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Bridging the Gap between Evidence-Based Care and Medical Humanities

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Maria Giulia Marini
Research and Health Care Director
Fondazione ISTUD
Milan, Italy

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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

Preface

Narrative medicine as a bridge among clinical care and 'humanitas'

> Science writers often get asked how to bridge the sciences and humanities, and frankly, I never know what to say. After all, math gets you much further in understanding quantum mechanics than sculpture or opera ever will. Still, sometimes the humanities can inform science, even improve it. Science led me into an uncanny valley, and I learned a lot down there about how the brain works. But the humanities helped me scale my way out, and gain the kind of perspective that comes only from leaving a valley behind.
>
> Sam Kean, "Beyond the Damaged Brain", The New York Times (May 4, 2014)

> Bridging the doctor-patient gap: narrative medicine aims to improve communication and care.
>
> Gordon 2012, Health US News

Being a social animal, our human nature inevitably drives us to, connect, bond, and seek affection and consideration by our fellows. And perhaps, among today's most recurrent idioms of modern language—despite the epochal changes brought by modernization—the metaphorical concept of a *bridge* is one of the most meaningful and powerful. "Bridges", "building bridges", and "bridging the gap" have become part of our everyday language and of our heritage. We seem to want to build bridges everywhere: between cultures, realms of knowledge, specializations, and so forth.

This means that mostly there is a river to cross, in a landscape with different borders, and this water stream marks different territories. Although each territory could be separated, the bridge creates interdependence, interconnection with the other land, friendly, hostile, or neutral.

A concept that can be easily transposed to many settings, as we shall see also to that of clinical science and humanities, as well as to the relationship between carers and patients. The river, however, is the same and is the expression of balance—or unbalance—between health status and disease which is impacting or eventually will impact our lives sometime in our future.

Clinical science is not only technologic but it has become more and more technocratic:

In the roaring age of Evidence-Based Medicine, as is today, based on the clinical trials science, numbers, plots, probabilities, confidence intervals, and totally aloof to any elements of subjectivity, personal perceptions, opinions, or preferences, we feel a deep cultural and spiritual need for a lost sense of humanity.

Bridging the gap between clinical science and Medical Humanities is possible.

In addition to fulfilling our instinctive need for recognition as persons, making medicine more fit to the inner needs of us human beings, the introduction of a more person-centred approach has proven to lead to great impact on patient care. This is because Humanitas ~~by itself~~ considers what we are as human beings and what constitutes genuine human flourishing. Human beings are complex, and the investigation of what is *human* is similarly complex. But it is the responsibility and privilege of humanities to engage the fundamental issues and questions of life, as those that have been synthetized so well by Paul Gaugain, with his masterpiece *D' où Venons Nous/Que Sommes Nous/Où Allons Nous (Where Do We Come From? What Are We? Where Are We Going?)* immortalizing the stages of life through a mesmeric portrait of women and children.

Such universal and existential questions, shared by every human being, become especially pressing when health status is *broken*. If health is in danger, and a disease is mastering the body and the psyche of a person, it is normal to try to find a new framework of thought, of Humanitas, in order to live with this changed condition. This is not something medicine—as practised in its present form—can provide.

This is hence where narrative medicine comes in, bridging the gap of unmet needs. The current era of research is facing a moment of historical crisis, torn between technological advances and unsolved issues of human mortality. Searching for a balance between the uniqueness of individual experience and the occurrence of common phenomena and mathematical models for different patients, not only in a "life" but in many "lives": this gives life to the narrative evidence-based medicine.

As narrative medicine is flourishing and finding widespread acceptance, it is also developing, moving from a singular vision, or one of few cases, toward a perspective of plurality defined within "galaxies of individuals", each with its own asymmetry but governed by a joint force of universal gravitation.

Paradoxically, narrative medicine in its thriving for a less technological approach to humanity is turning the technological advances available today to serve its own purposes relying on the semantic mapping software that analyses words, synonyms, expressions, and metaphors. Narrative medicine, originally "centred on the individual", may be able to embrace a more universal approach, without falling into easy generalizations, by simply reading and absorbing patients' stories, in their uniqueness, yet observing the "occurrences" of common factors and similarities which define us individuals.

In discussing the topic of narrative medicine, in this book we shall start by drawing upon the art of listening of the ancient times, using mythological narrative, to transport us in the contemporary age of medical humanities and narrative medicine. The referral to the world of Humanities will be a constant *fil rouge* of the style, in a going back and forward between present, past, and future. All for improving quality of care.

This book was conceived for everybody interested in caring and curing *others*: in particular, it is dedicated to all providers of care, physicians, nurses, psychotherapist, counsellors, social workers, aid supporters, health-care managers, scientific societies, and scientists and social academics or experts, and—not least—to students as well. It is addressed to pharmaceutical, biotechnological, biomedical, food, and well-being products companies, who are longsighted enough to grasp the potential benefit of listening to patient populations' real needs.

And—of course—to patients, their families, caregivers, citizen associations, but above all to each unique individual who has faced, is facing, or will face the existential issue of bridging between illness and well-being.

For the reader, this is the beginning of the journey along the river of health and illness. As we will be crossing the bridge and observing the waters below flowing, the chapters invite us to stop and meditate watching the river from different point of observation.

Milano, Italy Maria Giulia Marini

Acknowledgements

The heart asks for pleasure is the title of Micheal Nyman's soundtrack for the movie *The Piano*. The heart asks for pleasure even in the most desperate conditions. And we, as carers, curers, citizen, individual, others, and egos, can try to ask and to give back this pleasure.

And it is a pleasure to write thanks to the people who were with me in my development for this passion of narrative medicine, which is a very important step in my life. Going back "*to the edge of my earth*" (from the title of a song included in Nyman's soundtrack of *The Piano*), I want to thank my teachers, who are not anymore there, of my classic High School, of philosophy, latin and ancient Greek literature. And to my chemistry teacher who inspired me to study pharmaceutical chemistry at the university in Milan. It seems odd, but chemistry is a much more humanistic subject as one could imagine. My next study encounters, pharmacology, but the big move was the achievement of specialization in Epidemiology and Health Care planning at the University in Pavia. In the meanwhile, *on a wild and distant shore* (again, a song by Michael Nyman), I worked for pharmaceutical company in Italy, the USA, and Germany, and for consultancy. The constant attention to people's quality of life was my target, even if I worked in private sector, where I found marvellous people with thorough methodology and knowledge. The counselling school on Transactional Analysis was a conquer, going *Deep Into the forest*, allowing to myself, a scientist manager, to return and to expand humanities knowledge, somehow hidden in an ancient drawer. And then *The Promise*, the encounter with Fondazione ISTUD, which gave me the extraordinary opportunity to build the Health Care Area from nothing: and here the names of the people who believed and still believe in their efforts, enthusiasm, and competence to this group: Marella Caramazza, Luigi Reale, Giorgia Andreoli, Antonio Nastri, Nicola Castelli, Alessandra Cosso, Valeria Prandoni, Nicoletta Martone, Valeria Gatti, Antonietta Cappuccio, Tommaso Limonta, Paola Chesi, Alessandra Fiorencis, Andrea Guarini, Tania Ponta, and many other wonderful people who work for Fondazione ISTUD.

The embrace, I had with patients, physicians, nurses, pharmacists, psychologists, counsellors, social workers, volunteers, all people who trusted us and our approach in Narrative Medicine and left their witness. And *the embrace* provided by the most

competent experts who study Medical Humanities as Brian Hurwitz and John Launer, in the UK, and our beautiful Italian brain escaped to UK, Maria Vaccarella. And *The Embrace*, given by my Italian friends who know and love narrative medicine, Stefania Polvani and Antonio Virzì who always fight with me to build a real cooperative group. Now *Big my secret*, a special thanks to Emilio Iannitto, an haematologist teased by most of other participants to an education event on Quality in Health Care, since he proposed to try to apply in his department narrative medicine in 2006.

The promise, it was a gift of Manuella Walker, the review of my English of the whole book: it was an extraordinary challenge for a medical and scientific writer to be fascinated by narrative medicine and to dedicate so much care to these pages. Thank you Manuella.

The scent of love, of my man who has been waiting me and this book for many years, a smart listener who gave me the energy to write down in these last months the book. And in the *Lost and Found*, my wonderful and complex family, my father, always open to life and to joy until his last breath, and my mother, still full of zest for life and a model of altruism. To my sisters, Marina and Lucia, *lost and found*, and again *lost and found*.

Finally, my *dreams of the journey*, thanks to my son Gabriele, who is now facing youth, with all his dreams of his journey, who taught me to the pure listening and the acting.

And *my heart asks for pleasure* for all past and present and future people, some who might become friends, some not, encountered and to be encountered in this humanization path of science and of ourselves living this world.

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About the Author

Maria Giulia Marini is key opinionist in Humanities for Health in Italy and, since 2002, Director of the Health Care Area at Fondazione ISTUD in Milano, Italy, a not-for-profit research and business school, whose activity is mainly focused on governance, sustainability models, and value creation. “Coming from a classic humanistic high school”, Dr. Marini recalls, “I chose to integrate this kind of knowledge with scientific university studies”. She got her Degree in Pharmaceutical Chemistry and a postgraduate degree in Pharmacology at the University of Milan. She also got a Ph. D. in Epidemiology from the University of Pavia. She attended two internships at the Brigham and Women’s Hospital in Boston, in clinical research and trial organization. After the international experiences in the USA and also in Germany, she attended the Institute for Gestalt and Transactional Analysis in Milan and attained the Counsellor title.

She has been working for 25 years in the health-care field in international companies and as a consultant. “Fondazione ISTUD, with a humanistic management approach, represented the possibility to build a bridge between science and humanities in health care”. Her major fields of interests are the development and performance of sustainable health-care models, performance evaluation, medical humanities, and the humanization of care.

Evidence-Based Medicine and Narrative Medicine: A Harmonic Couple

1

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.

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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 Sacket'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 test 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 patents 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.

References

Charon R (1993) Medical interpretation: implications of literary theory of narrative for clinical work. J Narrat Life Hist 3:79–97

Evans JG (1995) Evidence-based and evidence-biased medicine. Age Ageing 24(6):461–463

Evidence-Based Medicine Working Group (1992) Evidence-based medicine. A new approach to teaching the practice of medicine. JAMA 268(17):2420–2425

Feinstein A (1967) Clinical judgment. Williams & Wilkins, Baltimore, MD

Genette G (1980) Narrative discourse: an essay in method. Cornell University Press, Ithaca, NY, Lewin J, trans

Goldman J, Shih TL (2011) The limitations of evidence-based medicine—applying population-based recommendations to individual patients. J Ethics 13(1):26–30

Greenhalgh T (1999) Narrative based medicine in an evidence based world. BMJ 318 (7179):323–325

Greenhalgh T (2014) Is evidence-based medicine broken? Project Syndicate: the world's opinion page 2014. http://www.project-syndicate.org/commentary/is-evidence-based-medicine-broken-by-trish-greenhalgh-2014-10. Accessed 28 Apr 2015

Groopman J (1998) The measure of our days: a spiritual exploration of illness. Penguin, New York, NY

Howick J (2015) A new generation of bias in EBM. http://www.cebm.net/a-new-generation-of-bias-in-ebm/. Accessed 28 Apr 2015

Marini MG, Arreghini L (2012) Medicina Narrativa per una Sanità Sostenibile. Edizioni Lupetti, Milano

Marini MG (2013) Medicina-narrativa: quando la terapia passa attraverso il racconto. http://magazine.paginemediche.it/it/567/interviste/medicina-generale/detail_203794_medicina-narrativa-quando-la-terapia-passa-attraverso-il-racconto.aspx?c1=50 [News interview]

Marini M, Reale L, Cappuccio A et al (2014) Narrative medicine to highlight values of Italian pain therapists in a changing healthcare system. Pain Manag 4(5):351–362 (Review)

Turner E, Matthews A, Linardatos E et al (2008) Selective publication of antidepressant trials and its influence on apparent efficacy. N Engl J Med 358:252–260

Editorial Board of the Economist, How science goes wrong: Scientific research has changed the world. Now it needs to change itself. The Economist 2013. October 19 (News article)

Sackett DL, Haynes RB (eds) (1976) Compliance with therapeutic regimens. Johns Hopkins University Press, Baltimore, MD

Spiro HM, Curnen MGM, Peschel E (1993) Empathy and the practice of medicine: beyond pills and the scalpel. Yale University Press, New Haven, CT

Symborska W (1989) The Joy of writing

Weine SM (1996) The witnessing imagination: social trauma, creative artists, and witnessing professionals. Lit Med 15:167–182

Bridging from Mythology to Contemporary Care: The Art of Listening

2

> *"Poseidon was angry with us because we are the happy couriers of everybody"*
>
> *"You have to know that there are no pilots among the Phaeacians, and there are no rudders, as have other ships, but the ships alone know the thoughts and intentions of the men, and know the city and the fertile fields of all nations and very rapid cross the abyss of the sea, enveloped in a cloud of fog: the Phaeacians don't think to bow but always masts and oars and well balanced rowing boats"* (Homer)

Homer's *Odyssey* is an epic poem that evokes everlasting existential issues. Odysseus in his journey is much more than the fearless adventurer and triumphant war hero whom we are acquainted with. In the 24-chapter poem, entirely written in metrics, every word has a specific meaning which goes beyond the mere plot. Before entering in the world of narrative medicine, we find appropriate to build an analogy with one of the supreme masterpieces of human writing ever composed, to understand how stories and, in this case, myths, can be interpreted and analysed at different level: a first one, "contingent" on the plot of the given events, a second level "moral", which shows the "habits" of the characters, and a third, hidden, the "core", which reveals us the identity of our hero.

So, learning through analogy, let's spend some time, before embarking ourselves in narrative medicine, on this poem, and in particular to the real journey who will bring our hero at home, to Ithaca. The treacherous journey will make Odysseus' bravery and certainty dwindle, challenging Odysseus to resort to his most inner strengths and humanity. His literally fantastic journey gradually escalates in complexity and culminates with an interior crisis that will ultimately help him find himself and his way home.

The story of Odysseus is a fantastic one, but can be used to represent human weakness and skilfulness. On the importance of myths as sources of knowledge to pose questions and answers to existential issues of human beings, essay literature is endless: one of the most seductive definitions of the value of mythology is that, differently from ideology which ends up in fragility of human beings, it brings human being from fragility to antifragility. While fragile persons love control, protocols, and

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known events, antifragile people are attracted by the unknown, randomness, and ambiguity. Mythology is ambiguous, differently to history which deals with facts: and through mythology, restraining the power of rational thought, we become antifragile, beyond resilience and robustness, as Thaleb, radical and paradoxical philosopher of our time, states (Thaleb 2013). This is why, we are exploiting Odysseus, utmost antifragile hero to enter in the contemporary realm of narrative medicine.

The last stop before Ithaca is the wreckage of Odysseus, completely alone, with his destroyed raft, beaten by the undertow, on the shore of the island of Scheria, inhabited by the Phaeacians. The last encounter with these people will change Odysseus' life. This episode represents perhaps the highest intensity of the interior search and the call for a deeper reflection and elaboration of all the past events of Odysseus' life. A search through that begins thanks to the intervention of the Phaeacians, who are able to engage the hero in the narration of his story. The Phaeacians are a people of peace and moderation, who have developed such refined mental skills to the point that they are able to command their ships through sheer mind power. They are ruled by King Alcinous and his wise and kind-hearted wife Queen Arete (in greek *Virtue*). They represent the ferrymen of humanity. As Odysseus will present himself before them, he is "Nobody" (Odysseus from the root *oudos*, which means Nobody): he has lost his kingdom of Ithaca, his wife, his son, his friends, his ship.

Alcinous supports Odysseus and promises that the *Phaeacians* will bring him back home to Ithaca: it looks easier than he had anticipated; the people are kind, Arete is kind, the ships are ready, but Odysseus who rationally declares his intent, as a matter of fact, is not ready at all.

At Alcinous's court a bard begins to sing of the deeds of Ilium, and *"Odysseus covered his head and wept, so shed tears without being seen by others"*. Alcinous interrupts the narrative, giving rest to the torment of Odysseus: but on the next day, the bard gives no respite and again resumed, "and sang of the sons of the Achaeans who destroyed the city, creeping out of the horse, leaving their hiding place ..." And Odysseus was dying ... like a crying bride embracing the beloved husband who fell in front of his city and its people... so Odysseus tears poured down from the lashes to arouse pity. "Only Alcinous sees it, he is the lucid observer, asks the bards to stop singing and gives him the time to recover, to finally ask him" and tell me why are you crying and listening? ... Or maybe did you have some relative who died? At that point Odysseus capitulates. Collapse is total. This is where the true story is told, the genuine one; no longer made of half-truths, but the authentic version of the facts. After mourning the experienced horrors and crimes, for the first time, Odysseus lets down the mask and reveals his true identity.

The *Phaeacians* are there to listen, without expressing a moral judgement, condemnation, or praise of approval: they are the welcome point; with the heart and mind, King and Queen and together with their sons and the 12 members of the council of wise men offer a total and unconditional listening, similar to the one which takes place in the analyst's practice. King Odysseus narrates not asking for forgiveness and through the time of his narration, a period in which objectively the return is delayed, he cries and is moved and then faces his life crisis. Through time of reflection, the ability to be introspective in this suspended place, his identity sees light again, with these attentive focused listeners: he heals, evolves, becoming himself ready for the real *nostos*, the return to himself and not only to Ithaca—the story of a hero and the ordeals of life, the healing power of the art of listening of narration.

The analogy with the reality of patients is clear. Listening, especially with fragile patients, or better, people who just had received a tough diagnosis should be authentic and deep. Odysseus is impatient to obtain the remedy for returning home (the patient wanting the drug prescription to feel well and return to life before illness), but the timing for that remedy is not appropriate, not for him at that moment in his life. The triggering event is a storyteller who starts to narrate about the past, so common at that time that it was like universal, and so, Odysseus starts through his narratives to become aware of his disease (sick of power and curiosity?): the Phaeacians are those who pose the right questions, and embrace his guilty feelings, sorrows, wish, and hopes. Time for curiosity is over; time for showing the strong side of the personality is gone: through the narrative, Odysseus becomes aware of his vices and virtues and gives a meaning to the need to go home. Too much pain and too much sufferance had to be shared with other humans.

Here, the encounter between humans could go far beyond a superficial hospitality, but lies in mutual understanding, revealing, in an environment where trust built gradually to allow the mask to come down and reveal the truth. To afford to rediscover through the story to others, clear navigation and drive by our own boat, on the quest to the very oneself. And this is of main importance in times of disease, when a patient is shocked, somehow shy, and does not want to express what he or she feels like. *Phaeacians* are very good healers, being able to build a bridge which connects an ill person's life with healthy lives. That's one of the possible meanings of the island of the *Phaeacians*, the sounding board of the narrative of human events.

The Purpose for Narrative

In the first chapter, we have stressed our apology defending the importance of narrative as a tool to bring well-being and awareness in the sick people. Mythology, metaphor, and literature are regularly used in the teaching of Medical Humanities at Columbia University, and their use is widely spreading to inspire the learning of narrative medicine.

Narrative medicine as well as medical humanities mainly developed in the twentieth and twenty-first century as a tool to give voice back to patients, fragile people, and persons who had no right to speak and claim how they lived their disease. A cult book for narrative applied to medicine is *The Wounded Story Teller: Body, Illness, and Ethics*, by Arthur Frank, a sociologist who teaches at Calgary University and who had a direct experience facing a cancer (Frank 1995). Frank states: illness narratives can be appointed to three major categories: restitution, chaos, and quest. "Restitution stories attempt to outdistance mortality by rendering illness transitory. Chaos stories are sucked into the undertow of illness and the disasters that attend it. Quest stories meet suffering head on: they accept illness and seek to use it. Illness is the chance for turning a journey into a quest". According to Frank, the illness narratives of restitution are fictions and possibly alienating: "Are restitution narratives capable of generating stories? No, meaning that restitution stories bear witness not to struggles of the self but to the expertise of others: their competence and their caring that affect the cure. In this witness restitution stories reveal themselves to be told by a self but not about that self", as Frank states. In restitution stories, ill people meticulously describe the visits they have undergone, the lab tests, the drugs taken, the surgery, and eventually the "getting better phase". According to Frank, patients producing restitutions stories are not opening their inner realm of emotions: they are very close to that semantic of the disease which is represented as an alteration in biological structure or functioning", developed by Arthur Kleinman (Kleinman et al. 1978). *Disease* is thought as an objective condition, linked to a malfunctioning of the body, which is considered closer to a machine than as a thinking, feeling, living organism. In the biomedical context, as defined in the medical anthropological field, "biomedicine" refers to the "Western" medicine based on the application of biological sciences to clinical practice and the doctor risks taking a reductionist approach which focuses the attentions to signs and symptoms, and not to the patients' global life.

And trying to fit the disease model with the restitution stories, it might turn out that the real self is hidden, or worse, vanished behind the *Homo Technologicus (Longo* 2001*)*, described as an hybrid between human and machine: no emotions, no interpretations, just "*take your protein pills and put your helmet on (Bowie* 1966*)*". The restitution for having been submissive to the protocols of care is the healing, the getting better, without considering any possibility for the least *quantum leap* of awareness. Going back to Odysseus, from a chronological point of view, this is the starting phase when he lands to Scheria and immediately claims a ship to return to Ithaca—the health status: if the King had satisfied him immediately, this would have been a story of restitution, with no modification of Odysseus' inner self that led to a Quest story.

Moving one step further, Frank considers the category of the *chaos* narratives by patients. These stories are entangled, messy, and they don't allow to bring order to facts, or rather as Franck argues that they are not narrative: "If narrative implies a sequence of events connected to each other through time, chaos stories are not narrative. When I refer below to chaos narratives, I mean an anti-narrative of time without sequence, telling without mediation, and speaking about oneself without being fully able to reflect on oneself: Although I will continue to write of chaos stories being told, those stories cannot literally be told but can only be lived". It's a severe judgement on chaos stories, and it's a position which denies the possibility to move back and forward between illness and health and between different levels of consciousness. However, the illness paradigm is taken into account, this being an evolutionary step which leads from disease, the body machine, to the realm of mind and emotions (Kleinman et al. 1978)—although not in the condition of reaching the awareness, or in a more epic way, the enlightenment.

According to Frank, epic matters and in fact identifies a third style in which patient's narratives can be categorized as the *Quest*, the Bildung narratives which occur when *"the ill person meets suffering head on; they accept illness and seek to use it. Illness is the occasion of a journey that becomes a quest."* And again returning to our Odysseus, the hero, we see him suffer through his tears and memories, and put his vicissitudes in order, composing a plot which will lead him again to his real self. The Quest, la *recherche*, is a constant soul and mind movement to understand the meaning of living with the illness and what can be learnt by the illness.

In 2012 the ISTUD Foundation performed a study on the narrative classification with multiple sclerosis (MS) (Marini et al. 2015). The project collected patient narratives and focused on the semantic analysis of the names patients attributed to their illness and classified them as "*chaos*", as "stuck stories", in which no evolution is traceable, in stories "in movement" "*or progressive*", with a progression included in the narratives.

Findings showed that the *stuck* stories, "still in chaos"—in which only a poor inner quest is undertaken from the moment of being informed about the disease—were mainly dominated by a chaotic situation: in the 121 stories collected, multiple sclerosis is defined as a monster in 40 % of cases, an inconvenient mate in another 20 %, an enemy to fight in 12 %, a hurdle in 7 %, and a sentence in 7 % of cases. Only 6 % of patients deemed the disease to be a friend. Names given to the disease recalled emotions of fear, anger, rage, and sorrow.

Conversely, stories, which showed a radical movement from the initial depression after the communication of diagnosis, were characterized by a lighter and more serene semantic choice: multiple sclerosis became a friend in 42 % of cases, a new point of view in 9 % of other narratives, something to keep under control in 6 %; nevertheless, in other patients who reacted to the disease showing their "antifragility", multiple sclerosis is still conceived as an enemy to fight in 12 % of stories and an uncomfortable mate in 10 %: and disease defined as a monster is only in 2 % of the cases.

From these terms, it is possible to distinguish fragile and antifragile patterns of behaviour: if nature could be meaningless and unpredictable, affecting persons with particular diseases, and here the paradigm of Thaleb is extraordinary powerful, leading ourselves to become antifragile facing uncertainties, however, it is possible to develop different habits of mind to counteract what life brought us, even if it is a life condition event.

Now that we know the names and the narratives of people with multiple sclerosis, *Cui prodest?* (SO WHAT?) [Seneca] Who will derive the benefit? Maybe the community in which the patients live, so that they can act, pro-act, and react to patients' point of view, maybe the providers of care, physicians, nurses, who might work on trying to elicit putting into words the emotions of their patients, so that they can ease sorrow, reassure about fears, and take seriously rage according to emotional intelligence.

Non Narrative: Another Way of Living?

Do we all need to heal as in the archetypal story of a hero's journey, referring to the evolution pattern of Odysseus, as in the quest narratives, when we are facing an illness? And do we all need narratives according to the *psychology narrativity thesis* which states that "*Human beings typically see or live their lives as a narrative or a story of some sort*" (Brody 1987) or according to the *ethical narrativity thesis,* according to which *"experiencing and conceiving one's life as narrative is a good thing: a richly narrative is essential to a well lived life, to true of full personhood"*.

However, in *Against Narrativity*, Strawson (2004), contemporary philosopher, follower of panpsychism—a view that consciousness, mind, or soul is a universal feature of all things—states "*that is not that there is only one good way for human beings to experience their being in time. There are deeply non-Narrative people and there are good ways to live that are deeply non-Narrative. I think the Narrativity theses hinder human self-understanding, close down important avenues of thought, impoverish our grasp of ethical possibilities, needlessly and wrongly distress those who do not fit their model, and are potentially destructive in psychotherapeutic contexts."*

Strawson identifies two personality types, which he calls the d*iachronic* type, the kind of person open to conceive themselves as connected to their past and future selves, according to a linear concept of going through time (from the Greek terms *dia* "through" and *cronos* "time") and the e*pisodic* type, which is the kind of person who does not tend to conceive of their momentary self as part of a chain of selves stretching into the past and future. The diachronic person has a mindset open to narrativity, while the episodic does not. The Diachronic and Narrative outlooks or personalities generalize from their own case with that special, fabulously misplaced confidence that people feel when considering elements of their own experience that are existentially fundamental for them and assume they are just as meaningful to everyone else.

"...and I have absolutely no sense of my life as a narrative with form, or indeed as a narrative without form. Absolutely none. Nor do I have great or special interest in my past. Nor do I have a great deal concern for my future", Strawson keeps on saying in his provocative essay, *against narrativity*. It looks like that Episodic people are more prone to marry the "*carpe diem*"—seize the day concept [Horace], without finding any cause consequence effect, or in an everlasting *chaos* philosophy, which do not try to drag conclusions from the events of the past to anticipate the future.

The question to be posed is *"does illness propel us in the dimension of diachonicity, forcing us to mourn a health past which cannot be recuperated or a future which feels more fraught, more finite?" (Woods 2011)*. The moment of the notification of a diagnosis of a severe disease is a fact-based event; it might cause a dis-rupture with the past previous life and can push people, from episodic "style of life" to become "diachronic" patients, nostalgic for a *Golden Age* which is not anymore there. And this occurs mainly in free narratives left by patients: however, when starting to cope with the unbalanced broken state of health, I can say that I saw sparkles of episodic mind, finally disconnected from time sequence, in patients, learning to stop to worry too much for their future and to ask to themselves the fateful question *“Why this occurred to me”?* The antilinear narrative is a tool to become antifragile. A disease occurred, and it’s a part of life, linked to the loss events, like growing up, aging, and dying, Narrating the reasons why and all facts associated is of course a rational structure which helps individuals and, in my point of view, is not only a door for ethics, but it’s a natural way of reacting to the *stressful questions without an answer* provided by life. Narratives, indeed, help when we enter into the fragility mode, and we can find inner resources, like Odysseus, becoming diachronic in the *Phaeacians*’ island. However, there comes a time when even Odysseus, once back in Ithaca and killed the *Proci*, stops to fight, listening to his defender Goddess *Athena*. And, episodically, *he felt happy*.

References

Bowie D (1966) Space Oddity (Song)

Brody H (1987) Stories of sickness. Yale University Press, New Haven, CT

Homer. Odyssey, most likely end of VIII century BC

Frank A (1995) The wounded story teller: body, illness and ethics, 2nd edn. University of Chicago, Chicago, IL

Horace. Odes: Book 1(11) in 23 BC

Kleinman A, Eisenberg L, Good B (1978) Culture, illness, and care: clinical lessons from anthropologic and cross-cultural research. Ann Intern Med 88(2):251–258

Longo G (2001) Homo Technologicus. Meltemi Editore

Marini MG et al (2015) Storie Luminose di Sclerosi Multipla, RCS

Seneca LA. Medea, I century BC

Strawson G (2004) Against narrativity. Ratio 17:428–452

Thaleb N (2013) Antifragile, things that gain from disorder. Penguin Books, London

Woods A (2011) The limits of narrative: provocations for the medical humanities. Med Humanit 37:73–78

Bridging from Oral Tradition to Writing: The Art of Empathy

3

> *"The jacket had splendid drawings, inspired by Norwegian legends, but were invisible in the eyes of normal people, having been obtained in soft shades of brown and purple, colours not very mixed . . . Britt, instead of just reacting to the luminance, saw them perfectly. "My art is special and secret" he said. "You have to be completely blind to the colours to observe them."* (Sacks 1997)

> *"The clinic, the laboratory, the department are made to curb and focus behaviour, if not for erasing it all . . .. What is better for this purpose instead of a street in New York; an anonymous public street in a large city where the subject of bizarre and impulsive disorders can enjoy and exhibit the full monstrous freedom or slavery of their condition?"* (Sacks 1985)

Narrative medicine would not be as we know it today if it weren't for a forerunner and a visionary talent such as Oliver Sacks. A man of many virtues and extraordinary accomplishments, perhaps known by most for his story inspiring the filmmaking success of *Awakening* rather than his philanthropic teachings and profound respect and curiosity for the happenings of mankind. He created narrative medicine before nominalists labelled this discipline driven by their innate need to attribute a name to everything and classify currents of thought and study, according to the logic evolution of science, from Aristotle to Linnaeus and so forth, up to our days with continuous creation of new specialties and hypo specialties. Indeed, whenever I am asked by students or colleagues to suggest resources and examples of narrative medicine, I cannot but turn them to the numerous writings of Oliver Sacks.

Aside from being one of the most productive contemporary authors in the field of medicine, Sacks is a biologist, a physician, an anthropologist, a neurologist, and to some extent also a bit psychologist as well.

As a biologist, we see him through his descriptions as a Darwinian appreciator when he describes the islands of mental illness—almost a chemist in his description of microcosmos of symptoms and signs.

As a physician, treating the body of his patients, we read of his stories on finding new treatments (the famous case of L-Dopa in *Awakenings*, in patients affected by

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lethargic encephalitis—from the illusion of having discovered a cure to the disappointment of the failure of treatment).

As an anthropologist, defiant of privacy regulations, he secretly followed his patients through the anonymous streets of New York to understand their wanderings and whereabouts outside the dry setting and format proper to the medical consultation.

As a neurologist who studies neuronal psychic disorders that differentiate the human being, and who goes beyond clinical parameters investigating the pieces of "microcosomial tissue" and the "patient's macrocosmo" which constitute the patient's entirety.

As a writer, who feels compelled to report his clinical cases through a wealth of details with his unique synthetic trait. "*If we wish to know about a man, we ask 'what is his story—his real, inmost story?'—for each of us it's a biography, a story. Each of us is a singular narrative, which is constructed, continually, unconsciously, by, through, and in us—through our perceptions, our feelings, our thoughts, our actions; and, not least, our discourse, our spoken narrations. Biologically, physiologically, we are not so different from each other; historically, as narratives—we are each of us unique.*" (Sacks 1985).

In addition, to being a good-hearted "curing scientist", we could also label him as "systems-oriented": he believed that all the different disciplines, from humanities to science and medicine, involve a wealth of competencies which can be put into connection, and brought them back closer to the theory of Galeno, according to which the alchemic reaction of closeness of the elements triggers their transformation until they bond together. He challenged the reductionist culture of medical specialties, where different disciplines continually thrive and grow part.

But in either role we see him, what distinguishes Sacks the most is an uncommon ability of seeing beyond the disease and the ward, and capture the subjective reality of the persons afflicted by illness. He describes the visual experiences of his patients affected by achromatopsia (a disease which forces those affected to live a life in black and white) as coloured in the endless range of whites and greys and the many tones of blacks, as in an endless tapestry. Or, as in the case of patients with autisms, where he describes his patients as "islands" who remain insensitive to those surrounding them, and separated from the mainland of the dominating social culture, and further capturing their existential dilemma *"is there a place where the genial autonomy of autistic persons can be used without being impaired by it?"* (Sacks 1985)

Sacks' strong spiritual connotation drives him to look at his patients and see the human needs of the spirit: *"Whenever Jimmie was taken by something for a short time, a brain teaser, a game, a math operation kept within their purely mental stimulus, and he reached the solution he would become lost and fall into the abyss of his nothingness, into his amnesia. But if was engaged by a spiritual or emotional feeling—in contemplating nature and art, listening to music, or taking part to the celebration in the chapel—his attention, his "mood", his calm went on for some time and within him was a thoughtfulness and a peace that we saw rarely or never in other moments of his at the clinic"* (Sacks 1986). In other words, we can say he is a person who is attentive to the needs of others, and clever observer of what is happening around him—a curing scientist, not merely a reductionist doctor.

As Sacks claims, *"It should be said that from its onset, a disease is never just a loss or an excess, and that there is always a reaction on behalf of the body or the individual aiming to re-establish or replace, compensate and preserve its identity despite the strangeness of the ways used to achieve this"* (Sacks 1985). It's a chaos that finds its order: reading Sack's pages we absorb by osmosis that attitude of deep respect towards conditions which are not only neurological but also undefined thresholds in which being and acting different prevail over what we define as "normal". Acting normally as holding the fork in the left hand and the knife in the right: the mind maps that these patients must follow in order to perceive—as they are unable to see the knife to their right and the fork to their left—become distressful mazes from which patients helped by carers often emerge tired but happy as they have succeeded in the undertaking.

He opened us the way to a new spirit of observing and reporting illness, in stark contrast with current tradition. As he wrote in "*The man who mistook his wife for a hat*": "*we were far too concerned with 'defectology', and far too little with 'narratology', the neglected and needed science of the concrete … It is this narrative or symbolic power which gives a sense of the world—a concrete reality in the imaginative form of symbol and story—when abstract thought can provide nothing at all."* (Sacks 1985).

The science of narrating is not fiction; it doesn't have to be drama or comedy that makes the audience laugh or cry. It is simply a chronicle, a report on layers of the body, of the mind and the soul of the patients and the persons around it. It's the science of the tangible and not of the intangible—few theories, but a lot of discipline in writing and reporting facts, emotions, and thoughts. In other words, Sacks is the Picasso of the Blue and Pink periods: especially nowadays: in this time of partial lack of masters, I like considering him so.

It's interesting to notice also how Sacks' stories of patients often cross stories of his personal life, and the shift in narrating person—speaking in first person singular to first person plural, as a continual recognition of team work and participating in his patients' endeavours and frustrations. The moving from the *I* position to the *we* statement is proof for providers of care that they think, work, and feel as an affiliated équipe.

In conclusion, the greatest teaching emerging from his writings is the extraordinary faith he is able to repose in the resources of the Other, towards whom many would simply manifest pity and embarrassment. He sees the Other, the *different* one, as a peer, a relationship founded on *Empathy*.

Empathy, at the Basis of Humanities

But what is *empathy*? Despite today's current use in everyday language, there seems to be a global confusion around the meaning of this term. When we ask the question on *what Empathy is*, we obtain the most diverse replies: "*to be in someone else's shoes; to share someone's grief*; *to cheer someone up in moment of sorrow; to celebrate together in period of happiness*".

From an etymological point of view, the term is relatively new and was introduced in the English language in the nineteenth century by the English psychologist Edward Titchener. He was an experimental psychologist mostly focused on more tangible aspects of consciousness, with little interest on more abstract ones such as instincts of the unconscious. Yet, he was very much concerned about harmony of human relationship. Thus, in translating the German word, *Einfühlung (feeling into)* in use at the time, he felt the obsolete Greek term *pathos* (feeling) was more suitable in describing the concept of in-passion (*en pathos*), which thus became *empathy*.

From a conceptual point of view, there are basically two major distinctions for the term *empathy*: (i) a cognitive empathy, which is the understanding of the Other's point of view, and (ii) an affective Empathy, which is the understanding of the Other's feelings.

As such, empathy is a pivotal issue in the path towards humanization of care and is one of the cornerstones of narrative medicine. Yet, in the social context we are today, rather than empathy we are most often forced to speak about the *lack of* empathy.

Indeed, the most active supporters of narrative medicine have more than once denounced the emotionally aseptic approach to patient care in today's current practice and across all medical disciplines. This was strongly voiced at the world congress "*A narrative future for health care*", held in London in 2013. In a provoking argument, one of the speakers—the American psychiatrist Steven Schlozman—compared young physicians to Zombies, creatures who are living dead: famelic, sluggish, and missing the mirror neurons necessary to develop empathy. It appears that from the third year of med school on, students start to become less empathic, but more effective in mastering the "detached" medical gaze. It is the gaze that Foucault described in its famous essay, "*Naissance de la Clinique*" (Foucault 1963), the *"regard medical"* that prevents carers from having emotional approaches to patients and rather endorses a detachment and more *distant care*.

In fact, based on today's teaching methods and ethics in the medical field, students are encouraged to become more rational with strict focus on the *medical objects*—the body and its parts.

Another perhaps even more provocative claim was launched by Catherine Belling (Bowman 2013), who gave an impressive lecture on tortures and hypochondria—the latter being compared to a form of self-torture. According to her "*medicine can become aggressive as torture*". Despite being two opposite concepts, medicine and torture share two similarities: first, they both act on the body and, second, they both act towards finding the truth by the way of investigations. Though a very provocative image and, not fully appreciated by the audience, it was surely capable of stirring up deeper reactions.

A global alarm for lack of empathy in clinical setting was raised, pinpointing that before becoming a good carer, one first has to be a good listener and observers, exactly as the Phaecians were with Odysseus and other lost shipwrecked and Sacks is with his diversely skilled patients.

The Devil in the Third Year of Medical School

Although deceiving, this is not the title from some heavy metal piece, but it's the title of a paper published on *Academic Medicine* in 2009: the study focuses on the erosion of empathy among future physicians which apparently begins from the third year of medical school on (Bowman 2013). The authors provide a brilliant definition of empathy (Hojat et al. 2009): "*To clarify the conceptual ambiguity associated with empathy, based on an extensive review of relevant literature, we defined empathy in the context of medical education and patient care as a predominantly cognitive (as opposed to affective or emotional) attribute that involves an understanding) of patients' experiences, concerns, and perspectives combined with a capacity to communicate this understanding. An intention to help by preventing and alleviating pain and suffering is an additional feature of empathy in the context of patient care*". In this definition of empathy, sympathy is conflicting, since the former is a very evolved understanding of human nature, and the latter is a more primitive and limbic-triggered feeling. In the study, authors claim that sympathy brings to unproductivity whereas empathy produces a better quality of care. Moreover, in delving on social and ethical behaviours, they further explain "*the escalation of cynicism and atrophy of idealism has long been recognized as part of students' socialization in medical school and their adaptation to a professional role. This downward trend has also been observed in the ethical erosion of medical students during their clinical training. . . . this transformation as a form of "socialized amnesia" in which some medical students unwittingly acquire the unempathic quality they pledge not to adopt in the Socratic Oath. Empathy in medical education often fades away like an endangered species.*"

The Fight Against the Devil

What the authors propose to contrast this trend is an interesting ten-item checklist of actions that can be easily implemented in the academic environment.

"To prevent extinction of this valuable human quality, we need to make profound changes in medical education by developing targeted educational programs at the undergraduate, graduate, and continuing medical education levels. There are different approaches that can be implemented in medical schools to retain and enhance empathy. For example, the following ten approaches have been described to enhance empathy in medical education: improving interpersonal skills, analyzing audio- or video-taped encounters with patients, being exposed to role models, role-playing, shadowing a patient, experiencing hospitalization, studying literature and the arts, improving narrative skills, watching theatrical performances, and engaging in the Balint method of small-group discussion. It is also important to pay attention to the importance of role models, patients, and the environment in which care is given. Most of us in medical education advocate empathy, but the effect of simply advocating empathy without embracing it and living with it, and without implementing targeted programs to enhance it, is analogous to singing a lovely song only in one's own mind without others ever

enjoying it! Tangible changes in medical education outcomes can be made by actual implementation of targeted programs, not by simply advocating good ideas." (Hojat et al. 2009).

In fact, since then several Universities have tested and validated a number of education programs which have now become part of core academic curriculum at medical schools and nurses academies. Among these, one project worthwhile mentioning is the one undertaken by Johanna Shapiro, from the Department of Family Medicine, University of Irvine California. Being aware of specifically addressing the frustration and cynicism felt by medical students at their home institution during the clinical years, she specifically designed the course "The Art of Doctoring" to empower the soft skill knowledge required in the institution of care (Shapiro et al. 2006).

The course goals aimed at helping students to develop self-reflective skills; improve awareness of and ability to modify personal attitudes and behaviours that compromise patient care; increase altruism, empathy and compassion toward patients; and sustain commitment to patient care, service and personal well-being. Five skill sets were identified: learning from role models and peers; on-site readings of works by medical student- and physician-authors; self- and other-observation; self-reflective techniques; and case-based problem-solving. The students also learned to use a coping algorithm towards challenging situations. Class discussions revealed three issues of recurring importance to students: loss of idealism, non-compliant patients, and indifferent, harsh or otherwise unpleasant attendings and residents. Quantitative and qualitative student evaluations overall indicated a generally favourable response to the course. Problems and barriers included attendance difficulties and variable levels of student engagement.

Another issue we believe to be relevant is, however, the educational material used by medical students and the style in which the information is provided throughout textbooks, scientific journals, and most communication formats used by the scientific community.

Contents rarely speak about "patients" and their lives, but rather they fragmentarily report about parts of the body, organs, diagnostic parameters, or imaging findings, to figures and statistics. The description of clinical cases is strictly focused on the patient as clinical objects, leaving no space to depicting the "case" as a person, with an authentic life, with thoughts, and with fears and expectations, in a social context. If medical cases in the textbooks and scientific publications were narrated in a more holistic way, simply by *making more human the already human being of the patients*, empathy could be easily fostered, since health-care providers would be touched by the proximity of the patients' narratives.

The skill of Cognitive Empathy brings light to care, based on an intelligent altruism, through which it is possible to move from the protocol, the procedure, the algorithm, to the narrative, the chronicle, the story of both patients and physicians in a mutual and constant intersubjectivity exchange. Affective Empathy is however a very important, since, if well acted, it is the common sharing of sorrow and bitterness by patient and carer: however, one risk is around, which is that even the carer loses his or her contact with the "reality" and might be overwhelmed by emotions. In 2001, Rita Charon teaches us "*Narrative considerations probe the* *intersubjective domains of human knowledge and activity, that is to say, those aspects of life that are enacted in the relation between two persons*" (Charon 2001). She had the smartest vision to move from the Objectivity of the Disease to the Subjectivity of the Illness, towards the definition of intersubjective relationship between carers and patients who are in a dynamic evolution. Intersubjectivity is a daughter of Empathy, and it is at the basis of narrative medicine.

Oliver Sacks: gratitude for a master, dead on Monday August 31, 2015

"Gratitude" is the title of the newsletter sent by Oliver Sacks on this August 14th, thanking his readers for all the letters, the stories, and the memories that supported him during his struggle "with" cancer (and not "against" cancer). He wanted to greet us, independently from our educational title, but all united by the passion in helping individuals and society to reach well-being, by the everyday devotion to encompass physical and psychic diversity, and by the desire to connect disciplines, knowledge, and arts—separated for many centuries because of political and organizational utilities.

Thanks, Doctor Sacks to have studied not only patients' "text", but also their context, the environment they live in, to have spread, without altering them, their narratives in the society, so that to put in contact everyone with the culture of illness, and to have always respected the extraordinary resources hidden in every patient.

Thanks, Doctor Sacks for having been somewhat an "antagonist" to the clinical and scientific opinion, so strict in its care and publication protocols, and to have narrated "odd" situations without preconceptions: you have studied hallucinations respecting them and not considering them as a form of madness; you have inserted music among therapeutic tools, after having observed that patients who could not talk could sing and that rhythm could give again a movement steadiness to people with Parkinson disease.

Your own life was for us a continuous surprise, up to the very last moment: studying, teaching, reading, writing, sharing ideas, and staying always curious until the very moment to leave us.

References

Bowman D, Greenhalgh, Tomlinson J. A narrative future for healthcare: conference report. http://centreformedicalhumanities.org/a-narrative-future-for-healthcare-conference-report-by-deborah-bowman-trisha-greenhalgh-and-jonathon-tomlinson/

Charon R (2001) Narrative medicine: a model for empathy, reflection, profession, and trust. AMA 286(15):1897–1902

Foucault M (1963) Naissance de la Clinique. Edition Quadrige, Grands Texts, Presse Universitaire de France

Hojat M, Vergare M, Maxwell K et al (2009) The devil is in the third year: a longitudinal study of erosion of empathy in medical school. Acad Med 84:1182–1191

Sacks O (1997) The Island of the Colorblind. Vintage Books, New York, NY

Sacks O (1985) The man who mistook his wife for a hat. Summit Books, New York, NY

Shapiro J, Rucker L, Robitshek J (2006) Teaching the art of doctoring: an innovative medical student elective. Med Teach 28(1):30–35

4

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

> *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 symbolisms 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).

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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 *other*s 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 didascalic 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 (Sonntag 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 Ceasar*].

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 and 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 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 be 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.

References

Aitken L, Rattray J, Hull A, Kenardy J et al (2013) The use of diaries in psychological recovery from intensive care. Crit Care 17:253

Bury M (2001) Illness narratives: fact or fiction? Sociol Health Illn 23(3):263–285

Caesar C. De Bello Gallico

Charon R (2006) Honoring the stories of illness. Oxford University Press, New York, NY

Charon R (2008) From inside out: interview with Rita Charon. www.mainehumanities.org

Dante A. De vulgari eloquentia, cen XIII. A special acknowledgment to Francesco Varanini for his interpretation of the Tower of Babel in Dante. http://www.bloom.it/vara68.htm

Dasgupta S, Charon R (2004) Personal illness narratives: using reflective writing to teach empathy. Acad Med 79(4):351–356

Frank A (1995) The wounded storyteller. The University of Chicago Press, Chicago

Good B (1994) Medicine, rationality and experience: an anthropological perspective. Cambridge University Press, Cambridge

Hurwitz B, Greenhalgh T (1999) Why study narrative? West J Med 170(6):367–369

Kalitzkus V, Matthiessen P (2009) Narrative-based medicine: potential, pitfalls, and practice. Perm J 13(1):80–86

Launer J (2006) New stories for old: narrative-based primary care in Great Britain. Fam Syst Health 24(3):336–344

Miselli V (2013) Differenti Storie di Diabete. Aliberti Editore, Reggio Emilia

Shapiro J (2011) Illness narratives; reliability, authenticity and the empathic witness. Med Humanit 37:68–72

Sonntag S (1978) Illness as metaphor, Newsweek, and reedited by Penguin Books in 2002 https://www.nlm.nih.gov/. . ./video/58_1_trans.html (2008)

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

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Narcissus' syndrome is documented in literature and is relatively known, much less is known about Echo's syndrome—perhaps because more difficult to perceive.

As we have mentioned above, the pivotal issue here is *coping*. Coping is defined as the conscious effort to solve personal and interpersonal problems, and seeking to master, minimize, or tolerate stress or conflict. However, as reported by Carvers, the effectiveness of coping does not only depend on the type of stressor—which can be the onset of a disease, the death of a beloved, or a job loss, but also on personality traits—but rather on other attitudes such as optimism, extraversion, openness to new experiences, agreeableness, and consciousness, which are positive markers to engage with coping (Carver and Connor-Smith 2010). Conversely neuroticism, with obsessive thought, is related to disengagement with coping; therefore, personality is a key factor for activating coping strategies against a stressor. In addition to personality, coping is equally influenced by a number of social factors involved in the phases of falling and being ill, starting from communication. If the mythological pair of Narcissus and Echo couldn't talk, couldn't share, couldn't express their personality, their subsequent behaviour defeated them, and they failed.

A study by Lord and Kumar highlighted the role of communication comparing outcomes between British patients of different ethnic backgrounds. The belonging to the British Asian Indian immigrant population in the UK rather than to the British White Population activated less coping resources, most likely attributable to poor communication and language barriers. This limited the potential for extraversion as well as sharing the burden of illness with the providers of care and with society at large, outside the Asian Indian community (Lord et al. 2013).

Among the other social factors influencing maladaptive coping, there are hopelessness, helplessness, fatalism, avoidance, and denial. At baseline, the use of these maladaptive strategies correlated with a higher incidence of depression in this study; however, the degree to which they actually favour coping is under debate. In fact, a Medline review has investigated a number of studies addressing these aspects and found the results impossible to generalize to all contexts because of the research method used. As Carvers evidenced, all studies have been investigated mainly through strict and quantitative questionnaires with closed items: in fact, results in his Brief Cope questionnaire may lead to completely different patterns from community to community (Valvano 2013). Narrative might be a useful tool to investigate any common patterns which would be missed by quantitative questionnaires or real differences that cannot fit into patterns.

In a study involving persons with multiple sclerosis, participants were administered the standard Brief Cope questionnaire and an open story form (no plot suggested) in which they were invited to narrate their illness, from the time of onset to the present, with a glance towards imagining the future. The brief Cope Questionnaire, based again on Carver's studies on coping, is composed by these variables:

Self-distraction, Active coping, Denial, Substance use, Use of emotional support, Use of instrumental support, Behavioral disengagement, Venting, Positive reframing, Planning, Humor, Acceptance, Religion, Self-blame.

The consistency between patients who gave positive reply to the Brief Test Coping Questionnaire and the stories in total or partial evolution showed a 49 % agreement; this result demonstrated that quantitative measurement tools tend to collect worse results as participants were extremely severe with themselves in judging their ability to cope; on the other hand, free narrative (for which today we still lack a system of measurement) provided different, more "optimistic" results as each participant was called to reflect on inner powers and treasures/resources. This stimulated participants to think in broader terms, setting their present and future with their disease in better perspective, something that cannot be achieved through the formal style and format used in questionnaires which do not allow people to express, and to get the awareness of the tremendous amount of inner resources.

When we speak of stressor events related to coping, we do not however limit to patients, as these also apply to the world of caregivers who have to face daily the disease in their environment: To date, the measurement of caregivers' stress is, from a sound scientific point of view, evaluated through standard questionnaires, such as the Caregiver Self Assessment Questionnaire (Epstein-Lubow et al. 2010). This 18-item self-administered survey was designed by the American Medical Association to provide physicians a measurement tool to assess the stress levels of those family caregivers who accompany chronically ill elderly patients to their medical visits. Caregivers are asked to respond either "Yes" or "No" to a series of statements, such as *"During the past week or so, I have felt completely overwhelmed"* or "*During the past week or so, I have felt strained between work and family responsibilities*". For one item, family caregivers are asked to rate their level of stress on a 1–10 basis. For another item, they are asked to rate their perception of their current health compared to their health a year before. A simple scoring system allows family caregivers to score their results and to determine whether or not they are highly stressed. The accompanying scoring sheet suggests that, in the case of high stress results, caregivers should consider seeing a doctor for a check-up and reach out for caregiver support services.

How Does All this Fit with Narrative Medicine?

Narrative medicine is a tool which explores the patient's everyday experience of living with illness, which can equally be applied to the other parties involved, such as their caregivers and their providers of care. Narrative medicine uses completely different tools from standardized questionnaires and aims to achieve a wider and deeper understanding of how the patients and their family think, feel, and act facing the illness. It sounds logical that whilst patients and caregivers write their stories, they refer to the level of stress (the stressor agent) and to the engagement or disengagement of coping strategies, that is to say, adaptive or maladaptive coping. This emerges clearly by reading patients' stories; a first very impressive classification could be envisioned in those stories in which a change occurs in thoughts, feelings, and actions and in those other ones in which no change occurs. There is a second cluster of stories, where no change occurs, mirroring lives stuck on themselves, and no further change transpires following the initial trauma of communication, when the disease occurs.

It is known (Greenhalgh and Hurwitz 1999) that the communication of a diagnosis of a severe condition immediately impairs the person's health/disease balance: the announcement of a disease, especially if chronic and perhaps fatal one, represents a source of sorrow and fear—as can be witnessed by most (85 %) of the collected stories. The trauma of this broken balance is clear from the written text in many different diseases, moving from acute disease to chronic conditions. On the other hand, semantic analyses reveal that the remaining 15 % of stories do not allow to detect any bitterness or sorrow. As time goes by, we assist the activation and metamorphisms of coping: people who initially wrote that they couldn't see or hope for any future later state that by means of activated thoughts, emotions, and behaviour they could start imagining again some kind of future, even in their impaired condition or severe disability. These autobiographic stories of living with illness are apparent proof of change towards a positive coping, showing extraversion, consciousness, openness, and agreeableness.

In a nationwide Italian study carried out by our group and presented at the 2014 European Haematology Association conference, we analysed both the results from the ***Self Assessment Caregiver Questionnaire*** and the narrative plots of stories of caregivers of patients affected by myelofibrosis, a chronic myeloproliferative neoplasm, which seriously impacts quality of life of patients and their families. The study considered **98 caregivers,** who were close family members (sons, daughters, siblings, 41 % male, 55 % female; mean age 55 years). Caregivers were administered the AMA *Caregiver self-assessment questionnaire* and then were asked to compose a piece of writing about their experience. Based on results of the structured questionnaire, 87 % of caregivers reported high levels of stress as result of the impact of the disease, with poor engagement coping. On the other hand, the narrative analysis carried out by means of a 2-step analysis.

A direct reading of the stories followed by analysis using semantic analytic software revealed that 53 % were actively coping with their situation. The observed success factors which emerged from the stories were responsibility, affection, and the possibility of relying on health professionals, friends, or colleagues. Therefore, what seems at first glance to represent a risky population, from the AMA "*Caregiver quantitative self assessment questionnaire*" of stress, in reality could be less since 60 % of caregivers showed, in the narratives, features of personality more prone to a better coping: extraversion first, with the capability to share with others sorrow and sadness also reinforced (Marini 2014).

Conscience—that sense of responsibility and duty related to rational and moral parts of the individual (*the Adult according to Transactional Analysis, and The Normative Parent according to Transactional Analysis, and for a better description see the Glossary*) is in fact an essential element. Analyses on the narratives evidence that people who don't share/open up to others, who keep complaining, or who live segregated in their rooms are at higher risk of disengagement to coping, whereas those showing an attitude towards change—starting from the initial existential position of sorrow and fear arising from diagnosis of their beloved one—are more capable of coping and we see their attitude led them to hope and later on face their experience with serenity and calm.

Relationship is another fundamental aspect, especially in chronic condition where they face long-term stress. In general, the best type of coping was achieved through open, intimate, and authentic relationships, in which arguments and discussion are accepted and allow for reconciliation.

Love, as a Fuel for Coping

From the narratives of caregivers, love was one of the most powerful coping factors: and love is only rarely mentioned in scientific literature on coping: it sounds very bizarre in a structured questionnaire to pose a question such as "*In a score from 1 to 10, how much do you love...?*" and no scientific community would validate such an item. But narratives give caregivers this opportunity to express themselves freely, writing down their deepest feelings, dropping the social mask which protects but also inhibits revealing inner emotions and thoughts. *Love* is a very dangerous term in scientific publication, as we have already seen analysing the style of writing of physicians, but what surprises us is that this taboo also extends to professionals of the "psyche": the word *love* is somehow forbidden and replaced with terms as interdependence, connection, bond, relationship. A set of neutral words which limits the driving force of the loving energy, which in the circumstance of facing a disease can help overcome hardship and develop positive coping attitude. In our society, as a matter of fact, only few completely *free* spaces allow to speak of love, and this is merely the world of entertainment, as we assist in movies, fictions, music, and novels, or in religions or in the New Age literature. Outside of those boundaries, this word appears too "scary" to be allowed as part of the care process in scientific literature.

Love associated with consciousness might be the energy which, following an initial absence of communication (the patient—the ill Narcissus too frightened by his/her illness to talk and to communicate, and *a caregiver*—the feeble Echo, who does not know what to say and how to behave), activates the interrupted relationship, and transforms an introverted system into an extraverted one in which people react and cope. And we could even dare to change the ending to the sad story of Narcissus and Echo: not fancying about a honeymoon, simply a healthier dialogue between them.

Ode to Joy: An die Freude, Towards Optimism

Another driving power to be considered, underlined by Carver, is the tendency to optimism. There is currently some debate around whether optimism is a good quality or a blind *naif* facing the "reality" of the world which might yield to underestimating the difficult challenges brought by life. Neuroscience is helping in providing explanations to where the optimistic and pessimistic brains are located in our brain. Tali Sharot on Nature publishes; *"humans expect positive events in the future even when there is no evidence to support such expectations. For example, people expect to live longer and be healthier than average, they underestimate their likelihood of getting a divorce, and overestimate their prospects for success on the job market. We examined how the brain generates this pervasive optimism bias. We report that this tendency was related specifically to enhanced activation in the amygdala and in the rostral anterior cingulate cortex when imagining positive future events relative to negative ones, suggesting a key role for areas involved in* *monitoring emotional salience in mediating the optimism bias. These are the same regions that show irregularities in depression, which has been related to pessimism. Across individuals, activity in the rostral anterior cingulate cortex was correlated with trait optimism… the brain may generate the tendency to engage in the projection of positive future events, suggesting that the effective integration and regulation of emotional and autobiographical information supports the projection of positive future events in healthy individuals, and is related to optimism."* (Sharot et al. 2007)

In another study she explains "*collectively we can grow pessimistic—about the direction of our country or the ability of our leaders to improve education and reduce crime. But private optimism, about our personal future, remains incredibly resilient. A survey conducted in 2007 found that while 70 % thought families in general were less successful than in their parents' day, 76 % of respondents were optimistic about the future of their own family. Overly positive assumptions can lead to disastrous miscalculations—make us less likely to get health check-up, apply sunscreen or open a savings account, and more likely to bet the farm on a bad investment. But the bias also protects and inspires us: it keeps us moving forward rather than to the nearest high-rise ledge. Without optimism, our ancestors might never have ventured far from their tribes and we might all be cave dwellers, still huddled together and dreaming of light and heat.* (Sharot 2012)

To make progress, we need to be able to imagine alternative realities—better ones—and we need to believe that we can achieve them. Such faith helps motivate us to pursue our goals. Optimists in general work longer hours and tend to earn more. … And although they are not less likely to divorce, they are more likely to remarry—an act that is, as Samuel Johnson wrote, the triumph of hope over experience. Even if that better future is often an illusion, optimism has clear benefits in the present. Hope keeps our minds at ease, lowers stress and improves physical health. Researchers studying heart-disease patients found that optimists were more likely than non-optimistic patients to take vitamins, eat low-fat diets and exercise, thereby reducing their overall coronary risk. A study of cancer patients revealed that pessimistic patients under 60 were more likely to die within eight months than non-pessimistic patients of the same initial health, status and age.

In fact, a growing body of scientific evidence points to the conclusion that optimism may be hardwired by evolution into the human brain. The science of optimism, once scorned as an intellectually suspect province of pep rallies and smiley faces, is opening a new window on the workings of human consciousness. What it shows could fuel a revolution in psychology, as the field comes to grips with accumulating evidence that our brains aren't just stamped by the past. They are constantly being shaped by the future." (Sharot 2012)

One of the best lessons I received in my life was the dialogue I had with the past president of the Italian Federation of persons with Paraplegia and Tetraplegia: we were at the very moment to embark in a socioeconomic study to evaluate the Burden of this Disability. He called me quite upset and commented "*what's this story about "burden"? We paraplegic people and tetraplegic people don't want to be a burden and don't feel like a burden to the society*". I explained that this the term was borrowed from economic language and was a standard way to define this type of economic study evaluating the cost of care. We eventually came to a conciliation point, writing in the title that we were going to evaluate both the burden and resources of people living with paraplegia and tetraplegia condition *"Needs, costs and resources of people with spinal cord injury"* . He was and still is a tremendously optimistic and joyfully person: but this is just one story of thousands narratives on optimistic inner resources to face a condition of disability and disease. There are so many sparks of optimism in patients' narratives, which somehow are not enough taken into account by a part of physicians who, undoubtedly, can see a more objective truth, but also trying to prevent any possible defensive medicine attack, are keen but to demolish these types of "narrative with happy ending" that patients tell to themselves.

It is very reductive to state—as I heard once during a narrative medicine congress—that Narrative Medicine is here to create an inner grief, sorrow. Of course, we might be compelled by facing our human *finitudo*, the limit, but Narrative Medicine cannot be only focused only on mourning. And this is why it is so important to focus also on the optimistic behaviour, beyond the quest of what an illness experience can teach us. This is why we focus so much attention on coping, stopping pitying oneself, getting out from a bended down Narcissus overwhelmed by the beauty of his reflected image, and a vanishing Echo who escapes to a hidden cave: positive attitudes evoke our hero which is guiding us through this journey in Narrative Medicine, Odysseus, owner of all the features that Carver pointed out for a successful coping: *openness*—curiosity about life mysteries, even if unpleasant, *optimism*—the trust to survive and to move on in front of the most desperate tragedies, *agreeableness*—the kindness with which he tried anyhow to be accepted by all the peoples and characters he met during his journey; the *consciousness*—the arousal attitude which rang an alarm in the Polyphemus cave, where kindness alone was not enough to fight a monster, and finally the *extraversion*—the capability to share his experience with the Other listeners, Phaecians first. Up to the final joy of his encounter with his beloved wife, Penelope.

The Probe of Narrative Medicine

Narrative medicine is able to probe deeper than any structured questionnaire of medicine; it highlights the complexity of the human being, in *darkful and lightful time*: despite objectively living in very stressful situations, people can still find unexpected resources for coping. Therefore, before labelling a person as being part of a "population at risk" through quantitative measurements, in a "yes" or "no" box, consider that they could be in *at risk* setting, yet qualitatively manifest through their writing surprising inner treasures.

Therefore, the warranted metamorphosis of unifying quantitative and qualitative research would bring energy and richness to both methods.

The mere action of each writing their own pattern of living with the disease is already shown to be therapeutic in itself (Baikie and Wilhelm 2005). If coping is achieved though arousal, through a better state of consciousness, an extraversion with an intimate diary, these are the possible reasons for allowing narrative medicine become by itself a medicament to better master the unbalanced situation of an illness.

References

Berne E (1972) What do you say after you say hello? New York Times Book

Carver C, Connor-Smith J (2010) Personality and coping. Annu Rev Psychol 61:679–704

Baikie K, Wilhelm K (2005) Emotional and physical health benefits of expressive writing. Br J Psychol. doi:10.1192/apt.11.5.338

Epstein-Lubow G, Gaudiano BA, Hinckley M et al (2010) Evidence for the validity of the American Medical Association’s Caregiver Self-Assessment Questionnaire as a screening measure for depression. J Am Geriatr Soc 58(2):387–388

Greenhalgh T, Hurwitz B (1999) Why study narratives? BMJ 318(7175):48–50

Lord K, Ibrahim K, Kumar S et al (2013) Are depressive symptoms more common among British South Asian patients compared with British White patients with cancer? A cross-sectional survey. BMJ Open 3

Marini MG (2014) EHA Learning Center. 14 Jun 2014; 54359

Sharot T (2012) The optimism bias by Tali Sharot: extract. www.theguardian.com/science/2012/Jan/01

Sharot T, Riccardi A, Raio C, Phelps E (2007) Neural mechanisms mediating optimism bias. Nature 450:102–105. doi:10.1038/nature06280

Valvano A, Stepleman L (2013) Critical synthesis package: brief COPE questionnaire. MedEdPORTAL. www.mededportal.org/publication/9453

6

The Muted Desire for Well-Being and the Abuse of the Word "Normality" in Medicine

"I thought I would do a search on the internet to be aware of what I had to face and I decided to live in the "normality" and seek solutions in other centers"
"I feel normal and independent"
"My body and my feelings are normal"
"Now I feel normal"
"The treatment has been very important to keep the discomfort away and keep a normal life"
"The disease is now almost gone. My body and my feelings are quite normal"
"I feel relatively well and lead a normal and peaceful life"
How did you feel in being able to tell his story? "normal"
"The moment they told me I had myelofibrosis I felt normal"
"I feel almost normal"
"I feel normal and able to continue to work"
"The paediatrician told me that my son was normal"
"I expect my daughter to have a normal life like all her peers"
"I guess a normal future"
"The positive aspect is that he has grown, he will never be a giant, if nothing else he is normal"
"I decided to love myself even if I was not normal at the eyes of the others"
(Testimonials written by patients and relatives in the narratives between years 2013–2014)

Beginning this Tour from the History of Normality and Diversity

Michael Foucault, a French philosopher—or more specifically a *historian of systems of thought*—is generally accepted as having been one of the most influential social theorist of the second half of the twentieth century. In his *Birth of the Clinic*, he provides a critical examination of the hospital environment, or better, of any form of hospitalization and institutionalization, and analyses the historical shift before and after the French revolution (Foucault 1963). Until then, hospices and care institutions were primarily run by ecclesiastical groups who were by tradition dedicated to curing the worldly and spiritual needs of men. Hospices were

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conceived as a place that provided care and shelter to the poor and emarginated members of society but, as recurring plagues afflicted the continent century over century, they gradually came to represent an isolation facility to host and isolate people with contagious disease, severe illness, or constituting a danger for the healthy part of the population.

Otherwise, disease and illness was commonly dealt within the household walls by the nurturing and protective cares of family members, as described by Foucault *"Le lieu de la maladie natural c'est le lieu de la vie: la famille*", in which, he continues, "*observer la nature aider lui sans faire violence*," remarking how hospitals were a place where "violence" according to Foucault's view could be perpetrated on the patient more or less subtly.

With the advent of the French revolution and the establishment of the State authority, health became a public issue and hospital places of scientific, economic, and social activity, administered by lay people. The State was appointed the responsibility of growing a *normal* population, with equal rights, duties, and income; thus, treatment in hospitals could no longer be limited to infected people, but needed to extend care to the underprivileged, the marginalized, those who did not have any family support (and that before the revolution had no other expectation than dying), whereas all others, in a functioning society, could have been treated at home by their family. This gave rise to debate around the most appropriate approach to treating people: whether at home in the familiar environment, or in hospitals or other residential facilities.

This is the epiphenomenon of the choice of the location of the possible best care, the dual opposition between home and hospitals. Taking a further step, the underlying phenomenology that Foucault emphasizes, launched by the intellectuals of the revolution, consists in the disappearance of the previous dyad, the split between the disease and the well-being, to include a new divisional paradigm, the *disease* versus the *normality*. The word *normality* replaces the word *well-being*. As if the *Egalitè*—equity—moral code could not move beyond the assumption of normality: the natural well-being will be considered in full blossom again, after the Humanistic period, only with the utopic health declaration by the World Health Organization in 1948, *"health is a state of complete physical, psychological and social well-being and not simply absence of the disease"*. Nevertheless, despite the campaign endorsed by the WHO to promote the culture of well-being, the term NORMAL is so rooted into today's vocabulary that we find it widely embedded in patient records, in medical texts, and in the professional language of doctors and health operator. In fact, whenever the patient is simply "okay"—not problematic, this situation is *rinsed away* with a general statement, NORMAL; "the patient is normal", "normal body", "normally tall", and "red blood cells have returned within a normal range" "normal blood pressure".

The unspoken greatness of Foucault is that of having identified this shift of this alignment, which once was much wider and at its maximum power during the period of Humanism, before the period of the Enlightenment and Positivism, towards a new dichotomy, that related to disease and normality, confining the word "well-being" on the back stage. In the Renaissance period, there were the physicians studying in the academy, but far away from patients' home (except for the wealthier classes) and healers who were self-taught people, probably based on a tacit knowledge of folk, which was often originating by the observation of the nature rhythms and cycles. No hospital beds, except the beds of highly contagious patients in quarantine (Cosmacini 1998). Strong was the loss of patient's identity in an impersonal place, without memory or an institution such as a hospital or care hospice institution admission, especially those for long-term hospitalization such as many of today's Retirement Residences, or Nursing Homes for the Elderly.

As a final remark, it is also true that it is only in the twentieth century that life span has expanded: families have changed and are continually changing their characteristics, making it historically difficult to transpose to here and now the humanistic concept of well-being and healing: the acute illnesses of those time are not the chronic, everlasting, diseases of today.

In the Middle of the Tour Around the Contemporary Concept of the Word Normality

The concept of Normality, as we know it today, had been approached by the liberal Adam Smith. He was an economist and philosopher who, in the XVIII century, wrote what is considered the "bible of capitalism", *The Wealth of Nations*, in which he details the first system of political economy. The patient can be treated as a good and might undergo a process of industrial production in a factory in health, where the hospital is the *locus* of a "normal health" production. As for moving from a single patient care to a multiple organized health-care delivery process, we might rely on Adam Smith and his famous example of the pin factory: *"One man draws out the wire, another straights it, a third cuts it, a fourth points it, a fifth grinds it at the top for receiving the head; to make the head requires two or three distinct operations; to put it on, is a peculiar business, to whiten the pins is another; it is even a trade by itself to put them into the paper; and the important business of making a pin is, in this manner, divided into about eighteen distinct operations, which, in some manufactories, are all performed by distinct hands, though in others the same man will sometimes perform two or three of them. I have seen a small manufactory of this kind where ten men only were employed, and where some of them consequently performed two or three distinct operations. But though they were very poor, and therefore but indifferently accommodated with the necessary machinery, they could, when they exerted themselves, make among them about twelve pounds of pins in a day. There are in a pound upwards of four thousand pins of a middling size. Those ten persons, therefore, could make among them upwards of forty-eight thousand pins in a day. Each person, therefore, making a tenth part of forty-eight thousand pins, might be considered as making four thousand eight hundred pins in a day. But if they had all wrought separately and independently, and without any of them having been educated to this peculiar business, they certainly could not each of them have made twenty, perhaps not one pin in a day; that is, certainly, not the two hundred and fortieth, perhaps not the* *four thousand eight hundredth part of what they are at present capable of performing, in consequence of a proper division and combination of their different operations" (Smith* 1776*).*

Foucault writes: The medicine of individual perception—the subjective—of the family and home care cannot find other support if not from a collectively controlled facility that covers the social environment in its whole. It is very similar to the factory paradigm of the liberal Adam Smith: no matter the different political ideology behind the French Revolution or the Industrial revolution, care shifts from the home to the health factory, where industrial production of health can be managed in a collective manner, entailing—however—the very risk that we are still facing today, that is, of the patient becoming the "factory-produced pin", standardized, in accordance with Smith's view. It is curious to observe how both Smith's liberal approach and the equalitarian one of Enlightenment converge towards the principle of standard, of *normality*. Indeed, the difference is no longer in the product "health" or "pin", but rather in the concept of *profit*: the revolutionary *non-profit* does not envision anyone becoming wealthy, quite differently from what envisioned by economic liberalism.

The ideals of *Liberté*, *Egalité*, *Fraternité*, the strong words that inspired the revolution, on the other hand eliminated any aspiration towards excellence, without any "well-standing" person, as if aspiring to an even distribution of "normality" across the entire population. The personalization of care in this context is an unacceptable fantasy, since it will cause again differences in the society. And to remind the cross-country contamination, we have to consider that the word *Standard*, which in the ancient time was meaning a flag to be inspired by, here, during the Industrial revolution becomes the term to identify the "MEAN", the "AVERAGE", the "NORMA".

The Progression of the Explanation on Normality in Disease and Wellbeing

Interestingly, the concept of ***normality*** **and** ***well-being*** is a recurrent theme in patient narratives, especially in the stories describing the unfolding of events and of their reactions, bearing the weight of personal conditions of loss of health, or disability, and their coping with disease. Whenever patients tell they perceive a slight improvement, or describe their interpersonal relationships at home or at work, they mostly opt for the term "*normal*"—or, with a hint of judgement, "*adequate*"—to describe their status. Even in conditions in which the disease is under control, they state they feel *normal*, that their relationships with family are *normal*, and that on the workplace everything is *normal*. Only a minority show a true positive and optimistic coping engagement "I feel *good*, at *ease*, calm; I'm *glad*, now it is *perfect*".

From an etymological point of view, it's noteworthy to remind where the term *normal* derives from: in Latin *norma*, which translates as the *rule*, the *law*, was used by the Romans to refer to *norma* the hand square used to measure *right* angles, as well as the tool for farm surveying. In turn also the adjective *right* takes on the meaning of *appropriate*, as well as walking down the *right* path, while the left side led to dispersion.

The Follow-up to the Contemporary View of the Word Normality, up to the Denial of Feelings

The fact that *normal* has become a *shield* word is apparent: behind the term *normal* lays a mixed concept of well-being, discomfort, lack of courage, peacefulness; yet it also can be read according to an anthropological interpretation, perhaps the legacy of revolutionary contagion of the principles of equality: you must statistically fit within the Gaussian wave (Gauss 1801) keeping on the mask required for social acceptance, without flaunting emotions, especially in places of discomfort, such as hospitals and care institutions.

In today's culture, the spontaneous expression of feelings is very often despised and considered as inappropriate in most of the institutional, professional, company, academic, working, and school environments. Feelings and emotions difficulty find social acceptance, if not limitedly as poetic licence in movies, figurative arts, and performances. Society today seems to lack the ability of dealing with emotions or rather—to be more accurate—it seems to possess the ability of considering and embracing mainly positive emotions, but tries to escape and to hide any pain and sorrow. In the specific case of sickness, when the disease breaks down the balance between health and illness, emotions inevitably ensue and people must suddenly deal with the fear and pain of losing a healthy part of them (which till then was reactive and alive) but yet do not have the tools to do so.

Our contemporary society still has to go a long way to appreciate, accept, and study emotional grammar. Freud wrote in "Civilization and its Discontents": *freedom is not a benefit of culture: it was greater before the advent of culture, and has been restricted by the evolution of civilization*. And this relates to the freedom of expressing desires and emotions—a trend which has continued to be throughout the ages, up to the present time, in which we see a steady contraction of the space of unrestricted drive and of self-expression (Freud 1930).

In his historical review of the Birth of Clinic, Foucault analyses the clinical movements between the Eighteenth and Nineteenth centuries of the clinic's old age and studied the rebirth of the new clinical science that labels diseases into an "alphabetical structure". According to his interpretation, the more and more prevailing equation over the last centuries: language is composed of letters assembled into words that take on a specific meaning and connotation in communication as the body becomes a collector of letters—those signs and symptoms which we must encode in a grammar in order to understand them. This requires having a place to collect such words—a library—which is represented by the hospital: the only space for the collection of patients, where doctors can learn from books made of flesh as; in other words, the *books* symbolize the bodies of the patients' bodies (either living or deceased).

And under this undifferentiated reading, from body to body, which does not take into account pathos and psyche, as forcibly driving the physician to classify that what can be seen, the patient will start to restrict any statements of desire, instinct, and putting it in Freud’s terms, will be deprived of his or her desires, and will say that once he is cured, he or she will return normal or stabilized, and no longer be the bearer of the anomalies that build the medical grammar, the rationale by which the patient was hospitalized. The person will be a pin within normal range, not a production scrap. Farewell individual perception, subjectivity, and hence diversity. Up to the risk of farewell respect for the individual. Here is the discomfort of civilization for which Freud exposed himself, along with Jung and the social mask: in order to be socially accepted one must appear *normal*. And this fragmentation of identity, to fit into the Gaussian curve, is also fostered by the hyper-segmentation of medical knowledge into specialties, and then subspecialties, with the consequence of losing the global view of the patient. A contemporary “soulless” laboratory medicine, which deals with sub-receptors, genetic codes, and invisible parts of the body, had replaced the bed side medicine, creating a new medical cosmology. In this paradigm, *normal* no longer refers to the body, but to the microcell, the receptor activity, the coding genes. Disembodied hospitals and disembodied care settings where laboratory biotechnology and imaging primarily establish the law: it is the Disappearance of a Sick Man (Jewson 1976). It makes sense that “micro reality” mirrors “macro reality”, so, in building an equation, we obtain that receptors mirror body signs and symptoms, but these unavoidable fragmentation of specialties, this dissection, not only lead far always from the “wholeness of the body” but also from the “wholeness of our complex human living being”. Do our receptors feel emotions? Or simply they have to be normal?

As a metaphor to this, I shall recall a scene from a movie of an Italian director, Giorgio Diritti, “*someday you should go*” (You should go, 1 day). The movie tells the story of a young lady, Augusta, who is grieving the loss of an unborn son and her late father, and who undertakes an interior journey leaving Europe and embracing a new life as a missionary in the favelas of Manau, in Brazil. One day, she asks a priest what he thinks science is. To her question he replies comparing scientific knowledge to a dissected flower. First petals are torn out, then sepals, then styles, and the pistil at the end. What is left of the wholeness of the flower? Of its beauty? Nothing. With this anatomic and rational dissection, the risk of missing the global view is very high and with dangerous consequence for striving towards a “beautiful knowledge”. Adriana will get herself into normalcy, first as an activist in the favelas, but then she will go for her well-being alone, on a sandy beach along the river, waiting still for something unknown to come.

The End, the Human Desire of Being Normal

But normalcy is not only “evil”, it can indeed be a target to pursue, a deficit to fill, a conquer; one word with many meanings: *everything is fine; as ordinary*; *within the daily regimen*; *nature is flowing according to its rules*; *no extraordinary event scheduled*.

Narrative medicine that has the potential to serve as a sounding board “*of the virtues and disasters of mankind*” is likely to flatten out into a mileu of half shades, deprived of its bold hues. This is what occurs as we see reading for example sentences of patients with multiple sclerosis, or lost weight after a gastric bypass, suffering from a malignant disease of the blood, stating: “now my life is *normal*”. It’s worth mentioning that the use of this term that replaces another, perhaps more ambitious one, such as “good”, which connotes a positive feature, is the daughter of a continuous process of standardization. Out of 210 narratives of patients suffering from a rare disease, the words “normal,” “average”, “normality”, “adequate”, and “appropriate” appear in 66 % of the stories collected—which we call *an evidence-based linguistic consistency* [Marini 2014].

The desire of being “normal” is a very wishful thinking for people who experience a condition of disability, and especially for parents of disabled children who are constantly fighting every day for the rights so that their kids are regarded with the same equal rights of the people “who live” under the Gaussian curve of normality. Narrative medicine allows a better personalization of care, moving a step further from equality, in the attempt to understand and provide an answer, giving to the other what might be beneficial, with respect to his/her force, fragility, age, family, job, resources. The journey or quest undertaken by patients through narration helps them deal with the issue of normalcy: in some cases, this exercise makes them feel they fall within normalcy; in other cases, patient may feel he/she falls out of normalcy and is drawn by sad and sorrow emotions, whereas others yet are even proud to be different from normality.

Therefore, it depends also on the Normality code encrypted in the society, and, considering illness, if the “sickness” concept of stigma is abused. According to the “provocative” urbandictionary.com, *the word NORMAL is a word made up by this corrupt society so they could single out and attack those who are different*. [Urbandictionary]. Even if this definition is far more annoying than our starting point of view, in restricted and closed societies living outside from Normality is to live in a Sickness “cloud”, embittered with discrimination towards any deviation from social and natural rules.

To conclude though I wish to share a story that stood out the Gaussian curve: a young patient cured from Basedow’s disease writing this testimony: “now my life is perfect”.

Beyond the Lines, a New Frontier to Define the Concept of Normality

The divide between Nature and Culture is a concept that has mainly developed throughout the previous century as claimed by Claude Levi-Strauss, the social anthropologist, who considerably influenced the development of social and medical anthropology, in the footpath of earlier thinkers in more ancient times. The normality paradigm is to be put in the proper context, to evaluate whether it is referred to a biological, natural frame, of a “body properly functioning” or if Normality considers social relationship, the world, and the perception of oneself with the others of a community. However, the Greek philosopher Aristotle stated: *“Mankind is by nature a social animal; an individual who is unsocial naturally and not accidentally is either beneath our notice or more than human. Society is something that precedes the individual. Anyone who either cannot lead the common life or is so self-sufficient as not to need to, and therefore does not partake of society, is either a beast or a god.”* [Aristotle] This division between biological and social being is so thin, almost intangible, that it is more appropriate to speak about an *ecosystem* in which there is a mutual exchange between biology and society is constantly there. And, if we take into account a mutual society, every citizen is a carer and is responsible for the well-being of the others—even in the most desperate conditions as in severe rare diseases, enduring chronic sickness, and terminally ill conditions.

In the attempt of getting out from “normalcy” schemes, and encourage healthcare providers and patients, to express themselves freely with creativity, emotions, and thoughts, we engaged participants in an open frame activity. Our only instruction was to develop an assigned title. “Imagine an ideal location for caring”. The respondents came up with many creative proposals, some belonging to science fiction, with “happiness” microchips, or the disease which lasted just enough for the person to provide an experience to elaborate. The most interesting I’d like to share here are three examples focused on the development of well-being despite the abnormality of the disease: “the smiling care”—a sort of Patch Adams style of curing, “the sharing of burden of sorrow”—the not leaving the ill person alone with the burden of the disease, and the “harmonic place of care”—in which harmony is a proper balance between Nature and Culture, despite biological values being very far away from Normality threshold.

References

Aristotle. Politics. 384–322 BC

Cosmacini G (1998) Tra medicina e ciarlataneria: cure maschere e ciarle. Edizioni Cortina, Milano

Foucault M (1963) Naissance de la clinique, 8th edn. Grands Texts, Quadriges 2009

Freud S (1930) Das Unbehangen in der Kultur. Internationaler Psychoanaytisher Verlag, Wien
Gauss CF (1801) Disquisitiones Arithmeticae, Lipsiae
Jewson ND (1976) The disappearance of the sick-man from medical cosmology: 1770–1870. Sociology 10:225
Marini MG (2014) EHA Learning Center. 14 Jun 2014; 54359
Smith A (1776) The wealth of nations
www.urbandictionary.com/define.php?term=normal

Bridging the Gap Between Personalization of Care and Research

7

In our contemporary scientific world, where disease and pathways of care are primarily driven by numbers and statistics on the likelihood of disease and success of therapies, a shortsighted view about narrative medicine is that this "cultural wave" can represent the antidote to the use and abuse of the metric and predictive values of clinical trials and clinical practice. At the end of this chapter, we will discover how Narrative Medicine, despite the differing philosophical issues distinguishing it from EBM, can itself produce "metrics" and numbers—tools that are valid for a fast decision-making. Retracing the genesis of narrative medicine, it is true that at its origin it has placed an emphasis on space and time for greater personalization of care. Narrative medicine has set the basic premises that individuals are profoundly different and patients live, feel, think, and act with rhythms and values in similar and dissimilar ways, especially when confronted with complex issues such as those related to illness and the loss of health and wellness (see Chap. 1) (Greenhalgh and Hurwitz 1999).

The innovation behind narrative medicine is thus having shifted the focus from the abstraction of *objective* numbers to the richness of information springing from contents of *subjective* written testimonies (personal considerations, interpretations, descriptions, insight, re-elaboration of events, contextualization of disease) and resources (health and Quality of Life assessment questionnaires, diaries, surveys, etc.) the shift from quantitative analysis to qualitative analysis.

Before this revolutionary concept, loose commentary and subjective testimonies were considered to bring little or no value to scientific research, and were often disregarded. Even in the case of validated questionnaires foreseeing open questions, replies have never been taken much into consideration as a resource for finding replies to research questions. If, on one hand, this may be attributed to a scarce lack of interest on behalf of the scientific community, on the other hand, this should also be partially attributed to the lack of adequate tools to handle and analyse descriptive contents.

Up until a few years ago, technology was unable to support the analysis of narrated texts and limited its scope to analysis and production of numerical results

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such as means, standard deviations, and inferences, and likewise for the analyses of questionnaires and surveys administered to patients and clinicians. Today, the advances in linguistics and informatics have introduced a number of instruments for analysing texts, such as the semantic mapping software that analyses words, synonyms, expressions, and metaphors. Semantic software allows us to organize and analyse non-numerical or unstructured data to obtain metrics. It allows users to classify, sort, and arrange information; examine relationships within the data; and combine analysis with linking, shaping, searching, and modelling. The researchers or analyst can test theories on any narrative text, written or filmed, to identify trends and cross-examine information in a multitude of ways using its search engine and query functions. For instance, the NVIVO (*Non-numerical Unstructured Data Indexing, Searching and Theorizing Vivo*) software accommodates a wide range of research methods, including network and organizational analysis, action or evidence-based research, discourse analysis, grounded theory, conversation analysis, ethnography, literature reviews, phenomenology, mixed methods research, and the framework methodology (National Centre for Social Research 2011). In fact, in viewing Sackett's EBM pyramid, we can see that the physicians' notes occupy the lowest level in the EBM pyramid, as well as the patients' diaries (so what can we think about consideration given to patients' diaries?) (Sackett et al. 2000). Quality, according to Sackett's point of view, moves from the bottom with patients' and physicians' opinion, to the middle with randomized clinical trial, up to the top of the pyramid with systematic reviews. The ticks on a questionnaire of quality of life survey are more reliable, but still deemed to be less objective than the clinical judgement of the physician, according to current EBM rules.

This aspect is being increasingly debated by patients and associations, and carers who have opposed this professional view of the science of care, trying to express themselves freely through their stories, but also physicians and carers. The disappearance of the "comment" sections from questionnaires, which might be considered as golden sections for us researchers of narrative medicine to include also a developing approach, paradoxically has removed and muted the voice of people who are objectively passing through the phases of illness and health. And this is one of the possible reasons why, due to this hierarchy imposed of what is worth to consider or what is not, Narrative Medicine had encompassed somehow the "voice of something odd and bizarre (see Chap. 1), linked only to single patient's perception and physicians' opinion.

Hopefully, as knowledge improves through dialectic processes, new theories are appearing. A new era of research is taking shape, looking for a balance between the uniqueness of individual experience and the occurrence of common phenomena in different patients, not only in a "life" but in many "lives": *the narrative evidence-based medicine* (Charon et al. 2008). Narrative medicine is moving from a singular vision, or one of few cases, towards a perspective of plurality defined within "galaxies of individuals", each with its own asymmetry but governed by a joint force of universal gravitation.

Narrative medicine, originally "centred on the individual", proved able to embrace a more universal approach without falling into easy generalizations by simply looking, in every disease condition, at the story of a patient, the next patient, and the next again to observe the "occurrences" of common factors and similarities which define us when confronted with the cyclone of a disease. In technical terms, this is known as the *recursion phenomenon*, a mathematical theory which is applied in social sciences to help read events occurring throughout time (Odifreddi 1989). In our setting, some examples are how often physicians are able to alleviate the anxiety of the patients when communicating a diagnosis; how and when does solidarity between family members develop in the unfolding of a chronic disease; when and how often discrimination in the workplace begins; and how much effort goes into managing a chronic disabling illness. These patterns can be revealed through this analysis in the stories of illness.

What more does the narrative offer than grouping a series of "yes" or "no" questions? The narrative explores root causes, analysing and providing answers that are not deducible from clinical trials. It unveils the person's deepest needs, the patient's identity reshaped by a change in thinking, and actions in "coexistence" with a disease. The stories provide a canvas on which to interpret the dynamic or static nature of the situation.

Therefore, it can be considered as a reconciliation between the population statistics and an individual's uniqueness. Epidemiology allows us to calculate the statistical occurrence of a "sample" of the population—in more poetic terms a "representative galaxy"—of sick people to be able to collect the written voices of memories, thoughts, emotions, hopes, and perceptions of the events in the care environment, family, workplace, with friends and others. It overcomes the single witness, switching to a collective vision. However, with our narrative medicine, the sample calculation is quantified epidemiologically and is representative of the prevalence or incidence of a specific disease taking the place of the classical statistical inference of the clinical trials developed from the formulation of a hypothesis to the possible evolution of the patients according to therapeutic interventions adopted.

To date, this type of application is still relatively unknown, yet it offers great potential; there is much to do to persuade the clinical study profession of the effectiveness of soundings capacity of the narrative in its plural version, but, on the other hand, there is also a challenge to persuade the psychosocial science profession to marry the narrative dimension to the possibility of using numbers to count how many stories are necessary to reach a resonating pattern.

With narrative, we are in the purity of observation realm without prejudice and assumptions, and the free is the story, not influenced by too rigid, closed spaces, numbers, words tracks, the greater the absence of interference that the study has. At a first glance, it may appear one is blindly relying on the uncertainty principle, theories of complexity, ambiguity given by presence of diametrically opposing results, which may emerge from the same story. Progressing with the interpretation of the text—or better texts—we realize that there are common denominators of "universality" when the disease bursts, advances, evolves, and regresses.

Nowadays, even the framework within which we view disease is being reshaped. During his study of quantum theory, Albert Einstein was faced with contradictory concepts of light particle and light wave but was prepared to accept both pictures of reality to explain the phenomena of light. It depends on the context, electrons can be discrete and move through quantum leap, as individual, or can move in a continuum wave according to Schroedinger's equation, moving to a more universal and predictive approach: so, the population living with an illness can be considered as a continuum or as a discrete sum of individuals. Meanwhile, as most of scientific community was still debating whether "matter" was discrete or continuum, Dirac—an English physicist and mathematician of the last century—had a bright intuition, leaving aside the old and never-ending struggle between continuum and particular: "*to matter there is always an antimatter field present in our cosmos*: *to each electron there is a corresponding positron, an energetic field that fills the vacuum"* (*Farmelo* 2009). Dirac's equation is very difficult and is beyond the scope of this book on narrative medicine to explain it in detail; however, it may orient us to leave the rough dichotomy between a singular story and multiple narratives. Now let's see in a concrete case how technology can help the plurality of NBM.

The Case of the CRESCERE Project

In 2013, ISTUD was called to collaborate with endocrinologist paediatric centres over Italy in a project of narrative medicine in the field of growth Hormone deficit. The CRESCERE project (which in Italian literally means "growing up": *Creating through stories of experiences of care for Growth Hormone deficiency the empowerment toward the excellence, (Marini et al.* 2015*))* aimed to understand and depict the first-hand experience of children and teenagers' dealing with Growth Hormone Deficiency (GHD) as well as the experience of other stakeholders involved.

For in its kind the project adopted a narrative-based approach to the issues involved in the path patients and caregivers (parents, siblings and the health care providers who composed the clinical teams of participating expert Centres) undertake on the way towards treatment. Overall, the project collected 80 stories from young patients with GHD, 80 narratives from parents, and 36 stories from their care providers. Narratives were then analysed to gain insight into the perceptions regarding the management and organization of pathways of care, the true impact this condition has on family, social, and school life, and ultimately identify needs and expectations from all parties, and useful recommendations to improve the care services.

The narrative plot was outlined so that participants would distinguish the three main phases of the illness (see Chap. 4): "falling ill-the past", "being ill-the present", and "getting better-the future". In order to properly address communication and usability issues of different parties involved, participating patients were divided into different age groups (children with GHD, 8–12 years old, adolescents with GHD, 13–17 years old, patients' parents), whereas patients' siblings and the team of caregivers were included in two other separate groups.

The plot foreseen for children and adolescents with Growth Hormone (GH) deficiency stimulated them to write about their family, school, and social life, to describe living with medical visits and therapy, and their expectations for the future.

The plot addressed to parents explored the entire pathway, from first signals, through diagnosis, until the impact of this condition on the whole family's life and the coping strategies. Furthermore, parents were invited to write about their feelings, needs, fears, and expectations for the future.

The drafts for care providers aimed to explore their motivations, living the relationships and communication with patients and families, and their considerations regarding the organization and management of pathways.

Health-care professionals were also given an optional possibility to experiment the parallel chart in which they write the story of care on a specific patient, their relationship between him/her and the family,and their feelings and opinions about the compliance and the general management of that pathway. Diaries were analysed separately from the semi-structured stories, as their narrative free form was not considered comparable with the semi-structured format. The plots were administered to patients on paper copy through the Centres.

Analysis of Stories

Narratives were completely anonymous and the stories collected were analysed through an integrated approach between quantitative and qualitative research, which foresees a qualitative interpretation of stories, along with the Nvivo software. It is shown that a combination of both thought and computer-assisted methods is likely to achieve the best results; the quality, rigour, and trustworthiness of the research are enhanced (Kelle and Laurie 1995). Adults' stories, both from parents and providers of care, were also classified on the basis of the style of narration, which combines content with used language and length of sentences. Three clusters were identified: "disease-centred" stories, "illness-centred" stories, "between disease and illness-centred" stories.

A total of 182 stories were collected throughout the project: 32 from children, 35 from adolescents, 72 from parents, 7 from siblings, 19 from providers of care, and 17 from parallel charts.

Findings from Children and Adolescents with GH Deficiency

The testimonies collected from young patients were written by males in 56 % of cases and by teenagers in 60 %. No significant gender effects were reported regarding style and content of stories, neither in their living with the GHD, nor towards clinical visits and therapy. Analysis of narratives from children and adolescents highlighted the terms "good" (38 % of children, 42 % of adolescents) or "very good" (26 % of children, 30 % of adolescents) in reference to their social and school life, without revealing any social stigma from their peers. They mainly indicated that their height had not represented a particular social problem because they began growing up: "*After having started therapy I feel very good with my friends, and I live my life like everyone*"; "*Now I feel good with my classmates because I am growing up*". From narratives, discriminations were mentioned in a few cases (9 % from both youth and children):

"*I don't feel very comfortable with my schoolmates and friends, because they often tease me, picking on the difference between me and them*".

The moment of communication of the diagnosis and therapy did not represent a traumatic phase, and 26 % of adolescents remembered to have been followed to this phase by their Centres of care and families. Despite the described general appreciation for health-care professionals, and the common satisfaction regarding the results of growth through GH injections (55 % of children, 47 % of adolescents), differences between the two groups of age emerged with reference to pathway and therapy. 40 % of children referred to living the cure with tranquillity and in some cases enthusiasm. They wrote to appreciate medical visits, describing them as calm with also funny moments: "*I enjoy the medical visits, where I meet the doctor and nice nurses, they make me smile*"; "*I like coming here, everybody is good and nice!*" Adolescents reported a different and more annoyed mood, and 39 % of them defined the follow-up as long and boring, revealing impatience "*Medical visits here at the Centre are boring, especially during the day hospital*"; "*Medical visits are very boring but I have to understand that they are useful to me*"; "*I have been coming to this Center for 10 years. I cannot say that medical visits delight me*". There is also a different way of living therapy. Children mainly reported to suffer the pain of injection (54 %), while adolescents were more annoyed by the daily task (50 %). Children were shown to be willing to face the pain of the needle in order to "conquer" centimetres, their most important objective and reason for satisfaction, since they felt already rewarded for their sacrifice: "*Therapy makes me grow up. I am already taller than my desk mate*"; "*Therapy is a little bit painful, but it makes me stronger*". On the other hand, adolescents described feelings of impatience and boredom towards the long period of sacrifice: "*I hope to finish therapy as soon as possible. I think that all this is positive for my growth but at the same time it is boring*"; "*I think therapy is helping me, but in the evening I become discouraged*"¸ "*It is annoying doing therapy every evening*"; "*It is a constant task*"; "*I'd like a weekly or better monthly drug, or at least to have a free day from therapy*".

Finally, the future expectations were different from children and adolescents, as this latter group expressed an overview of the future in a more explicit way linked to their growth and their desire to become taller (32 % of adolescents): "*For the future I imagine to be tall enough and to not be different from other people anymore*"; "*In the future I think I will be tall, powerful, proud of myself*".

Findings from Parents of Children and Adolescents

Parents' narrations offered great detail on the story of pathway, from the beginning, when the first signals and suspicions appeared, through the development of the phases during the years of therapy. Parents were represented by mothers in 66 % of cases and fathers in 34 %, without revealing remarkable differences in their living and telling the experience of care. Stories did not show differences depending on their sons/daughters' gender. Fifty-four per cent of parents had noticed the slowing down of their children's growth process on their own, usually during the first years of primary school, comparing them with their schoolmates and friends. But there was also a proportion of parents (11 %) who reported a delay of the medical intervention due to the paediatricians' underestimation of the problem: "*I remarked problems in my son's growth immediately, but my paediatrician told me that it was normal and I had to keep calm*". 40 % of parents told how they spent the period of waiting for diagnosis with anxiety and concern about the risk of an early hospitalization: "*Waiting for the diagnosis caused me anxiety, and I was scared about beginning treatment*"; "*I was worried, suspicious about so many medical exams for diagnosis (sample taking, cardiology tests, kidney scan, endocrinologic visit, day hospital...)*".

With reference to therapy, contrasting feelings were described. On one side, 29 % of parents reported feeling happy and relieved by the existence of a treatment, but 30 % of them were worried and not completely convinced about therapy. Eventually, since they deemed this option was the only solution, they decided to follow the therapeutic project, but in their deepest thoughts they revealed being scared about the possible implications of hormonal administration: "*When I knew about the existence of a care, it flared a bit of hope, even if I was not so confident*"; "*Regarding treatment I am happy but at the same time hesitant*"; "*I have only some doubts regarding therapy*".

In most stories, the hormonal injection was described as an organizational issue, due daily management of drug storage (33 %), and as a cause of pain to their children (21 %). But 50 % of parents were satisfied—"my son/daughter is growing well"—and 13 % of them were greatly satisfied—"my son/daughter is growing very well"—after the first results in their children's growth. "Well" and "very well" were one of the most common words used in the stories, to indicate the quality of services and the general satisfaction with therapy.

Furthermore, the word "nothing" was the most frequently used when families talked about changes in their lives. The GHD condition and therapy, even if a daily task, did not cause a strong impact, and 20 % of parents wrote about an increase in their sons/daughters' self-confidence. Growth was their main aim and they were witnesses to the first successful outcomes; the value of the pathway was underlined in many stories: "*Nobody makes fun of my son at school anymore*"; "*My son is more self-confident*"; "*He's growing up like his peers*".

Despite this general positive attitude towards the pathway, when asked about their worries, the issue of the consequences of therapy came out again: 67 % of parents revealed being worried about possible side effects; "*I am worried about the possibility of developing a tumour*"; "*I wish therapy does not have future contraindications*"; "*I am wondering if my daughter will be able to have a child*"; "*I feel worried when I read the possible contraindications*".

The doubts expressed revealed a general confusion and lack of knowledge on the physical consequences of the hormonal therapy. This means that, although families were followed and empowered through the diagnosis and the beginning of the treatment, and despite their satisfaction with the results and living with the daily injections without particular impacts, their deepest thoughts had persistent worries about side effects, sometimes questioning their original decision. They did not feel reassured enough about the secondary effects of treatment that might arise in the future. They were confident in the result of the growth, but were wondering whether there would be a price to pay for these results. Concerning the style of narration, 48 % of stories were classified as "illness-centred", since narrations contained emotional considerations on the familiar and social impact caused by the pathway. 25 % of stories were clustered into the "disease-centred" category, as the whole narration was written with technical language, using scientific words and expressions, and texts were limited to a description of the clinical pathway, without opening up to more personal considerations. Finally, 27 % of stories were considered "between disease and illness-centred", as texts alternated technical elements with more narrative parts in which reflections and feelings were sketched.

Findings from Health-Care Professional GHD Experts

This last group was composed by paediatrician endocrinologists, chief physicians, postgraduate students, nurses, and psychotherapists. Professional experts revealed having a strong motivation, even those who had been working for over 20 years. Interest in paediatric growth problems (41 %) and passion (35 %) were the reasons that stimulated their daily job, as highlighted also by the expressed metaphors: "*I would describe my job through the figure of a gardener who cares for his little plants helping them to grow up*"; "*I feel like an athlete who unfailingly runs to improve his performance*". From the narrations, they reported carrying out the medical visits for GHD in a constructive way, trying to transmit tranquillity (39 %), availability (31 %), and empathy (27 %) to children and families, from the beginning of care. The communication of diagnosis was made with attention to the language used (52 %) and focusing on the solution given for treatment (31 %), in order to reassure families.

Regarding therapy, their main concern was about its daily administration and correct management (38 %), the length of pathway (23 %), the young patients' reaction (16 %), and the family's level of compliance (10 %), investigated in every follow-up. 53 % of them reported being in difficulty when the failure of therapy caused disappointment of expectations. Relationships with young patients in 44 % of stories were defined as an important condition to support them in the care. Particular attention was given to the relationship with children (35 %), considered the weakest subjects of the pathway: "*I care in particular about children's expressions, what they don't say, their fears and hopes*"; "*I try to play with my little patients*"; "*I try to make children comfortable and place them at the centre of my attention*".

However, aside from these testimonies revealing their attention towards supporting children at the beginning of the treatment, only few references mentioned adolescents, revealing a possible underestimation of care for their compliance and the relationship with them. One fundamental aspect involved in providing support to children during treatment revealed to be the relationships built with the patients' families, as indicated by 42 % of experts. Nevertheless, as compared to their patients' stories, the experts' narrations hardly ever mentioned concerns of side effects of therapy. Relationships with colleagues were considered important as well, a potential positive asset but still to be empowered by improving the exchange of knowledge and collaboration among the multidisciplinary team and they were positive towards the future (44 %).

In the case of care providers, the style of narration used was split between 39 % of "illness-centred stories", in which emotional considerations appeared, 33 % of "disease-centred stories" written with a technical language, as in a clinical chart, and 28 % of alternations between narration and professional descriptions. Although the illness-centred stories prevailed, compared to families' stories, there was an increase in the disease-centred narrations.

Physicians' Parallel Charts

From parallel charts, the most important point of attention was the monitoring of both patients' and parents' compliance (41 %), followed by the interest in social and school children's lives (24 %) and family dynamics (21 %). These stories evidenced a certain level of autonomy among adolescents (14 %), although most considered still depended on their parents to manage therapy (69 %).

Discussion and Conclusions

Through their recurring words and expressions, the 182 collected stories can be joined to compose a "story of stories", suggesting a wealth of recommendations on new strategies for pathways, communication, relationships, and organization of this condition. Analogies among the three points of view were more common than dissimilarities. Indeed, pathways of care were considered as effective from all the subjects, from both the clinical and organizational aspect.

The narrations were mainly stories of healing, although pathways were represented as long and demanding. Using Arthur Frank's Illness Narrative classification (see Chap. 2), the collection gathered stories of "restitution", in which the plot involves returning to one's previous state of health: after the suffering and the sacrifice, the victory comes and the treatment "repairs" the body. In this specific case, the "achievement" of an acceptable growth leads to well-being and social inclusion.

Despite these common elements, different ways of living the care emerged with reference to therapy. Teenagers underlined their impatience, up to the point of intolerance, towards the daily injection; they followed the pathway for years and, even if satisfied with their growth and still willing to become taller, showed signals of rebellion. This is probably connected to their age, but it is also indicative of the underestimation of the importance of their empowerment and active involvement in the pathway. Through their rebellion, they asked for another kind of relationship with parents and professionals, more focused on an autonomous role in the care. Empowering adolescents to be the main ones responsible for their care probably can help them to find the strength and the willpower to go on with therapy, avoiding the risk of discontinuity or withdrawal. As referred by providers of care, a lot of attention was paid to children, especially at the beginning of treatment, to follow them through this particularly difficult and decisive phase of the care.

Overall text shares an increasing demand for physicians in paediatric settings to address not only the physical but also the psychosocial health of their adolescent patients, to prevent or intervene on health risk behaviours and make sure patients adhere to treatment recommendations. Adolescents appear to be more sensitive with a common "dilemma" between the need for more attention on one hand, and a more independent role on the other hand, in order to help them achieve age-appropriate skills and feel adequate when they do not reach the height they would like.

If Centres wish to achieve levels of excellence, they should adopt specific policies for specifically managing adolescents through dedicated programmes. The paediatric settings which they attend for their check-ups are mainly designed and adapted to welcome children (the colours on the walls, furniture, toys, and books) and make them feel out of place.

As to parents' stories, 67 % of them revealed having a persistent worry about possible and unknown side effects of therapy. They have lived the conflict since the beginning of treatment, torn between the desire to offer to their children the solution to the growth problem and to "get" a normal child, and their doubts regarding the hormonal ordinary and long-term—almost chronic—administration.

In conclusion, the study has led to important findings pinpointing two fundamental aspects, which would not have emerged otherwise. Basically, the results point to two considerations on relationships; as suggested by the stories, care teams should find a more engaging way of communication with adolescents, who require attention but in a different way compared to children, and should not neglect the families' constant need for reassurance about therapy and its possible effects.

Considering that the care providers were aware of the importance of communication and empathy in this particular pathway, there is a fertile ground on which to work on, to improve relational skills, together with a high level of clinical competences.

This study provides evidence that Narrative Medicine, beyond any possible prejudice, is also suitable for handling a plurality of cases and a plurality of stakeholders as patients' caregivers and providers of care. The outcomes emerging from this research could be considered a case of Evidence-Based Narrative Medicine.

References

Charon R, Wyer P, Chase H et al (2008) Narrative evidence based medicine. Lancet 371:296–297

Greenhalgh T, Hurwitz B (1999) Narrative based medicine in an evidence based world. BMJ 318

Farmelo G (2009) The Strangest Man: the Life of Paul Dirac. Faber and Faber, London

Kelle U, Laurie H (1995) Computer use in qualitative research and issues of validity. In: Kelle U (ed) Computer-aided qualitative data analysis: theory, methods and practice. Sage, London, pp 19–28

Marini MG, Chesi P, Guazzarotti L et al (2015) Creating through stories of experiences of care for GH deficiency the empowerment toward the excellence – The C.R.ES.C.E.R.E. project, Stories about life with GH deficiency. Submitted to Future Science open

Odifreddi P (1989) Classical recursion theory. North-Holland, Amsterdam

Sackett DL, Straus SE, Richardson WS et al (2000) Evidence-based medicine: how to practice and teach EBM, 2nd edn. Churchill Livingstone, Edinburgh

Strategic partnership delivers greater flexibility to qualitative researchers in the UK and around the world, National Centre for Social Research, 17 Oct 2011

The Place of Illness-Centred Movies in Medical Humanities

8

Narrative humility is a developing concept that requires the listener, reader, or viewer to honour the variety of possible patient truths, grounding on the premise that each story cannot be classified as pure *fact* or *fiction* and that it should be regarded as an entangled loom of truth and fantasy (Shapiro 2011). Shapiro writes: "*patients' tellings are not objects to be comprehended or mastered, but rather dynamic entities that we approach and engage with, while simultaneously remaining open to their ambiguity and contradiction. Such an attitude admits the possibility that self-representation is not entirely driven by motives of placating or pleasing others, conforming to prevailing norms or being well regarded*". The concept of normality (Chap. 6) can be envisioned as a force dictated by both biological and socio-ethical rules: the narration of stories allows patients to show their core identity, "*to make meaning out of suffering, connect with one's highest personal aspirations or with an eye to one's legacy with family and loved ones, and that regardless of what drives the story, it remains the story the patient wanted to tell. For patients facing serious illness, telling their stories is one of the few aspects of their lives that remains somewhat under their control. Are these 'true' stories?*" (Egnew 2005). As the starting point of a good carer–patient relation, stories and the process of putting it together may have a therapeutic role themselves, despite the contents and their distance from objective reality. They can represent a sort of *true truth*, even though they may be distant and hardly acceptable by conventional wisdom, as written by David Mitchell in his post-apocalyptic novel "Cloud Atlas" (Mitchell 2004): all societal rules failed and there is no other way for the humankind to go back to their ancestors' *true truth*, in which they were able to get inside the very heart of the leftovers.

From an ethical point of view "telling the truth" and being reliable may seem fundamental rules and expectations in intrapersonal relationships, yet if we consider that clinicians and carers sometimes omit to tell the entire truth for the patient's sake or for the patient's peace of mind, we must admit that breaches to the rule commonly occur and thus perhaps should be reconsidered. For the sake of coherence, breaches should be considered acceptable on both sides, allowing the

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patient to omit or add, as he/she considers appropriate (or as dictated by their suffering), and tell imaginary stories as true ones. The issue of truth-telling in bioethics is closely related to that of Informed Consent, as it involves weighing *paternalistic* concerns—*accepting the fact of withholding potentially dangerous information*—against the autonomy interests of fully informed patients, who can decide how to get cured and what to do with the time left to live. *For genuinely good reasons—out of a concern for promoting health, and preventing harm—a physician may wonder whether it is always best to tell the complete truth to patients.* (Gillon 2001). To what extent does the patient need to be informed about the severity of their disease? This raises the issue on the morality of lying itself. People might believe the choice is clear-cut: the virtue of honesty imposes us not to lie. However, the settings are not so straightforward, as there is also a duty in safeguarding the patient from unnecessary stress. Lying or deceiving poses a possible conflict between promoting the good and what philosophers sometimes call '*moral side constraints*' or non-consequentialist duties: German philosopher Immanuel Kant suggests that in some circumstances lying in the sake of promote the good can be considered acceptable. As he writes in his Critique of Practical Reason, the lying agency is allowed only if it yields to the best welfare situation (Kant 1788).

Given the fact that there is not an absolute clear convergence in knowing the truth in all cases, both from the physicians and patients' sides, we must conclude that every case should be considered according to the best possible moral option.

The Use of Disease Centered Movie: Straightforward or Twisted?

Creativity of patient narrations represents an extraordinary treasure of stories for society, and over the years many of them have also been adapted for the large audiences of theatres and books. Producers and movie directors have drawn upon the most dramatic aspects of illness to achieve sensation and emotion among their audiences.

Illness indeed always thrived on the pages of literature, dramas, and in figurative arts. All this production is the extraordinary heritage of medical humanities, yet there is a fine line between philanthropic inspiration and interpretation on one hand and the more ambitious deed to create an award-winning box office hit.

In the following pages, we will see how this art has been applied to the condition of being ill, keeping faith to our position according to which manipulation and exploitation of patients' dramatic stories are unethical.

Illness representations through movies can serve different purposes in which artistic creativity is put at the service of humanities to sensitize and show how life of a person and his or her family, or environment, is completely unbalanced, in the best cases, with slow changes, and in the worse cases with "tsunami"-like effects. Visual art use among the possible senses mainly the sight, which use more than 50 % of our brain's resources. In other words, our sense of vision/sight often dominates our other senses. People are familiar with the Chinese statement: "*A picture is worth a thousand words.*" Now, what if we took it one step further and made the picture animate? There you will find a truly emotional impact. That's the beauty of cinema (Schwertly 2015). And this is why the humans are so easily impressed by the view of disease-centered movies, because they can reach our inside within immense power: let's consider that, not only the sight is activated, but also through soundtracks, our hearing sense is switched on, and the "alchemic wedding" between music and vision can bring to breathtaking situation.

In congresses and seminars of narrative medicine, illness-centred movies are widely used as a tool to describe with vivid images and sounds the unfolding of a personal experience of living a particular condition of impairment and the care pathway, either the patient or a close family member or caregiver. In the world of cinema, these experiences are largely emphasized so as to move the audience and trigger feelings of sorrow or joy, and identifying oneself with the main character. In pedagogical essence, these movies are perfect architectures of didactic cases and able to delicately open the "hearts" of the evidence-based health-care providers, beyond the hearts of common people. Cinematic is very powerful in this, unless a boomerang effect is originated: after too many tears, and falsifications, the pure scientists want to go back to their odds and probabilities, confidence intervals, made by numbers and statistics. Somehow to take one step back from that induced compassion, affective empathy, and sympathy.

Other movies are purely artistic, and openly declared as fiction, as the sharp and sweet "*The barbarian invasion*" by Denys Arcand, or the visionary "*Big Fish*" by Tim Burton, both of which focus on "dying phase" of life, the "leaving this world", but some plots are declared to represent a real story, or, in the most accurate and transparent definition, to be based on a true story of a disease. However, the real stories inspire the movie setting, but they don't represent the true: think only to the music, which can evoke sweetest, or most melancholic, or angry emotions: whenever in real life this music was there?

Movies that can strongly influence society and trends, yet being a revisited or distorted portrait of reality, such as the story told in the movie Patch Adams, which provides another example yet. A touching story that despite its predictable Hollywood format was able to move generations of caregivers and introduce a new approach to disease management in institutions and hospitals. It was inspired by the real story of Hunter Doherty Adams, the inventor of the clown therapy. It is clearly a distorted picture of reality resulting from its storyboard and the genius and spontaneity of Robin Williams' interpretation. So, basically being a distorted vision of the true story, we can all agree it served its purpose: according to Kant's principle, that is better lying in an acceptable way to produce more welfare for the society. Thanks to Patch Adams, because now hospitals and nursing homes are less sad institutions thanks to the laughing skills that volunteers practice in these settings in their daily practice.

There are, of course, more faithful narrations of disease experience. The self-portraying documentary of Tiziano Terzani (a great Italian war journalist), as an end-stage cancer patient who died after a 7-year battle against cancer, is an excellent example of truthful storytelling, which however did not quite compare to the real story. In a direct interview taken over the last months of his life, Tiziano himself narrated his biography (with the intention of leaving his last thoughts and his last wills). After his death, his son, Folco Terzani, decided to make a movie, out of the documentary that he shot: "*La fine è il mio inizio*"—"The end is my beginning". Despite being a faithful copy of the interview, it was not influential as the true interview, much more powerful to use as a didactic and inspiring case.

In some cases of movie narrations, the cinematographic licence is a bit more subtle, as in the case of "the Diving Bell and the Butterfly" (Bauby 1999) which provides an accurate description of the illness, but introduces deceiving elements on the people involved in the story.

A French movie directed by Julian Schnabel. This movie was built around with the diary of Jean Dominique Bauby, a successful editor—the director of Elle France—who was suddenly hit by a stroke that left him paralysed affected by the "locked-in syndrome", with the only residual movements left in his eyelids. Astonishingly he learned how to communicate by means of the *silent alphabet* which translated blinks of the eyelids into letters of the alphabet; thanks to a volunteer (as put by the movie version) who was assisting him while he is in the rehabilitation centre at Berck-sur-Mer, he was able to communicate and dictate his entire personal diary. The diary in itself is breathtaking and documents an extraordinary coping strategy (Bauby's memory and imagination of allowed him to go everywhere). These two forces gave him the willingness to live even in these extreme conditions. Unfortunately the main author died soon after the publication of the diary. Overall, the movie was a close recount of the author's experience, as collected in his diaries, and presents an extraordinary example of care and coping strategy. Yet, the movie is extremely misleading about the persons involved in this path of life and who covered the most important roles in his experience of illness. Unfortunately, behind the real story, there is an untold ousting of star female roles of Bauby's ex-wife over the new girlfriend in office at the time the stroke occurred. While the unknowing audience fell in love with the movie and the characters of its story, they were totally misled on relationships, which thus undermine the movie's authenticity and recognition in a setting of narrative medicine.

Intriguingly, there is more mystery around this story, as a very similar story seems to have been published years earlier, in 1962 (Simenon 1962). "The Bells of Bicetre" analyses the effect of a stroke in a man in the prime of his life, who became a publisher of a highly influential Paris newspaper. Then suddenly he finds himself in a Paris hospital, speechless and paralyzed, yet surprisingly clear of mind. For the first time in his life, he is forced to stop and think. Also here, angelic female figures are taking care of him, and for them, Simenon uses very similar "erotic" words that Bauby will use later in his diary to define the beautiful carers practising in his rehabilitation institute. Strange analogies are there when both the journalists will reflect on the women of their lives, their root families, and their approach to work. The book was published in 1963: it is odd to witness such a coincidence. Was it clairvoyance? Who was inspired by the reading of whom? Bauby himself? Or the movie director Schnabel? Experts in narrative medicine are still debating and we, as in a movie of Akira Kurosawa, Rashomon, with many different versions of the truth or as in the Pirandello's play "One, No One and One Hundred Thousand, with many different portraits of the main character, will probably never know the truth.

So with all these examples above, we are left with the doubt on where to find the best sources for genuine patient narratives and stories.

To attempt to answer this question we are going to close with a quick review of some movies in with Oscar-winning actors and actresses from 1927 to 2012 (Kassenbrock 2015), which, according to the figures reported by BBC News, portrayed a person with a physical disability or mental illness. Disease led to a 16 % of Oscar rewards, since the institution of the prize, with an escalation in the last years, indicating the urgency to give free expression to sick and ill people and their process of care.

"The Theory of Everything" (2014)

"The Theory of Everything" is an intimate portrayal of Stephen Hawking's life beyond his professional contributions to theoretical physics. The film depicts his relationship with his wife of the time, Jane, and how it helped him cope with his debilitating ALS. The actor, Redmayne, spent 4 months studying Hawkins' life to prepare for the role and interiorize Hawking's speech and movement and created a chart of how the disease advances, which he used as a guide throughout the filming process. Despite the actor's superb ability in his interpretation, there was some debate on the need to assign the role to an able-bodied actor to play a character with a disability: this tendency to assign disability role to not disabled people might create "allergies" in patients and carers as well (Zacharin 2014).

"The Sessions" (2012)

"The Sessions" is based on the article "On Seeing a Sex Surrogate" by Mark O'Brien, a poet paralyzed from the neck down due to polio. This moving drama examines the often overlooked intersection between disability and sexuality (Di Giovanni J). Forced to live in an iron lung, O'Brien (John Hawkes) has never had sex and, sensing he may be near death, hires Cheryl Cohen-Greene (Helen Hunt), a professional role defined "sex surrogate", to help him change that.

"The Sessions" was praised for countering the myth that people with disabilities are uninterested in or not capable of expressing sexuality. "In addition to the social stigmas and structural barriers directed toward disability, those with disabilities are routinely perceived as non-sexual." Cindy Allen, an actress with cerebral palsy, noted that despite Hawkes' impressive performance, filmmakers could have cast an actor with a disability. *"Playing a disabled role is not about getting an Oscar, it's about dealing with a disability"*, this to confirm the allergy that real disabled people feel towards not disabled people playing their role. *"I'm not taking anything away from his acting ability, but there are thousands of equally qualified disabled actors out there who can bring more authenticity to the role."*

"A Beautiful Mind" (2001)

"A Beautiful Mind" is based on Sylvia Nasar's 1998 biography. The film follows John Forbes Nash, Jr. (starred by Russell Crowe), a brilliant mathematician who lives with schizophrenia. It focuses on the harrowing delusions Nash endured and their effect on his career as he developed his mathematical theories.

The film was roundly criticized for oversimplifying mental illness and sanitizing Nash's story, but the actor's portrayal of Nash was awarded a Golden Globe as best actor and praised for how he depicted schizophrenia symptoms. This opinion was confirmed in an interview also by Dr. Ken Davis, chairman of psychiatry at Mount Sinai School of Medicine *"On the other hand, the notion that willpower can really overcome schizophrenia is ludicrous."* In his severe commentary, the psychiatrist wants to underline potential illusions which may originate from watching in the movie the partial recovery of John Nash, especially when he receives the Nobel Prize. From the movie it looks like that John Nash has learnt to cope with the disease, when reading Sylvia Nasar's biography, we can interpret that the situation of schizophrenia is worse than one played by Russell Crow, and as a "caveat", psychiatrist might feel fears of overselling promises of a possible recovery from this disease.

"Children of a Lesser God" (1986)

Sarah Norman (starred by Marlee Matlin) is a deaf woman and former student working as a custodian at a school for the deaf. When a new teacher, James Leeds (starred by William Hurt), arrives and wants to teach her to speak aloud, she resists, content to keep on using sign language for the rest of her life. Soon, romantic feelings form between the two. He continues to encourage her to speak phonetically, but she insists that if he loves her, he will communicate with her on her terms.

"Children of a Lesser God" is memorable in having assigned the role to a deaf actress who could realistically portray a deaf character on camera, yet this also had instigated great criticisms for the same reason, as many critics considered her Oscar victory to be a "pity vote" and that she was not worthy of the award because she was a deaf actor portraying a deaf character and it was not really acting at all. The negative feedback she refers to highlights some of the discrimination actors with disabilities face in the film industry.

Though the acting in the film was well received, it was criticized for employing deafness as a gimmick in an otherwise contrived love story. Roger Ebert remarked in his review of the film that love stories where one of the characters has a disability "seem to treat the handicap as sort of a bonus, conferring greater moral authenticity on the handicapped character," calling it "a form of subtle condescension."

In conclusion, for many actors nowadays being able to play the part of an ill person is like reaching the top of their career: thinking Julianne Moore in Still Alice or Matthew Mc Conaughey in Dallas Buyers Club, as in the past Dustin Hoffman in the wonderful RainMan. It's a virtuosic target for an actor who cannot call himself as real professional if not able to enter into the patient's skin. Is it just art, ambition, or something which falls into exploitation of the show business?

Learning to Interpret a Movie Using the Keys to Illness, Sickness, and Disease: the "Philomena" Case

Now let us dive into an anthropological exercise, writing the analysis of Philomena, based on a book *The Lost Child of Philomena Lee* based on a true story set in Ireland, in the 1950s. The story is embematic in its description of sickness, at its broadest acception.

The story is that of a young pregnant woman, who has been repudiated by her family and is forced to enter the convent Homes of Magdalene where women were kept obliged to slave-like condition. The houses of Magdalene took its name from the *Saint Mary of Magdala*, the sinner who had asked forgiveness to Jesus and had atoned. Because she committed the so-called "obscene sexual act outside of marriage", she was doomed to sickness. The sickness of Philomena in the movie represents the quintessence of discrimination by a certain dogmatic part of the Irish society.

What "others" perceive as an abnormal situation, out from social standards, often leads to social stigma. In this movie, the discrimination of the nuns of this house towards this young girl yielded to the absurd judgement that if Philomena's son would die at birth, the religious belief that this is a right solution, since it is the proper atonement, provided for the future suffering as a remedy to the disease of being a sinner. However, Anthony, the son of Philomena, does not die at his birth.

As the story of Philomena unfolds, we see her suffer the loss of her young son who was sold to wealthy American families as it was a illegal habit in those days. Although Philomena had signed a document stating she would never have searched for her son, she secretly never abandons the hope of reuniting him again one day.

In search of his son, the Irish Philomena will be assisted by an Englishman, the cynical journalist Sixsmith, who will write her biography "The lost son of Philomena Lee"—At that time, Martin Sixsmith, torpedoed by the BBC, tried to reinvent himself as a journalist and writer, through research of news that makes clamour, true stories of high emotional impact. The stories, according to its columnist, must have a ending sad or happy, and never can remain in an open-ended version or offer weak emotions which do not engage the reader.

The story of Philomena and Sixsmith is a "quest" or a search, where it is mainly the educated and brilliant Sixsmisth who studied at Ox-bridge (as he is teased by Philomena, building a wordplay on the names Oxford and Cambridge) to learn humanity, determination, and a sense of forgiveness by Philomena. She would have all the rights to fret instead of anger for the treatment she has received from the time of her becoming pregnant up to her becoming adult and old. Instead, she speaks to Sixsmith so sweetly, telling him, "but are you tired of living so angry?", and she is serene in the tragedy because she feels that she never committed any fault, and even she remembers with huge tenderness the pleasure of motherhood.

Philomena grows up and becomes a nurse; meanwhile she brings on the quest for her son and finds him, discovering that he, too, has a secret to keep. As a successful lawyer called into politics, he must deny his sexual orientation and his compromised health status with AIDS. He, too, had been searching for his mother, and as disease progresses he tries to find and reconciliate with his mother, despite the odds. In short, Philomena and Sixsmith discover that Anthony was "shipped" to the United States many years ago, and this odd couple, made by an ignorant old woman and a man in his middle age existential crisis, reaches Washington. An evanescent happiness because terrible news emerge that Anthony is dead because of AIDS. Anthony, before dying and facing the last phase of his illness, wishes to reconcile with his mother and he flies back to Ireland. But the attempt of a final encounter with his mother on the Irish soil is opposed by the nuns, till the end filled with their ideology of sins and atonement. Philomena and Sixsmith will fly back to Roscrea, in the Irish County Limerick, where they will find the grave of Anthony, buried by the nuns without ever informing Philomena of the fact that his son wanted to see her for the very last time. Astonishing: after having visited the grave, the nuns will keep on saying to Philomena that she behaved as a sinner and that she did not deserve any reconciliation with her son. Getting out from the House, she asks to the impatient journalist Sixsmith to write the whole story and to let it known to the whole world.

Examining things from anthropological frames, we can diagnose a major sicknesses pervading the three countries in which the story happens: Ireland, England, and the United States. Ireland is portrayed revealing a manipulative bigotry; we see pain inflicted by the sense of atonement to manage the sickness of naive teenage girls and, in a bigoted society that allowed them to be secluded into monastic enclosures (legally operating up until 1995, year in which they were abolished). The result is a country characterized by exaltation of religion and traditional values that take pride in distinguishing themselves from the sickness of the British. Sickness in England, from the Irish point of view, is the general lack of values and excessive permissiveness among the things that mattered (and still counting) career, and of culture replaced by rational atheism, where any form of religious superstition is a sickness. Across the ocean, we see the sickness of the American society (puritan plutocracy), where famous and wealthy families buy Irish blond children with blue eyes, as they did up to a century earlier in the slave trade, so conservative and controversial that despite the freedom claimed poor or homosexuals, in the shadow of prejudice, the stigma, are not worth anything, or *sick*.

On these three scenarios the figure of Philomena is imposed, who has healed from her illness (the way in which the subject is able to react to a disease, the way Philomena found her own style in everything that happens) but which left the pieces of the fragile Magdelene girl to evolve to a resolute and resourceful woman: through innate mechanisms of adaptation—the coping—she developed the carer qualities as a nurse, the qualities of hope through reading romance novels as "trash literature" with a happy ending, and the gift of an extraordinary faith in God and the Saints which she entrusted throughout her life, and made her life meaningful despite the evil received.

Philomena is hardly tried by life: she cries, laughs, is surprised, asks, thinks, embraces, and is embraced; she never seeks the confrontation but rather to every person in America she gives this statement "you are unique." She knows how to make them unique.

Compared to the generalization spelled by the nuns (so we would call in neurolinguistic programming) "you all have sinned, and then you all have to repent", a slogan that is repeated almost obsessively throughout the whole story, she simply dismisses this sentence with a brilliant "I forgive you", to Sister Hildegard, the very she who had pulled away her son, and many years later, prevented the last reconciliation.

"I forgive you" and then she gets out from the Magdelene house, telling Sixsmith, who meanwhile wonders how she can manage to appease her resentment—simply because she does not have one, the plot of the last pink romance in which the poor hero manages to marry the rich girl, despite the hostility of the family sickness. However, she asks a great action: that the journalist Sixsmith should make known and narrate to the entire world what happened in that place, RoseCrea, at Limerick. Recovering well from her illness as the subject, leaving the silence, it seems that the word "narrative" is born from the synthesis of: gna (which has lost g)—root meaning to make known, to make scientific and igare for Latin *agere*, to act, which means action; to raise awareness of telling (etymological dictionary). Through the etymology of narration, unlike what is supposed with a superficial preliminary separation between the narrative (just facts)—and paradigmatic (just science) thought, actually, it is possible the combination between science and facts.

Philomena's story is a gift that teaches us a strategy of adaptation and possible happy ending, coping again, even in a tragic situation. Philomena at the end of the film is a serene woman because she discovered the truth, she metabolized it, and she came out a winner. And by this oxymoron—the ability to find a piece of happiness and vitality despite disgrace—Sixsmith grows up. We owe a lot to this true story and true character, to learn how to get out of corporate contexts where the label Sickness is glued linked to the social context, it's a scarlet letter, and one learns as main player to go through his or her own illness, finding resources for the healing. First of all willpower, lightness, and good feelings.

Does narrative medicine have a scarlet letter of sickness? Does evidence-based medicine have a scarlet letter of sickness? If we slightly might think so, we should recall the role of Philomena who teaches us not to make big drama on scarlet letters. They come and go, as waves. And in it's our power to foster the abolition of the wall between Narrative Medicine and Evidence-Based Medicine. While I'm writing, these two approaches are already changing.

References

Bauby JD (1999) Le scaphandre et le Papillion. Robert Laffont, Paris

Di Giovanni J. The real story of the diving bell and the butterfly. http://www.theguardian.com/lifeandstyle/2008/nov/30/diving-bell-butterfly-florence-bensadoun

Egnew TR (2005) The meaning of healing: transcending suffering. Ann Fam Med 3:255e62

Gillon R (2001) Telling the truth, confidentiality, and respect for autonomy. In: Harris J (ed) Bioethics. OUP, Oxford, pp 507–528

Shapiro J (2011) Illness narratives: reliability, authenticity and the empathic witness. Med Humanit 37(2):68–72

Kant I (1788) Kritik der praktischen Vernunft

Mitchell D (2004) The Cloud Atlas, editor Paperback

Kassenbrock R (2015) 9 Oscar nominated film that got disease and disability (mostly right), BBC news. www.themighty.com

Schwertly S (2015) https://blog.slideshare.net/2015/04/27/cinemagraphs. 27 Apr 2015

Simenon G (1962) Le Anneaux de Bicetre. Press de La Cité

Zacharin J (2014) Stephen Hawking give his approval to ‘The Theory of Everything’. https://www.yahoo.com/movies/watch-stephen-hawking-give-his-approval-to-the-102542644887.html

Designing Health Care Based on Patient's Needs and Rights

9

> *Money is better than poverty, if only for financial reasons.*
>
> —Woody Allen

Narrative Medicine is democratic. It does not belong to, or side with, anybody or a specific role but belongs to all individuals, and at least once in a lifetime, each human being has to deal with the patterns of balance/imbalance of health and illness. It is transversal and crosses all roles and specialties and requires a **systemic approach** to attain a multiple stakeholder consensus uniting the listening and collection of stories from patients, caregivers, friends, employers, and teachers.

If *governance* is a word born from the synthesis of two terms, *government*, with a so-called top-down approach, and *alliance*, with an acknowledged bottom-up direction, *narrative medicine* can be defined, indeed, as a governance tool, with a bidirectional flow between the health-care system and the patients and vice versa. *Governance is in fact an establishment of policies, and a continuous monitoring of their proper implementation, by the members of the governing body of an organization. It includes the mechanisms required to balance the powers of the members (with the associated accountability), and their primary duty of enhancing the prosperity and viability of the organization.*

Thinking about implementation of Narrative Medicine into medical practice, we automatically acknowledge a possible clinical benefit of a therapeutic alignment with patients, but we rarely envision this as a potential tool for building an eco-friendly sustainable health-care system that can deliver accessible quality care without impacting our future generations. Sustainability in health care is composed by different features which should be all embraced with complexity management: the road to sustainable well-being must consider the overall impact/benefit of environment, resiliency, patient education, and cost and payment of value health-care activities. Among these, resiliency, perhaps a scarcely considered aspect, is a quite interesting issue and concept that is recently gaining some attention. As stated by Dr. David Pencheon, director of the Sustainable

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Development Unit (SDU), and consultant for NHS England and Public Health England, claims "*the health and care system is increasingly aware of the benefit of helping to develop resilient communities: resilience that is fundamental to health and wellbeing, both in times of relative stability, and in times of crisis*". Indeed, narrative practice is widely applied to booster resiliency (or better antifragility skills) following traumatic issues both in patients and in care providers who need to be prepared to support the person they assist (Porter 2010).

Pencheon declares: "*The health and care system can take every opportunity to work with people to prevent the preventable and manage the manageable. This means helping us all improve our understanding and control over our own health, illnesses, and life chances, within our homes and communities. The traditional model of us being well, then ill, then treated, then better, is increasingly outdated. Most of us will live with multiple conditions that we will largely manage ourselves with the support and guidance of the health and care system using improved information, integration, collaboration and technology*." Since Narrative Medicine encompasses the patient from a global point of view, being chronically ill with multiple conditions will better be probed through patients, who, by writing, will develop a leap of awareness and will foster the coping ability, by reflections on their situation. After reflective writing they will become active, informing themselves, sharing their stories of care through the digital network. Pencheon continues: "*This […] plank requires a cultural shift for public, patients and particularly professionals. We may need more diverse business models for providers of care. We could reward care providers for the amount they reduce death rates or health inequalities or survival times or for simply improving the experiences of patients. Those who commission healthcare are increasingly choosing to pay for outcomes*".

Pencheon refers to macro-economic elements and dynamics, but eco-friendly and sustainable practices could begin even in everyday-life contexts. In such perspective, some interesting data come from the work of Langewitz and colleagues that offers a starting point for reflecting on the moment of doctor–patient communication. It is often assumed that letting the patient talk is only a distraction from the medical encounter from the patient's problem: yet, the findings of this study point out that in 80 % of cases it takes patients only 2 min of the uninterrupted talking (and of active listening by the professional) to narrate their illness stories, and reveal those key elements useful for the diagnosis (Langewitz 2002). So, this study can be seen as an example of a totally eco-friendly sustainable and feasible practice to carry on in our Western health-care services to improve the diagnostic process and to reduce time and money wastefulness.

Outcomes should represent value for patients and providers, to *water* the garden of an eco-friendly health-care system: as Michael Porter, Harvard Business School Professor and Institute for Strategy and Competitiveness Director, points out, "*value should be the preeminent goal in the health care system, because it is what ultimately matters for customers (patients) and unites the interests of all system actors. If value improves, patients, payers, providers, and suppliers can all benefit while the economic sustainability of the health care system improves. Value encompasses many of the other goals already embraced in health care, such as quality, safety, patient centeredness, and cost containment, and integrates them.*

It is also fundamental to achieving other important goals such as improving equity and expanding access at reasonable cost." (Porter 2010). Governance here is strongly taken into account; since value for patients is what matters, the patients have the main power to decide which type of health-care system they wish, and not only to faintly influence from very far away the decision-makers.

This transition towards a truly sustainable health-care service based on governance practice will only happen through honesty, collaboration, public involvement, and the innovative use of business models and technology (already in wide use elsewhere in society to deliver a safer, fairer future). It is remarkable that both Pencheon's and Porter's visions, both fully engaged in designing sustainability concepts, respectively, from the UK and USA, are similar in terms of a moral code which empowers patients' voice and then that of providers of care, and lastly to money makers: *"a sustainable, system-wide approach avoids the trap of false choices, thinking, for example, that a growing economy is more important than a lively community for our children"*.

A key factor that has strongly limited the development of a sustainable health-care system so far is the use and abuse of defensive medicine, the practice of recommending diagnostic tests or treatments which may not be necessary or the best option for a specific patient, but are prescribed against any liabilities or malpractice claims. Studies show that the distorted behaviour of defensive medicine can sum up to 34 % (Scherz and Oliver 2013) of unneeded medical visits, According to a recent USA physicians' survey by Jackson Healthcare, the nation's third largest health-care staffing agency, 75 % of doctors say that they order more tests, procedures, and medicines than are medically necessary in an attempt to avoid lawsuits. Gallup reports that one in four health-care dollars spent in health care can be attributed to defensive medicine—about $650 billion annually. These costs are passed along to everyone, significantly driving up health insurance premiums, taxes to cover public health insurance programs, co-pays, and out-of-pocket costs. As to the European setting, in particular to the UK, a recent survey addressed to hospital doctors found that up to 78 % ($n = 159$) were practising—in one way or another—defensive medicine (Ortashi et al. 2013). In Italy, from the last report of Health Care Authorities, published in March 2015, the habits of defensive medicine are practised at least once a month by 80 % of the physicians. The fear of being sued hits 80 % of the Italian physicians; drugs, visits tests, and hospital stay that are not necessary cost to the Italian population 1 % of the GDP (Ministry of health 2015). In the mainframe of governance, since the citizens are the payers of the health-care service (public or private), it turns out clear that their "money" is not being spent wisely when defensive medicine is applied, and irremediably wasted. It's a useless expenditure of money, which contributes to maintain a corrupted, non-sustainable system very far from eco-friendly services.

The Patient's Narrative in Relation to Investment Economics in the Health-Care System

One of the dilemmas that narrative raises concerns **the shift from the single individual case—the personalization of a therapy, to a general level, when large-scale decisions for populations are needed**. In the previous chapters, our main focus has been on patients, caregiver, and physicians; in these last pages, we have been highlighting the governance and sustainability concepts,; therefore, the scope of narrative medicine has come to include two other main stakeholders: health economists and decision-makers. In the health-care system, there are those who decide on reimbursing or not reimbursing a pathway of care, introducing an innovation, a drug, a new device for a welfare system—which is currently at risk of bankruptcy with ever shrinking budgets to invest in health care at country, region, district, and hospital level. These experts have to make difficult decisions on the basis of data on populations, epidemiological forecasting, and response to treatment: at a first glance, apparently leaving no room for personalization of care. Decision-makers need figures and numbers and heavily rely on robust Evidence-Based findings, but do not see the potential in other kind of evidence. As we have seen in previous chapters, EBM comes short in many aspects which have proven to be critical to optimal patient management, whereas narrative medicine again presents to be an alternative way of thinking outside the box for finding new solutions. During an open debate on the use of narrative medicine with health economist from main European country, after they encountered themselves to evaluate whether narrative medicine could have been a tool for a more precise decision-making, no clear consensus was reached, with different opinions on its possible uses. One basic comment by a health economist was: "*All patient stories are the same, because we all have to face the physical laws of nature, growing, being adult, getting old and dying. . ..*" Of course, the big picture is the same, even if some die prematurely, but we cannot stop at this generalistic and oversimplified approach to deal with the complexity of real life, which could be a straight line for somebody, a more circular one for others, or even a spiral. And if it's true that we all human beings have to face the natural laws all over life and death, it is also true that we react slightly differently in peculiar turning point for us. A turning point is a decisive point at which a significant change or event occurs, or at which a decision must be made.

Narrative Medicine not only addressed the story of our lives but also the illness, the so-called breaking of the balance between well-being and feeling ill. **Stories of illness, that is, the living with the disease**, cannot be the same, just as there cannot be two identical curriculum vitae: they can be similar, "*but never identical, although we're different (we concur) just as two drops of water are*" (Bandler and Grindler 1976). My first personal thought, when I heard that patients' stories *are* (not even *might* be, using a probabilistic verb tense, but with an indicative tense) *identical*, was to be left before a too rough generalization and distortion according to neurolinguistic programming (Bandler and Grindler 1976). Words as *never, ever, all, always, nobody, same, identical, everything, everyone*—defined as Universal

Quantifier and (intended to help us simplify communication)—create stereotypes. Stereotyping can of course facilitate fast decisions, as in the hilarious line "*I stereotype, it's faster*" pronounced by George Clooney in *Up in the Air*, when the character is trying to choose the fastest flowing queue at the airport and drew quick conclusions after carefully observing how many Japanese and other Oriental people are in front of him, women with newborns and children, and so on. Unfortunately, at the end of the movie, his stereotyping framework turns out to be a total failure, preventing him to develop tools to build a better life. Stereotyping subtracts from reality and adherence to the real world. We know that epidemiologists and health economists have to take decisions based on an impoverished information, a pale indication of what each system and environment is and of what is universal truth forcefully fit onto all patients.

In reading about this, we should be taken by a doubt worth of Hamlet: "what if" the very tendency to oversimplify, to use "means and medians," was behind the collapse of the welfare system? Who says that the right to reimbursement suitable for me is also suitable for a completely different person? Another issue: who says that one can be cured with only evidence-based treatment, sponsored by huge trials enrolling thousands of patients? What if one would like to go for complementary medicine which unfortunately does not have behind the companies financing to provide evidence of its efficacy? If our mother wants to be treated with certified EBM antihypertensive drug, but her dearest friend takes care of herself with yoga, and they both perceived that both the ways of caring are valuable, and yoga costs less than drugs: why should decision-maker reimburse only drugs? This is what collecting narrative stories stands for: it is not a matter of spoiling people, catering to their whims, but of aligning care to their real needs and values.

Moving from Disease Management to a Sustainable Illness Management

The tailored approach can be used though road maps to identify a patient's journey: this is no longer the "disease management program" of the nineties. Instead, it focuses on what patient's will do, whether they want to heal in the first place and secondly how they want to be cured. Who says that welfare is tons of white tablets sold in pharmacies and reimbursed? Couldn't it start from good food reimbursed to address the quality of life? Couldn't it start from having free gym courses? Couldn't it start from heaving free counselling and/or and psychotherapy to counteract the neuroses of our age like time management or to help in dealing with unemployment? I think that welfare needs to rethink what it really is and what it is not, and needs to stop denying attention to emerging strategies of taking care of oneself, which are becoming on the day by day more of values in the perception of the population. As Michel Drummond, University of York says (Drummond 2009): *decisions should be taken integrating quantitative and qualitative studies to bridge the gap between patients and decision makers: in health care we are too far away from the people and qualitative interviews, the collection of experience, should be* *integrated with quantitative economic data*. Tools which might help are relying on deliberative democracy, structured methods to interview people and to get their informed opinions. Deliberative democracy is to be found in authentic deliberation among those affected by a collective decision. A defensible theory of democracy should be critical of established power, pluralistic, reflexive in questioning established traditions, transnational in its capacity to extend across state boundaries, ecological, and dynamic in its openness to changing constraints upon, and opportunities for, democratization. To reach a democratic consensus on investment in health care, we have proved methodologies as deliberative democracy: tools are there and now, we have the possibility to move from a paleo-welfare decision-making to a newer more sophisticated approach, integrating numbers with the richness of the patients' narrated experiences, which could be so similar and so different and the same time in a court of patients. If we want welfare to succeed one day, one might work on similarities, leaving free choice to the individual. Statistics should remind us of the "chicken fable" of the roman poet Trilussa—date of the poem is unknown, we can have two chickens for two people a year, the mean of which is one chicken per person, but in the fact Mr. A eats both of them whilst Mr. B gets nothing but a very small burnt wing. Trilussa explains through this satirical poem how statistics can erroneously be applied and lie, and the need to read beyond the data in order to collect the whole picture, not just the façade of the averages. This is why statistics with its generalizations can be misleading and—if not integrated with narratives which can help to interpret the data—be a rather superficial tool for the welfare system to use appropriately.

As a piece of advice for the decision-maker, if we want to change the welfare state we must detach from the framework of identical treatments: this is denial of diversity, a masking of reality, which is determined, as in the literature is reported, even if not statically determined, in a X % by genes—nature, in a Y % by education, and in a Z % by the environment: (Dryzek 2003) these percentages, so difficult to detect, may vary from setting to setting, but it includes three key factors which are claiming that we are not the same and our stories cannot be identical. Welfare system, in using only gross numbers, wastes a huge amount of money on guidelines, and defensive medicine, and loses the capability to understand needs, context, and soul. This is why health-care services need to be local and shouldn't be centralized too much, because anthropological differences do exist; otherwise globalization will continue with its irreversible process, cancelling out diversity. The basic needs for us humans on this planet are food, water, and working—as a means to survival and self-expression—and peacefulness of mind when going to bed. To these we must also add positive human relationships, which can be cultivated by listening reciprocally to stories of illness, but more than these, of lives. For a better and more intelligent redesign of eco-friendly and sustainable welfare systems.

It's Not Science Fiction: Concrete Applications of the Use of Narrative Medicine Are Already Running

Narrative Medicine, therefore, to be acknowledged as an integrated tool, has to be tested, to demonstrate its potential clinical effectiveness to the scientific community. Currently, providers of care are on the path to understanding that Narrative can not only give them the possibility to treat their patients better, but can also give them back something that "was somehow stolen" in the frantic management of the health-care system: the sense and the mission of healing, taking into account the systemic issues that each patient brings. Narrative is not for easy generalization or oversimplification: it does not complicate but it is complex. We are seeing that a new class of physicians is feeling good with this movement: it gives them back part a part of their soul lost in the system: in deed it's food for the soul.

Evidence of Economic Value of Narrative, Point 1

In the Back to Life study on myelofibrosis (Marini 2014), in which we used narrative to evaluate the coping strategy of patients, one of the findings was the correlation between type of evolution of the story and cost-related issues. Patients who wrote according to a progressing pattern, which we can define as a "story in evolution", showing a positive reframing were shown to be affected by a lower loss in income compared to the average. Patients who coped positively managed to save 1.365 € (−18 %) compared with the average annual loss, a figure that increased to 3.491 € (−45 %) for patients treated with a new drug to treat myelofibrosis. Patients with a "story in evolution" and treated with other therapies stated that their average annual loss was 819 € (−10 %) less than the average annual loss. Furthermore, the relationship of trust and support with the physicians of the centre allowed patients to understand the course of the pathology they suffered from, and the honesty and clarity of doctors made them feel reassured and cared for. As a result, patients trusted the treatment, considering it as the best possible one. Hence, costs aside, also the quality displayed by the physicians had an impact on achieving an eco-friendly sustainable model.

Conversely, the patients with "stuck" stories described their physician as professionally and technically prepared, describing them as friendly, emphatic, and helpful in only 22 % of cases. This latter figure was lower compared with the "in evolution" stories (48 %); the observation should be a warning for physicians because, even though their knowledge is deeply recognized, they could lack humanity according to patients' perceptions.

Evidence, Point 2: Narrative Medicine as a Probe to Detect Waste and Defensive Medicine—the Stories of Patients with Chronic Spontaneous Urticarial (Marini 2015)

Chronic spontaneous urticaria (CSU) is still perceived as an uncontrollable and difficult disease to manage and its negative impact on quality of life is well established. The study was performed with the aim of highlighting the lives of people with CSU, with a focus on medical, emotional, and relational dimensions of the disease: narratives were collected from persons with CSU with the methodology of narrative medicine. From June to November 2014, CSU-diagnosed patients were asked to write their story. Informed consent to participate was preliminary obtained. Stories were assessed first by three researchers who performed an independent reading and interpretation, and then as foreseen according to the Grounded Theory methodology, was processed by a semantic software (NVivo 10) which analysed the linguistic structure and occurrences of the words, synonymous, and metaphors.

The results: 155 Italian patients (51 % Northern, 25 % Central, 21 % Southern Italy) wrote their story. People narrating their experience were mainly women (74 %) with a mean age of 46 years, living with CSU from an average of 8 years. Itching was the prevailing symptom (82 %) and the metaphors used to describe CSU were mainly related to “fire”, “needles”, or “insects”. The care pathways were described as unsatisfactory in 81 % of cases. 73 % of people had visited three or more physicians before the final diagnosis and 22 % exceeded ten consulted physicians, with perceived waste of time and resources. The relationship with the physician was perceived mostly negatively in 82 % of the narratives. Even the therapeutic pathways were described as unsatisfactory in most cases. 85 % of patients hoped for an easier and faster healing. Patients reported stress and fatigue. Anger has been reported to be the life-dominant emotion in 82 % of patients (Confidence Level 95 %, Confidence Interval 6.05 %). Even familiar relationships were negatively influenced by the illness: only 17 % of patients found support within the family. Interactions with the outside world were driven mostly by a feeling of shame (63 %), which negatively affect social interactions as well as the job.

In conclusion: 93 % of patients appreciated the opportunity to tell their story and express their inner feelings, claiming a general lack of attention to their erratic care and their secluded lives hidden at workplace or home. Given these results, a campaign to physicians and citizenship of awareness of how uneasy is life with CSU is warranted and how many cases of doctor's shopping and defensive medicine are present in treating this skin condition.

A Single Narrative of a Woman Affected by Hives, Aged 42 with Onset of Symptoms in 2008

Reporting this narrative, we decide to maintain it as faithful as possible to the woman's original manuscript, even if doing so implies keeping some syntactic errors.

In April 2008, I felt itching in the legs I looked and they were extras of raised red blisters that caused me severe itching. I immediately thought to have eaten something that had bothered me or to an insect bite since at that time I regularly went horse riding.

After about three weeks, and the persistence of these bubbles I went to my family doctor which diagnosted an episode of hives and he prescribed an antihistamine .... thinking it was just an episode.

Time passed, but the problem was getting worse, taken several appointments with dermatologists and allergologists and immunologists: the response was always the same giant chronic idiopatic urticaria.

They told me to undergo tests and to move forward with cortisone and antihistamine. I did not know that cortisone would become my life partner for the next years to come. . . An uncomfortable companion that would relieve the hives, but with its own set of problems.

In the days immediately following the cortisone improved the wheals decreased but made my body swollen, red and greasy everywhere; I was not feeling well anyway.

The rash comes when you least expect it. I have my heavy encounter with rush in the evening and at night when I go to bed I never know how I wake up in the morning, big red thick wheals that hurt everywhere, on the head, on the body, inside the mouth and my eyes swell to the point of not seeing anything. . . They haven't gone away and they last days ..... those at the joints hurt the legs leave bruises when they go away.

And it was as if I was not living my life the most. All this keeps me from doing a normal life and affects the nervous system having to resort to drugs and anti-anxiety . . . is a continuous search of normality that we assure you that those who have this disease do not live a normal life

The time step and in 2009 I turned to D. G. and I followed in day hospital for more than a year I underwent several tests, I was administered immunosuppressants associated with antihistamines and always my "friend/enemy" cortisone was a very bad period because increasingly worse despite treatment. After a year of treatment examinations and consultations attempts worsening things to think about? Certainly I was not positive indeed I fell more and more depressed I was living a nightmare . . . eventually threw in the towel and even doctors did not know what to do .... . . .and I almost went to the emergency room nearest hospital M. S. I was admitted for 10 days ....

I have visited allergists made me rush back tests but found nothing attacked me with IV antibiotics for bronchitis cortisone and antihistamine for hives and an antidepressive drug

Meanwhile neither at home things were going well; family members will stand up to a certain point; you' re more nervous then less tolerant towards others; I came to the oint of not talkning about it anymore since I am the only one knowing how I feel;

at work it' s a nightmare, my biggest concern is wakeing up in the morning and not being able to go to work if I' m not well .... or having to go anyhow wearing a pair of sunglasses to hide the swollen face, or having to go in the bathroom to be able to scratch and cry exasperation to go back to your job pretending that all is well .... the worst part is not being able to make a normal life for me now are six years...

To understand the causes of urticaria do not know it seems that today no one knows .... I have also paid to homeopaths, or who practiced acupuncture ..... I think I have tried everything and have not missed anything... After excluding all causes, food, clothing, lifestyle, thyroid, the doctors themselves were puzzled. I felt desperate.

And I decided that as from 2010, after trying a couple of visits to P. at the 'hospital (but they agreed with D.) and after that I went to M. by a dermatologist (the result of research on the internet) which I was administered an anti-dizziness for 3 cycles with a break of seven days between cycles and the other full suspension of cortisone, I continued to get worse and probably feel terrible lack of cortisone in my later created a kind of withdrawal symptoms....... this was the last attempt .... from 2011 are the doctor myself increase and decrease depending on the drugs crisis hives daily.

Today I live with the hives is say that if you have a chronic disease over time you learn to live with it .... for me it is not so ..... I pass from moments of complete despair when I want to scream to let out all this pain inside me, and then gain back some hope and have a little 'of relief— but even when I do, nothing changes and on comes another day, another crisis, painful wheals doses of cortisone pending an improvement that if there is too little and start over so hard all the days to come I consider devastating and with the others I do not feel I can open up as they cannot understand....I tried also with psychologists. The person I care is dermatologist at the hospital of S. G. dermatology social and I feel taken care of now after years of do it yourself because no one was following me; I met a dermatologist that is working with his coleagues to discover more about the chronic urticaria are; it is a disease that is little considered, and many do not know that is crippling. I' m happy because now I am followed and they gave me a hope that is not a certainty, but for me it is already much and I thank these doctors for giving me an opportunity and not leaving to deal with the disease alone. Looking back on the path to this day if I look back and I think fatigue, pain and money spent .... Thanks for your time, energy and thought that he dedicated."

References

Governance, http://www.businessdictionary.com/definition/governance.html

Bandler R, Grindler J (1976) The structure of magic: a book about language and therapy. Science and Behavior Books, Palo Alto, CA

Drummond M (2009) Toward a consensus of the QALY. Value Health 12(s1):S31–S35, Special Issue: Moving the QALY Forward: Building a Pragmatic Road

Dryzek J (2003) Deliberative democracy and beyond: liberals, critics, contestations. Oxford University Press, New York, NY

Langewitz W et al (2002) Spontaneous talking time at start of consultation in outpatient clinic: cohort study. BMJ 325(7366):682–3

Marini MG (2014) Back to live – living, treating, managing myelofibrosis: the burden of illness for patients and their families. In: European Hematological Association congress. Poster session

Marini MG (2015) Living with chronic urticarial: a study through narrative medicine to improve the quality of care. In: European academy of allergy and clinical immunology, Barcelona, 9 June 2015. Oral communication

Ortashi O, Virdee J, Hassan R et al (2013) The practice of defensive medicine among hospital doctors in the United Kingdom. BMC Med Ethics 14:42

http://www.quotidianosanita.it/governo-e-parlamento/articolo.php?articolo_id=26843. Accessed 26 March 2015

Porter M (2010) What is value in health care? N Engl J Med 363:2477–81

Scherz H, Oliver W (2013) Defensive medicine: a cure worse than the disease. http://www.forbes.com/sites/realspin/2013/08/27/defensive-medicine-a-cure-worse-than-the-disease/, Forbes

Trilussa- Poesie, XX century

Building a Bridge Between Economic Investment and Medical Humanities: The Fears to Overcome

10

"My Mother Gave Birth to Twins: Myself and Fear": Thomas Hobbes

Thomas Hobbes was born prematurely on April 5, 1588, when his mother heard of the coming invasion of the Spanish Armada. His father, also named Thomas Hobbes, was the vicar of Westport in Gloucestershire, England. After being involved in a fight with another clergyman outside his own church, the elder Thomas Hobbes was forced to flee to London, England, leaving his wife, two boys, and a girl behind.

The global economic crisis of recent years is quickly leading to changes in direction in today's society and cultural traditions—subtle changes that can have drastic implications for future generations. There is a general feeling of uncertainty and fear of poverty and unemployment; a more and more fragmented society is altogether influencing society's attitude, with inevitable impact on health-care system and social services as well.

In these years, undoubtedly, the financial economy has prevailed on the real economy, with a dangerous withdrawal of investments and funding in culture and welfare services in both the public and private sector. In addition, the prevailing of the financial system over the real economy system has caused the chain of monetary debts which cross countries and continents: "*At the same time, the crisis itself has compressed potential growth, while low inflation is a hurdle to debt reduction. While not belittling the progress achieved by crisis countries, the fact is that debt sustainability has deteriorated everywhere. Clearly, the disconnection between economic and financial developments cannot persist for too long. Sooner or later, one has to adjust to the other. It would of course be far preferable for economic developments to align with the markets' implied expectations, rather than for valuations to adjust to disappointing economic developments.*" *(Liebold* 2014*). In fact*, Market has to be considered here as real good and services production, and not subprime mortgage or bonds, or stock market which should reflect the real-world

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economy but unfortunately, due to easy speculation, took directions very far away from the real market economy.

Of course, the Western world economic crisis has impacted the welfare of the society, with the first linear cuts being applied to social services and those "elements" which would generally be the "markers" of a wealthy and evolved society. The cultural crisis was officially confirmed in the 2012 Euridice report by the European Commission, which documented by the numbers the impact of economic crisis had on the European education system (Euridice 2012), with its drastic reduction in the number of schools, funding to Universities, salaries of teachers, and reduced investments for educational programmes. As for many other areas of study, also humanities studies have been affected, perhaps even to a greater extent compared to areas of scientific research and technological studies. From all over Western countries, there are denunciations of cuts to the University System: in Australia "The reduction of $900 million to university funding over 2014 and 2015 will significantly erode the ability of regional universities to take full advantage of the student demand-driven system, grow our student numbers, and contribute to lifting higher education participation and attainment in regional Australia" (Perkins 2014) in Scotland "Scottish universities' research funding cut by £13 million. Edinburgh University alone is on course to lose nearly £8 million in 2015/2016, a sum that will increase to £14 million in later years, while Glasgow suffered a £2.4 million cut. Professor Sir Timothy O'Shea, Edinburgh University's principal, said the net result would be to cut investment in Scotland's future jobs and prospects." (Johnson 2015). In a similar scenario for US university, linear cuts are announced from Wisconsin to Lousiana University. And in Italy, for what it is called the "stability law", education is facing tremendous linear cuts, to try to buffer the spread towards Europe. It is Western world crisis of immense magnitude which impacts culture and the education system.

Therefore, if continuous education is severely in danger, humanities which develop mainly by education and not only by technological skill courses are "endangered species" as well, especially in those countries which have serious debt issues as Italy, France, Portugal, Spain, and Greece. It is bizarre to notice that countries that are now investing the least in education are the very same who gave birth to classic humanities, and who are today suffering from the globalization disease of technocracy and plutocracy. *The rise of the plutocrats, however, is directly linked to the waves of globalization that have buffeted nation-states and the middle class in the past 20 years. Their wealth is also one by-product of the vast profits accrued by global corporations, which continue to register double-digit growth even as global economic growth barely registers a pulse. Companies have been able to externalize or outsource costs that once would have showed up on balance sheets, such as pensions, healthcare and disability and environmental consequences, not to mention some commitment to employees. The result is that nation-states have been saddled with costs, while corporations have been graced with profits (Karebell* 2012*)*. Trying to find a conciliation between the welfare states, which bear the costs of all basic public services as education, health care, and retirement funds, at the basis of a democratic system and private global companies' owner of a hidden paradigm of a plutocracy regimen is quite a dilemma. A humanistic management tries to establish a balance between short-term revenue and long-term investment, whereas an aggressive prevaricating management is not interested about long-term care, and is only focused on the day-by-day results without building for the future, or worse, leaving debts for the future in a not sustainable economy. Especially in these years of crisis, the fears of investing in big cultural changes to promote wealth and health (not for the few but for the society) have prevailed, focusing more on a strategy of survival than on development. And this was also applied to health care services, which have been heavily hit by linear cuts despite the progressive ageing of the society: while most efforts have been dedicated to technology and ruling the system at an accelerated speed on one hand, not enough time has been dedicated to forge the human beings involved in the health-care system, providers of care, and patients.

What does this preface of objective economic crisis and consequent fears have to do with narrative medicine and well-being? Shall we try to get rid of old automatisms and leave behind us old useless time- and money-consuming habits? Then we should consider that the trigger behind all this is the *Homo Homini Lupus* concept.

"Homo Homini Lupus"

Thomas Hobbes, the English philosopher (with whom we opened this chapter) popular for his *Homo Homini Lupus* concept, a *man is a wolf to another man*—in other words *Mors Tua*, *Vita Mea*, your death is my life—clearly explained, through this concept of *lupitudo* the justification for the establishment of law, that is, to control a prevailing individual egoism and to prevent evil doings onto one another. Nonetheless, even Thomas Hobbes is still confident that *something good may happen* and that human nature can somehow undergo a metamorphosis. Hobbes enunciates also that among people who know themselves well reciprocally, not living in a world apart, man to man is God, so *Homo Homini Deus*: of course, reciprocal knowledge is mandatory.

A number of studies have shown that during patient consultations most physicians interrupt patients after an average time of 18 s, starting to prescribe lab tests and pills, hardly even listening to what the patient is saying, overlooking the human aspect and reasons of illness and focusing on the more mechanistic aspects of a broken machine (Mavromatis 2012). As stated by David J. Rothman, who studies history of medicine at Columbia University's College of Physicians and Surgeons *"Doctors have one eye on the patient and one eye on the clock". By all accounts, short visits take a toll on the doctor–patient relationship, which is considered a key ingredient of good care, and may represent a missed opportunity for getting patients more actively involved in their own health. There is less of a dialogue between patient and doctor, studies show, increasing the odds patients will leave the office frustrated. Shorter visits also increase the likelihood the patient* *will leave with a prescription for medication, rather than for behavioural change—like trying to lose a few pounds, or going to the gym." (Rabin* 2014*).*

When doctors are given the opportunity to engage in a deeper physician–patient relationship, there is a general attitude of resistance with replies of justification such as: *"I don't have time; only few minutes for each visit"*. However, as we have seen in Chap. 9, in most cases it only takes 2 min of uninterrupted patient talk, to enable the doctor to find a suitable solution. So why **don't doctors rebel against these cumbersome time constraints imposed by their managers for visiting their patients, if time is not enough to ensure the good outcome of the visit?** And why aren't nurses (who are the ones who most closely interact with patients) legally allowed in many countries (as in Italy) to have a role in establishing or suggest changes of therapy or react to patients' request?

The answer to these questions is likely: *fear*. Fear, the *Homo Homini Lupus* terror, the ghost that something unwarranted can happen—for instance, angry patients advancing a complaint in court, the anxiety of losing the job, of being despised by the scientific community, and by one's own enclave. The terror of losing some acquired privilege.

If on one hand in the very far 1966, excellence of care (Donabedian 2003) was based on the concept of structure, process, and outcome, understanding outcome as well-being, caring, and healing, today it is mainly focused towards efficiency, or worse "hyper-efficiency" overwhelming effectiveness, to the point to endanger the very concept of excellence of care. Today, it appears to be easier, and thus more common, to issue the economic bonuses and incentives for linear cuts of human resources, shorter time for visits, saving on education. But it would be wiser to implement a policy to measure performance based on quality of given care, as witnessed and narrated by the patients' experience.

As an example of reckless in patient management, we can mention the fact that hospital budgets and trusts are already spent by the beginning of fall, leaving no resources to spend for the rest of the year, as underlined by an unpublished interview carried out by ISTUD Foundation addressed to hospital physicians and nurses. This survey actually confirmed the common *folk* belief of the higher risks involved in undergoing a surgery after fall, and hence advising to postpone (whenever possible) to the beginning of the coming year. As shown by statistical figures of a retrospective observational survivorship study, on all admissions to the English National Health Service (NHS) during the financial year 2009/2010, assessing whether weekend admissions to hospital and/or weekend assistance to patients were associated with any increase in risk of mortality (Fremantle 2012). Results were: 4,217,640 admissions included in the principal analysis, with 187,337 in-hospital deaths reported within 30 days of admission. Admission on weekend days was associated with a considerable increase in risk of subsequent death compared with admission on weekdays, hazard ratio for Sunday versus Wednesday 1.16 (95 % CI 1.14–1.18; $P < .0001$), and for Saturday versus Wednesday 1.11 (95 % CI 1.09–1.13; $P < .0001$). Admission at the weekend is associated with increased risk of subsequent death within 30 days of admission. The authors remark as possible causes: *there may be aspects of care associated with weekend* *admissions which disadvantage patients including reduced or altered staffing and skill mix; impact of shift system and/or changed training system for junior doctors; reduced availability of diagnostics; less availability of senior staff to review cases and to be readily available for escalation; less awareness (amongst staff unfamiliar to acute units) of unit policies around medication, therapy, communication and escalation.* Another evidence on disinvestment on human capital, the human resources inside the clinical setting.

IT investment, electronic case records, and new buildings of hospitals are not enough to save lives, when human resources are starved in times of crisis to the point of increasing the risk of a very "hard" outcome as mortality. However, investments are being made directed to IT, new hospital facilities, and architectures, while very few are directed towards other areas such as human resources, training, and education.

A visionary prospective multicentre study (Starmer et al. 2014) aimed at preventing medical errors caused by faulty communication among hospital staff and towards patients set up a resident handoff-improvement programme in nine US hospitals. The intervention included a mnemonic to standardize oral and written handoffs, handoff and communication training, a faculty development and observation programme, and a sustainability campaign. Error rates were measured through active surveillance. Results showed that in 10,740 patient admissions, the medical-error rate decreased by 23 % from the pre-intervention period to the post-intervention period (24.5 vs. 18.8 per 100 admissions, $P < 0.001$), and the rate of preventable adverse events decreased by 30 % (4.7 vs. 3.3 events per 100 admissions, $P < 0.001$). Across sites, significant increases were observed in the inclusion of all pre-specified key elements in written documents and oral communication during handoff (nine written and five oral elements; $P < 0.001$ for all 14 comparisons). Implementation of communication skills was associated with reductions in medical errors and in preventable adverse events, without a negative effect on workflow.

Such results thus make us suppose that positive results might also be reached through the introduction and implementation of methods from the medical humanities, in narrative medicine, in communication skills. In the perspective of excellence of care, this would not only create economic value in patient management but would also add moral value.

Indeed, Narrative medicine has shown and proved to produce better outcomes of care, to reduce errors and to improve team affiliation, in other words, to improve *happiness*, which is a very desirable state also for reaching a better job climate, and a re-discovery of the meaning of the vocation of the art of caring. It is a somewhat radical change of ways of taking care of the patients, not only through technology but also through listening and understanding the person who is behind the *potential feared wolf* which might bring you to Court, or in the best condition might tell that the cures that you have prescribed have not worked at all. Listening might show that there is a human being behind the patient—as well as behind the carer—both with their burden of fear, hope, human flaws, and resources.

Now let us open a parenthesis and go back to re-read the sentence of Hobbes: *"My mother gave birth to twins: myself and fear"*. Imagine for a while Hobbes' childhood, apparently not the most pleasant one. As a general rule, the key to comprehend the mindset of our speaker when she/he is referring to particular concept is to go back to that person's biography: after all, asking questions and showing interest is legitimate.

Narrative medicine collects biographies of patients and physicians and nurses and many other professional figures involved.

In the mental framework of reference, the *Weltanschaung*, childhood covers a very important role, as in the case of Thomas Hobbes who had been always fed breast milk and fears. Recent studies by MIT Researchers studying human cognitive behaviours show that most of our automatisms on basic reactions are formed during our childhood.

One can deem the outside realm as a magnificent world where to live and play, or as a very hostile environment from which we have to defend ourselves—or even both. In any case, in accordance with Berne's Transactional Analysis, whenever we find fear dominating us in our adulthood we have to remember that we are always going back to our childhood (Berne 1962). Back to our ancient patterns, which are the frame of reference which has dominated our first years which re-emerge and rule our adult life. Adult people who work in health care must deal with fears on a daily basis; health care can be a realm full of dangers: fears felt by patients as their body is "broken", fears felt by providers who might make mistakes unable to alleviate their patient's pain and sufferance. There are great existential fears: those of not finding the right resources, those masked by daily routine, fears of lack of power to face a curable disease.

Having searched a little on the childhood of Hobbes to understand how much this period of his life impacted on his mindset amplifying his fears, we now have to make the change and to face our automatism and our fears of changing in health care.

Health care has to go through a metamorphosis re-uptaking the natural vocation to care, re-considering the human being behind, being able to see the importance of the intangible words, and not only pushing sales on technology and bricks. Private and public should invest not only on drug research for inducing serotonin, the *queen of mediators of happiness*, but also on continuous education to the words and behaviours that are shown with scientific evidence to stimulate the production of serotonin (Young), the producer of happiness even in very difficult situations of illness and in very restricted times of crisis. Hostile behaviour is depletory of serotonin and therefore of happiness.

In 2002, the writer Celia Engel Bandman had been called to become a member of the interdisciplinary health-care team at a regional cancer centre in Vermont. A Medical Humanist (as she defined herself) she gave a great contribution to the development of medical humanities through the writing of poetry in the clinic. Not only patients and their family members but also physicians were invited to express themselves both with reflective writing and creative writing. Definitely, it was a daring act the inclusion of a poet within a cancer centre, and this is an acknowledged contract with her institution. Despite the recognized value of her work in bringing "spirituality" through the development of creative art as a remedy to face the objective dramatic condition of cancers, both in support to patients and to medical staff, her position was closed due to budget constraints. As we read in her impressive Good-bye letter from this hospital published on JAMA in 2008. "*To my colleagues on the medical staff. Today health care institutions are faced with having to make difficult budgetary decisions. As a result, the medical humanist's position at the cancer center will soon be coming to the end. Thank you for the willingness to integrate this role in the care of your patients... Upon reflection we have demonstrated that the humanist's role had a catalysing effect and changed the manner in which medical services were delivered.*" Celia sends the letter and immediately a physician replies by mail: "*Sadness, quiet denial, a lump in the throat, These are what I feel as I read your message. And a smile at the end for the civility, the kindness, the clarity of the focus and the premise of the future. Thank you for all that you have done for me and the patients we shared. It meant a lot to me*" (Bandman 2008).

So, it is obvious that also in the most open-minded environments, budget favours more traditional approaches sacrificing investments in more *abstract* human aspects: but let's consider the resources are definitely scarce, as economists teach us; are we really sure that cutting the "medical humanist" role we are saving money for more concrete resources? As we have seen in Chap. 9, defensive medicine represents a waste for Western health-care services. Perhaps, we could avoid the haemorrhage of money spent to prevent legal actions and we could invest in interdisciplinary teams at the centres. Maybe, at the end of the year, we will find a solution with saving due to less litigations because patients and physicians were more free to express themselves, the patients to come to terms in a quest mode to what the disease might mean for them and the physicians and nurses, reconciling technology with aspirations, wishes, beliefs, values, and a new style to cope with the disease. This for making feeling better suffering ill people and suffering care providers, too much at risk of burnout. Private and public health care could invest money in re-humanizing the care process that is becoming day by day more emotionless, bureaucratized, and technological.

Medical Humanities represent the missing link to many uncured, not curable, or chronic diseases: but if investments are not made, medical humanities will be considered always as a "*nice to have*" and not a "*must*", despite the shown "Narrative Medicine-Based Evidence": less litigations cost, less Dr. Shopping, a better perceived quality, better patients' mood at the end of the visit (Marini et al. 2014). Because, we as society are ultimately left to decision-makers, since we are paying the health-care services through our fiscal contributions, we should require clinical centres and providers to manifest a human touch, but even more to be treated according to our values. For this, our carers should receive adequate training, that is, training and education on the ability to cure by caring.

Private industries as pharmaceutical, biotechnological, and biomedical companies can invest funds in narrative medicine, with the aim of understanding in the very best conditions the deepest patients' and physicians' and all providers needs: narrative is the tool which could allow a better concordance to adequate treatment. Health Care Area of Istud Foundation is grateful to those enlightened pharmaceutical companies which have allowed grants for carrying out part of our research activities in narrative medicine, in a thorough ethical and independent fashion, instead of only investing money in somewhat obsolete activities of congress sponsorship. Research together with education is the fuel for developing the culture of narrative medicine and medical humanities.

In this closing paragraph, we shall thus reassure you there is hope ahead. In the last years, medical humanities and narrative medicine have proven to be capable of bringing health-care delivery towards excellence, improving also the economic outcomes, changing a bit at a time the health-care context: we are living in a metamorphosis time, in which we have the chance of building these bridges not only between clinical sciences and humanity but between medical organization and health-care economics.

We must, however, remember that according to the governance philosophy, as taxpayers and users of a public health-care service (now more and more so also in the USA after the Obama act), we have the power to express our voice and influence the patterns of care, either individually or through active citizenship, or through patient's associations.

The VEDUTA Project

A concrete application of a frontier kind of narrative medicine was carried out by Fondazione ISTUD in 2012 (Marini et al. 2012); until 2010 in Italy, the costs of pain management were only partially covered and no structural and qualitative mapping had ever been created. The VEDUTA project was designed to provide a tool to unite pain therapists in national cooperation. 187 pain therapists participated (mean age 50.9 years; 64 % men, 36 % women) homogenously representing Northern, Central, and Southern Italy. Eight-seven (46 %) participants actively contributed with full narrations, according to the classic morphological structure of fairy tales: the path to reach the village of *pain fighting*, the encounters, the overcoming hurdles, and the possible happy ending to imagine; this symbolic journey was used to interpret the beliefs of the pain therapists in the inward and outward of their organizations. Along with this Narrative tool, also the Maslach Burnout Inventory (MBI) was tested. Analysis of stories identified four *idealtypes* of persons: benefactors, hectic professionals, saviour heroes, and prisoners, the latter category being composed by those who perceive their organization as strongly compromised. The most common values emerging from the tale were help, caring of others, patients and families and colleagues, sense of mission, and an unbridled eagerness to learn.

Inside the "village" of the story, the hurdles were the paucity of remedies, cutting of therapists who leave the place, wars by foreign lords imposing "bureaucracy", and falling ill of the same therapists, being unable to face pain daily and poorly supported by the institutions.

Nevertheless, the success factors for rejoicing are given by a constant cooperation to defend the right storage of remedies, to negotiate against excess of spending review, and to cooperate among the village inhabitants to cure the ill therapist.

Transposing the fable to real world, despite the strong vocational values of the pain therapists and the new, health-care managers, resulted in being too deaf to the patients' right. The establishment of the Act against pain has improved the awareness on health-care providers external to pain therapy, but was not powerful enough to sensitize administrative decision-makers at hospital and trusts.

By means of Maslach Burnout Inventory analysis, burnout was assessed as low in 38 % cases and at moderate risk in 51 % of health professionals involved Maslach et al. (1997). High professional motivation and the good system of value contribute to keep burnout under control. Just 11 % of responders showed signs of having a high risk of burnout, and these data should not be underestimated. On the other hand, fast action should be taken in order to avoid its increase and to safeguard new pain therapists.

As we can see, this narrative method in this case allowed us to obtain a cultural analysis, by means of both quantitative assessment, including the Burnout Evaluation, and narrative plots, to probe the hidden and inner value of the pain therapists. It is possible to make interacting quantitative and qualitative research, in this case to assess the "health status" of a community of practice. And again, as a "mantra" that we keep on repeating since Chap. 1, Qualitative method and Quantitative metrics are not struggling with each other, but they, together, create a deeper knowledge.

This analysis was later used by the Italian Federation of pain therapists to review the leadership style and to fill the gaps of the affiliation among pain therapist, towards a more engaged and "re-oxygenated" community of pain therapists. The research was funded by a private pharmaceutical company as an act of Corporate Social Responsibility. This is a best practice that we would like to share, believing that enlighted managers can in fact trust and rely on this alternative approach and help the development of a better health-care system, providing funds for Medical Humanities, supporting advocacy programmes, or similar in an independent way in a non-profit mindset.

Here, I would like to share some short quotes from the fairy tales:

"Once upon a time there was a physician who used to consider medicine only as a technological path. Through a very long journey, he started to doubt on his real mission; he arrived to the village in which people suffered, and here, he understood that patients were, before all, people with their own precise life experience." What the story teaches us: medicine is not only technology.

"Once upon a time, there was a magician healer who, through a long journey in the most remote countries on earth, came to the country of care for people suffering from an unknown illness. The country was on a hill from which apparently gushed a spring of pure water. When the magician healer came to the country, he saw the faces of people intent on curing and thought that those expressions were those of people who had a kind soul because they cared with all their heart, then he looked at their hands and thought that those hands were golden hands for trying to alleviate the suffering and then looked at the suffering people and listened to

their words made of moaning and twitching in pain. Then he decided that he would be staying in that country because he could lend a hand to find out the cause of this terrible disease, but a bad day it happened that he found himself getting sick as many others there. But then it happened he discovered a plant and found that chewing the leaves made him feel better." What the story teaches us: the fragility of being physicians.

"There once was a boy who, after a long journey along with his friends Dream, Passion and Determination, came to a village. In that village, there were suffering people made of glass, who came from remote villages, but there were also their loved ones and they were made of clay. Then, in that country, lived all the others who had stopped there to take care of those who needed it and were made of cotton. He eventually decided to stay in that country because he could learn caress the glass and clay without breaking it, as the cotton people did: the clay seemed more resistant but the glass was too fragile, and the glass was delicate and transparent, and sometimes too easy to read through. Now the village is inhabited by people of clay and glass cotton arriving from all parts of the world, each speaking a different language, but all able to communicate with each other. The village is happy if people of cotton can caress and heal without ever even scratching the so delicate glass." What the story teaches us: the ability of diversity management in health care.

The Farewell From You, Reader

Metamorphosis is a must: *Though there was land and sea and air, it was unstable land, un swimmable water, air needing light. Nothing retained its shape, one thing obstructed another, because in the one body, cold fought with heat, moist with dry, soft with hard, and weight with weightless things.*

This conflict was ended by a god and a greater order of nature, since he split off the earth from the sky, and the sea from the land, and divided the transparent heavens from the dense air. When he had disentangled the elements, and freed them from the obscure mass, he connected them in separate spaces in harmonious peace "dissociata locis concordi pace ligavit". (Ovid)

Elements like land and sea were chaotically entangled in a messy and unproductive disorder and a supreme God came to bring a peaceful harmony: by defining the rules and the spaces to be given to clinical science, medical humanities, health economics, and medical organizations—now too much considered in a noisy entangled structure, with no clear bridge of interdependence, the war between the different disciplines can realistically be ended so that the health-care system can flourish in excellence, for all the dedicated providers of care, the patients, their families, their life environment, and citizenship. With no useless cuts of responsibilities: narrative medicine is not to accomplish any desire of childish patients or childish providers: no, it is here to bring awareness of the potential hidden resources, to make people more responsible of their movement towards well-being, even in desperate conditions, and to regain the lost voice of a soul kept in silence for too long. So that at the end the caring act could become poetry, where the word poetry comes from the Greek root—*poiesis*, which means “creation”. The caring act as a creation.

References

Bandman CE (2008) A Medical Humanist says good-bye. JAMA 300(2):149–150

Berne E (1962) The basic script of transactional analysis. Games people play

Donabedian A (2003) An introduction to quality assurance in health care, vol 1, 1st edn. Oxford University Press, New York, NY

Freemantle N et al (2012) Weekend hospitalization and additional risk of death: an analysis of inpatient data. J R Soc Med 105(2):74–84

Hobbes. http://www.notablebiographies.com/He-Ho/Hobbes-Thomas.html

Johnson Simon, www.telegraph.co.uk/education/universityeducation/11455882/Scottish-universities-research-funding-cut-by-13-million.html. March 2015

Karebell Z (2012) Reuter’s, Use plutocracy to broaden our economic debate, October 22, 2012

Liebold A. Financial markets and the real economy: the inevitable recoupling, Il Sole24 Ore. http://www.ilsole24ore.com/art/english-version/2014-04-06/financial-markets-and-the-real-economy-the-inevitable-recoupling-145201.shtml?uuid=ABRJMm8. Accessed 6 Apr 2014

Marini MG et al (2014) Narrative medicine to highlight values of Italian pain therapists in a changing healthcare system. Pain Manag 4(5):351–362

Marini MG et al (2012) Medicina Narrativa per una Sanità Sostenibile. Edizione Lupetti, Milano

Maslach C et al (1997) The truth about burnout. Jossey–Bass, San Francisco, CA

Mavromatis J (2012) Why Doctors Interrupt, by Juliet, thehealthcareblog.com, June, 2012

Ovid – The methamorphoses – 1-8 AD

Perkins C (2014) http://www.run.edu.au/cb_pages/news/Funding_cuts_response.php

Rabin RC (2014) 15-Minute visits take a toll on the doctor-patient relationship. http://kaiserhealthnews.org/news/15-minute-doctor-visits/. Accessed 21 Apr 2014

Starmer A, et al for the I-PASS Study Group (2014) Changes in medical errors after implementation of a handoff program. N Engl J Med. 371:1803–1812

A Selection of Narratives

11

This chapter is a selection of narratives from ISTUD research projects in neurology, oncology, haematology, dermatology, ophthalmology, perinatal intensive therapy, and paediatric endocrinology fields. Different diseases, different conditions, different ages. Not only patients' stories are included but also those of caregivers, nurses, and physicians.

As far as ethics is concerned, written narratives were collected only after obtaining informed consent and having informed (when requested) the local Ethics committee or the General Management of the Health Care institutions about the study project. These stories represent a very restricted selection, since all projects planned the collection on a population-based approach, often according to an epidemiological observational sample size. Stories were written by patients via web or on paper.

In gathering these narratives from our international projects, we wanted to preserve as much as possible the wording and meaning of the original stories, as written by their authors. In doing so, we intentionally left most of these stories unedited, maintaining the informal language, grammar, alliterations, pauses, and exclamations used in the original language.

We are very grateful to all researchers, providers, and patients who believed in narrative medicine and shared their experience with us and the community.

Before reading the stories

Dear Reader, what about using these narratives for some practice?

As a first step, simply go through the stories and let yourself be inspired by what they say. Go once without trying to confirm any hypothesis you want to test: an unconditioned reading, through pure observation.

As a second step, try to read the story using the possible classifications reported in the glossary:

- Disease, Illness, or Sickness or two of these elements, or all these elements combined together?
- Restitution, Chaos, or Quest?

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- Regressive, Stable, or Progressive?
- Contingent, Moral, and Core?
- What about the genres used?
- When evaluating the diagnostic path, do you think it was logic or erratic and chaotic? When evaluating the relationship with the providers of care, do you think that it was a productive and rich empathic context?
- What about the coping factor?
- What about the level of facts and fictions written?
- Do you think that it is a useful tool to enter into the real inner patient's realm?
- In some stories, simple prompts were provided to guide the path of narrating the experience of living with the disease: try to understand which are totally free narratives and which have been slightly channelled into "past, present, and future" tenses.

These are just few of the hundreds questions which might arise from reading patient's and carers narratives. Perhaps, there are two additional steps we can suggest.

Third step: after the reading you might like to write what the story inspired to you, what you have learnt from the possible key words of classification, anything new you caught from the story, and finally the meaning you see in this story.

Fourth step: if you wish, you could do this practice and share your considerations with other providers of care, students, patients, managers, citizens, individuals.

Narrative Medicine in Neurology

A 34-Year-Old Woman with Multiple Sclerosis, Diagnosed in 2006: Written Via Web in 2014

I realized that something was wrong nearly 1 year after my graduation: the left half of my body was sore and the left arm tingled. It was a big deal because I'm left-handed and it was hard even to put my signature. My family doctor was telling me that I just had to rest because it was only fatigue. I was feeling always exhausted. The moment they told me that I had multiple sclerosis, I went ahead to seek consultations for a couple of years without success. I knew something was wrong, but nobody was taking me seriously. Until, one morning in October of 2006 .... I woke up and I could not see through my right eye! I went to the emergency room and the ophthalmologist knew what it was. He looked at me sadly and he requested my admission to the neurology department. "Findings" they said. 10 days between analysis, evoked potentials, spinal tap, and CT. And then the head of the department and the doctor who had followed me gave me the ruling. I do not remember much, I do not remember how I felt in that moment. The doctors had explained me the situation and kept on telling—four or five times—that I should not give up, I had to continue my life and that there was no healing from the disease that there were cures: .... yes, I just remember that I said "tell me when I have to start with these injections." A week later, I had my first jab.

I was not sure what would have happen. I just knew I had to fight and that I should not waste time wondering "*Why me*?" Because there is no answer. You're in it and you have to do everything as if there were no tomorrow. I did, however, start a path with a friend psychologist. I knew that I needed it, sometimes I thought to become crazy of rage. In the days immediately following the diagnosis, I did some research on the therapy and began my first few shots. Immediately, subcutaneous therapy three times a week. The heaviest. I quickly realized that my relationship with the syringe would have not be at all easy. I did not want others to see me worried, I was the "defiant" as usual. But a person who recognizes the authority of the uniform and that relies on it. But not so with my people, no. I could not be of concern, I already lived three hundred miles from home . . . I could not demand toll for the unknown anxiety I had. The others around me were overwhelming and apprehensive .... but I needed it, and then I realized that, as I have done a path, they have to go through it as well.

My road became bumpy, tiring, full of question marks. I may spend part of my life without a person by my side and I'm able to be alone, but I never thought that I would have suffered the illness, lady of *solitude*. I saw multiple sclerosis as a ghost that would have accompanied me through life, and it was "my forever". To me, the person who had not wanted to say *yes* to anyone, this was my retaliation. I gave up a job with few certainties. Better fixed salary, just so I would be able to put something aside if my condition worsened.

My achievements have been a hint of recklessness, because I have nothing to lose in relationships with others. Then the courage to learn to play the cello at 35 years of age! I with others . . . who know .... one should ask others. Those very few friends that I have left. The others do what they can with me, but they have their troubles, families, children. I'd rather not be a burden. The environment around me was made of work and music. So I'm fine. The best would be having a partner. But you know, you cannot have everything. What do the elderly say? The only thing that counts is health! Heheh!

Playing the cello gave me comfort. Who cares if I'll never play in the orchestra! My fingers are better than a keyboard and my body resonates with the instrument! Today I will be starting a new therapy, I'm moving in a smaller apartment and that has air conditioning.

Multiple sclerosis for me is an unwelcome guest in my body. The representation of all my limits. The forever that motivates me to try new strategies. My daily life made up of the little things, alpha lipoic acid for fatigue, vitamin D. I bet how many stairs I can do today before stopping. I cannot walk for long distances, run, take ten commitments one after the other. I liked to do it. But that's okay. To be honest, I feel I haven't gained much since I found out I had multiple sclerosis. One thing, however, is that I am more aware of my body and have more desire to not waste time doing things I do not want to do. . . At work they know everything. You have to, so that they become your allies and are quieter and you face the disease at least without bureaucratic anxieties.

If I imagine tomorrow, I wish it were with a person who works a stretch of road with me.

A Woman Aged 25, with Multiple Sclerosis, Diagnosed in 2008: She Left Her Narrative Via Web in 2014

I realized that I was not seeing well through the left eye, everything seemed blurry, as if there was foggy, and everyone told me that I probably had a vision fatigue because of too many hours on the books. I took some days before going to the emergency room ... from there I was admitted to the neurology department for 15 days, to make investigations and to take inflammation away from the optic nerve with cortisone. Since 2005, once a year, around February/March, I would have optic neuritis, which had always been treated only with cortisone at the day-care center for sclerosis. I kept asking if I had the disease, but nobody confirmed it to me ... Then in 2008, I changed the hospital, doctors, and therapies, and I finally got the diagnosis.

The moment they told me that I had multiple sclerosis I felt like dying: I was not sure what this disease was, so I started looking on the internet ... at 17 years of age every street seems the good one to get information ... I wanted to know at all costs to what I'd have to go through.

I decided to look for news everywhere, read blogs, encyclopaedias, and more. I was angry with everyone ... no one understood how I was ... I hated myself because until that point, I had not said anything. I felt alone in something much bigger than me.

In the following days, always with anger in my heart, I pretended I felt good and that it did not touch me in any way and instead, every night, I was alone in my bed crying.

I was angry with the others, with my family in particular, and friends who did not say anything ... I felt different ... a sucker ... that could not have any more fun joyful to them.

People around me were silent ... nobody said anything, never a word of comfort, help, an explanation. I felt ignored by doctors because they wanted to talk to my mother and not with me ... she must always be present, even after reaching 18 ... and it was something that I did just not tolerate ... almost a challenge against her: before, I did not know there was something wrong and now, I did not want to know anything about myself.

... I did not know what would become of my life, my relationships, my future ... I was afraid of not being able to study and not being able to find a job. Multiple sclerosis for me was my verdict, a punishment that I did not understand.

I gave up a thousand evenings with friends, high school trips, and holidays because of the therapy. At 18/19 years, my life was set according to the therapy and to the findings.

My achievements have been several ... I enrolled in law school, I continued to study, I worked a bit, I met many people, I have found new friends to talk about my illness, always ready to encourage me and help me when I'm tired, and I continue to swim at least twice a week.

I speak about sclerosis only with those who can give advice or suggestions and understand my mood and my difficulties. My family members speak little, and when they talk about it they say "the disease that you have" . . . it is the great nameless thing, well . . .

Multiple sclerosis has become a fixed idea for me . . . every day I wonder if the therapy is working well, if I can continue it throughout life, if and when I have some failures . . . it is a source of questions to which I do not always answer.

My everyday life is fairly quiet . . . when I study, the concentration is not always the best, when I do some work at home or in the garden, then I have to stop because I'm tired . . . but everyone can take a break. . .

I think the support I received during my journey has been full of obstacles . . . self-injection therapy made me sick, intravenous seemed to work fine, but because of the risks involved it has been suspended until the arrival of oral therapy, about which I was not told much. . . and as always I had to search the web . . .

No project for tomorrow . . . I live day by day

Narrative Medicine in Oncology

Collection of Stories About a 35-Year-Old Woman in Cancer Treatment in Italian Hospital, Written by the Medical Team Writes and by the Patient Herself, Stories Written on Paper at the Hospital, in 2013

The First Nurse

I met the patient during the first administration. She looked like a frightened and arrogant girl. I inform the patient that, in my opinion, there is a need to place a PORTH A CATH for the therapeutic programme and her poor venous "heritage"; at that time her anger is unleashed. In my heart, I hope that chemotherapy does not cause chemical phlebitis. Getting in contacts with my colleagues because of the successive administrations they would have been responsible for further administration. I re-encounter the patient after 3 months: she is a very sweet girl and willing to talk, probably during this period was able to tolerate fairly symptoms and metabolize the disease as a whole. In my opinion, the patient claims my professionalism that is simply about the correctness of administration of therapy, combined with a good dose of human energy which makes also establish a good relationship of mutual respect and confidence. The patient, to date, has passed the most difficult phase of her treatment programme, so I think I will continue to lend my support as I have done so far.

The Second Nurse

I measure the words because she is a patient who lives with anxiety disorder and therefore tends to weigh what is said. She expects me to be a competent professional who knows how to handle both technical and verbal information of her course of treatment. According to the patient's point of view, the disease is quite a punishment from the religious point of view, as her own guilt for something evil committed. I propose to create a climate as serene and peaceful as possible for both her and her mom who always accompanies her and absorbs much of her moods (i.e. if the patient is quiet so is the mother).

The Third Nurse

With the patient I relate just the needed time to understand how her previous CT was. The patient is for most of the time accompanied by her mother and I feel I'm interfering in a sphere which is not mine. The patient is very young, I'm afraid to say things that undermine her hopes of healing. … When we talk I always try to joke on the negative situations she lives and sees around. If there are doubts about the therapy to be taken at home, I explain what to do and what to avoid to worsening the symptoms. The patient hopefully will tolerate the side effects of the therapy to have a positive result. However, she is quiet and seemingly serene. With the patient, given her young age, I always try to be positive and serene, often I involve the mother as she is the person who always accompanies and protects her. Whenever there are doubts, I always try to solve them, we seek the best solution to stay healthy, avoiding the possible side effects of CT.

The Fourth Nurse

I remember the morning when I saw her admitted to the Day Hospital. She was accompanied by her frightened husband, a man with big and wet eyes. Shortly after the start of chemotherapy I saw her cry, her husband struggled to comfort her, and it was not easy either for my colleague. I approach her at the end of the session and I can only say, "you'll see that everything will be fine!!". I saw her again after 2 weeks, yet sad, worried about the loss of hair, and the news that about positioning the PCH because there was no venous access. A few months go by and I do not encounter her because of shift change. After 2 months I am on my Sunday walk with my husband on the lake and she was the one who recognizes me. She calls me and tells me a lot quieter, "you were right in telling me that it would go well." I see her again in the department for the therapy and she is highly tolerant and therefore this makes me quiet. She trusts us a lot of nurses. I saw her a few weeks ago, very happy because she returned to work. The hair started to grow and she feels much better. I am glad of the change that the patient has made from the first chemotherapy and I hope that our professionalism has managed to bring it to life more peaceful and calm.

The First Doctor

The lady is not a patient I followed directly and my last visit with her was a few months ago so I do not remember exactly her clinical and emotional situation. I remember myself feeling sorry for her situation since she underwent hormonal stimulation for infertility without success, and discovered she had a malignant cancer in the breast. I can only imagine her state of mind and I felt worried for her life. Although the opportunities for contact with the patient have been few, my goal is to prescribe effective treatment without giving toxicity so intolerable as to interfere with the life of the patient. Indeed the patient is young and I would not want that she fails to live her daily life because of the cure.

The Second Doctor

When I heard the story of the patient, a laborious search of a woman who wanted to become a mother, serene in the choice to seek treatment to regenerate into a new life, the disappointment for not having generated a seed and a sense of being ill with cancer, I had a melancholy and a sense of rebellion. I learned from her to accept that life is measured by several meters. We are walking together, we do not need to tell us, one is the engine and the other gasoline. When you jump with the parachute, you chill in the skin and then learn to love the wind that combs hair, and you feel an eagle, learn to dominate the blood and sweat, and eventually will resume life. Take the days, time after time.

The Patient

I have always been a healthy woman with perfect tests, with such zest for life and things to do. I led a normal quiet, relaxing, pleasure, and fun life, in the last 13 years I've been living together with a man who gives me everything, we love each other and we enjoy life. After so many years together, with so much love, we decide to have a baby, but unfortunately it does not come and we proceed with artificial assisted procreation. After three inseminations, after the bombardment of hormones, medicines, and injections, the so longed baby is still not coming. With such bitterness and sadness illusion we go forward, and 2012 does not start positively, we have a death in the family due to a terrifying cancer, but we also overcome this event. Unfortunately, in early April I discover by chance of having breast cancer myself and metastases to the axilla. I say that the year has not started in the best way, but despite that I tell myself "be strong" and try to move forward, with the help of my sweet family. In mid-April I underwent surgery which went well, I'm back again calm and serene and I live in a kind of dream, I don't worry about the histologic test, I think the worst is over, but unfortunately it is not so. The histological test arrives and the cancer was not a light one, it was bully with its proliferation, I don't have positive receptors and I'm forced to undergo chemotherapy. This makes me so afraid, but I am forced to deal with it, the word makes me shiver, unfortunately in a few months I'll be bald . . . I . . . I . . . I will lose my long hair, and then lose the eyebrows, eyelashes, and all hairs will disappear from my body. I do not want to lose my hair, I do not want to wear a wig, and I do not want to undergo chemotherapy. I am forced to do it, I want to live I do not want to die. To get used to the idea of getting bald, I began to cut my hair, stepping down from a "carrè", military, and finally I decided to shave them all and, in no time I'll lose them all. It is not easy to see myself in the mirror without hair, it is very hard to accept, and after many tears I accept my "new hair" and I try to smile. I realize that the effect of chemotherapy is devastating, nausea, fatigue, vomiting are hard to bear, and I realize that losing hair compared to these effects is not so as bad. I have moments of anger, and I say this because I have to endure all this, what have I done wrong to have this, and initially I' m angry also with the Lord. I asked for a child, and at the end I got a cancer, the effects of chemo are like those of pregnancy but the difference is remarkable, I'm sick of fighting cancer and of not having a child. I cannot stand the sickness I get after chemo; you're fine the day before, it seems that the nightmare is over and it comes back to surface once the chemo is injected you have to fight to not feel sick, not to let yourself go, not to cry, and overcome this trial the best I can. Yes, I guess it's called trial, life's trials, hard to understand and fight. Cancer changes you, it makes you grow; it makes you meet special people, and people like me who are fighting and with whom I share a kind of complicity and understanding. I have changed since the disease, of course I feel stronger and the stupid fears I had before are gone, because I faced with extreme bravery my biggest fear: the enemy called cancer. I've always been afraid of cancer, this particular disease that changes the life of a person, which causes death, and for this reason I have always wanted to be far away from it, I have never wanted to be informed on the topic, I wanted to be ignorant and ignore believing that by doing so it would never have been part of my life. How wrong I was . . . Now I'm still on chemotherapy, a biologic drug that fortunately does not have contraindications, my hair are growing back and I am calm, I'm slowly recovering my precious life—life that cancer wanted to take away from me. . . But I'm a fighter.

Stories About a 46-Year-Old Man in Treatment at an Italian Hospital Written by Members of Medical Team and by the Patient as Well: Written in 2013 on Paper

The First Nurse

During the first treatment I did not have the chance to get closer to him. Then I made his acquaintance: he is a solar person, I think he is aware of the disease and the prognosis being a young man . . . His treatment does not imply a prolonged stay, his time here is limited, and we often do not have more than 5 min to interact while I learn about his health. I'm not sure—because I was told by a colleague—but I believe he does not have an easy family situation, because he is a widower with a daughter and remarried; who knows how many thoughts crowded his mind but nothing apparently transpires. I think the patient is serene and I have no specific aim with him, only to continue to be professional.

The Second Nurse

He is a patient who is always nice to interact with because he is always sunny and friendly. Knowing the patient's family history (a widower with a child), I'm sure that it is crucial for him that the child continues to have a point of reference with the woman to whom he is remarried now, so that she will be there in any case.

The Third Nurse

I have no problem talking with the patient, know his story from the beginning, and in spite of everything he is always, so he makes me feel positive too. He does not expect much from his illness so this is why he tried to protect his new family, especially his little girl. In any case, he is never negative, he always tells the beautiful things that actually happened. I honestly do not know what I can do for him, if not to definitely agree with his positivity.

The Fourth Nurse

I met this man during the first administration of chemotherapy. I was available to listen to his story, certainly not an easy one. Accompanied by his "wife", a daughter of school age, a widower for some years. (His previous wife died of cancer disease.) I'm impressed by the affection the woman shows towards the patient's daughter. He was very well informed about treatment and aware but very optimistic and hopeful. The best piece of news was in December when he tells me, during the chemotherapy session, that he and his partner have decided to marry. I still follow him and his path continues positively due to his desire to heal and stay healthy. The patient expresses a desire to be comfortable and spend more time with his girlfriend and his little girl. Every now and then I really think that the patient is well and can heal, so to spare further pain to his daughter who has already lost her mother. I like to interact with Mr. X because he is a person who always has a topic to discuss about. . . . I think that the presence of a "fixed" woman in the family makes him definitely more serene.

The Patient

Hallo, my name is X, I was born in L. and I am 45 years old, I live in V. and I have a daughter named X, 12 years old. My daughter lost her mother 4 years ago, after a period of illness. We now live with my new wife and we're fine, we live peacefully, or at least we did until June 2012, when new events upset us our life ..! I was admitted in the hospital for an illness and I was diagnosed with pancreatic cancer. . . In a minute life changes, my thoughts turn to my wife and to my daughter and how to deal with everything. A thousand things that go through your mind, 1000 and 1000 *whys*, but no answers. The first obstacle is the operation, then the heavy postoperative period, and now all the cancer care, which with the drip will inject chemotherapy into my veins, with light and heavy side effects: there are days that are good days and you feel better, but a question rumbles constantly . . . Day after day and is why . . . Why me ?? Well I do not know! I have no answer, it happened . . . and it happened to me! And the same happens to other people, younger people, older people; one person with one type of cancer and another person with another type of cancer, but still people who, like me, have a life to live;.. and when the cancer is all upset, it comes without you even realizing it, and you find yourself fighting with all of yourself for your life. Your mind runs, talk with your loved ones and make yourself feeling strong, the mind will continue to present the usual question and the many fears, but you are convinced that the only thing that can give you more strength is BELIEVING! Believing in the what the doctors and nurses are doing; you know they are there and that can help us through their dedication and sensitivity to understand how and what to do when something comes along, when the symptoms manifest themselves under one form or another . . . Knowing that if we do not want, if we do not believe, the cure is worth the half, so I know and I am convinced that the treatment is effective and I have found the strength and courage to live, looking in, but above all without feeling pity for myself and avoiding to keep on wondering "why," and being brave and optimistic so to look toward the future and fight the challenges that are presented to me. Affectionately X

Narrative Medicine in Haematology

Narrative of a Man, Caregiver to His Wife: Story Written on Paper in 2014

When my wife began feeling she was not well, I noticed she would easily crying for anything all the time, thinking of the family and the future; we tried to figure out what the problem was. To understand what was going on, we turned to a specialized center and we found out about the disease, myelofibrosis. However, we were not convinced and we moved to P. but the diagnosis did not change. My wife began a treatment with X with initial improvements in values. I have been suffering because I saw my wife crying and not accepting the problem, but I tried to give her positive thoughts, to distract her and help her psychologically.

While I could see my wife suffering physically, I felt powerless.

My emotional state was quite despondent, a detached mood hovered over me; then taking care of her became difficult due to her lack of desire to talk and of because of her strong pessimism.

My wife was admitted at the center and I thought they were taking care of her, giving her appropriate care. She visited other centers because she wanted to reach a correct diagnosis. I felt taken into account as part of the medical team.

My relationship with my wife during the period of treatment was positive.

At home, the situation was difficult, often my wife was nervous, because she complained of my lack of proximity due to my frequent work commitments and the people close to me were hit by the difficulties that had come between me and my wife. It seemed to me that my wife's illness had a depressing effect on me because I wanted to help her, but her character and my wrong ways day by day created separation and conflict with my wife, and she often would not sleep at night or had nightmares.

Now, with the help of the care of the family my wife is more serene, but her mood swings often lead to situations of tension that lead to imbalance.

My feelings are troublesome, figuring out how to help and how to get close to her in her distress.

At home there are moments of nervousness because my wife cannot stand some of my behaviors, but it is also true that she is very nervous and agitated at the slightest dispute and I do not know what to do.

I think that treatments were good, but we should have been given also an adequate psychological support, to us as a couple to avoid stress due to misunderstandings. In the course of the illness of my dear, money has never been a problem. The only thing that matters is the health and harmony for her and the whole family.

If I think of tomorrow, I want it happy, peaceful, because there is still much to do and enjoy with my wife and the family we have created.

Narrative of a Woman, Caregiver of Her Husband: Story Written on Paper in 2014

I was at home when my husband started to feel sick and had an abdominal colic. To understand what was going on, we went to the emergency room. The moment they told me that my husband was suffering from myelofibrosis, I had feelings of panic. I thought the worst and decided I would stand by him at all times.

In seeing my husband, I physically weakened myself. My emotional state was miserable, but I had to be strong. With me, he had ups and downs, there were times when he wanted me always close to him.

My husband was visited later at the center where he had the diagnosis of his disease and I had the opinion they were providing him optimal care. He visited other centers as he was sent to a research hospital to be able to take an experimental drug.

I have never been at the center because there was no need. My relationship during the period of treatment was normal. At home the situation was normal (with the intake of study drug), and the people close to me were normal.

It seemed to me that my husband's illness at the beginning had a devastating effect on me. Then, when he started to feel better, I've been better too. Of course the disease is always there... But until everything goes well, all is well then we'll see.

Now the disease is managed and my husband is stable. My body and my feelings are positive. We have learned to live with the disease and think positive. I find myself thinking back to when we discovered the disease and when my husband took the drug, and how he felt physically, and to how moody he was.

If I think about tomorrow I would like the situation to remain stable as it is today and I would like to hope in a miracle! An effective therapy for a complex healing without transplant.

Narrative of a Woman, a Patient: Story Written on Paper in 2013

I was under medical supervision and I underwent chemical investigations following a deep vein thrombosis (December 1999) when I was asked to perform a bone marrow biopsy to detect possible blood disorders. I was advised to go to X to make this investigation. The haematologist diagnosed me with a chronic myeloproliferative disease, at the beginning. When I was told "myelofibrosis", at first I did not realize the importance of the disease. Later the doctors of the center explained me everything and I became further informed by reading and gathering information. At that time, I was in a state of non-acceptance of the disease and I was very stressed by previous experience. I thought it was necessary, however, to rely on the medical center in order to keep on, as long as possible, leading a life similar to what it was before.

At home, however, I could go ahead and do everything as usual, except physical activity. But I would become tired sooner than usual. At work I would perform my business with greater commitment because physical activity is not required. I have avoided, however, engaging myself in strenuous activities. Away from home I managed to take relaxing walks.

With my loved ones, I would express nervousness in situations of physical fatigue. Over time I would become easily irritable as I felt physically tiredness. I felt that my body got tired easily after each prolonged effort or commitment.

At the center where I had received the diagnosis of the disease, I felt adequately followed.

I always referred to the same center because it was qualified for following the disease, although at first the therapy prescribed caused a decrease in my platelets. When I was at home, I continued my usual activities because I had a young son who required energy and commitment.

In some moments I feared the disease would lead me to death in a short time, other times I wished I could have been cured by a new therapy that had not been discovered until then.

The spleen was enlarged, but its steady growth and my blood was low in oxygen and other elements made me easily feel tired.

Now I feel that the disease is slowly progressing because I'm getting tired more easily and I cannot say how far the disease has come to affect the blood production.

My body reflects the lack of physical activity and reflects the psychological need to comfort myself with food. I gained weight and do not feel like going on a diet. I feel physically inadequate compared to what I would like to be, and compared to how I was 10 years ago. I also have to take into account the older age. I feel I can continue to live decently if the disease continues to proceed slowly.

I hope that we will soon have access to a new treatment that takes control of the disease. Therapy with X used for only 1 month has been ineffective and even harmful. At home I can do what needs to be done with the help of a domestic aide. This past summer, I have complied with everything needed to accommodate my sons and their families to spend holidays with them. In the evening, I felt very tired but I wanted to distract myself. At the end of the season, I was somewhat exhausted physically and psychologically as my sons still do not understand that they need to take on responsibility and help me around on the rare occasions I need it.

At work, I get to do what I am asked to do, but I no longer really want to go out on a mission as often as I used to before. Outside the household, I can maintain friendships and leisure activities.

When I think about tomorrow I do not want to think about how it will be and if there will be one. I just hope I do not have to bother my sons and that my youngest son has finished studying and will not need me.

Narrative of a Woman, a Patient: Story Written on Paper

I was doing my usual housekeeping, at home when I experienced a tremendous pain in the center/below the ribs. I had a very swollen belly and I thought it was gastritis. A constant pain ever felt before continued for 1 week without improvement. I asked for help from a friend of mine, a surgeon. I underwent blood tests and the CT scan. From the tests, high platelets counts emerged and the doctors thought to an infection.

The CT confirmed an enlarged spleen. They sent me home and decided to perform the CT a couple of days later, since I was still in pain and agony. The second CT discovered vein thrombosis and they sent me to X in the medical clinic where I was in-staying for a week. I underwent a gastroscopy and bone marrow biopsy . . ..

After I made a visit in hematology where they explained the MF and other myeloproliferative disorders. The moment they told me that I had myelofibrosis I felt like a kind of relief to have 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 on my life. I was looking for information on the internet and found depressing information, of survival of 18 months maximum, debility, etc.

I thought of my daughter, not to see her grow and be there for her. Afraid not to be there any longer, could not do all the things I want.

I stayed for 1 month at home. I had to cancel a planned trip with my daughter in the U.S., a thing so desired. I felt like a wreck in general. At work I could somehow detach from negative thoughts, it kept me to fill the mind and stay surrounded by nothing but disease. I felt that my body was not under my control, but perhaps even telling me to change something in my life and that I was actually very strong and successful.

At the center where the disease was diagnosed I felt taken care of myself in an attentive, knowledgeable, helpful, skillful way. When I was at home, I often felt sad and frustrated, I felt if I had something useful to do and I kept myself busy. I was afraid that I would not be able to do what I wanted, but I had hope to be able to overcome the disease and symptoms. The spleen was large and gave me slight discomfort at some time.

Now I feel normal. I feel I can do almost everything even though I'm careful not to push too hard, to respect my body that in spite of everything keeps me alive and keeps me hard, and the disease is now a part of me. I do not understand why it happened, but I live there and I am sure to find a cure and improve and I do not give up. I enjoy my house, I'm careful not to get too "black" and depressant thoughts. At work, I can remove negative thoughts and focus on something else. It's my therapy and I cannot imagine myself not working. If I think to tomorrow I will 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.

Narratives in Dermatology

Narrative of a Man, Aged 64, with Diagnosis of Chronic Urticaria in 2014: Story Collected Through Web

Since I was about 40 years old, I am suffering from Lupus: so far, this enemy of my skin brought damage both aesthetically and psychologically for the "impossibility of living" in the light of the sun. I spent my years in search of the shadow, I gave up the joy of swimming in the sea with my son, I had repulsion to mountain walks, I conditioned the lives of those I was living with me because I was unable to live a normal life. All this in order to survive and not clearly tell my pain to others because I had the clear feeling that they did not understand. Too many episodes: my avoidance of the sun had been a question mark for whom was close to me, being all certain that what little exposure could not cause any damage.

Lupus has been for me an abundantly intrusive mate in my life, as dreadfully present as cholesterol. For the rest, often or sometimes, to all "irritation" that my skin had, but never traumatic: it was said "is a temporary irritation" . . . you will be allergic to something ".. A poor judgment of popular medical science.

Not even in the early summer of this year, and the lupus, following a heavy emotional stress and an inevitable sun exposure filtered with creams with protective factor 50+, decided to turn the battle itself the attention on urticaria. Despite the usual treatment with antirheumatics and I remained constantly at home in the shadows, throughout the summer without ever leaving except for three times with proper precautions protective, lupus attacked mercilessly expanding its area of action: in addition to face, an intense attack had started on the backs of the hands and of the forearms. Therefore, the change from the usual lupus were all these redness, burning strong, various injuries. At first I thought that lupus was alone in threatening me and get me very painful burning sensations, feelings of warmth similar to sunburn, redness, graphic signs such as grooves and striations especially on the arms. The same signs that leaves you on your pyjamas when you twist your arms and, upon waking up, you are drawn by arabesques on the skin. But you know that those drawings after night disappear, and above all, they do you no harm. My arabesques instead burned and shrunk as when a wound is doing a scar.

I contacted the dermatologist, who has followed me for years for lupus in very short time. In 2 min, after a test on my back like a series of painless scratches and a visual examination, he said, we have a partner that is an unpleasant rash in addition to lupus.

Well, what should I do and how much additional danger now than before... Difficult to give certain answers, this was the reply, complicated mechanisms, but certainly we try to resolve the situation by moderating the reactivity of the immune system . . . hence the usual drug for lupus and antihistamines .... now we are in

November and I am continuing the same therapy without permanent solution of the stinging phenomenon .. some day goes better, some days it gets worse ..

Here, between the pain and discomfort that this rash is creating me and fear that is a prelude of particularly harmful messages, definitely wins the fear ..... all this affects the very quality of life ..... the only positive thing I know is that I have a lot of confidence in my dermatologist so I think he's doing the right thing in the way of therapy he suggests to me . . .

. . . If lupus is associated to rash chronically, then cholesterol and then something else, I begin to understand those whining speeches always heard on the lack of health by old people, when I was a boy .... they told me that life is a cycle, a spin of the wheel that is for all .... well, I knew but I did not think . . . the novelty is that I'm living and I think with a little 'of sadness . . .

Narrative of a Woman with Psoriasis: Story Collected on Paper

"Together. My Psoriasis and me"

I do not remember exactly the debut. Perhaps the first period of the university. Or, the first responsibility. Many people say it depends on the psyche. This large, unknowable container where conscious and unconscious are mixed: a box that holds emotional, processes, catalogue, forgets . . . and when not truly heard, sends the bill directly to the sender. The account can take various forms: anxiety, depression, trouble live, various forms of curable diseases, and a large group of events incurable. In my case, Mr. Unconscious perhaps pulled Psoriasis: begins with caution, timidly, then gradually takes courage and, consequently, the field . . .

And the story begins. I would not call an ordeal. I think I can say that, after a moment of discouragement, I decided to accept this strange travelling companion. Certainly, it was not easy to share everything. The disease is a type intrusive, exhibitionist, if speaking would almost certainly talkative. She, the disease, does not like people, and as a result, people do not like her. She avoids crowded places, sometimes even those with small populations, she requires attention and if not gets puffed up, moves, changes shape, is a weapon against you. She has a capricious, want to control . . . this does not compromise. And she is hegemonic like all strong characters. Even when she subsides, she does it for a few moments, short periods that you glimpse the arrival of an armistice but then ...... suddenly she rebels, manifesting itself in all its power. Every now and then pulls seductive aspects. . . but always to get more. There is very good: you cuddle, you bonus, and you isolate in this world of you and her ....

. . . The skin becomes more alive, more vibrant, more receptive: the request usually comes in the form of shy itching. A "nothing", an innocent rise, you will say. No! The beginning of the catastrophe. You begin to scratch, scratch, scratch, till you drop. You turn into a "scratch-dependent" and if you do not feel, I procure ....Are you sitting at the bar? In a somewhat difficult meeting? A bit 'of anxiety? Here the onset of itching, his trustworthy employee, who knows where to touch and knows how to reward you ....with some priceless second of genuine enjoyment.

Like all pleasure things, this also presents difficulties. “Do not scratch, lady, I recommend”, “Try to stay serene and calm”, “You will see that this will diminish.” And the devastation starts freewheeling and the emotional box over there to observe: “But is not that we have exaggerated? Okay gratification but up to strip the flesh . . . .and really unbelievable!” “Let’s send a signal, do you meet someone to help.” “Who? That stubborn head there? But do not you know it’s from primary school that she does not listen to anyone? .. “Come on, let’s make a last attempt. If nothing happens, it will mean that you’re right . . . and we leave it to its fate.”

Then after a while, countless embarrassing situations, avoidances pitying (“I hate the sea” and you would move all year in the Maldives), pathetic circus disguises (“I only like huge dress” and you would get into perforated nude-look pants), YOU DECIDE THE BIG STEP: “Hallo doctor, I’m . . ., do you remember me? .... That case of psoriasis of a few years ago? Noo ?? Well, it’s been a few years, in fact .... More than one ?? .... How sometimes time pass by, eh? Okay I would like to get an appointment .... Urgent? Nooo, no, I do not think maybe you .... I would say yes .... .Better to see me right away? Tomorrow 15:00? .... And ‘...... .. perfect.”

Narratives in Ophthalmology

A Man, Affected by Senile Degenerative Maculopathy: Story Left with Oral Interview in 2014 at the Centre

I’ve been an engineer for 53 years, I have always drawn well, I saw better than the others. I worked like crazy, worked very hard, 10–11 h a day. I had a professional office, I stopped by 5/6 years ago; now I only work for friends. I do my job and this makes me very very happy. Loving one’s job is vital, and I always did mine with pleasure: evaluations, expert, build, design, invent things. I liked drawing, sketching. Now the computer fans all over them. Once there was more our effort. Technology was younger but it was more manageable . . . Now you must be careful to put in the calculations, if you mess one thing, everything screws up.

13 years ago, I realized that I had an eye problem: I liked the dartboard at the funfair, and suddenly, I could not see the target. And then, I saw the lines that swayed in the street. I went to a doctor but he left me uncertain, he did not tell me anything definite.

I then went to another doctor in France, and then by another always in France. Things are that between one thing and another, the eye has become dry. And then, he pushed me to surgery of cataracts in both eyes, which was totally useless. Then they sent me to another doctor: he told me I had to do the injections and sent me to San Martino: here I have 3 + 1 course of injections.

Now I find it hard to read but I react fighting. I liked to read. I wear a helmet with the lenses, I think it’s called Magnifier. And then I use audiobooks. Audiobooks are a good thing, I hear them in bed. The problem is the technical books. I cannot see the geometric shapes.

The stronger limitation is reading, and the car. However, I arrange as I can, even if I do not drive since more than 2 years. I do not want to endanger the lives of others. I have a bus pass and here in town I'm moving well. If you start feeling sorry for yourself is over. Once I had to go to my son who lives in Paris by train, I was wrong and I took the train for Turin. It's unfeasible by plane, I don't understand where to go. My kids are all gone, one in Paris, the other in Singapore.

I have also had problems with arthritis in the hip, and that gave me the most trouble. I'm managing also this. Swimming, I love swimming. There are many alternatives. Now I am more careful to squirts, and I reflect more. I use my imagination. I would hate to see us not at all.

A Woman, Affected by Senile Degenerative Maculopathy: Story Left with Oral Interview in 2014 at the Centre

Mine was a normal life, I was a housewife, I was at home with my siblings and taking care of my mother who had Parkinson's. I liked the music, played the piano as a girl but since I got married . . . I was not born to be married! But at that time, you could not, you were labeled a spinster. But if I go back, I wouldn't marry. My wish was to become a girl of a mission in Africa.

I already as a child I was short-sighted, I could not see the blackboard . . . Then the teacher called my mom to tell her I had not seen the numbers and from there I started my ordeal if I may say so. I put the glasses and at that time was discrimination, you are teased with nickname as Goldeneye and stuff like that. Then at 18–20 years I went for rigid lenses, but I was still short-sighted. And then, for the lenses I have always had problems of eye discomfort, conjunctivitis . . . I did not miss anything done to my eyes! And so, I quit after 20 years with the lenses and I came back to the glasses. For 12 years until recently, everything was normal. Then blood pressure increased, also in the eye, but I did not go to regular controls. I have a character like that. Then at some point, around July I began to see strange faces, ugly faces. I have done three injections and now I have control for the retina. Now I see a stain, I see the peripheral it but I do not see the center. Before I went by my eye doctor who gave me eye drops and just now from July took me here and I come also for the pressure to the retina.

It goes wrong, because I cannot see. Because the good eye is nearsighted so I cannot see. If I had to take a train I'll lose it, a plane even less. I have invalidated so many things. Now I have to replace the lens of the eye good to make it stronger. The last visit I did, they told me that the other eye is not dead . . . Maybe you can do something . . . now reading is a problem, including eyeglasses . . . It 'a mess!

By injecting therapy, the stain has become less dark but there is more fog. I see all day as if I had a mist before my eyes. And now you have to see the good eye, because if I'm part of this too . . . blind! now I have to figure out what this pressure is it may also depend on the body's pressure, who knows.

All things are important in the human body, but the view is terrible. Good thing I've got a character that shake off a bit'. I try to play down. But if I were to have a computer, or crush the keys of television . . . is terrible! To date, there are many limitations in my life. Of course, the age . . . But I carry on. With my temper, I don't want to have people on the side, I live alone and my sister would like to accompany me but I do not want. I am too independent.

Narrative in Perinatal Intensive Therapy

Narrative of a Mother of a Premature Baby: Story Left on the Web in 2015

The period of my pregnancy was completely normal . . . At first, I was fine. Then, at 22 weeks, a small leakage put me in alarm. I rushed to the hospital and I was admitted for an ongoing infection. I was losing the baby, I was already dilated to 3 cm. It seemed I had to give birth at any moment and losing the baby. On the contrary, everything stopped and the pregnancy continued for other 4 weeks. Terrible weeks, spent in the pathology of pregnancy, with the fear that the child could born at any moment.

Since I was admitted so fast, I have not even thought to continue. What troubled me was being in a hospital bed, while my eldest son, at that time 3 and a half years, was at home with my husband, who then among other things worked in another city and couldn't do enough to manage it all.

I found some fantastic doctors and others less, including gynecologists. Mostly no one knew what to say, no one could make predictions about how long I would be remained in those conditions.

When I felt the first signs that something was not going as I expected, we decided to run to the gynecological emergency. I was immediately hospitalized. I had left my eldest son telling him that I would be back after a few hours, but . . . no.

When I arrived in the center of Neonatology, doctors initially led me in the delivery room. I spent hours and hours there, I seemed to be losing my baby, I was only 22 weeks. They told me that I would have given birth within a maximum of 24 or 48 h. Fortunately, they were wrong . . .

My moods in those moments . . . I wanted this to finish everything as soon as possible: if I had to give birth to a fetus of 22 weeks, I wanted it to happen as soon as possible, to come back to my other son who was waiting for me at home. I listened to the other mothers who gave birth, the cries of the children who were born, and I felt like in a nightmare. I was wondering whether or not I wanted to see my baby to die. I was desperate. . .

Actually, I then pulled another 4 weeks that have saved the child. One day I started having contractions, *I have broken the water*: there was nothing to do, one could not wait any longer. I was rushed to the delivery room and I did the C-section. I was lucid, calm. I kept telling the doctors to call neonatologists quickly. My husband was trying to be strong and optimistic, to keep our spirits for another child. My parents were haggard and terrified. We have been very close to each other.

I met the nurses and neonatologists of M. which were for long months my references overtime. I asked all to them who have always been fantastic. I was afraid to go see my baby at the beginning. Then when I saw so small and so perfect … I felt strong. And I thought, “I’ll take you out of here.” I pulled the milk and colostrum see in small syringe connected to her feeding tube and this was nice, I had the impression of doing something concrete for him.

There are no words to describe the wonderful staff who followed our baby. They were professional from the medical point of view, but also extraordinarily human. They made those terrible months an extraordinary life experience. The treatments were explained there day by day, we were taught the importance of waiting and patience.

I was trying to force me, to be normal with my child at home, to be in the hospital every afternoon for marsupial care. I felt strong, full of energy. I moved to M. with the bike, carrying bottles of milk that I had pulled every 3–4 h. I did not stop ever.

Well, it was hard, especially for my eldest son. Everyone was trying to help, to get busy. To me it was important to bring my eldest son to see his little brother in the ICU: it helped me to understand what was going on, he was not impressed, indeed. He still remembers his brother’s tiny little hand.

Our life was completely changed, after a month and a half after the birth the baby has undergone a delicate intestinal surgery. It seemed that he could not make it, we were ready for anything, and then … The positive aspects were the relationships with doctors and nurses and the unbreakable friendships that are born with other moms of Neonatal ICU. A unique solidarity and complicity.

After a while ‘there, I felt at home. I loved the marsupial therapy, unrepeatable moments.

Before discharge, doctors have told me that the child would be followed in the follow up. We went home with the monitor to the breath … that anxiety! I felt a bit lost, I longed to get out of there, but when I went home I started to feel afraid, I was no longer protected as in the hospital.

We went out December 23 from the hospital. Beautiful days, even though we were a bit ‘terrified that something would happen …

The controls in the hospital, the care that followed my son at that time and the pediatrician … The first time I seemed to always be in the hospital. The thing weighed on me, because I was afraid that something was wrong … then the controls were gradually thinned. Even my pediatrician has always been very good, competent, and friendly.

My life with my husband and the family was trying to get back to normal, but at the beginning it was not easy. I felt a little ‘emptied after months and months of adrenaline to a thousand.

The resumption of work …oh, I had my task, I was lucky, I started gradually, without haste. It was hard to leave the child to other …

My son today … He is a great joy. He’s fine, he did not report any type of damage. No one could imagine seeing his story of baby born 26 weeks with 830 g in weight. When I see him in the morning I feel almost guilty: I have not deserved this chance, I just happened upon. And I wish all the mothers who were with me today to have healthy children, intelligent, cute as mine.

Today we continue with the follow-up but the child's condition now falls to normal. He gets sick like everyone, he has just started kindergarten and has no problem.

I'm still angry to think of losing a "normal", second pregnancy, not being able to give birth naturally or breastfeed. I would love another child, even though my husband does not want even to mention. But I gained so much: my life has been enriched, I grew up and mature. I am happy, I have learned what matters in life and what is not. The child grows well, for me is a small miracle.

Narrative of a Mother of a Premature Baby: Story Left on the Web in 2015

The period of my pregnancy was . . . A complete reversal of the usual way I thought . . . I always slept. . . I slept a lot both night and day, I got tired quickly, I had a dreadful hunger, frequent mood swings. ..before getting pregnant I weighed 50 kg and I am 1.62 m . . . I was doing aerobics regularly . . . I loved swimming, cycling, long walks . . . I slept very little and only at night . . . getting pregnant was (as well as an immense joy) a total change. I started gaining weight very fast . . . 3 kg already the first month . . . around 17 until the 30th week . . . when I gave birth by emergency caesarean section for preeclampsia.

In pregnancy, even though I was forcing myself to do something (even a simple walk) I was doing wrong . . . if I was not sleeping in the afternoon . . . I had very strong headaches.

I visited a gynaecologist once a month . . . he performed the ultrasound (internal for the first three visits). He weighed me . . . and regularly reproached me without giving me any directions and without explaining the risks to which I was getting into. I measured my pressure before pregnancy and it was low . . . already the second visit was a bit 'high . . . but the doctor considered my pressure normal . . . only later he told me to remove the salt from all foods . . . and when my ankles became swollen, he had me do tests to measure the amount of protein in the urine . . . I was already in the sixth month and a half. Proteinuria was skyrocketing and high blood pressure. He then recommended hospitalization.

Everything I've learned about gestosis I learnt it from reading . . . I was never explained anything . . . yet now I cannot understand why . . . I guess to not be alarmed . . . but if I had not documented myself, I would come to the hospital without having the faintest idea of what was going to happen. I was reading an article about a girl of my age suffering from preeclampsia who found herself looking after a premature baby . . . Without ever having heard of it before. I burst into tears .... I did not even know anything of prematurity.

I gave birth in the hospital . . . it was dirty, poorly organized, not refurbished. But the neonatal ICU is running and will always thank them!

After a week of hospitalization my condition got worse . . . the nephrologist told me he could expect no more than 24 h because the kidneys were suffering . . . he did not tell me more about what was coming not to alarm me. . . further pressure on my family, and we decide for cesarean . . . I'll never forget the words of the gynaecologist who told me I had to sign a consent . . . but more than his words what hurt me even more was the tone and detachment with which he uttered: Ms. sign these sheets . . . your daughter almost certainly will die, at least we'll try to save you. And I was crying like a full river. . . And he again, lady but did you listen to me? Did you understood what I said? Then a gynecologist who was in the room with us intervenes and tells the doctor "give her time to calm down". I arrived in the operating room so tense and nervous that the staff said, it seemed to be cutting an apple! Then . . . the sweetest sound I've ever heard . . . my baby . . . a little moan . . . but this was enough for me . . . she was alive . . . I saw her . . . the paediatrician took her right away . . . I had news of my baby from my husband . . . paediatricians spoke with him . . . that I was informed that she was not the strongest . . . and that they have intubated her. I saw her in her crib the next day . . . finally after 3 days I went to her with the wheelchair. It was me . . . my husband and my baby in the tiny incubator. . . there was only an assistant who controlled that the alarm would not ring.

Such a sense of helplessness . . . of inadequacy . . . sadness . . . endless! For days, I wondered what was the wrong . . . Not enough to touch . . . a deep pain . . . I shattered my heart. Seeing my daughter so small . . . helpless . . . suffering . . . and not being able to do anything . . . just suffer with her. I always miss the first contact . . . the first bath . . . the first change . . . things that others have done in my place . . . even the umbilical cord . . . I was not there when it fell. I was on a new planet . . . unknown . . . that sounds . . . smells . . . machinery . . . never seen before. I remember the anxiety when the alarm rang . . . terrible, the dream of the night . . . and I woke up with a racing pulse. Go home without her . . . how can you explain something like that . . . you cannot . . . If you do not live it yourself you cannot understand . . .

I knew how I would call my daughter since I was in high school . . . and I fell in love with philosophy . . . Sofia . . . then when I found out that Sofia (greek) is the same as Sonia (Russian), that is my name, I fell in love . . . Our Sofia was born in the 30th week . . . 1135 k to 42 cm . . . All eyes . . . bones and skin . . .! She was intubated because of hospitalization in the week prior to the cesarean they injected me 2 times the B . . . but she often needed oxygen. For more than 2 weeks she was fed parenterally.

My husband was immediately positive . . . and with me he always showed to be strong and cheerful . . . even while the child was inside the incubator, he joked and talked as any loving father . . . he wiped my tears . . . and made me strong. . . he supported me and helped me in everything . . . especially during breastfeeding . . . he was close to me in the room with the breast pump . . . and he always tried to make me laugh! But I knew he was suffering . . . and that fear inside devoured him too . . . The family . . . grandparents and uncles came every day to watch the progress of Sofia from behind the glass . . . tears . . . smiles . . . strong emotions for them behind glass . . . the sense of powerlessness was amplified . . .

There was a paediatrician who had empathy towards me, that I have not seen in others . . . and not only with me but also with many of the relatives who populated the ICU in that period. A big problem in this ICU was and I think there is still . . . the many pediatricians (as well as all nurses) working in the center did not have the same answers to the thousand doubts that a parent of a premature baby may have.. .. and I think this is a big gap. Be told one thing by a pediatrician and the exact opposite by another pediatrician . . . this destabilizes and confuses you, or at least me. Fortunately Sofia did not need special care . . . she got no infections . . . she only had to gain weight . . . learn how to suck

I started to feel better, after the second week of ICU, when my daughter finally began to feed on the breast (again uncontrollable tears ..but of joy!) . . . she has been moved from the incubator to warm room and everything began to seem more "normal" for me . . . my life was there .. I would get up in the morning I prepared and I went to her . . . the entrance was at 9 . . . but often for problems of other children there was a delay to let us in . . . I was there until I came home at 12.30 and then back again from 15 to 21 when I was kindly asked to leave. Everything had become so habitual that . . . when it came time to bring Sofia home . . . I began to fear . . . fear of not being suitable to be a normal mom (alone at home with no equipment and doctors around) for a small extraordinary premature baby!

My husband after the first week of life of Sofia returned to work . . . we were meeting in the afternoon at the hospital. Even with the rest of the family we met always in the hospital . . . or heard each other by phone at lunch or dinner . . . they invited us to come to their house . . . but we refused every invitation . . . we accepted only one of the Easter dinner . . . but the being there with them . . . and not with our little girl made me feel bad.

Before discharge, doctors have told me to avoid contact with people. Sofia was still very small and therefore very fragile . . . 1650 k (was discharged April 5 I was in isolation at home until then 22 June I opened the doors to close family . . . the others have to wait until the last of July). keep her warm . . . avoid sounds and bright lights . . . practice extensively the pouch therapy. It gave me the schedule of meetings to assess the growth and for eye examinations . . . ah, and also that in the period winter I should vaccinate her. Who can forget the moment when they finally released the leg of my Sofia from the cable that kept her connected to that damned alarm . . . and that once I picked her up . . . there was no clutter of wires. .. machinery . . . annoying sounds . . . but it was only me and her . . . a mother and a daughter . . . and nothing else! A whirlwind of emotions . . . liberation . . . joy but also anxiety . . . anxiety . . . As all the way until then .... positive and negative emotions together.

The first few days, or rather the first few months . . . it was very tough . . . my husband and I took turns and slept 3 h each .... we never removed our eyes away from her . . . we would not turn off the light . . . in case she choked with milk. At home I was alone . . . panic. Then there were those moments of tranquillity, where there was only room for the joy of having made it, looking at her and think, so small yet so strong!

The first bath .... I was scared . . . but how nice it was. . . my daughter immersed in the hot water in my hands . . . wrapped in pampering and sweet songs . . . unforgettable! For all vitamin supplements and drugs I took a scaffold to put them in order weekly and times of administration . . . when I had doubts or fears . . .I always called the pediatrician with whom I had established a relationship.

The child grew and pediatricians were always satisfied. The only torture remained the eye examinations . . . that always ended with tears of my daughter and myself!

Since my daughter came home with us . . . I never separated from her . . . the first time that I left her alone with my sister for 2 h was towards the beginning of December, Sofia was 10 months . . . I preferred other people could not keep Sophia in their arms. . . I was wrong . . .I was still taken by an anxiety that I could not control. And that makes me think of how it would be a great help to have a psychologist as a support in this path. A role that in this ICU is completely missing.

Today my girl is wonderful .... 18 months, sleeping in her cradle . . . only a few nights she fell asleep in our bed. . . she eats everything (except the pasta and fish) and she eats alone! She loves music . . . and books .... she always wants me to read any book in her hand . . . she is everything to me.

I’ve learned not to underestimate anything . . . I’m always there to explain to Sophia gently why that particular thing is not done. ..but I cannot yell or scold her . . . she cries . . . normal things for every child. ..and I appreciate everything . . . everything . . . even when I’m tired, I smile and say .... but how much do I love you?

Sofia is loved by all . . . she does not love kisses and sticky hugs . . . she keeps everyone awake and alert when she is there . . . the eyes are all for her . . . even my friends love it . . . for you are like uncles acquired . . .

Narrative of a Father of a Premature Baby: Story Left on the Web in 2015

We could not have children. With assisted fertilization, two embryos were implanted. At first, it seemed that we were going for one, but they were two. And it was the beginning of a pregnancy at risk: it was full of episodes that have not been fully captured in their severity and underestimated by the gynaecologist who was treating my wife. Despite the title of head of the hospital department, the gynaecologist proved to be inadequate with my wife, at least in complex situations.

When we understood the first signs that something was not going as we expected, we decided to go to the nearest emergency room where they were able to send us back home with “do not worry it’s all ok”: luckily we then went to the S. Hospital in which we knew we had the neonatal ICU and where, the next day, the girls were born.

Lavinia who lived only 10 days was 640 g, 570 after falling touted for its smallness, Lucrezia 830 g, 740 after the drop was doomed because she had a severe brain hemorrhage, sepsis, and other high concern for which no one was giving to her a chance. We all were shocked and destabilized.

At first I did not understand much. However operators were the best, but working at St. in improper conditions. A doctor of S. has proposed the interruption of care for Lucrezia, evidently mistaking. It 'was the worst moment of my life. Before discharge with Lucrezia, doctors have told us ... to be very careful. It seemed almost a trial period. At home, it was beautiful, with a little 'of anguish in the background, but beautiful.

The controls in the hospital, the care that followed Lucrezia at that time and the pediatrician ... were very accurate. At work at that time ... it was a mess. My daughter now is 18 months old today ... a lot 'of problems, but a great fighting spirit and will to overcome all great.

I have a beautiful little girl, difficult but that will surprise everyone.

Narratives in Paediatric Endocrinology

Narrative of a 12-Year-Old Boy, with a Growth Deficit, Written on Paper in 2013

Hi, my name is M. I'm 12 years old and a half, this year I'm going to be in sixth grade and I'm a bit excited. My family is composed of my dad G and my mum C and my brother D who is younger. I enjoy doing many things but what I like best is playing. With my friends I get along pretty well and I have a good relationship with my schoolmates.

When I come for an appointment at the Center I'm a bit afraid because I know I will get a shot. The people I meet during the appointments are doctors and they are very nice. About treatment I like that I'm seeing improvements and not having the shot every night cause I don't like needles.

I still don't know what I want to be when I grow up; I've got many things in mind and surely I want to do something nice and clever".

Narrative of a 14-Year-Old Boy, with a Growth Deficit, Written on Paper on 2013

"I'm almost 14 years old, I'm the second son, I've got an older sister with a pleasant character, also if she's a bit rude sometimes. She speaks very proper Italian and I would like to speak the way she does; she is good at school, I can't understand how she can spend all day studying; instead I play with the play station, a bit soccer, and I study very little. In fact I am very worried because tomorrow I have my middle school graduation test. I get along well with my friends, we joke together, and they let me share their toys; for example yesterday one of them lent me their laser. On Saturdays the group of school kids and the groups of my friends get together with my friend at the desk next to mine, L, I have a privileged relationship with him, he knows everything about me and I know everything about him.

I’ve been coming to the Center for 10 years, I cannot say that it’s a pleasure, but when I have to come here on Thursdays and I miss school, I’m happy. The people in the waiting room sometimes are nice, today I found a girl who was too *sticky*. I like the doctor a lot, but I cannot forget the professor who is unique, each time I see her it’s a nightmare because she shouts at me: she says it’s to make me become thinner but I believe it’s also to joke with me. The first years were scary, but slowly I started to feel more and more involved and it became a habit. My first memory goes back to when I used to have my blood drawn for the tests the only nice thing was that my dad was always close to me and he would talk to me. At the beginning they didn’t explain me anything but then I asked my dad some questions and he told me I wouldn’t have reached a good height, so I had to have shots. I remember that during my first hospitalization, I didn’t understand what was going on, I even though I was there for mum. We would sleep in the same bed and at nighttime I would always wake up, then when I understood it was for me I felt safe because my mum was with me. Then when they gave me the toy US Ferrari it was like having a new toy. I think that the therapy is helping me, but it exhausts me in the evening; on Sundays I don’t have to do it and I can stay up longer. I definitely like the therapy because it makes me grow, I don’t like it when the needle gets into my arm because I’m always afraid dad might hit the vein.

When I grow up I imagine myself having a nice job like a rapper’s manager.”

Narrative of a Father of a Girl with a Growth Deficit, Written on Paper in 2013

“At about 5–6 years of age my daughter was not growing as the other kids of her age. The waiting time for the diagnosis was 1 year. The moment we received the diagnosis was full of discouragement. When I heard about the cure I gained some hope also if I’m no longer as faithful. The diagnosis was communicated in a very professional way and I was immediately presented the possibility of the substitutive hormone therapy.

I’ve been attending this center since 2010, because it’s close to my home and I trust the doctor who is following us. I have a lot of faith in the hospital team, my specific reference is Dr. . .who personally follows my child’s therapy with periodic check-ups.

The most critical aspect of the treatment is the daily shot, the positive one is that when we do the auxology check-up I see my daughter slowly—yet gradually—growing. My daughter is growing quite well. I believe there haven’t been many changes in her relationship with others and I think that the purpose of treatment is indeed to avoid these changes helping her live a life as normal as possible. When I give my daughter treatment I’m sad because it hurts, but yet I’m faithful as I’m positive the therapy can improve her quality of life. This experience has changed everything in me. I only share this experience with my wife who is the only one to feel the same sensations. In our family we all live this path with the hope of reaching the results expected (target height). There is the need to be aware that there is a Therapy that can help a child grow.

What I expect for my daughter is to live a normal life like other kids of her age. I am worried the therapy won't give the expected result, and any contraindications to the therapy".

Narrative of a Mother of a Boy with a Growth Deficit, Written on Paper in 2013

"We noticed our son was not growing month by month about 10 years ago with our pediatrician, my son was 2 and a half. But I had already noticed he wasn't growing when he was 8 months, the pediatrician said to wait a bit. Then when the child was two the pediatrician told us to do some tests. The waiting time for the diagnosis lasted 4–5 months; it wasn't pleasant, I was discouraged. I thought it was a hereditary factor, since everyone in the family is short, instead the doctor explained that his growth process was blocked. I don't recall the exact words, but always pronounced with warmth. I told my son that it was a medication that would have made him grow because his growth was blocked and that we had to do something to help him.

At the beginning we went to…. but then his pediatrician suggested to go to…... and we've been coming here ever since. We are satisfied. I trust the medical team. I feel reassured. My personal of referral is always Dr…

The moments during which my son undergoes his treatment are awful because—after all—it is a shot, and so it's as if I was getting it. I'm afraid of needles. My husband is the one giving the shot and he feels fine, he's relaxed; I did it only once when my husband was out of town, but is not good. Plus at the beginning he was very young and he fussed that he didn't want to take the shot. At the beginning we were assisted by the pharmacy support who used to bring him a toy, they made him play, also when the car broke down, or if you called them half an hour earlier they would rush here. My son never accepted the needle as well as the hospital check-ups. Now he is older and he is embarrassed to be visited naked because there are female doctors. The positive aspect is that we are seeing results because he has begun growing again.

My son is growing well. At the beginning, at school he was aware he was shorter than his classmates, then as he grew there were no problems. This hasn't changed me. I talk about the experience with my friends, I've always talked about it, normally, sharing it with others helped me. The family has accepted the therapeutic path well and nothing has changed. My mother didn't agree on giving the shot because she is from another generation, but once we explained what it was about she accepted it too.

This experience is teaching me to be approach life with plenty of faith, that it's not good to let yourself get discouraged, while instead you have to fight; it made me stronger. I imagine a good future, hoping that all will go well".

Glossary: A Tool to Bridge the Gap Between Medical Humanities, Medical Science, Health-Care Organization, and Health-Care Economics

The purpose of this glossary is to provide the reader further insight into concepts frequently encountered and investigated in this book, defining them in a systematic and referenced manner. *It is presented in alphabetical order and includes the reference to resources used to create this glossary and a list of further readings.*

Art therapy A therapeutic approach based on the idea that the creating process supports reparation and recovery could be defined as a form of non-verbal communication of thoughts and feelings: it can help individuals in creating meaning and achieving insight, finding relief from overpowering emotions or trauma, resolving conflicts and problems, and reaching an increased sense of well-being. The approach is grounded on the belief that people have the capacity to express themselves creatively and that the most important thing is the therapeutic process rather than its product—so the therapist's focus is not on the aesthetic merits of art making but on the therapeutic needs of the person to express him- or herself. What is important is the person's involvement in the work, choosing and initiating helpful art activities (in which some authors include also the blog therapy), assisting the person in finding meaning in the creative process, and facilitating the sharing of the experience of image making with the therapist.

Burden of disease A measure used to assess and compare the relative impact of different diseases and injuries on a certain population (or on two or more compared populations) by quantifying health loss caused by these, especially the one which remains after a treatment, rehabilitation, or prevention effort of the health system and society. Burden of disease can be quantified in terms of quality-adjusted life years (QALYs) or disability-adjusted life years (DALYs), both of which quantify the number of years lost due to disease. One DALY can be considered as 1 year of "healthy" life lost, and the overall burden of disease can be considered as a measure of the gap between current health status and the ideal health status. The World Health Organization considers consistent and comparative description of the burden of disease and injuries and the risk factors that cause an important input to health decision-making and planning processes. Countries can combine this type of evidence along with information about policies and their costs to decide how to set their health-care agenda for budgeting resources.

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Burden of illness Some authors point out how the term “burden” simply means the negative impact of illness; alternatively, it can indicate the cost of illness where the cost is meant to encompass the full social cost of illness, including subjective quality of life, hard-to-quantify elements—and for this it differs from the burden of disease which included most objective information. In particular, burden of illness should be regarded as the impact on the feeling of well-being of the person with illness, and the person’s social network (partners, familiars, and so on). Burden of illness also includes the impact on members of society that can flow from the collective way in which health care is paid for, interrelationships among individuals through work and residence, and a general concern that society shares for the welfare of its members. However, it’s important to recognize that a correct definition of burden is broad in terms of the people affected and in terms of the forms of negative impact. According to some authors, existing approaches to measuring burden are only partially successful: the most widely used approach is to measure the cost of illness, where this cost is composed of a direct cost of treatment and other resources, and an indirect cost composed of the lost productivity associated with the illness. Direct costs of illness are readily measurable; on the contrary indirect costs are much more difficult to quantify because they involve econometric estimates of the impact of illness on work and wages. The main alternative to cost measures is to rate the “quality” of life with illness in comparison to the quality in full health: one purpose could be to incorporate the subjective burden of illness. In addition, a QALY or DALY approach provides a way to compare burden across illnesses. Similarly, burden of illness can be compared for different populations, such as comparisons of relative burden of illness produced across disease conditions within and across different countries.

Carer Generally, a family member, friend, or neighbour who looks after a person who is either elderly, with disabilities, or suffering from chronic or terminal illness; they perform medical tasks and personal care, manage housekeeping and financial affairs, and provide emotional support. Carers might be unpaid if belonging to the patients’ core environment or paid for their service of support to the patient and, often, the family as well.

Case study A qualitative case study examines a phenomenon in its real-life context. Data are collected on or about a single individual, group, or event. The main purpose of a case study is to understand something that is unique to the case (or to the cases): knowledge from the study is then used to apply to other cases and context. Qualitative case study methods often include several in-depth interviews with each case—these allow to explore the unique aspects of the case in great detail. Implications of a case study approach are several: participants and/or cases should be selected for their unique properties; sample sizes are generally small; inquiry focuses largely on case’s features, and the difference they exhibit from other individuals/events in the larger population.

Classification of illness narratives according to Mike Bury This type of classification foresees that analysis must consider three types of narrative forms: contingent, moral, and core narratives. Under the heading of contingent narratives, narrative analysis is concerned with those aspects of the patient's story that deal with beliefs and knowledge about factors that influence the start of disorder. If this kind of narratives describes events, their proximate causes, and their unfolding effects in relation to the per-formative of everyday life, moral narratives provide accounts of changes between the person, the illness, and social identity, and help to (re)establish the moral status of the individual or help maintain social distance, introducing an evaluative dimension into the links between the personal and the social. Core narratives reveal connections between the person's experiences and deeper cultural levels of meaning linked to suffering and illness.

Classification of illness narrative according to Kenneth Burke and Moira Kelly A series of genres that can be seen to underpin all forms of narrative—these include: epic or heroic, tragic, comic or ironic, disembodied or romantic, didactic. Although individuals may draw on more than one of these genres, it may be the case that the reconstruction of identity and interaction with others is expressed more or less within a particular narrative form.

Classification of illness narratives according to Arthur Frank Classification of stories into three common story types. (i) Restitution narrative: this is the story most favoured by physicians and other medical professionals, and poses the emphasis on restoring health. These narratives often have three moments: they start with physical misery and social default, continue with the remedy (what needs to be undertaken), and finish with the moment in which remedy is taken; moreover, the narrator describes how physical comfort and social duties are restored. These are often stories told about patients rather than by patients, also because they give little agency to the narrator: patients simply have to "take the medicine" and get well. (ii) Chaos narrative, which is really a non-story: there is little narrative drive or sequence, just a list of negative things that will never improve and by which the narrator is almost overwhelmed. The story signals a loss or lack of control, and medicine cannot do anything. (iii) Quest narrative: this is the teller's story, where the teller is in control of things. Narrators tell how they met the illness "head on" and sought to use it, to gain something from the experience; the story is a kind of journey, with a recognized departure, an initiation (the mental, physical, and social suffering that people have experienced), and a return (the narrator is no longer ill but is still marked by the experience).

Classification of illness narrative according to John Launer Stories can be analysed with a three-type classification, in which narratives are divided into progressive, regressive, and stable one. Progressive narratives move towards the personally valued goals; regressive narratives move away from such valued goals, and stable narratives sustain the same position in relation to the valued goals throughout the narrative sequence. This last kind of narrative could be seen as less engaging than others, because it tends to relate a sequence of events without great drama—a form of storytelling that goes under the heading of the so-called contingent narratives. The use of a progressive, regressive, and stable framework allows an analysis that safeguards against over-interpreting the range of meanings conveyed by patients' accounts. It is important to underline that whatever narrative form may be identified in analysis, many accounts move from one to another, for example, from regressive to stable. Consistency in narrative accounts may be achieved or sought by patients, but it may not: much depends on the context in which narratives are constructed and presented, and on the intentional acts which they help to constitute. This classification is very useful to focus on the coping strategies acted by patients: if regressive or stable narrative may show no positive engagement, if narratives are progressive, this may represent an evolving positively situation.

Clinical pathway The clinical pathway is a tool used to guide evidence-based health care that has been implemented internationally since 1980. According to some authors, there is a widespread lack of agreement on the impact of clinical pathways on patient outcomes and hospital resources: this could be partially attributed to the confusion for researchers and health-care workers regarding clinical pathway's definition—and there is a non-standardized one yet. Several terms may mean a clinical pathway: these include—among others—care map, care pathway, critical pathway, protocol, and guideline. This lack of a uniformly accepted definition impacts in capacity to test the evidence base and compromises planning, resourcing, and implementation of clinical pathway. Five criteria are proposed to identify a clinical pathway:

- the intervention is a structured multidisciplinary plan of care;
- the intervention is used to channel the translation of guidelines or evidence into local structures;
- the intervention details the steps in a course of treatment or care in a plan, pathway, guideline, protocol;
- the intervention has time frames or criteria-based progression;
- the intervention aims to standardize care for a specific clinical problem, procedure, or episode of health care in a specific population.

Columbia University The University, in which Narrative Medicine originated (2000), when an interdisciplinary group of faculty from the College of Physician and Surgeons and the School of Arts and Sciences conceptualized principles and practices of including Humanities and Arts into the health-care context. Since then, the field has grown exponentially; currently, the Programme in Narrative Medicine at Columbia offers the Master of Science in Narrative Medicine graduate degree programme, oversees required curricula for all medical students, provides writing seminars for clinicians, hosts intensive Narrative Medicine Workshops for scholars and clinicians, and supervises NIH-funded and private foundation-supported research projects examining consequences of Narrative Medicine training. In 2010, a group of graduate students in the Master of Science Programme in Narrative Medicine created *The Intima: a Journal of Narrative Medicine*, a literary journal dedicated to promoting theories and practice of Narrative Medicine that has attracted writers in the literary and medical fields from around the world.

Coping Coping strategies refer to the specific behavioural and psychological efforts employed to master, tolerate, reduce, or minimize stressful events. Two main coping strategies have been distinguished: problem-solving strategies, that is, the proactive efforts to alleviate stressful circumstances, and emotion-focused coping strategies, which involve efforts to regulate the emotional consequences of stressful (or potentially stressful) events. Some researches indicate that people use both types of strategies to combat most stressful events. The predominance of one type over another is determined, in part, by personal style and by the type of stressful event. An additional distinction, often made in coping literature, is between *active* and *avoidant* coping strategies: active strategies are behavioural or psychological responses to change the nature of the stressor itself or how one thinks about it; avoidant strategies lead people into activities or mental state that keep them from directly addressing stressful events. Generally, active strategies are thought to be better ways to deal with stressful events, whereas avoidant strategies appear to be a psychological risk factor or marker for adverse responses to stressful life events. Broad distinctions, such as problem-solving versus emotion-focused, have only limited utility for understanding coping, and so research on coping and its measurement has evolved to address a variety of more specific coping strategies.

Defensive medicine The practice of medicine based on requesting tests, procedures, or visits, or avoiding high-risk patients or procedures, primarily—but not solely—to reduce their exposure to malpractice liability. When clinicians provide extra tests or procedures to reduce malpractice liability, they are practising the so-called *positive* defensive medicine; when they avoid certain patients or procedures, they are practising the so-called *negative* defensive medicine. This definition recognizes that practices defined as "defensive" may be motivated by a range of factors, and may either enhance or reduce quality of care. It's difficult to classify most practices as totally "good" or "bad"; in addition, a substantial proportion of defensive medicine may occur unconsciously, and physicians receive "signals" from the malpractice system in a variety of ways, such as personal litigation experiences, their colleagues' one, the media, risk management and quality assurance activities, and their malpractice insurance premiums.

Digital Humanities Digital Humanities could be defined as research and education that relies on information technology as a central part of its methodology for creating and processing data. From many points of view, all the Humanities are now involved with the digital sphere: virtually most of researchers use generic digital resources of various kinds, but Digital Humanities go beyond this to make more systematic use of specialist digital technologies. Digital technologies have the potential to transform research in Humanities field, making it more efficient, enabling new ways of working, stimulating questions and creating new knowledge, or answering existing questions more systematically; they provide to integrate collections of research materials, find new ways of processing and representing data, and create new connections between different types of data and new support for collaboration, networking, and community building.

Exchange is the key-term: Digital Humanities are most successful where there is a two-way collaboration between scholars and technologists. In the education pattern, Digital Humanities are a resource for linking health-care and humanistic professionals through digital to organize webinars, knowledge sharing platforms, and internet libraries.

Digital Narrative Medicine The so-called digital revolution impact has been considered as explosive and very different in respect to technological innovation in the past: many authors think that this digital turn could change the disease pathway and the patient's role in the diagnosis and care process, facilitate the use of Narrative Medicine as a tool to improve the patient–physician relationship, and collect information that contributes to the diagnosis, to the management of care, and to the compliance. Researchers in Digital Narrative Medicine want to inquire how narratives could positively and efficaciously complete those innovative processes that use new technologies in the Digital Health field, starting from the prerequisite that the technologies are a means and not a purpose, a tool in the field of a personalization and care pertinence process. Patients and carers can type their illness narratives freely on social media, as Facebook, or in private blogs and forums, or can leave their witness in dedicated platforms. More often Digital Narrative Medicine is fostered by patient and caregivers' associations.

Digital storytelling According to the Digital Storytelling Association, digital storytelling is the modern expression of the ancient art of storytelling: throughout history, storytelling has been used to share knowledge, experiences, and values. Stories have taken many different forms, and have been adapted to each successive medium that has emerged—now, the computer screen. Collecting and preserving histories has become an academic endeavour since 1970; digital storytelling is not just about the transfer of knowledge, it is also a movement designed to amplify the voice of a community. Digital storytelling is an online personal narrative in digital format, supported by the use of multimedia components of narrative, text, images, and so on. Physical and social media communities are engaging in digital storytelling to give voice to themselves and others: digital communication has the potential to revolutionize the sharing of knowledge, ideas, and culture in the way that written communication did in the past, and people are creating digital stories in order to participate in what has become a massive and meaningful conversation. Community engagement in digital storytelling involves sharing human experiences, and this phenomenon reveals the power of the individual voice to influence positive change: digital storytelling has the potential for connecting a community through shared experiences and developing tolerance by understanding someone else's story.

Discourse/conversation analysis Discourse and conversation analysis approaches stem from the ethno-methodological tradition, which is the study of the ways in which people produce recognizable social orders and processes. These two types of analysis are similar, but there are some key differences. Discourse analysis is generally broader in what it studies, utilizing any naturally occurring text, while conversation analysis is a subset of the first: its scope is narrower and confined to natural conversations between two (or more) people. Discourse analysis emphasizes how humans construct meaning through speech and text, and its object of analysis typically goes beyond individual sentences; conversation analysis tends to be more granular, looking at elements such as grammatical structures and concentrating on smaller units of text, such as phrases and sentences.

Disease The biomedical definition of the "pathological condition", objectified as system alteration and named in a nosological label in biomedical knowledge, on the strength of signs and symptoms interpreted from an external point of view to the suffering body—the physician's diagnostic gaze. Moreover, the practitioner reconfigures the patient's illness problems as narrow technical issues, disease problems: in this process, the healer interprets the health problem within a particular nomenclature and taxonomy, a disease nosology, that creates a new diagnostic entity—the disease. Disease is a problem from the practitioner's perspective, and in narrow biological terms of the biomedical model, it is reconfigured merely as an alteration in biological structure or functioning. So, if we think the pathological condition as a symbolic reality, ignoring the patient's perspective, it means keeping out from clinical action a fundamental dimension of health process: the significant elaboration of experience. Cultural predilection for the disease brings biomedicine to the therapeutic structural ineffectiveness, because it eludes the patients' need to give sense to their suffering experience.

Durham University's Centre for Medical Humanities Durham University's Centre for Medical Humanities dedicates its research programme to the exploration of expectations in Medicine and relationships and ideas embedded in the so-called "human side of Medicine", with the support of a Wellcome Trust Medical Humanities Strategic Award. The research programme has several key themes of inquiry: the contribution of creative imagination to medicine, health care, and public health within a shared reflective practice that established effective arts in health as a hybrid rather than specialist activity; perspectives from outside the context of medical practices, in order to take a critical view of the ways in which those practices have evolved, to question the assumptions that underlie them, and to work with practitioners; the interdependence of mind, body, and affect, exploring the history of these ideas and their relationships views of the self. These themes, together, are planned to advance the understanding of medicine's role in sustainable conceptions of human flourishing.

Education The call for a cross-disciplinary re-contextualization of medicine places Medical Humanities close to the core of the profession. Professionalism, narrativity, and competencies are concepts currently acknowledged as critical in medical education; then, the attention focused in these fields from the Medical Humanities will help these disciplines to be seen as essential: taking seriously the scholarly traditions of the Humanities can demonstrate their intellectual challenges and rigour and students would less likely succumb to intellectual bait-and-switch complaints. Furthermore, regular collaboration in teaching, clinical correlates, grand rounds, and other pedagogical exercises need not entail major curricular battles or changes in time allocation, and it would reduce the prevailing insider–outsider distinction between physician and not-physician faculty; it would also improve the perceived fidelity and credibility of Medical Humanities educators. This approach would stimulate investigation of and dialogue about these concepts and would help to stem the moral stagnation and erosion that can occur over the course of training. Required Medical Humanities curricula would reinforce all the dimensions of relevance, intellectual rigour, pedagogical trustworthiness, and moral inquiry.

Empathy An attitude or approach to others consisting of three components: a cognitive component (in which the physician "enters" the perspective of the patient), an emotional component (in which the physician puts himself or herself in the patient's shoes), and an action one (in which the physician communicates understanding by checking back with the patient). Other authors have demonstrated that writing "personal illness narratives" allowed participants to benefit from reflective writing in a new way: rather than maintaining a clinical point of view (or adopting the point of view of the "Other"), narrative writings allow medical students to explore subjective experiences of illness, and such experiences may critically inform the nature of student's professional caregiving. Altruism, compassion, humility, and trustworthiness become encapsulated into the physician's mind by the authentic care of the person: diagnosis and treatment require schooled and practised use of narrative capacities of the physician. Then, one of the physician's most potent therapeutic instrument is the self, which is attuned and available to the patient through engagement, compassion, and reflection.

Evidence-Based Medicine Evidence-Based Medicine (EBM), whose philosophical origins extend back to the mid-nineteenth century, remains a reference topic for clinicians, researchers, health practitioners, planners, and the public. EBM has been defined as the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients. The practice of EBM means integrating individual clinical expertise—that is, the proficiency and judgement that individual clinicians acquire through clinical experience and clinical practice—with the best available external clinical evidence—that is, clinically relevant research, often from the basic sciences of medicine, but especially from patient-centred clinical research into the accuracy and precision of diagnostic tests, the power of prognostic markers, and the efficacy and safety of therapeutic, rehabilitative, and preventive regimens from systematic research: increased expertise is reflected especially in more effective and efficient diagnosis and in the more thoughtful identification and compassionate use of individual patients' predicaments, rights, and preferences in making clinical decisions. External clinical evidences replace previously accepted diagnostic tests and treatments with new ones that are more powerful, more efficacious, and safer. In this perspective, "good doctors" use both individual clinical expertise and the best available external evidence: without clinical expertise, practice risks becoming tyrannized by evidence, and without current best evidence, practice risks becoming rapidly out of date, to the detriment of patients.

Grounded theory Grounded theory is composed by inductive data collection and analytic methods: it's a set of iterative techniques designed to identify categories and concepts within text that are then linked into formal theoretical models. Grounded theory can be also defined as a set of methods that consist of systematic but flexible guidelines for collecting and analysing qualitative data to construct grounded theories in the data themselves. This methodology uses systematic and exhaustive comparison of text segments to build thematic structure and theory from a body text; theoretical models are created and continuously revised as data are progressively collected and analysed. In-depth interviews and focus groups are the most common data collection techniques associated with grounded theory; sample sizes for grounded theory are more limited than for inductive thematic analysis, because the analytic process is more intensive and time-consuming.

Harvard Medical School Researchers of Harvard School start from the premise that biomedicine must be examined as a specific ethno-medicine, culturally characterized by an exclusive consideration of biophysical dimensions of the pathological condition. This condition, however, could not be merely considered as a "natural fact": a certain condition is qualified as a medical problem by particular cultural norms. From this point of view, Arthur Kleinman, medical anthropologist, and his collaborators proposed to consider biomedical categories as cultural categories, through which a specific interpretation of the pathological condition is constructed. In this scenario, the distinction between disease, illness, and sickness emerged. According to this perspective, Medical Anthropology must work on two directions: the comparative analysis of different medical systems, and its clinical application in biomedicine itself. Narratives become the cultural tools that aim to recompose suffering experiences in a meaning order. Harvard Medical School anthropologists used narrative and literary tools to analyse and interpret stories, and to reconstruct the narrative logic of illness narratives, with the aim of bringing to light patient's experience.

Health The World Health Organization defines "health" a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity. There are other generally accepted definitions of "health": it could be defined as a dynamic state of well-being characterized by a physical and mental potential, which satisfies the demands of life commensurate with age, culture, and personal responsibility, or a condition of well-being free of disease or infirmity, and a basic and universal human right. Some societies, for example Australian Aboriginal people, assert that health does not just mean the physical well-being of the individual but refers to the social, emotional, spiritual, and cultural well-being of the whole community, a whole of life view that includes the cyclical concept of life–death–life. So, there are many critics arguing that the WHO definition of health is utopian, inflexible, and unrealistic, and that including the word "complete" in the definition makes it highly unlikely that anyone would be healthy for a reasonable period of time.

Health economics Health economics can be defined as a branch of economics that addresses issues relating to efficiency, effectiveness, value, and behaviour in the production and consumption of health care: health economists analyse the functioning of health-care systems and health-affecting behaviours. It is standard to consider "health economics" as the discipline of economics applied to the topic of health: their philosophical and methodological bases are, as a result, founded upon their similar bases in economics. Health services research has become a multidisciplinary enterprise first because of the complexity of health, health care, and the organization of services: multidisciplinary research entails not just practitioners of different disciplines, but also the opportunity to develop innovative ways of researching particular questions in a cross-disciplinary manner. Health economics—as a component of health services research as well as economics—has the opportunity to draw on these innovative cross-disciplinary ways of working. Particular questions can be addressed by using qualitative methods such as interviews, focus groups, observation—with the aim of obtaining an overview of this area of study and to understand the ways in which people think and act in their everyday life in relationship to action of care. Outcomes are investigated in health-care economics and they can be clinical, epidemiological, economics, organizational, and humanistic. Among humanistic outcomes, patient's preference and quality of life measurement are considered: patient's preferences are related to the informed consent ethical issue as far as the personalization of care is concerned and to a wider population approach, if new intervention therapies have to be implemented. A new stream deriving from outcome research is the health technology assessment to evaluate the economic, clinical, organizational, and patient's point of view as a consequence of a new intervention in medical practice.

Health-care provider A professional involved in the context of care, whose role in the setting of narrative medicine is pivotal towards the improvement and progress in patient care. In the specific case of physicians, their ordinary professional actions are naturally filled by narrative and can be made more effective once recognized as such. Students become physicians by functioning as a medium for medicine's continuity of knowledge, learning about in the process of living through their passages. In professional life, physicians rely on one another for honesty, criticism, and the courageous blend of uncertainty and authority in the phrase "We see this". Medicine is considered a profession in part because of the strength of these bonds among physicians, who accrue responsibility for one another's competence and conscience. However, specialized physicians seem isolated from other specialists and from their colleagues in nursing, social work, and other health professions. The most effective methods to reinforce professionalism, perhaps, are to endow them with the competence required to fulfil their narrative duties, to envision the stories of science, to teach students responsibly, to give and accept collegial oversight, and to enforce bonds among health-care professionals.

Holistic medicine Biomedical science has been successful in explaining processes on the level of the molecule and the cell, but often unsuccessful in explaining the processes at the level of the organism. It has not been able yet to explain what happens when patients spontaneously recover or heal completely: to explain what happens on the level of the whole organism is the objective of holistic medicine. Then, the aim of the holistic medicine is to help the patient to create a "sense of coherence", an experience in the depth of life, related to the concepts of meaning, understanding, and action. In recovering the sense of coherence, the patient accesses hidden resources and improves quality of life, health, and ability to function at the same time.

Humanities Set of academic disciplines that study what is defined as "human culture", and the ways through which people process and document human experiences: they involve inquiry into consciousness, values, ideas, and ideals as they seek to describe how these experiences shape the understanding of the world. Philosophy, literature, religion, art, music, history, and language are modes of expression that have become some of the traditional subjects falling under the "Humanities umbrella", areas that are sometimes regarded as Social Sciences and sometimes as Humanities include Anthropology, Area Studies, Communication Studies, Classical Studies, Semiotics, and Linguistics. Humanities use methods that are primarily critical, or speculative, and have a significant historical element—as distinguished from the mainly empirical approaches of the Natural Sciences. Human disciplines like History and Cultural Anthropology study subject matters that the experimental method does not apply to—and instead mainly use the comparative method and comparative research.

Illness The innate human experience of symptoms and suffering. Illness refers to the way a sick person and the members of the family or close social network perceive, live with, and respond to symptoms and disability. Moreover, illness is the lived experience of monitoring bodily processes, and this illness experience includes categorizing and explaining, in ways that are comprehensible and accessible to all lay persons in the social group, the forms of distress caused by those pathophysiological processes. When we speak about illness, one must include the patient's judgements about how best to cope with distress and practical problems in daily living it creates, and one must consider that it is shaped by cultural factors governing perception, labelling, explanation, and valuation embedded in a complex family, social, and cultural nexus.

King's College, Centre for the Humanities and Health, London Established in XXX? The Centre for the Humanities and Health of the King's College London was conceived with the aim of gathering a world leadership in research in the Medical Humanities field, through a multi-stranded programme of research on "the boundaries of illness". The Centre engages scholars from Arts, Humanities, and Health disciplines nationally and internationally recognized, all of whom support the development of a Master program in Medical Humanities, and extend the College's existing capacity in this field at master, doctoral, postdoctoral, and international level.

Listening Listening to stories of illness demands the courage and generosity to tolerate to support witness to unfair losses and random tragedies. Achieving such witnessing allows the physician to proceed to his or her more recognizably clinical narrative tasks: to establish a therapeutic alliance, to generate a differential diagnosis, to correctly interpret physical findings and laboratory reports, to experience empathy for the patient's experience, and to engage the patient in obtaining effective care. If the physician or the carer cannot perform these tasks, the patient might not tell the whole story, might not feel heard: so, the resultant diagnostic workup might be unfocused, the correct diagnosis might be missed, and the therapeutic relationship might be ineffective. Now medicine has begun to affirm the importance of telling and listening to patients' narratives, and narrative skills can provide the more powerful methods to help physicians join with their patients, honouring all they tell them.

Medical Humanities A field of inquiry in which Humanities and Social Sciences perspectives are brought together to explore human aspects of medicine. These perspectives play a key role in analysing our expectations of medicine (term which includes biomedicine and other medicines), and the relationship between medicine and our broader ideas of health, well-being, and flourishing. As some authors highlight, despite a lack of clarity on what exactly the Medical Humanities involve and how they should be integrated into medical education, Medical Humanities share several characteristics. First, they use methods, concepts, and content from one or more of the humanistic disciplines to investigate illness, pain, suffering, disability, healing, therapeutic and care relationships, and other aspects of medicine and health-care practice. Second, they employ these methods, concepts, and practices in teaching health profession students how to better understand and critically reflect on their professions with the intention of becoming more self-aware practitioners. Third, their activities are interdisciplinary in theory and practice and necessarily nurture collaboration among scholars, healers, and patients. These conditions imply that Medical Humanities have a moral function: an important goal for them is to re-conceptualize health care, through influencing students and practitioners to query their own attitudes and behaviours, while offering an integrated perspective on the fundamental aspects of illness, suffering, and healing.

Mixed methods approach Mixed methods approach involves collecting and analysing both WHICH? forms of data in a single study: the first researchers in this field recognized that all methods have limitations, and felt that biases inherent in any single method could neutralize or cancel the biases of other methods. There are three main strategies of inquiry. The first, the sequential procedures, in which researchers seek to elaborate or expand the findings of one method with another method. This may involve beginning with a qualitative method for exploratory purposes and following up with a quantitative method with a large sample, or it may begin with a quantitative method in which theories or concepts are tested, to be followed by a qualitative method involving detailed exploration. The second, the concurrent procedures, in which the researcher converges quantitative and qualitative data in order to provide a comprehensive analysis of the research problem. The third, the transformative procedures, in which researchers use a theoretical lens as an overarching perspective within a design that contains both qualitative and quantitative data; this lens provides a framework for topics of interest, methods for collecting data, and outcomes or changes anticipated by the study.

Narrative One can talk about "narrative" (or story) when somebody shares with another person through narration that considers a teller, a listener, a time course, a possible plot. Broadly speaking, narrative does not require language: it can be expressed by means of dancing, art, and music as well as speech, and writing. The form of the narrative also conveys information and meaning. Narratives are about particular events, rather than about events in general, although several narratives can share the same narrative type in that they can be the same kind of story. Representing real-life dimensions, narrative allows to elaborate interpretations that concern the discourse of a specific reality. The narrative form is influenced by precedent models of storytelling; narrative groups several genres, made by a variety of styles that go from complex (spoken or written) language to images; it is present in myth, legends, stories, tragedy, comedy, books, movies, and so on. Even if the central importance of narrative in medicine has been understood centuries ago, it has been only in last 20 years that narrative has become an essential area of research in health sector. In medicine, narrative survives in several forms that can model future interactions in different contexts. However, these forms become constantly fragmented: the recognizing of narrative is central in clinical methodology, because it puts together and communicates what symptoms mean to patients, inquires their perspectives, why they are searching for help and why now, and recognizes their role in facing difficult situations.

Narrative-(based) medicine The practice of medicine with these skills of recognizing, absorbing, interpreting by the stories of illness; as a new frame for health care, it aims to create an effective health-care system than recognizing and respecting the persons undergoing care. Medicine has never been without narrative concerns—on the contrary, this binomial has always been grounded in life's intersubjective domain: medical practice requires the engagement of one person with another and realizes that authentic engagement is transformative for all participants, like narrative. Medicine has become increasingly schooled in narrative knowledge: this growing narrative sophistication has provided medicine with new and useful ways in which to consider relationships between patients, physicians, caregivers, researchers, and all the figures involved in care, and also diagnostic reasoning, medical ethics, and professional training. As a result, medicine can better understand the experiences of sick people, the journeys of individual physicians, and the duties incurred by physicians and by the profession of medicine. Narrative Medicine can be also defined as a tool that permits on one hand a meeting point between the patient's level and the physician's one, allowing to understand feelings from both sides of care, and on the other hand to elaborate a new and more focused care plan, with an probable higher level of compliance.

Narrative analysis Narrative analysis is based on the study of discourse and the textual representation of discourse. Narratives, in this context, refer to stories that represent a sequence of events: they can be generated during the data collection process, such as through in-depth interviews or focus groups, or they can be incidentally captured during participant observation, or they can be embedded in written forms (including Internet, for example). Narrative analysis is represented within a large range of academic traditions—social sciences, anthropology, health sciences, cultural studies—and it can be used for a wide range of purposes: formative research for a subsequent study, comparative analysis, diagnosing medical conditions.

Parallel Chart An informal patient chart, in which physicians can collect their impressions as opposed to clinical data invented by Rita Charon in 1993 and first introduced as a teaching tool, in some settings also considered as a practice tool of narrative reflective strategy for medical students. It's primary goal was to enable students to recognize more fully what their patients endure and to examine explicitly their own journeys through medicine, and not (as Charon distinguishes) as a form of support group therapy, venting sessions, or group therapy intended to support students' emotional well-being.

This textual work is a practical and essential part of medical training, designed to increase the student's capacity for effective clinical work. Reflective writing in medicine should be thought of as a mainstream part of the training of clinicians; parallel chart must be part of clinical training: it is not a general exploration of one's life and times, it is, instead, narrative writing in the service of the care of a particular patient. In the course of writing about patients, students write a great deal about themselves. The patient's biography is always intertwined with the student's autobiography. Students recognize this presence of the *self* very forcefully while writing their own parallel charts and reading and listening to one another's.

Pathography The genre of narrative descriptions of illness, most often used to designate patients' first-person accounts; the construction of a pathography, in this sense, is an interpretive and narrative act that gives coherence, unity, and form to an event or experience. Sociocultural metaphors that invade and consecrate medical narratives enable patients to achieve "transcendence" over their illness.

Patient The "patient" can be defined as a person receiving health care, for acute or chronic disease or a traumatic event. In particular, the use of this term as in *patient-centred care* is intended to underline the active involvement of patients and their carers according to a new model of care and treatment decision-making, built around and in consideration of the patient's story, experience, preferences, needs, and values.

Patient–physician encounter The patient–physician encounter triggers a sort of conversation: the patient narrates his or her story through words, gestures, physical findings, also silences—a story that is fraught with "objective" information about illness as well as with fears, hopes, and implications associated with it. As the physician listens to the patient, he or she follows the gist of the story, imagines the situation, and tries to recognize the multiple (and contradictory) meanings of the words used by the patient. Diagnostic listening acts engage the listener's resources, such as memories, creativity, interpretive powers, and so on, to identify meanings.

Person Anthropologically speaking, the act of giving an individual the status of "person" presumes the existence of a symbolical order, of a representations logic, and of a ritual apparatus appointing this individual a place and a role in society, and assuring a juridical and moral recognition. Every anthropological inquiry on the notion of person makes us question not only about several conceptions elaborated by cultures and societies, but also about the status of the person, that is, institutional systems conceding rights and imposing obligations to individual. The notion of "person" has been considered as a stimulus to examine ways in which societies and cultures think, act, and define relationships. People affected by chronic condition nowadays do not wish to be labelled with the word "patient" if not just for acute care setting, but prefer to be acknowledged as individuals of persons.

Phenomenology Phenomenology can be defined as the study of conscious experience, and can be traced back to the early twentieth-century philosophers such as Husserl and Merleau-Ponty. In contemporary social sciences, the term is used more extensively to indicate the study of people's perceptions, feelings, and experiences. Phenomenology is a philosophical approach to the study of experience that shares a particular interest in thinking about what the experience of being human is like, in all of its various aspects, but especially in terms of the things that matter to us, and which constitute our world. Many of the tools and the ideas within the phenomenological field are embedded, in general, within qualitative research, in that it attempts to understand individuals' lived experiences and the behavioural, emotive, and social meanings that these experiences have for them. In-depth interviews and focus groups are ideal methods for collecting phenomenological data.

Professions of Narrative Medicine and Medical Humanities The group of specialists from Human and Social Sciences, sociologists, psychologists, counsellors, cultural, and medical anthropologists, art therapists, social workers, and experts of quality in health care (such as epidemiologists and nurses with management roles) operating in the field of Narrative Medicine and Medical Humanities. Several experiences have been reported in which medical departments' work was supported by Narrative Medicine practices in a multidisciplinary and continuous way. The use of appropriate tools for the evaluation of care and illness narratives—semi-structured interviews, videos of conversations, claims analysis, diaries and poetry use, lecture and analysis groups—stimulated the acknowledgement and the check of some advantages: Narrative Medicine improves clinical practice, permits deeper diagnoses, and supports relationships between patient, familiars, physicians, and medical personnel, and therapy adherence. Operative integrated and theoretical work, by methodologists and medical specialists together, allowed the ideation and the realization of Narrative Medicine experimental laboratories with the aim to improve the quality of care and the sustainability of cares.

Qualitative research Qualitative research methods are often used to answer questions regarding human behaviours, opinions, and experiences: difficult information to obtain through more quantitatively oriented methods of data collection. Despite the interdisciplinary recognition of its value, qualitative research—theoretically and practically—is not a unified field: a plethora of viewpoints exist on the subject of qualitative analysis. Some authors emphasize the research purpose and focus, others highlight an epistemological stance, others focus more on the process and context of data collection.

We can propose an outcome-oriented definition, that is, qualitative research involves any research that uses data that do not indicate ordinal values. Such a definition avoids generalizations and the dichotomy between qualitative and quantitative research: furthermore, it allows for the inclusion of different kinds of data collection and analysis techniques, as well as the diversity of theoretical and epistemological frameworks that are associated with qualitative research. In this model of inquiry, the epistemological landscape is as complex as the various disciplines that employ qualitative methods. The two main perspectives, here, are the interpretive and the post-positivistic ones. Authors from the first school (like Geertz) argue that the scientific method is reductionist; instead, stemming from a hermeneutic tradition, this approach is more interested in interpreting deeper meaning discourse that is represented in a collection of personal narratives or observed behaviours and activities. An interpretive perspective is based on the idea that qualitative research efforts should be concerned with revealing multiple realities as opposed to searching for one objective reality. On the contrary, a post-positivistic approach is based on the fundamental ideas that interpretations should be derived directly from data observed, and that data collection and analysis methods should be systematic and transparent. Post-positivism is closely associated with the scientific method, and it distances itself from the strict epistemological position that a truly objective reality can be assessed and represented. Indeed, from a theoretical and philosophical perspective, the notion of being able to observe and document one true objective reality is a dubious concept, particularly for social and behavioural phenomena. Post-positivists accept the premise that a completely objective reality is impossible to apprehend but assume that research accounts can approximate, or at least attempt to approximate, an objective truth. The main approaches to collecting and using qualitative data are: phenomenology, ethnography, inductive thematic analysis, grounded theory, case study, discourse/conversation analysis, narrative analysis, and mixed methods—this last defined as integrating quantitative and qualitative research methods in one study. Therefore, qualitative research is a valid tool for listening, observing, and understanding multiple realities brought by patients and carers throughout the illness process.

Quantitative research Quantitative research can be defined as explaining phenomena by collecting numerical data that are analysed using mathematical-based methods (in particular, statistics). A quantitative approach is the one in which the investigator primarily uses post-positivists claim for developing knowledge (for example, cause and effect thinking, reduction to specific variables and hypotheses and questions, use of measurement and observation, and the test of theories), and uses strategies of inquiry such as experiments and surveys, and collects data on predetermined instruments that produce statistical data. In this scenario, the researcher tests a theory by specifying narrow hypotheses and the collection of data to support or refute the hypotheses, and it uses an experimental design in which attitudes are assessed both before and after an experimental treatment. Data are collected on an instrument that measures attitudes, and the information collected is analysed using statistical procedures and hypothesis testing. Evidence-based medicine, for example, heavily relies on quantitative research with its metrics and statistics. Nowadays, quantitative research is even applied to Narrative Medicine in the analysis of occurrence patterns within the stories narrating about living with the disease.

Reflective writing Reflection is a process of personal insight and exploration of an issue of concern; it is generally triggered by having lived an experience, and it helps the individual to create and clarify meaning of the event in terms of self, and that results in a changed conceptual perspective. In recent years, reflective writing exercises have been used in the education of medical trainees presenting in many forms, as critical incident reports and clinical journal writing. The student is asked to describe clinical scenarios in which he or she is on the doctor side of the doctor–patient relationship. Exercises in writing a clinical story from the patient's point of view or rewriting a patient's narrative from a first-person perspective encourage students to reduce the emotional distance between self and patient. These narrative writing exercises require students to reflect upon clinical experiences from the perspective of themselves as clinicians and from the perspective of the others. In particular, exercises such as personal illness narratives have been shown to enable medical students to articulate and examine feelings about bodily realities of illness, health, and selfhood. Students are able to interpret and translate their experiences and gain a better understanding of themselves as practitioners and of their patients. The personal illness narrative allows the physician to enter more fully into the reality of the patient's world by recognizing and integrating the similarities in his or her own personal experiences and those of the patient.

Also from the patient's point of view, reflective writing can be defined a therapy, with the benefit of having less stress during the visits, a better functioning immune system, a decrease of blood pressure, a deeper breath, and fewer depressive symptoms. Writing allows to face unexpressed emotions, the cognitive elaboration of disease and traumatic experiences: it allows to reveal reason and feelings of a suffering person.

Semantic alignment Semantic alignment is a constant and iterative planning co-construction with the patient, and can be defined as the tool that allows to reduce the ambiguities in patient–physician relationships. Alignment implies thinking on an analogue level, comprehending and sharing identities—a purpose achievable during and after a process made by listening, accepting the non-linearity of thinking, and feeling of the "Other". The act of giving a sense is allowed by active listening, writing, reflection, interpretation of the patient's story.

Sickness The social meaning of the pathological condition, the patient's social role formalized with the diagnostic act. If sickness is defined as the understanding of a disorder in its generic sense across a population in relation to macrosocial (economic, political, institutional) forces, this term can also be understood as the process of production of medical knowledge and pathologies: social processes determine what is considered a "medical problem", just like validation processes determine what counts as "medical knowledge". Accordingly, one can move from an individual-centred vision to a social perspective able to contextualize its object of inquiry. It is interesting to note that the sickness perspective tries to correct a sort of "individualism", such as the Harvard Medical School one, but at the price of eliminating every consideration for personal dimensions of suffering experience.

Software Semantic Analysis Researchers engage in projects involving interpretation of unstructured or semi-structured data for several reasons, such as exploration, description, comparison, pattern analysis, theory building, testing, and evaluation. Qualitative methods are chosen in situations where a detailed understanding of a process or experience is wanted, where more information is needed to determine the characteristics of the investigated issue, or where the only information available is in a non-numeric form—such investigations typically necessitate gathering intensive and/or extensive information from a purposively derived sample. Software Semantic Analysis allows to use a set of tools to process qualitative data: organizing and keeping track of records that go into making a qualitative project (these might include data files from interviews, questionnaires, focus group, fields observations, and also published researches, images, diagrams). It allows also data generation that supports it through the organization and access to conceptual and theoretical knowledge generated in the course of the study. It allows querying (to ask simple or complex questions of the data, and to retrieve from database all relevant information to determine an answer to research questions); it allows visualizing, showing the content and/or structure of cases, ideas, concepts at various stages of the interpretive process. The relationships among these items are visually depicted in a range of displays.

Total Quality Management (TQM) in Health care TQM is a structured approach towards the continual implementation of quality, which can be applied to any field of services, and patient care as well. In reference to the health-care sector, and five broad attributes have been identified for understanding quality:

- reliability—the ability to perform the promised services dependably and accurately;
- assurance—knowledge and courtesy of employees;
- tangibles—physical facilities, equipment, and appearance of personnel;
- empathy—caring, individualized attention provided to the costumers;
- responsiveness—willingness to help customers and provide prompt service.

In business organization, the process of quality improvement is now dominated by theory and application of TQM. In health-care management, the key concepts of TQM are a top management leadership based on governance, the creation of a framework for quality, the transformation of organizational culture, a customer focus, a process focus, a collaborative approach to process improvement, an employee education and training, benchmarking, employee empowerment, and management integration. The process of TQM is a long-term strategic initiative that requires adequate time for incorporation with the organizational culture.

Transactional analysis Berne's transactional analysis can be defined as the method for studying interactions between individuals. The basic interest of this approach is the investigating of what Berne called the "ego states", that is, coherent systems of thought and feeling manifested by corresponding patterns of behaviour. Everyone exhibits three types of ego-states. A first to develop is the little boy/girl inside us who feels, thinks, acts, talks, and responds just the way when we were children. A second ego state modelled on parental figures—the Parent, which performs the functions of a conscience and the moral law. A third one, last in developing, the ego state in which individual appraises his/her environment objectively, and calculates its possibilities and probabilities on the basis of past experience—the Adult. Therefore, when two people enter in a relationship, there are six possible ego states involved, three in each person. Since these ego states are as different from each other as actual people are, it is important to know which ego state is active in each person, when something takes place between them. When analysing transactions, one must look beyond what is being said, at how the words are being delivered as the non-verbal signs accompanying those words: transactional analysis will pay attention to all of these cues when analysing a transaction and identifying which ego states are involved. Written text narrating on health and disease can be analysed through transactional analysis to evaluate which ego state is the prevalent mode of a story, if inner transactions are present due to the inner dialogue. When a patient is told about a disease, he or she generally is pushed back to the Child ego state, often twisting with a Critical parent when not accomplishing the construction of a trustful relationship with the carers. The Adult is a desired ego state, the one which enables the person to react positively and to actively coping with the disease.

Well-being Well-being is a growing area of research, but the question of how it should be defined remains unanswered: there is a greater necessity to be clear about what is being measured, and how data should be interpreted, in order to undertake a valid assessment. Any new definition must go beyond an account or description of well-being itself, and be able to make a clear statement of the meaning of the term. The knowledge of the historical background of the study of well-being can be necessary for this purpose, and one can focus on two main approaches:

- the hedonic tradition, which accentuated constructs such as happiness, positive affect, low negative affect, and satisfaction with life;
- the eudaimonic tradition, which underlined positive psychological functioning and human development.

Despite these two different approaches, most researchers now believe that well-being is a multidimensional construct—and, consequently, the diversity of dimensions has created a confusing and contradictory research base. To move closer to a new definition of well-being, we may focus on three key areas: the idea of a set point for well-being, the inevitability of equilibrium/homeostasis, and the fluctuating state between challenges and resources. Consequently, the research has proposed a new definition of well-being as the balance point between an individual's resource (psychological, social, and physical) pool and the challenges (psychological, social, and physical) faced.

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