



Since January 2020 Elsevier has created a COVID-19 resource centre with free information in English and Mandarin on the novel coronavirus COVID-19. The COVID-19 resource centre is hosted on Elsevier Connect, the company's public news and information website.

Elsevier hereby grants permission to make all its COVID-19-related research that is available on the COVID-19 resource centre - including this research content - immediately available in PubMed Central and other publicly funded repositories, such as the WHO COVID database with rights for unrestricted research re-use and analyses in any form or by any means with acknowledgement of the original source. These permissions are granted for free by Elsevier for as long as the COVID-19 resource centre remains active.

Humanities: Art, Language, and Spirituality in Health Care

Close Encounters of the First Kind: An Interdisciplinary Ethics of Care Approach Mitigates Moral Injury and Family Division in the Midst of Covid-19



Ana Berlin, MD, MPH, FACS

Department of Surgery, Division of General Surgery, Department of Medicine, Division of Hematology/Oncology, Adult Palliative Medicine Service, Columbia University Irving Medical Center, New York, New York

Abstract

In this compelling personal narrative describing a case from the front lines of the COVID-19 pandemic, a palliative care physician harnesses the creative powers and strengths of the interdisciplinary team to provide compassionate care to a critically ill patient and his family. The author describes the process of identifying a surrogate decision maker from among the patient's many adult children—several of whom were estranged from him and each other—and facilitating weighty decisions about his end-of-life care. Over the course of this journey, the author grapples with her inner biases and struggles with the emotional trauma associated with bearing witness to extraordinary suffering and social isolation imposed by COVID-19. Not only does the ethics of care approach embodied here lead to the creation of enduring vibrant works of art for this patient and others, but it also affirms a guiding principle of palliative care in which interdisciplinary collaboration is marshalled in the service of cultivating relationships, upholding responsibilities, and intensifying empathy among persons tied together by a common narrative. J Pain Symptom Manage 2022;64:e159–e164. © 2021 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Palliative care, hospice, end-of-life, COVID-19, care ethics, creative arts, art therapy

On March 28, 2020, a 74-year-old man—we'll call him Norbert—saw his internist for a sore throat. The next day, he was admitted to a community academic hospital with shortness of breath and diagnosed with Covid pneumonia. The following day, he was transferred to our flagship hospital for persistent hypoxia with an escalating oxygen requirement. And on April 1, 2020, Norbert was intubated and swallowed up by the ORICU.

The Operating Room Intensive Care Unit (ORICU) was, for many of us at Columbia University Irving Medical Center, the center of the Covid-19 Spring surge. Dozens of newly-minted critical care providers of all stripes led by an intrepid team of oversight intensivists braved long days and nights in a makeshift ICU popped up practically overnight in the footprint of 23 operating rooms on two floors of the hospital. In this palpably hostile environment, the roaring of air handlers and

the constant barrage of fatiguing alarms—from vents, monitors, dialysis machines, beds—left scarcely any space between our ears for an organized series of thoughts. Three, four, and even six to a room, patients in varying states of delirium, agitation, paralysis, and unresponsiveness were cared for, turned when able, and kept alive by a surreal network of tubes, lines, pumps, computers and humans, oddly reminiscent of a scene from *The Matrix*.

I first met Norbert when he was three weeks into his stay in the ORICU. Since his arrival there, he had received antibiotics, pressors, inotropes, inhaled nitric oxide, chest tubes, investigational monoclonal antibody therapies, and myriad other treatments with the hope of seeing him through his complicated viral illness. Throughout this time, his daughter, Yolanda—who, of course, was barred from visiting in person—received daily updates from the team. It was a roller-coaster ride

Address correspondence to: Ana Berlin, MD, MPH, FACS, Division of General Surgery, Columbia University Vagelos College of Physicians and Surgeons, Department of Surgery, 161

Fort Washington Avenue, Suite 562, New York, NY 10032 E-mail: Ab1254@cumc.columbia.edu

Accepted for publication: 31 March 2021.

of information; on several occasions the team was not sure if he would survive the night. On April 22, with no progress made against his respiratory failure and poor neurologic status, the team asked me to help discuss with Yolanda the fact that her dad was at a crossroads: he would either need a tracheostomy for continued treatment, or he would be transferred to the pop-up hospice unit¹ for removal of life support. Only in the latter case would Yolanda have the chance to visit in person to say goodbye. Which did she think he would prefer?

A cardinal rule of palliative care, of course, is to make sure you're speaking with the right person. So it was that in the course of my first conversation with Yolanda, I came to recognize that Norbert had not one, but nine, adult children—some of whom had only learned of each other's existence during their father's critical illness—and a girlfriend overseas. As I reached out to these individuals in turn, and sometimes concurrently, over video calls, I noticed that even though they all described Norbert's personhood in nearly identical terms—"the life of the party," "fun loving," "charming," "dignified," "stubborn," and "young at heart"—they all had highly divergent hopes for his future. For example, the only two children whom he had helped raise—Yolanda and Iris—were most resolute about seeing him in person one last time, even if that meant knowing that he would die in the palliative care unit. Norbert Jr, a son who had only recently learned his true birth story, fantasized about developing a future relationship with his father and watching him pitch baseballs to grandchildren he had yet to meet; he was adamant about continuing aggressive treatment. One removed daughter, Yvette, harbored similar hopes of deepening her recently-established father-daughter relationship. Several more were agnostic on the matter, stating neither one of them knew their father well enough to know what he would choose for himself. Still others lived outside the United States, had not been in contact with the family for decades, and could not be reached.

The New York State Family Health Care Decisions Act of 2010 grants an incapacitated patient's family members or close friends the authority to make end-of-life medical decisions, even in the absence of previously documented treatment preferences or an appointed health care agent. The order of priority for establishing surrogacy is such that, in the absence of a guardian, spouse, or domestic partner, all adult children share equal claim to surrogacy over the patient. So, every day, I would squeeze myself into an equipment room in the ORICU to attempt, over video conference, to establish consensus in Norbert's family about how to proceed in his care, all the while working against multiple racing clocks: biologic fate, dwindling hospital and human resources, and the pressing imperative to clear the operating rooms in order to restore their availability

for other patients in desperate need of life-saving operations.

Each day that ended in ongoing discord within Norbert's family, I would trudge home worried that overnight, nature would take his life, converting the situation into a lose-lose-lose scenario for all involved. On these walks, I grappled with my guilt about being complicit in a coercive system where family members were only granted visitation privileges if they agreed to proceed with comfort-only care. This perverse rule, grounded in institutional and governmental efforts to contain the coronavirus, seemed to me to compound the sense of injustice that would be one of the defining features of the pandemic and its greater context. I wondered whether the questionable benefits offered by the visitation restrictions outweighed the unintended collateral trauma and harm that I was witnessing. I worried that these circumstances, my internal reactions to them, and my personal orientation toward end-of-life care, had biased me into alignment with Yolanda. But, the more I spoke to the other adult children, the more my heart warmed to them—even as I grew increasingly frustrated with their delusional perceptions of their father's "progress" and potential for recovery. In this case and others, I found it especially agonizing to endure holding the mobile tablet while family members implored their loved one to "rise up," and to field their beseeching requests that I validate their interpretation of the patient's agitation and physical suffering as positive signs of neurologic recovery and purposeful communication.

I had other conflicting feelings, too. On the one hand, I felt deeply grateful each day for possessing a rare combination of skills and a calling that could be so deeply tapped in the midst of the hopelessness and existential impotence engendered by the pandemic. At the same time, I resented feeling repeatedly traumatized by simply doing my job, not only bearing witness to the family's dysfunctional relationships, but also having to so actively facilitate these counter-therapeutic virtual interactions. And I wondered uncomfortably whether my personal investment in the outcome of this case exceeded what was professionally appropriate. I needed help.

Another cardinal rule of palliative care is that you don't go it alone, we lean on the other members of our interdisciplinary team to better serve the needs of our patients and our families. Help in this case came from our veteran social worker, Fran Heller, and our long-time chaplain, Soren Glassing. While Fran provided a supportive virtual embrace for this struggling family, and a listening and reflective ear for their individual worries and grievances, I tapped into Soren's skills as a graphic designer and artist. I asked Soren if he could make a giant word cloud highlighting the consensus among Norbert's children's views of their father. My

hope was that such a unifying image would help anchor them together on common ground, so that we could move forward in his care without anyone feeling left behind, unheard, or disregarded. Soren jumped in with both feet, and sent me on a sleuthing mission to gather data for his project. One thing Soren asked me to find out was Norbert's favorite animal. Dutifully, every time I would ask one of his children to tell me about their father, I would casually work in a question about animals, to which the replies were all shockingly consistent: "Our dad hates animals!" I got my break when, in describing his customized Jeep in his native country, Yolanda mentioned her father had wallpapered it with Tweety Bird decals. In my next conversation that day, daughter Yvette shared that the only thing she still owned from her father was a Tweety Bird stuffed animal that he left for her when she was a baby. I immediately texted Soren: "Tweety Bird!"

Armed with all of this reconnaissance, Soren did better than just an ordinary word cloud, channeling his creative energy and own history of recent and remote personal grief into the poster shown in [Fig. 1](#). The artwork literally brought Norbert's family together on one page, and launched an entire series of beautiful and evocative parting gifts for our patients and family members who came through the palliative care unit. To date, over 35 patients have been memorialized with these colorful, vibrant, enduring, and humanizing tributes (see [Fig. 2](#) for additional examples), which are appreciated as much by family members as they are by nurses, doctors, and other staff.

In addition to Fran and Soren, I sought input from colleagues on the Ethics Committee and Hospital legal counsel. We were issued with a directive to achieve consensus from the family—not on a plan of care for Norbert, but rather on the nomination of a sole surrogate decision maker on his behalf. On May 4th, we held a virtual meeting with Norbert's eight reachable children. Although several of them made clear their personal disagreement with Yolanda's decisions for her father, the meeting resulted in unanimous acceptance that she would serve in the role of surrogate, based on her being the only one having been raised to adulthood by the patient and her prior role as his caregiver. All of them agreed that she knew him best, and was best poised to make decisions on his behalf grounded in substituted judgment.

Over the next two days, we supported Yolanda and each other through a journey in which we mutually confronted unexpected ambivalence head-on. Yolanda especially had to come to terms with the pressure of that which she had sought and finally obtained: her newly established position of authority within the family. I, too, was caught off-guard by what felt like a new conflict of interest; despite the directive to engage solely with Yolanda

for decision-making, I had formed relationships with other members of the family whom I was loath to abandon. So, as a team, we provided the other relatives with additional support and virtual visits to ensure they did not feel cut off. In addition, all of us grappled with significant prognostic uncertainty about Norbert's potential survivability. But we kept falling back on two solid girders: first, our objective assessment that his prospects for a return to his functional baseline were nil, and second, Yolanda's confident determination that bringing her father to the best possible outcome would be associated with burdens far in excess of what he would deem acceptable. It was clarifying to realize that a "compromise" among the siblings would have compromised the patient's goals and values. Eventually, despite significant anger and bullying behaviors directed at Yolanda by her siblings, she opted to proceed with palliative extubation.

Forty days after originally seeking care for his sore throat, Norbert was transferred from the ORICU to the Palliative Care Unit, along with his poster displayed at the bedside. Seven family members—several of whom had never met in person—met in the hospital lobby at the appointed time. All had the opportunity to ask questions and speak with the palliative care and ORICU team members, and provided their assent to proceed with extubation according to Yolanda's wishes. By bringing various family members to the unit in waves for different phases of the patient's treatment withdrawal, we accommodated different relatives' hopes and expectations of seeing their father in varying states of alertness as his life came to a natural close. Virtual visits were facilitated throughout the day for Yvette and the patient's girlfriend overseas, and chaplaincy was on hand throughout for prayer and additional support. Though not exactly supporting each other, family members set aside their philosophical differences in a moment of great grief and vulnerability, finding the strength and courage to be cordial and collaborative with each other throughout the afternoon.

I admit I had lingering misgivings about our chosen course of action, right up to and even beyond the moment of extubation. Some relief to my conscience came when another patient was wheeled from the ORICU into the same room of the palliative care unit where Norbert and his family were gathering to say goodbye. The second patient had already undergone a tracheostomy, and he too was to have his ventilator withdrawn. When Yolanda saw the patient with the trach, she said it was just what she needed to know that she had made the right choice for her father. Despite this, in the ensuing months, whenever I would see a "Covid miracle" come to fruition, I felt haunted about



Fig. 1. Word Art poster by Staff Chaplain Soren Ed Glassing created for the patient and family presented in this case. This work was inspired by the common terms with which the estranged adult children of a patient dying of Covid-19 described their father. This concept behind the work was to anchor the family together on common ground, literally bringing them onto the same page so that they could make unified decisions about their father's end-of-life care. Reproduced with permission from Soren Glassing.

whether we did the right thing. In those instances, I found solace in recalling the scene in our palliative care unit, with Norbert comfortable and just responsive enough to acknowledge his children's presence as he

passed away: a moment of unity and physical closeness, experienced by the family as an unexpected gift. In the words of our social worker, Fran, "to see the children together with their father [for the first time and] as a

case. In this model, developed by Carol Gilligan, morality is grounded not in normative notions of justice and beneficence that oppose the self to others, but in the cultivation of relationships, upholding of responsibilities, and intensifying of compassion among persons tied together by a common narrative.^{2,3} When guided by relational ethics, we find ourselves bending rules and considering a broader range of factors than the patient's autonomy and personhood, where our care and decisions are grounded, motivated, and justified by relational considerations. Working as an interdisciplinary crew, we are best equipped to deploy a full complement of skills and attentiveness to the caring relationships, mutual vulnerabilities, and interconnectedness that we share with our patients, families, communities, and colleagues. While this approach is particularly well-suited to the unique context imposed by the COVID-19 pandemic, the applicability of the ethics of care model is hardly exclusive to such extraordinary circumstances. If anything, the turmoil that we have endured together this year has strengthened our commitment to caring for our patients, each other, and ourselves in just this way going forward.

Disclosures and Acknowledgments

No conflicts or financial relationships to disclose.

The names of patients and family members in this case and the accompanying graphics, as well as dates and other identifying details, have been altered to protect confidentiality. The patient's daughter and

surrogate has graciously given permission for publication of her family's story and the poster image portraying her father. Neither this work nor the case on which it is based would have been possible without the partnership of my palliative care interdisciplinary team. The collaboration and artwork of Staff Chaplain Soren Glassing was critical to our support of this patient and his family, and Soren has graciously and expressly granted permission for reproduction of his work as figures accompanying this manuscript. Thank you to Frances Eichholz-Heller for her clinical contributions to this case as well as for her professional and personal support in the crafting of this piece. And I am grateful to Craig Blinderman, Chief of our Adult Palliative Medicine Service, for his support, leadership, and academic insights; I owe particular credit to his contributions to the discussion of the ethics of care approach embodied in this case.

References

1. Blinderman CD, Adelman R, Kumaraiah D, et al. A comprehensive approach to palliative care during the coronavirus pandemic. *J Palliat Med* 2020. <https://doi.org/10.1089/jpm.2020.0481>. Epub ahead of print. PMID:33264065.
2. Gilligan C. *In a different voice: psychological theory and women's development*. Cambridge, Massachusetts: Harvard University Press; 1982.
3. Schuchter P, Heller A. The Care Dialog: the "ethics of care" approach and its importance for clinical ethics consultation. *Med Health Care Philos* 2018;21:51–62.