

A Heart Set on Living

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A HEART SET ON LIVING

Ana Berlin, MD, MPH

Department of Surgery, Rutgers – New Jersey Medical School, Newark, New Jersey, USA

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ABSTRACT

Quality of life is a highly subjective element on which to base health care decision-making. This narrative reflection after the death of a family member uses poetry as a prompt to explore themes related to quality of life—including symptom burden, interpersonal relationships in the face of illness, and the will to live. Through penetrating inquiry and reflection, physicians and other care providers can gain insight into the underlying motivations, loyalties, and abilities that lend meaning to patients' lives and shape attitudes toward death and dying. By better recognizing and appreciating these factors, clinicians can develop patient-centered quality-of-life constructs that empower them to honor patient goals and preferences at the end of life. Physicians are encouraged to explore poetry and other artistic media to help foster the reflective capacity required to deeply understand and faithfully serve patients in this regard.

KEY WORDS: quality of life, will to live, end-of-life care, patient-centered decision-making, narrative reflection, poetry and medicine

A Heart Set on Living

I recently had the honor of speaking at a memorial service for a grandmother of mine named Ruth who died some time ago, less than two months shy of her 104th birthday. This unique opportunity enriched me in unexpected ways, for not only did it lead me to understand my grandmother more deeply, but it also shed light on my professional work. As a surgeon dedicated to addressing the palliative care and end-of-life needs of vulnerable patients with acute surgical problems, much of my work focuses on the process of “letting go.” Inspired by Atul Gawande and others, early in my career I developed an interest in unpacking the burdens of intervention, which for many patients outweigh the benefits. My focus became the runaway “treatment train” that so many of our patients find themselves on, and I dedicated myself to developing ways, through both educational and systems-based changes, to halt the frequent pattern of high-intensity treatments and interventions with more harm than benefit, and redirect the “train” to a more appropriate destination.

My recent experience has broadened my understanding of patient perspectives of quality of life in one’s final chapter, and, I think, inspired a more sophisticated and complex understanding of my role as a physician and patient advocate. I have learned some important lessons about the “treatment train.” First, it matters who the conductor is. A patient with agency and self-determination who pursues treatments in the hope of improving symptoms and maximizing quality of life is a much better conductor than a healthcare system that is

fixated on “moving patients along” in their trajectory of care! Second, what the destination is, and when to reroute the train, is not always obvious; despite our best intentions we may push too hard in one direction or another if we do not consciously acknowledge and check our own agenda, and maintain the patient’s subjective experience strictly at the forefront.

My grandmother Ruth hung on to life with a tenacity that left her family, friends, and caregivers in awe. She remained steadfastly in her own home until her nineties, despite hip replacement, severe arthritis, and many other limitations. Though her long-term memory remained astonishingly rich and intact until her death, she was frequently afflicted by mild delirium and confusion. Eventually she gave in to moving first to an assisted living facility, and then to a nursing home. Well into her late nineties, she complained of difficulty swallowing. Her food was “getting stuck on the way down.” After much persistence, her caregivers and doctors capitulated, and she underwent an upper endoscopy that revealed a Schatzki ring. This was successfully dilated and her symptoms resolved. As she aged into her second century, Ruth’s hearing and eyesight dwindled dramatically. First, she had to abandon her weekly listening session of the Metropolitan Opera radio show—but not before being interviewed about this on National Public Radio on the occasion of her 100th birthday. We—and she—took comfort in the fact that at least she could still read, and read she did. She continued to read *The New Yorker* until her macular degeneration no longer permitted that pleasure, either.

Slowly but surely, Ruth’s world, and her body, began to shrink. She became increasingly dependent on others. When minor illnesses such as bouts of diarrhea or urinary tract infection occurred, her doctors took a palliative approach, prioritizing comfort-oriented

treatments over those with curative intent. But Ruth lived on, seemingly in defiance of the inevitable. Never once, through all the discomforts and trials of aging, did she ever say she had had enough. On the contrary, she always wanted to keep trying new therapies, exercises, and interventions to address her symptoms, from her dwindling vision to her osteoarthritis. Several potential orthopedic operations were denied on grounds of her age and frailty, but well into her late nineties, she insisted on physical therapy for her shoulder (despite the lack of muscle to work with), and cortisone shots for her knees. Into her last year, she persisted with visits to the ophthalmologist in the hopes of a miracle treatment for her vision loss. The physical benefits were marginal, but the psychological benefits were undoubtedly substantial, in that these activities seemed to fulfill her existential drive to counteract the ravages of age and defy her approaching death.

Who was this woman who simply would not quit? In her obituary, my grandmother's son-in-law eloquently described how uniquely Ruth had encompassed past, present, and future, literally spanning more than a century of a lifetime. Emblematic of this blending of times and attitudes was the way in which Ruth was simultaneously progressive and traditional. She was without argument a trailblazing woman, who had struck off to college at a time when few did, who shook the hand of Sergei Prokofiev, who drove cross country from Boston to Chicago for the "Century of Progress" exhibition of 1933, and who traveled to Morocco alone in the 1960s to retrieve her newborn granddaughter, born to young Peace Corps volunteers. Even on the last day my stepfather saw her alive—when she lay in bed after having spontaneously emerged from being unresponsive for 24 hours—Ruth kept looking forward. "What are we waiting for? Where are we going?" she asked. My stepfather asked her where she wanted to go.

And in reply, she asked, "Where can we go?" The metaphorical power of this exchange still gives me goosebumps. But on a concrete level Ruth never ceased wanting to go places. At the same time, there was also something old-fashioned about Ruth. Holidays and special occasions at her home were steeped in the traditional tranquility and sensibility of a bygone era, the wallpaper and furniture in their natural muted tones, the ritual of washing and drying the dishes by hand, the clickety-clack of the slide projector.

Many years ago, Ruth gave me a little book of sonnets by Edna St. Vincent Millay, one of her favorite poets. Reading them after Ruth's passing gave me a whole new perspective on these poems, many of which touch upon aging, death, and dying. I wonder if Ruth as a young woman reading Millay was especially drawn in by these themes, and if they might have shaped her approach to old age. Here is an example that I like to think stuck with Ruth until the very end:

"Thou famished grave, I will not fill thee yet,
 Roar though thou dost, I am too happy here;
 Gnaw thine own sides, fast on; I have no fear
 Of thy dark project, but my heart is set
 On living--I have heroes to beget
 Before I die; I will not come anear
 Thy dismal jaws for many a splendid year;
 Till I be old, I aim not to be eat.
 I cannot starve thee out: I am thy prey
 And thou shalt have me; but I dare defend
 That I can stave thee off; and I dare say
 What with the life I lead, the force I spend,

I'll be but bones and jewels on that day,
And leave thee hungry, even in the end."

-- Edna St. Vincent Millay¹. Edna St. Vincent Millay, "Thou famished grave, I will not fill thee yet," from *Collected Poems*. Copyright 1939, 1967 by Edna St. Vincent Millay and Norma Millay Ellis. Reprinted with the permission of The Permissions Company, Inc., on behalf of Holly Peppe, Literary Executor, The Edna St. Vincent Millay Society, www.millay.org.

Indeed, Ruth left her grave more than hungry in the end. Ruth's great legacy was as a grounding matriarch for a large and wonderful family. She gave us all an anchor tying us to a rich past, yet also served as an inspiration to pursue our passions and create a brighter future. Seeing her large family gathered at her memorial, especially all the grandchildren and great-grandchildren, made it easy to appreciate just how many heroes Ruth did "beget," long after she stopped procreating! Whether it was a performing well on the violin, writing an award-winning poem, teaching and learning worldwide, rescuing endangered turtles, or founding a progressive school, Ruth inspired many "heroes" with her encouragement and pride in the achievements of others. She instilled in others her own persistence and drive to try new things. No doubt this is what kept her going for so long.

But for many of us, Ruth's insistence on defying death stirred conflicting emotions. It took a veritable village of caregivers to see Ruth through decades of dependence on others. While her relationships with her family, sisters, friends, and caregivers sustained her, there were substantial financial, social, and emotional costs. Ruth was never shy about making her demands: for visits from those who lived far away, a special reading lamp, outings to lunch or a favorite bookstore, her hair done a certain way... and she also seemed more than willing to use guilt as an incentive! Themes emerged: selfishness, entitlement, duty, obligation. The lines and

sides were not always clear, and often it did not seem that there was enough empathy to go around. Many of us grew increasingly concerned as Ruth grew closer and closer to her inevitable fate. One of the great sources of tension was that as she aged and became more limited, Ruth's quality of life dropped far below the threshold with which many of those around her were comfortable. Seeing her linger for so long forced many to question "Would I really want to live like that?" And for many, the answer was a resounding "No!"

Only once did I ever witness a crack in Ruth's stoic façade. Visiting her around her 102nd birthday, she once muttered, barely audibly, and with not a modicum of regret, "Perhaps I've hung on for too long..." This was far from an admission of defeat. Instead, it was a mere statement of potential fact, devoid of any interpretation. There was never any question that Ruth was determined to "hang on," even if it was for "too long." Indeed, Ruth would continue to "hang on" in loyalty to her life mission of inspiring others, leaving a legacy, and fully exhausting her "force" in the world before she finally passed away.

Having witnessed Ruth's final three decades, and through my reading of her favorite poems in the wake of her death, I internalized an important lesson about quality of life. For although it is easy to teach and talk about the subjective nature of what we call "quality of life," we all have certain personal biases that are difficult to eradicate. My quality-of-life bar is quite a bit higher than Ruth's... but this may very well change as I age and progress through life's developmental stages or grapple with illness and limitations. Millay's sonnet showed me—eloquently, beautifully, surprisingly, and humorously—just where Ruth's quality threshold lay, contextualizing it with reference to her very *raison d'être*.

For any given patient, just how high or low the quality-of-life threshold is depends upon the functional capacity required to carry out the life missions that matter most to that individual—balanced, of course, by the burdens of any unmitigated symptoms. Elucidating the loyalties, abilities, and quality-of-life and symptom-burden thresholds important to each and every one of our patients is the key to having effective conversations about patient goals and preferences with respect to health care options. Clearly, physicians need to incorporate into routine care the simple asking of these questions, through effective methods and tools being developed and described in the palliative care literature today.²⁻⁴ In the case of my grandmother Ruth, poetry was an important tool in my finally comprehending and achieving peace with her end-of-life trajectory. I believe that Millay's poems—as well as more broadly the literary, visual, and performing arts, all of which aim to explore and reflect the depth of human experience—can help clinicians understand and appreciate the range of motivations and attitudes toward death and dying that our patients may espouse, and I encourage readers to explore these and other media further to hone and deepen their ability to recognize and honor the end-of-life preferences of patients.

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