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## 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.

**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** 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 different 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 multi-disciplinary 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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