



Post-Intensive Care Syndrome and the Role of Chaplains

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Today, a patient was discharged after an extended stay in the hospital. As we do for many patients who have survived COVID-19, we celebrated the patient's discharge. Staff who had cared for the patient lined the halls — smiling, clapping and some even had tears in their eyes. There were balloons, and a celebratory song was played over the loud-speaker as the nurse wheeled the patient to their spouse, who was eager and ready to take their loved one home at last. As a hospital chaplain, I know the value of having a case like this patient, to the family, certainly, but also to the medical community. When illness feels overwhelming, having someone who was so sick recover so beautifully changes the mood of all those who worked with them. For many staff in our hospital, this patient was our miracle — that ray of hope that reminded us even the sickest person can get better.

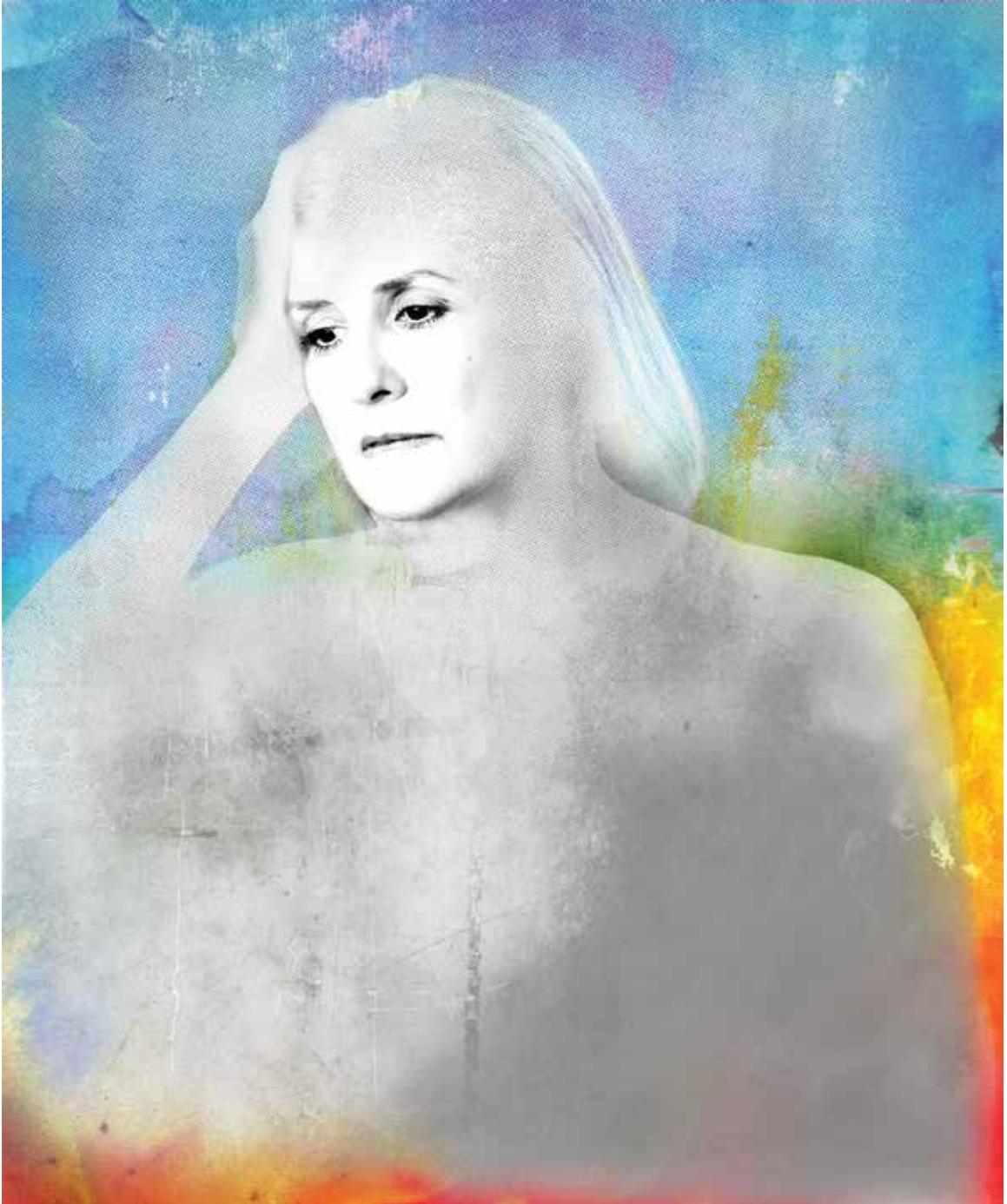
As the patient left, I was happy and wished the patient and family the best of recoveries and a good and long life. But I also found myself concerned not just for the patient, but for many of the survivors of COVID-19. This was particularly true because I had recently spoken to several patients who were recovering from long stays in the intensive care unit and was struck by the consistency of their symptoms. Most notably, it seemed that there were patients who seemed to have nightmares, anxiety or panic attacks and bouts of depression; it was notable because these were patients who for the most part had not experienced those symptoms before. There were also symptoms of a spiritual or existential nature. The recovering patients were processing their survival, their closeness to death, and their loss of memory of

what had happened to them over the last few weeks.

Many of these symptoms seemed to be connected with what is now known as post-intensive care syndrome or PICS, which is a series of health problems that follow a critical illness with a stay in the ICU. These symptoms can last days or even months after discharge from the hospital. Some of

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these symptoms include intensive care-acquired weakness that can last up to a year, cognitive or brain dysfunction, and other mental health problems. The symptoms typically include muscle



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weakness, problems with balance, problems with thinking and memory, severe anxiety, depression and nightmares.¹

A variety of treatments for PICS have been found to be effective. Treatments include the utilization of an interdisciplinary team to follow the patients as they return home. Some disciplines recommended to follow patients post-discharge include physical therapists, occupational therapists, psychiatrists, psychologists and speech therapists. Other useful interventions while in the hospital include creating an ICU diary, encouraging the presence of family, and continuing follow-up emotional support.² Although the research doesn't necessarily specify the use of chaplains, I would argue that at least in the hospital setting many of the treatments for PICS lend themselves to the skill sets that many professional chaplains have developed.

As a chaplain, the symptoms of PICS that I notice the most are of an emotional nature, such as anxiety, depression, nightmares, or sleep disturbance, and the spiritual nature that has to do with the existential processing of having been near death. I remember one patient who, after a long stay in the ICU, reflected on the experience of being intubated for days and not being able to have her family with her due to COVID-19 restrictions. She had experienced many of the emotional symptoms mentioned above. When she was moved to the main floors, she was given the option to be intubated again and returned to the ICU for further treatment. As she reflected on the trauma of being intubated and separated from family, she chose hospice rather than risk the chance of dying alone, away from her husband, and on a ventilator. Although she was not a religious person, I spent a

substantial amount of time listening to her story, her experiences, her dreams, and her struggles with fear and anxiety. As a chaplain, I supported her in making goals of care decisions that honored her experience, her beliefs and values.

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For this patient and for many others, there are two common themes that need to be processed. The first is what has happened, in particular, the fact that they almost died, and the second is the fact that time has passed and they do not have all their memories intact. In these cases, time has literally been stolen from them.

One helpful tool according to numerous studies is the use of an ICU diary as it has been shown to decrease future symptoms of PICS. An ICU diary is a record that catalogues the events of each day in the ICU so that at a later time, the patient can make sense of what has happened during the stay in the ICU. In the ICU diary, family members are encouraged to write notes of encouragement. In one such study, nurses made entries in the diary at the end of each shift. Patients who had an ICU diary were shown to have decreased rates of depression, anxiety and post-traumatic stress disorder symptoms related to their ICU stay.³

The other important issue following a long ICU stay is the patient's ability to process the reality that they have been on life support and, by definition, very near death. The questions of "why am I still here" and "what is my purpose" are reasonable questions to ask and, in the hospital's rush to heal the body, the spiritual and existential questions often get missed. I once spoke to a patient who survived COVID-19 and after over 40 days on the ventilator the first words he told me were, "I shouldn't be here." I have learned that great feeling, depth and loss can be expressed in very few words.

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In this period of COVID-19, when we have an increased number of patients coming off long-term periods of being intubated, we should be mindful of not just the physical recovery of patients but also the spiritual and emotional needs that may surface in the weeks and months after returning home. Contributing to the ICU diary and following up with the patient after leaving the ICU are roles well suited to the chaplain's skill set and would benefit a patient's recovery. Chaplains are a valuable resource for the patient and the care team in developing a plan of care for patients in ICU that are at high risk for PICS and in following the patient's early recovery stages. We often have the time, training and ability to listen deeply and to work with patients in telling their stories. This can help move a patient from merely having survived an illness to having the ability to thrive and recover from a variety of challenges. Spirituality, the support of family and the good care staff can provide may be that extra bit

of strength a patient needs to overcome the challenges of a long-term ICU recovery.

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NOTES

1. Amy Nordon-Craft et al., "Intensive Care Unit-Acquired Weakness: Implications for Physical Therapist Management," 92, no. 12 (December 2012): 1494-506, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3513482/>.
2. For more on post-intensive care syndrome, see <https://www.sccm.org/MyICUCare/THRIVE/Post-intensive-Care-Syndrome>.
3. K.T.A. Blair et al., "Improving the Patient Experience by Implementing an ICU Diary for Those at Risk of Post-Intensive Care Syndrome," *Journal of Patient Experience* 4, no. 1 (September 2017): 4-9, <https://doi.org/10.1177/23743735176927>.

JOURNAL OF THE CATHOLIC HEALTH ASSOCIATION OF THE UNITED STATES

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