The experience of COVID-19 ward's patients: a narrative medicine approach

Patrizia Pisanu,[1] Daniela Lucchetti,[2] Dario Lucchetti,[1] Nicolò Contu,[1] Vincenzo Maria Saraceni[1]

[1]Post-acute Rehabilitation and Neurorehabilitation Departement, Mater Olbia Hospital, Olbia, Italy; [2]Istituto Gestalt Analitica, Centro Studi Psicosomatica, Roma, Italy

ABSTRACT

Narrative Medicine approach has increased in popularity in the medical context as an effective model to approach their patients' experiences of illness with more understanding and compassion, offering fresh opportunities for empathic, respectful, and nourishing medical care. The goal of our work has been to study the overall experience of COVID-19 patients, putting the personal dimension at the center of the dialogue and the ability to acknowledge, absorb, interpret, and act on the stories and plights of others. Firstly, we considered their reaction to the consequences of the Lockdown, then we asked if they were fearful of potentially being infected, and finally, we asked about their illness and arrival at the hospital, having little to no information about their future. The interdisciplinary intersection between neuropsychology, micro-sociology of health, and physical and rehabilitative medicine has made it possible for us to report the following experience, providing new insights on the pre-existent doctor-patient relationship and the importance of hospitalization stories, for humane and effective medical practice.

Correspondence: Patrizia Pisanu, PhD, Psychologist and Psychoterapist, Post-acute Rehabilitation and Neurorehabilitation Departement , Mater Olbia Hospital, S.S. 125 Orientale Sarda, Località Padrongianus, 07026 Olbia, Italy.
Tel.: +39.07891899420.
E-mail: patrizia.pisanu@materolbia.com

Key words: COVID-19; sociology of medicine; psychology; hospitalized patient; health care.

Acknowledgments: we would like to thank Mater Olbia Hospital's General Manager, Dr. Francesco Meloni, and Deputy General Manager, Dr. Carlo Maria Cellucci, all the doctors, psychologists, physiotherapists, rehabilitation therapists, nurses and healthcare assistants of the Functional Rehabilitation and Neurorehabilitation Department, COVID Department and COVID Intensive Care Unit who have contributed to the realization of this paper.

Conflict of interest: the authors declare no potential conflict of interest.

Funding: none.

Ethical approval and consent to participate: written informed consent was obtained from the patients.

Availability of data and material: data and materials are available by the authors.

Informed consent: the manuscript does not contain any individual person's data in any form.

Received: 4 May 2023.
Accepted: 12 May 2023.

Italian Journal of Medicine 2023; 17:1602
doi:10.4081/itjm.2023.1602

Introduction

According to Harari, any historical time that has been able to guarantee long periods of well-being and peace, while permitting the flourishment of the arts, literature, and scientific discoveries, has sooner or later been forced to a halt because of two main enemies: famine and epidemics.[1] Consequently, the occurrence of the world pandemic has forced individuals to conduct a long reflection on their interpersonal relationships. This is because, factors such as the health emergency, isolation from social life, and fear, have left individuals feeling invisible, marginalized, alone, and hostile. The events invaded and affected the most intimate side of humankind. Therefore, it should not come as a surprise that fear is the most frequent emotion emerging from the testimonies of COVID wards' patients since both uncertainty and ignorance are responsible for generating fear. The COVID-19 pandemic interrupts daily routines and people struggle to accept the new reality. They tend to wonder *why me*, by transforming themselves into metaphysical philosophers. Their initial frenetic and inertial lives were replaced by struggle and fear, making it possible for them to truly appreciate and grasp any positive aspect of their day. In this frame, Narrative Medicine

carries out a fundamental role: to put the personal dimension at center of the dialogue, in order to create a place where patients can feel comfortable sharing their thoughts with doctors and nurses. While describing their illness and the stage they are at, patients can express their feelings, emotions, fears, and concerns to health professionals. Storytelling alleviates suffering and allows sick people to create a connection with others who have lived the same experience or may want to participate in giving comfort to the patient.[2] This allowed us to keep humanizing health assistance as well as the general care of patients. A mission that has concerned the entire personnel of the COVID-19 ward. These workers work for and with the sick, by combining the scientific aspect of care with a more human and personal approach to his/her specific experience.[3] Accordingly, particular attention was paid to the patients' stories, but also to their emotions and thoughts, which were then transcribed in order to become tangible tools to use during the treatment process.

Materials and Methods

Objectives

This work's objectives can be divided into three main points: i) investigate what aspects of daily life were affected the most by the Lockdown; ii) investigate how the government-made decisions to contain the virus have affected both personal and inter-personal relationships; iii) investigate the experience of patients since the got infected up until their arrival to the COVID department: what were their emotions and recurring thoughts, but also how has the constant sight of harnessed healthcare workers affected their stay.

Participants

Between December 2020 and February 2021, 29 patients have been selected. They belonged to the COVID-19 and intensive care wards of the Mater Olbia Hospital but also to other nearby structures. The selection of patients participating in the study was carried out following all the indications imparted by the EU General Data Protection Regulation.

The patients' admission criteria were the following: i) both female and male; ii) over 18; iii) caucasian; iv) medical history of SARS-CoV-2; v) stable clinical picture.

The exclusion criteria were the following: i) patients with severe psychiatric disorders (Axis 1 or 2 of DSM V), and internal pathologies that could alter the overall understanding of the semi-structured interview; ii) patients with a severe cognitive impairment that would not allow the semi-structured interview to be carried out.

According to these criteria, 5 patients were excluded: i) 1 patient with severe cognitive impairment; ii) 1 patient with severe psychiatric disorders; iii) 3 clinically unstable patients due to severe respiratory impairment.

As reported in Table 1, the final sample is composed of 24 patients diagnosed with SARS-CoV-2 related pneumonia: 17 males and 7 females with an average age of 67.83±5.66.

Out of the 24 patients studied: i) 17 were admitted to the COVID-19 department of Mater Olbia Hospital with a diagnosis of SARS-CoV-2 related pneumonia; ii) 3 were admitted to the COVID-19 department of Mater Olbia Hospital respectively with a neurological diagnosis of previous cerebral hemorrhages and multiple sclerosis. Subsequently, they were transferred to the Post-acute Rehabilitation and Neurorehabilitation Department of the same hospital; iii) 3 were admitted to the intensive care of Mater Olbia Hospital due to

Table 1. The final simple composed of 24 patients diagnosed with SARS CoV-2 related pneumonia.

Patient	Age	Sex
001	58	M
002	45	M
003	80	M
004	81	M
005	80	M
006	65	M
007	62	F
008	48	F
009	65	M
010	74	M
011	90	M
012	62	F
013	70	M
014	86	F
015	63	M
016	74	F
017	68	M
018	67	M
019	55	F
020	69	F
021	51	M
022	73	M
023	76	M
024	66	M
Average	67,83	17M 7F
Standard deviation (SD)	±5,66	

worsening symptoms of COVID-19, with a subsequent transfer to the Post-acute Rehabilitation and Neurorehabilitation Department of the same hospital; iv) 1 was admitted to the Intensive Care Unit of another territorial facility due to a COVID-related respiratory insufficiency. The patient was also relocated to the Post-acute Rehabilitation and Neurorehabilitation Department of the same hospital.

Semi-structured interview

At the end of each physician visit conducted by the COVID department's operators, each patient had a video call with a psychologist that lasted around 40 minutes. This is because the semi-structured interview shown in Table 2 was created *ad hoc*, in order to acquire all the previously mentioned information and to allow each patient to voluntarily speak about their experience.

This work's objective has been to investigate the experience of patients since the got infected up until their arrival to the COVID department: what were their emotions and recurring thoughts, but also how has the constant sight of harnessed healthcare workers affected their stay.

Results

This study's findings show that during Lockdown, the most affected aspects of daily life were: i) freedom for 33% of patients; ii) peace of mind for 21% of patients; iii) social relationships for 17% of patients; iv) 29% of patients have not experienced any considerable change, because they were retired or because they continued with normal work activities, while maintaining constant social interactions.

Work activity decreased for 23% of patients, while the remaining 77% did not witness any changes.

According to 30% of patients, the information reported by the mass media is real. Furthermore, some have even underlined how "*only those who have experienced it can understand*" or that the information shown "*is not psychological terrorism, it is reality*", but also "*It's all true, it's a matter of seconds*" (P 5).

However, 70% of patients stated that the information was most likely exaggerated because it was the only way to keep the entire population calm. This is because the completely unknown nature of the virus made it difficult to provide immediate answers in the beginning. This kind of information causes a high state of anxiety in 100% of patients: "*when you have no idea about what is going on, you live in complete fear*" (P 3).

When analyzing any change in personal and interpersonal relationships, 80% of patients said they maintained their social relationships thanks to phone and video calls. In fact, they stressed how this was the only way for them to feel close to their loved ones. The remaining 20% was not affected by any major change, as they continued working respecting government rules, or because they lived at home with their partners and/or children. Concerning the behaviors dictated by fear, 29% of patients shared that they were only measuring their body temperature from 1 to 2 times a day, while the entirety of patients interviewed was not aware of the oximeter before arriving at the hospital. Finally, the testimonies of the four infected patients admitted to the ICU, and the "Medicina COVID" ward, were significantly different. The ones in the intensive care unit described it as it appeared to them while they were clinically unstable. For example, they used words such as: dark, back to the window, death, hell and heaven. According to the patients' testimonies, the most difficult moment was when they woke up. In fact, they all experienced

Table 2. The semi-structured interview created ad hoc to allow each patient to speak about their COVID-19 experience.

"Storytelling": a COVID experience
1. The Lockdown
• What aspect of everyday life has changed the most during Lockdown?
• How has work changed?
• Do you think that the media have accurately spoken about the reality we are experiencing today?
• How did you feel when you listened to the information they provided?
2. Personal and inter-personal relationships
• Since government restrictions have been in place, how have relationships changed?
• Can you describe to me what kind of behavior did you adopt in order to avoid contracting the virus?
• How often did you measure your body temperature?
• Prior to the pandemic, did you have any knowledge about oximeters and their usage?
3. Contagion of the virus and hospitalization in the COVID ward
• You contracted the virus: tell me about how you managed the idea of unconsciously being able to infect others.
• Close your eyes: you are hospitalized in the COVID ward. Can you tell me the first word/ image that comes to mind?
• Do you have any thoughts? Perhaps a recurring phrase?
• Have you ever been hospitalized before? In your opinion, what makes this department different?
• What is your experience in this department?
• Can you describe to me how is the constant sight of the harnessed healthcare workers affecting you?

a state of confusion in which "*reality mixed with fantasy*", leading them to imagine and say complete nonsense. "*You constantly feel unable to breathe well... you are afraid... for yourself and your family, then you wake up incredibly confused... you don't know where you are, what happened... you find yourself in front of strangers dressed in white, who remind you why you are there... but in that moment, you don't even remember what COVID is. An absolute nightmare. Then little by little, you start to get better, you see others in the same situation, you understand that you are not alone, you gain some strength and clarity back, you begin to remember*" (P 23).

While their clinical conditions were improving, all patients had one recurring thought: going back home to their families. In addition, they expressed how the ward represented a lifesaving place, while all health workers were like *"guardian angels dressed in white"*, who protected and cared for them. The operators were constantly motivating and updating the patients on their improvements, using phrases such as "*you are doing great*; *keep it up*" (P 3).

Contrastingly, the testimonies of those admitted to the Medicina COVID ward were significantly different. As a matter of fact, 30% of patients identified their medical condition with blue, which symbolized the color of their hospital room, while the other 70% identified it with white as the healthcare workers' protective harness. The words most often used by patients to describe their time in the ward, were related to their health condition and hope of returning home soon. But also, to the uncertainty of their future, and not being able to be surrounded by family. Most notably: worry, emptiness, healing, suffering, absence, gratitude, doctors and nurses, end, first week, naked, death. The recurring thought was getting better and returning home to embrace those family members who were "*going through hell at a distance*" (P 3).

Two of the sampled patients felt the need to go home: one to embrace his/her daughter after two years of not speaking to each other, and the other one to meet his/her newborn grandchild. The COVID ward hospitalization was the first for 20% of patients, while the remaining 80% referred to their previous experience as different, particularly because they felt less uncertain about their future: "*everything can change quicker than in other wards*" (P 20).

Therefore, people fear even more for their life. Subsequently, 100% of patients reportedly found their living conditions in the ward to be good, thanks to the qualified and trained healthcare staff. Patients stated that hospital workers "*make you feel at home; you don't feel distant to them because of their harness. It is quite the opposite! Fear unites all of us*" (P 13).

They mentioned how they would not understand who was in front of them in the beginning, but with time this strange sensation became the norm: "*we had learned to recognize them by the tone of their voice*" (P 9); "*We had learned to recognize them from the moment they would entered the room, some would come in the morning and some would come in the evening*" (P 1).

Discussion

Our work derives from a perpetual reflection on the importance of hospitalization stories. The idea of gathering information through a semi-structured interview paved the way for the healthcare workers to immediately recognize, absorb, interpret and be moved by the patients' illness stories.[4,5] A story of illness cannot be considered just as an anamnesis, a collection of events and data followed by reports and diagnoses. A step forward is needed. There must be room for the patient's thoughts, feelings, sufferings and impressions about life and the disease. It is a question of absorbing these stories, whose key elements are doubts, fears, sensations, interpretations, reactions, and emotions toward a particularly painful situation.[6] Among the first emotions we had to connect with, there were the two opposite perceptions of fleetingness and slowing down. On the one hand, there is a patient who declares that "*it's all a matter of seconds*", while on the other hand, there is one who highlights the incredible confusion of awakening and not understanding where you are and what happened to you.

Furthermore, he/she explains having experienced the sensation of floating between the reality of the ward and other distant oneiric dimensions. As we progressed with our investigation, we kept track of the specific words that were mentioned by patients, reusing them with constant attention and listening exercises. These relationships were built meticulously to provide patients with not only the perception of trust that emerged in the staff's description as guardian angels dressed in white, but also with the possibility of tidying up their memories while getting a clear idea of the chronological order of the events.

Lastly, they helped patients realize more about where they were staying. Not only thanks to the blue and white colors mentioned in their interview but also thanks to the operators' schedules and the surrounding noises. The questions formulated offered us the information we needed to relocate them, and make them feel protected while making them ready to return to their families. Ordinarily, our conversations with the patients are conducted paying barely any attention to their opinion. This is because many things happen at once: the ward's telephone rings, the colleagues ask for an opinion on a certain issue, the bell rings, it is already 2 o'clock and

therapy needs to be done, there is a new patient to hospitalize, and so on. We run, we are in a hurry and the patient does not know how to hold us back, he/she struggles to communicate with us, and in that little amount of time, he/she cannot find the words to express everything that he/she is going through. The lexicon does not help us either. This is because, sometimes, operators use specific definitions to explain the disease to the patient. The offered description can often be elusive, too sterile, or even inexistent. However, we observed that by trying to speak with the patient using his/her same verbs and answers, we finally managed to get in contact with their world. Furthermore, it gave us a chance to build bridges with them and realize our affinities and limitations towards each other's positions. For the first time, we paid attention to what was happening during the "before hospitalization" period. This allowed us to understand the different stages of the disease, and the events that caused it. By taking notes, we tried to remember the exact words, as well as the metaphors and evocative images the patients used to explain their feelings. We would re-use these words during meetings, in order to satisfy the patients' need to talk about themselves and to allow them to be explicit about their fear. As a matter of fact, after speaking with their doctors, they identified a common enemy and became more aware of how subjective a cure can be. They stopped holding doctors accountable for everything happening to them while shifting some of the responsibility back to the disease itself. This small but significant conversation helped patients reflect on the fact that life and illness are intrinsically linked and that everyone is allowed to react in their own way. Patients realized that they could use their own abilities and resources to overcome the situation, even if, on other occasions, they might have acted differently. Healthcare operators stressed how essential it was for patients to speak about their treatment, and to reflect upon the power of contact and the respect of their culture during the healing process.

Finally, the patients provided insights into the power and value of trusting someone that has fully acknowledged them during their illness. The healthcare professional who follows this process by taking care of the patient does not act as an external observer but as an active participant. Therefore, the patient is once again at the center of attention, and the therapeutic path is built together. Most importantly, the discussion is not only about the patient, but it is also conducted with the patient. Without a real understanding of the patient's individual experience, medicine will be able to achieve technical objectives, but it will always lack personalization, empathy, and humanization.[7]

Conclusions

The first lockdown paved the way for people to express their necessity to talk about themselves and with others. Not everyone had the same experience, but certainly, the feeling of being lost and fearful prevailed over all others. After the first weeks, social networks were filled with events, seminars, round tables, and meetings with exponents of many disciplines speaking about these sensations. Each one tried to talk about their own perspective on the matter.

Illness generates stories, as Charon wrote. The stories we collected felt colossal, epical, and objectively global.[5,8] Our work derives from a perpetual reflection on the importance of hospitalization stories, and on the indispensability, of the healthcare personnel to be recognized by patients. During the first "fittings" of the COVID ward harness, it was impossible for us not to ask each other: how will they recognize us if we are so harnessed?

The term harnessed is not a flattering term; it is used to define the harness of horses. But that is exactly how we felt, harnessed and faceless. Lévinas said "*the epiphany of the human face constitutes an opening on the surface of existence*" and those who work in the hospital know it very well. A recognizable and/or expected face can make the patient feel relieved, hopeful, and even courageous. Accordingly, being able to recognize a face inside a hospital has the power to transform the entire experience of being sick.[9]

Because the face has become off-limits, we constructed this paper on the intuition of a smile and the importance of making patients feel recognized through dialogue. We took the opportunity to reflect on the relationships we have built with our patients, which can be relatively durable, impactful, and effective.

Conclusively, this study has allowed us to meditate on how much our words, gestures, and attitudes resonate with our patients and *vice versa*. We have finally become aware that each of us is a story worth listening to.

References

1. Harari YN. Homo deus. Breve storia del futuro. 2018: 560.
2. Berglund M, Westin L, Svanström R, Sundler A. Suffering caused by care—Patients' experiences from hospital settings. Int J Qual Stud Health Well-being. 2012 Aug 27 [cited 2023 Feb 15]; Available from: https://www.tandfonline.com/doi/abs/10.3402/qhw.v7i0.18688
3. Andermann A. Taking action on the social determinants of health in clinical practice: a framework for health professionals. CMAJ 2016;188:E474-83.
4. Zaharias G. What is narrative-based medicine?

Narrative-based medicine 1. Can Fam Physician. 2018; 64:176-80.
5. Malina D. Book Review Narrative Medicine: Honoring the Stories of Illness By Rita Charon. New York, Oxford University Press, N Eng J Medi 2006;355:2160-1. Available from: http://dx.doi.org/10.1056/nejmbkrev 57383
6. Keen S. A Theory of Narrative Empathy. 2006;14.207-36. Available from: http://dx.doi.org/10.1353/nar.2006.0015
7. Moreto G, Blasco PG, De Benedetto MAC, Levites MR. Reflections in Medical Education: Empathy, Emotions, and Possible Pedagogical Resources for the Emotional Education of Medical Students. Medical Education for the 21st Century, 2022. Available from: http://dx.doi.org/10.5772/intechopen.101832
8. Narrative Medicine: Honoring the Stories of Illness. Ann Intern Med 2007;146:152. Available from: http://dx.doi.org/10.7326/0003-4819-146-2-200701160-00021
9. Lévinas E, Riva F. L'epifania del volto. Servitium Editrice, 2010:32.