**Continue with ICU care – he is a spiritual being**

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**Abstract**

This case study describes a recent case at an oncology center where the teams deemed the care of a patient as non-beneficial/futile. However, there were differences of opinion between the care team and the patient’s surrogate decision-maker (his wife) who argued that there was still meaning in trying to reverse her husband’s current acute events. This case study illustrates the inertia that could result in differences of ICU care and consequently also the moral distress. These issues are described and addressed by virtue of involving an ethics consultant, as well as creating institutional mechanisms to address issues, as described, at an earlier stage.

**Case Study**

Mr. BM was a 59-year-old gentleman, with relapsed T-Cell Acute Lymphoblastic Leukemia (T-Cell ALL). T-Cell ALL, is a leukemia blood cancer which interrupts the normal development of cells, in specific those which would develop into T-cell lymphocytes – which are the building blocks of the body’s immunity system (1). This kind of adult leukemia is not very common, and treatment would usually include a combination of chemotherapy, stem-cell transplant, and, sometimes, clinical trials.

Mr. BM received various lines of therapy, however he still had persistent disease. While his oncology team was looking into investigational chemotherapy Mr. BM developed left upper extremity pain and upper limb edema. Mrs. BM decided to bring her husband to the Emergency Center (EC) and it was found that he was febrile, had sepsis, Acute Kidney Injury (AKI), hyperkalemia and also had sever metabolic acidosis. As the EC physician was busy with his work-up, Mr. BM had a cardiac event and coded. He was resuscitated and transferred to the Intensive Care Unit (ICU), intubated (for airway protection) and started on 4 pressors (to regulate blood pressure). Unfortunately, Mr. BM had altered mental status, was passing large blood clots per rectum and a Gastro Intestinal bleed.

This sudden onset of the acute events was quite distressing to Mrs. BM who was preparing to bring her husband in for another round of therapy and not for life-sustaining measures. In her own right Mrs. BM was a highly educated and well-read person. Her relationship with her husband was more than just the physical, they were spiritual partners as well. To this effect she shared her husbands wishes with the care team and said, “it’s fine if his body doesn’t function as long as his mental acuity is still present, it will be quality of life for him.” This expression is common in the ICU when family members, especially when the onset of the acute event was rapid, prefers to opt for aggressive treatments and to give it a “shot”. Giving up too early (by the surrogate decision-maker/family) can be seen as not trying and advocating for the patient. Studies indicate that emotional distress experienced by family members in the ICU when they need to make difficult decisions often result in severe Post-Traumatic Stress Syndrome, also referred to in literature as Family Intensive Care Unit Syndrome (2).

The role of the ethics consultant is to get a better understanding of the patient’s (and surrogate/family) context. These include things like their value systems, what they see as important in life, their spiritual/religious outlook, their support systems, any other crises they are experiencing (which often translates into existential anxiety). In the initial interaction with Mrs. BM, it was found that both her husband and she did not ascribe to any specific religion, but that they saw themselves as free-spirited beings, akin to nature. She also mentioned that this was their second marriages, which was vastly different from both their first, which were abusive. At last they found happiness, and that she was not ready to let go if it, given that they have only been married for 6 months. Of note was the fact that they rescued a dog together, which became their surrogate child, but that this dog was also facing health issues and nearing the end of her life. All of these emotions were relevant to the ethics consult as it helped the team understand the decisions Mrs. BM made within context. She was scared and was not ready to let go of her husband and also their dog. It became evident during the discussion that Mrs. BM had transference of grief, which resulted in a more complicated picture of anticipated grief.

Unfortunately, as is the case in ICUs across the globe, the care team viewed the case of Mr. BM as futile/non-beneficial and consequently there was disconnect between what they viewed as appropriate and what Mrs. BM viewed as appropriate. The teams continued to give Mr. BM appropriate care, however taking care of him created moral distress to many of the nursing teams, as they were the ones interacting with him on a regular basis and seeing his decline and even skin breakdown. In these cases, the care teams often view the decisions of surrogate decision-makers as inflicting more harm and suffering on a patient, which from their perspective is immoral. This personal view of the situation consequently leads to the individuals of the care team to feel their value system is attacked and separating it from professional values becomes challenging.

It was clear for the ethics consultant that there was a breakdown in communication between the patient’s wife, and his care team and that trust had to be restored. The care team focused on medical futility/non-beneficial treatment, while Mrs. BM countered this with arguing there was still emotional value for her to keep on fighting for her husband’s life. This feeling was intensified when their dog passed away while Mrs. BM was in the ICU at bedside.

Mr. BM’s hospitalization happened at the start of the COVID pandemic. Due to hospital policy Mrs. BM had to shelter-in-place and was not allowed to leave the hospital due to fear of COVID infection. Consequently, she was not able to have any emotional support from friends and family. This isolation took its toll on her, in the effect that she started to get fixated on the smallest change in the daily lab values/vent settings. Any positive change was seen as an improvement and that Mr. BM would recover to baseline. Sadly, Mrs. BM was in total denial of the overall big picture of multi-organ failure and general decline.

**Discussion**

This case has played out in many other ICUs around the globe. Many ethical issues can be identified in this case. Issues that has been highlighted by this case include whether it is appropriate that during a National crisis, where frontline workers are getting exhausted, to extend a month’s worth of ICU care for a patient who was destined to die due to medical futility? Furthermore, why sincere discussions were not had earlier on to circumvent 1 million dollars of healthcare expenditures; burnout of the healthcare team; and causing discomfort with all the labs and test to allow the family to come to terms with the patient’s prognosis? Another issue is that there are several conflicts that take place especially now with COVID, where it is hard for surrogates (mainly because nothing is normal in the ICU) to make these decisions in physical isolation to other members of the support network.

Healthcare practice has moved away in large from a paternalistic approach to embrace patient/surrogate decision-making as the center of healthcare choices. These choices would oftentimes align with the patient’s goals of care and wishes for further treatment. However, when there is an ethical dilemma, as illustrated in this case, then it is important for an ethicist to assist with the case and give guidance. Legislation in different parts of the world give different power-of-authority to healthcare workers, albeit to refuse or limit treatment. The legal framework of where this case took place, has put a lot of emphasis on patient/surrogate’s choices. Consequently, it was important for the ethicist to “build a bridge” with Mrs. BM and to understand her context.

As discussed earlier, the ethicist did exactly that and kept on checking in daily with her. The focus of these check-ins was to normalize the process of decision-making and to be an emotional support in these times of isolation. It was three weeks into Mr. BM’s ICU stay that Mrs. BM acknowledged her great fear of being without Mr. BM. The ethicist, together with a social worker addressed this anticipated grief often manifests as separation anxiety. Through reflective discussions the ethicist-social worker team was able to help Mrs. BM to develop coping skills and help her transfer her fear of being alone to making sure her husband does not suffer anymore and have a dignified death. It took her another 3 days to fully come to grips with this realization, upon which she asked the ICU team to withdraw life-sustaining care and only focus on comfort care. Mr. BM passed without any anxiety within 30 minutes.

Lessons to learn from this case is that the medical team needs to be cognizant of the fact that their timeline is not necessarily the timeline of the patient/surrogate decision-maker. Furthermore, physical isolation causes individuals to hold on to hope, even if it in the bigger picture not realistic. As healthcare workers, we have a duty to understand where our patients/surrogates are in their contextual reality and understanding, and then to meet them on their journey. The authors hold that the services of the ethicist should have been requested earlier, which might have helped to address some of the moral distress experienced by the team.

Just prior to this case’s end, a Goals of Care Rapid Response Teams (GOC RRT) model was developed by a group of stakeholders (including the ethicist) to address similar cases earlier on in the ICU stay. The aim of the GOC RRT is to bring different members of the team together early on in an ICU admission and to facilitate a GOC conversation with all the patients. These conversations have been proven to be highly successful and has now become one of the strategic focus points of the institution where the ethicist is serving.

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