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(Not) dying alone: recommendations from Palliative Care during COVID-19 pandemic

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During the dramatic new Coronavirus pandemic, the world of Palliative Care is facing a mandatory change in the relationship of care with patients, families and even health professionals.

The implementation in the daily practice of pre-existing Internet-based devices (1) (together to the development of telemedicine care pathways), the modulation of the intensity in referral in all settings of Palliative Care (Hospital, outpatients service, Hospice and home care) and the caregivers' restriction of access in Hospice and other settings, have led to the reversal of some consolidated practices considered essential elements of "taking care". Some colleagues felt a "loss of identity" as a result of this.

We work in every setting of specialistic palliative care as physicians, psychologist and bioethicist, and we would like to put the focus on facing a profoundly changed scenario, still in evolution.

We must ask ourselves how to deal with the care of patients and family members in Palliative Care while preserving dignity. We have to find new meanings and new ways to be in the relationship of care (2): it will be challenging to approach the discipline as a new beginning, starting from what we learned over the years.

We think we should accept the need to develop both "soft skills and hard skills" and let them grow, without decreasing importance of Palliative Care legacy, together with the choice to sustain the fatigue of being in the relationship in a way never considered before (3).

COVID-19 epidemic explains how health care professionals have the ethical and deontological duty to protect public health (patients, families and professionals).

We think there are no "privileged" settings that can be considered off this duty, and our opinion is that Palliative Care needs a deep rearrangement to protect public health and, at the same time, individual health as WHO stated i.e. physical mental and spiritual health.

The primary issue of contemporary Palliative Care is person-centered care to guarantee an individual and multi-professional evaluation based on the complexity of patient and family's needs (3,4).

Palliative Care in "Covid-19 days" will find new ways to continue to take care of every person, all along the story of illness and death.

The outbreak is an extraordinary opportunity for the development of self-awareness, not only for Palliative Care professionals but also for all health care professionals dealing with the death of many patients, in order to preserve their dignity in a new way. It is time for a deep, humble, cultural and professional reflection on how some old paradigms are changing.

Facing the challenge of increasing our skills and the closeness to patients and families (in terms of Compassion and conscious presence), will defeat the so-called "lonely death", in the extraordinary emergency we are experiencing.

The human "connectedness" among caregivers, patients and families can be increased with new technologies (together with the telephone recall, an evidence-based specialistic Palliative Care practice): the "tech" part can be delivered with adequate "touch" by professionals.

We think that the only distance to keep is to the virus and not to the care, to learn a new way of taking care of patients and families, with the real *Compassion*, facing the burden of moving away in physical distance, to provide Palliative Care as useful as they are.

A “lonely death” can be considered as a “different” final phase of life, where life itself is clear and present, and where new issues of good practice, the relationship of care and Compassion arise (5).

The limits with competence and Compassion are our professional limits, and they must be improved: it is crucial to consider that feelings and actions of the “beholder” can be the way to deliver respect and dignity to patients, not to let them die alone (people dying alone was a tragic scenario also before Covid-19 pandemic).

Palliative Care needs to learn the “paradigm shift”: it can be useful in supporting other care teams in the relationship and communication with patients and families.

It is a singular moment to stay at patients’ bedside teaching our colleagues to do the same. “To stay”, to treat symptoms properly, to avoid inappropriate or harmful interventions at the end of life, and to give relief to suffering at the end of life, is a way to guaranteeing a death with dignity (5).

We have to embody proper care in our “DNA” *modus operandi*, because people will die alone in all settings also in future, and this is a challenge in which we must improve our skills.

We are fully aware that it is now necessary to change strategy compared to the first stage of the outbreak (when we only know that social distancing could stop infection).

Therefore, we think there is a need for a “phase 2” in delivering palliative care too. We then propose the following recommendations, hoping that they will stimulate the debate:

- progressive and gradual re-opening of the Hospice to family visits, only for patients at the end of life in order to support the usual rituals and comforts of grieving (providing Individual Protection Devices for visitors, together with a specific scheduled time).
- Real continuity of care through settings (from Hospital to home care or inpatient hospice, enhancing telemedicine practices).
- greater protection of patients and people with high complexity and/or Palliative care needs in long term care facilities or nursing homes, in collaboration with Family Medicine and Palliative Care Teams.
- Developing Advance Care Planning programs to personalized care based on personal patients’ values and goals.

Finally, we hope that the pandemic will improve communication among service providers, focusing on the proper referral to care of patients and families, using the professional partnership as a tool of care.

If patients and family members perceive continuity of care between the different care settings, they will not be abandoned, but accompanied in the best care setting in a pandemic. It is our experience that poor communication between professionals of different care settings limits the possibility of continuity of care even before Covid-19. In this extraordinary emergency, we are called to ‘be there’ to the best of our ability and services we can offer to patients and families.

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