

Advocating for Palliative Care is Our Role: A Physical Therapist Perspective

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Introduction

Physical therapy (PT) students are required to complete clinical placements to gain experience with patients and clinician guidance before graduating and practicing independently. My clinical placements were profoundly formative, exposing me to deep human suffering, challenging my view of a physical therapist's role in neurorehabilitation and care for the seriously ill, and introducing me to the field of palliative care. Through (critical) reflections on key patients over time, each journeying through their own story with brain cancer, I came to see important underlying structures, assumptions, and expectations surrounding palliative care. While providers, patients, and the public often aim to avoid palliative care, I saw that its providers and approaches drastically improve a patient's quality of life. I also saw the gaps in patient care created by an aversion to palliative care discussions.

Palliative care is a medical specialty focused on maximizing quality of life while minimizing symptoms and stressors associated with serious illness, regardless of disease stage.¹ The purpose of this perspective is to interrogate my personal experiences to uncover healthcare structures, clinicians' assumptions, and

social expectations influencing attitudes toward palliative care in the context of rehabilitation. I also aim to challenge current and future physical therapists to critically reflect on their own experiences with palliative care and advocate for better integration of palliative care principles into PT practice.

Background

I am the oldest child and only daughter of a small-town doctor practicing deep in South Georgia (USA). My white, well-educated parents were relocated to my hometown, a place where people rarely move, and seldom leave, holding a level of skepticism for all newcomers. My childhood served as my introduction to the complexities of healthcare. My dad's peers and friends were my physicians on the rare occasion that I needed one. I am able-bodied with the gift of good health, so I have largely associated going to the doctor's office or hospital with a social visit more than any medical experience. I never had to wonder what an obscure diagnosis or scary-sounding medical test meant, never had to navigate the twisted world of health insurance alone, never had to hope that medical help would arrive on time. I quickly learned that this is not the norm.

As best he could, my dad did not hide from me the stark contrast between my experience of healthcare and that of many others in my rural community. I saw the long hours and sleepless nights he spent caring for patients he knew would not be able to pay. Mothers of children with serious special needs spoke to me in public how grateful they were for his care, as I helplessly tried to empathize with a situation I could never fully understand because of my position of privilege. Kids looked up to him as a reliable source of stability they could not find in other places. Even as he compassionately and sacrificially provided healthcare to an under-educated, economically-disadvantaged community, he knew that the needs were far greater than what he could meet on his own. I gradually recognized the unearned advantages of medical literacy, quality education, financial resources, and positive experiences with healthcare professionals.

However, this realization was not what initiated my pursuit of a career in healthcare. As a university student, I found myself enthralled with neuroscience, anatomy and physiology, and human psychology. Eventually a healthcare degree seemed inevitable, but for far too long the deep sense of care and responsibility for people and the unfair determinants of health that I observed through my father's eyes as a child remained largely on the periphery. Sure, I began PT school wanting to help people regain their lives through functional mobility, but I had only begun to consider the scope of requirements to do this well. I certainly did not anticipate my most valuable lessons would come from those grappling with the realities of death, states away from home but with a strangely familiar contextual backdrop.

CRITICAL REFLEXIVITY

Critical reflexivity has served as a useful lens through which to examine my own experiences and the evidence that I have consumed, to appreciate the social, structural, emotional, and cultural dimensions of healthcare broadly, and palliative care in neurorehabilitation specifically.²

Critical reflexivity, informed by the social sciences and humanities, is a concept that guides clinicians to consider their own power, knowledge, and limitations in their field along with the unspoken norms, assumptions, and social realities influencing practice.^{3,4} Both intended and unintended consequences of actions are considered in the process of critical reflexivity, with emphasis placed on the underlying forces in health professions education, clinical practice, and healthcare delivery.^{3,5} The ultimate aim of critical reflexivity is to provoke system-wide change in the structures and norms that surround patient care.^{2,4} I recognized, wrestled with, and questioned these structures and norms as a PT student. I have sought to reflect on my personal experiences and, through reflexivity, uncover healthcare structures, assumptions, and social expectations influencing attitudes toward palliative care in the context of rehabilitation.

A PATIENT TO REMEMBER

I spent one PT school clinical placement in a rural hospital where I met Tina.* She was pushing away her bedside table and throwing off her sheets as I walked into her room. She glanced at me like I was interrupting something important and continued on. I introduced myself and asked her what she was doing, aware that my interviewing was not going to disrupt what she had made up her mind to do. "Going to the g—damn bathroom young lady, what does it look like?" Her occupational therapist and I jumped in with shoes and

a walker, content to continue our unannounced mobility assessment.

Bed mobility, check.

Transfers, check.

Cognitive awareness and impulsivity... TBD.

I managed to slip a gait belt on before we made it too far, fearing a professor might retroactively fail me on the practical exams I had passed to reach this point in my education. Once we started walking, I was glad to have the belt and overjoyed we arrived at her room when we did. Our presence did not deter her from starting a trip to the bathroom, but it ensured she reached her destination safely.

As we walked, I began seeing in person what her chart detailed in text. Tina's gait was ataxic. Her breathing was labored and shallow. Balance and body awareness were hazardous. I eventually concluded cognition and behaviors were baseline, a fitting display of her fiery stubbornness that had aided her fight against lung cancer thus far. Metastatic lesions from rouge bits of tumor now riddled her brain but that was not going to stop her from voiding her bladder and doing anything else she "damn-well pleased." She had been hospitalized several times recently, but she was like most patients I saw on that clinical placement.

She had gone decades without seeing any healthcare professional. She couldn't remember a day in her life she *hadn't* smoked—until she arrived at the hospital that stripped away the most basic facets of her day. She had a mild distrust of anything remotely institutionalized, with frequent remarks about how everyone at the hospital was trying to control her, how any living arrangement but her own home would be unacceptably restrictive, and how the government had ruined everything, including the hospital. She had no family nearby, preferring to spend her days

independently in her own home. The company she chose included her long-time neighbors and her beloved dog. She had a simple life, but she was content. Despite the poor prognosis associated with her lung, and now brain, cancer, she had managed to continue living alone, doing the things she desired. She had no idea she would never leave the hospital again; neither did I.

PROGRESS – AT FIRST

Initially, Tina made progress. She accepted using a walker and showed improving endurance. She agreed to enlist her neighbors more formally for help. We were not thrilled about her going home, but no community options for discharge would accept Tina's package deal—her and the dog. She was looking forward to their reunion more than anything else. She moved from progressive care up to the medical floor, a positive step toward discharge. The first day I saw her in her new room was awful. It was like she had left herself behind on the lower level. Before, she walked laps around the unit. Now, she could not get out of bed. She could not even keep her eyes open. A switch had flipped. She was actively dying right before my eyes.

Over the course of my rotation, I learned that hospitals are where the poor and marginalized members of our society go to die. People with the means to keep up with maintenance healthcare, fund a healthy lifestyle, and cover large procedural expenses only go to the hospital for life-saving measures. They get in, receive care, and get out. People who do not have access to these things avoid the medical system for most of their lives. Then, they go to the emergency room knowing they will receive treatment regardless of their ability to pay. They bring an impossible case before the healthcare team, and we are left grappling with their

expectations while knowing that going back to one's former life is no longer an option. This is exacerbated in the context of rural healthcare, where multiple social determinants of health (SDOH) compound to influence the care of serious illness.^{6,7}

INTERSECTIONALITY AND OUTCOMES

Using intersectionality, Cohen emphasized that limited financial resources, older age, and living in rural areas compound to limit access to healthcare and, thus, worsen overall healthcare outcomes.⁷ Others have highlighted the intersectional relationship between healthcare access, singleness as a female, and lower financial means.⁸ In light of such literature, Tina's experience is not uncommon. Various contextual factors, including rurality, social isolation, financial resources, age, and gender, interacted and shaped the trajectory of her health outcomes across the lifespan. It was within this context of multiple SDOH known to contribute to worse health outcomes that I witnessed the resolve and grace demonstrated by Tina's small-town providers. The physicians prioritizing Tina's wishes did not see her as a smoker with avoidable lung cancer or a stubborn patient who should have sought medical care sooner, but instead as a dignified human worthy of respect simply because she was a person.

During later clinical placements I saw that certain lifestyle behaviors, including smoking, are seen as morally inferior choices that patients engage in, resulting in stigmatization toward and shame within those practicing these behaviors.⁹ What is rarely discussed, however, is that it may be this stigma associated with smoking behaviors that actually contributed to Tina's avoidance of healthcare, as secrecy, not cessation, has been cited as a byproduct of emphasizing patient responsibility over other social,

political, and structural forces promoting smoking behaviors.⁹ Patient perception of stigma from healthcare providers in general seems to be a barrier of particular importance in rural healthcare settings.¹⁰

Outside of Tina's care, I have been struck by the ease with which healthcare providers minimize patients to insensitive one-liners. These dehumanizing, stereotypical views that frame patients as solely responsible for "demoralizing" behaviors ignore the broader SDOH at play and influence a provider's willingness to individualize care. While this approach can be taken to create emotional distance as a byproduct of overworked, compassion-fatigued providers' attempts to survive the demands of rural healthcare, I have learned that both patient care and provider end up at a loss with this stigmatized approach.¹¹

Amazingly, medical team discussions about Tina turned to what we could do for her to maintain dignity and comfort. Despite the general lack of specialized training for rural providers contending with these challenges in the face of serious illness,⁶ several of the hospitalists had developed great skill for managing patients in this setting of poor prognosis and limited resources. This skill set them apart from other providers who had settled to ignore the reality of their workplace. The plan for Tina became focused on managing pain, providing comfort, and, most importantly, briefly ignoring hospital policy concerning furry visitors. PT was not going to drag her out of bed for walks she did not want to take, she would not be forced to eat, the horrible side effects of futile cancer treatment would no longer govern her life. She was going to enjoy her dog, listen to her loyal neighbors recount stories, and then die peacefully.

Discovering Palliative Care

By reflecting on the stories of Tina and the other patients to follow, I have realized the lessons they taught me do not fit neatly with what I know and love about restorative neurorehabilitation. I have hoped these patients are the exception and conversations about serious illness are not my responsibility. Ultimately, I have been alerted to the fault in this reasoning and the breadth of responsibility that is granted to rehabilitation professionals. We would all prefer to celebrate the amazing advances of modern medicine and think no more, but healthcare providers have the responsibility to honestly assess the holes in our system. Only by carefully assessing the world we operate in can we identify appropriate solutions.

While it would be several months before I had a name for the approach Tina's medical team took in her final days of life, her story catalyzed my own questioning of the scope of rehabilitation. I began to wonder if my view of rehabilitative care was too narrow, if it excluded people like Tina and those I had grown up watching my dad care for. I glorified success stories that highlighted innovative advances in restorative rehabilitation at the expense of those flippantly classified as having too many poor prognostic indicators. Learning about palliative care has shifted my perspective. Although it is a field that is still growing, evolving, and grappling with its own challenges, witnessing palliative care at the end of Tina's life showed me that meaningful PT could not be limited to the one, narrow approach I had conceptualized in my head to make earning a degree and passing standardized tests feel more manageable.

I came to learn that palliative care can be provided to anyone living with a serious illness, even as they receive curative treatment.¹ However, in practice and research

it is largely employed toward the end of life,^{12–15} likely contributing to the inaccurate conflation of choosing palliative care and ushering in death.¹³ The primary goal of palliative care is to provide relief from symptoms and stress associated with serious illness¹ while attuning to patients' social circumstances to give them a better life.

Formal palliative care and, more broadly, personalized care of patients with serious illness comes with unique challenges in the context of a rural medical system like the one where I met Tina. Some have systematically investigated the SDOH contributing to disparities in palliative care.^{6,16} Using the United States Department of Health and Human Services' SDOH framework, one group identified determinants particularly evident during my interactions with Tina including lack of patient access to resources, distrust in healthcare, limited social and community support, and environmental injustice.⁶ These factors compound with rurality to strain healthcare delivery, especially for those with high medical complexity and those approaching end of life.^{6,7,16} Community-based palliative care has been implemented with some success;¹⁷ however, placing this responsibility on communities with few resources, limited health literacy, and differing conceptualizations of death has been rightfully questioned.¹⁸ In Tina's case, community-based palliative care was not an option, and she encountered hospital-based services later in her disease process than is desirable for maintaining quality of life with serious illness. Without addressing the SDOH and disease gradient that unequally impacts rural communities, the benefits of palliative care principles will not be felt by patients like Tina.

I later learned that eliminating rurality, poverty, and poor healthcare access greatly improve a patient's options for navigating serious illness; however, even

when these factors are eliminated, other barriers impact the use and delivery of palliative care services.

The Hospital Where Failure is Not an Option

After my rural hospital placement, I spent four months at one of the best neurorehabilitation hospitals in the United States. The rural hospital had just fired its CEO as their last-ditch effort to avoid bankruptcy in favor of an interim CEO with historical success at helping financially-struggling hospitals survive. Major efforts were being taken to reduce time in the hospital, identify factors contributing to frequent re-admissions, stretch minimal personnel resources as far as possible, and manage the seemingly impossible socio-economic challenges for patients. If patients were well enough to avoid an immediate return to the hospital, their discharge was deemed successful. In contrast, the concept of scarcity seemed foreign at the neurorehabilitation hospital. With cutting-edge technology, a saturation of expertise, and abundant financial resources, they gained a reputation for providing fertile ground to grow miracles. It was a place that promised big, and then—against all odds—delivered.

During the same semester, I enrolled in a Palliative Care class. I had not realized conversations began to take the form of palliative care at the end of Tina's life; however, as I heard class lectures and discussions, I knew what I was hearing was beneficial because I had seen it work. I knew this class would help make sense of past experiences and benefit my future patients. Naively, I failed to see how it could serve me in an odds-defying neurorehabilitation hospital. Soon, I

would learn that personalized palliative care might be the next miracle worth fighting for.

TWO NEW PATIENTS

I did not expect to be reminded of Tina in a place that was so opposite from her experience—abundant resources, full of hope and promise. During my neurorehabilitation rotation, I had two patients with brain cancer. One recently learned of the masses growing between her ears. She had practiced law to improve the lives of foster children, was eagerly anticipating meeting her grandchild, and simply wanted to sit on the porch with her dogs. While sharing a common diagnosis and special affinity for dogs, the similarities with Tina largely stopped there. Tina was a single woman with minimal social support and no college education, living on one meagre income with public insurance in a rural, medically-underserved community. My neurorehabilitation patient was advantaged in all aforementioned areas.

The contrast of their lives highlights the intersectionality of SDOH when considering the type of medical care they received across the lifespan.⁶⁻⁸ While Tina encountered palliative care when she was well overdue for routine care, my neurorehabilitation patient had received exceptional care every step of the way. Interestingly, however, expectations for exceptional care remained narrowly focused on medical outcomes even as this second patient's glioblastoma became more aggressive, while the severity of Tina's illness prompted personalized care in the face of medical uncertainty.

ILLUSIONS AND UNMET EXPECTATIONS

My neuro-oncology rehabilitation patients had a terminal diagnosis; however, it seemed a trivial detail to

the operations of their care. On a brain injury unit, most patients have a non-progressive etiology, so we can aim for restoration. But cancer pays no mind to these rules. The patients with brain cancer had something fundamentally different: an acute awareness of their finitude. They knew they could not go back, and so did everyone on their team. Yet, providers continued their roles as usual. They discussed the sad, impossible state of these patients and then proceeded to set goals, make discharge plans, and consult specialists as though glioblastoma could be lumped into the same category as all other brain injuries. I was at one of the best hospitals in the country and, as far as I could tell, palliative care referrals weren't being made by inpatient physicians *at all*.

What started as legitimate outcomes demonstrating the amazing power of neurorehabilitation had become an illusion. To patients and families, all they needed to do was figure out how to get admitted; we would take care of the rest. The privileges afforded to most patients selected for admission to the neurorehabilitation hospital overwhelmingly improve healthcare outcomes, so they did tend to have better prognosis than those directed elsewhere for admission due to poor insurance coverage, limited social support, or unreliable disposition. Patients and families at the neurorehabilitation hospital were used to having their expectations met and exceeded. Not only had miracles become the expectation, but somewhere along the way, that expectation had become laced with stipulations; everyone's miracle must be achieved the same way. Here, like in other places,¹⁵ palliative care was viewed as failure and, therefore, not an option.

The Narrow Scope of Healthcare

Why did palliative care seem so foreign, so unimaginable? I believed, with the right measure of

resources, knowledge, and grit, medicine could always deliver. This is what I was trained to believe, and what I so deeply want to believe: improving patient's lives *should* be the goal. Defining "improvement," however, must be framed appropriately. Gawande suggests our framing may be limited by the narrow scope of healthcare:

*"The problem with medicine and the institutions it has spawned for the care of the sick and the old is not that they have had an incorrect view of what makes life significant. The problem is that they have had almost no view at all. Medicine's focus is narrow. Medical professionals concentrate on repair of health, not sustenance of the soul. Yet—and this is the painful paradox—we have decided that they should be the ones who largely define how we live in our waning days."*¹⁹

THE VALUE OF PALLIATIVE CARE GOES UNTAPPED

Even the phrase "waning days" makes most of us tune out. We think if our patient is not facing imminent death, then palliative care is not appropriate.¹⁵ But this further reflects our ignorance. The singular aim of palliative care is to give life to your days even if unable to add days to your life. PT should be similar, with an unrelenting commitment to quality of life. And yet, the overwhelming majority of my classmates will never sit through any formal education on palliative care. Even in medical schools where palliative education is a curricular requirement, the quality and extent are variable and largely lacking.²⁰ If the very providers who are expected to discuss serious illness with patients do not know the value of palliative care, is it surprising these conversations are not happening?

Because we do not know how to have such conversations, we assume it must not be our problem. While providers in the rural hospital did not have the

luxury of delegating tasks not directly related to their technical skillset, as specialists and adjunct services were scarce, the neurorehabilitation hospital providers were accustomed to division of labor so that everyone could become highly skilled at their narrow scope of practice.

While most in neurorehabilitation recognized that palliative care would be a good option for the patients battling brain cancer, no one took responsibility for making that recommendation to the patients. The rehab physicians thought it was the oncologist's job. The oncologist saw tumor shrinkage on MRI so provided hopeful updates, with no preparation for the day the tumor would grow again. Therapists and nurses witnessed rapid functional decline but felt a transparent discussion with the family would be overstepping the oncologist's wishes—a frequent barrier to transitioning to palliative care, as the physician's communication during this time largely sets the tone for the discussions patients and families have with the rest of the team.^{15,21}

In addition to the team power dynamics at play with therapists feeling voiceless, I found myself wrestling with my role as a student. I was actively undergoing palliative care education whereas the rest of the team was years out from school, if they ever received any formal introduction to palliative care at all. Only later did I realize this should have empowered me to take a more active role in team conversations, instead of allowing the seasoned therapists to “protect” me from the rehab team. When I did begin to see my essential role as an advocate, it prompted conversations with supervisors that alerted them to this important area for hospital-wide growth. However, it was too late for the patients I worked with as a student.

While plenty of time was spent pointing fingers, patients were going home without the resources they needed to successfully face whatever came next. One physical therapist predicted our patient would fall within one month of being home, her family was in way over their heads, and she would soon need to be carried downstairs for family game nights in the basement. I never encouraged the patient to ask more questions about the care she was receiving. She went home the next week with no mention of palliative services while we were sitting around making predictions about how quickly things would fall apart.

A NARROW FOCUS ON POSITIVITY

One neurorehabilitation therapist credited a culture of “toxic positivity” with the overwhelming refusal to accept the limitations of medicine and benefits of palliative care for the sake of providing unwavering hope. Other therapists have also noted, presumably through their own reflection, a tendency to overemphasize the positives, even when patients and families are open to wrestling with the negatives that mark serious illness.^{21,22} It is as though medical advances are making us feel invincible even as we are faced with glaring limitations of the human body. Gawande offers an alternative view to our often-narrow approach:

“If to be human is to be limited, then the role of caring professions and institutions - from surgeons to nursing homes - ought to be aiding people in their struggle with those limits. Sometimes we can offer a cure, sometimes only a salve, sometimes not even that. But whatever we can offer, our interventions, and the risks and sacrifices they entail, are justified only if they serve the large aims of a person's life. When we forget that, the suffering we

*inflict can be barbaric. When we remember it, the good we do can be breathtaking.*¹⁹

As Gawande argues, if the point of palliative care is to maximize quality of life on *this* day, shouldn't that be something we all advocate for? If my patient wants to play with her grandkids, shouldn't the PT plan of care promote that goal? While my training equips me to provide floor transfer practice, a wheelchair with postural reinforcements, or adaptations that compensate for a hemi extremity, none of these options are meaningful unless they align with what matters to the patient.¹⁷ The intervention selected must be informed by illness trajectory, as predicted by diagnosis but more importantly by patient priorities as their condition evolves.¹⁷

Beyond alignment with goals of care through intentional collaboration with the patient and context provided by illness trajectory, multiple authors have emphasized SDOH as an important concept when considering palliative care implementation.^{6,16,17} Furthermore, suffering in the context of serious illness is compounded by the experiences of social injustice across the lifespan.¹⁶ Those most impacted by this gradient of disease burden are least likely to access or maintain palliative care resources when needed.¹⁶

Tina's case demonstrates just this, as she received short-lived, informal palliative care in the acute versus community setting, which is reportedly common for those living in poverty.¹⁶ Conversely, my neurorehabilitation patients were receiving medical care earlier in their disease progression and had the socioeconomic resources to use community-based palliative care. However, other expectations driven by societal perceptions of terminal illness and the privilege of healthcare access deterred these patients from recognizing the potential benefits of palliative care,

emphasizing that the impact of SDOH on healthcare access and utilization is quite nuanced.

Uncovering the Large Aims of Life

Prioritizing "the large aims of a person's life"¹⁹ is especially important when existing medical evidence provides no clear options for curative treatment. The wife of my second neurorehabilitation patient with glioblastoma was navigating this tension. She knew that fighting for a longer stay at the neurorehabilitation hospital would maximize his physical gains. At the same time, she didn't want him missing winter holidays with the kids or opportunities to see his son compete in college athletics. However, she was sadly unaware of how narrow his margin for physical improvement was given the stage of his tumor. Both the patient and his beloved wife's quality of life were reduced as they kept telling themselves he was in the best place for neurorehabilitation. This was true, but his hospital stay far outlasted the amount of time required to realize that none of the patient's or family's top priorities included being able to independently walk household distances.

These examples highlight the critical role that care-planning conversations play in palliative care. Paul Kalanithi said:

*"The physician's duty is not to stave off death or return patients to their old lives, but to take into our arms a patient and family whose lives have disintegrated and work until they can stand back up and face, and make sense of, their own existence."*²³

THE BENEFITS OF CARE-PLANNING CONVERSATIONS

This is the goal of care-planning conversations: not to make everything right in a patient's world, but to help them understand the good, the bad, and the ugly of the world they find themselves living in.¹³ Palliative care opens the door to conversations about a patient's values and preferences for end-of-life care, ideally when patients have the cognitive faculties and energy to engage in such a conversation. Failure to have open conversations with patients early on may be the greatest pitfall in delaying enlistment of palliative services.

Care-planning conversations clarify what patients understand and prioritize in light of their serious illness. Often, patients do not have a realistic view of their condition due to an avoidance of clarifying conversations, as was the case with my neurorehabilitation patient. Naturally when faced with a life-altering diagnosis, my female patient and her family wanted all possible treatments. However, as chemo and radiation therapies began, her remarks surprised me. She was shocked at how her body was changing, yet her experience closely mirrored textbook side effects. With each new symptom, she re-lived shock and, when she became incontinent, horror.

It seemed that her expressed interest in curative treatment was taken as permission to expose her to unknown side effects without a conversation to determine if she was willing to live with the downstream effects of her decision to aggressively fight a cancer with miniscule chances of remission. Her frequent endorsement of her medical team and statements about the doctors knowing best may have been part of her maintaining a positive outlook to cope with the emotional roller-coaster of her diagnosis.

However, it also emphasizes the inherent power imbalance when patients with serious illness interact with healthcare providers, regardless of their own education, resources, or familiarity with the medical field, as discussed by one researcher experiencing the same diagnosis as those her academic work centered on.²⁴ Although my neurorehabilitation patient's SDOH were predictive of better outcomes than Tina's, power dynamics were nonetheless at play in the conversations between patient and provider, contributing to an avoidance of important conversations.

To emphasize the importance of conversations about treatment options and establishing goals of care with a terminal diagnosis, one group investigated the impact of palliative care on quality of life, mood, and length of survival for patients with terminal cancer. Patients receiving standard care plus palliative services reported better quality of life and mood, experienced less suffering, and lived 25% longer than patients only receiving standard care.²⁵ As Gawande bluntly noted:

*"Our decision making in medicine has failed so spectacularly that we have reached the point of actively inflicting harm on patients rather than confronting the subject of mortality."*¹⁹

THE NEED FOR A GREATER ACCEPTANCE OF MORTALITY

When mortality is discussed in neurorehabilitation settings, it is unrecognizable or contentious.²⁶ Where patients, families, and clinicians have some awareness of the terminal nature of the illness, death feels "inevitable" but "unacknowledged."²⁶ This is despite patients and families emphasizing time investment and clear communication as important components of care for critical illness^{13,15}—a conversation that cannot rightly happen through ambiguous allusions to mortality.²⁶ Physician uncertainty, patient/family denial, time, and a desire to maintain hope have been

cited by providers as reasons to avoid direct conversations about death despite its likely nearness²⁷. However, these reasons prioritize the provider's comfort at the expense of the patient. Providers working in close proximity to death and suffering report experiencing lasting emotional distress that is often managed through detachment and/or suppression due to workplace expectations and temporal limitations, common sentiments that may contribute to an aversion to care-planning conversations as a means of self-protection.^{11,12}

THE VITAL ROLE OF THERAPISTS

In most settings, therapists spend more time with patients than other providers, so are afforded the gift of time, which physicians report they lack²⁷ and patients say they need.^{13,15} Thus, it is crucial that physical therapists actively fight against the documented tendency to focus only on positives, treat death as an “object to be managed,” and avoid uncomfortable conversations among peers.^{21,22,26} Instead, we have an essential role in the ongoing dialogue surrounding care-planning and goals-of-care conversations, often with unique insight to patient's preferences and motivators that, if gathered and shared appropriately, would allow all team members to provide care in alignment with patients' needs.

While my time knowing Tina was brief, I witnessed the evolution of her care-planning conversations. During her hospital admission, she understood that the cancer riddling her body was going to kill her. She understood that going home alone was unsafe. She understood that further medical treatment was available, but unlikely to offer substantial benefits. Her wishes were clear. With this knowledge, the team set out to ready her for home. In her final days when it became obvious this would

no longer happen, the conversation evolved with her medical status but never removed Tina from the center. While working with Tina, I happened to pick up Paul Kalanithi's book, written in the final days of his training to become a neurosurgeon and his battle with terminal cancer.²³ Together, his words and Tina's final days encapsulate care-planning conversations done well:

“The tricky part of illness is that, as you go through it, your values are constantly changing. You try to figure out what matters to you, and then you keep figuring it out... Death may be a one-time event, but living with terminal illness is a process.”²³

Social Expectations Influence Acceptance

Tina seemed far more comfortable with the declaration that medicine could no longer offer her a prolonged life worth living. Unlike patients at the neurorehabilitation hospital who were more accustomed to financial resources, easy healthcare access, and getting the results they asked for, the patients I saw in rural America seemed better at identifying when the healthcare system could no longer help them. Sadly, this may be because they are more accustomed to being failed by a system that is largely stacked against them.^{7,10,16} As healthcare providers, we assume people always want all medical interventions that we have to offer. What we forget, however, is that there is almost always *something* medicine has to offer.¹⁹ Perhaps the skepticism for medicine—or expectation for scarcity—in rural America¹⁰ was of service in some ways. Families and patients were far more willing to accept that no other good could come from sticking in another tube, running another test, or consulting another specialist. Doctors did not assume that

showing up to the hospital gave permission to do all they were trained to do in school. Bringing up palliative care was always a legitimate option.

With the elevated level of care, however, the general assumption seemed to be that if patients showed up for neurorehabilitation, they were not interested in any sort of palliative care discussion. This may be an assumption fairly made, as many families do refuse to consider that a terminal diagnosis might actually take their loved one's life.^{15,27} It becomes problematic, however, when we assume all patients and families have this view at all points of their disease progression. Furthermore, it is unfair to expect them to know what palliative care has to offer when, as discussed previously, most who have spent years to become a healthcare provider do not know themselves nor do they feel comfortable having these conversations with desperate patients and families.^{15,28} The challenge becomes figuring out what the patient knows, what they expect, and what events will change those expectations. Viewing practice through a palliative care lens guides this "figuring out" process and serves as a promising approach for rehabilitation professionals caring for patients with serious illnesses.

Moving Forward With Palliative Care

So, why is palliative care something that healthcare providers, patients, and the public seem so hesitant to embrace? By allowing the narrative of my own patient experiences to drive my critical analysis of this issue, I have gained a more nuanced, thorough view of factors at play including healthcare's traditional scope and structures that do not cater toward the large aims of a patient's life; provider, patient, and family assumptions that palliative care represents failure; and social

expectations that demand neurorehabilitation focus only on restoration, especially for those with socioeconomic advantages that allow them to access cutting-edge care.

Moving forward will require thoughtful consideration of SDOH,^{6–8,16} current challenges with palliative care structures,^{13,17,18,27} and diverse perspectives of suffering.^{16,26} Healthcare providers interact with human suffering on a regular basis and have the responsibility and the privilege to ensure that these patients receive the best possible care and outcomes that align with the patient's wishes, regardless of the interacting barriers and facilitators at play. For patients experiencing serious illness, palliative care offers a helpful alternative to the narrow focus of our medical-dominated system that governs patient care today.

Integration of palliative perspectives and principles into PT practice will require critical analysis of care provided to those with a serious illness in a way that addresses power dynamics, SDOH, and stakeholders' assumptions in order to work toward a more just approach that upholds human dignity across all stages of illness and life. Practicing physical therapists and those responsible for educating the next generation have an important role in advocating for this shift in practice. This is no small task but one that we must embrace if our patients experiencing serious illness are to receive the care and life that they deserve.

*Patient names and identifying details have been altered to protect patient privacy.

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