The COVID-19 Storytelling: Nurses, Patients and the Power of Death

Storytelling del Covid-19: infermieri, pazienti e la forza del fine vita

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ABSTRACT

Introduction: Personal stories accompanying the COVID-19 pandemic are of utmost relevance when considering policy adjustments and future improvements in the field of nursing.

Methods: To gather data and offer a more detailed overview of the complexity of nurses' responsibilities in times of a global health crisis, the method used is ethnographic research.

Results: The paper demonstrates that the nature of the COVID-19 pandemic, characterized by major uncertainties, has altered nurses' daily routines to the extent that they have been exposed to additional sets of duties, as well as to higher levels of exhaustion and risks with potentially fatal consequences.

Conclusion: Nurses' narratives provide a valuable input to the debate on their own status, as well as on the state of healthcare. The paper extends the current knowledge and contributes to wider discussions about nursing and our society's ability to handle outbreaks of large-scale health crises.

Keywords: Covid-19, Death, Healthcare, Loneliness, Nurse–patient relationship

ABSTRACT

Introduzione: Le storie personali che accompagnano la pandemia COVID-19 sono di estrema rilevanza quando si considerano gli aggiustamenti delle politiche e i miglioramenti futuri nel campo dell'assistenza.

Metodo: Al fine di raccogliere dati e offrire una panoramica più dettagliata della complessità delle responsabilità degli infermieri in tempi di crisi sanitaria globale, abbiamo optato per una ricerca etnografica.

Risultati: In tal senso, l'articolo dimostra che la natura della pandemia COVID-19, caratterizzata da grandi incertezze, ha alterato la routine quotidiana degli infermieri nella misura in cui sono stati esposti a ulteriori serie di doveri, così come a livelli più elevati di esaurimento e rischi con conseguenze potenzialmente fatali.

Conclusioni: Le narrazioni forniscono un prezioso contributo al dibattito sulla condizione degli operatori stessi, così come sullo stato dell'assistenza sanitaria. L'articolo estende le conoscenze attuali e contribuisce a discussioni più ampie sul nursing e sulla capacità della nostra società di gestire crisi sanitarie su larga scala.

Parole Chiave: Covid-19, Morte, Assistenza sanitaria, Solitudine, Rapporto infermiere–paziente

INTRODUCTION

The emergence and rapid spread of COVID-19 was a huge shock. The accompanying stories and images of medical staff from around the world (commonly presented in personal protective equipment), as well as strict measures aimed to restrict movement (curfew and lockdown) and prevent the spread of virus (quarantine, hand-sanitizing and the use of face mask) suggested that the world was at war against a new, invisible enemy (Deutsche Welle, 2020; Élysée, 2020; UK Government, 2020; White House, 2020; Xinhua, 2020). In fact, a war metaphor "may resonate with the public, may help people recognize the threat to public health, may help them take their obligations such as physical distancing seriously" (Isaacs & Priesz, 2000: 2).

To offer a sound response, policymakers kept jumping between recommendations coming from the World Health Organization and instruments available in their national contexts. Accordingly, the adoption of certain decisions frequently necessitated ad hoc input, the provision of mandates, and alteration of rules and regulations. By depicting COVID-19 as an existential threat to humanity and by having to halt the crash of their often-struggling healthcare systems, many domestic leaderships decided to treat the question of public health as a securitization affair (Radeljić & González-Villa, 2021). Nevertheless, the fact that different executives opted for measures diametrically opposed to one another – all of them insisted that their approach on how to handle the COVID-19 health crisis was a product of thorough consultation with different field experts, and as such, it was in the best interest of their fellow citizens – created a major confusion in terms of trust and (in)competence.

However, in contrast to policymakers, healthcare workers were, understandably, much more exposed to the virus. While they were not necessarily against the elites' approaches that were supposed to provide for a greater unity and thus a timely response, health heroes did start to dispute the ruling structures ahead of lacking protection. As rightly summarized elsewhere, "[i]n a war, heroes get medals, but deserters are shot, so are those vulnerable healthcare workers who feel unable to work on the frontline and request redeployment also 'deserters'? Healthcare workers may arguably have accepted a slightly higher risk to themselves by pursuing their vocation. While they have a duty to care for patients, they have no obligation to sacrifice themselves" (Isaacs & Priesz, 2000: 2; Marron et al., 2020).

Thinking about nurses, with the outbreak of the COVID-19 pandemic they received immediate attention by media outlets, regularly depicting them as protectors of both individual and collective health (Anwar et al., 2020; Bagnasco et al., 2020; Cox, 2020; Huang et al., 2020; Ritter et al., 2021). For the state, their role of martyrs – ready to sacrifice their own well-being to comply with deontological ethics despite the fear of the unknown and the ever-growing sense of fatigue (Arasli et al., 2020; Lynch et al., 2021) – served as a basis (and often a shield in the absence of meaningful alternatives) to introduce emergency measures with the aim of preventing the spread of virus. This widely exploited public presentation also has its other, much private and therefore invisible dimension, which is that of nurses themselves.

So far, the literature has already dedicated a lot of attention to nurses' reputation (Mohammed et al., 2021), recruitment and investment in nursing (Hoogendoorn et al., 2021; Rosa et al., 2020; Stievano et al., 2021), experience of high levels of stress and fatigue (Hossain & Clatty, 2020; Mo et al., 2020; Wang et al., 2022; Zhao et al., 2020) and ethical dilemmas and corresponding professional challenges (González-Pando et al., 2021; Jia et al., 2020; McKenna, 2020; Newham & Hewison, 2021; Sperling, 2020). To complement the existing accounts, which have identified and successfully examined key trends, and recommended a range of improvements on how to take care of nurses should similar scenarios happen in the future, we bring nurses even more to the forefront of the debate and thus even closer to the readership, both general and professional. To do so, we contacted them, directly or through acquaintances, and asked them whether they would be interested in taking part in our ethnographic research.

Our approach was rather spontaneous, and therefore we ended up with primarily female nurses, who had recently embarked on their professional journey. As the result of their participation, we aim to paint a fuller picture of the complexity of the nursing profession in times of global pandemic. Their narratives are about experiences in relation to the new normal and lengthy lockdowns, but also their fears of coming into contact with a COVID-positive patient, especially in the very beginning when the available information and protective equipment were admittedly scarce. During the period between March and December 2020, our nurses were mostly employed by hospitals, care homes and different private facilities in the Turin area, Italy. To share their first-hand experience, they kept diaries; in addition to the nurses' own notes and observations, these illuminating primary sources also contain stories of other healthcare workers and patients, and their relatives or family members.

WHAT DO NURSES HAVE TO SAY?

The COVID-19 pandemic has altered nurses' understanding of their daily routine, including the dressing and cleaning practices, and interaction with patients (and management of those dying), all characterized by higher levels of pressure and mounting work-related stress (Alharbi et al., 2020; Fawaz et al., 2020; Ford, 2021; LoGiudice & Bartos, 2021). As per some testimonies, the change was obvious from the very entry into the workplace, seen as a "dirty" and "risky" environment because of potential sources of contamination. In this new, "ritualistic setting" (Cozzi & Nigris, 1996), the body seems to lose its features and functions, pushing its owner to ignore physiological needs such as hydration and urina-

tion since the process of getting undressed and then again dressed is extremely complicated. It is a ritual of protection and depersonalization, in which words and conversations transform into paraverbal communication, or kinesics and proxemics between anonymous bodies. Thinking of her dressing ritual every morning, Laura wrote:

"Here starts the long, but by now habitual, dressing procedure. The personal protective equipment covers the uniform of which I was so proud since its colour lit up my face; it covers the hands that served me to perform so many actions, including blood sampling, resuscitation manoeuvres, and, equally important, pats on the back or handshakes to reassure a patient or a caregiver; it covers the hair I tended to tie with an elastic band at the beginning of each shift as a small habit for a good day ahead; it covers the ears that helped me hear that gurgling breath, that tremor in the voice of a patient who hates being at the hospital or quite inaudibly requests some help; and it covers the mouth I used to clearly communicate everything that was necessary, and offer a smile to a simple 'thank you' or when something was funny." (7 April 2020)

The nurses working in the field have highlighted the impossibility of direct interaction with the patient and of introducing themselves or expressing some genuine understanding for their condition, while simultaneously their relatives and family members had to stay away:

"You try to answer all sorts of questions that patients might ask you and you try to comfort them when they are about to collapse, fearing a severe COVID-19 pneumonia. You try to make them realize that hospitalization is necessary so their lungs can continue to function. You try to console them, given that they will not be able to see their dear ones for some time. At best, they will be able to do so by means of a video call." (Francesco, 10 March 2020)

The above extracts reflect on the role of health workers in the emergency wards and intensive care units, where patients are left alone in their fight against the virus (Gallagher, 2021), without being able to see anyone apart from the medical staff whose eye expressions are the only messenger of the state of affairs. As reported by two nurses: "I miss showing my smile, but luckily my eyes are visible and, as we say, they are the mirror of the soul; they can also communicate a hidden smile. I have also learnt to distinguish the muffled voices of my colleagues and replace the absence of verbal expression with a simple look." (Laura, 7 April 2020)

"We have become silhouettes, whose faces are difficult to identify. Patients struggle to separate us and can barely recognize a smile from our eye movements … I, the doctor and other nurses, in addition to the patient in the neighbouring bed, are the only source of 'dialogue' for patients who have been in hospital for days and without any external contact (if we exclude cell phone conversations). The biggest tragedy caused by this virus is the loneliness in which some patients die. I always hope, during my shift, to have enough time for the patients, to exchange a few words with each of them." (Noemi, 23 March 2020)

The difficulty in maintaining steady enthusiasm towards the job (and particularly in such difficult circumstances, which involve high levels of risk), has been compensated with the gratitude expressed by patients themselves, and by their relatives or family members. This way, the duty itself acquires additional meanings; apart from following the previously established requirements, it comes to represent part of one's identity of a wider action – a life-saving mission. Nurse Marina noted:

"After all, you cheer up because there are so many people who thank you; obviously, the patients gratify you the most, which is followed by acknowledgements from the outside. This is a joy for our hearts and minds; it is exactly this aspect that makes you continue and repeat that 'everything will be alright'." (15 March 2020)

Given their presence throughout, nurses also formed part of a "calm, dignified death"; they were the ones to call families and relatives of the dying patient who would shortly be wrapped in a disinfected sack, ready for an unattended funeral, one that neither follows the traditions nor allows any attendees (Carr et al., 2020). As the key point of contact, nurses would make calls to break the news of death and then engage in the management of a contagious corpse (Fantauzzi, 2020a). According to one nurse's experience:

"... with a mobile phone or tablet, you [the nurse] would call the main contact person, for example, the son of a dying gentleman, and then in the background you would also hear his wife praying in tears and repeating 'amore mio'. At that point, you would like to hug your patient, but you are not allowed; you feel like a robot. You are a kind of an extended arm and the voice of the dying person, and then when you see them lose their final breath, it feels as though a part of you has also died." (Fabio, 5 April 2020)

The above experiences reveal major empathy dominating the caregiver's approach towards the patient, whereas their behaviour should have primarily been exotopic. Considering the nurse–patient relationship, Cozzi argues that "while exotopia includes empathy, it detaches it from emotional subjectivity, from believing that our understanding has universal value and from the risk of assimilation, aiming at equality of dialogical rights and the right of diversity. It is a way to learn to connect with oneself and with others, to displace ourselves, allowing us to comprehend 'same things' in a different way." (Cozzi, 2002: 36; also Fantauzzi, 2020b). While looking after dying COVID-19 patients, nurses also know that their infection, anguish of loneliness and the struggle for another breath, are uniquely theirs, and that the reality outside the department is completely different (it continues, even if under special circumstances). Otherwise, by being too invested and swallowed up by the suffering of others, nurses could run a real risk of no longer being able to do their job.

Aware of all this, the nurses' narratives turn out to be their medicine, the cure that provides strength and courage to face a new day and stay at the forefront, ready to manage the pandemic through the expression of contrasting emotions and self-confrontation between the private sphere and their professional affiliation. This is especially the experience of those working in care homes (Cousins et

al., 2020; Gardner et al., 2020; Ryoo et al., 2020). In her long account, nurse Samantha described in detail every day of the pandemic, including festivities that come about as moments of sadness:

"Holidays are a joy for many, but for others, mainly the elderly, they are a source of sadness caused by loneliness and old memories. Today is Easter and I see the cooks preparing a special lunch for our 'guests'. This year, their Easter will be different from usual; the fact that they are not allowed to see their relatives and spend this day with them makes many of them sad. Some others seek a more positive side to it, and there are also few who have no idea what day it is today. They suffer from senile dementia, which involves a gradual and irreversible reduction of cognitive functions. There exist several types characterized by various signs and symptoms including progressive memory loss. This is very tough to manage, not only for those directly affected, but also for family members who may one day find themselves no longer recognized by the elderly. Now they are the ones who handle the pandemic much better than the rest, since they watch the days go by and cannot remember what happened the day before and usually do not experience any suffering for not seeing relatives." (12 April 2020)

Given that the COVID-19 crisis did not allow rituals to take place or family presence at the moment of death, many nurses remembered the first wave as a period of intense loneliness. They found themselves alone in front of corpses believed to be infected and infesting, having to treat them as plague victims that were to be got rid of as soon as possible:

"Once death was confirmed, we were told to put the bodies inside the designated big bags, similar to those used for rubbish, sprinkle them with disinfectant and then have them collected by hearse or, sometimes, military trucks. We have realized what inhumanity looks like: these people died, they died alone, they could not even cling to us or look us in the face since we were all fully covered." (Fabio, 10 April 2020)

However, death is also observed in the eyes of the sick, yet still alive, or the elderly left on their own. In this respect, writing is an instrument to confront hidden feelings that, even for professional reasons, are not easily disclosed; this exposes the fragility even of those who take care of the life and death of others, or of their very moment of death:

"I enter the rooms and see death in their eyes, the light they had is no longer there, it is abandoning them. Dull faces, sweaty bodies, shallow breathing … Even my favourite star is leaving me. […] I have arrived home and received a message that he has left us. He was one of the youngest, but with lung and heart problems. Then he caught the virus, had fever which did not go down, so he was getting weaker and weaker … When we called the emergency department, they did not want him in since it was obvious that he was going to die. A second call a few days later and this time they took him away. […] Tonight, I have received the news that he passed away from COVID-19." (Samantha, March 2020)

NURSE AS A COVID-19 PATIENT

The full picture and appreciation of patients' own level of suffering is only possible when nurses catch the coronavirus themselves and, in accordance with the procedure, are hospitalized or have to self-isolate. In their position of patients, yet aware of the risks much more than other, non-expert people, nurses know what can happen (He et al., 2021; Wyatt, 2020). While monitoring symptoms and identifying the most appropriate precautions, they are also aware of the forthcoming loneliness brought by the infection. As we have witnessed, before the disease or pathological condition, the patient has already acquired the reputation of a sick person (Kleinman et al., 1989), a biopolitical body (Foucault, 1976), controlled and supervised by the health, judicial and military authorities, obliging the patients to isolate even from their closest ones, to stop their regular activities, to limit personal freedoms.

Nurses have found the above aspects extremely challenging; apart from their own loneliness, they have felt deprived of the paradoxical privilege of being alongside COVID-19 patients. In fact, we have collected a number of poems written by nurses who fell ill a few weeks after the outbreak of the pandemic and had to quarantine in last-minute rented houses so they would not have any interaction with their families or colleagues. In some of them, the interlocutor is the virus itself, meaning an unwelcomed guest that is present at the table laid for one person, an intrusive agent in the new highly uncertain and therefore ever-upsetting reality. In most cases, reference is made to a torment, mainly because of the long duration of self-isolation and suspension of daily practices.

Eventually, the negative PCR test is seen as the moment of liberation, permitting nurses to reunite with their patients and to resume their old activity and ongoing mission. Many of the poems denounce the condition of imprisonment and tyranny that the virus exercises over its victims, sometimes calling it "the king". Here, we share two of such poems (in full), both expressing nurse Marta's emotional charge during her days of isolation.

All this highlights the democratic nature of the pandemic, since it can hit anyone, without discrimination, although in very different ways depending on personal circumstances. However, the type of treatment reserved for the infected ones has not always been equally democratic, in the sense that the pandemic has exacerbated the existing fragility of the system and created new layers of poverty, without allowing everyone to have the same access to healthcare (Arawi et al., 2020; Laurencin, 2020; McGreal, 2020; Semino, 2021; Shippee et al., 2020; Whitehead et al., 2020). This complexity has been additionally problematized by the dilemma as to whether to give priority to elderly or homeless people over younger people, or to give priority to political figures or those from the entertainment industry (Fantauzzi, 2020c).

THE NARRATIVE OF COMFORT

Nurses have also served as the voice and "spokespersons" of patients in COVID-19 wards (Maaskant et al.,

Torment	**I am hungry for air**
You are a thorn in the flesh, pressing me to take my breath away. My freedom is imprisoned; what is the category of my offense? I am in chains with hyenas, I want to exit this annoyance, this betrayal, stemming from your pride. The torment has ended! It has expired with a simple greeting! Yes, you got me, but I am out, your strategy has not worked. I look forward to rainbows and better days, to live my life in harmony and joy. Do not look for me in the streets, do not occupy your mind with me, do not seek refuge in my lungs. Go away, you unpleasant lie! This is what you deserve. You had better disappear. You were not welcome, no one looked for you or wanted you. Still, I am sure you will totally vanish to provide space for love in your absence	I am hungry for air, I am hungry for you, I would do anything to have you nearby. I have laid the table with the Flemish tablecloth and porcelain tableware, just as you like it; all is white to make you happy, so you can oxygenate purity. I am waiting for you at the table, but you are not coming, and minutes turn into hours, and still nothing. You have always been on time filling my lungs by making them elastic and active… And now, what happened? I realize that I am not alone. Alas! Someone has self-invited himself, which is a bit rude. He has a crown, says he is a king, of which kingdom we do not know, but he claims to be venerated, considered special. He is bold, he waves his tentacles to scare me, he wants to subjugate me, he raises his voice and provokes me. He confirms his decision not to want you here at our table, he considers you useless and lazy... He is badmouthing you! I am petrified. My heart is crying, how can someone be so bad and violent? Please do not leave me alone, I know it is scary, but come to me anyway, I am hungry for you! I need your help to inhale a gust of wind, to rejoice with you every moment, and united with the power of love we will be able to dethrone the king!

Table 1.

2021). They write and speak for them, getting their emotions across to family members but also to other caregivers. Tablets, projectors and mobile phones are used as the main means of communication, done on behalf of patients who are mostly intubated and in intensive care. We call messages and testimonies that are gathered in this manner the narrative of comfort; it is indirect and thus mediated, not produced by the sender themselves, but dictated or simply whispered. As reported, nurses have tried to allocate some time to maintaining contact with their patients' families, including verbatim transcriptions of the words dedicated to their dear ones, without adding their own interpretation or distorting the message in any other way.

The collection of these short writings, often sent by email or mobile phone, and accompanied by emoticons (hearts, smiles, flowers, rainbows and handshakes) represent hope for better days or, more specifically, for a longer and more stable breathing and for an opportunity to see each other again and spend time together at home. Writing becomes an expectation of the transition from the state of illness to that of full recovery, from the hospital to the home environment, and from the whiteness of hyper medicalization to the warmth and colourfulness of one's family setting (Charon, 2019). Here are some examples

"I know you are not allowed to visit me, but I know that you are all doing fine. I am doing my best; everyone here is very kind and attentive. Try to keep well and wait for me to come back. I miss our bed so much, our bed of love. I miss you, my treasure." (a male patient's message to his wife)

"My dear daughter, stay calm, your daddy will return soon. I am giving my all and you need to be close to your mother who is crying all the time. I do not want you to see me in this condition, you must think of me as strong as I have always been. Laura, I miss you so much, I miss you all. Lots of kisses, dad." (a male patient's message to his daughter)

"I cannot breathe, I am not very well, though everyone is great to me. Keep me in your thoughts, pray for me. Tell Mattia that her grandma is coming back soon so we can play together. My situation is scary, but I am fighting hard, so I can be with you all. Our home will be my medicine and you will be my greatest hope of getting better. I love you very much." (a female patient's message to her husband and granddaughter)

The digital writing, through the hand of the nurse, is often the last farewell of the dying patient to their family. This writing is often coupled with a tired gaze and slow movement of eyes, before the final call. Few mumbling words and a thread of breath carry messages of sadness and goodbye. For example,

"I will not be able to hug you again, I feel that I will not make it. I fought a lot, but the virus is killing me. It took me away from you and you away from me. I cannot stand it anymore, I just cannot. Excuse me if I go away in this way, possibly somewhat cowardly, but these tubes are not my life." (a young male patient's message to his mother)

"This virus is taking away my strength, breath, air. I would have liked to hug you once more and tell you how much I love you. I have always loved you. Take care of yourself and our grandchildren; our children are strong and will look after themselves. I am fighting with all my strength, but the virus is stronger. I have no tears left, either for my suffering or for not being able to see you again." (an old male patient's message to his wife).

The narrative becomes another uniform of nurses, playing the most humane and humanizing role in the face of the pandemic, both in terms of the quality of the relationship and correspondence, with and on behalf of the patient. As such, writing fulfils a triple function: as a voice of hidden and dormant emotions, and of fears and bitterness experienced in front of the many dying patients; as a therapeutic strategy for one's illness and strength during the recovery process; and finally, as a means of contact with the dear ones for those on the verge of death or who have passed away.

Narrative medicine, in this sense, also touches upon a forbidden and dormant mourning; it gives oxygen to the suffering that follows from the loss and a bitter justification for not having been able to do otherwise – to touch the body, prepare it properly and then wait for its final hour on earth. Occasionally, before wrapping the bodies in

anonymous plastic bags, health workers found notes, letters and poems. Sometimes they placed these writings inside the coffin, together with the body, also to be removed out of fear of contagion. As some nurses recalled,

> *"I put a note inside the coffin that read: 'Why is this happening to me? Why will I not see you die, nor give you the last hug and take you to the cemetery myself? I miss your gaze and your warm hand; this virus has taken you away from me.'"* (Stefano, 7 April 2020)
>
> *"I kept a dedication from a granddaughter writing to her dying grandfather: 'Grandpa, I know that this little monster is taking you away. I told him that I would fight him with my sword and shield, which you bought me last year at the carnival; come home soon, we still have to eat those chocolate chip cookies together, but without this little monster. Bye, bye'."* (Luisa, 12 April 2020)

CONCLUSION

This paper has sought to bring nurses' own stories to the forefront of the debate concerning the state of their vocation, especially during major disruptions such as the COVID-19 pandemic. As we have seen, nurses were not only efficient operators in their care practice, by seeking to offer the best possible treatment to patients infected with the coronavirus. They also served as intermediaries, by aiming to provide some dignified comfort and continuation of contact and thus closeness between patients and their dear ones, especially when the worst possible outcome – death – became highly likely. Their diaries, including a wide range of written testimonies, outline the magnitude of the health crisis and the meaning of life in front of a new, invisible enemy.

Thinking of their own position, nurses' embracement of writing is a means of better understanding the circumstances, a form of comfort and therapy. Such an approach corresponds to what has happened throughout, with many health workers providing their service on a daily basis under extremely challenging conditions. Because of their level of dedication and self-denial, especially at the very beginning of the COVID-19 outbreak, doctors and nurses were regularly portrayed as heroes and martyrs. They were exposed to the risk of contagion and to take care of others; many have committed to performing gruelling shifts. Unfortunately, many health workers have also fallen ill themselves and many have died.

While the existing accounts of roles and responsibilities of nurses during the COVID-19 crisis have painted a rather complex picture about the profession, much more emphasis should be placed on questions concerning risks and rights. With this in mind, the global pandemic is a wake-up call to revisit the existing frameworks, to be exploited both by nursing associations and national leaderships, to ensure a greater protection of nurses (in terms of their well-being and compensation), as well as a better preparedness for any future crises (in terms of crisis management and health system infrastructure).

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