Ethics of rooming-in with COVID-19 patients: Mitigating loneliness at the end of life

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The COVID-19 pandemic is taking many lives around the world. When patients infected with SARS-CoV-2 become critically ill or are dying in hospitals, they must often make do without the physical presence of family members. Family visitation is commonly restricted based on safety concerns. Although spread of the SARS-CoV-2 virus should be prevented, and imposing limits on family visitation in hospitals may be instrumental to this end, separation of family members from critically ill patients is not humane. The moral costs of not being able to be together at the end of life may not outweigh the benefits of reducing risk of infection with SARS-CoV-2. Relaxation of family visitation policies in hospitals is therefore of paramount importance to patients critically ill with COVID-19 and their family members.

As member and chair, respectively, of the Medical Ethics Committee of Erasmus MC, a large university hospital in the Netherlands, two of us (EB and RBV) challenged an institutional policy, implemented in 2020, to stop allowing family members to ‘room in’ with patients. This hospital has single-patient rooms, which facilitates the continuous presence and involvement in care provision of family members, and normally allows rooming in by family members. Per day and/or night, one family member is invited to stay with the patient, with no restrictions regarding visiting time. Rooming in can be continued for as long as the patient, family and healthcare professionals consider it helpful. In the case of dying patients, two family members are allowed to stay 24/7 without restrictions. This policy is meant to help patients experience a peaceful and dignified death. Families feel no need to take their loved ones home to die to ensure presence of family members at the death bed. This is especially important because end-of-life care may not always be adequate at home.

Rooming in seems especially beneficial to help prevent – and, to a lesser extent, treat – delirium, an acute confusional state associated with poorer prognosis, in hospitalized patients [1]. A significant proportion of COVID-19 patients admitted to the ICU are affected by delirium; up to 38% according to a Dutch study [2]. While little research has been conducted to gather evidence on the effectiveness of family involvement in the care of delirious patients, clinical experience suggests that the continuous presence of a family member – day and night – helps to avoid and treat delirium. Also, it helps avert the use of physical restraints, which has adverse effects on patient health and well-being, and may exacerbate delirium [3]. A multicenter cohort study including over 4500 COVID-19 patients admitted to ICUs, showed family visitation to be associated with a lower risk of delirium [4]. In sum, there are medical reasons to allow family members to visit and room in with COVID-19 patients recovering from critical illness.

The Erasmus MC rooming-in policy was abandoned at the height of the first wave of the COVID-19 pandemic, based on three arguments: firstly, to protect family members against infection; secondly, to economize on personal protective equipment, which was, at that time, scarce in the Netherlands and reserved for healthcare personnel; and thirdly, to help minimize the transmission of the new coronavirus, and thus serve important societal interests. Although this policy was consistent with state efforts to protect the health of the population and to keep the pandemic under control, it was not in the interests of individual patients, and went against the express wishes of family members.

The first argument is paternalistic; many family members were willing to risk infection with SARS-CoV-2 in order to be with their loved ones and felt that the importance of nearness outweighed any personal risks. It should be noted that decisions to expose oneself to risk must be made freely by competent adults, and based on adequate information. Elderly partners, unvaccinated relatives and relatives with compromised immune systems especially should be informed about the possibility of severe illness after infection with SARS-CoV-2. Also, physicians should be free to advise against rooming in at-risk family members, and to express a preference for healthy and/or vaccinated family members to room in, instead. At the Erasmus MC university medical centre, we screened family members by telephone or at the hospital entrance, asking them whether they had symptoms associated with COVID-19 and if so, whether they had been tested. Vaccines were not yet available at the time. Family members with symptoms associated with COVID-19 or confirmed COVID-19 were advised not to visit. We did not implement rapid antigen testing as a precondition for family visitation, as this was considered incompatible with (healthy) visitors’ privacy rights.
contrary to prevailing policy of public health services (i.e. testing was made available only to individuals with symptoms associated with COVID-19), and fraught with financial and organizational concerns.

Further, the risk of infection could be minimized: adequate use of personal protective equipment rendered infection or transmission of SARS-CoV-2 very unlikely. However, at the outset of the pandemic, personal protective equipment was scarce. In order to not use up scarce personal protective equipment, family members were willing to remain in the single-patient rooms for long durations of time, or go without protective equipment. Some actually preferred not to wear protective equipment, as they felt they could provide better comfort without wearing masks and gloves. Today, with stocks replenished, there is no longer a need to economize on protecting clothing, gloves and masks in the Netherlands.

The third argument, however, remains: when (unvaccinated) family members are in rooms with COVID-19 patients for sustained periods of time and without adequate personal protective equipment, they risk contracting the disease and transmitting the virus, which is especially important as it could lead to harm to others. However, the risk of harm to others can be minimized if, after rooming in, family members take appropriate hygienic measures, including keeping distance from others, not using public transportation to travel home, and self-quarantine at home. This requires healthcare personnel to give family members careful instructions before leaving the hospital room, and family members to adhere to these instructions.

The Medical Ethics Committee of Erasmus MC university medical centre concluded that the arguments against family visitation and rooming in were not insurmountable. Also, we observed that limits to family visitation were difficult for healthcare professionals. They reported experiencing moral distress as they felt that they had provided substandard care, having to resort to isolation, at times, to avoid harm to the patient. With an eye to the ethical principles of beneficence and respect for autonomy, we reintroduced rooming in at our hospital. Well-informed, healthy family members, who are willing to take on the risk of infection, are allowed to room in with COVID-19 patients, with or without vaccination or protective equipment.

Currently in the US, most hospitals are allowing family visitation for non-COVID-19 patients, but to a much more limited degree for COVID-19 patients, mostly end-of-life visits only. There is no uniform policy, and state laws may mandate differing policies, depending in part on the local state of the pandemic. However, there is ethical premise to argue for a more liberal visitation policy for all patients in the US [5], especially for those who have delirium or may benefit from close contact with their families. In hospitals with more restrictive visitation policies, healthcare professionals are advised to provide visual and vocal contact with family members, using technology devices [6]. There are indications that family video messaging, for instance, helps to reduce agitation in patients with delirium [7].

However, video is not a substitute for real human contact [8]. Physical contact with family members is vital for patients with critical illness. “Having no direct support from the family may lead to the feeling of abandonment and fear of dying alone,” write Kotifs and colleagues [9]. Family members, too, may suffer serious harm when they are not allowed to have physical contact with dying loved ones: “watching someone die on a device is simply cruel and a cause of insurmountable grief” [8]. In all probability, we have only one life to live, and one death to die. To be able to die with dignity is one of the most important moral ends that we can strive towards [10]. Family members should not be withheld from making their own calls about the health risks associated with being present to hold their loved ones and support them in dying or in recovering from critical illness.

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