

New Views

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December 11, 2008

ABSTRACT

This ESRD-care perspective piece comments on the growing number of scientific articles and media coverage concerning high-dose/frequency hemodialysis. Researchers and individual patients have been reporting dramatic changes in health-related quality of life with daily and/or nocturnal hemodialysis. Asked for their personal preferences, ESRD-industry professionals now overwhelmingly reject conventional in-center treatment that is based on the long-held and widely accepted definition of “adequate dialysis”. The concept, validity, and consequences of this definition of dialysis adequacy are examined.

Four views are presented of an emerging new stage of ESRD care: 1) a new definition of “adequate dialysis”, 2) a new “type” of dialysis patient and related changes in patient care, 3) a new metric for measuring quality dialysis care based on employment, and 4) the necessity of embedding patient participation in ESRD policy formation. By adopting these new views simultaneously, the author suggests that long-term missteps in ESRD care policies and practices can be corrected, as well as gaining significant long-term patient benefits.

INTRODUCTION

Every autumn when I walk on a trail near my home, an interesting thing happens. Deep in the woods – just when my mind returns to the present after wandering down some train of thought – I find that I don’t recognize where I am. I feel lost on a path I have walked hundreds of times before. My customary visual landmarks have either changed with the new season or are gone entirely. For a few seconds, the combination of fewer leaves, more light, bright colors, and the suddenly long sight lines makes me feel completely disoriented. When this first happened several years ago, I thought I was losing my mind. When it happened to me again last month – now that I am older and arguably somewhat wiser - I knew to calmly enjoy the new views. I found myself seeing many things I had never previously noticed.

For the last ten years as the editor and publisher of RenalWEB™, I have been scanning hundreds of news stories and scientific papers about dialysis and end-stage renal disease (ESRD) each and every workday. In the last few years, I’ve seen a growing number of stories and articles about profound changes in the lives of dialysis patients who are receiving much more therapy than the conventional definition of “adequate dialysis.” With more and more ESRD patients receiving longer and more frequent hemodialysis treatments, completely new views of life and living with ESRD are emerging.

FOUR NEW VIEWS: EMBARKING UPON A NEW STAGE OF ESRD CARE

I believe we are at the beginning of a new stage, or age, of ESRD care. This phase will correct several major mistakes that began a generation ago, yet are only noticed by a few today. A precise name for this emerging stage has not yet been adopted, but something along the lines of “optimal-health dialysis”, “well-CKD5 patient care” (chronic kidney disease stage 5), “high-dose/frequency dialysis” or “dialysis 3.0” seem applicable.

From my perspective, there are four essential and interconnected new views emerging in this stage. Any one of these views will eventually create the others, albeit slowly. I believe by adopting all four nearly simultaneously, improvements in standards of care for all patients can be made with a broad and thorough approach that corrects missteps from the past and minimizes delays going forward.

- In this new stage, the definition of adequate dialysis will change. Most patients today are being under-dialyzed and are living their lives as though they were being chronically poisoned or drugged. The widespread use of urea kinetic modeling (Kt/V and URR) will likely be seen as a long-term mistake. The definition of adequate dialysis will become a personal one, rather than being statistically defined.
- In this new stage, a new “type” of dialysis patient will emerge. With much more frequent and longer dialysis treatments, the patients stop being sick and instead become healthy people living with ESRD. They feel, act, and live differently. We will recognize that well-CKD5 patients are very different – physiologically and cognitively – from the typical patient now found in our dialysis centers. They can thrive while on long-term hemodialysis. What they need from medical professionals, dialysis providers, and government agencies changes in this new stage. It is not surprising that much of the ESRD infrastructure and many of the ESRD policies formulated over the last thirty years, no longer best serve these patients.
- In this new stage, employment will be a clear measure of successful ESRD care for working-age patients. For most individuals, earning an honest living is a major component of their dignity as human beings. While the original intent of the Medicare ESRD program was for most dialysis patients to be employed, it is a forgotten value and a little-reported statistic today. The best estimate that I have heard is that only about 15% work after one year on dialysis. By making employment a goal for those who can work, it provides a strong trickle-down effect for those who cannot. It also improves the payer mix for clinics, to the extent that working patients have employer group health plans.
- In this new stage, a new, balanced framework will emerge that embeds patient participation in policymaking. New types of patient voices must be heard and developed by organizations, corporations, and especially government agencies. This new framework will embrace and encourage patient participation, focusing

on these “well” and “healthy” patient experiences. These well patients, both individually and collectively, will articulate ideas, views, needs, and solutions that have not been heard before now. The collective voice of healthy and long-term ESRD patients is an incredibly valuable resource that is currently being overlooked for direction on patient well-being and cost-containment.

(Each of these four views is discussed in length in separate sections that follow.)

Providing care we would not accept for ourselves

At some level, industry professionals are already acknowledging this new stage. At last month’s American Society of Nephrology meeting, I queried well over 100 long-term employees in the dialysis industry as to what treatment modality they would select if they suddenly faced ESRD. The results were surprising, but not totally unexpected. Not a single individual chose conventional in-center hemodialysis, which is currently where more than 90% of U.S. patients end up. Nearly all these physicians and nurses wanted to remain employed and would demand much more therapy (or hemodiafiltration) than the vast majority of dialysis patients are receiving today. As dialysis professionals, I suggest that each of us needs to admit that we have legitimized and institutionalized standards of care that provide a quality of life that few of us would actually accept for ourselves today. As a matter of professional ethics, we simply cannot deny for much longer the clear improvements in health-related quality of life that are seen by patients who dialyze much longer.

Once we accept the premise we have been under-dialyzing ESRD patients for decades, essential and fundamental changes can occur in our thinking and perspectives. We will experience new views and epiphanies about our professional and medical environments. We will see that patients have been living in a sort of Catch-22 for thirty years. Sadly, their “adequate” therapy was not enough for them to feel well, but they were often unfairly judged by dialysis professionals for not returning to work or their other life-affirming activities. Now that they are receiving much more therapy, the reemerging vitality of these well ESRD patients will profoundly change our perception of their capabilities as well as our roles in their care. Instead of minimizing or ignoring their experiences, we need to recognize that they are our most valuable asset for improving care for all.

A pivotal opportunity

It can certainly be upsetting to see that our long-held views of ESRD care are increasingly invalid and even unethical. However, this new stage is bringing long overdue corrections in the care we provide. With the incoming Obama administration bringing so many possibilities for change, it is my sincere hope that many ESRD professionals will embrace this pivotal opportunity for making wide-ranging improvements in ESRD care.

BEYOND UREA KINETICS: A NEW DEFINITION OF “ADEQUATE DIALYSIS”

Up until now, we have based far too much of ESRD patient care on urea kinetic modeling, commonly known as Kt/V and its derivative, URR (urea reduction ratio). We have let urea kinetics represent far more about patient well-being than it should. By not recognizing its limitations, urea kinetics has wrongly become the definition of “adequate dialysis.” Even worse, we have often allowed it to represent excellence in patient care.

As the first widely used computer application in dialysis, urea kinetics was touted as a gold standard of care in the 1980s. While it definitely benefited ESRD patients that were severely under-dialyzed or malnourished and allowed dialysis providers to treat more patients in a treatment day, I now believe urea kinetics has significantly diminished the lives of most ESRD patients over the last three decades. By focusing on blood test values instead of the patients’ health-related sense of well being, it has reduced quality patient care to “Your numbers are good” in many dialysis centers.

Definitions of “adequate dialysis”

Urea kinetic modeling was formulated using data collected in the 1970s (when hemodialysis membranes were primitive). It showed a direct relationship between the amount of dialysis therapy and a risk of hospitalization and/or death. If the Kt/V was less than 0.9, researchers found they could reduce the risk of hospitalizations or death by giving the patient more dialysis therapy – either by increasing time on dialysis or by using a larger dialyzer. Essentially, it established minimum dialysis treatment times scientifically.

While urea kinetics used sophisticated and intimidating mathematics, it defined adequate therapy simply in terms of hospitalization and mortality risk. In essence, “adequate dialysis” means “not dead or in the hospital.” Unfortunately, some leading nephrologist/scientists adopted this very low standard of patient health for all their patients. Even more unfortunately, almost everyone else followed suit. There were, however, other nephrologists who pursued a much broader definition of dialysis adequacy. As early as 1963, Belding Scribner was saying, "If the treatment of chronic uremia cannot fully rehabilitate the patient, the treatment is inadequate." In 1971 in *The New England Journal of Medicine*, John De Palma described an adequate dialysis dose definition that allowed patients to reach their potential for rehabilitation, eat a reasonable diet, maintain acceptable blood pressures, and prevent the development or progression of neuropathy.

Limitations of urea kinetic modeling

Urea kinetics was never designed to define how much therapy was needed for the patient to feel well. Hemodialysis patients could feel awful, have no energy, stop participating in their normal societal roles, become malnourished, and be depressed, but as long as they were never hospitalized and had prescribed a Kt/V of 0.9 or higher, statistical analyses

would count them as a member of the group of patients that were being adequately dialyzed. Even today, hospitalizations and mortality remain the definition of adequate dialysis therapy ($Kt/V=1.2$ or $URR=65\%$).

Urea kinetics was also never designed to recommend the amount of treatment time or the frequency of treatments that a patient would need to stay employed. Under urea kinetics, how a patient felt or their involvement in life's activities was not considered. Nor was it designed to control phosphorus levels, prevent depression, itching, left ventricular hypertrophy, sleep disturbances, nausea, skin discolorations, fatigue, or a host of other ESRD-related symptoms. These limitations have been greatly underappreciated in the ESRD community.

Impact on patients' lives

I believe that today's minimal standard Kt/V of 1.2 (or $URR=65\%$) does not represent anywhere near adequate dialysis treatment and should never be a target for nephrologists. In my opinion, it should be considered "minimal health dialysis" or the "legally most meager treatment allowed" for kidney failure. (And even that minimal target therapy is frequently under-delivered.) A standard of care based on a Kt/V of 1.2 will keep patients alive to dialyze again, but it will assuredly not provide enough therapy for the vast majority of patients to "feel alive". I believe this is the single most important reason as to why the ESRD program never attained its goal of returning a large percentage of patients back to the workforce. They simply haven't been dialyzed enough so they can feel well enough to work again.

Mounting evidence for change

As mentioned previously, as the editor of RenalWEB, I have the good fortune to scan hundreds of news and scientific articles about dialysis. What I have seen over most of those 10 years was an overwhelming chorus of despair and resignation from dialysis patients. There was a terrible dichotomy - the patients felt awful, but their Kt/V or URR numbers were "good." Despite the efforts of many dedicated and caring professionals, these patients fell into physical and emotional declines. The attitude of professionals became - unfortunately - that yes, dialysis patients felt poorly, but they simply had to wait for their transplant, while many professionals downplayed risks and complications of transplantation. And the transplant lists grew longer and longer as the number of deceased donors remained stagnant.

In the last few years, I've seen study after study showing the benefits of much more hemodialysis therapy. I now see local newspapers and TV stations carry stories nearly every week about a hemodialysis patient who feels so much better, so much more alive, after he or she greatly increased their dialysis therapy by switching to either daily or nocturnal hemodialysis. They speak of coming alive again, just as kidney transplant patients do after long periods of relying on dialysis. (Some patients also experience this phenomenon when they switch peritoneal dialysis.) They no longer exhibit many of the

symptoms of under-treatment. Paraphrasing, patients speak of the changes in these terms:

- *It's like being a diabetic and realizing I've been getting half the insulin I need to feel well.*
- *I no longer feel like I'm a zombie.*
- *I feel like I've finally stopped taking an endless dose of Sudafed.*
- *I no longer have that dragged out feeling as if I had a cold all the time.*

It seems more hemodialysis therapy, double or more of today's accepted minimal therapy, makes patients simply feel so much better. It appears that with longer and/or more frequent treatments and by using today's improved dialysis membranes, patients can receive enough dialysis to return to their normal life activities. The growing testimonials of home hemodialysis and nocturnal dialysis patients are showing us that we have been under-dialyzing patients for decades. One small study even showed daily hemodialysis patients have the same longevity of those who receive cadaveric kidney transplants.

Ethical healthcare treatment

The ESRD professional community is well aware of the numerous small scientific studies, as well as the large amounts of anecdotal evidence, about the benefits of greatly increased hemodialysis therapy. Some say we need to wait for large scientific studies to be done to confirm the validity of the benefits of more therapy. However, in light of the fact that virtually all of the dialysis professionals would refuse to accept the standard prescribed therapy for themselves if they faced ESRD, I believe this has now become an urgent ethical issue facing our industry.

The most important change is probably to recognize, first and foremost, that only the patient knows what adequate dialysis is for him or her. Once they have received the minimal legal amount of dialysis therapy, only the patient can tell us how much more therapy makes them feel well – or makes them feel like they are no longer being chronically poisoned. (However, we all know that some patients will not want more than the legal minimum amount of dialysis therapy.) Patients can and should feel as if they have the potential to participate in their normal life activities. No one wants to spend more time hooked to a dialysis machine, but I believe the majority will want more therapy in exchange for the opportunity to enjoy optimal health.

Another side of history

The possible definitions of dialysis adequacy cover a wide spectrum, from simply keeping patients alive to fully replacing native kidney function. Unfortunately, we have been caring for patients using a definition from the low end of this scale. While many

explanations have been offered for this, I feel it is important to share a personal experience that may shed light on a possible contributing factor.

In 1984, I worked in the dialysis facility where Dr. Frank Gotch, the co-founder of urea kinetics, was the medical director. During that year, I only recall him talking to a patient twice in the dialysis treatment area. Once was related to a machine issue, while the other was at the nursing staff's request. I remember being surprised to see him out of his office and on the floor during my last month there. I can only recall seeing one patient in his office, which was completely cluttered with books and papers, and she was visiting from Mexico. I never saw him make patient rounds in the dialysis unit, but he was in his office on the same floor nearly all day doing calculations and writing.

Reflecting on this now, while we will always admire Dr. Gotch's intellect and his devotion to scientific truths, it was obvious that he far preferred being a scientist to being a hands-on physician. I believe we practice a very different type of patient care when we talk to our patients, look them in the eye, and listen to them on a regular basis. By simply including some human considerations in the definition of dialysis adequacy, we can move that definition closer to the middle of the spectrum. This shift is essential in this new stage of dialysis care.

By the way, it is worth noting that the patient from Mexico was a home hemodialysis patient. Under Dr. Gotch's care, she had one of the first successful pregnancies while on dialysis. During her pregnancy, she had longer and more frequent dialysis treatments.

THE "WELL" ESRD PATIENT: A NEW TYPE OF DIALYSIS PATIENT

Prior to this new stage, there were "low dose," "underdialyzed," or "sick" ESRD patients.

Today, we are seeing some "high-dose/frequency," "optimally dialyzed," or "well" ESRD patients. With nocturnal and home hemodialysis programs once again growing, my best estimate is that approximately two percent of the ESRD patients fall into this group.

Going forward, we will have to see two types of patients. Physiologically and cognitively, they are completely different. Accordingly, we must practice two types of patient care. Everything we consider for the patients will have to be seen as applying either to "low-dose patients" or to "high-dose/frequency patients." We can no longer lump them together into a single group.

Two types of patients, two types of patient care

The ever-increasing testimonials of high-dose/frequency patients are making many of scientific studies done in the last three decades increasingly irrelevant. It makes no sense to apply the findings of scientific studies that were done on sick and under-dialyzed ESRD patients and apply them to well ESRD patients. This is notably true of anemia studies, where the life span of the red blood cells is greatly reduced in under-dialyzed

patients. The nutritional and inflammatory conditions of these patients are also likely to be vastly different. It is possible that many studies from the last thirty years, which are what current policies are based upon, are going to be invalid for a well-dialyzed ESRD patient population. In many areas of CKD5 care, we might need to start from scratch. As many small studies have already shown, we will likely find that the quality of life for most patients is greatly improved when we buy more dialysis – and administer fewer drugs – for the same amount of money.

Nearly everyone involved in providing ESRD care is invested – professionally, psychologically, and financially – in the “sick” ESRD patient care model. We will come to realize that we have trained and educated two generations of medical professionals who see hemodialysis patients as sick. Most professional dialysis care givers have never been involved in the care of thriving, well-dialyzed, hemodialysis patients. All their skills and experiences are based on taking care of minimally-dialyzed patients. Many of the usual medicine and nursing interventions are for symptoms or conditions that only exist when patients are under-dialyzed.

Most importantly, at this new stage, changes must occur at CMS (Center for Medicare & Medicaid Service). Medicare will spend approximately \$25 billion on ESRD care this year. Currently, Medicare policies only apply to sick ESRD patients. The Dialysis Facility Compare web site defines adequate dialysis as being a URR of 65%. Medicare’s measurement of quality dialysis care is based on blood test values and deaths.

New relationships

This new type of patient will have a completely different relationship with nursing and medical staff. When patients don’t feel well and are overwhelmed, they often become dependent on professional staff and little is expected of them. The staff, in turn, settles into routines that “infantilize” the patients. Now, patients and medical professionals must be collaborators, focused on optimizing each individual patient’s overall health-related quality of life.

With longer and more frequent dialysis treatments required in this new stage, nearly everyone will need help adjusting psychologically. Companies should be actively soliciting the advice of patients for ideas on devices and technology that will make longer dialysis treatments more tolerable. Instead of solely focusing on diversionary electronic devices during treatment, meditation and mind/body practices may become accepted and normal components of the care in this stage. Clinical social workers and patients, sharing ideas and approaches, can change this paradigm.

These patients know the unique power and effectiveness of patient-to-patient mentoring and advocacy. The Renal Support Network (www.rsnhope.org) is the patient-led organization that I feel has been most effective in providing hope, understanding, and education to dialysis patients. They focus on patients helping patients and rely on the support of the community to make this happen..

Patient activism

These patients will fight for their optimal health. These people know how well they can feel on chronic hemodialysis – and how badly they feel when getting an "adequate" Kt/V of 1.2 or a URR of 65%. They know that when they receive much more dialysis therapy, they are different people. Blogs and discussion forums are excellent vehicles for sharing these positive patient experiences. The more press that these patient experiences receive, the faster change will come.

This new type of patient will be much more of an activist than dialysis patients have been in the past, as they finally feel well enough to participate and can see real benefits of their advocacy. They will also no longer need to rely solely on the dialysis provider corporations for their “education” about ESRD policies.

For those individuals who are setting overall goals and policies for ESRD, this new type of patient must be the new focus. The “Dialysis from the Sharp End of the Needle” [web site](#) is an excellent example of the views and ideas of this new type of patient. These “dialyzors” have valuable ideas, experiences, beliefs, and wisdom to share with policy makers. We must recognize that these patients, who are often seen as “difficult” by the medical and corporate worlds, are simply taking responsibility for their own health – as we would.

EMPLOYMENT: THE NEW MEASURE OF SUCCESS

In 1972, when the U.S. Congress passed the ESRD provision of Medicare, one of the biggest reasons that lawmakers agreed to pick up the costs of these expensive treatments was that nearly all of these people were expected to return to the workforce. A large percentage of these early patients worked. At that time, there was no Kt/V or URR. These patients dialyzed long hours to replace as much of their native kidneys’ function as possible. Based on their experiences, it appeared that ESRD patients simply needed dialysis treatments to return to the productive and meaningful lives they had enjoyed before they became ill.

By this measure, the Medicare ESRD program has been a significant failure.

As the medical community increasingly embraced the science of urea kinetics, fewer and fewer patients felt well enough to work. Their dialysis treatments kept them alive, but not thriving. Since urea kinetics became commonly used, most people have found ESRD to be a devastating and disempowering diagnosis. It has overwhelmed most people with profound lifestyle and diet changes, enormous psychological and cognitive issues, changed family dynamics, a multitude of medical complications, sleep disturbances, changes in physical appearance, paperwork, and much more. As a final indignity for many of them, they lost their jobs and watched their families become impoverished.

Low expectations

Sadly, everyone has failed to understand why patients weren't working. As a result, we now have thirty five years of entrenched low expectations about ESRD patients. Those who tried to assist patients in their rehabilitation often found it an exercise in futility. Neither the Medicare nor any dialysis provider corporation reports the percentage of patients that are employed after one year, two years, or five years of dialysis, information that I believe patients would truly find valuable. In 2005, only 18.4% of dialysis facilities had a shift starting after 5 p.m.

I was shocked to discover last month that not a single dialysis patient is employed by American Association of Kidney Patients (AAKP). The national office of the National Kidney Foundation currently has no employees that are dialysis patients. The one organization that actually employs a significant percentage of dialysis patients is the Renal Support Network.

No government agency or private organization has the knowledge to turn this situation around quickly or by itself. In my opinion, only a group of "well" ESRD patients, sharing their experiences to identify their most important needs and the hardest obstacles to overcome, could quickly and efficiently provide the specific remedies that will help keep ESRD patients employed and thriving. A government agency could eventually do this, but it would likely take a decade to design the study, gather the data, analyze it, and then write the report.

Need for information

Half of all ESRD patients are of working age. It is time to begin reporting detailed employment data in annual USRDS and ESRD Networks reports, the Dialysis Facility Compare website, and the corporate reports of dialysis providers. There would certainly need to be discussion on a number of issues, such as whether to continue to cap the age for reporting at 55 or whether to report through full retirement age. However, no other easily measurable statistic can bring about massive improvements in patient care faster for patients of all ages than employment. Employment data will force CMS, corporations, and medical organizations to include patient voices in their policymaking. Use of employment statistics will naturally shift the perspective on patient care to a "whole patient" approach. With that change, many of the common complications of under-dialysis (depression, itching, sleep disturbances, nausea, malnutrition, skin discolorations, fatigue) will become far less prevalent.

The Medical Education Institute (MEI [web site](#)) appears to have the most experience in dialysis patient employment issues. Beginning 16 years ago, they focused on patient rehabilitation through their Life Options Rehabilitation Program, developing educational materials and successfully advocating for CMS to add an employment status to the 2728 intake form. As they discovered how much better patients felt with longer and/or more frequent dialysis – how truly "rehabilitated" they could be, they started the Home Dialysis Central web site to raise awareness and use of peritoneal dialysis and home hemodialysis.

Employment is an area where tremendous potential exists for patients and companies to collaborate. Dialysis providers receive significantly higher reimbursements from employer group health plans for dialysis treatments than from Medicare. With computer work stations and Internet access available in dialysis centers, is there a logical reason why dialysis providers don't currently employ dialysis patients and offer them private health insurance – from which they could collect these higher payments? Or why can't the corporation that has a monopoly within Medicare and has enjoyed the highest profits for the longest time for any major product in any industry in U.S. history...employ the patients that use this product?

VOICE OF THE PATIENT: A KEY IMPERATIVE FOR OPTIMAL POLICY FORMATION

The framework used to formulate ESRD policy in the U.S. must undergo significant changes. The most fundamental omission of the current ESRD “systems approach” is that it does not nurture and develop educated and informed patient voices. There are over 350,000 dialysis patients, yet the number of patients participating in the formulation of clinical guidelines and Medicare policies is extremely low. In every business, gathering voice-of-the-customer data has become integral to developing new products and services to best serve the customer. It is obvious that patient voices are critical to developing effective ESRD policies.

Yet to be developed collective voice

It is nearly impossible for a single dialysis patient to master the huge body of knowledge that ESRD entails, as well the complexities of how nationwide ESRD policies are formed. Ironically, the complexities of Kt/V and urea kinetics have kept most patients from questioning the soundness and validity of their care. Only a few patients are able to effectively debate with ESRD professionals on the best clinical approaches in ESRD care. Unfortunately for all, little has done by policymakers to amplify these patient voices, either as individuals or as a group.

Patient voices are now several developmental stages behind professional organizations and corporations in being effectively heard in Washington. Now that these patients at last feel well enough to participate in policymaking, we cannot continue the enormous mistake of excluding them. We finally have an opportunity to establish a balanced systems approach to formulating ESRD-related health and economic policies.

To accomplish this objective, the federal government should embed a national patient organization in its policymaking. What is especially needed - immediately - is a permanently funded organization that includes these ‘high-dose/frequency’ patients. This organization could be funded similarly to the ESRD Networks or the USRDs and would be separate from any dialysis provider organization. As they will need access to the same data, it could be an independent part of these organizations. This combination would also provide patients with the ability to interact with large numbers of experts, increasing their

knowledge and personal connections. Just as the physicians, nurses, and administrators have long seen the benefits of national organizations for sharing ideas, solving problems, and bringing change, so too will patients.

Conditions for success

To be successful, this organization must control factors that can influence, intimidate, and/or limit patient participation. Patients must chair the meetings and control the agenda of their organization, instead of being merely members of committees and councils. Patients would no longer be expected to be in Washington with only a week's notice if they wanted to participate in policymaking.

I have found that most of the great ideas I have personally heard in the last few years have come from long-term patients. When these "well" patients are given the time and financial support to freely talk and formulate collective views, they will bring policymakers insights unheard before now. They will also report on the dialysis facilities that are providing the best care, practices, and utilization of technology, as well as offer ideas on how to reward these best-in-class practices.

It is essential this patient organization have financial independence from the multi-billion dollar corporations. The few national patient organizations that exist today must rely heavily on financial contributions from pharmaceutical companies and large dialysis provider organizations. Unfortunately, the interests of these corporations are increasingly in direct conflict with the interests of high-dose/frequency patients. Patient organizations that rely on corporate backing have found it safest to avoid political issues that conflict with corporate interests and have focused instead on educational topics.

Urgent need for new voices

It is finally time to recognize that the patients' interests are no longer best represented by the large dialysis provider corporations and drug companies. Going forward, these well patients will fight for better health, overall disease cost containment, and reasonable corporate profits. These patients will also want more frequent and longer dialysis treatments, fewer drugs, wearable artificial kidneys, patient advocates, more social workers and dietitians, better trained staff, regenerative medicine research, and more transplant options. All of these may ultimately reduce the profits of these multi-billion-dollar corporations, so it is unlikely that these issues will be effectively raised on the patients' behalf by lobbyists representing these companies.

Corporations such as Amgen have been using the enormous profits they make in ESRD to "educate" lawmakers and physicians about ESRD financial matters and the best clinical practices for patients. Over the last decade, they have spent millions of dollars for lobbying Congress so as to control policy formation. While this has resulted in billions of profits for one corporation, as well as eight-digit yearly incomes for a few top executives, it has not brought optimal health for most dialysis patients.

Financial and human benefits

Policymakers may say that they cannot afford to fund another dialysis-related organization, but I would say they cannot afford not to do so. Considering that ESRD care now consumes more than six percent of the Medicare budget, for less than the cost of one of the existing 18 ESRD Networks, Congress could have a better version of MedPAC (Medicare Payment Advisory Commission) for ESRD (– and one that Congress might actually listen to). Patients would quickly identify financial and policy disincentives to better care. With their reports and feedback embedded in the policymaking process, they would provide policymakers and lawmakers with wider and more comprehensive perspectives on excellence in patient care than they have seen before. If given the resources and direction to make recommendations for overall cost containment, they would provide reports and financial analyses that are independent of corporate influence and would thus become invaluable tools for lawmakers, CMS, physician groups, and corporations.

This new framework will finally recognize that while medical science and statistics are valuable, they have limitations that must be recognized and appreciated. We have too often reduced patients to their blood test values and placed far too much emphasis on scientific metrics. We must value having educated and informed patients, as well as listening to them, both individually and collectively, in our facilities and in Washington, in this new framework. In this new stage, by working to increase their dignity, we increase our own.

NEXT STEPS: THE PATH FORWARD

The one topic yet to be addressed here is how to pay for additional dialysis treatment. Much has been written about the substantial savings – realized and potential - that can be achieved with high-dose/frequency dialysis. I believe it can be done with little or no increase in overall ESRD program costs (and provide savings in overall societal costs), but this needs to be challenged and validated. Many ESRD professionals with experience in high-dose/frequency dialysis can provide the clinical data and financial models that demonstrate these benefits.

As we realign our patient care practices to meet a new philosophy of ESRD care, financial and corporate realities will also change and evolve. In our currently troubled economy, corporations that currently enjoy significant profits within the current ESRD program are likely to see those profits reduced by the need to provide longer and more frequent hemodialysis treatments. In this new stage, we may find that corporations that must serve shareholders first are simply not best suited for providing optimal-health dialysis care. I believe the voices of educated and informed patients can serve as better forces than corporate shareholders for bringing long-term efficiencies to ESRD care.

As improbable as an Obama presidency seemed a year ago, it would now appear that major changes in ESRD care are indeed possible. Hundreds of thousands of patients entrust their lives to our care. There are now hundreds of thousands of opportunities to

greatly improve and enrich these lives. Isn't that the reason nearly all of us chose the medical field? At this pivotal time in history, many splendid new views are emerging in healthcare and it can be energizing to see familiar things in a new light.

Additional resources on RenalWEB

RenalWEB will continue to address these issues in the coming year, along with the help of many others. RenalWEB has set up [discussion forums](#) specifically for the topics raised regarding this new stage of dialysis care. It is my hope that both patients and dialysis professionals will participate in sharing their ideas, questions, experiences and thoughts, along with constructive criticism of the many issues raised here.

Beginning next week, RenalWEB will also maintain a Topic Page dedicated to high-dose/frequency dialysis and will include news, articles, and scientific articles as they appear. I hope that both patients and caregivers will continue to inform their local press outlets about the changes patients are experiencing with more frequent and longer dialysis treatments. RenalWEB will be sure to include these on this coming Topic Page.

Finally, I strongly recommend supporting the [Renal Support Network](#), the [Medical Education Institute](#), and the [Dialysis from the Sharp End of the Needle](#) web site. These are organizations that truly benefit dialysis patients.

Gary Peterson, Publisher and Editor of RenalWEB

The opinions and beliefs expressed in this article are solely those of the author.

The author wishes to thank the following individuals for their guidance, feedback, and assistance during the preparation of this article: Dr. Christopher R. Blagg, Bill Peckham, Beth Witten, Jeff Burbank, Lori Hartwell, Dori Schatell, Dr. Tom F. Parker, George Rovegno, Brady Augustine, Sheila Weiner, Dennis Cotter, and Francine Bernitz.

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