CMS
CENTERS FOR MEDICARE & MEDICAID SERVICES

Case STUDY

Learning Systems
for Accountable Care Organizations

The Rogosin Institute's Initiative to Promote Health Literacy

This case study describes The Rogosin Institute's (Rogosin's) experience in implementing a health literacy initiative focused on chronic kidney disease (CKD). Motivated by feedback from its patients and staff, Rogosin crafted strategies specifically to provide health literacy education to patients with end stage renal disease (ESRD) and who are pre-ESRD, its own staff, and the community. The initiative supports Rogosin's goal of providing better care to patients with kidney disease while lowering costs. Rogosin's strategy for educating pre-ESRD patients consists of two programs: the Program for the Education of People with Advanced Kidney Disease (PEAK) and Inpatient PEAK (iPEAK). Preliminary results suggest that both PEAK and iPEAK have improved the quality of care received by participants with advanced CKD. These results and Rogosin's implementation experience will be useful to ESRD Seamless Care Organizations (ESCOs), accountable care organizations, and other health care entities that are seeking to develop and implement health literacy initiatives.

BACKGROUND

Organization

The Rogosin Kidney Care Alliance of New York City joined the Comprehensive ESRD Care (CEC) Model in 2015. Two dialysis units make up the Rogosin Kidney Care Alliance ESCO, and an additional dialysis unit is expected to join this ESCO in January 2019. The dialysis units are part of the larger Rogosin Institute, which, through eight dialysis units, serves about 20,000 CKD patients and 1,600 dialysis patients. In 2015, Rogosin's education and policy center, the Center for Health Action and Policy (CHAP), launched the health literacy initiative. CHAP is dedicated to improving the lives of people with kidney disease and other chronic illnesses. It achieves this goal through its work with a variety of partners, including patients with kidney disease and their families, community activists, health care leaders, and policymakers. Rogosin's objective is to leverage the best practices it has learned from its broader dialysis organization in its ESCO units to intensify its work toward the ESCO's goals of improving quality for the ESCO's aligned beneficiaries while managing costs.

Launching the strategies to improve health literacy

In early 2015, Rogosin started developing a health literacy initiative that was informed by insights gained from patient interviews and a roundtable discussion with community activists and experts in health literacy and chronic

illness.[1] Rogosin found that patients wanted to learn more about CKD and ESRD care options, and to receive this information in an educationally and culturally appropriate manner. In addition, patients and Rogosin staff did not fully understand how health literacy impacts health outcomes, and the staff had limited access to health literacy resources. Based on these insights, Rogosin began developing and implementing strategies to improve health literacy across the organization.

> ***"One thing that has made Rogosin's health literacy initiative so successful is making sure that we have patients' voice[s]. . . . Ongoing conversations, whether it's through a more formal survey or informal interview process, to me have been something that's really valuable in developing these various initiatives . . ."***
>
> —Pamela Hoyt-Hudson, Director of CHAP

Rogosin determined that a health literacy initiative has the potential to reduce the overall cost of care while preserving or enhancing its quality. This feature supports the goals of both the organization and the CEC Model. Patients may be overwhelmed by the life-changing transition from CKD to ESRD. If they require emergency hospitalization and dialysis because of kidney failure, they may become depressed or unable to manage the new commitment that dialysis represents. By providing health literacy education before patients reach ESRD, Rogosin helps to prepare patients for an easier transition to ESRD and to receive dialysis treatment in Rogosin's ESCO units. When patients are "health literate," they understand the services and the care options that are available to them. They also know their care team better and are less likely to seek unnecessary and expensive care alternatives.

OVERVIEW OF THE PROGRAMS

Rogosin has two stand-alone programs that provide health literacy education to its pre-ESRD patients: (1) PEAK, a pre-dialysis program for advanced CKD patients who receive treatment in an outpatient setting and (2) iPEAK, a program for advanced CKD patients who receive treatment in an inpatient setting. Both programs coordinate patient care and provide education about CKD, dialysis modalities, and general kidney health.

Patients are eligible for PEAK if they have a glomerular filtration rate (GFR) of less than 30 and are referred to the program by their primary Rogosin nephrologist. Patients in PEAK remain in the program until they transition to ESRD. One Rogosin nephrologist noted that some patients have been in the program since its inception in April 2015. Rogosin educates all patients with advanced CKD who are eligible for and referred to PEAK, including patients who might not enter the ESCO after they transition to ESRD. Once patients are aligned with the ESCO, they meet with their designated ESCO care coordinator to map out their treatment plan.[2]

To join iPEAK, patients must be admitted to Rogosin's network of hospitals with a diagnosis of pre-ESRD or new ESRD (that is, in-hospital "crash starts," in which a patient is admitted to the hospital with kidney failure). Dr. Frank Liu, Medical Director of Rogosin's home hemodialysis program, noted, "We would rather have had the patients come into the clinic, but often they have already ended up in the hospital. These are basically your 'crash-start' patients, so we don't have the opportunity to engage with them months and months . . . before they start dialysis." Patients transition out of iPEAK once they are discharged from the hospital.

PROGRAM FOR THE EDUCATION OF PEOPLE WITH ADVANCED KIDNEY DISEASE

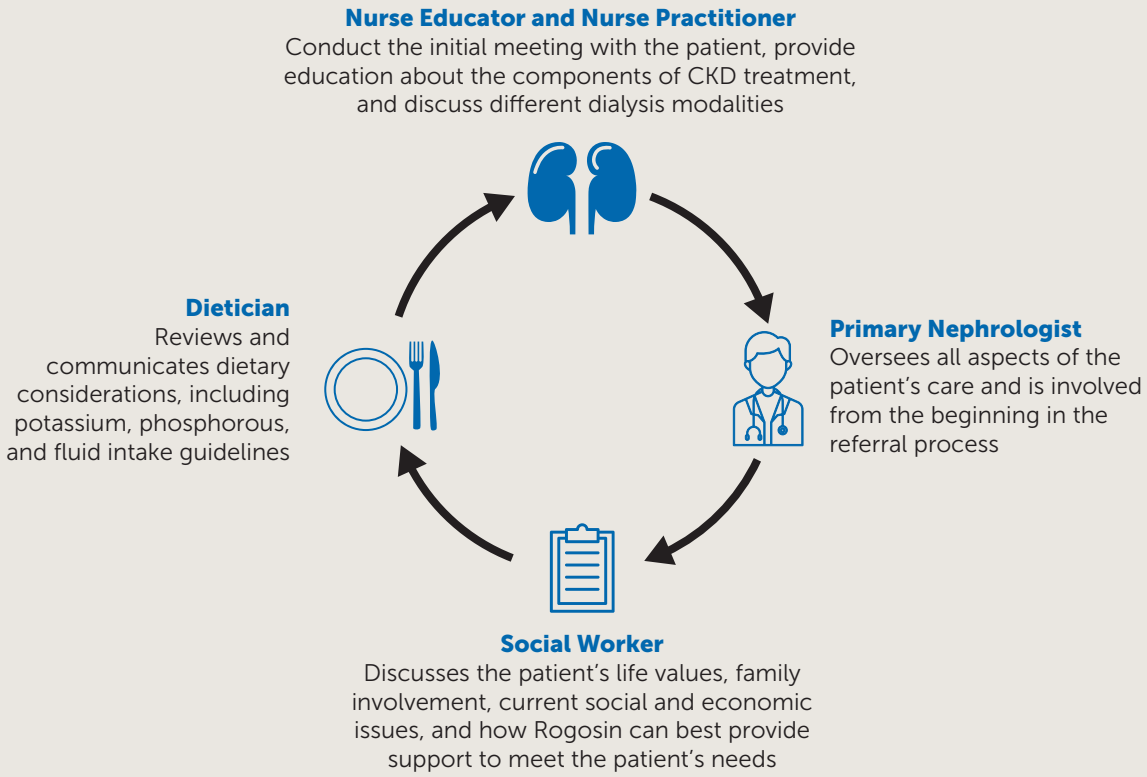
PEAK is an intensive, multidisciplinary education program designed to give patients with advanced CKD (CKD 4 and CKD 5) who receive outpatient care information about treatment options to help them manage their transition to ESRD and engage them in decision-making. The program also gives patients greater access to their care teams. This helps patients to build close relationships with their care teams early in the process and ensures that their needs are met with a personalized approach.

Three goals guide the PEAK program:

1. Improve decision-making on renal replacement options (focusing on transplant and home dialysis)
2. Emphasize the creation of optimal vascular access as standard-of-care policy (that is, less than 10 percent vascular catheter versus arteriovenous fistula [AVF] or arteriovenous graft [AVG] creation)
3. Increase compliance with the guidelines in the Kidney Disease Outcomes Quality Initiative

A patient referred to PEAK has an initial meeting with the program's Nurse Practitioner and Nurse Educator. This initial meeting, which can last up to two hours, focuses on educating the patient about the state of his/her kidney disease, the purpose of the PEAK program, and his/her care options going forward. During this meeting, the Nurse Practitioner and the Nurse Educator also introduce the patient to all the members of his/her multidisciplinary care team and schedule a series of one-on-one meetings between the patient and each member of the care team. These follow-up meetings help to further engage the patient and improve the transition to ESRD care. Figure 1 shows the members of the multidisciplinary care team and their roles in caring for patients in the PEAK program.

Figure 1
PEAK Multidisciplinary Care Team Members and Roles



After the initial meeting, the entire multidisciplinary care team attends weekly care plan meetings to review any changes in the patient's condition. These meetings are the foundation of PEAK. They keep each team member informed of the patient's status and of each other's activities with respect to the patient, and they help to ensure that the patient is meeting his/her care-related milestones and has all of the information he/she needs. To facilitate this process, Rogosin has developed an electronic medical record dashboard specifically for PEAK patients. The team uses this dashboard for updates at the meetings and for the ongoing development and revision of the patient's care plan. One Rogosin physician noted that poor patient outcomes are often a result of suboptimal follow-up by the care team, the results of which include incomplete kidney transplant paperwork and the failure to place vascular access either at all or in a timely manner such that it is mature before dialysis begins. The weekly care plan meetings and the dashboard prevent these poor outcomes by providing a forum in which the care team can regularly (1) discuss the patient and the state of his/her care and (2) coordinate with other members of the patient's health care team both within and outside of Rogosin.

The multidisciplinary approach is a key element of PEAK. It gives patients the opportunity to discuss any non-medical issues with the social worker, who is trained to guide and support patients on issues such as the family environment, financial burdens, and other social stressors. The diversity of the care team also gives patients an opportunity to talk openly to the member(s) of the team with whom they feel most comfortable. This flexibility and the parity between medical and non-medical issues allows the care team to better communicate complex, challenging information to the patient, gain a better understanding of each patient's situation, and thereby provide more personalized care.

> *"From the PEAK Program perspective, the most valuable thing has been the emphasis on non-medical stuff that patients want to talk about to figure out 'the why' of their health struggles."*
>
> —Dr. Frank Liu, Medical Director of Rogosin's home hemodialysis program

Because PEAK depends on internal referrals for patient participation, Rogosin noted that a lack of support from physicians has been a barrier to enrolling people. For example, some physicians believe they are already providing the services that a patient would receive in PEAK and see no reason to refer them. Rogosin continues to seek physician buy-in through

ongoing education that includes presenting data on the improved patient outcomes associated with PEAK participation at monthly physician meetings.

INPATIENT PROGRAM FOR THE EDUCATION OF PEOPLE WITH ADVANCED KIDNEY DISEASE

iPEAK is designed to give advanced CKD patients, as well as new ESRD patients, who receive care in an inpatient setting structured, in-person education about CKD, dialysis modalities, and dialysis access. Because iPEAK operates in a hospital environment in which the patients have co-morbidities and the time of discharge is uncertain, the Nurse Practitioner must educate patients about kidney disease within a time frame that is necessarily more compressed than that of PEAK. In addition, the stresses associated with the hospitalization itself can affect the patient and the care choices that are available to him/her. For example, the patient may be in a state of emotional distress or shock because of kidney failure, so he/she may not be prepared to consider dialysis options.

Figure 2 shows the roles that care providers in Rogosin hospitals play to support the iPEAK program. Rogosin's hospital network allows the inpatient teams (for example, the consult service, inpatient medicine service, and ICU service) to identify and refer patients to a specially trained, dedicated Nurse Practitioner. Once a patient has been identified, the Nurse Practitioner meets with the patient and family members up to three times while the patient is in the hospital.

In addition, Rogosin recently incorporated an urgent-start peritoneal dialysis (PD) program as an option for iPEAK patients who need to start dialysis right away while giving them the option to participate in the urgent-start home PD program after discharge. In this optional program, iPEAK's Nurse Practitioner educates the patient and his/her family about PD and the supplies that the patient will need for it. The patient's family members or caretakers are given the opportunity to visit the outpatient PD center to talk with other patients about their PD experience and to meet with the dedicated staff. The patient can then decide whether or not to proceed with PD. If the patient pursues this option, PD is administered in the hospital, and the patient is then discharged directly to the urgent-start home PD program to receive further training and treatment.

In addition to providing patients with a care alternative post-discharge, Rogosin's urgent-start PD program mitigates one of the major challenges of iPEAK: maintaining patient contact. Following up with patients after hospitalization has proven to be difficult, especially for patients who do not receive care at one of Rogosin's clinics or for those who move to a rehabilitation facility after discharge. Rogosin sometimes loses all contact with patients, but it is exploring options to address this challenge.

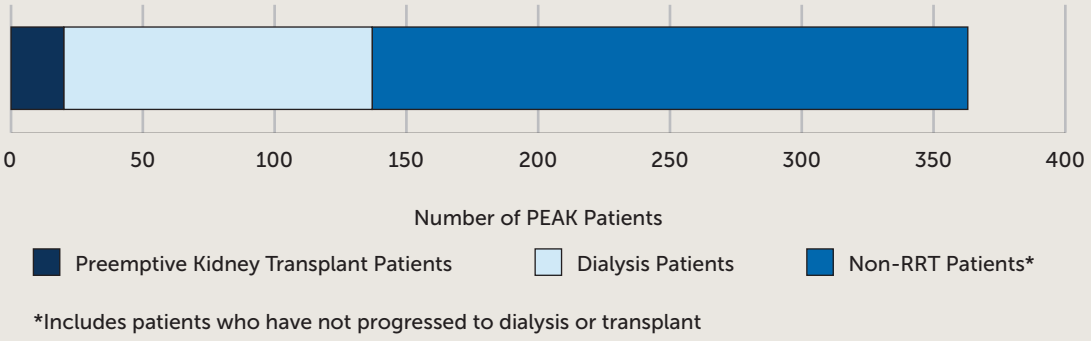
RESULTS

Rogosin's analysis of outcomes data from May 2015 through July 2018 suggests that the PEAK and iPEAK health literacy programs have had a positive effect on participating patients with advanced CKD by making informed and timely decisions during their transition to ESRD. For example, Rogosin noted that the rates of timely, peripheral vascular access placement and decisions for starting home dialysis have been higher among program participants than among nonparticipants. In addition, the rate of preemptive transplant rates among PEAK participants is higher than the national average. These positive outcomes suggest that PEAK and iPEAK participants have responded to the two programs.

PEAK. Since PEAK began in May 2015, Rogosin has tracked outcomes for the 363 patients who have participated in the program. Of these 363 patients, 137 (38 percent) have required renal replacement therapy (RRT) (either dialysis or transplant; see Figure 3). Twenty PEAK participants (15 percent) had a preemptive kidney transplant from May 2015 through July 2018, compared with the national preemptive transplant rate of 2.5 percent.

Figure 2
iPEAK Care Providers and Roles

Figure 3
PEAK Patient Outcomes, RRT vs. non-RRT

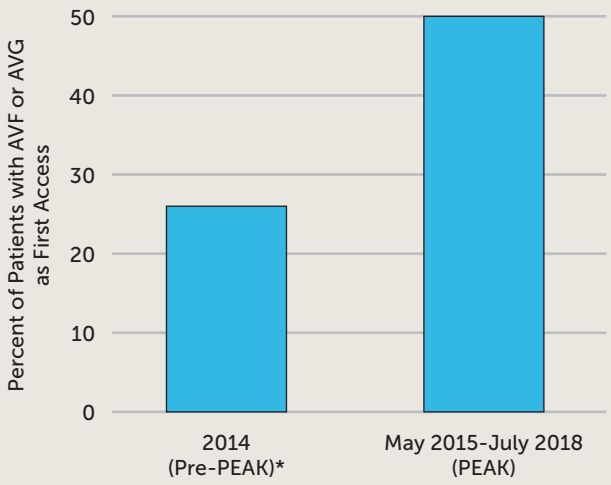


*Includes patients who have not progressed to dialysis or transplant

With regard to the placement of vascular access during the same time period, 50 percent of PEAK dialysis patients had AVF or AVG placement as their first access. In comparison, only 26 percent of such patients in Rogosin's Manhattan ESCO unit in 2014, before PEAK was introduced, had AVF or AVG placed as their first access (see Figure 4). Although the rate has improved since the program began, the use of catheters among PEAK patients remains higher than Rogosin's target of less than 10 percent. Beyond improved vascular access, 19 percent of PEAK dialysis patients have opted for home dialysis, compared with Rogosin's estimated rate of less than 4 percent in New York City.

iPEAK. To gauge the effect of iPEAK, Rogosin has tracked the rate of peripheral vascular access placement among patients who receive hemodialysis during their index hospitalization, which is the initial hospitalization within a sequence of hospitalizations. Data from the first year of the program showed positive results. From August 2015 through September 2016, inpatient teams selected 90 patients who began hemodialysis during their index hospitalization to participate in and receive education through iPEAK. Of these patients, 41 were deemed eligible to have a peripheral vascular access placed, and 19 did so. In comparison, Rogosin noted that from 2013 to 2014, prior to the start of iPEAK, peripheral access was not placed in any patients during their index hospitalization.

Figure 4
AVF or AVG Vascular Access Placement Among Dialysis Patients



*Includes only patients in Rogosin's Manhattan ESCO unit

NEXT STEPS

Rogosin's 2017 survey of patients across all of its dialysis units found that many patients still do not know about home dialysis modalities even though providers are required to discuss home dialysis with patients at least once a year. With the results of this survey in mind, and based on the positive effects of its PEAK and iPEAK programs on patient outcomes, Rogosin plans to continue to prioritize and expand its health literacy work.

"There is clearly more work to do to further improve both PEAK and iPEAK," said Dr. Andrew Bohmart, Medical Director of Rogosin's Manhattan East dialysis unit. To that end, Rogosin has launched a performance improvement project to review data on patients who participated in PEAK but did not start dialysis with AVF or AVG access in an outpatient setting or who did not choose home dialysis. Rogosin is also investigating the optimal duration of participation in PEAK. Rogosin hopes to expand the scope of PEAK such that it becomes a transitional program extending to the first several months of dialysis. Rogosin also plans to extend the reach of iPEAK to include maintaining contact with patients post-discharge in order to provide prompt and appropriate educational information on basic kidney health, physiology, and the dialysis process, with an eye toward the broader goal of improving patient outcomes and quality of life overall.

Leveraging the Momentum of PEAK and iPEAK to Expand Health Literacy Efforts

- **Patient engagement.** Rogosin hosts a variety of educational events for patients, including presentations and topical roundtables on home dialysis, access to transplantation, mental health, and nutrition. Rogosin also operates an iPad-based education program for patients, which consists of a series of interactive e-books.
- **Staff education.** Rogosin trains new staff on health literacy in its orientation process and uses a train-the-trainer model to teach existing staff how to become health literacy "staff champions" in their dialysis units. Once these staff are trained, they are expected to train others at their respective facilities. All staff are trained using a short tool developed by the Agency for Healthcare Research and Quality (AHRQ) that breaks down the teach-back method into discrete action steps. The method seeks to mitigate any misunderstanding about health literacy by asking patients to describe instructions given to them in their own words (AHRQ 2015).
- **Community partnerships.** Rogosin recently hired a health educator who works with faith-based community partners and other consultant groups to plan outreach events, including sessions on nutrition and general health; focus groups; and broad-based meetings on violence, mental health, depression, and anxiety. In addition, Rogosin is using the results of a community survey of almost 10,000 people on the subject of kidney health and organ donation to work with partners across New York City on increasing the number of organ donors. A key principle of these partnerships is empowering community residents to take more responsibility for improving their own health.

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ENDNOTES

[1]Health literacy is defined as the extent to which health information and services are accessible, comprehendible, and usable by individuals (U.S. Department of Education, National Center for Education Statistics 2006).

[2]Alignment includes identifying beneficiaries eligible for the CEC Model, assigning beneficiaries to a specific ESCO depending on whether they visit the ESCO's dialysis clinics, and providing the beneficiaries' information to the ESCO (Centers for Medicare & Medicaid Services 2016).

About the ACO Learning Systems project
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