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How to communicate with families living in complete isolation

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ABSTRACT

Importance During the SARS-CoV-2 pandemic, a complete physical isolation has been worldwide introduced. The impossibility of visiting their loved ones during the hospital stay causes additional distress for families: in addition to the worries about clinical recovery, they may feel exclusion and powerlessness, anxiety, depression, mistrust in the care team and post-traumatic stress disorder. The impossibility of conducting the daily meetings with families poses a challenge for healthcare professionals.

Objective This paper aims to delineate and share consensus statements in order to enable healthcare team to provide by telephone or video calls an optimal level of communication with patient's relatives under circumstances of complete isolation.

Evidence review PubMed, Cochrane Database of Systematic Reviews, Database of Abstracts and Reviews of Effectiveness and the AHCPR Clinical Guidelines and Evidence Reports were explored from 1999 to 2019. Exclusion criteria were: poor or absent relevance regarding the aim of the consensus statements, studies prior to 1999, non-English language. Since the present pandemic context is completely new, unexpected and unexplored, there are not randomised controlled trials regarding clinical communication in a setting of complete isolation. Thus, a multiprofessional taskforce of physicians, nurses, psychologists and legal experts, together with some family members and former intensive care unit patients was established by four Italian national scientific societies. Using an e-Delphi methodology, general and specific questions were posed, relevant topics were argumented, until arriving to delineate position statements and practical checklist, which were set and evaluated through an evidence-based consensus procedure.

Findings Ten statements and two practical checklists for phone or video calls were drafted and evaluated; they are related to who, when, why and how family members must be given clinical information under circumstances of complete isolation.

Conclusions and relevance The statements and the checklists offer a structured

Key points

Question

- What is the best way for doctors and nurses to communicate with family members under circumstances of complete isolation such as during SARS-CoV-2 pandemic?

Findings

- Ten consensus statements and two practical checklists for phone or video calls were obtained from a multidisciplinary task force through an e-Delphi consensus procedure.

Meaning

- The statements and the checklists may represent helpful tools for ensuring a good quality in clinical communication between healthcare team and families living in complete isolation.

methodology in order to ensure a good-quality communication between healthcare team and family members even in isolation, confirming that time dedicated to communication has to be intended as a time of care.

INTRODUCTION

The global emergency caused by the SARS-CoV-2 pandemic has suddenly changed how we communicate with patients and their families.[1] Healthcare professionals are isolated from their families and forced to manage the consequences of this isolation just like the patients. Patients and their relatives perceive not only the clinical results but also the personal attitudes, closeness and psychological support from care teams.[2] This perception of genuine participation by the healthcare professionals is especially important when a patient dies, and may influence the whole process of grief.[3]

Thus, a multiprofessional taskforce was created by four national scientific societies in April 2020: the Italian Society of Anesthesia and Intensive Care, the Italian Society of Critical Care Nurses, the Italian Society of Emergency Medicine and the Italian Society of Palliative Care, which principal characteristics are described in the online supplemental material table S1. The aim was to formulate a position paper intended for all healthcare professionals caring for patients with CoViD-19, particularly those in more severe conditions, to help the care team in communicating with families living in complete isolation. The full version of the position paper is available as online supplemental appendix of the present paper.

METHODS

The spread of the SARS-CoV-2 has generated an unprecedented pandemic in modern medicine. There are no randomised controlled trials nor meta-analyses regarding clinical communication in settings of complete isolation, or in a condition of imbalance between demand and supply of healthcare resources. Thus, considering the available scientific evidence[4] and the guidelines[5–7] currently existing, mainly referring to similar settings, and all information from collegues with direct experience in the treatment of CoViD-19 patients, the authors used a modified e-Delphi method described below to draft the shared recommendations.

Creating an interdisciplinary working group

In 2 April 2020, the steering committee of the Intensiva 2.0 Project[8] (a network of 335 Italian intensive care units (ICUs), including intensivists physicians and nurses actively involved in the field of clinical communication), has been mandated by the SIAARTI National Executive Committee to develop recommendations regarding how to communicate with families of patients affected by CoViD-19 with or without acute respiratory failure, admitted in intensive or sub-ICUs in complete isolation.

Based on the new interdisciplinary approach imposed by the unprecedented working practices required by CoViD-19, the members of the Intensiva 2.0 steering committee first asked to the National Executive Committees of three other Scientific Societies above mentioned to formally include their representative members, specially selected among those most experienced in the field of communication, to form a joint task force aimed to draw up the shared recommendations and to write a position paper. The interdisciplinary working group (IWG) was then effective from 4 April 2020.

Building the experts panel

According to the e-Delphi procedure, to ensure a comprehensive argumentation, an experts panel was recruited by the IWG covering the characteristics relevant to the theme of communication in isolation and its future perspective. The specific fields of necessary expertise were identified through a PESTEL framework analysis.[9]

The six general perspectives were modifyed accordingly with the topics of main interest as follows:

- Political: how the mesures adopted by the Italian government to fighting the pandemic have affected the relationship between doctors, patients and their families?
- Economic: is there a financial burden caused by the new ways (smartphone and tablets for patients) to communicate in isolation?
- Social: what are emerging social issues (healthcare system organisation strengths and weaknesses, linguistic and/or psychological, cultural, religious issues)?
- Technological: what technological innovations could affect the subject of communication in isolation?
- Environmental: what surrounding conditions influence our subject?
- Legal: could specific aspects or changes in legislation impact the new organisation for communicating in isolation?

The experts panel, consisting of 46 members, was established as a task force from 6 April 2020. Participants were splitted in two, between lead authors and expert reviewers accordingly to personal competencies, previous experiences and actual availability. Extreme rapidity was used in creating this task force, since many physicians and other healthcare allied were asking clear indications to communicate during complete isolation, and the Italian hospitals were overwhelmed because of the pandemic peak: the four Scientific Societies required then to proceed with the utmost speed to write a shared document. The complete description of the members of the CommuniCoViD task force is presented in the online supplemental file 2.

In a web conference the task force, using the SWOT analysis,[10] identified first:

- Strengths: all factors allowing the caring teams to produce better performances in communicating in isolation with patients and their families.

- Weaknesses: the areas where the caring teams need, in contrast, to improve.
- Opportunities: the external factors that could support the caring teams to achieve the difficult goal to communicate in a way as better as possible.
- Threats: all factors that have the potential to prevent the caring teams to communicate in isolation with patients and families as effectively and efficiently as possible.

Building the queries

In relation to the outcomes deriving from the SWOT analysis, during two further web conferences, the task force identified the five fundamental aims of communication with family members. Through the related topics debated next, two general questions and five specific questions, relevant for drafting the shared statements and the checklists, were identified.

In building the modified e-Delphi process, the primary questions a priori established were devoted: (1) to find the general reasons leading the need for communication with families living in complete isolation and (2) to create the consensus statements and the checklists for daily clinical practice.

Questions about communication in general:

1. What are the goals of communication?
2. What are the special attentions to be had in time of complete isolation?

Questions leading the building of consensus statements:

1. When is it opportune to make the communication with families in complete isolation?
2. Who has to communicate with family members of isolated patients?
3. What instruments can be used for clinical communication in complete isolation?
4. What are the essential contents of the clinical communication in complete isolation?
5. How to operatively make a phone call/video call for clinical communication in complete isolation?

Figure 1 provides a comprehensive work plan summarising all the above-mentioned procedures regarding the consensus statements. A similar procedure was then adopted to build a checklist for making a telephone/video call during isolation. Lastly, a consensus evaluation was done on the contents of each statement and on a phone call checklist.

Executing the consensus on statements rounds

The statements for the communication with family members in complete isolation and the checklist for telephone call items presented here, summarize the shared answers made by the task force during the web conferences: each member explicited an agreement, by rating each statement and each phone call item, contemporarily with the other task force members (1=strong disagreement, 2=disagreement, 3=neutral, 4=agreement, 5=strong agreement). Consensus ratings for both statements and checklist for telephone call items are reported in figures 2 and 3, and are expressed as mean±SD.

At the end of the procedure, the document CommuniCoViD was approved by the National Executive Commitees of the four Scientific Societies involved, and sent to the Society members in 18 April 2020 (see in online supplemental appendix for the document full version).

RESULTS

Aims of communication and related topics

The pillars of effective communication are truthfulness, consistency and gradualness.[11] Clinical communication with families has five essential aims:

- Give understandable information about the disease and treatment options.
- Obtain information on the relatives' expectations and the patient's values and choices.
- Show empathy and participation.
- Allow relatives to express their emotions.
- Prevent misunderstandings and conflicts with the care team.

Each aim is grounded on specific consideratons, agreed by the authors, which are discussed below.

Relational aptitude

In a pandemic, establishing effective communication between healthcare professionals and patients is a difficult task because the need to use personal protective equipment (PPE) impedes recognition and limits non-verbal communication. Despite these limitations, professionals are required to play the relational role normally performed[12] by relatives, even in case of the patient's death. Talking to a relative on the phone is also complicated[13] and some family members are not able to use video call technology.[14]

Preparing for communication

In an emergency, the accessibility of information must be prioritised. Checking information comprehension has been proven to provide reassurance to relatives and staff. All team members involved in communication have to pay the utmost attention in avoiding ambiguous messages, especially since the therapeutic value of commucation is severely limited because of the lack of non-verbal components.[15] Supporting the relatives and offering honest and motivating feedback to collegues, enables healthcare professionals to pursue their care work: communication, compassion, promoting quality of life, and, where possible, healing.

Justice during a pandemic

In case of a large imbalance between demand and supply of healthcare resources,[16 17] clinical choices can be modified in accordance with ethical recommendations and local pandemic plans.[18] During communication with family members, all clinical and organisational efforts to deliver the most adequate treatments have to be underlined.

Aims of communication with family members	Topics discussed in this position paper	Statements on communication with families
A To **provide understandable information** about the disease and treatment options	A1 Relational aptitude	S1 Relatives must be given clinical information at least once a day, and more often in case of any substantial and unexpected worsening in the patient's condition.
	A2 Preparation	S2 A doctor who knows the patient directly must be the person to give the relatives clinical information.
	A3 Justice	S3 Any healthworker who feels it is too much of a burden at that specific time is not obliged to give the relatives information.
B To **obtain information** on expectations and choices	B1 Confidentiality	S4 The staff's mental and emotional wellbeing must be taken into consideration and protected.
C To show **collaboration**	C1 Health workers' wellbeing	S5 Different modes of communication can be used - such as phone, video call or email.
	C2 Internal communication	S6 Communicating by email or, in general, in writing can be useful as a complement to verbal communication.
D To **allow** relatives to express **their emotions**	D1 Grief	S7 Information must be given in an appropriate, unequivocal, truthful way.
		S8 Attempts to reconstruct the patient's preferences should be carried out together with the family.
E To **prevent misunderstandings** and conflicts with the care team	E1 Management of different tasks	S9 Relatives should be given full information about pain control.
	E2 Truth, coherence, gradualness	S10 Room should be made for relatives' emotions.
	E3 Legal aspects	

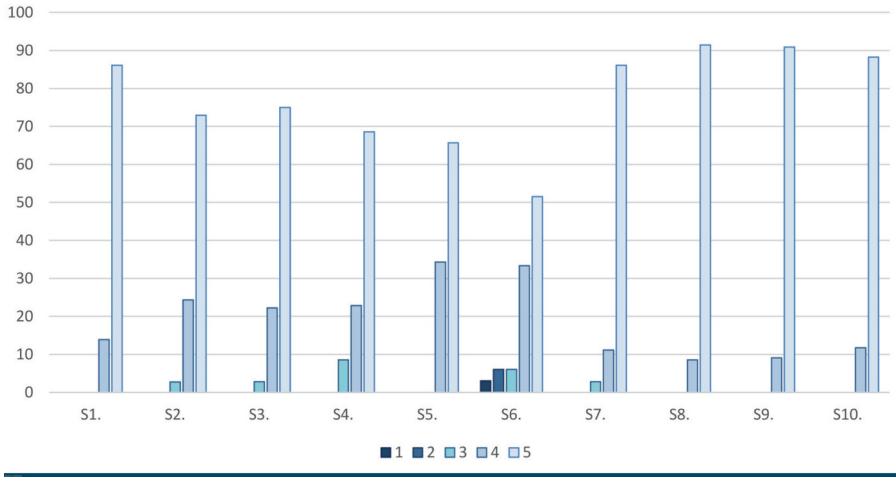
Figure 1 Synthesis of the eDelphi process results.

Confidentiality

Paying attention to professional confidentiality builds trust in the care team.[19] In isolation, visual communication by video systems is helpful to combat the inevitable lonelyness. For this reason it is preferable, when possible, to make video calls between doctors and family members, rather than a simple phone call. Video calls between patients and relatives may be encouraged.

Protecting the healthcare professionals' psychological well-being

During a pandemic, protecting healthcare professionals' psychological well-being is crucial. Insomnia, flashbacks, intrusive thoughts betray post-traumatic stress disorder. In a condition of limited resources, the best possible behaviour may not coincide with one's ethical and professional values, triggering moral distress (due to having to solve an ethical conflict). Psychologists should maintain constant contact with



Statement	Mean ± SD
S1.	4.86 ± 0.35
S2.	4.70 ± 0.52
S3.	4.72 ± 0.51
S4.	4.60 ± 0.65
S5.	4.66 ± 0.48
S6.	4.24 ± 1.03
S7.	4.83 ± 0.45
S8.	4.91 ± 0.28
S9.	4.91 ± 0.29
S10.	4.88 ± 0.33

Figure 2 Consensus ratings on statements for communicating with family members in isolation.

healthcare professionals.[20] Additionally, debriefing and defusing meetings involving all staff may be helpful.

Internal communication

In a pandemic, clinical uncertainty, PPE obstructing movement, fake news bombing, the fear of contagion, the distance from and fear for one's family reduce emotional relief. A structured chain of command is a proven support for professionals. Internal communication oriented towards therapeutic successes and reduced numbers of ICUs admissions may help to establish a positive climate among staff members.

Grief

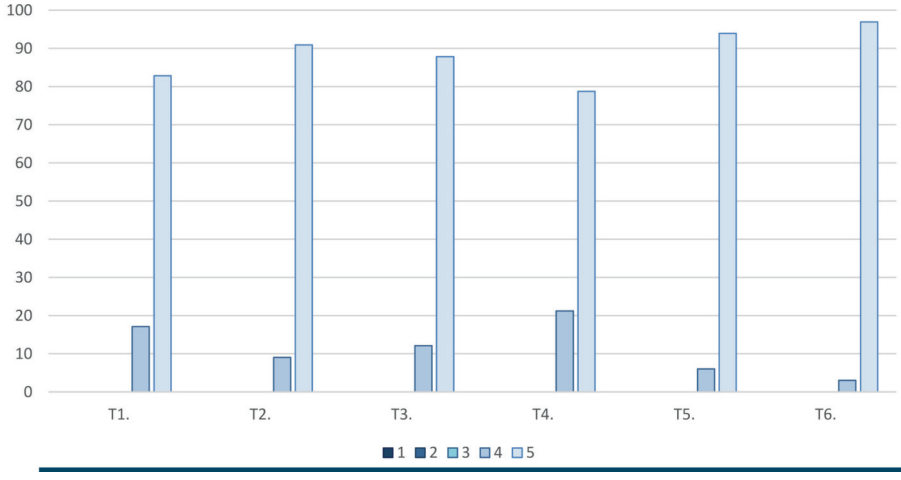
In isolation, elaboration of grief may be limited due to restrictions on funeral services.[21 22] Family members cannot visit their dying relative, but we can describe to them the final moments of their loved one's life.[23] In order to establish rapport with the family, healthcare professionals can focus on particular strategies with which they feel comfortable. Informing on the specific procedures applied after the patient's death is mandatory. Religious assistance must always be offered.

Compatibility of the different tasks

A dedicated time should be assigned to the communication as a part of care. If family information cannot take place immediately, it must be allowed as soon as possible. Frequently the same healthcare worker communicates with the family, makes decisions regarding the allocation of resources, and is responsible for clinical and organisational management. The hospital managers should help to ease the emotional burden deriving from this overload by distributing these tasks to different healthcare professionals, whenever possible.

The content of the communication

The content of the clinical information communicated should be based on respect for patient autonomy, confidentiality of the doctor–patient and family relationship, and an assessment of the family's desire and need for information. In communicating bad news, the truth must be honestly coveyed but this does not necessarily require going into great detail. Decisions to withhold or withdraw treatments must be inspired



Statement	Mean ± SD
T1.	4.83 ± 0.38
T2.	4.91 ± 0.29
T3.	4.88 ± 0.33
T4.	4.79 ± 0.42
T5.	4.94 ± 0.24
T6.	4.97 ± 0.17

Figure 3 Consensus ratings on checklist items for telephone call.

by clinical and ethical principles and communicated honestly, clearly and unequivocally.[24–27]

Communication to family members: the legal aspects

In the case of competent patients in isolation, consent to treatments and the processing of personal data is required together with the name of a family member authorised to receive medical information and choices among technological tools for communicating. If the patient can no longer communicate, it is essential that medical staff promptly collect the wishes regarding present and future treatments. If the patient is already incompetent, in the absence of their healthcare proxy or legal representative or advance directives/advance care planning (in Italy according to legislation no.219/2017),[28] communication with family members is necessary even if they cannot decide in the patient's place. If the patient is incompetent or legally unable to give their own consent, processing personal data regarding their healthcare is considered legitimate when it is necessary to protect the patient's life[29] keeping in mind the principles of necessity, proportionality and adequacy.[30]

Statements on communication with families

Through an in-depth discussion amidst authors about the content of any single topic reported above, ten statements were finally drawn up. Among them, there is an overlap between some widespread messages, already published and deeply discussed elsewhere, and some new messages, highlighted by the clinical context due to the pandemic condition. The authors decided to consider both because even the recommendations generic and not specific to CoViD-19 were considered having higher relevance in a scenario of complete isolation. The statements S1, S2, S7, S8, S9 and S10 are based on recommendation already published and not specific for CoViD-19 patients. The statements S3, S4, S5 and S6, together with the two checklists for phone and video calls, are completely new and developed in the unique CoViD-19 isolation scenario.

In any cases, all recommendations and checklists apply to all patients admitted during isolation. Until family members will be not once again allowed to return into the ICUs, and in general into the hospital wards, the present recommendations will have a great importance, both for CoViD-19 and non-CoViD-19 hospitalised patients. Over the improvement of communication, they can be relevant in supporting the maintenance of a culture of family centred care among healthcare professional, during a pandemic that undermined all aspects of patients' care.

Family members must be given clinical information at least once a day, and more often in case of any substantial and unexpected deterioration in the patient's condition

Information must be provided daily[12] via any technological tools agreed between the healthcare professionals and the relatives, based on their preferences. If a video call between relative and patient is planned, both should be prepared in advance, especially in case of other painful events in the family.

Clinical information should always be communicated to the family by the same doctor

To ensure continuity, the same doctor should be always involved in communication whenever possible. During a video call, the speaker's face should be visible. When possible another healthcare worker should be present or connected remotely. Nursing staff should be included in conversation.[31]

When possible, any healthcare professional who feels that s/he is not fit to bear the emotional burden of communicating at that time should be exempted from the task.

If a healthcare worker considers him/herself temporarily unable to make a phone call, consistently with resources, s/he should be permitted to honestly express discomfort and ask for help from available colleagues. In case of persistent difficulties, psychological support must be ensured.

Healthcare professionals' mental and emotional well-being must be taken into consideration and protected

Emotional fatigue may compromise the healthcare worker's ability to act effectively and efficiently.[32] They should, therefore, be encouraged to admit this and to tackle it with the support of team colleagues and with psychologists, both coming from hospital clinical staff or from external on-line services.

Healthcare professionals should decide with the hospital management how to organise communications with relatives

All the different communication tools may be used for communicating between doctor and family members, or between patient and families. Concerning the connected legal issues, the different communication tools should be first agreed with hospital management.

Communicating by email/text message can be useful to enable relatives to have another careful look at the patient's information at a time suitable to them.

If the patient is in an ICU, a standard introductory email from the ward[8] can be sent, followed up by personalised emails regarding the specific patient.

Communication must be unequivocal, truthful, well argued and commensurate with the recipient's ability to understand, their emotional state and life situation, with particular attention to frailty (eg, elderly family members, language barriers or mental disorders)

Speak honestly and sensitively, avoiding technical language and euphemisms. Clarify misunderstandings. Suggest hope without creating or encouraging unrealistic expectations. Evaluate the need for a cultural mediator.[33 34]

SIAARTI / Aniarti / SICP / SIMEU	**FAMILY PHONE CALL OPERATING FORM**

Patient name and surname:

Family member's name:

Family member's phone:

☐ Husband/Wife ☐ Son/Daughter ☐ Other _____

PAST MEDICAL HISTORY:

CURRENT CLINICAL SITUATION:

Call notes

Date _____

Caller:

Date _____

Caller:

Date _____

Caller:

Date _____

Caller:

Date _____

Caller:

Date _____

Caller:

Date _____

Caller:

Date _____

Caller:

Important comunications:

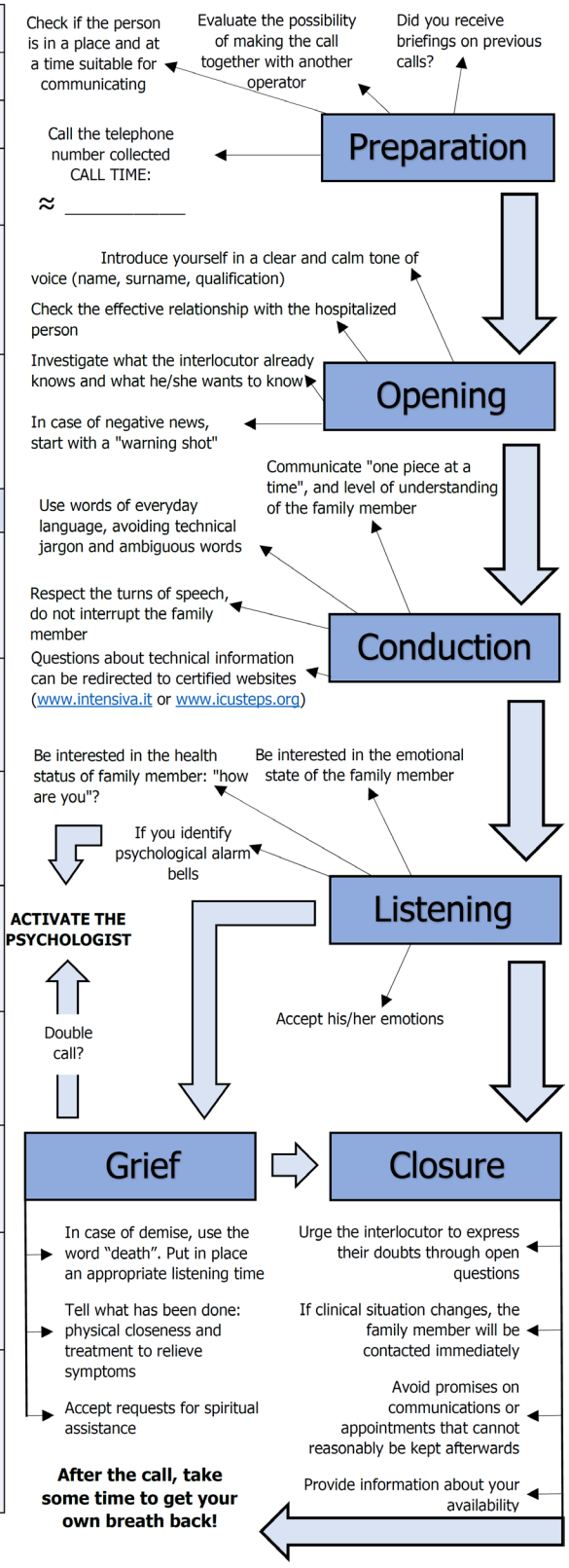


Figure 4 Family phone call operating form. SIAARTI, Italian Society of Anaesthesia and Intensive Care; Aniarti, Italian Critical Care Nurses Association; SICP, Italian Society of Palliative Care; SIMEU, Italian Society of Emergency Medicine.

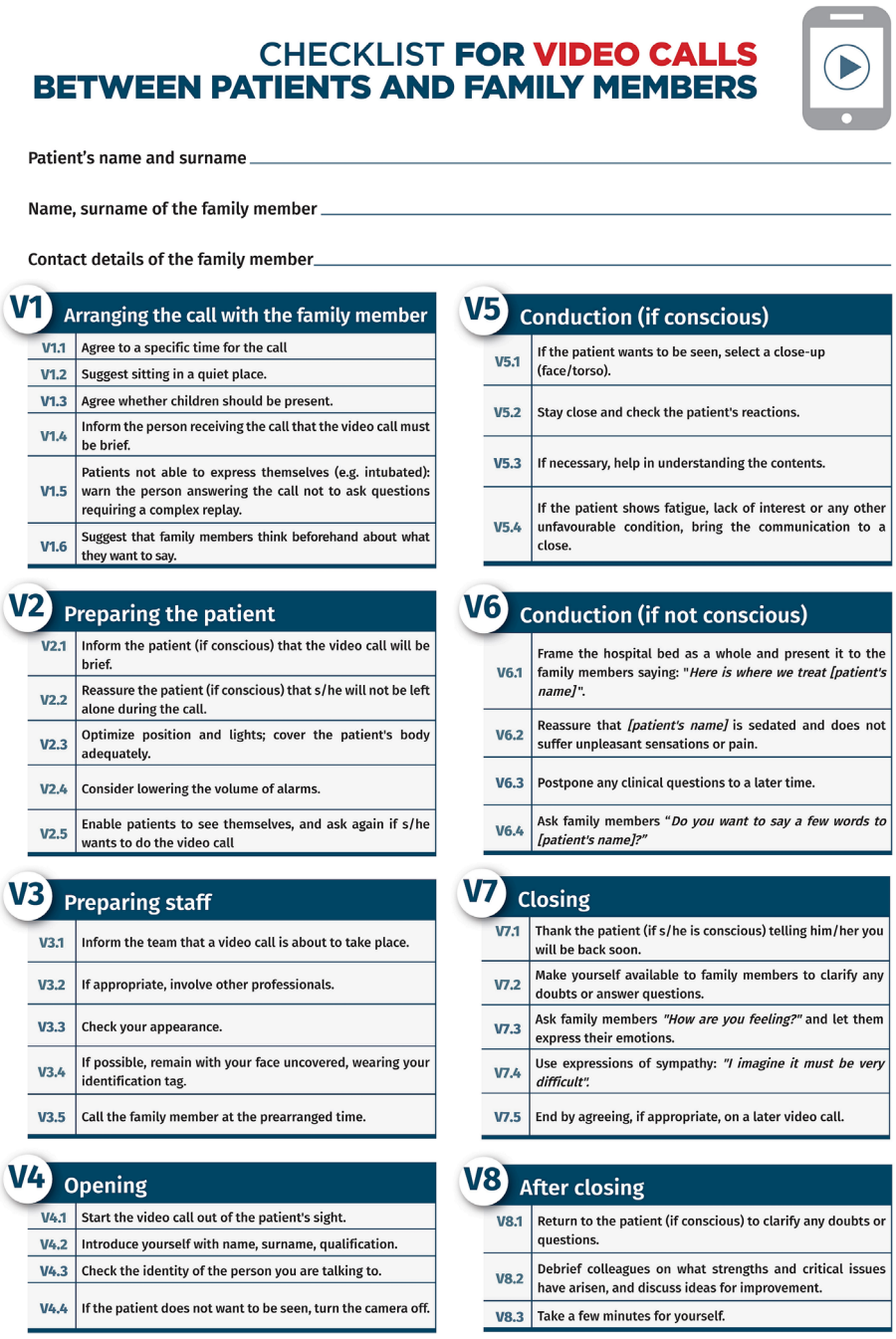


Figure 5 Checklist for video calls between patients and family members.

Reconstruct the patient's preferences and values, also through a dialogue with family members, to respect his self-determination

Respect for autonomy is essential and must always be maintained. Therefore, as far as possible, informed consent should be requested, shared care planning implemented and any advance healthcare directive respected. The preferences and values of patients should be reconstructed with family members, too.[35 36]

Give full information about pain control

It is essential to reassure the family that palliative treatment of distressing symptoms is a goal that is constantly pursued and achieved even in the most challenging stages of care.

Leave room for and welcome the relatives' emotions

If there is any very intense emotional reaction, or difficulty in adapting to the situation (denial, aggression), it is advisable to suggest support from a psychologist, and be ready to ask for it.

Checklist for phone calls to the family members

During a pandemic, the telephone is the most used and straightforward tool of communication between healthcare professionals and patient's families. However, it is relevant to note that communicating by phone in regard of a patient in isolation in an unstable or severe clinical condition is a challenging task for all: doctors, nurses and family members frequently present the previously described emotional burdens.

The authors agreed to provide a checklist based on a consensus procedure for adequately organising and successfully conducting a phone call with the family members. Thus, they have identified and discussed six topics (preparation, opening, conduction, listening, managing grief, closure) and, for each of them, five items aimed to prepare and structure the phone call.

Preparation

Healthcare professionals must know the name and surname of the patient and family member, and be aware of the patient's current clinical conditions and past medical history.

It is preferable to organise a quiet place for the call. Check all the technical equipment before calling.

If the healthcare worker who is calling needs to be changed during the week, include in the handover data on communication with family members (contact person, family resources, content, critical issues).

When possible make the call together with another healthcare worker connected remotely both for greater effectiveness and feedback.

In order to avoid anxiety-provoking expectations call the telephone number indicated at admission and at a pre-established time.

Opening

Introduce yourself in a clear and calm tone of voice (name, surname, qualification).

Ask to speak with the person identified as the contact person, referring to him by name and surname, and checking his effective relationship with the hospitalised person.

In case of potentially vulnerable family (elderly, foreigners, people with psychiatric disorders): propose to disclose clinical information to a third person at home, who can act as an intermediary.

Before starting, check if the person is in a place and at a time suitable for communicating.

Find out what the interlocutor already knows and what s/he wants to know.[37] In case of negative news, start with a *warning shot* (eg, 'I have to warn you that unfortunately I have no good news…').

Conducting the call

Communicate 'one piece at a time', gradually presenting the clinical severity in order to adapt the information to the needs and level of understanding of the family members.

Frequently assess the understanding of what has been said, also through the interlocutor's emotional reactions; when in doubt, invite them to tell you what they have understood.

Use simple, short sentences and everyday language, avoiding technical and scientific jargon and ambiguities.[38]

Pay attention to listening to whoever is answering. Do not interrupt the family member and accept interruptions without getting impatient.[39]

Questions about technical information on ICUs can be redirected to certified websites.[40]

Listening

Show interest in the emotional state of the family member. Detecting and recognising emotions as legitimate enables you to create trust and therapeutic alliance.[41]

Give the prognostic estimate honestly in response to an explicit request from the family member. It should be specified that the prognosis is merely an estimate, and may well change.

Welcome the interlocutor's emotional response (fear, sadness, anxiety, anger), both through silence and by allowing the interlocutor to cry or make verbal outbursts.[42]

Psychological alarm bells: if you notice very intense emotional reactions or fatigue in adapting to the clinical situation (negation, aggression), it is advisable to offer psychological support and make yourself available to activate it.

Be interested in the healthcare situation of family members, both psychological and physical.

Managing grief

When a patient dies, use the word 'death'. Allow for an appropriate listening time, before providing clinical/organisational indications. In the event of a critical clinical condition, replace the word 'serious' with unequivocal phrases (eg, 'need to prepare for the worst').

Welcome the emotions of the interlocutor, keeping silent and listening.[43]

In case of death, make it clear that even though the treatments were ineffective, patient care was never interrupted, both in terms of physical proximity (eg, 'your husband was isolated, but never left alone'), and in terms of treatment aimed at relieving pain or other symptoms of suffering.

Accept requests for religious assistance and facilitate their implementation.[23]

In case of death, consider whether to make two calls. In the first one, the doctor reports the death. In the second, another healthcare worker (nurse or psychologist)[44] gathers the grief, helps the person(s) process the loss in conditions of distance and isolation, verifies the

family's spontaneous psychoemotional resources and supports them.

Closure

Solicit the person to express their doubts through open questions (eg, 'is there anything else you want to know?').[45]

Offer suggestions for technological solutions for video calls, if requested.

Provide information on your availability (repeat your name and surname, department, your phone number). Specify that the next day she/he will be called again, at an agreed time, unless unexpected hospital emergencies arise.

Avoid promises of communication or appointments that cannot reasonably be kept: unfulfilled expectations break the bond of trust.

End the interview with reassurance that in the event of any major clinical changes, the family members will be promptly contacted by the healthcare professionals.

Figure 4 reports a family phone call operating form, to help physicians and allied healthcare staff in conducting a telephone call. It may also be used for handover about family communication.

Figure 5 shows a further checklist for videocalls. Since the systems to make this kind of communication are very common, but also they are particularly challenging, the care team should perform this type of communication only after adequate preparation.

Study limitations

The present Consensus Statement presents several limitations. First, it is based only on the expert opinion of the authors: even if there is a quite large body of literature on the topic of family communication, nothing has been pulished about it in the specific context of complete social isolation because of a pandemic. The consensus procedure was then built only on the authors opinion. Moreover, the statements' efficacy and usefulness have been not evauated prospectively in the real scenario, since the need for complete isolation had progressively end from May 2020. This could be an important study to do, in the unlucky case the social lockdown will become once again necessary.

Second, this Consensus Statement was prepared and written in the dramatic circustances of a pandemic peak with overcharged hospitals: a very short time was granted to the taskforce by the endorsing scientific societies, since the need for these statements were coming from healthcare professionals from all around Italy. Moreover, even if members of the expert panel were coming from 14 different Italian regions (on a total of 20), they are all Italian people, with cultural, social, legal background limiting the possibility to use the presented statements in other countries exactly as they are here presented and discussed.

Third, the physicians and nurses selected for the taskforce were all working in emergency or in critical care settings: neighter pneumolgists, epidemiologists, infectious diseases specialists, nor healthcare manager or religious authorities were involved. Furthermore, only the steering committee of four national scientific societies approved the document, without the evaluation of other scientific societies or other healthcare experts coming from other disciplines.

The presence into the taskforce of two previous ICU patients and two family members of patients admitted in ICU for CoViD-19 was very important and appreciated: they offered a very interesting interpretation of the reality, together with some useful indication to improve the communication quality.

CONCLUSION

The communication typical of the globalised world, during an overwhelming pandemic, can give way to an experience of silent solitude: the loneliness of the patient and anguished isolation of family members and of healthcare professionals within their hospitals.

A phone call, a video call, an email, a written story try to replace the physical contact that the isolation prohibits: communicating with the family allows people to create a listening space where worries, anguish of death and fears are collected for themselves and their loved ones far away, and in which they try to build trust and hope.

It is crucial to establish contact with family members. A well-conducted phone call by the doctor on the clinical conditions, in a daily communication round, becomes a tool to care for those who cannot personally see their loved one, who suffer the anxiety of not having direct information and, often, ease the sense of guilt linked to 'the feeling of abandoning his/her own loved one'.

We inform, reassure, collect tears and together we build the hope for containing and eventually overcoming a psychological trauma that will leave its marks in future years. Otherwise we end up accompanying the pain of a death without closeness and with no direct participation, but at least not loneliness.

The time dedicated to communication has to be intended as a time of care. As such, it emerges as a whole area of expertise and demands the same high level of knowledge and competence as all other areas of clinical practice. If this is true and experienced in 'normal' conditions, it is much more important in the dramatic emergency conditions spawned by the SARS-CoV-2 pandemic. The experience we witnessed during the pandemic gives us a clear indication that the time has come to include communication in the pregraduation and postgraduation curricula of our schools of medicine.

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JOINT DOCUMENT: **SIAARTI - Aniarti - SICP - SIMEU**

COMMUNICoViD
POSITION PAPER

HOW TO COMMUNICATE WITH FAMILIES LIVING IN COMPLETE ISOLATION

SIAARTI PRO VITA CONTRA DOLOREM SEMPER

aniarti associazione nazionale infermieri di area critica

SICP Società Italiana di Cure Palliative

SIMEU società italiana medicina d'emergenza-urgenza

COMMUNICoViD - Position Paper
How to communicate with families living in complete isolation - Version 01
Published on April 18, 2020

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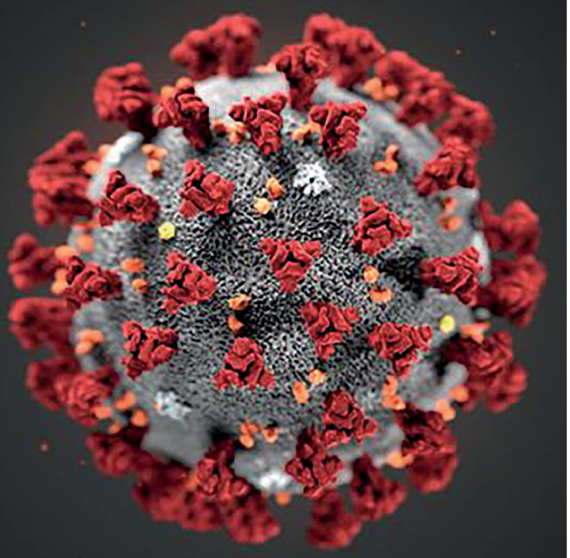

COMMUNICoViD
POSITION PAPER

HOW TO COMMUNICATE WITH FAMILIES LIVING IN COMPLETE ISOLATION

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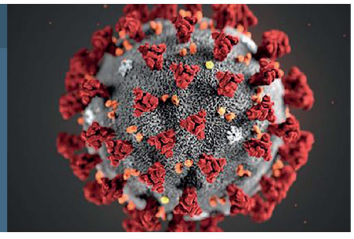
COMMUNICoViD - Position Paper
How to communicate with families living in complete isolation

Summary

List of abbreviations
SARS-CoV-2 - Severe Acute Respiratory Syndrome - Corona Virus-2
CoViD19 - Corona Virus Disease 2019
PPE - Personal Protective Equipment
SIAARTI - Società Italiana di Anestesia, Analgesia, Rianimazione e Terapia Intensiva
Aniarti - Associazione Nazionale Infermieri di Area Critica
SICP - Società Italiana di Cure Palliative
SIMEU - Società Italiana di Medicina d'Emergenza-Urgenza



1 Graphical abstract

Aims of communication with family members	Topics discussed in this position paper	Statements on communication with families
A To **provide understandable information** about the disease and treatment options	**A1** Relational aptitude	**S1** Relatives must be given clinical information at least once a day, and more often in case of any substantial and unexpected worsening in the patient's condition.
	A2 Preparation	**S2** A doctor who knows the patient directly must be the person to give the relatives clinical information.
	A3 Justice	**S3** Any healthworker who feels it is too much of a burden at that specific time is not obliged to give the relatives information.
B To **obtain information** on expectations and choices	**B1** Confidentiality	**S4** The staff's mental and emotional wellbeing must be taken into consideration and protected.
C To show **collaboration**	**C1** Health workers' wellbeing	**S5** Different modes of communication can be used - such as phone, video call or email.
	C2 Internal communication	**S6** Communicating by email or, in general, in writing can be useful as a complement to verbal communication.
D To **allow** relatives to express **their emotions**	**D1** Grief	**S7** Information must be given in an appropriate, unequivocal, truthful way.
		S8 Attempts to reconstruct the patient's preferences should be carried out together with the family.
E To **prevent misunder-standings** and conflicts with the care team	**E1** Management of different tasks	**S9** Relatives should be given full information about pain control.
	E2 Truth, coherence, gradualness	**S10** Room should be made for relatives' emotions.
	E3 Legal aspects	

COMMUNICoViD - Position Paper

How to communicate with families living in complete isolation

2 Background and aims

The peculiarities of complete isolation

The global emergency caused by the SARS-CoV-2 pandemic [1] **has suddenly changed how we communicate with families in all the CoViD19 care settings**, on account of the need to maintain complete social isolation. [2] Far-reaching **mental suffering** manifests itself in widespread anxiety. Health workers are isolated from their families, and must manage the consequences of this isolation just like the patients under their care.

Patients and their families perceive not only the clinical results but also the **personal attitudes, closeness and psychological support** from the care teams. [3] This perception of genuine participation by the health worker in the course of the treatment is especially important when a patient dies, and may influence the whole process of grief. [4]

Clinical communication with family members

The pillars of effective communication are truthfulness, consistency and gradualness.

Clinical communication has several precise aims:

A. **to give understandable information about the disease and treatment options;**

B. **to obtain information** on the relatives' expectations about the disease and the patient's values and choices;

C. to show empathy and **participation** (through non-technical language and with an attitude that is neither too detached nor excessively emotional, and is adapted on a case-by-case basis to create the best possible caring relationship with family members); [5]

D. **to allow relatives to express** their emotions;

E. **to prevent misunderstandings and conflicts** with the care team.

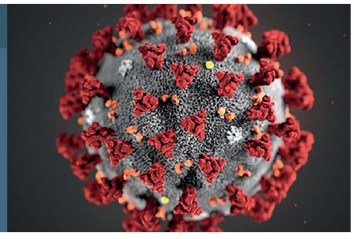
Aims of the present document

This document is intended for all healthcare institutions that handle **people with CoViD19**, particularly those in an unstable clinical condition.

This document aims to help the care team **in communicating with families living in complete isolation from the patient**.

The document consists of three parts:

- presentation of the statements for communicating with family members in isolation;
- instructions for telephone communication, with checklist and worksheet;
- discussion of key points of the current situation, as a theoretical framework for the statements.



3 Methods

The spread of the SARS-CoV-2 virus has generated an unprecedented pandemic in modern medicine. As yet there are no randomized controlled trials or any meta-analysis in the scientific literature about clinical communication in settings of complete isolation, and inadequate healthcare resources in relation to needs.

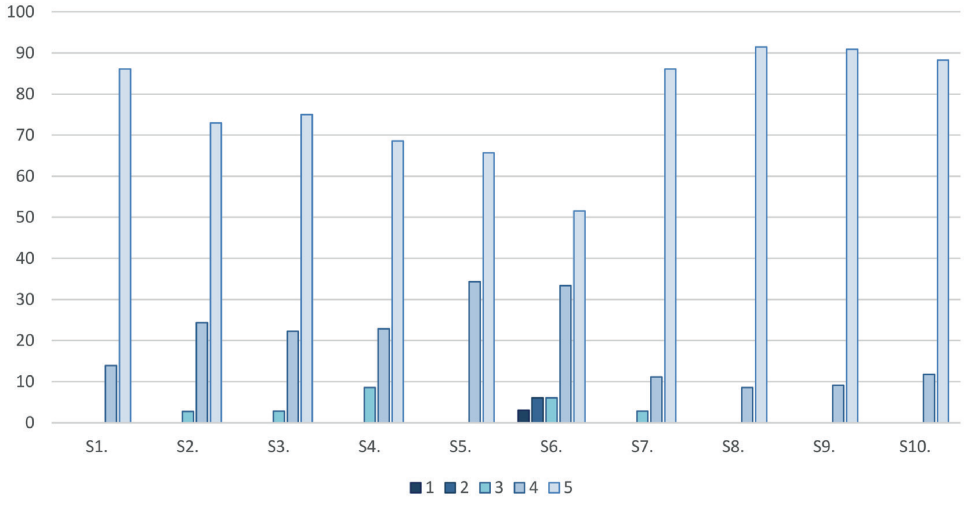
The authors took into consideration in this analysis the scientific evidence [6] and guidelines [7, 8, 9] currently existing, [10, 11] **mainly referring to other settings**, and have collected information from specialists with direct experience in the treatment of CoViD19 patients. This document was written by **authors from different disciplines** (doctors, nurses, psychologists, jurists) and was then reviewed by a group of experts comprising professionals, people who have experienced ICU hospitalization, and their families. It was approved by the National Boards of the scientific associations SIAARTI, Aniarti, SICP, and SIMEU.

The statements will be updated as the social/health situation shifts.

4 Consensus on statements

The statements set out here were written by the lead authors, reviewed by experts, and then shared in a web conference during which all the authors reached agreement. In a second web conference, all the authors rated their approval of each single statement (1 = complete disagreement, 5 = maximum agreement). Ratings are illustrated below.

PREVALENCE OF CONSENSUS ON INDIVIDUAL STATEMENTS (37 voters)



Statement	Mean ± SD
S1.	4.86 ± 0.35
S2.	4.70 ± 0.52
S3.	4.72 ± 0.51
S4.	4.60 ± 0.65
S5.	4.66 ± 0.48
S6.	4.24 ± 1.03
S7.	4.83 ± 0.45
S8.	4.91 ± 0.28
S9.	4.91 ± 0.29
S10.	4.88 ± 0.33

COMMUNICoViD - Position Paper

How to communicate with families living in complete isolation

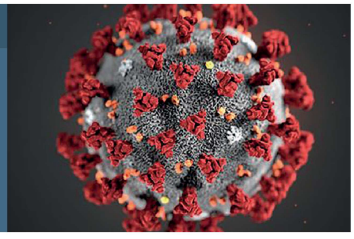
5 Statements for communication with families

S1 Family members **must be given clinical information at least once a day**, and more often in case of any substantial and unexpected deterioration in the patient's condition.
These daily communications must cover the diagnosis and prognosis.[12] Information can be provided by any means (e.g. telephone, video call or e-mail), agreed between the healthworker and relatives, based on their preferences.

S2 **A doctor who knows the patient directly** must give the clinical information to the family members, and this must be specified in the medical record.
If possible, **nursing staff** who have direct contact with the patient **should be included in the conversation**,[13] and communication should be organized so that **the same doctor is always involved**, to ensure continuity, avoid repetition and build trust. If this is not possible, in addition to the documentation in the folder it is useful to give the newly involved doctor specific information (during staff briefings).
In case of a video call, **the speaker's face should be visible** (without a mask), and if possible **another health worker should be connected** remotely or be present, by speakerphone.

S3 If resources and organizational needs permit, **any healthcare professional who feels it is too much of a burden at that specific time should be exempted from the above task.**
Communication to family members must be guaranteed. If a health worker considers him/herself temporarily unable to make a telephone call, s/he should be permitted to honestly express discomfort - without feeling obligated to participate - if resources allow or if it is possible to ask for help from colleagues. In case of persistent difficulties, the health worker should receive psycho-emotional attention in order to overcome these critical issues.

S4 Health workers' **mental and emotional balance** must be taken into consideration and protected.
Emotional fatigue due to protracted emergencies may compromise the health worker's ability to act effectively and efficiently.[14] They must therefore be encouraged to admit this and to tackle it with the support of team colleagues, and with the facility's clinical psychologists. If this is not possible, it is advisable to seek the support of external associations, specialized in psychological management of emergencies, if appropriate with professionals consulted by videoconference.



S5 **Health workers should decide with the hospital management how to organize communications with relatives.**
The different communication possibilities include phone or video calls with family members, video message/video call with the patient (if requested by patients and their families), or email/text messages (if requested by family members).
If a video call between the relative and the patient is planned, **both should be prepared for it**, especially if the patient has signs that are obvious consequences of the disease or the intensive treatment (swelling of the face, tubes, etc.) or if s/he is not aware of other traumatic events in the family during the hospital stay (e.g. bereavement). In these cases, it is advisable for the health worker to first make a preparatory call to a family member, and then a second call including the health worker, patient and family member.

S6 **Communicating by email/text message can be useful to enable relatives to read again and learn about the patient's information whenever it suits them.**
If the patient is in an Intensive Care Unit, a standard introductory email from the ward (provided by the Project Intensiva 2.0) [15] can be sent to start with, followed up with personalized emails regarding the specific case.

S7 **Health communication must be unequivocal, truthful, reasoned,** and appropriate to the recipient's ability to understand, their emotional state and life situation, with particular attention to frailty (e.g. elderly family members, language barriers or mental disorders). [16]
Speak honestly and sensitively, **avoiding technical language and euphemisms.** Clarify misunderstandings. Suggest hope by not creating or encouraging unrealistic expectations. Evaluate the need for a cultural mediator. [17]

S8 **Reconstruct the patient's preferences and values** - also through communications with family members - **so as to respect their autonomy.** [18]
Respect for autonomy is essential and must always be maintained. Therefore, as far as possible, informed consent should be requested, Shared Care Planning implemented and any Advance Healthcare Directive respected. The preferences and values of patients should be reconstructed with family members, too. [19]

S9 **Give full information about pain control.**
It is essential to reassure the family that palliative treatment of distressing symptoms is a goal that is constantly pursued and achieved even in the most difficult stages of care. [9]

S10 **Leave room for and welcome the relatives' emotions.**
If there is any noticeable, very intense emotional reaction, or difficulty in adapting to the situation (denial, aggression), it is advisable to suggest support from a psychologist, and be ready to ask for it.

COMMUNICoViD - Position Paper
How to communicate with families living in complete isolation

6 Checklist for phone calls to family members

T1. Preparation

T1.1 Health workers should **know the name and surname of the patient** and family member, and be aware of the patient's current **clinical conditions**, **past medical history**, resources and conditions of particular fragility.

T1.2 It is preferable to **organize a suitable quiet place**, even if not optimal, for the call. Check the technical equipment (e.g. cordless/mobile phone battery, video call platform, and connection, audio and video function...).

T1.3 If the health worker who is calling needs to be changed during the week, **include in the handover data on communication** with family members (contact person, family resources, content, critical issues).

T1.4 Evaluate the possibility of **making the call together with another health worker** (connected remotely or hands-free), both for greater effectiveness and for feedback.

T1.5 Call the telephone **number indicated at admission and at a pre-established time** (in order to avoid anxiety-provoking expectations).

T2. Opening

T2.1 **Introduce yourself in a clear and calm tone of voice (name, surname, qualification).**

T2.2 Ask to speak with the person identified as the contact person, referring to them by name and surname, and **checking their actual relationship with the hospitalized person.**

T2.3 In case of vulnerable family members (elderly, foreigners, people with psychiatric disorders): **propose to disclose clinical information to a third person at home**, who can act as an intermediary for the vulnerable family members.

T2.4 Before starting the interview, check if the person is **in a place and at a time suitable** for communicating.

T2.5 **Find out what the interlocutor already knows** and what s/he wants to know.[20] In case of negative news, start with a "**warning shot**" (e.g. *"I have to warn you that unfortunately I have no good news ..."*).

T3. Conduction

T3.1 **Communicate "one piece at a time"**, gradually presenting the clinical severity in order to adapt the information to the needs and level of understanding of the family members.

T3.2 **Frequently assess the understanding of what has been said**, also through the interlocutor's emotional reactions; when in doubt, invite them to tell you what they have understood.

T3.3 **Use everyday language**, avoiding technical and scientific jargon and ambiguous words or euphemisms.[21] Speak directly, **using simple, short sentences**, avoid being vague or too harsh.

T3.4 Pay the utmost attention **to listening to whoever is answering** - better a second of silence than two people talking at once. **Do not interrupt the family member** and accept interruptions without getting impatient: the health workers are the professionals![22]

T3.5 Questions about technical information on intensive care units can be redirected to **certified websites** (e.g. www.intensiva.it or www.icusteps.org).[23]

T4. Listening

T4.1 Take interest in the **emotional state of the family member. Detecting and recognizing emotions** as legitimate enables you to create trust and therapeutic alliance. [24]

T4.2 **Give the prognostic estimate honestly** in response to an explicit request from the family member. (e.g. *"How long will s/he stay?", "When will it happen?"*). It should be specified that the prognosis forecast by the team is merely an estimate, and may well change.

T4.3 **Welcome the interlocutor's emotional response** (fear, sadness, anxiety, anger), both through silence and by allowing the interlocutor to cry or make verbal outbursts. [25]

T4.4 **Psychological alarm bells**: if you notice very intense emotional reactions or fatigue in adapting to the clinical situation (negation, aggression), it is advisable to offer psychological support and make yourself available to activate it.

T4.5 Be interested in **the health situation of family members** (e.g. *"how are you?"*), both psychological and physical (e.g. *"Can you sleep at night? Do you have respiratory symptoms? Are you alone or with someone?"*).

T5. Managing grief

T5.1 **When a patient dies, use the word "death". Allow for an appropriate listening time**, before providing clinical/organizational indications. In the event of **extreme clinical severity**, replace the word *"serious"* with **unequivocal phrases** such as *"desperate condition", "high risk of death", "need to prepare for the worst".*

T5.2 Welcome the emotions of the interlocutor, **making good use of silence**. [26]

T5.3 In case of death, make it clear that even though the treatments were ineffective, **patient care was never interrupted**, both in terms of **physical proximity** (e.g. *"your husband was isolated, but never left alone"*), and in terms of treatment **aimed at relieving pain or other symptoms of suffering** (e.g. *"we can guarantee you that your father did not suffer"*). [9]

T5.4 **Accept requests for religious assistance** and facilitate their implementation, if possible. [27]

T5.5 In case of death, **consider whether to make two calls**. In the first one, the doctor reports the death. In the second, another healthworker (nurse or psychologist) [28] gathers the grief, helps the person(s) process of the loss in conditions of distance and isolation, verifies the family's spontaneous psycho-emotional resources and supports them.

T6. Closure

T6.1 **Urge the person answering the phone to express their doubts through open questions** (e.g. *"is there anything else you want to know?"* Or *"do you want to tell me more?"*). Answer questions **sincerely**, honestly stating what we know and what we don't from a scientific point of view. [29]

T6.2 **Offer suggestions for operative solutions** for video calls, if requested.

T6.3 **Provide information on your availability** (repeat your name and surname, department from which you are calling, number at which you can be called). Specify that the **next day s/he will be called again, at an agreed time**, **unless unexpected** hospital emergencies arise.

T6.4 **Avoid promises on communications or appointments** that cannot reasonably be kept: **unfulfilled expectations** break the bond of trust.

T6.5 End the interviews with reassurance that in the event of any **major clinical changes**, the family members will be **promptly contacted** by the health workers.

After a call it is a good idea to take a few minutes to restore your own calm, perhaps sharing the emotion of what happened with your colleagues, if this compatible with your work schedule.

There are on-line courses for 'remote learning' on the complicated issue of informing relatives of the death of a loved one. For example:
https://www.simeu.it/w/articoli/leggiArticolo/4020/leggi

Other on-line courses in English are available, free, for instance at "Center to Advance Palliative Care"
https://www.capc.org/toolkits/covid-19-response-resources/

7 Operating tools for telephone and video calls

The following pages give:

- a single-sheet checklist, to be hung on the bulletin board or where you call;
- an "operational card" for the schedules of calls for the next 7 days;
- a checklist for video calls.

Video calls with conscious, oriented and collaborating patients:
Suggest they see their family in a video call.
If they agree, ask whether they want their family to see them.

Video calls with unconscious patients:
Request from family members to see their relative.
If deemed feasible in the light of local conditions, first recommend a visit to a certified website (if the patient is in intensive care) to familiarize themselves with the ICU environment: www.intensiva.it or www.icusteps.org.

Video calling is not recommended for patients who are conscious but uncooperative.

It is better to use the communication platform with which you are most confident.

It is preferable to make video calls rather than sending photos or videos (in view of the risk of their not promptly reaching the person concerned, and they could be forwarded to third parties).

CHECKLIST FOR PHONE CALLS

T1 Preparation

T1.1	Do you know their full names (patient and family member), medical history, current clinical situation?
T1.2	Are you in the best possible place? Can you find somewhere quieter?
T1.3	Have you had briefings on previous calls?
T1.4	Is there another colleague you can involve in the call?
T1.5	Call the family member at the prearranged time.

T2 Opening

T2.1	Introduce yourself with name, surname, qualification.
T2.2	Check who you are talking to and their relationship with the patient.
T2.3	If family members are "vulnerable": is it possible to involve someone else?
T2.4	Check whether it is the right time for the family member.
T2.5	What do you already know? What do you want to know? Think if a "warning shot" is necessary.

T3 Making the call

T3.1	Communicate "one piece at a time" and check what has been understood.
T3.2	Use everyday words and simple, short sentences.
T3.3	Avoid technicalities and euphemisms. Avoid being vague or too brutally direct.
T3.4	Allow people to speak in turn - do not interrupt the family member.
T3.5	For more detailed information, refer to certified sites (www.intensiva.it, www.icusteps.org).

T4 Listening

T4.1	Acknowledge the emotional state of the person receiving the call.
T4.2	If requested, honestly communicate the estimated prognosis.
T4.3	Accept his/her emotions!
T4.4	Are there alarm bells? Does s/he need a psychologist for further calls?
T4.5	Show interest in the health of family members: "How are you"?

T5 Grief

T5.1	When the patient dies, use the word “death” or “died”. Then wait a moment.
T5.2	Leave room for the listener’s emotions, making good use of silence.
T5.3	Explain that patient care was never interrupted, particularly in avoiding pain and suffering.
T5.4	Accept requests for religious assistance.
T5.5	When a patient dies, consider whether two calls are appropriate.

T6 Closure

T6.1	Solicit the expression of doubts through open questions.
T6.2	Offer, if required, suggestions for video calls.
T6.3	Let them know where you can be reached, and tell them someone will call the next day.
T6.4	Avoid promises you cannot keep, so as to main the relatives’ trust.
T6.5	If the clinical situation changes, assure the relatives that they will be contacted immediately.

After the call, take some time to get your own breath back!

FAMILY PHONE CALL FORM

Patient name and surname: _____

Family member's name: _____

Family member's phone: _____

☐ Husband / Wife ☐ Son / Daughter ☐ Other _____

PAST MEDICAL HISTORY:

CURRENT CLINICAL SITUATION:

CALL NOTES:

Date:

Caller:

Date:

Caller:

Date:

Caller:

Date:

Caller:

Date:

Caller:

Date:

Caller:

Date:

Caller:

IMPORTANT COMUNICATIONS:

1 PREPARATION
- CHECK THAT THE PERSON IS IN A PLACE AND AT A TIME SUITABLE FOR COMMUNICATING
- EVALUATE THE POSSIBILITY OF MACKING THE CALL TOGETHER WITH A NURSE
- DID YOU RECEIVE REPORTS ON PREVIOUS CALLS?
- CALL THE TELEPHONE NUMBER AT A PRE-ESTABLISHED TIME _____

2 OPENING
- INTRODUCE YOURSELF IN A CLEAR AND CALM TONE OF VOICE (NAME, SURNAME, QUALIFICATION)
- CHECK THE ACTUAL RELATIONSHIP WITH THE HOSPITALIZED PERSON
- INVESTIGATE WHAT THE INTERLOCUTOR ALREADY KNOWS AND WHAT S/HE WANTS TO KNOW
- IN CASE OF NEGATIVE NEWS, START WITH A "WARNING SHOT"

3 CONDUCTION
- COMUNICATE "ONE PIECE AT A TIME", AND CHECK THE LEVEL OF UNDERSTANDING
- USE EVERYDAY LANGUAGE, AVOIDING TECHNICAL JARGON, AMBIGUOUS WORDS AND EUPHEMISMS
- RESPECT THE ORDER OF SPEAKING, DO NOT INTERRUPT THE RELATIVE
- QUESTIONS ABOUT TECHNICAL INFORMATION CAN BE REDIRECTED TO CERTIFIED WEBSITES **(WWW.INTENSIVA.IT** OR **WWW.ICUSTEPS.ORG)**

4 LISTENING
- ACKNOWLEDGE HIS/HER EMOTIONAL STATUS
- IF REQUESTED, HONESTLY COMMUNICATE THE ESTIMATED PROGNOSIS
- ACCEPT HIS/HER EMOTIONS
- IF YOU IDENTIFY PSYCHOLOGICAL ALARM BELLS

ACTIVATE THE PSYCHOLOGIST

DOUBLE CALL?

5 GRIEF
- IF THE PATIENT DIES, USE THE WORD "DEATH", ALLOW TIME TO LISTEN TO THE RESPONSE.
- TELL THEM WHAT WAS DONE: ENSURE PHYSICAL CLOSENESS AND RELIEVE SYMPTOMS
- ACCEPT REQUESTS FOR SPIRITUAL ASSISTANCE

6 CLOSURE
- URGE THE RELATIVE TO EXPRESS ANY DOUBTS IN CLEAR OPEN QUESTIONS
- IF CLINICAL SITUATION CHANGES, THE FAMILY MEMBER WILL BE CONTACTED IMMEDIATELY
- AVOID MAKING PROMISES ABOUT COMMUNICATIONS OR APPOINTMENTS AFTERWARDS THAT CANNOT BE KEPT
- PROVIDE YOUR CONTACT DETAILS

AFTER THE CALL, TAKE SOME TIME TO GET YOUR OWN BREATH BACK!

CHECKLIST FOR VIDEO CALLS BETWEEN PATIENTS AND FAMILY MEMBERS

Patient's name and surname _____

Name, surname of the family member _____

Contact details of the family member _____

V1 Arranging the call with the family member

V1.1	Agree to a specific time for the call
V1.2	Suggest sitting in a quiet place.
V1.3	Agree whether children should be present.
V1.4	Inform the person receiving the call that the video call must be brief.
V1.5	Patients not able to express themselves (e.g. intubated): warn the person answering the call not to ask questions requiring a complex replay.
V1.6	Suggest that family members think beforehand about what they want to say.

V2 Preparing the patient

V2.1	Inform the patient (if conscious) that the video call will be brief.
V2.2	Reassure the patient (if conscious) that s/he will not be left alone during the call.
V2.3	Optimize position and lights; cover the patient's body adequately.
V2.4	Consider lowering the volume of alarms.
V2.5	Enable patients to see themselves, and ask again if s/he wants to do the video call

V3 Preparing staff

V3.1	Inform the team that a video call is about to take place.
V3.2	If appropriate, involve other professionals.
V3.3	Check your appearance.
V3.4	If possible, remain with your face uncovered, wearing your identification tag.
V3.5	Call the family member at the prearranged time.

V4 Opening

V4.1	Start the video call out of the patient's sight.
V4.2	Introduce yourself with name, surname, qualification.
V4.3	Check the identity of the person you are talking to.
V4.4	If the patient does not want to be seen, turn the camera off.

V5 Conduction (if conscious)

V5.1	If the patient wants to be seen, select a close-up (face/torso).
V5.2	Stay close and check the patient's reactions.
V5.3	If necessary, help in understanding the contents.
V5.4	If the patient shows fatigue, lack of interest or any other unfavourable condition, bring the communication to a close.

V6 Conduction (if not conscious)

V6.1	Frame the hospital bed as a whole and present it to the family members saying: "*Here is where we treat [patient's name]*".
V6.2	Reassure that *[patient's name]* is sedated and does not suffer unpleasant sensations or pain.
V6.3	Postpone any clinical questions to a later time.
V6.4	Ask family members "*Do you want to say a few words to [patient's name]?*"

V7 Closing

V7.1	Thank the patient (if s/he is conscious) telling him/her you will be back soon.
V7.2	Make yourself available to family members to clarify any doubts or answer questions.
V7.3	Ask family members *"How are you feeling?"* and let them express their emotions.
V7.4	Use expressions of sympathy: *"I imagine it must be very difficult".*
V7.5	End by agreeing, if appropriate, on a later video call.

V8 After closing

V8.1	Return to the patient (if conscious) to clarify any doubts or questions.
V8.2	Debrief colleagues on what strengths and critical issues have arisen, and discuss ideas for improvement.
V8.3	Take a few minutes for yourself.

9 Discussion

A1 Relational aptitude

In this pandemic, where isolation is necessary, **the relational and human dimension,** always fundamental in any treatment situation, becomes even more important. Establishing and maintaining effective verbal communication between healthcare staff and patients is harder than usual, partly because of the unstable clinical picture but also because of the need to use personal protective equipment (PPE) that makes it difficult to recognize people. At the same time good communication is essential, because the patient in a CoViD19 care setting can interact in person only with the staff.

Besides verbal communication, non-verbal interaction also takes on special meaning. Despite the limitations of PPE that make the health workers unrecognizable, with no detectable facial expressions, **they are required to play the relational role normally held by relatives and friends** and are the only people who can stay close to the patient even at the moment of death.

Talking to a family member on the phone is also complicated,[30] because one must provide clinical information about unexpected or even dramatic situations **in the absence of a face-to-face therapeutic relationship**. Family members themselves experience a sensation of isolation, as they are not backed by their local social network and many are not able to use computerized means of communication independently. Now as ever, it is clear that **treatment is always a 'relational' matter - even in emergency settings.**[31]

A2 Preparing the communication

Good communication **reduces stress for the healthcare professional, the patient and family members.** In an emergency, priority must be given **to the accessibility of information** and the clarity of the messages that guarantee the patient's care is a priority. Checking that this has all been understood provides reassurance for relatives and staff.

The ordinary procedures of clinical communication are inevitably distorted by the workload and limited time available to all involved. **It is important that communications with family members follow unambiguous schedules and methods shared by the whole team.** Family members must be guaranteed an appropriate time for communication in a situation where, in view of the characteristics of the emergency setting, its non-verbal components and its therapeutic value are unfortunately severely limited.

Nonetheless, there is still room for us **to improve how we communicate** disease, suffering and death, regardless of the circumstances.[32] To achieve this, all available professionals must be engaged synergistically. **They can each encourage, correct and support** their colleagues, offering honest and motivating feedback, sometimes via telephone or video calls. This helps preserve the mental health of the health workers, enabling them at the same time to pursue their care work: communication, compassion, quality of life and, where possible, healing.

A3 Justice during a pandemic

The four general ethical principles that guide every clinical decision (**autonomy, beneficence, non-maleficence, justice**)[33] remain valid even in the face of a massive influx of seriously ill people into the hospital. In extreme cases where the care pathways (particularly intensive and palliative treatments) are affected by the enormous disproportion between need and limited resources,[34] clinical choices can be modified according to the conditions in which you have to make decisions.[35] When communicating with family members, pay close attention to **describing all the efforts made**, clinical and organizational, to try to overcome the difficulties imposed by the tragedy of the situation and to deliver **adequate treatments in every case**. Unfortunately, all too often scarce human resources are likely to limit the possibility of good communication.

B1 Confidentiality

Confidentiality signifies attention to professional secrecy and the relationship of **mutual trust that unites the healthcare professional and the patient** in the course of caring. [36] The team is required to know and respect the values and choices of the hospitalized person, acting in this situation as their **custodian**.

Doctors and nurses are witnesses - with a frequency never experienced before - both of the **fragility of human beings**, in their illness and unfortunately in their deaths, and the emotional suffering of their families. **This important role can be extremely demanding from an emotional point of view, for the whole care team.**

In the setting of isolation, the **visual communication** made possible by video systems is of enormous benefit to combat the inevitable feeling that loved ones have vanished, or are cared for by faceless strangers: for this reason it is preferable, when technically possible, to make video calls between doctors and family members, rather than a simple phone call. In addition, if those who are in hospital want it, and compatibly with their family situations, it is good to encourage video calls between patients and their families too.

C1 Protecting the healthcare workers' psychological well-being

In an emergency, **self-awareness of one's resources but also of one's limits and one's emotional state is fundamental**, in order to promptly take measures to protect one's own psychological balance. The heavy workloads and emotional stress mean that it is common to suffer insomnia, flashbacks, intrusive thoughts. In addition, the objective risk of viral contamination exposes one to the risk of **post-traumatic stress** symptoms related to concern for one's own physical safety.

With today's limited resources, it may happen that the best possible behavior is not aligned with one's ethical and professional values, and this can lead to **moral distress** (inevitably having to do something that one considers morally questionable or inappropriate).

In these situations, as never before, **it is useful to get in touch with your colleagues**, reference people or psychologists. [37] When possible, *debriefing* meetings are useful at the end of the shift, or *defusing* occasions involving all staff. In this way it is possible to build a common understanding of how best to communicate with patients and their families, and thus manage particularly stressful situations more effectively.

Good communication enables you to maintain a **sense of effectiveness**, to build trusting relationships with family members, and avoid further suffering.

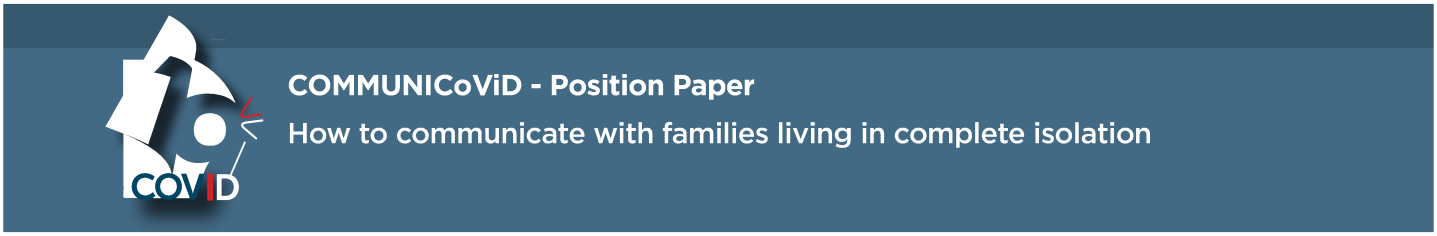
C2 Internal communication

The present extraordinary emergency leads professionals to operate in conditions of **stressful overwork**. Clinical uncertainty, impediment of movement by PPE, collaboration with new colleagues, media bombardment of often inflated and unfounded news, the sense of helplessness, fear of contagion, the distance from and fear for one's family aggravate the already scarce spaces for emotional decompression.

The clarity of orders in a solid and organized chain of command are proven elements of support for professionals. The forms of internal communication that quantify therapeutic successes, transfers to less intensive care units, and **information related to good news** are strong motivators for all staff and help establish a positive climate.

D1 Grief

Experiencing grief when the patient is in isolation is traumatic. [38] The proximity of the family and the funeral rituals normally help one cope with the loss and facilitate the process of grief. In a time of isolation this is all lacking, and poses a risk for the development of elaborate grief. [39]



The chance to see a loved one who died is essential for natural grief; it is an objective to be pursued[27] in line with official directives, structural limits and legal obligations. Even if in today's situation family members cannot visit their relative just before death, we can at least do something so that the story of the loss of that person can begin to be told.
In order to prepare for communication with the family of a patient who died alone, health workers can focus on their own emotional regulation, on the preparation of particular communication strategies that feel suitable for themselves, and on emotional recovery.

After the doctor has informed the family about the death, **a second call** can be made (by nurses or psychologists) to acknowledge the grief, help processing the loss in conditions of distance and isolation, and verify and support the family's spontaneous mental and emotional resources.

If religious assistance is available, one can ask family members if they want the blessing of the body, partly to give them the opportunity for decision-making in a situation of powerlessness and isolation. This small but significant gesture can meet **a family's need to feel they can part from their loved one with dignity**, and to know that health workers took care of him/her in the best possible way.

Returning the body and its belongings is an important stage of bereavement but, in a pandemic it cannot always be organized, for sanitary reasons. **Information on what happens after** the patient's death and the procedure applied in each hospital can partially replace the support offered in a normal situation. Prompt information about returning personal belongings, or procedures for managing the body, and the probable timing for its return to the family, can prevent behaviors arising from psychological distress, sometimes accompanied by reprisal moves.

E1 Compatibility of the different tasks

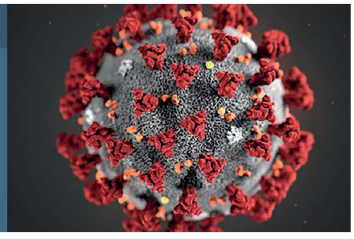
Since communication time is part of treatment time, this task must be explicitly assigned a suitable slot. If it is not possible to entrust this task to any single person, it is advisable to integrate the activities carried out in three areas: allocation of resources, management of therapy, and communication to relatives, through **work organization that allows them to be carried out as far as possible at different times.**

Inevitably cases will arise in which these tasks can only be carried out by the same person, but this must provide the possibility of lightening the emotional weight of the allocation of resources from that of clinical and organizational management, and from that of communication to family. To be sustainable over time, these tasks tend to be separated, to maintain the high quality of their performance and to defend the psychological and moral balance of the healthcare operators.

The aggressiveness of family members, while understandable and foreseeable, can create discomfort and disorientate health care, already strained by clinical fatigue and difficulties. One must keep in mind that family anger is often a response to the situation, not towards the person bearing the news. Recognizing the efforts of family members can be useful, especially by naming other underlying emotions (e.g. "I feel s/he is amazed, disappointed, incredulous, ..."). In any case, one must be ready to identify it early and ignore threatening and useless comments, preventing any escalation of aggression. After having accepted the fatigue of others and using firm courtesy, without responding to sterile criticism or verbal aggression, attention has to return to the salient aspects of the conversation, and to the news that must be transmitted.

E2 The content of the communication

The content of communication has to be managed in relation to the care relationship, with responsibility, benevolence and reassurance. After establishing a relationship with the reference family member, **the content of the clinical information is decided in full respect of the autonomy, confidentiality and secrecy of the care relationship** (emotional, psychological, practical aspects) and the dignity of the patient.[40] The treating communicator selects the most important clinical information and presents it within the time allowed by the circumstances, taking responsibility for deciding how much of the situation to describe and in what timeframe to share health information, depending on the family member's situation. **Omissions in communication should ideally be avoided**, but it is also appropriate to assess the family's desire and need for information from time to time.



In communicating bad news to patients, one must also focus on the "how" and "when". **Honestly offering a presentation of the truth** does not mean it is necessary to go into great detail and unless this is explicitly requested it may not be deemed necessary, or there may be good reasons to postpone full communication.

Even in a situation like this pandemic, **decisions to limit or discontinue disproportionate treatments must be inspired by the approach and clinical and ethical principles** recommended in various official documents, and must be communicated honestly, clearly and unequivocally.[41, 42, 43] It is always advisable to investigate and respect the patient's wishes, and communication with family members also has the important purpose of acquiring information on the patient's expected wishes and preferences regarding treatments.[44]

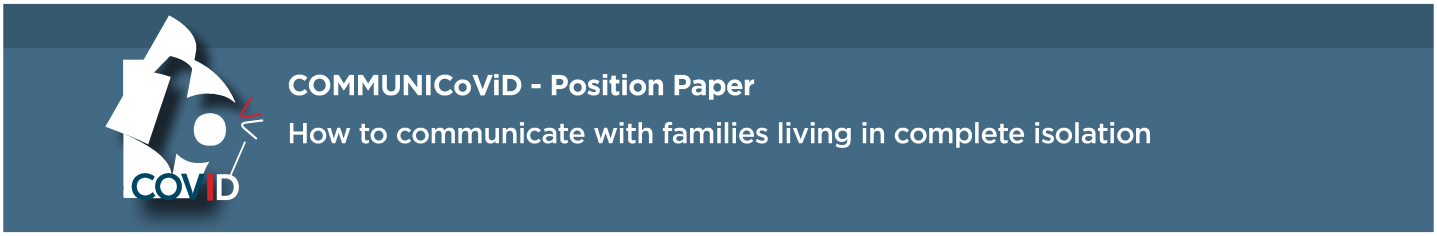
The final decision on the clinical appropriateness of the therapies is, however, always made by the care team.[45] The need to make clinically appropriate and ethically legitimate choices should be explained to family members. It is important to make it clear **that relatives have no decision-making responsibilities and therefore should not feel guilty about the choices.**[46]
The content of communications with patients and their family members must be briefly reported in the medical record and presented to colleagues during the handover, so as to share the communication strategy between colleagues, and to ensure consistent messages.[47]

E3 Communication to family members: the legal point of view

Even in an emergency situation, when the patient is capable **consent for processing personal data is always required**, together with the indication of a family member authorized to receive medical information and the methods for communicating that information. If the patient can no longer communicate with the medical staff, his/her wishes must be respected. Examining the clinical histories of patients with CoViD-19, in most cases they enjoy a long time during which they are able to communicate, understand and decide. Therefore, it is important that **the medical staff promptly collect the wishes regarding present and future treatments from all patients**, together with their contacts' phone numbers, and the names of persons of trust, and that they organize themselves according to their means of communication. These may change depending on how the situation develops.

If the patient is already incompetent, in the absence of their trustee (in Italy according to legislation no.219/2017)[48] or a legal representative (e.g. parents for minors, legal guardian, support administrator previously nominated for a person who is partially or totally non-autonomous) **communications with family members are necessary even when it is not possible to obtain consent from the patient.** It is important to try and identify the appropriate contact person. When patients find themselves physically incapable or legally unable to give their own consent, processing personal data regarding their health is considered legitimate **if it is necessary to protect the patient's or another person's life** - even more so for public health reasons (see reg. EU, no. 679/2016, art. 9). The most appropriate form of communication must be decided on a case-by-case basis, keeping in mind the principles of **necessity, proportionality and adequacy** and - depending on the emergency situation - trying to limit any possible risks linked to the data processing. One must be careful to act according to the principles set out in art 5, reg. EU 679/2016 and to agree about the modalities with the coordinator of the facility and the data protection officer.

It is useful to recommend that **it is in the patient's interest to involve family members**; it allows their medical history, life history and values to be traced. The patient is not alone and future home care can be arranged in the best possible way, with caregivers aware of the clinical course. **The inclusion of a relative is also in their own interest**: communication with the medical staff establishes a relationship with their loved ones and permits the best possible health care. From a physical point of view, correct, accurate and reassuring communication reduces the family's stress response and allows the use of the best therapeutic and preventive measures to limit the spread of the virus and its clinical consequences for people who have been contaminated. From the psychological and social points of view, there is no doubt that communication about the clinical course of a loved one plays an important role **in reducing the psychological anguish of the family**.



10 Legal considerations

As far as the law is concerned, when it comes to communication with the patient's family members of trust, it is important in Italy to recall **legislation no. 219/2017** (with regard to informed consent and prior instructions regarding treatment). This legislation is based on a **judicial, ethical and cultural understanding** that considers the treatment on a personal level and lays stress on **doctor-patient communication** during the treatment itself.

According to this legislation, communicative and relational skills are complemented by technical expertise, and involve the organizational aspects of the healthcare facilities called upon to ensure its implementation. Implementing the tools to guarantee **correct communication** also enhances the **consistency and quality of the therapeutic and caregiving process**, restores the therapeutic alliance, generates faith in the national healthcare system, and prevents errors.

In legislation it is also important to bear in mind that the **therapeutic relationship takes on a multi-subjective dimension**, engaging all the healthcare workers who are part of the team and, if the **patient wishes, family members** (the spouse or life partner, or the person of trust), who are authorized to receive information about the patient's health and to **express consent regarding the treatment on his/her behalf**.

Especially in an emergency, both the disease and the treatment concern not only the patient but also their loved ones. Fundamentally it is the patient who specifies the people they do or do not want to involve in their own treatment. However, communication may still be necessary to protect their family members' wellbeing as well as public health. In cases where there is no indication from the patient, **the law does not specify criteria to identify the family members of trust.**

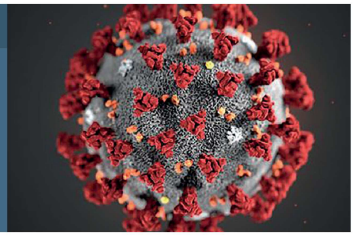
It may be useful here to recall some criteria from a particular regulatory source (article 3, page 2, paragraph 91/1999 in the matter of organ and tissue removals and transplants; article 408, page 1,...). These criteria are intended to be approximate, non-hierarchical and flexible. The primary point of consideration for selecting the person to whom the information is given **is always the patient's best interests**. In addition, moral solidarity, rights and duties which drive family relationships and have their own constitutional recognition (arts 2,29,30 of the Italian Constitution), stand out.

In the exceptional context of a health emergency and total isolation of the patients (often from their close family too) - also involving extreme psychological stress - **any omissions or impairment on a communicative or relationship level can have important negative implications on the mental and physical health of the patients and their families, as well as public health**, which is a basic constitutional right (art 32, Constitution).

Also, in an emergency the patient's right to self-determination must be respected, and **wishes and directives regarding treatments must be applied as far as possible**. If the patient is incapable or has a legal representative (e.g. parents, legal guardian or similar) they must always be involved in the therapeutic relation in a manner appropriate to their abilities (see art. 3, page 1; legislation no. 219/17).

According to the legislation, in an emergency the doctor and the medical staff need to ensure **necessary treatment is provided**, respecting the patient's wishes in all the clinical circumstances in which they are able to express them. Relatives should be informed and reassured about the patient's right of access to palliative care and pain therapy (legislation no. 38/10; legislation no. 219/17).

When a patient is not able to express an opinion, or faces incapacity, if the prognosis is poor it seems **useful to plan "shared treatment" involving family members**, or registered partners, or a cohabitee, or a trustee. Good communication with family members is necessary in order to respect the patient's wishes and find solutions best adapted to their personal interests.



The right to the protection of personal data **is not an absolute priority**, but must be **considered in relation to its function in society** and be balanced against other fundamental rights, like health, in both the individual and collective dimensions, in accordance with the principle of proportionality.

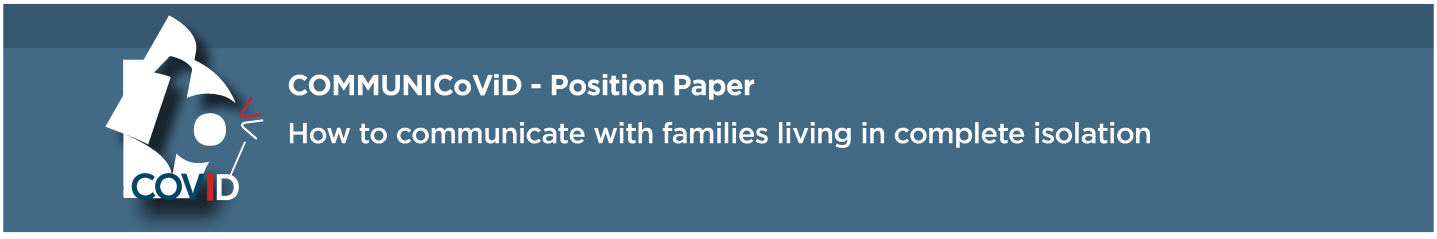
If the patient is physically or legally unable to express opinions, processing personal data **will be lawful when necessary to protect the best interest of that patient or other people**, as well as for reasons of public health (arts. 4, 46, 54, Reg. EU 2016/679).

According to European regulation on specific categories of personal information, such as the state of health, personal data processing **is lawful** when it protects the involved person's life or that of someone else **if the involved person is physically or legally unable** to give free and informed consent, as well as for reasons of public interest in the field of public health (cf. art. 9 paragraph 2 lett. c), i), Reg. EU 2016/679).

The urgent decree for strengthening the Italian national health service in relation to the CoViD19 emergency (art. 14, DL 14/20) provides **rules derogating from the privacy legislation** and simplifications aimed at balancing the management needs of the emergency with confidentiality of the parties concerned, without prejudice to compliance with the principles relating to the processing of data pursuant to art. 5 of EU Reg. 2016/679 on the lawfulness, correctness, transparency, accuracy and minimization of data communication and the adoption of adequate technical and organizational measures aimed at guaranteeing their safety.

When a patient is in total isolation for the protection of individual and public health, **the means of communication must minimize** – as far as possible - the risks concerning personal data processing connected also to technology, considering, however, the present period of extraordinary emergency.

Any **evaluation in terms of responsibility** for a violation now **cannot be separated from this extraordinary health emergency** we are witnessing.



11 Narration and sharing of own experience

We believe in the healing power of words ...

Project "We write history"
https://vissuto.intensiva.it

"SIMEU stories" project
https://www.simeu.it/w/articoli/leggiArticolo/335/dir

The communication typical of the globalized world, in this period of an overwhelming pandemic, can give way to **silent solitude**: loneliness for the patient, the anguished isolation of family members, and of health workers within their own hospitals.

There is the loneliness of illness and often the loneliness of a death unaccompanied by affection. Moreover, in the future there will be the stress of a trauma that has marked us all and that we will have to learn to manage.

In the combined efforts to save the lives of the thousands of infected people, **the absolute therapeutic commitment** of doctors and nurses, however, **has touched a peak of humanity in this inhuman condition**. The relational space aims at establishing a form of contact with the patient, with family members, and healthcare professionals, driven by a **feeling of dedication** not only towards others but that becomes a need for ourselves, to give meaning to this terrible isolation from affections.

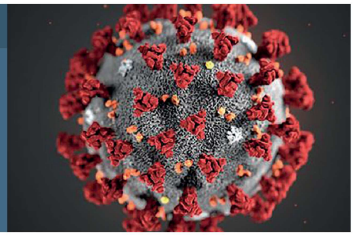
A phone call, a video call, an email, a written story ... all try to replace the physical contact that the virus prohibits: **communicating with the family** allows people to create a listening space where worries, anguish of death, and fears are collected for themselves and their loved ones far away, and in which they try **to instil trust and hope**. A path of solidarity is perhaps the only gift of this tragedy.

It is extremely important to establish contact with family members. A phone call, without ever replacing the doctor's daily communication on the development of the disease, becomes a tool to help those who cannot personally assist their loved one, suffering the anxiety of not having direct information and often the burden of a sense of guilt linked to 'the feeling of abandoning one's family'. **We inform, reassure, collect tears, and together we identify a path of hope** for containing and eventually overcoming a trauma that will leave its marks in future years. Otherwise we end up accompanying the pain of a death, without closeness and with no direct participation - only unsustainable distance - but **at least not loneliness**.

Rapid clinical choices engage the ethical and moral spheres of health care, leaving a load that never abandons those involved; day and night the terrible match with death is replayed, isolated, far from loved ones, from the embrace of their children. Psychologists do all they can to help, building up support and listening, to contain the anguish and stress of those who, although trained to work with death, could never have imagined managing this huge amount of pain, without the right weapons that research is still preparing.

Psychological support in groups formed by doctors and nurses is an immediate measure that helps regenerate forces in the daily battle, but **accompaniment and support will also be important in the near future** when in the emotional sphere compromised by such vast pain, emotions and images will resurface in the memory, causing great distress.

Someone must look after those who look after, first of all **breaking up the loneliness with gatherings and narration**. We are all players in this hard struggle, it is true, but we will never give up.



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How to communicate with families living in complete isolation

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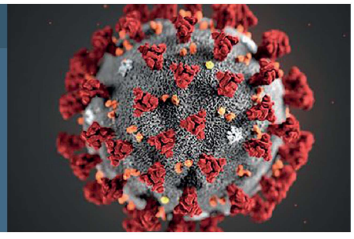

SIAARTI
PRO VITA CONTRA DOLOREM SEMPER

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A path to follow together

HEROICbundle
HUMANIZATION TO ENHANCE RECOVERY ON INTENSIVE CARE

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ESM x BMJ-SPC – 02oct20

HOW TO COMMUNICATE WITH FAMILIES LIVING IN COMPLETE ISOLATION

Electronic Supplementary Material

Table 1S - Characteristics of the four national Societies endorsing the Project.

	SIAARTI	ANIARTI	SICP	SIMEU
Year of foundation	1934	1981	1986	2000
Number of members	8483	1189	2310	3105
Percentage of Society members on the total number of Italian professionals	56% on 15.000	10% on 12.000	58% on 4.000	54% on 5.800
Journal of the Society	Minerva Anestesiologica	Scenario	Rivista Italiana di Cure Palliative	Italian Journal of Emergency Medicine
ISSN	p 0375-9393 e 1827-1596	p 1592-5951 e 2239-6403	p 1976-6481	e 2532-1285
Number of events made yearly by each Society or officially endorsed				
Courses	120	20	15	85
Thematic congresses	5	1	3	2
National Congress	1	1	1	1
Endorsement	100	50	20	30

Table 2S - Characteristics of the authors

	Expert panel N=46	**Lead Authors N=23**	**Reviewers N=23**
Age (years)	52.4 ± 10.8	46.6 ± 9.8	58.2 ± 8.4
Male sex (N)	25 (54.4)	11 (47.8)	14 (60.9)
Experience in communication (years)	20.6 ± 10.6	16.3 ± 10.5	25.5 ± 8.6
Region of origin on the total Italian regions (N)	14 (70)	8 (40)	12 (60)
Region of origin (N)			
Piemonte	6 (13.0)	2 (8.7)	4 (17.4)
Lombardia	12 (26.1)	7 (30.4)	5 (21.7)
Liguria	1 (2.2)	0 (0)	1 (4.3)
Veneto	6 (13.0)	5 (21.7)	1 (4.3)
Trentino Alto Adige	1 (2.2)	0 (0)	1 (4.3)
Friuli Venezia Giulia	1 (2.2)	0 (0)	1 (4.3)
Emilia-Romagna	4 (8.7)	2 (8.7)	2 (8.7)
Toscana	1 (2.2)	0 (0)	1 (4.3)
Marche	1 (2.2)	1 (4.3)	0 (0)
Umbria	1 (2.2)	1 (4.3)	0 (0)
Lazio	6 (13.0)	4 (17.4)	2 (8.7)
Abruzzo	2 (4.3)	0 (0)	2 (8.7)
Campania	2 (4.3)	0 (0)	2 (8.7)
Sardegna	2 (4.3)	1 (4.3)	1 (4.3)
Type of contribution (N)			
Hospital staff member	42 (91.4)	23 (100)	19 (82.6)
Previous ICU patient	2 (4.3)	0 (0)	2 (8.7)
Family member of ICU patient	2 (4.3)	0 (0)	2 (8.7)
Occupation (N)			
Physician	23	10	13
Nurse	9	5	4
Psychologist	7	5	2
Legal work	3	2	1
Other	4	1	3
University staff member (N)	11 (23.9)	5 (21.7)	6 (26.1)
Public hospital staff member (N)	35 (76.1)	17 (73.9)	18 (78.3)
Hospital bed number (N)	700 [400-895]	700 [586-975]	600 [365-870]
Hospital treating CoViD-19 patients (N)	36 (87.8)	19 (86.4)	17 (89.5)
Scientific affiliation (N)			
SIAARTI	16 (34.8)	7 (30.4)	9 (39.1)
ANIARTI	8 (17.4)	4 (17.4)	4 (17.4)
SICP	3 (6.5)	2 (8.7)	1 (4.3)
SIMEU	4 (8.7)	2 (8.7)	2 (8.7)
President, past president, vice-president, or elected member of the national board of the scientific societies endorsing the Document CommuniCoViD (N)	16 (34.8)	3 (13.0)	13 (56.5)
Hirsch Index (Scopus)	4.5 [2-12]	4 [2-8]	5 [2-14]
Previous participation in Delphi / eDelphi procedures or Guidelines author (N)	32 (69.6)	16 (69.6)	16 (69.6)
Papers about clinical communication (N)	2 [0-5]	1 [0-6]	2 [0-3]
Member of the Intensiva 2.0 Project (N)	26 (56.5)	13 (56.5)	13 (56.5)
Member of the Steering Committee of the Intensiva 2.0 Project (N)	16 (34.8)	9 (39.1)	7 (30.4)
Member of the Ethical committee or of the Bioethical study group of each Society (N)	12 (26.1)	7 (30.4)	5 (21.7)
Teacher in educational courses about clinical communication (N)	37 (80.4)	21 (91.3)	16 (69.6)

Numbers are presented as mean ± standard deviation, absolute number (percentage), or median [interquartile range], when appropriate.