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Emergency communication in COVID-19 Units. Ethical aspects

COVID-19 Bioethics Working Group

Version of May 25, 2020

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COVID-19 Bioethics Working Group

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The COVID-19 outbreak has subverted both procedures and circumstances of communication within the healthcare setting. Communication is impacted by the isolation of patients in dedicated units, assisted by health care professionals with personal protective equipment. Within this background, changes in communication between healthcare professionals, patients, and their relatives are needed. This report underlines, through an ethical and bioethical analysis, some relevant aspects that can support communication and reaffirms its role at the cornerstone of care.

The original Italian version of ISS COVID-19 Reports are available from: **https://www.iss.it/rapporti-COVID-19**

The reports translated in English are available from: **https://www.iss.it/rapporti-iss-COVID-19-in-english**

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Preface

The COVID-19 pandemic has had an overwhelming impact on individuals and on the entire human community.

The spread of the disease has brought up countless issues with considerable ethical implications. The Istituto Superiore di Sanità (ISS, the National Institute of Health in Italy), as the technical and scientific body of the National Health Service, has had to respond to many of these issues. Indeed, the mission of the Institute is to promote and protect national and international public health through research, surveillance, regulation, control, prevention, communication, consultancy and training: within each of these areas, the pandemic emergency has posed issues of ethical relevance.

Although the Institute is not a research and care delivery facility and its mission is above all focused on public health, it does not overlook the "bedside" dimension and the associated dilemmas of clinical ethics. An essential component of this dimension is communication: the Code of Medical Ethics, indeed, recognizes communication to be part of patient treatment.

In the hospital units where COVID-19 patients are treated, situations are often dramatic and, despite the efforts of doctors and of other health professionals to be in constant contact with each patient, at times the conditions and, in particular, the clinical status of the patients who are in isolation to prevent the spread of the disease, hinder the possibility of effective communication.

This report presents some operational proposals along with the relevant ethical considerations. The ISS COVID-19 Reports are aimed at providing "essential and urgent information for emergency management". This report also serves that purpose. Giving priority to operational proposals over an in-depth analysis of the ethical values on which communication is based does not mean that the ethical dimension is overlooked. The values of reference are stated explicitly, although not detailed in an in-depth theoretical discussion.

Communication of clinical information to patients is the exclusive task of the doctor. However, the doctor is part of a team and all team members provide care to the patients and hence communicate with them. For this reason, the term "healthcare professionals" has been widely used in the report, which includes a multiplicity of professionals, with their respective and equally fundamental roles and tasks that are codified in the rules governing the health professions.

This report attests to the vast horizon in which the COVID-19 Bioethics Working Group operates, set up as part of the activities that the Italian National Institute of Health carries out to respond to the pandemic emergency. The documents produced by the Working Group, in fact, range from the public health scenario, to research, to the role of health professionals, to the vision of patient-centred care.

In each of these areas, ethics demands that the focus be always placed on the individual.

Carlo Petrini

Introduction

In the context of the COVID-19 emergency, the nature and experience of communication between the representatives of the healthcare professionals and patients – and where present, relatives[1] – have suddenly undergone a structural transformation, whose repercussions have major ethical implications in the dimension of care.

These implications affect various fields such as, for example, the institutional, scientific, medical-health, educational and social sectors, each characterized by its own specific characteristics. This document presents an analysis of the ethical aspects of communication within the hospital units where patients with SARS-CoV-2 infection are treated in isolation. Indeed, this is precisely one of the communicative dimensions in which the criticalities associated with the disease have been most exacerbated by the new barriers imposed by the need to contain the contagion.

The critical importance of communication in emergency situations is evidenced by the recent dissemination of operational documents and indications issued by leading scientific societies and associations of doctors and health professionals.[2] With reference to these documents, the intent of this brief report is to support, as far as possible, the healthcare professionals involved in the emergency by underlining the importance of some main aspects raised by the issue from an ethical and bioethical standpoint.

Healthcare professionals who operate at all the levels in the context of the COVID-19 emergency, have experienced the dramatic effects of these aspects in the front line and in extreme conditions, coping with the emergency with extraordinary dedication and professionalism. As is known, in the medical-health context each member of the team carries out a specific task which is substantiated by adequate training and professionalism. In everyday clinical practice, and even more so in emergency conditions, it is essential that these roles, whose specificity is essential and irreplaceable, be respected so as to guarantee adequate levels of care. Considering, however, the purely ethical and bioethical relevance of the document, reference will be made generically, with some exceptions, to healthcare professionals without further distinction.

1 The FAQ published by the Presidency of the Council of Ministers, in accordance to the DPCM of 26 April 2020, state that the term "relative" includes spouses, cohabiting partners, partners of civil unions, and persons who are linked by a stable emotional bond, as well as relatives up to the sixth degree (such as, for example, the children of cousins with each other) and relatives up to the fourth degree (such as, for example, the cousins of the spouse)".

2 Among others mention can be made of: 1. the document on communication in emergency situations issued by SIAARTI, Aniarti, SICP, SIMEU bearing the title “How to communicate with relatives in total isolation”; 2. the guidelines available on the website of the Tuscany Region on “How to communicate with suspected COVID-19 patients”; 3. with regard to the e-learning ECM module 5 “Fight the COVID” ECM, module 5 run by Lara Bellardita “Communication in the ward and in outpatient clinics during the Coronavirus outbreak: empathy, compassion and gratitude”.

COVID-19 emergency and communication: ethical aspects

Communication is a fundamental pillar of the dimension of care and is particularly precious in emergency healthcare circumstances characterized by scarcity of time and of available resources. In such situations, the fragility and vulnerability of the patient (and of his/her next of kin, where present) causes an asymmetry in the relationship with the medical healthcare professionals whose competence and expertise are crucial since the patient's health and life depend on them. The skewed situation in which this communication takes place is also influenced by the hospital context, which may be perceived as extraneous and unwelcoming by the patient, regardless of the competence of the healthcare professionals. In conditions of vulnerability, being enabled to express one's choices and needs allows patients to actively participate, within the limits of their conditions, in their treatment choices. Therefore, in an emergency hospital context, communication takes on a very central role grounded in medical deontology.

The COVID-19 emergency has disrupted, in a very short time, the places, modalities, structure and possibilities of communication in the hospital context, generating non-negligible repercussions on the dimension of care. The nature of these implications is profoundly heterogeneous and this short report is dedicated to an analysis of the ethical aspects that the pandemic context has brought to light with regard to communication.

The epidemic wave has caused a contraction in terms of available time and human resources which have affected the possibilities of communication. But the one factor that has affected most the quality and way of communicating within the healthcare context has been the urgent need to contain the infection, which has imposed stringent isolation measures for hospitalized patients with potential or confirmed SARS-CoV-2 infection. The high transmissibility of the virus has immediately imposed the need to reorganize entire hospital structures and adopt strict protocols aimed at containing the infection. Areas accommodating exclusively infected patients have immediately been identified to which taskforce teams have been assigned with dedicated transit routes. The imperative need to keep these areas totally impermeable to the outside world have produced new ways of communicating with the patients.

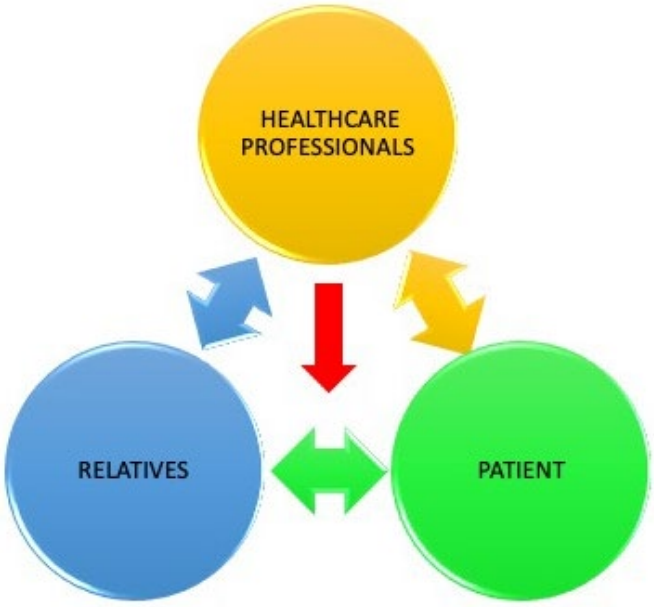
The complete isolation of these patients has meant that they cannot interact with nor see their relatives, except through devices such as the telephone, tablets or smartphones. But unfortunately, the patients with acute infection are often unconscious, semi-conscious, or are machine-dependent and hence communication is often significantly limited, if not totally absent.

In conditions of danger, restricted communication is a source of intense psychological, physical and emotional stress for all parties involved, and this adds to the anguish and bewilderment caused by the emergency and widespread isolation of all COVID-19 patients. These feelings are particularly evident in all critically ill patients in isolation who are not unconscious. The prohibition to be visited by loved ones and therefore being deprived of receiving comfort through direct contact in particularly difficult conditions means causing intense suffering that has non-negligible ethical implications. The patient's relatives also experience deep suffering and anguish for not being able to support, assist and physically and psychologically accompany their loved ones. This circumstance may be exacerbated if relatives are forced to isolation for having come into contact with the COVID-19 patient.

But the condition of psychological, physical and emotional stress does not only concern the patients and their relatives. It also concerns the healthcare professionals who, despite the fear of being infected and thus of putting the lives of their relatives at risk, work tirelessly in conditions of high post-traumatic stress, physically and psychologically overloaded by an influx of requests that exceed the available resources. In

this context, which is already particularly complex, the role of the healthcare professionals takes on a new central role. In fact, in addition to delivering regular assistance in extraordinary conditions, healthcare professionals are called upon to play a central role in communication and constitute the sole link between the patients and their relatives.

By attributing a central role to the healthcare professionals, communication takes on the structure of a triangle between the latter, the patients in isolation and their relatives, in which each binomial has its own specific characteristics.



Complexity of communication: from the illness of the patients to the relationship with their loved ones

Communication between healthcare professionals and patient's relatives

In the context of the COVID-19 emergency, communication between the healthcare professionals (who have the responsibility and prerogative of providing clinical information) and the relatives of a patient in isolation is characterized by multiple aspects that are important from an ethical point of view. As a result of the contagion containment measures, the medical staff are the only link hospitalized patients have with the outside world. When patients are unconscious or unable to communicate independently with their loved ones, the healthcare professionals are an extraordinary guarantor as well as the only means for informing relatives about the conditions of their loved ones. And in spite of the dramatic scenarios of the COVID-19 emergency, the healthcare professionals have done their utmost to perform this function. Indeed, this function assumes a particularly relevant ethical and deontological value and reflects the need for the medical staff to be a point of reference and a source of trust and reliability for the relatives of a hospitalized patient. Being able to communicate with awareness and being empathic are a fundamental tool for dealing with conditions of uncertainty, fear and despair, giving those at home the sense of security they need. It is therefore essential to promote sustainable communication procedures in emergency conditions that, at one and the same time, are exhaustive and effective for those to whom they are addressed.

In these cases, the communication problems also concern the relational aspects between the internal-external contexts of the hospital. In particular, the impossibility of giving access to relatives, combined with their anxiety when receiving news about the state of health and treatment delivered to their loved ones, can generate and / or exacerbate conflicts in communication and in the reception of the information provided.

To this end, it is desirable to bear in mind some considerations which in this type of situation take on special importance from an ethical point of view.

The following are worth recalling:

- **Establish direct contact**
  It is essential for the healthcare professionals to introduce themselves by specifying their name, surname and role. They must verify the identity of the interlocutor, make sure that they are willing to receive updates and that there is no language impairment. In case of need, it is important to have available upon request a translator (if the interlocutor does not speak Italian) or sign language interpreter (LIS) besides having the equipment for video calls in case of interlocutors with difficulty in verbal communication.

- **Use words and a language that are easy to understand**
  The language used in these conversations must be simple and understandable for the listener. Avoid technical terms as much as possible while trying, at the same time, to provide exhaustive information to those who are at home, probably in very precarious psychological conditions, and who are eager to understand the clinical situation of their relative;

- **Do not take anything for granted**
  The impossibility of seeing with one's own eyes the physical and psychological condition of a loved one prevents those at home from having a full representation of reality. It is important for hospital staff not to assume that the aspects that are known and clear to them are actually understood by outsiders. It is essential to check the quality of the information provided and how much of that information is actually understood by those at home.

- **Establish a communication window between the healthcare professionals providing the information and the patients' relatives**
  To avoid being flooded by telephone calls by relatives and acquaintances, even improvised ones, prevention and filtering measures such as those suggested in this paragraph should be adopted. It is always advisable that a time slot be fixed when staff members appointed to the task by the medical director of the ward, can be called by relatives to receive information on their loved ones, in the form of a medical bulletin – in much the same way as is done in other circumstances. It is worth pointing out that when there are changes in the patient's condition, relatives are to be promptly informed.

- **Put in place shift handover procedures for the staff in charge of providing information to relatives**
  It is essential to note down the information to be provided on a day-to-day basis to relatives and that such notes be put in an accessible place so that they are available to the medical staff of the next shift. This procedure makes it possible to avoid information leaks and ensures a timely update to relatives without gaps.

- **Be specific about the patient's pain management**
  One of the most common concerns of patients' relatives who cannot see their loved ones because access to the hospital is prohibited is about physical suffering and pain. Knowing it is being managed is of great relief for them. Even if no specific question is directly asked by those at home, it is important to explain, where applicable, that the patient's pain and suffering are controlled and managed with medication. Ensuring that the patient's pain is being managed and showing empathy for the patient will reassure relatives at home so that they know that their loved ones have not been left alone.

- **Establish a relationship of responsibility and trust**
  In communicating with relatives, it is important to establish a relationship of trust and reliability. Therefore, it is important to ask them if they have any questions, special needs or if they need any clarification.

- **Be transparent**
  The emergency conditions caused by the pandemic must not, as far as possible, prevent the healthcare professionals from being clear and exhaustive with relatives about the conditions of their loved ones. In circumstances with an uncertain outcome, it is essential to be transparent about what cannot be predicted or about what, in fact, is not known (such as, for example, the validity of experimental treatments for SARS-CoV-2 infection). It is important to avoid creating expectations in those at home that may fail to be met.

Communication between healthcare professionals and patients with difficulty in expressing themselves

Mention needs to be made also of the ethical implications of the communication problems that exist between patients in isolation and healthcare professionals.

The possibility for conscious patients to communicate and be understood is a necessary prerequisite for there to be a relationship between healthcare professionals and the patient, so that the patient can be involved and be made aware of his/her therapeutic plan, be able to accept or refuse treatment and express his/her needs. Therefore, the communication between healthcare professionals and the patient has a significant impact on the patient's quality of life at such a critical moment in his/her life. This dimension plays a central role in the dimension of care and must be encouraged even, and especially, in emergency conditions, where isolation and feelings of fear and uncertainty are so overwhelming. Unfortunately, in emergency contexts, establishing an optimal communication relationship between medical staff and patient may present several barriers due to the progression of the disease.

SARS-CoV-2 infection is characterized, in its most acute manifestations, by unconsciousness or partial consciousness of the patient and the patient's dependence on machinery that supports or assists vital functions. Where the patient has communication difficulties (is intubated, has a helmet for CPAP-Continuous Positive Airway Pressure therapy, etc.), it is advisable to establish - where possible - an "alternative" communication channel so as to enable interaction with the healthcare professionals. This is important in order for the patient to be able to express his/her needs and difficulties so that adequate care can be provided.

Aware of the value of this need, in the context of COVID-19, healthcare professionals have adopted different ways of interacting with patients who have limited possibilities of expressing themselves. One possible solution is to use charts containing simple and intuitive drawings of needs that the patient may want to communicate. He/she may point to them or simply look at them to communicate[3] with the healthcare professionals. Among the needs patients may wish to communicate there are the following:

- presence of pain, its location, and a score to express its intensity;
- breathlessness and difficulty in breathing;
- anxiety, or emotional stress;
- need to drink, eat, or sleep;
- need to speak with their relatives.

On the part of the healthcare professionals, in relation to the patient:

- explain or remind the patient where he/she is, and what has happened;
- interact with the patient to know what he/she needs;
- inform the patient of his/her conditions and prognosis;
- share information about the need to keep him/her in isolation.

[3] Regarding the many solutions produced during the COVID-19 emergency, by way of example, reference can be made to the charts available on the web page "COVID-19, use of AAC in Intensive Care Units".

As stated previously, it is essential to be able to accommodate the needs of patients who do not know the Italian language or who have limited possibilities of expressing themselves verbally by involving, if necessary, cultural mediators, translators and LIS interpreters (Italian Sign Language).

A possible communication barrier between healthcare professionals and patients in isolation is represented by the personal protection equipment worn by the healthcare professionals which is essential to contain the infection and protect the staff. First of all, facial protection (masks, shields) which covers most of the face, prevents the interlocutor from perceiving the speaker's facial expressions, an important aspect in communication, and impoverishes the quality of the interaction. Furthermore, the protection equipment makes it very difficult to recognize and distinguish the healthcare workers. Mitigating the negative impact of these aspects on communication is not easy, but some measures may be useful such as, for example, accentuating the expressiveness of the gaze for more direct communication and writing the names and qualifications of the staff on their coveralls, so that they can be recognized; this lessens the feeling of isolation and incommunicability that is felt sharply by patients in isolation.

In conditions of emergency and intense physical suffering, it is important to reduce the patient's emotional stress as much as possible by ensuring, despite the complexities, continuity in the relational dialogue and empathy that is the basis of the dimension of care.

Communication between patients in isolation and their relatives

The impossibility of physical contact between patients hospitalized in isolation and their loved ones is a source of understandable anxiety and emotional stress on both sides. Whenever possible, and for patients who are conscious, it is desirable to encourage communication between the parties also by means of videoconferencing. The possibility of seeing each other, albeit through a screen, helps to alleviate, albeit marginally, the condition of anxiety and uncertainty of those at home with regard to the conditions of their hospitalized loved ones. At the same time, seeing their relatives gives patients some comfort and makes them feel closer at a time of great vulnerability and pain. It is crucial to promote these forms of communication where possible, after obtaining the patient's consent, and providing him/her with adequate support if he/she is unfamiliar with the devices. In this context, the role of healthcare professionals is decisive since, even though they are not a direct interlocutor, they do represent the heart and custodian of communication between patient and relatives.

In the event that the patient is unconscious and the relatives express the desire to "see" the patient, it is important to consider if and how this request can be accommodated.

Legal aspects of emergency communication

In the absence of the patient's consent, which may have been validly expressed upon receiving specific information prior to losing their mental capacity (a solution that is obviously to be preferred), one may consider the use of communication tools and photographs to meet the requests of close relatives and provide some comfort to the situation of anxiety they are experiencing. It should be noted that for all intents and purposes photographs come under the definition of personal data and therefore they are regulated not only by the provisions of Article 97 of the copyright law, which prohibits the disclosure of images that are prejudicial to the honour, reputation and decorum of the person portrayed, but also by the European Regulation on the protection of personal data (Regulation EU 2016 / 679 or General Data Protection Regulation, GDPR). Article 6 (1), letter e) and Article 9 (1), letter g), h) and i) of the Regulations make processing possible, even in the absence of consent, for purposes of public interest, especially in the public health sector in the presence of a specific legislative basis provided for by national law. Indeed, Article 17-bis, (2), of Law no 27 of 24 April 2020, allows disclosure of personal data to private parties if this is "indispensable for the purpose of carrying out the activities associated with the management of the current health emergency".

Since the transmission of photographs or video clips to the patient's relatives technically constitutes a "communication of personal data", and, unless this does not cause prejudice to the patient's dignity, this activity could be considered to be legitimate, as it is dictated by the need to organize the units in such a way as to avoid the risk of contact with outsiders and at the same time ensure comfort, albeit "virtual", to the patient and his relatives by using remote means of communication. In any case, before sending images, it would be advisable to obtain clearance from patients accompanied by a specific commitment of confidentiality and non-dissemination of the images in question.

Conclusion

Within the framework of the COVID-19 emergency, the measures put in place to contain the infection in health facilities have designed a new scenario for communication. The condition of isolation of patients in dedicated units, assisted by healthcare professionals with full body personal protection equipment, has disrupted the methods and possibilities of communication between patients, close relatives and healthcare professionals, making it necessary to adopt a new communication structure.

The emergency situation and the rapidity with which it came into being have overly amplified the complexity of these changes, raising major ethical issues that have been highlighted in this brief report. The conditions of vulnerability, anguish and stress that exist in an emergency context, such as the current one, affect indiscriminately, albeit in different degrees, patients, their families, and the healthcare professionals who are in the front line of the fight against the virus. Furthermore, besides being engaged in delivering ordinary levels of care in extraordinary situations, with the enormous physical and psychological pressure that this involves, the healthcare professionals must also take on the additional role of being the link between relatives and patients for whom they are the only means of contact with the outside world. In the context of the relationship between patients and relatives, and between relatives and healthcare professionals, and between the latter and the patients, communication - the cornerstone of the dimension of care - takes on an unprecedented structure where the healthcare professionals are at the heart. Despite the dramatic conditions caused by the COVID-19 emergency, the healthcare professionals have been the guarantors and medium of communication and have been constantly committed to ensuring the steady flow of information. In this context, the objective of the analysis proposed in this report was to underline, through an ethical and bioethical analysis, some relevant aspects that may facilitate the process and management of the new communication conditions in the aforementioned emergency contexts.

Rapporti ISS COVID-19 (ISS COVID-19 Reports)

ISS COVID-19 Reports are mainly addressed to healthcare professionals to cope with different aspects of the COVID pandemic. They provide essential and urgent directions for emergency management and are subject to updates. All reports have an English abstract.

The complete list is available at **https://www.iss.it/rapporti-COVID-19**.

Some reports (highlighted below) are also translated in English and are available at **https://www.iss.it/rapporti-iss-COVID-19-in-english**

2021

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10. Gruppo di Lavoro ISS Cause di morte COVID-19, Gruppo di lavoro Sovrintendenza sanitaria centrale – INAIL, ISTAT. *COVID-19: rapporto ad interim su definizione, certificazione e classificazione delle cause di morte.*

Aggiornamento del Rapporto ISS COVID-19 n. 49/2020. Versione del 26 aprile 2021. Roma: Istituto Superiore di Sanità; 2021. (Rapporto ISS COVID-19 n. 10/2021).

11. Gruppo di *lavoro* ISS Ambiente e Qualità dell'aria *indoor*. *Indicazioni ad interim per la prevenzione e gestione degli ambienti indoor in relazione alla trasmissione dell'infezione da virus SARS-CoV-2. Aggiornamento del Rapporto ISS COVID-19 n. 5/2020 Rev. 2. Versione del 18 aprile 2021.* Roma: Istituto Superiore di Sanità; 2021. (Rapporto ISS COVID-19, n. 11/2021).
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