Palliative Care in the COVID-19 Pandemic

Briefing Note

The Suffering of Isolated Patients and Families

The psychological and social implications of physical isolation for patients and families during the coronavirus pandemic

Issue

Isolation deprives COVID-19 patients in intensive or palliative care, patients suffering in isolation in home settings, and associated family members, of the support and human connection they need to manage the psychological impact of severe or refractory infection, and end of life anxieties. Families deprived of adequate farewells may face complicated bereavement.

Background

- Palliative care providers play a unique role in symptom control and in support for patients experiencing psychological and spiritual suffering, as well as for bereaved family members;
- Although physical and social distancing are the most effective means of preventing community spread, the resulting isolation undermines the essential human need for close connection with others. This loss of human connection is particularly problematic for patients who are seriously ill, hospitalized, or at the end of life in an isolated home setting.
- The reprioritization of the criteria for ICU admissions and for other potentially curative or life-preserving treatments in many settings and the simultaneous disconnection of patients from their regular health care providers can produce enormous distress in patients and their families. Those who do receive medical care in hospital often have to manage their anxiety or confusion alone, without the support of their family caregivers or social network
- COVID-19 infections that progress rapidly and with intensive care unit (ICU) admissions, allow little or no time for advance care planning or discussions about goals of care, unlike the gradual progression of noncommunicable disease which allows for early palliative care, with advance care planning, meaning-making, and preparation for the end-of-life.
- Patients nursed in isolation, with minimal contact with their families, are likely to have suboptimal quality of dying and death. Further, in regions such as Sub-Saharan Africa, where large numbers of citizens work abroad, families who have lost loved ones have had no means of returning their bodies or of holding family funeral services.

Key Facts

- Symptom control, particularly of breathlessness and anxiety, and management of delirium, helps isolated patients with severe illness face the end of life without the presence of loved ones. Empathic communication, anxiolytic and sedating medication, and facilitation of digital communication with families and loved ones, including to say goodbye, can help to reduce distress and complicated grief.
- Palliative care can be adapted in the context of infection control measures, to situations where patients are separated from their families, with high physical and psychological symptom burden.
- It can address the escalating incidence of rapidly progressing disease and death in the ICU setting, including the need for more urgent discussions about goals of care, and the potential for greater bereavement morbidity
- Consistent and reliable communication of information from government and public health leaders and from health care providers, can enhance the sense of community and provide a greater sense of mastery over a frightening and invisible adversary.
Current Status

- Palliative care, where available, is activated on an emergency basis with severe COVID-19 infections in order to assess and implement symptom control measures, to alleviate distress in patient and families, to initiate goals of care discussions, to facilitate virtual communication between patients and families as needed and to provide support to bereaved families, when needed.
- There is limited integration and availability of PC in critical care settings or nursing homes, and the activities of hospice services that do exist for homecare have been severely restricted or shut down.

Recommendations to UN member states and civil society organizations

- Develop holistic national strategies for COVID-19 incorporating prevention, medical, palliative and psychosocial care and education that dispels myths and stereotypes related to COVID-19;
- Integrate emergency palliative care with internal medicine and primary care; discuss goals of care with patients and families, including considerations of intensive care admission, in early stages;
- Ensure availability of anxiolytic and sedating medications for use by appropriately trained practitioners;
- Provide healthcare practitioners with coaching in empathic communication and facilitate digital communication with families and loved ones, including for farewells;
- Request that public health officials and health care practitioners deliver clear and consistent communications about precautionary measures, signs of disease progression, treatment access and financial and caregiver support needed to support patients and families. This is particularly important in impoverished areas where there may be limited access of family members to adequate caregiving, health care services, medication, cellphones and internet access, or ability to remove themselves from violent or abusive environments;
- Provide bereavement support as needed for families, particularly those who faced the sudden loss of a family member without time to prepare or to process their distress, including guilt about not being present at the end of life.

References

5. Palliative care and the COVID-19 epidemic. The Lancet. DOI: 10.1016/S0140-6736(20)30822-9

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