



Two trees in the forest

A patient's perception of quality of life

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WROTE A SPEECH A FEW YEARS BACK, based on a parable about "Susie," a fictional character who lived with a chronic illness most of her life. She was in search of the key to a loving relationship.

Susie exhausted all angles, to no avail. It seemed no one had the key to lasting love. She talked to her friends and family, and read many books, but nowhere did she find just the right words. Then one day, an old woman approached her as she took a break on her hike through the hills.

"What is your problem, my child?" the woman asked, squatting down next to Susie. "Why do you sit with such a long face?"



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Susie told the woman about her quest. The woman said, "Take a look at the trees around you. What do you see?"

"They are beautiful," Susie answered.

"What about them is beautiful?" the woman asked.

"Their colors and shapes," Susie replied. "They each have a unique silhouette against the sky, and their leaves are in a million shades of green, yellow, gold, and orange."

"Oh," said the woman, pausing to think for a moment. "They are beautiful because they are different?"

"Yes, I think so," said Susie.

"See," said the woman, "you already know the first lesson in love: Honor our differences, for they are what make us beautiful."

Then the old woman walked up a small hill. Susie followed after her. "See those two trees over there?" asked the woman. "They have stood next to each other for hundreds of years, each planted firmly with its own roots. But see how

they have slowly grown together, their limbs delicately intertwining? The trees are separate," she continued, "but they will always stand side by side."

Perceptions of quality of life

I might be "going out on a limb" with this analogy, but I find the similarities striking between the story of the trees and patients' perceptions of quality of life. We are all different. All we ask is that you, as caregivers, honor those differences, because they are what make us beautiful.

I've heard the phrase "the patients" uttered countless times during my 37 years of living with renal disease. We tend to be viewed as an amorphous group. Nothing could be further from the truth. We might have lost our kidney function, but we have not lost our identities.

Just as many types of trees make up the forest, there are many types of patients in the dialysis unit, each with individual needs. Some patients are harder than others, and some require more attention than others. We can't all be treated the same.

The health care profession uses clinical measures—hemoglobin, iron stores, Kt/V, etc.—to determine a patient's quality of life. But it is equally important to take into account process measures as well.

Being offered the complete spectrum of dialysis modality options, including home hemodialysis, is a process. Being offered an early morning or late evening dialysis shift is a process. Giving patients a better understanding of why medications are prescribed and the effects of non-adherence is a process. Understanding why it is important to exercise and eat the right foods is a process.

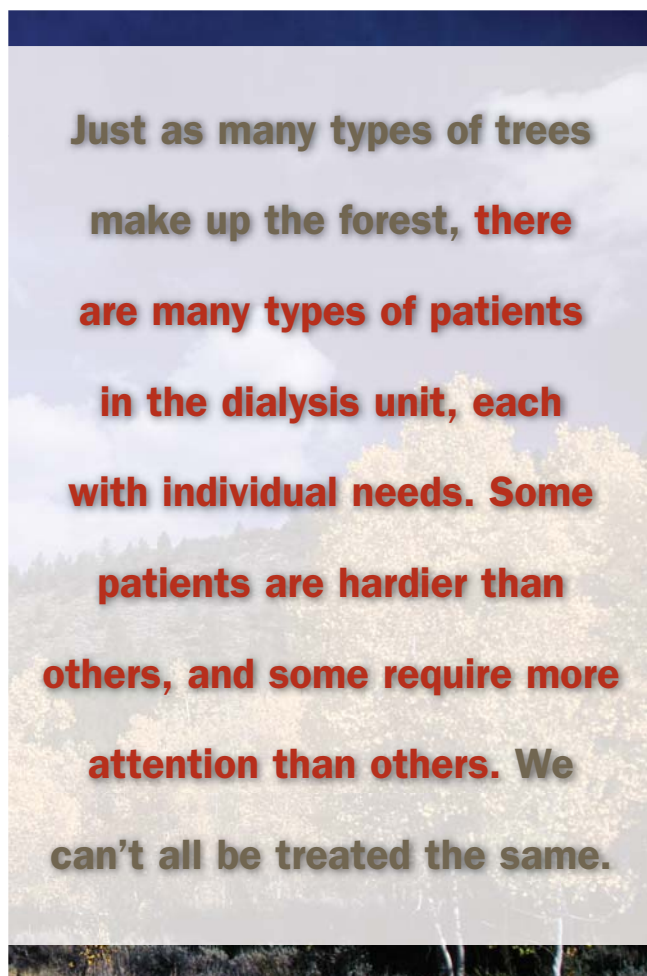
The resulting process measures would include having more time to spend with one's family, being able to work a full-time job, and not being subject to the devastating comorbidities of secondary hyperparathyroidism. Process measures are like a gentle rainfall that helps patients grow and thrive.

The problem is that process measures are hard to quantify, which is why they can be overlooked. But they are integral to the renal patients' quality of life.

All intertwined

There is an ecosystem in the forest in which all life forms are intertwined. Taller trees provide shade for seedlings, allowing them to mature. The soil provides nutrients for the trees. The dying leaves provide nutrients for the soil. Clinical measures and process measures are similarly intertwined and cannot stand alone when defining quality of life.

To the patient, quality of life is the perception of one's abilities at a given point in time. Renal disease forces one to redefine that perception. Just as no one expects an old tree to withstand a strong gust of wind, no one expects a dialysis patient to run a marathon (though some do). What we can expect, or at least hope for, is that those processes



which truly define the quality of our lives are given as much attention as are the clinical processes that keep us alive in the first place. Quality of life is centered on the foundation of hope and the belief that life is still worth living.

Patients are happiest when they have choices, when they feel they are in control. Like two trees in the forest, the health care provider and the patient stand side by side, intertwined. The health care provider can help the patient grow by not overlooking those processes that will allow the patient to reach their goals. ♦