

Palliative Care vs. Hospice for the Lung Transplant Family

by

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Lung transplant candidates, recipients and their caregivers face many challenges as they address serious illness and a changing quality of life. Although healthcare teams dedicate their interventions towards preparing the person & caregiver for transplant and, later, recovery as a recipient, often more is needed. Most transplant centers rarely consider palliative care. Many often confuse this with hospice care and do not know the difference between the two.

Palliative care (PC) is based on individual needs and has no time limits. It was recognized as separate from hospice in 1974 and the World Health Organization recognized it as a specialty in 1990 (Sheikh et al. 2022) The focus is on pain, symptoms, stress related to the illness, and treatments. It adds an extra layer of family support during the transplant journey. A referral to the PC team means that you have a team of people to focus on your needs. It does not replace care from your primary care provider or transplant team. It can include art & music therapists, psychologists, home health aides, nutritionists, pharmacists, chaplains, respite providers and others. Every team varies depending on the hospital or agency used. Khayal and Barnato (2022) provided a list of functions based on focus groups with at one academic medical center. They were aimed at the patient and family to 1). deliver support and advance care planning, 2). deliver culturally sensitive serves, 3). deliver symptom management treatment, 4). deliver coping management strategies or other therapies, 5). deliver spiritual services, 6). deliver social services, and 7). communicate and coordinate across clinical environments. Most insurance companies cover PC, but some copays or coinsurance deductibles might apply. This type of care can be provided in any setting: hospital, home, or rehabilitation center. It can include face-to-face, or telephonic, or Zoom visits. Patients leave PC care when they improve and no longer need those services or when they progress to hospice care,

Hospice, which is more familiar to most people, was started in 1967 in the UK and became a movement in the US in 1975 (Sheikh et al, 2022). It is care provided by an interdisciplinary team for those who have been identified as having a terminal illness. This

terminal phase is expected to be 6 months or less. The focus in hospice is quality of life and comfort through pain and symptoms management with psychosocial and spiritual support. With hospice there is usually 24-hour on-call service with in-person visits, medical equipment, and continuous care in the home. There is spiritual care, bereavement care, and counseling services. The key here is holistic care for the entire family. This also is usually covered by insurance, but it does vary by plan.

Now, you might be wondering why you have never heard about this. Zou and his research team (2019) conducted a chart review of pre-transplant patients with idiopathic pulmonary fibrosis (IPF) evaluated between 2000 and 2016 at one center and found only 13% had a PC referral. They tended to be over 72 years, had several coexisting illnesses, and lived close to the center. The positive point was that PC care was associated with fewer in-hospital deaths. Pawlow et al (2020) looked at the PC care needs of 111 lung transplant candidates at one center and only 6.4% reported seeing a PC specialist and 48% were unsure of what PC was. They reported that their greatest identified needs were difficulty being physically active, physical symptoms, missing work due to the illness, and concerns about end-of-life issues. Nolley et al. (2019) looked at lung transplant recipients and found 27% had a PC referral in year one but by year five that had increased to 43%. Kim et al (2022) examined the barriers to PC care in patients with interstitial lung disease in a systematic review that included ten studies and 4073 people. They reported that PC referrals ranged from 0% to 38%. They cited delays in referrals were secondary to patients' fear of talking about the future, uncertainty with their prognosis, and confusion about roles of PC services. Pullen (2021) who has coauthored several articles on liver transplantation and PC, stated that a new generation of physicians and nurses are being educated about PC and this gap will be reduced in the future. She concluded that PC services can match the aims of the transplant candidates.

You might ask: should I ask my health care team for a PC referral? There are few studies that examined outcomes of PC care and lung transplant patients. However, there are many studies looking at PC care and many other physical diseases and dementia. Every study showed comparable results. These include improved patient symptoms, mood, quality of life, pain reduction, reduced hospital admissions and family satisfaction with caregiving (Merluzzi et al, 2024). Sheikh et al. (2022) reported that the adoption of Palliative Care and its transition to Hospice care had reduced the financial burden on the patients. Borelli et al (2021) conducted a

series of interviews with seventy-eight patients with cancer and 48 caregivers. They reported similar results as previous studies, but they also spoke about a sense of empowerment and an increased acceptance of their end-of-life and their expectation of a painless future as a result of their PC services. Broese et al (2023) did look at PC care and 222 patients with COPD. They found those patients had lower hospital admissions. Considering these positive results with non-transplant patients, patients and caregivers involved in the transplant journey should discuss PC care with their transplant team.

Let me share the journey of one of our former SW board members: Karen Couture. Some here might recognize her name as the author of the book, “The Lung Transplantation Handbook (second edition)”. She had her bilateral lung transplant in 1996, secondary to lymphangioleiomyomatosis. She was an accomplished public speaker and contributed to several articles and book chapters. She often wrote about frequent rejection episodes and experiences with high doses of prednisone. She tried part-time work and even returned to school to become massage therapist to work with patients in pain. Over the next few years Karen needed several Mohs surgeries for skin cancers. In 2015 she developed non-Hodgkins’s lymphoma and completed several rounds of chemotherapy. By 2019 her lung function was deteriorating and her immunosuppressants were increased . She did not qualify for a re-transplant because of her other health issues. Thus, in July 2019 she accepted PC services with the hope that she would stabilize. Karen continued to deteriorate and in early May 2021 it was clear that there were no other options. She moved into Hospice care at home surrounded by her spouse, mother, sister, and friends. Karen died on May 25th, 2021.

For more information go to:

American Cancer Society <https://www.cancer.org/cancer/managing-cancer/palliative-care/what-is-palliative-care.html>

Hospice Foundation of America <https://hospicefoundation.org/Hospice-Care>

National Cancer Institute <https://www.cancer.gov/about-cancer/advanced-cancer/care-choices/care-fact-sheet>

The National Institute on Aging <https://www.nia.nih.gov/health/hospice-and-palliative-care/frequently-asked-questions-about-palliative-care>

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