

## **January 19, 2011 MEDCAC Comments**

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Controversy over the use and misuse of ESAs has been ongoing and wide ranging involving an alphabet soup of studies including CHOIR, CREATE, and TREAT. However, in the frenzy to establish safe guidelines for ESA usage, one aspect has been repeatedly ignored. That missing piece is the anecdotal evidence offered by the patient and care partner experience. Whether addressing pre-dialysis, dialysis or post-transplant usage of ESAs, the overriding issue for patients is quality of life. Patients are not just physical beings. They have psychological, social and spiritual needs, as well.

In an era when many health professionals worship solely at the altar of EBM and RCTs and treat biochemical markers as the bible of outcomes, it is wise to remember that there needs to be a common sense balance between science and the real world patient experience.

A quick history: My late husband was diagnosed with CKD in 1967, began dialysis in early 1980 and received a deceased donor transplant shortly thereafter. When the kidney rejected later that same year, we resumed home hemodialysis and continued with that modality for 25 years until his untimely death in 2004. During his two and half decades on dialysis, my husband was an active, employed, tax paying citizen. We experienced life both before and after the introduction of ESAs. It is a gross understatement to say that we noticed a remarkable difference.

We all recognize that transplant is not a cure for CKD5, but simply another treatment option and that every treatment has side effects, anemia being one of the adverse effects that can persist after transplant. The cause of post transplant anemia is multi factorial and includes factors common to CKD patients such as erythropoietin deficiency, malnutrition, inflammation, iron deficiency, and oxidative stress. Additional post transplant etiology may encompass blood loss, medication and allograft function. The prevalence is as high as 30-40% in the post transplant period and anemic patients are 3.8 times more likely to lose the graft (Andrade et al., Int. Urol. Nephrol., Dec 2010). Just as in CKD patients, anemia in transplant patients is an important risk factor for cardiovascular events. Daniel Coyne and colleagues found that while anemia is associated with a 25% greater risk of allograft loss, improvement in anemia results not only in better outcomes but also in improved quality of life.

Although fatigue may be the hallmark of anemia, it is nearly impossible to function well with its other disabling symptoms such as weakness, headache, shortness of breath, dizziness, difficulty sleeping, inability to concentrate, irritability and depression. Those symptoms are totally inconsistent with an optimal quality of life. So, while transplant precludes the need for dialysis, transplant patients are still rightfully concerned about the effects of anemia on their lifestyle. Treating anemia involves balancing clinical concerns with patients' quality of life goals. In my late husband's case that translated into not only employment but also traveling, playing golf and being an integral part of our son's busy life.

There is also the dilemma of risk vs. benefit! If the kidney community would focus on encouraging and expecting patients to become equal partners in their care with a commensurate emphasis on education, then the risk vs. benefit of ESAs is a simple matter of shared decision making. Professionals must ditch the “I know best because I have the medical/nursing knowledge attitude” and really listen to what is important to patients, balancing sensible anemia treatment with the patient's self defined acceptable level of functioning.

The Institute of Medicine has recognized that patient centered care is an essential component in order for the quality of health care to improve. An integral part of that concept is individualizing care—one size does not fit all. In her book *Counting on Kindness*, social worker Wendy Lustbader says “When time management techniques belonging to factories are applied to health care settings, patients feel efficiently processed rather than humanely served.” Nothing could be truer than when those thoughts are applied to anemia management. Rigid, factory like ESA protocols should not be followed blindly, disregarding individual holistic aspects of care. Instead, they should be regarded as guidelines only.

Lastly, employment is often treated like a dirty word in the renal community where disability has become the norm. Again, Ms Lustbader quoted a woman in her 80's who said “I could wipe out 90% of old people's woes by finding them suitable work...Real work and real education, that's the open secret of satisfaction from birth to death.” While the term work has various personal definitions, it can include traditional employment, creative endeavors, educational interests, community volunteerism, hobbies, or helping others. However, none of those pursuits are possible without the corresponding energy to accomplish them. In my husband's case, ESAs allowed him to work more productively across the entire spectrum of CKD.

Undoubtedly, ESAs have become an valuable addition to the drug armament. Their judicious use to enhance both outcomes and quality of life is admirable. Their overuse for financial gain or their underuse due to fear of possible side effects is not.

I have been a nurse for many years and would be foolish not to embrace what scientific research can teach us. Further studies are needed to investigate the prevalence, causes, and treatments of anemia. However, all the RCTs, protocols, decision trees and algorithms cannot, and should not, replace the evidence offered by patients' real life experiences and their personal meaning of quality of life.