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When using Medical Humanities and when Narrative Medicine in Education…

Maria Giulia Marini, June 5, 2018

Projecto SHARE

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Agenda

- Defining medical humanities and narrative medicine

In health care system

- Education using Medical Humanities
- Education using Narrative Medicine
- Towards a balance?

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Socrates approach; the searching of the truth caused his execution?

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Socrates was looking for the a-lezeia (the untoldable true)

- Through the narrative approach
- Through the art of question
- In the streets of Athens (in daily practice life)
- From everybody, with no hierarchy in mind
- Everybody was able, through the narrative dialogue on something happening in real life time, to seek for the true
- Facts were not manipulated with Gods and Myth

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Narrative medicine is…

- Narratives recount authentic experiences as perceived by the narrating subject, and they are not told to impress but to share a personal experience relating to disease and the pathway of care. [Launer, 2007].
- The narrations are often the result of the interaction between patients and healthcare professionals and can be told or written either by the patient or by the healthcare professional [Greenhalgh, 2016].
- Narratives are collected not mainly as material with literary value but rather as a means for gathering insight into experience and reforming health care [Marini, 2016].
- It is a spoken or written dialogue between who writes and a few listeners/readers.

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Evidence-Based Medicine alone does not Promote an Eco-Friendly System

- "…. Research-derived facts about the average patient must not outweigh individual patients' observations of their own bodies and illnesses. New processes for capturing and accommodating patients "personal experiences' – which are typically idiosyncratic, subjective, and impossible to standardise,"… are needed.

T Greenhalgh, BMJ, 2014

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What is Evidence Based Medicine?

Precision Medicine

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Where is the patient voice?

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Narrative Stories Unite Epidemiology and EBM Guidelines WHO, 2016, Narrative research

The appropriate and rigorous use of narrative methods, collection of real authentic narratives from:

-patients

-caregivers

- carers

should be encouraged when assessing the cultural contexts of health because their use in **communication** with quantitative data supports a more values-based approach.

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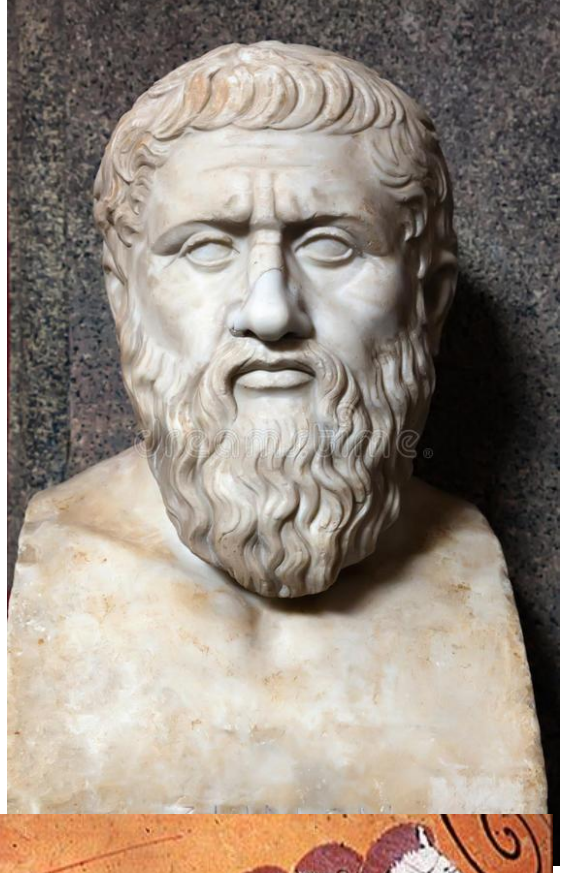
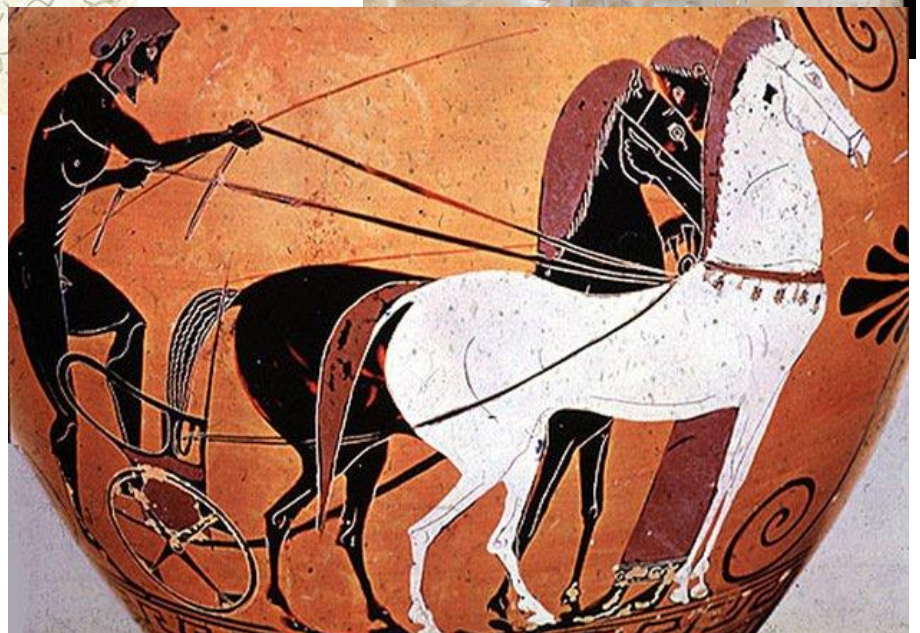
Plato, the founder of Academia





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Plato, among the greatest story tellers of ever

- He created the most beautiful stories with his fictious dialogues
- He was continuously creating stories as the myth of the cave, asintotically seeking for a true humankind will never know, the myth of the androgyne that once split, kept on searching the lost counterpart, the myth of the black horse (the pleasure) and the white horse (the emotional mind) guided by the Charioteer)...
- He had (a part from some years in prison in Syracuse) a successful life and founder the Academia

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Medical Humanities and the story telling

- Stories may be inspired by true experiences, but are most often factitious, and belongs to the world of medical humanities [O' Hara, 2014].
- Stories are narrated by an individual and are generally oriented to a large audience [Neeley, 2016].
- Stories are not collected in clinical practice, but they belong more to free time and performance.
- Stories are perpetuated through many artistic forms such as movies, drama, comedy, books and artworks [Turow, 2010].
- Essentially, the narrator is a 'storyteller' entertaining a large public [Silverman, 2017].

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The problem in the Scientific Faculties:

The Devil is in the third year: a longitudinal study of erosion of empathy in medical school. Hojat et al. Academic Medicine, Vol.84 n.9, 2009.

Feature	**Empathy**	**Sympathy**
Contribution of learning	More significant	Less significant
Contribution of cognition	More significant	Less significant
Contribution of affects	Less significant	More significant
Contribution of innate of genetic factors	Less innate	More innate
Objectivity versus subjectivity	More objective	More subjective
Likelihood of accuracy	More accurate	Less accurate
Behavioral roots	Advanced	Primitive
Required efforts	More effortful	More effortless

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Feature	Empathy	Sympathy
Relation to clinician's performance	Linear	Inverted U shape
Reaction time	Non spontaneous	Spontaneous
Patient's emotions	Appreciated without joining	Perceived by joining
Feeling felt	The kind and quality of patient's feelings	The degree and quantity of feelings
Brain processing area	Predominantly neocortex	Predominantly limbic system
Psychological regulatory process	Appraisal	Arousal
Psychological state	Energy conserving	Energy consuming
Behavioral motivation	Altruistic	Egoistic
State of mind	Intellectual	Emotional
Effect on caregiver	Personal growth, career satisfaction	Exhaustion, fatigue, burnout
Typical expression to patient	I understand your suffering	I feel your pain
Key mental processing mechanism	Cognitive/Intellectual/Understanding	Affective/Emotional/Feeling

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When fiction could be warrented to make the unpleasant truths of Narrative Medicine more soothing

- Some truths are harsh to know, and courage is a gift to face them: there are some cases in which ‘knowing’ that are fictions, just remotely inspired to true facts, is much better than working, in the Education process, on true cases in the health care system.
- Even, if this ‘truth’ is totally anonymous, and names of healthcare providers, places and patients as well, some facts—real facts, or at least perceived real by patients are so strong, that some carers refuse to face them and prefer to refugee in imagined narratives, belonging to the world of medical humanities.

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A kind of dying in Medical Humanities…

The death of Ivan Il'ič [Tolstoj, 1886], a classic of medical humanities**,** talks about a patient left to die alone. The Tolstoj's pen protects us: it looks like an act of pure invention, with some glances to our world, and talks about the dignity/ not dignity of dying.

"What sort of a night have you had?" Ivan Ilych looks at him as much as to say: "Are you really never ashamed of lying?" But the doctor does not wish to understand this question, and Ivan Ilych says: "Just as terrible as ever. The pain never leaves me and never subsides. If only something … " "

"Yes, you sick people are always like that…. "

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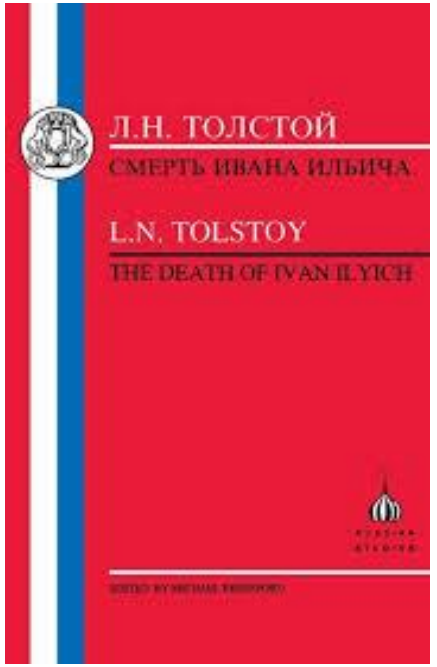
Ivan Ili'c, an evergreen novel ?

"His son had always seemed pathetic to him, and now it was dreadful to see the boy's frightened look of pity. It seemed to Ivan Ilych that Vasya was the only one besides Gerasim who understood and pitied him".

"It is finished!" said someone near him."

After at least thirty years, this book is mandatory for Palliative Care providers, and is an evergreen always mentioned and proposed in Education on Medical Humanities.



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… and in Narrative Medicine, Italy, 2017

In a letter written by an angry son to the hospital who had to face his father's death in that hospital, which took place without any relatives near the old man, the son had asked many times if he could stay that decisive night of the death; the doctor told him '*everything will be okay, just go home'.*

Things went unfortunately different, and in the middle of the night, the son received the phone call by the hospital *'come, your father is getting worse', 'Is he dead?', 'I only can tell you that he worsened'.* The son ran to the hospital, but the father was not anymore in his bed.

A nurse, not looking at him but continuing to put in order some blood samples, said to him '*Do you know that your father died?'.*

The son asked to have a formal dialogue with a doctor, however, nobody came.

Eventually, the personal belongings of his father were delivered to the son in a rubbish bag.

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Impact of the Class of the True Narrative

The reading of this case induced an earthquake. The class split in two: a part which was happy that finally these things related to poor communication and wrong setting were coming at the light of the sun, but another part was too scared to consider this case as happening in a real place.

The latter part was saying that the son invented the whole story: he was still in grief for the sudden and unexpected death of his father, and he had to find an escape goat, which was the hospital.

This is a very complex situation, with no right or wrong position to be taken. However, it has to do with the dignity of dying, and all guidelines of end-of-life care mention the possibility to have family members at bedside, possibly in a better and more human place.

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Ivan Illi’c and the son’s letter…

…share something. The lack of dignity of death.

- In the class, during the discussion, the dignity of death, was not tackled during the discussion by a wave of rage of how these patients, and caregivers can lie and bring damage to the hospital. Possibly, doctors and nurses overreacted because they were somehow unpleased with what they do, too scared of making possible errors and too scared of being legally persecuted.
- Eighty per cent of doctors and nurses in Italy apply defensive medicine and are many of them are living in burn out. In short, an ill healthcare system comes out with discomfort and conflict because people are overwhelmed by excessive workloads, continuous staff cuts and are struggling to have a minute more to talk about and talk to the patient.

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Better using «the evergreen novels» to empower narrative competences, empathy, and compassion?

There is no yes or no: it depends. There are times to use medical humanities, movies, literature, art, theatre, music or whatever is able to ‘say something true’ within the lines of untold and of the emotional manipulation of the performance.

Sometimes, an aversion reaction is not something only acted by patients when getting bad news, but it is acted as well by their carers.

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… The impossibility to stand the true

The world of fiction is preferred and, it is likely to return somehow to childhood when we feel that something threatening is happening, and we want to listen to fairy tales, fictions where *the bad wolf is far in the woods….*

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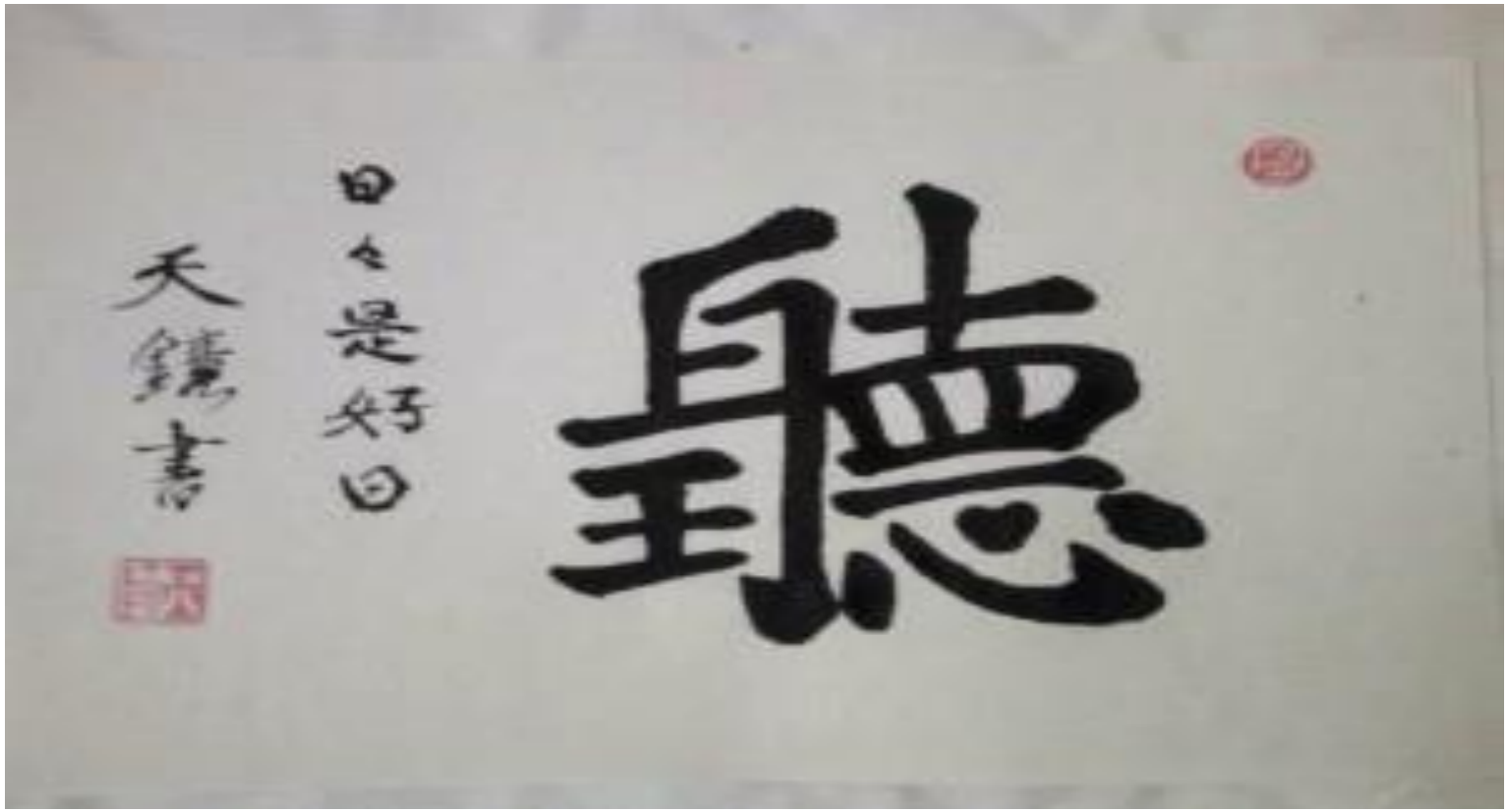
The art of listening requires courage



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Listening is a full understanding

It is divided into quadrants, with a stylised ear on the top left quadrant, an eye in the lower right quadrant and a line in between that means unit or unitary attention. There is a heart at the end of this line.

To end the cycle, there is the representation of a king in the lower left part.

Understanding is worth of a king (a metaphoric figure)); it requires observation, listening, total attention to what happens, and the heart that is the seat of, the spirit Shen.

If Shen is strong, the heart will be daring, the listening will be allowing the entering of the true and the consequent actions will be straight [Lo, 2017]

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How should we use narrative competence?

Jerome Bruner says that narrative in not only plot structure or dramatism. Nor is just “historicity” or diachronicity. It is also a way of using language. Without metaphors, metonymies, analogies, we speak an *“anaemic”* language.

Language is important in narrative medicine to empower technical jargon “*Medicalish*”, with ordinary contextual language: this allows the alignment between doctors and carers.

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Can Metaphors and Analogies Improve Communication with Seriously Ill Patients?

In a sample of 101 conversations between doctors and patients, coders identified 193 metaphors and 75 analogies. Metaphors appeared in approximately twice as many conversations as analogies did (65/101, 64% versus 31/101, 31%; sign test $p < 0.001$). Conversations also contained more metaphors than analogies (mean 1.6, range 0–11 versus mean 0.6, range 0–5; sign rank test $p < 0.001$). Physicians who used more metaphors elicited better patient ratings of communication ($\rho = 0.27$; $p = 0.006$), as did physicians who used more analogies (Spearman $\rho = 0.34$; $p < 0.001$).

Casarett D, et al, Journal of Palliative Care 2010

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Metaphors and medically unexplained symptoms

Estimates of the prevalence of medically unexplained symptoms range from 5–65% in primary care to 37–66% in specialty clinics. It is difficult to pin down a solid approximation partly because it's hard to define what constitutes a medically unexplained symptom. This question was addressed in the overhaul of the previously termed somatoform disorders in the Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-5) when the overly restrictive somatisation disorder was supplanted by the exponentially more inclusive somatic symptom disorder …

"[t]he individual's suffering is authentic, whether or not it is medically explained".

People become patients when they bring medically unexplained symptoms to the doctor.

Shwartz E, The Lancet 2015

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Metaphors come to help when other technical words are lacking…

When health professionals choose to rope off medically unexplained symptoms from everything else, what is at issue is not the reality of those symptoms, but rather what they mean.

Beliefs about the sensations of the internal world guide our interpretation, categorisation, and experience of them.

We need to exchange existing metaphors for more pragmatic ones that integrate psychological processes, without so much health accorded to pleasantness and pathology to discomfort.

Perhaps this new somatic symptom disorder is one step in that direction.

Shwartz E, The Lancet 2015

A Randomized Controlled Trial of Storytelling as a Communication Tool

Lisa Hartling[1*], Shannon D. Scott[2], David W. Johnson[3], Ted Bishop[4], Terry P. Klassen[5]

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Abstract

Introduction: Stories may be an effective tool to communicate with patients because of their ability to engage the reader. Our objective was to evaluate the effectiveness of story booklets compared to standard information sheets for parents of children attending the emergency department (ED) with a child with croup.

Methods: Parents were randomized to receive story booklets (n=208) or standard information sheets (n=205) during their ED visit. The primary outcome was change in anxiety between triage to ED discharge as measured by the State-Trait Anxiety Inventory. Follow-up telephone interviews were conducted at 1 and 3 days after discharge, then every other day until 9 days (or until resolution of symptoms), and at 1 year. Secondary outcomes included: expected future anxiety, event impact, parental knowledge, satisfaction, decision regret, healthcare utilization, time to symptom resolution.

Results: There was no significant difference in the primary outcome of change in parental anxiety between recruitment and ED discharge (change of 5 points for the story group vs. 6 points for the comparison group, p=0.78). The story group showed significantly greater decision regret regarding their decision to go to the ED (p<0.001): 6.7% of the story group vs. 1.5% of the comparison group strongly disagreed with the statement "I would go for the same choice if I had to do it over again". The story group reported shorter time to resolution of symptoms (mean 3.7 days story group vs. 4.0 days comparison group, median 3 days both groups; log rank test, p=0.04). No other outcomes were different between study groups.

Conclusions: Stories about parent experiences managing a child with croup did not reduce parental anxiety. The story group showed significantly greater decision regret and quicker time to resolution of symptoms. Further research is needed to better understand whether stories can be effective in improving patient-important outcomes.

Trial Registration: Current Controlled Trials, ISRCTN39642997 (http://www.controlled-trials.com/ISRCTN39642997)

Citation: Hartling L, Scott SD, Johnson DW, Bishop T, Klassen TP (2013) A Randomized Controlled Trial of Storytelling as a Communication Tool. PLoS ONE 8(10): e77800. doi:10.1371/journal.pone.0077800

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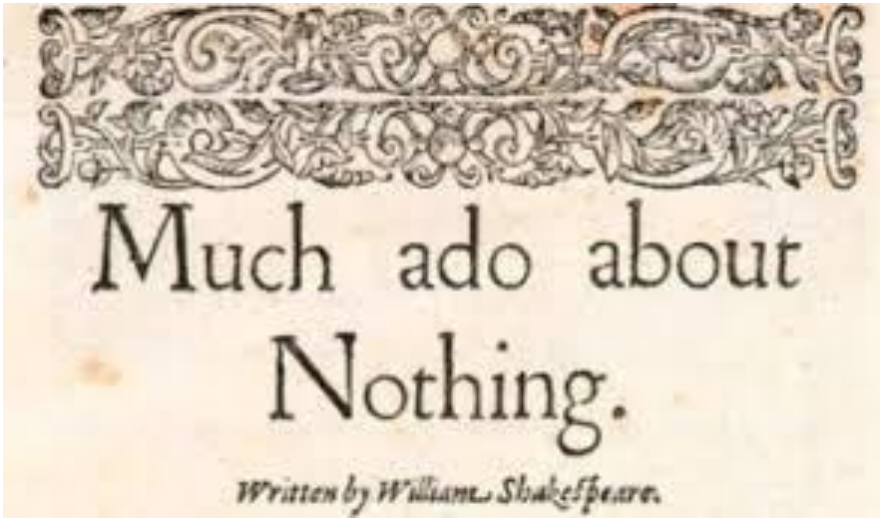
Stories might help as memory tracing…

… and to become more reflective, less impulsive, and more confident, when the Happy Ending by the relieve of the symptoms are there, that…

Sometimes…*Much A Do About Nothing,*

in clinical practice.



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How Can we foster the Education program on Medical Humanities and Narrative Medicine?

- Investigating the “class mood” to understand whether to use Medical Humanities and/or Narrative medicine from real life?
- Understanding whether Teachers are Used to convey something confortable or unncofortable to health care providers?
- Changing the style, in a sustained rhythm so to convey both real life narratives and medical humanities? There are NO Cinderella Position?
- Following the illness plot narrated by patient’s?
- Creating new metaphors and neologism to explain the disease?
- Testing the outcome of using the different contents and style?

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Progetti

Persone con sclerosi multipla in rete: quali orizzonti – 2013

Obiettivo del progetto Persone con Slerosi multipla in rete è quello di studiare il vissuto dei pazienti affetti da sclerosi multipla attraverso i loro canali di comunicazione rappresentati dai principali blog e forum online: attraverso un esame dei loro testi scritti si propone di offrire una serie di chiavi interpretative innovative che possano aiutare a ...

Vedi pagina »

Storie di vita negli anni d'argento – 2013

La terza età vista con gli occhi di chi la vive, sulla propria pelle o attraverso una persona cara. E' "Storie di vita negli anni d'argento", un libro che raccoglie 50 racconti di anziani fragili e dei loro assistenti familiari. Un esempio concreto di medicina narrativa, presentato a Milano e frutto di una ricerca condotta ...

Vedi pagina »

Back to life: la narrazione dei pazienti con mielofibrosi – 2013

Lo scopo del progetto Back to life è quello di approfondire, attraverso la medicina narrativa, la conoscenza del carico emozionale, fisico e psicologico della mielofibrosi sui pazienti e sulle loro famiglie, al fine di delineare un quadro il

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http://www.narrativemedicine.eu/progetti