

# What Strategies Might Reduce Barriers to Routine Integration of Palliative Care Services in Patients With Pulmonary Arterial Hypertension?

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Despite remarkable advances in therapy for pulmonary arterial hypertension (PAH), this disease remains life-threatening and incurable, and often has a profoundly negative impact on quality of life. As the illness progresses, common symptoms including fatigue, dyspnea, chest discomfort, and lower-extremity edema may become disabling as PAH is less responsive or refractory to therapy. In this issue of *Advances*, Fenstad and colleagues provide an outstanding overview of palliative care, including definitions and opportunities for addressing disabling symptoms as a primary goal rather than simply viewing them as indicators of underlying disease stability.<sup>1</sup> These authors also present sobering survey data that indicate only 40% of providers recommended palliative care consultation for a patient with advanced PAH in a clinical vignette, highlighting a potential “growth opportunity.”

The obstacles to achieving this increased utilization of palliative care may include patient fears/possible misunderstanding of the terminology (such as equating palliative care with hospice) and other physician-perceived barriers to palliative care.<sup>2</sup> The discussion that follows considers some practical steps that might be taken in the near term to lower the barriers to palliative care access in patients with PAH, such that the benefits described

so well by Fenstad et al. may be better realized. These barriers to improved integration of palliative care with PAH may be loosely classified under 3 headings: those that can be addressed by increased education, those that can improve patient and provider communication, and those that can address access to palliative care services.

## EDUCATION TO IMPROVE UNDERSTANDING AND ACCEPTANCE OF PALLIATIVE CARE

Given the challenges surrounding the understanding of palliative care and a suboptimal level of comfort in accessing these specialized services, efforts to educate patients, caregivers, and PAH providers will likely be necessary to achieve a higher level of integration between palliative care and PAH. The patient/caregiver education aspect is often spearheaded by their peers (through PAH support groups) with the support of the Pulmonary Hypertension Association (PHA). PHA recognizes the opportunity to engage patients and caregivers through their established and trusted online presence. PHA's patient services staff is developing expanded palliative care content to address this area of need.<sup>3</sup>

Engaging physicians in education and/or retraining in palliative care is also key to improving their ability to

consider and refer patients for palliative care consultation earlier in their illness trajectory, especially if more aggressive treatment of symptoms is of potential benefit. Multiple online resources have been developed for physician reference (eg, <https://getpalliativecare.org/resources/clinicians/>, <http://www.nhpco.org/resources/end-life-care-resources>); however, the improvements necessary for transformational integration of PAH and palliative care may require a systems-level solution. To that end, palliative care advocacy groups including the Center to Advance Palliative Care have proposed opportunities for workforce development that would be best supported by congressional action. These proposals may involve: 1) expanding palliative care centers (addressed in greater detail below), which would take a role in developing palliative care curricula for providers; 2) establishing incentives (eg, research funding) for palliative care team members such as physicians, nurses, social workers, and chaplains to train clinician educators to disseminate palliative care strategies; and 3) reforming medical education to support specialty development in areas such as palliative care.<sup>4</sup> As patients/caregivers and providers progressively gain knowledge and acceptance regarding the value of palliative care, there is potential for a synergistic effect that may result in more PAH patients benefitting from improved symptom control and better quality of life.

## IMPROVING PATIENT AND PROVIDER COMMUNICATION

Precise communication of the present functional state of patients with PAH has benefited from use of structured test results, including 6-minute walk distance, World Health Organization functional class, serum brain natriuretic peptide levels, and echocardiographic data. Communication between health care providers, patients, and families regarding experience and impact of daily symptoms in PAH is arguably more challenging than that pertaining to functional capacity. This can hinder the delivery of appropriate palliative care and suggests the need for a formal assessment tool for PAH symptoms.

The gold standard for diagnosing the severity of a symptom is patient self-reporting. However, symptom communication may be imprecise (eg, “is it better or worse than it was before?”) and may represent an important unmet need in PAH management. The Edmonton Symptom Assessment System (ESAS),<sup>5</sup> as a tool designed to assist in the assessment of symptoms common in a patient with any life-limiting/life-threatening disease, may offer some ability to address this need.

The ESAS provides a clinical profile of symptom severity (rated from 0-10) over time, and provides a context within which symptoms can begin to be understood. However, it is important to remember that it is not a complete symptom assessment in itself and should be used as just one part of a holistic clinical assessment. Repeated assessments may be completed either by the patient alone, by the patient with nursing assistance, or by the patient’s caregivers, at defined intervals until the symptoms are well-controlled.<sup>6</sup> These assessments may occur daily for patients in an institutional care setting (eg, hospital or subacute rehabilitation center) or perhaps weekly for patients at home. If symptom control is not attained at an acceptable level or consultation about possible care options is needed, patient assessments by palliative care consultants should be considered. The ESAS is, of course, not the only instrument to improve communication regarding symptoms between patients and providers. Hopefully future

research will either validate the utility of the ESAS in PAH or provide effective alternative assessment tools.

## ACCESS TO PALLIATIVE CARE SERVICES

A 2002 report titled “The Supply, Demand and Use of Palliative Care Physicians in the United States,” prepared for the Bureau of HIV/AIDS, Health Resources and Services Administration, revealed that 64% of American Academy of Palliative and Hospice Medicine-certified physicians felt there was a need for more palliative physicians to meet patient needs.<sup>7</sup> Thus, it is encouraging that palliative care is one of the fastest growing services in modern health care. Since the 2002 report, the number of palliative care teams within US hospitals with 50 or more beds has increased by 157%: from 658 in the year 2000 to more than 1692 in 2012.<sup>8</sup> Of hospitals with more than 100 beds, 55% offer a palliative care program, and nearly one-fifth of community hospitals have palliative care programs. Furthermore, over the past 10 years, more than 1000 new hospital-based palliative care programs have been created. While these data reflect overall trends, regional variation in access to palliative care is considerable. The prevalence of palliative care in hospitals is highest in the Northeast and lowest in the South (when considering facilities of all bed sizes); however, the South has the highest prevalence of palliative care programs in hospitals with more than 50 beds.<sup>8</sup>

The major ongoing barriers to offering palliative care at all health care facilities presently seems related to the lack of workforce training programs, inadequate funding for research, and payment models linked to quality measures.<sup>4</sup> The US Department of Veterans Affairs has launched a program to address workforce training with a goal of making palliative care available in all regions and settings.<sup>9</sup> Future funding for research and efforts to establish payment mechanisms based on quality show great promise for the coming years, due to interest in all the key stakeholders. The Center to Advance Palliative Care has proposed specific policy initiatives at the federal level to help convert that promise to a reality.<sup>4</sup>

A Palliative Care Provider Directory of Hospitals is available online as a practical resource and may help patients and providers across the United States locate hospitals that provide palliative care. Additional resources available on the [www.getpalliativecare.org](http://www.getpalliativecare.org) website identify its value and include basic definitions of palliative care and handouts for patients and families.

In conclusion, a marker of successful integration of palliative care for patients with PAH will be the consideration and implementation of a palliative care consult in a manner similar to, for example, a renal consult. Renal consults are widely accepted by patients and providers: details of the renal illness can generally be communicated in precise terms. These consults are often performed well before end-stage illness, and access to nephrologists is widespread. Palliative care integration in PAH faces challenges to reach a similar state. However, the recent nationwide expansion of palliative care programs, combined with stakeholder interest in increasing research and establishing viable payment models, suggest optimism regarding the future of palliative care integration in the care of patients with PAH.

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