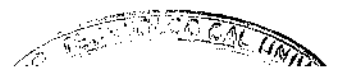

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Narrative Medicine

Bridging the Gap between Evidence-Based Care and Medical Humanities



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Foreword

This book introduces “narrative medicine” in connection with evidence-based medicine and clinical research. It uses the metaphor of it being a “bridge” between clinical sciences and humanities/social sciences. The write-up eloquently integrates insight from mythology, literature, cinema, personal anecdotes, research experiences, multinational media, and newspapers to explain narrative medicine and lobby its importance for seeking a “non-scientific” understanding of patients in their most vulnerable moments. These anecdotal quotes from literature are constructive bringing in rich descriptions. Thus, the book arguably offers narrative medicine as a conceptual base that has allowed the practice of evidence-based medicine to be pursued across a broader canvas. Narrative medicine in various clinical specialties emerges and the notion of listening to patient’s inner voices addressing the whole system in which individuals exist is innovative. The book highlights the importance of gathering multiple narratives of patient care experiences, so that physicians are privy to a holistic version of their patients that fosters meaningful and informed care. As one scrolls through various chapters, the importance of evaluating the ways we train medical doctors becomes imminent. It is quite obvious that the fragmented and scientific view of patients we rely on to train doctors takes the empathy right out of them. After reading the book, we are optimistic that narrative medicine has reached a point of maturity that will falsify earlier myths in the field. Unlike the statistics quoted in high impact factor journals, the patient’s perspectives will now continue to live in our memories forever.

Karachi, Pakistan

Fauziah Rabbani
Kausar Khan
Leah Shipton

*Come, come, you forward and unable worms!
My mind hath been as big as one of yours,
My heart as great, my reason haply more,
To bandy word for word and frown for frown;
But now I see our lances are but straws,
Our strength as weak, our weakness past compare,
That seeming to be most which we indeed least are.*
The taming of the Shrew, William Shakespeare

The battled and passionate relationship between William Shakespeare's characters Petrucho and Catharina in the *Taming of The Shrew* is perhaps the most fitting analogy to portray Narrative medicine in today's era of evidence medicine. The story of two lovers, so different and determined in keeping their own identity, and who, despite the odds, achieve a state of harmony, which acts as an elevating force—for both as they become husband and wife—and irradiates onto everything surrounding them. As the plot develops, we see an intense love affair between the impulsive and defiant Catharina and the bold Petrucho, who seeks to conquer the object of his desire by acting as a mad man—living above social conventions and protocols, yet never being brutal towards her. Likewise, Evidence-Based Medicine (EBM) might resemble the social duty of marriage (a value that at the beginning of the plot may be embodied by Petrucho); Narrative Medicine (Catharina), with its bizarre and lateral paradigm of thought and behaviour, is able to look outside the box. It will be the marriage of these two characters after a story of oddness, fights, and peace which will give rise to the “perfect couple”, in a form of conciliation of two paradigms of thoughts which at first sight appeared so different.

Evidence-Based Medicine: Where It Started and Where It Stands Today

A cornerstone of medicine and of today's clinical research, the concept of Evidence-Based Medicine (EBM) was first introduced in the 1970s by the epidemiologist David Sackett and his pioneering approach to introducing standardization into clinical research methodology. His studies indisputably evidenced the many flaws in research and addressed ways to reduce bias in clinical research by standardizing the design, conduct, and report of randomized clinical trials in scientific literature. Likewise, Sackett was just as methodical in analysing health conditions and disorders, focusing on their cause, diagnosis, prognosis, clinical prediction, prevention, treatment, and amelioration in the prospective of defining a balance between quality and cost-effectiveness of health services. Founder of the first department of clinical epidemiology in Canada at McMaster University, in the late 1970s Sackett actively advocated the use of clinical epidemiologic principles in the practice of medicine and other health-care disciplines; he understood medicine needed to move from a paternalistic and auto-referral approach to a more scientific one. This ethical-scientific approach to research—initially termed “critical appraisal of the medical literature”—aimed to help practitioners keep up with scientific advances in health care (Sackett and Haynes 1976). As defined by Sackett in 1996, EBM matured into “the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients”.

As EBM had finally set a shift from the subjective “opinion” of the carer to a more reliable and organized way of performing research, it gained growing acceptance and has become in just a few decades the dominant paradigm of science and medicine—and not least the main philosophy at the basis of the teaching system in scientific academy, medicine, nursing, and biomedical sciences. After almost 20 years from Sackett's definition, EBM has spread throughout North America and Europe, in a globalizing trend, such to be acknowledged by the World Health Organization as the *primum movens* of the evolution of clinical science.

Despite its purely ethical and scientific aims, EBM inevitably extended to other intrinsically related fields, such as health-care management, health economics, and even law; indeed recommendations based on EBM became a benchmark of good clinical practice, later developing into a decision-making tool for practitioners, medical management, the insurance industry (Evidence-Based Medicine Working Group 1992), and ultimately in courts to safeguard physicians from claims of malpractice (Goldman and Shih 2011).

Accordingly, in the last decades, EBM has served an important role in elevating medical science from a paternalistic and superhuman/religious approach displayed by the medical community, and, from a historical point of view, it has helped counteract and balance the power of physicians over patients.

However, Sackett's definition—the *care of individual patients*—leads us to approach the paramount issue of patients as individuals. We must notice here that the term *individual* relates to a singularity, whereas *patients* refer to a plural entity. Such nuance per se is an extremely relevant issue. Yet for years appears to have

been neglected by researchers involved in designing and performing clinical trials, who have remained oriented to addressing the exclusively populations and patient subgroups, where individuality is sacrificed in favour of the broader picture, and generalization of results.

Returning to reflect upon Sackett's definition, the words “individual patients” seem to anticipate a philosophical paradox, making us wonder how can an individual solution be fit for an entire population? He was introducing a *caveat* in itself—and within his own school—of clinical epidemiology and biostatistics at McMaster University in Canada. Despite Sackett's careful formulation of his own thought, and despite him wanting to find a conciliation between science and the clinical own judgement, EBM has developed (perhaps beyond his control) untamed, restricting the issue of patients' individuality to a secondary backstage role.

In fact, to date, this has become quite evident and several voices from within the scientific community are starting to speak up, calling for some critical judgement to the unconditioned use of EBM. Among these voices.

Trisha Greenhalgh, epidemiologist, Professor of Primary Health Care and Dean for Research Impact at the Centre for Primary Care and Public Health at Queen Mary University of London, states:

“It is time to stop overloading doctors with evidence and deploying fast-talking industry salespeople to manipulate them with clever marketing pitches. . . 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 standardize—would go a long way toward ensuring that each patient receives the right treatment.”

The medical community must develop the science of shared decision-making, in which epidemiological evidence informs conversations about what matters to the patient and how best to achieve those goals. In doing so, we can take evidence-based medicine beyond its current limits and develop a holistic approach that accounts for patients' experience of illness and promotes good clinical practice.” (Greenhalgh 2014)

In 2014, the epidemiologist and *narratologist* Greenhalgh rose quite a few eyebrows with her provocative article “*Is Evidence Based Medicine broken?*” in which she indirectly questions the utility and role of EBM. Her considerations developed around a survey addressed to British physicians through the British Medical Journal, in which readers were asked quite directly whether they believed evidence-based medicine was malfunctioning or not, with a YES or NO answer allowed. The responses approximately split even: 51 % answered positively, and 49 % negatively. Participants to the survey attributed their answer to several aspects, among which are the choice of a golden standard in trials over other alternatives not acknowledged by scientific community that have yet proven useful by the medical praxis (as yoga for instance); the invention of ghost diseases (such as *female sexual arousal disorder*) by different stakeholders—academics and private companies; or the implementation of EBM, with its decision-making tools which in fact are inadequate to handle and master the messy, unpredictable, real-world clinical practice.

Numbers aside, the findings seem somewhat to suggest a feeble democracy in favour of EBM, as well as uncertainty around the soundness and logic behind scientific methodology in use today.

In addition to the considerations highlighted in the survey above, we can certainly add on to the list of EBM's shortcoming the exclusion criteria for patients with comorbidities, or elderly patients—a bias that had already been mentioned at the dawn of EBM, in an article by Evans in 1995, who questioned whether the scientific totem of the new millennium could have been Evidence-Based or Evidence-Biased Medicine (Evans 1995).

Another issue is large sample sizes which are able to demonstrate only statistically significant results that from a clinical meaningful point of view may not be worthy of being considered medical evidence. *"The larger the effect of a specific treatment, the smaller the required trial"* Howick 2015.

Publication bias is another pitfall. Most published trials concern trials with positive results, whereas there are very few publications dedicated to those reporting negative findings. Although journal editors endorse and welcome the submission of trials with negative findings, it appears that only trials with convenient results—mainly from the sponsors' point of view—get to reach publication (Turner et al. 2008); for instance, in reference to works on antidepressant therapies, the FDA deemed 38 of 74 submitted studies (51 %) positive, and all but 1 of the 38 were published on scientific journals. Other 36 studies (49 %) were deemed by the FDA to be either negative (24 studies) or questionable (12). Of these 36 studies, 3 were published as non-positive, whereas the remaining 33 either were not published (22 studies) or were published, as Turner states, positive (11) and therefore conflicted with the FDA's conclusion. Overall, the studies that the FDA judged as positive were approximately 12 times as likely to be published in a way that agreed with the FDA analysis as were studies with non-positive results according to the FDA (risk ratio, 11.7; 95 % confidence interval [CI], 6.2–22.0; $P < 0.001$). Here statistics matter and show in a very likely way that the publication bias exists despite the international guidelines on publication ethics require that all results are published, both positive (good) and negative (poor) ones.

Yet, as said above, because of its leading role as a decision-making tool, EBM inevitably exerts strong influences well beyond the medical field, representing a strong economical driver in a number of areas of industry, such as pharmaceutical, health care, insurance, and others.

In its October 2013 article *Why science goes wrong?*, the Economist itself wonders about the reliability of scientific publication and questions how scientific knowledge can be achieved and shared in a more appropriate and effective way: *"The obligation to 'publish or perish' has come to rule over academic life. Competition for jobs is cut-throat. ... Careerism also encourages exaggeration and the cherry-picking of results. In order to safeguard their exclusivity, the leading journals impose high rejection rates: in excess of 90 % of submitted manuscripts. The most striking findings have the greatest chance of making it onto the page. Little wonder that one in three researchers knows of a colleague who has pepped up a paper by, say, excluding inconvenient data from results 'based on a gut feeling'."*

And as more research teams around the world investigate around a hypothesis, the odds that at least one will fall prey to an honest confusion between the sweet signal of a genuine discovery and a freak of the statistical noise become narrower. Such spurious correlations are often recorded in journals eager for startling papers." (The Economist 2013). The statistical noise is also here coming to cover the genuine discovery, which cannot allow itself big trials to be tested, or it is so innovative that it is neglected by the caste of the scientific academy. Numbers are self-explanatory. *"A rule of thumb among biotechnology venture-capitalists is that half of published research cannot be replicated. Even that may be optimistic. Last year researchers at one biotech firm, Amgen, found they could reproduce just six of 53 'landmark' studies in cancer research. Earlier, a group at Bayer, a drug company, managed to repeat just a quarter of 67 similarly important papers. A leading computer scientist frets that three-quarters of papers in his subfield are bunk. From 2000 to 2010 roughly 80,000 patients took part in clinical trials based on research that was later retracted because of mistakes or improprieties."* The Economist takes on a very strong standing, and criticizes and talks about careerism and possible fraud: but putting together the complexity of the human being of the patients as already described by Greenhalgh and this information we could come up that there is something beyond the number of publications, the bias of EBM, the careerism, and the earnings of the Health-care system and life sciences, there is the impossibility or huge difficulty to transfer the real genuine science from centre to centre, from paper to paper, for some hypothetical reasons that I wish to list: first, every text is in a unique context and so only, maybe, in a perfect physics close system the experiment can reproduce itself. Second, the way in which scientific publications are structured is so structured that it obstructs the possibility to transfer the intangible knowledge, the shades according to which the specific scientific text can be repeated. It will never be the same. *Nothing can ever happen twice*, as 1996 literature Nobel prize winner Wislawa Symborska (1989) writes her poem *Nothing twice*:

Nothing can ever happen twice.

In consequence, the sorry fact is

that we arrive here improvised

and leave without the chance to practice.

Even if there is no one dumber,

if you're the planet's biggest dunce,

you can't repeat the class in summer:

this course is only offered once. . . .

And perhaps nothing happens exactly in the same way also in the world of science: and this is why it is so difficult to repeat a scientific experiment in the exact same manner and even more difficult with the same outcomes/findings.

Scientific journals are modelled on the dominant paradigm of quantitative EBM, and the scientific publication frameworks are so structured and somewhat rigid, so "armoured" that in the last years they seem unfit for transferring knowledge, especially *fresh* knowledge which is still fragile and not so easily classifiable with a binary "yes" or "no" answer, or in histograms and plots. Case reports are more

often confined to brief sections of the Journal—in those few journals who still have a dedicated section—with the good aim of being often didactic cases, but the used language is that one “archetypal” of EBM.

As researchers in narrative medicine, we constantly face the orthodoxy of peer reviewers at EBM journals who reject or rebut any breach from EBM standard. Personally I have experienced quite some diffidence towards the topic and some closure. In 2014, we had tried to submit an article on Narrative medicine which highlighted the values of Italian pain therapists in a changing health-care system (Marini et al. 2014) to an important European peer-reviewed journal on pain treatment. To our astonishment, our article received a direct and speedy reply by the editor in chief claiming: “We will not forward your article to any referees, because we publish only quantitative results”. Here the totems are numbers, digits, probabilities: no narration nor context descriptions seem to be allowed and appreciated. Although I cannot deny I was quite disappointed, what made me most angry was the superficiality with which our paper was considered. Good news is that we were able to publish our work with another and more open-minded publisher. EBM holds the keys of current scientific paradise in the behaviours of most reviewers of scientific papers describing scientific research. And this is an orthodoxy; we could define it also an abuse of power, which has to be tamed: we cannot rely uniquely on only numbers from trials, but must consider also numbers from real-life world, and, in addition to these, not only digits but also narratives which show the complexity and the subjectivity of the world of providers of care and patients and their caregivers.

Trisha Greenhalgh writes. “Indeed, only Aunt Nora can tell you how her celiac disease behaves. She also happens to be opposed to taking blue-coloured pills. And she insists that, years ago, when she took drug x, it made her feel like a new woman—despite the fact that, in 1000 patients, drug x has demonstrated, on average, no effect. The computer model’s treatment recommendations would probably not work for Aunt Nora.”

These are the glories and miseries, or better strengths and pitfalls of EBM: but his book is mainly on Narrative Medicine, and now let’s enter into its magical world.

The Reasons for Narrative Medicine

Narrative Medicine refers to the set of stories on symptoms and perceptions narrated by the persons most directly and closely involved—hence most often the patients themselves, but also loved ones and carers—which invite/give space to the description of feelings, emotions, mindset (i.e., the *Weltanschauung*—synthesis of *Welt*, world, and *Anschauung*, view, referring to their wide world perception).

As Greenhalgh states, Narrative Based Medicine can be defined:

“Narrative medicine is what occurs between the health provider and the patient: from the collection of information of events before the occurrence of the disease, how the disease showed up, with attention to physical, psychological, social and

ontological features (Greenhalgh 1999). Ontological refers to the view of the world, his or her paradigmatic microcosm.

Currently, Narrative Medicine is taught and applied in many centres worldwide, but the two main schools of thought are London’s King’s College Center for Humanities for Health and the New York Columbia University Medical Center, Program in Narrative Medicine.

Brian Hurwitz and Tricia Greenhalgh (1999) of King’s College in London were the first to describe the benefits of this discipline in their “*Why study Narrative*”, referring to health-care practice:

“Narrative provides meaning, context, perspective for the patient’s predicament. It defines how, why, and what way he or she is ill. It offers, in short, a possibility of understanding which cannot be arrived at by any other means.

- *In the diagnostic encounter, narratives:*
 - *Are the phenomenal form in which patients experience ill health*
 - *Encourage empathy and promote understanding between clinician and patient*
 - *Allow for the construction of meaning*
 - *May supply useful analytical clues and categories*
- *In the therapeutic process, narratives:*
 - *Encourage a holistic approach to management*
 - *Are intrinsically therapeutic or palliative*
 - *May suggest or precipitate additional therapeutic options*
- *In the education of patients and health professionals, narratives:*
 - *Are often memorable*
 - *Are grounded on experience*
 - *Encourage reflection*
- *In research, narratives:*
 - *Help to set a patient-centered agenda*
 - *May challenge received wisdom*
 - *May generate new hypotheses”*

Rita Charon, at Columbia University in New York was the first to theoretically define narrative medicine and translate it into health-care practice. In 1987, she was the first physician to receive Columbia University’s Virginia Kneeland Frantz Award for Outstanding Woman Doctor of the Year. She was awarded Outstanding Woman Physician of the year in 1996, and in 1997, she received the National Award for Innovation in Medical Education from the Society of General Internal Medicine. In 2011, she was awarded the Alma Dea Morani, M.D. Renaissance Woman Award from the Foundation for the History of Women in Medicine.

According to her interpretation narrative medicine is “*medicine practiced with the narrative competence to recognize, absorb, interpret, and be moved by the stories of illness.*”

“*As patient meets physician, a conversation ensues. A story—a state of affairs or a set of events—is recounted by the patient in his or her acts of narrating, resulting in a complicated narrative of illness told in words, gestures, physical findings, and silences and burdened not only with the objective information about the illness but also with the fears, hopes, and implications associated with it. (Genette 1980). . . As the physician listens to the patient, he or she follows the narrative thread of the story, imagines the situation of the teller (the biological, familial, cultural, and existential situation), recognizes the multiple and often contradictory meanings of the words used and the events described, and in some way enters into and is moved by the narrative world of the patient (Groopman 1998). Not unlike acts of reading literature, acts of diagnostic listening enlist the listener’s interior resources—memories, associations, curiosities, creativity, interpretive powers, allusions to other stories told by this teller and others—to identify meaning. Only then can the physician hear—and then attempt to face, if not to answer fully—the patient’s narrative questions: “What is wrong with me?” “Why did this happen to me?” and “What will become of me?” (Charon 1993)*

Listening to stories of illness and recognizing that there are often no clear answers to patients’ narrative questions demand the courage and generosity to tolerate and to bear witness to unfair losses and random tragedies (Weine 1996). Accomplishing such acts of witnessing allows the physician to proceed to his or her more recognizably clinical narrative tasks: to establish a therapeutic alliance, to generate and proceed through a differential diagnosis (Feinstein 1967) to interpret physical findings and laboratory reports correctly, to experience and convey empathy for the patient’s experience and, as a result of all these, to engage the patient in obtaining effective care.” (Spiro et al. 1993)

These words let us appreciate the efforts undertaken to change and enrich medical practice.

Going one step further we would like to consider that medical care is related to health care and that narrative medicine might belong to all health-care providers (nurses, social workers, psychological professionals) who are already prepared to think and act through narratives. Broadening this view, Narrative Medicine can involve also decision-makers in Health Care, and active citizenship associations, patient associations, and carers (Marini and Arreghini 2012).

Narrative medicine is democratic (Marini 2013): it is able to connect patients and health-care providers and link evidence-based medicine and medicine based on narrative, as well as clinical sciences and human science. Narrative medicine involves everybody and could evolve in its terminology from Narrative Medicine or Narrative-Based Medicine to Narrative Health Care and Narrative Based Health Care.

In the *Taming of the Shrew*, EBM could have been the socially perfect Petrucho seen in the first acts, who still has to grow to conquer his beloved Catharina, Narrative Medicine, the beautiful crazy and fear-inducing woman: the only way

that they come to a harmonic wedding is by Petrucho—our EBM—accepting her oddness and behaving somehow like “an individual out of normal rules” and by Catharina—our NBM (narrative-based medicine) losing “her proudness of being out of the schemes”, by starting to accept the good and useful rules. *But now I see our lances are but straws.* Lances represents two fighting ideologies, and they can be reduced as straws. Without any hierarchy, in the pair between EBM and Narrative Medicine, just as a conquer resulting from matching logic, intuitivism, and emotions and feelings.

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The Tower of Babel: The Language of Physicians, Patients, and Providers of Care

4

And the whole earth was of one language, and of one speech. And it came to pass, as they journeyed from the east, that they found a plain in the land of Shinar; and they dwelt there. And they said one to another, Go to, let us make brick, and burn them thoroughly. And they had brick for stone, and slime had they for mortar. And they said, Go to, let us build us a city and a tower, whose top may reach unto heaven; and let us make us a name, lest we be scattered abroad upon the face of the whole earth. And the Lord came down to see the city and the tower, which the children of men had built. And the Lord said, Behold, the people is one, and they have all one language; and this they begin to do: and now nothing will be restrained from them, which they have imagined to do. Go to, let us go down, and there confound their language, that they may not understand one another's speech. So the Lord scattered them abroad from thence upon the face of all the earth: and they left off building the city. Therefore is the name of it called Babel; because the Lord did there confound the language of all the earth: and from thence did the Lord scatter them abroad upon the face of all the earth. [Genesis 11, 1–9]

Any attempt of improving physician–patient relationship and of bridging the communicational gap between the two entities must necessarily consider the long-standing barriers of spoken and written language, and the unconscious influences, as Jacques Lacan—French psychoanalyst and believer that our language is the mirror of our personality—would argue. Lacan considers language symptomatic of a specific behaviour and our words are doors not only to our consciousness but also to our unconsciousness.

In the context of Narrative Medicine, whose mission is to give voice and dignity to patients' inner experience, the analysis of the linguistic styles used by patients is extensively used to interpret personal patient stories.

Patient narratives are the expression of the patient's coping with the disease. They are fraught with emotions, personal anecdotes, considerations, fears, hopes, and fantasies expressed through a plethora of idioms, expressions, and symbolism belonging to each patient's personal background. In many cases, they are so extraordinary to the point they are difficult to accept as truthful, being classified as "factions" (*faction illness narratives*) presenting a core of truth embedded in a falsified perception of reality (Shapiro 2011).

Yet, despite the legitimate doubt arising upon reading the stories, we must keep in mind the whole purpose behind the writing and collection of these narrations. Patients who are asked to write their experience are often tormented by a hovering ghost of an everlasting chronic disease—or even death—which inevitably affects the way one interprets and recounts reality. The patient is forced by the events to look at life from a different perspective and find resources within to react to reality. Hence, as narrative medicine has been developing over the years, we have seen the establishment of an etiquette, or globally accepted rule, to honour the patients' stories of the disease—whatever the stories narrate—so to safeguard and legitimate the patient's voice.

In the setting of narrative medicine, the general approach to patient stories is to examine its contents in search of unifying trends (within a group of patients affected by a same disease, or in the writings of a same patient) as well as distinguishing features (from patient to patient, or in a same patient through time), throughout the descriptions of the unfolding of the disease (Bury 2001). For example, we can find out some trends among age groups: younger people use a very ironic, humoristic style, whereas adults facing a chronic condition are more familiar with different registers and the elderly affected by cancer express themselves through a markedly disembodied spiritual language.

In 2014, Fondazione ISTUD was called to perform a narrative medicine study in Italy on patients with multiple sclerosis conditions: stories were collected, after having signed informed consent on web from North, Centre, and South Italy.

The narratives were a collection of the patients' experiences beginning from the moment of the breaking of the body's health status to present; they were formulated in a romantic style, with an open flow of emotions and *sturm und drang*. I had thus proposed to attribute such collection a subtitle *Omnia Amor Vincit* (*Love wins everything*): despite the patients considering it a beautiful and appropriate title, most of the physicians who participated in the project had banished it and considered it unfitting.

Yet, in reading these 121 narratives, love emerges as an astonishing core of truth, coloured by strong emotions: once the diagnosis of multiple sclerosis was communicated, the main picture portrayed appears that their natal family or the family that they will be able to build are a continuous and everlasting loving and affective harbour to their disease. Indeed, not surprisingly, in response to the prompt that introduced the section of open text... "*what did you have to give up on*"... And "*what did you get back*", many people answered that they gave up on physical ability, in sports and movement, but that they gained back love, spouses, wives, and children... solid families. Love and affective boundaries. And the deepest sign of change in mind-set they report is represented as their gained skill of understanding *others* better.

(continued)

An expansion of empathy, but not that learnt on a didactic manual, Empathy with capital letter—that one which is possible to achieve only through the direct experience.

My romantic title *Omnia Amor Vincit* proposed for this collection of stories—which I believed mirrored the style used by most of the patients in this condition—was considered too sensational by some members of the scientific community; hence we negotiated to come up with a title that satisfied both physicians and myself: *Enlightened stories of people who live with multiple sclerosis*. However, if this was accepted by the physicians on the Board, it was not so fully appreciated by the patients who were instead very glad to promote at least on paper, this energetic loving feeling.

Contrasting Communication Styles

But why was there so much opposition on behalf of the physicians? From their point of view, patients' narrative styles were too emphatic and romanced, far from the standards of scientific language and style they are most used to. Current standards of scientific communication recommend scientific papers should be written in a clear linear fashion so that colleague clinicians and scientific community across the globe can reproduce the experiments being reported and likely come up with the same findings. Accordingly, this means that all elements of subjectivity (otherwise *bias*) that cannot be supported by evidence must be left out, putting to silence emotions, inner realms, disembodiment, or spiritual drive, and especially humour. Only numbers, methods, facts, figures, and references, expressed through a very dry and concise text, using English as vehicular language, similarly to Latin used by the Church and Political Power in the past. A communication obstacle—just like in the metaphor of the Tower of Babel—which makes "honouring the stories of illness" difficult to pursue (Charon 2006).

Thus, illness narratives written by patients inevitably contrast with the scientific communication styles and tools physicians are akin to. Yet, they offer a unique opportunity to examine the dynamics of disease from the point of view of those directly involved.

An interesting work by Mike Bury (2001) analyses the connections between patient and biomedical narratives; they can be clustered according to *contingent*, when they deal with didascallic and didactic style, and this is shown when they report very simply about the fact of the disease, or *moral*, when they embrace a military/heroic style when narrating the good and evil about the relationship with the physicians and *core*, when narratives touch and reveal inner and deep value of patients, and these are written mainly with a *disembodied* and *romantic* style.

Narrative styles in medicine seem to fall within specific clusters and styles which she identified as military/heroic, tragic, disembodied, romantic, ironic/comic, didactic. With specific reference to patient narratives, beneath the surface we find

a hidden layer composed by the military/heroic style, with some flares of a tragic style: there is always an explicit war between the weapon—the treatment used in Group A of patients—versus the weapon treatment—alias Golden Standard—to defeat or overcome patients of Group B. Thus, the paradigm appears to be conflict of a battlefield: in her treatise *Illness as Metaphor*, Susan Sontag clearly evidenced the *crusade* language against AIDS and Cancer used in medical reporting (Sontag 1978). Here, I will attempt to transfer such military metaphors to the context of Evidence-Based Medicine.

This is also mirrored in EBM communication styles: patients are envisioned as enrolled “soldiers” as belonging to an army, and are equipped with weapons: in the feat against what? The meta-objective is fighting the disease, but the current objective of each trial is to defeat the opposite group.

And what about the use of the term “cohort” in epidemiological studies, a word that has always been used to define a group of soldiers? And again, “drops-out” in surveys? The same term used in competition, and failures cases. A very military language, with some nuances of heroic language when referring to the survivors and the cases of death. Yet, with few emotions behind it: it’s like the Caesarian statement, *Veni, Vidi, Vici—I came, I saw, and I won [Julius Caesar]*.

In brief, EBM presents a surface layer featuring a didactic language cover a deeper core-level canvas characterized by a heroic plot, and a battle with no room for romantic or spiritual flights. The restitution of health or of stable life conditions is a continuous series of battle trials starring diagnostic defences and treatment weapons to win the final war (Frank 1995).

This is probably one of the possible reasons behind such a difficult alignment between the languages—which mirrors the mind-set of the physicians (very logic and sharp, close to the medical regard of Foucault), and the language used by the patients, reflecting their mind-set of emotions, hopes, love, attachment, and fears. Other explanations might be found in the sociological and historical venue, for which the health-care system and in particular the schools of medicine developed in the centuries also over the wars, and had a very strict hierarchic code inside.

So, how can we combine this Tower of Babel and join both the misunderstood and rejected patient language with the physician linguistic style? Had there ever been a common language between patients and physicians before the building of the Tower of Babel? Had there ever been a golden age of better communication? In the book of Genesis, it is told that people used bricks instead of stone, showing a technology is in an expansion rate with a price to pay which might be the shrinkage of the language of the souls, the language of emotions. However, technology now is there, a matter of fact, and it cannot be denied in our contemporary age, especially in medicine. The archetype of the Babel tower reminds us of the everlasting feat between the innate emotional language and the technological languages that have brought complexity and somehow clouded the social relationship among scientists. In the Babel archetype, there is a heroic tension of challenging the current situation, the denial of the easiness of having a broader, more inclusive, common language to allow the alignment among human beings. God came and confused the languages merely because human cultures and trades and crafts were transforming men the

more they got specialized the less they were prone to be understood by the other communities [Dante Alighieri].

Should we accept this Babel of styles between physicians and patients, this city, and *confused medley of sounds*? Couldn’t we hope for a better semantic alignment, a line which trespasses and links the patient’s narratives and the physician’s peer reviewed publication?

Indeed, there are some love-sweet stories which may sound as exaggerations, too much *honey embedded*, in the “*Omnia Amor Vincit*” collection of the 121 patients with multiple sclerosis: physicians behave cautiously in front of this language as patients might suddenly relapse the day after, and fall in a depressive phase where no love is capable of curing their disease. This is what physicians fear, they have declared it; however, it is the doctor’s fear, not the patients’. It could well happen that physicians who at first glance reacted impulsively pushing off these romantic stories one day find benefit from this language, opening their military, heroic style to a less technological and more emotional language.

In an ideal world even in the peer-reviewed journal—where the language is comparable to a cryptic military code (jargon) just for the trained professionals—there should be room for other styles of expression, a humbler language which is able to explain and to describe the inner realms of the essence of living with a chronic condition. This would not only provide a more complete portrait of disease but would ultimately benefit the patient as well, facilitating patient education, participation within patient associations, patient empowerment, without impoverishing the personal elaboration of experience of illness in their daily living, with spiritual belief, or of with irony and very personal ways of coping with the disease.

A balance could be found, with no insurmountable walls about the different styles: just using mere reflections to understand why some language styles are used more frequently in specific communities of practice and of being. The Tower of Babel is one of the most beautiful metaphors to express the possibility and the complexity for human kind to interact through language.

Genres in Narrative Medicine

After having debated on the style of writing in medical context, let’s focus on the sources for narrative medicine, in medical humanities. Several authors have identified four main genres in narrative medicine: Patient stories, Physician’s stories, Narratives about Physician–Patient Encounters, Grand Stories—Metanarratives (Kalitzkus and Matthiessen 2009).

Patient Stories: Classic Illness Narratives

As Vera Kalitzkus, medical anthropologist, claims: “Patient stories allow making sense of their suffering and how it feels from the inside. They offer a biographic and

social context of the illness experience and suggest coping strategies." Patients' stories can range from totally free narratives, in which patients are given the highest degree of freedom of narrating without any plot to follow, to patient diaries bounded to a time grid to respect.

In the case of diabetes, these diaries, which traditionally had the purpose of collecting clinical information (vital functions, glycaemia, weight, dietary regimen, glycosylated haemoglobin) to monitor the disease following a fixed scheduled calendar, now foresee the prospective collection of patient narratives, as an effort of improving patient engagement (Miselli 2013).

However, patient narratives can be also woven into a given plot, following their linear chronological evolution: the *past*-realm of memory, *present*-realm of the here and now facts and perceptions, and *future*-the realm of expectations, hope, and fear. An inspiring example of plot is provided by the work of Hurwitz and Greenhalgh (1999). Illness is scanned into three main phases: initially, "the falling ill" period in which the body starts to ache and the diagnosis tour begins, followed by the "being ill phase" with the therapeutic pattern displayed, and eventually, the "getting worse" or "getting better phase", announcing both an objective healing (as a restitution phase according to Franck) or a subjective ability to cope independently from the severity of illness.

Here below is an example of linear plot, from the narrative of a 49-year-old woman living with myelofibrosis.

'I'm careful not to push too hard'

"I went on normally with work, home and keep up with my daughter when I felt a tremendous pain in the centre/below the ribs. I had a very swollen belly. I thought it was gastritis. It continued for 1 week without improvement and it was very strong, a constant pain never felt before.

So to understand what was going on I asked for help from a friend of mine, a surgeon. I underwent blood tests and the CT scan. The tests showed high platelets and the doctors thought it was infection.

The CT noted the enlarged spleen. They sent me home and decided to do again the contrast CT a couple of days later, still in pain and agony. The second CT discovered vein thrombosis and they sent me to X in the medical clinic where I was hospitalized a week. I actually had a gastroscopy and osteo-medullary biopsy and put on . . .

Later, the experts sent me home, and after I was given a consultancy in haematology . . .

The moment they told me that I had myelofibrosis I felt a kind of relief having understood what was going on, but soon after I felt anguish, anxiety for what I was getting into, and the consequences that it would have had on my life. I was looking for information on the Internet and I found depressing information, of survival of 18 months maximum, debility, etc.

I thought about my daughter, not seeing her growing and being there for her. Afraid of no longer being there, I could have no longer done all the things I would have wanted to.

I stayed at home for a month. I had to cancel a trip I had planned to the USA with my daughter, which we were so much looking forward to. I felt like a rag in general.

At work I could somehow get way from negative thoughts, It kept my mind busy . . .

I felt that my body was not under my control, but perhaps even telling me to change something in my life and that actually I was very strong and successful.

At the centre where the disease was diagnosed I felt taken care for by attentive, knowledgeable, helpful, skillful people. I visited other centres because I wanted to hear as much information as possible.

When I was home I often felt sad and frustrated, I felt as if I had something useful to do and I kept myself busy.

In some moments I was afraid that I would not be able to do what I want, and in other times I hoped to be able to overcome the disease and symptoms.

The people close to me were worried and tried to help with international research.

The spleen was enlarged and gave me slight discomfort at some time.

I feel normal. I feel I can do almost everything even though I'm careful not to push too hard and I cuddle myself more often. I want to respect my body, which in spite of everything keeps me alive and keeps me strong; the disease is now a part of me. I do not understand why it happened, but I live with it and I am sure to find a cure and improve and I do not give up.

I'm glad the research is going on now, where there was nothing before, and I'm open to trying new therapies to improve. I feel old, but it is probably independent of the disease.

I think that the treatment has been very important to keep the discomfort away and to keep a normal life.

When I'm at home I can relax, enjoy my house. I'm careful not to get too "into dark and depressive thoughts. I'm fine with my loved ones.

At work I can remove negative thoughts and focus on something else. It's my therapy and I cannot imagine not working.

If I think about tomorrow I do everything to stay positive. I want to be there for my daughter who has only me. I want to travel and learn/see new things. And I want to see a cure was found.

Thanks for your time, energy, and thought that you gave me.

How did you feel in being able to tell us your experience?

It was a bit "strange having to put on paper many very personal thoughts that mix up in my mind."

By means of a given plot, inviting the patient to tell us about the chronology of first symptoms, the present and the future, we are able to follow this woman in the journey she has undertaken with this myeloproliferative disease. It's a short story, yet it clearly tells us how much this patient is engaged in mastering her condition, how she overcame her fears, and the positive attitude she is keeping in the present.

Physicians' Stories

As Vera Kalitzkus says: *Physicians' stories can contribute to the rehumanization of medicine in the same way as patient narratives. After all, human beings deliver medical care. A special genre constitutes stories about physicians as patients. Reflections on physicians' own vulnerability are not very prominent, and even less so in public; however, these accounts show how physicians' illness experiences changed their understanding of their professional role and their relation to their patients. DasGupta and Charon tried to foster that kind of reflexivity—i.e., taking on a reflexive stance toward their own experience—in medical students, asking them to write about a time of experienced bodily vulnerability or suffering. This means of reflection helps physicians to develop empathy and understanding for the situation of their patients. DasGupta and Charon conclude: "The personal illness narrative allows the reader-writer to more fully enter the reality of the patient world by recognizing, describing, and integrating the similarities in her own personal experiences and those of the patient."* (Dasgupta and Charon 2004)

Here below, as an example, the illness narrative of a physician, aged 48 years, affected by urticaria, is presented.

'It was easy for me to get an appointment'

"It was a winter evening. I was alone, outside the home and outside the region to follow the course of specialization in occupational medicine. It was more than 10 years ago, but I still remember that moment as if it were yesterday: the chair in front of the TV tuned to the usual series, suddenly a sense of itchy feet. I put my slippers on, I felt like walking with coins in the shoes... disturbing. I went to bed and when I woke up in the morning it was gone. At the hospital I started my usual routine day: visits in ward, and this went on for about a month. Christmas parties came, and under the Christmas tree I couldn't find a nice gift. When I looked at myself in the mirror, a leap back in time. Primary school, being questioned up in front of the board, dreaded matter: geography. But the map was me: the mirror.

[...] The cobbler has always broken shoes, and I told myself, "a little cortisone and everything will go away". I went back to the hospital and I talked with a colleague. Shrugs, questioning looks, someone who said that I was a bit 'stressed out... a little' too. In the immediately following days a new surprise, not very pleasant: after a while I used my hands and they began to itch, reddening and swelling. And after a while it was as if I had gloves, instead of hands: red like those with which I used to throw snowballs when I was a child, but my hands were warm inside, swollen and itching.

Then I turned to a colleague, who for the first time did not dismiss me with the usual shrug and look, the usual mixed impatience and boredom that drove me to seek a second opinion—and see what came out. I thought why not, let's see what comes out. Hives never sent me to the emergency room, though it would have been easy for me: just to go down three flights and I would be there. But I felt like I was wasting my colleagues' time: heart attacks, accidents, infections, nothing compared to hives. Then I went to a specialist first, who was recommended by the family

doctor, a rheumatologist. He was bearded, very nice, and advised me to "do further two exams; let's see what comes out".

Meanwhile in the family setting, I was not feeling very well. Symptoms went on. There wasn't a day I did not have events, and sometimes I felt I was annoying, boring my family with complaints of being unable to do certain things on my own. At work none of this, ignoring it and moving on. I was grateful to be a doctor who does not need to use his hands much. If I had been a plumber, I would have been out of the job!

When they told me I had urticaria, I felt lost, lost, undecided; yes of course before the word had tried hard to reopen the drawer of memories. I looked terrible. The first person who I sought for a diagnosis was a colleague from the occupational medicine department, and besides, one of my teachers. When I told him about the symptoms he shrugged his shoulders. I looked at him expectantly. He handed me a publication in English. I translated it despite my broken English: "Hives, the great mystery", and from there I began the carnival. Visiting other specialists, other university hospitals. It was easy for me to get an appointment: all I had to do was say the magic word: "colleague" and the doors opened like blossoming flowers in spring.

And then the diet! Draconian, impossible, impossible to follow. I only remember asking if an antidepressant was included—and then new exams. "You know I do not think that is the case, however, we should test for two cancer markers... you know the paraneoplastic syndromes". Okay, I did not believe it was my case but you never know. Luckily tests turned out negative!

At that time I found relief working like crazy. Visits, visits, and still visits. I got home tired at night, sometimes really exhausted. But it was the only way not to think about my problem. Then antihistamine and sleep. I noticed that the rash became acute when I was stressed out. And I could go on. Antihistamines work and then finally the magnetic resonance. Negative (how beautiful the radiology suite!). While I could not do some manual tasks that I liked.

I felt embarrassed in front of others. Even doctors wore short-sleeved shirts in summer—and sometimes the signs were right on the arms. I felt uncomfortable, I thought about what patients would think by seeing me so. Someone might have thought I was contagious.

Today I live more peacefully with my hives. Ten years have passed. Statistically, in half the cases it should already be gone, but evidently this in the other half of the cases. So many things have changed in the last decade, worldwide and in the staff... but not my hives.

I feel better now, I have accepted it. I gave up antihistamines, and I would say that nothing has changed by taking them—and I've taken them for 10 years, every night. I explained the issue to the people I care about the most: those who really love me understand, and those who do not, well, I don't care at all. I'm okay with myself and with my close circle of people who love me.

Accepting a disease is a long and difficult process, full of curves and with few straight paths, full of doubts, and very few certainties. I tried to associate the symptoms with diet, with work, with stress, with time and with the pastimes.

Looking back on the path to this day if I look back I see a lot of theories, a set of ideas, a plethora of hypotheses, but also a lot of checks, withdrawals, exams. Sometimes I even wondered if I went to the right places. I would say yes, maybe I could go elsewhere, maybe.

Today I can live in peace. I accepted the illness but I'm not a saint. While I still cannot do certain things, I forgot how to walk on the pebbles where the wave of the sea breaks. I imagine that tomorrow treatment of hives will be easy, fast, safe, painless. We hope, there is always hope. . . . And if it is not for me, it is for the next generation or the one after that. Indeed I am sure that we will find a way to defeat it, today or tomorrow. . . ."

The double role of being both a patient and a physician is clear and powerful: and it is astonishing the series of fragments of remembering of the tons of tests performed, with a light sense of irony behind, and the gradually acquiring the skill of living chronically with hives, never ceasing to hope coming across a therapy.

Narratives About Physician–Patient Encounters

Illness, and the process of being ill, is formed and displayed also through the physician–patient relationship. The patients' experience of symptoms is interpreted by the physicians through their medical knowledge, eventually leading to a diagnosis and a therapeutic intervention. The physicians' action on the patients influences in turn the patients' narratives about patient experience.

In reference to this peculiar aspect, Rita Charon, physician and founder of the Narrative Medicine at Columbia University (see Chap. 1), decided to introduce a new tool health-care providers could use to track their own personal experience with their patients. Known as the "Parallel Chart", it is literally a parallel record. As she tells her students: "*And I invented the Parallel Chart. I told them every day you write in the hospital chart of your patients. You may have 3, or 4, or 5 patients, and every day you write in each chart, and you know exactly what to write. It's very proscribed. I told them, there are things that are critical to the care of your patient that don't belong in the hospital chart, but they have to be written somewhere. And I would say, if you're taking care of an elderly gentleman who has prostate cancer, and he reminds you of your grandfather who died of that disease, every time you go in his room, you weep. You weep for your loss, you weep for your grandfather. I said, you can't write that in the hospital chart. I won't let you. And yet, it has to be written. Because this is the deep part of what you yourself are undergoing in becoming a doctor. Only when you write do you know what you think. And there is no way to know what you think, or even what you experience, without letting your thoughts achieve the status of language. And writing is better than talking. We thought when we designed this chart, that by writing about their own feelings and by writing about patients, that the students would somehow mirror the patient*" (Charon 2008).

Physicians have the potential to take on an important supportive role in the creation of the illness narrative. As family physician John Launer points out,

physicians can create and formulate their own stories, which can help them support patients in their coping process and perhaps even a process of personal growth (Launer 2006).

An interesting example of the usefulness of physician diaries is in Intensive Care Unit, where patients frequently experience memory loss, nightmares, and delusional memories and in some cases may develop symptoms of anxiety, depression, and post-traumatic stress. The use of diaries is emerging as a putative tool to "fill the memory gaps" and promote psychological recovery (Aitken et al. 2013). If well performed, narrative medicine through written diaries by the multidisciplinary clinical team can help both parties in the phase in which the patient in a life-threatening condition returns conscious and starts to metabolizing what he/she has just been through. There are interesting and successful experiences in the USA and North Europe in the use of a diary to help people in ICU overcome the trauma caused by prolonged sedation.

Diaries are written also by patients' caregivers, nurses, and other components of the team. Upon recovering after an extremely critical event, the patient can read the story of his/her experience and understand what happened to him/her, and reduce the risk of a permanent shock.

Grand Stories—Metanarratives

In the background of individual narratives, there are always grand narratives of sociocultural understandings of the body in health and illness. They are mainly essays focusing on the patterns to describe specific Human Bodies and Therapeutic Approach from an anthropological point of view. Among the experts, I like to remind the above-mentioned Michael Foucault and Arthur Kleinman, and then also Byron Good: this medical anthropologist argues that medicine supposedly offers a scientific account of the human body and of illness, and he states that Western medicine pretends to catalogue the beliefs of natural medicine as mere superstitions. By doing this, the real inner patients' beliefs and values are neglected and not caught, and, as a consequence, it is almost impossible to create a true relationship among patients and carers. He argues that this impoverished perspective neglects many facets of Western medical practice and obscures its kinship with healing in other traditions (Good 1994). He continues to explore the place of culture theory in medical anthropology, with a special focus on the use of narrative techniques for studies of the cultural shaping of mental illness and client–practitioner relationships.

One More Genre

Finally, to these four categories we would like to add a fifth category, based on individual stories, those written by family caregivers, those who voluntarily donate their time and assistance to their beloved ones. The Burden of Illness does not

impact only the patient but the whole core of family members close to this person. The reading of caregivers' stories is a very powerful exercise to develop empathy and to think that an adequate health care system should not only provide care to patients but to the caregivers as well. In their narratives, regrets of a "possible other life" to be lived, to be elsewhere, but also the face of love, the drive which enables to stay close to their patients and foster the coping. And coping through loving energy will be the topic of the next chapter.

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Patient's Narrative as a Probe for Successful Coping

5

Poor Echo was neglected by Narcissus. The handsome boy despised everybody; all the nymphs and young men living in the wood. Echo never had her own voice, but she kept repeating what the others were saying... another victim of Narcissus' cruelty, Nemesis, prayed to Zeus for Narcissus to fall in love with somebody who was always out of reach. And the prayer was answered; Narcissus fell in love with his own image mirrored in the water spring, and eventually died of thirst, hunger and lack of sleep. Eventually he fell into the river and metamorphosed into the beautiful yellow flower we all know at spring time. What we are not familiar with is that Echo had to go on living in the caves forever, as a skin and bones woman, left only with her voice, repeating the last letters or tune of the words or music she was listening to [synthesis from the original version of the Metamorphosis ... [Ovid].

This extract from Ovid depicts two opposite personalities: on one hand, we have Narcissus, who represents the total lack of extraversion to the world, and the other hand, we have Echo, who represents the total absence of self-identity and personal frame of mind, overridden by those surrounding her.

In both cases, however, these mythological beings fail to cope with a destabilized and broken balance, which reflects the fall into a changed state of consciousness, an insane passion. Echo is the symbol of the complete lack of personality in a human relationship: neither assertive nor aggressive; she is just a passive and fragile girl and, as Berne would define in the transactional analysis, a *Submitted Child* (Berne 1972), totally thoughtless. She is overwhelmed by her tremendous passion for Narcissus and dominated by her emotions that she cannot figure out how to cope with his silence, without destroying herself. Their story is a drama of isolationism from both sides, two frantically ill people who are unable to share any glimpse of rationality. The real metamorphoses would have been for Echo to transform herself by way of independent thought and speech, therefore keeping her body, and for Narcissus to be able, for the very first time, to listen to other people's words and to enter into a dialogue, forsaking his monologues.

Again, the use of mythology provides us an illuminating analysis of mankind and the many facets of human behaviour. Its characters are built and inspired upon human weaknesses and as such also Echo and Narcissus, but, interestingly, while