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Palliative care in the time of COVID-19

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ABSTRACT

After covid-19 crisis in Italy, serious restrictions have been introduced for relatives, with limitations or prohibitions on hospital visits. To partially overcome these issues “WhatsApp” has been adopted to get family members to participate in clinical rounds. Family members of patients admitted to the acute palliative care unit and hospice were screened for a period of 2 weeks. Four formal questions were posed: 1) Are you happy to virtually attend the clinical round? 2) Are you happy with the information gained in this occasion? 3) Do you think that your loved one was happy to see you during the clinical rounds? 4) This technology may substitute your presence during the clinical rounds? The scores were 0 = no, 1 = a little bit, 2 = much, 3 = very much. Relatives were free to comment about these points. Sixteen of 25 screened family members were interviewed. Most family members had a good impression, providing scores of 2 or 3 for the first three items. However, the real presence bedside (forth question) was considered irreplaceable. They perceived that their loved one, when admitted to hospice, had to say good-bye before dying.

In the last months Italy, the first country to face covid-19 in Europe, has been overwhelmed by the spread of the contagion. After the coronavirus has reached Northern Italy, it spread throughout the entire country. Despite the good palliative care network existing in Italy, this crisis has highlighted some weaknesses of the health care system that could not be foreseen (1).

One of the most important was the lack of availability of equipment required for the protection of patients and health workers (2). Face masks, for example, were unavailable for many weeks and have fueled a disreputable black market. Moreover, there were no exact provisions for physicians who were following patients at home. In Palermo, a metropolitan city of Southern Italy, in March the requests of home care assistance doubled compared to the same period of the previous year, putting stressed teams accustomed to following fewer patients. This was due to a reduced possibility of hospitalization and the shortage of beds for patients with cancer or non-cancer chronic diseases. Ironically, some patients refused the visits for fear of contagion (3).

On the other hand, hospital activity has changed dramatically, due to the barriers imposed for security reasons. The government issued increasingly stringent decrees to limit the conduct of daily life with the aim of preventing contagion. Irrespective of the obligations for health personnel, serious restrictions have also been introduced for relatives, with limitations or prohibitions on visits. They too were forced to use personal protective equipment. All this caused a surreal atmosphere for palliative care in which the presence of a family member next to the patient is essential. Patients remain alone all the day without support, except that provided by the health workers. It is well known that family support in a Mediterranean country is of paramount importance. In response some patients can ask to be discharged earlier than necessary. Sadly, some others die without any final contact with relatives or say good-bye before being admitted to hospice.

Before this crisis, in the acute supportive/palliative care unit, family members were allowed to stay "eight days a week" alongside their loved ones, as it occurs in the hospice, possibly even at night. In the first two weeks after the restrictions enacted by the Health Minister, we have patients and family members been discouraged to do this, drastically changing our way of operating according to the philosophy of palliative care.

This also happened in the hospice, where a caregiver who wanted to stay in the room with his loved one, had to remain all day, without the possibility of going out (3). This was a compromise obtained with our administration. Other visits were prohibited. In such cases patients died alone,

without any relatives' comfort. Indeed, some hospices stopped their activities. To partially overcome these issues we have been adopted "WhatsApp" to get family members to participate in clinical rounds (4). The family members were called live from the patient's telephone number during the doctors' visit to exchange information on the clinical progress and share the choices to be made.

We interviewed the family members of a consecutive sample of patients who were admitted to our acute palliative care unit (8 beds) and hospice (10 beds) in a period of two weeks. The family members of patients who were unable to communicate were excluded. A voluntary interview was performed by phone, about the use of this remote technology, just after the WhatsApp session. Four formal questions were posed: 1) Are you happy to virtually attend the clinical round? 2) Are you happy with the information gained in this occasion? 3) Do you think that your loved one was happy to see you during the clinical rounds? 4) This technology may substitute your presence during the clinical rounds? The scores were 0 = no, 1= a little bit, 2=much, 3=very much. Relatives were free to comment about these points.

Twenty-five patients-relatives couples were screened in the period of 2 weeks. Two relatives refused, six had their loved one unable to communicate. One patient did not agree with the relatives' interview. In such cases information was given by telephone. Thus, sixteen family members were interviewed. Seven patients did not have a smart telephone or an e-Paid. In these cases, a smart phone was offered by the team. The characteristics of patients and family members who agreed with the interview and scores regarding the questionnaire are reported in Table 1. Most family members were happy to virtually attend the visit: "I was happy to see him and you while talking about the treatment"; "It was a pleasure to note the smart atmosphere surrounding my loved one you created "; "I was happy to be updated on the results of the investigations and treatment you proposed, explaining the reasons for such decisions"; "I liked to share your information about the treatments and the next follow-up, albeit at a distance". "I was happily surprised by this initiative". However, most of relatives also added: "I recognize the actual situation is regulated by law, but no technology can provide the same effects experienced by my presence" or "It could be the last time I see him/her". Thus, some of the problems related to government restrictions, could be overcome with simple technology available to most population, proposing a temporary, hopefully, communication model of adaptation to this crisis. However, as expected, this modality of communication cannot substitute the real presence

bedside and should be considered as a temporary measure. While patients admitted to the acute palliative care unit in the majority of cases will be discharged home, hospice patients have a high mortality rate. In fact, in Italy the mean admission time in hospice is less than three weeks, and 86% of patients will die in hospice (5). It is sad to say that patients who are admitted to hospice will say good-bye before dying.

No conflict of interest

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	Patients	Relatives
Age (median, range)	64 (45-83)	49 (40-65)
Karnofsky (median, range)	40 (40-60)	
Gender (M/F)	9/7	5/11
Question 1 (median, range)		3 (2-3)
Question 2 (median, range))		3 (2-3)
Question 3 (median, range)		3 (2-3)
Question 4 (median, range)		0 (0-2)

Table 1. Characteristics of patients and relatives interviewed