Gainful Employment of ESRD Patients QIA Project Overview

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Timeline: January – October 2019

Scope: 10.00% of Network 5 facilities

AIM: To increase referral rates 10% for the participating facilities' patients and increase those receiving services 5% by the end of September 2019, through positive culture change and increased access to services.

Baseline: CROWNWeb data Oct 2017 – Jun 2018*

Goal: TBD

BACKGROUND and OBJECTIVES:

In 1972, Congress established the Medicare End-Stage Renal Disease (ESRD) program with the "expectation that payment for dialysis would return patients to the work force as taxpaying citizens". Since that time, there has been tremendous growth in the ESRD patient population as well as a change in demographics, but the initial expectation of returning patients back to work has not occurred. Employment rates in the ESRD population are dismal compared to overall national rates, as much as 61% less.[1]

A robust data review conducted by DaVita identified 37,160 patients in their system as unemployed from Nov 2015. About 21% of those unemployed patients were interested in working, but reported lack of energy/feeling too ill, did not think they should work because they have a disability, or needed training. Older patients were more likely to have the "disability" view, and younger patients were more likely to identify training as a barrier. Their findings also showed the employed patients had higher quality of life scores.[2]

* Source of data: CROWNWeb- Patient are excluded if 1) younger than 18 or older than 55, 2) completed VR prior to 10/1/2017, 3) employed or in school, or 4) marked "not eligible" in CROWNWeb for VR status.

Changes in employment levels are common among working-age people with ESRD. Large numbers of patients give up jobs or reduce work hours before or after initiating dialysis. Once out of the job market, many are not able to re-enter due to the physical demands placed on them by the disease and the dialysis treatment they need to survive. Working individuals initiating dialysis are less likely to maintain the same level of employment they had 6 months before initiation of chronic dialysis if they are non-white, women, and Hispanic. Patients seen as most likely to maintain employment have less comorbidities and their renal disease was not secondary to another diagnosis such as diabetes or hypertension. Correlation has also been found between rate of impairment and decreased perception of employability.[1,3]

> "I wanted to have a sense of normalcy and decided to stay employed as long as I could. I ultimately chose to leave because I was being treated unfairly because I had a disability... I was working in HR and my personal medical information was disclosed to several people. I did not have the energy to fight and they certainly attributed [sic] to my high blood pressure. As an HR professional I know that gaps in employment are a red flag. I didn't receive assistance from my facility, but went through vocational rehab and found it helpful." –Artemeshia Adams

The loss of employment has negative ramifications for ESRD patients such as psychological problems including anxiety and depression.[3,4,5] It can also negatively impact patients' self-esteem[3] and financial security. Patients who were once the breadwinner of the family may have to defer that role to their spouse or partner. There is a real sense of grief and loss associated with losing one's identity as a worker and productive member of society.[3] Yet, loss of employment is not an inevitable consequence of ESRD for working-age individuals.[1] It has been suggested that depression and lack of ability to engage in activity may actually contribute to unemployment; and management of depression and support of an increased activity level may help maintain employment levels, and improve overall quality of life.[5]

Another recognized disincentive is the entitlement to disability benefits conveyed by renal failure which requires dialysis.[5] It is known in the renal community that practitioners and others often counsel patients: now they are "disabled" they should sign up for benefits. Availability of VR services is also impacted by disability status and can limit access to these resources.[3]

> "I did work with [my state's] vocational rehabilitation services…to find employment when I was doing in-center hemodialysis. They were very helpful and provided more than a few leads, but none were in areas or careers that I was interested in." –Dave White

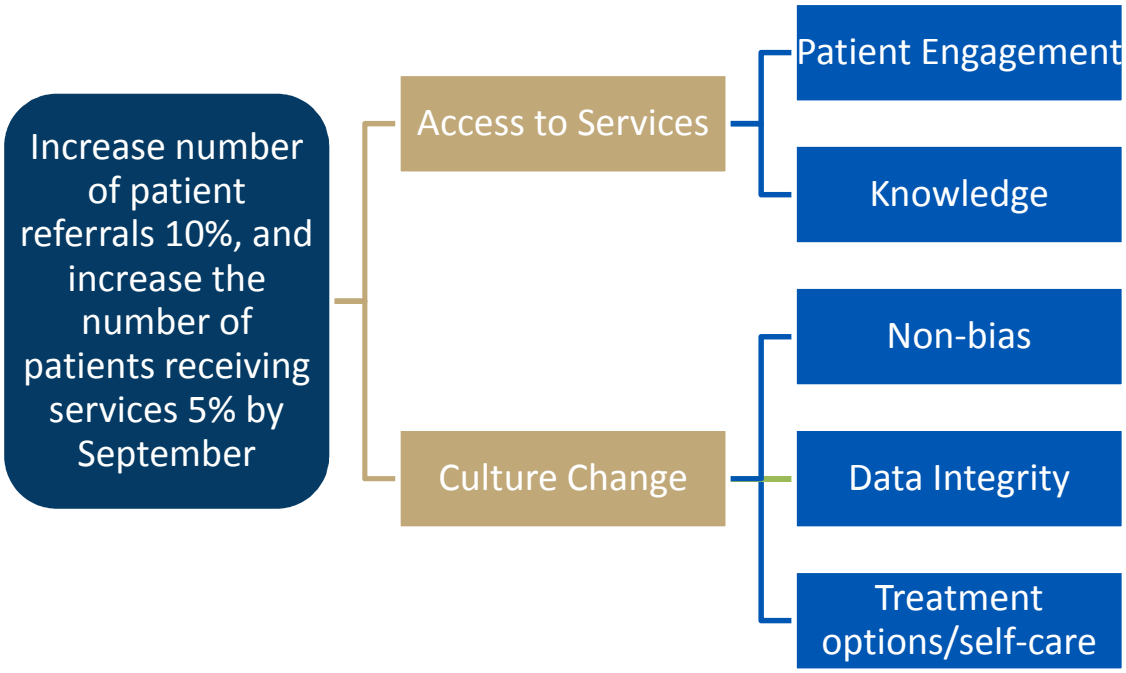
> "Trying to use the resources that are said to be available was most difficult. I ended up going around what is supposed to be a resource for us to obtain work or training and figure out on my own how to obtain what I was seeking." –Andrew Williams

During project development, discussions were held with patient Subject Matter Experts (SMEs) from our Medical Review Board, Board of Directors and Patient Advisory Committee (PAC) to get their input into the potential reasons for unemployment among dialysis patients. They contributed the following insights:

- Patients feel tired after treatment and the possibility of going to work after treatment becomes difficult. Not all facilities offer accommodating treatment schedules.

- Some employers do not want to take the chance on hiring someone that has a "disability", in fear that they may have a high rate of tardiness, absenteeism, too weak to work a full day, or that insurance rates will increase.
- Transportation availability/accessibility.
- Disability is easier than working. Some people would simply rather not work. For others, a disability check is the first time they have ever had a steady income, and that is a powerful incentive to stay right where they are.
- Patients are not aware of the resources available to assist them in retraining for employment.
- Community resources are limited.

Figure 1: Driver Diagram to Achieve Vocational Rehabilitation Goals



Based on the literature and patient feedback, two main drivers were identified for achieving goals in this project (Figure 1):

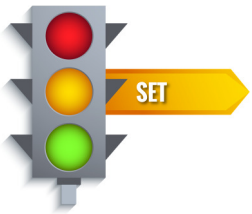
- **Access to services:** Achieving access to services will require patient to have full knowledge of their availability, and a willingness and ability to take advantage of them.
- **Culture change:** ESRD may be a qualifier for disability benefits, but it should not be assumed disabling. All clinicians should set goals with patients about ways to maintain/regain employment. Part of the care planning should include encouragement for selection of treatment options that provide more flexibility around a job/school schedule. Facilities are presumed to not be updating employment status in CROWNWeb as they

should, and will need to take ownership of this to ensure accurate representation of the magnitude of this rehabilitation issue.

Determining why some patients are motivated to maintain/regain employment while others are not is a question each facility will attempt to clarify for itself. Each participating facility will complete root cause analyses to determine what issues prevent patients from maintaining employment and what part the facilities can play in improving this outcome.

Ready, Set, Go Get 'Em! is the theme of our project. Three stages will make up the process:

Assess patients for their readiness, and identify barriers:
Facilities will target new patients for maintaining employment they may already have in place. Most patients starting dialysis do not already have disability benefits in place and can be more fully informed about options, particularly about the limited income provided by disability. Existing patients will be screened for depression, previous work experience, and current level of activity, which will provide more information about resource needs, and movement to the next level of the process.



Pair patients with resources to meet their needs, including referrals to DVR/ENs:
Needs identified in the assessment are addressed at this stage. Facilities will be encouraged to start with those patients who indicate interest. In conjunction with the national Learning and Action Network (LAN) for this project, facilities will be assisted in identifying and adding resources to their toolkit.

Connecting patients with services in the community:
Patients will be connected with community services, such as DORS, and the Ticket to Work Program. Some may obtain employment on their own. Some may pursue education independently with identification of funding. Stakeholders may work together to provide tools/services specifically for the dialysis population.

FACILITY SELECTION PROCESS

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FACILITY ACTIVITIES:

The main activities of the project will include

- Team Approach: The literature shows that anyone approaching a patient with vocational information, whether a nurse, PCT, physician, social worker, or peer, affects the patient's interest and pursuit of services. Therefore, ALL staffs have a role to play in this project.
- Root cause analysis (RCA): RCA will be conducted with use of 5-Whys and Fishbone diagrams (http://www.esrdnet5.org/Dialysis-Providers/Quality-Improvement.aspx) by facilities to determine why patients are not accessing and utilizing vocational services. Facilities will then collaborate with their teams and other project facilities to identify interventions.
- Data analysis: Vocational rehabilitation trend reviews are part of QAPI and required by the Medicare Conditions for Coverage. The QAPI team should be actively engaged in the project monthly. Patients should be a part of the QAPI and QIA team(s).
- Reporting: Monthly project reporting is due the 1st of each month and submitted utilizing the online tool.
- Patient engagement: Facilities will complete two self-assessments gauging their current level of patient engagement, at the beginning and end of the project to provide a measurement of change in practice. SMEs will be invited to participate on monthly calls. Facilities will be expected to recruit patients to participate as part of their project team and to welcome them on calls. Facilities should also share information about the project with all staff/patients for feedback.
- Facility collaboration: Monthly calls will be held encouraging participation in sharing of approaches, challenges, and best practices. At least two national calls will be held during the project period. Facilities are expected to actively participate, and are encouraged to include patients on these calls with them.
- Feedback: Reports will be provided to each facility by the Network on a monthly basis demonstrating progress in this project for both the individual facility and project facilities as a whole. Individualized goals will be included.

> Facilities should pull together a team for this project. The team should review their data, identify root causes, and consider interventions.
>
> Please include a patient on your team.
>
> Share information about this project and your rates with patients, and ask them for feedback.

References

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4. Linn, MW, Sandifer R, Stein S: Effects of unemployment on mental and physical health. Am J Public Health 75: 502-506, 1985.