

Approaching end-of-life care in organ transplantation: the impact of transplant patients' death and dying

Despite the success of transplantation, many transplant candidates and transplant recipients die each year. Some die awaiting transplants and some die months or years after receiving an organ. Quality end-of-life care can play a valuable role in easing the impact of death and dying in transplantation, as it focuses on enhancing patients' quality of life near death. Quality end-of-life care recognizes the values and preferences of patients and their families, and involves a process of shared decision making about patients' healthcare treatment in collaboration with healthcare practitioners. Advance care planning involves discussions with patients about their wishes and values about care, in the event that the patient becomes incapable of making such decisions. This article focuses on the application to transplantation of quality end-of-life care and advance care planning and identifies the effects that death and dying of transplant patients have on others. The information herein encourages healthcare practitioners to view and deliver quality end-of-life care as part of transplant patients' overall treatment management. (*Progress in Transplantation*. 2007;17:57-62)

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Notice to CE enrollees:

A closed-book, multiple-choice examination following this article tests your ability to accomplish the following objectives:

1. Understand ethical principles related to end-of-life care
2. Identify family complexities associated with transplant symptoms, treatment options, and emotional support
3. Identify strategies to help families cope with the death of a transplant recipient

Since the development of immunosuppressive drugs,¹ organ transplantation has progressed from an experimental procedure to the treatment of choice for end-stage organ disease. Organ transplantation may extend the lives of recipients by 10, 15, or 20 years,^{2,3} while enabling them to enjoy a reasonably good quality of life (QOL).^{2,4,5} Not surprisingly, transplantation is often viewed as a "miracle" in the form of life extension. Recipients are deeply grateful to have undergone a successful transplantation.

The procedure is similarly gratifying for healthcare practitioners, and especially for living donors, their families, and the families of deceased donors, who are closely connected to the "life-giving" organ.

The success of transplantation has created a demand for organs that greatly exceeds the supply. As a result, transplant candidates, while waiting for organs, may grow too ill to warrant transplantation and subsequently die. In 2005, 4025 patients were listed for organs in Canada and 283 died awaiting transplants.⁶ In the same year, in the United States, approximately 90 000 patients were on the waiting list and 6568 died waiting to receive an organ.⁷ Transplant recipients may also die months or years after receiving an organ.

Patient survival rates decrease each year following transplantation. According to the Organ Procurement and Transplantation Network,⁸ patient survival rates in 2004 at 3, 5, and 10 years were 88%, 81%, and 58% for deceased donor kidneys, respectively; 94.2%, 89.8%, and 75.5% for living donor kidneys, respectively; 77.9%, 72.6%, and 55.3% for deceased donor

Table 1 Strategies for initiating conversations with patients about advance care planning for end of life²⁴

Acknowledge emotions	"Is talking about these issues difficult for you?"
Legitimize the feelings	"Of course, talking about this makes you sad – it wouldn't be normal if it didn't."
Offer support	"No matter what the road holds ahead, I'm going to be there with you."
Explore	"You just mentioned feeling scared. Can you tell me more about what scares you the most?"
Hope for the best but prepare for the worst	"Have you thought about what might happen if things don't go as you wish? Sometimes having a plan that prepares you for the worst makes it easier to focus on what you hope for the most."
	"I wish too that this transplant had lasted longer. If we cannot do another transplantation, what other short-term goals might we work toward?"
	"What sorts of things are left undone for you? Let's talk about how we might be able to make these happen."

livers, respectively; and 77.9%, 78.0%, and 73.8% for living donor livers, respectively.

The death and dying of transplant patients, both candidates and recipients, are significant aspects of transplantation. Healthcare practitioners in the transplant community should acknowledge and be able to address, where appropriate, the emotional and psychological impact of death and dying on the dying patient, his or her family, the deceased donor family, the living donor, other transplant candidates, recipients, and themselves. This article discusses the role of quality end-of-life care and advance care planning in mitigating the impact of death and dying in transplantation, and briefly describes the different potential impact on each of the above people. Strategies are also suggested to prevent vicarious trauma, a psychological condition that affects healthcare practitioners working with survivors or victims of traumatic life events.⁹

Approaching End-of-Life Care for Transplant Patients and Their Families

End-of-life care broadly comprises control of pain and other symptoms, treatment options (eg, life-sustaining treatment), and emotional support of dying patients and their families.¹⁰ The goal is to maximize patients' QOL during their remaining time alive. The definition of quality is highly individual. Healthcare practitioners must tailor healthcare treatment at the end of life according to patients' and families' unique values and wishes.¹¹ Patients and families, commonly, highly value the following end-of-life care attributes: (1) effective physical and emotional symptom management, (2) clear communication about patients' clinical condition and treatment options, (3) self-determination related to treatment, (4) avoidance of prolonging death, (5) minimizing the burden to the family, (6) strengthening relationships with loved ones, (7) attending to issues of spirituality, and (8) respecting patients' wishes about the desired place of death.¹²⁻¹⁴

Healthcare practitioners should attempt to establish these preferences through routine and structured conversations with transplant recipients, candidates, and their families. These conversations should be positive, proactive, and responsive to the emotional needs of the patient and family. Neglecting these discussions or managing them poorly can seriously jeopardize the remaining life for a patient.¹⁵ For instance, a patient (and family) could be denied the opportunity to "say goodbye," to complete any unfinished business, or to set the record straight on important matters such as a patient's wishes and preferences related to future treatment options.¹⁶

Initiating end-of-life discussions including those related to advance care planning presents challenges (Table 1).¹⁸ Healthcare practitioners may avoid such conversations from fear of causing a patient pain, lack of training in delivering bad news, the view of death as an enemy to be defeated, the expectation of disagreement with a patient or family, or feeling threatened to broach the topic.¹⁵ However, social research indicates that a significant percentage of patients value the opportunity to prepare for the end of life.¹⁹ Therefore, healthcare practitioners need to discuss preferences about end-of-life care with transplant patients and families before a crisis occurs; also, by discussing end-of-life care before a crisis occurs families avoid having to make serious decisions during a highly emotional and distressing period.

The optimal time to discuss end-of-life care and advance care planning may be when patients are listed for transplantation. Discussing end-of-life issues early in the transplant process may be viewed as essential to patients' overall treatment management. A simple question such as "As you think about the future, what is most important to you?" can be effective in initiating this discussion.²⁰ Because some patients change their preferences about care or life-sustaining treatments over time,²¹ or as their conditions worsen, it is important

that healthcare practitioners review patients' wishes at progressive stages throughout the transplant process.

Ethics in End-of-Life Care

Quality end-of-life care is increasingly recognized as an ethical duty for healthcare practitioners.¹³ The ethical principle of beneficence, the foundation of end-of-life care, requires that a patient's pain and other symptoms be controlled.¹⁰ Decision making at the end of life is based on the ethical principle of autonomy or self-determination. It requires that a patient be allowed to determine how he or she will be treated and to make decisions on the basis of personal preferences, beliefs, and values. Advance care planning is also based on autonomy, as well as the legal doctrine of informed consent, to ensure the norm of consent is honored when the patient becomes incapable of making decisions about treatment.²¹ Advance care planning recognizes that dying patients suffer a loss of dignity when they cannot command respect for their preferred intentions.²¹ Respecting the dignity of patients is also part of the broader goal of quality end-of-life care.²²

Impact of Transplant Patients' Death and Dying Patients' Families

A dying transplant recipient can cause family members to reexperience the sad and dreadful expectation of his or her death, which the transplant had until then forestalled. Although families appreciate that transplantation prolonged their loved one's life, some families may view the recipient's terminal prognosis as a failure of transplantation. This reinforces the need for healthcare practitioners to assist transplant recipients and their families in forming realistic expectations about transplantation outcomes. The authors believe that patients, their families, and healthcare practitioners may benefit from viewing end-of-life care as part of the transplantation process—a part focused on achieving a “good death.” A well-managed end-of-life process can be viewed as a success in itself.²³

Discussing end-of-life issues and engaging in advance care planning with a patient and his or her family can help mitigate the impact of the recipient's death and dying, and any resulting sense of failure. Such discussions are also appropriate for relatives of transplant candidates whose health declines to the point that transplantation is no longer an option. The burden of a relative's death and dying on his or her family is reduced when they know their loved one's end-of-life wishes and preferences will be respected. As a dying relative nears death, or dies, families need to be offered bereavement counselling and emotional support.

Donor Families

Family members of a deceased organ donor may consent to donation hoping their loved one will “live

on” in the recipient.²⁴ As a result, when the donor family and the recipient know each other, the donor family may experience a “second death” when the recipient dies. The dying recipient may rekindle memories of the family's loved one's death, resulting in retraumatization as they reexperience the tragic event.²⁵ To mitigate the impact of a recipient's death and dying, healthcare practitioners should attempt to ensure that donor families' expectations about transplant outcomes are realistic. Donor families should be offered bereavement counseling and emotional support when they know that the recipient is near death or dies.

Living Donors

The majority of living donors report high levels of satisfaction from donation, but a University of Minnesota study²⁶ of living donors' QOL revealed that living kidney donors whose recipient died within the first year of transplantation stated they would not donate again. In this study, 4% of donors regretted their decision to donate. There have also been reports of living kidney donors committing suicide following the death of their recipient.²⁷

An emotional bond usually exists between living donors and their recipients, especially if they are genetically or emotionally related. A recipient's death and dying may be extremely difficult for the donor, especially if it occurs a short time after transplantation. In the event of a recipient's death and dying, healthcare practitioners should keep close contact with the living donor to assess levels of coping and the need for emotional and psychological support.²⁸ Also, these cases reinforce the need for healthcare practitioners to ensure that donors have realistic expectations about recipient transplant outcomes.²⁹

Other Candidates and Recipients

The death and dying of transplant recipients and candidates can remind other recipients and candidates of their own mortality, prompting the dreaded question, “Am I next?” Transplant recipients who mentor transplant candidates (ie, transplant mentors) react similarly when the candidate dies awaiting transplantation; they are reminded of life's tenuous nature, and may also question why they were “lucky enough” to receive and survive a transplantation, whereas the mentored patient was not.³⁰ By engaging these transplant patients and transplant mentors in discussions about end-of-life care and advance care planning, healthcare practitioners have an opportunity to prepare them psychologically and emotionally for their own death.

Healthcare Practitioners

Healthcare practitioners who are frequently exposed to the death and dying of transplant candidates and recipients are vulnerable to developing vicarious trauma

Table 2 Strategies for dealing with vicarious trauma³⁵

Short-term coping strategies

- Engage in self-care activities: Exercise, meditation, journaling, recreation
- Enjoy nonwork relationships
- Maintain positive thinking and positive attitude
- Debrief with colleagues informally after stressful days
- Debrief with colleagues formally after deaths

Long-term coping strategies

- Develop stress management techniques
- Develop supportive relationships, both personally and professionally
- Develop an awareness of personal triggers for “compassion fatigue”
- Develop rituals for situations dealing with loss, grieving, or death

(also called compassion fatigue,^{31,32} empathic strain,³³ and indirect trauma³⁴). As healthcare practitioners engage empathetically with transplant patients who are experiencing trauma, they may unconsciously assimilate the traumatic elements into their own reality,³⁴ causing vicarious trauma. The effects of vicarious trauma include distressing dreams, difficulty sleeping, irritability, reduced concentration, and emotional distress. Such effects can compromise healthcare practitioners’ ability to care for patients.

Healthcare practitioners involved in transplantation can help prevent vicarious trauma by acknowledging that it exists and appreciating their susceptibility to it.³⁴ Coping strategies range from short- to long-term, and focus on releasing stress, maintaining a balance between one’s personal and professional life, and seeking supportive relationships at home and at work (Table 2).

Conclusion

The death and dying of transplant candidates and recipients are significant aspects of transplantation. Healthcare practitioners in the transplant community should be aware of the emotional and psychological effects of a patient’s death and dying. Quality end-of-life care and advance care planning can play valuable roles in mitigating such effects, particularly for dying patients and their families. By engaging transplant patients and their families in a process of communication and dialogue about wishes and preferences for end-of-life care, healthcare practitioners can improve patients’ QOL near death. We recommend that healthcare practitioners begin discussing end-of-life care and advance care planning early in the transplantation process as part of transplant patients’ overall treatment management. Healthcare practitioners have an ethical duty to deliver quality end-of-life care to dying patients, which respects the ethical principles of beneficence and autonomy. More research is needed on applying end-of-life care and advance care plan-

ning to organ transplantation to increase our knowledge and improve practice.

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Learning objectives: 1. Understand ethical principles related to end-of-life care 2. Identify family complexities associated with transplant symptoms, treatment options, and emotional support 3. Identify strategies to help families cope with the death of a transplant recipient

1. Organ transplantation may extend the lives of recipients for how many years?

- a. For 15, 25, 30 years
- b. For 5, 10, 15 years
- c. For 10, 15, 20 years
- d. For longer than 30 years

2. How many patients waiting for a transplant in 2005 in the United States died before receiving a transplant?

- a. 7600
- b. 6568
- c. 3467
- d. 283

3. Which of the following best illustrates the 3-, 5-, and 10-year survival rate of living kidney donors in 2004?

- a. 94.2%, 89.8%, and 75.5%
- b. 88.9%, 74.2%, and 66.4%
- c. 98.9%, 86.8%, and 78.2%
- d. 77.9%, 72.6%, and 78.0%

4. As described in the article, patients and families value what end-of-life care attributes?

- a. Seclusion from other families, acceptance of death, and compassion from the healthcare team
- b. Minimizing the burden to the family, minimizing spiritual relationships, and being proactive in the patient's death
- c. Achieving a "good death" and a well managed end-of-life process, and avoidance of prolonging death
- d. Clear communications about patients' clinical condition and treatment options, avoidance of prolonging death, and respecting patients' wishes about the desired place of death

5. According to the study, when is the optimal time to discuss end-of-life care issues?

- a. When the patient is on the transplant list
- b. When the patient is scheduled for the transplant surgery
- c. Whenever the patient and family bring up the issue
- d. After all treatment options have been exhausted

6. Decision making at the end of life is based on which of the following ethical principles?

- a. Self-acceptance and autonomy
- b. Integrity and dignity
- c. Autonomy and self-determination
- d. Dignity and autonomy

7. Autonomy is based on which of the following legal doctrines?

- a. Subjective reasoning
- b. Beneficence
- c. Implied consent
- d. Informed consent

8. When donor and recipient families know each other and the recipient dies, what is likely to occur?

- a. The recipient's family may develop animosity toward the donor family.
- b. The donor family may experience a second death.
- c. The bond existing between the families may grow stronger.
- d. The recipient family may experience a second death.

9. According to the Minnesota study, what percentage of living donors regretted donation after the recipients died?

- a. 8%
- b. 6%
- c. 4%
- d. 10%

10. Which of the following symptoms best describe healthcare providers exhibiting vicarious trauma?

- a. Distressing dreams, irritability, and emotional distress
- b. Increased spiritual guidance, increased productivity, and less social contact
- c. Difficulties sleeping, heightened sense of mortality, and irrational behavior
- d. Increased awareness of mortality, frequently calling in sick, and inability to cope with the loss

Test answers: Mark only one box for your answer to each question. You may photocopy this form.

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