Hospice care pathways and COVID-19

Italy was the first Western country to face COVID-19. It was endemic in Northern Italy,1 but minor in Southern Italy, particularly Sardinia and Sicily. On 9 March the government issued a complete lockdown to prevent contagion. The decree included serious restrictions and prohibitions on visits to patients in hospital.2 As a consequence admission to hospice stopped. After long negotiations, patients might be admitted—but alone, and after death just one relative was allowed see the body. This continued until the last week of May, when relatives (just one) were again allowed to stay in the mini-apartment in hospice.

We analysed hospice activity before and after the COVID-19 crisis. The 10-bed hospice opened in November 2019 to support the existing acute palliative care unit with 8 beds, in a comprehensive cancer centre. The latter unit has its own peculiarities, being particularly devoted to symptom management during active antitumour treatments. Simple available technologies provided temporary communication models, but did not substitute for physical presence. One relative reported: ‘After hospice admission, I will not see him/her anymore’.3 While those admitted to the acute palliative care unit are mostly discharged home, hospice patients have high mortality.4 From February (precrisis) to May, bed occupancy rate dropped from 95% to 40%. Many patients/relatives refused hospice admission (‘He/she cannot die alone...’). Three patients referred to hospice from the acute palliative care unit refused the transfer once relatives were informed about visiting restrictions. Two asked to be moved to another hospice where caregivers were allowed, while others preferred to be discharged home. One patient died before being transferred to another hospice.

COVID-19 impacted the common pattern of hospice admissions and discharges, as restrictions were strictly followed, after compromise with the administration. Fear of possible contagion from relatives was significant, given the hospice is based in a cancer centre where the usual hospital routines would be difficult to follow with a patient with positive COVID-19. As occurred in some residential non-medical centres, the risk of closure of the entire department as determined by the local healthcare system was significant. While the decision to stop visits for persons at the end of life is morally disputable, alternatives were objectively hard to find. Indeed, since the beginning of the crisis, no patient in the palliative care network of the province of Palermo (two home care programmes, three hospices and one acute palliative care unit), reported a case of COVID-19. One hospice was closed to be available for patients with COVID-19, but never used.

It was striking to observe the psychological reactions to solitary deaths,5 criticised on social media, as such authoritative messages for some stigmatised the limits of palliative care. People complained that the absence of relatives could be offset by the palliative care team and patients would never die alone. This was a surprising interpretation of what was just a fact, not an opinion. The solitary death was the truth, not an impression. A ‘pallialic language’, a neologism to explain the palliative care omnipotence of some physicians, which often masks clinical inadequacy, is unhelpful.

Palliative care is a formidable discipline which renders more acceptable the last days of life for patients and families. It is based on calm analysis of the problem in each individual, reasoning from reality. For example, it was evident many fragile patients with comorbidities were unsuitable for intensive care unit (ICU) admission. Instead, skilled palliative care physicians, particularly experienced in ventilatory support, may in a dedicated space (‘COVID19-hospice’), offer the most appropriate modality of withdrawing or withholding treatments along with ICU physicians, fully integrating their prognostic competences, rather than just providing better symptom control.

Non-hospital spaces and better territorial care would have better prevented the dramatisation of the initial phase. While we can consider new models and strategies to overcome such situations for sure nobody could say: ‘do not worry, although your wife is not here for your death, I will be near you in her place’. As a dying patient, one rather would say: ‘thanks for your offer, but move and bring my life next to me’.

The lesson is that information and directives from the healthcare system and scientific societies, should be cautiously reported to prevent misinterpretations, given that palliative care is still not a priority. On the other side, palliative care physicians have to do the best for their patients and families without an excess of ‘pallialia’. We are no heroes, just good physicians, hopefully.

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