

Narratives and Quest for Meaning: Making sense of disease

**Prov. Doz. Dr. Dennis Linder, MD,
MSc**

*Padua University Hospital
Department of Dermatology
Padua, Italy*

*Medical University of Graz
Clinic of Medical Psychology and Psychotherapy,
Graz, Austria*

*Ben Gurion University of the Negev, Beer-Sheva,
Israel*

No conflicts of interest

- There is neither a personal nor an economic relationship with a commercial company in connection with the content of this lecture.



Doc ..

- “Where does this come from?”
- “Did I eat something which made me sick??”



Take home message

- Experience of illness leads to loss of meaning, feelings of disorganization, suffering: the world loses coherence.
- Patients want to know "why do I have this" rather than "how do I get rid of it".
- The narrative approach facilitates the integration of the disturbing elements into one's own image of life.

Silvia Bonino - THE LIVED ILLNESS: 1000
THREADS KEEP ME HERE (I)

- Throughout everybody's life course there are moments when finding a meaning to one's existence becomes particularly critical. Such are all turning points, whether positive or negative as well as all important biological or social changes, such as adolescence or retirement.

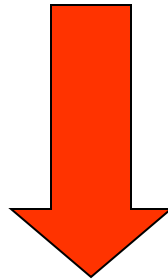
Silvia Bonino - THE LIVED ILLNESS: 1000
THREADS KEEP ME HERE (II)

- Since disease is a lack of order (English disease = disorder!) that is not only incomprehensible by itself, but makes also incomprehensible, and hence scaring, both past and future, to find a meaning to chronic disease is a demanding but necessary task, even more than in conditions of good health.

Silvia Bonino - THE LIVED ILLNESS: 1000 THREADS KEEP ME HERE (III)

- In chronic disease, when there is no hope for healing, everything is deprived of its meaning. The concrete capability of realizing projects is questioned, of fulfilling roles and duties as well as to reach those goals that had been previously been deemed as worthy, like being a good parent, or being successful in one's profession.

- Trauma, loss, death of a close relative
- Cancer diagnosis and survival
- Diagnosis of a chronic disease



- “Illness is experienced as a **disruption of the lived body rather than a disfunction of the biological body [...]**”
- “Fundamental features as [...] primary meaning [...] temporality [...] are disrupted in illness causing a concurrent **disorganization of the patient’ s self and world**”

S.Kay Toombs – Illness and the paradigm of the lived body, Theor Medicine, 1988, 201-206

Disease Onset

- Disruption of the lived body
- Disorganization of the patient's self and of the patient's world.
- Loss of meaning

The Landscape ..



Hardiness

Self Complexity (Kobasa 1969)
(Linville 1985)

Shattered Beliefs

Loss of the assumptive world



R. Janoff-Bulman

Diagnosis of a chronic disease

Narrative Medicine

J Bruner, R. Charon



Susan Sontag

Coping

Improved adherence to
treatment, less suffering

Meaning, Sense

Sense of Coherence
(Salutogenesis)



Aaron Antonovsky

Meaning of Illness – Schema

Acceptance of disease
Anna Zalewska et

Lipowski

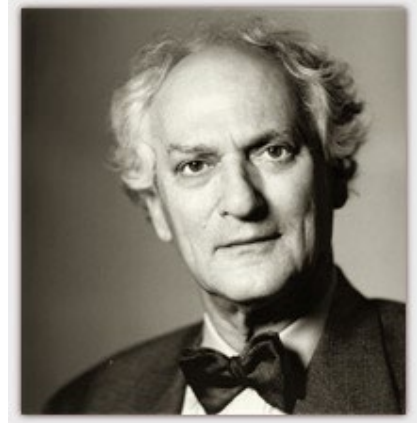


Man's Search for Meaning
Viktor Frankl

Suffering

Tom Sensky, Stephan Buechi
Eric Cassell

Eric Cassell



SPECIAL ARTICLE

THE NATURE OF SUFFERING AND THE GOALS OF MEDICINE

ERIC J. CASSEL, M.D.

Abstract The question of suffering and its relation to organic illness has rarely been addressed in the medical literature. This article offers a description of the nature and causes of suffering in patients undergoing medical treatment. A distinction based on clinical observations is made between suffering and physical distress. Suffering is experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological enti-

ty. Suffering can include physical pain but is by no means limited to it. The relief of suffering and the cure of disease must be seen as twin obligations of a medical profession that is truly dedicated to the care of the sick. Physicians' failure to understand the nature of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering but becomes a source of suffering itself. (N Engl J Med. 1982; 306:639-45.)

SUFFERING

- A state of severe distress associated with events that **threaten the intactness of the person.**
- Occurs when an impending **destruction of the person is perceived**; it continues until the threat of disintegration has passed or **until the integrity of the person can be restored in some other manner.**

Cassell EJ (1982) NEJM 306:639-645

- Disorganization, Disorder imply loss of sense of all elements of the patient's person (Eric Cassell's *personhood*). Connections are severed.

Meaning, Sense etc..

- In most languages, these words have two meanings :
- To mean - to have the intention ..
- To signify ..
- Old German: meinen = to have in Mind but also to intend.
- German SINN
- Italian SENSO, French SENSE

- Orientation, Direction
- Intepretation

Meaning, sense



• “Verbalized
” reality

Yet
unarticulated
, not
verbalized
experience

- Meaning comes into being through experience, in moving back and forth between what is already verbalized and what is as yet unarticulated.

“Experienced Meaning” (E. Gendlin)

- “Meaning is *experienced*. It is not only a verbal relationship between verbal symbols, between symbols and things or between symbols and perceptions. [..]”
- *Meaning occurs for us when something experienced assumes a symbolic character*
- (Eugene Gendlin - *Experiencing and the Creation of Meaning*; - Northwestern University Press, 1997)

Meaning of Illness Schema (Lipowski, 1970)

Illness as challenge (e.g. another hurdle in life that I can overcome)

Illness as value (e.g. this experience will make me a stronger person)

Illness as enemy (e.g. unfair attack that has to be defended against)

Illness as punishment (e.g. something that I am paying for)

Illness as strategy (e.g. family and friends are more attentive to me when I am ill)

Illness as weakness (e.g. a failing in myself, a loss of control)

Illness as relief (e.g. a welcome relief from other problems)

Illness as irreparable loss (e.g. my disease is getting worse, I may die or lose my ability to function as I used to)

Lipowski:

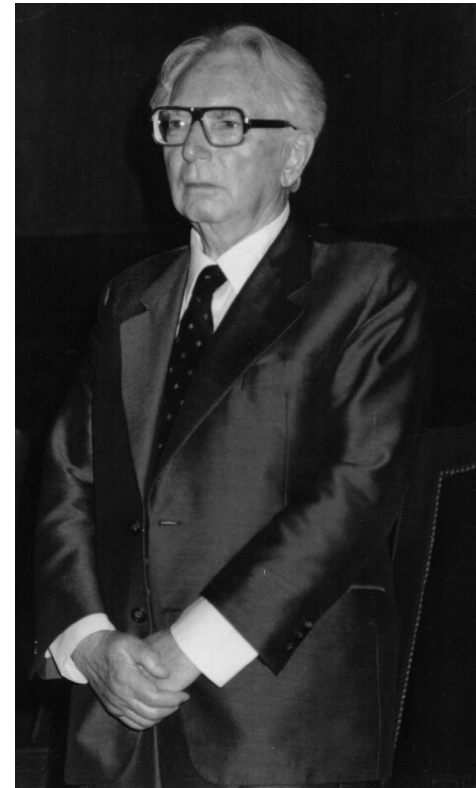
- **Meaning of a specific event**



- Coping strategies chosen to deal with the stress encountered

Chaos and Disruption ..

- .. prevent experience to allow us to assign meaning to life events.
- ..and although deprivation and physical discomfort are not enough to cause suffering, once existence becomes meaning- and purposeless, suffering is experienced.



Viktor Frankl 1905- 1997

Meaning of Illness Schema (Lipowski, 1970)

Illness as challenge (e.g. another hurdle in life that I can overcome)

Illness as value (e.g. this experience will make me a stronger person)

Illness as enemy (e.g. unfair attack that has to be defended against)

Illness as punishment (e.g. something that I am paying for)

Illness as strategy (e.g. family and friends are more attentive to me when I am ill)

Illness as weakness (e.g. a failing in myself, a loss of control)

Illness as relief (e.g. a welcome relief from other problems)

Illness as irreparable loss (e.g. my disease is getting worse, I may die or lose my ability to function as I used to)





Rav Meir Mazuz: We are being punished with the Covid Panemics by G*d because of homosexuality

A short time later..



The Israeli minister of health Yaakov Litzman tests positive for COVID ...



- In 1977, Susan Sontag published *Illness as Metaphor*; a cancer survivor, she condemned current thinking about illness because of the negative cultural meanings that society attaches to illnesses, and the risk that these meanings pose for patients



Quoting Nietzsche, Susan Sontag argued that people invest illness with *punitive* meaning; illness should be deprived of that stigma. More generally, she claimed:

“ Illness is no metaphor and the sincerest way to deal with it - as well as the healthiest way to be sick – lies in trying to get loose as much as possible from metaphorical thinking, and to offer the strongest possible resistance”

(Illness as metaphor, 1977)

- “...a semantics of metaphor can clarify the tensions between the essential irrationality of illness experience and the biomedical presumption of rationality”

Kirmayer LJ The Body's Insistence on Meaning, Med Anthropol Quart 6 (4) 323-326..

Aaron Antonowsky 1923 - 1994



- Observations on Holocaust survivors who were doing well despite terrible experiences. What helps People overcome Stressful Conditions?

Aaron Antonovsky 1923 - 1994



SALUTOGENESIS

SENSE OF COHERENCE

- Comprehensibility
- Meaningfulness
- Manageability

Sense of coherence

- **feeling of confidence that one's internal and external environments are *predictable***
- **there is a high probability that things will work out as well as can *reasonably be expected* (Antonowsky, 1979)**

Is the SOC a good predictor of physical health?

- The SOC is only a weak predictor of physical health, but a very powerful predictor of psychological health, including stress and behavioural aspects
- Flensburg Madsen et al, Scientific World J, (2005) 5, 665 673

Sense of Coherence among Psoriatics as a Predictor of Symptom-Free Time Following Dermatological Inpatient Therapy

J. Kupfer^a V. Niemeier^b B. Brosig^b U. Pauli-Pott^a G. Karpinski^c W. Küster^c U. Gieler^b

^aDepartment of Medical Psychology,

^bClinic for Psychosomatics and Psychotherapy, University of Giessen,

^cTOMESA Clinic, Bad Salzschlirf, Germany

- **Conclusion:** The data suggest that the SOC could play a protective role in respect of the tendency towards relapse among psoriatics.

Open Questions

- SOC: state or trait?
- If SOC is a state – are interventions to improve it possible?
- Do they have a favourable influence on the course of chronic disease? (e.g. longer relapse free intervals, less therapy needed ..)

Self-complexity as a cognitive buffer against stress-related illness and depression

- Linville PW (1987)
- “The greater the complexity in a person’s self-description, the less likely it is that the Self will be profoundly affected by the onset of illness”.

“Self complexity”

- *In working clinically with people who have serious illnesses, I often focus on demonstrating to them that there are aspects of their lives that should be valued (but are oftentimes taken for granted) that are not substantially affected by their illness (Tom Sensky, personal communication, 2006)*

“Hardiness”

- A personality characteristic describing an individual with three closely related tendencies: **challenge, commitment, and control.**
- Hardy individuals have an internal sense of personal mastery, confronting problems with confidence in their ability to implement effective solutions, rather than feeling powerless, lacking self-confidence and initiative, and manipulating others.

NARRATIVES



NARRATIVES

- Arthur Kleinman's (1988) *The Illness Narratives*: patients use narrative to order and create meaning to their painful experiences



Jerome Bruner
Actual Minds, Possible Worlds
(1986)

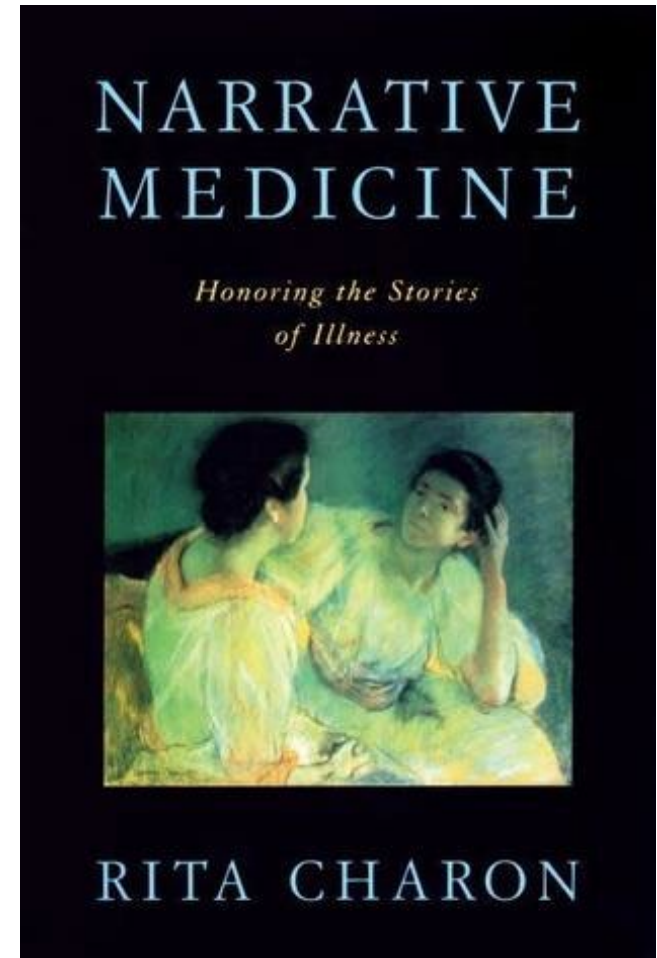
Narrative is a fundamental mode of thought that offers a way of ordering experience, of constructing reality.

Narrative Medicine

- At first, illness may seem to lack all connection with earlier events, and thus it ruptures our sense of temporal continuity – and if the rupture is not mended, the fabric of our lives may be ripped to shreds. (Bury, 1982)
- Narrative offers an opportunity to knit together the split ends of time, to construct a new context and to fit the illness disruption into a temporal framework. (Lars-Christer Hydèn, 1997)

Rita Charon, NARRATIVE MEDICINE

- Narrative medicine is a medical approach that utilizes people's narratives in clinical practice, research, and education as a way to promote healing. It aims to address the relational and psychological dimensions that occur in tandem with physical illness, with an attempt to deal with the individual stories of patients. In doing this, narrative medicine aims not only to validate the experience of the patient, but also to encourage creativity and self-reflection in the physician.



ARTHUR W. FRANK

*The
Wounded Storyteller*



Body,
Illness, and
Ethics

« we are all wounded
and the process of
healing takes place by
telling our story »

3 Types of Narrative according to Frank

- The Restitution Narrative
- The Chaos Narrative
- The Quest Narrative

The Restitution Narrative

- The plot of the restitution narrative is about being healthy, getting sick, and then recovering again. It is the culturally preferred story because it reinforces what medicine expects of the sick person and what society expects from medicine. The narrator of the restitution story wants control and predictability restored.

The Chaos Narrative

- The plot of the chaos narrative is that things will never get better; disruption has destroyed continuity with no end in sight.
- The sick person only *lives* the chaos story *because it cannot be told*

The Quest Narrative

- The narrator confronts illness and embarks on a journey of discovery.
- The plot typically follows the pattern of departure, initiation, and return.
- The journey *redefines reality and the patients „self“*.

TYPES OF ILLNESS NARRATIVE AND THE SELF



RESTITUTION

- *'I was well, now I'm ill, in the future I'll be well again'*
- Often favoured by clinicians
- Excludes the need to change the Self

CHAOS

- Not really a narrative at all – patient's experience impossible to form into a coherent story
- The 'narrative wreck'
- The Self is fragmented and impossible to define

QUEST

- Involves growth or transformation through the experience of illness
- Acknowledges the need to change the Self

Narrative Identity?

- Galen Strawson

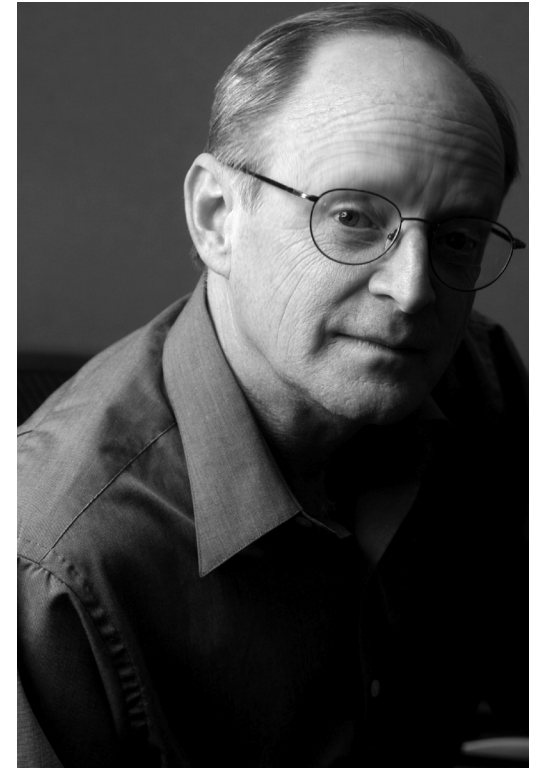


“Things that bother me”

[To “measure” a life using the stories we tell about it means:] ..hindering human self-understanding, closing important paths of thought, impoverishing our understanding of ethical possibilities, ... and possibly being extremely destructive in psychotherapeutic contexts.

Expressive Writing, Written Emotional Disclosure Experimental Disclosure

- James W. Pennebaker



Emotional disclosure

- Jama 1999

JAMA[®]

Online article and related content
current as of September 25, 2008.

**Effects of Writing About Stressful Experiences on
Symptom Reduction in Patients With Asthma or
Rheumatoid Arthritis: A Randomized Trial**

Joshua M. Smyth; Arthur A. Stone; Adam Hurewitz; et al.

JAMA. 1999;281(14):1304-1309 (doi:10.1001/jama.281.14.1304)

<http://jama.ama-assn.org/cgi/content/full/281/14/1304>

**Effects of Writing About Stressful Experiences
on Symptom Reduction in Patients
With Asthma or Rheumatoid Arthritis**
A Randomized Trial

- Patients with mild to moderately severe asthma or rheumatoid arthritis who wrote about stressful life experiences had **clinically relevant changes** in health status at 4 months compared with those in the control group.
- **These gains were beyond those attributable to the standard medical care that all participants were receiving**

British Journal of Health Psychology (2008), 13, 95–102
© 2008 The British Psychological Society



The
British
Psychological
Society

Enhanced wound healing after emotional disclosure intervention

John Weinman^{1*}, Marcel Ebrecht¹, Suzanne Scott¹,
Jessica Walburn¹ and Mary Dyson²

¹Institute of Psychiatry, King's College London, London, UK

²Department of Physical Therapy, University of Kansas, Lawrence, Kansas, USA

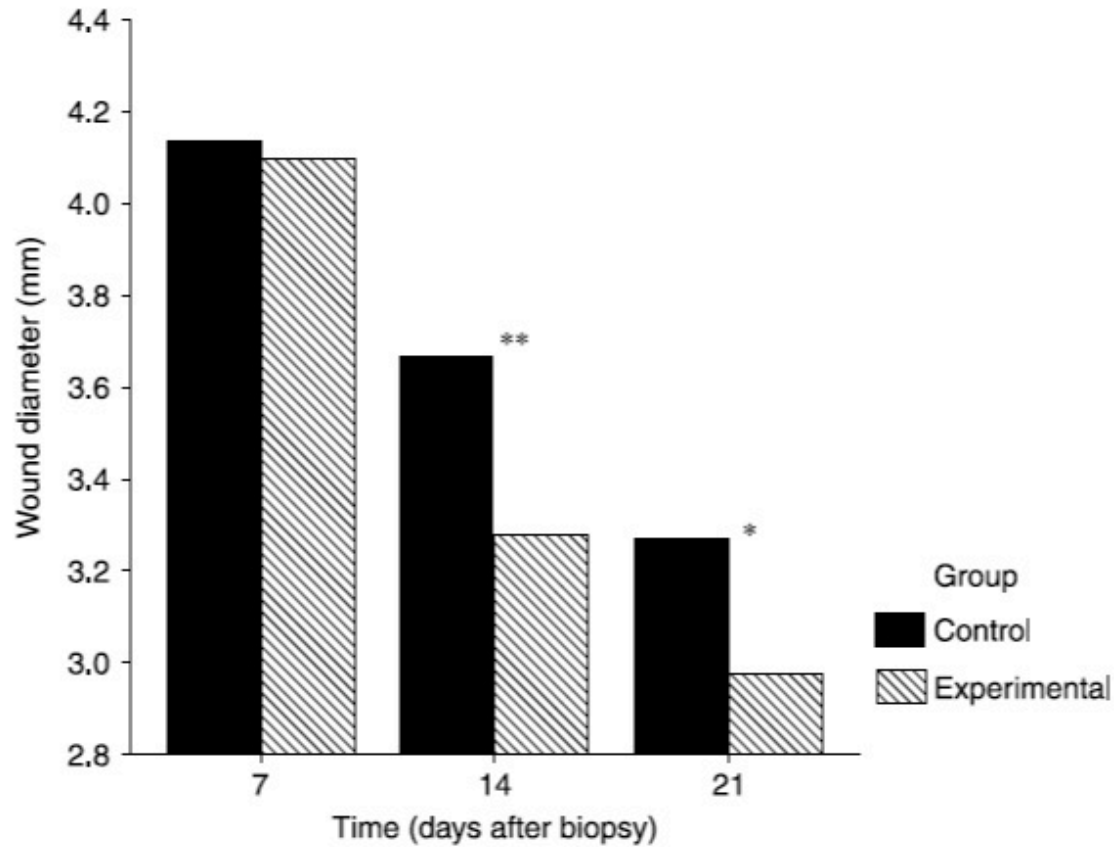


Figure 1. Bar graph of wound diameter over time for the experimental and control group. * $p < .05$; ** $p < .01$

Experimental Disclosure and Its Moderators: A Meta-Analysis

Joanne Frattaroli
University of California, Riverside

Disclosing information, thoughts, and feelings about personal and meaningful topics (experimental disclosure) is purported to have various health and psychological consequences (e.g., J. W. Pennebaker, 1993). Although the results of 2 small meta-analyses (P. G. Frisina, J. C. Borod, & S. J. Lepore, 2004; J. M. Smyth, 1998) suggest that experimental disclosure has a positive and significant effect, both used a fixed effects approach, limiting generalizability. Also, a plethora of studies on experimental disclosure have been completed that were not included in the previous analyses. One hundred forty-six randomized studies of experimental disclosure were collected and included in the present meta-analysis. Results of random effects analyses indicate that experimental disclosure is effective, with a positive and significant average *r*-effect size of .075. In addition, a number of moderators were identified.

Keywords: expressive writing, emotional disclosure, meta-analysis, Pennebaker, intervention

Erzählen als Prozess der (Wieder-) Herstellung von Selbstkohärenz. Überlegungen zur Verarbeitung traumatischer Erfahrungen

Nicola Waller¹, Carl Eduard Scheidt²

Summary

Narration as a means of restoring self-coherency: Thoughts on processing traumatic experiences

Objective: Traumatic memories are characterized by not being accessible to intentional recall nor being integrated into the matrix of autobiographical memory. Based on this description, the authors discuss the process of narration as a central means of regaining a sense of self-coherence after traumatic experiences. Formally correct narratives are characterized by three functions: orientation, reference and evaluation. Through so-called “memory talk” with socio-culturally competent partners, children learn how to reconstruct memories and to represent experience by narration. It is therefore suggested that narratives are the basic ingredient of autobiographical memory. The process of re-establishing a sense of coherence after trauma relies on the capacity for coherent narration. The latter is often not possible with traumatic experiences.

Method and Result: We conducted a literature search in multiple databases for linguistic analyses of trauma narratives empirically correlating narrative style and posttraumatic psychopathology.

Discussion: It is recommended that research in psychopathology and psychotherapy should take issues of language into account more systematically.

- Personal Identity is not « given by nature » but much rather a narrative construction, which is continuously updated throughout life.
- Fragmented Identity – Impaired Narrative capability?
- Narrative competence as tool for psychological assessment?

Consequences for practice

- If the patient's and the doctor's narratives have nothing in common, no therapeutic alliance is possible.
- The doctor has to share in some way the patient's interpretation of the illness.

Kleinman, 1988

- (a) reconstruct the illness narrative of the patient;
- (b) analyze it for meanings associated with symptoms, culture, personal, and interpersonal relationships;
- (c) record the psychosocial problems associated with the disease and the steps the patient has taken to resolve them;
- (d) capture a brief life history of the patient;
- (e) discover the patient and family's explanatory models about the disease;
- (f) negotiate treatment with the patient and family based on a discussion of all the explanatory models, including the physician's;
- (g) reassess the physician's model for bias based on previous negotiation with the patient and family

The same language ?



“La maladie du malade”

- = the profane, subjective representation of the disease
- “..the *disease of the patient* returns to be now .. the appropriate concept of disease, anyway more appropriate than the concept of the pathologist..”
- *Georges Canguilhem, Le normal et le pathologique, Paris 1966*

“La maladie du malade” (II)

- Western medicine is [...] based on the separation between the allegedly objective representation of the disease, the one of the doctor, and the more profane, more subjective one, the one of the patient. Taïeb et al, Donner un sens à la maladie, de l'anthropologie médicale à l'épidémiologie culturelle, Med et Mal inf, 35(2005), 173-185

No man is an Island

- *No man is an island entire of itself; every man is a piece of the continent, a part of the main..Any man 's death diminishes me because I am involved in Mankind; and therefore never send to know for whom the bell tolls; it tolls for thee;*
- *John Donne, Meditation XVII*

My ideal doctor would be my Virgil, leading through my purgatory or inferno, pointing out the sights as we go. (..) I can imagine.. [him] ..entering my condition, looking around at it from the inside like a benevolent landlord with a tenant, trying to see how he could make the premises more livable for me. He would see the genius of my illness.

He would mingle his daemon with mine; we would wrestle with my fate together.

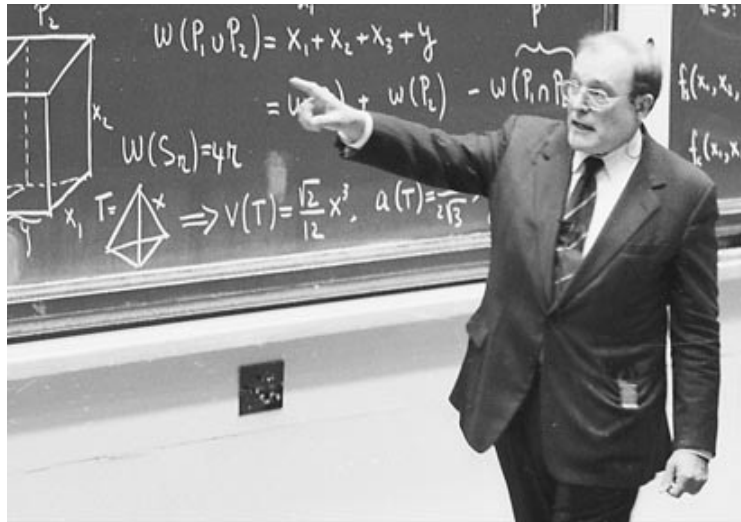
(..)

*I would like to think of him as going through my character, as he goes through my flesh, to get at **my illness**, **for each man is ill in his own way.***



*Anatole Broyard -
1920 - 1990.*

*INTOXICATED BY
MY ILLNESS*



Gian-Carlo Rota
1932 -1999

1. **Every lecture should make only one point.**
2. Never run overtime
3. Relate to your audience.
4. **Give them something to take home.**

Take home message

- Disease -> loss of meaning, disruption, disorganization.
- Loss of meaning, disruption, threat to self -> Suffering
- Meaning is recovered through Narratives which allows to re-establish a reality where events are connected « over » time and hence acquire meaning
- Narratives may allow thus to « redefine the self ».



dennis.linder@me.com