



Providing Compassionate End of Life Care in the Setting of Mechanical Circulatory Support

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Abstract

Purpose of Review To outline key elements in providing compassionate end-of-life care for pediatric patients with end-stage heart failure on mechanical circulatory support (MCS) such as extracorporeal membrane oxygenation (ECMO) and ventricular assist devices (VADs).

Recent Findings Approximately one in five pediatric patients with end-stage heart failure die on VAD support, with higher mortality associated with patients supported on ECMO. While it is considered ethically and legally permissible to withdraw MCS, pediatric-specific guidelines regarding indications and end-of-life management on MCS are lacking.

Summary A multidisciplinary approach with early consultation of the palliative care team is essential for all patients being considered for MCS. Guiding families through end-of-life care on MCS requires frequent and honest communication by engaging in shared decision-making regarding prognosis and potential clinical pathways, advanced care and preparedness planning, and identifying and meeting patients'/families' goals of care.

Keywords Palliative care · Pediatric cardiology · Ventricular assist device · Extracorporeal mechanical support

Introduction

Some of the most difficult medical decisions faced by pediatric providers and families of seriously ill children are whether and how to use (and/or discontinue) life-sustaining medical technologies. Mechanical circulatory support (MCS) technologies, such as extracorporeal membrane oxygenation (ECMO) or ventricular assist devices (VADs), are among the most invasive and intensive of interventions, typically employed in a variety of life-threatening situations where heart and/or lung function has failed maximal medical therapy. The goal for pediatric patients is typically to “bridge” the patient to recovery of lung and/or heart function, or, for

patients with irreversible heart failure, to heart transplantation. Unfortunately, recovery is not always possible, and the wait for heart transplantation may take too long or patients may suffer adverse events leading to devastating consequences that alter the burden versus benefit considerations of continued MCS support. Families and providers are subsequently faced with end-of-life decisions for a child on MCS.

How can the care team help families navigate the significant emotional roller coaster and complex decision-making entailed with deploying and then discontinuing life-sustaining technologies such as VADs and ECMO? How and when should palliative care consultants be involved? What are the relevant ethical considerations? What is the best time to have these difficult conversations? And how can the care team ensure excellent end-of-life care during compassionate deactivation of MCS? In this review article, we explore the nuances of palliative care and MCS technology in pediatric patients with end-stage heart failure and address these important questions.

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Background

Mechanical circulatory support is reserved for children with end-stage heart failure refractory to maximal medical

management. ECMO is often employed when patients acutely present with refractory cardiogenic shock and impending cardiovascular collapse. ECMO may also be deployed in the midst of cardiopulmonary resuscitation (extracorporeal cardiopulmonary resuscitation, ECPR) to acutely support the patient from a cardiopulmonary perspective, recover end-organ function, and allow for further assessment and treatment. In these cases, there is often not time for a prolonged multidisciplinary discussion about next steps, but rather ECMO is deployed acutely to avoid death. In contrast, elective or semi-elective implantation of a VAD, or transition from ECMO to a VAD after initial stabilization, is often a complex decision undertaken by the multidisciplinary team of surgeons, cardiologists, critical care physicians, and nurses in the setting of progressive decline [1]. In all cases, the decision to place a child on MCS should ideally be made before emergent support is needed to allow time for adequate discussions with family and caregivers about the implications of the decision.

Outcomes of Pediatric Mechanical Circulatory Support

When discussing outcomes of MCS, it is important to consider ECMO and VAD outcomes separately, as well as the indication for support. Overall, the survival to ECMO decannulation for cardiac patients is 69% among neonates and 74% in the pediatric age-group. However, not all patients who survive ECMO decannulation survive to hospital discharge (only 45% and 57% survival to discharge in the neonatal and pediatric cardiac populations, respectively). Survival for patients requiring ECPR is worse with only 43% survival to hospital discharge [2]. In the modern era, the average ECMO course lasts approximately 1 week with increasing morbidity and mortality associated with longer ECMO duration [2–4]. For children requiring a prolonged ECMO course (≥ 14 days), survival falls to $< 25\%$ and very few who required continued support survived to transplantation [5]. Given these poor outcomes and long waitlist times for heart transplantation, many centers will transition appropriate patients from ECMO to long-term VAD support once end-organ function and respiratory status improves to better rehabilitate patients awaiting transplantation [6, 7].

Outcomes for patients supported with VADs vary significantly based on patient age, size, and underlying diagnosis, in part because of the interplay of complex anatomy, hemodynamics, and device capability and selection. Older children and teenagers are able to accommodate intra-corporeal devices that were originally designed and FDA-approved for adults, whereas infants and younger children are typically supported by ECMO or para-corporeal (pulsatile or continuous-flow) devices [1]. Survival varies significantly by age and device type with a 6-month actuarial survival of

52% in neonates compared with 86% in teenagers. Overall, by 6 months post-implantation, 51% were successfully bridged to transplant, 7% underwent explantation related to cardiac recovery, 18% of patients died, and 23% were still alive on VAD support [1]. Despite the growing experience with pediatric VAD support, adverse event rates are high with 62% of patients experiencing at least 1 major adverse event. Complications are highest in the first 3 months after implantation with bleeding (27%), infection (24%), and neurologic dysfunction (23%) being the most common [1]. Often, the most concerning adverse events in this population are either ischemic or hemorrhagic strokes which occurred in 19% of paracorporeal pulsatile devices, 11% of the paracorporeal continuous devices, and 11% of the intracorporeal devices [1].

Indications for Discontinuation of Mechanical Circulatory Support

Unfortunately, despite best intentions, a child may be placed on MCS only to find out there is no definitive end-point if the child is unable to wean from support and is ultimately deemed not a heart transplantation candidate. Determining heart transplantation candidacy is itself a complex decision requiring input from the various members of a multidisciplinary heart transplantation team. Children may have an underlying disease (e.g., certain mitochondrial disorders) or persistent multi-organ dysfunction that precludes heart transplantation. Alternatively, the child may experience a serious complication as an adverse event related to MCS (e.g., ischemic or hemorrhagic stroke or dialysis-dependent renal failure) that results in a situation that is no longer consistent with the families' goals of care or successful heart transplantation. While MCS may be able to maintain the circulatory system, it alone cannot always provide a quality of life that would be acceptable to the patient and family. In these cases, the medical team is tasked with having discussions with the patient and caregivers regarding the best path forward for that patient and family.

Ethics of Withdrawal of Life-Sustaining Technology

In the USA, it is legally and ethically permissible for patients or their surrogates to decline initiation or request withdrawal of life-sustaining medical therapies [8–10]. This right is grounded in respect for persons and the principles of autonomy (self-determination), beneficence, and nonmaleficence [11]. For children, parents and healthcare providers are tasked to use the best interest standard as the basis of their decision-making, pursuing the option that optimizes the benefit-to-burden ratio. Although it may seem counterintuitive to think of death as being in anyone's "best interest," The American

Academy of Pediatrics, in its statement on “Guidance on Forgoing Life Sustaining Medical Treatment,” states that “when the balance of benefits and burdens to the child shifts, forgoing life-sustaining medical treatment is ethically supportable and advisable” [12••]. Similar ethical analysis in pediatric care that allows for withdrawal from mechanical ventilation and in some circumstance nutrition and hydration can also apply to MCS [13–15]. When possible, this conversation should also involve the child or adolescent to provide an opportunity to participate in an age- and developmentally appropriate fashion in decisions that affect his or her life and care plan.

Despite the consensus evident in the ethics literature, pediatric providers have variable knowledge and beliefs about ethical and legal aspects of compassionate deactivation of MCS [16–18]. In a recent survey of pediatric VAD providers, in which most respondents had participated in compassionate deactivation of a VAD for a pediatric patient, only 38% of respondents felt fully informed of the ethical issues, and 15% of respondents felt fully informed of the legal issues related to pediatric VAD deactivation [17••]. Furthermore, while pediatric VAD providers agreed “that VAD deactivation is sometimes necessary to relieve suffering”, there was wide variability on the specific indications for VAD deactivation, with strongest agreement (88%) for stroke or severe neurologic injury but no consensus on examples such as ventilator dependence (45% agreed, 34% disagreed) or “other life-shortening condition” (48% agreed, 23% disagreed) as indications for VAD deactivation [17••]. This ambivalence likely contributes to moral distress experienced by providers, and there is widespread agreement that additional pediatric MCS and VAD-specific guidelines on compassionate deactivation need to be established [16, 17••, 19••, 20••].

Palliative Care Consult

Early integration of palliative care for pediatric patients with life-limiting conditions and their families has been shown to enhance quality of life, improve symptom management, and facilitate communication and decision-making [19••, 21, 22]. Palliative care consultation is now a required component of comprehensive care for advanced heart failure in adults and is increasingly recommended for children with heart failure [19••, 23–25]. Strong partnership between the primary heart transplant/intensive care unit (ICU) teams and the palliative care consultants allows for families to be optimally supported throughout the emotionally difficult process of pursuing and then discontinuing MCS. While primary palliative care, including symptom management, attention to quality of life, discussion of prognosis, and advance care planning, can be provided by the primary heart transplant/ICU teams, the particularly complex and often time-pressured nature of decision-

making related to MCS is widely considered an appropriate trigger for specialty palliative care consultation [19••]. Additional benefits provided by specialty palliative care consultation include expertise in pharmacologic and non-pharmacologic management of pain, nausea, dyspnea, and fatigue, and an additional source of continuity in providers.

Palliative care consulting teams are multidisciplinary and take a holistic approach to assess for physical, emotional, and spiritual support needs and to understand the patient’s and family’s values and goals. When the initial consult is coordinated with the heart transplantation team, this discussion can occur in the context of patient-specific diagnostic and prognostic information best provided by the primary team. Subsequent conversations may be prompted by changes in the child’s condition, adverse events that shift the benefit to burden ratio of MCS, or evolution of the patient’s/family’s goals of care; these discussions may also be best accomplished in a collaborative, coordinated manner between primary and specialty teams.

Shared Decision-Making

Early Conversations and Informed Consent

End-of-life discussions between caregivers and healthcare providers about a child who has developed a poor prognosis on MCS do not occur in isolation. Rather they evolve over a series of conversations that ideally begin before a child is placed on MCS. The opportunities for in-depth family meetings prior to MCS in part will depend on the child’s clinical status, which may vary from resuscitating a critically ill child emergently onto ECMO to a relatively stable teenager with end-stage cardiomyopathy on inotropes scheduled for durable VAD. As part of the informed consent process with families about these advanced technologies, it is important to review the risks of mortality and development of adverse events and their potential implications [26].

Informed consent around introduction of MCS must include both ethical and psychological considerations and can be divided into 3 phases: (1) initial information phase to review consent, indications for MCS, the surgical procedure, the technology, expected recovery, and potential for unexpected events; (2) a pre-implant preparation phase to discuss advanced care and preparedness planning; and (3) a palliative plan phase to discuss potential MCS-specific end-of-life issues and to define when and how to withdraw life-sustaining technology, if indicated [27].

It is important to counsel families through patient-specific scenarios. For example, a patient on MCS as a bridge to transplant could suffer a catastrophic stroke or develop significant end-organ damage and subsequently become ineligible for heart transplantation, resulting in removal from the wait list.

In starting these conversations prior to implantation as part of the informed consent process, it gives an opportunity for providers and families to consider potential difficult pathways, including removal from life-sustaining technology, and decision-points that may lie ahead. A useful resource from the adult literature published by Swetz et al. describes a “how-to” guide on preparedness planning before MCS [28•]. The authors include sample statements to guide open discussions with families about commonly encountered complications of MCS, such as “Bleeding or strokes can develop in up to 20% of patients at some time. If a stroke affected your quality of life, how would you feel about continuing VAD therapy if you could not accomplish what was originally intended?” [28•]. Unfortunately, guidelines for how to talk with children about preparedness planning during MCS are lacking, and a family-oriented and developmentally appropriate approach is essential [19••].

Discussing Prognosis and Goals of Care

Throughout the course of any child on MCS, but especially when the child experiences a complication or develops a poor prognosis, it is important for clinical team members to provide families with honest and frequent communication using clear language [29]. Although much of this communication will happen at the bedside, offering formal meetings with families can be helpful in ensuring a unified message. Be mindful about the timing, location, and participants of family meetings, as these events are often quite stressful for caregivers. Ensure that the appropriate people are present, including sources of emotional support identified by the family. Identify which team members and how many people will be present for family meetings—ideally providers who know the family well—which may include critical care physicians, primary cardiologists, palliative care, social work, chaplaincy, and nursing staff. The team members should prepare and meet in advance to discuss the patient’s clinical status, ensure the team has a shared mental model of the patient’s prognosis, and to identify goals and structure of discussion [26].

Shared decision-making is a key element of providing family-centered care and is widely endorsed as the ideal framework for complex medical decision-making in critical illness [30]. Decisions about MCS for children with advanced heart failure present a unique set of choices about potential tests, treatments, and clinical decisions which rarely fit neatly into the published models, and for which there is often no “right” answer. We recommend a recent series of articles published in the journal *Pediatrics* that highlight the nuances of shared decision-making in the pediatric population [31–35]. Essential elements of a discussion around goals of care according to Walters et al. include the following: (1) The identification of what families know or have been told about their child’s disease or condition; (2) A clear delineation for families of their child’s current clinical status and

prognosis; (3) An assessment of whether the family is prepared to continue the difficult conversation and what questions they may have; (4) A review of the potential options, e.g., “loving parents make different decisions about where to go from here”; (5) A description “in detail of the different paths forward”; (6) The eliciting of parental and patient concerns or questions, “Can you tell me what your concerns are if we go down path A?” (7) An inquiry as to how much healthcare provider input the family wants in making decisions; (8) A discussion around the families values and how to align those values with the potential care plan; (9) If asked, offering “a recommendation on the basis of the parents’ values and your medical expertise”; (10) Providing the family assistance to make a decision or defer a decision to a later time; and (11) Making plans for follow-up [32••].

Throughout the course of treatment of heart failure, but especially when it is recognized that the child is unlikely to survive, it is important to be honest with families and prepare them for what is happening with their child. Blume et al. performed a multicenter survey of bereaved parents of children with advanced heart disease and found that these parents realized that their child had no realistic chance for survival a median of 2 days prior to death, and 18% of parents reported they never realized their child had no realistic chance to survive [36]. About half of parents also reported that their child suffered “a great deal”, “a lot” or “somewhat”, and identified difficulty breathing, difficulty feeding, and pain as the most common symptoms associated with suffering [36]. This data suggests that waiting until death is imminent to talk about end-of-life care causes harm, and highlights opportunities for significant improvement in end-of-life care for the pediatric heart failure population. In preparation for end-of-life and withdrawal of life-sustaining technology, it is important to discuss with families what to expect, the symptoms their child may have and how the team will address those symptoms to prevent and alleviate suffering. The team should also acknowledge and address other types of suffering experienced by the patient and the family, including psychological and spiritual distress, and should include spiritual care and psychosocial support as indicated.

These conversations must be grounded in an empathic, culturally sensitive, family-centered and patient-centered approach [37•, 38•]. Such skills are increasingly being incorporated in medical school and post-graduate training and are the cornerstone of palliative care education. We recommend that cardiology and critical care trainees seek out elective experiences with multidisciplinary palliative care teams and guide the reader to practical educational resources for enhancing communication skills, courses such as *VitalTalk*, and other published curricula [39, 40].

Developmentally Appropriate Approach

It is important to use a developmentally appropriate and family-oriented approach when talking with children and

mature minors about MCS and advanced care and preparedness planning. Depending on the critical nature of the illness and the child's age and development, children will have varying degrees of awareness. When possible, prior to MCS implantation, children should be included as part of the informed consent and assent process. Particularly for mature minors, it is important to explore and understand their wishes ahead of time. With guidance from the palliative care team, these early conversations of the wishes of the child/teenager can be explored with advanced care planning resources such as *Voicing My Choices, My Wishes*, [41–43], and *Five Wishes* [19••, 44].

At end-of-life, there are three themes often identified that contribute to a child's distress: "loss of control over their bodies and what is happening to them at any given moment, loss of personal identity (e.g. soccer player, cheerleader, social leader, class clown), and loss of interpersonal relationships (e.g. best friends, friendship groupings)" [45]. It is important to identify these losses and address the emotional and psychological needs of the child and adolescent, often with guidance from child psychology, child life, palliative care, social work, and chaplains. Communication can take many forms and may include drawing, writing, playing, and conversations [29, 45]. Similarly, the impact on siblings must be addressed in a developmentally appropriate manner to help them understand, cope, and grieve.

Approach to Conflict

Given the subjective nature of applying the best interest standard and balancing burden and benefits of a given treatment such as MCS, conflict may arise between parents or other caregivers and physicians. Usually these can be resolved with careful discussion, understanding goals of care, identifying the root cause of the conflict, and correcting any misunderstandings. Given the invasiveness and high risk of MCS, significant latitude is typically given to parental authority to decline or request withdrawal, but conflict can more easily arise between the medical team and patients and parents/caregivers considering initiation or discontinuation of MCS. When parents disagree with the medical team's recommendation for compassionate deactivation, significant distress for both the family and the medical team ensues. Unilateral decision-making (i.e., discontinuing ECMO against the parents' wishes) is vulnerable to bias, difficult to apply equitably, and risks legal repercussions for the hospital as well as severely complicated grief for the family. Rather, the medical team should engage the family in a supportive, compassionate manner to carefully explore parental goals of care, speak frankly about whether those goals are indeed achievable, and consider together which treatments best support those goals. The official joint policy statement on "Responding to Requests for Potentially Inappropriate Treatments in Intensive Care Units," as well as the AAP, reminds providers to proactively employ

intensive communication and basic principles of negotiation and conflict resolution, to engage the support of spiritual care providers and consultants in palliative care or ethics, and to allow families reasonable accommodation in terms of timing of discontinuation while avoiding prolonging suffering for the patient [12••, 46]. In anticipation of the very rare situations in which conflict cannot be resolved through these steps, institutions should develop policies to ensure a fair process, including hospital review, meaningful attempts to find a willing provider at another institution, and opportunity for external review of decisions [46].

Compassionate Deactivation

There are many considerations, planning, and logistics involved in proceeding with compassionate deactivation of MCS. We highly recommend a review by Dryden-Palmer et al. on the practical considerations of withdrawal of life-sustaining therapies for children cared for in a pediatric ICU as well as a checklist by Machado et al. on VAD compassionate deactivation in pediatrics [20••, 47••]. Both reports stress phases of preparation and the importance of anticipatory guidance. Machado et al. highlight four key categories of preparation specific to pediatric VAD compassionate deactivation: (1) team communication and preparedness planning, (2) the family meeting, (3) interdisciplinary end-of-life care at the bedside, and (4) preparation of family at the bedside [20••].

First, the providers must identify the key team members and review plans for each life-sustaining therapy including MCS, nutrition, fluids, dialysis, inotropes and vasoactive medications, inhaled nitric oxide, mechanical ventilation, pacemaker or implantable cardioverter defibrillator. Second, the family meeting should identify the families' goals and wishes and help prepare families for what to expect next. Who do they want present at the bedside? Do they want to hold their child, be in bed with them, or in a chair? Discuss bereavement rituals and plans for after death. It is important to review with families what to expect in terms of timing of death and its unpredictability, whether it might be minutes, hours, or days. The team should document advanced directives per hospital policies and local laws. Next, team members should enter and adjust appropriate medication orders, outline roles, and rehearse the sequence of steps involved in compassionate deactivation. Specific to withdrawal of MCS, it is important to know how to deactivate alarms ahead of time. Each device has specific steps and contacting the device representative beforehand can be helpful for step-by-step instructions to maintain respectful silence at the bedside. Lastly, it is important to prepare families for being at the bedside. Explain to families the ongoing comfort care the child will be receiving and how the team will address symptoms and strategies for discomfort [20••].

Symptom Management

As MCS is withdrawn, close attention and aggressive symptom management must be employed to prevent and relieve any suffering. A multi-modal approach will be most effective, utilizing both pharmacologic and non-pharmacologic strategies. The pathophysiology of profound heart failure can be used to advantage: if circulatory support is weaned rather than abruptly discontinued, diminishing cardiac output will gradually result in a decreased level of consciousness that can prevent significant suffering in and of itself. For patients who are mechanically ventilated, simultaneously decreasing minute ventilation will allow hypercarbia's relaxing, somnolent effect to facilitate sedation. Additional sedation can be provided with opioids, GABA-agonists such as benzodiazepines or barbiturates, or with a dissociative agent such as propofol.

Opioids can effectively relieve pain from manipulation of cannulae or other procedures, and also addresses dyspnea, typically at lower doses than what is necessary for analgesia. Many, if not most, patients for whom MCS is being withdrawn will have been on continuous opioid infusions or receiving regularly scheduled opioids, so it is important to adjust dosing to account for tolerance.

As part of holistic care provision, families may be interested in additional integrative medicine strategies such as aromatherapy, acupuncture, massage, meditation, reflexology, and energy therapies such as reiki, among others. There are limited studies on the benefit to patients in terms of symptom burden at end-of-life [48]; however, evaluating the effectiveness of these therapies often are not well suited to analysis using the traditional scientific method. Importantly, the use of such modalities might carry a great deal of meaning to some families, and as long as they do not detract from the child's comfort or disrupt or delay medical care, it is well worth accommodating families' wishes.

Family/Caregiver Bereavement Support

As for any patient, bereavement support for the family should be integrated with palliative care, such that it begins before and carries on after the child's death. The time leading up to withdrawal of MCS is an opportunity to provide families with anticipatory guidance about what to expect before, during, and after their child's death, to assess for important beliefs and logistics related to religious and cultural rituals, to evaluate for practical needs (e.g., inability to afford a burial or cremation), to remind families of the support services available to them, and to offer the opportunity for memory-making. Such services will vary by location, but may include making handprints, footprints, plaster molds, a memory box with locks of hair and other remembrances, or professional photography services [49].

Families are deeply touched and appreciative when hospital staff who helped care for their child attends the funeral or

memorial service or send a thoughtful card or phone call [50]. Hospital-based bereavement programs can provide much-needed support and connection for parents and siblings after a child's death. Physicians and other staff from the heart failure team should offer to meet with families in follow-up to provide emotional support, answer questions about the child's medical course, and invite feedback regarding the family's experience [51].

Conclusion

The decision to proceed with MCS implantation in pediatrics is usually performed with the goal of bridge to recovery or heart transplantation. When faced with devastating adverse events or a poor prognosis, the transition for families and providers towards end-of-life care while on life-sustaining technology is extraordinarily challenging. Essential to compassionate care at end-of-life on MCS is clear, honest, and frequent communication between the medical team and the family, with an emphasis on preparedness planning. Palliative care consultation is recommended prior to device implantation to guide families through difficult decisions as well as anticipation of symptom management. Through the process of shared decision-making, the medical team and the family should weigh the perceived benefits and burdens of continued life-sustaining technology, aligning treatment with the patient and family's goals of care. Once the decision is made to proceed with compassionate deactivation, it is important to prepare and review logistics with the team and to provide families with anticipatory guidance of what to expect. Guiding families through the loss of a child is a difficult journey, and through multidisciplinary collaboration and a family-centered approach, we hope to provide compassionate care to minimize children's suffering and to support grieving families.

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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