Human connection has taken on an uncomfortable duality during the COVID-19 pandemic—necessary for our well-being but detrimental to the containment of a deadly and easily transmissible virus. In this context, many hospitals chose to restrict family presence in intensive care units (ICUs) out of concern for family and health care worker safety. Data are accumulating regarding the negative consequences of these policies. Clinicians have reported moral distress stemming from their role in enforcing restrictive family visitation policies, and patients may be spending more time in ICUs because of delayed family conferences about their goals, values, and preferences. However, the experiences of family members, told in their own words, have rarely been heard.

The study by Kentish-Barnes and colleagues in JAMA Network Open is an important contribution to this literature because it highlights the deeply moving lived experiences of family members of patients who died near the height of the COVID-19 pandemic (between April and May 2020) in 12 French ICUs. Three months after each patient's death, the investigators conducted a semistructured interview focused on a family member's experience with critical illness, death, and grief. As a result of being unable to bear witness to illness and at times death, many families reported a sense of unreality or feeling as if their loved one had simply disappeared. They also shared their struggle to cope while separated from their loved one as well as from their usual support networks. In this solitude, ICU clinicians became their sole source of connection to their loved one. Unfortunately, most families reported that communication with clinicians was infrequent or inconsistent and focused solely on sharing medical information rather than providing much needed emotional support. However, a few families offered a more hopeful narrative. They described meaningful connections with clinicians who engaged in simple family-centered tasks, such as reliably calling at the same time each day or delivering messages from families to patients. Some family members also shared their experiences using videoconferencing technologies to convene friends and family to participate in modified grief rituals, such as livestreamed funerals or shared moments of silence.

These narratives share the common thread of disruption and restoration of human connection. Because it was considered necessary to disrupt family presence in the ICU, we must think deeply and creatively about how we can restore meaningful connections among families, patients, and ICU clinicians—and at a distance, if need be. In other words, our challenge is to optimize family-centered ICU care absent the physical presence of family members. The study by Kentish-Barnes and colleagues offers some guidance.

First, we must provide accessible ways for families to see and support their loved ones virtually. One example could be keeping a mobile device in a patient's room to facilitate frequent audio or video communication with their family, ideally in an on-demand fashion rather than waiting for busy ICU clinicians to initiate communication. We have used smartphones, tablets, and streaming cameras to connect patients and families as well as baby monitors and walkie-talkies to connect ICU staff with isolated patients. Other examples may include allowing families to send comforting personal items to their loved ones or encouraging families to keep ICU diaries documenting the experience.

Second, ICU clinicians must communicate with families more frequently than usual, using established frameworks of shared decision-making and empathic communication. We have found that giving updates at regular times, such as after rounds by physicians and at shift change by nurses,
is reassuring and deeply appreciated by family members. Communicating more creatively and often in a different role has become a necessity during the past year. Sometimes, playing the role of message carrier can reinvigorate our perspective on building more humanistic therapeutic alliances. However, we must also recognize the tremendous emotional burden that ICU clinicians have borne during the pandemic. Therefore, when possible, family support should also be shared by other members of the multidisciplinary team, including social workers or family navigators, possibly guided by mobile applications that assess types and severities of families’ unmet needs.

Third, ICU teams should inquire about and accommodate important end-of-life rituals for dying patients to optimize the quality of death and dying for patients and promote the psychological well-being of families. Although there are challenges to providing palliative and end-of-life care in this environment, it is important to remember that these are defining moments in families’ lives that can either create meaning or complicated grief. Pausing to celebrate the lives of our patients may also be an antidote to the depersonalization that so many clinicians have experienced during the pandemic.

We must urgently implement such strategies to promote remote, yet high-quality, family-centered ICU care while reassessing the continued need for restrictive family visitation policies. Unbalanced or unjustified separation of families from their loved ones risks further eroding the trustworthiness of health care institutions. This is particularly relevant in the United States, given the disproportionate impact of the COVID-19 pandemic on racial and ethnic minority communities that have endured a long legacy of forced family separation by institutions.

As access to multiple highly effective COVID-19 vaccines grows, the day may soon come when we can welcome families back into the ICU. We anticipate that the novel strategies that are developed to provide remote family-centered care during the COVID-19 pandemic will continue to be relevant for family members who cannot be physically present in the ICU due to illness, lack of access to reliable transportation, or inability to take paid leave from their workplaces. We hope that our experiences during the pandemic, such as those described in the excellent and timely work by Kentish-Barnes et al., will serve as constant reminders about the central role of families in ICU care and the importance of meaningful human connection to families, patients, and ICU clinicians.

ARTICLE INFORMATION
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REFERENCES

