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The Journal of
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THE JOURNAL OF NEPHROLOGY SOCIAL WORK

The Council of Nephrology Social Workers (CNSW) of the National Kidney Foundation (NKF) is a professional membership organization of social workers dedicated to improving the quality of psychosocial services delivered to ESRD patients, as well as supporting the profession of nephrology social work.

The Council of Nephrology Social Workers of the National Kidney Foundation

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The Journal of Nephrology Social Work is always interested in attracting talented CNSW members to serve as Editorial Board members to help with the planning, solicitation, and review of manuscripts for publication.

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The Editorial Board of *The Journal of Nephrology Social Work* encourages the submission of original manuscripts. The *JNSW* contains articles addressing contemporary issues/topics relevant to nephrology social work. Authors may wish to address any of the following topics, which are listed as guidelines:

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Manuscripts submitted to *JNSW* are peer-reviewed, with the byline removed, by at least two Editorial Board members. The review process generally takes two to three months. *JNSW* reserves the right to edit all manuscripts for clarity or length. Minor changes in style and clarity are made at the discretion of the reviewers and editorial staff. Substantial changes will only be made with the primary author's approval.

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TYPES OF MANUSCRIPTS BEING SOUGHT

Research and Review. The *JNSW* welcomes reports of original research on any topic related to renal social work. The editors will also consider manuscripts that document the development of new concepts or that review and update topics in the social sciences that are relevant to professionals working in the field of renal social work.

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Practical Aspects Section. Contributions to this section are detailed protocols, forms, or other such materials that are successfully utilized for delivery of outcomes-based clinical social work services.

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1) Title page
2) Abstract
3) Text
4) References
5) Appendices (optional)
6) Author note
7) Tables
8) Figures with captions

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Impact of Insurance Status on Outcomes After Kidney Transplant Among Out-of-state Recipients

Marcia Garcia, LCSW; Francis L. Weng, MD, MSCE; Tracy Grogan, MS; Lisandra D. Achaibar, MPH, Saint Barnabas Medical Center, Livingston, NJ

Patients with end-stage renal disease (ESRD) who wish to get a kidney transplant must have adequate insurance in order to be considered suitable candidates. States are not required to accept patients with out-of-state Medicaid coverage and are free to impose restrictions on coverage (Ehlers, 2002; Preussler, Farnia, Denzen, & Majhail, 2014). This study sought to determine, among out-of-state recipients who received kidney transplants at Saint Barnabas Medical Center between 2010 and 2014, the impact of having Medicaid as a secondary insurance provider. We also examined the relationship between patient outcomes and psychosocial variables. Patients with Medicaid as a secondary insurance plan had similar one-year allograft survival and similar rates of readmissions compared to patients with other insurance types.

INTRODUCTION

End-stage renal disease (ESRD) has been defined as complete and permanent kidney failure treated with either a kidney transplant or dialysis. ESRD is a chronic illness that requires patients to select the treatment modality that best fits their lifestyle. As of December 31, 2014, more than 650,000 people were suffering from ESRD, 70.3% of people with ESRD were receiving some type of dialysis, and 29.7% had a functioning kidney transplant (United States Renal Data System (USRDS), 2016). Patients who receive a diagnosis of ESRD are encouraged by their renal team to seek kidney transplantation as an alternative treatment to dialysis. Patients who select kidney transplantation as a treatment modality commit to taking medications for the rest of their lives to support the transplanted kidney. Transplant recipients also need reliable access to medical care, as they are closely followed by the transplant team for the life of the transplanted kidney (Organ Procurement Transplant Network (OPTN) Minority Affairs Committee, 2014).

Kidney transplantation is usually the optimal treatment for ESRD, but the wait times for kidneys vary throughout the country for this procedure (Mathur, Ashby, Sands, & Wolfe, 2010; OPTN Minority Affairs Committee, 2014). “The median wait time for a person’s first kidney transplant is 3.6 years, and can vary, depending on health, compatibility, and availability of organs” (National Kidney Foundation (NKF), 2017). In an effort to reduce wait time, patients may choose to list themselves at centers in other donation service areas, a process referred to as “multiple listing.” Out of the 65,383 people active on the United Network for Organ Sharing (UNOS) national kidney transplant waiting list, 4,762 are listed at multiple centers as of May 21, 2017 (OPTN, 2017).

To be listed for a kidney transplant at a center, ESRD patients must have an acceptable form of insurance to pay for the costs of transplantation. ESRD patients who are receiving treatment for their renal disease are deemed Medicare eligible. To qualify for Medicare benefits, ESRD patients must have a work history inclusive of 40 work quarters. In 2007, approximately 209,000 people received Medicare coverage as a result of ESRD. Part B of Medicare covers 80% of outpatient services, including dialysis treatments and outpatient medical care that post-transplant patients receive (Paradise & Garfield, 2013). The cost of Medicare Part B premiums is determined by the income of the recipient. Out of the 209,000 ESRD Medicare beneficiaries, less than 1 in 10 rely solely on Medicare for healthcare coverage. This means that only 18,100 people have Medicare and some form of supplemental insurance coverage to fully cover outpatient healthcare expenses. To be fully insured under Medicare benefits, patients need to obtain a secondary policy that picks up the 20% of what Medicare Part B does not cover. This includes 20% of transplant patients’ immunosuppressive medications and 20% of the cost of the patient’s post-transplant clinic visits (Umans & Nonnemaker, 2009).

To qualify for Medicaid, an individual needs to be a resident of the state where they are applying for the entitlement, 65 years or older, blind, or permanently disabled and must meet specific financial criteria that vary from state to state. Nationally, the Medicaid program finances over 16% of all personal healthcare spending in the U.S. (Paradise, 2017). Most Medicaid beneficiaries would be uninsured or underinsured without this entitlement.

Insurance type influences a patient’s access to healthcare providers. ESRD patients with private insurance have a greater likelihood of being assessed for transplant and being

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deemed suitable candidates than patients with Medicare or Medicaid (Johansen, Zhang, Huang, Patzer, & Kutner, 2012). Medicaid patients who cross state lines have less access to kidney transplant centers compared to patients with private insurance (Mathur et al., 2010). There have been few studies specifically examining barriers faced by out-of-state Medicaid recipients attempting to access kidney transplant services (Dubay et al., 2016). Since Medicaid is jointly administered through the federal government and individual states, coverage for medical services differs from state to state (OPTN Minority Affairs Committee, 2014). Additionally, centers are not required to accept patients with out-of-state Medicaid coverage (Preussler, Farnia, Denzen, & Majhail, 2014). States are also free to impose restrictions on coverage for Medicaid patients who travel out-of-state (Ehlers, 2002). The healthcare advocacy organization, Families USA, states, "providers have little incentive to enroll in another state's Medicaid program if this would entail accepting a reimbursement rate that is lower than the Medicaid rates in the provider's home state" (Families USA, 2003).

Our study sought to determine, among out-of-state recipients who received kidney transplants at our center, the impact of having Medicaid as a secondary insurance provider. A retrospective chart review was used to compare outcomes. We looked specifically to see if these patients have worse outcomes (graft loss), required more readmissions, have greater financial need, and needed more staff involvement post-transplant, compared to out-of-state recipients who did not have Medicaid as their secondary insurance.

METHODS

Sample

A retrospective chart review was performed on 79 patients. This study was approved for human subjects by the Institutional Review Board at Saint Barnabas Medical Center (SBMC). Informed consent was not required for completing a retrospective chart review.

Inclusion criteria

Patients were included in data collection if they were adults (over 18 years old), received a kidney transplant between January 1, 2010, and December 31, 2014, and had a home address in a state other than New Jersey. This resulted in 81 medical charts to review. Only patients who received a transplant from SBMC and had a legal home address in a state other than New Jersey were included. Two patients were excluded due to missing information regarding post-transplant outcomes.

Study setting

Saint Barnabas Medical Center is a large kidney transplant center located in north-central New Jersey. Since 2007, SBMC has performed more than 200 kidney transplants annually.

Our center uses a multidisciplinary approach when evaluating a patient's suitability for kidney transplant listing. On evaluation day, pre-transplant patients and their families receive formal education about our transplant program, including the benefits of multiple listing. Patients and their families then meet with the transplant physician, nurse, social worker, and dietitian. The social work assessment is comprehensive. The purpose of this assessment is to identify certain psychosocial variables that are considered to be low, moderate, or high risk factors that contribute to poor patient outcomes. The initial assessment provides the transplant social worker with the opportunity to educate patients about their potential financial responsibilities following a transplant, including copays for medications and cost of insurance premiums. Patients are also educated about the restrictions they will have post-transplant, including crowd avoidance and no driving for several weeks after surgery.

During the pre-transplant evaluation, the social worker asks the patient to identify their support system, the people closest to them who will provide transportation and assist them with some of their activities of daily living after transplant. The social worker also collects self-reported information about a patient's compliance with medical care and medications.

The social work team at our center recognizes that patients who present with adequate insurance coverage, an intact support system, and access to viable transportation have less risk for poor outcomes, compared to patients who have transportation issues, a limited support system, and inadequate insurance coverage for transplant costs. The latter of these two patient groups are considered to have moderate risk factors and would be required to meet with the transplant social worker every six months after activation on the transplant waiting list to ensure psychosocial stability.

VARIABLES

Patients were stratified into three insurance categories for analysis. This included people with private insurance as their primary insurance (referred to as private insurance patients). Patients with Medicare as their primary insurance and Medicaid as their secondary insurance were referred to as Medicaid patients. Patients with Medicare as their primary insurance and with no secondary insurance or a secondary insurance besides Medicaid were referred to as patients with other insurance.

Demographic information abstracted from patients' charts included date of transplant, type of transplant donor (deceased or living), primary and secondary medical insurance at the time of transplant, home state of the patient, barriers to post-transplant care (including access to lab services and transportation), and transplant outcomes. This information is available to the public on the Centers for Medicare & Medicaid Services (CMS) website.

To determine patient outcomes, hospital readmission data was collected. This was separated into two categories 1) readmissions within 1 year post-transplant, and 2) readmissions within 1 to 3 years post-transplant. Patients who required hospitalization for treatment of rejection and infection episodes signify a poor outcome (Uysal et al., 2016).

The next outcome abstracted was subacute rehabilitation. This is required when patients have been hospitalized for an extended period of time and are unable take care of themselves independently. Therefore, it is unsafe to discharge them home, especially if they reside alone. As this outcome required an additional short-term institutional stay, this was considered a poor outcome (Allen et al., 2011).

Lastly, the graft function variable was abstracted. "Graft function" means the kidney (graft) was still functioning at the time of data abstraction. Those who no longer had graft function were considered to have graft failure and needed dialysis. For analysis, this has been divided into time intervals: 1) graft failure within 1 year post-transplant; 2) graft failure between 1 year and the patient's last visit; and 3) no graft failure which means the transplanted kidney was still functioning at the time of data collection.

Analysis

Descriptive statistics and chi square tests were used to summarize the data. Analyses were completed by two trained researchers. Analyses were performed in IBM SPSS Statistics (23.0). Regression analyses were not run on outcomes because of the small sample size and the limited amount of outcomes data available.

RESULTS

Baseline characteristics (Table 1A and Table 1B)

This study included 79 kidney transplant recipients who lived outside of New Jersey (where our transplant center is located). Of those, 25 patients (31.6%) had primary private insurance at the time of transplant (private insurance patients). Forty patients (50.6%) had Medicare as their primary insurance and a secondary insurance provider other than Medicaid (other patients). Fourteen patients (17.7%) had Medicare as their primary insurance and Medicaid as the secondary insurance (Medicaid patients) at the time of transplant. Patients were followed for a mean of 3.3 years, within a range of 1–6 years and for a median of 4 years. More than half of the sample was over 50 years old at the time of transplant (65.8%), white (58.2%), or male (73.4%). Most of the participants were married (78.5%) or living with someone (89.95%). More than half of the sample was disabled (60.8%) or unemployed (57.5%) at the time of transplant. A little more than half of the sample received a deceased donor renal transplant (DDRT) (57%) as compared to 43% who received a living donor renal transplant (LDRT). Overall, 29.1% of our sample required extra staff support/interventions after transplant took place. We found that more than half of the total sample (62%) did not require readmission within the first year after transplant surgery. 92.4% of patients did not require readmission 1–3 years post-transplant. Only three of the 79 patients required subacute rehabilitation. 92.4% of the sample had a functioning kidney at the end of data abstraction (**Table 1A and Table 1B**).

Characteristics of Medicare & Medicaid Patients Post-Transplant (Table 2A and Table 2B)

Of particular interest to our study were patients who lived outside of New Jersey and had Medicare as their primary insurance and Medicaid as their secondary insurance. We categorized the 79 patients into three insurance groups: private insurance (n = 25), Medicare with Medicaid secondary (n = 14), and Medicare with other non-Medicaid secondary insurance (n = 40). Of the Medicaid patients, 71.4% were unemployed and 92.9% were disabled. 21.4 percent of the Medicaid patients were living alone at the time of transplant. Almost half of Medicaid patients required extra staff support after transplant (42.9%) (**Table 2A**). 14.3% of Medicaid patients also utilized financial grants provided by outside charitable organizations to assist with a variety of their post-transplant out-of-pocket costs (referred to as the "extra funding given" variable, **Table 2A**). Although it was not guaranteed that Medicaid would cover annual checkups out-of-state, 92.9% of Medicaid patients opted to receive their post-transplant care at SBMC despite the possibility of incurring additional medical costs (Umans & Nonnemaker, 2009). Compared to the other two insurance groups, patients with Medicaid received more deceased donor renal transplants (85.7%) than living donor renal transplants (14.3%, $p < 0.01$).

In terms of post-transplant outcomes, patients in the Medicaid insurance group did not have the worst outcomes out of the three different insurance categories. When comparing all outcome variables designated in **Table 2B**, Medicaid patients did not have the worst results of each category. Private insurance patients had the same percentage of readmissions within 1 year post-transplant as Medicaid patients (44.0% private, 43.9% Medicaid, $p > 0.6$). The Medicaid group had the highest frequency of readmissions 1–3 yrs. post-transplant (21.4% Medicaid, 8.0% private, 2.5% other, $p < 0.07$). Ninety-three percent of Medicaid patients had a functioning kidney at the time of data collection completion (92.9%). This was similar to the allograft survival of patients in the private insurance group (88.0%) and other insurance group (95%) which can be found in **Table 2B** ($p > 0.47$).

Table 1A. Sociodemographic characteristics of out-of-state patients who received a kidney transplant at SBMC between 2010–2014

		Total, *n* = 79 (100), *n* (%)
Age at transplant (years old)	< 40	6 (7.6)
	40–49.99	21 (26.6)
	50–59.99	21 (26.6)
	< 60	31 (39.2)
Sex	Male	58 (73.4)
	Female	21 (26.6)
Race	White	46 (58.2)
	Non-white	33 (41.8)
Race (expanded)	Asian	6 (7.6)
	Black	19 (24.1)
	Hispanic	8 (10.1)
	White	46 (58.2)
Home state	NY	46 (58.2)
	PA	23 (29.1)
	Other	10 (12.7)
Marital status	Married	62 (78.5)
	Not married	17 (21.5)
Lives alone	Yes	8 (10.1)
	No	71 (89.95)
Disabled	Yes	48 (60.8)
	No	31 (39.2)
Driver's license	Yes	24 (30.4)
	No	2 (2.5)
	Unknown	53 (67.1)
Employment	Full time	7 (17.5)
	Part time	2 (5.0)
	Retired	8 (20)
	Unemployed	23 (57.5)
U.S. citizen	Yes	76 (96.2)
	No	3 (3.8)
Type of transplant	DDRT	45 (57.0)
	LDRT	34 (43.0)
Number of prior kidney transplants	No prior kidney transplants	60 (75.9)
	1 prior kidney transplant	17 (21.5)
	2 prior kidney transplants	2 (2.5)
Utilized Post-Transplant Surveillance (PTS*)	Yes	23 (29.1)
	No	56 (70.9)
Received patient grants **	Yes	5 (6.7)
	No	74 (93.2)
Labs completed outside of SBMC	Yes	20 (25.3)
	No	59 (74.7)

continued…

Table 1A. **Sociodemographic characteristics of out-of-state patients who received a kidney transplant at SBMC between 2010–2014** *continued…*

Received psych evaluation post-transplant	Yes	2 (2.5)
	No	77 (97.5)
Transfer-of-care to local transplant center***	Yes	4 (5.1)
	No	75 (94.9)
Insurance type	Private	25 (31.6)
	Medicare & Medicaid	14 (17.7)
	Medicare & non-Medicaid	40 (50.6)

79 patients were included in the study who received a kidney transplant from Saint Barnabas Medical Center (SBMC) and lived outside of New Jersey.

** Post-Transplant Surveillance (PTS) Team involves an intervention by one or several members of the multidisciplinary team for high-risk patients in need of extra support to promote a positive outcome.*

***Received patient grants; includes funding by private organizations given to patients who need help obtaining medication, transportation, or insurance payment.*

****Some patients preferred to receive post-transplant care in their own home state, which would be covered by Medicaid, instead of out-of-state coverage at SBMC.*

Table 1B. **Post-transplant characteristics of out-of-state patients who received a kidney transplant at SBMC between 2010–2014**

Variables		**Total *n* = 79 (100%), *n* (%)**
Readmissions within 1 year post-transplant	Yes	30 (38.0)
	No	49 (62.0)
Readmissions 1–3 years post-transplant	Yes	6 (7.6)
	No	73 (92.4)
Subacute rehabilitation*	Yes	3 (3.8)
	No	76 (96.2)
Graft function	Yes	73 (92.4)
	No	6 (7.6)
Graft failure	Within 1 year post-transplant	2 (2.5)
	Between 1 year and last visit	4 (5.1)
	No graft failure	73 (92.4)
Patient deaths	Yes	8 (10.1)
	No	71 (89.9)

79 patients were included in the study who received a kidney transplant from Saint Barnabas Medical Center (SBMC) and lived outside of New Jersey.

**Subacute rehabilitation is required when patients cannot independently take care of themselves post-transplant.*

Table 2A. Sociodemographic characteristics of out-of-state patients who received a kidney transplant at SBMC between 2010–2014 by insurance type

		Private, *n* = 25 *n* (%)	**Medicare + Medicaid, *n* = 14 *n* (%)**	**Medicare + Other Secondary /None, *n* = 40 *n* (%)**	***p*-value**
Age at transplant (years old)	< 40	1 (4.0)	2 (14.3)	3 (7.5)	.51
	40–49.99	5 (20.0)	6 (42.9)	10 (25.0)	
	50–59.99	9 (36.0)	2 (14.3)	10 (25.0)	
	> 60	10 (40.0)	4 (28.6)	17 (42.5)	
Sex	Male	20 (80.0)	9 (64.3)	29 (72.5)	.56
	Female	5 (20.0)	5 (35.7)	11 (27.5)	
Race	White	18 (72.0)	5 (35.7)	23 (57.5)	.09
	Non-white	7 (28.0)	9 (64.3)	17 (42.5)	
Race (expanded)	White	18 (72.0)	5 (35.7)	23 (57.5)	.18
	Black	2 (8.0)	7 (50.0)	10 (25.0)	
	Hispanic	3 (12.0)	1 (7.1)	4 (10.0)	
	Asian	2 (8.0)	1 (7.1)	3 (7.5)	
Home state	NY	15 (60.0)	12 (85.7)	19 (47.5)	.10
	PA	8 (32.0)	2 (14.3)	13 (32.5)	
	Other	2 (8.0)	0 (0.0)	8 (20.0)	
Marital status	Married	23 (92.0)	7 (50.0)	32 (80.0)	.01
	Not married	2 (8.0)	7 (50.0)	8 (20.0)	
Lives alone	Yes	3 (12.0)	3 (21.4)	2 (5.0)	.20
	No	22 (88.0)	11 (78.6)	38 (95.0)	
Disabled	Yes	10 (40.0)	13 (92.9)	25 (62.5)	< .01
	No	15 (60.0)	1 (7.1)	15 (37.5)	
Driver’s license	Yes	4 (16.0)	7 (50.0)	13 (32.5)	.11
	No	0 (0.0)	1 (7.1)	1 (2.5)	
	Unknown	21 (84.0)	6 (42.9)	26 (65)	
Employment	Full time	9 (36.0)	0 (0.0)	7 (17.5)	.14
	Part Time	2 (8.0)	1 (7.1)	2 (5.0)	
	Retired	6 (24.0)	3 (21.4)	8 (20.0)	
	Unemployed	8 (32.0)	10 (71.4)	23 (57.5)	
U.S. citizen	Yes	25 (100.0)	12 (85.7)	39 (97.5)	.07
	No	0 (0.0)	2 (14.3)	1 (2.5)	
Type of transplant	DDRT	8 (32.0)	12 (85.7)	25 (62.5)	< .01
	LDRT	17 (68.0)	2 (14.3)	15 (37.5)	
Number of prior kidney transplants	No prior kidney transplants	17 (68.0)	10 (71.4)	33 (82.5)	.24
	1 prior kidney transplant	8 (32.0)	4 (28.6)	5(12.5)	
	Two prior kidney transplants	0 (0.0)	0 (0.0)	2 (5.0)	
Utilized post-transplant surveillance (PTS*)	Yes	3 (12.0)	6 (42.9)	14 (35.0)	.06
	No	22 (88.0)	8 (57.1)	26 (65.0)	

continued…

Table 2A. Sociodemographic characteristics of out-of-state patients who received a kidney transplant at SBMC between 2010–2014 by insurance type *continued…*

Received patient grants**	Yes	2 (8.0)	2 (14.3)	1 (2.5)	.27
	No	23 (92.0)	12 (85.7)	39 (97.5)	
Labs completed outside of SBMC	Yes	7 (28.0)	1 (7.1)	12 (30.0)	.22
	No	18 (72.0)	13 (92.9)	28 (70.0)	
Received psych evaluation post-transplant	Yes	0 (0.0)	2 (14.3)	0 (0.0)	.01
	No	25 (100.0)	12 (85.7)	40 (100.0)	
Transfer-of-care to local transplant center***	Yes	0 (0.0)	1 (7.1)	3 (7.5)	.38
	No	25 (100.0)	13 (92.9)	37 (92.5)	

79 patients were included in the study who received a kidney transplant from Saint Barnabas Medical Center (SBMC) and lived outside of New Jersey.

** Post-Transplant Surveillance (PTS) Team involves an intervention by one or several members of the multidisciplinary team for high-risk patients in need of extra support to promote a positive outcome.*

***Received patient grants; includes funding by private organizations given to patients who need help obtaining medication, transportation, or insurance payment.*

****Some patients preferred to receive post-transplant care in their own home state, which would be covered by Medicaid, instead of out-of-state coverage at SBMC.*

Table 2B. Post-transplant characteristics of out-of-state patients who received a kidney transplant at SBMC between 2010–2014 by Insurance type

		Private, n = 25 n (%)	**Medicare + Medicaid, n = 14 n (%)**	**Medicare + Other Secondary/ None, n = 40 n (%)**	***p*-value**
Readmissions within 1 year post-transplant	Yes	11 (44.0)	6 (43.9)	13 (32.5)	.60
	No	14 (56.0)	8 (57.1)	27 (67.5)	
Readmissions 1–3 years post-transplant	Yes	2 (8.0)	3 (21.4)	1 (2.5)	.07
	No	23 (92.0)	11 (78.6)	39 (97.5)	
Subacute rehabilitation*	Yes	0 (0.0)	1 (7.1)	2 (5.0)	.46
	No	25 (100.0)	13 (92.9)	38 (95.0)	
Graft function	Yes	22 (88.0)	13 (92.9)	38 (95.0)	.58
	No	3 (12.0)	1 (7.1)	2 (5.0)	
Graft failure	Within 1 year post txp	0 (0.0)	1 (7.1)	1 (2.5)	.24
	Between 1 year and last visit	3 (12.0)	0 (0)	1 (2.5)	
	No graft failure	22 (88.0)	13 (92.9)	38 (95.0)	
Patient deaths	Yes	1 (4.0)	1 (7.1)	6 (15.0)	.33
	No	24 (96.0)	13 (92.9)	34 (85.0)	

79 patients were included in the study who received a kidney transplant from Saint Barnabas Medical Center and lived outside of New Jersey.

**Subacute Rehabilitation is required when patients cannot independently take care of themselves post-transplant.*

DISCUSSION

This study sought to determine the impact of Medicaid as a secondary insurance provider among out-of-state recipients who received kidney transplants. Previous studies have examined social support and specific financial needs/barriers that Medicaid beneficiaries face after transplant. Several studies report that Medicaid patients often lack access to adequate transportation (Allen et al., 2011; Davis et al., 2014; DuBay et al., 2016; Evans et al., 2010; Mathur et al., 2010). In our study, patients with Medicare and out-of-state Medicaid did not have worse outcomes than patients in the other insurance categories. Almost all of Medicare and out-of-state Medicaid patients had a functioning kidney at the time of follow-up (92.9%). The United States Renal Data System (USRDS) reports, nationally, the percentage of patients with functioning kidneys 3 years after transplant in 2013 was 95.1% for living donor transplants and 91.1% for deceased donor transplants (USRDS, 2016). The results of our study indicated that Medicaid patient outcomes are comparable to the national average.

In this study, 92.9% of patients with Medicaid were deemed disabled at the time of transplant and 71.4% were unemployed (**Table 2A**). Both of these patient subsets faced financial challenges with affording their post-transplant care. Our center has access to two privately funded charitable organizations which provide limited funding resources to transplant recipients who meet specific psychosocial criteria. Medicaid patients were deemed eligible to receive and utilize grants from outside private charitable organizations (14.3%). These grants were used toward the cost of a variety of post-transplant expenses, including patients' primary insurance premiums, copays on medications, and transportation services. Supermarket gift cards and gas cards were given to recipients as needed. In short, patients with Medicaid required some financial support from our center, as compared to patients with other types of insurance. Transplant centers are concerned that patients with Medicaid as secondary insurance are more likely to miss their post-transplant appointments due to lack of access to paid transportation services (Evans et al., 2010). In previous studies, a lack of transportation may serve as a significant barrier for Medicaid patients (Davis et al., 2014). Despite Medicaid patients' lack of access to transportation in past studies, 92.9% of patients continued to receive care at SBMC and did not transfer to a center closer to home (**Table 2A**). Given that almost all patients received pre- and post-transplant medical care at our center, a lack of access to transportation was not an issue for Medicaid patients.

In 2010, our center recognized that specific subsets of our post-transplant recipients have a higher chance of developing psychosocial complications immediately after transplant. Our center assembled a team of our own practitioners to provide these patients with extra support. The Post-Transplant Surveillance (PTS) Team consists of a nurse practitioner, social worker, registered dietitian, registered nurse, financial coordinator, and pharmacist. Our PTS program has become a useful internal resource for our patients and has helped to improve outcomes. We had hypothesized that Medicaid patients would require additional staff support. Our results revealed that almost half (42.9%) of these patients were referred to and utilized the PTS program. This finding, in particular, reinforced the significance of the patient-identified support system and impact on patient outcomes.

Patients with out-of-state Medicare and secondary Medicaid had outcomes that are comparable to patients in the other insurance groups. When measuring allograft function, patients with secondary Medicaid fared better than patients with private insurance (**Table 2B**).

LIMITATIONS

This study should be interpreted in light of the following limitations. This study had a small sample size. This was a result of the majority of our center's transplant recipients living in New Jersey. Only 18% of our sample had Medicare and out-of-state Medicaid insurance. Despite these limitations, patient histories obtained from charts reviewed contained sufficient detail to create a larger picture of the barriers out-of-state patients face with multiple listing in other areas.

The acceptable short-term and medium-term outcomes for the out-of-state kidney transplant recipients in our study may not be applicable to other transplant centers. These acceptable outcomes partially stem from our PTS program, which provides extra support to patients, post-transplant. The size of our transplant program allows for sufficient staffing to provide extra support to patients who meet the criteria for either referral to the PTS program or for outside funding resources. Additionally, our center has established relationships with two privately funded charitable organizations that provide grants to transplant recipients who meet predetermined criteria. In order to understand the influence of the PTS program on patient outcomes, an in-depth study examining patient outcomes before and after the implementation of the PTS program would add comparable data.

Future studies could examine a larger sample of out-of-state transplant recipients at other centers to allow for sufficient power to run regression analyses on outcomes. This could determine statistically significant relationships between provision of home care services, for example, and insurance providers and its impact on graft survival. Since a number of patients included in the study utilized our PTS program (**Table 2A**) a larger study examining insurance outcomes on centers without a PTS program could determine whether our findings resembled those of other centers.

CONCLUSION

Our study sought to determine the impact of Medicaid as a secondary insurance provider among out-of-state recipients who received kidney transplants. While small in sample size, the study has shown that patients with Medicaid as a secondary insurance provider required additional staff interventions and extra funding resources. Additionally, our PTS program addressed some of the post-transplant psychosocial issues we identified amongst Medicaid patients. Fortunately, the out-of-state transplant recipients with secondary Medicaid benefits did not have worse outcomes as compared to patients in the two other specified insurance categories. Our study determined that there are psychosocial risk factors, such as the early identification of a patient's support system, which holds significant value in determining patient outcomes. Based upon the results of our study, transplant centers can carefully consider patients who live out-of-state and have Medicaid as their secondary insurance coverage as potentially suitable transplant candidates.

AUTHOR NOTE

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Physical Health Score Assessment May Not Predict Mental Health Score of Dialysis Patients

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The state of physical and mental health has been an important factor influencing the quality of life in the hemodialysis patient population. The SF-36 in the past, and now the KDQOL-36 questionnaire have been used routinely to assess illness perception and quality of life (QOL) among hemodialysis patients. However, it is not clear whether these surveys can truly predict the effect of physical illness on mental health. We present routine quality improvement data from a small cohort studied in an urban dialysis unit in which the social worker performed standard questionnaires per mandate, compared results to unstructured verbal interviews, and noted a poor correlation. The patients who were not expected to have negative perceptions of quality of life actually had negative findings. The findings were more prominent for the mental health aspect of the survey than the physical health aspect, which correlated with patients' symptoms. A total of 92 patients were surveyed and interviewed, and their mental health score could not be correlated in 44% of patients who had a low mental health score and 17.5% of those with a high mental health score.

INTRODUCTION

There are various scales and questionnaires used to assess quality of life (QOL) in the general population. However, many of these have not been adequate in the hemodialysis cohort, where the need is imperative, as the incidence of patients starting dialysis in the U.S. is estimated at > 100,000 persons per year (USRDS, 2015). Numerous studies have evaluated the effects of chronic kidney disease (CKD) on patients' QOL and particular aspects of their lives. In one Brazilian study, the areas associated with the lowest QOL were related to employment status, CKD burden, general health, and physical function (Cavalcante et al., 2013). Other studies have observed a correlation between anxiety and depression and poor QOL in ESRD patients (Olagunju, Campbell, & Adeyemi, 2015). While the QOL surveys have been major tools used in many studies, there is still the need to assess whether these surveys are effective methods of assessment.

Dialysis units use standard QOL questionnaires to assess mental and physical health in their patients. The SF-36 is a Short Form Health Survey that evaluates a set of generic and easily administered QOL measures related to chronic disease. In the past, the assessment of QOL in CKD patients used the SF-36 questionnaire with additional areas relevant to the CKD population. More recently, KDQOL-36 was developed and validated for use in the CKD population (Hays, Kallich, Mapes, Coons, & Carter, 1994). The KDQOL-36 uses a shorter version of SF-36 (SF-12), with 24 kidney-specific questions. The 24 kidney-specific questions address items such as fluid restriction, diet restrictions, symptoms after dialysis, and personal appearance. It is used routinely as part of CMS requirements for the assessment of dialysis patients' QOL, and is performed on patients by the unit social worker annually. Exclusions to performing a QOL assessment using the KDQOL include: patients under 18; patients unable to complete the survey due to dementia, cognitive impairment, and active psychosis; non-English speakers/readers (if the survey is not available in their native language or an interpreter is not available); dialysis time of less than 3 months; and patient refusal. While the survey has become available in many languages over time, it may not be available in all dialects (Kidney Disease Quality of Life (KDQOL) Instrument, n.d.).

Aspects of CKD evaluated by the KDQOL-36 include disease interference with patients' lives in terms of time and daily activities or frustration with disease. In addition, focus is placed on the effects of CKD on diet and personal life. Although these are appropriate additions to the SF-36 survey, they may not be adequate to correlate a disease state with QOL in all patients. In addition to particular factors related to CKD such as those described above, there are specific cultural differences and perceptions that cannot be overcome by simply correlating symptoms with CKD. Moreover, one study noted better QOL when patients perceived their illness seriously, leading to better adherence to treatment (Nabolsi, Wardam, & Al-Halabi, 2013). This is important because cultural variations can influence understanding of and seriousness toward a disease. Additionally, cultural variations can alter responses to the questions asked on these surveys. For example, a question pertaining to personal life issues such as sexuality and personal appearance may appear

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inappropriate, leading to refusal to participate or dishonest answers. It was not clear whether specific cultural aspects are addressed when performing our QOL surveys. The importance of language and cultural sensitivity was exemplified in a study done on a population of multiple sclerosis patients (Michel et al., 2015). In this study, surveys were done in a variety of languages. The results demonstrated better insight into individual perception when culturally sensitive QOL surveys were used (Michel et al., 2015).

Quality of life assessments are performed by our social workers to estimate disease burden to analyze how perception of illness can affect disease self-management. An additional goal is to recognize barriers to effective care. In fact, if illness perception prevents effective medication and treatment administration, it can prevent further care such as renal transplant, as this would reflect a patient having poor self-management during the pre-transplant psychosocial assessment (Lim, 2014). Therefore, it is imperative to have a true assessment of the mental and physical health in our facility's dialysis population.

In this paper, we discuss some issues related to the QOL surveys that have been used in the dialysis cohort. We look at the results of a QOL survey (SF-36) in comparison to a verbal survey, both performed by the dialysis unit social worker. This is important, since CKD treatment is a large part of our healthcare system and there is a perception of disease burden that is based on the types of surveys used (Cavalcante et al., 2013). It is important to understand the variations in the disease perceptions, as they can affect the perception of the extent of the CKD burden.

METHODS

The SF-36 questionnaire was given to patients by the unit social worker in an urban outpatient dialysis unit in Philadelphia, PA. The unit social worker also performed non-structured verbal interviews with each of the patients to be used in comparison to the SF-36 answers. The total number of patients was 92. The average age was 57 years; the F:M ratio was 64:46; 40% had diabetes, and 10% had amputations.

The statistical analysis of data was done using the IBM SPSS V.22 with a Pearson chi score. This study was conducted in the years 2007–2008. The study was exempt from IRB by Dialysis Corporation, Inc., East Falls, PA, since it was part of a routine quality improvement project. Of note, at the time of this study, KDQOL-36 was not established as the standard QOL survey. Hence, SF-36 was used at this dialysis unit.

The three general aspects assessed by the SF-36 survey were: Physical Component Summary (PCS), Mental Component Summary (MCS), and Mental Health (MH). Physical Component Summary (PCS) correlates with physical functioning and body pain scales. Mental Component Summary (MCS) correlates with mental health, role-emotional, and social functioning scales. Mental Health (MH) scale includes: nervousness, feeling down-in-the-dumps, peaceful, sad, and happy. The vitality, general health, and social functioning scales correlated with both PCS and MCS. The score of the survey can vary with each individual, so a particular range is not given, although a lower score correlates with lower QOL (Hays, Sherbourne, & Mazel, 1993).

RESULTS

The results of the SF-36 questionnaire revealed 19.6% (18/92) of patients had an MH score of less than 52, and (80.4%) 74/92 had a score higher than 52. 27.2% of patients (25/92) had MCS score less than 42, and 57.6% (53/92) had PCS score less than 34. The social worker's observations with the non-structured verbal interview questionnaire differed when compared with SF-36 survey in terms of the MH scale. 44% (8/18) of the patients with low MH scores and 17.5% (13/74) of those with high MH scores could not be predicted by the unit social worker closely following the patients using SF-36 in addition to routine interactions with patients. The social worker observed these patients on a routine basis, some for many years through routine patient care rounds. The discordance was surprising because she was unable to correlate the patients with low and high MH scores. The predictability using unstructured interview by the social worker was better with the higher MH score when compared to low MH scores (Pearson chi = 5.9 and *p*-value = 0.015). This means the social worker's observations were more correlated and predictable in patients with a higher MH score, and less correlated in those with a lower MH score. Those expected to have a lower MH score due to a negative attitude towards their chronic illness did not have lower MH scores. Furthermore, in terms of correlation of MH scores with QOL, there was more correlation in the group with better reported QOL than those reporting poor QOL (Pearson chi = 11.1 and *p*-value = 0.001). These two statistically significant findings may suggest that unstructured interviews and casual assessment may not be a good screening tool to assess mental health in those with poor illness perception and QOL, and supports the use of structured measurement of mental health.

The unit social worker had expected certain results based on her non-structured and casual observations of patients but was unable to correlate these expectations with the standard SF-36 survey. In effect, it was assumed that those patients with a negative attitude or more debilitating medical conditions will have lower QOL per survey results, but this was not the case. On the other hand, while the surveys are validated and effective tools in assessing QOL using mental and physical health questions, there can be limitations. These can be related to patient-specific factors, such as acute stressors, cultural variations, socioeconomic status, and varying degree of understanding the survey, per patient level of education.

DISCUSSION

An assessment of illness perception and mental health and its correlation with the physical health state is an important aspect predicting morbidity and mortality in patients. Although there are multiple factors, such as socioeconomic status, education level, and multiple comorbidities that affect QOL (Cavalcante et. al, 2013), "disease burden" plays an important role in perception of illness and future outcomes. While this is important in the general population, we particularly discuss the effects and benefits of these assessments in the dialysis cohort. Assessments are performed by dialysis unit social workers, using the standard SF-36 questionnaire in the past, and since 2008, the KDQOL-36.

As we noted with the results of this study in the outpatient dialysis unit, there was poor correlation of mental health scores and QOL when survey answers were compared with the non-structured verbal interview questionnaires performed by the unit social worker. The predictability was poor in those patients with lower MH scores more than those with higher MH scores. Additionally, those with reported poor QOL had lower correlations with MH scores. Therefore, it can be concluded that there is more difficulty in subjectively identifying patients with worse mental health status.

One of the explanations for this finding from the unit social workers and staff was likely related to patient mobility and freedom. The amputee patient who has poor mobility is out of the home and interacting with persons while at dialysis; these patients do not perceive their illness as a hindrance but as a way of staying involved with the outside world. The younger patient who is otherwise well and is working, is now bound to a dialysis session for 4 hours 3 times a week, may perceive his illness as a giant setback in routine life.

The assessments and scales used to evaluate QOL and mental health in outpatient dialysis units can vary among different companies, but generally it is standardized for an annual QOL assessment using the KDQOL-36, based on current CMS guidelines. While the new assessment questionnaires include CKD-specific questions, there may still be lack of correlation due to patient-specific factors not addressed by the survey. Using the results of our study, we noted that a correlation between routine observations and survey results was not always predictable. While this may be specific to one dialysis unit or social worker, there still needs to be thought as to what factors still need work to have a more robust assessment of QOL in the dialysis cohort. The surveys are available in many languages, but not every single language and dialect, and patients with negative disease attitudes or perceptions may be refusing to participate. Evaluating QOL in survey participants is of great value, but we are still missing assessments of patients who consistently refuse and those may be the patients who need immediate help. Therefore, this is a concern that remains and needs further evaluation on a larger scale to assess whether our routine surveying tools are effective measures of our patients' QOL.

The results of data analysis from this small quality care study exemplify that there is need for a more robust method of assessment of the mental status of our dialysis population to be able to recognize true illness perceptions. We need a method to individualize our assessments as they pertain to every patient. While we cannot coerce patients to participate, we must try to identify the reasons for poor QOL and high disease burden in our patients by individualizing our assessments on a routine basis. Social work plays an important part in helping improve hemodialysis patients' QOL.

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Saved and Missing CMS-2728 Forms Could Affect ESRD Patients' Medicare Enrollment Benefits

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Since 2012, healthcare professionals at Medicare-certified dialysis facilities have used CROWNWeb to electronically submit CMS-2728 Medicare Entitlement and/or Patient Registration forms directly to the Centers for Medicare & Medicaid Services (CMS). While a vast majority of CMS-2728 forms continue to be submitted to CMS and the Social Security Administration (SSA) correctly, data reveal an increase in the number of incomplete forms between 2012 and 2016. This article discusses the reasons forms remain incomplete in CROWNWeb, identifies how users can work to complete forms within a timely manner, and provides an overview of CMS's 2017 CMS-2728 form submission goals.

INTRODUCTION

Dialysis healthcare professionals affiliated with Medicare-certified dialysis facilities may be familiar with CROWNWeb—the Centers for Medicare & Medicaid Services' (CMS) web-based data collection system, that is used by more than 6,000 Medicare-certified dialysis facilities and select transplantation centers throughout the United States and U.S. territories. CROWNWeb is used to report patient treatment information, clinical data, and forms, including the CMS-2728 ESRD Medicare Entitlement and/or Patient Registration form that is completed for all newly diagnosed ESRD patients (regardless of their Medicare status) in order to support patients' Medicare entitlement, and to add these patients to a national renal registry. Currently, thousands of CMS-2728 forms for patients applying for Medicare benefits have not been submitted to CMS. These forms have not been received by CMS because either a facility representative never started the submission process via the CROWNWeb system, causing the forms to be placed in "missing" status, or the forms were started and "saved," but never sent to CMS. CMS-2728 forms are removed from "saved" once they are accessed, reviewed, and submitted to CMS via CROWNWeb.

Each month, CMS works closely with its CROWN Data Discrepancy Support (CDDS) contractor to closely monitor the number of CMS-2728 forms that are "missing" or remain in "saved" status to help ensure that facility representatives are working to submit these forms. During their evaluation in May 2016, CMS and CDDS identified approximately 10,321 forms that were entered into CROWNWeb since the system's national release, but have remained in "saved" status. In the first year of CROWNWeb, 87 forms were started, saved, but never submitted to CMS. And as more people used CROWNWeb to submit data, additional forms were started, but never submitted to CMS. In 2016 alone, 6,953 forms were placed in "saved" status but never submitted. **Table 1** provides an overview of the "saved" CMS-2728 forms by year.

Table 1. Number of "Saved" CMS-2728 Forms by Year.

Year	Total
2012	87
2013	401
2014	916
2015	1,964
2016	6,953
Total	**10,321**

The CMS-2728 form, which is completed only for patients with chronic kidney disease (CKD), serves multiple purposes. Data from the form supports ESRD patient benefits. This information also presents a means by which CMS and ESRD research and data reporting groups, such as the United States Renal Data System (USRDS) and the End-Stage Renal Disease National Coordinating Center (ESRD NCC), can acquire data that are for reporting on the ESRD patient population.

There are currently three versions of the CMS-2728 form that are completed at various stages of a patient's treatment cycle.

- **Initial:** Completed for new ESRD patients for whom a regular course of dialysis has been prescribed by a physician because they have reached that stage of renal impairment that a kidney transplant or regular course of dialysis is necessary to maintain life (CMS, 2006).

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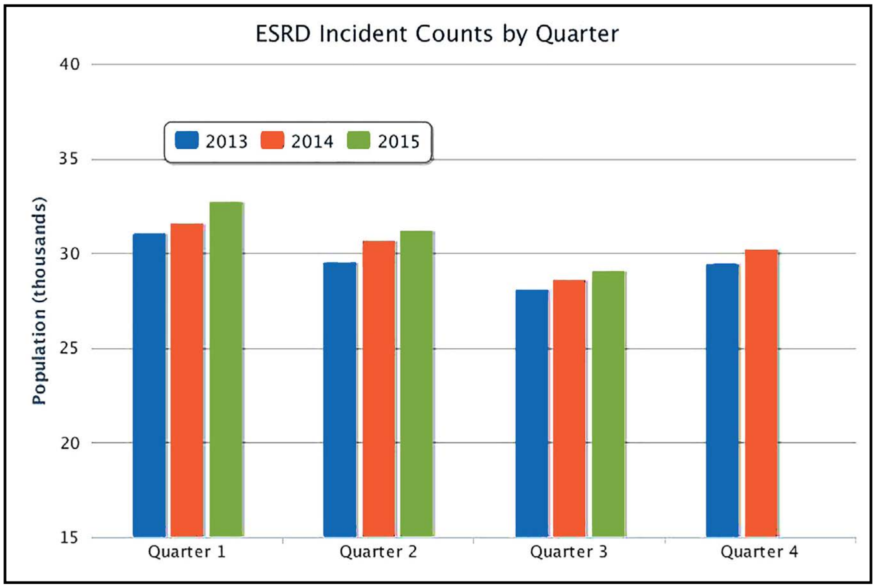
Figure 1. **ESRD Incident Counts by Quarter**



From United States Renal Data System. 2016 USRDS annual data report: Epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2016.

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.

- **Supplemental:** Completed for patients who have received a transplant or have received training for self-care dialysis within the first three months of the first date of dialysis and an initial form was submitted (CMS, 2006).

- **Re-entitlement:** Completed for beneficiaries who have already been entitled to ESRD Medicare benefits; those whose benefits were terminated because their coverage stopped three years post-transplant, but are again applying for Medicare ESRD benefits because they returned to dialysis or received another kidney transplant; or beneficiaries who stopped dialysis for more than 12 months, had their Medicare ESRD benefits terminated, and are now returning to dialysis or kidney transplant recipients. These patients are reapplying for Medicare ESRD benefits (CMS, 2006).

According to the instructions found on page four of the CMS-2728 form, there are two specific items that are to be filled out by the patient and seven by the attending physician. However, an attending physician, head nurse, or social worker who is familiar with the patient's ESRD care may complete the other 46 items listed on the form (CMS, 2006).

Furthermore, while CMS does not mandate who at each facility is responsible for entering the CMS-2728 data into its CROWNWeb system; some facilities have designated that role to their social workers. It is vital that the designated staff at each clinic work together to support the submission of all necessary CMS-2728 forms to CMS and the Social Security Administration (SSA) to ensure that all ESRD beneficiaries have access to Medicare, if other conditions are met.

INCIDENT AND PREVALENT ESRD PATIENTS

According to the National Kidney Foundation, 30 million American adults have chronic kidney disease, and most do not know it (CDC, 2017; NKF, 2016). Furthermore, data obtained from USRDS indicates that as of the third quarter of 2015, there were 701,353 prevalent ESRD patients (USRDS, 2016). USRDS highlights that there was a total of 332,115 incident (new) ESRD patients from January 1, 2013, to the end of third quarter of 2015 — with 92,965 of those individuals being new ESRD patients in the first three quarters of 2015 (USRDS, 2016). On average, since 2013, there have been approximately 30,000 new ESRD patients each quarter. See **Figure 1** for an overview of the ESRD incident counts by quarter.

THE CMS-2728 FORM AND ESRD PATIENT BENEFITS

Since June 2012, authorized facility representatives (including social workers) have used the CROWNWeb system to fill out CMS-2728 forms. Field 11 on the form asks if the patient is applying for Medicare ESRD coverage. According to CMS's CDDS contractor, of the total CMS-2728 forms that were submitted via CROWNWeb in 2015, 210,850 forms indicated patients applying for Medicare ESRD coverage. Furthermore, CDDS indicated that of the CMS-2728 forms "saved" but not submitted from June 2012 to May 2016, 6,138 were for patients who were applying for Medicare ESRD coverage. See **Table 2** for an overview of the "saved" CMS-2728 forms for patients are applying for Medicare ESRD coverage.

An Initial CMS-2728 form is required for all newly diagnosed ESRD patients, regardless of their Medicare status

Table 2. Number of "Saved" CMS-2728 Forms for Patients Applying for Medicare ESRD Coverage

Year	Number of Patients with "Saved" CMS-2728 Forms Applying for Medicare ESRD Benefits
2012 (as of June 14, 2012)	52
2013	238
2014	534
2015	1,127
2016 (as of May 20, 2016)	4,187

or treatment modality (Quality Insights Renal Network 4, n.d.). Furthermore, in addition to being used to register patients into a national renal registry, the initial form provides medical evidence of an end-stage renal condition for Medicare entitlement. The CMS-2728 initial form is used to help initiate renal failure patients' Medicare ESRD coverage via the SSA.

While the total number of submitted forms is substantially higher than the number of "saved" or "missing" forms, there are still a relatively large number of incomplete CMS-2728 forms in CMS' CROWNWeb system that require immediate attention. Forms that are not submitted or even those incorrectly submitted could negatively affect patients' Medicare ESRD coverage by delaying the enrollment date or, even worse, the patient may not receive coverage at all. Ensuring that all necessary CMS-2728 forms are completed and submitted to CMS and the SSA within their designated timeframes will reduce the number of patients who are waiting for their Medicare ESRD benefits to begin due to missing forms.

REASONS FORMS FALL INTO "SAVED" STATUS

When completing a CMS-2728, authorized users start the process by generating an electronic version of the form via CROWNWeb. As part of the data entry process, authorized users access the Form 2728 screen in CROWNWeb to enter patient-specific data, such as:

- Demographics
- Current medical coverage
- Primary cause of renal failure
- Comorbid conditions
- Laboratory values within 45 days prior to the most recent ESRD episode
- Treatment type
- Date that regular chronic dialysis began

During this process, users must save the CMS-2728 in CROWNWeb, and then print it so the form can be taken to the attending physician and the patient for necessary signatures. This is the means by which the form can be reviewed by the patient's attending physician and staff for accuracy prior to submission. Furthermore, a printed version of the CMS-2728 form is required for submission to SSA. CROWNWeb is used to submit data to CMS only. The SSA does not use CROWNWeb. Therefore, facility representatives must continue to follow the SSA's submission methods to help ensure that the government agency receives documents. Once the forms are signed, users must return to the CROWNWeb system to complete the submission process by indicating the date that the physician and patient signed the form. Additionally, users must mail the original signed form to the SSA if the patient is applying for Medicare ESRD coverage, and keep a copy of the completed form with each patient's records.

According to CDDS' findings, of the forms that were in a "saved" status in CROWNWeb, as of May 20, 2016, 333 were missing the doctor and patient signatures only. Another 36 forms were missing due to validation errors pertaining to field 19b, which asks for the patient's serum creatinine value; this lab result must have been obtained within 45 days prior to the first dialysis treatment or kidney transplant. In all, 748 forms remained in a "saved" status due to a combination of validation errors from field 19b and other missing elements. Furthermore, 200 CMS-2728 forms remained in a "saved" status in CROWNWeb without any missing values. These forms were completed, and even included the signature dates for both the attending physicians and patients. The only thing needed in this case is for an authorized representative to log into CROWNWeb and simply click the "submit" button. Of the 10,321 CMS-2728 forms that were in a "saved" status, approximately 2,700 were still within 45 days of when the patient began dialyzing at the unit. To ensure that all necessary forms are submitted in a timely manner, CMS recommends that the Initial CMS-2728 form be completed with 10 business days of when the patient begins to dialyze at the unit, but no later than 45 days. (See page 33 of the CROWNWeb Data Management Guidelines available via **www.mycrownwebg.org** for details.)

Table 3. CMS' 2728 Form Submission Goals to be Reached by March 2017

Goal	Baseline	Target Date
30% Fewer “Missing” CMS-2728 forms in CROWNWeb	January 31, 2016	March 31, 2017
50% Fewer “Saved” CMS-2728 forms in CROWNWeb	January 31, 2016	March 31, 2017

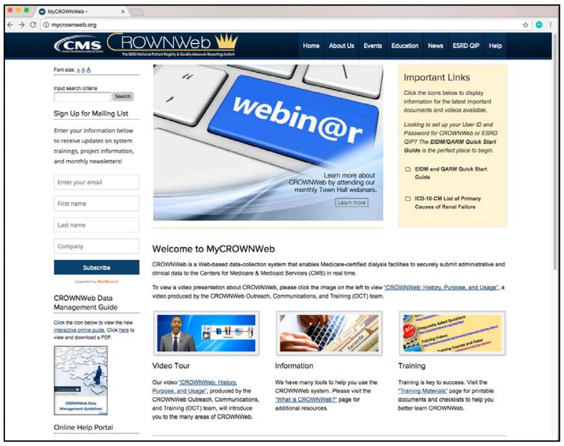
To identify incomplete forms, CROWNWeb presents users with the ability to generate a “Missing Forms Report,” as well as a chance to run a “Saved Status Report.” Both are accessible via the “Reports” screen in CROWNWeb.

CMS 2728 FORM SUBMISSION GOALS

CMS works to improve the quality of data available from CROWNWeb. CMS’s goal is to provide support to ESRD Networks and Medicare-certified dialysis facilities to reduce the number of “missing” and “saved” forms. To support these efforts, in January 2016 CMS established goals of reducing the number of “missing” CMS-2728 forms by 30%, and decreasing by 50% the number of CMS-2728 forms in a “saved” status by March 2017. Working with the kidney healthcare community, CMS reduced the number of “missing” forms from 32,400 in early 2016 to 20,104 at the end of March 2017—a 38% reduction. Additionally, after running its report in May 2016 to identify “saved” CMS-2728 forms, CMS saw a reduction from 10,321 forms in early 2016 to approximately 8,500 by the end of June 2016. This reduction continued, and 6,554 “saved” forms were reported at the end of March 2017. See **Table 3** for an overview of CMS’s 2728 form submission goals.

FOR MORE INFORMATION

For more information on CROWNWeb and the system’s features, visit the My CROWNWeb website at **http://mycrownweb.org/**, or visit the CMS CROWNWeb website at **https://www.qualitynet.org/** and click on the "ESRD" tab.



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- EIDM and QARM Quick Start Guide
- ICD-10-CM List of Primary Causes of Renal Failure

CROWNWeb Data Management Guide

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Welcome to MyCROWNWeb

CROWNWeb is a Web-based data-collection system that enables Medicare-certified dialysis facilities to securely submit administrative and clinical data to the Centers for Medicare & Medicaid Services (CMS) in real time.

To view a video presentation about CROWNWeb, please click the image on the left to view "CROWNWeb: History, Purpose, and Usage", a video produced by the CROWNWeb Outreach, Communications, and Training (OCT) team.

Video Tour

Our video "CROWNWeb: History, Purpose, and Usage", produced by the CROWNWeb Outreach, Communications, and Training (OCT) team, will introduce you to the many areas of CROWNWeb.

Information

We have many tools to help you use the CROWNWeb system. Please visit the "What is CROWNWeb?" page for additional resources.

Training

Training is key to success. Visit the "Training Materials" page for printable documents and checklists to help you better learn CROWNWeb.

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Utilizing Community Programs to Build Kidney Disease Self-Management Skills CE

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Kidney disease self-management relies on patient knowledge and self-efficacy to develop skills for day-to-day care of their chronic condition(s). The Chronic Disease Self-Management Program (CDSMP) is effective in promoting chronic disease self-management among people with a variety of health conditions, but has not been studied among people with kidney disease. In 2016, the National Kidney Foundation of Michigan (NKFM) collaborated with Metro Detroit transplant programs to offer the CDSMP for people living with kidney disease and their caregivers. The study examined the effectiveness of the CDSMP with kidney disease patients by adding two kidney disease-specific sessions. A total of 45 people participated in the pilot program. Results included improvements in patient activation and self-efficacy to manage kidney disease.

INTRODUCTION

Kidney disease is a demanding chronic condition that presents challenges with patient self-management. In the absence of self-management skills, people with kidney disease are at risk for a host of complications and decreased quality of life. Positive health outcomes for kidney patients depend heavily on the individual's ability to manage the day-to-day tasks required to live well with the disease. Those affected by kidney disease must take an active role in their care, gain information, and build self-management skills to achieve optimal health outcomes. Self-management skills for those with kidney disease include communicating effectively, developing an active partnership with the care team, taking part in self-care activities (including making dietary changes and increasing physical activity), and adherence to medication and treatment regimens (Curtin et al., 2008). According to the Chronic Care Model, the health system must partner with the community to foster active, informed patients to reach optimal health outcomes for those living with a chronic condition (Barr et al., 2003). However, few studies have focused on the development of kidney disease-focused, community-based programs to support self-management skills. Self-management is associated with improved health, including lower self-reported pain and fatigue, improved healthcare utilization and physician communication, decreased emergency room visits, and lower hospitalization rates (Ory et al., 2013). It is essential for providers to refer individuals to community-based self-management programs to encourage self-management and improve health outcomes.

In this study, we examined the effectiveness of the Chronic Disease Self-Management Program (CDSMP) with the addition of two modules pertaining to kidney disease self-management. Implemented worldwide, the CDSMP, a six-week, community-based self-management program, helps individuals manage chronic conditions through improving self-efficacy and skill development. The CDSMP workshops meet for one session per week; each session is 2.5 hours. CDSMP participants learn self-management tasks, such as action planning, problem solving, communicating with support system and providers, healthy eating, physical activity, relaxation techniques, and medication management. CDSMP workshops are open to anyone with any chronic condition and led by two trained leaders, at least one of whom has a chronic condition. Leaders are trained to uphold program fidelity by following the CDSMP curriculum closely and leading group discussion and brainstorming in a manner which enhances participant development. For this study, leader training was provided by the National Kidney Foundation of Michigan (NKFM).

A 2013 meta-analysis of 23 studies regarding the effectiveness of CDSMP in English-speaking countries found the CDSMP provided health benefits for participants through improving communication with physicians, cognitive symptom management, and energy/fatigue management, as well as increasing aerobic activity (Brady, Murphy, O'Colmain, & Beauchesne, 2013). This program is a beneficial component to comprehensive chronic disease management, and is accessible to many communities, as the program is widely implemented. Information about the program's availability can be found on the Evidence-Based Leadership Council website (**www.eblcprograms.org**).

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The CDSMP has been recommended for those living with kidney disease (Washington, Hilliard, & McGill, 2013). Based on Lorig's findings that a program specifically designed for individuals with arthritis was more effective than the generic CDSMP, we hypothesized that the addition of kidney-specific content to the CDSMP curriculum may result in improved symptom management and improved self-efficacy for participants living with kidney disease (Lorig, Ritter, & Plant, 2005). Our initial experience of offering the six-week CDSMP to a cohort comprised exclusively of individuals with kidney disease showed the participants bonded more quickly than those in a cohort of individuals with varied conditions. The NKFM created two sessions focusing on kidney disease self-management offered with the original six-week CDSMP. A pilot program began in 2012 in partnership with the University of Michigan Transplant Center (UMTC). The eight-week workshops were led by two trained leaders, at least one of whom had kidney disease.

METHOD

The research focused on determining the effectiveness of a kidney-disease self-management program for individuals with kidney disease in southeast Michigan. The study examined levels of patient activation and self-efficacy. All study procedures and protocols were approved by the Argis Institutional Review Board.

Study Setting and Sample

The study was conducted in 2016 in four Michigan counties, Washtenaw, Wayne, Oakland, and Genesee. NKFM partnered with local transplant centers to reach people with kidney disease and their caregivers; these centers included Beaumont Hospital Transplant Program, the University of Michigan Transplant Center, and St. John Hospital Transplant Program. Participants were recruited through transplant center mailings; flyers distributed at dialysis centers; promotion through both the Michigan Council of Nephrology Social Work and Council on Renal Nutrition listservs and their quarterly meetings; and utilized testimonials from previous workshop participants to talk with their nephrologists and fellow patients.

Data and Measures

We reached 45 people living with kidney disease and their caregivers for the Kidney CDSMP pilot project. Four scales were used to assess kidney disease self-management and patient activation at baseline and follow-up: Patient Activation Measure (PAM) (Hibbard, Mahoney, Stockard, & Tusler, 2005); the Chronic Kidney Disease Self-Efficacy (CKD-SE) instrument (Lin et al., 2012); the Self-Efficacy for Managing Chronic Disease (SEMCD) scale (Lorig et al., 2000); and the Communication with Physicians Scale (CPS) (Lorig, 1996). Participants completed demographic questions and a baseline survey at the first workshop session. At the last session, participants completed a follow-up survey identical to the baseline survey.

Demographics

Self-reported demographic variables (age, gender, and race) were captured on a separate form completed at the start of the workshop. An additional demographic question was used at baseline and follow-up to determine each participant's kidney disease status. They were asked if they were currently on dialysis, had a functioning transplant, had CKD and were not yet on dialysis, or were they a caregiver. Participants were also asked the self-rated health question, "In general, would you say your health is…" (Idler & Angel, 1990).

Patient Activation Measure

The 13-item version of the Patient Activation Measure (PAM) was used to assess workshop participants' self-reported knowledge, skills, and confidence for self-management of their chronic disease(s) (Hibbard et al., 2005). Patient activation level is considered a broader underlying construct than prior related concepts, such as self-efficacy, locus of control, and readiness for change (transtheoretical model) (Greene & Hibbard, 2012). Sample items include "When all is said and done, I am the person responsible for taking care of my health"; "I know what each of my medications do"; and "I am confident that I can tell when I need to go to the doctor and when I can take care of a health problem myself."

There are 4 levels of patient activation, with higher scores indicating higher levels of activation. Patients scoring in Level 1 (score 0–47) are disengaged from care, low in confidence and rely on the healthcare team to manage their disease. In Level 2 (47.1–55.1), patients are starting to become aware of the importance of self-management and are beginning to set health-related goals. In Level 3 (score 55.2–67.0), patients are starting to take action towards disease self-management and understand the importance of their own roles in managing their disease(s). To manage a chronic disease well, patients will ideally reach Level 4 (score 67.1–100), at which patients are routinely self-managing their condition and can continue to do so during times of adversity or stress.

CKD Self-efficacy Instrument

An adaptation of the 25-item CKD-SE (CKD Self-efficacy) instrument was used to measure patients' perceived self-efficacy related to kidney disease management (Lin et al., 2012). We included the 6-item "problem solving" subscale and the 4-item "seeking social support" subscale. Sample items included, "I can understand the meaning of relevant laboratory data," and "I can discuss my questions and worries about CKD with my friends and family."

Self-Efficacy for Managing Chronic Disease

The 6-item scale developed for the Chronic Disease Self-Management Program was used to measure symptom control, role function, and emotional functioning (Lorig, Sobel, Ritter, Laurent, & Hobbs, 2000). Sample items on this scale include, "How confident are you that you can keep the fatigue caused by your disease from interfering with the

Table 1. **Participant demographics (*n* = 45)**

	N(%)
Age Group	
Below 50	4 (8.89)
50-59	14 (31.11)
60-69	15 (33.33)
70-79	8 (17.78)
Above 80	2 (4.44)
Missing	2 (4.44)
Gender (Female)	28 (62)
Race	
American Indian/Alaska Native	2 (4.44)
Asian	0 (0)
Black/African American	22 (48.89)
Native Hawaiian/Pacific Islander	0 (0)
White	19 (42.22)
Multi-racial	1 (2.22)
Missing	2 (4.44)
Kidney disease status	
On dialysis	9 (20.00)
Has a functioning transplant	6 (13.33)
CKD (no dialysis)	16 (35.56)
Caregiver	11 (24.44)
No response	3 (6.67)

things you want to do?" and "How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?"

Medical Care Scale

The 3-item Communication Scale was incorporated to measure patient participation in shared decision-making during healthcare visits (Lorig, 1996). Participants were asked how often they performed each item during visits with their doctors. Sample items included "prepare a list of questions for your doctor" and "discuss any personal problems that may be related to your illness."

RESULTS

A total of 50 patients and caregivers enrolled in five Kidney CDSMP workshops, held between March and December 2016. Of these, 45 completed the baseline survey, and 26 (58%) completed the follow-up survey; their surveys were analyzed and are presented here. There is missing post-test data from the first workshop, as the workshop leaders did not administer the post-test survey related to kidney disease with the group. The workshop completion rate was 68%; completion was defined as attending at least 4 of 6 CDSMP sessions and 1 of 2 kidney disease sessions. The average attendance was 5 out of 8 sessions among the 50 participants enrolled.

Sample Characteristics

Table 1 provides data on workshop participant demographics. More than half (62%) of participants identified as female. The average age of participants was 62 years; 31.1% were between ages 50–59 and 33% were ages 60–69, while 18% were ages 70–79. About half (49%) of participants identified as Black/African American. Regarding modality; 36% of participants were early stage kidney disease not needing dialysis; 13% had a functioning kidney transplant, 20% were on dialysis; and 24% of participants were caregivers of individuals living with kidney disease.

Patient Activation Measure (PAM) Findings

The mean PAM score for the sample was 70.15 (SD = 18.51) at baseline and rose to 71.15 (SD = 22.79) at follow up. **Table 2** shows the descriptive statistics of the PAM scores, stratified by kidney disease status. People with CKD not yet on dialysis at baseline experienced decreased PAM scores and decreased patient activation level. After completing the workshop, 46% of participants remained at the same patient activation level; 27% increased one patient activation level; and 23% decreased by one patient activation level.

CKD Self-efficacy (CKD-SE) Findings

The mean score for the "problem-solving" subscale of the CKD-SE instrument was 7 (SD = 3.35) at baseline and 8 (SD = 2.48) at follow-up. The mean score for the "seeking social support" subscale of the CKD-SE instrument also increased from 7 (SD = 3.40) at baseline to 8 (SD = 2.18) post-workshop. **Table 3** shows the descriptive statistics of the CKD-SE measure with pre-/post-mean scores for each survey question.

Self-efficacy for Managing Chronic Disease (SEMCD)

The mean score was 7 out of 10 at baseline and follow-up **(Table 3)**. Mean scores improved by 1 point for 5 of the 6 items on the Self-Efficacy for Managing Chronic Disease scale.

Medical Care Scale

The mean score on the Communication with Physicians scale was 3 at both baseline and follow-up **(Table 3)**. There were no changes in mean score on individual items. For the self-rated health question, there was a slight decrease in mean scores from baseline (3.00 SD = 1.41) to follow-up (3.00 SD = 1.43). Results were not statistically significant.

DISCUSSION

The results indicate that the Kidney CDSMP is beneficial to people living with kidney disease and their caregivers. However, more research is needed to determine the extent

Table 2. Patient Activation Measure (PAM) findings

Kidney disease status (at baseline)	Pre-test	Post-test	Difference
	Mean Score (SD)	Mean Score (SD)	(***P*** value; 95% CI)
On dialysis [a]	74.49 (23.05)	72.28 (18.81)	-2.21 (*p* = 0.87; -26.85 – 31.27)
Functioning transplant [b]	74.40 (20.78)	85.83 (13.55)	11.43 (*p* = 0.36; -38.83 – 15.97)
CKD (no dialysis) [c]	64.19 (15.98)	56.00 (27.29)	-8.19 (*p* = 0.36; -10.02 – 26.40)
Caregiver [d]	73.05 (19.28)	73.33 (19.02)	0.28 (*p* = 0.97; -19.94 – 19.38)
Missing [e]	71.13 (11.90)	85.40 (17.85)	14.27 (*p* = 0.31; -48.66 – 20.12)
TOTAL [f]	70.15 (18.51)	71.15 (22.79)	1.00 (*p* = 0.84; -10.91 – 8.91)
Patient Activation Level (pre- vs. post-)	*N*(%)		
Remained at same level	12 (46.15)		
Increases one level	7 (26.92)		
Decreased one level	6 (23.08)		
No response	1 (3.85)		
TOTAL	26		

a Pre: *n* = 9, Post: *n* = 4; **b** Pre: *n* = 6, Post: *n* = 4; **c** Pre: *n* = 16, Post: *n* = 8; **d** Pre: *n* = 11, Post: *n* = 7; **e** Pre: *n* = 3, Post: *n* = 3; **f** Pre: *n* = 45, Post: *n* = 26

which the program affects kidney disease self-management skills. Although not statistically significant, due to the small sample size, the participants did see an increase in average PAM score after completing the workshop. Increased patient activation is associated with improved patient self-management (Hibbard, Mahoney, Stock, & Tusler, 2007), and is associated with a broad range of health-related outcomes (Greene & Hibbard, 2012). Improving patient activation levels among this population may also result in healthcare cost savings (Greene, Hibbard, Sacks, Overton, & Parrotta, 2015). Participants also experienced an increase in mean scores related to "problem solving" and "seeking social support," as assessed by the CKD-SE measure. This suggests the Kidney CDSMP is effective in improving aspects of patient self-management essential to living well with kidney disease.

Baseline patient activation scores collected for this pilot project were higher compared to those reported in a study published in 2016 by Michelle Johnson and colleagues (Johnson et al., 2016). Johnson's team examined group differences in patient activation levels among each stage of kidney disease. Patients with stage 3 kidney disease were found to be the most activated, and those in stage 5 CKD least activated. The authors theorized that decreased activation for people with stage 5 CKD may suggest that those starting dialysis may feel less confident in self-management as the disease becomes more complex to manage and prevention of complications more challenging (Johnson et al., 2016). However, we did not find participants with early stage CKD to have higher patient activation scores; these participants had slightly lower PAM scores. The mean PAM scores in Johnson's study was 58.04 (SD = 13.46) for those with end-stage renal disease (ESRD), while the mean PAM scores collected for our pilot were approximately 74.4 for both participants on dialysis (SD = 23.05) and living with a kidney transplant (SD = 20.78). This suggests that patients with higher patient activation are more likely to attend a workshop compared to the overall community living with kidney disease.

The Kidney CDSMP was successful in engaging participants living with kidney disease as participants bonded over sharing similar disease experiences. Further research is needed to determine the extent of benefits Kidney CDSMP provides to those with kidney disease compared to how the generic program may benefit the same population. Both programs have a positive impact, and in some disease populations, the disease-specific programs should be considered first when resources allow (Lorig et al., 2005).

The study has several limitations. The small sample size did not yield conclusive results on the impact of the program. We were not able to collect clinical outcomes to assess the impact of the measures. Our team will continue to offer the Kidney CDSMP and evaluate its effectiveness. One of the most significant limitations of this pilot project was missing post-test data, as the leaders of an early 2016 workshop did

Table 3. **Chronic Kidney Disease Self-Efficacy and Medical Care Scales**

	Pre- (*N* = 45) Mean Score (SD)	**Post- (*N* = 26) Mean Score (SD)**
CKD-SE Instrument: Problem Solving		
1. Understand meaning of relevant lab data	7 (3.18)	8 (2.53)
2. Seek out information that explains CKD-related signs and symptoms	8 (2.86)	8 (2.41)
3. Find information about kidney disease from a variety of sources	8 (3.07)	9 (1.77)
4. Actively understand the risk factors associated with CKD	7 (3.32)	8 (2.30)
5. Find resources needed to better control my CKD	6 (3.91)	8 (2.90)
6. Actively seek out precautions to prevent CKD from worsening	7 (3.78)	8 (2.97)
TOTAL	**7 (3.35)**	**8 (2.48)**
CKD-SE Instrument: Seeking Social Support		
7. Find help when I am feeling stressed	8 (2.97)	9 (1.37)
8. Discuss questions/worries about CKD with my family and/or friends	7 (3.63)	8 (2.90)
9. Ask family or friends for help when I am feeling helpless or frustrated	8 (3.22)	8 (1.78)
10. Actively discuss treatment plan with family/friends to gain support	7 (3.77)	8 (2.67)
TOTAL	**7 (3.40)**	**8 (2.18)**
Self-Efficacy for Managing Chronic Disease		
11. Keep fatigue caused by disease from interfering with activities	6 (3.46)	7 (3.28)
12. Keep physical discomfort or pain of disease from interfering with activities	6 (3.46)	7 (3.31)
13. Keep emotional distress caused by disease from interfering with activities	6 (3.40)	7 (3.44)
14. Keep other symptoms or health problems from interfering with activities	7 (2.73)	8 (2.29)
15. Can do different tasks/activities needed to manage health to reduce doctor visits.	7 (3.08)	8 (2.26)
16. Can do things other than taking medication to reduce how illness affects everyday life	7 (3.11)	7 (2.80)
TOTAL	**7 (3.21)**	**7 (2.90)**
Medical Care Scale		
17. Prepare list of questions for doctor	3 (1.52)	3 (1.68)
18. Ask questions about things I want to know or don't understand about my treatment	4 (1.25)	4 (1.08)
19. Discuss personal problems related to illness	3 (1.44)	3 (1.54)
TOTAL	**3 (1.41)**	**3 (1.43)**

not administer all follow-up surveys. In order to address this issue, the project team improved the Kidney CDSMP leader training to better explain the evaluation components. We also changed how we organized the program file box, which sorts all program materials for leaders, making it clearer when to administer each evaluation component. These changes helped to avoid missing further evaluation data. We also did not capture the treatment modality for patients who reported being on dialysis. Through leader feedback, we know that the patients were on various forms of dialysis, including in-center hemodialysis, home hemodialysis, and peritoneal dialysis. We will capture this data in the future by changing the survey tool. In this study, caregivers completed the same survey tool as the kidney patients. In the future, we will include a separate tool to assess caregiver burden. We also found that our program tends to attract people with high patient activation scores at baseline. We will continue to experiment with different forms of participant recruitment to reach people with lower patient activation scores, including utilizing more face-to-face recruitment instead of passive recruitment strategies (mailings and posting flyers).

Community-based programs serve as a resource for people living with kidney disease. Providers should refer patients to evidence-based programs, which can help them build kidney-disease self-management skills. The Kidney CDSMP shows promise in increasing patient activation and self-efficacy among people living with kidney disease and their caregivers. Further research is needed on the Kidney CDSMP to determine the extent of its impact on those managing kidney disease.

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