ASK THE EXPERT

Might Rebranding Palliative Care Improve its Integration into Treatment for Those Patients Diagnosed With Pulmonary Arterial Hypertension?

Section Editor and Author
Sean M. Studer, MD, MSc, FCCP

The original name of the Patagonian toothfish, *Dissostichus eleginoides*, did not likely inspire many fantasies of fine dining until it was renamed the Chilean sea bass in 1977 by a fisherman named Lee Lantz. That this fish is not a bass at all, but rather part of the cod family—and often caught nowhere near the coast of Chile—did not detract from its epic rebranding that resulted in "broad resonance among American seafood eaters."[1] A similar medical example of rebranding is that of nuclear magnetic resonance (NMR) imaging, which was developed for clinical use as early as 1973. Although NMR imaging was generally agreed to be a more technically accurate description of the imaging modality, there was controversy regarding the inclusion of the word "nuclear" in the name as it might dissuade patients from embracing it. A 1986 editorial in the *Journal of the American College of Cardiology* acknowledged the prominent radiology journals' preference at the time for the simplified "magnetic resonance imaging" (sans nuclear). These cardiologists recommended the more "scientifically descriptive and specific" term NMR be retained, however. They realized that, to be accepted, this term would require more education to the public explaining the true meaning of NMR.[2]

While improved education of patients and the general public is noncontroversial, a reasonable consideration related to patients with pulmonary arterial hypertension (PAH) is whether rebranding palliative care may be an underappreciated yet effective measure for increasing early access to palliative care in the near term. To address this main question, the discussion that follows will examine several subquestions: 1) is the term "palliative care" opaque and/or associated with negative connotations by physicians, patients, and their families; 2) is there evidence that an alternative term, such as "supportive care," may be viewed more favorably; and 3) has rebranding using "supportive care" been adopted by medical centers with improved outcomes?

To address this first subquestion, an argument favoring rebranding is the seeming inaccessibility of the word "palliative" for many patients: in fact, "palliative" is listed on a prominent website detailing the "most important SAT words"[3] for high school students studying for their college entrance scholastic aptitude test (SAT) to learn. While the terminology "palliative care" is much more familiar to health care workers, it is not always well regarded. In one survey that was conducted at a large comprehensive cancer center, a group of physicians and midlevel providers perceived the term "palliative care" as more distressing and diminishing hope to patients and families compared with "supportive care."[4] Similar data have been collected regarding negative initial impressions of the term "palliative care" directly from patients and their caregivers. A study using qualitative interviews with patients and their caregivers described the term "palliative care" as stigmatizing, while the alternative name "supportive care" was found to be more favorable.[5] One of that study's main authors, Dr Camilla Zimmerman, summarized that study's conclusions as follows: "Patients told us if palliative care were called something else they wouldn't feel so stigmatized.... We have a branding issue and that's the central message of this research."[7] While this work suggests that improving initial impressions of palliative care may be achieved by rebranding as supportive care, the ultimate goal is to increase referral to palliative services earlier in the disease course when the interventions may have their greatest impact.

A Canadian survey of oncologists regarding referral patterns to specialized palliative care discovered that one-third would refer for palliative services earlier if it was renamed supportive care.[6] Even more robust support regarding the effect of rebranding was shown in the report of a large US comprehensive cancer center that evaluated the timing of first palliative care consultation for 4701 consecutive patients before and after a name change from "palliative care" to "supportive care." These investigators noted an increase in inpatient referrals after the name change as well as earlier referrals to palliative services in the outpatient setting.[8] The authors concluded that the name change resulted in improved access and should be considered in more centers.

It may be valuable to consider that a name change alone is unlikely to result in rapid acceptance and full integration of palliative care into the management of patients with pulmonary hypertension (PH). A renaming may merely represent a step toward improving initial acceptance of palliative symptom management and other support services to help patients with PAH maintain their highest possible functional capacity. Broader discussions of this potentially life-limiting illness with patients and families will likely still be required to realize palliative care's full potential and facilitate the difficult decisions regarding end of life or bridging to hospice when appropriate. These complex issues are explored

 DOI: 10.21693/1933-088X-17.1.34

further in the Roundtable discussion in this issue of *Advances,* which includes a unique PH patient's perspective. The concept that palliative care represents "making every day the best it can be" is considered, and if changing the name helps even in a small way to achieve that goal, then it may be worth it.

In conclusion, achieving earlier and more consistent access to palliative care services for patients with PAH is certainly a complex issue that is not likely to be resolved by rebranding alone. To return to the example of the Chilean sea bass: it has a mild consistency that pairs well with any spice and is difficult to overcook, so clearly more than its new name led to its identification as *Bon Appetit* magazine's 2001 "Dish of the Year."[9] The growing medical literature favoring the term "supportive care" in place of "palliative care," combined with the real-world experience of the positive effect of that change in improving the volume and timing of access to palliative care services, bolsters the argument for rebranding. While "supportive care" as an alternative name for palliative care might be considered less medically accurate or specific, the lesson from nuclear magnetic resonance imaging appears to be that improving acceptance (ie, removing the word "nuclear") seems more valuable than retaining a traditional, more precise name.

References

1. Priceonomics website. The Invention of the Chilean Sea Bass. https://priceonomics.com/the-invention-of-the-chilean-sea-bass/. Published April 28, 2014. Accessed March 22, 2018.
2. Pohost GM, Elgavish GA, Evanochko WT. Nuclear magnetic resonance imaging: with or without nuclear? *J Am Coll Cardiol*. 1986;7(3):709-710.
3. Rosewood Media. SAT Most Important Word List. https://satvocabulary.us. Accessed March 22, 2018.
4. Fadul N, Elsayem A, Palmer JL, et al. Supportive versus palliative care: what's in a name?: a survey of medical oncologists and midlevel providers at a comprehensive cancer center. *Cancer*. 2009;115(9):2013-2021.
5. Zimmerman C, Swami N, Krzyzanowska MK, et al. Perceptions of palliative care among patients with advanced cancer and their caregivers. *CMAJ*. 2016;188(10):E217-E227.
6. Wentlandt K, Krzyzanowska MK, Swami N, Rodin GM, Le LW, Zimmerman C. Referral practices of oncologists to specialized palliative care. *J Clin Onc*. 2012;30(35):4380-4386.
7. University of Toronto website. U of T News: Does Palliative Care Need a Rebrand? https://www.utoronto.ca/news/does-palliative-care-need-rebrand. Accessed April 2, 2018.
8. Dalal S, Palla S, Hui D, et al. Association between a name change from palliative care to supportive care and timing of patient referrals at a comprehensive cancer center. *Oncologist*. 2011;16(1):105-111.
9. USA Today website. Restaurants remove toothfish from menus. http://usatoday30.usatoday.com/news/science/cold-science/2002-02-19-toothfish.htm. Accessed March 22, 2018.