



EUNAMES – Narrative Medicine Survey across WHO-Europe countries

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INTRODUCTION

The European Narrative Medicine Society was born from an idea of the Italian Society of Narrative Medicine and is an association of non-profit researchers dedicated to the investigation of Medical Humanities in the medical field, for health, narrative medicine and other languages of care. The purpose of the Association is to improve the health systems, at a European country level, aiming at the creation of a psychosocial and spiritual care model. **EUNAMES** agreed upon mapping centres and people involved in Narrative Medicine.

Narrative is every kind of text, oral, written, body, art, music, film, which can be used together with quantitative data from Evidence-Based Care, to improve the quality of life of patients, people living in critical conditions, their caregivers and family members and care professionals and citizens. The Medical Humanities refer in particular to “artificial” texts, invented or inspired by the object of illness. Narrative medicine concerns real, oral or written narratives collected during daily clinical practice from patients, health care professionals, family members and other stakeholders involved in the health care process.

The purpose of this European Society is to promote and strengthen dialogues, discussions on the present and the future of Medical Humanities and Narrative Medicine, for health professionals, researchers (both academics and non-academics), humanists, teachers and other professionals coming from every branch. All this with the aim to contribute to improving both the well-being of people who suffer from a physical condition or a mental illness, and their health workers. Europe is today undergoing a profound transformation due to the great migratory movements on the one hand, and the need to proclaim and defend the sovereignty of different countries on the other: this was at the beginning of the 2020, the main reason for the Call to establish the European Society of Narrative Medicine.

Namely health is a Human Right endorsed and defended by the World Health Organization, and indeed the WHO-Europe has drawn up guidelines for narrative research, for this purpose which are



a very important document to underline the equalitarian importance of narrative discipline and the clinical and scientific competence. Beyond this WHO- Europe has launched in November 2019 the first report concerning Art Therapy (Humanities for Health) and Clinical Outcomes. Since there is no European Network of Narrative Medicine, this society is now ready to fill the gap in networking at a time when European community is in danger from a cultural point of view and to promote in every participating country transdisciplinary approach between narrative and scientific competences to promote a better quality in the health care system. Moreover, the pandemic of COVID-19, which drained so many energies and efforts to all health care workers and social health planners in the world, now needs cooperation across Europe, not only by the use of Evidence Based Medicine but also of Narrative Medicine.

The pillars of EUNAMES are:

- Plurality of approaches
- Inclusivity
- Multidisciplinary
- Open to every country also outside Europe
- Community of practice

EUNAMES bases its being on a plurality of approaches, inclusiveness and multidisciplinary, openness to the world and creating a community based on practice and direct experience.

Fifty-three are the countries belonging to WHO-Europe: here their list. Please remind that in every country, there are long educated or new educated experts and scholars of Medical Humanities, sometimes working alone, sometimes working in groups. Everywhere, from Albania, Andorra, Armenia, Austria, Azerbaijan, Belarus, Belgium, Bosnia and Herzegovina, Bulgaria, Croatia, Cyprus, Czechia, Denmark, Estonia, Finland, France, Georgia, Germany, Greece, Hungary, Iceland, Ireland, Israel, Italy, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, Luxembourg, Malta, Monaco, Bulgaria, Croatia, Denmark, Estonia, Finland, France, Georgia, Germany, Greece, Hungary, Montenegro, Netherlands, North Macedonia, Norway, Poland, Portugal, Republic of Moldova, Romania, Russian Federation, San Marino, Serbia, Slovakia, Slovenia, Spain, Sweden, Switzerland, Tajikistan, Turkey, Turkmenistan, Ukraine, United Kingdom of Great Britain and Northern Ireland, Uzbekistan.



Who are the people using, exploring, studying Medical Humanities and Narrative Medicine, and what do they need from EUNAMES? These are the scope of the present survey.

AIM OF THE RESEARCH

The research has the fundamental purpose of creating a network of contacts, experiences, centres, professionals who in different ways have the approach of narrative medicine. The goal is not just to take a picture of what exists but to create a stimulus for communication, exchange, and interconnection. This kind of research wishes also to understand the Identity of people involved in narrative medicine and medical humanities, their reasons why for embracing this field of knowledge. From a preliminary desk research, it emerged that the community of medical humanities is very nuanced in terms of backgrounds i.e. (scientific, medical, philosophical, literature, psychology, sociology, anthropology, art...) and blended of different competencies. This research explores the short biographies of experts and scholar of Narrative medicine in Europe, who were the main influencers, which kind of approaches are undertaken, are all important elements to understand the reason why of the narrative and artistic competence in this evidence-based world.

METHODS AND TOOLS

The research of the centres and names:

The research was articulated using the Google search engine by entering the keywords that guided us throughout our journey of discovery and imaginary journey through European countries. The keywords used were the following: *narrative medicine, Medical humanities, Humanities for health, medical storytelling, narrative nursing, medical and care communication, health language, therapeutic writing, humanization of care, narrative care.*

The results were then collected in an excel table divided by countries and with the name of the specialists or centres of reference, peculiarities, or particular brief information, addresses an email contacts where present. The table was also greatly enriched by indirect contacts recovered from articles or publications by other authors.

The survey



Following the collections of the names of the centres, a survey was sent to the identified email addresses all over Europe. A narrative and quantitative questionnaire was asked to the participants, which required not only the personal data but also the effort to comment on choices, how they approached humanities for health, such as paths and activities related to narrative medicine, a short biography to depict oneself and what people need from EUNAMES a collaborative network.

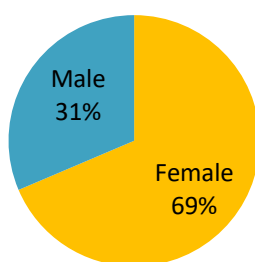
RESULTS AND SHORT COMMENTS

Response Statistics

Among the 94 narrative and quantitative questionnaires received, 26.1% were fully completed and 79.1% were not fully completed perhaps also due to the modest relevance of contacts with narrative medicine, as people or specialists who know it, share the objectives and methods but do not have specific education in this regard.

1. Gender

In relation to the sex of the people who answered almost double are women, 69 % and 31 % of men, this showing a prevalence of women in the humanities field as thought to be still “gender based discipline”.



2. Age

The occurrence of the ages classes is the following:

<30	None
30-40	22.5%
40-55	42%
>55	56%



The youngest age is 37 years and the eldest is 70. The most represented class age is between 50 and 62 years. It looks like that students in Medical and Nursing Academies are still centered on scientific and technical programs and that Humanities are disciplines for long life learning.

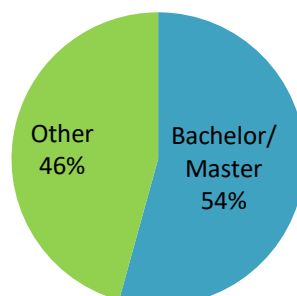
3. Nationality and Country

Six % of respondents were not European, 94% were European based. The most represented countries are the European ones, a small part comes from non-European countries. Specifically: 11 from Italy, 7 from Portugal, 6 from UK, 2 from France and the other European states from 1 answer. As for the non-European states, the Arab Emirates and Singapore.



4. Education level

The level of studies shows 54,3 % of graduates or masters and 45,7 % other; highly educated people, in the niche of what is currently the average education.



5. Could you narrate your educational background?

Going to analyzing the school background: modern languages and master in bioethics, family therapist, pharmaceutical sciences, psychology of art, nursing, PhD in American studies, science



communication, History and Ethnology, student, philosophy, teacher in the secondary school. Some studies and professional education followed a "coherent" path in humanities, a degree in literature and teaching, while others were more varied and touched on different educational and professional experiences.



SHORT NARRATIVES

I took a degree in Modern languages and Literature (English/German); then I took a Master in Anglo-American Culture, a Phd in Bioethics and a postdoc in narrative medicine

Medical school, family therapist

MD, MA, PhD

I started off in biological sciences taking a B.Sc (Microbiology and Biochemistry) but moved onto the humanities where I took my M.A (English Studies) and PhD (Literary and Cultural Studies),

Pharmaceutical sciences

The preamble is Clinical Psychology, the main text is Educational Psychology and the last written chapter of my "educational narrative" are in Psychology of Art. The end of the story is still to be known.

Nursing

PhD in American Studies (US Contemporary Poetry)

Started off in straight science (botany), then switched focus to science communication and then to medical humanities.

After studying literature and creative writing training, I received a PhD in French literature in 2013.

Master's studies in 18 and 19th century British literature (the novel) and contemporary socio-linguistics. Doctoral studies in 19th century British fiction and the history of women in medicine: my dissertation research was a survey of late-19 century British novels featuring a woman doctor as the main character.

Humanities-Literature

Hmm... A little unusual combination: University Diploma in History and in Ethnology; postgraduate in communication and media; postgraduate in survival biology and nature conservation; currently ongoing Phd in experience design



I was a teacher in the secondary school but as I loved to study, I decided to do the Master and PhD

My schooling was done in Singapore which included primary, secondary and junior college. Then I went to Melbourne, Australia to join medical school there. After I completed medicine I worked there for a year and then moved back to Singapore.

I attended Imperial College London for my undergraduate medical degree in 2000 and I am currently back on their part-time medical education masters programme.

Scientific High School- Degree in Economia e Commercio Bergamo) - Master in Patient Advocacy Management (university Cattolica - Roma)- now Student at the faculty of Psychology

Classic and scientific high school and humanistic university education in the field of public health

Starting from Classic high school than Pharmacology, Epidemiology and Counseling and Art Coach. Always fascinates by linguistic science as tool of expression

Modern literature degree with a thesis on adults' educations

I am an MD, specialist in Cardiology, with a PhD in Cellular and Molecular Cardiology. I attended also a master in Narrative Medicine

Born and raised as a Pediatrician and Neonatologist in Italy, 7 years back I moved with my family to Abu Dhabi where I continue to do happily my amazing job 😊 Practicing NM for 20 years!

I Nurse, mother three times, in love with thinking and writing. I attended a master's degree in methodologies and narrative practices in care contexts.

High School Diploma, Bachelor's Degree in Nursing, Master's Degree in Management, Master's Degree in Nursing and Midwifery

I have a PhD in French literature and creative writing studies

I am a medical doctor, with MB from TCD. I am a specialist in occupational medicine and family medicine. I have a Masters in Medical Humanities degree from the University of Sydney. Other Postgraduate degrees include FRCGP and FRCPI . I am an adjunct professor of narrative medicine in the medical school of Trinity College Dublin(TCD), where I teach courses to undergraduates and postgraduates. I am a Medical Humanities researcher with the Department of Academic Neurology in TCD.

Various CME programs on Narrative Medicine High Education in Narrative Practice (Bicocca Milano) Online Narrative Medicine Certification (Columbia University)

My cultural/family setting has been characterized by communication difficulties related to rigid educational settings. My path of study in medicine has had purely scientific and not very humanistic characteristics. My attitude has always been the same and contrary to my path, so I have personally cultivated this aspect.

Bachelors in medical science, MD with a focus on neuroimaging and stroke medicine, PhD in neuroscience and neuroimaging, postgraduate certificates in mentoring and teaching.

Medical Doctor, cardiologist

BSc(Hons) in botany, MSc in Science Communication, MA in Literature and Medicine, currently undertaking a PhD in Health Science Research.

Mostly philosophy...



6. Please specify your current job or activities:

Respect to the profession practiced, they range from the doctor, to the university professor, lecturer, medical assistants and professors, expert in strategies and communication in health, student, Responsible Conduct in Research at the Institute for Research and Innovation in Health, Teaching and researcher, Researcher in Medical Humanities.



ROLES

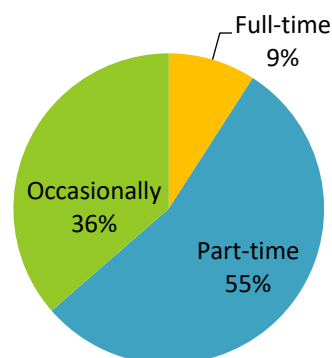
<i>I am the Head of the Unit for Responsible Conduct in Research at the Institute for Research and Innovation in Health (i3S)</i>
<i>Medical educator</i>
<i>Postdoc at Stanford</i>
<i>Visiting Assistant Professor</i>
<i>Teaching and research</i>
<i>Professor at the University of Lisbon</i>
<i>Adjunct Professor at Nursing School of Lisbon (ESEL) - teaching Mental Health contents Currently - Vice-president of ESEL</i>
<i>Invited Assistant Professor (English for the Social Sciences); Researcher in Medical Humanities</i>
<i>Currently a Principal Teaching Fellow and course lead for an intercalated BSc in Medical Sciences with Humanities, Philosophy & Law.</i>
<i>I am an associate professor in Cergy Paris Université (France). I currently lead an academic program dedicated to Narrative Medicine.</i>
<i>Currently, professor of English and Director of the Health Humanities program at MCPHS University in Boston Massachusetts. I teach first-year writing, 19th century British fiction, narrative and medicine, and the "capstone" seminar for graduating pre-med and health humanities students. My research over the years has focused on ways in which we learn about health and wellness through popular media (topics have included fitness and body image for women, "psychosomatic" and contested illness, and, currently, "eco-anxiety").</i>



<i>I am a teacher and researcher</i>
<i>strategic communication expert in public health</i>
<i>I am a university teacher</i>
<i>I am currently a final year resident in psychiatry in Singapore. My job involves managing inpatients and outpatients at the tertiary psychiatric institution in Singapore.</i>
<i>GP, clinical educator, I have been invited to teach on a humanities module</i>
<i>Student and Cancer coach</i>
<i>physician physiatrist</i>
<i>I'm trying to bring wellbeing to patients, health care providers, students through different languages of care other than drugs and medical procedures. This is quite tough in this Covid time but very challenging at the moment.</i>
<i>selection of personnel in the health care sector and management of public contracts in the health care sector</i>
<i>I work as a Cardiologist in an Academic Hospital. I also teach a Narrative Medicine course at Third year students in Medicine and Surgery</i>
<i>Pediatrician and Neonatologist Love walking , reading and ... writing!</i>
<i>Home care nurse</i>
<i>Currently retired since 1.5.2020, previously in charge of organizational function of nursing management</i>
<i>I am an associate professor in CY Cergy Paris Université</i>
<i>Adjunct Prof Narrative Medicine TCD Writer in Residence ESI programme, NUI Galway Medical columnist and author Clinical Strategist/ consultant in occupational medicine with the Health Service Executive</i>
<i>Head of a Continuous Medical Education center Narrative Medicine teacher and facilitator</i>
<i>Medical coordinator of a Palliative Care service.</i>
<i>Teaching undergraduate science, medical and dental students. Teaching qualified healthcare professionals. Research on imaging and scholarship of teaching and learning with a focus on object-based learning and medical humanities. Science communication.</i>
<i>Heart Math Trainer</i>
<i>Principal Teaching Fellow at a university where I am course lead for an intercalated BSc in Medical Sciences with Humanities, Philosophy & Law. Part-time PhD student.</i>
<i>Associate Professor - University of Bucharest</i>

7. How much time do you dedicate to work on Narrative Medicine, Medical Humanities or Art Therapies?

As for the time that every single person and professional dedicates to narrative medicine, 9 % full time, 55% part time and 36 % occasionally. This is because survey have reached groups working only in research and education in narrative medicine, and many other individual health care providers working in the setting of care.



8. What metaphor would you use to describe your professional role?

Expressive linguistic process, and figure of traditional rhetoric, based on an underlying similarity, i.e. on an analogical relationship, the metaphor uses a word or a locution to express a concept different from the one they normally express or to emphasize an emotion, a lived experience, a perception. When asked to represent one's role through a metaphor, the responses were interesting and varied.

The sower who treats and waters his seeds and wait to grow: the care and attention for this activity is not individual but has a vision of balance and the surrounding ecosystem. The water component is represented across the river and also the ship that is facing storms and calm waters but keeps the course of the journey. The journey and adventure are expressed through the explorer who shares his discoveries, the one who, like a small child, tries to decipher unknown languages through signs and traces, a map tracer for students to travel through.

The use of animals ranges from the chameleon that acts by adapting to the environment and blending in with the surrounding reality; to the octopus that tries to cling with its tentacles moves and explores, the silent and industrious ant. The lantern that lights up the night and the grate that creates a barrier but does not prevent the eye from looking beyond. Some answers are didactic, explaining the actions through factual and not symbolic language.

NARRATIVES

A sower: I plant seeds and wait for them to grow; I water and I care about keeping the balance of the ecosystem: both in Narrative Medicine and in research integrity

Chameleon

river



<i>An explorer that shares his discoveries</i>
<i>Inspirational educator</i>
<i>I am a conductor of students (as musicians in an orchestra).</i>
<i>I think of myself as a coach or a trainer - my job is to help others improve their skills - I provide the guidance and motivation, but they have to provide the sweat and tears!</i>
<i>As my superiors sometimes say I practice witchcraft and make people do what they originally didn't want to do</i>
<i>Giving maps to my students, they must walk</i>
<i>Listens to stories- that is actually on my Twitter profile!</i>
<i>HELP OTHERS TAKE CARE OF THEMSELVES</i>
<i>a sailing boat, in open sea. Some time there is a storm, sometime no wind, some time Zephyrus (the good wind) blows....</i>
<i>are a relational network and sometimes an octopus that acts with its tentacles</i>
<i>I just need to revive the historical metaphor of a Pediatrician seen like an Explorer interpreting everything day the language of signs and trying to understand foreign languages as small children don't talk 😊</i>
<i>The lantern that illuminates the darkest night</i>
<i>My professional role was to facilitate the acquisition and/or improvement of skills through training and research.</i>
<i>Educator, facilitator and leading narrative medicine practitioner in Ireland</i>
<i>Look through a grille at life and the world and realize that you are actually looking from the outside.</i>
<i>Unraveller of human structures</i>
<i>Ant</i>

9. Please, write a short professional biography

Having to describe a short professional biography, some have detailed the path just like a CV, others have highlighted paths, setbacks and changes in perspectives and professional fields

The reasons that prompted the interviewees to deal with or use narrative medicine or humanities for health have roots that can be traced back to a better and greater humanization of the doctor-patient relationship, the possibility of combining research and knowledge of art. with narrative medicine, the fascination of how a book or the vision of a film can activate the nervous system, the awareness of the inadequacy of medicine towards compassion, the different cultural representation of health and disease and of how literature and arts in general can favor this distance, the possibility for literature and popular culture specialists to overcome ideological boundaries and barriers



through narrative medicine, the awareness that narrative medicine is not a science far from the medical sciences, narrative medicine for some it was just the beginning because afterwards we focused on languages science and neuroscience and other healing languages to broaden the spectrum of one's knowledge.

NARRATIVES

I started my professional career as a University teacher and I have been teaching for 25 years. Narrative Medicine refocused my research interest back in 2012 and since then it has been both my favorite research object and my favorite teaching area. I am now focused on research integrity, but narrative medicine goes on to be one of the pillars of my professional and personal life.

English literature degree Medical training Family therapy training Use a combination of these to teach narrative medicine and medical humanities Special interest in supervision

I have worked in industry and education all my life.

Debut as a practical psychologist, doing educational, clinical and social work. Temporary service in the air-force for personnel selection. Definitive work of research and teaching at the University

I'm a course director for the intercalated BSc in Medical Sciences with Humanities, Philosophy & Law at Imperial College which she combines with part-time PhD study at King's College London . Originally trained as a botanist in South Africa, before moving to London where she worked in publishing and at the Science Museum. After completing an MSc in Science Communication at Imperial College London, she joined the staff to develop a cross-faculty humanities programme. Awarded the Imperial College President's Medal for outstanding contribution to teaching in 2015 and was made a National Teaching Fellow in 2016. Her PhD topic is the expression and reception of gratitude in healthcare. I have a particular interest in the role of the arts in fostering understandings of the phenomenology of illness experiences.

I have taught in all levels of education. I currently head academic degrees in the French departement of my university: master degrees in literature and creative writing and 4 ongoing training programmes in creative writing, narrative medicine and writing workshops training. I am a specialist of writing workshops in an comparative perspective. I studied writing training in many contexts in France, USA and Canada. I currently lead an international research program about creative writing research (episte.fr).

*Professor of English at MCPHS University, where she teaches writing, nineteenth-century fiction, and health humanities. In 2020 she will direct the University's new undergraduate degree program in health humanities. With a background in Victorian, cultural, and composition studies, she specializes in the interdisciplinary study of medicine and wellness in popular culture. She is the the editor of *Reading the Psychosomatic in Medical and Popular Culture: Something, Nothing, Everything* (Routledge 2017). Her current research focuses on the ways in which we turn to popular media to learn about, and cope with, eco-anxiety.*

For 20 years I worked as a filmmaker making documentary and educational films for TV; for 7 years I worked as a freelance journalist/reporter and heritage interpretation planner and instructor; for 13 years I did part time teaching of experience design in heritage tourism and nature based tourism; since 2008 I work as a strategic and clinical communication advisor in public health



I love my profession, mainly because I like to learn and to think. Teaching and investigating are made of it

MEDICAL SPECIALIST IN HYGIENE AND PREVENTIVE MEDICINE, PHYSICAL AND REHABILITATIVE MEDICINE, MANAGER OF TERRITORIAL REHABILITATION in the National health Service.

My professional life is the result of my confused interest: I love neuroscience, sciences, arts, writing reading, all humanities and social sciences related to demography and epidemiology. Therefore, I never wanted to become "a doctor", "a scientist" but more as a "gipsy" wandering through the different competences.

graduated in literature and passionate about theater, following courses in theater direction, then I changed my interest in adult education with a thesis published on adult education whose title is complex creativity and empowerment in business training

i am a Pediatrician and Neonatologist since 30 years and still I am happy every day when I meet my little patients and their families. They give me energy even in the most tiring conditions 😊 Love writing 🖋 about my professional experiences especially if challenging

Graduated in 2002, I started working in pediatrics in 2004, after the birth of my first daughter. All my optional training has always been spent in the relational, communicative, narrative field. In 2010, for about two years I worked in medicine and in 2012 I started my professional adventure in the home environment. In 2014 I participated in the realization of a video in which is narrated who is the home nurse, emphasizing the educational role and the importance of the concept of taking charge. In 2019 I had the great opportunity to participate in the master in Methodologies and Narrative Practices in Care contexts, thanks to which I acquired the necessary skills to experience an exciting reflective narrative work with my colleagues, 33 nurses. As a result of this experimentation was born a poster in which I analyze in a very rational way a work born and conducted with the heart ... now I'm looking for new possibilities to make people know, experience, love medicine and nursing narrative.

Nurse at SC of medicine and obstetrics and gynecology, pedagogical tutor at the nurses school, coordinator in charge of the Management of Health Professions and teacher of formal education at the Faculty of Medicine and Surgery, teacher for company refresher courses, member of company quality improvement groups, member of the company root cause analysis group, member of the company CIO, member of the scientific committee of company training, in charge of organizational function of management of health care professions in training and research.

Teaching narrative medicine for over 10 years to undergraduates in NUI Galway and Trinity College Dublin. Appointed adjunct professor of narrative medicine with the Academic Neurology department in the TCD medical school in 2015. Researcher and writer in narrative medicine. Guest lecturer in narrative medicine.

After higher studies between philosophy and medicine I choose the latter. I specialize in oncological surgery and during the specialization I realize the abandonment of patients no longer susceptible to active therapies. I specialize in 98, in Italy just a year later the very first law on Palliative Care was passed. I launch myself and I still work there.

Lecturer in Anatomy with a BSc and an MD.PhD with a project investigating new functional and structural magnetic resonance imaging measures for patients with minor acute focal neurology. Holder of a PgCert and an Associate Fellow of the Higher Education Academy, teaching anatomy to science, medical



and dental students, from sub-honours to honours levels, with specialist areas including head and neck region, and imaging. Strong advocator of medical humanities. Main research includes imaging with a strong focus on ultrasound, clinically-applied anatomy and scholarship of teaching and learning on medical humanities, object-based learning and the anatomy-art relationship.

Even though I am a professor for more than 25 years, I feel still like a student.

10. People influencing you in this interest

From sounded names, acknowledged all over the world, from Rita Charon to Brian Hurwitz, Trish Greenhalgh and John Launer to, surprisingly, the neuroscientist Antonio Damasio, founder of the Brain and Creativity Institute, who has shown the cognitive biases of our brain functioning, down-sizing *de facto* our strong belief in the scientific method as sole source to seek the true facts. And not famous names, but very important people as well as influencers: patients, colleagues and friends.

RESPONSES

Maria Giulia Marini Paola Chesi Maria de Jesus Cabral Isabel Fernandes Rita Charon

Caroline Lindsey (family therapist) Arthur Kleinman Arthur Frank Trish Greenhalgh most of all

Isabel Fernandes (University of Lisbon) Rita Charon (Columbia University) Norman Holland (University of Florida)

The team of CEAUL (University of Lisbon) that works in narrative medicine and medical humanities

Neil Vickers Deborah Padfield Jo Winning Brian Hurwitz Arthur Frank Paul Crawford

I read in particular the books of Rita Charron. I am in contact with several French teams interested by Narrative Medicine: François Goupy, Nathalie Dzierzynski, Clément Bonhomme, Nicole Squinazi-Teboul, Anne Demerlé-Got, Mathieu Simonet, Michèle Levy-Soussan, Serge Perrot, Sara Greaves, Nicole Biagioli....

My professional mentors at the start of my career, Jennifer Tebbe Grossman, and David Tanner (now retired, both colleagues at MCPHS University).

Regarding communication and importance of narrative in healthcare the strongest influence (by far) was prof. emeritus Johnathan Silverman (Cambridge).

António Damásio

patients and my teachers (especially the GPs who taught me in medical school)

COLLEAGUES BUT ABOVE ALL THE SICK PEOPLE I HAVE TAKEN CARE OF

Trish Greenhalgh, Brian Hurwitz, Anna Wierzbicka

a friend, at work

-The Psychologist supporting Parents and Staff in Neonatal Intensive Care Unit in The hospital where I started working - my patients

Colleagues with whom I share thoughts and ways of being, coordinator sensitive to the topic, training service of my company always supporter of being as well as doing.



Colleagues and general management oriented to this approach

John Launer Rita Sharon, Brian Hurwitz My patients

The existential problems of patients and equally of my collaborators but lived from a different point of view.

My own teachers and mentors.

Antonio Damasio

11. In which way do you think and feel that Humanities for Health and Narrative Medicine can improve the quality of health care?

Among the words used to express how narrative medicine can improve treatment, we highlighted: care, adherence, greater knowledge of the human being, reciprocity, empathy. In particular Narrative Medicine can have an impact on the geography of healthcare, concerning physical spaces and organizational ones. It requires a change of mindset, focusing on Being and not only on Doing and urging for an interdisciplinary approach. N.M. can offer a space for reflection and change. It can encourage healthcare professionals to be more aware of the needs of patient and the necessity to encourage patients to engage fully in the relationship of care. The health humanities create bridges between disciplines - and health care NEEDS what we have to offer, in terms of cultural critique, and the cultivation of imagination, creativity, and empathy. Stories are intrinsic to medicine, and the vast majority of diagnoses still depend on the patient's story. A better understand of narrative can help inform treatment and care. Evidence base medicine is very rational and this is very good because we need order in this chaos, but we should not be scared by the unknown, by the enigma of life. Poetry is faster than EBM language. N.M. places the patient narrative at the center of healthcare professional education at a time when the huge technical advances in medicine threaten to devalue it. In professional practice it can avoid the burnout of the operators and aim at a perception of higher quality of the offered and perceived care.

NARRATIVES

I feel and think, so I believe, that Narrative Medicine can have an impact on the geography of healthcare, concerning physical spaces and organizational ones. It requires a change of mindset, focusing on Being and not only on Doing and urging for an interdisciplinary approach. It allows for a different definition of the term evidence and for a different interpretation of what it means to be a good doctor, a good nurse, a good psychologist...

Emotional literacy Philosophical perspective



It can offer a space for reflection and change. It can encourage healthcare professionals to be more aware of the needs of patient and the necessity to encourage patients to engage fully in the relationship of care. I consider they can help patients be more aware of themselves and their bodies so that they can articulate their conditions better

Ameliorating health staff ' patient centered care and health staff / patients relationship, with consequent improvement of clinical quality and satisfaction

Stories are intrinsic to medicine, and the vast majority of diagnoses still depend on the patient's story. A better understand of narrative can help inform treatment and care.

To tell its own experience of care and disease and to listen to others' stories develop the empathy. Furthermore, when you are focusing on the challenge of an accomplished writing, you make the search for the meaning of life more significant.

*Health care in the United States is so hindered by bureaucracy and ideology, and health care disciplines are really not very *open* to intervention or critique from lay people. The health humanities create bridges between disciplines - and health care NEEDS what we have to offer, in terms of cultural critique, and the cultivation of imagination, creativity, and empathy!*

In every possible way - from quality of experience for both patients and healthcare workers to better medical outcomes.

It brings more information, more awareness, more knowledge about being human.

IN A MULTIFACTORIAL WAY STARTING FROM THE RECIPROCITY OF THE RELATIONSHIP UP TO THE GREATER ADHERENCE TO THE WELFARE PROJECT

We have a body, but we are much more than a body and a mind. WE neglect our values, our beliefs, the spiritual part. Now even the physics is describing that the thinking process is a continuous wave of energy, so that we can be considered as sources of inter-collaborating energetic fields... Evidence base medicine is very rational and this is very good because we need order in this chaos, but we should not be scared by the unknown, the enigma of life. Poetry is faster than EBM language.

incredible, but also difficult this cultural change

medical humanities and NM can improve the quality of care helping professionals in cultivating empathy, fostering tolerance, listening, acknowledging and interpreting the stories of the patients. This will bring to a better Patient - Doctor partnership with mutual respect and partnership

to externalize aspects of oneself, of the therapeutic relationship, of fears, of the joys of a difficult work almost never predictable and standardizable. The time dedicated to those who care is time dedicated to those who must be cared for. A spiral in perfect balance.

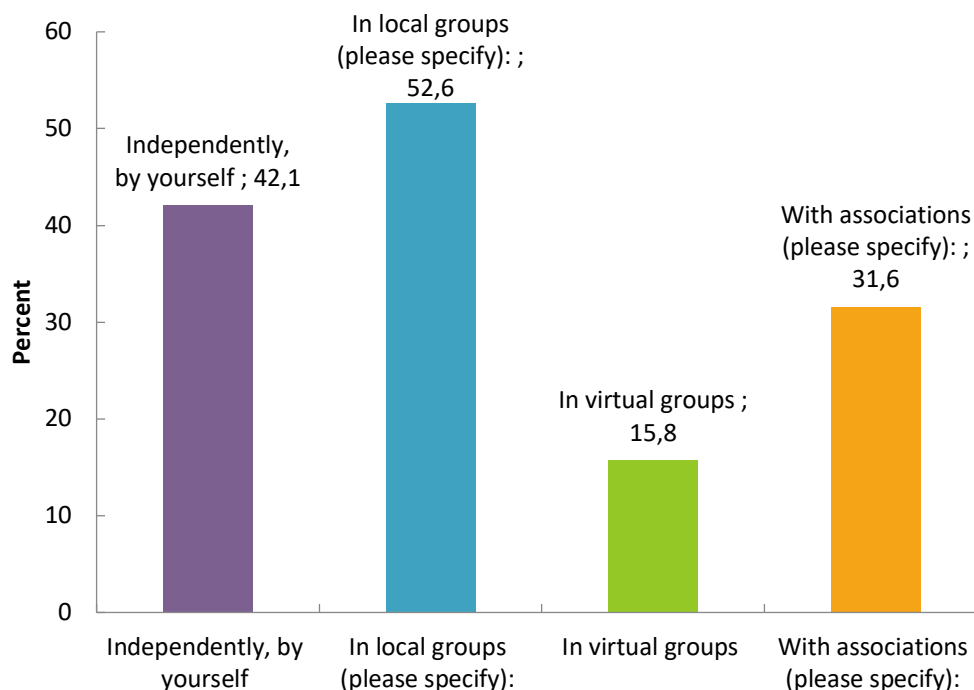
Listening and involvement of users related to a narrative description of the individual paths trace the path to follow that allows the collection of data useful for the categorization of events and the elaboration of new theories and models

It places the patient narrative at the center of healthcare professional education at a time when the huge technical advances in medicine threaten to devalue it.

There are many aspects, I would go on. I am convinced that it can be a formidable tool to avoid Burn-out, which in palliative care is an inevitable price to pay.

Humanizing medicine, Provision of holistic medicine, developing humanistic values, Appreciating ethics Substantially!!

12. How do you work on Medical Humanities and Narrative Medicine?



Academic organizations and research institutions are preponderant: difficult to analyse the many acronyms used to name the associations. It turns clear that in future there is an option of improvement, mentioning together with acronyms also the full name of the association.

IN LOCAL GROUPS (PLEASE SPECIFY)

CEAUL team, University of Lisbon

GERMEN (a group of study and reflection in narrative medicine)

In Fondazione Istud there is a group dedicated to medical Humanities and narrative medicine

I worked with many corporate groups

Medical Humanities Project - ULICES (University of Lisbon Centre for English Studies)

I worked with many corporate groups

in an academic structure: CY Cergy Paris Université

university teams

with colleagues from philosophy and medicine

WITH ASSOCIATIONS (PLEASE SPECIFY):

Association for Narrative Practice in Healthcare

DASH, AMH

In a university project

TCD, NUIG, ICGP, RCGP



participation in conferences, writing projects, visits/exchanges with colleagues at institutions such as the narrative medicine group at ISTUD

13. Please comment on your local and global network connections

The questionnaire then tried to investigate what the local or international connection networks are and from this input it emerged that most of the interviewees consider themselves lucky since their work is connected to international, interdisciplinary and well-organized networks. Also, the way of working used by the interviewees is to look for connections and links as a support to their work.

NARRATIVE

GERMEN has been spreading in and outside Porto, due to the roundtables we have been organizing at Porto University Rectorship on Narrative Medicine Theory, Principles and Practice. The network is also growing based on the courses that we have been organizing at Portuguese Catholic University (Porto). In 2019/2020 new optional curricular units on Narrative Medicine have been integrated in the Medicine Course at the Faculty of Medicine in Porto. Physicians and Nurses of various portuguese hospitals have been implementing changes in their practice and team organization based on Narrative Medicine Principles and Methods.

I am lucky because I am connected in many ways internationally with groups in Europe, North America and elsewhere through many years of international teaching

Rich (but sometimes difficult to handle) interdisciplinarity

Connections are ad hoc rather than particularly well organized.

The network formed at CY Cergy Paris Université is specialized in the mentoring and support of projects to get people with impairments or disease to write.

I am a member of EACH I try to follow what experts in narrative medicine do and publish, at least occasionally. Knowledge of Italian helps (Italy with Medicina narrativa is my neighboring country).

Education lead RCGP NW London former secretary of young doctors' movement in UK (part of WONCA)

Networking is part of my job and I find it essential at a local national level and at an international level. I love inclusive networking

at the moment it is a passion

Used to work very nicely on NM when I was in Italy, feeling alone now in UAE

I believe we can invest more even if my reality is already full of winning examples

Work with John Launer and Jonathan Mc Farland Attended narrative Medicine courses in Columbia University, NY. Have contacts in Australia and New Zealand from my time as a Masters student in U Syd As co-creator of the international medical humanities conference dot MD, I have contacts across Europe, Canada and the US.

<https://www.medical-humanities.glasgow.ac.uk>

I am now active in both national and international networks dedicated to medical humanities.

14. The activities of yourself and/or your group in Humanities for Health and Narrative Medicine are (tick everything which is appropriated)

Value	Percent
<i>Education to students in a university</i>	65.0%
<i>Education to health care providers in a university</i>	55.0%
<i>Education to health care providers in other institutions</i>	55.0%
<i>Research (qualitative)</i>	50.0%
<i>Research (qualitative and quantitative)</i>	45.0%
<i>Clinical practice</i>	35.0%
<i>Art therapist</i>	15.0%
<i>Theatre therapy</i>	5.0%
<i>Communications Training</i>	40.0%
<i>Self-care</i>	35.0%
<i>Taking care of the community</i>	25.0%
<i>Other - Write In</i>	20.0%

OTHER – WRITE IN
<i>Museum studies</i>
<i>Roundtables open to the community</i>
<i>creative writing</i>
<i>editor of the on-line Journal Chronicle of Narrative Medicine</i>

15. Could you please describe the way you run your activities in Medical Humanities and Narrative Medicine?

As regards the activities of individuals or organizations to which they belong specifically in narrative medicine, teaching to university students or entities that collaborate with universities or other training institutions is more represented; This is followed by research, self-help, therapeutic artistic activities, activities for the community. Consequently, even the individual specific activities in narrative medicine are expressed through teaching, medical practice, own and ongoing training.

The perennial study from which emerges the figure of the lifelong student, of the subject who continues his personal and professional training, is highlighted as a peculiar characteristic of people or specialists who deal with narrative medicine or humanization of care. Specialists, professionals and more who continue tirelessly and with vivid curiosity to deepen, to learn, to experiment. A continuous path of growth and deepening in progress.



RESPONSE

I run my activities in Narrative Medicine with a network of people who are interested in this field. I teach, do research and promote/organize events. I disseminate this area in Portugal and abroad as well.

Mainly through intensive experiential workshops and courses, usually live but currently all online

Training and research

I organize and deliver teaching to students in a mix of lectures, seminars and workshops.

I teach a course in Narrative and Medicine, and am a founding member of our University's Center for Health Humanities - that Center in turn has supported the development of a new undergraduate degree (bachelor of arts) in health humanities. And I fit those activities in with teaching and managing writing courses for our first-year students and other administrative work within my school.

So far I was able to include at least a hint of narrative skills (including listening others) in modules I teach postgraduate registered nurses. I was also delivering a part (one day - 7 hours) of a module in cultural competences in healthcare, offered by Institute of Public Health do small groups of healthcare providers. I am not sure these programs will continue - they were financed by EU projects that expire at the end of this year.

MEETINGS WITH OTHER PROFESSIONALS, INTERVIEWS WITH PATIENTS

Through Master in narrative medicine, dedicated workshops and research.... Through web meeting and through writing educational articles and books

I have recently approached the project; therefore, I am in the process of being defined.

Writing on my challenging experiences, sharing in virtual groups, getting the feedbacks from experts. Currently completing a Master in Medical Humanities

It is not always easy to reconcile practical work with a reflective space, but the attempt is to dedicate a moment of reflection on oneself and practices to my working group.

I am training and trying to convey the humanistic approach to the operators.

Workshop, Seminars, Lectures. Use of hands on approaches with museum objects. courses, articles, presentations, books

16. Which are the biggest challenges you encounter when promoting/disseminating Humanities for Health and Narrative Medicine?

One of the major changes that the encounter with narrative medicine or the proposal for its use has produced is the overcoming of myths or prejudices underlying the practice of treatment; the inexact belief that doing things fast is more effective than doing them slowly; the way of working "as a detective" can find support and beauty in narrative medicine, trying to undermine the deep conviction that a solid scientific knowledge is sufficient in the treatment relationship; at times it has been difficult to make people understand that it is not a waste of time or energy or a luxury.



NARRATIVES

The biggest challenge is to deconstruct the myths and the prejudices that are at the basis of healthcare training and practice. I am talking about the idea that medicine is all about developing a detective kind of work, for which you need to have solid knowledge in health sciences. This detective kind of work can be embellished by Arts and Humanities, but nothing effective will come out of it. Deconstructing this idea requires unveiling the essence of narrative medicine, which is nothing about embellishment or waste of time.

The incorrect belief that doing things quickly is more effective than doing things slowly.

Interdisciplinary groups; Occasional resistance to quantitative research methods. Publishing

Overcoming intrinsic biases against the humanities in science-driven environments.

*I've been surprised at how disinterested most health professionals are here in the US. Partly it's just that health care is so overextended no-one practicing has the time to pursue interests in the humanities, but there's also the "hidden curriculum" of health care, which still teaches future providers to be paternalistic towards patients, and very narrowly focused on health care (where intellectual and cultural pursuits outside of health care are seen as *nice* and important, but never AS valuable as health care itself).*

Medical doctors do not take it seriously, not necessary, a luxury, a hocus-pocus, not worth spending time and energy

The doctors' distrust

TO MAKE PEOPLE UNDERSTAND THE USEFULNESS OF THIS APPROACH

not listening

- the "original sin" that the Doctor shouldn't feel any emotion - Old paternalistic approach

Reticence from superiors and colleagues who live the narrative and reflection space as a waste of time. Their frame of thought is purely scientific. They love little openness to the emotions and feelings of themselves and the patient ... unfortunately

The abolition of the "Time Barrier" and the "pornography of communication".

Not appreciated/accepted as a valid method, Skepticism, Criticism, Not being respect.

The mentality of most of the professor in medical education, which still do not see a substantial role of medical humanities in medical curriculum and for changing the doctor in order to obtain a better, holistic approach of their patients.

17. What would you like to receive from a network such as EUNAMES?

Compared to the expectations towards EUNAMES everyone said they were happy and eager to belong to this important albeit embryonic network of contacts, hoping to acquire more knowledge, more exchanges as well as moral support especially in those situations of professional isolation or where medicine is still fiction must join as a practice; hopefully in project collaborations or even operational suggestions, connections with colleagues teaching undergraduates in the health humanities, as well as those doing comparable research; knowledge sharing, Collegial support and the opportunity to contribute to the expansion and development of narrative medicine in Europe:



NARRATIVES

I would like to find a network for research collaborations as well as a source of ideas that can help to make narrative medicine more active in everyday life of healthcare practitioners, patients and caregivers.

Happy to stay in touch and follow developments

Research projects. Knowledge sharing

Yes

Connections with colleagues teaching undergraduates in the health humanities, as well as those doing comparable research - to learn from one another and collaborate on teaching and research projects.



*news and some more knowledge moral support - it is so good to know I am not the only witch
I would like to learn from people in this field and develop my own interest.*

OPERATIONAL SUGGESTIONS

the exchange and dissemination of thought and experience

Culture Chance of sharing my experience with other professionals all around the world

The concrete possibility to do training in narrative medicine, spreading the culture of medical humanities more widely

Collegial support and the opportunity to contribute to the expansion and development of narrative medicine in Europe

A complete training

Learn from and exchange knowledge with like-minded colleagues, Network, Collaborate.

Yes

18. How would you like to contribute to this network?

Everyone can make their own contribution as a researcher, sharing experiences, even virtual lessons with their students, others with their own ideas or even with little while expressing deep gratitude for the existence of this network. I would love to invite scholars and teachers to visit my classes in person or virtually! And I would be happy to do the same, own experience in object-based learning on the anatomy-art relation, use of poetry in medical humanities and work with museums.

RESPONSE

I would like to contribute with my own ideas, terms and concepts; with ideas for training activities and with my participation in debates/workshops/guidelines drafting.

I am on the committee

Research. Training. Knowledge sharing

Not sure.

I would love to invite scholars and teachers to visit my classes in person or virtually! And I would be happy to do the same!

I am afraid I can contribute very little - apart from being very grateful that this network exists

EXCHANGE OF EXPERIENCES

making culture and spreading information

Sharing my experiences with other Colleagues. Sharing my experiences with young Students Writing articles

Widen the practice and write about it

Representative in Ireland and for Ireland at EU level

I don't know yet

Own experience in object-based learning on the anatomy-art relation, Use of poetry in medical humanities, Work with museums

Yes



19. In this period of fear for the COVID-19 outbreak, one of the strongest pandemic events, how do you think that Narrative Medicine, Medical Humanities and art therapy can be useful for patients and healthcare providers?

The current pandemic that has hit us has upset every rule, has put organizations in crisis but has also deeply affected every single person around the world. Nothing is and will be the same as before but the N.M. can make its contribution Improving the quality of distance health communication, research and communication are necessary to flesh out the rhetoric of numbers which dominates epidemiology in a pandemic. There are people behind the numbers. could make HUGE difference, creating cohesion and relationships using a universal language of Literature, music and all form of art manageable in the future; telling the stories of Covid-19 so that the extraordinary experiences of patients, their families, and healthcare staff can be heard. Mitigating the stress and anxiety caused by Covid -19. It is still we are in need for a rational approach of our emotional basis, and for integrative view, where our soul stands together with our biological body, and both asked to be treated at once.

But most of all Just keep going!

NARRATIVES

I believe it can help patients and healthcare providers to give a memory to the future; it can help build more solid scientific knowledge; it can provide us with the opportunity to see what was already there but was invisible: all the gaps and lacks in healthcare that need to be addressed if we want to have a sustainable healthcare system; it also provides means for self-care and for working out the moral residues that remain after all the loved ones that parted away/ all the patients that could not be saved/all the mourning that could not take place.

Just keep going!

Reducing stress. Improving the quality of distance health communication

There are obvious connections with wellness, but there is a danger that the arts are conceived of as part of self-care rather than an integral part of understanding social processes during the pandemic. Research and communication are necessary to flesh out the rhetoric of numbers which dominates epidemiology in a pandemic. There are people behind the numbers.

*Some of the biggest barriers to combatting COVID have been social and political - understanding how people's relationship to medical and scientific authority works or *doesn't* work is vital, and that's where the expertise of social scientists and cultural critics lies. As well - art, creativity, and the sharing of stories is what saves us, and brings us together in communities in times of crisis - again, that's something we health humanists can help with while doctors, nurses, and researchers have their hands full with trying to save lives.*



I could make HUGE difference - if it could be applied at all. (In my country it is unfortunately impossible - with all consequences...)

IMPROVING AND IMPLEMENTING COMMUNICATION ON HEALTH AND PREVENTION ISSUES

Creating cohesion and relationships. During the pandemic, illness and social isolation can be a disaster not only in physical terms but in psychological terms as well. Literature, music, art have a universal language

Conducting some moments of sharing experiences, ordering the emotional chaos through which to create a new self-awareness

Telling the stories of Covid-19 so that the extraordinary experiences of patients, their families and healthcare staff can be heard. Mitigating the stress and anxiety caused by Covid -19.

Social distancing is the second great barrier that has been added in this era after the hurry.

More than ever! To rehumanize information and put them into context so that the psychological sequelae are more manageable in the future.

In many ways, both for doctors and health providers and the society as a whole. We are in need for a rational approach of our emotional basis, and for integrative view, where our soul stands together with our biological body, and both asked to be treated at once.

STRENGTHS AND WEAKNESSES

Among the aspects to be highlighted the difficulty and the not always easy availability of contacts through the Internet; very often the addresses are those of the Faculties or study centers where people work or have collaborated; some contacts are to be requested. Through the most common social media such as Facebook, Instagram, or professional sites such as LinkedIn and others. Very often this required a priority registration and contact to which a response is not always followed. Furthermore, the sites on the internet are not always up to date. We have seen firsthand how surfing the Internet is not always easy to find update information; some recovered emails were later found to be incorrect or perhaps just obsolete. Some email contacts could not be found because they are protected or hidden. Among the strengths of this careful work were: virtual contact with different places, realities, experiences, rich in information, getting into the stories of some of the protagonists, reading their articles, learning about their work or scrolling through their CVs opening ourselves to other realities as accurate bibliographies have provided other roads and other paths.



CONCLUSIONS

Most of all keep going, it was a comment on how narrative medicine can help during the pandemic. Covid-19 has not at all ceased to bite, as many of us hoped during summertime, no it is here, stronger than ever, hitting eating our psychological, and physical energies and eating our social life in presence.

With the COVID-19 pandemic causing global unemployment figures to rise to unprecedented levels, a recent research ¹ suggests two-thirds of workers are actively reacting, using this time to re-evaluate their career choices. In the same report, 70 percent of workers said they are considering changing career paths entirely, with over half driven by the desire to either challenge themselves or learn a new skillset. This also includes the health care workers, who are not at risk to lose their job during the pandemic, but who wish to enrich their technical background with health humanistic assets.

This in particular, related to humanistic science: proof is the boosting of Masters in Neuroscience, exploring brain function, impact on spoken and written languages, origins and handling of the emotions for building empathy, and as a final aim to promote wellbeing, despite the pandemic.

Many are now considering the value of higher education offers when it comes to lifelong learning, improved skillsets and network opportunities, and also related to personal wellbeing to defeat the mental distress given by the uncertainties not only for the health conditions, but for the changes that the pandemic had on our lives.

There is a compelling need in these harsh times to find “something consolatory” in culture which goes beyond the drug’s use or abuse, dangerously frightening in this 2020.

Lifelong leaning requires energies at the beginning but gives back energies, strategies and consolation especially now in times of change.

Peter Drucker, a XX century humanistic economist and founder of the concept of lifelong learning at the work place said “We now accept the fact that learning is a lifelong process of keeping abreast of change. And the most pressing task is to teach people how to learn.”

¹ <https://www.totaljobs.com/recruiter-advice/transferable-skills-recruiting-from-compatible-industries>



This short preamble is a gateway to comment the identikit which emerged from the short biographies of the participants to this first pilot EUNAMES survey: the lifelong learning student or scholar look like to be a common denominator of the answers, not only for the institutions which have education in their DNA, as academies, but also for ordinary daily clinical practice, in clinical settings.

The acknowledged beauty of daring to explore many different competences, on a variety that goes from poetry to anatomy, from oncology to literature, from art to autism, and so on and so forth is the nourishment of teachers, scholars and practitioners of narrative medicine and medical humanities. The biographies of the participants are very seldom characterized by a straight line of acquiring technical competence but more by an arabesque of competences which are a pillar for an evolution of the professional self. Here we face the concept of Humanities for Health changed from the Latin concept of *Humanitas*, a concept which includes the humbleness of the human being, the sense of compassion, the empathy, the building of trustful relationship, and this, at the Roman time was more an attitude than a full competence. Here we face the Humanism historicized in the Renaissance period, the reawakening time after the Darkest time of the Black Death: it is a full blossom of sciences, medicine, arts, literature, philosophy, and other studies intermingled together, not separable: they all were and are useful for a better life, and it would be insane to keep arts, or medicine split in concrete compartments. There is no room for answers as “I’m just a doctor, sometime I amuse myself going at the museums or reading one book”: that book will reverberate on the clinical profession, and the difference that we all who participated at the survey, is that we are aware of it.

Time is rigid yes, is running, is short, but it looks like that with a good attitude, the willing to start and continuing culturing this interest, the health care providers can learn to use different tools to make a faster diagnosis, producing a better caring for the others and also for themselves. Burn out was a complex word which appeared several times on the survey, and medical humanities are there, in all the countries to help to prevent the crisis, especially now, in which all of us are called to show an immense maturity, creativity and self-control at the same time.



Last thought goes to Europe, our Europe made by so many countries and languages and cultural traditions: because of the great number of perspectives which can be taken on the subject, it is impossible to form a single, all-embracing conception of European culture. Nonetheless, there are core elements which are generally agreed upon as forming the cultural foundation of modern Europe: ²

- A common cultural and spiritual heritage derived from Greco-Roman antiquity, Christianity, Judaism, the Renaissance and its Humanism, the political thinking of the Enlightenment, and the French Revolution, and the developments of Modernity, including all types of socialism;
- A rich and dynamic material culture that has been extended to the other continents as the result of industrialization and colonialism during the "Great Divergence";
- A specific conception of the individual expressed by the existence of, and respect for, a legality that guarantees human rights and the liberty of the individual;
- A plurality of states with different political orders, which are feeding each other with new ideas;
- Respect for peoples, states and nations outside Europe.

The concept of European culture is generally linked to the classical definition of the Western world. In this definition Western culture is the set of literary, scientific, political, artistic and philosophical principles which set it apart from other civilizations.

EUNAMES is welcoming not only the European culture with its roots, but it is open also to other cultures: nevertheless, since this networking of narrative medicine was lacking in Europe, here we are to fill the gap, and this survey is just a preliminary action to know better ourselves so to establish an evolving community of research and education. Now, this is not simply “a nice to have” but “a must” to coping with the current Darkest time: however, we should not wait a century for coming forth to see again the stars (from Dante) as it happened after the Middle Age before the

² K. Bochmann (1990) *L'idée d'Europe jusqu'au XX^e siècle*, quoted in Berting (2006:52). Cf. Davies (1996:15)



Renaissance. No, we have to light up the sunshine and the stars of Renaissance from today, despite the back surrounding environment.