Performance Measures in Dialysis Facilities: What Is the Goal?
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Abstract
As the care of patients gets more focused and directed by predetermined standards of care, physicians must not lose sight of the primary focus of their treatment goal—maximizing the quality of life of each patient. Physicians must recognize the uniqueness of each individual’s experience and make every effort to understand the domains that are of concern to each patient. In addition, physicians must make sure that this focus is not obscured by the setting of arbitrary standards and targets that lend themselves to easy assessments and reporting by simple laboratory measures or computer-generated data. Finally, physicians must focus on modifying and tailoring treatment to maximize each patient’s health-related quality of life.


Over the last several years, there has been a substantial decline in the mortality rates for both hemodialysis and peritoneal dialysis patients in the United States (1). The reasons for this are multifactorial, likely reflecting a variety of different modifications in treatment regimens and a better understanding of treatment paradigms. For hemodialysis patients, improved dialyzers and machines, increased focus on the amount of dialysis and rates of ultrafiltration, and increased attention to volume status and BP control have all contributed to improved outcomes. For peritoneal dialysis patients, improved connectology, better management of infections (with international guidelines being widely applied), increased focus on the amount of dialysis, and better understanding of peritoneal physiology and accompanying management of volume status have all been beneficial.

The US Centers for Medicare and Medicaid Services (CMS) has been intimately involved with improving the standards of care provided by dialysis facilities (2). The CMS has focused on selected standards—generally on those that are easy to measure and report, but nevertheless important. These include closely monitoring the percentages of patients achieving specified urea reduction ratios or KT/V urea targets, having hemoglobin levels above or below selected numbers, and receiving dialysis with central venous catheters. Similar approaches were taken by the Working Group of Chief Medical Officers of Dialysis Facilities, which was recently formed and is striving to improve outcomes of patients with ESRD (3). These initiatives may well have had a beneficial effect on patient outcomes, but it needs to be pointed out that these standards of care had already been accepted worldwide, as clinicians became aware of the differing global practice patterns and the effect of these differences on patient outcomes (4). Thus, many dialysis facilities have appointed anemia coordinators to implement predetermined protocols of anemia management, have funded designated access coordinators to reduce the number of central venous catheters, and have set strict and detailed standards for tracking targeted dialysis dosing. A challenging question that the nephrology community faces is whether the CMS’s focus on these measures, which obligates facilities to allocate resources to achieve these targets, is actually the place where the majority of such resources should be directed. In addition, should not patients be consulted as to whether the attention paid by the CMS and the efforts expended by dialysis facilities to achieve these predetermined targets and standards of care are meeting their individual needs and improving their adjustment to and living with ESRD and its treatment?

Eric Kandel, the Nobel Prize neuroscientist from Columbia University, argues in his book The Age of Insight that rather than looking at art through predetermined standards of beauty, we should try to bridge art and science (5). Kandel is writing about Vienna in the early 1900s and suggests that the Vienna School of Medicine had a profound influence on the dynamic art and music culture at that time in the city through the realization that truth lies hidden beneath the surface. He argues that the perception of art depends on the beholder and the culture. He emphasizes the uniqueness of the individual’s role in appreciating, understanding, and responding emotionally to a work of art. Each individual sees the same painting (or hears the same piece of music) differently, uniquely interpreted and reconstructed by his or her brain. This results from unconscious and conscious processes in the mind that enable each viewer to see each work uniquely. This is what the art and science of Vienna in the early 1900s tried to understand in the writings of Freud, the art of Klimt and Schiele, and the music of Mahler.

What does this have to do with standards of care in dialysis facilities? Kandel’s (and Viennese scholars’) understanding of the uniqueness of each individual’s
experience encourages us to think about how each patient is experiencing, understanding, and adapting to the realities of ESRD and its treatment. In many ways, the dictums of the CMS concerning standards of care are focusing on those measurements that can be easily documented and have clear association with some outcome measures (4). But what are the implications for the individual patient? Most facilities have already come to terms with and developed strategies to manage the basics of ESRD care, such as anemia management and providing an “adequate” dose of dialysis. Should facilities allocate substantial resources to make sure that hemoglobin levels are maintained over 10 g% (and not 9.5 g%) and that KT/V urea levels are 1.3 and not 1.1? Is it clear that patients feel better at a hemoglobin of 10 g% versus 9.5 g% or that their morbidity and mortality are lower at KT/V of 1.3 versus 1.1? Or should facilities focus attention on how patients are coping with the demands and effect of ESRD care on their lives (6)?

Matt Taibbi’s new book The Divide: American Injustice in the Age of the Wealth Gap perhaps helps us think about this question (7). Timothy Noah, reviewing this book in The New York Times, suggests that “We may be approaching a day when any kind of personal attention from a large institution that wields substantial control over your life becomes a luxury available only to the few....” (8). Noah is referring to what Taibbi emphasizes in his book—that inequalities may be driven by technology and that computers encourage large institutions (including the government) to operate on a large enough scale that the consideration of or attention to individual circumstances becomes untenable and not possible. In other words, as dialysis facilities accumulate large amounts of data to demonstrate compliance with arbitrary standards of care, where does that leave the individual patient and the nephrologist trying to understand how best to provide care for each patient?

This conundrum was, to some extent, addressed by Allen Nissens, chief medical officer for DaVita, in a recent article in CJASN (9). Nissens underscores the importance of assessing patients’ perceptions of their quality of life by emphasizing that the overarching goal of our care is to maximize the quality of life of patients and that in a “patient focused quality hierarchy,” health-related quality of life (HRQOL) is clearly at the top. Nissens argues and understands that our ultimate goal is to maximize the patient’s perception of his or her quality of life. He suggests that insuring that the fundamentals of care (hemoglobin and KT/V targets, BP control, creation of arteriovenous fistulas, and so forth) are critically important building blocks to achieve this target.

What makes this focus on the quality of life of the patient so challenging is what Kandel has emphasized—that each patient’s perception is unique. Understanding each patient’s view thus requires that an ongoing dialogue be maintained between the patient and the health care provider. This clearly cannot be done with standardized annual quality of life assessments (as is now mandated by the CMS) and is routinely done in dialysis facilities using the recommended Kidney Disease Quality of Life (KDQOL)-36 questionnaire. Importantly, what is mandated now is that the arbitrary scoring of this questionnaire must be dutifully recorded in the chart annually, with some comment on how these scores compare with so-called “standardized values.”

There are certain obvious problems and limitations with this approach. First, individuals’ perception of their quality of life varies and fluctuates regularly over time (even on a day-to-day basis) depending on a variety of health, family, financial, and personal circumstances. This has been emphasized in studies examining the quality of life of patients with ESRD. For example, Kimmel et al. and Troidle et al. were able to demonstrate an association between depressive symptoms and morbidity and mortality rates in hemodialysis and peritoneal dialysis patients only by using a time-varying analysis, recognizing that depressive symptoms can change over time (10,11). Chris McIntyre’s group recently began using computerized testing to document patient-reported outcomes and have observed a substantial variation in these reports within relatively short time frames, often, but not always, associated with identifiable events (Pittman et al., unpublished observations).

Second, the KDQOL instrument (as well as virtually all HRQOL instruments) examines only preselected domains. These are important, especially because some of these questions and domains have been shown to correlate with patient morbidity and mortality and thus provide potentially clinically useful information (6). However, the questionnaires may not capture the specific challenges that the individual patient is dealing with—that is, they ignore the uniqueness of the individual’s experience and they may not address the specific domains that are problematic for an individual patient. For example, for elderly patients maintained on or approaching hemodialysis, Blake et al. have questioned whether the potential negative effect on the quality of life presented by the creation of arteriovenous fistulas (as well as possible increased risks) should make us question the dogma that fistulas should be encouraged for all hemodialysis patients (12).

We then need to consider how the information obtained from the questionnaires translates into improving the patient’s health, experience, and adjustment to the realities of ESRD. This brings us to the third, and perhaps most important, limitation of this approach—the information gleaned from these instruments provides little, if any, information about how the dialysis staff can affect an individual patient’s problems. One striking example is that simple documentation of a domain of difficulty does not provide information about the effect of that domain on the individual. Thus, Mor et al. observed that although the vast majority of women maintained on hemodialysis rarely have sexual intercourse, only 10% of women not having intercourse identified this issue as an area of concern (13).

What should we do moving forward? We must recognize and acknowledge that the care of patients with ESRD is complex and that in providing care we must evaluate, discuss, and address a wide variety of domains. The CMS’s and facilities’ attention has been focused, thus far, on the more obvious and easily identifiable ones—those that are readily measured and quantified and for which technology can provide straightforward reportable documentation. Although these domains are important and can positively affect patient outcomes, we need to recognize that improving the HRQOL of patients—the ultimate goal of our care—does not lend itself to such standardized assessments. We must come to terms with Timothy Noah’s warning about the loss of individual attention in a technological age.
controlled and managed by large institutions or government. In addition, we must recognize the importance of Eric Kandel’s view of the uniqueness of the individual’s experience, whether it be in appreciation of art, music, or the effect of ESRD and its treatment. The challenge to the nephrology community is to embrace the emphasis now being placed on “patient-centered care” and “shared decision-making” and actively engage patients in making choices, empowering them to articulate their concerns and preferences, and breaking down the barriers between patients and health care providers (14, 15). As posited by Barry and Edelman-Levitan, this requires physicians relinquishing their role “as the single paternalistic authority... and learning... how to ask ‘What matters to you?’ as well as ‘What is the matter?’” (15). Our focus then needs to be not just on arbitrary standards set by the CMS, but also on unique domains that matter to individual patients. This requires a reassessment of the role of the physician, dialysis staff, and dialysis facility and rethinking of the approach that the CMS itself articulates. Can the nephrology community be more assertive in not simply adhering to the CMS’s limited and narrow directives, but also insisting that these directives be reassessed and brought more in line with current initiatives in patient-centered care and shared decision-making?

A major difficulty is how to quantify such patient-centered care and interactions. This is indeed problematic; it does not lend itself to simply entering a number, as with hemoglobin and KT/V urea. It involves a process, incorporating a cohesive clinical team that is open to dialogue and feedback. Measuring such a process is challenging. This is something that the nephrology community needs to explore and study. Although I do not have the definitive answer to this problem, I offer the following suggestions of strategies of how we as a community should proceed. First, foster the development of a clinical team where open communication is expected and a dialogue with patients is encouraged. Second, mandate that a curriculum be developed for shared decision-making to be incorporated into nephrology training programs. Third, develop educational programs at national nephrology conferences on patient-centered care and shared decision-making. Fourth, change the focus of social work, nursing, dietary, and physician interactions in the dialysis units to focus on patient education, shared decision-making, and exploring patients’ unique concerns, utilizing a team approach. Fifth, change the focus of charting from obsessive documentation of laboratory values to a discussion of patients’ concerns. Sixth, work with the CMS to change the regulatory environment to support a patient-centered care approach. Finally, mandate that dialysis facilities address patient-centered care and shared decision-making as part of routine clinical care, but let facilities develop individual approaches; these approaches could then be reviewed as part of continuous quality improvement programs and at times of regulatory site visits.

In summary, the nephrology community must not lose sight of its primary focus—providing the best possible care to the each ESRD patient, maximizing his or her quality of life. To achieve this goal, we must recognize and strive to better understand the uniqueness of the individual’s experience. We must move beyond focusing attention on hemoglobin targets, dose of dialysis, and phosphate levels and recognize that HRQOL questionnaires can only give us limited information about the individual’s experience. We need to engage the patient in an active dialogue about his or her care, experience, concerns, and life. This requires a concerted effort and team approach on the part of all of the dialysis providers. Nephrologists, social workers, dieticians, nurses, and technicians must talk to patients and not simply check boxes and respond to standardized prompts in a computer program. These care provider interactions with patients can hopefully provide us with a better understanding of the uniqueness of each individual’s experience with ESRD and enable us to modify and tailor his or her treatment to maximize each patient’s HRQOL.

Disclosures

F.O.F. has served on advisory boards for AbbVie and Amgen, received speaking fees/honoraria from Baxter, and received research support from and provided medical directorship to the Renal Research Institute.

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5. Kandel E: The Age of Insight: The Quest to Understand the Unconscious in Art, Mind, and Brain, from Vienna 1900 to the Present, New York, Random House, 2012

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