What's in a Word – Caregiver or Care Partner?

Denise Eilers

My late husband was on home hemodialysis for 25 years, but I never considered myself his caregiver. Rather, I was his care "partner." During his decades on dialysis, he worked full time, played golf, and volunteered in our community. Together, we raised our son, traveled, and restored an old home. We functioned as a team, dealing with the ups and downs of a busy life, which just happened to include dialysis.

When I hear the word caregiver, I tend to picture a one-sided relationship – a rather helpless, debilitated patient being waited on by an overworked and stressed family member. In contrast, care partner implies equality, trust, a give and take attitude, and a shared experience.

So is the distinction merely a matter of semantics, or does the concept of care partner imply a fundamental change in practice? I would argue that fully embracing the idea of care partnering is a real paradigm shift.

The Eden Alternative, a long-term care patient-centered model, places a large emphasis on the care partner, who they describe using phrases such as mutual respect and working together effectively. They do not limit care partners to relatives, nor do they describe the division of the workload. According to the Eden Alternative, "The Care Partner concept implies a balance of care, an acknowledgement that opportunities to give as well as receive are abundant and experienced by everyone involved in the care relationship. The term Care Partner evens the playing field, as it is often easy to get trapped in a one dimensional experience of the caring relationship" (Eden Alternative, 2009). Maybe there are some lessons to be learned that can be applied to the kidney community.

We traditionally assume that a care partner is a spouse, a family member, or a friend. However, bearing in mind the Eden model, a healthcare professional can – and should – also be considered a care partner.

Why should professionals shift to a care partner philosophy?

It's a new world in which concepts like patient-centered care, patient empowerment, and shared decision making are no longer just idle terms to be bandied about. Instead, they are becoming part of everyday life and practice. Partnering with patients and families creates a whole new dynamic with an emphasis on cooperation rather than compliance and adherence. The paternalistic approach is gradually disappearing.

Patients and families are increasingly technology savvy, with the Internet literally at their fingertips. The result is that, unlike in previous generations, medical information is no longer the sole province of professionals. Although medicine may not be a patient's typical area of expertise, the vast majority is eager to learn more about their condition and treatment choice.

Defining patients by laboratory values, interdialytic weight gain, and other biochemical markers is a secondary concern for most of those who dialyze. Patients with chronic kidney failure are more worried about their ability to enjoy the best quality of life possible and to live a normal life.

What can professionals do to become true partners with their patients?

Resist the urge to adopt the "I know best because I have the education" attitude. Only the patient and family totally understand what best fits their unique lifestyle. Therefore, it is crucial to talk with patients about their personal life goals and the actions you can take to help them reach those objectives. Every patient should be able to define quality of life in his or her own terms, and then achieve those goals through the optimal treatment of their choice.

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Repeat and rephrase information. Patients are overwhelmed by the diagnosis of chronic kidney failure and overloaded with information at a time of maximum stress and impaired cognition. Chronic kidney failure is a condition that affects every single aspect of a patient's life from the kitchen table to the bedroom and beyond into the larger community.

What are some tips for partnering with patients?

Different patients respond differently to the diagnosis of chronic kidney failure and its treatment. As a care partner professional, a variety of points should be considered when working with patients and families to help them integrate treatment into their life's routine.

- Guide patients and families toward informative and reliable Web sites. For those who shy away from computers, provide written or audio materials, but remember that giving a handout to a patient is not the same as interactively discussing educational material.
- Be attuned to non-verbal cues. The most significant communication is seldom verbal.
- Respond promptly to patient concerns in a realistic and caring way. If a problem can't be solved immediately, be honest and say so. Patients and families will trust and respect you more.
- Work with patients rather than dictating, blaming, or scolding. No one is perfect. For example: "I know that limiting fluid intake is difficult. How can we help you with that?" is far better than saying "You gained too much weight. You need to stop drinking so much."
- Use a team approach to problem solving, remembering that patients and families are equal members of the team. Try patient-led care conferences for those who would like to participate in this type of model.
- Regardless of initial modality choice, revisit the therapy choice on a regular basis and as life circumstances change.
- Never assume a patient or family is not suitable for home treatment. Sometimes the most uncooperative in-center patients flourish when they are in control. Home Dialysis Central's Method to Assess Treatment Choice (MATCH-D) (www.homedialysis.org/MATCH-D) is an excellent resource.
- Make use of peer mentoring either within the facility or by referral to patient organizations. Home Dialyzors United (www.homedialyzorsunited.org) has a "buddy system," and the Renal Support Network (www.rsnhope.org) utilizes its Hopeline. Both groups offer peer-to-peer support from those who have lived the dialysis experience.
- Foster a culture of renal rehabilitation by addressing the holistic needs of patients.
- Create a work-friendly dialysis schedule by establishing evening shifts or starting a nocturnal program. Work not only confers a sense of accomplishment and identity, but also provides greater physical and financial independence, creates more opportunities for socialization, and lessens depression. Astoundingly, according to the most recent Consolidated ESRD Network Report by the Centers for Medicare and Medicaid Services (CMS) (2012), 80% of patients on dialysis in the 18- to 54-year-old age brackets are unemployed.
- Actively listen to patients and families and hear what they are saying. Try to understand what patients are feeling.

In a somewhat tongue-in-cheek moment, I once commented that pets could even be considered care partners. After all, they listen to us with rapt attention, accept us with all our faults, love us unconditionally, and stay by our side during the good times and the bad. Perhaps, in the final analysis, that is what care partnering is all about.

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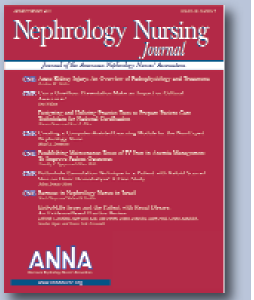

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