

Chapter 13

Palliative Care in the Adult Solid Organ Transplant Recipient



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Introduction: Overview of Palliative Care

Palliative care is specialized medical care for people living with serious illness that focuses on quality of life for both the patient and family [1]. Palliative care interventions can be provided regardless of prognosis and have been associated with improvements in quality of life, symptom burden, and patient and caregiver satisfaction [1, 2]. A common misconception is that palliative care cannot be delivered if a patient is being actively treated for a disease; rather, palliative care is completely compatible with disease-directed therapies. Additionally, palliative care interventions increase rates of advance care planning and decrease overall healthcare utilization [1, 3, 4].

The Institute of Medicine's 2014 report *Dying in America* calls for training all clinicians in the core principles of palliative care: pain and symptom management, communication skills to determine patient/family goals, and coordination of care to achieve those goals [5, 6]. The term "primary palliative care" refers to basic palliative care skills that all clinicians should learn regardless of specialty, such as aligning medical treatment with patient goals and basic symptom management [3]. When

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Table 13.1 Primary versus specialty palliative care

Primary palliative care	Specialty palliative care
Basic palliative care skills Pain and symptom management Communication skills, especially eliciting patient and family goals, coordinating care May be delivered by primary care providers, specialists, or any member of a patient's care team Both inpatient and outpatient	Advanced palliative care skills Treating refractory symptoms Facilitating complex medical decision-making around approaching end of life, worsening health status or organ dysfunction, or cognitive decline Navigating challenging family dynamics Performed by practitioners who have completed additional training, e.g., fellowship, board certification Both inpatient and outpatient

patients with serious illness present to their primary care clinicians, this may be an opportunity to incorporate palliative care interventions into their medical care. Referral to specialty palliative care may be needed in cases of refractory symptoms, worsening health status or cognitive decline, approaching end of life, consideration of a high-risk procedure or other advanced therapy, complex existential distress, or conducting a challenging family meeting (Table 13.1) [3, 4].

Palliative Care in the Solid Organ Transplant Recipient

Palliative care has been proposed for patients with advanced organ failure beginning at diagnosis and continuing through transplant and beyond, given the associated high morbidity and mortality awaiting transplantation and post-transplantation [4, 7–12]. Palliative care interventions in patients awaiting solid organ transplantation have been associated with improvement in patient symptoms and increased documentation of advance care planning discussions [4]. There is some evidence to suggest that palliative care after transplantation may also improve symptoms [13].

Primary care providers have a unique opportunity to incorporate palliative care interventions, such as revisiting advance care planning and basic symptom management, into the care of solid organ transplant recipients. As noted in previous chapters, the increasing number of solid organ transplant recipients creates a larger role for primary care providers. Furthermore, palliative care specialists are few in number and do not have the capacity to provide consultation on all transplant recipients before and after transplantation. Therefore, primary care providers with palliative care skills ideally would fill this need whenever possible [3]. Depending on a patient's transplantation course, the transplant specialist's time may be completely occupied by managing immunosuppression, treating infectious complications, warding off rejection, and checking for graft dysfunction. Primary care providers often have the advantage of having a long-term therapeutic relationship, in some cases both before and after transplantation. The primary care provider typically continues to manage chronic and acute medical problems, provide preventative care, and may have a history of knowing the patient's decision-making preferences and

values, as well as familiarity with a patient's social situation. Studies have consistently shown that patients want the physicians caring for them, rather than outside specialists, to discuss advance care planning [14, 15]. While solid organ transplant recipients may have a close relationship with their transplant specialists, they may be hesitant to bring up palliative concerns with their transplant specialist because of concern for disappointing them—some patients may feel more comfortable broaching this topic with the primary care provider.

Advance Care Planning

Advance care planning (ACP) is the ongoing process by which patients share personal values, goals, and preferences regarding current and future medical care [16]. These preferences should then be documented in the medical record and in an advance directive (AD). Conversations between patients and their physicians regarding preferences for care in the setting of serious illness have been associated with increased goal-concordant care, decreased use of unwanted life-sustaining treatments, higher incidence of preferred place of death, and increased hospice use at end of life [17–20].

Advance Directives

An advance directive (AD) is a legal document that indicates a person's preferences for medical care if he or she were to become seriously ill or incapacitated [21, 22]. Having written documentation of a person's wishes can promote more goal-concordant care, unburden caregivers with having to guess the wishes of their loved one in a health crisis, and help avoid unwanted medical care [17, 18, 23, 24]. An advance directive typically includes preferences for life-sustaining treatments in the setting of serious illness (Living Will) and addresses who would be the person's surrogate decision maker if he or she were to become incapacitated (Durable Power of Attorney for Healthcare, DPOA-HC).

Whereas an advance directive can be completed by an adult at any age or stage of health, a "Provider Orders for Life Sustaining Treatment" form is an optional document in the United States (terminology varies, also called POLST, MOLST, POST, MOST, COLST, or TPOPP) that focuses on adults with serious illness or frailty. The POLST serves as a physician's order to guide care outside of the hospital. Unlike an AD which is completed by a patient and signed by a witness or notary, a POLST form must be completed and signed by the patient and a physician or advanced practice provider. These forms serve distinct purposes and are complementary, not duplicative [21].

There are many types of advance directive documents available, some specific to a given state or institution [21, 22].

Table 13.2 Types of advance directives in the United States^a

Type of AD	Comments
Living Will [21, 22]	Typically includes wishes related to life support, CPR, ventilator use, artificial nutrition, and hydration in different circumstances, such as a persistent vegetative state or terminal illness Requirements for these documents are based on state-specific regulations; most require signatures from two witnesses with many restrictions on who can serve as witness (e.g., excluding patient's family members, health care power of attorney, and medical providers and staff) and some require a notarized signature
Five Wishes	Only available in some states https://fivewishes.org/
Veterans Affairs Documentation	For patients who receive care through the United States Veterans Affairs healthcare system https://www.va.gov/geriatrics/Guide/LongTermCare/Advance_Care_Planning.asp#
End of Life Washington	Example of state-specific advance directive (United States) https://endoflifewa.org/advance-directive/
Provider Orders for Life Sustaining Treatment (POLST)	https://polst.org/

^aMay vary by state; other countries often have similar types of documents, although local laws may vary. For example, the following websites are available in the United Kingdom: <https://mydecisions.org.uk/> and <https://compassionindying.org.uk/library/advance-decision-pack/>

Table 13.2 summarizes advance directive documents used commonly in the United States.

Internationally, while the fundamental concept of advance directives is similar (a patient's right to self-determination of health), laws and practices differ with regard to duration of effect, surrogate decision-makers, and government oversight [25]. Additionally, advance care planning tools and research are largely based on Western concepts of autonomy and decision-making [26]. Advance care planning discussions should be approached with cultural and narrative humility, including consideration of cultural and religious beliefs and acknowledgment of the provider's roles and responsibilities in a patient's story and that "patients' stories are not objects we can comprehend or master" [27].

Advance Care Planning in Solid Organ Transplant Recipients

Solid organ transplant recipients have unique aspects to their advance care planning. First, they have all, by definition, dealt with (and survived) life-threatening organ failure. Their pre-transplant illness may vary considerably, however. Many patients who have successively received a solid organ transplantation have indeed had a difficult pre-transplantation course, including progressive decline in health, multiple hospitalizations for organ failure, complications, difficult symptom control, and

healthcare-associated trauma. However, a relatively smaller subset of patients may have had a comparatively smoother course. For example, some patients with end-stage renal disease are able to successfully live through dialysis and kidney transplantation and still maintain a good quality of life prior to transplantation. A patient with fulminant hepatic failure from an ingestion may have had a severe but brief illness, with good health prior to liver transplantation. If the primary care provider did not know the patient prior to transplantation, it is important to review the patient's pre-transplant history for duration of illness, quality of life, and complications (see Chap. 2).

Second, because advance care planning discussions should recur as health or life circumstances change [6, 16], a major life event such as solid organ transplantation should prompt revisiting of advance care planning. In addition to reviewing the pre-transplant history, the primary care provider should review the post-transplant course the patient has experienced before returning to primary care. As with the pre-transplant course, the perioperative and early postoperative experience can vary widely by individual; some patients may enjoy a relatively smooth journey free of complications, while others may have early difficulties with graft function, rejection, infections and other hospital complications. Although patients may have had pre-transplant conversations with their clinicians and/or families about their preferences, their goals and wishes may change during the transplant process. Goals of care may evolve following transplant, and it is recommended that any prior documentation is reviewed with patients once they have recovered and returned to primary care. It is important not to assume that prior discussions or advance care planning documents still represent the patient's current wishes; therefore, even in those with prior discussions and directives, it is important to revisit them as the patient's preferences may have changed. If patients have not had advance care planning discussions or completed an advance directive, it should be encouraged.

Third, while the life expectancy and quality of life of solid organ transplant recipients have significantly improved over time, these patients are still at increased risk for complications such as infections, graft dysfunction, organ failure, and malignancy [28, 29]. One feature of effective ACP programs is repeated discussions over time, and this is certainly merited post-transplantation given these risks [16]. Approximately one in three adults in the United States has completed any advance care planning documentation with rates highest among patients over age 65; notably, although age is no longer a strict contraindication to transplantation in most centers, only 12% of transplant recipients are over 65 years old [30, 31].

Despite these clear rationales to address advance care planning in the care of solid organ transplant recipients, there is sparse literature with specific guidance on ACP post-transplantation. Nevertheless, given the experience of end-organ failure, transplantation, and ongoing risks of complications, it is reasonable to have advance care planning be a part of a routine post-transplantation care for all solid organ transplant recipients. There is some data to support using a disease-specific approach for ACP discussions. Studies of patients with heart failure or with end-stage renal disease on dialysis suggest that disease-specific approaches result in better surrogate understanding of patients' goals and more goal-concordant care decisions at

Table 13.3 Primary care assessment after organ transplantation: advance care planning and cues to further discuss palliative care

Topic	Example questions
Post-transplant primary care—Routine assessment at initial visit(s) Review pre- and post-transplant course Duration of illness, complications, end-of-life or near-death experiences, hospitalizations, healthcare trauma	<i>How has the transplant experience been for you?</i> <i>What surprised you about the experience?</i> <i>Was anything more difficult than you expected?</i> <i>Was anything easier than you expected?</i>
Symptom assessment at all visits	<i>Do you have any symptoms that are troubling you?/Tell me about any symptoms that may be bothering you.</i>
Previous advance care planning Documents, including advance directive, power of attorney for healthcare Prior discussions	<i>Are you familiar with advance care planning?</i> <i>Have you discussed advance care planning before transplantation? Would you be willing to talk about it today?</i> <i>Have you reviewed your advance care planning documents since your transplant?</i> <i>Who are the important people with you in your health and wellness? Who are your sources of support?</i>
Situations in which revisiting palliative care discussions is indicated: Organ dysfunction Irreversible graft failure Discussion of re-transplantation or needing a different organ transplantation Ongoing problems with symptom control Recurrent hospitalizations	

the end of life [32, 33]. Table 13.3 summarizes suggested assessment of advance care planning and palliative care needs for solid organ transplant recipients in the primary care setting.

Challenges with Advance Care Planning in the Primary Care Setting

Challenges to ongoing advance care planning and completion of advance directives in the primary care setting include inadequate time during patient visits, lack of education and resources related to advance care planning, billing concerns, and problems with documentation and access in electronic health records (EHRs) [34, 35]. In the United States, as of January 2016, Medicare reimburses physicians and advanced practice providers for advance care planning counseling under a separate billing code; however, estimates suggest that use of this reimbursement remains low [36, 37].

Documentation of advance care planning conversations is essential for the information to be used by patients over time and should be accessible to clinicians in

various settings and across the care continuum. Ongoing efforts are being made by EHR vendors to enable clinicians to store and find advance care planning information so that it is easily accessed. Despite this, there are ongoing challenges, such as lack of training and no centralized and consistent location for advance care planning information in the EHR [34].

Resources for Improving Advance Care Planning Skills

There are decision aids for patients and resources to help clinicians build their skills in having conversations about patient's preferences regarding future medical care and personal values (Tables 13.4 and 13.5).

Symptom Management in Solid Organ Transplant Recipients

Advanced chronic disease, including in solid organ transplant recipients, can lead to symptoms of fatigue, depression, anxiety, pain, shortness of breath, peripheral edema, ascites, nausea, pruritus, decreased appetite, sleep disturbances, and encephalopathy [4, 9–12]. Patients may have symptoms post-transplantation due to surgical recovery, toxicity from immunosuppressive medications, or graft dysfunction

Table 13.4 Resources for advance care planning conversations

Resource	Description	Links
Advance Care Planning Decisions	Non-profit subscription service for providers with free videos on advance care planning for patients	For clinicians: https://acpdecisions.org/ For patients: https://acpdecisions.org/patients/
IHI Conversation Project	Guide in multiple languages for families to use in having the initial conversation	https://theconversationproject.org/
VitalTalk	Communication frameworks for goals of care conversations and delivering difficult news	https://www.vitaltalk.org VitalTips App (Apple or Android)
CAPC Communication Skills	Online course on communication skills Membership required and CME available	https://www.capc.org/training/communication-skills/
Conversation Resources Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life	Variety of Resources from the National Academies of Sciences, Engineering, Medicine	http://nationalacademies.org/HMD/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life/The-Conversation.aspx%20

Table 13.5 Helpful questions and statements for discussing advance care planning

<i>Exploring</i>
“How do you feel things are going with your health?”
“Can you talk more about what you mean when you say...?”
“Will you tell me more about...?”
<i>Responding to emotion</i>
“This must be frustrating, I know you’ve been waiting a long time for...”
“Will you tell me more about what you’re worried about?”
“I know this can be hard to talk about...”
<i>Support</i>
“I would like regular appointments with you to continue to support you in this.”
“I appreciate your willingness to talk about this.”

[4, 12]. Lung transplantation is associated with high symptom burden [12]. In the early post-transplant period, the transplant team and/or pain specialists manage symptoms. When patients return to primary care, the primary care provider may begin to manage pain and other symptoms.

A symptom screening tool, such as the Edmonton Symptom Assessment System (ESAS), may be helpful for screening and longitudinal monitoring of symptoms in solid organ transplant recipients [38]. If the etiology of a symptom is unknown, diagnostic evaluation may be warranted to determine the underlying cause.

Symptom management goals often differ pre-transplantation, in the immediate post-operative recovery period, and long-term post-transplantation. Whenever possible, it is recommended to treat the underlying cause of pain and other symptoms. This is dependent on whether an effective treatment is available and on the patient’s prognosis and goals of care. For patients who have undergone successful solid organ transplantation and have a resulting improvement in symptoms, the focus may be on discontinuing opioids and other symptom medications. In one study, patients receiving palliative care while awaiting lung transplantation had opioids discontinued in a timely manner postoperatively [4]. Non-pharmacologic and less-invasive measures should be utilized to treat pain and other symptoms whenever possible.

Patients with persistent symptoms from post-transplantation complications or other causes may require opioids or other medications. Opioids are effective in treating pain and dyspnea, common symptoms in advanced chronic disease, but caution is warranted due to the risks of addiction and opioid overdose that may result in death, and other adverse effects such as worsening encephalopathy and constipation [38]. Patients with liver and kidney dysfunction have a higher risk of adverse medication side effects, including with opioids, due to impaired clearance of drugs and their metabolites. Initiation or escalation of opioid therapy, for any symptom indication, may be a good time to revisit goals of care discussions with patients.

Pain

Pain management in the solid organ transplant recipient can be a significant challenge. Transplant recipients may have pain related to transplantation or chronic or acute pain due to other causes. After evaluation and treatment, if appropriate, of the underlying cause of pain, non-pharmacologic interventions should be considered. Non-pharmacologic interventions associated with improvement in chronic and/or postoperative pain include manipulative therapy, acupuncture, massage therapy, mindfulness-based stress reduction (MBSR), cognitive behavioral therapy (CBT), physical therapy, biofeedback, and movement therapies such as yoga [39].

When medications are utilized, it is recommended to start with non-opioid analgesics. Over-the-counter pain medications such as acetaminophen may benefit some patients, even those with liver failure. Short-term use of acetaminophen at 4 g/day may be appropriate; one study showed no adverse effects when acetaminophen was given to patients with stable liver disease [40]. Recommendations for longer term use include decreasing the dose to 2–3 g/day and should always be discussed with transplant team before using doses that exceed 3 g/day in the liver transplant recipient [11]. Nonsteroidal anti-inflammatory drugs (NSAIDs) are not recommended in patients with liver or kidney failure because of increased risk of kidney injury, hepatorenal syndrome, and bleeding, and they interfere with the effect of diuretics [11]. Furthermore, chronic kidney disease is common in solid organ transplant recipients, and NSAIDs are often routinely avoided in this population because of the high risk of kidney disease (see Chap. 11). Heart transplant recipients receive routine aspirin therapy and the use of NSAIDs increase the risk of bleeding and cardiovascular disease (see Chap. 6). Gabapentin and pregabalin should be dose-reduced or discontinued in renal failure patients, in particular in end-stage renal disease (ESRD) patients when dialysis is stopped [41].

For patients with moderate to severe acute or persistent pain, opioids may be appropriate to manage pain. Initiation or escalation of opioid therapy for persistent or worsening pain or other symptoms may warrant a discussion of goals of care. If oxycodone, morphine, or hydromorphone is prescribed in the setting of end-stage liver disease, dose reduction and increased dosing intervals are recommended due to impaired elimination [11]. In kidney and liver failure, toxic morphine and hydromorphone metabolites accumulate and may cause adverse effects [11, 41]. Morphine should be avoided in patients with both liver and renal dysfunction due to the resulting risk of neurotoxicity [11].

Fentanyl and methadone are good options for patients with severe liver or kidney disease as they do not have known altered kinetics. The recommendation is to start with low doses and titrate slowly, and methadone should be prescribed by those with adequate clinical experience with its use [11, 41]. If these medications need to be used, consider consultation with a pain specialist or palliative care specialist.

Dyspnea, Cough

Solid organ transplant recipients may experience dyspnea and cough from advanced chronic disease or complications of transplantation. The underlying cause should be determined and treated whenever possible. Dyspnea can be difficult to manage and can be a sign of advanced disease or graft failure. In cases of refractory or difficult-to-manage dyspnea, especially when initiating or escalating opioids or benzodiazepines, patients' goals of care should be revisited.

Management of dyspnea should often include nonpharmacologic measures in conjunction with medications. Nonpharmacologic measures that can improve symptoms include upright positioning and/or use of a fan (or open window) to increase air movement [42]. For patients with hypoxia, oxygen therapy may help ease their discomfort. Opioids often provide relief from dyspnea refractory to the treatment of the underlying cause [42]. In opioid-naïve patient, start with low doses of an oral opioid such as morphine. Patients who are opioid tolerant often need higher doses. Benzodiazepines can also be considered for breathlessness, though they may have more sedating effects than opioids and are considered second- or third-line treatment [43].

Diarrhea, Nausea, and Constipation

Diarrhea is common in solid organ transplant recipients and can lead to serious complications and impact the quality of life. It is important to determine the cause of diarrhea in solid organ transplant recipients since they have a higher incidence of opportunistic infections, chronic diarrhea, and diarrhea as a medication side effect (see Chaps. 3, 8, and 9). Targeted treatment against pathogen(s) identified and fluid replacement should be prioritized [44]. Reduction of transplant medication dose or changing to other immunosuppressive regimens can be attempted by the transplant team when pathogens are ruled out [44]. For patients that have a negative test for *C. difficile* and no evidence of megacolon or inflammatory diarrhea, empiric antimotility agents should be considered [44].

Nausea and constipation are common symptoms in advanced chronic disease. As with other symptoms, the underlying cause must be evaluated and treated whenever possible. Nausea and constipation may be the result of a medication side effect and discontinuation is recommended if possible. Acupuncture, ginger, pyridoxine (vitamin B6), or a low-fat or liquid diet may provide relief from nausea [45]. The cause of nausea may be helpful in choosing an antiemetic, though the etiology may be multifactorial or uncertain. Types of antiemetics include anticholinergics, antihistamines, benzodiazepines, atypical and typical antipsychotics (for example, haloperidol and olanzapine), cannabinoids, corticosteroids, phenothiazines, serotonin 5HT₃ antagonists, and pro-motility drugs such as metoclopramide. Due to side effects and drug-drug interactions, caution is recommended with choosing an antiemetic. Phenothiazines and metoclopramide can cause extrapyramidal side effects.

Serotonin antagonists, such as ondansetron, have constipation as a side effect [45]. If uncertain, the primary care provider should consult with the transplant team or a transplant pharmacist to minimize the risk of adverse drug effects or interactions.

Non-pharmacologic measures for constipation may provide some relief, though evidence is limited, and include scheduled toileting, exercise, and increased water and fiber intake [46]. Pharmacologic options for constipation include osmotic laxatives, such as polyethylene glycol and lactulose, and stimulant laxatives, such as senna and bisacodyl. For opioid-induced constipation refractory to other laxatives, a mu-opioid antagonist may provide relief [45]. Stool softeners such as docusate have not been shown to be effective in treating constipation [47].

Edema

Heart, liver, or kidney failure can all lead to fluid accumulation, which can build up in many areas including the abdomen, lungs, and extremities. Diuretics and sodium restriction are the mainstays of treatment for edema in patients with heart failure and liver disease, with close monitoring needed for volume status, electrolyte abnormalities, and renal function. The symptom burden of edema, and the need or desire for medical optimization of volume status, should be balanced against the potential inconveniences of pill burden, frequent urination, and laboratory monitoring. Refractory ascites may require procedural interventions for management, depending on feasibility and a patient's goals of care.

Depression and Anxiety

Depression is the most prevalent psychiatric disorder in the post-transplantation population [48]. Current recommendations for screening for depression and anxiety in the outpatient setting include use of patient-reported measures, such as Patient Health Questionnaire-9 (PHQ-9) and General Anxiety Disorder -7 (GAD-7) [49]. Solid organ transplant recipients may experience feelings of guilt for the donor or other patients who are still on the waiting list or did not survive [50]. It is important to differentiate guilty feelings from depression (which can include guilt) based on history, presence of other depressive symptoms, and examination findings. Adjustment-related symptoms can also occur. Medication therapy includes a selective serotonin reuptake inhibitor (SSRI), with preference for escitalopram and sertraline because of fewer drug interactions with anti-rejection medications [48]. Citalopram may be used, but it may cause QT prolongation; the maximum dose of citalopram recommended for patients over the age of 60 or with liver impairment is 20 mg/day and caution is advised for patients with congestive heart failure, bradyarrhythmia, and if receiving other medications that prolong the QT interval [51]. Venlafaxine, duloxetine, and mirtazapine are also reasonable options since they

appear to have few effects on cytochrome P450 and therefore not likely to significantly interact with immunosuppressants [50, 52]. Mirtazapine can be considered a second-line treatment in post-cardiac transplant patients with cachexia, since they may benefit from its side effect of appetite stimulation [50]. For patients with renal and/or liver dysfunction, caution is advised, and for some antidepressants dose reduction is recommended [50, 52, 53] (see Chap. 3). Mindfulness-based stress reduction techniques can help decrease depressive symptoms and increase quality of life in solid organ transplant recipients [54]. Psychotherapy with an SSRI has been shown to be effective in treating patients with depression after cardiac transplantation [50].

Palliative Care Resources for Clinicians

There are resources available for palliative care clinical questions that include symptom management topics (Table 13.6).

Transplant Failure

Even with perfect preparation, technical skill, postoperative care, and medical management, some transplants will fail. Any solid organ transplant failure should trigger additional conversations around goals of care as they may shift over time. Consider palliative care consultation in any patient with organ failure with any of the following signs: significant change in health status, significant change in functional status or cognitive decline, high or increasing symptom burden, worsening disease based on disease-specific classification or markers, consideration of advanced therapies, frequent visits to the ER or ICU admissions, patient or family request, or approaching the end of life [4]. Most importantly, primary care providers should have a low threshold to consult with a palliative care provider if there are ongoing symptoms or potential changes in goals of care, both of which are likely to occur with end-stage disease. Palliative care consults are often called late

Table 13.6 Palliative care resources for symptom management

Resource	Description
Palliative Care Network of Wisconsin: Fast Facts and Concepts	Search palliative care topics via website or mobile app https://www.mypcnow.org/fast-facts/
Primer of Palliative Care, 7th edition (American Academy of Hospice and Palliative Medicine)	Pocket-sized handbook with a variety of palliative care topics, which includes opioid conversation table
CAPC Symptom Management Courses	https://www.capc.org/training/symptom-management/

in the course of organ transplant failure or not at all, but are likely most beneficial when patients have a therapeutic relationship with palliative care providers prior to graft failure [4].

Each solid organ transplant presents different considerations with respect to readdressing advanced care planning if graft failure occurs.

Kidney transplant recipients more frequently are able to receive another transplant compared to other solid organ transplant recipients—in the United States in 2017, retransplants represented 11% of adult kidney transplant recipients [55]. This comparatively high rate may be due to patient factors, donor availability, and the option of dialysis. However, decisions surrounding the initiation (or re-initiation) of dialysis and pursuing retransplantation are appropriate opportunities for reassessing a patient's goals of care. Even if a patient is familiar with dialysis from prior to transplantation, the post-transplantation dialysis goals of care may have changed: the patient will now be older, may have had more health complications, and is now immunosuppressed—these experiences may factor into the decision-making pertaining to dialysis and retransplantation. If dialysis and retransplantation are not options or not chosen, then management should include relieving the symptoms of end-stage renal disease, including treatment of volume overload and uremia.

Liver transplant recipients sometimes receive re-transplantation, more commonly early after initial transplantation—for example due to vascular complications—and less commonly performed in the late period after transplantation [56]. Unlike kidney transplant recipients, they do not have dialysis or other bridging therapies as options. In patients with end-stage liver disease who are not candidates for or who do not pursue retransplantation, symptom management will likely include care of volume overload, encephalopathy, and bleeding.

Heart retransplantation is less common than kidney or liver retransplantation, representing only 2–3% of heart transplants based on registry data [57]. The use of mechanical circulatory support such as left ventricular assist devices is generally not an option in the post-heart transplant setting because of anatomy, thrombosis, and risk of infection. Given the relative infrequency of retransplantation, early involvement with palliative care should be considered for heart transplant recipients with graft failure. Dyspnea and volume management will be necessary to improve quality of life.

Similar to heart transplant recipients, retransplantation is uncommon in lung transplant recipients, representing 2–3% of lung transplants [58], and is associated with poorer outcome compared with initial transplantation [59, 60]. Because of these outcomes, early palliative care involvement is recommended, as the patient will most likely need management of dyspnea as respiratory failure progresses.

Discussions of comfort-focused care and/or hospice in patients with end-stage disease after solid organ transplantation failure are appropriate if retransplantation is not an option or not desired.

Conclusion

Palliative care is specialized medical care for people living with serious illness that focuses on quality of life for both the patient and family [1]. Palliative care has been proposed for patients with advanced organ failure beginning at diagnosis and continuing through transplant and beyond, given the associated high morbidity and mortality awaiting transplantation and post-transplantation [4, 7–12]. When solid organ transplant recipients present to the outpatient clinic, it may be an opportunity for the primary care provider to incorporate primary palliative care interventions into their medical care. Primary palliative care interventions include advance care planning and basic pain and symptom management. There are clinical resources available for advance care planning, communication skills, and symptom management. Advance care planning discussions should recur as health circumstances change, including post-transplantation, with worsening health status, or cognitive decline. Initiation or escalation of opioid therapy for managing refractory symptoms is an appropriate time to readdress patients' goals of care. Referral to a palliative care specialist may be needed in cases of refractory symptoms, worsening health status including graft failure, cognitive decline, approaching end of life, or challenging decision-making when considering high-risk procedures.

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