

Leaning In to Serious Illness Care Through Stories and Science

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This volume was planned prior to the COVID-19 pandemic as the North Carolina Institute of Medicine (NCIOM) completed a yearlong task force on serious illness. Beyond the task force report, we wanted to dedicate a special edition of the *NCMJ* to serious illness issues. We commissioned authors who could discuss the challenges, the current practices, and the extensive personal and professional skills needed to navigate these complicated medical diagnoses that often end in death. Little did we know how timely this would be in light of the current pandemic, and we can only speculate on how the world will look as this is published. Our pre-COVID planning reflected personal experiences we all face with the common denominator of serious illness impacting and shaping our lives. As guest editors, we considered how this *NCMJ* edition would address personal concerns for you, our reader, as well as ourselves. A physician, a social worker, and a nurse, we each have our stories and we want to invite you to *lean in* and bring both your head and your heart to this reading. We start by relating two very personal experiences that shaped not only life following loss, but also career choices, clinical practices, and scholarship. As you focus on this journal's content, we hope you will also reflect on the people you care for, as well as the issues we all inevitably face.

Jonathan's Story

"Fifty percent of patients who have this, die within five years." It was a call from my brother, telling me that our mother, Ann, had just been diagnosed with ALS, more commonly known as Lou Gehrig's disease. It was December of my freshman year of college, and my brother was in his second year of veterinary school. He understood the physiology and knew the statistics. So, even though I was stunned and concussed by his words, there was no doubting what I'd heard. Why hadn't my parents told me that my mother was having trouble and getting evaluated?

I didn't know it then, but this was reflective of what was to be a critical, core challenge with this illness, both for my mother and for our family. Communication was being disrupted, disturbed, thwarted, or even extinguished across many channels. Physiologically, in my mother's newly unveiled disease, nerves were losing their ability to send messages to muscles, leading to atrophy and functional loss.

The loquacious woman who could spend hours on the phone, renowned for quickly boasting about her children and their accomplishments, was being gradually, painfully silenced. What began as difficulty with mild slurred speech left her capable of only producing guttural wails within a year. As the disease unfolded, my mother progressively lost the ability to speak, to swallow, to move, and ultimately, by Thanksgiving week of my senior year, to breathe.

Throughout her illness, my mother couldn't, or wouldn't, talk with me about her struggles. There was the dysarthria—the physical speech challenges—which she tried to overcome by first typing over the phone line with a TDD machine typically used by people who are deaf or hard of hearing, and then by using the computer, whose cursor she later learned to move with her head. As she became increasingly frustrated with these workarounds, angry at the cruelty of her situation, she withdrew and desperately willed herself to not show tears, or fear.

Communication was seemingly hard for everyone, including the medical establishment, whose efforts were clearly deficient. For my mother, the dwindling capacity to speak, as well as the painful emotional hurdles, proved devastating. What was the medical system's excuse? The neurologists evaluated diagnoses, generated differential assessments, and shared dismal statistics, while my parents were otherwise alone to navigate the thorny, forced march ahead. Why weren't they given more guidance about the disease's progression pattern? Weren't there technologies or assistive devices that might help my mother to compensate for her mounting functional debility? How would my father know how to appropriately care for her? What further decisions still loomed ahead, and where could they get help and support?

As my mother's swallowing diminished and her hands and arms became flaccid and less useful, the caregiving burden landed squarely on my father. He reduced his hours as a university rabbi, moved their bedroom downstairs, and rearranged the house for accessibility. Nevertheless,

Electronically published July 6, 2020.

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NC Med J. 2020;81(4):237-241. ©2020 by the North Carolina Institute of Medicine and The Duke Endowment. All rights reserved. 0029-2559/2020/81404

it was becoming indescribably overwhelming. My mother became increasingly taciturn and depressed as she used a PEG tube for nutrition, required frequent mouth suctioning, and needed assistance to move to the bathroom, where she also had to have help. Initially, my mother was determined to keep the disease from disrupting her family's life and insisted that my brother and I remain in school. We worked to honor her wish, but nevertheless spent increasingly more time at home. I'm sure it was challenging for her to know we were witnesses to her decline, especially as we occasionally assisted with her most intimate needs.

My family was not wealthy, and despite the benefit of health insurance, the costs of hiring additional caregivers for even a few hours a day quickly added up. We were blessed that our local Jewish community was generous with finances and volunteers, and we appreciated their expressions of love, such as building a wheelchair ramp to the front door.

I was particularly fortunate to connect with a clinical social worker who helped me to understand that, despite withholding her thoughts or fears, my mother didn't want me to squelch my own emotions and simply remain silent. Thus, while home for the summer, I summoned up the strength to ask my mother about what she was going to do when the disease eventually affected her breathing. She looked at me wide-eyed, and then painstakingly moved the mouse to say, "Your father will know." So, when sitting later at the kitchen table with my father and brother, I cautiously relayed, "She says you will know." My father was taken aback and offered a bewildered, "Well I don't know." My brother interjected, "So you say you just want to let her go!?" No, that's not what we were saying. This was hard. We needed to know what my mother wanted, but the conversation was too difficult for us to navigate alone.

In a rare example of good communication skills, my parents' family physician came to our home and spoke with my mother. With plaintive cries and tears filling her eyes as she blinked a signaled yes or no, she indicated she had suffered long enough. She did not want to be on a ventilator.

Three months later, an early morning call from my father woke me in my school dorm bed in New York City. My mother wasn't waking up and my father said her breathing looked shallow. He asked me what to do. "Just do what she asked," I told him. "Just be with her and say that we love her."

While I theoretically started college in pre-med, I found myself more drawn to religion and philosophy classes than chemistry labs when confronted with my mother's unfathomable suffering. So, I graduated with a religion degree, spent a season in organic farming (soothing for the soul, though not for the back), and then a couple of years as a social worker with homeless families in NYC. This path helped me feel productive and impactful, in marked contrast to the profound helplessness that had characterized my mother's illness. But in the boroughs of NYC I came face to face with social determinants of health and the challenges of access, and this ultimately propelled me back toward medicine.

I needed to see death within the broader context of life. This orientation, combined with my social work instincts, drew me to family medicine—prenatal care, well-child visits, and the full life cycle of primary care services for individuals. Community health centers were the ideal workplace where I could routinely work collaboratively with social workers, and which, over time, provided a profoundly meaningful mission in helping families navigate serious illness. Echoing the gifts of conversations where I learned what was most important to my mother as she approached end of life, a refined focus in palliative care now allows me to walk the path with families while helping facilitate difficult conversations. I've also gained a heartfelt commitment to teaching other providers the critical communication skills that I have learned are the foundation of patient-centered, compassionate, quality care.

Karen's Story

I was born into a Southern Baptist family that was an integral part of a Christian community and was raised to believe in a "higher power" that would sustain me in times of sickness and in health. This was true with or without tangible resources of wealth or the worldly power to overcome adversity. From my intergenerational family that included many wise and respected older adults—grandmother, aunts, uncles, and fictive kin—I learned firsthand the African proverb that says, "It takes a village to raise a child." In Warren County, North Carolina, we knew that we must take care of one another. We valued collective decision-making, narrative transfer of knowledge and awareness, and the verbalization of intent and expectation of our cultural group members. In other words, we were of an oral tradition that confirmed and validated the need to surround ourselves with people who understood our ways of thinking and doing, and trusted the integrity and authenticity of our culture. Our faith told us we are not the master of our fate, and thus, we "look to the hills from which our help comes... indeed, our help comes from the Lord who made heaven and earth (Psalms 121)." This was never more apparent to me than when my mother was diagnosed with metastatic lung cancer and then died before age 70, despite her mother having lived to be 102 years old.

Like her mother, prior to her serious illness diagnosis I cannot remember a time when my mother visited a health care provider for preventive care. For most of my life, she worked for a manufacturing company that did not provide health care insurance. This meant neither she nor her children had any pathway to risk assessment or the early detection of serious illness. Thus, when my mother was diagnosed with cancer, it was stage IV and incurable.

In keeping with our oral tradition of sharing and leaning on each other for informal support, my mother immediately invited me, her only daughter, on the journey of living with cancer until the end. As it turned out, it was only a brief road to navigate.

I will always remember the day she called me in Boston, saying, "The doctor found a spot on my lung." I immedi-

ately sought solace through denial, although I knew all too well the environmental toxins to which she was exposed in Warren County, North Carolina. Pentachlorophenol (PCP) was prevalent, and combined with very limited ventilation and no outdoor breaks during long double shifts inside a cotton mill, my mother had faced significant health risks, as had many other family members. In retrospect, denial was the self-imposed protective mechanism I used to create resilience, which ultimately enabled me to focus on my doctoral dissertation and continue mothering my baby girl, who desperately needed her mother while I was losing mine.

I *leaned in* and became the primary caregiver for my mother, even from a distance. I accompanied her to each appointment at Duke and UNC hospitals, where she received excellent care. I helped her to exercise her right to self-determine her path and to decline interventions like chemotherapy and radiation treatments when she felt inclined to do so. I was there as her health care proxy to ensure her wishes and preferences were honored when she transitioned from Maria Parham Hospital to home hospice. When the time came, it was me and not her who decided to accept in-home hospice care on her behalf because I knew, better than she had ever been allowed to know, that people who don't look like you can actually be trusted to provide exemplary care that is person centered and culturally competent. My mother ended her days in quality hospice and palliative care, comfortably surrounded by her children, siblings, friends, and other loved ones.

This experience compelled me to personally commit to a professional practice in clinical social work, working to educate communities and promote interdisciplinary cultural competency in person-centered care for serious illness across health care settings.

For the past 25 years, I have studied health disparities and practiced in settings where I witnessed individuals and families struggle with the recommendations of medical teams to accept hospice and palliative care when faced with serious, non-curable illnesses. Consistently, I've found that cultural beliefs and values predominate. While culture cannot predict health status, and race cannot reliably determine a population's health condition, they must play an integral part in how we address serious illness, lest we deprive our patients of the care they desire.

About This Edition

At first blush, these stories describe very different family circumstances and environments, but they are not unlike those we face every day as care providers, patient to patient, disease to disease. We see different faces, upbringings, beliefs, economics, resources, settings, diagnoses, and lived experiences, and yet, like Jonathan and Karen, our patients are not so different. The journey involved in serious illness care is complex, emotional, and very personal, challenging us to find the best way forward for those we care for and love.

The effective presence—or lack thereof—of the health care team is the common denominator in these scenarios. Providers are asked to assess the circumstances of each patient and propose a plan of care based on their unique (yet similar) needs, which is to *lean in* and engage as an integral part of the village. There is an expectation and a hope that we can be comprehensive in our approach, culturally sensitive and skilled enough that all the unmet needs we see can be identified and addressed. As providers, we often find our skill sets are not as refined as we'd like, our resources are more limited than they should be, and the trusted relationships we want are yet to be created—and yet we persist, because we have little other choice.

In this publication, we define serious illness as “that time when chronic or acute health conditions become serious enough to affect a person's general health and functioning, effectiveness of curative treatment begins to decrease, and the focus of care may shift towards comfort” [1]. It is a time when health providers are asked to intervene, to identify and mobilize needed resources, and to help their patients and families navigate care, much of which takes place at home and is dependent on community resources. For that reason, societal challenges (including poverty, inequity, and injustice) encompass many of the situations we confront, compelling us to advocate on behalf of those experiencing life-limiting illness.

Our authors discuss many issues surrounding serious illness care and suggest what is still needed to deliver coordinated care in our complex society. They discuss the professional skills of health providers and the availability and affordability of needed resources, including technologies and their role in how patients and caregivers identify and obtain services. They also address the relational and communication skills brought to encounters with those who need care. They challenge us to *lean in*, to use all of the resources available to us, and to engage with those who seek our assistance.

We find in the first article, “Expanding and Enhancing Advance Care Planning to Promote Goal-Concordant Care,” that Wood and Winzelberg challenge us to increase advance care planning (ACP) within our communities and provide medical care that matches the person's goals for care at the end of life [2]. They provide a basic history of ACP and analyze its use in North Carolina, including current implementation of advance directives. They propose five guiding principles for successful ACP. Importantly, these authors discuss the promise of a new ACP process while calling out longstanding challenges for completion rates in advance directives. Fortunately, in recent years we've seen a cultural shift among health professionals on end-of-life issues, prompting federal reimbursement for ACP discussions. There is also a noted increase in interest among the population to have conversations about patient self-determination and planning for care in advance.

Two sidebars complement the ACP discussion. In

“Understanding Medical Orders for Advance Care Planning,” Darden brings us up to date on how patients and providers in North Carolina can use medical orders to help direct care at the end of life [3]. In addition to the North Carolina-specific MOST (Medical Orders for Scope of Treatment) documents, she suggests that early advance care planning should broadly encompass individual decision-making, including conversations with loved ones. She notes that a variety of tools are available for documenting desired treatment options. Specifically, she points out that health care power of attorney (HCPOA) and living wills are available for use by North Carolinians with serious illness.

In the second sidebar to Wood and Winzelberg’s piece, “Enhancing Technology to Better Communicate Advance Care Planning Information,” Burriss and Sevier write of technology across the health care delivery system that enables individuals’ wishes to be known wherever and whenever care is provided [4]. They point to the goal of the NCIOM’s Task Force on Serious Illness Care to recommend more robust health IT resources for serious illness care, including easier transfer of ACP documents between providers. They stress that effective, readily discoverable communication enables individuals, families, and providers to honor an individual’s wishes while also promoting appropriate and timely care.

As we move to the second invited commentary, “A Call for North Carolina to Surround the Seriously Ill and Caregivers with Interprofessional Collaborative Teams,” the focus shifts to challenges facing members of our health care workforce as they navigate the complex needs of the seriously ill [5]. Lake, a health care leader, clinician, educator, and caregiver, provides a perspective from years of observational experience. As caregiver of her 84-year-old mother, she recounts the personal challenges of the journey and the increasing need for coordination among a large number of resources.

Turning to workforce shortages and care coordination gaps, Lake focuses on the growing need for greater expertise in serious illness and palliative care specialties [5]. Highlighting the need for interprofessional collaboration, she suggests a culture shift is needed to create a more focused team practice that would reduce fragmented care and enhance provider, patient, and family goals.

As we see that minorities are disproportionately affected by COVID-19, Barrett, Hasan, Bethea, and Johnson’s “The Fierce Urgency of Now: Addressing Racial and Ethnic Disparities in Serious Illness Care” could not be more timely. The authors focus attention on inequalities in serious illness care and put a real face on their observations [6]. Their story of Ms. Mixon’s journey accentuates the importance of family engagement at end of life and also highlights the roles of trusted community organizations and faith groups. The authors emphasize the racial and ethnic disparities in serious illness care and strongly advocate for change, including specific recommendations for health care organizations, providers, and policymakers.

In “Health Equity in Aging for Transgender People,”

Simmons makes us aware of the intense challenges facing people who do not identify with the gender assigned to them at birth, as well as other LGBTQ persons [7]. In this thought-provoking piece, we learn of the experience of transgender people, a small but growing segment of the population who are at risk in various care settings, especially as they age. Simmons points out that older transgender individuals may experience greater challenges than cisgender sexual minorities, while also noting that traditional advance directives do not typically include the legal language to meet their specific needs [7]. Simmons challenges us to advocate for greater sensitivity in providing care, while also increasing research on health disparities among marginalized populations.

“Advance Care Planning Engagement: Meeting People Wherever They Are” addresses the challenges and opportunities of community engagement for advance care planning. Ward describes Mary, a petite woman in her 60s who, when facing transplant surgery, appointed a non-relative health care proxy [8]. Ward challenges us to expand our thinking and make space for the Marys of the world, whose stories reminds us that greater communication and openness can lead to richer and deeper dialogue and unpredictable decisions.

Following our focus on embracing difference, we are next challenged to consider new models of support and care outside the hospital. Gualtieri-Reed and Morris, in “Meeting the Needs of Those with Serious Illness In their Homes and Communities,” use another case study to highlight the complexities of serious illness and palliative care in the community [9]. They discuss skill sets, metrics, and payment models that are important to achieving the goals of quality care and emphasize the importance of changing current models to support coordinated care.

Lavin and Zimmerman, in a companion sidebar on “Using Patient-Reported Outcomes to Facilitate High-Quality Virtual Care for the Seriously Ill,” suggest the COVID-19 pandemic has accelerated a move to virtual care, altering routine clinical practice approaches, perhaps forever [10]. They cite the importance of designing comprehensive quality measurement processes to better understand these changes and promote patient-reported outcomes as foundational measures.

In our next commentary, we make an important shift to comprehensive care reimbursement. In “Designing Effective Payer Models to Improve Serious Illness Care,” Spragens proposes important concepts for designing sustainable payer solutions to improve serious illness care delivery [11]. She describes national and North Carolina-based innovations and discusses strategies for testing and preparing for new models. Spragens illustrates the importance of proactively convening groups like the NCIOM Task Force on Serious Illness Care to explore the varied roles, affiliations, and practices necessary for change.

Our final commentary focuses on challenges facing caregivers of seriously ill adults or children. Blater, in “1 in 5 North

Carolina Adults are Caregivers: Addressing Unpaid Family Caregiver Burden with Supportive Services," underscores the stark reality that we will each probably be a caregiver or a care recipient at some point [12]. The author emphasizes that the majority of daily caregiving tasks are custodial, not medical in nature, and therefore largely unreimbursed by insurance programs. She then describes caregiver burden, highlighting the emotional, physical, and financial toll of long-term care in homes. Thankfully, the author also describes services in place to support family caregivers, offering the hope that these may actually expand in the near future.

And finally, in Register, Lakis, Pogers, Parnell, and Gilmore's sidebar, "Serious Illness Care for Children and Adolescents in North Carolina," we are reminded of the unique circumstances faced by seriously ill children and their families [13]. While fewer in number than adults, there is a strong case for improving specialized teams to help children with serious illness and their families navigate complex needs and obtain quality psychosocial support.

Returning to the beginning, we invite you again to *lean in* and reflect on the complexities, the challenges, and the opportunities for engaging those with serious illness in a life-honoring way that assures the care we would want for our loved ones, or ourselves. **NCMJ**

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Acknowledgments

Potential conflicts of interest. The authors report no relevant conflicts of interest.

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