Overview of Palliative Care and Hospice Services

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Why Palliative Care in End-Stage Liver Disease?

End-stage chronic liver disease (ESLD) affects thousands of Americans. Up to 10% of eligible patients will die without undergoing transplantation, and those who await transplantation may have high symptom burden; thus, palliative care consultation for such patients to improve quality of life (and possibly quantity of life) has been proposed.¹⁻³ Palliative care has become increasingly utilized in other life-limiting illnesses such as cancer and advanced heart failure. Such diseases may not be imminently fatal and more so mimic chronic illness states; however, a high symptom burden from the disease or its treatment often exists. Patients with ESLD can have high morbidity and mortality and their trajectory of care may be complex, making prognostication challenging. As patients progress through life with the chronic burdens of ESLD, patients and their caregivers may have need for complex symptom management, multifaceted psychosocial evaluation, and the continual reassessment of medical options and goals of care. Here, we discuss an overview what palliative care is and can often provide, and how this differs from traditional hospice care.

Overview of Palliative Care

Palliative care (PC) is a burgeoning multidisciplinary field focusing on the complex supportive care needs of patients with advanced and life-limiting illness. Between 2000 and 2010, there was a 148% increase in the number of PC teams, and more than 85% of hospitals in the United States with greater than 300 beds have PC teams.⁴ PC physicians are board-certified subspecialists with expertise in complex symptom management of pain and non-pain symptoms, psychosocial and spiritual support, and advanced care

planning. PC is delivered by an interdisciplinary team (Table 1) and aims to provide comprehensive and concurrent care of patients with life-limiting illnesses alongside primary teams. This care can be provided together with any disease-directed or disease-modifying treatment a patient may be receiving; indeed, no therapy is excluded when a patient is receiving PC if it aims to help the patient meet his/her goals of care. PC can be provided in a variety of settings, including hospitals and outpatient clinics and can include home-based visits, but this varies widely in different health care systems.

Domains of care addressed with PC include the physical, social, psychological, existential, and spiritual needs of a patient and their loved ones with the objective of providing care that honors the goals, preferences, and values expressed by the patient. In fact, it has been shown that the degree to which staff address patients' emotional and spiritual concerns strongly correlates with overall patient satisfaction.⁵ The relationship in PC extends beyond the traditional doctor-patient relationship to include the patient and whomever is important to them, as well as the entire interdisciplinary team. PC can be provided at any stage of a life-limiting illness, beginning with the identification of a disease process that cannot be cured. This represents a paradigm shift from how PC was previously perceived. The model now promotes the early involvement of PC in the care of these patients across the continuum of their care (Fig. 1).

Overview of Hospice Care

Hospice is playing a growing role in the care of patients approaching end of life, including those with ESLD, but is a distinct type of PC used when patients are terminally ill

Abbreviations: ESLD, end-stage liver disease; PC, palliative care

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TABLE 1 Palliative Care Is a Team-Based Care (modified after <http://palliativedoctors.org/team>)

- The patient
- The patient's loved ones
- Palliative doctor
- Other subspecialist doctors
- Advanced care practitioners (nurse practitioners, physician assistants, clinical nurse specialists)
- Nursing
- Social workers
- Pharmacists
- Chaplains
- Physical therapists
- Dieticians
- Other specialized providers (grief/bereavement; music therapy, art therapy)
- Volunteers

The Expanding Role of Palliative Therapy

Figure 1 Classic conceptualization of integrated palliative care with curative or disease-targeted therapy. Originally conceived by the World Health Organization in 1990, reformulated by many others since then.⁶

(Fig. 2, Table 2). The hospice movement developed out of caring for patients with advanced malignancy and AIDS; however, it has evolved over the past 25 years to care for patients with any life limiting illness where the patient has an anticipated prognosis of 6 months or less. Hospice is a Medicare (or private insurance) benefit that provides care focused on comfort and quality of life over disease-targeted therapy; thus, patients receiving hospice are typically not receiving disease-directed care such as chemotherapy or advanced interventions. Hospice care is primarily provided in patients' homes or care facilities as intermittent care with the ability to provide emergent care in times of crisis. Hospice also has the ability to provide short-term aggressive symptom management or respite care in inpatient hospice units. Hospice teams are interdisciplinary and made up of similar members to the PC team, but may rely more heavily on nursing assistants, volunteers, and bereavement specialists than the PC team.

Prognostic uncertainty should not be a barrier to hospice enrollment. However, patients are often referred to hospice only in the last days of life, missing the benefits of care at

TABLE 2 Palliative Care, Hospice, and Comfort Care^{6,7}

- Palliative Care
 - Can begin with onset of serious, life-limiting illness
 - Focuses on
 - Goals of Care
 - Symptom Management
 - Quality of Life
 - Family Support
- Hospice Care
 - A specific subset of palliative care
 - Generally begins when life expectancy is <6 months if the disease runs its expected course
 - Focuses on
 - Team-Based Support Services
 - To Support Patient
 - To Support Family
 - To Support Caregivers
 - Aggressive Symptom Management
 - Assessing Goals of Care on Regular Basis
 - Quality of Life
 - Family Support
 - Bereavement and Volunteer support more prominent
- Comfort Care
 - A subset of palliative care and/or hospice care
 - Generally focuses on the final hours or days of life
 - Focus is purely on comfort of the patient
 - Medications that are not contributing to comfort are discontinued
 - Use of pain management, anxiolytics and sedatives as needed to allow for maximal comfort
 - Not ALL medications should be stopped if they can help the patient to achieve their goals of comfort
 - Diuretics
 - Other ESLD treatments may not contribute to comfort (ie, beta blockers for esophageal varices) or burdens may be greater than benefits (ie, ongoing lactulose for hepatic encephalopathy treatment/prevention)

Figure 2 Palliative Care, Hospice, and Comfort Care^{6,7}

home, where most patients express they prefer to die.⁸ Patients can remain enrolled in hospice beyond 6 months, and require regular reassessment to certify that they still have an imminently terminal prognosis and demonstrate ongoing functional or clinical decline. PC subspecialists are able to provide specific guidance regarding hospice certification if needed.

TABLE 3 Reasons to Consider a Palliative Care Consultation (used with permission)⁶

Assistance with Complex Symptom Management
<ul style="list-style-type: none"> Managing escalating or refractory symptoms (eg, pain, dyspnea, and nausea) Complex pharmacologic management in patients facing a life-limiting illness (eg, opioid infusions, opioid rotations, patient-controlled analgesia, methadone initiation, and ketamine initiation) Addressing complex depression, anxiety, grief, and existential, spiritual, or psychosocial distress Respite and/or palliative sedation for intractable symptoms
Care of Complex, Severely Ill Patients Over Time
<ul style="list-style-type: none"> New diagnosis with metastatic cancer and/or malignancy with high symptom burden Frequent hospital admissions for the same diagnosis of a serious illness Intensive care unit admission with metastatic cancer Intensive care unit admission with poor prognosis Prolonged intensive care unit stay
Assistance with Medical Decision-making and Determining Goals of Care
<ul style="list-style-type: none"> Discussing transitions in care Discussing complex and/or evolving goals of care Assisting with conflict resolution regarding goals or methods of treatment, whether that conflict is within the family, between the family and the medical teams, or between treatment teams Redefining hope in the setting of complex illness Discussing complex code status Managing patient and/or family conflict or complex social issues Discussing ethical dilemmas
Questions Regarding Future Planning Needs
<ul style="list-style-type: none"> Determining and discussing prognosis where desired Care and planning in the setting of advanced illness (consider referral when one would answer “yes” to the question: Would I be surprised if my patient died within 12 months?) Discussing issues pertaining to artificial feeding or hydration Determining present and future care needs Help with determining hospice eligibility and providing hospice education

Why Is This Important?

Quality of life issues, complex symptom management, and care coordination needs are significant for many patients with ESLD. Medical practice in the 21st century no longer can view hospice and PC as the same, because patients often highly value these components of their care.¹⁻³

It is no longer acceptable to fall back on the adage that PC is only for “end-of-life” care and thus avoid opportunities to maximally support quality of life. To this end, it is increasingly important for providers to choose their words carefully when presenting PC options. This may include seeking opportunities to reframe hope and what it means for a patient, appreciating that longest survival possible may

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not be the goal of care that is most important to the patient, and understanding that a choice to involve PC is not consistent with “giving up” or “not fighting.” PC has not been associated with shorter survival in the setting of less aggressive, tumor-directed care for patients with non-small cell lung cancer⁹ and is increasingly being mentioned in the literature as important for the care of patients with ESLD including those being considered for transplantation.¹⁻³ With the goal of transplantation to increase survival and palliate symptoms, transplant medicine and palliative medicine can be viewed as harmonious, not diametrically opposed as was previously considered.

Limited organ availability means some patients will die waiting for an organ. In addition, many patients are not candidates for transplantation due to comorbid conditions or ongoing complications dictating a quality-of-life-based approach. Such care may be best delivered by joining disease-directed and life-sustaining therapy alongside PC. In a seriously ill patient population often subject to repeated hospitalizations, all providers should address advanced care planning and basic symptom management, and PC teams can add value in the face of complex symptoms, limited prognosis, and complex care needs.⁷ Reasons to consider PC consultation are included in Table 3.⁶

Conclusion

Palliative care is a subspecialty focused on augmenting the care of patients with advanced and life-limiting illnesses to support maximal symptom management, address psychosocial needs and engage in shared decision-making in the context of a patient's goals, preferences, and values. PC is increasingly being engaged in the care of seriously ill patients early in the trajectory of illness to support quality of life across the continuum of care, versus hospice, which is designed for patients in the terminal phase of illness with an anticipated prognosis of less than 6 months.

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