Giving Hope to Chronic Kidney Disease Patients

Using multi-channel education technology to enhance human connections helps patients manage late-stage CKD and ESRD with confidence and fidelity to treatment adherence.
Healthcare has a $100 billion problem hiding in plain sight—the care and transition management of patients with late-stage chronic kidney disease (CKD).

More than 20 million adults in the United States have some stage of CKD. However, one of the most insidious aspects of the disease is that most patients—up to 90 percent—go undiagnosed until the late stages of the disease or when they have already progressed to kidney failure—end-stage renal disease (ESRD). According to the latest data (2014) of the United States Renal Data System (USRDS), there are 678,383 cases of ESRD, with up to 38 percent of those patients receiving “little or no pre-ESRD nephrology care.”

For many patients, the diagnosis of late-stage CKD or ESRD is a physical and psychological shock to the system. A single conversation with their physician suddenly and irrevocably changes the anticipated course of their lives. Questions and confusion quickly mount and the path forward is obscure and uncertain.

To make matters worse, this vulnerable population is thrown into a management system that is riddled with education and care coordination gaps, and is often papered-over with narrow and expensive treatment options that fail to account for the patient’s lifestyle and personal values. Inconsistent patient education on the part of the provider and poor health literacy on the part of the patient often lead to a delayed or incomplete plan of action and tremendous cost burdens on the healthcare system.

Part of the problem may be how the disease is viewed by the healthcare community. It has been suggested that late-stage CKD is so different and more complex than its early stages that treating it as a single continuous affliction may be a contributor to inadequate treatment, funding and management.
A Better Way

The Centers for Medicare & Medicaid Services is encouraging greater use of at-home treatment modalities and upstream patient education and intervention strategies, which could save the health system $63 billion annually and also tackle the vast racial, gender and financial disparities within the CKD community.

The move toward more cost-effective care and treatment environments has been well-documented in healthcare for years. For example, some types of surgery and rehabilitation have migrated to outpatient centers and other less expensive care settings. Today, many care and treatment services are extending all the way into patients’ homes. Moreover, these services are being designed with more than just disease treatment in mind; they are factoring the patient’s work, life and family situation into the equation.

In addition, recent studies and self-care trials have shown that a shift toward patient-centric education, particularly multi-channel modalities education, for those managing chronic diseases “have shown improvements in self-efficacy, patient satisfaction, coping skills, and perceptions of social support.”

For the healthcare system, comprehensive patient education strategies—and the resulting compliance and management successes within the patient population—are essential to meeting numerous regulatory requirements in a risk-based world, including value-based purchasing and hospital readmission reduction.

This paper will look at leveraging technology to connect late-stage CKD patients to engaging content, clinical expertise and a network of healthcare professionals, peers and mentors. The result is empowering patients to choose ESRD treatment modalities that fit their lifestyles and reflect their personal values, and helps them make enduring treatment decisions with confidence.
Defining the Problem
A near-perfect storm of factors have quietly made late-stage CKD and ESRD a significant and costly epidemic in healthcare.

Before 1960, dialysis for ESRD was still considered an experimental treatment\(^5\), and in the early 1960s nephrology was a new and emerging medical specialty.\(^6\) In 1973 congress amended Medicare to provide insurance for eligible ESRD patients, and the people who received treatment mostly “comprised the youngest, healthiest, most educated and most highly motivated portion of the kidney failure population.”\(^7\)

According to the USRDS Annual Report, the number of ESRD cases has risen to approximately 21,000 cases per year. In addition, racial disparities are acute. Compared to Whites, incidence of ESRD is “3.7 times greater in African-Americans, 1.4 times greater in Native Americans and 1.5 times greater in Asians.”\(^8\)
A Devastating Diagnosis
It’s difficult to overstate the shock and confusion that patients feel upon the diagnosis of advanced-stage CKD.

Due in part to the lack of symptoms in early stages, CKD is often not diagnosed until the patient is already progressing toward kidney failure. Even with the recent and ongoing industry-wide shift toward prevention, wellness, and value-based care, identification and stratification of at-risk populations remain sub-optimal.

If a patient is lucky, he or she is directed to a setting with care providers—doctors, nurses, dieticians and social workers—well-versed in education and treatment options and working in coordination for the patient.

Unfortunately, for many patients there are few options to normalize or overcome those acute feelings of fear and uncertainty. In many cases, the emotional and mental impacts of late-stage CKD are often lost during treatment.

Patients with advanced CKD and ESRD—along with their families and loved ones—confront many challenges beyond those related to co-morbidities and to the pathophysiology of their disease. They must become ‘health literate’ about the nature of CKD and its consequences; difficult treatment choices must be made, including consideration of only conservative care; lifestyle adjustments; the natural history and prognosis of advanced CKD and ESRD must be understood, confronted and accepted, and life expectations must be adjusted.9

Even a rudimentary crash-course in late-stage CKD and ESRD treatment modalities is beyond the reach of most patients. When education is not readily available, most people fall back on the experience of others, which are often described as traumatic, or scrounging the Internet for information that may or may not be scientifically valid.
A Broken System
Outcomes for late-stage CKD patients are generally considered poor, and are often compared to other intensively treated chronic conditions, such as COPD and diabetes. Indeed, the rate of hospitalizations for Medicare patients with CKD is 617 per 1,000 patient years at risk, compared to a rate of 230 for non-CKD patients; and the re-hospitalization rate (defined as returning to a care environment within 30 days of initial discharge) of late-stage CKD (stages 4-5) patients of 22.9 percent, compared to 15.3 percent for patients without CKD.10

To make matters worse, many who are diagnosed with late-stage CKD face a broken care and management system, one that is poorly coordinated and defined by a narrow list of expensive treatment options that rarely consider the adverse implications for patients’ work, family and personal lives.

Lack of choice and control
Most late-stage CKD and ESRD patients are treated with in-center hemodialysis, a costly and disruptive treatment, even though less expensive and less intrusive home dialysis modalities are available.

The latest data (2014) from USRDS indicates that “63.1 percent of all prevalent ESRD cases were receiving hemodialysis therapy, 6.9 percent were being treated with peritoneal dialysis, and 29.6 percent had a functioning kidney transplant. Among hemodialysis cases, 88 percent used in-center hemodialysis.”11 Less than 2 percent of patients use home hemodialysis in the United States, compared to 9.4 percent and 18.3 percent of dialysis patients in Australia and New Zealand, respectively.12

In many cases, patients aren’t aware that home dialysis is an option, suggesting a significant gap in shared decision-making between patient and provider. A recent study of 197 ESRD patients demonstrated a gap in the degree to which they wanted joint decision-making and the degree to which they were afforded it
Morton et al described the usual ‘influencers’ of important decisions such as dialysis modality choice and withdrawal from dialysis and showed that shared decision-making is not common in such circumstances. Various studies on end-of-life care in the advanced CKD and ESRD populations support this view.\textsuperscript{13}

Finding the person behind CKD
CKD management rarely considers the life-altering repercussions of the diagnosis, which is significant because the disease has “one of the highest burdens of daily pill intake” of all chronic conditions\textsuperscript{14} and may often require extraordinary behavior and lifestyle changes, as well as strict treatment adherence and compliance, in order to achieve the desired outcomes.

How will treatment affect patients’ ability to work? To care for their families? How will treatment affect their budget—from medication costs to doctor appointments to long commutes to and from the treatment center? How will they ever hope to lead happy and productive lives?

The questions spill forth like a tsunami, and without answers it’s easy for patients to spiral into a vortex of hopelessness and doom. In fact, depression has been cited as the most common psychological disorder in ESRD patients, with some estimates as high as 20 percent to 25 percent.\textsuperscript{15}

Poor care coordination and education
Late-stage CKD is usually associated with other chronic conditions and often requires patients to visit several healthcare providers, in addition to their primary care physician. Inadequate coordination and poor communication often result in a care pathway that is fragmented and lacks unification.\textsuperscript{16}

This fragmentation extends to education, and ultimately, patients’ confidence in and adherence to treatment modalities. “Lack of disease state education results in patients ill equipped to cope with
the critical decisions imposed by late-stage CKD and leaves patients prone to complications of the disease. Educational needs extend broadly in late-stage kidney disease.”17

Patients need to be informed advocates of their own healthcare. Studies indicate that a patient’s understanding of kidney disease is an essential component of successful management and treatment compliance, especially in areas concerning self-management.18

For example, poorly coordinated and incomplete CKD education compels many patients to default to in-center hemodialysis. A recent survey indicated that “one-third of dialysis patients received little or no education regarding dialysis modality.” For patients to make an informed choice of dialysis modality, education plays a key role.19

Knowledge is ‘HOPE’
Healthcare delivery in the United States has three main stakeholders: providers, payers and patients. For decades, the system tilted toward providers and payers, with patients having little to no real decision-making power.

Today, healthcare is gravitating toward a patient-centered model of care. More and more people are choosing their own health plans and often have a greater financial responsibility for their healthcare choices. However, it’s not enough to simply give patients greater say in the management of their own health. They need to be supported with a level of knowledge and guidance that gives them the confidence to make enduring choices about treatments and care management.

The care, treatment and transition management of late-stage CKD patients is ripe for innovation in many areas, particularly patient education, engagement and support.
HOPE
In 2016, Cricket Health unveiled Health Options Patient Education (HOPE), an online education program that connects late-stage CKD patients to engaging content and a network of healthcare professionals, peers and mentors. HOPE allows patients to access clinical expertise and peer-to-peer support, empowering them to choose ESRD treatment options that fit their lifestyle and reflect their personal values.

A central idea behind HOPE is that patients who are more engaged—who feel more in control—in their own care have a better chance of managing their condition. Educated and engaged patients are more willing to openly address concerns and anxieties, ask questions, explore options for treatment modalities, and hold themselves accountable regarding quality of life issues.

Digital technology, peer support and on-demand, multi-channel information has been successfully leveraged to help people lose weight, quit smoking and manage chronic diseases. A recent Cochrane Review noted:

Computer-based programs for people with chronic disease… have been shown to increase knowledge, feelings of social support, and some clinical outcomes among users. There is evidence that home-based information technology interventions can reduce healthcare costs. …A systematic review found that decision aids improved knowledge and accuracy of risk perception and increased people’s involvement and degree of comfort with decision making.²⁰

The same principles used for smoking cessation or improved nutrition can be applied to late-stage CKD patients—empowering them with the support and knowledge necessary to make critical and enduring treatment decisions with confidence. Studies show that an individual’s ability to cope and manage a disease, then adhere to treatment decisions is often based on their fundamental understanding of their condition and symptoms.
Understanding patients’ perspectives towards their illness and treatment may... positively [impact] patient outcomes. These beliefs... inform an individual’s coping strategy, including their willingness to engage in self-management [behaviors] such as dietary control and medication adherence.21

An interactive, multi-channel platform provides late-stage CKD patients with on-demand access to a host of resources—from clinically reviewed content and mentorship initiatives to guidance from a myriad of healthcare professionals and a network of peers to share and interact with.

Target patient outcomes include:
- Increase awareness of ESRD treatment options;
- Prioritize ESRD treatment options based on lifestyle and personal values;
- Build confidence in a treatment modality decision; and
- Ensure the durability of that choice.

Meeting Patients Where They Are
Current CKD management is too one-size-fits-all and makes the patient feel like a passive element in the process. Creating education and treatment modalities that meet patients where they are in their lives begins with a self-assessment that helps the patient identify the criteria that is important to them—and their loved ones—for making an enduring treatment decision.

Shared decision-making requires patient health literacy, augmented communication skills and engaged patients—each of which is far from universally present.22

On-Demand, Multi-Channel Engagement
In the confines of a doctor’s visit, information may be too sparse, or worse, delivered with such volume that it is impossible for any patient to properly digest. For patients who may be overwhelmed with the diagnosis or other life events, such as work or school, the
on-demand nature of the platform allows them to absorb this information on their own time and at their own speed.

In patients with chronic disease, active patient involvement in their health care can lead to better health outcomes, and potentially lower costs. ...Education must be provided at a level appropriate for the patient’s learning ability. Patient engagement increases as he or she expresses preferences in the treatment plan, and finally treatment decisions are made based on patient preferences, medical evidence and clinician judgment. An important consideration is community engagement.23

HOPE allows patients to share information with their loved ones and caregivers. Multi-channel content—such as video, chat, and written information—also take into account the different ways people excel at learning. Some people are visual. Some people are auditory. Some people are readers. The idea behind HOPE is to build a program where people can learn in different ways.

Peer Support and Mentorship
Peer-to-peer support and mentorship help patients stay accountable and feel that they are not alone in their struggle. Think of a program like Weight-Watchers, which uses group support to help members stay accountable for their decisions and actions. Peer-to-peer support is supported by myriad healthcare professionals who offer clinically reviewed and trustworthy guidance on treatment and care management options.
Summary
Patient education is more than just the transmission of information. Patients who are well-informed about their disease and the options available to treat or manage their condition are proactive stakeholders in the decision-making process.

More than 50 years ago, the United States recognized late-stage CKD as an emerging health crisis. Unfortunately, the management infrastructure put in place has not changed with the times. However, value-based healthcare reforms, digital technology and a cultural shift to the patient has given CKD management the resources and incentives it needs to innovate.

References


so different and more complex than its early stages that treating it as a healthcare community. It has been suggested that late-stage CKD is designated as end-stage renal disease (ESRD) and includes "little or no pre-ESRD nephrology care."1

In the United States, with up to 38 percent of those patients receiving treatment for ESRD, there are over 20 million adults in the United States who have some stage of chronic kidney disease (CKD). Many of these patients are already managing multiple care and treatment services, extending all the way into their daily work, life, and family situations. Patients with advanced CKD and ESRD—along with their families—are essential to meeting the challenges and opportunities in the management of their chronic kidney disease. Patients with advanced CKD and ESRD need to be supported toward patient-centric education, particularly multi-channel education, for those managing chronic diseases "have patient's work, life and family situation into the equation. Many care and treatment services are extending all the way into the patient's work, life, and family situation into the equation. The move toward more cost-effective care and treatment is driving an increase in the use of at-home treatment modalities and upstream patient prevention, wellness, and value-based care, identification and coordination for the patient. It's difficult to overstate the shock and confusion that patients feel as they are prepared for the challenges and opportunities in the management of their chronic kidney disease. They need to be supported in the development of the skills, and perceptions of social support."3

Patient education, engagement, and support are essential to meeting patient outcomes include:

- Personal Health Literacy
- Prepared patients to make informed choices about treatments and care, including consideration of only conservative care; lifestyle changes; and ESRD treatment options that fit their lifestyle and reflect their personal values; as well as strict treatment adherence and compliance, in order to achieve extraordinary behavior and lifestyle changes, disease state education results in patients ill equipped to cope with the knowledge and loss during treatment.

"Knowledge is HOPE," and ESRD must be understood, confronted and accepted, and its consequences; difficult treatment choices must be made, and patients without CKD.10

A Broken System

Disparities are acute. Compared to Whites, incidence of ESRD is "3.7 times greater in African-Americans, 1.4 times greater in Native Americans, and 1.6 times greater in Hispanics.11"11

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About Cricket Health

Cricket Health develops scalable healthcare technology services designed to fundamentally transform the care and treatment of people with chronic kidney disease (CKD) who are at high-risk of progressing to end-stage renal disease (ESRD). Cricket Health’s goal is to significantly improve patient’s lives and reduce the clinical, psychosocial and economic burdens associated with chronic kidney disease. Cricket Health’s flagship education program, HOPE, helps CKD patients understand their treatment options and plan ahead to ensure an orderly transition for those who progress to ESRD. The company’s team and advisers include leaders in healthcare, technology and design from Stanford, UCSF, LinkedIn, Twitter, Facebook, Proteus Digital Health and Aberdare Ventures. Cricket Health is based in San Francisco, CA.

Disclaimer

Some of the data reported here have been supplied by the United States Renal Data System (USRDS). The interpretation and reporting of these data are the responsibility of the author(s) and in no way should be seen as an official policy or interpretation of the U.S. government.

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