

## ***Helping the Demand Find the Supply: Messaging the Value of Specialty Palliative Care Directly to Those With Serious Illnesses***



To the Editor

Palliative care needs and services have experienced tremendous growth over the last decade<sup>1</sup> because of expansions of the evidence base<sup>2</sup> coupled with a timely need in health care to demonstrate value and increase quality of care for those with serious illnesses.<sup>3</sup> Having eclipsed its first decade as a recognized specialty, and despite remarkable growth in access to services, most patients eligible for services still do not receive timely access to palliative care. This gap highlights the need to explore whether any shifts in strategy will help more patients receive the palliative services they need.

To date, palliative care has prioritized the needs of partnering clinical stakeholders, including referring clinicians such as primary care and specialty clinicians, when developing communications and materials regarding its benefits. Indeed, many collaborative initiatives exist to implement clinical triggers for consultation, ranging from policies that standardize best practices through electronic health-record–based reminders and alerts. These novel and impactful collaborations have created methods to increase the delivery of palliative care that include co-rounding hospital services<sup>4</sup> and integrated delivery within interdisciplinary cancer teams.<sup>5</sup> Also, palliative care clinicians commonly present at medical conferences and case reviews of other specialties, purposely reviewing the data on the value of palliative care involvement, with aims to encourage colleagues to refer earlier and more often.

Meanwhile, health systems and payers have attempted to improve the availability and coverage of palliative care services, such as expanding clinical availability and improved access to hospital-based palliative care services for patients with serious illness. Furthermore, federal, state, and commercial payers have increased coverage of services, making services available to many more who need it.<sup>6</sup> Also, on the cutting edge are deep learning techniques led by health systems and payers to identify patients who could benefit from palliative care by predicting risk of untoward events (e.g., hospital admission, death).<sup>7</sup> Altogether, these efforts have helped administrators and payers identify patients who would benefit from palliative care and also to increase the number of clinicians who can provide the care. Although these efforts are decidedly about patients, they only are addressing the supply side of the equation.

The focus now needs to shift to the demand side of the equation as “you build it and they will come” has

not worked. We have recognized since 2011 that most patients do not understand palliative care yet ask for it emphatically when they do understand what it provides.<sup>8</sup> There exist deleterious effects of patients not yet educated or engaged around palliative care, as some have reported no-show rates to clinic as high as 40%.<sup>9</sup> Many equate palliative care with hospice, and thus, fear seeing a palliative care clinician thinking that they are near death. Furthermore, when patients do not understand palliative care, much of the initial encounter must be spent explaining what it is, which is not an efficient use of the sparse number of palliative care clinicians’ time.

We strongly advocate that the field strengthen its focus on helping patients become more educated and less fearful of palliative care. Such an approach respects the autonomy and agency for decision-making among our sickest and most vulnerable patients, while practically honoring two time-tested economics principles: supply-and-demand economics and basics of marketing. First, put simply both supply-side and demand-side needs within a market must be addressed to achieve balance, whereas an overabundance of supply (i.e., palliative care clinicians) in certain areas leads to the drop in perceived value of services (think price of petroleum and Organization of Petroleum Exporting Countries output) or an unsustainable business model due to mismatch between costs and revenue (think 9000 Blockbuster Video brick-and-mortar stores in the midst of new online competitors). If palliative care clinicians are the supply and patients are the demand, it remains clear that the continued underutilization of palliative care stems partially from low demand.

Understanding principles of marketing yields some answers on how to address this gap. Two common adages in marketing involve “knowing your customer” and “leading with benefits, not features.” To address the first, we must think carefully about who is the end consumer of our services. The end consumer is not referring clinicians, health systems, or payers; rather, it is patients with serious illness and their caregivers. Patients receive, benefit from, and can thus demand more of our services. Thus, we should dedicate efforts to understanding the educational and engagement needs of our patients and tailor interventions to activate them around palliative care so they are partners in its delivery. Regarding “benefits, not features,” oftentimes publicly available resources on palliative care address definitions (e.g., palliative care vs. hospice), composition (e.g., who is on team), and coverage (e.g., who pays for it). Few resources discuss individual and practical benefits to patients and families, who are often very worried about care logistics (e.g., nursing support at home), opportunity costs (e.g., what palliative care adds but does not take away), and quality of life. There remains enormous potential

to use technology to dynamically understand patient and caregiver needs and target education to their specific questions and concerns.

As we aim to center all we do around our patients with serious illness and their caregivers, we strongly urge our field to strengthen its efforts to educate, engage, and prepare patients about palliative care services. More research is needed to shift toward consumer-facing engagement, particularly in developing low-cost, scalable methods that impact patient perceptions of palliative care, increase their readiness to engage with services, and provide them the language to share their positive experiences with other loved ones with serious illness. Technology-based platforms are ideal to educate and engage patients, as they are 1) agile enough to be updated continuously (i.e., compare to paper pamphlets); 2) support scalable dissemination (e.g., national roll-out of a mobile health application); 3) provide a personalized patient experience (e.g., content delivered based on how patients identify themselves or their needs); and 4) have low variable (i.e., based on number of users) costs after initial development. Well-recognized examples of using technology to engage patients in palliative care exist,<sup>10,11</sup> and we believe the potential is much larger. A future where patients not only understand palliative care but also demand its integration into usual care is not far off if we invest in impactful research that put patients' demand for knowledge and engagement at the center.

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## Frequency of Concomitant Use of Opioids and Psychoactive Medications Among Cancer Patients Referred to Outpatient Palliative Care



Dear Editor,

Patients with cancer suffer from multiple complex symptoms.<sup>1</sup> These patients are often on multiple medications (polypharmacy) including opioids.<sup>2</sup> These combinations may be necessary for adequate control of symptoms. However, there are potentially severe effects when patients taking opioids receive other

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