Republic of San Marino

San Marino Bioethics Committee

Law no. 34 of 29 January 2010

HUMANISATION OF CARE AND END-OF-LIFE SUPPORT IN THE EVENT OF PANDEMICS

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TABLE OF CONTENTS

PRESENTATION

The COVID-19 pandemic has offered unprecedented scenarios for bioethics to reflect upon.

More specifically, bioethics had taken on board the principles that must guide the support of the person during illness and at the end of life, considering them as human rights and consequently as an indisputable heritage of science, medicine and law.

The violent and simultaneous impact of the pandemic on all societies around the world swept away principles and rights with such rapidity that, in the very early stages, any consideration other than the confused, harried and contradictory responses that science and State decision-makers tried to provide was nullified.

As experience common to all countries progressed, we began to understand that also the response provided by societies and health systems was pandemic, introducing new forms of dehumanisation "legitimised" by the emergency.

However, despite being perceived as an unexpected event, COVID-19 was largely predictable. In this regard, disaster medicine has provided the necessary tools to develop measures to deal with emergency and maxi-emergency situations, although it is impossible to standardise them.

In 2017, San Marino Bioethics Committee (CSB) dedicated a specific document to disaster bioethics and, emphasising the role of ongoing training specific to the type of events and professionals involved, identified the pre-emergency phase as the crucial stage to focus on, in order to avoid being overwhelmed by catastrophic events.

The COVID-19 pandemic has also eroded certainties based on this knowledge, which was gained until early 2020 as a pillar of societies.

In the light of the above, the CSB deemed it necessary to immediately carry out an analysis of the situations that have created an unimaginable condition for our time and our societies, namely the person's *de facto* loss of the "right to have rights" (to use Hannah Arendt's expression), in other words the dehumanisation of the person.

The CSB's attention to detect the danger of such violations was evident from the outset and led to opinions and answers to ethical questions.

Therefore, this document is the result of the process undertaken a year ago and strongly emphasises that no situation, not even during an emergency and a pandemic, can justify dehumanisation, at any stage of life or death.

In line with its previous documents, the CSB has focused on the groups of persons who suffer more than others from the heavy effects of highly critical situations, such as the COVID-19 pandemic, including children, persons with disabilities of all ages and healthcare professionals.

This document also deals with a topic that is often barely mentioned in the international bioethical debate, but which, had it been discussed in detail from the very beginning of the COVID-19 pandemic, would have been crucial to understand and subsequently define the approach to be applied in case of an unknown disease: post-mortem investigations, which are inevitably linked to the management of the body and funeral procedures.

The extent, also emotional, of such a process of dehumanisation, going even beyond the moment of death, is demonstrated by the fact that each member of the CSB was involved in the drafting of this document - also with the collaboration of Dr. Roberto Ercolani as external expert psychologist. For this reason, the document was approved within a few months of its conception.

This document was unanimously approved at the meeting of 12 May 2021 by all members: Borgia, Cantelli Forti, Carinci, Garofalo, Griffo, Guttmann, Hrelia, Iwanejko, Raschi, Santori, Selva, Strollo, Tagliabracci.

Luisa M. Borgia
CSB President

INTRODUCTION

Dehumanisation practices have been thoroughly studied, bringing to the attention of the scientific community the negative implications and consequences that stigmatise various groups of the affected population, denying their full humanness and/or regarding them as less than human[1], thus justifying violence and inhuman and degrading treatment.

The SARS-CoV-2 pandemic has highlighted new dehumanisation forms justified by a global emergency - characterised by a substantial unpreparedness in dealing with it - which led to a failure to respect social and human principles and practices.

In this pandemic emergency, States, and not groups of citizens, have rapidly taken decisions in a drastic and imperative manner, with very strict deadlines. These decisions have resulted in substantial restrictions on social and religious activities, limitation of important human relations and underestimation of essential human rights. Moreover, these decisions have had a strong impact not only on human relations but also on the psychological perceptions of individuals and societies.

This document aims at analysing the main aspects of the above-mentioned practices, in the awareness that it is not possible to completely exhaust this theme, which is vast and still little investigated.

The clinical aspects of the SARS-CoV-2 infection, the development of contagion and the epidemiological dimension that are still unfolding have presented many new elements that were at least partly foreseeable, but for which, unfortunately, the world has had to acknowledge its unpreparedness.

It is for this reason that the collective effort to tackle this pandemic on several fronts initially went through a period of profound uncertainty due to contradictory prevention and treatment strategies, which gradually evolved into a continuous process of adaptation and institutional decisions adopted in a turbulent and irrevocable manner due to the pandemic emergency.

Such situation has had a strong impact not only on human relations but also on the psychological perceptions of individuals and societies.

The evident difficulties first experienced only at a clinical level, due to the emergence of new and dramatic conditions, then extended to moral issues, generating concerns and making it both urgent and risky to find the necessary solutions.

Therefore, the CSB deemed it appropriate to examine the recent events linked to the outbreak of the pandemic in the light of bioethical principles[2], underlining the extent to which they are still applicable as they are or, in the event of possible or systematic breaches of these principles, they require that the society develops valid strategies to correct perspectives, choices and behaviours.

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[1] *Deumanizzazione/dehumanization*. Minority reports. Cultural disability studies, n. 10, 2020/I.

[2] Beauchamp T, Childress JF. *Principles of Biomedical Ethics*, Oxford University Press, Oxford, 1978.

This operation seems most appropriate. Undoubtedly, the unique impetuousness of the pandemic outbreak has highlighted critical issues and caused major disruptions on several fronts, increasing the risk of errors and omissions.

However, when analysing the various elements that make up the complex event of the pandemic from the point of view of bioethics, it is necessary to reflect on the general scenario in which it is still developing today.

The key word of the most painful component of the COVID-19 pandemic is **"dehumanisation".**

Indeed, the estrangement caused by this health emergency has appeared when social distancing, personal protective equipment and closure of many social activities were first introduced.

These measures, which are *de facto* inevitable, should actually be accepted by all, although with some difficulty, since they are valid and at least partially effective for a future socio-health and economic recovery[3].

However, at the same time, all dehumanising effects that these have inevitably entailed must be stigmatised in order to make the most valid corrections.

The purpose of this document is to offer a reflection on the technical and social tools used in similar emergencies. The question is whether it is sufficient to impose simplifying behaviours aimed at creating instruments to combat pandemics that date back to the great medieval epidemics (such as lockdown, quarantine and social distancing) or whether it is more appropriate to update and refine choices on the basis of the COVID-19 experience and in accordance with ethical principles and human rights.

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[3] This is also true for many other human activities, which, starting from the current historical moment, will change, perhaps definitively, their characteristics, thus increasing the scope for action to the benefit of health and communications, while generating, however, social disaggregation. Worth mentioning are, for example, the increasing use of technological means of communication and treatment and the possibilities of "telemedicine". If, on the one hand, the latter present apparently fundamental characteristics of effectiveness and efficiency, on the other hand we will also have to take into account the possible dehumanisation linked to the choice of a remote doctor and, more generally, the potential social impoverishment, which the use of these means may entail, if inappropriately used.

PRINCIPLES OF BENEFICENCE AND AUTONOMY: A NEW LESSON

It is common knowledge that, due to the congestion caused by the rapid spread of the contagion, intensive care units were the scene of sometimes unexpected healing but also of distressing deaths.

Healthcare professionals gradually learned to recognise the typical symptoms of the final stages of the illness, characterised by dyspnoea and suffocation, death anxiety, agitation and delirium.

However, in such terrible moments, confusion and urgency ruled in intensive care units, where new patients constantly arrived and suddenly worsened, and the health staff was stressed in searching for effective remedies to an almost unknown illness. This led to a certain degree of neglect of terminally ill persons.

Indeed, as one can imagine, those who worked at the bedside of such sick persons in dramatic circumstances paid the utmost attention to the pursuit of healing at all costs.

Therefore, directing energies and resources to saving as many lives as possible makes it obviously difficult to identify the already vague boundary between survival expectancy and the need for abandoning treatment, and to modify care strategies based on the recognition of this boundary.

Moreover, at present, expertise in resuscitation is rarely accompanied by a valid expertise in palliative care. Therefore, the condition of urgency typically linked to pandemics has further worsened the great difficulties already faced by the care team in recognising the time to possibly change the treatment of a sick person, from a more strictly resuscitation treatment to palliative care[4].

In several cases, this resulted in a “bad death”, not sufficiently supported by the usual and well-tested remedies offered by palliative care.

From the point of view of bioethics, this forced the care team, constitutionally driven by the need to act according to the **principle of beneficence**, to deal with the discomfort of a sudden and sometimes ineffective shift of objectives from resuscitation to palliative care, with consequent negative repercussions for the sick person in terms of increased suffering and less survival possibilities.

What has been described is only one of the elements of dehumanisation that the CSB intends to analyse, despite the vagueness of figures and the probable good faith of those who were unwittingly responsible for such dehumanisation.

Proposals for medical triage by categories of patients rather than by clinical conditions, made on the basis of an alleged maximisation of benefits, have also brought to light apparently consolidated discriminatory practices, triggering the disapproval of the entire international community.

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[4] SIAARTI, *Grandi insufficienze d’organo “end stage”: cure intensive o cure palliative? “Documento condiviso” per una pianificazione delle scelte di cura.* September 2013.

Something equally critical has happened with regard to the **principle of autonomy.**

As we know, this principle is inspired by the priority respect for sick persons' choices made with full freedom to act and to make informed decisions.

Contrary to what might be assumed, according to the modern bioethical interpretation of this condition, the principle of autonomy cannot prevail over the principle of beneficence. On the contrary, the two principles should be harmonised and a more balanced space should be ensured to the patient and the doctor as stakeholders.

According to literature[5], when dealing with patients with COVID-19 in acute phase, only rarely was their will rightly and adequately taken into account when the most demanding therapeutic decisions had to be made, especially if invasive, such as assisted ventilation or cardiac care and artificial nutrition practices.

This means that the **principle of autonomy** was applied with difficulty in some cases, while in others it was completely ignored, with the consequent large omission of the legitimate participation of patients in the choices pertaining to them and the required consent, duly preceded by the relevant information, in accordance with the legislation of many countries[6].

On a human level, it is very uncomfortable to think about what may have happened in wards where patients at the end of their tether were given neither adequate information nor the possibility to decide their own fate, and faced their final journey unaware and discouraged.

Healthcare professionals' lack of knowledge about this new disease hardly allowed them to provide answers capable of freeing the victims of the pandemic from fear.

The lack of definite treatments, approved medicines or shared guidelines prevented the care team from being a comfort to those seeking answers in science.

The inability to reliably predict the course of the disease may have led to non-compliance with the principle of autonomy because of the difficulty to fully inform patients of their condition and, in the very short time allowed by the urgency outlined above, may have led many doctors to ignore persons with a poor prognosis.

In other words, the incomplete, if not omitted, application of valid palliative care led to a gap in the strictly "technical" component of this care, due to the probably insufficient use of the therapeutic equipment that such care requires.

In addition to the above, there was also a loss of the human component of support, as well as of close relationship, last handshake and last looks, which are essential for these patients, most of whom are elderly, to trigger a positive psychophysical reaction.

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[5] Spinsanti S, *L'etica al tempo della pandemia,* Saluteinternazionale.info; 2020.

[6] With regard to the participation of patients in the decision-making process through information previously given on treatments, see the CSB document "***Guide on the decision-making process regarding medical treatment in end-of-life***", 2019. All CSB documents are available at the following address: http://www.sanita.sm/on-line/home/bioetica/comitato-sammarinese-di-bioetica.html

Spiritual support at the end of life and a dignified respect for the *post-mortem* phase were also almost totally ignored, because of the large number of deaths and the speed of interventions.

In this way, years of training and of planning of end-of-life support in the wards have been rapidly wiped out.

Despite all this, some beneficial actions, as a glimmer of light, were spontaneously carried out in the dramatic darkness of the wards.

For example, in care homes for elderly persons, but only after several months from the beginning of the pandemic, relatives were brought closer to the sight of patients through the windows of the wards, and this unexpectedly led to their clinical recovery. Large plastic tarps were used to allow people to hug without direct contact. Modern technological means of communication were used to allow patients to exchange looks and greetings with their relatives, albeit at a distance.

In other words, an attempt was made to restore some of the threatened humanity of close relations, rightly considered vital and salvific.

Those who were able to reflect (even if only for a short time in the frenzy of interventions) responded, almost spontaneously, to the danger of dehumanisation with available impulses of humanisation rediscovering the human relationship of care within themselves.

THE APPARENT CONTRADICTIONS OF THE PRINCIPLE OF JUSTICE

A further critical element added to the scenario described above. Indeed, in the in-patient wards, there was a sudden increase in urgent requests for treatment for a progressively and unpredictably growing number of cases.

Indeed, the supply of care, in terms of beds and, more generally, of material and human resources, progressively proved to be insufficient.

In other words, there was a close resemblance to the better-known "Disaster Medicine" scenarios, to which the CSB has dedicated a specific document[7].

Indeed, as in such dramatic circumstances, also in this case the critical situation occurred of having to modulate the available resources on the simple principle that, on the basis of purely clinical criteria, those with the best chance of survival should be treated first[8].

In order to adequately deal with the emergency, in-patient wards were extended as far as possible, additional equipment for intensive care units was allocated, available healthcare staff was redeployed and extra staff was recruited from various sources, according to solidarity schemes.

As can be inferred, despite the fundamental need to save as many lives as possible, unfortunately countless patients with few or no chances of recovery were sacrificed.

In the meantime, scientific literature has been enriched by several contributions in an attempt to set appropriate guidelines for healthcare professionals. These guidelines are mainly in line with what has already been recalled about Disaster Medicine, mostly outlining the aforementioned discriminatory criteria based on the degree of clinical severity and recommending specific behaviours in the wards[9] .

The CSB has already expressed its opinion[10] on these guidelines, strongly calling for respect for the only valid parameter of choice, i.e. correct application of triage that respects every human life, based on the criteria of clinical appropriateness, proportionality of care and respect for human rights[11].

Applying the **principle of justice** in these terms removes the risk of being subject to arbitrary and discriminatory criteria.

The pandemic has highlighted other decision-making elements, such as the priority in the administration of vaccines, which must be guided by the same **principle of justice and equity**, a

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[7] *San Marino Bioethics Committee, Bioethics of Disasters*. 10 July 2017.

[8] Dyer C. *COVID-19: Guidance is urgently needed on who should be treated in event of shortages, say lawyers*. BMJ 2020; 369: m1503 (Published 15 Apr 2020).

[9] SIAARTI, *Raccomandazioni di etica clinica per l'ammissione a trattamenti intensivi e per la loro sospensione, in condizioni eccezionali di squilibrio tra necessità e risorse disponibili.* 6 March 2020.

[10] *San Marino Bioethics Committee, Answer to the requested urgent opinion on ethical issues regarding to the use of invasive assisted ventilation in patients all age with serious disabilities in relation to COVID-19 Pandemic*. 16 March 2020.

[11] Borgia L, Griffo G. *SARS-COVID-19 pandemic and persons with disabilities in Italy and in Europe* pp. 33-44 in Journal of Philosophy and Ethics in Health Care and Medicine, n. 15, February 2021.

subject to which the CSB has dedicated a specific document[12] and to which we refer for further details.

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[12] San Marino Bioethics Committee, *Vaccine coverage against SARS-COV-2. The bioethical basis for a health pact.* 13 January 2021.

HUMANISATION OF CARE AND OF DEATH IN THE WARDS

The above mentioned dehumanisation scenarios were strongly influenced, as recalled several times, by the sudden outbreak of the pandemic, which may constitute a mitigating factor if we consider that damages were involuntarily caused and that all were unprepared.

However, precisely because of the failings that have emerged as a result of the widespread lack of preparedness to deal with the pandemic emergency, the CSB deems it necessary to highlight the absolute need to plan the entire health service system in the light of new organisational criteria, hopefully based on the imperative values of humanisation and respect for human life, at whatever stage and in whatever condition it may be.

Special attention will have to be paid to all in-patient areas, but especially to the intensive and semi-intensive care units.

The presence of a relative at the bedside of a sick person, far from being regarded as acceptable, should rather be regarded as ordinary, if not essential, while respecting the appropriate provisions on isolation, distancing and individual protection, where required.

Appropriate human relations between patients and their relatives must therefore be ensured, given the vitalistic nature of such relations, by providing appropriate space and time for relations with family members and friends, according to individual needs. Precedence should be given to the closest person as caregiver and the best possible use of computerised means of communication should be made in case of mandatory isolation.

For some groups of uncooperative persons (persons with intellectual and relational disabilities or highly dependent on care) the presence of caregivers or personal assistants is indispensable to ensure appropriate communication with patients and continuously adequate care[13].

In addition, the CSB believes that care protocols capable of guaranteeing continuity between the hospital and the territory are rewarding, because of the proven comfort and completeness provided by a uniform care system between the hospital and home care, which in the future will be called upon to integrate more and more.

The lockdown involving services has severely affected persons with disabilities and their families. The latter had to face a disproportionate burden in terms of care at home compared to other citizens and were exposed to the enormous difficulty of getting persons with intellectual and relational disabilities - for whom daily routine represents a reassuring life condition - to accept the new situation[14].

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[13] See the experience of ASMeD network (Association for the Study of Medical Care for Persons with Disabilities, http://www.fmc-onlus.org/nasce-asmed-primo-passo-verso-la-rete-dama-nazionale/) promoted by the DAMA project of the San Paolo Hospital in Milan, http://www.progettodama.it/DAMA/Home_Page.html

[14] Borgia L, Griffo G. *Il carico sproporzionato di problemi che hanno colpito le persone con disabilità e le loro famiglie durante la pandemia Covid-19* pages 130-142 in Nuova Secondaria Ricerca. Monthly magazine of culture, pedagogical research and educational guidelines, no. 2, October 2020, *Dossier I, La scuola durante e dopo il COVID,* La scuola, Brescia. ISSN 1828-4582.

Finally, the request for spiritual assistance, which is present in every sick person, especially in critical phases, cannot be ignored, according to individual desires and orientations.

Caring for the sick person cannot be limited to its physical and biological component. On the contrary, the proven experience of the effectiveness and strong beneficial impact of spiritual care in an individual's entire clinical history requires that such spiritual care be ensured in every feasible way, through the implementation of a comprehensive care plan that respects the authenticity of human life.

Even the completion of a person's life will necessarily have to benefit from the ordinary rituals of dignified and respectful support of death.

Respect for life cannot be considered complete if the liturgy of death is ignored.

The humanity of grief and closeness is the only response to the dehumanisation of a bad death. A dignified health service that takes care of the holistic nature of the person cannot neglect this element.

THE CONTRIBUTION OF POST-MORTEM INVESTIGATIONS TO THE HUMANISATION OF CARE AND DEATH

The humanisation of death can be achieved through a new and different cultural and legal approach to persons who die in healthcare facilities at the end of a course of care that has failed to save their lives.

It is widely believed that the moment the patient dies nothing more is owed to him or her by the facility and the health personnel that have been engaged in the fight against the disease until that moment.

However, this attitude oriented to the treatment of the disease no longer seems feasible in a context where the focus must be on the caring relationship.

The ultimate aim of Medicine is to cure persons, which goes beyond therapeutic possibilities and continues even after all such possibilities have been exhausted.

Many times, probably due to an unconscious reaction to the disappointment of the failure to save a person's life, there is a desire to forget the matter, or even a refusal to go through the various stages of care, as is sometimes observed in clinical risk management and health litigation.

In working through a loss, the first step is denial, but until there is acceptance and subsequent understanding, there can be no working through of what has happened.

Based on the same motivations, diagnostic tests might not be requested if the cause of death is uncertain, or cooperation might not be offered in an audit (a sort of discussion open to the whole care team[15]) to assess the clinical risk, in the awareness that this activity effectively contributes to the protection of health as required by universal rules[16].

In order to identify ways of humanising the management of death in emergencies such as those related to the COVID-19 pandemic - which have been characterised, and are still characterised, by dehumanisation provisions necessarily imposed by the health authorities - the CSB considers it essential to address a number of substantive questions: to whom does the body of the deceased person belong? Whom should it be entrusted to? Family members? Does the competence of the health authority, referred to in mortuary police regulations, prevail over that of the judicial authority?

Individuals who are incapacitated, either naturally or by law, such as patients who may be unconscious in intensive care units, have a legal status and are protected in decisions concerning them through advance treatment declarations or through legal representatives.

The body of the deceased cannot be considered *res nullius* or *res derelicta*, by analogy with surgically removed anatomical parts or biological fluids.

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[15] Process by which doctors, nurses and other health professionals systematically review their clinical practice on a regular basis and modify it if necessary (Primary Health Care Clinical Audit Working Group, 1995).

[16] In the Republic of San Marino see Law no. 42/1955: *Establishment of a compulsory social security system.*

There are internationally agreed legal provisions, in criminal, civil and special laws, according to which the body of the deceased belongs to the relatives, who must take care of it, are the subject of testamentary dispositions, can bring legal actions, claim compensation for the moral damage suffered by the loss of their relative - *iure proprio* - or be transferred the damage suffered by the victim following the death - *iure hereditatis* - and so on.

Therefore, there is a legally recognised right that a deceased relative is taken care of, including in relation to the funeral arrangements, obviously taking into account mortuary police regulations and other provisions issued by the technical and political authorities governing local and national health in specific risk situations such as the one we are experiencing.

In the case of persons who have died of COVID-19, the health authorities in many countries intervened harshly and without taking into account the legitimate legal and emotional needs of the relatives of the deceased.

The funeral regulations issued by the health authorities of the various States since the beginning of the pandemic generally appear to be based on an overly prudential and unrealistic view of the risk of transmission from the corpse to a living person[17].

Families were prevented from preparing for bereavement by restrictions on visits to care facilities.

They were prevented from saying farewell to their dying relative. The body was wrapped in a sheet and placed in the coffin; the coffin was sealed and never opened again.

There was an impressive number of cremations, represented in the collective imagination by the procession of military vehicles transporting the victims of COVID-19 to the crematoriums.

Ultimately, families were prevented a dignified funeral ceremony and to effectively work through the grief.

Death refers to a personal and collective dimension, and the abolition of mortuary practices and funeral rites, in a situation that is already delicate due to the high infection-related mortality, can have devastating psychological consequences for the victims' relatives.

In the light of what has happened, the CSB cannot but consider whether such funeral restrictions issued by some States, including Italy - which may be involved in assisting San Marino citizens due to its proximity - were necessary and reasonable. Indeed, according to WHO instructions[18] the families of victims were allowed to see the body of their relative, using the necessary precautions (personal protection equipment), except for the (justified) prohibition to touch or kiss it.

The data currently available show a low risk, certainly much lower than for other pathogens, of *post-mortem* transmission of the virus.

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[17] Worth mentioning, as an example among many, is the Circular of the Italian Ministry of Health, *Indicazioni emergenziali connesse ad epidemia SARS-CoV-2 riguardanti il settore funebre, cimiteriale e della cremazione* - Version 11 January 2021.

[18] *WHO Infection Prevention and Control for the safe management of a dead body in the context of COVID-19,* Interim guidance. 24 March 2020.

Even when carrying out autopsies and diagnostic tests, the risk of virus transmission is reduced by the appropriate use of personal protection equipment[19].

Many States initially shared strict rules, while others have modified their provisions over time on the basis of emerging scientific evidence, allowing for last offices procedures, farewell to the deceased and funeral service[20].

On the basis of these restrictive directives, diagnostic tests and forensic autopsies were discouraged and had to be carried out, when necessary, in rooms with Biological Security Level 3.

It should be emphasised that, at the beginning of the pandemic, there were very few autopsy rooms equipped for this purpose, as provided for in the guidelines issued by the *Centers for Disease Control and Prevention* (CDC)[21].

However, the CSB notes that, notwithstanding these limits, in many countries nothing (or almost nothing) was done to upgrade rooms not complying with the standards, despite the invitations addressed to the competent authorities by the scientific societies involved, such as the Italian Society of Legal Medicine (SIMLA) to the Italian Ministers of Health and of Justice[22], asking them to urgently adopt all necessary measures to address non-compliances.

What initially took the form of a recommendation has *de facto* become an obstacle to the performance of autopsies.

It is only recently that the number of standardised autopsy rooms has increased, at the express wish of some health authorities, which has led to a significant increase in the number of diagnostic tests on the corpses of persons died of COVID-19.

As a consequence, autopsies were not performed, especially when they were considered necessary, i.e. for deaths occurring without medical assistance and without a cause of death, whether or not suspected to have occurred from COVID-19[23].

It is universally acknowledged that the performance of autopsies is a valuable aid to clinical practice.[24].

The information obtained from such investigations is indispensable for combating a rapidly fatal disease such as SARS-CoV-2 infection. An in-depth understanding of the physiopathogenetic

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[19] Davis GG, Williamson AK. *Risk of Coronavirus Disease 2019 Transmission During Autopsy*. Arch Pathol Lab Med. 1 December 2020; 144 (12): 1445a–1445.

[20] For example, the Haut Conseil de la Santè Publique, a body supporting the French Ministry of Health, has recently issued a notice concerning the management of the body of a deceased person infected with SARS-CoV-2, according to which the body of a deceased person is no longer considered contagious after ten days from the date of the appearance of clinical signs or of a positive test result for COVID-19. Under these conditions, the French body allows the usual funeral procedures to be applied: Haut Conseil de la santé publique. *AVIS relatif à la prise en charge du corps d'une personne décédée et infectée par le SARS-CoV-2.* 30 novembre 2020.

[21] CDC. *Collection and Submission of Postmortem Specimens from Deceased Persons with Known or Suspected. Centers for Disease Control and Prevention*; Atlanta, GA, USA: 2020. Ad Interim Guide.

[22] SIMLA. Note Ref. 05/20 of 4 April 2020, *Indicazioni emergenziali per l'espletamento di autopsie giudiziarie e riscontri diagnostiche nel contesto pandemico COVID-19.*

[23] Hanley B, Lucas SB, Youd E, et al. *Autopsy in suspected COVID-19 cases.* Journal of Clinical Pathology 2020;73:239-242.

[24] De Cock KM, Zielinski-Gutiérrez E, Lucas SB. *Learning from the Dead*. N Engl J Med. 2019 Nov 14;381(20):1889-1891. doi: 10.1056/NEJMp1909017. PMID: 31722148. The Royal College of Pathologists. *Briefing on COVID-19, Autopsy practice relating to possible cases of COVID-19 (2019-nCov, novel coronavirus from China 2019/2020)*. February 2020.

mechanisms underlying the disease makes it possible to implement effective therapeutic strategies, modify those already undertaken or seek new ones[25].

In addition, performing an autopsy on individuals who have had a previous SARS-CoV-2 infection could provide information on the long-term effects of this yet unknown disease.

In other words, the performance of autopsies at the beginning of the pandemic would not only have provided important information about the causes of the increase in deaths we have witnessed in recent months, clarifying the emblematic and popular question of "dying with" or "dying of" COVID-19, but above all would have made it possible to understand the etiopathogenetic mechanisms responsible for death and, through these, to manage the course of treatment differently.

In this context, the CSB points out that the very few autopsies performed at the beginning of the pandemic[26], together with clinical information, made it possible to identify a multi-organ involvement of the disease on a vasculopathic basis and, consequently, to radically change the management, even at home, of therapy.

In addition to the unquestionable clinical benefit discussed above from the perspective of protecting collective health, knowledge of the causes of death is an absolute right of patients in every case, even though they cannot directly exercise or benefit from it.

The recognition of this right, including the use of diagnostic tests if the conditions for their performance are met, protects the dignity of the person, especially in a context of difficult humanisation of care due to the pandemic.

Failure to recognise this right takes the doctor-patient relationship back to the now obsolete tradition of paternalistic medicine, according to which little or no importance was attached to the need for patients to be aware of - and participate in - the therapeutic strategies applied to them.

Therefore, the CSB believes that the performance of autopsies is connected with the protection of health professionals in the workplace[27], without forgetting, however, that forensic pathologists, as well as anatomo-pathologists, daily face high-risk situations in their work, as in the case of investigations carried out on persons suffering from chronic viral hepatitis, HIV or other infectious diseases.

For this reason, the risk associated with the performance of autopsies on corpses of persons with, or suspected of having, COVID-19 takes on the value of a calculated risk, to the service of public health.

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[25] Pomara C, Li Volti G, Cappello F. *COVID-19 Deaths: Are We Sure It Is Pneumonia? Please, Autopsy, Autopsy, Autopsy!* J Clin Med. 2020 Apr 26;9(5):1259. doi: 10.3390/jcm9051259. PMID: 32357503; PMCID: PMC7287760.

[26] Wichmann D, Sperhake JP, Lütgehetmann M, Steurer S, Edler C, Heinemann A, Heinrich F, Mushumba H, Kniep I, Schröder AS, Burdelski C, de Heer G, Nierhaus A, Frings D, Pfefferle S, Becker H, Bredereke-Wiedling H, de Weerth A, Paschen HR, Sheikhzadeh-Eggers S, Stang A, Schmiedel S, Bokemeyer C, Addo MM, Aepfelbacher M, Püschel K, Kluge S. *Autopsy Findings and Venous Thromboembolism in Patients With COVID-19: A Prospective Cohort Study.* Ann Intern Med. 2020 Aug 18;173(4):268-277. doi: 10.7326/M20-2003. Epub 2020 May 6. PMID: 32374815; PMCID: PMC7240772.

[27] COMLAS E SIAPEC-IAP. *COVID-19 respiratory infection. DOCUMENT ON AUTOPSY AND DIAGNOSTIC TEST*. 20 March 2020.

This right is therefore to the service of the community, so that life and illness do not end with death, and death can come to the rescue of life (*“Hic est locus ubi mors gaudet succurrere vitae”*).

HUMANISATION OF CARE IN PAEDIATRIC WARDS AND PREVENTION OF CHILD DISTRESS

The presence of a relative at the bedside of a sick person is essential mainly in the field of paediatrics, because of that particular symbiosis between mother and child, which completely excludes separation, especially when the child is suffering, and which many recognise as a single suffering.

Research on the benefits of mother-infant bonding for early childhood health indicates that the human brain and immune system develop best when, moment by moment, the child's senses are affectively nurtured and actively stimulated and engaged by the mother[28].

Furthermore, studies investigating the consequences of bonding in early childhood suggest that children, adolescents and eventually adults who have bonded strongly with their primary caregiver during childhood demonstrate not only a better health but also a better emotional balance and better stress reduction strategies. In addition, they develop emotional capacities such as empathy, kindness and compassion (neural traits that appear to be enduring, rather than temporary emotional conditions).[29].

If they lose the bond they have started to experience in the womb, children lose security, may experience abandonment, severe sadness and distress, both mental and physical, also due to the loss of sensory stimuli from the mother (touch, smell, taste, sound and sight of her and other family members), and, as a result of the stress caused by abandonment, they may not develop emotional resilience.[30].

An Italian study on the effects of the pandemic on children with disabilities from 0 to 3 years of age, carried out by “La Nostra Famiglia” operators on their patients, showed some effects also on this group of children.[31].

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[28] Tichelman E, Westerneng M, Witteveen AB, van Baar AL, van der Horst HE, de Jonge A, et al. *Correlates of prenatal and postnatal mother-to-infant bonding quality: A systematic review.* PLoS ONE 14(9): e0222998. 2019. https://doi.org/10.1371/journal.pone.0222998. Tichelman E, Westerneng M, Witteveen AB, van Baar AL, van der Horst HE, de Jonge A, et al. *Correlates of prenatal and postnatal mother-to-infant bonding quality: A systematic review.* PLoS ONE 14(9): e0222998. 2019. https://doi.org/10.1371/journal.pone.0222998.

[29] Wan MW, Downey D, Strachan H, Elliott R, Williams SR, Abel KM. *The Neural Basis of Maternal Bonding*. PLoS ONE 9(3): e88436. 2014. https://doi.org/10.1371/journal.pone.0088436 E 14(9): e0222998. https://doi.org/10.1371/journal.pone.0222998. Studies exploring the biology and effectiveness of kindness show the importance of a mother's positive emotionality towards her child. Therefore, while the lack of genuine acts of kindness can have a detrimental effect on an infant's physical and mental health, the opposite is also true, and kind, stimulating and affectionate attention can reverse destructive neural traits. The brain continues to change according to our emotional life and, contrary to previous paradigms that an infant's brain is not sufficiently developed at birth to experience the physical and emotional agony caused by abandonment, it is now clear that an infant's brain, although not fully grown, perceives all emotions.

[30] Winston R, & Chicot R. *The importance of early bonding on the long-term mental health and resilience of children.* London journal of primary care, 8(1), 12–14. 2016. https://doi.org/10.1080/17571472.2015.1133012. Howard K, Martin A, Berlin LJ, & Brooks-Gunn J. *Early mother-child separation, parenting, and child well-being in Early Head Start families.* Attachment & human development, 13(1), 5–26. 2011. *https://doi.org/10.1080/14616734.2010.488119.* Medina IMF, Granerò-Molina J, Fernandez-Sola C, Padilla JMH, Camacho M. (2017). *Bonding in neonatal intensive care units: Experiences of extremely preterm infants' mothers.* In *Woman and Birth* (August 2018) Volume 31, Issue 4. Pages 325-330.

[31] Worth mentioning is the survey Radar promoted by “La Nostra Famiglia” of Bosisio Parini (EspeRienze nell'emergenzA COVID-19 nei bambini con disabilità e nei loro genitori), which focused on children with speech and learning disabilities, motor deficits, autism spectrum disorder, intellectual disabilities.... The researchers found in children of all ages a significant increase in certain “problem behaviours”, which indicates a greater difficulty in regulating emotions. For one third of the children, an average increase in withdrawal behaviour, anxious-depressive behaviour, attention problems and aggressive behaviour was recorded. In addition, parental stress emerged clearly, but also resilience, which indicates a greater difficulty in regulating emotions. https://emedea.it/medea/it/news-it/329-covid-e-distanziamento-sociale-il-disagio-psicologico-nei-bambini-con-disabilita-e-nelle-loro-famiglie.

For these reasons, and because the mother experiences the same feelings of anguish and anxiety caused by separation from her child, an increasing number of hospitals also provide mothers with beds and services close to their sick children.

The pandemic emergency has confirmed, in a global manner, that the absolute or relative separation imposed by circumstances at the time of birth particularly affects the health of the mother and child. Moreover, numerous studies on the impact of the COVID-19 pandemic on pregnancy and childbirth show that pregnant women and foetuses are at no greater risk of being infected or contracting the disease than the general population.[32.]

In addition, some data on the presence of antibodies against COVID-19 in infants following vaccination by their mothers during pregnancy[33] confirm the transfer of antibodies, already seen with other vaccines, from the woman to her baby via the umbilical cord.

The creation of a pregnancy and breastfeeding registry to establish the efficacy and safety of COVID-19 vaccines in pregnant and new mothers could facilitate the entry and staying of mothers in neonatal wards.

Indeed, mothers who are positive for COVID-19 and adopt the appropriate precautionary measures have a very low risk of infecting their newborn baby. Therefore, if they have mild symptoms, they can avoid separation from their babies because the benefits of rooming-in and breastfeeding outweigh the risk of infection.[34].

In the light of the above, infected mothers in good clinical condition and willing to do so should be encouraged to care for their babies, including by breastfeeding, after being well instructed on the preventive measures to be taken[35].

However, already immediately after birth, isolation and lack of social support can adversely affect both, due to the acute aggravation of the typical anxiety of the unknown generated by any kind of quarantine, especially during pregnancy[36], and which often takes the form of stress reactions[37], depression, irritability and insomnia, and even increases suicide risk[38].

Indeed, an Italian study[39] confirmed what had already been reported internationally: in the COVID-19-related period of isolation, women giving birth experienced perinatal anxiety and depression much more frequently than in the previous year[40].

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[32] Topalidou A, Thomson G, Downe S. *COVID-19 and maternal mental health: are we getting the balance right.* MedRxiv 2020. doi: 10.1101/2020.03.30.20047969.

[33] Gilbert P, Rudnick C. *Newborn Antibodies to SARS-CoV-2 detected in cord blood after maternal vaccination.* medRxiv 2021.02.03.21250579; doi: https://doi.org/10.1101/2021.02.03.21250579 .

[34] Ronchi A, Pietrasanta C, Zavattoni M, et al. *Evaluation of Rooming-in Practice for Neonates Born to Mothers With Severe Acute Respiratory Syndrome Coronavirus 2 Infection in Italy*. JAMA Pediatr. 2021;175(3):260–266. doi:10.1001/jamapediatrics.2020.5086.

[35] Constant use of a mask when approaching the newborn baby and during breastfeeding, careful hand hygiene and keeping the cot away from the mother's bed.

[36] Brooks SK. et al. *The psychological impact of quarantine and how to reduce it: rapid review of the evidence.* Lancet 2020;395(10227):912-20.

[37] Di Giovanni C. et al. *Factors influencing compliance with quarantine in Toronto during the 2003 SARS outbreak.* Biosecur Bioterror 2004; 2(4):265-72.

[38] Gunnell D. et al. *Suicide risk and prevention during the COVID-19 pandemic.* Lancet Psychiatry 2020;7(6):468-71.

[39] Zanardo V. et al. *Psychological impact of COVID-19 quarantine measures in northeastern Italy on mothers in the immediate postpartum period.* Int J Gynaecol Obstet 2020;150(2):184-88.

This seems to depend largely on the loss of the physical presence of so many relatives and friends who normally contribute to the new parents' protective network[41], positively influencing the mother's mental health and counteracting a possible latent suicidal tendency, which is always possible at a very delicate time in the mother's emotional and social life[42].

Such an event occurred frequently, especially - but not only - in the initial period of the pandemic, in many US hospitals. After delivery, such hospitals recommended minimising the risk of contagion by separating newborns from infected mothers and entrusting them to the care of fathers or relatives, who would breastfeed the babies with the milk extracted from their mothers, wearing personal protection equipment[43].

If this was not, or is not, possible, a separation screen was, and still is, placed in the room, while keeping the cot two metres away from the bed of the mother[44], who is always asked to wear a mask and wash her hands thoroughly before breastfeeding[45].

Faced with such limitations, new mothers may adopt an optimistic attitude and choose to breastfeed themselves, or refuse to breastfeed.

In the latter case, there is often intimate discomfort about the choice made, sometimes exaggerated by the attitudes of family members or the care team, who can unintentionally generate inappropriate feelings of guilt.

This explains the need for careful training in this area, also for ward staff[46], in the awareness that neonatal separation contradicts all current notions about the need for early contact with the mother's breast[47] for the harmonious and stable development of the newborn[48].

Indeed, newborn babies absolutely need to establish an intense relationship by exchanging looks with their mother in order to lay the foundations of a normal neuro-behavioural development. This also favours the establishment of a positive maternal relationship, rather than a sudden reaction of rejection of the baby by the mother, which is always possible.

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[40] Wu Y. et al. *Perinatal depressive and anxiety symptoms of pregnant women along with COVID-19 outbreak in China.* Am J Obstet Gynecol 2020;223(2):240e1-e9. Berthelot N. et al. *Uptrend in distress and psychiatric symptomatology in pregnant women during the Coronavirus disease 2019 pandemic.* Acta Obstet Gynecol Scand 2020;99(7):848-55.

[41] Corbett GA, Milne SJ, Hehir MP, Lindow SW, O'connell MP. *Health anxiety and behavioural changes of pregnant women during the COVID-19 pandemic.* Eur J Obstet Gynecol Reprod Biol 2020;249:96-97.

[42] Gunnell D. et al. *Suicide risk…*, cit. Lega I et al., *Regional maternal mortality working group. Maternal suicide in Italy.* Arch Womens Ment Health 2020;23(2):199-206. Camoni L. et al. *A screening and treatment programme to deal with perinatal anxiety and depression during the COVID-19 pandemic.* Epidemiol Prev 2020; 44 (5-6) Suppl 2:369-373.

[43] Dotters-Katz SK. et al. *Considerations for Obstetric Care during the COVID-19 Pandemic.* Am J Perinatol 2020;37:773–779.

[44] CDC. *Interim Guidance on Breastfeeding for a Mother Confirmed or Under Investigation For COVID-19*. http://www.e-lactancia.org/media/papers/Interim_Guidance_on_Breastfeeding_for_a_Mother_COVID-19-CDC-2020.pdf.

[45] Dotters-Katz SK, Hughes BL. Considerations for Obstetric Care during the COVID-19 Pandemic. Am J Perinatol. 2020 Jun;37(8):773-779.

[46] Renfrew MJ. et al. *Optimising mother-baby contact and infant feeding in a pandemic. Rapid review.* 2020. https://www.rcpch.ac.uk/sites/default/files/2020-06/optimising_mother_baby_contact_and_infant_feeding_in_a_pandemic_version_2_final_24th_june_2020.pdf

[47] Pérez-Escamilla R. et al.. *Impact of the Baby-friendly Hospital Initiative on breastfeeding and child health outcomes: A systematic review.* Maternal & Child Nutrition, 2016, 12(3),402–417. Renfrew MJ. et al. *Sustaining quality midwifery care in a pandemic and beyond.* Midwifery, 2020, 88, 102759. https://doi.org/10.1016/j.midw.2020.102759.

[48] Ahn SY. et al. *The effect of rooming-in care on the emotional stability of newborn infants.* Korean Journal of Pediatrics. 2008, 51(12), 1315–1319. Brown A, Shenker N. *Experiences of breastfeeding during COVID-19: Lessons for future practical and emotional support.* Matern Child Nutr. 2021;17:e13088. doi.org/10.1111/mcn.13088.

In the light of the above, even a face mask interferes to some extent with early contact, which is made up of intense olfactory, tactile and, above all, visual stimuli[49].

Recent literature reiterates the need to avoid the absence of direct eye-to-eye contact[50]. It favours instead an overall attitude by the care team to allow both parents access to the newborn baby, especially in terms of physical contact, and to provide the psychological support needed to help the mother-baby pair overcome any moments of separation that could not otherwise be avoided.[51].

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[49] Ong S. *How face masks affect our communication.* BBC Future. 2020, 9 June. https://www.bbc.com/future/article/20200609-how-face-masks-affect-our-communication.

[50] Green J. et al. *The implications of face masks for babies and families during the COVID-19 pandemic: A discussion paper.* J Neonatal Nurs. 2021, Feb;27(1):21-25.

[51] Tscherning C. et al. *Promoting attachment between parents and neonates despite the COVID-19 pandemic.* Acta Paediatr. 2020, Oct;109(10):1937-1943. doi: 10.1111/apa.15455.

WOUNDED HUMANITY AND LONELINESS OF HEALTHCARE PROFESSIONALS

Taking into account the Code of Ethics for Nurses of the Republic of San Marino[52] and what has been said in the paragraph of this document concerning the humanisation of care and of death in wards, the CSB considers it necessary, especially in the context of the COVID-19 pandemic, to pay particular attention to the difficulties faced not only by nurses, but by all healthcare personnel when the rules protecting public health advise against or, even worse, prohibit imprudent behaviour suggested by individual conscience or affectivity.

The pandemic has profoundly changed people's outlook on life: nothing is taken for granted anymore and everyone is paying more attention to details that until early 2020 were considered almost insignificant, in order to preserve their own and others' health.

Therefore, it is likely that such a revolution in everyday life will leave an indelible mark on all healthcare professionals, which will be reflected in the persistence of particularly careful and responsible behaviour even after the COVID-19 emergency has ended.

The ad hoc creation of hospital wards in an attempt to counteract the difficulties created by the pandemic as effectively as possible has led to a largely unprecedented situation for health professionals.

This situation is characterised by conflicts linked to the overload of often exhausting work shifts and by serious emotional tensions due to the lack of adequate personal protective equipment and, in some cases, the impossibility of using ordinary and other leaves as before due to pre-existing organisational gaps.

In this regard, the category under the greatest pressure was certainly that of nurses.

Indeed, because of close contact with patients and the shortage of staff, nurses, more than other professionals, were victims of isolation due to the constant fear of being infected with the virus as a result of close contact with the patient and, above all, of infecting their own family members, with the consequent forced removal from them.

Moreover, the role of nurses integrates two functions: the technical-scientific one and the relational one. The first one is perceived as very strong both within and outside the group, because, like all those working in the healthcare environment, nurses base their activities on scientific data.

However, the second one is most typically expressed through listening, communication and therapeutic relationship, and fully involves this category, although it is perhaps less clearly perceived by the general public.

The fundamental value shared by the two functions is the fact of taking care of the person with real and potential health problems as a whole, i.e. in full respect of the patient's emotional state.

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[52] San Marino Nurses Association, *Nursing Code of Ethics*. 2017

The frustration that professionals experience today when faced with the dehumanisation of death, when they realise that it is impossible for them to be as close to their patients as they would like, entails a high risk of closing in on themselves, which is bound to amplify the seemingly unbridgeable gap between ideal and real situations.

Among the most destabilising factors are the high number of deaths and the sometimes very rapid course of the disease, characterised by sudden systemic crises that can rapidly worsen a clinical condition that appeared under control only a few hours earlier when the patient entered hospital.

Moreover, the staff mostly works on people who, affected by serious respiratory problems, are unable to cooperate in the collection of their medical history and therefore remain totally unknown to the system in terms of both comorbidity and previous and current therapies. Therefore, the staff is almost forced into a "blind" therapeutic intervention.

The greatest difficulty for all healthcare professionals, at the end of an unsuccessful battle, is communicating the death of a relative to family members, usually by telephone, for obvious reasons of isolation.

Although most of the professionals have already been vaccinated against the SARS-CoV-2 virus, they still feel a strong sense of anxiety, combined with the fear of contracting the infection or transmitting it to their family members, which in turn is a source of distress that will increase day by day.

The emotional experience of the staff is often further burdened by the functional overload of the National Health Service, requiring newly graduated nurses and doctors still in training to deal with emergencies for which more experience would normally be needed.

Always because of organisational shortcomings, professionals who have been in service for years are required to intervene in matters other than their own specialisation field and to continue to work even when they believe they are highly likely to have contracted the infection, albeit asymptomatically, due to close contact with patients with COVID-19.

The World Health Organisation (WHO) points out that the first step in protecting the health of healthcare professionals during an epidemic is to implement all necessary measures to protect their occupational safety.

Employers and managers of healthcare facilities should ensure that the necessary preventive and protective measures are taken, by making available adequate supplies of personal protective equipment (PPE) in sufficient quantities for those dealing with suspected or confirmed patients, and by consulting healthcare professionals on day-to-day aspects of occupational safety and health.

A serious lack of PPE was sometimes reported. However, it should be considered that during an epidemic, even when preventive and protective measures are adequate, other causal factors contribute to the high level of psycho-emotional stress, in addition to those already widely described.

The latter are represented in particular by the periodic suffering caused by the loss of patients and colleagues and, in the strictly physiopathological sphere, by respiratory difficulties linked to the prolonged use of PPE in a restricted environment, an element that is perhaps underestimated but easily traceable to the accumulation of carbon dioxide in persons undergoing in various ways the rebreathing test[53].

Professionals demonstrated enormous humanity.

The time when they were hailed as today's heroes is over. They now absolutely need not to be left alone to deal with the heavy burden of human frailty with which they have been, and still are, forced to live.

It is likely that professionals are not yet fully aware of the trauma they are experiencing and, overwhelmed by the rapid succession of events, they feel extremely tired, but they almost remove the feeling of fatigue to focus their attention on the only priority they perceive to be true, i.e. to maintain a high level of vigilance during working hours and to get as much restful sleep as possible during free hours.

Nonetheless, they experience a bleak feeling of helplessness, often mixed in various ways with an overwhelming, albeit unjustified, sense of guilt at seeing persons dying completely alone in the ward, without even the comfort of family members, and at the same time at feeling invaded by an unspeakable instinct of self-defence in the form of fear of being infected, which curbs the impulsive expressions of humanity and paralyses body and soul.

The certainty that continuous defeats are inevitable and the disappointment of seeing their image as "all-powerful healers" profoundly undermined generate great suffering in those who have chosen to work as healthcare professionals precisely in order to treat and heal persons and who therefore need good results to feel fulfilled in their work.

Therefore, with the new pandemic, they need to re-elaborate their image, revise their ideals and give a new meaning to the verb "treat", adapting it to different spaces and times.

It is necessary to balance the ideal of "healing-fighting-solving" with the ideal of "caring-relieving-helping", which is more understandable and satisfying for the patient, as well as always achievable. This ideal can be expressed in terms of know-how, finally understood not only as technical but also as relational.

In the light of the above, it is crucial to emphasise the difference between ***treating*** and ***caring***.

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[53] Rebreathing test: a method used in general anaesthesia and for functional respiratory testing or cardiac output assessment, which consists of assessing closed-circuit breathing by capturing in special devices carbon dioxide and exhaled gases accumulated inside a nose-mouth mask. https://www.cosmed.com/hires/innocorCO_flyerbrochure_A4_C05035-01-93%20_IT_web.pdf.

Indeed, even when there is no ***treatment*** available, in the sense of a decisive therapy, healthcare professionals can ***take care*** of patients by alleviating their physical and psychological suffering and by offering their reassuring presence as much as possible.

Taking care of patients includes the human relationship between patients and the medical staff, which is often essential to encourage a positive reaction of patients to the disease, strengthening their immune defences.

Moreover, in their professional lives, doctors and nurses periodically experience fatal illnesses or ineffective treatments. However, during the pandemic they have no control over too many elements that can upset the already precarious equilibrium of the persons entrusted to them, with the aggravating factor of the limited availability of highly effective protocols and therapies.

Many doctors are crushed under the weight of the responsibility of constantly having to face the “mission impossible” of making decisions with irreversible consequences at a safe distance and in a very short time, without being able to rely neither on proven treatment strategies, nor on contact with patients.

Many nurses, on the other hand, are tormented by the terrified gazes of patients locked in the solitude of their respirators and are unable to recover the necessary serenity of mind at the end of the working day. Back at home, they find a physically safe haven, but encounter difficulties in sharing this professional drama with someone who can listen without being in turn shocked by that immense suffering.

Dealing with sick persons involves considerable psychic energy and generates stress when the relationship becomes intimate and emotionally engaging, thus undermining defence mechanisms.

Sick persons experience strong and explosive emotions, among which fear, anguish, anger, sadness, depression, aggression and guilt. In a very close relationship such as that between the healthcare professional and the sick person, these emotions tend to be transmitted on every communication occasion and become contagious and burning.

Patients in isolation are afraid of a situation that they can hardly understand and for this very reason have a deep and inexhaustible desire for contact, which however cannot be satisfied due to the need to protect all possible contacts.

The nurse, acting as a link between the patient and the doctor who decides on the most appropriate course of treatment, is able to recognise the patient's need, but is frustrated by the impossibility to effectively intervene to this end.

In case of technologically more advanced patients, the new mobile phones and PDAs make it possible to maintain contact with family members, thus overcoming, at least partially, the unbearable loneliness involving all those who are in isolation. On the other hand, the elderly, who are less technologically advanced, suffer a lot because they remain locked in the white, aseptic “prison” of dedicated wards, from which they know perfectly well they cannot escape.

This suffering is immediately apparent to nurses who, however, while being able to understand everything, cannot meet patients’ wishes as they would like because of health requirements.

The consequent sense of failure can lead to anger, which in turn can give way to sadness and compassion. These feelings do not disappear in the short term and, indeed, they linger as traumatising events accumulate and become an absolutely unbearable situation.

Unfortunately, in the end, in the absence of adequate training and a contact person to whom one can turn for supportive supervision, such an experience can easily lead to burnout, namely the feeling of having completely lost control of events and of one's own emotional reactions.

In the impossibility of completely mastering pain, illness and death, the professional, who is lost in an unbearable feeling of loneliness, experiences burnout, which amounts to a kind of relational paralysis.

To prevent such a detrimental outcome, it is essential to organise health debriefing meetings with a time-optimised frequency. During these meetings, nurses can talk to their colleagues to become aware of the fact that the feelings experienced are common to all.

In this moment of exchange of experiences and factual elements, one can speak freely, without judging or fearing to be judged, about those events in which one has felt useless or, at least, unable to offer concrete help.

The aim of debriefing meetings is to prevent emotional distress and to protect the mental health of those who have been passive “victims” of a potentially traumatic situation.

Debriefing meetings consist of a detailed analysis of the critical event in order to take stock of the thoughts, feelings, reactions and emotions that invaded the mind and strained the body.

This allows people to speak about their distress and understand their reactions in order to master stress and prevent it from leading to a misinterpretation of the event and triggering the chain mechanism causing burnout.

However, it seems essential to point out that such a daily practice is not only functional to the need to prevent that stressful events cause a relational paralysis. Indeed, debriefing meetings aim at enriching professionals in terms of motivation by offering new meanings to their activity in each situation. This guarantees an even better relationship with the patient, with the greatest possible benefit also at a psychological level and acting positively on work experiences, to the benefit of the current and future emotional well-being of individual participants.

DEHUMANISATION OF PERSONS WITH DISABILITIES DURING THE PANDEMIC

Dehumanisation affected persons with disabilities and their families during all phases of the SARS-CoV-2 epidemic.

At the beginning of the coronavirus outbreak, this process took the form of invisibility, which affected and overwhelmed the rights of persons with disabilities and their families, who were ignored by the emergency systems (lack of attention in relation to the distribution of PPE, protection in residences, lockdown of all services dedicated to them, etc.).

Therefore, the dehumanisation related to invisibility just described occurs through silence, inattention, disregard and recourse to statistical data that nullifies the importance of personal and social identity.

Even today, there are no data on how many persons with disabilities have been affected by the pandemic and on how many of them have died, especially in long-stay care homes.

Dehumanisation related to invisibility combines explicit aspects, desired by the institutions, and unapparent aspects, which allow civil society to look the other way, without taking responsibility for the deprivation of humanity that affects certain groups of people.

However, the veil of invisibility was fortunately torn by representative associations, which were ready to call for action to meet the needs cancelled by the lockdown policy, such as the possibility for persons with intellectual and relational disabilities to leave their homes or to be exempted from the obligation to wear masks or respect physical distancing.

At the beginning of March 2020, in order to “maximise the benefits for the greatest number of people” due to scarce instrumental and human resources, some recommendations were published according to which it would be possible to avoid assisting the elderly or severely disabled persons (dehumanising the individual).

This proposal was promptly denounced by the CSB and condemned by the entire international community as a violation of human rights. In particular, it was pointed out that the international framework of disaster medicine had profoundly changed after the approval of the UN Convention on the Rights of Persons with Disabilities (CRPD) [54].

The recommendations issued at the beginning of the pandemic were useful to justify doctors' choices on patient triage. At the same time, they risked giving rise to a form of individual disengagement that could weaken moral control by distorting and minimising the consequences of the acts performed. Moreover, the imputation of responsibility to the specific psychophysical disability for the suffering of these dehumanised persons was taken for granted as a socially acceptable practice.

It follows that dehumanisation is a powerful “deactivator” of common moral rules.

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[54] Approved by the UN General Assembly on 13 December 2006. The *Convention on the Rights of Persons with Disabilities* was ratified by the Republic of San Marino through Parliamentary Decree no. 19 of 4 February 2008.

When we perceive that a person is a human being, our empathic reaction makes it difficult to harm him or her without feeling anguish, stress and remorse. These sentiments are reduced in intensity or inhibited when we attribute inhuman characteristics to anyone.

In other words, dehumanisation attenuates, and in some cases suppresses, the empathy and compassion one feels when faced with the suffering of others.

There are three main functions of dehumanisation: justification of violence, legitimation of the *status quo*, and distancing from a potentially distressing situation.

Studies on this theme indicate that dehumanisation is a necessary condition for individuals or groups to be marginalised and for extreme violence against them.

A fourth function of dehumanisation - the least studied in social psychology - is the “protection” of those in positions of power who have to make potentially dangerous and painful decisions for other human beings.

It can be defined as defensive and does not necessarily have the negative impact of the other functions mentioned above. It nevertheless has serious consequences in many institutional settings because it allows social operators (doctors, psychiatrists, nurses, social workers, judges, law enforcement officers, prison staff) to intervene in risky situations and to make difficult decisions within heavy and engaging working relationships, sometimes overshadowing the suffering of those under their care or control.

In caregivers, dehumanisation of the patient is associated with lower levels of stress and burnout. At the same time, it can deteriorate the therapeutic relationship and damage the patient from an emotional and cognitive point of view.

The high number of deaths in care homes for non-self-sufficient elderly persons and persons with disabilities also[55] calls for reflection: the prevailing welfare system for these people should be a protective system, but in reality, it did not protect them during the pandemic.

We will have to rethink welfare to make it an inclusive system, respectful of the principles of the CRPD, and aimed at keeping people in their communities and at supporting full citizenship.

The disproportionate burden of problems experienced by persons with disabilities and their families was highlighted by the European Commissioner for Equality Helena Dalli[56] and underlined by research activities carried out by international organisations representing this group of people[57] and by scientific societies[58].

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[55] A UK House of Commons research based on the survey of the National Statistics Institute shows that 59% of residents with disabilities died in care homes in England and Wales, https://researchbriefings.files.parliament.uk/documents/CDP-2020-0101/CDP-2020-0101.pdf ; similar data emerged from the survey of the Italian National Institute of Health, according to which more than 41% of residents of care homes for the non-self-sufficient elderly died from the start of the pandemic to 5 May 2020. https://www.epicentro.iss.it/en/coronavirus/sars-cov-2-survey-rsa .

[56] See https://ec.europa.eu/commission/commissioners/2019-2024/dalli/announcements/speech-commissioner-dalli-impact-coronavirus-outbreak-persons-disabilities_en

[57] See, *inter alia*, International Disability Alliance and Disability Rights Monitor (2020) http://www.internationaldisabilityalliance.org/covid-drm, Disability Rights Fund (2020) https://disabilityrightsfund.org/, IDDC (2020) in developing countries https://www.iddcconsortium.net/

[58] See American Psychological Association https://www.apa.org/topics/covid-19/research-disabilities , UNICEF report on *Child Disability and Covid-19* (April 2020) https://data.unicef.org/topic/child-disability/covid-19/, the report of the American Association on Health and

CONCLUSIONS AND RECOMMENDATIONS

In conclusion, the CSB believes that the well-known principles of bioethics should not be overturned in any way during an emergency health situation such as a pandemic, however difficult it may be to interpret certain circumstances in which these principles deserve to be called into question.

The CSB, in line with what was stated in the document ***"Bioethics of Disasters"***, reiterates that the principles of **beneficence, autonomy and justice** remain, if they are well harmonised, the most valid references for the often difficult choices that must be made even during a pandemic.

Actually, despite its shocking severity, COVID-19 was largely predictable.

However, perhaps as a result of having had to accept institutional decisions that were not always comprehensible and acceptable, the entire population interpreted COVID-19 as something unexpected and sudden, as did healthcare professionals, overwhelmed by the need to apply protocols that were mostly required by the emergency.

Moreover, the fact that human history has been marked by a long series of pandemics has not been sufficient to prompt science, medicine and society to take adequate measures to deal with any return of such health "scourges", despite the undoubted scientific progress made so far.

Indeed, when pandemics occur, institutions do not immediately draw on the extensive knowledge acquired in the field of Disaster Medicine, to which the CSB devoted an entire document when the last earthquake occurred.

This document clearly shows that Disaster Medicine has clarified the fundamental role of active prevention, alongside that of immediate assistance when the event occurs. Precisely in this regard, this document has provided clear indications on an accurate and systematic planning of the pre-emergency phase, based on continuous training not only for all the decision-makers and operators involved, but also for the entire population, albeit at very different levels of specialisation.

Worth considering is also the need to ensure the greatest possible humanisation of care and death, against any temptation to dehumanise and thus disrespect the reality of man.

As already extensively discussed in the document ***"Guide on the decision-making process regarding medical treatment in end-of-life"***, the CSB reaffirms that under no circumstances can the search for therapeutic remedies lead to the abandonment of a person *in limine vitae* (at the end of their life), depriving him or her of that "holistic" support guaranteed by palliative care, which represents a precise ethical and deontological duty for health professionals.

The CSB is aware that humanising treatment is the only possible approach, not only for the benefit of patients and their families, but also of health professionals. Indeed, the latter are often the only link between patients and their relatives in highly critical situations, such as that experienced during the pandemic, and bear the heavy physical and psychological burden of the suffering and death of patients.

Such a process is also possible through the implementation of the biopsychosocial model. By envisaging intervention by a multi-professional team (a strategy suggested by the WHO in 2001), this model places the patient at the centre of a system influenced by a multitude of interacting variables (organic, psychological, social and family-related), which can influence the development of the disease.[59].

This model, borrowed from the CRPD, implements the principle of full respect for human rights. Moreover, on the basis of the right to choose with whom and where to live in the community, without any discrimination and, on the contrary, in full compliance with the principle of equal opportunities for the achievement of the highest levels of autonomy, self-determination, independence and inter-independence, this model aims at including everyone in the community to which they belong, so that, with appropriate support, they can fully play their role as citizens[60].

Moreover, if the patient is not to be left alone, healthcare professionals need to feel that they are also not isolated. In this regard, the best solution is to work as a team, strengthened by routine debriefing, which, while protecting healthcare professionals, also enables them to always keep their attention focused on the patient as a whole.

Similarly, the CSB is deeply aware that respect for the life of every person is also implemented through observance of the liturgy of death, which cannot be omitted even during a pandemic.

Humanisation of death also includes a rigorous diagnostic test in all cases where the cause is uncertain and continues with the return of the body to the family members, so that they can exercise their legally recognised right to care for the deceased and carry out funeral arrangements in accordance with the deceased's belief.

In the light of the foregoing, the CSB makes the following **Recommendations**:

- What has emerged from the COVID-19 pandemic constitutes a valuable experience that can be used to plan the entire health service system in the light of new organisational criteria, hopefully based on the imperative values of humanisation and respect for human life, at whatever stage and in whatever condition it may be;
- A post-emergency public debate is encouraged on the risk of dehumanisation posed by any possible future event, in order to build on this experience for the development of appropriate pre-emergency plans;
- The current welfare system, based on maximum protection but often inadequate to achieve full respect for human rights, should undergo a critical review in favour of a

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[59] Engel GL. *The need for a new medical model. A challenge for biomedicine*. Science. 1977. 196:129-136; Van Weel C. *Teamwork. Primary care tomorrow*. Lancet. 2002. 344:1276-1279; OMS. *ICF. Classificazione Internazionale del Funzionamento, della disabilità e della salute.* Edizioni Erickson, Gardolo (TN). 2002; Becchi MA, Carulli N. *Università e Formazione medica nel settore delle Cure Primarie*. MED 09, 2009. no. 1; Becchi MA, Aggazzotti G. *Progetto "Insegnamento della Medicina Generale e delle Cure Primarie" nel CLM in Medicina e Chirurgia dell'Università di Modena e Reggio Emilia*. Med Chir. 2008. 42:1785-1789.

[60] *Il nuovo welfare coerente con i principi della CRPD. L'empowerment e l'inclusione delle persone con disabilità.* Edited by Griffo G. Preface by Barbieri PV. Lamezia Terme, Comunità edizioni, 2018.

welfare based on inclusion and participation, in which people remain in their own communities and are appropriately supported;

- While complying with risk prevention measures, and isolation, distancing and individual protection provisions, in hospitals - especially paediatric and obstetrics wards -, in care homes for non-self-sufficient elderly persons or persons with disabilities, or in any other care facilities, spaces should ensure the closeness of a family member and/or personal assistant, as well as relations with relatives, in order to guarantee essential levels of both care and communication and relations through appropriate technical and/or IT solutions;
- Health emergencies should not deprive patients of the necessary pain management and end-of-life support through palliative care;
- The care protocol should provide for:
    - integrated management between hospital and territorial services to ensure continuity;
    - ongoing psychological support for health professionals working in situations of psycho-physical stress;
- In the event of an uncertain aetiology of death, diagnostic tests should always be guaranteed, including through the provision of standardised autopsy rooms, to ensure that every human being has the right to know the cause of death and to understand the physiopathological mechanisms involved, and use them on subsequent occasions, in order to appropriately manage the course of treatment;
- A solid civic education policy should be implemented with perseverance, geared towards correct behaviour aimed at preventing contagion. At the same time, unnecessary and psychologically damaging isolation (including preventive cremation) of persons who have died of COVID-19 should be avoided, since they cannot transmit the virus, except through direct contact;
- Therefore, it should always be ensured that the body of the deceased is returned to the relatives, so that they can carry out the appropriate funeral arrangements, which are necessary for family, friends and communities to work through the grief.

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