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EDITORIAL

End-of-Life Care in the Time of Covid-19 in Brazil: Grief and Communication Issues

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ABSTRACT

The authors comment on communication problems with patients and families in ICUs during the social isolation caused by the COVID-19 pandemic in Brazil. They report new techniques used, such as a virtual visit via WhatsApp, and the creation of multidisciplinary teams to assist family members in overcoming grief after the death of their loved ones.

Introduction

Since the coronavirus disease 2019 (COVID-19) ravages the world, many people have died in a short time. In Brazil, the number of descendent raised 700 thousand persons and go on. The pandemic affected the way terminally ill patients were being cared for, because of requirements for physical distancing, and bereavement rituals could not be performed as usual¹. As stated by Ersek et al.² “these restrictions increase a sense of isolation and distress for families, patients, and staff, and can have significant consequences, including complicated grief reactions for patients’ families”. The key point of high-quality palliative and end-of-life (EOL) care is open communication. New communication techniques were tried to facilitate contact between families and patients, and between medical staff and family members, during this period of social isolation. Thus, alternative communication approaches have been developed to overcome these limitations on interpersonal interaction among patients and their families. Rose, Yu, Casey, et al.³ promoted a survey of 217 UK hospitals, to “understand strategies use to facilitate virtual visiting and associated benefits and barriers” of it. They concluded that “virtual visiting and dedicated communication team were common COVID-19 pandemic addressing the restrictions to family ICU visiting, and they resulted in valuable benefits in terms of patient recovery and staff morale”. In some Brazilian hospitals, the ICU staff promoted a kind of video call using WhatsApp conversation between a patient and his (her) family, with a tablet or mobile phone. Besides, “the situation created by the COVID-19 pandemic brings additional challenges to having a meaningful discussion about advance care planning”, and led Gaur et al. to create a structured tool for communication and care planning that was successfully used in Brazil too⁴.

The Brazilian Experience

However, there is not much information about the effectiveness of these tools in promoting positive patient and family outcomes². In the Brazilian experience, the empirical results seem to support the importance of remote communication among family, patients, and healthcare teams. Most families have no complaints, they were informed every step of the way, and the conversation has no time limit and no rush. On the other way, mainly in the situation where the staff option was to interrupt the treatment (e.g. orthothanasia), the family’s reaction was not so good. There were some complaints about conflicting information between doctors and nurses; if was there any

prospect of prolonging life etc. But the main problem in this situation was obtaining informed consent from the family, especially when the patient was in a coma. There was doubt about the legal validity of consent obtained online. And also an ethical questioning about the information passed on to the family. That is: if the family was really and fully enlightened about the clinical condition of their loved one.

In any case, the use of virtual visit techniques for communication between the medical team and family members has been adopted by Brazilian hospitals in their common intensive care units (not only ICU for Covid-19 patients).

Bereavement and grief issues

Goveas & Shear¹ define bereavement as the “experience of losing a loved one, and grief is the natural response to this loss”. Culturally, Brazilians have the habit of mourning their dead soon after death. Typically, they say, “acute grief is intensely painful and disruptive and often feels overwhelming and unmanageable”¹.

During the pandemic, wakes were banned in Brazil, and those dead due to COVID-19 were buried without the usual services. In our opinion, grief is a complex process, and in sudden deaths, it is elaborated in phases: surprise, denial, revolt, and acceptance. The feeling of guilt for not having been by the side of the loved one in their final moments is also one of the stages of the process, and the most difficult to overcome.

Thus, the wake is an important part of this process, as it allows final contact with the dead and accelerates the acceptance of death as part of life. At the wake there is a tendency for the relative to feel less pain, and, at that moment he begins to work on his feelings towards the deceased, honoring him. Honoring him is often a way to lessen the feeling of guilt for not being by his side in his final moments.

Many family members in Brazil complained about not having been able to mourn their dead and, therefore, not being able to overcome their mourning. For this reason, multidisciplinary teams, including psychologists and religious leaders, were created to help those relatives who were unable to watch over their dead to face mourning and grief. These teams today also help other people, not just family members of COVID-19 victims, to face similar problems.

In summary, despite all the tragedy caused by the Covid-19 pandemic, learning the lessons it brought us was able to promote advances in the management of problems related to the end of life in Brazil.

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