, patients. Gioia herself has more answers than before about her medical condition.

A project which aims is not only to be a knowledge instrument toward a rare disease but also to teach, by someone who lives it on her skin, to react and never miss the smile.

P MEDICAL AND FAMILY HISTORY OF A PATIENT SUFFERING FROM A RARE DISEASE: FAMILIAL TUMORAL CALCINOSIS

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Objectives. A group of doctors and dentists of the Interregional Reference Centre for Rare Diseases Odontostomatology Clinic, University of Bari is engaged in the diagnosis and treatment of patients with rare diseases that have maxillo-facial dimorphisms, dental and soft tissue abnormalities. They are adopting a multidisciplinary approach that includes counseling, radiographic and genetic diagnosis with identification of new mutations. This article describes the story of a patient with Familial Tumor Calcinosis (FTC), gained to our attention after several hospitalizations in various Italian hospitals trying to define a "name" to his rare disease of the bone and then, in our clinic, subjected to oral surgery and orthodontic-orthopedic treatment.

Methods. FTC is a group of rare autosomal recessive disease characterized by deposition of calcium phosphate crystals in iuxta-articular and visceral tissue. The hip, shoulder and elbow are common locations with functional limitation of the motion, episodes of pain and fistula formation. This article illustrates the history of a Caucasian 17-years-old boy who from the age of 9 years refers recurrent parossistic episodes of pain at the legs, unresponsive to NSAIDs and analgesic therapy, mostly during the night. The biopsies rised the suspicion of a chronic recurrent multifocal osteomyelitis, then osteogenesis imperfecta, and finally after radiological, laboratory and genetic exams FTC. Clinical examination of the face and oral cavity shows skeletal deformity of class II, included ipoplastic teeth, shortened and bulbous teeth roots, enamel hypoplasia and obliteration of the pulp chamber. The patient was treated with surgical removal included teeth, gingival tissue biopsy and histological examination, orthopedic-orthodontic treatment to correct the oro-facial deformity.

Results. The treatment has solved the deformity, performed dental alignment and harmonious smile.

Discussion. The dental treatment of patients with FTC is made difficult by the characteristics of teeth, alteration of the bone metabolism and by drug therapies. The ability to perform these treatments in patients with FTC as well as for other rare diseases is a major therapeutic target that improves the quality of life of these patients who want to feel normal.

Conclusion. The monthly checks improves the doctor-patient-family relationship, the quality of care, the outcome of therapy and promotes doctor-patient communication. Hence, the dentist becomes a figure capable of receiving the patient's history as something unique, unrepeatabe, which belongs to the individual. This approach ensures an increased self-esteem and improves individual's social life.

P END-OF-LIFE STORIES: TWO CASE STUDIES IN A HOSPICE IN ITALY

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Introduction and objectives. Narrative medicine is an acknowledgment of a person's complexity and of his/her point of view as a patient. The diagnosis of terminal stage of illness leads the patient to review his/her life. In this moment the narrative of his/her history has a special meaning. At the Hospice Sergio Sugliano of the F.A.R.O. Foundation in Turin we collected and analyzed two end-of-life stories: our aim was the attempt of capturing the patients' experience to understand the way in which illness is experienced.

Materials and methods. The stories were analyzed through the "River Allegory" (Mishler 1999, Elliott 2005, Thomas et al. 2009) which allows to capture the flow of events through the passage of time, the disease evolution, the experiences related to their "self", to their beloved ones, to health workers. Patients told freely, without a fixed order, and the stories were collected and transcribed in full.

Results. Despite their differences, the stories are united by issues such as cancer diagnosis and course of disease, experiences of care, impact of illness on their lives and on those of their beloved ones, emotions and challenges related to cancer and the discovery of valuable sources of support. Lina's full story entitled *Purity and perversion in the splendor of immortality* is written in third person and consists of fifty-two pages. In the four months spent at the Hospice she was able to complete this work that she wanted to leave to her grandchildren. Mary's full story entitled *Why* is written in first person, it is composed of twenty-four pages divided into fifteen subsections, each of which represents an important step in her life.

Discussion. From the analysis of the stories we remarked the patients' will of tracing memories, with extreme attention to details. Two different personalities, two stories far away in time and space, two lives linked by the need to bring order into the events, emotions, and the vivid memory of those people who had an important place in the flowing of their days.

Conclusions. The narrative analysis of these life stories offers the opportunity to access patients' personal worlds, their perspectives and their end-of-life outlooks. The discussion and sharing of these experiences can provide a better understanding of terminally ill cancer patients, suggesting possible improvements to be implemented in care pathways.

References

- Elliott J. *Using narrative in social research. Qualitative and quantitative approaches.* London: Sage; 2005
Mishler EG. *Storylines. Craft artists' narratives of identity.* Cambridge, MA: Harvard University Press; 1999.
Thomas C, Reeve J, Bingley A, Brown J, Payne S, Lynch T. Narrative research methods in palliative care contexts: two case studies. *Journal of Pain and Symptom Management* 2009;37(5):788-96.

P THE MYTH AND THE CURE. PROPOSAL FOR A GROUP EXPERIENCE, IN NARRATIVE MEDICINE, WITH NEUROLOGICAL PATIENTS

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Introduction. For over three years in the IRCSS S. Camillo we have applied Narrative Medicine through the construction of stories in MusicArTherapy groups. The group setting with Narrative Medicine workshops is a privileged scope to go through subjects whose individual treatment would be difficult. The analysis of the stories made up by patients have stressed how the spontaneous use of metaphor and symbol was easily understood and shared by the group. We have thought to use an instrument, such as the myth, already culturally codified, like a medium for a further development of these elaboration processes.

So, it has been established an area of creativity shared by all group members, which allows to overcome the stereotypes and build an identity through comparison and mutual exchange. The myth has a metaphorical relationship with difficulties that have to be faced, without introducing a clearly rational relationship with the problem, and evading the conscious purpose of the subject in this way. So, metaphors allow to evade the resistance the patient opposes to change: they are an indirect way of suggesting some solution tracks to unconscious.

Objectives. The objective is to facilitate hospitalized people in a neurological rehabilitation centre to recognize and express their emotions by starting from personal revision of the myth. In addition, comparison and reflection with other members of the group and narrative-expressive workshops are intended to allow patients to rewrite their own story of illness, and therefore, they offer the opportunity to live it in a different way.

Materials & methods. The recipients of this study will be those patients who have been hospitalized at the IRCSS S. Camillo for a cycle of intensive rehabilitation. We will recruit patients with chronic and degenerative diseases and with discreetly preserved cognitive abilities, but with different degrees of motor disability.

Participants: 5 to 8 patients per group.

There will be 8 meetings of 1 hour and 30 minutes each, 2 times a week for 4 weeks, and the 2nd, 5th and 7th meeting will be about expressive-narrative workshops.

The first workshop is about the creation of the personal labyrinth through the collage technique. The second workshop is about rebuilding a labyrinth situation, real or fictional, through written narration, and describing the way of exiting the labyrinth. The third workshop is still an invitation to written narration, in which change is the given stimulus.

The group will be limited in number of participants, and meetings will take place twice a week.

At the beginning and end of the meeting, the following tests will be given:

- SCL- 90 (*Symptom Checklist-90*);
- TAS- 20 (*Toronto Alexithymia Scale*);
- Questionnaire on group climate.

The conductors will be a psychologist-psychotherapist and a musictherapist.

Discussion. As it is clear from many studies, the common characteristics to these patients are a fragile sense of the self, a weakening of the ability of the ego to carry out its functions and use of primitive defence mechanisms. We therefore believe that the suggested way of intervention,

with the workshops of Narrative Medicine and its development within a group, is the preferred setting for addressing these issues. Even if the fear of the evolution of the disease and the resulting disabilities in a first phase stimulates a deep and almost intolerable anxiety, later it leads to question the meaning of the existence and the need to give it a meaning. Group work allows the creation of the chance of enhancing the personal characteristics of the patients, who are no longer related only to their own being, in a physical sense. This also increases self-observation and the possibility of looking at themselves as people, in their own psycho-physical complexity.

Results. The proposal for a team work in the previously introduced ways was welcomed by both the structure and from people with disease. The first results show a good compliance to treatment. Additional data will be introduced later.

P NARRATION AND THE CODE OF ETHICS: THE “INSTRUMENTS” FOR AN ETHIC REFLECTION ON NURSING PRACTICE

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Objectives. In the period from October 2009 to February 2011, each month a focus group was carried out at the IPASVI's (Federazione Nazionale Collegi Infermieri professionali, Assistenti sanitari, Vigilatrici d'infanzia) venue, for a total number of 12 focus groups. They all were about the narration of nursing clinical cases with an ethic value. All the narrated cases were analyzed and discussed by a group of 20 nurses, using the new Code of Ethics of nurses as the most important point of reference. The research hypothesis, which guided the entire project, was: “Does the Code of Ethics represent a useful/valid instrument for a nurse who has to take a decision concerning an ethic problem in everyday nursing practice?”. Each focus group focused on the written narration of real cases that happened in hospital general units as, for example, medicine/hospice. But also unusual areas of ethic problems, as for example the organizational, the educational and the territorial ones, were investigated.

Methods. The participants were asked to describe, through narration, a real, personally experienced clinical nursing situation which generated an ethic problem in the multidisciplinary team. The participants were given specific indications to write their texts, in order to make the different participants' styles as uniform as possible. Many of the topics were: nursing the preterm newborn, the respect of the living will of a person affected by amyotrophic lateral sclerosis, obtaining the (little) informed consent, the administering of the abortion pill, the role of nurses in clinical trials. The analysis was conducted using the Code of Ethics articles related to the problem; the analysis frame developed by professor Spinsanti of the Institute Giano in Rome, other documentations referring to the specific topic (guidelines, scientific societies documents, laws) and the personal and professional stories of the participants.

Results. The research hypothesis was confirmed in 9 cases out of 11: we can say that nurses often must take decisions that not only have technical/professional content, but which also create ethic-deontological problems with reference to the relation with the other person, with the patient, the family and the colleagues. The Code of Ethics represents an useful, valid instrument that can be used in nursing practice.

Conclusions. This study was the starting point for a change that is already being carried out: a group of nurses systematically met, wanted to share through narration their professional experience, considering emotions too, which can't be eluded by nursing profession.

P CROSSROADS OF CARING: FOSTERING ETHICAL COMPETENCE IN EVERYDAY DILEMMAS THROUGH MEDICAL HUMANITIES AND NARRATIVE MEDICINE

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Healthcare institutions should promote and foster “ethical competence” in healthcare professionals. This is the ability to analyze a situation, evaluate its contextual elements and create specific and holistic answers. It is implied in the rare occasions of major dilemmas but overall in everyday’s working life, which presents dilemmatic situations for which coding an appropriate behavior would be almost impossible. Medical Humanities and Narrative Medicine share a humanistic educational framework, able to promote the ability to deal with ambivalent matters.

Theatre and Greek tragedy are widely acknowledged as instrumental to foster ethical learning and Sofocle’s *Antigone* is a work in which the thematic of the dilemmas of caring is represented in a very universal and exemplary way.

As part of a broader strategy of integration of humanistic approach, Policlinico Tor Vergata offered a specific course called “The crossroads of caring: everyday’s dilemmas in healthcare”. 35 participants attended the 2010 and the 2011 editions: nurses, physicians and administrative employees of the hospital.

The program is divided in three main parts. The first part includes:

- a brief theoretical introduction on ethics in the everyday’s care;
- writing session about personal professional experiences;
- small group reading;
- plenary discussion.

In the second part, each small group is randomly combined to a specific character of *Antigone*’s tragedy, to assume its character’s reasons, even if distant from personal beliefs and values. After the first part of *Antigone*, time to discuss in small group is provided, in order to arrive at the plenary session with some agreements. Then, each group advocates its character stance and answers all the questions other participants want to raise about character’s choices and behavior. In the final part of the course, the last part of *Antigone* is showed and a plenary session for discussion, confrontation and evaluation is provided.

In 2012 a follow-up evaluation was performed, using a semi-structured questionnaire, to assess the course’s impact once back at work.

The results showed:

- a high level of consistency between learning goals and outcomes;
- utility of sharing personal experiences of dilemma;
- experiential learning on communication skill.

Attending the course was remembered also as:

- a moment of relief and detachment from everyday’s stress;
- an empowering and coping situation;
- an experience of active listening e conflict resolution.

Humanistic approach and classical art – like Greek tragedy – and autobiographical writing can be integrated in the continuing medical education, addressing a wide range of learning needs.

P USING THE ICF IN NARRATIVE MEDICINE

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The work stems from a dissertation, “Rare diseases: arthrogryposis multiplex and consciousness of self”, carried out by a student in occupational therapy from the University of Chieti, sister of a person suffering from this disease.

Without the use of the ICF (International Classification of Functions), the candidate had identified as the basic need, the problem of the individual motor, with emphasis on aspects of orthopaedic and psychiatrics (surgery on the spine, etc.).

The reading of the ICF with the profile of disability issues has allowed to move from the problems of mobility, suggesting a range of strategies to improve participation, not only in the domain of mobility but also in the domains of activities of domestic life.

Declined in the profile of disability, the candidate has had to face the problem of self-consciousness. Forcing her to tell the story of a person with multiple arthrogryposis, she has revealed not only the needs of people with disabilities, but also of people who live around.

The same candidate at the end of his career has been, somehow, through the use of the ICF, “forced” to tell the story of his sister, highlighting the importance of the concept of resilience. Furthermore, the variation according to the ICF domain of participation for the first time brought to the attention of the candidate a need overlooked in the life of his sister: construction and development of consciousness of self, suggesting the occupational therapist compensatory strategies on the domain of care of person. It also improved depth and quality of aid that she wanted to give to his sister, but she could not give her. This has enabled the candidate to investigate issues related to siblings and to reflect on the importance of body image in the construction and self-consciousness, to establish a relationship with the sibling based on emotional exchanges with her sister and not surgery. The link was actually symbiotic overprotective (“... my sister is good, because when I get tired, you take me in your arms...”). The story showed that she was using a quad in the back yard, which was not used for outdoor mobility.

P ADULTS WITH SPINA BIFIDA: TRANSITIONAL CARE OR LEAVING PATIENTS ALONE? TWO DIFFERENT POINTS OF VIEW

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An Italian multicentric study investigated pathways of patients with spina bifida, their carers and physicians through narrative medicine. The study involved 12 Italian Spina Bifida Centres and 61 stories were collected among persons with spina bifida, their parents and physicians.

The objective was to analyse pathways for this rare disease, focusing on the phase of *Transitional Care*, a delicate changeover from the paediatric to the adult age, and to investigate the meaning and consequences of this for the different points of view. Since a definitive pathway for this phase has not been developed yet and 50% of paediatric Spina Bifida Centres continue to take care of adult patients, each Centre is carrying out a local solution.

Two interview forms were predisposed, for patients and physicians respectively; the items were structured to facilitate the persons to tell their own living with the illness, describing not just the clinical steps but also their feelings, fears, achievements, criticisms. The stories were collected in presence and transcribed.

Different points of view and issues were expressed by providers and patients. The primary concern for physicians is the *Transitional Care* organization, because currently this phase has been confirmed as not defined and there is a lack of specialized Spina Bifida Centres for adults; Spinal Unit could be the destination. Most of them consider their team not prepared to face the adult people demands, especially regarding sexuality: "Sexuality is faced by our team with a clear inadequacy, although the good intentions". On the contrary, patients living with spina bifida are not well disposed to the *Transitional Care*, because they prefer to maintain the paediatric points of referent; changing health centre and physicians is often perceived as a left alone and a possible shock for the family: "Now I'm adult, but I continue to refer to the same physicians; sometimes I think what I'll do when they won't be anymore"; "This Centre is like our home"; "Even if my son has grown up, he needs of constant reference point". Furthermore, although the 62% of the subjects with spina bifida were between 16-50 years old, in the 84% of the interviews parents were involved; this is a proof of a strong maturation which does not foster the young patients with spina bifida towards autonomy.

A double maturation is revealed, as a *matriosca* doll, one carried by the reference centre, one by the family.

P TRAINING HEALTHCARE PROFESSIONALS THROUGH LITERATURE. CASE STUDY: “A HOLE IN THE HEART”, AN AUTOBIOGRAPHICAL CHRONICLE OF A HEART SURGERY

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The book *Con un buco nel cuore (A Hole in the heart)* by Sasha Perugini is a biographical chronicle of the author's heart surgery at 39 years old. Through the detailed and ironically detached description of her experience, from learning she needed the operation to her return to work, the author touches on themes that are crucial to Narrative Based Medicine such as the communication between patients and health care professionals.

Describing the days preceding the extraordinary event in a detached tone, the young woman questions, without being accusatory, to what extent she should pursue the information she feels she is not being given.

She also wonders how patients, especially female patients, are perceived/depicted in the training of health professionals. The intimate journal even provides a very practical checklist of possible improvements: everything from having the doctor introduce him/herself to the patient to adding the patient's gender to the hospital admittance forms.

The book was successfully presented to medical students at the University of Florence and the ASL (health service) of Tuscany has deemed it a possible training tool. As such, it is currently being used to spark discussion in numerous training settings in order to expose health care professionals to issues that are as relevant to the therapeutic process as the medical follow up. The authors will use this case study to discuss the patient's role in exploring new training opportunities from a humanistic perspective.

P NaMe EXPERIENCE IN FLORENCE

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Since 2004 Florence's Community Health Centre have been carrying out some research in Narrative Medicine. So, we would like to illustrate our studies chronologically, in order to show that it is possible to implement narrative medicine in ASL (Local Health Unit) and hopefully recommend some operational methods. Firstly, in 2004-2005 we did some training courses in Narrative Medicine designed for physicians, nurses, health workers, hospital volunteers. In this occasion we could identify three important scope: oncology, cardiology and Alzheimer. Consequently, from 2006 to 2008, we conducted the first research, NaMe, by doing thirty semi-structured interviews: ten for each area as stated above. These interviews permitted us to collect information about illness told by patients and caregivers. So we were able to recognize critical path cares for each area. The outcomes were explained at the First International Congress on Narrative Medicine in Florence (2009).

After that – observed the success in dealing with this topic – a second research, NaMe2, was done in 2010. This time the scope was concerning cardiology, oncology and intensive therapy. The aim was studying relationship between patients and medical doctors as to find out and underline good or bad practice in the communication's styles. In order to observe it, we used an innovative and pioneer tool in narrative medicine: conversation's videotapes. Thanks to it, we could analyze verbal and non verbal doctor's behaviour. It allowed us to draft two decalogues where we try to show ten good attitudes for physicians and ten good attitudes for patients. Last February we explained these outcomes at the Second International Congress in Florence.

At the moment, we are carrying out a third research on Narrative Medicine as to create a permanent Narrative Medicine's laboratory in some hospital wards. Furthermore we are taken part in the first narrative research conducted by web, "Viverla Tutta", in collaboration with the Italian National Centre for Rare Diseases, European Society for Medical Sociology, Repubblica Salute and Pfizer Italia.

Hopefully this wide work will allow us to find out indicators regarding rare and chronic diseases as to combine NBM (Narrative Based Medicine) and EBM (Evidence Based Medicine).

P TELLING A SERVICE THROUGH THE STORIES OF PATIENTS

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The training program reconstructs the story of “Home Care Service dedicated to AIDS patients” (from the Local Health Unit TO2) after 20 years from its birth. In order to witness, through the telling of the patient’s story all the changing, learning, satisfaction and difficulties experienced by the nurses; and the change occurred in HIV/AIDS treatment. This History writing and reading showed the different meaning of the practices, letting them become a common heritage while reading and discussing the text itself. Writing as a practice of attribution of meaning: it shows to oneself and to the others paths of meaning that occur when you go back to past experiences; it throws meanings in the world, making them touchable; thoughts are deposited on paper and become something different from you, something that happens and becomes transmittable only through reading.

During the training meeting there is the reading of a patient’s story written by an operator, then there is the analysis and the discussion on the text, in this way all the other operators can contribute to the text, changing it in a co-constructed story. The track is agreed and includes the story of the patient’s world and the operator’s story. A general plan has been developed for the interview to witnesses who have been involved in this 20 years history service. A publication will follow that will be presented to celebrate the “Home Care Service dedicate to AIDS patients” 20th anniversary.

Life, death, illness experiences are affecting all living things, but our daily work with them can become a source of stress for people, groups and organizations. The setting is the patient’s home and this exposes the operator to further emotional stress because it can’t implement defensive strategies related to the institutional contexts. Special moments should be structured to allow operators to work on emotional difficulties with the goal of developing functional defensive strategies. The training program allows to back over past experiences and co-related meaning. Text reading and discussion allows to compare styles, practices and emotions, showing similarities and differences.

Our stories’ characters are patients in their complexity and humanity, eventually evaluated in their fullness and not flattened in their role as patients.

P MOM, WILL I HEAL?

Giuseppina Salente

Relative of a person with a rare disease, Padua

Is it worth to assist a rare disease patient in a public institution, if everybody knows that no cure is possible for him, as it doesn't even exist a cure? How can a mother be listened when asking for help for her son, if all doctors tell her that nothing, nothing can be done to help him? There is the personal suffering and the cruel reality to face. Your son is dying and nobody can do anything for him. But a mother has always a word, a touch that can help him to go smoothly away, that can make him feel not alone and abandoned by the world. A mother must find away to be near her son even if it is tiring, painful in the heart... I found it! I kept his hand in my hand and I washed him in his bed, polling him smoothly from one side first and then from the other. He could not even move a finger, he could not even tell me if he liked it or not. I just assumed so. The bed was all wet, and when I finished to dress him, I used to grab him and move into another bed, next to the first one. There he stayed with all his tubes connected: the one for feeding, the one for breathing, the one for the oximeter. All tubes and no life, after all. No real life, actually, but a lot of intense emotions.

Caring for a person, knowing that each day could be the last. I hope that he felt my love, I hope that he forgave me for not being able to find a solution for his health. He had asked for my help when he was still able to. Yes, once he was able to!

Rare disease do not appear in our lives just at birth. They appear at any time. You think you are healthy and all your family is, so you don't have anything to do with rare, genetic disease. But it's not so! Some diseases attack you or your beloved unexpectedly. And from that day, you are alone and unarmed.

P LABORATORY MEDICINE NONFICTION ICF (INTERNATIONAL CLASSIFICATION OF FUNCTIONS) IN THE DEPARTMENT OF REHABILITATION ASL3 UMBRIA

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The experience of Narrative Medicine in the ASL 3 in Umbria (Italy) comes from a structured training program over several years on various issues that led to the construction of a laboratory for self-study and application of this approach in clinical practice and experimentation in the ICF classification.

A training course was started on communication in the doctor-patient relationship and between therapist-patient on EBM (Evidence Based Medicine), on ICF in Narrative Medicine as a tool for treatment planning and evaluation of the effectiveness of interventions and the possibility of integrating EBM and NBM (Narrative Based Medicine). The Department of Rehabilitation was identified as the most appropriate corporate structure to enable training and testing in Narrative Medicine for cultural reasons, the availability of professionals with training already oriented toward these issues, because the Rehabilitation has an ecological approach that is attentive to the patient-context-environment relationships, which naturally lends itself to a narrative approach.

The Laboratory has been constructed to train: through direct experiences, expertise in the collection of patient stories (through freely narrated stories, structured interviews, semi-structured, questionnaires) content analysis, detection of recurrences. The workgroup has discussed and reflected on some particular “recurrences” in the paths of the patient, especially at critical stages (taking in charge, project communication, resignation), in the critical relationship between practitioners and patients:

- first of all, learning is a process, and not a possession, and be constantly fed;
- in addition, you learn more and better through direct experience;
- narrating the disease gives meaning and shape to the experience;
- dealing with patient histories therefore means, not only listening but is a more complex co-construction of meaning;
- we also understand that a narrative cannot be bound by a single representation of reality, but is available to what is “strange”, new and singular. It can create new connections, generating new ideas, the ability to create fractures where there is a system of rigid codes.

The laboratory has analyzed the ICF elements by evaluating their applicability through the EBM, the NBM individually or through their original combination.

This is constructed by a grid application through the narration of the ICF classification. It is seen as “activity” and “participation”, although with some quantifiable scales representing a peculiarity of the narrative as well as environmental factors. The structures of the body, however, are a classic element to the basis of the EBM. Unfortunately, the ICF classifications do not cover problems related to the Quality of Life and in some circumstances may result incomplete.

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