Gallerani, Manuela. "Ethical Responsibilities in the Curing/Caring Relationship". *Rethinking Medical Humanities: Perspectives from the Arts and the Social Sciences*, edited by Rinaldo F. Canalis, Massimo Ciavolella and Valeria Finucci, Berlin, Boston: De Gruyter, 2023, pp. 71-94.

The final publication is available at https://doi.org/10.1515/9783110788501-005

Manuela Gallerani

Ethical Responsibilities in the Curing/Caring Relationship

Introduction

If we adopt an epistemological multi-perspective approach[1] and attempt to go beyond the illusion of human's inexhaustible efficiency or a "cult" (culture) of efficiency we can see that both *health* and *illness* inevitably trace their mark (and accompany) throughout every person's life.[2] If we *comprehend* these existential aspects at their very core, will we think of life as a life-long personal *project* that is both authentic and makes true sense.[3] This *existential project* should, in the first place, give a meaning and *value* to every instant of a person's life, under any conditions and at any moment, whether defined by health and well-being, or by pain and suffering.[4] Secondly,

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[1] Or rather a systemic (cf. Balint 1957, *The Doctor, His Patient and the Illness*; Charon 2006a, *Honoring the Stories of Illnes*; Greenhalgh 1999, *Narrative based medicine in an evidence-based world*; Bert 2007, *Medicina narrativa. Storie e parole nella relazione di cura*), multidisciplinary (Benedetti 2011, *The Patient's Brain. The Neuroscience Behind the Doctor – Patient Relationship*; Good 1994, *Medicine, Rationality, and Experience. An Anthropological Perspective*; Foucault 1963, *Naissance de la clinique: une archéologie du regard médical*; Lévinas 1991, *Entre Nous. Essais sur le penser-à-l'autre*; Bruner 1990, *Acts of Meaning*; Borgna 2017b, *Le parole che ci salvano*) and complex approach (Morin 1999, *L'Intelligence de la complexité*; Bocchi and Ceruti (eds.) 2007, *La sfida della complessità*), i.e. a global approach that brings together the results obtained with idiographic methodologies (from the Greek ιδιος-γραφικος = ídios and graphikós, which means "describe the particular") aimed at the study of single specific cases (therefore not generalizable) and nomothetic methodologies based on large collections of data and on 'evidence' that allow generalizations.

[2] Within this work, the term *illness* is used to describe anything and everything that alters a person's state of general well-being. So, this concept covers everything that a person perceives in terms of the associated phenomena, going back to the deep personal experience of whoever (user, patient) feels the need for care, whether because of bodily discomfort, malaise or pain (the symptoms of illness) or because of feeling afraid, worried and in need of help. The term *disease* is instead used to describe organic illnesses and symptoms caused by a pathology requiring surgery.

[3] Wittgenstein 1953, *Philosophische Untersuchungen*; Costa 1987, *Binswanger. Il mondo come progetto*; Foucault 2008, *Le gouvernement de soi et des autres: Cours au Collège de France (1982–1983)*; Bodei 2002, *Destini personali. L'età della colonizzazione delle coscienze*; Damasio 1999, *The Feeling of What Happens: Body and Emotion in the Making of Consciousness*; Gallerani 2015, *Prossimità inattuale. Un contributo alla filosofia dell'educazione problematicistica*.

[4] Jonas 1985, *Technik, Medizin und Ethik: Zur Praxis des Prinzips Verantwortung*.

Note: For the purposes of clarity, in this essay, the title of the works referred to in the notes has been left.

https://doi.org/10.1515/9783110788501-005

it should lie at the foundation of a *culture* of *cure* and *prevention* – the prevention of illness, to smoothen the way for a person's global well-being and good health – by which we mean the *copying strategies* we use, in a constructive-critical way, to counter both a desire to distance ourselves or our *removal* (in the words of, among others, Hans Jonas, Norbert Elias, Michel Foucault and Edgar Morin),[5] from the illness or pain and our *indifference* towards human fragility. A fragility intended/understood as inherent in the intimate essence of human existence.[6] Following the above outlined approaches and in accordance with the tenets of the Medical Humanities movement (henceforth referred to as MHs), setting an *etiquette* of suffering for professional health carers means thinking of a new way to interact both with the *patient* (who is first and foremost a unique and non-replicable *person*), with that person's caregivers as well as with that patient's *illness*.[7]

The Curing/Caring Relationship

Starting from these premises, one may observe that the curing/caring *relationship* as well as the manner in which this relationship is co-constructed, communicated and experienced, take on a crucial role.[8] This relationship must, primarily, be based on *actively listening* to the Other (the not-self) and on *taking care* to establish a significant relationship with the Other and the Other's world (in the meaning of Heidegger's *In-der-Welt-Sein*, Being-in-the-world; *Dasein*, the peculiar experience of human being), to transform the curative/caring relationship into one defined by *ethical commitment*, *deontological responsibility* and the ability to co-construct common meanings or common, *collective narratives* (in the words of the psychologist Jerome Bruner).[9] It is well known from statistical evidence that, to a large measure, the efficacy of any therapeutic intervention depends on the *type* of curing/caring

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[5] Jonas 1979, *Das Prinzip Verantwortung: Versuch einer Ethik für die technologische Zivilisation*; Elias 1982, *Ueber die Einsamkeit der Sterbenden in unseren Tagen*; Foucault 2001, *Biopolitica e liberalismo: detti e scritti su potere ed etica, 1975–1984*; Idem 1994, *Poteri e strategie. L'assoggettamento dei corpi e l'elemento sfuggente*; Morin 1970, *L'homme et la mort*.

[6] Agamben 1998, *Homo Sacer: Sovereign Power and Bare Life*; Goffman 1963, *Stigma: Notes on the Management of Spoiled Identity; L'identità negata*; Sontag 2003, *Regarding the Pain of Others*.

[7] Halpern 2004, *The Etiquette of Illness. What to say when you can't find the word*.

[8] The interesting etymology of the word *relationship* comes from the Latin *relatio* and, in turn, from *relatus*, the past participle of the verb *referre*, in the meaning of *establishing a bond*.

[9] Within this essay, the word 'Other' is written with a capital O, following the Lévinas perspective, cf. Lévinas (1980), *Totality and Infinity* (originally 1961) and Idem (1991), *Entre Nous. Essais sur le penser-à-l'autre*. On the meanings of the *collective narratives* see, among others: Bruner 2002, *Making Stories. Law, Literature, Life*. On this issue see also: Nussbaum 2016, *Not for Profit: Why Democracy Needs the Humanities*; Gottschall 2012, *The Storytelling Animal: How Stories Make Us Human*; Peters and Biesta (eds.) 2008, *Derrida, Deconstruction, and the Politics of Pedagogy*.

relationship that is established between doctor and patient.[10] Furthermore, when the relationship is truly meaningful and thus based upon reciprocal co-constructed trust (which the interlocutors build up together), then whoever is sick and being cared for is seen as a *person*, fully and totally, that is with all his/her physical, psychic, cognitive, emotional and imaginative aspects, and not merely as a *patient* or a customer/user; and by extension, as a person with *needs, emotions* and *desires* that transcend the condition of being ill.[11]

This essay is an attempt to analyze the meaning of *responsibility for what is said* in a curing/caring relationship, relating to both *care* (in its two-fold meaning of caring and of *curing* in a medical sense). By a caring relationship, we mean the set of actions taken or not taken by the caregiver that have the purpose of *extrapolating* or *receiving* the patient's life experience.[12] All of this occurring within a perspective of *co-responsibility* (the *co-* means shared, reciprocal, agreed with the Other) and respect for the *times* and *ways* of elaborating the traumatic life episodes of the person being cared for. *Cure-care*, in this sense, relates to both in its Latin meaning of *cura sui* (take care of your Self) and as *taking care* of a relationship, which implies mastery over a wide linguistic repertoire, ranging from *verbal* and *non-verbal language* to *paraverbal communication*, which encompasses all the messages we transmit through verbal sounds, glances, gestures, pauses and silences.[13] From here on, we can infer how the curing/caring relationship is directed, firstly, to *receive* with respect and rigor – what is said and done, and also what is not said and *not* done – by someone who is too fragile or ill to express his/her need. This need has deep roots and a *desire* to be acknowledged.[14]

Reaching a *diagnosis* is preliminary to any later intervention, both when it is part of the actual process of curing/caring for a patient and when it addresses the wider community or society, for example when promoting the right lifestyle in terms of diet or preventive care.[15] But only when there is the capacity to co-construct a relationship based upon mutual trust (between doctor and patient) can the curing/caring process actually start. In this way, the sick person and the doctor can establish the *right distance* (between each other) and the *right mental outlook* about the path that both, in

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[10] Bert 2003, *Parole di medici, parole di pazienti: counselling e narrativa in medicina*; Lingiardi 2018, *Diagnosi e destino*; Orletti and Iovino 2018, *Il parlar chiaro nella comunicazione medica. Tra etica e linguistica*; Orletti 2000, *La conversazione diseguale. Potere e interazione*.

[11] On these aspects see Ekman and Friesen 1976, *Pictures of Facial Affect*; Ekman 1999, *Handbook of Cognition and Emotion*; Panksepp 1998, *Affective Neuroscience: The Foundations of Human and Animal Emotions;* Nadel and Camaioni (eds.) 1993, *New Perspectives in Early Communicative Development*; Billig 2008, *The Hidden Roots of Critical Psychology*.

[12] Launer 2002, *Narrative-Based Primary care: A Practical Guide*.

[13] Cf. Watzlawick, Beavin Bavelas, Jackson 1967, *Pragmatics of Human Communication: A Study of Interactional Patterns*, *Pathologies and Paradoxes*.

[14] Lacan 1991, *Le séminaire, Livre VIII. Le transfert*.

[15] Lingiardi and McWilliams 2017, The *Psychodynamic Diagnostic Manual. PDM-2*.

their own roles, will have to undertake. As a consequence, the professional scope of physicians includes their capacity of activating *relational* and *decisional* pathways in their patients who will thus consider their doctor's words as an indispensable *co-adjuvant* of a drug. On the other hand, *dialogue* and *relationship* between doctor and patient are regulated through (verbal and non-verbal) behavior, by their respective roles and also through their own *social representations* of the illness.[16] Communicating a diagnosis in an effective way is important, first, to explain the *symptoms* of an illness, its causes and possible cures while discouraging patients from turning to unproven sources of treatment, such as may be found on the internet or social networking sites. A correct diagnosis must be delivered to each person being cured/cared for using words and tones that are *personalized* for that person. Doctors and caregivers must identify the right words for each patient according to his/her age, culture, sensitivity and the expected emotional response to the information received.

Let us proceed with order and take a step back. A few years before the MHs emerged within scientific debate – in the United States around the mid-1960s – the physician Michael Balint published a seminal book entitled *The Doctor*, *his Patient and the Illness* which can be considered, under certain aspects, the programmatic manifesto of the MHs movement.[17] Balint considered the complex dynamics that play out in the clinical relationship between doctor and patient and claimed that, in medicine, the *doctor* himself/herself is the most frequently prescribes *medication*, although we have no list of all the possible contraindications that may emerge

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[16] Cf. Goffman 1963, *Stigma: Notes on the Management of Spoiled Identify*; Idem 1986, *Frame Analysis: An Essay on the Organization of Experience*.

[17] A well-known *method* is to work in groups (cooperating) and in training groups that go under the name 'Balint Groups' (see Balint 1957, *The Doctor, His Patient and the Illness*). The conceptual premises of Balint's approach can be summarized thus: a) the most frequently prescribed *medication* is the *doctor* himself/herself, but the relative pharmacology (therapeutic action, posology, toxicity and collateral effects) is virtually unknown; b) the doctor, in general, pays considerable attention to the illness and symptoms, less to the *patient* and far less to the doctor-patient *relationship*; nevertheless, a dysfunctional relationship can generate more than just anxiety and lead to therapeutic or diagnostic errors; c) the modern system of cure/care requires doctors to have a new emotional and relational skillset, without which their work can become less effective but more draining (with the risk of burnout). The conceptual nucleus of this approach is *transferable* to other caring professions, because it in centred on: 1) the analysis of the *relationship* between professional and user (with careful attention to the emotional-relational skills in play); 2) actions taken by the work team as an enabler of thought (looking carefully at the best understanding of group processes, the dynamics of communication and organization of the system); 3) learning based upon *caring/curing practices* and on *experience*, as well as on scientific knowledge. This, therefore, sets in motion a process of systematic caring/curing, at the heart of which are four essential *objectives*. The first is to improve the caring *relationship* (care in listening to the patient's needs and emotions). The second is that this team work involves reciprocal debate, and the third is that there is supervision over the *role* of the person providing the care/cure (and that of the person receiving it). The fourth is that this process induces a serious *reflection* about caring/curing practices, to create good practice.

during the relationship between doctor and patient. Pursuing his analysis, Balint highlighted the fact that the persons who cure/care often tend to exercise a sort of *conviction* or persuasion over their patients, akin to converting the patient to the doctor's own approach to the illness, healing and medical expertise. Nevertheless, paraphrasing the words of the American philosopher John Dewey, we must not forget that we do not learn from experience: we learn from reflecting on experience.[18] The rigour of this Deweyan thought is even more fitting when we are talking about a curing/caring process. People who are being cared for must be helped by cure/care professionals (not only doctors) to *think about* the *sense/meaning* of their illness experience every day, as it represents a phase, a step in their life path. This critical phase is part of the complexity and plurality of life experience and, while painful, is just one phase among many Others – and often the source of deep changes brought about by the very processes of reflection and self-analysis.

In this sense – despite the increasingly pressing rhythms dictated by healthcare facilities – the time necessary to establish a relationship of trust between the caregiver and the person cared for can be used to encourage well-being (individual and for the team) and to curtail anxieties and reciprocal misunderstandings, as well as avoiding possible errors in therapy. Caregivers must have developed *emotional, relational and empathetic* skills (and other life skills), without which their work could easily be less effective and more exhausting (with the risk of burnout). On the other hand, the capacity of *reflecting* on one's experience also plays a large part in promoting *best practice*, in the sense that it leads to improvements both in individual and team decision-making processes and the dynamics of organization and communication, through continuous interaction between thinking *in*-action (when acting) and *on the* action (after acting).[19]

In the United States, ahead of Europe, the MHs approach introduced a shift in paradigm within the world of medicine and professional cure/care, from a predominantly *biomedical* model to a *biopsychosocial* approach, where the *person-patient* and that person's pathology/illness are studied with equal attention. In the *biomedical model*, attention is centered on illnesses understood as biological entities. By studying the effects of the chosen interventions, an illness can be observed through rigorous clinical and laboratory procedures used to investigate both its pathogenesis and its progress. The basic assumptions in the biomedical model (nomological approach) are confirmed in *Evidence-Based Medicine* (hence to fore, EBM), where scientific evidence establishes the guidelines in the fields of diagnosis and therapy.

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[18] On this issue, see Dewey 1996, *The Collected Works of John Dewey, 1882–1953: The Electronic Edition.*

[19] On this aspect see, for example: Argyris and Schön 1974, *Theory in Practice: Increasing Professional Effectiveness*; Schön 1984, *The Reflective Practitioner: How Professionals Think in Action*; Schön 1987, *Educating the Reflective Practitioner: Toward a New Design for Teaching and Learning in the Professions*; Schön (ed.) 1991, *The Reflective Turn.*

Clinic and research work is conducted using statistical and qualitative criteria, and interest converges above all on pathology, while the sick person seems to remain in the background, having become completely identified with the illness.

A clear difference emerges between the *nomological* approach (pursued through the biomedical model that, because of its epistemological status, tends to formulate 'general laws' that refer to the illness rather than the sick person) and the *idiographic* approach envisaged by the MHs movement. This approach is interested in learning about the sick person and that person's individual and family history, as these elements are essential to create a comprehensive clinical picture and, as a consequence, lead to a more effective therapeutic intervention. It follows that patients are recognized as subjects with rights and so become an active part of the therapeutic pathway, with full respect of their entitlement to an informed consent explaining their treatment. In this approach, there is the recognition that, within clinical practice and in the relationship with the sick person, factors external to the illness come into play. Among these are the psychological, cultural and social factors that interact heavily and at various levels of awareness, affecting both the patients and their internal world (their fears, anxieties, sense of fragility and loss of independence) and their doctor. From an ethical point of view, the introduction of an 'informed consent' recalls the four keystone principles *(basic ethical principles)* of bioethics: establishing that all patients have the right to be fully informed about their state of health and the potential risks and benefits of the treatment they are receiving.[20] Patients can also decide to delegate another person to make decisions on their behalf. This right falls within the principle of personal *independence* and is strictly linked to the other bioethics principles: a) respect for the patient's *autonomy* and right to self-determination (*voluntas aegroti suprema lex*); b) *beneficence*, knowing how to make decisions in the best interest of the patient (*salus aegroti suprema lex*); c) non-*maleficence* (*primum non nuocere*) which in turn is balanced against beneficence, as the effect of the two principles together can produce a *double effect*, explained as the *consequences* deriving from a given set of actions) and d) *justice*, which states that everyone has the right to receive suitable, fair and correct treatment according to the principle of equality without discrimination. In a broader sense, these ethical principles are reconnected to Amartya Sen's and Martha Nussbaum's *capability approach* and the ethics of a substantial freedom (based upon principles of equity and justice, agency and substantial freedom or capability, quality of human life and well-being). Taking up the thread of Amartya Sen's thought, we can say that caring means to give meaning to the human experience and the

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[20] Beauchamp and Childress 2001, *Principles of Biomedical Ethics*; Walter and Klein (eds.) 2003, *The Story of Bioethics. From seminal Works to contemporary Explorations*; Leone and Privitera (eds.), 2004, *Nuovo Dizionario di Bioetica*.

quality of life. And even better caring means ensuring good quality of life, substantive freedom and capabilities.[21]

The Medicine as *Scientia et Humanitas* (and *recte loqui*/speak rightly and properly)

Another approach slotting into the tracks of the *biopsychosocial* model, and in particular within the context of MHs, is that of *Narrative Evidence-Based Medicine* (NEBM). Elaborated by Rita Charon, this approach states that the relationship between doctor and patient should be defined by empathy, reflection, professionalism and trust (we shall return to this point later).[22, 23] In these approaches (and perspectives), people are recognized as complex dynamic systems where their personal experiences and cultural conditioning have a bearing on the mental (and social) representations of their illness and also, at a deeper/inner level, on 'their feeling of Self' as a sick person. Starting from these premises, to help us gain a better understanding of the person in his or her totality, rather than gathering anamnestic data through the usual questions in a clinical report or protocol, we will proceed through a language that *intentionally* places the person being cared for at ease, *escorted* during the process of formulating an organic and truthful story of the Self. In other words, the person cared for is helped to compose a *responsible* story that allows the caregiver to activate and co-construct a relationship that makes sense. The caregiver, in this case, is a *reflective professional* with *emotional intelligence* who believes in the value of the relationship itself, which is perceived as the first element on which the cure/care is based.[24] This relationship must be built on and is fueled by words said and not said, emotions, gestures, silences and glances that can create a climate of participation, commitment and reciprocal project-making.[25] In other words, there is a shift from a doctor and disease-centered medicine to a patient-centered medicine, where, in the first instance, the fundamental aim is the specialist expertise of the doctor treating the

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[21] Sen 1999, *Development as Freedom*; Idem 2005, "Human Rights and Capabilities"; Idem 2010, *The Idea of Justice*; Nussbaum, *Creating Capabilities: The Human Development Approach*; Nussbaum and Sen (eds.) 1993, *The Quality of Life*.

[22] *Scientia et Humanitas* are two words that appear on the *logo* of the eminent *Bologna's Medical Surgical Society* and underline the double *role* of the doctor: as scientist and humanist (in the *classical* meaning of the word *humanitas*). The Medical Surgical Society was founded in Bologna in 1802. This historical Italian medical association has been publishing the Medical Journal *Bullettino delle Scienze Mediche* since 1829

[23] Charon 2001, "Narrative Medicine. A Model for Empathy, Reflection, Profession, and Trust."

[24] Goleman 2007, *Social Intelligence: The New Science of Human Relationships*.

[25] Argyris 1982, *Reasoning, Learning, and Action. Individual and Organizational*.

illness/disease, which is often decontextualized from the person suffering from this ailment. In the second instance the patients' *life experiences* are re-evaluated and, alongside their own personal stories, their illness reveals the interiorized cultural models that unconsciously guide the painful experience itself.[26]

Inevitably, different styles of doctor/caregiver-patient relationships, spring from these two models. In the first, the predominant element is the controlling behavior of the doctor, who, as the disease expert, can become paternalistic and authoritarian. The doctor manages the relationship, setting the times and ways for consultations, asks questions designed to investigate the symptoms, builds diagnostic hypotheses, informs and prescribes the treatment, but all in a framework where clinical interest is concerned with the illness. As if to say, the need for a precise clinical anamnesis prevails over attention or concern for the subjective component in the form of the sick person. It may be the case that when they have to communicate dismal diagnoses or other "bad news," doctors use reassuring expressions to protect the patient from anxiety and anguish but, without immersing themselves into the patient's individual and unique life experience. In these proceedings, it is as if the doctor is placed above the true needs of the person being care for, who must be stimulated into fighting a *battle* against the illness without giving up. But, unless they are shared and co-constructed with the person being cared for, certain apparently reassuring words (which have entered medical semantics) are fated to fall on deaf ears without producing any positive reaction in the person to whom they are spoken. Patients, on the contrary, may feel crushed by the doctor's words, if they are difficult to understand and interpreted as alien to them and their life experience, because they are a source of disappointment and disorientation. It is well known, for example, that the diagnosis of a serious pathology can affect the patient's behavior, mood and self-perception, engendering *dysphoric,* emotional and physiological responses described in the literature as an anxiety-depressive disorder. Patients must be helped to understand and give a new meaning to the doctor's words, through shared words, re-elaborating them and relocating life experiences linked to the illness within the entirety of their life experience, in the knowledge that their life does not coincide *only* with their illness. It is much more than that.

In the patient-centered medicine, doctors receive the sick person's storyline (as the expression of the patient's needs, desires and fears) and they *observe and learn* about the sick person, in a multi-dimensional perspective that combines biological knowledge of the illness and of the ill person. This knowledge is initially reached through "active listening" (in the words of Thomas Gordon, the American clinical psychologist colleague of Carl Rogers), *syntony* and *empathic care*, as these are skills that amplify the caregiver's own ability in interpretation and prediction. In this sense, doctors manage to combine their *social awareness* (a wide range of

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[26] Augé 2014, *Une ethnologie de soi: Le temps sans âge*.

perceptions that include perceiving another person's mental state and emotions and the ability to grasp and understand complex situations), with their *social* skills (synchrony, concern, capacity to guide and orient another person) and *clinical expertise*. Going into greater detail, *primary empathy* means being able to feel and *endure the pain*[27] of other people, and know how to sense their world and accept their uniqueness (*as if* trying to feel like those people, with them, while keeping the "correct distance," i.e, the requisite clarity of mind and strength to evaluate a situation without being overwhelmed by a patient's emotions or words). *Syntony* means listening carefully and being receptive to the words of the other person, described as being on the *same wavelength*. Lastly, *empathic listening* is the ability to recognize and comprehend[28] the thoughts, feelings and intentions of the other person.[29]

The Gentle Listening

In a sick person, the benefit of knowing that one is listened to carefully and without judgment produces further emotional and cognitive benefits. In telling their story, patients can quench – at least in part – their inner tension that can set in motion defense mechanisms such as negation or removal, and other types of refusal behavior that can be self-destructive and self-harmful. Translating suffering into (spoken or written) words releases the patients' intrapsychic anxiety because of the cathartic effect of presenting their inner life experience (their internal world), and, more than that, it also provides the means for the person to tell a story that may be recounted

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27 *Endure pain* is used here in the sense of sharing the emotion of suffering. The verb comes from the Greek πάθος (*pàthos)*, deriving from the theme παθ- of the verb πάσχω, which in turn can be traced back to the verb πάσχειν (in vox media or the middle voice, a Greek construction that is neither in the active nor in the passive voice) meaning *to suffer* or *to become emotional*, and to συμπάθεια, in the literal sense of 'affinity of feeling'.

28 *Comprehend* (from the Latin *cum* and *prehendere*) is a verb of great semantic density meaning contain, include, understand. It can be traced to knowing how *to understand* and *grasp*, therefore reorganizing one's balance of knowledge. In other words, to understand what one can make one's own, so that it becomes part of one's way of being, perceiving, thinking. The etymological connotation underlines that this process takes place through the intellect and emotions and also through the senses and body.

29 Newman, Danziger, Cohen (eds.) 1987, *Communication in Business Today*; Goleman 2006, *Emotional Intelligence*; Adolphs 2001, "The neurobiology of social cognition"; Baron-Cohen 2003, *The Essential Difference: The Truth about the Male and Female Brain*; Baron-Cohen, Golan, Wheelwright, and Hill 2004, *Mind Reading: The Interactive Guide to Emotions*; Gallese 2003, "La molteplice natura delle relazioni interpersonali: la ricerca di un comune meccanismo neurofisiologico"; Gallese, Goldman 1998, "Mirror Neurons and the Simulation Theory of Mind-Reading"; Gallese, Keysers, Rizzolatti 2004, "A unifying View of the Basis of Social Cognition"; Gallese, Fadiga, Fogassi, Rizzolatti 1996, "Action recognition in the premotor cortex"; Rizzolatti and Craighero 2004, "The Mirror-Neuron System"; Rizzolatti and Sinigaglia 2006, *So quel che fai. Il cervello che agisce e i neuroni specchio*.

in more or less ordered syntactic sequences in time and space, but can be expressed and shared. However, for this to occur, it is necessary for patients to be *motivated* to search for the right words to express their *pain* or *suffering* and for them to have *trust* in the person listening, who, therefore, is engaging with this story telling and *listening gently*. In the words of the Italian psychiatrist Eugenio Borgna, *gentle listening* implies that the listener opens up to the Others, to acknowledge and respect them, with humanity and participation, as well as with trust, consideration and gentleness.[30]

In a relationship based upon sharing, caregivers can gain information from the story told by the persons being cared for that can help them formulate a diagnosis. And more, the caregiver can gain entrance into that person's inner world, now helping to strengthen defenses, now suggesting other interpretations of suffering and illness apart from those which, due to dejection, that person is unable to perceive.

On the other hand, it is well known that in any social context story telling (narrations) is an ideal *medium* defining, as it does, a space and time that encourages the meeting between thoughts, cultures, persons and social representations. As mentioned earlier, respect for the patient's words and stories lies at the basis of *narrative medicine* or, better, of *Narrative Evidence-Based Medicine* which weaves *evidence-based* studies of molecular medicine with humanities.[31] According to this approach, *curing/caring* does not merely coincide with external treatment (drugs, therapies) to be administered to the patient, but it is also based on a therapeutic alliance and involves totally reconsidering the role played by the intersubjective *relationship*, across two facets. Focus is directed, on one side, to the relationship between the caregiver (doctor, nurse) and the person being cared for (patient), concentrating on the story-telling of illnesses (spoken and written), and life experiences of discomfort and suffering. On the other side, this narrative fine-tunes the careful evaluation of the relationship between curing/caring *theory* and *practice*, in order to understand the origins of the disease and the painful experience, and to derive from it the hypothesis of a personalized intervention shared between doctor and the receiver of cures and care. In the curing/caring relationship and in the search for shared meanings, the person who is curing/caring will keep an asymmetric position relative to the person receiving the cure/care, and so avoid generating intimating divergencies or inappropriate transversal dynamics (known as transference or in French and Italian as trasfert). The former joins in the story of the latter, trying to re-elaborate and understand this life experience and, as far as possible, to establish empathy with it. For this very reason, because of each patient's unique experience, the usual repertory of clinical phrases offered to the sick person can be

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[30] Borgna 2017b, *Le parole che ci salvano*; Idem 2017a, *L'ascolto gentile* (gentle listening); Idem 2020, *Speranza e disperazione*.

[31] Bucci (ed.) 2006, *Manuale di medical humanities*; Charon, Montello (eds.) 2002, *Stories Matter: The Role of Narrative in Medical Ethics and Psychoanalysis and Narrative Medicine*.

unsatisfactory or barely pertinent, especially when all the patient's possible resources must be called into play, and all his or her energies employed to elaborate the experience of suffering from this disease. In this sense, if the assumptions at the foundations of EBM and NEBM can be interwoven, this can trigger a genuine and virtuous hermeneutic process.[32] This last statement is confirmed in experimental research and clinical observations – think of the studies on the placebo effect – which demonstrate how the *mind-body problem* can be identified with the *mind-brain problem*. The brain, notoriously, is the seat of thought, conscience, emotions, intelligence: it is where our mental events occur. So, recent studies have demonstrated that mental activity is always correlated with the activation of a cerebral region. This means that thought is closely linked to the nervous activity emerging from the brain, and this can be recorded through positron emission tomography (PET scans) or functional magnetic resonance imaging (fMRI scans). Both these methods can be used to observe which cerebral regions are activated in any given moment of a person's life. Despite this, science today is still unable to explain whether, within the complex and dynamic mind-brain system, it is thought (mind) that determines the activation in this cerebral region, or if it is the other way round. Experimental studies tend to go *beyond* the molecular and physiological description of the illness, overcoming an idea that re-proposes rigid mechanistic schemes of how the brain works.[33] This is also propounded in MHs, with the elaboration of a more global and eco-systemic vision of the illness, placing themselves sometimes in dialogue with and sometimes in opposition with other approaches or functionalist theories, without for this refuting their originality.

In any case, the true Gordian knot lies in settling the question of *conscience*, because scientists are not yet able to confirm whether conscience and mental events are global characteristics that emerge from the combination of cerebral regions, neurons and molecules (and their connections) or whether they are, instead, responsible for guiding and influencing human behaviour. With regards to this dilemma, MHs propose, in first instance, that a person's global conscience is the prerequisite for a relationship that is both curing and *caring,* of *being at the side* of patients – even when they are suffering from serious, incapacitating, chronic or oncological pathologies – in their path towards independence. In other words, when they are searching for well-being that can give back meaning to their life and to the experience of the illness itself. The curing process, therefore, develops along a complex pathway of *comprehension* directed towards re-connecting the "clinical" perspective of the cure/care giver (with its set of exams, diagnostic checks, medicinal therapies) and the perspective of the person being cured or, better still, that

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32 See among others: Charon 2006a, *Honoring the Stories of Illness*; Bert 2007, *Medicina narrativa*; Frank 1985, *The Wounded Storyteller*; Brody 1987, *Stories of Sickness*.

33 Benedetti 2013, *Il caso di G.L. La medicina narrativa e le dinamiche nascoste della mente*; Idem 2008, *Placebo Effects: Understanding the Mechanisms in Health and Disease*.

person's self-cure mechanisms. By applying *technologies of the self* (remembering Michel Foucault's work),[34] such as *reflective writing* and the *telling of oneself*, the patient reassembles the threads and the texture/weave of his or her life story. The caregiver has the task of providing the structure to the story when there is none, recognizing and illuminating the *plot woven* within the *hidden* storyline. There will never be one single interpretation of the sick person's story, as the viewpoint will be personal and relative, so it must be received and *interpreted* whatever its *form* (linear or confused) or its content.

The Role of Active Listening

The process of curing/caring is based on a relationship involving both *active listening* (in the words of the psychologist Carl R. Rogers) and on a willingness on both sides to learn from each other. This brings to light, in all its urgency, the role of the body, because *knowledge* is always *embodied*, by which it is meant the knowledge of one's own body, which is often tacit.[35] The ranks of caregiving professionals are filled with many teachers, doctors, nurses, social care workers who know this well. Within their daily work and practice, they are called upon to put into play their *competences* and *life skills*. In other words, they must engage with their *knowledge* (their expert, specialized knowledge), their ability to *know what to do* (their skills and practice), to *know how to be* (knowing how to make decisions, knowing how to interact with Others and with complex problems) to *know how to communicate* (knowing how to cooperate and work effectively in teams) and to *know how to learn* (life-long learning).[36] Indeed, the body is not only a means to gain knowledge, but it is itself at the basis of knowledge. People know factual reality through their bodies and so develop their abilities in the sensory, cognitive, emotional and sentimental sphere. At the same time, they elaborate an "embodied knowledge," which is experiential, produced *by* and *within* our "being as a body."[37] A body that is never unhistorical, but is programmed for social interaction within the socio-historical *hic*

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[34] Cf. Martin, Gutman and Hutton (eds.) 1988, *Technologies of the Self: A Seminar with Michel Foucault*. See also: Foucault 2008, *Le gouvernement de soi et des autres: Cours au Collège de France (1982–1983)*; Foucault 2001, *Biopolitica e liberalismo: detti e scritti su potere ed etica, 1975–1984*; Foucault 1994a, *Poteri e strategie. L'assoggettamento dei corpi e l'elemento sfuggente*.

[35] Maturana and Varela 1987, *The Tree of Knowledge: The Biological Roots of Human Understanding*; Damasio 1994, *Descartes' Error: Emotion, Reason, and the Human Brain*.

[36] Kannen 2012, "*My body speaks to them: Instructor reflections on the complexities of power and social embodiments*"; Kolb 1984, *Experiential Learning: Experience as the Source of Learning and Development*; Lawrence 2012, "Intuitive Knowing and Embodied Consciousness."

[37] Leder 1992, *The Body in Medical Thought and Practice*.

et nunc (here and now) and is, therefore, regulated by the political and cultural system of the *milieu* to which every person belongs.

To understand the role of *active listening* in the sense of a welcoming, non-judgmental *attitude*, one may uncover how the *person-centered approach* developed by humanistic psychology scholars (starting from the lesson of Carl R. Rogers) helps to explain how effective listening is in terms of improving practice and relationships in both the personal and professional spheres.[38] This is especially so when listening is combined with empathy (see above), *unconditional positive regard* and *authenticity* (transparency, clarity and *congruence* in proposing oneself). *Unconditional regard* is the capacity of appreciating and accepting the other person's existential reality (what the person being cured/cared for has lived through his or her experiences) refraining from any form of interpretation and/or judgment. Acceptance, nevertheless, does not mean sharing or approving other people's ideas, opinions or feelings *tout court* but, rather, it is acknowledging that the other person is free to have these ideas, opinions and feelings. It is more a form of deep *respect* for the other person and is also the means for developing reciprocal *trust*, which is an indispensable part of a curative relationship (see Carl R. Rogers and the person-centered therapy, also known as person-centered psychotherapy, person-centered counselling and client-centered therapy).[39] *Authenticity*, on the contrary, denotes being spontaneous, consistent and transparent in one's relationships. People are authentic when they express and behave as they really are with their own feelings and perceptions, without using stereotypes or platitudes, clichés in their speech, and when they remain in empathy with Others.[40]

Following the footsteps of Jacques Lacan, the Italian psychotherapist Massimo Recalcati states that, rather than in the function that defines and bonds the *significant* and the *signifier*, the unconscious dimension of an artwork lies in the *cleft*, the fracture that separates them. An artwork, in other words, defines a *cut* (a separation, a cleft, a resistance). It is, therefore, the impossibility of fully reconducting the "significant storyline" to its primary meanings. More correctly, the *unconsciousness of the artwork* consists in its not being translatable, its eccentricity compared to any hermeneutic interpretation.[41] Therefore, an art image, like a visual metaphor or a poem, enjoys its own intrinsic semantic density, which is impossible to translate unless symbolically. Starting from these premises, in the next part of this essay, I will try to extract the deepest meaning of the curing/caring relationship by proposing a few peculiar examples from literature (chosen among thousands of possibilities,

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[38] Rogers 1951, *Client-Centred Therapy: Its Current Practice, Implications, and Theory*.

[39] Ibid. Rogers, "Client-Centered Therapy" in Arieti (ed.), *American Handbook of Psychiatry*, vol. 3.

[40] See among others: Rizzolatti and Sinigaglia 2006, *So quel che fai. Il cervello che agisce e i neuroni specchio*; Rizzolatti and Sinigaglia 2019, *Specchi nel cervello. Come comprendiamo gli altri dall'interno*.

[41] Recalcati 2011, *Il miracolo della forma*, and Idem 2016, *Il mistero delle cose*.

leaving aside the most famous authors, those akin to Francesco Petrarca, Giovanni Boccaccio, Michel de Montaigne, Luigi Pirandello, Italo Svevo, Umberto Saba and Carlo Michelstaedter, because these would require another and different work, more space and are beyond the scope of this essay). As in a trick with mirrors, where the past dialogues with the present, we take up the paradigmatic thoughts of several writers who question themselves about curing and caring, disease and death. They take it upon themselves to describe them, sometimes through metaphors[42] (often seeing curing as a *fight* or battle) and other times trying to trace, within their poems the most intimate meanings of life. Among these, for example, is the ideal 'doctor and philosopher' described by the ancient Greek physician Galen (Pergamon 129 CE – Rome c. 201 CE). He reflects on whether to tell his patient the true facts, stating that a doctor is the 'friend of truth,' because he tells his patients the truth, but truth that is measured (or in a Latin word, *temperantia*).

Moreover, how is it possible not to remember the life experience and the effect produced by the words spoken by the doctor consulted by the quiet, calm and patient *Ivan Ilyich*? – in Tolstoy's famous 1886 novel – and his understanding: ". . . Maybe I didn't live as I should have done?" came the sudden thought. "But how can that be when I did everything properly?"[43] "This conclusion left Ivan Ilyich with a sickly feeling, filling him with self-pity and great animosity towards the doctor who showed so much indifference to such an important question. And in the light of the doctor's confusing pronouncements the pain, that dull, nagging pain that never went away, was taking on a new and more serious significance."[44] The illness worsens, despite the treatment and he continues to consult doctors, but "The time for fooling himself was over: something new and dreadful was going on inside Ivan Ilyich, something significant, more significant than anything in his whole life. And he was the only one who knew it; the people around him didn't know, or didn't want to know,"[45] until the pain became such that "He took in some air . . . stretched out, and died."[46]

Virginia Woolf in *On Being Ill* also considers the important role of *language* and observes that ". . . but let a sufferer try to describe a pain in his head to a doctor and language at once runs dry. There is nothing ready made for him. He is forced to coin words himself, and, taking his pain in one hand, and a lump of pure sound in the other . . . so to crush them together that a brand new word in the end drops out" (Woolf, 1926, p. 34).[47] This permanent search for meaning and the search for

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[42] Lakoff and Johnson 1980, *Metaphors We Live By*; Lakoff and Johnson 1999, *Philosophy in the Flesh: The Embodied Mind and Its Challenge to Western Thought*.

[43] Tolstoy (1886) 2016: 80.

[44] Id.: 41.

[45] Id.: 42.

[46] Id.: 90.

[47] Woolf 1926, *On Being Ill*.

the precise words to express it is a distinctive trait of Woolf's narrative style. And, nevertheless of an existence that alternates moments of profound discomfort with "moments of being":[48] that is, those particular epiphanies, those instants (or involuntary memories) able of illuminating, just for a moment, the daily routine.

The words used – in the Seventeenth Century – by Molière in *The Imaginary Invalid* (1673), also translated as *The Hypochondriac*, are totally different in tone, register and basic purpose. In this case, the satirical topic concerns the invalid's hypochondria and also the incompetence of the doctors caring for him. All of them are characters sporting pompous and ridiculous names, Monsieur Purgon the physician, Monsieur Fleurant the apothecary, Monsieur Diafoirus the physician. Towards the end of the play, the character Béralde, expresses his opinion saying: "I don't see anything more ridiculous, than for one man to undertake to cure another." This reveals a certain truth, because it is indeed difficult to cure the sick person who does not wish to take on the personal responsibility or commitment to cure him or herself.

At this point of the analysis, based on what has been said so far, it is interesting to recall the value of the "circumstantial paradigm" (in the words of the Italian historian Carlo Ginzburg). This is an interpretive method that re-evaluates marginal data or phenomena (usually considered unimportant and undervalued) by considering them, instead, as revealing clues: they provide the key to accessing the most complex levels of existence and most hidden movements of human experience.[49] Moreover, Edgar Wind argues that the true human personality is revealed, above all, in non-verbal language and in those small, unconscious gestures that more fully reveal the true character of each person than any formal attitude, carefully thought out and externally expressed.[50] Hence, the meaning of the words of both the scientists and the artists mentioned in the present analysis is even better understood.

Peculiar Words of Care

Moving our attention from the meaning of the words of contemporary writers and poets, one may discover how each one was able to present an exemplary picture of his or her identity and his or her experience of *disease* and *cure*, providing care for

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[48] Jensen 2007, "Tradition and Revelation. Moments of Being in Virginia Woolf's Major Novels."

[49] Cf. Ginzburg 1986, *Miti emblemi spie. Morfologia e storia*. On these aspects (and the 'circumstantial paradigm') see also: Romano 2019, "Freud, Morelli e la nascita del paradigma indiziario in psicoanalisi"; Gallerani 2021b, "Images, Thoughts and Words on Disease in the Works of Michelangelo"; Eadem 2021a, "Disease in Art and Art(ist) in Disease: Reflections on Paradigmatic Works by Leonardo da Vinci and Michelangelo Buonarroti."

[50] Cf. Wind 1968, *Arte e anarchia*, p. 62 (author's translation).

loved ones or received this care (see the poem by Francesco Tomada, as it will be addressed in the following pages).[51] It is as if they transformed a personal experience into high literature, or better still, into a universal message that can send very diverse messages to different people. These words resound in each one of us differently, and we can reflect in (or distance ourselves from) them. But they are unlikely to leave us *indifferent*, because even when they connect to deep, shared meanings, they can always be read in a different way, or be interpreted newly. They evoke vision, intuition and sudden powerful realizations that surprise us and throw wide windows open into reality, *illuminating*, observing and analyzing it as never before. And so it is when we address an aesthetic experience, in *real presence, living* a very personal experience that, for this very reason, we are often unable even to *explain*. We cannot explain it because, that emerging moment of emotion – stimulated by words, images, colours, sounds or the natural environment – has the power of rapidly transforming both our interior reality and the reality around us, and place a question mark over everything that first appeared obvious, reasonable and serious.

Any aesthetic experience (in a Dewey's meaning) will consult, question, surprise, make us think and, unexpectedly, let us discover new meanings where none appeared to be. And conduct us further, beyond conventions, norms or precise expectations.[52] For this reason, the words of the poets are peculiar and precise. Precise in the sense that they are chosen with care and attention: they are selected from common and less common words, to compose original verses able of express an idea or a thought, to identify an emotion and to make them understandable in a concise narrative text, that is *essential*. Every poem can be considered a real *distillation* of words, because every single word refers to deep meanings: it refers to uncommon emotions, feelings, moods, images, colors (and much more), because uncommon are the people who read those words and make them live in themselves. Indeed, in Nancy's words: ". . . if in some way we have access to a threshold of meaning, this happens thanks to poetry."[53]

Therefore, one may note the sensitivity, incisiveness and pained irony that runs through Raymond Carver's poem entitled *What the Doctor Said*.[54] And how, in his

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[51] On the question of identity and how does a mind build itself, see among others: Freeman 2001, *How Brains Make Up Their Minds*; Ammaniti and Gallese 2014, *The Birth of Intersubjectivity. Psychodynamics, Neurobiology, and the Self*; Rizzolatti and Gnoli 2016, *In te mi specchio. Per una scienza dell'empatia*; Northoff 2019, *La neurofilosofia e la mente sana. Imparare dal cervello malato*.

[52] Clover, Sanford and Butterwick (eds.) 2013, *Aesthetic Practices and Adult Education*; Reid and West (eds.) 2014, C*onstructing Narratives of Continuity and Change. A transdisciplinary Approach to Researching Lives*; Merrill and West 2009, *Using Biographical Methods in Social Research*; Leavy 2021. *Method Meets Art etc. (no 2009), Metho 2009d Meets Art. Arts-Based Research Practice*.

[53] Nancy 2017, *La custodia del senso. Necessità e resistenza della poesia*, p. 21 (author's translation); Gallerani 2012, *L'impegno lieve. Il razionalismo critico e l'ideale estetico*.

[54] Carver 1996, 'What the Doctor Said', *in All of Us: Collected Poems*. See also: Pivano, *Pagine americane. Narrativa e poesia 1943–2005*.

final poem (*Things I'll Not Do*), Allen Ginsberg instead sheds light on the life of a man who responds to a diagnosis of terminal illness (cancer) with the will and courage to continue writing, despite everything. So, while the poet is saying farewell to the world, he dwells once more on his attachment to life, as if to observe once again that, while he did not look after his body much (or his health), he certainly took care of "looking after his mind." He writes a farewell to life (and farewell to all the things he will not do, again or ever) which is without doubt melancholic, but in a certain way also soothing. This is the last act in an existence that was both tormented and overflowing with experiences, with his writing acting as a unifying theme throughout. He also expresses his mood and life experience through the emblematic verses of two poems entitled *Things I'll Not Do* (now in *Death & Fame*, 1997) and *When I die*.[55]

The choice to consider these authors is intentional and deliberate, searching for revealing clues about the meaning and significance of an artist's work, thanks to the circumstantial paradigm. It is a motivated choice, first of all, to highlight the words of care and the personal narrative style (the sensibility) of each of them. Secondly, to observe how writers and poets – so different from each other – have been able to use writing as an *instrument* of self-knowledge and, perhaps, of self-care. In any case, every storytelling clearly expresses the urgency to narrate and share experiences of illness (or caring) that are both intimate and painful. A narrative able of recomposing a privileged relationship with the one's own inner world and with external world.

What The Doctor Said by Raymond Carver

On the meanings of the narrative and to better highlight what has been said so far, Carver's verses are very eloquent (i.e., vv. no. 3–5, vv. no. 12–13, vv. no. 20–22):

> He said it doesn't look good
> he said it looks bad in fact real bad
> he said I counted thirty-two of them on one lung before
> I quit counting them
> I said I'm glad I wouldn't want to know
> about any more being there than that
> he said are you a religious man do you kneel down
> in forest groves and let yourself ask for help
> when you come to a waterfall
> mist blowing against your face and arms
> do you stop and ask for understanding at those moments
> I said not yet but I intend to start today
> he said I'm real sorry he said
> I wish I had some other kind of news to give you

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[55] Ginsberg 1999, *Death & Fame: Poems 1993–1997*, pp. 98–99 and Ginsberg 2006, *Collected Poems, 1947–1997*, p. 1130.

I said Amen and he said something else
I didn’t catch and not knowing what else to do
and not wanting him to have to repeat it
and me to have to fully digest it
I just looked at him
for a minute and he looked back it was then
I jumped up and shook hands with this man who’d just given me
something no one else on earth had ever given me
I may have even thanked him habit being so strong.

Things I’ll Not Do (*Nostalgias*) by Allen Ginsberg

To better highlight both the mood of poet and impact of illness and death on himself (after a long terminally ill), the Ginsberg’s verses appear very touching (i.e., v. no. 1, v. no. 11, vv. no. 35–36 and also the icastic final verse). This particular lyric is very interesting, because it represents both a sort of testament and the last lines of one’s autobiography:

Never go to Bulgaria, had a booklet & invitation
Same Albania, invited last year, privately by Lottery scammers or
recovering alcoholics,
Or enlightened poets of the antique land of Hades Gates
Nor visit Lhasa live in Hilton or Ngawang Gelek’s household & weary
ascend Potala
Nor ever return to Kashi ‘oldest continuously habited city in the world’
bathe in Ganges & sit again at Manikarnika ghat with Peter,
visit Lord Jagganath again in Puri, never back to Birbhum take
notes tales of Khaki Baba
Or hear music festivals in Madras with Philip
Or return to enter to have Chai with older Sunil & the Young coffeeshop poets,
Tie my head on a block in the Chinatown opium den, pass by Moslem
Hotel, its rooftop Tinsmith Street Choudui Chowh Nimtallah
Burning ground nor smoke ganja on the Hooghly
Nor the alleyways of Achmed’s Fez, nevermore drink mint tea at Soco
Chico, visit Paul B. in Tangiers
Or see the Sphinx in Desert at Sunrise or sunset, morn & dusk in the
desert
Ancient collapsed Beirut, sad bombed Babylon & Ur of old, Syria’s
grim mysteries all Araby & Saudi Deserts, Yemen’s sprightly
folk,
Old opium tribal Afghanistan, Tibet – Templed Beluchistan
See Shanghai again, nor cares of Dunhuang
Nor climb E. 12th Street’s stairway 3 flights again,
Nor go to literary Argentina, accompany Glass to Sao Paolo & live a
month in a flat Rio’s beaches & favella boys, Bahia’s great
Carnival

> Nor more daydream of Bali, too far Adelaide's festival to get new song
> sticks
> Not see the new slums of Jakarta, mysterious Borneo forests & painted
> men & women
> No more Sunset Boulevard, Melrose Avenue, Oz on Ocean Way
> Old cousin Danny Leegant, memories of Aunt Edith in Santa Monica
> No more sweet summers with lovers, teaching Blake at Naropa,
> Mind Writing Slogans, new modern American Poetics, Williams
> Kerouac Reznikoff Rakosi Corso Creeley Orlovsky
> Any visits to B'nai Israel graves of Buba, Aunt Rose, Harry Meltzer and
> Aunt Clara, Father Louis
> Not myself except in an urn of ashes.
> March 30, 1997, A.M.

Death & Fame

Words of care also are hidden in the ironic and sarcastic verses of this Ginsberg's poem about death (see in particular the following verses):

> When I die
> I don't care what happens to my body
> throw ashes in the air, scatter'em in East River
> bury an urn in Elizabeth New Jersey, B'nai Israel Cemetery
> But I want a big funeral
> St. Patrick's Cathedral, St. Mark's Church, the largest synagogue in
> Manhattan
> First, there's family, brother, nephews, spry aged Edith stepmother
> 96, Aunt Honey from old Newark
> [. . .]
> 'Father Death comforted me when my sister died Boston 1982'
> 'I read what he said in a newsmagazine, blew my mind, realized
> others like me out there'
> Deaf & Dumb bards with hand signing quick brilliant gestures
> Then Journalists, editors's secretaries, agents, portraitists & photo-
> graphy aficionados, rock critics, cultured laborors, cultural
> historians come to witness the historic funeral
> Super-fans, poetasters, aging Beatnicks & Deadheads, autograph-
> hunters, distinguished paparazzi, intelligent gawkers
> Everyone knew they were part of 'History' except the deceased
> who never knew exactly what was happening even when I was alive.
> February 22, 1997

These words (and verses) seem to remind us, once again, that disease does not coincide with *diagnosis*, but can bring to light the entire world of relationships that envelop the sick person. This world is lain bare, telling, alongside one person's story, also the story of that person's family, revealing the familiar illnesses, the types of cure received, the relationships co-constructed between people (parents, friends and partners). All this is tightly linked to a capacity for self-care and looking after Others. Philip Roth returns to these topics and unfurls them in his autobiographical book entitled *Patrimony: A True Story* (edited in 1991).[56] Here, he explores the relationship between a terminally ill father and his son, who becomes his carer (and caregiver), pulling away the veil from a family's story and its arrangements, its dynamics and, within these dynamics, inhibiting the things that are said and not said. And so it is possible to observe life memories emerging, of how the writer was cared for by his parents and how the roles will be exchanged when it is him, the son, to care for his elderly father. In a circular physiological process that is part of the circle of life, but which prompts a sense of powerlessness and defeat when faced with a relentless disease. The incipit of *Patrimony: A True Story* is very expressive: "My father had lost most of the sight in his right eye by the time he'd reached eighty-six, but otherwise he seemed in phenomenal health for a man his age when he came down with what the Florida doctor diagnosed, incorrectly, as Bell's palsy, a viral infection that causes paralysis, usually temporary, to one side of the face." Then, in a later chapter, he writes an impressive description of his father's tone of voice (during a medical visit) not meant to be one of anger but, rather, it was more anxiety and bewilderment. This was all new, and he felt powerless to find a way to help him. They went through this experience together.

Finally, it is interesting to consider – in order to complete and conclude this analysis – the poetics of a contemporary Italian poet Francesco Tomada. Many illustrious Italian poets have written poems dedicated to their mothers or to a symbolic idea of mother, such as, for example, Dante Alighieri (referring to a Heavenly Mother, the Virgin Mother), Giovanni Pascoli, Salvatore Quasimodo, Pierpaolo Pasolini, Giuseppe Ungaretti and Eugenio Montale, just to mention some of the most important. Nonetheless, the choice to evoke Tomada's words of care is explained by the unexpected adherence of his poetic (sense and sensibility) to the analysis and the theses advocated in this essay.

In his profound poetic *voice* (words) Tomada shows an intimate feel/sensitivity and, at the same time, a deep attention into take care of the Other and, in particular, to one's mother. A deep emphaty expressed through gestures of *respect* and *care* towards the mother. As is well known, the mother represents the first *significant adult* or the primary best caregiver for each child: all this, without wishing to carry out any psychoanalytic investigation of the writer's Oedipus complex, but only with the aim to observe the point of view of a man who takes care of a woman, his mother. And more, *how* and *why* in doing so he feels the urge to write and share his personal experience with Others. That is to say, he feels the need to express himself with writing (poetry) and to use words, at first to describe emotions, thoughts and experiences

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[56] Roth 1991, *Patrimony. A True Story*.

both of his inner world and his life. Secondly, to fix their experiences on the blank page as well as in their own memory and consequently to share this sensibility with Others (i.e. the readers). This last point is also noteworthy.

In his poem entitled *Saved souls* Francesco Tomada expresses simple and delicately, the ways in which he cares for his fragile elderly mother.[57] In his case, the act of caring sanctions, on the one side, an intergenerational passage and a clear inversion of roles, but under the form of reciprocal mirroring of the one (the now adult son who cares) in the other (the elderly mother who needs care). Care, therefore, is transformed into an act of restitution and gratitude, the son's *gift* of caring for his mother as she had cared for him in times past.

The style and ways for caring of a son/daughter for a mother (or father) broadly reflect the set of caring practices learnt in the bosom of a family, from parents or other carers (caregivers). Having care (for oneself or Others) is linked to the human being and is truly a way of being human (*à la* Heidegger).[58] And more. Having care, thus interpreted, presents some interesting analogies with the Latin's meaning of *pìetas* that is intended as a feeling that does not perfectly coincide with piety as we understand it, but is much more complex and nuanced: it is a mixture of devotion and respect towards both high moral values and ethical ideals but also towards Others (i.e. the family, humankind).

As is well known – starting from the studies of Sigmund Freud, Anna Freud and Melanie Klein – how indispensable is, in early infancy, to give the child a harmonious, well-balanced upbringing and instil resilience, but it is still a primary need in other ages, throughout life. As a pre-social skill, caring encourages well-being and is a precious lifelong act that people can share and co-construct together. Hence, learning the 'ethics of care' means developing not only a personal disposition (or attitude)

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57 Francesco Tomada's poem is here reported in original Italian version to highlight the carefully research of each word and meaning. So that it is possible to *hear*, feel and make experience both the sound and *rhythm* of the verses in two different languages (Italian and English). *Anime Salve* (Saved Souls): "Dieci anni fa cambiavo i vestiti ai miei bambini, / lavavo la loro nudità e lo sporco / Prima di averli, pensavo che mi avrebbe impressionato, e invece no / Oggi faccio lo stesso con te / E quel pudore assoluto che ci ha sempre accompagnati / non esiste più, / Non c'è vergogna in nessuno dei due / Ho imparato prima ad essere padre / e solo dopo figlio / Appena in tempo, mamma, / Ma ce l'ho fatta adesso puoi andare."

58 Being-in-the-world. A fundamental basis of our being-in-the-world is, for the German philosopher Martin Heidegger, not matter or spirit but care. The core of human beings lies in their basic structure of care. This is expressed by Martin Heidegger in his *History of the Concept of Time: Prolegomena* (the text is that of a course of lectures that Heidegger gave at the University of Marburg during the summer semester 1925) where he states that human beings should be "shepherds of Being," meaning that they are such through what they do and through what they take care of. Cf. M. Heidegger, *History of the Concept of Time: Prolegomena*, Bloomington, Indiana University Press 2009.

but also appropriating practices (actions) that can be shared socially: not only with family or friends:[59]

Saved souls by Francesco Tomada

Ten years ago I changed my children's clothes,
I bathed their nakedness and washed away their dirt
Before having them, I thought this would bother me,
But it was not so

I do the same for you today
And the complete modesty once always present between us
Is there no longer,
There is no shame for either of us

I learnt first to be a father
And only later to be a son
Just in time, Mother,
But I got there and now you can
go . . .[60]

Conclusions

As it has been suggested and argued in the analysis throughout this essay, active listening is the prerequisite for an effective relationship of care. A care that is understood as *measured, respectful and equitable*: the three keywords of the *Slow Medicine* approach promoted by Carlo Petrini and other founding members.[61] If we analyze the meaning of each of these three words, we can observe that the Slow Medicine recognizes that "doing more" does not always mean doing better. In fact, the dissemination and use of treatments or new diagnostic procedures is not always necessary (or accompanied by benefits for patients). Moreover, it should not be

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[59] Gilligan 1982, *In a Different Voice. Psychological Theory and Women's Development*; Noddings 2013, *Caring. A Relational Approach to Ethics and Moral Education*; Manning 1992, *Speaking from the Heart. A Feminist Perspective on Ethics*; Tronto 1994, *Moral Boundaries: A Political Argument for an Ethic of Care*.

[60] *Saved Souls* (*Anime Salve*), in Francesco Tomada 2014, *Portarsi avanti con gli addii* (no page numbers), English translation by Manuela Gallerani.

[61] The first Italian National Conference on Slow Medicine (held in Turin in November 2011) attended by Alberto Dolara and Carlo Petrini set the stage for a broadly represented organization for a medical *reform*. Indeed, hyperactivity in clinical practice is often *unnecessary*. In the *slow medicine* network, healthcare professionals, especially the doctors and nurses, are given the time they need to run through their patient's personal, family and social problems exhaustively, to help them overcome excessive anxiety when faced with non-urgent diagnostic and therapeutic procedures, to assess new methods and technologies *carefully* and to offer adequate emotional support to terminally ill patients and their loved ones.

overlooked that economic interests encourage both an excessive use of drugs or health services and an expansion of people's expectations on health (and life span). In this sense, a *measured* medicine implies the ability to act with moderation, in a gradual and essential way (and without waste). A measured medicine is engaged in the respect of both the environment and the integrity of the natural and social ecosystem. A *respectful* medicine is able to take into consideration the orientations and the values of each person in different moments of life and, at the same time, the professionals of caring act with empathy and respect. *Consequently*, an *equitable* medicine asks appropriate care and a good *quality* of curing/caring, for both patients and health professionals. Therefore, an equitable medicine facilitates people to access both to social and health service network and is against inequality treatments.

In this framework, care becomes a *rule of life*, embracing the underlying assumption of (ethical) *responsibility* that can be traced to the notion of *epimeleia heautou* (care of Self and of the Other) and to *parresia* (to speak candidly or to ask forgiveness for so speaking), which is also a way of speaking to a person's *soul* and is an act relating to *how* this soul will be formed (in the words of Michel Foucault). In this sense, the care becomes an ethical and also *political* action, because the purpose is to find well-being and the *good* for a good life or at least *good enough*. That means with dignity, at any age, time or condition (including frailty) one finds oneself in.

In other words, in a respectful, measured, equitable *curative* relationship, caregivers must be most careful to say the right things, at the right time – from diagnosis to cure – and in the right way to that unique, unreplaceable person who is in front of them, face-to-face.[62] To take up the words of Paul Ricœur ethics are defined through three levels: "I would define the ethical perspective with these three terms: hope for a good life, with and for Others, within the right institutions."[63] From here, the contribution of Medical Humanities appears essential in an ethics of curing/caring that encourages good health as the grounds for a good life.[64] By this it is possible to mean a life directed towards self-fulfillment and empowerment, individually and socially, as well as towards *good* and *happiness* (in the meaning of *eudaimonia*), pursued because it is the intrinsic aim of a human and engaged life project.

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[62] Cassidy, Werner, Rourke, Zubernis and Balaraman 2003, "The Relationship Between Psychological Understanding and Positive Social Behavior"; Gallerani 2016, "Narrative Medicine and Stories of Illness: Caring for the Sick requires active Listening"; Gallerani 2020, "The Responsibility in speaking of Care."

[63] Ricœur 2007, *Etica e morale*, p. 34 (author's translation). On this theme see also: Bauman 2008, *Does Ethic have a Chance in a World of Consumers*? *Le sfide dell'etica*.

[64] Veatch 1981, *A Theory of Medical Ethics*; Nussbaum and Sen (ed.) 1993, *The Quality of Life*.