Special Article

The Limits of "Life-Limiting"

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Abstract

The field of hospice and palliative medicine has struggled to define the conditions that are appropriate for palliative care. "Life-threatening" appropriately encompasses lethal conditions and helpfully incorporates the concept of probability, which is a necessary variable in any risk calculation. Yet it leaves one important group of patients unaccounted for: those whose primary need for palliative care is not expected abbreviation of life but rather the quality of that life. In an attempt to include these patients, the term "life-limiting" has come to be used more frequently. Although attractive in its breadth—and at first glance appearing to be a less threatening way to introduce palliative care—the term is inherently flawed. It denotes a certain outcome, without any consideration of the likelihood of that outcome. Rather than "softening the blow" of introducing palliative care, the term seems to condemn a patient to the very outcome that palliative care is tasked to ameliorate, namely, the limitation of life. As such, it may provide a distorted view of what palliative care is, especially in pediatrics where the term is used with disproportionate frequency. The inherent misplaced certainty of "life-limiting" and the self-defeating message it sends to patients should be acknowledged. J Pain Symptom Manage 2019;57:1176–1181. © *2019 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

Life-limiting, life-threatening, terminal, hospice, pediatric, risk

Case

Our pediatric palliative care team routinely consults on every baby born before 28 weeks' gestation, given the increased morbidity and mortality associated with extreme prematurity. Recently, we were asked to meet with the parents of a baby born at 24 weeks' gestation, who had approximately a 50% chance of surviving with approximately half of survivors experiencing less than moderate neurodevelopmental impairment.[1] To prevent inaccurate inferences, in introducing ourselves we made a point of distinguishing palliative care from hospice. Aware of qualitative research regarding public opinion of palliative care, we described our role as an "extra layer of support"[2] in challenging times, which the parents seemed to welcome. At the conclusion of a very productive and heartfelt conversation, we provided them with our contact information in the form of a brochure which describes the team's mission as "improving symptoms and quality of life in children with life-limiting illness."

The patient's mother's reaction was immediate and intensely negative. She restated her hope that her baby would make a full recovery and lead a rich and full life. She went on to question whether their family would benefit from palliative care, after all.

This encounter helped us see that the brochure's description of our patient population unintentionally conveyed a definitive—and potentially inaccurate—prognosis, thereby damaging the relationship we were attempting to establish with this family. Acknowledging this called into question the words the field of hospice and palliative medicine (HPM) uses to define itself, which are often esoteric and susceptible to negative associations. One such term is "life-limiting," which has come to be used more frequently (especially in pediatrics) in an attempt to expand beyond end-of-life care by moving palliative care "upstream." Although helpful in decoupling palliative care from death, this term is frequently misunderstood and runs the risk of associating our work with the primary

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outcome that we are tasked to prevent. By tracing the historical evolution of the field's definitions and highlighting modern-day deficiencies, it becomes clear that additional work is needed to develop definitional elements that are appropriate to varied populations.

Historical Evolution

Not long after the dawn of the modern hospice movement, advocates recognized that the term "hospice" is not always helpful. Although the term has come to specifically refer to a philosophy of end-of-life care in the U.S.—especially after the creation of the Medicare Hospice Benefit in 1982—in other countries it is more restrictive physically (often referring to facilities rather than an approach to care) but less so conceptually (without the requirement of a life expectancy of six months or less). The term also carries negative connotations in some cultures, including the French Canadian context where Balfour Mount practiced.

This led Mount to use the term "palliative," which was not at risk of being misunderstood because it was not understood in the first place.[3] Literary references were infrequent and generally limited to Victorian contexts such as George Eliot's *Middlemarch*: "My own imperfect health has induced me to give some attention to those palliative resources which the divine mercy has placed within our reach." Medical references were equally rare. In fact, before Dame Cicely Saunders' seminal 1963 article on pain management at the end of life,[4] the word "palliative" had appeared in fewer than 500 articles in the entire searchable medical literature, dating back to the preceding century. By way of reference, "palliative" appeared in over 7000 articles in 2018 alone.

Despite its unencumbered beginnings, over time the term "palliative" came to acquire much of the same baggage as "hospice." The two are often falsely equated, which in the well-documented "death-denying" culture of the U.S.[5] may lead to a case of "guilt by association." Equally misunderstood is the role of palliative care, especially its compatibility with ongoing curative treatment.[6] As a result, some practitioners now favor the term "supportive care," which studies indicate is more favorably received by patients.[7]

The titular struggles of the field of HPM were mirrored by definitional struggles. Hospice care is restricted (at least in the U.S.) to patients with "terminal" illness,[8] but the field of HPM also endeavors to ameliorate suffering and improve quality of life for patients who are expected to live longer than six months or even be cured of their disease.

To encompass patients with a longer life expectancy, the broader term "life-threatening" came into use.[9] Like "terminal," it is defined exclusively by abbreviated duration of life, although the degree of abbreviation is not as extreme. But "life-threatening" also incorporates the other variable required for any risk calculation: probability.[10] Whereas a terminal illness denotes a condition that is expected to lead to the patient's death within six months, a "life-threatening" illness may or may not shorten the patient's life, without any specification of duration. By reinforcing that death is neither certain nor imminent, the risk of equating palliative care with hospice is minimized. "Life-threatening" therefore avoids implicitly offering a prognosis—and especially an inaccurate one—through the introduction of a service that could be very helpful to patients and their families.

Expanding the Reach of the Field

This still leaves one important group of patients unaccounted for: those whose primary need for palliative care is not expected abbreviation of life but rather the quality of that life. Such patients are clearly not "terminal," and the disease from which they suffer may not even be "life-threatening." To include such patients, the field of HPM once again chose a rarely used term which—like "palliative"—was not widely understood and thus would hopefully allow the field to define as it saw fit.

The term "life-limiting" first appeared in the medical literature in 1979,[11] but not until 1993 was the term used in an HPM article.[12] Over the next quarter century, however, the term has been used much more frequently. During that period, references in the HPM literature outnumbered those in the rest of the medical literature by more than two-to-one (Fig. 1).

Even if people were unsure what this fairly novel term meant, they were at least clear—or at least thought they were—as to what it did not mean: nothing in the term suggests a requirement that the patient has a life expectancy of six months or less if the disease runs its normal course. Quite the contrary, it would seem profoundly odd to inform a patient who is imminently dying that they are suffering from a "life-limiting" condition. This shift from prognostication to palliative care needs as a determinant of eligibility was endorsed by the Lancet Commission, primarily out of concern for the millions of people around the world (including children) who suffer needlessly for lack of basic palliative care.[13]

Precisely because "life-limiting" lacks specificity, many commentators now use it as an overarching term to encompass all conditions appropriate for hospice or palliative care. After all, the imminence or real possibility of approaching death clearly limits what a patient is able to do with their life, as well as frequently

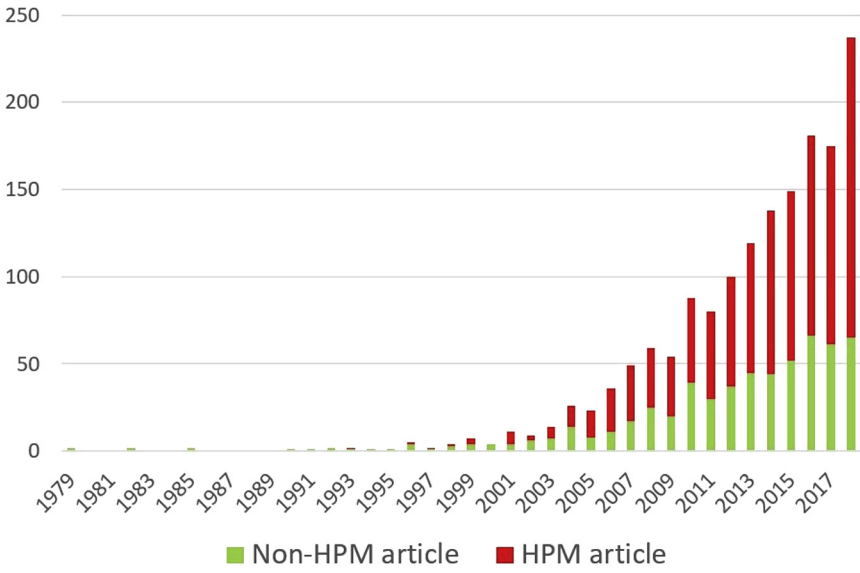

Fig. 1. Annual Pubmed references to "life-limiting." HPM = hospice and palliative medicine.

being associated with a wide range of symptoms from the physical to the spiritual. As the term has become more commonly used, many authors no longer bother trying to define it,[14] instead relying on a generally understood definition that does not exist.

Unique Needs of Pediatric Palliative Care

By virtue of incorporating the additional variable of quality of life, "life-limiting" is especially applicable to pediatric palliative care because children generally survive for much longer periods after initial palliative care consultation than do adults.[15,16] To some degree, this reflects the presumption toward aggressive treatment that is inherent in pediatrics. But other factors also contribute to longer life expectancies among children receiving palliative care, including the flatter trajectory of many pediatric conditions. Indeed, one of the four categories of diseases appropriate for pediatric palliative care is "irreversible but nonprogressive conditions causing severe disability."[17] Although these conditions may increase the probability of premature death, they in no way make this inevitable (let alone imminent).

"Life-limiting" may, therefore, seem a less threatening way to introduce pediatric palliative care because it appears to "soften the blow" by allowing parents to focus entirely on quality rather than quantity of life, especially when they may not have accepted the likelihood (let alone inevitability) of an abbreviated life for their child. This helps explain why, after first appearing in the HPM literature in a pediatric-specific article, "life-limiting" has come to be used with disproportionate frequency in the pediatric HPM literature. Only one-tenth of all HPM articles specifically address pediatrics, but one-third of HPM articles using the term "life-limiting" do (Fig. 2).

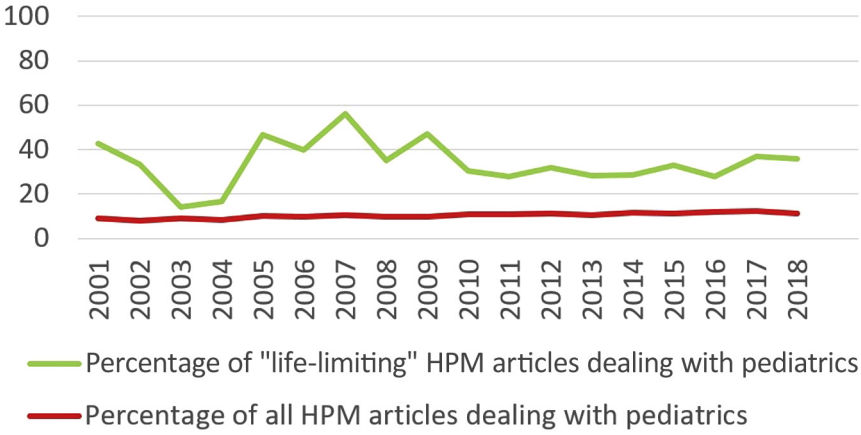

Fig. 2. Percentage of "life-limiting" HPM articles dealing with pediatrics. HPM = hospice and palliative medicine.

Yet although "life-limiting" helpfully expands the reach of palliative care by incorporating both forms of future harm (i.e., shortened life and/or burden of disease), it also sacrifices the second factor intrinsic to any measurement of risk: probability. In contrast to "life-threatening"—which recognizes a degree of uncertainty in the undesired outcome—"life-limiting" (like "terminal") implies an inevitable outcome. To declare that a patient has a life-limiting condition essentially condemns that patient to a limitation significant enough to warrant palliative care involvement. The only question remaining is how severe the limitation will turn out to be.

This highlights the danger of using "life-limiting" to broadly describe all palliative care patients. For although many patients receiving palliative care will ultimately have "limited" lives—whether in terms of duration or quality—some will not. Imagine, for instance, a patient whose advanced cancer is eventually cured. There were likely burdens associated with prior treatment as well as subsequent worries for recurrence—and the patient may well wish never to have gone through such an experience—but it is at least possible that the patient does not view their current life as "limited." Conceivably, the experience of illness may have enhanced the patient's life in the form of perspective, gratitude, and ultimate meaning. The same could be said for patients who experience illness-related disability, who far from feeling "limited" often report a higher quality of life than patients who do not report any disability.[18]

In the pediatric context, a prime example of the flaws of "life-limiting" is extreme prematurity. Palliative care teams are often consulted to support the parents of a baby born at the cusp of viability, as in the aforementioned case of the baby born at 24 weeks' gestation. To say that the extremely premature baby's condition was "life-threatening" would appropriately recognize that a substantial portion of these babies do not survive. But terming that condition "life-limiting" overlooked the fact that a significant subset of these patients not only survive but do so with less than moderate/severe neurodevelopmental impairment.[19] Rather than affirming the understandable (and not irrational) hope of the mother of the 24-week baby, the language we used unwittingly disregarded—and potentially even damaged—it.

Future Steps

Others have recognized the limits of "life-limiting," including its ambiguity of meaning as well as certainty of limitation. For instance, the International Association for Hospice and Palliative Care—through a multistage process involving a steering group and over 400 association members—recently replaced this term in their core definition of palliative care. The new definition refers to "individuals of all ages with serious health-related suffering due to severe illness."[20]

Not surprisingly, given the ongoing debates in the field, several groups chose not to endorse the revised definition. The European Association for Palliative Care specifically objected to the shift away from "life-limiting," deeming the new phrasing "too ambiguous and broad and needs refinement to reflect the nature of palliative care practice."[21] In other words, however ambiguous "life-limiting" was, the proposed alternative was felt to be worse.

For its part, the Worldwide Hospice and Palliative Care Alliance rejected terms like "severe" which could be seen as "negative and unnecessarily frightening."[22] (Presumably unlike "life-limiting," which can soften the blow of introducing palliative care, except when it doesn't.) The WHPCA also felt that the newer definition "did not accurately reflect the foundation of palliative care as a program of services for people where cure is not likely," preferring a return to "life-limiting" for the very reason that the latter term can be so detrimental in pediatrics, as it seems to negate even the possibility of a life without significant limitation, let alone cure.

Given the ongoing debate about "life-limiting," a possible fix would be the addition of "potentially" as a modifier. This would incorporate the element of probability in the risk calculation, thereby avoiding any definitive prediction of an uncertain future. Such a modifier is not without its own drawbacks, however. One is that the term becomes not only unwieldy but even more opaque; if it was hard to pin down what "life-limiting" meant, all the more so for "potentially life-limiting." The term would now be so broad as to include essentially every illness, as nearly anything could potentially alter life in a way that could be considered limiting.

Beyond technical imprecision, the more fundamental problem with "life-limiting" and its variants is that they define the field of palliative care in terms of the primary outcome that we are tasked to prevent. What is more central to the practice of palliative care, after all, than optimizing quality of life such that whatever limitations might have seemed inevitable are minimized or even eradicated? One need only look at the common slogans of our field—such as "Palliative care: It's about how you live"[23]—to recognize that life's limitations are a challenge, not an assumption. This is especially true of pediatric palliative care, whose primary goal of adding "life to the child's years, not simply years to the child's life,"[24] was not well served by our team's definition.

Our field's journey of titles began with hospice for "terminal" patients, and the ensuing noble attempt

to simultaneously expand our reach and jettison unhelpful baggage led us first to "palliative" and now to "life-limiting." Choosing terms that lack consensus definitions may have seemed a promising route to determining the scope and purpose of the field, but what is not restrictive is open to misunderstanding, and "life-limiting" turns out to have baggage all its own. It is at best counterintuitive—and at worst counterproductive—to initiate a conversation about how we can minimize (or even remove) a patient's limitations by proclaiming their illness "life-limiting."

Such persistent disagreements about something as central as the defining characteristic of our patient population illustrate the ways in which our field often works at cross-purposes. Candor (e.g., "severe") may frighten patients away, while more welcoming terms (e.g., "supportive care" or "extra layer of support") are imprecise and often do not prepare patients for what palliative care really is. Attempts to broaden the reach of the field—to include all patients who suffer—prompt concern that this will distract us from the task of caring for people near death, diluting precious resources in the process. Recognizing these competing concerns, one might reasonably wonder whether certain unique subsets of the field require their own definition. At least for pediatric palliative care—with its distinct disease trajectories and specific parental concerns—this would not include "life-limiting."

In the end, perhaps the one thing that everyone can agree on is that our field's journey of titles is not over yet.

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