"Living with chronic urticaria": a study through narrative medicine to improve the quality of care

Maria Giulia Marini, 9 June 2015, Barcelona

Antonietta Cappuccio[1], Tommaso Limonta[1], Aurora Parodi[2], Oliviero Rossi[3], Carlotta Gurioli[4], Alice Vignoli[5], Roberta Parente[6], Enrico Iemoli[7], Giacomo Caldarola[8], Ornella De Pità[9], Silvia Santoro[10], Mauro Cancian[11], Concetta Potenza[12], Marco Caminati[13], Luca Stingeni[14], Saraceno Rosita[15], Sara Trevisini[16], Angelo Piccirillo[17], Claudio Sciarrone[18], Rosanna Panebianco[19], Massimo Gola[20], Antonio Costanzo[21], Teresa Grieco[22], Filomena Bugliaro[23], Serafinella P. Cannavò[24], Antonio Cristaudo[25], Katia Massaroni[26], Luigi Reale[1], Maria Giulia Marini[1]

[1]Fondazione ISTUD, Milano [2]DiSSal Sezione Dermatologia, Università di Genova/IRCCS AOU San Martino-IST, Genova [3]Immunoallergologic Unit AOU Careggi, Firenze [4]Dipartimento di Medicina Specialistica Diagnostica e Sperimentale, Divisione di Dermatologia, Università di Bologna [5]UO di Dermatologia, Servizio di Allergologia, Policlinico di Modena [6]Dipartimento di Medicina, Università di Salerno [7]UOS Allergologia e Immunologia clinica, AO Luigi Sacco, Milano [8]Istituto di Dermatologia, Università Cattolica del Sacro Cuore, Roma [9]Lab. Immunologia e Allergologia- IDI IRCCS- Roma [10]UO Dermatologia, Ospedale Maggiore di Parma [11]Clinica Medica 1, Università di Padova [12]UOC di Dermatologia Universitaria "Daniele Innocenzi" Università degli Studi di Roma Sapienza Polo Pontino [13]Allergy Unit, Università di Verona e Ospedale Generale, Verona [14]Sezione di Dermatologia clinica, allergologica e venereologica Dipartimento di Medicina, Università degli studi di Perugia [15]Clinica dermatologica, Università degli Studi di Tor Vergata, Roma [16]Clinica Dermatologica, Ospedale Maggiore, Trieste [17]Azienda Ospedaliera San Carlo, Potenza [18]Ospedale Papardo, Messina[19]Dipartimento di Scienze Biomediche ed Oncologia Umana, Clinica Dermatologica, Policlinico di Bari [20]Dipartimento di chirurgia e medicina traslazionale, Azienda Sanitaria e Università di Firenze [21]Unità di dermatologia, Dipartimento di neuroscienze, salute mentale e organi sensoriali Università la Sapienza, Roma [22]Clinica dermatologica, Università degli studi di Roma "Sapienza", Policlinico Umberto I, Roma [23]FederASMA e ALLERGIE, Prato [24]Dipartmento di Medicina Clinica Sperimentale, Dermatologia, Università di Messina [25]San Gallicano, Istituto Dermatologico -IRCCS- Roma [26] Novartis Farma, Origgio

Disclosure

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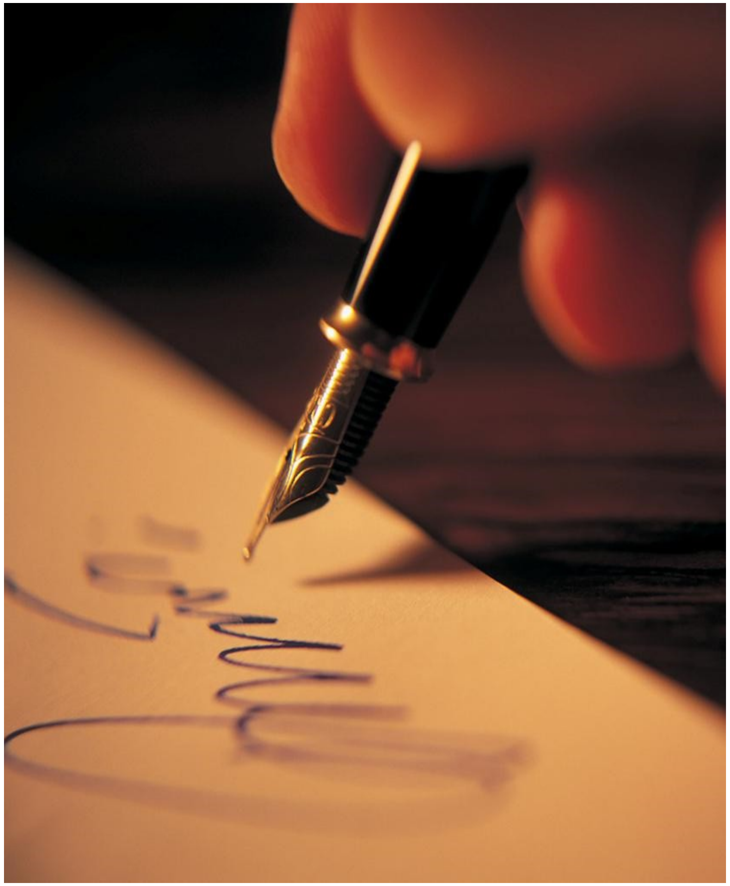
Narrative Medicine

Narrative medicine, or the collection of the stories of patients, the core of reference, caregivers and health professionals, deals with how the person lives the being ill, and what is the possible meaning of a pathway of care, to initiate and to maintain, together with health professionals.



> *"Narrative Medicine fortifies clinical practice with the narrative competence to recognize, absorb, metabolize, interpret, and be moved by the stories of illness."*
>
> Rita Charon, JAMA, 2001

Why study narrative?

The analysis of the written experiences of people living with a disease reveals an useful guidance for **understanding the inner and outer needs and expectations** regarding the health care system, with a focus on the human, emotional and relational dimensions of the pathology.

The **single narrative** can provide important information about the way of living with the disease (work, feelings, satisfaction, values problems, projects). ***A collection of narratives*** *on the same disease can be analyzed from a quantitative point of view, by extracting semantic maps, most frequent words and expressions, narrator profiles and care pathways.*

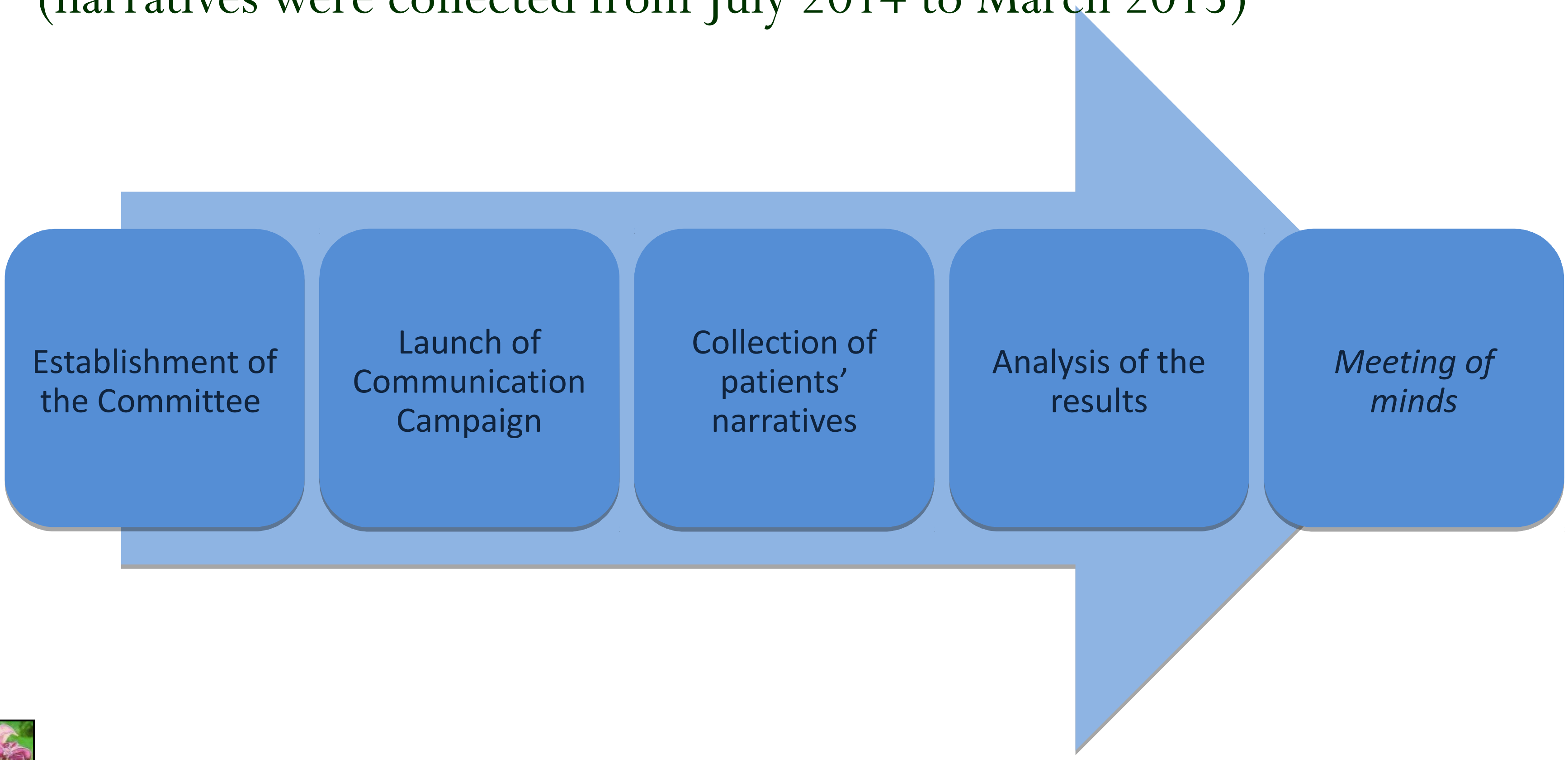
The aim and the figures of the project of narrative medicine in CSU

The project was born with the aim of stimulating a reflection of the immunologist, dermatologist and allergist who in various ways are involved in the care of patients with chronic spontaneous urticaria by collecting **narratives of patients.**

Given the robustness of the quantitative data, meaning an occurrence of “analogue semantics” equal or higher than 80% in the collected narratives, a sample of 150 narrations reaches a **confidence interval of 95%** with a margin of error of 6%, based on a prevalence of disease of 0.3% on the total Italian population.

The phases of the project

The project was carried out from April 2014 to March 2015 (narratives were collected from July 2014 to March 2015)



- Establishment of the Committee
- Launch of Communication Campaign
- Collection of patients' narratives
- Analysis of the results
- *Meeting of minds*

The 25 involved Italian Centers; North, Center and South

Ospedale L. Sacco, Milano

AOUPoliclinico Verona

AOU, Padova

Ospedale Maggiore, Trieste

Policlinico, Parma

Policlinico S. Orsola, Bologna

Policlinico, Modena

AOU S. Martino, Genova

Azienda Ospedaliera, Perugia

Azienda Ospedale Universitaria, Siena

Ospedale Fiorini, Terracina

AOU Careggi, Ospedale Palagi, Firenze

IFO San Gallicano,
Policlinico Umberto I,
Policlinico Gemelli,
Policlinico Tor Vergata,
IDI,
Ospedale S. Andrea,
Roma

AOU Policlinico, Clinica Dermatologica Bari

AO S. Gennaro Napoli

AOU San Giovanni di Dio e Ruggi d'Aragona, Salerno

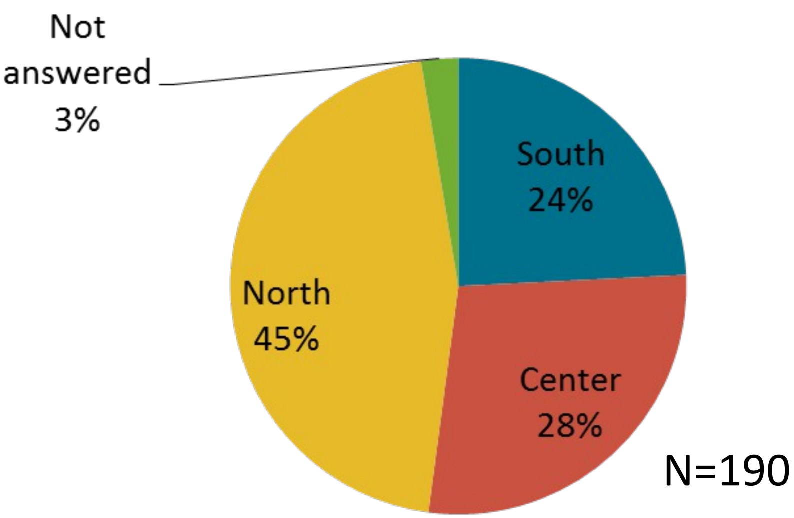
AO S.Carlo, Potenza

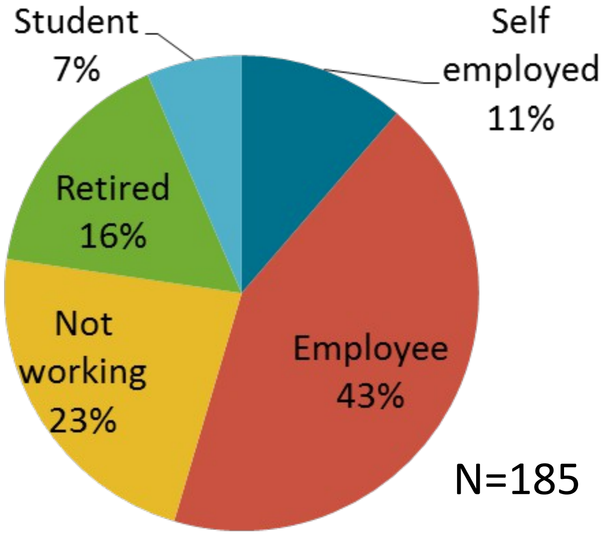
Policlinico, Ospedale Papardo, Messina

190 people left the stories out of 1810 access to the website: almost 10%

unique visits ▾	responses	completion
1,810	190	10%

People narrating their experience were mainly women (71%) with a mean age of 47 years (min:11, max: 82), living with CSU from an average of 7 years.



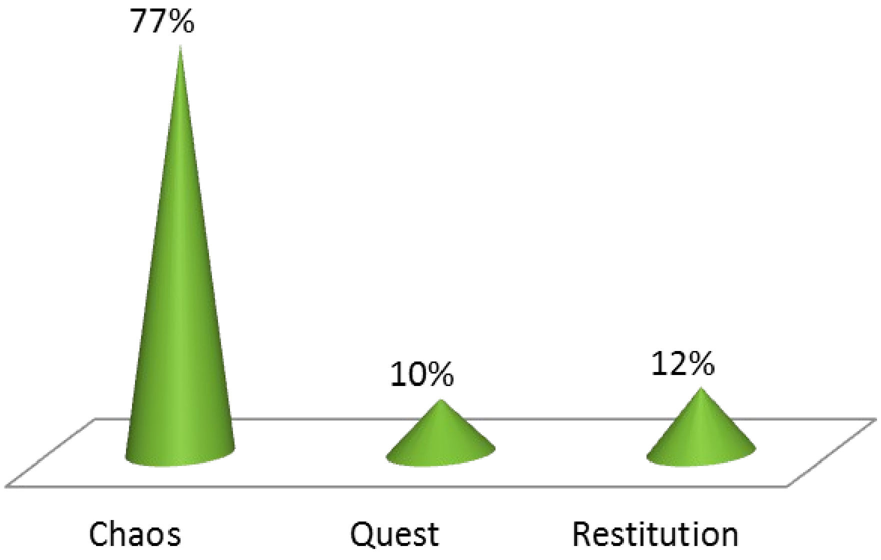


The classification of narratives

- *Stories of chaos*: the narrative is a loop and it looks like there is no ending to the situation of the disease. There is a total lack of coping strategies.

- *Stories of restitution*: the disease is pain, but if the person submits him/herself to proper tests, visits and drugs he/she would be restituted of his/her health.

- *Stories of quest*: typical classification of chronic disease, the disease is a trigger for an inner and outer research.

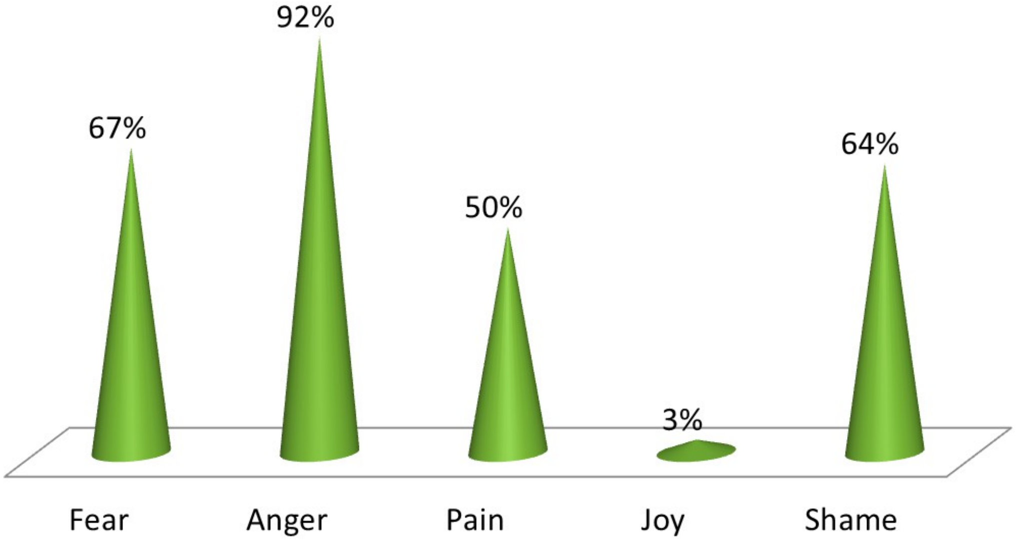


N=185

Arthur Frank, *The wounded storyteller, (1995)* University of Chicago Press

Anger is the chronic life-dominant emotion, followed by fear and shame

For an analysis of the emotions, the used classification distinguishes between four primary emotions: fear, anger, sorrow and joy. To this a social emotion should be added that is the shame.



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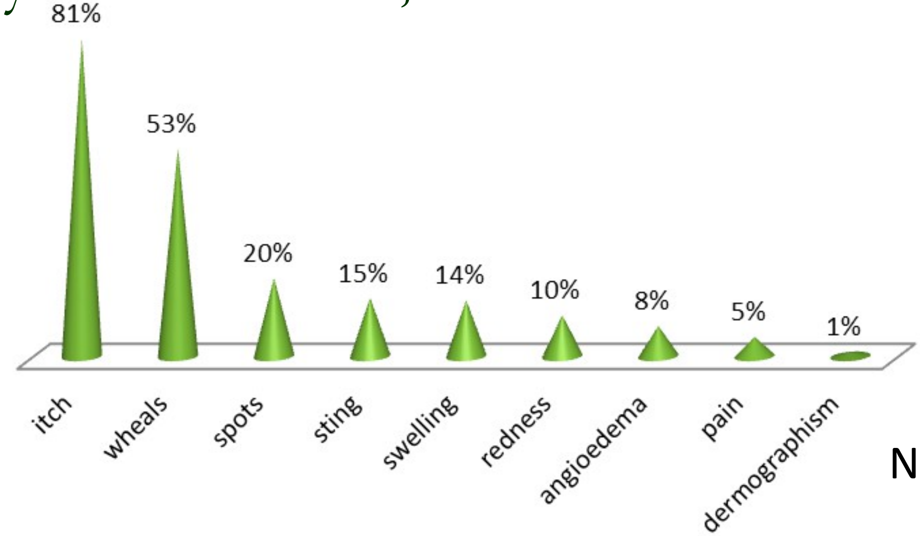
"From the emotional point of view, the states are alternated between anger, anguish and sadness"
"I was not living anymore, I was in constant anxiety, I could not accept this disease"
"With others I was ashamed because my face swelled, I looked like a monster"
"I was ashamed to talk about my problem."

Daniel Goleman , "*Emotional Intelligence:Why It Can Matter More Than IQ*"*(1995)*, Bantam Books

The methaphors of the symptoms of CSU

Itching was the more prevailing symptom (81%) and the metaphors used to describe CSU were mainly related to “fire”, “needles” or “insects”.



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“I felt some itching in some parts of the body, as if I had fleas on me or some other insect, but then I thought that the ants could have strung under the clothes I was wearing, so increased the tingling I felt suddenly.”

"It's like having flame under the skin"

"It was like so many pins stung me in almost the whole body"

The daily relationship

Familiar relationships are negatively influenced by the illness: only 17% of patients found support within the family. Interactions with the outside world are driven mostly by a feeling of shame (63%), which negatively affect social interactions as well as the job.

Family

"They were worried, because this thing stresses me greatly and makes me live badly"

"Everyone is conditioned by my nervousness and moodiness"

"My loved ones were amazed every day by the sudden and abundant eruptions"

Social life

"I speak of my illness and I try to explain what it is; also to remove any doubt that it is contagious and the consequent fear that evokes”.

"Some times it was difficult, I had to postpone evenings with friends or other not to be seen if the hives were visible, or invent toothache for not giving explanations that I did not have"

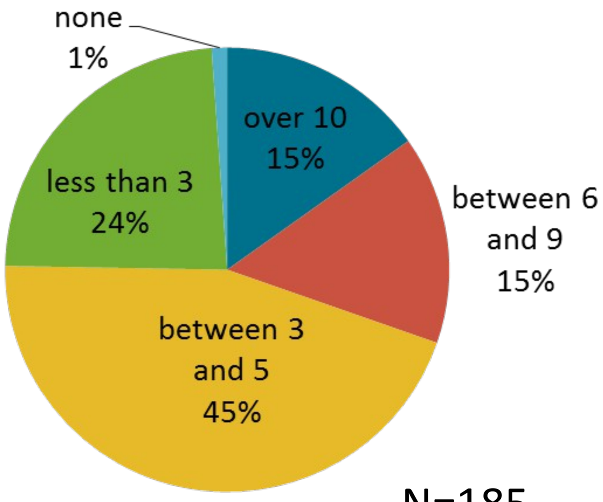
At work

"I was often absent from work because of the bumps on the face or on the limbs, or unable to walk"

"I had many problems because colleagues and superiors do not believe it is a disabling disease, but for me yes, and a lot."

The care pathways: not ecofriendly enough, time and money consuming?

Care pathways were described as unsatisfactory in 81% of cases. 75% of people visited 3 or more physicians before the final diagnosis and 15% exceeded 10 consulted physicians. The relationship with the physician was perceived mostly negatively in 76% of the narratives..



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"If I look back and I think to the fatigue, the pain, the money spent …. and no results achieved, I feel defeated, a loser"

"I got angry only when the doctors told me that the hives could be derived from the stress, because in my opinion it was a diagnosis that they did when they did not know what to say. Or when they told me that there can be many causes, but, in most cases, are unknown"
"I wanted more human understanding!! "

The therapies

Even if never directly requested, the therapeutic tools were described as unsatisfactory in most cases. 85% of patients hoped for an easier and faster healing.

The therapies

"I'm doing a treatment but I do not feel cured because my problems are always present"

“I would definitely eliminated unnecessary antihistamines and led a life much more peaceful”

"After the initial shock I began a series of visits and efforts to care especially with cortisone that led inevitably to a state of discomfort that went beyond the disease”

I would like that treat urticaria would be…

"Much easier with a fast diagnosis and many more clarification"

"Simple as a cold '

"Managed … with admissions in day hospital … make the diagnosis and treatment with natural therapies also"

"A process faster than what happened to me, maybe more awareness of the practitioners about this disease“

“with excellent results and especially more rapid”

The opportunity to express themselves

93% of patients appreciated the opportunity to tell their story and express themselves in deeply, reporting the lack of attention to their erratic care and their live hidden at workplace and family.

"Very well! Retracing my experience made me relive a series of moments and moods. It 's true that writing helps ... then if there is to read someone who cares ... it helps even more!"
"I felt heard and considered although I must say that all the specialists I met in this adventure have considered me without underestimating the problem"
"I hope this will shed light on the 40% of unexplained causes (including my own)"
"Well! Probably I could not say everything but it is nice that there is someone who will listen, because sometimes the others tell me that I am a whining!"

In conclusion

The challenge for the doctors is to **transform** the angry and shameful narratives of **chaos** into stories of **quest** by means of their **proximity**, expecially if the family avoid relationships with patients, by **telling the true** on the complexity of this disease and by **reassuring** them that there are new therapeutic tools which are not just empty hopes. In addition, a campaign to physicians and citizenship of **awareness** of how uneasy, frustrating, full of shame and impredictable is life with CSU is warranted to help both patients and their physicians.

> *"It is the first doctor that gave me satisfaction. He made it clear that it is almost impossible to heal, that my case is very complicated because it is chronic. He keeps me updated and often goes to conferences to seek novelty. It has become a bit my family. I feel that he does not tease me, but he wants so much to heal me."*

Credits

- Italian Observatorty for palliative treatments - 2006
- SLANCIO Project – Stories of people affected by lateral amyotrophic sclerosis - 2010
- INAIL - The odyssey of people with medullary lesions – 2011
- ONICE Project – Narrated obesity in Italy: towards an effective care pathway - 2011
- Master in narrative medicine for the healthcare organizations, MNEMOS – 2012, 2013
- Narrative medicine for a sustainable healthcare system, (supported by King's College, Center for Humanities for Health, London) – 2012
- VEDUTA Project, Organizational climate analysis for pain therapists - 2012
- Back to Life project, Nursing and living with myelofibrosis – 2012,2013
- Sories of life in the aging years – 2012, 2013
- Narrative medicine experimentation at the oncology department of the Lecco Hospital - 2013
- CRESCERE project – Fostering empowerment to support the excellence research, the value of experience stories - 2013
- Speeches at the *"International Network for Narrative Medicine", June 2013, King's College London*
- Master in Applied Narrative Medicine - 2013
- People with Multiple Sclerosis in the network: what horizons? – 2013
- Hiv Patient's journey – 2014
- Well-being and health status in the world of services in Italy: a gender perspective (supported by the Ministry of Labour and Social Policy) – 2014
- Bright stories: experiences of extraordinary daily life with Multiple Sclerosis 2014
- Vision AMD: Value in Stories of Illness on Neovascular wet AMD – 2014
- Robotics at the service of people with spinal cord injury 2014
- II and III ed. Master in Applied Narrative Medicine – 2014/2015
- Born before their time: the experience of families in Italy – 2014
- Narrative medicine as a bridge between medical humanities and science- Maria Giulia Marini- Springer, 2015, in press

http://www.medicinanarrativa.eu/