



Special Aspects of ICU Care: Is There an Art to It?

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Ann C. Long

7.1 Introduction

Intensive care unit (ICU) admission is common following hematopoietic cell transplant (HCT) (Saillard et al. 2016; Bayraktar and Nates 2016), and despite advances in both critical care and transplant processes, patients who develop critical illness following transplant continue to experience high mortality (Bayraktar and Nates 2016; Saillard et al. 2016). Many of these individuals will receive aggressive interventions, dying in the ICU after the terminal withdrawal of mechanical ventilation or discontinuation of other life-sustaining measures. For those who survive, the sequelae of critical illness, including physical impairment and symptoms of psychological distress, may follow the patient long after discharge from the ICU (Brummel et al., 2017; Hashem et al. 2016). Given the significant ramifications of critical illness for these patients and their family members, the importance of pursuing high-quality supportive care cannot be overstated. The key components of supportive care—high-quality communication, symptom control, and emotional and spiritual support—are no different for these patients than for other critically ill patients; however, there are special aspects to supportive care for critically ill patients undergoing HCT that warrant consideration.

For patients undergoing transplant, critical illness often occurs against a backdrop of pre-existing physical dysfunction, symptoms from transplant-related complications, and psychological distress (Pallua et al. 2010; Bevans et al. 2014; Chaudhry et al. 2016; Mosher et al. 2009; Cohen et al. 2012; El-Jawahri et al. 2016b). Although most intensivists possess a core set of supportive care skills and

A. C. Long (✉)
Division of Pulmonary and Critical Care Medicine, University of Washington,
Seattle, WA, USA
e-mail: along11@uw.edu

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are adept at providing primary supportive care, the management of severe pain and complex psychosocial symptoms may exceed their capabilities. In addition to these challenges, intensivists must also help patients and their family members navigate the tenuous balance between hope for a lasting cure of the patient's underlying disease process and the real possibility of death in the ICU. This balancing act must occur in close concert with the patient's hematologists, who bring specific expertise to the table and in many instances have long-standing relationships with the patient and their family.

The provision of excellent supportive care to critically ill patients and their family members requires dedicated attention to several aspects of ICU care. First, high-quality communication between providers of different disciplines must be considered as essential as communication with the patient and family. Second, specialty supportive care providers should be introduced early during a patient's ICU stay, particularly when symptom management or psychosocial concerns are prominent or the risk of death is very high. Finally, for patients who will not survive their ICU admission, providers should consider several end-of-life care issues unique to this population, including the support of patients and family members as they cope with a major shift in the focus of care, challenges related to maintaining social support networks, and the need to foster closure of the therapeutic relationship with outpatient providers. This chapter will focus on these specific aspects of ICU care for patients undergoing HCT.

7.2 Importance of Interdisciplinary Shared Decision-Making for Patients in the ICU

Early during the assessment and management of a critically ill patient, ICU providers are primarily focused on addressing the life-threatening physiologic derangements that led to ICU admission. As the patient stabilizes, the ICU team begins to develop an understanding of the patient's overall trajectory, and for many critically ill patients, the intensivist has all of the expertise he or she needs to provide prognostic information to patients and their family members. Patients who have undergone HCT, however, present unique challenges for ICU providers who may not have a complete understanding of the patient's underlying disease process or how it relates to overall prognosis. For this reason, hematologists should be considered essential members of the critical care team to ensure that intensivists have all of the information they need to provide appropriate care. The intensivist needs key details about the disease process that led to transplant, the post-transplant course to date, and any estimates of projected disease-free survival in the event that the critical illness is overcome. The hematologist, on the other hand, should respect the intensivist's experience managing critically ill patients, as many conditions managed in the ICU, such as acute respiratory distress syndrome or septic shock, carry their own prognostic implications. All involved parties must acknowledge that an ICU admission for a patient following HCT is a critical transition in a patient's course that may dramatically affect the patient's overall trajectory (Mayer et al. 2017; Platon et al. 2016). Residual prognostic uncertainty can set the stage for discord among various providers, often specifically related to the application of aggressive, life-sustaining

therapies. When such situations arise, it is imperative that all involved providers find common ground, in order to present clear and consistent communication about prognosis and treatment goals to patients and their family members. Conflicting information may generate confusion and frustration for patients and family members and also contribute to difficulties with decision-making (Iverson et al. 2014; Reeves et al. 2015; McNeese et al. 2016).

Although many providers may feel that they collaborate well with other members of the healthcare team, there is evidence to suggest that much of the decision-making that occurs in the ICU takes place independently (DeKeyser Ganz et al. 2016). Following HCT, independent decision-making by intensivists or hematologists about prognosis or treatment options may thwart efforts to engage in primary supportive care or may delay the involvement of specialty supportive care providers. In the ICU, interdisciplinary shared decision-making should be viewed as an essential component of supportive care in transplant. Although there is no standard approach to interdisciplinary care in the ICU, there are many different ways in which providers can improve the current processes in place at their institutions. One potential method involves daily multidisciplinary meetings between critical care providers and hematology team members. Multidisciplinary care has been championed in the ICU environment in the form of multidisciplinary rounds (Durbin 2006; Kim et al. 2010), but these interactions are typically confined to members of the ICU team, including nurses, pharmacists, respiratory therapists, advanced care practitioners, and physicians. There is limited information about the impact of multidisciplinary meetings that specifically involve the patient's critical care team and other subspecialty providers involved in the patient's care; however, the potential benefits of these meetings seem readily apparent. Multidisciplinary meetings provide an opportunity for providers who may have very different impressions of the patient's clinical condition to develop a shared perspective about the patient's disease process and overall prognosis. Based upon these conversations, a consistent message about the treatment plan can be shared with the patient and family. Although these meetings may not completely mitigate the provision of inconsistent information to patients or their family members, they are certainly a step in the right direction. Furthermore, multidisciplinary meetings offer healthcare providers an opportunity to address intra- and inter-team conflicts, including concerns that the care being provided is not concordant with the patient's expressed values and preferences. Efforts to improve communication between providers may attenuate disagreement, resolving conflicts that have the potential to negatively impact patient care and provider well-being (Azoulay et al. 2009; Danjoux Meth et al. 2009; Fassier and Azoulay 2010; Martins Pereira et al. 2016).

7.3 Early Involvement of Specialty Supportive Care in the ICU

Specialty supportive care has been shown to attenuate decrements in quality of life for patients with hematologic malignancies hospitalized for hematopoietic stem cell transplant (El-Jawahri et al. 2016a). Although there is little to no evidence assessing the effects of specialty supportive care on patient-centered

outcomes for these patients in the ICU, benefits from specialty supportive care for those who are not critically ill supports the concept that specialty supportive care could also improve outcomes for critically ill patients. However, barriers to the introduction of specialty supportive care in transplant still exist (Roeland and Ku 2015). HCT is an intense process, which carries significant risk for the patient but also the potential for a sustainable cure of what might otherwise be a terminal disease process. Patients consent to the receipt of toxic therapies and may experience significant pain and suffering in the pursuit of long-term survival. In some ways, HCT may seem at odds with the goals of supportive care, which is largely focused on quality of life, not necessarily quantity of life. However, there are many circumstances in which a patient can receive care directed at sustaining both quantity *and* quality of life. For example, a patient with septic shock can receive fluid resuscitation, undergo placement of central venous access, and begin vasopressor support to maintain mean arterial pressure, all while receiving supportive therapies intended to control severe oral pain from mucositis or manage the anxiety associated with a period of clinical deterioration. Supportive care is not at odds with the management of a patient who has elected to pursue aggressive interventions in the ICU. Rather, patients who have already dealt with significant pain and suffering prior to ICU admission should be expected to have even more of a need for supportive care once critically ill. The case can be made that any patient admitted to the ICU following HCT should be evaluated by specialty supportive care. However, the reality is that there are a limited number of specialty supportive care providers available to care for the growing number of patients undergoing HCT (Lupu 2010; Kamal et al. 2017). There is a clear need to increase the available workforce of specialty supportive care providers, but until this need can be met, critical care providers can take the patient's symptom burden and overall prognosis into consideration to help ensure that the benefits of specialty supportive care are realized by patients and family members most in need.

Among patients who face critical illness in the setting of transplant, several subpopulations should receive strong consideration for early involvement of specialty supportive care. Patients with severe symptoms or complex psychosocial needs should be considered a priority for specialty supportive care consultation. For patients admitted to the ICU with severe symptoms related to the transplant process, including pain, nausea, mucositis, or diarrhea, specialty supportive care can provide tremendous assistance by helping the critical care team develop a treatment plan that will be effective in the context of new physiologic derangements (Roeland et al. 2010a). Psychosocial symptoms may also be a significant concern, and specialty supportive care providers can help patients and family members cope with illness, recognize, and treat symptoms of psychological distress, and process grief and loss (Roeland et al. 2010b). Furthermore, for many patients in the ICU, ongoing prognostic assessments allow patients and their family members to reassess their willingness to focus on quantity of life when it may actually interfere with the relief of pain and suffering, for instance, when mechanical ventilation is involved. Specialty supportive care providers can dedicate their

time and expertise to helping the patient and family understand the role of comfort care measures in the ICU as they consider the process of terminal withdrawal of life-sustaining therapies.

Another group of patients who should be high priority for specialty supportive care referral includes individuals whose overall prognosis is grim. For patients who have undergone HCT, several factors have been consistently associated with a poor prognosis following ICU admission. These include the need for mechanical ventilation (Paz et al. 1993; Price et al. 1998; Kroschinsky et al. 2002; Afessa et al. 2003; Soubani et al. 2004; Pene et al. 2006; Scales et al. 2008; Huynh et al. 2009; Trinkaus et al. 2009; Townsend et al. 2013; Lengline et al. 2015; Mokart et al. 2015; Faucher et al. 2016; Platon et al. 2016; Mayer et al. 2017), the presence of multi-organ failure (Soubani et al. 2004; Pene et al. 2006; Trinkaus et al. 2009; Agarwal et al. 2012; Benz et al. 2014), and the need for vasopressor support (Kew et al. 2006; Huynh et al. 2009; Trinkaus et al. 2009; Boyaci et al. 2014; Mayer et al. 2017). Other special populations who may also be at high risk for mortality include patients experiencing early relapse, particularly with high-risk hematologic malignancies (Mielcarek et al. 2007), patients with active or acute graft versus host disease (Pene et al. 2006; Bayraktar et al. 2013; Lengline et al. 2015; Escobar et al. 2015; Platon et al. 2016), and patients who develop idiopathic pneumonia syndrome (Crawford and Hackman 1993; Kantrow et al. 1997; Afessa et al. 2001; Yanik et al. 2014). The impetus for involving specialty supportive care providers for patients with these risk factors is not only related to the significant potential for death in the ICU, but also related to poor prognosis among those who survive to ICU discharge. Patients with these risk factors may survive their ICU stay but then experience death within the coming weeks to months. Specialty supportive care providers can be introduced in the ICU and then supportive care can be continued outside of the critical care setting for those who survive. In many ways, an ICU admission for respiratory failure, multi-organ failure, or shock should serve as a clear signal to the healthcare team that specialty supportive care may be indicated, particularly when prognostic uncertainty may have curtailed previous discussions about supportive or end-of-life care (Odejide et al. 2014). Involvement of specialty supportive care providers should occur early for these patients, as late referrals may make it difficult for consultants to adequately address symptom burden, explore psychosocial needs, or assist in the transition from full, aggressive measures to a comfort-focused approach (Button et al. 2014).

7.4 End-of-Life Care for Patients Undergoing Hematopoietic Cell Transplant and Their Family Members in the ICU

For patients undergoing HCT, critical illness often leads to death (Saillard et al. 2016; Bayraktar and Nates 2016). Key elements of end-of-life care for these patients are identical to those recommended for other critically ill patients, and should include a focus on shared decision-making with patients and their family members,

high-quality communication about the dying process, and a well-planned approach to symptom control and the withdrawal of life-sustaining therapies (Truog et al. 2008). In addition to providing these core elements of care at the end of life, intensivists should also consider aspects of care that may be unique to these patients and their families. Specific issues include the support of patients and family members as they cope with a major shift in the focus of care, challenges related to maintaining social support networks, and the need to foster closure of the therapeutic relationship with outpatient providers.

Transitioning from the pursuit of life-sustaining therapies to a focus on comfort is often a major shift in care for patients following HCT. Transplantation is typically undertaken with the central objective of curing an underlying malignancy and sustaining life, and when it becomes apparent that this objective will not be met, the patient and their family members may feel completely overwhelmed. When this realization occurs hours or days prior to the patient's death, which is often the case in the ICU, patients and their family members have little time to process a complex array of emotions. Compared to bereaved family of patients who have not undergone transplant, family of patients who have undergone HCT may experience higher levels of psychological distress following the patient's death (Drew et al. 2005; Jalmisell et al. 2011). This seemingly abrupt transition in treatment goals may contribute to these symptoms of psychological distress, making bereavement and support services an especially important element of end-of-life care for these patients and their family members. The potential for such emotional upheaval is yet another reason why patients at high risk of death in the ICU may benefit from the early involvement of specialty supportive care providers who can help patients and family members cope with this sense of loss and grief.

Another aspect of end-of-life care that may require special attention for patients following transplant relates to the presence of social support from friends and family members. Many patients have travelled far from their homes to receive care at specialized transplant centers. For these individuals, their support system in the ICU may only consist of a small number of immediate family members, with the majority of their social support network left in the patient's hometown. The healthcare team should make efforts to facilitate patient interaction with loved ones who cannot be near and also support the family in their desire to make the ICU feel as much like home as possible for the patient. Following death, social workers can play an integral role in helping the family coordinate funeral arrangements, especially for those who plan to transport the decedent to another state.

Finally, the role of the patient's outpatient transplant team cannot be forgotten during the end-of-life process. There is often a long-standing relationship between the patient and family and the providers who have guided them through the transplant process. In some circumstances, providers from the outpatient setting also provide inpatient services and may be very familiar with the patient's ICU course. However, in other situations, the outpatient provider may not be aware of the course of events that led to ICU admission or the patient's severity of illness. In these cases, it is reasonable for the critical care team to update the outpatient

hematologist and also explain any plans regarding the patient's end-of-life care. Concerns about loss of continuity and abandonment at the end of life are very real for patients and their family members (Back et al. 2009), and the critical care team can play an important role in helping to maintain the link between the outpatient and inpatient realms. In addition, this kind of communication allows the patient's primary hematologist to engage in the grieving process with the family and gives them an opportunity to seek closure of the patient-family-clinician therapeutic relationship.

7.5 Expert Opinion

ICU admission is common among patients undergoing HCT, and the development of critical illness is often a major event influencing a patient's overall trajectory. Many of these patients will die following ICU admission. For those who survive critical illness, physical disability and symptoms of psychological distress may affect quality of life long after discharge from the ICU. Importantly, caregivers for these patients must also cope with the burden imposed by critical illness. Supportive care is essential for critically ill patients and their family members, and should include high-quality communication between providers of different disciplines and early involvement of specialty supportive care providers, particularly when symptom management or psychosocial concerns are prominent or the risk of death is very high. For those patients who will not survive their ICU admission, end-of-life care must address issues unique to this patient population, including the support of patients and family members as they cope with a major shift in the focus of care, challenges related to maintaining social support networks, and the need to foster closure of the therapeutic relationship with outpatient providers.

7.6 Future Directions

There is a paucity of evidence to inform the best approach to providing high-quality supportive care for patients who develop critical illness following hematopoietic stem cell transplant. Rigorous study of the role of supportive care in the ICU is necessary, and particular attention should be paid to addressing outcomes that matter most to patients and their family members. Strategies to improve existing supportive care practices in the ICU include interventions to enhance interdisciplinary shared decision-making and efforts to promote early involvement of specialty supportive care. Future research should also focus on the potential role of intensivists and specialty supportive care providers outside of the ICU, specifically in the decision-making processes that occur immediately prior to ICU admission. Additionally, there is a need to develop a better understanding of the experiences of family members of patients who die in the ICU following HCT, in order to ensure that their supportive care needs are met.

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