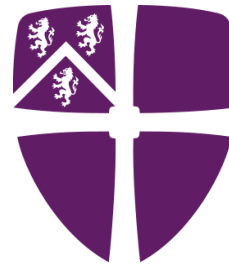




FONDAZIONE ISTUD

Religion and Spirituality as coping factors for recovery in illness time



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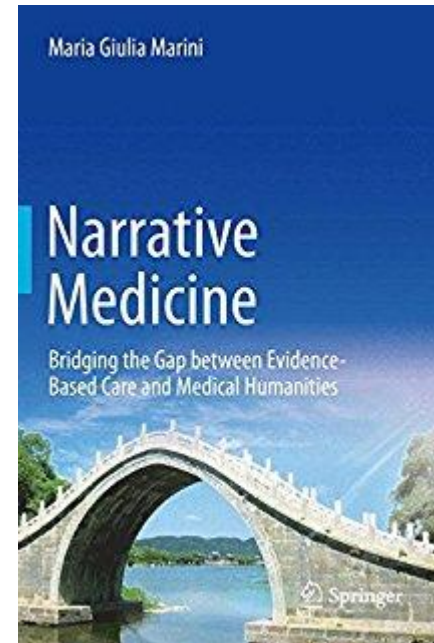
Between religion and spirituality

- Catholic religion is deeply rooted in-daily life of Italian society, despite an increasing detachment from religious tradition of younger generations towards “free” spirituality.
- Such religious and spiritual feeling often finds renewed momentum in times of adverse health conditions with mental distress. The investigation of religion and spirituality of patients’ narratives provides semantic insight, yielding useful elements for building coping strategies to overcome trauma of diseases, as cancer or physical disability.

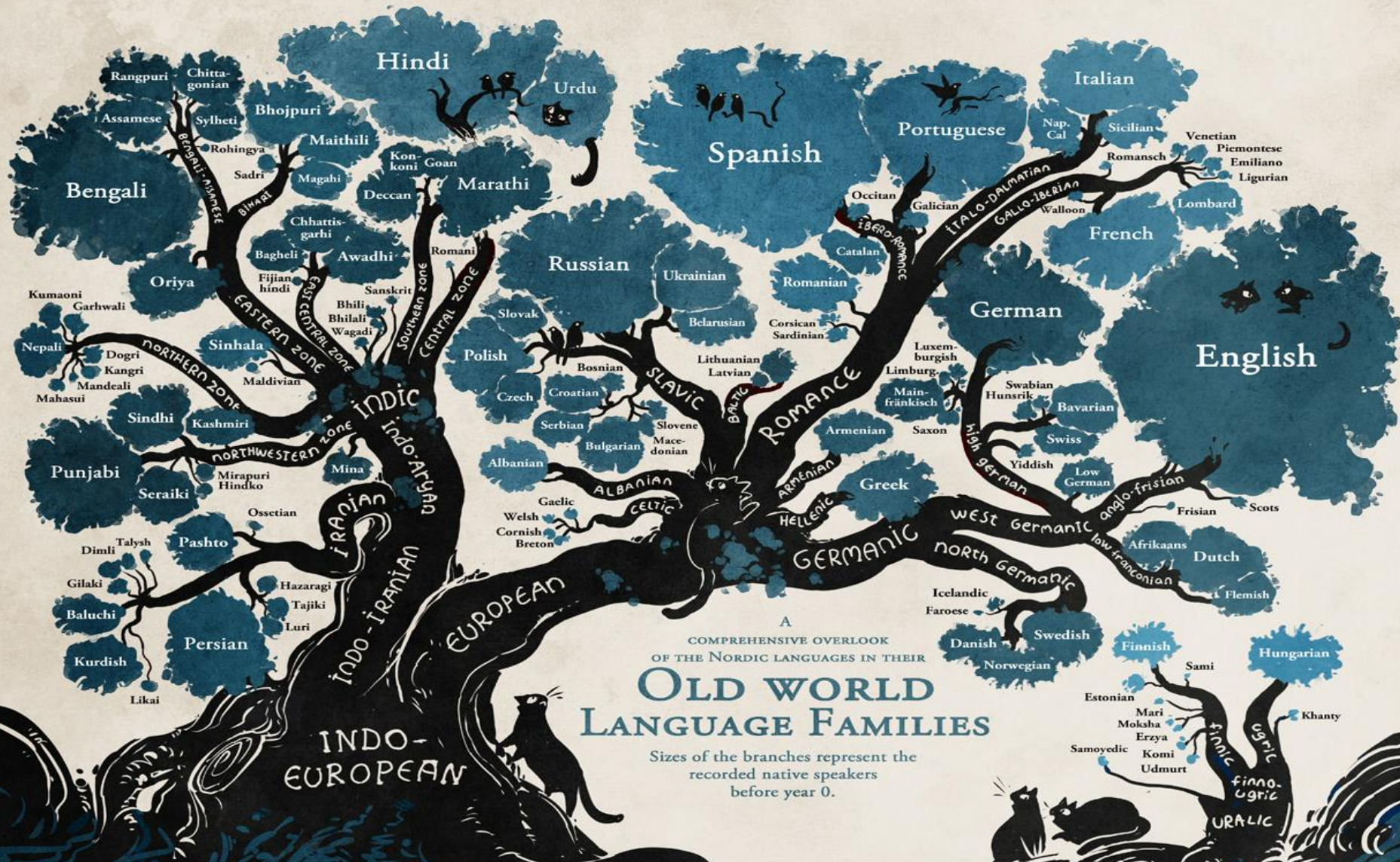


What is narrative medicine?

- 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 possible 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.



LINGUISTICS BEFORE LITERATURE



Communication accross countries; an Australian discovery, the natural semantic metalanguage

The Natural Semantic Metalanguage (NSM) is a decompositional system of meaning representation based on empirically established universal semantic primes, i.e., simple indefinable meanings that appear to be present as *word meanings in all languages*.
(ANU University, Anna Wierzbicka and Cliff Goddard)

The words? Here some of the 65 semantic primes....
I, Me, You, Mine, People, Body, Good, Bad, Things, Part, Kind, to live, someone, something, anything, to die, to feel, to think, to know, to want, don't want, to happen, to see, to hear, not, to say, before, now, after, inside, one, many, a few, maybe, inside, true....



Pangea—250 million years ago

An illness plot based on Natural Semantic Meta-language comparability allowed across all countries

My story

Before the illness.....

Something has changed

It happened like this.... I was
something

when I felt Then, to know what was
happening, I spoke to

After some time, they said to me that I
felt because

My body I thought..... I
wanted.....because of this

At home In other places:

The people in my life

The journey in care

At the center that had / had not diagnosed my
disease, I felt cared so.....

When I was at home ...I felt.....

it happened that the illness.....

The person / people close to me was / were

Today

Now I feel.....the illness nowMy body.....

I feel I can do

I think that the cares have beenand in particular
therapies were

When I'm at home I can / can not

With the people close to me.....

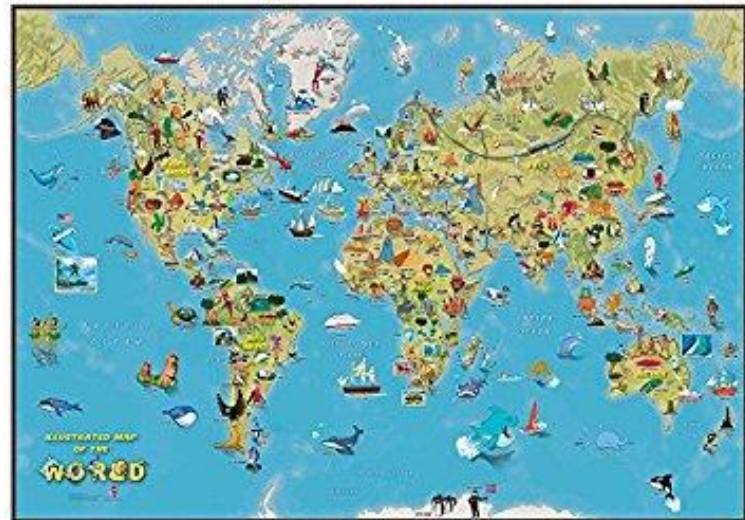
In other places I can / can not

Out from home I can / can not

With friends.....

If I think about tomorrow

And I would like that it could happen



The coping factors

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

- Agreeableness
- Openness
- Awareness
- Responsibility
- Optimism



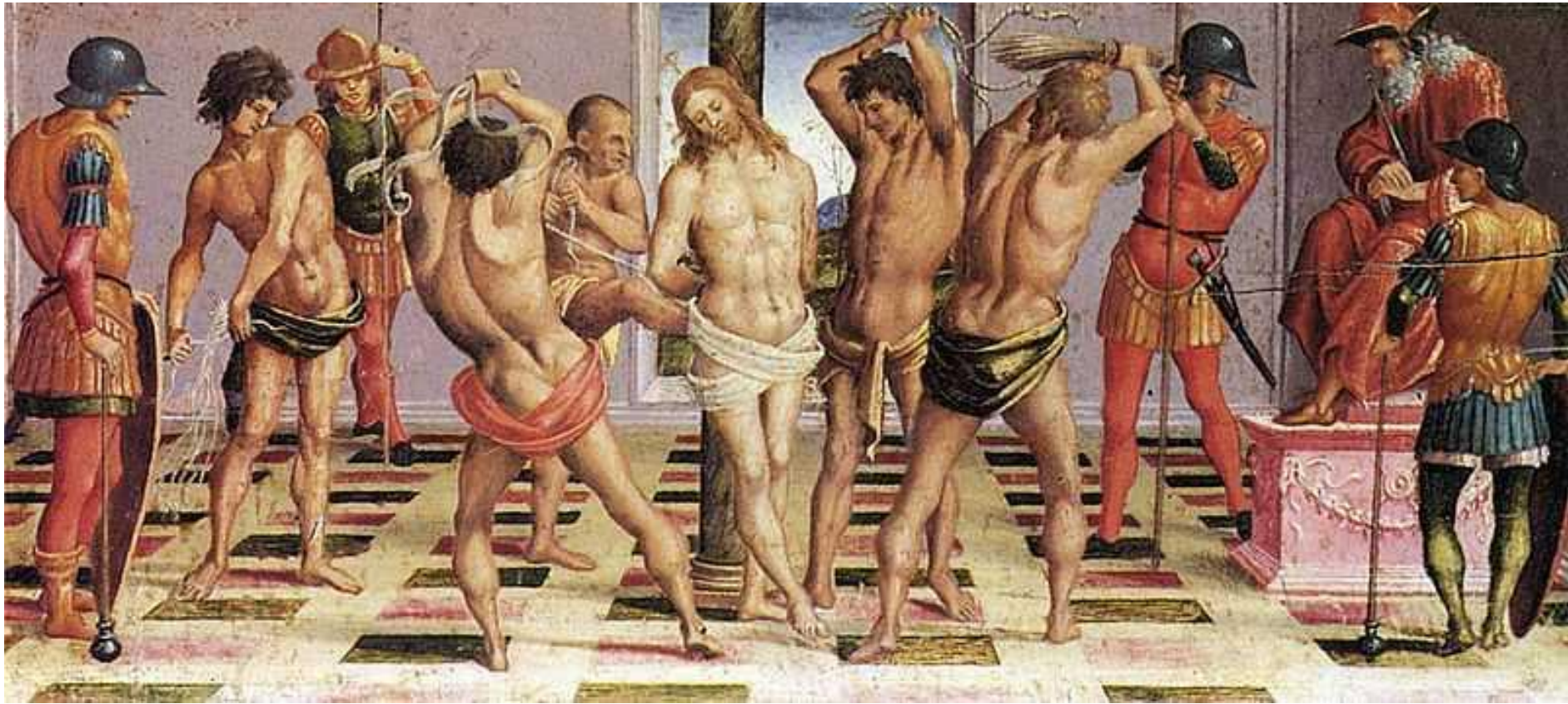
The three negative factors for coping:

- Denial
- Isolation
- Obsessive thought



Coping after the trauma of a disease is very much multifactorial and goes far beyond these elements. From the narratives, we can see that many adaptation modes fall into religion and spirituality elements.

Religion from the narratives: the patients' journey



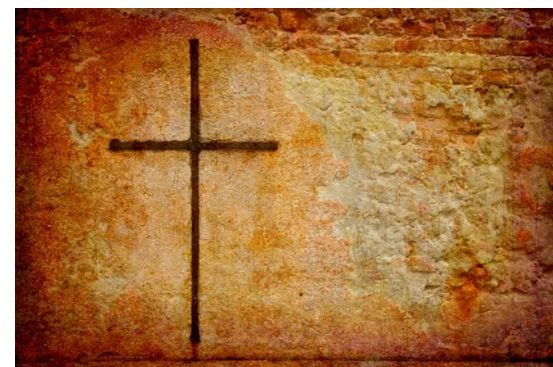
The mind equation “disease as a passion of Christ”

The diagnostic path as well as the treatments, are often mentioned in patients’ narratives affected by serious disease as a “via crucis” as a “calvary” or as a cross to bear.

For the psychological sorrow and the physical body pain, there is like a mirroring with the pain assigned to the last earthy journey to the figure of Jesus.

Hence, patients use these metaphors, to communicate the process they are going through, with the aim to be accepted and understood by the others, family members and carers.

According to FRANK these are restitution narratives.

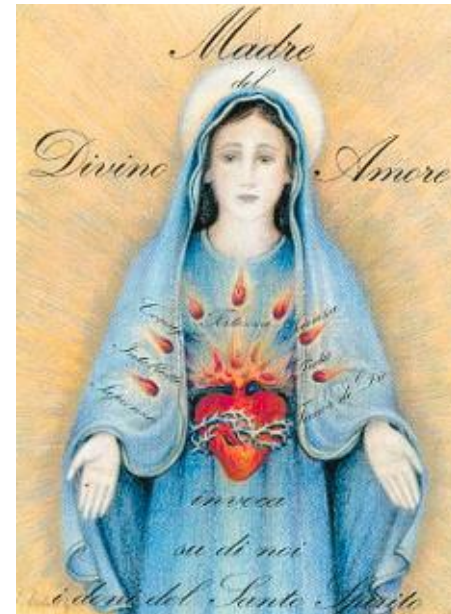


Religion from the narrative: total unconditional trust

Narratives of patients with cancer patients and religion, locally in one cancer hospital of Northern Italy and here are the results: 45% of patient indicated faith and prayer as a fundamental support in dealing with the illness *"the Lord is my shepherd, I lack nothing ... He is my support and my walking stick. I will not be afraid of the assault of even one thousand enemies "*.

here is no need for healing (eg, miracle) but there is an unconditioned trust to what will be, will be the willing of the divine, *"without finding any answer you one accepts what our "master "has reserved "*, but God is also seen as the creator, the one whom we must be thankful for the gifts of life , *"my prayer, because I am a believer, a Catholic, and I realize the value of life, the Greatness of God, creator and redeemer "*.

Cancer led many patients to a rediscovery of faith and prayer as a guide in moments of difficulty and as a value to convey: *"Thanks to you, cancer, I rediscovered, indeed enriched my faith; even in times of discomfort I know someone up there I'm close and with prayer I can find in me so much serenity and tranquility"*.



Social discrimination in contemporary society for being religious?

- One patient writes to us *“I cannot tell it to anybody, because otherwise they will tease me, but I have on my mobile phone an APP with which reading the gospel every day and praying”*.
- Religion is from a scientific and professional point of view -and now even into the wider society - is a belief for poor and less instructed people.
- Even the most cultivated people sometimes have to hide their beliefs, or wish of believing, in the name of a Ratio barely capable to explain the basic existential question of life and death.
- Elderly people are more allowed to be religious.



Spirituality

Spirituality is less controversial in Italy and is widely accepted and nourished by individuals, but not by the Official National Health Service (NHS).

It includes the “caring of people relationship”- as in the first petal of the Blue Flower with all associated feelings, the seize the day, as second petal of the flower, which is the beauty of simple daily life, and setting of new priorities, as in the third petal of the flower, linked to new values to live...and many other possible factors.

All of these are coping factors related to Carver’s ones: openness, agreeableness, and awareness and optimism are catalyzers for this blooming of spirituality.



An attempt to match spirituality patterns in the collected narratives



First petal: loving relationship

In Italy, spirituality is very much embedded in “**loving relationship**»: family around is something “holy.» Through Natural Semantic Metalanguage we found cultural difference on the “importance of family” between Italia and Australia, in patients with colon cancer who live with a stoma.

“The people you would like at your side....”

80% of Italian patients (out of 152) answered family members, while 80% (out of 76) of the Australian patients mentioned “nobody,” or “health care professionals”..



Romantic boundaries

In 123 patients affected to multiple sclerosis, it turned out clear that people who were able to live a nearly serene life were those who had a solid family behind or who were able to develop boundaries in a new family or building new friendship.

Many narratives of patients were very “romantic”, much dedicated to protect the others healthy people.

There are narratives of caregivers who writes about protection and love as main reason for staying close to the patients: how ever tiredness and rage of the family members are evident because the feel somewhat powerless in front of the illness.



Second petal: being in the present moment

From these patients, we learn the importance of being able to enjoy the small things of the here and now daily life, as the **seize the day**, *“a smile, a gesture of kindness, are so important, before the illness I was not able to notice them, but now yes”*, *“being able to do a flight of stairs”*, *“learning to listen and to accomplish to the limits of the body”*. The future is not given to be explored, or is not wanted to be thought about. Having the skills to stay in the here and now make patients happier and less worried of the future.



Enjoying the slowness

From a patient with chronic obstructive pulmonary disease we learn: *“I cannot walk as fast as the others. I enjoy the landscape, moment by moment, as I have never seen it so beautiful before, when I was always running”.*



Third petal: meaning and purpose of the things we value

"before I was taken by the commitment of work and by so many small things, as all of this risked me to get away from the people I love them ".

In a project with 33 young women with cancer, preservation of fertility by means of cryo conservation of the oocytes, was offered them before undergoing traditional protocols of chemotherapy and radiotherapy. Here some of their narratives....



The discovered value of maternity

"Protect my dream ... The joy of being a mother. ... Have finally something eternal. Love for a Son "; "I was 34 years old and we were looking for a baby ... instead we found the tumor, strongly hormonal, which therefore required long-term care that involved chemical menopause for five years»

"For me maternity is the meaning of life. A woman in her baby encloses everything. Love, strength, values. All.Obviously, I'm scared to think something can go wrong but I'll try to be afraid of them ";

"To be honest, before diagnosis, maternity was something that made me anxious, and I had put it in" a closet "waiting for my new balance to arrive .. and I was surprised to want to open that closet, not wanting to give up the chance to become mother, not wanting to allow the cancer sweeping away this joy".



And after a premature birth...

"After the first 40 days, we began to believe that we could make it. We could bring our baby back home. slowly grew in us day by day the hope of progress "; "I started to feel better ... in the sense of being more... when my daughter finally started to stick to her breast ...and it all started to look more "normal";

"What we have experienced has certainly made me stronger, and I really do. I've learned that sometimes you just have to wait and it's all over.... "; "I earned so much: my life has become enriched, I grew up, matured. I'm happy, I learned what's important in life and what's not "; " I learned to give the right weight to things, I got so much affection "



Fourth petal: Inner freedom and wellbeing and peace

There is a poor attitude to dedicate to oneself, to find an inner peace and freedom. Probably in Italy, a huge devotion to family, boundaries, babies, children, partners, quite in a romantic way is there.

However, the fourth petal – which might come from contemplation, concentration, self dialogue towards a peace of mind -is still very rare and to be empowered.

There is a tremendous lack of culture on this in our country.

Only spot practices are spread to bring relief, mainly in patients who live with cancer and are terminally ill in hospices.



The quite after the storm...

- *"I am much stronger and aware of my strength, my emotional resources. I want to be comfortable and surround myself with positive people. Despite the therapeutic path I carry out a normal life, indeed, go out more than before and I much appreciate leisure more various happy moments and people who support me and surround ";*
- *"It is a life still to discover and build a piece at a time, but with a smile and courage in the DNA. I need normality and equanimity that for too long I didn't have, I need to meditate and to feel good about myself and who I'm close to "*



Fifth petal: flourishing and finding hope

- Hope is “By the way it is the opposite of fear “to think, to feel that something good can happen in a short time or in a long time”. to think, to feel that something bad can happen in a short time or in a long time”.
- Hope may mediate major life events, as illness and main human relationships, while optimism may mediate more routine more or minor problems.
- When patients are seriously ill, it is self-evident that hope becomes a tool for a better coping with the current condition of the disease, as well as optimism which is indicated by Carver being one of the five key factors for coping



The ambiguity of clinicians

Clinicians have quite an ambiguous reaction about the possibility of **giving or taking out hope to patients**. On one hand, they have to inform clearly patients about their conditions and even about their survival times.

Doctors say “everything” to the patient: they may take out hope of a longer life, simply by saying, that few months are left to live. Physicians base these information on Evidence Based Medicine (EBM), which deals with probability numbers calculated in clinical trials, and therefore, as most of scientists, provide information based on these probabilities.

Thus their **“everything told” is based on probabilities not on certainties.**



The black swan

- *“Hey, sir, are you still here?”* Is a question written in one patient’s narrative asked by a young doctress to the patient who returns to the hospital. Patient does not reply to her but writes to us: *“she wanted to see me buried, already in the grave”*. The sentence pronounced by this physician was considered similar to a capital execution, and it was a cool shower indeed for the patient.
- Why she, along with other doctors, was so much surprised to see this patient still alive? He was an oddity for the probability scales of EBM.
- He was like the “Black Swan” of Taleb, that means the extreme impact of certain kinds of rare and unpredictable events, the outliers related to the humans’ tendency to find simplistic explanations for these events retrospectively.
- The mistake lies in the professional education which consider EBM as a dogma, which provides undeniable trues, “all the swans are white”, whereas, EBM can only provide probabilities which do not cover the opacity of the real world.
- Some patients can be black swans.



Narrative medicine and hope

- Narrative medicine is a basic tool to discover if hope, as well as the other coping factor is there, and to build up a trustful and positive relationship with the patients, curers and family members.
- *“Since the greatest hope, when embarking on this path, is to be able, in the end, to resume normal life ...”* Patients’ hope sometimes fall into the trap of “resuming a normal life, the life of before”.
- The real adventure, is the hope, when living with a chronic disease, to be able to change the life style, in a quest mode, so to broaden that inner freedom and peace of the fourth petal. This, forgetting the absolute basic need of being “normal”, putting oneself in a «quest attitude»



Acknowledgment

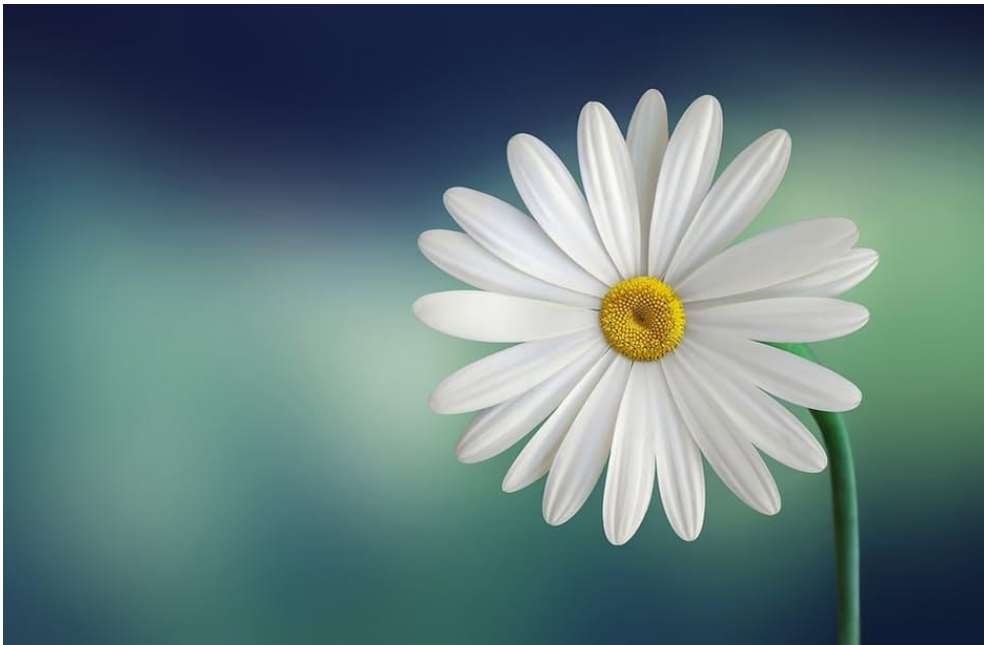
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Expanding the five
petal flower
to a daisy....
We could get more
options
to define our
spirituality....