Bridging Neurorehabilitation and Neuropalliative Care to Help People Live Well With Neurological Conditions

What does successful care look like for people living with serious neurological conditions?

Improved strength, mobility, communication, or independence may be part of the answer. But patients and families are often navigating much more than a collection of physical or cognitive symptoms. Factors like pain, uncertainty, changing relationships, care partner stress, loss of identity, and difficult decisions about what matters most are also important to consider in our effort to provide more comprehensive care.

Addressing this fuller picture requires clinicians to ask not only what functions can be restored or preserved, but also what will help each person live as well as possible. In this regard, neurorehabilitation and neuropalliative care share common goals.

In a recent conversation, ASNR Member Darcy Reisman, PT, PhD, Professor and Chair of the Department of Physical Therapy at the University of Delaware, and Sandhya Seshadri, PhD, Assistant Professor of Neurology in the Division of Neuropalliative Care, Department of Neurology at the University of Rochester, explored how closer connections between these fields could improve outcomes and quality of life for people with neurological conditions and their families.

Palliative Care Is Not Just End-of-Life Care

One barrier to bringing the fields of neurorehabilitation and neuropalliative care together is the common misconception that palliative care is synonymous with hospice and is meant only for those at end-of-life.

Hospice is specifically focused on end-of-life care and generally becomes available when a person meets criteria related to life expectancy. Palliative care is both an approach and a specialization in medicine and the goal is to minimize suffering and symptom burden, and improve quality of life. As an approach, palliative care is about the care patients and families receive and includes building a trusting relationship and aligning treatment with patient and family preferences. Neuropalliative care is a subspecialty of Neurology that focuses on improving quality of life of those affected by neurological illnesses by addressing symptom management, existential suffering, and caregiver needs, while honoring the values and preferences of both patients and their families.

Because palliative care has historically been closely associated with terminal illness and cancer, patients and family members may interpret a referral as a sign that clinicians believe death is

imminent. In neurological care, however, a palliative approach can be applied much earlier. It could start as soon as the time of diagnosis of a progressive or neurodegenerative condition, and it may remain relevant for the duration of an individual's life.

In addition to goals focused on restoring function, rehabilitation professionals also work to improve quality of life, reduce the impacts of illness or injury, and help people participate more fully in the activities that matter to them. The two fields may use different approaches, but their overlapping purpose highlights the potential for collaboration and interdisciplinary efforts to enhance clinical care.

Looking Beyond Physical Symptoms

Neurorehabilitation often addresses readily apparent manifestations of neurological illness: changes in walking, balance, speech, swallowing, cognition, dexterity, or the ability to complete everyday tasks. Yet the consequences of those changes extend well beyond the body.

A person whose mobility has changed may experience physical pain, but they may also feel embarrassed about walking differently in public. Someone with aphasia may be able to produce words more accurately in therapy while still feeling isolated during conversations with family and friends. A person with a progressive neurological disease may grieve the loss of a professional role, independence, privacy, or their sense of self.

Palliative care offers the concept of "total pain," which recognizes that suffering may have physical, psychological, social, spiritual, and existential dimensions. Neurorehabilitation professionals are well positioned to notice and respond to these interconnected pain points because they often spend a substantial portion of their time with patients and families working towards achieving goals related to meaningful daily activities.

For example, physical therapists may address pain that limits mobility and participation. Occupational therapists may help people adapt valued routines and roles. Speech-language pathologists may address communication goals in the context of communication between the patient and a family member which can positively impact relationships, autonomy, and social connection. Recreational, music, and art therapists may create additional opportunities for individuals to engage and express themselves.

Bringing a palliative lens into rehabilitation does not mean abandoning efforts to improve function. It means understanding function in a broader context. We should think about what an ability allows the person to do, why it matters to them, and what might prevent them from using that ability in everyday life.

Starting With the Person, Not the Diagnosis

Both neurorehabilitation and neuropalliative care increasingly emphasize that a diagnosis alone generally doesn't tell clinicians what a patient needs.

Two people with the same neurological condition may have different responsibilities, environments, relationships, goals, fears, and definitions of living well. Even a clinically meaningful improvement may have limited value if it does not translate into something the person wants or needs to do.

This distinction is reflected in the International Classification of Functioning, Disability and Health (ICF) Model. The ICF Model separates a person's capacity to do something in a structured setting, such as a clinic, from their actual performance in everyday life in their usual environment.

A patient may show that they can walk a certain distance during therapy, but they still may not return to grocery shopping, attending community events, or moving around their home with confidence. Fatigue, pain, fear, transportation, care partner availability, social stigma, motivation, and other personal and environmental factors can all influence the gap between capacity and performance.

As Dr. Reisman observed that healthcare professionals must understand "what is a patient's definition of living well?" A person may have the physical capacity to run a marathon without having any interest in doing so. Similarly, a patient may be capable of performing a prescribed exercise, but they may not see a meaningful connection between that exercise and their own priorities.

This perspective can also change how clinicians interpret and respond to patients who do not follow recommendations. Rather than immediately labeling someone as noncompliant, clinicians can ask, what is getting in the way? Does the patient understand how the recommendation supports their goal? Is the plan realistic in the context of their life? Are we addressing something they actually value?

A palliative approach encourages curiosity about these questions instead of judgment.

Connecting Clinical Outcomes to Everyday Life

Clinicians and researchers need measurable and meaningful outcomes. Standardized assessments are essential for evaluating changes, communicating findings, and demonstrating the efficacy and value of treatment. But clinical measures may not capture whether a patient's life has meaningfully improved.

One patient may perform a communication task with high accuracy in the clinic but continue to struggle during conversations at home. A different patient may increase their walking speed, but that speed increase doesn't translate to being more active in their community. A pain score may decrease while loneliness, care partner strain, or fear continue to limit their participation.

The goal is not to replace standardized measures, but to connect them more explicitly to activities and outcomes that matter outside the clinic. A goal of walking 600 feet becomes more

meaningful when it is linked to shopping independently, visiting a neighbor, or attending a family event.

Wearable devices and other technologies may eventually provide better information about real-world mobility and activity. But even then, numbers will tell only part of the story. Self-report, qualitative research, and conversations with patients and families remain necessary for understanding how an intervention affects overall wellbeing.

The challenge is to measure not only whether a person can complete a task, but whether that capacity helps them live the life they value.

Continuing Team-Based Care After the Acute Phase

Neurorehabilitation is often most coordinated during acute and inpatient care. Therapists, physicians, nurses, and other professionals may hold team meetings, share goals, and work together closely.

Once a patient moves into long-term or community-based care, that coordinated infrastructure often disappears. Yet this is when patients and families may spend years managing a chronic or progressive neurological condition. “The majority of the person’s time is spent living with their chronic condition without that team-based infrastructure,” Dr. Reisman noted.

Fragmented care can prevent valuable information from reaching the right people to have maximal impact on outcomes. Rehabilitation professionals may recognize changes in mobility, communication, cognition, coping, or caregiver wellbeing that could inform decisions by neurologists or palliative care clinicians. Caregivers and direct-care staff may observe patterns that no clinician sees during a brief appointment.

Better integration could include shared assessments, more accessible health records, virtual team communication, and clearer processes for raising concerns across disciplines. It could also mean shifting from the idea that rehabilitation is something physicians refer patients “out” to. When neurorehabilitation or neuropalliative professionals are viewed as part of the central care team, their observations and expertise can more readily inform the overall plan.

Current payment structures, however, make this difficult. Time spent communicating with another clinician, speaking extensively with a caregiver, or gathering information from a nursing assistant may be extremely valuable for care but not directly billable. A system organized around individual episodes of care may struggle to support the continuous collaboration required to best treat chronic neurological illness.

Recognizing the Role of Care Partners

Families and care partners are central figures in the lives of people with chronic neurological conditions, but healthcare systems do not always treat them as members of the care team.

Care partners may coordinate appointments, assist with exercises and personal care, interpret communication, monitor symptoms, make decisions, and manage the emotional and practical effects of illness. Despite this, they may feel that their role is reduced to transporting the patient to and from appointments.

The language used in research and clinical care also matters. “Caregiver burden” is a common term in research, but as Dr. Seshadri noted, “there has been so much written on caregiver burden, and yet, every single caregiver I have talked to does not like the word *burden*.” She went on to explain that care partners may resist describing a spouse, parent, or child as a burden. They may readily acknowledge that caregiving is exhausting or extraordinarily difficult while rejecting language that seems to define the person they love as the problem.

Listening to care partners can change the terminology we use, the questions we ask, the outcomes we select, and the interventions we design. Rather than assuming that the goal is simply to reduce burden, researchers might ask what care partners value, what support they want, what brings moments of joy, and what would help them feel less alone.

Reframing Research Around What Matters

Building on what was shared above, incorporating the perspectives of both care partners and individuals with lived experience of the neurological conditions we study has the potential to shape the research being done in our respective fields. And better integrating principles from neurorehabilitation and neuropalliative care can help.

Researchers often begin with outcomes that are familiar, measurable, or expected within a discipline. Patient and care partner involvement can reveal that the most pressing questions lie elsewhere. “You will not ask the same questions if you listen to them and really incorporate them as part of the work that you do,” Dr. Reisman said.

Beginning with open questions about how a condition affects a person’s life may produce a more complete understanding than beginning with predetermined categories such as barriers, facilitators, adherence, or burden. The way a research question is framed influences everything that follows, including the intervention, outcome measures, and conclusions.

A person-centered research agenda would not lower scientific rigor. It would help ensure that rigorous methods are being applied to questions that matter to the people the research is intended to serve.

Building the Future Together

Stronger collaborations between neurorehabilitation and neuropalliative care does not necessarily mean that every patient needs a referral to a specialist in both fields. It means that professionals across neurological care can learn from the principles each field brings.

Rehabilitation clinicians can incorporate more explicit attention to suffering, values, care partner needs, and quality of life. Neurologists and palliative care clinicians can more fully recognize rehabilitation as an ongoing part of helping people live with serious illness, rather than a short-term service focused on restoring isolated functions. You may already be incorporating some of these approaches and mindsets in the work that you do, and we hope to see this amplified with increased collaboration and discussion across fields.

Professional organizations can help build these bridges through shared workshops, conference programming, educational resources, and interdisciplinary conversations. ASNR is pleased to be contributing to the conversation to help clarify misconceptions and translate broad principles into practical changes in evaluation, goal-setting, research, and the delivery of care.

Ultimately, the intersection of neurorehabilitation and neuropalliative care asks clinicians and researchers to return to a deceptively simple starting point. What is important to this individual patient, and what does living well mean to them?

From there, the clinical tests, rehabilitation strategies, symptom treatments, technologies, and research methods can be directed toward the shared purpose of helping people with neurological conditions and their families live with greater comfort, meaning, participation, and support.