FONDAZIONEISTUD

Defeating the shame in illness narratives

The Shame and Medicine Project is an engagement between medical practitioners, social scientists, philosophers and medical humanities scholars seeking to investigate the role of shame in the context of health, medicine and medical practice.

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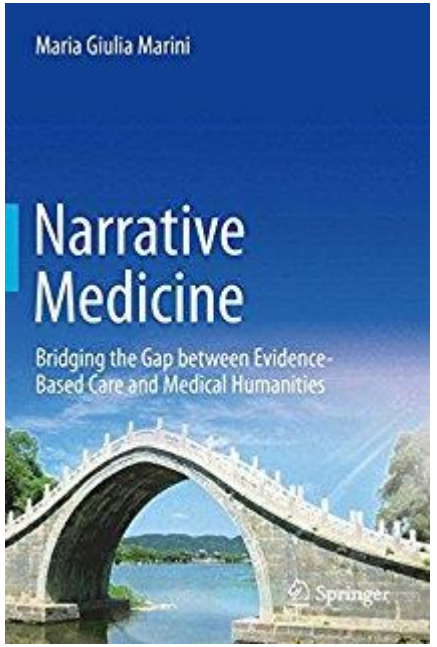
What is narrative medicine?

- It is based on the interaction among patients and health care professionals, with attention to when the disease showed up, how the disease is considered and treated and to the possibile health care outcomes.
- Narratives can be collected either through reflective writing, or verbally listened.
- Our narratives are basically all real, and they don't belong to the "Fiction" of "Fantastic fantasy".
- The aim of narrative medicine is to create aligned relationship between carers and patients, to allow patients to achieve and display the factors for coping, that is to master the stress induced by the disease.



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The «ordinary» coping factors

We study whether narratives are rich of coping abilities, that is the mastering of a stressful event as an illness, or lack of these factors. Carver highlighted five variables which do enhance coping as:

- Agreeableness
- Openness
- Awareness
- Responsibility
- Optimism

The three negative factors for coping:

- Denial
- Isolation
- Obsessive thought

Coping is very much multifactorial and goes far beyond these elements.

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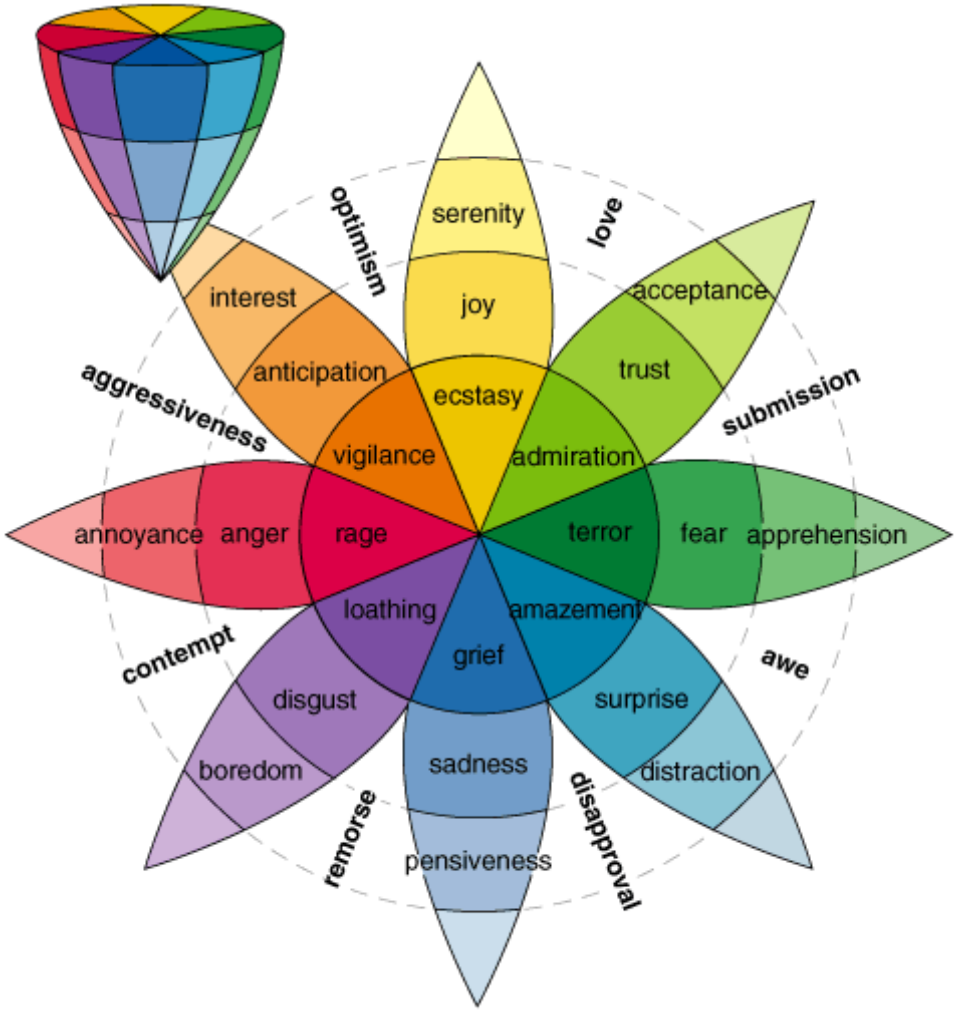
Shame= Fear + Disgust

Shame is a feeling which has to do with humiliation, inadequacy, disgrace, and inferiority. To experience the feeling of being ashamed, there should be always somebody else, “the else”, who is judging and moralizing both with verbal and not verbal communication putting the object of judgement in a condition of mixed fear and disgust of his/herself.

Shame, among all the variety of emotions is the most social one and has to do in majority of cases with a tertiary point of view, which could be both the microcosm or the macrocosm of the society of belonging.

As microcosm, family, work, school, friends are foreseen: as macrocosm, the “others”, the society of the wider community, the city, the country of belonging and the international**, globalized world.**

The Plutchick Wheel of Emotions



Fear + Disgust = Shame
Anticipation + Disgust = Cynicism

Disgust + Anger = Contempt

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Shame and «vergogna»

- “Vergogna” – from Latin “vereri” - means to feel a painful and humiliating perturbation inside. It is related to “**verecondia**” which surprising has to do to with a proper way of behaviour and respect for the other, generally upper classes, nobles, and in the relationship between men and women. “ “Shame” originates from **Skam**, a proto german word and has a strong impact, related to a committed sin: “**shame on you**” is almost like a cursing.
- Therefore, talking on “vergogna” or shame, there are two different histories: the Italian has to do with that noble sentiment of “humbleness”, which is not exclusively an **humiliation**. Symbolic is the ritual of village people removing their hats in front of knights or nobles, or of the peasants who concealed their dirty hands because they were feeling inadequate.
- “Vergogna”- shame has to do with **social classes, social beliefs and with social roles.**

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Shame and sickness

- Bsed on the classical definitions of **Arthur Kleinmann**, the word “disease” is the biomedical model, the body/mind as broken machines to repair, the word “illness”, the inner living of a patient with a disease, and the word, “**sickness”,** the way a disease is considered by the society.
- “Shame” falls especially into sickness with continuous impacts on the illness, the ”inside” of the patient. Two realms which might be in tune, that one of the patient and that one of the **social context**: in this case, the predominant emotions and behaviours are inclusions, attention, compassion, shared fears and shared rage, if any.
- When there is no tuning between the realm of the ill person and the **realm** of the others outside, sharing is very hard to get, and eventually exclusion and loneliness are there. Shame – vergogna- could be one the “culprit” of the discrimination.

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How to discover shame?

Shame is an emotion very difficult to uncover because, when someone feels embarrassed, he/she is not willing to speak about what are the causes of this feeling.

It is precisely this type of situation where narrative medicine can be of help: patients, in a comfort zone can open themselves by writing, and this can be empowered by the intimacy of **being anonymous**.

In fact, the oral interview to patients does not allow often the putting into words the feeling of humiliation, whilst, by writing, the word “shame” and “feeling ashamed and embarrassed” are recorded by the pen or by the keyboard.

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Shame and aesthetics

- Skin diseases which impact the aesthetics of the face and the body, as acne, psoriasis, atopic dermatitis, hives, are lived with shame by most of the affected people. Here some verbatim from narratives of **patients affected by psoriasis**:

- *"Taking away my clothes for me was a cause of shame and looking myself at the mirror was every time a trauma. Today, I have overcome the milder problems, phototherapy makes me feel good. I feel that because of psoriasis I have not lost anything, I do not have to let me go down … **bad illness are others..**"*
- *"They said there was nothing to do. I just had to be more serene and less nervous. But how do you do it? There were times that I was a crust walking, not leaving home for the shame and because the people around me, my family, was remarking it and I was ashamed that they were ashamed of me. **Psoriasis has taught me that we should never judge by appearances, that everybody of us suffers for something and we must go beyond, listen and become good and sensible."***
- *"After psoriasis appeared in my family, at work and with friends I felt so ashamed. Dressing up for me was impossible, looking at the mirror was not a nice thing. If I were to tell psoriasis today with an image for me it would be a bad image but I think that there is worse in life. Today **I'm resigned**."*

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Shame, Hair and Cancer

- Cancer has to do with survival, with the fear of dying, with invasive and "cruel" drugs and tests: however, what is one of the most common things considered by patients, even before the survival chance? "*Doctor, will I lose my hair?"* The loss of hair has to do with identity, but has to do also with aesthetics, with the social code of our society. Now, there are many campaigns which are trying to show bold women and men after chemotherapy, like the **Bald Mona Lisa**, to educate people and reinforce patients' self-esteem.

- Hair seems to be more powerful than life wish.

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Pride for the eye lost during the cancer

- A Spanish Lady, now aged 52, had a cancer, at first initiated through the discovery of nasal polyps, then cancer invaded the back of the eye bulb and the only thing the doctors could do was, after a standard series of chemio and radiotherapy protocols, “to take the eye off, and a piece of nose was partially rebuilt.”
- After the eye surgery that occurred seven years ago, she decided not to take any further action to put a fake eye on.
- In her writing , she tells that she recently enrolled in a master on the ancient Mediterranean and wants to take advantage of this second opportunity that life has given her to study the Greek beauty and thought, and feel alive and happy.

“***I’ve never felt the loss of my eye as a loss, for me it was the Door to Life. It is my medal, I feel very proud to be able to show that life deserves to be lived. ”***

Patients living with a stoma

In the narratives collected both from Italian and Australian Patients who underwent the creation of ostomy and with the consequent uses of pouches for ileum and colon cancer, only in few cases the word “shame” is clearly mentioned as it is. However, it is readable among the written lines.

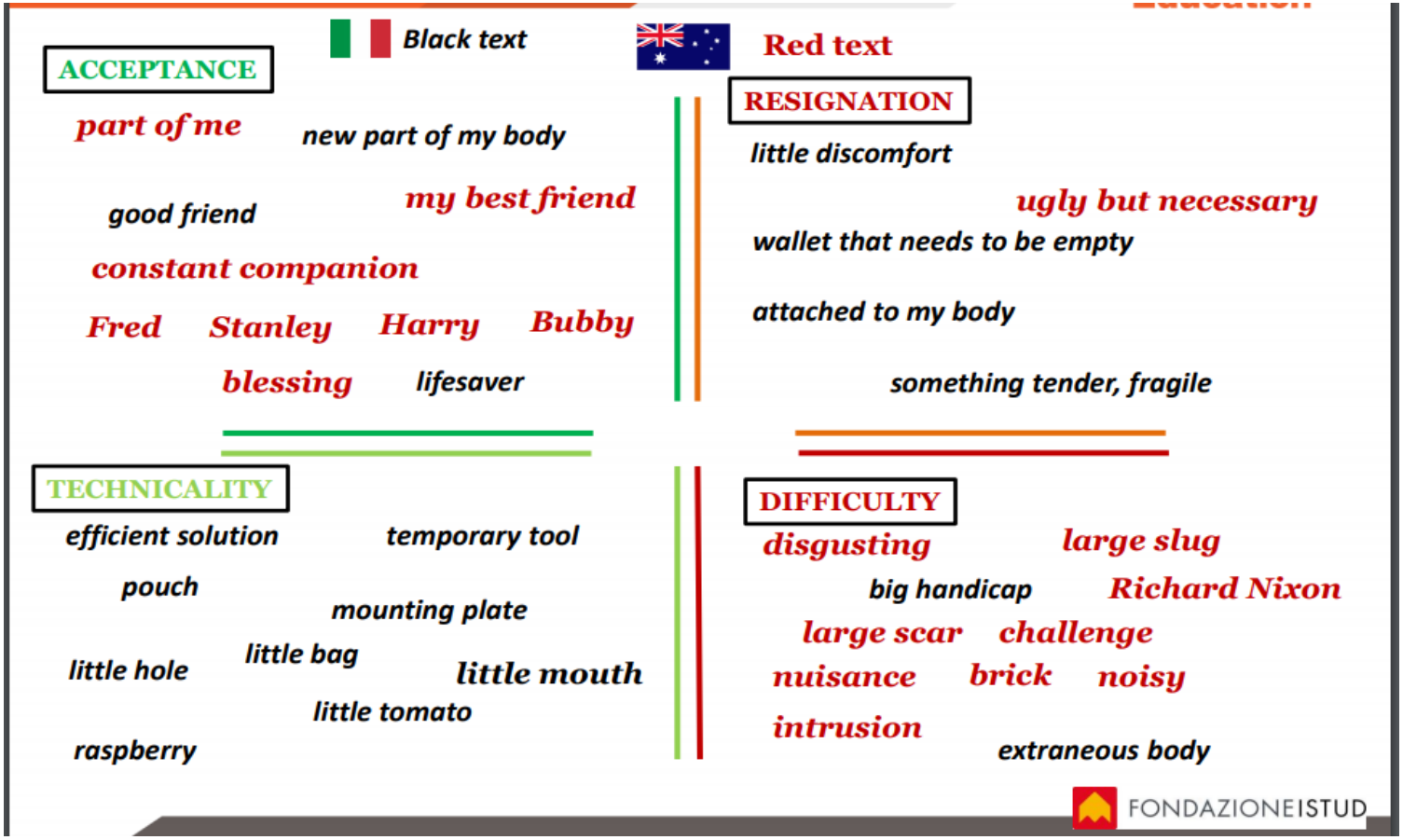
“I don’t want to look at myself”, “I don’t want to touch the pouch” up to“I have disgust of it”. Here, there is a mutilated body with an external bag collecting their faeces. Shame is definitely there, however the miracle of life comes at least in half of the patients.

The sharing with their relatives and their health care providers the fact that this feeling of humiliation can be beaten. Patients’ associations count a lot and help in a peer fashion people who live with a stoma.

Defeating the shame

After a good coping, the outcome is a sort of pacification with the traumatized body and *“now, after the surgery, I’m happy to wear a bikini and I go regularly to swim”,* this is the happy ending of a narrative of a girl.

The names given to the stoma are symptoms of an achieved coping and signs to understand if shame is still there:



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Shame and old age

Shame is often there in narratives of elderly people: in this case, this feeling is not associated with a particular severe disease, but with the human decay of body and mind over the years.

Shame here is even more difficult to decode, because it is not so clearly expressed by old people. The continuous complaints of elderly people of their doctors, the places they visit, the food they eat, and the constant attitude to “look at the past, when I was young…” as the *Golden Age*, when the body was strong and the mind was faster (perhaps less sharp)… all of this could be signal of shame.

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The old Lady who opens herself

After many days of constant complaining, she, aged 84 years, started to cry in tears expressing her fears to be discriminated:

"I am ashamed of my heart which is not answering at the right pace, and I am afraid to be put in a nursing home. Furthermore I'm a disaster with Internet and everything now goes through that technology".

Nobody around her suspected this, because she was looking as a very active and even proactive woman. The shame was silent, difficult to unmask, and was hidden by all of this **complaints** and nostalgic feelings.

The good news is that after the sharing with friends and relatives, and the clear asking of help, shame melted down like snow exposed to sunlight for this Lady.

Shame and health care providers

In a study carried out in Italy, narratives from paediatricians on children and adolescents affected by severe asthma were analysed to see if this writing approach allows the finetuning of both patients' and physicians' cultural construction, including emotions and values on the illness and the pathways of care.

Out of 68 parallel charts, the full narrative of a clinical case including also the attention to the illness, the sickness and the quality of the relationship, the most frequent risk factors for difficult relationships were physicians' moral judgment (73%), and patients' anger (50%). The mechanism that induces the patients to explode with anger, is often a sense of feeling ashamed for something that they should have/not have been done: keeping an animal at home, parents who continue smoking, or the mere sensation to feel just judged by looking at how they are dressed, how they talk, their parental styles, and how they behave by doctors.

Narrative medicine to evaluate the relationship between clinicians and patients living with severe asthma

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Introduction

The severity of asthma varies individually and the main factors leading to such differences are resignation towards the symptoms, stress and physical activity.[1] Narrative medicine is a medical approach that allows the accommodation of both patients' and physicians' cultural construction, including emotions and values on the illness and the pathways of care. The parallel chart is a narrative medicine tool that improves doctor–patient relationship, by asking physicians to write about patients' life, bringing out reflective thoughts on care [2].

Objective

The aims of the SOUND project "Writing narrative about patients with severe asthma to achieve new effective diversification and enhancement of care" were to evaluate risk factors and positive triggers in doctor-patient relationships and to give clinicians new strategies to improve quality of care.

Methods

In 2016 Italian pulmonologists, allergists and paediatricians, after an educational webinar, narrated their relationship with people living with severe asthma, through the use of the parallel charts (5 each). The narratives were collected online and analysed according to the Grounded Theory approach and using semantic software (NVivo 10).

Results

Out of the 314 narratives written by 66 clinicians (246 adult and 68 paediatric patients), the most frequent risk factors for difficult relationships are physicians' moral judgment (73%), frustration about treatments previously prescribed (60%) and patients' anger (50%), followed by smoking, independent internet researches, homeopathy and obesity. Difficult relationship lead patients to refuse a therapy change in half of the cases (50%) and to a lower rate of restored activities.

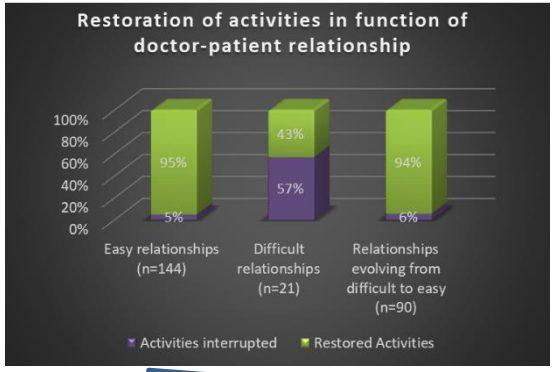
On the other hand, physicians could master, beyond acceptance and listening, difficult emotions as fear and sadness, providing reassurance and comfort. Thanks to the narrative medicine approach, many physicians were able to apply an empathic listening to their patients thus leading to make their decision to change therapy approved also by those patients were initially difficult to relate with (35%). As a result, when patients' trust had led to change therapy approval, the innovative therapy was considered a source for patients' "reborn" according to physicians' point of view (59%).

Smoking

"I must confess it was very tiring for me, as when they came to see me I sometimes didn't even visit F. But, I usually spend time explaining how damaging it was for their daughter to be exposed to their smoke and asking them to pay attention because the pharmacological therapy could be sabotaged by smoke. They justified themselves saying they only smoked on the terrace and only rarely inside the house, and never in the same room where the kid was. So, they were convinced they were not doing F. any harm."

Obesity

"Metaphor: Dear whale; The patient told me she was completely invalidated in doing her daily activities. She could not walk without shortness of breath so she never went out alone. Immediately, she started to cry and said her obesity was the fault for her unhappiness and illness. But, she swore to eat little with no results."



Anger

"So I felt anger and powerless in convincing her to take care of herself. Her bad adherence to therapy was particularly due to her rebellious attitude and behaviour in regard to her illness, but also to her relationships and problem management in general, as I could see in many medical visits. She was as a child who refuse to be aware of her problems. I thought I had to explain what I was feeling so I said her I was disappointed with her childish attitude. Consequently, I communicated my decision to the patient to prescribe her an important therapy for severe asthma and I tried to

Online researches

"The revaluation visit was particular; the patient was hasty, she did not want to listen me but only to propose something she'd read on-line or on journals. The patient seemed to be confused under all points of view because she was too guided by media."

Homeopathic therapies

"She immediately said she was against medical treatments because she preferred homeopathic drugs. Sincerely, I don't know what this lady was feeling because she was too distant from me so it was impossible for me feeling the same impressions with her. After explaining for 30 minutes long on what asthma is, how to treat it, what possible mistakes not to do with it, she insisted on requiring me for homeopathic drugs so I had a strong sense of rebellion against it. I thought I had to reexplain her all things from the beginning, but I had no desire; furthermore, talking with her was really unsatisfying for me."

Conclusion

This project allowed physicians to identify the right behaviours they must take to improve patients' alliance and effectiveness of treatments. The clinicians learnt to pay more attention to the cultural mindset of patients. The results are positive when dialogue, scientific expertise and effective therapies, as biological drugs, are there.

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2. Charon R. Narrative medicine in the international education of physicians. PRESSE MED. 2013;42(1):3-5.

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The dolphin is the signature picture of the project SOUND since their peculiar call that resemble the asthma wheezing.

…moral judgement evokes fears, guilty feeling, disgust and shame

- There are comments in their writing on the poor or excessive style of the mothers of their children. Sometimes doctors are evaluators of the qualities of being a good parent, and they are heavy judger if they see possible lacks in the parents' skills. *"The girl should go to live with the father because the mother is totally inadequate, lacking of empathy".*
- Because of this, difficult relationship lead patients to refuse a therapy change in half of the cases (50%) and to a lower rate of restored activities. That is to say, that the feeling of being humiliated and judged, creates in the patients the need to leave that physician and the suggested treatments to choose less moralizing carers.
- Physicians who are able to control the judgment attitude, can master, beyond acceptance and listening, patients' emotions as fear and sadness, providing reassurance and comfort.

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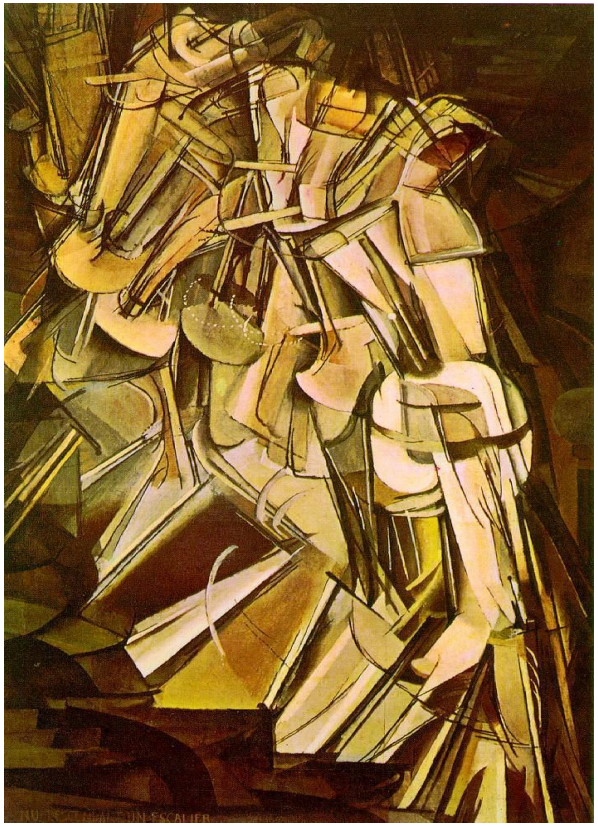
Medicine in (post)contemporary society

- (Post) Contemporary society which has a health care system made by lab tests, investigations and images, neglects more and more the presence of the body and the soul, putting in emphasis the mind and rational technology.
- However, changes in the bodies and in the minds will ever exist for the self and the society. Belonging to the history of the human beings, we all bear the catalogue of emotions including shame.
- So how to cope with everlasting shame?



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… the use of the ordinary coping factors

- Rationalization (awareness, sense of reality)
- Agreableness (the sharing with the others, looking for loving relationship, being extrovert, and being kind also with oneself limits, up to accepting and to forgiving)
- Responsibility (starting to cure the illness, ranking the illness with a responsible attitude towards more severe diseases)…
- Get away from the obsessive thought of shame by doing something else, a creative activity….

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… beyond the ordinary coping factors

Pride versus Shame

Pride is a secondary emotion, born from Mother Joy and Father Anger.

…Learning from the Medal of the lost eye- the daring to show after the breast mastectomy, no plastic surgery anymore but Tattoos and Decorations.

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The Kintsugi

- When a pot is broken into pieces in Japan, they don't use invisible glue, or they don't throw away the pot.
- With the Kintsugi art, they put gold all along the broken pieces and they rebuild the pot again. They will have a new pot, in which every rupture now is proud in its golden coating. Scars are all there and visible: the more scars there are, the more precious is the pot.

kintsukuroi

(n.) (v. phr.) "to repair with gold"; the art of repairing pottery with gold or silver lacquer and understanding that the piece is more beautiful for having been broken

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"Heaven knows we need never be ashamed of our tears, for they are rain upon the blinding dust of earth, overlying our hard hearts. I was better after I had cried, than before–more sorry, more aware of my own ingratitude, more gentle." – Charles Dickens, Great Expectations….

"When you make a hole in your dress, don't repair it with invisible mending, but sew laces and embroidery to make it even more beautiful." (Italian anonymous saying).

How to reach us

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And you?
Write down your best coping factors to defeat shame…