

TCRP Report 203
**Dialysis Transportation:
The Intersection of Transportation and Healthcare**

Supplemental Report

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Transit Cooperative Research Program
Transportation Research Board
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Chapter 1

Background and Context for the Research Project

INTRODUCTION

This Report documents the findings and research conducted in the first phase of TCRP Report 203, originally known as TCRP Project B-45, *Transportation to Dialysis Facilities – Health/Transportation Intersection*.

The report contains the following:

- Chapter 1 – Background and Context for the Research Project
- Chapter 2 – The Research Questions
- Chapter 3 – The Money
- Chapter 4 – The Community Data Tool
- Chapter 5 – Transit Agency Perspective
- Chapter 6 – Dialysis Facility Perspective
- Chapter 7 – Dialysis Patient Perspective
- Chapter 8 – Other Perspectives
- Appendix A – Literature Review

BACKGROUND

Transportation to dialysis facilities has become a significant issue for transit agencies and other providers of demand response and specialized transportation across the country.

Increasing numbers of individuals with the final stage of kidney disease are turning to their public transit agencies and other publicly-subsidized community transportation providers for trips to dialysis treatment. While some individuals on dialysis receive treatment at home, the vast majority are treated at dialysis facilities – free standing or in hospitals – requiring transportation three days each week to and from the facility.

Dialysis Transportation Demand Increasing

Demand for dialysis transportation is increasing with more than 678,000 people in the United States with end-stage kidney disease and estimates of almost 121,000 newly reported

cases each year¹. People on dialysis are also living longer, as dialysis care has improved over the decades, impacting demand for dialysis-related transportation.

Trips for dialysis are life-sustaining. Once an individual has end-stage kidney disease – also referred to as end-stage renal disease (ESRD) – the kidneys have stopped functioning. Unless the individual has a kidney transplant, that individual requires dialysis, which performs the function of the kidneys, filtering the blood and removing waste, salt and extra water and helping to control blood pressure.

While kidney transplantation is considered a preferred choice for many with ESRD, there is a shortage of organs available for donation. Thus, more than 70% of those with ESRD are treated with dialysis. As noted below, as of the end of 2014, approximately 63% of all ESRD cases were receiving hemodialysis therapy, 7% were being treated with peritoneal dialysis, and 30% had a functioning kidney transplant.

Dialysis Transportation Is Challenging for Public Transit Agencies and Other Specialized Transportation Providers

Shared Ride Service and Scheduling Practices

Transportation for those receiving treatment at dialysis facilities can be difficult for public transit agencies and other specialized transportation providers for a number of reasons, particularly because of the shared-ride nature of the service and scheduling practices. Providers typically schedule trips at least one day in advance, sometimes longer, allowing time to fit similar trips together on the same vehicle to achieve shared riding. But the advance scheduling makes it difficult for same-day, real time changes that often become necessary for dialysis trips.

Scheduling practices also commonly use a “window of time” for pick-ups rather than an exact time, a practice that facilitates shared riding. But this means that patients may not arrive for their treatment at the exact starting time of the dialysis appointment. The result is the patient may start treatment late and, if then the patient asks to end treatment at the original time so as to be ready for the return trip, the patient is not completely dialyzed.

Scheduling practices impact return trips from dialysis as well. Once a provider arrives to pick up a patient for the return trip home, the vehicle is not able to wait more than a defined five or ten minutes. But patients are often not ready to leave at the scheduled time due to medical complications after treatment or because they started treatment late.

After the defined waiting time, the provider will typically have to leave to maintain the vehicle’s schedule, transporting the remaining passengers on the vehicle. The transportation

¹ Annual Data Report, United States Renal Data System, Chapter 1, 2016.

provider must then schedule that vehicle to go back later or find capacity in another vehicle to serve the patient left behind. This in turn means that individual – severely fatigued and weak after treatment – must endure a lengthy wait for the trip home.

Location Mismatch

Transportation for dialysis can be impacted by the locational mismatch between where patients live and where they receive dialysis. Patients may receive treatment at a dialysis facility distant from their home location. In rural areas, long trip distances may be unavoidable with the lack of facility choices in rural settings. The mismatch combined with the shared ride nature of the transportation service results in indirect routes and often with long trip times. Research has shown that longer travel times create a burden for many dialysis patients, impacting their health-related quality of life.

Transportation Providers' Operational Characteristics and Geography Impact Health of Dialysis Patients

Thus, the operational characteristics of transit agencies and other specialized transportation providers, compounded by locational mismatch affecting patients' travel to dialysis facilities, can have adverse effects on the health of the individuals on dialysis.

Importantly, though, the trips for dialysis are critical and life-sustaining for those with ESRD. But the growth in these trips has become an operational and funding challenge for transit agencies and other publicly subsidized transportation providers. It has been said that the services of these providers are not designed to serve what are essentially medical trips. A shorthand version of this challenge is captured by terminology – transit agencies and other specialized transportation providers use the term *passenger* or *rider* or sometimes *customer* but a person on dialysis is a *patient*.

TERMS AND DEFINITIONS

Understanding Terms Relevant for the Research Project

Terms and definitions that provide a background and context for the research project on dialysis transportation are discussed below. Definitions and data have been obtained from the National Kidney Foundation (www.kidneyfund.org), Johns Hopkins University Medicine (www.hopkinsmedicine.org), the American Kidney Fund (<http://www.kidneyfund.org>) and the United States Renal Data System (USRDS at www.usrds.org/adr.aspx).

Chronic Kidney Disease (CKD): This disease includes all degrees of decreased kidney function, from damaged-at risk through mild, moderate and severe chronic kidney failure. There are five stages of chronic kidney disease, with Stage 5 being kidney failure. In the US, an estimated 14.8% of adults have CKD. (USRDS)

End-Stage Renal Disease (ESRD): This is the last stage of chronic kidney disease when the kidneys fail. With kidney failure, it means the kidneys no longer work well enough for a person to survive without dialysis or a kidney transplant.

Causes of ESRD: Diabetes is the most common, followed by high blood pressure. Other problems that can cause kidney failure include, among others, autoimmune diseases (e.g., lupus) and genetic diseases (e.g., polycystic kidney disease).

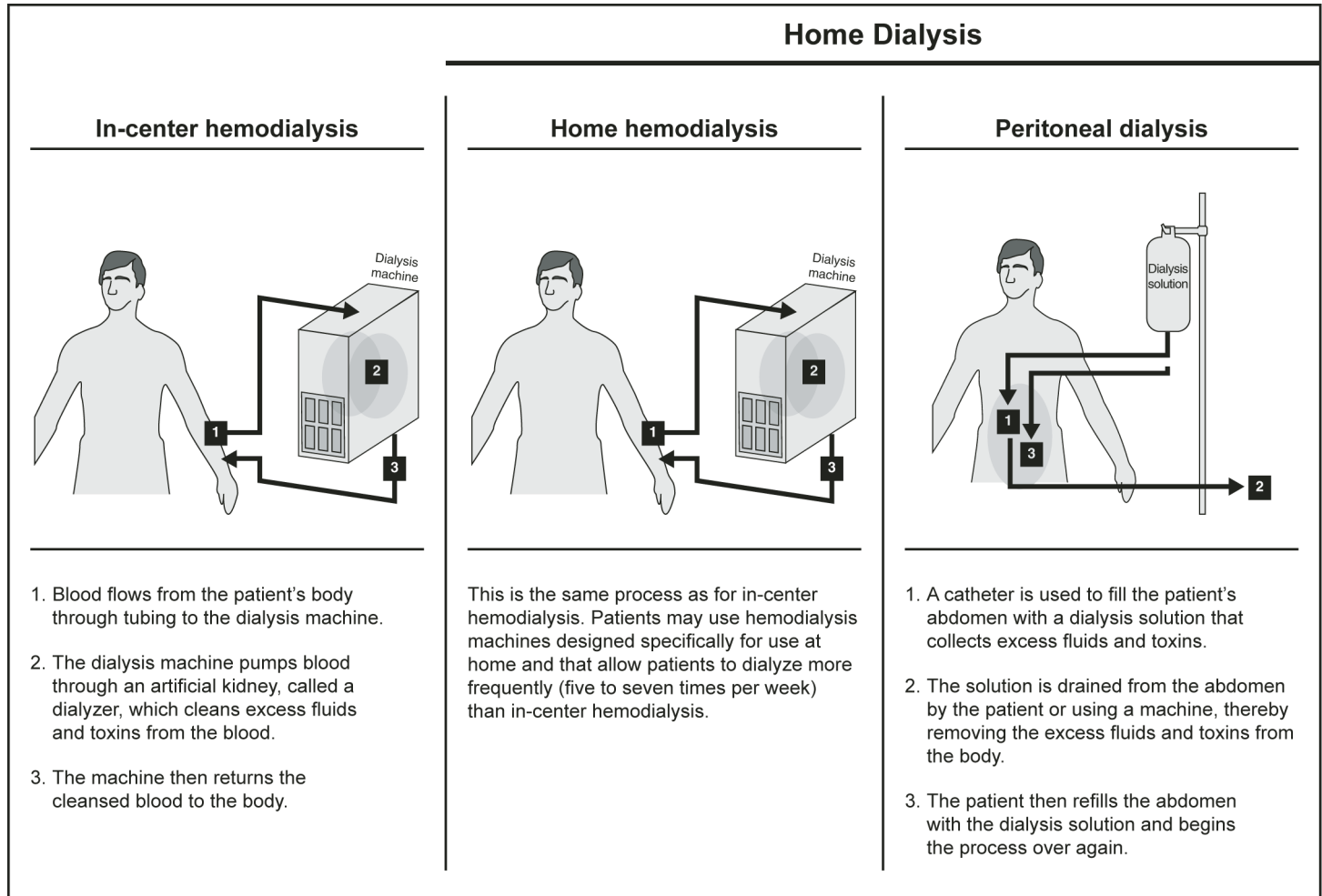
Kidney failure may also occur suddenly (acute kidney failure) which may be caused by heart attack and illegal drug use and drug abuse. Sudden failure may not always be permanent.

ESRD Prevalence vs. Incidence: “Prevalence” refers to the number of existing ESRD cases at a point in time, indicating how widespread the disease is, whereas “incidence” refers to new cases of ESRD during a given time period. Incidence may be reported as a count or a rate. The extent to which there are favorable things done to improve the survival rate of those with ESRD and the incidence rate stays the same, the prevalence of ESRD will increase. However, if medical efforts reduce the incidence rate of ESRD without changing the survival rate of ESRD patients, the prevalence of ESRD will decrease.

Treatment for ESRD – Dialysis or Kidney Transplant

Dialysis is a process that filters the patient’s blood once the kidneys no longer can, removing waste, salt and extra water to prevent them from building up in the body, keeping a safe level of certain chemicals in the blood and helping to control blood pressure. There are two types of dialysis – hemodialysis (HD) and peritoneal dialysis (PD). Exhibit I-1 provides a graphic of the two types of dialysis.

Exhibit 1-1: Process for In-center Hemodialysis and Home Dialysis



Source: GAO. | GAO-16-125

Excerpt from: *End-Stage Renal Disease Medicare Payment Refinements Could Promote Increased Use of Home Dialysis*
 Report to Subcommittee on Health, Committee on Ways and Means, House of Representatives, by the GAO, October 2015.

- Hemodialysis:** Blood is pumped out of the body to an artificial kidney machine (hemodialyzer), and returned to the body by tubes that connect the person to the machine. The machine is used to remove waste and extra chemicals and fluid from the blood. To get the blood into the artificial kidney, an access (entrance) into the blood vessels is needed, which is done by minor surgery to the arm or leg. Sometimes, an access is made by joining an artery to a vein under the skin to make a bigger blood vessel called a fistula.
- Peritoneal dialysis:** In peritoneal dialysis, a catheter is placed in the patient's abdomen through surgery. A sterile dialysis solution, called dialysate, is put into the abdomen via the catheter and the solution collects excess fluids and toxins. Once the

filtering process is complete, the excess fluids and toxins are taken out of the body when the patient drains the solution. This is done in cycles – the draining and then refilling the abdomen with the solution. Most patients use a machine that performs the exchanges during the night while asleep. Other patients do manual exchanges during the day. Proper training is needed for peritoneal dialysis; a trained helper may also be used. Peritoneal dialysis is typically done at patients' homes.

Kidney Transplant: Involves an operation in which a person with kidney failure receives a new kidney. Only one healthy kidney is needed to perform the kidney function. The new kidney may come from a living or deceased donor. The surgery typically lasts 3 to 5 hours. If the patient has a compatible and healthy living donor, the transplant may occur within a few weeks or months of diagnosis. If no living-related donor is available, it may take months or years on the waiting list before a suitable donor organ is available.

Kidney transplantation is the choice for most individuals with ESRD and is associated with the highest quality of life and survival. Nationally, the percentage of patients on a kidney transplant waiting list remained fairly consistent between 2011 and 2014, with 24% of patients younger than age 70 on a waiting list. (USRDS)

Dialysis: Dialysis is the more common treatment for ESRD. While transplantation is considered the preferred treatment choice for many patients, there is a shortage of organs available for donation. Moreover, some patients may not be candidates for a kidney transplant because of older age and severe heart disease, among other reasons.

Dialysis Treatment Locations: Dialysis is performed in:

- A dialysis facility (may be referred to as a dialysis center, unit or clinic)
- At a patient's home
- A hospital-based dialysis unit
- Long-term care facility

Dialysis facilities and hospital-based dialysis units provide hemodialysis and peritoneal dialysis. For in-facility or hospital dialysis, patients typically receive hemodialysis for 3 to 4 hours three times per week.

At-home dialysis can be hemodialysis or peritoneal dialysis, although home hemodialysis is less common. For at-home hemodialysis, the process is the same as in a dialysis center but the patient performs the treatments and may do so more frequently and at night. Home hemodialysis is used by less than 2% of all ESRD patients in 2014. (USRDS)

Home dialysis has been associated with greater patient independence and improved quality of life. Younger, more educated patients and those with fewer concurrent conditions and greater access to care are more likely to use home dialysis.

TREATMENT TRENDS FOR END STAGE RENAL DISEASE

ESRD in the United States Population

According to the most recent data provided, there were 120,688 incident cases (newly reported cases) of ESRD in 2014. While the number of ESRD incident cases plateaued in 2010, the number of ESRD prevalent cases continued to rise by about 21,000 cases per year. Since 2011, the number of incident cases has been rising.

At the end of 2014, there were 678,383 prevalent ESRD cases (the number of cases at that point in time), representing an increase of 3.5% over 2013 and an increase of 74% since 2000. The prevalence of ESRD increased steadily from 1996 through 2014. Because prevalence reflects both the incidence and course of the disease, the ESRD prevalence trends indicate the increasing number of incident cases and also longer survival among ESRD patients.

The implication of the incidence trend is that the burden of kidney failure in the United States — with respect to the expected impact on health-care utilization and costs — continues to increase.

Trends in Treatment Modalities (USRDS)

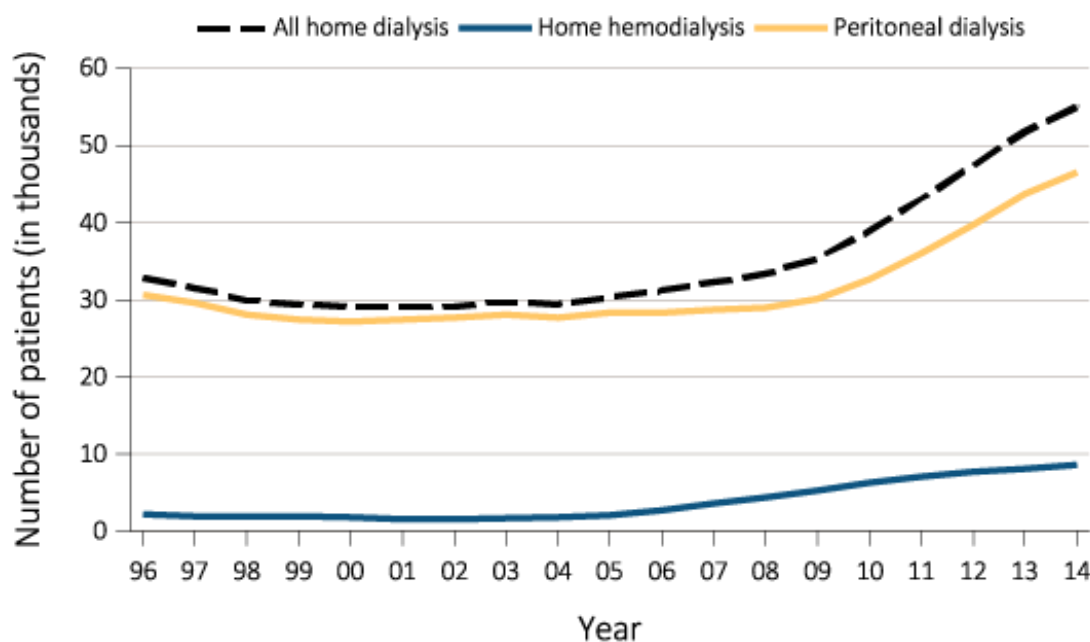
At the end of 2014, 63% of all prevalent ESRD cases were receiving hemodialysis, 7% were being treated with peritoneal dialysis, and 30% had a kidney transplant. Among hemodialysis cases, 88.0% used in-center hemodialysis, and 1.8% used home hemodialysis.

In 2014, 87.9% of all incident cases began treatment with hemodialysis, 9.3% started with peritoneal dialysis, and 2.6% received a pre-emptive kidney transplant.

Home Dialysis

The use of home dialysis (peritoneal dialysis or home hemodialysis) among prevalent ESRD cases has increased in recent years; see Exhibit 1-2 (USRDS Figure 1.19), which is similar to the pattern for incident dialysis cases. Home dialysis accounted for 11.6% of all prevalent dialysis patients in 2014, up from a low of 8.7% in 2008.

Exhibit 1-2: Trends in Use of Home Dialysis



Excerpt: USRDS, ANNUAL REPORT 2016, Chapter 1: Incidence, Prevalence, Patient Characteristics, And Treatment Modalities, FIGURE 1.19 *TRENDS IN NUMBER OF PREVALENT ESRD CASES (IN THOUSANDS) USING HOME DIALYSIS, BY TYPE OF THERAPY, IN THE UNITED STATES, 1996-2014*

Among home dialysis cases, the proportion using hemodialysis was higher in 2014 (15.6%) than in 2000 (6.2%). Despite the large relative rise in home hemodialysis, its overall use among incident ESRD patients is low, as only 3.4% of home dialysis patients were treated with hemodialysis in 2014. Peritoneal dialysis remains the dominant form of home dialysis. Home hemodialysis represents fewer than 2% of all ESRD patients in 2014.

Home dialysis therapies have been associated with greater patient independence and improved quality of life. Younger, more educated patients and those with fewer comorbid conditions and greater access to care tend to adopt these treatments more frequently.

Dialysis Providers

The two largest providers of dialysis, Fresenius and DaVita, operate almost two-thirds of the dialysis facilities in the US (6,757 units). Fresenius is a Germany-based company and DaVita is based in Denver. In 2014, these two providers collectively treated 69% of ESRD patients in the US – 460,675 patients. (USRDS)

Other providers serve smaller shares of dialysis patients, as shown in Table 1-1.

Table 1-1: Dialysis Providers, Calculated at End of 2014 (USRDS)

Provider	Patients Treated	Percent	Dialysis Units	Percent
Fresenius and DaVita	317,587	69%	4,362	65%
Non-Profit Clinics	14,287	3%	230	3%
Independent Providers	55,768	12%	814	12%
Hospital-Based Providers	18,350	4%	611	9%
Other (e.g., small for-profit dialysis providers)	54,683	12%	740	11%

International Trends in ESRD Treatment

The USRDS provides data on ESRD treatment in more than 30 countries. In 2014, there were more than 2.2 M patients being treated for ESRD in the reporting countries, with the highest number in the U.S.

The rate of ESRD incidence has been level or decreasing in many countries in recent years, but ESRD prevalence has increased in the 32 countries that provided data. From 2006 to 2013, the prevalence of ESRD steadily increased in all countries that provided data for 2013.

According to the data, Taiwan, the Jalisco region of Mexico and the U.S. report the highest incidence of ESRD, as has been the case for the past decade. The greatest proportionate increases in the incidence of treated ESRD from 2002 to 2014 were reported for Thailand, Bangladesh, Russia, the Philippines, Malaysia, the Republic of Korea, and the Jalisco region of Mexico.

Incidence rates of treated ESRD declined from 3 to 14% in Austria, Denmark, Iceland, Finland, Sweden and Scotland.

Treated ESRD prevalence was highest in the Asian countries of Taiwan, Japan, Singapore, and the Republic of Korea, as well as in the U.S., Portugal, and Jalisco region of Mexico.

Treatment

Use of the different treatments varied across the countries. Dialysis is the main treatment in the majority of the countries. In nearly 75% of reporting countries, at least 80% of dialysis patients were receiving in-center HD in 2014.

The highest utilization of peritoneal dialysis is found in Hong Kong (72%), the Jalisco region of Mexico (45%), Iceland (34%), New Zealand (32%), Colombia (30%), and Thailand (25%).

Home HD therapy was provided to 18.4% and 9.3% of dialysis patients, respectively, in New Zealand and Australia in 2013. Home HD was also used by 3.0 to 5.9% of dialysis patients in Canada, Denmark, Finland, the Netherlands, Sweden, and the United Kingdom. However, in

all other countries, home HD was either not provided, or used by fewer than three percent of dialysis patients.

In 2014, the percent of ESRD patients who were living with a kidney transplant ranges from less than 10% in some Asian and eastern European countries to 50-75% in the Nordic countries (Denmark, Finland, Iceland, Norway, and Sweden), Estonia, the Netherlands, the UK, Spain, Austria and Qatar.

The USRDS Annual Report provided the following comment: “A striking observation is that the countries with the highest proportion of kidney transplants among ESRD patients also tend to have lower treated ESRD incidence rates.” (USRDS Annual Report 2016, Vol. 2, International Comparisons at https://www.usrds.org/2016/view/v2_13.aspx).

IMPLICATIONS FOR TRANSPORTATION

The need for dialysis-related transportation depends on where a patient with ESRD is treated. Those patients receiving dialysis treatment at dialysis centers or clinics have the greatest need for transportation, typically requiring three round trips each week, to and from the dialysis facility, for a total of six one-way trips per week. Those who are treated at home or when in a hospital or long term care facility have less need for dialysis related transportation; see Table 1-2.

Table 1-2: Transportation Implications by Dialysis Treatment Modality

Dialysis Location and Treatment	Transportation Needs		Comments
	One-Way Trips Per Month	Annualized One-Way Trips	
Dialysis Facility - Hemodialysis	24: Assumes 6 trips/week and 52 weeks/year	312	Large majority of ESRD patients – approx. 90% - on dialysis go to dialysis facilities for treatment.
Patient's Home – Peritoneal Dialysis or Hemodialysis	During training period – 40: Assumes 2 trips each weekday for 4 weeks of training. After training period - 4-6 trips each month for periodic appointments at dialysis facility or with nephrologist.	84-112	Approx. 10% of ESRD patients have dialysis treatment at their homes.
Patient in Hospital or Long Term Care Facility	n/a	n/a	Assuming the patient is treated at the hospital or at the care facility, there are no ongoing transportation needs for dialysis.

Transportation: the Link to Healthcare and Dialysis Treatment

Transportation for dialysis can be viewed within the broader context of healthcare in the U.S. Recent years have witnessed an increasing recognition of the important role that transportation serves to provide access to healthcare. (This is discussed in more detail in Chapter 8.)

To this point are these introductory remarks at a workshop on the **Intersection of Healthcare and Transportation** sponsored by the National Academies of Sciences in June 2016 that were given by the Executive Director of the Transportation Research Board:

Transportation does not exist to serve itself. Transportation really exists so that we can [try] to achieve other more important things in life and in society. Things like improving the economy, things like improving quality of life. And I think more and more we are starting to recognize that transportation has a role in terms of supporting public health as well.²

At a basic level, transportation can be seen as a necessary step for healthcare, particularly for those with chronic diseases,³ such as ESRD. It is not surprising, then, that transportation is one of the acknowledged *social determinants of health*. These are “the structural determinants and conditions in which people are born, grow, live, work and age.”⁴ They are important in the goal of improving healthcare as poor health is influenced by unmet social needs – such as inadequate and unsafe housing, insufficient unhealthy food options, unreliable transportation, and so forth, as shown in Exhibit 1-3.

Those on dialysis, particularly the majority of ESRD patients who dialyze at a facility, have significant transportation needs – more than 300 trips each year. And patients who have private transportation fare better than those who must rely on public transportation.

One study was quite clear on the differences: patients who relied on public transportation had poorer attendance for their dialysis appointments and poorer outcomes.⁵

² Exploring Data and Metrics of Value at the Intersection of Health Care and Transportation, Proceedings of a Workshop, T. Wizemann and A. Baciú, Rapporteurs, Health and Medicine Division and Transportation Research Board, National Academies of Sciences, Washington, DC, June 2016: remarks by TRB Executive Director Neil Pederson.

³ Traveling Toward Disease: Transportation Barriers to Health Care Access, S. Syed, B. Gerber and L. Sharp, in J. Community Health, 2013 Oct;38(5):976-993.

⁴ <http://kff.org/disparities-policy/issue-brief/beyond-health-care-the-role-of-social-determinants-in-promoting-health-and-health-equity/>

⁵ Adherence Barriers to Chronic Dialysis in the United States, by Kevin E. Chan, Ravi I. Thadhani, and Franklin W. Maddux, J Am Soc Nephrol. 2014 Nov; 25(11): 2642–2648. Published online 2014 Apr 24.

Exhibit 1-3: Social Determinants of Health

Economic Stability	Neighborhood and Physical Environment	Education	Food	Community and Social Context	Health Care System
Employment	Housing	Literacy	Hunger	Social integration	Health coverage
Income	Transportation	Language	Access to healthy options	Support systems	Provider availability
Expenses	Safety	Early childhood education		Community engagement	Provider linguistic and cultural competency
Debt	Parks	Vocational training		Discrimination	Quality of care
Medical bills	Playgrounds	Higher education			
Support	Walkability				
Health Outcomes Mortality, Morbidity, Life Expectancy, Health Care Expenditures, Health Status, Functional Limitations					

Excerpt from *Beyond Health Care: The Role of Social Determinants in Promoting Health and Health Equity*, by H. Heiman and S. Artiga, Kaiser Family Foundation, 2015.

Public transit agencies and other providers of specialized transportation recognize their responsibility for serving dialysis trips for those who lack private transportation, but they provide those trips within the parameters and realities – policies, funding constraints, and the very real fact that the riders are often quite sick – within which they operate.

As stated in the literature and as we have found in our primary research documented in this report, those parameters and realities mean that transit agencies and other specialized transportation providers are not always providing the level of transportation necessary for individuals with ESRD. Despite this, transit agencies and other specialized providers are providing effective service in many cases and often go beyond what might be called normal or usual transit service to meet the more specialized needs of riders with ESRD.

This study is providing the opportunity to learn how public transit agencies and other specialized transportation can effectively serve those riders. What we have learned so far is documented in this report.

Chapter 2

The Research Questions

INTRODUCTION

This chapter provides a review of the literature and available data on ESRD – primarily from the United States Renal Data System (USRDS) – organized according to the 22 questions listed in the Request for Proposals (RFP) for this research project.

For each question, we provide a summary of the information and data gleaned from the literature and, where appropriate, from the USRDS that responds the question. We also include a reference to the full report or article from which we obtained the information and data. Appendix A provides a more detailed summary of the reports and articles included in the literature review.

Particularly for the RFP questions that request current and projected numbers of dialysis patients and treatment costs as well as the transportation implications, the summary response to the question is primarily drawn from the USRDS. It should also be noted that much of the data cited in the literature that we have reviewed for the study is based on the USRDS. Thus, there is some overlap between what we found in the literature and what we found in the USRDS data.

Chapter 4, titled The Community Data Tool, provides more detailed analyses of the USRDS data that are relevant towards building the data tool.

STUDY QUESTIONS AND INFORMATION FROM LITERATURE REVIEW AND USRDS

A. Current and Projected Demand and Cost for Kidney Dialysis

Study Questions

A.1 What is the current and projected number (through 2030) of people in the United States that receive dialysis?

A.2 What are the characteristics of this population and the methods by which they receive dialysis (including dialysis center, hospital-based and in-home dialysis)?

A.3 What are the current and projected costs through 2030 of dialysis treatments per person and nationally in the United States?

Information from the Literature and USRDS

A.1 What is the current and projected number (through 2030) of people in the United States that receive dialysis?

- As reported in the USRDS, there were 120,688 newly reported cases of end-stage kidney disease in 2014 – a slight increase of 1.1% when compared to 2013. While the number of new cases of ESRD has been stabilizing or increasing only slightly in recent years, the number of ESRD prevalent cases continues to rise by about 21,000 cases per year. At the end of 2014, there were 678,383 patients with ESRD receiving treatment (dialysis and/or transplant) – up 3.5% from 2013. An increasing lifespan among ESRD patients is likely the main reason for continued growth in the prevalent ESRD population. Overall mortality rates among ESRD (dialysis and transplant) patients continue to decline, with steeper declines in more recent years. (*USRDS Annual Report, 2016*).
- The projected number of people that will be receiving dialysis in 2030 is a complicated question. It is cautioned that there are a number of unknown that could affect these projections - for example, prevention measure may reduce the incidence rates and prevalence counts while improvements in care could reduce mortality rates and thereby increase prevalence counts. (*USRDS Annual Report, 2016*).
- The USRDS indicates that there are wide geographic variations by Health Service Area and Dialysis Networks that were notable with respect to incidence, prevalence, and home dialysis use. (*USRDS Annual Report, 2016*).

A.2 Characteristics of ESRD patients receiving dialysis and dialysis methods.

- The USRDS provides data on the demographic characteristics of ESRD patients. According to the USRDS, there are large variations in Incidence rates and Prevalence counts by Race and Ethnicity. The rate of incident ESRD is roughly 3-fold higher for Black/African Americans than for other races, and approximately 1.3-fold higher for Hispanics versus non-Hispanics. Compared to Whites, ESRD prevalence in 2014 was about 3.7 times greater in Blacks, 1.4 times greater in Native Americans, and 1.5 times greater in Asians. (*USRDS Annual Report, 2016*)
- Across all age groups, adjusted ESRD incidence rates have been generally stable or fallen for a decade or more. However, adjusted ESRD prevalence has seen steeper increases among older age groups. Among the age groups, ESRD prevalence per million is highest at 65-74 years. Although those aged 75 and older have the highest

ESRD incidence rate, lower prevalence per million is presumably due to higher mortality among ESRD patients in this age group. (*USRDS Annual Report, 2016*)

- According to the USRDS, home dialysis is increasing among prevalent cases, mirroring patterns shown for incident dialysis cases. On December 31, 2014, home dialysis accounted for 11.6% of all prevalent dialysis patients, up from a low of 8.7% in 2008. (*USRDS Annual Report, 2016*).
- Diabetes and hypertension together are the primary cause of 70% of new ESRD cases. Better primary care management of the risk factors for kidney disease can help prevent or delay the disease. The Medicare Payment Advisory Commission (MedPAC) has “long argued that primary care providers are undervalued in Medicare’s fee schedule.” (*Medicare Payment Advisory Commission, 2016*)
- Dialysis methods: The two types of dialysis—hemodialysis (HD) and peritoneal dialysis (PD)—remove waste products from the bloodstream differently. Most dialysis patients travel to a treatment facility to undergo hemodialysis three times per week, although patients can also undergo hemodialysis at home. Hemodialysis uses an artificial membrane encased in a dialyzer to filter the patient’s blood. There is increased interest in more frequent hemodialysis, administered five or more times per week while the patient sleeps, and short (two to three hours per treatment) daily dialysis administered during the day. New research also has increased interest in the use of “every-other-day” hemodialysis; reducing the two-day gap in thrice-weekly hemodialysis could be linked to improved outcomes. Peritoneal dialysis (PD) uses the peritoneal cavity in the abdomen to act as the filter. Wastes are taken out by means of a cleansing fluid called dialysate, which is washed in and out in cycles. PD is typically performed at a patient’s home.

Each dialysis method has advantages and disadvantages—no one method is best for everyone. People choose a particular dialysis method for many reasons, including quality of life, patients’ awareness of different treatment methods and personal preferences, and physician training and recommendations. (*Medicare Payment Advisory Commission, 2016; and GAO, 2015*)

- Dialysis Methods: In-center hemodialysis is the most common type of dialysis and was used by about 89% of dialysis patients in 2012; the remaining patients received either peritoneal dialysis (9%) or home hemodialysis (2%). Similarly, almost all – approximately 96% – of dialysis facilities had in-center hemodialysis patients in 2012; just over two-fifths of facilities had peritoneal dialysis patients and nearly one-fifth had home hemodialysis patients. Physicians and other stakeholders estimated that 15 to 25% of patients could realistically be on home dialysis. (*GAO, 2015*)
- Use of home dialysis: A 2010 study looked at the nonmedical factors that influenced the use of home dialysis at the facility level. This study also reports that a “well-

documented literature review” proposed that among the main reasons that PD use has declined was the rapid expansion of capacity at dialysis facilities and the aging of the ESRD population.

Using a variety of factors (such as whether the facility was a chain, size of facility, urban vs. rural location of the facility, and percent of patients 18-54 years of age) and a regression analysis, the study found the following:

- Facilities operated by chains had smaller percentages of home dialysis patients;
 - Facilities located in more rural areas, a geographically larger zip code or a high population-density zip code had lower use of home dialysis;
 - An inverse relationship between use of home dialysis and percent black population within a zip code;
 - Use of home dialysis was positively associated with facility size, younger patient population, and years a facility was Medicare certified. (*Walker et al., 2010*)
- Dialysis treatment is provided in a number of different settings:
 - Hospital affiliated facility
 - Freestanding dialysis facilities – operated for profit
 - For profit facility owned by a chain
 - For profit facility independently owned
 - Freestanding facilities – operated not for profit

The literature is mixed as to the quality of dialysis treatment among the different types of facilities, however it is in broader agreement that for profit dialysis facilities are more cost efficient. (*Wilson, 2013*)

- The provision of dialysis treatments by private providers is a “very competitive industry” and the major private providers “vie for new customers.” (*George Mason University School of Public Policy, 2004*)
- At the end of 2014, 63% of all prevalent ESRD cases were receiving hemodialysis, 7% were being treated with peritoneal dialysis, and 30% had a kidney transplant. (*USRDS*)

A.3 Cost of dialysis treatment.

- According to one report, the author states that USRDS data show that it costs about \$88,000 per year for a patient to have dialysis, which includes dialysis treatment as well as “collateral emergency room visits and hospitalizations.” Providing treatment is very profitable for the two large dialysis chains – Fresenius Medical Care (based in Germany) and DaVita Healthcare Partners (based in Denver). For patients with private insurance, that insurance provider pays for dialysis for the first 30 months. Private payers typically pay at least twice the Medicare rates, so that the private dialysis providers earn greater profits for the privately insured. “DaVita earns its entire

dialysis profit from the private insured, even though they represent only about 10% of patients.” (*Shinkman, 2016*)

- **Patient’s Cost:** For patients who have healthcare insurance through their employer or union, the group health plan is the primary payer for the first 30 months of treatment, with Medicare as the secondary payer. After 30 months, Medicare is the primary payer.

For those on Medicare, 80% of the cost of dialysis is paid by Medicare. For the remaining cost, those with Medicare insurance have options for supplemental coverage. (*The National Kidney Foundation at www.kidney.org*)

- ESRD is the only catastrophic illness whose care is funded by a national public program regardless of patient age or income. Medicare’s expenditure on ESRD accounts for approximately 1% of the entire federal budget. (*Wilson, 2013*)
- The majority of dialysis patients are covered by Medicare. About 75% are Medicare primary, which means that Medicare sets the reimbursement for treatment and pays 80% of that amount. For about half of the Medicare primary dialysis patients, the secondary insurer is Medicaid, which creates the category of patients called dual eligibles. About 10% of dialysis patients are Medicaid primary, with Medicaid paying 80-100% depending on the state. And finally, about 10% of dialysis patients are covered with some type of private insurance. (*Bogren, 2011*)
- According to USRDS, about 89% of all dialysis patients had Medicare coverage with Medicare as either a primary or secondary payer in 2012. (*GAO, 2015*)
- Data from a major NEMT provider that managed 48 M rides in 39 states in 2013 shows that 17.9% of the Medicaid NEMT was provided for dialysis (though there is variation among states). (*MJS & Co., 2014*)
- Healthcare costs for ESRD patients who use peritoneal dialysis (PD) rather than hemodialysis (HD) have been found to be less costly, according to a study of patients that looked at costs for a 12-month period after patients began dialysis. The HD patients were more than twice as likely as the PD patients to be hospitalized during the year after starting treatment. The median healthcare costs for the HD patients were 33% greater than the PD patients (\$173,507 vs. \$129,997), with the study period 2004 to 2006. The cost differences were mostly attributed to differences in the cost for inpatient care. (*Berger et al., 2009*)
- Dialysis patients are among the estimated 3.6 M people in the country that miss or delay non-emergency medical care each year because of transportation issues. Evaluating the benefits of improved access to medical care using a cost-effectiveness analysis, which measures the effectiveness-per-unit cost rather than a cost-to-cost

comparison, a 2005 TCRP study found that providing additional NEMT for ESRD patients is cost-effective, but not cost-saving. While not cost-saving, improvements in life expectancy or quality of life are sufficient to justify the added expense of NEMT for ESRD patients. The authors state, “in today’s economy, transportation is relatively inexpensive compared with the high and rapidly growing cost of healthcare.” (*Hughes-Cromwick et al., 2005*)

- While Medicare does not pay for NEMT, the ACA provides financial incentives that aim to reduce hospital admissions, improve care, and contain costs for vulnerable, high-cost Medicare populations. These include programs to improve care transitions when patients move between one care setting and provider to another and transportation may be part of the mix of support services. Focusing on better care transitions can help prevent costly hospital admissions and readmissions. (*Fox-Grage & Lynott, 2015*)

B. Decisions Regarding How and Where Clients Obtain Dialysis

Study Questions

- B.1 What criteria determine which method of treatment and dialysis center that patients use?
- B.2 Are health practitioners considering transportation options when recommending dialysis treatment methods?
- B.3 What factors affect patient’s choices for transportation for dialysis?

Information from the Literature

B.1 Criteria influencing methods of dialysis treatment.

- The medical perspective: A patient who must start dialysis urgently usually gets treated at a center since training for the patient is not required. There is some lead-time needed to start peritoneal dialysis because the patient must be trained. Also a patient with multiple chronic diseases may be better suited for in-center dialysis as the nephrologist is then able to more closely manage the other conditions. And a patient who has had multiple abdominal surgeries may not be appropriate for peritoneal dialysis. (*GAO, 2015*)
- Benefits associated with PD versus HD include fewer needle sticks and minimizing risk of blood-borne infections. (*Berger et al., 2009*)

- While hemodialysis in centers is the most common dialysis treatment method, many nephrologists believe that home hemodialysis and high-dose hemodialysis (longer and more frequent HD regimes) are better for the patients. An international survey found that 90% of patients were on in-center HD, 8% on peritoneal dialysis (PD) and 2% home HD. The predominance of in-center HD was seen across a survey of five countries (UK, Canada, Germany, France, US). The authors note that the survey did not include Australia and New Zealand where home dialysis is more common. (*Fluck et al., 2014*)
- The more limited use of home dialysis for ESRD patients appears impacted by several factors.
 - Medicare payment for treatment: While the payment policy seems to give dialysis facilities financial incentive to provide home dialysis, these incentives have a limited impact in the short term. With a facility payment for dialysis treatment the same regardless of type of dialysis treatment, facilities have a strong financial incentive to encourage peritoneal dialysis when appropriate, as it's generally less costly than other dialysis types. However, facilities also have a financial incentive in the short term to increase in-center hemodialysis: a dialysis facility can add an in-center patient without paying for an additional dialysis machine because each machine can be used by 6 to 8 in-center patients. In contrast, a facility may need to buy an additional machine for each new home patient. Also, there has been increased capacity to provide in-center dialysis, so facilities may have an incentive to treat patients in-center rather than at home.
 - Medicare payment to physicians: The payment policy may also constrain physicians' prescribing of home dialysis, since Medicare's monthly payment to physicians for managing care for home patients are often lower than for managing in-center patient even though the time required may be similar.
 - Predialysis education for patients: Another issue is the provision of predialysis education – Kidney Disease Education (KDE) – something that Medicare pays for. But very few (about 2%) of patients receive this education, which is due to limitations on the categories of providers and patients eligible for the benefit.
 - Demographic changes in the dialysis population: The increased age and prevalence of other health issues with dialysis patients may have reduced the portion of patients who are appropriate for home dialysis. The percentage of patients with diabetes as the primary cause of ESRD increased from 24.6% in 1988 to 43.1% in 2008. (*GAO, 2015*)
- The patient's perspective: Some may prefer home dialysis for greater flexibility, with time during the day for work or other pursuits as they do not have to travel to a dialysis center three times per week and can receive treatment at their home at night. There may also be fewer restrictions on diet and fluid as well as less recovery time after each dialysis treatment. However, home dialysis requires training and responsibilities

as well as a family member or another to help with the treatment; these are not needed if the patient gets treatment in a center. (GAO, 2015)

B.2 Criteria influencing choice of dialysis centers. Is transportation among the criteria?

- Health insurance influences the choice of dialysis center for an ESRD patient. While Medicare and Medicaid are neutral as to which center, private insurers have contracts with one or more of the dialysis providers. The patient's nephrologist may also influence placements, as these physicians often have contractual affiliation with particular dialysis centers or the corporate entity and may prefer that their patients use one of the affiliated centers. (*George Mason University School of Public Policy, 2004*)
- ESRD patients typically want to have dialysis treatment at facilities affiliated with their physician. Medicaid usually requires beneficiary to use the closest facilities to where they live, though some patients choose to be transported past close-by centers to reach a center chosen by their physician. (*Community Transportation Association, 2005*)
- A patient survey conducted in the Fairfax County study found that somewhat more than half (57%) went to the particular dialysis center because their physician recommended it; 30% said it was based on convenience of the center's location; 2% indicated the choice was influenced by the patient's insurance; 5% said because of customer service at the center; and 7% cited "other" reasons. (*George Mason University School of Public Policy, 2004*)
- The patient survey in Fairfax County found that 73% use a dialysis center closest to their home or other trip origin; the remaining 27% do not use the closest center. (*George Mason University School of Public Policy, 2004*)
- A study of dialysis transportation in West Texas reports a patient is assigned to a dialysis center by their nephrologist or a social worker. Various factors are used in the selection:
 - Availability of transportation by the patient
 - Availability of seats at the clinic
 - Distance from the patient's home to the center
 - Whether the clinic closest to the patient's home has space for new patients
 - Which centers the patient's nephrologist works with.

This study reports that the nephrologist's role is important since a nephrologist "would be reluctant in most cases to send his or her patient to a clinic not owned by a company he or she works with, since that would make treatment monitoring difficult." (*University of Texas at El Paso, 2013*)

- According to the Fairfax County study, hospital social workers help a patient who has been hospitalized with acute kidney failure with choosing a dialysis center, with transportation options taken into consideration. Other factors that the social worker considers in providing this assistance include the patient's insurance and where the patient lives (or otherwise the location of the patient's trip origin for dialysis transportation). Insurance, however, is often the overriding factor in the choice of the center. (*George Mason University School of Public Policy, 2004*)

B.3 Factors influencing patients' choices for dialysis transportation.

- Patients' choices are influenced by whether they can drive themselves or have family or friends who can drive them to dialysis centers. The choice may also be influenced by the patient's proximity to their dialysis center and if they can walk there or possibly take fixed route transit. If more personalized transportation is needed, the choice will be influenced by the type of insurance the patient carries. If the patient is a Medicaid beneficiary, Medicaid provides NEMT; this service is provided without charge to the patient. If the patient has Medicare, transportation to dialysis centers can be provided by ambulance if this mode is medically necessary for the patient but otherwise transportation is not provided. If a patient lives in a community with public transit and ADA paratransit and has a disability affecting mobility, another choice may be ADA paratransit. (*George Mason University School of Public Policy, 2004; Bogren, 2011; KFH Group, 2016*)

Access to Dialysis

Study Questions

- C.1 How do people who travel for dialysis get to and from their treatments?
- C.2 What is the current and projected number (through 2030) of trips for dialysis in the United States?
- C.3 Do current transportation options adequately provide access to dialysis?
- C.4 What are the critical characteristics of trips for dialysis?
- C.5 How does transportation demand for dialysis impact the availability of transportation services for other purposes?
- C.6 Do estimates exist of dialysis treatments missed and health cost increases due to inadequate transportation?

Information from the Literature and USRDS

C.1 Travel to dialysis centers.

- A study in Maryland estimated that 94% of people in the state with ESRD travel to dialysis centers for treatment. Of total trips to dialysis centers, the study estimated that 24% of the trips are provided as patients driving themselves, 16% of trips are provided by family or friends, and 49% are taken on public paratransit, which includes trips provided by public transit agencies as well as Medicaid NEMT. Other modes of travel with smaller shares of trips include, among others: 4% are on public fixed route transit; 2% by nursing homes; and 1% on taxis. (*KFH Group, Inc., 2013*)
- According to the Fairfax County study, patients who travel to dialysis used the following modes:
 - The county's specialized transportation provider – 39% to dialysis and 38% return
 - Patients provide own transportation – 24% to dialysis and 26% return
 - ADA paratransit provider – 8% to dialysis and 9% return
 - Medicaid NEMT – 8% to dialysis and 9% return
 - Taxi – 16% to dialysis and 12% return

(*George Mason University School of Public Policy, 2004*)

- According to a patient survey that was part of the Portland, Oregon study of dialysis transportation, patients indicated the following modes of travel to their dialysis center (patients could indicate more than one mode):
 - Patients drives themselves 30.5%
 - Family/friends drives 23%
 - ADA paratransit 30.5%
 - Medical transportation 20%
 - Ride Connection (specialized transportation provider) 13%
 - Public transportation 8.5%
 - Taxi 8.5%
 - Ambulance 6%
 - Walk 4%
 - Other 11%

(*Ride Connection, 2014*)

- ESRD patients who have private insurance and travel to dialysis centers are more likely to have a Monday-Wednesday-Friday schedule, with middle of the day shifts. Those on the Tuesday-Thursday-Saturday schedule and those with early morning or later night shifts are more likely to be Medicare patients. These latter patients are also more likely to depend on community and public transportation. (*Bogren, 2011*)

- A study of dialysis transportation in West Texas examined a sample of trips on specialized transportation providers and found that 42% of the patients' trips bypassed two or more dialysis clinics on their trip to dialysis before reaching their assigned clinic. (*University of Texas at El Paso, 2013*)
- The demand response and specialized transportation providers in Florida provide a significant amount of dialysis transportation, with an increase in dialysis trips provided by 51% over a five year period – 2008-2012. (*Audino and Goodwill, 2014*)
- Data from a nationwide Medicaid broker that provided 48 million Medicaid trips in 39 states in 2013 showed that 17.0% of the NEMT trips were for dialysis, with significant variation by state. (*MJS & Co., 2014*)
- A 2014 Community Transportation article cites national health data that reports that the majority of HD patients rely on others to get to dialysis centers at 66.8%, which includes being driven by others including ambulances. Nearly 8% used public transportation such as bus, subway, train or taxi. 25.3% drove themselves or walked. (*MJS & Co., 2014*)

C.2 What is the current and projected number (through 2030) of trips for dialysis in the United States?

- The USRDS reports that there were 678,383 patients with ESRD receiving treatment at the end of 2014 (dialysis and/or transplant). Of these, 70% of all prevalent ESRD cases were receiving dialysis therapy (about 475,000 patients) while 30% had a functioning kidney transplant. In 2014, nearly 90% of all dialysis patients received in-center hemodialysis. Assuming that all of these patients are traveling to centers (none of these patients are receiving dialysis at their care facility or if they are, the USRDS considers this treatment as “in home” dialysis), this translates into an upper-bound estimate of 131 million one-way trips needed to dialysis centers annually. Of course, not all of these trips need to be provided by the public sector. (*USRDS Annual Report, 2016*).
- If in-center dialysis remains at the same rate, the number of trips to centers will continue to rise into 2030. However, in addition to the trend toward an increase in number of ESRD patients needing treatment, there is also a trend toward an increase in home-dialysis. (*USRDS Annual Report, 2016*).

C.3.1 Do current options provide adequate access to dialysis?

- The Florida dialysis transportation study found that 23% of the demand response and specialized transportation providers surveyed could not serve all the dialysis trip requests. (*Audino and Goodwill, 2014*)

- The study of dialysis transportation in Maryland looked at the unmet demand for dialysis trips at the state's public transit agencies, estimating the number of dialysis trips that were not served due to capacity constraints on transit agencies' demand response services and due to trip requests that fell outside the operating days and hours of the agencies. Accordingly, the study reports that the public transit agencies deny about 22,000 trips annually for their paratransit services and estimates that an additional 53,000 dialysis trips are not possible on the agencies' services because of the limits of service days and hours. While ADA paratransit cannot have capacity constraints, the many smaller public transit agencies in Maryland operate general public or specialized demand response services which do experience capacity constraints. (*KFH Group, 2013*)

C.3.2 What are the results of inadequate transportation to dialysis?

- A survey of 30 dialysis patients, half who adhered to their treatment schedule and the other half who did not, found that the most common barriers cited for not going to dialysis treatment included: inadequate or unreliable transportation (cited by both groups) and lack of motivation or that dialysis is not a priority. These patients used a range of modes for dialysis transportation. Those who drove themselves, had family members drive them or took the city bus typically described those transportation modes as efficient and reliable. (These modes included ambulances but ambulance service is intended only when other transportation modes are not safe for the patients.) A number of patients took publicly sponsored van service and reported inconsistent pick up and center arrival times, long wait for trips and sometimes missed trips. Recommendations made by patients to improve dialysis attendance included improved transportation. (*Chenitz et al., 2015*)
- ESRD patients who have private transportation – either drive themselves or are driven by a family member or caregiver – have the significantly better attendance and outcomes compared to patients who relied on public transportation. (*Chan et al., 2014*)
- Medicaid NEMT is critical for beneficiaries, including for those eligible for Medicaid through the ACA. The report cites data from the National Health Interview Survey that found that 7% of Medicaid beneficiaries reported transportation as a barrier; only 0.6% of those with private insurance reported transportation as a barrier. There is concern that NEMT is threatened in some states which are proposing to waive NEMT in their expansion of Medicaid through premium assistance plans. (*MJS & Co., 2014*)
- To address problems with unreliable transportation, some health centers appear to be adding in buffer time around appointments, which serves to waste time and increase costs. (*Wizemann and Baci, 2016*)

- Problems with inadequate transportation reported in the dialysis transportation study in West Texas:

Expressed by patients who were surveyed:

- Long delays waiting to be taken home by transportation providers after finishing treatment
- Long trips to get to/from the dialysis center

Expressed by the transportation providers:

- Delays to start return trips from dialysis as the patient may not be medically stable to leave; if the driver must leave due to the waiting time policy (typically 5 – 10 min.) and given the commitments to the rest of his manifest, the transportation provider must send another vehicle back for the later return trips. This requires same-day rescheduling and a wait for the patient as the providers must find another vehicle with capacity in the manifest to add in the trip.

Expressed by the clinics:

- If patients arrive late or must leave when their vehicle arrives for the return trip, the dialysis treatment time may be shortened, which can affect the treatment quality and then the patient's health. This also creates anxiety for the patients and stress for the center staff who have to adapt to revised treatment schedules. Decreased dialysis treatment time is a serious issue that directly and negatively impacts the patients' health outcomes and may lead to a shorter life span. If this situation is repetitive, the toxins are not removed adequately from the patients' system and can lead to various afflictions, which will ultimately result in health complications that may lead to premature death. (*University of Texas at El Paso, 2013*)

- Transportation problems were reported by those patients who do not drive themselves to treatment, according to the patient survey that was part of the Portland, Oregon study:

- Treatment was shortened because the patient was late for the appointment (33% of non-drivers)
- Treatment was shortened because the patient was worried about missing the ride home (28% of non-drivers)
- Patient was left waiting at the clinic without a ride home (27% of non-drivers)
- Patient missed a dialysis treatment because the ride was canceled or did not show up (25% of non-drivers)
- Patient had to leave the clinic early in order to catch the ride home (23% of non-drivers)
- Patient rushed to catch the ride home and as result had trouble in the vehicle (bleeding, fainting, etc.) (17% of non-drivers)
- Patient missed a dialysis appointment because patient could not find a ride (17%)

The study reports: Late rides affect dialysis treatment and health conditions. This is a key issue and appears to happen frequently with one-third of non-driving patients surveyed indicating shorted treatment due to being late to the clinic at least once over the 3-month period prior to the study. Less dialysis time has negative health consequences for the patient. (*Ride Connection, 2014*)

C.4 Characteristics of trips for dialysis.

- Dialysis transportation may be the most difficult type of specialized transportation because of the frequency of the trips, the fact that passengers often have medical conditions in addition to ESRD, and the pickup times for return trips can vary because of the individuals' condition after treatment. The latter is one of the most difficult for dialysis transportation: the center may delay releasing the individuals due to bleeding after treatment. A transportation provider has to wait until the individual stops bleeding before starting the return trip. If a passenger with ESRD starts to bleed while on route for the return trip, the driver should return the person to the center or go to a hospital. (*Community Transportation Association, 2005*)
- Trips to dialysis may be cancelled or no-showed by patients. A study of Medicaid NEMT trips in Delaware, of which 75% were for dialysis, found that about 6% of the trips were cancelled/no-showed. Most of the dialysis trips were subscription trips and interestingly these trips were less likely to be cancelled/no-showed than one-time trips. (*MacLeod et al., 2013*)
- The Fairfax County study found that 5% of surveyed dialysis patients said they were frequently late to their dialysis appointments due to transportation issues; half of these patients used the ADA paratransit provider and the other half indicated "other" transportation. (*George Mason University School of Public Policy, 2004*)
- Long travel times to dialysis and their negative impacts on dialysis patients were described in two studies:
 - Longer travel time to dialysis treatment has a negative impact on ESRD patients' health and quality of life. Patients who traveled more than 60 minutes to dialysis had a 20% greater risk of death compared to those traveling 15 minutes or less. Patients who had longer travel times also scored lower when their health-related quality of life (HRQOL) was measured compared to those traveling 15 minutes or less. The study identifies travel time as a potentially modifiable variable affecting both mortality and HR-QOL. (*L. M. Moist, et al., 2008*)
 - Shorter travel times and distance to dialysis clinics is associated with improved patient outcomes and a higher health-related quality of life (HRQOL). Comparing travel to a central dialysis center versus a satellite center, the study

found that ESRD patients who traveled to a satellite center had a shorter travel time and lower transportation cost. For those patients traveling to the centers more proximate to where they lived, the study cited benefits of “less travel time, reduced driving stress, more time to spend with family and friends, less fatigue and increased energy and decreased cost.” The authors conclude that the issues related to travel, including distance and cost, played a large role in determining the patients’ perceived quality of life. (*Diamant et al., 2010*)

- Dialysis patients may receive treatment at a center that is not close to their homes, which results in long trip distances, compounded often by indirect routes because of shared riding. This contributes to transportation problems for patients: delays, long travel times that are particularly hard after treatment. One study referred to this as locational mismatch. This also results in less efficient service for transportation providers, resulting in extra miles and operating costs due to fuel and maintenance and often extended driver time. (*Ride Connection, 2014; and University of Texas at El Paso, 2013*)

C.5 How does transportation demand for dialysis impact the availability of transportation services for other purposes?

- Some community transportation providers have concerns that their general public service is being “taken over by dialysis transportation.” (*Bogren, 2011*)

C.6 Are there estimates of dialysis treatments missed and healthcare cost increases due to inadequate transportation?

- ESRD patients who miss their dialysis treatment place themselves at increased risk for hospitalization or death. A large scale study of dialysis patients over 5 years found the average missed treatment rate was 7.1 days per patient year; patients missed on average 1.8% of their scheduled dialysis treatments, which corresponded to 7.1 days off schedule. The risk of hospitalization, emergency room visit or intensive coronary care unit admission increased significantly after a missed treatment. Patients miss treatments because of depression, *unreliable transportation* (italics added), demographic factors, and lack of motivation. More than one-third (34.5%) of missed treatments happened on the day before the weekend and only 9.8% of missed treatments were successfully rescheduled for the next day. Missed treatments are more common among younger and non-Caucasian patients. Improving transportation could decrease hospitalization by 0.8 days per patient year. The study also found that moving clinics closer to where patients live was unlikely to result in meaningful improvement in patient morbidity. (*Chan et al., 2014*)
- Problems with transportation were a significantly more frequent reason given for either skipping or shortening a dialysis treatment for those ESRD patients who had longer travel times compared to those with shorter travel times (60+ min vs. <15 min.).

17% of dialysis center nurses agreed or strongly agreed that a full dialysis treatment was not provided to patients who arrived late. (*L. M. Moist et al., 2008*)

- Missed and shortened dialysis treatments have a negative impact on ESRD patients' mortality and hospitalization. "The adverse relationship between hospitalization and missed/shortened dialysis treatments is unequivocal." Frequent hospitalization contributes to rising cost of ESRD care. Missed and shortened dialysis treatments are universal but they are disproportionately more frequent in the US-ESRD population. Such treatments are more prevalent among minority populations, younger patients aged 55 or younger, and patients who get treatment on a Tuesday, Thursday, Saturday schedule. Using a patient questionnaire, the researchers asked patients in one center their reasons for skipping or shortening their dialysis treatment. The top three reasons included: family emergencies, transportation or weather issues, feeling "poorly." (*Obialo et al., 2012*)
- Missing even one dialysis treatment can cause severe complications and jeopardize patient health. Patients who traveled to dialysis treatment by a shared van or whose travel time is more than 17 minutes to a center are at increased risk of missing their dialysis treatment. Patients with private transportation to dialysis have better attendance and outcomes when compared to patients who rely on public transportation. (*These statements in this article are citations from other articles.*) During severe weather, dialysis patients face significant challenges getting transportation for treatment. In such case, patients may delay treatment, miss treatment or seek treatment in a hospital emergency room. This puts patient's health at risk and adds to the burdens of emergency rooms. The article lists a number of solutions to address dialysis transportation with weather emergencies, for example, provide dialysis prior to an emergency (e.g., hurricane). (*Hall et al., 2016*)

D. Transportation Costs for Dialysis

Study Questions

- D.1 What are the per trip and annual transportation costs per person for dialysis in the United States? This estimate should include the different methods for providing dialysis (including dialysis center, hospital-based and in-home dialysis) and the different transportation alternatives.
- D.2 What are the current total national transportation costs and the forecasted costs through 2030 for dialysis in the United States?
- D.3 What are the likely cumulative life-time costs per person of transportation to dialysis distributed by duration of treatment? How do the alternative transportation costs compare, including the cost of home dialysis?

Information from the Literature and USRDS

D.1 What are the per trip and annual transportation costs per person for dialysis in the United States?

- A CTAA article reported that community and public transportation managers that were interviewed by the author roughly estimated that the transportation costs incurred for a year of dialysis transports was about \$5,000 per patient, per year. (Bogren, 2011)
- Our study's survey of transit agencies estimates that a one-way trip to dialysis centers costs on average about \$28.56 and depends on the location of the trip. Assuming each patient needs 312 one-way trips a year to dialysis, the result is an estimate of over \$8,900 annually to serve one person on public sector transportation. (B-45 Transit Provider Survey, 2017)

D.2 What are the current total national transportation costs and the forecasted costs through 2030 for dialysis in the United States?

- Assuming that this question relates to costs associated with national transportation costs in the public sector, this can be estimated by determining how many of the upper-bound trips needed (131 million annually) would be required of the public sector. Preliminary results from the patient survey and results of the survey of dialysis facilities provide an estimate that about 46% of dialysis patients drive themselves or are driven to dialysis centers by family or friends. These trips use either the patient's or the family member or friend's personal car. The remaining 54% of patients depend on other modes, including public transit, Medicaid and other van services, and these trips – an estimated 70.8 million trips annually – can be considered trips that need to be provided by the public sector. (Even the tiny percent of patients taking private taxi trips because that is the mode available could prefer a free or less expensive mode for their trips and can be included in the 54% of trips needed.)

Taking this calculation farther, this would mean that the public sector trips to dialysis facilities require over \$2 billion annually. Again, this is an estimate based on the assumption that patients on center-based dialysis travel to all in-center treatments. (B-45 Transit Provider Survey, B-45 Patient Survey, B-45 Dialysis Facility Survey 2017 and USRDS, 2016)

D.3 What are the likely cumulative life-time costs per person of transportation to dialysis distributed by duration of treatment? How do the alternative transportation costs compare, including the cost of home dialysis?

- If a patient receives in-center dialysis and is relying on the public sector for transportation, the cost of that transportation to/from treatments is estimated at \$8,900 annually. Making the assumption that most in-center dialysis is HD and

using the 2014 annual per person per year (PPPY) cost of hemodialysis treatments from Medicare of \$87,640 means that almost \$97,000 is required to treat and transport these patients.

This cost can be compared to in-home dialysis. Transportation costs are appreciably lower. The first year requires approximately 100 one-way trips for training and periodic visits to the doctor. Adding to this the 2014 PPPY Medicare cost of peritoneal treatments (\$73,610) results in a first year cost of \$76,466. Subsequent years may only require about 60 one-way trips for periodic doctor visits bringing the annual cost of treatment and transport to \$75,232.

We note that the USRDS does not provide data on the relative survival rates for home versus facility-based dialysis treatments. (*B-45 Surveys and USRDS, 2016*)

E. Funding that Support Dialysis Transportation

Study Questions

E.1 What federal, state, local, and private funding sources support transportation for dialysis?

E.2 To what extent do tax dollars support dialysis transportation from each federal, state and local funding source?

Information from the Literature and USRDS

E.1 Funding sources that support dialysis transportation.

- Medicaid
 - Medicaid is a significant source of funding for dialysis transportation. A study of almost 126,000 Medicaid trips in Delaware between 2008 and 2010 found that 75% were for dialysis, with most of those trips booked as subscriptions.

Funding for Medicaid comes from the states and federal government, with the federal share accounting for at least 50% and no more than 83%, based on the state's average per capita income level compared with the national income average. There is no cap or ceiling on what the federal government will pay; federal payments to states for medical assistance do not have a limit or cap. Medicaid operates as a vendor payment program. States pay health care providers directly on a fee-for service (FFS) basis, or they may pay for Medicaid services through prepayment arrangements such as managed care organizations (MCOs). (*Hall et al., 2016; and KFH Group, Inc., 2016*)

- Medicaid NEMT is critical for beneficiaries, including for those eligible for Medicaid through the ACA. The report cites data from the National Health Interview Survey that found that 7% of Medicaid beneficiaries reported transportation as a barrier; only 0.6% of those with private insurance reported transportation as a barrier. There is concern that NEMT is threatened in some states which are proposing to waive NEMT in their expansion of Medicaid through premium assistance plans. (MJS & Co., 2014)
- Medicare
 - Medicare pays for non-emergency transportation by ambulance only when this level of transportation is required for the health and safety of the Medicare beneficiary. Apparently, there is overuse and improper use of this Medicare provision. Comments included in the HHS OIG ruling providing new safe harbors for healthcare entities to provide local transportation addressed this: the safe harbor for local transportation will save federal healthcare dollars for ESRD patients, as “dialysis patients are a population that has been identified as contributing to the increasing costs of nonemergency ambulance transportation and would benefit from local transportation furnished by providers.” (*Office of the Inspector of the federal Department of Health and Human Services, 2016*)
- A key challenge with dialysis transportation is that the majority of the dialysis patients are covered by Medicare, which unlike Medicaid does not provide NEMT. 75% of dialysis patients are Medicare primary, so that Medicare pays 80% of the cost, leaving 20% of dialysis cost to be paid by a secondary insurer. (*Bogren, 2011*)
- Federal transit grant programs also support dialysis transportation along with state and local match funding. In both urban and rural areas, ADA paratransit and other specialized transportation programs provide growing numbers of dialysis trips. Some of these trips are actually Medicaid eligible trips but are being provided on public transit without contribution of Medicaid dollars. (*KFH Group, Inc. 2016; and KFH Group, Inc. 2013*)

F. Effects of Regulations

Study Questions

- F.1 How do federal and state regulations governing major transportation funding programs or mandates including Medicare, Medicaid, and ADA paratransit affect the transportation options and choices for dialysis clients?
- F.2 What is the Stark Law and does it impact private sector subsidy of transportation for dialysis?

Information from the Literature

F.1 Federal/State regulations on transportation funding as well as CMS and ADA funding and impacts on transportation options and choices for dialysis clients.

- Medicare provides non-emergency transportation only by ambulance and only when such transportation is medically necessary for the patient. Thus Medicare beneficiaries traveling to dialysis centers, unless they are dually eligible for Medicaid, do not generally receive transportation unless ambulance transportation is deemed medically necessary. (Bogren, 2011)
- Unlike Medicare, Medicaid provides non-emergency medical transportation (NEMT). The states, which administer Medicaid, must assure necessary transportation so Medicaid recipients can get to and from providers of medical services. NEMT requirements include:
 - Transportation provided is to/from a Medicaid covered service;
 - The least expensive form of transportation available is used and is appropriate for the client;
 - Transportation is provided to the nearest qualified provider; and
 - No other transportation resources are available free of charge.

Following Medicaid requirements, many agencies that administer Medicaid NEMT refer – sometimes directly – Medicaid beneficiaries to the community’s public transit agency. Providing additional fixed route trips is usually not an issue as the marginal cost for additional fixed route trips is very small. This is not the case when the Medicaid agency refers Medicaid beneficiaries who have disabilities to the public transit agency for ADA paratransit. For the Medicaid NEMT administrator, referring trips to the transit agencies is a lower cost form of transportation than providing the trip itself. Moreover, given ADA regulations that prohibit capacity constraints, the transit agency must accept the trips. In selected states, the transit agency has an agreement with the Medicaid agency so that the Medicaid agency provides a payment for each Medicaid eligible trip provided by the transit agency. For larger transit agencies, this payment may not even reach half the fully allocated cost of an ADA trips. But in many cases, the transit agency must provide the Medicaid-eligible trips on its paratransit service without Medicaid participations. This is essentially cost transferring from Medicaid to public transit. (Bogren, 2011; and KFH Group, Inc., 2016)

F.2 The Stark Law and its impacts on private sector funding for dialysis transportation.

- The Stark Law governs physician self-referral for Medicare and Medicaid patients. Named after the U.S. Congressman who sponsored the initial legislation, it includes several provisions. Physician self-referral involves a physician referring a patient to a medical facility in which he or she has a financial interest, where there is ownership,

investment, or a structured compensation arrangement. This is considered a conflict of interest, since the physician is in position to benefit from the referral. The Stark Law is regulated by CMS.

The Stark Law is related to but not the same as the Federal Anti-Kickback Law. The latter, regulated by the federal HHS Office of the Inspector General, provides criminal penalties for individuals or entities that knowingly and willfully offer, pay, solicit, or receive remuneration so as to induce or reward the referral of business reimbursable under federal healthcare programs.

The Stark Law and Anti-Kickback Statute are complex, and healthcare providers must be careful to design business arrangements carefully to avoid problems. For example, a healthcare provider that wanted to provide transportation to pick up patients and bring them to appointments might be seen as giving *kickbacks* to patients to induce them to see the medical provider. The premise here is this: because generally the more patients a medical provider sees, the more revenue the provider gets from the federal healthcare programs (Medicare, Medicaid), so that something given to the patients (such as a free ride) will make the patients more likely to see that medical provider.

There are, however, various Anti-Kickback safe harbors and Stark Law exceptions. For example, exceptions and safe harbors that apply to the relations between dialysis companies and nephrologists have enabled fair market value joint ventures between these parties.

But given the broad reach, in particular of the Anti-Kickback Statute, the HHS OIG issued a ruling in December 2016 that provides new “safe harbors.” These include allowing healthcare providers, including dialysis clinics, to provide free or discounted local transportation with defined parameters. This opens up the opportunity for dialysis providers to fund local transportation for their patients, an opportunity that would help current transportation providers including public transit agencies, meet the increasing demand for dialysis trips. (*Office of the Inspector of the Federal Department of Health and Human Services, 2016; additional information from <http://www.starklaw.org/>, <https://www.cms.gov/Medicare/Fraud-and-Abuse/PhysicianSelfReferral/index.html?redirect=/physicianselfreferral/>,*

G. Effective Practices and New Strategies for Both Providing and Funding Transportation for Dialysis?

Study Questions

G.1 What are noteworthy effective practices and can they be more widely implemented?

G.2 What innovations and new strategies could improve the provision and funding of transportation for dialysis?

G.3 What are current and anticipated barriers to innovation and what strategies may overcome these barriers?

Information from the Literature

G.1 Noteworthy practices for dialysis transportation.

- According to a GAO report that provided examples of state practices that could address Medicaid NEMT costs, Wyoming Medicaid officials are working with Medicaid beneficiaries undergoing certain types of treatments such as chemotherapy and dialysis to identify treatment centers closer to their homes. (*GAO, 2016*)
- Dialysis centers in the Waco, Texas area have implemented what is referred to as empowered dialysis, whereby patients are actively involved in giving themselves dialysis treatments. These patients choose home dialysis, nocturnal therapy, or empowered in-center treatment. The health outcomes of these patients are better than for those using traditional in-center treatment, with low hospitalization and mortality rates. To the extent that patients who learn empowerment dialysis choose then to do home therapy, this reduces the transportation needs required for traditional in-center dialysis. (*Gibney, 2016*)

G.2 Strategies to improve provision and funding of transportation for dialysis.

- Transportation planning at the time of appointment scheduling can help address missed appointments, which are a significant cause for financial loss for practices. (*Wizemann and Baciu, 2016*)
- The Fairfax County study listed a number of options to improve dialysis transportation, which can be seen as increasing operational efficiency and increasing revenues or decreasing costs:
 - Increase operational efficiency
 - Among options in this category, implement new technology, e.g., AVL.

- Group dialysis trips by patient location and time. Schedule shifts at dialysis centers with greater considerations for coordinated transportation.
 - Establish limits on trip length for dialysis patients. Set up a zoning structure, so that a dialysis patient would need to use a dialysis center within the patient's own zone or a neighboring zone. This would reduce trip length and increase productivity.
 - Dialysis providers should consult with transportation providers when locating new facilities.
 - Coordinate center shift times to coordinate with paratransit providers' scheduling needs
- Increase revenues or decrease costs
 - Graduated fare structure by distance.
 - Cost sharing between centers and transportation providers.
 - Premium services.
 - Supplement the transportation provider's funding through government programs (e.g., maximize use of S. 5310, look for state funds).
 - Advertising.
 - Home dialysis. Perhaps mobile dialysis? Intriguing new concept but not in practice at time of study.
- The study included other options under its listing of recommendations. These include:
 - Implement a more formal transportation planning process for new patients, working with the centers' social workers
 - Patient education on transportation options
 - Encourage patients to carpool

(George Mason University School of Public Policy, 2004)
- Practices to improve dialysis transportation:
 - For dialysis centers
 - Dialysis centers could acknowledge that for many of their patients, transportation to/from the center is key to their treatment and should be addressed upfront.
 - Transportation planning – For example, could a patient take fixed route to treatment and then specialized service home?
 - Scheduling – Dialysis centers can help transportation providers by better scheduling of patients so as to try and group patients from similar areas so they are on the same dialysis shift.
 - Dialysis providers could consider their patients' mobility needs when deciding where to locate new centers.
 - For transportation providers
 - Group similar passenger trips. One way to do this is to divide the transportation service area into regions and keep runs within those regions. (This is zoning.)

- Transportation provider may need to place restrictions on where passengers can go for treatment. For example, a passenger would use a dialysis center only with his or her defined zone.
- Transportation funding from dialysis providers. Problem is the anti-kickback legislation.
(Community Transportation Association, 2005)
- The dialysis transportation study in West Texas provided a number of recommendations for improvements, including:
 - Have a certain number of vehicles assigned exclusively to transport dialysis patients, ensuring timely pickups and drop-offs and eliminate the possibility of shortened dialysis treatment time.
 - Assign patients to the clinic closest to their residence.
 - Establish zones so that one transportation provider is responsible for trips within that zone, serving patients who live and are treated within that zone (applicable where there are multiple public transportation providers)
 - Improve the scheduling system and communication between dispatchers and drivers; GPS/AVL technology would aid in this effort.
 - Add a buffer of time, e.g., 10-15 minutes, to each pickup from dialysis to ensure patients are stable and ready to leave. (University of Texas at El Paso, 2013)
- The Portland, Oregon study developed improvements for dialysis transportation in three categories:
 - Protocol changes for the specialized transportation agency
 - Among these include increased flexibility for return trips; allow will-calls for return trips; improved trip scheduling to ensure condition of riders is considered when scheduling each ride; expand service hours; fact sheet to explain to riders what the transportation provide can and cannot do
 - Outreach, advocacy, recruitment and education
 - These activities include a wide range, such as outreach and dialogue with other community transportation providers and a training program for dialysis support staff (e.g., fact sheet for dialysis clinics regarding transportation options)
 - A pilot transportation project
 - A pilot for a select clinic that would model the best in flexible, reliable and affordable dialysis patient transportation. (Ride Connection, 2014)
 - Information about the Ride Connection pilot was provided at the June 2016 National Academies Workshop:
 - The pilot was implemented, with components that included a dedicated dispatcher, collaboration with partners, no cost to patients, shared riding, training and a quarterly assessment of the level of service to patients.
 - Average trip cost was \$16.32, which included volunteer driver labor.

- With a goal to improve patient outcomes, the pilot achieved:
 - Majority of actual dialysis times more closely match the prescription times;
 - Missed appointments have decreased significantly; and
 - Patient health and quality of life have improved, with acknowledgement that quality of life is very difficult to assess, and the pilot relies on qualitative evidence from surveys.

(Wizemann and Baciu, 2016)

- According to the Florida dialysis transportation study, “best” practices include:
 - Have one staff person assigned to represent the transportation provider and conduct regular and frequent meetings with the dialysis centers
 - Assign the same driver as often as possible
 - Implement a “counseling” program to educate patients and their families about operational issues when patients no-show or cancel. (Audino and Goodwill, 2014)
- Strong “social supports,” which include transportation, can reduce healthcare use and costs and improve patients’ outcomes. Physicians understand the impact of social issues on patients, with 85% of a survey of physicians agreeing that “unmet social needs – such as nutritious food, *reliable transportation* (italics added), and adequate housing – are leading directly to worse health for all Americans.” There are many community-based organizations that could help address such social issues to benefit medical outcomes, but the funding streams between the social service system and healthcare delivery system are not coordinated. Provisions of the ACA have the potential to reduce the barriers by providing financial incentives for care coordination, with, for example, accountable care organizations. The ACA created the Community Based Transitions Program¹ to link hospitals and community organization in an effort to reduce hospital admissions. Meeting the CMS’s Triple Aim of better care for individuals, better health for populations, and lower per capita costs to improve healthcare will require better integrated care, which is particularly important for older patients, those with chronic conditions (such as ESRD) and with complex care needs. (Shier et al., 2013)
- There are several programs in the ACA that offer opportunities to increase transportation services for certain Medicare beneficiaries at least on a limited basis, focusing on improving care transition when patients move from one care setting (e.g., a hospital) to another (e.g., home) under the Care Transitions and Coordinated Care

¹ The Community-based Care Transitions Program (CCTP), created by Section 3026 of the Affordable Care Act, tests models for improving care transitions from the hospital to other settings and reducing readmissions for high-risk Medicare beneficiaries. The goals of the CCTP are to improve transitions of beneficiaries from the inpatient hospital setting to other care settings, to improve quality of care, to reduce readmissions for high-risk beneficiaries, and to document measurable savings to the Medicare program.

Programs heading. There is recognition that critical elements for improved care transitions should include nonmedical services including transportation. These include the Partnership for Patients, Community-based Care Transitions Program, the Hospital Readmissions Reduction Program, and Accountable Care Organizations (ACOs). Through Accountable Care Organizations, for example, the ACA encourages doctors, hospitals and other providers to join together on a voluntary basis to provide coordinated care to patients, especially those with chronic diseases. Atlanta, GA has a grant through the Community-based Care Transition Program that is trying to reduce hospital readmissions and the lead agency has provided short-term transportation for some of the patients, including those on dialysis, who needed the assistance. (Fox-Grage & Lynott, 2015)

G.3 Current and anticipated barriers to innovation.

- Constraints that affect the ability of paratransit providers to serve trips for dialysis efficiently:
 - HIPAA
 - ADA
 - Dialysis industry structure and facility location
 - Insurance
 - Physician/patient relationship
 - Patient preferences
 - Social worker transportation knowledge
 - Driver training and qualifications
 (George Mason University School of Public Policy, 2004)
- In rural areas, dialysis transportation is a particular challenge as it often involves long distance trips that may cross county and even state boundaries. Important operational issues: how does a rural system work to ensure full passenger loads for such long trips? How can the driver and vehicle be productively employed if they need to wait the 3 to 4 hours while the dialysis patients' receive treatment? (Burkhardt et al., 1998)
- According to the Florida dialysis transportation study, the following barriers impacted the ability of the demand response and specialized transportation providers to serve dialysis trips:
 - Requested trips were outside the service span (days and hours of service)
 - Insufficient funding
 - Vehicle availability
 (Audino and Goodwill, 2014)

Chapter 3

The Money

INTRODUCTION: FUNDING FOR DIALYSIS TRANSPORTATION

Funding for dialysis transportation is available from a number of sources, including the federal government, states and local jurisdictions. Private non-profit organizations also provide some support for dialysis transportation, for example, through organizations such as the National Kidney Foundation. In some communities, healthcare providers such as hospitals provide support for transportation, however it is not clear if ongoing transportation such as that required for dialysis treatment is available.¹

Significantly, a new ruling from the federal Health and Human Services' Office of the Inspector General now allows a broader range of healthcare providers, specifically including dialysis clinics, to provide free or discounted local transportation within defined parameters.² Such transportation was generally not allowed previously because of the Federal Anti-Kickback Law, but the new ruling opens up the opportunity for dialysis providers, including private companies, to fund local transportation for their patients.

From the federal government, funding that supports dialysis transportation is provided through the Department of Transportation's Federal Transit Administration (FTA) and the Department of Health and Human Services (HHS), which has many different programs that provide funding for specialized transportation including trips for non-emergency medical purposes.

A key HHS program supporting dialysis transportation is Medicaid, which is provided through HHS's Centers for Medicare and Medicaid Services (CMS). Medicaid is a federal-state partnership, with joint funding for health care services and substantial discretion at the state level to shape the program to meet the preferences of local lawmakers and communities.

Funding from the states is also significant. Many states have state-funded grant programs for transit. As just one example, Maryland has a long-established grant program targeted for seniors and people with disabilities, called the Statewide Special Transportation Assistance Program.

¹ See, for example: <http://www.uhhospitals.org/parma/patients-and-visitors/your-visit/patient-courtesy-transportation> and <https://www.woosterhospital.org/services/transportation-services>

² <https://www.federalregister.gov/documents/2016/12/07/2016-28297/medicare-and-state-health-care-programs-fraud-and-abuse-revisions-to-the-safe-harbors-under-the>

Local governments also contribute funding, through match arrangements for the FTA grant programs and through support of community-based specialized transportation programs serving seniors and people with disabilities. These local programs that provide paratransit and specialized transportation typically include a significant proportion of non-emergency medical trips including trips for dialysis.

This chapter discusses the more significant funding programs that support dialysis transportation.

FEDERAL FUNDING

Federal Transit Administration

The most recent authorizing legislation for federal transportation funding is the Fixing America's Surface Transportation (FAST) Act, which President Obama signed into law on December 4, 2015. The FAST Act authorizes Chapter 53 of Title 49 of the U.S. Code, and reauthorizes surface transportation programs, including those administered through the Federal Transit Administration (FTA) and Federal Highway Administration (FHWA), through Fiscal Year 2020. FTA funding programs that can support non-emergency medical transportation services include:



- Rides to Wellness pilot program
- Section 5310 Enhanced Mobility of Seniors and Individuals with Disabilities Program
- Section 5311 - Rural Program
- Section 5307 - Urbanized Area Program

Rides to Wellness Demonstration and Innovative Coordinated Access and Mobility Program (R2W Program)

Established under the FAST Act, the R2W Program is a discretionary pilot program that assists in financing innovative projects for the transportation disadvantaged. FTA competitively distributes funding for innovative projects that improve the coordination of transportation services that link with non-emergency medical care, with a focus on existing partnerships with specific goals for improving coordinated transportation efforts in a given locality. Authorized funding began at \$2 million in FY16 and increases incrementally each year, topping out at \$3.5 million in FY19 and FY20.

Eligible projects under this program are implementation-ready capital and operating projects that enhance public transportation access such as: mobility management; health and transportation provider service partnerships; technology; and other activities. These demonstration grants are meant to build upon previous private or federally funded efforts,

and test promising, replicable public transportation healthcare access solutions that support increased access to care, improved health outcomes and reduced healthcare costs. Examples of projects to be funded under this program include deployment of coordination technology and projects that create or increase access to community “one-call/one-click” centers.

Eligible grantees include states, tribes, designated or direct recipients under 49 U.S.C. 5307, 5310 or 5311. Applicants must serve as the lead agency of a local consortium that includes stakeholders from the transportation, healthcare, human service or other sectors, with members of this consortium eligible to be subrecipients.

In November 2016, FTA announced FY 2016 Rides to Wellness project selections. The \$2 million in FY 2016 R2W project funding under 49 U.S.C. Section 5310 / FAST Act Section 3006(b) were supplemented with \$5.3 million from the 49 U.S.C. Section 5312 / FAST Act Section 3008 Public Transportation Innovation program, for a total of \$7.2 million. A total of 19 projects across the U.S. were selected for FY 2016 (including the Maryland project introduced in the box below).

Allegany County, MD Awarded FTA “Rides to Wellness” Grant - In FY 2016, the Maryland Transit Administration (MTA) was awarded \$103,344 to increase the capacity of a mobility management program that addresses barriers for low-income individuals in Allegany County who lack reliable access to transportation to receive non-emergency medical care. The program, which will be updated with transportation coordination software, coordinates and provides transportation to and from non-emergency medical appointments at no cost to the individuals. The project partners are Western Maryland Health System, the Tri-State Community Health Center, the Allegany County Health Department and the Core Service Agency.

Enhanced Mobility of Seniors and Individuals with Disabilities Program (49 U.S.C. Section 5310 / FAST Act Section 3006)

The FAST Act re-authorized the Section 5310 - Enhanced Mobility of Seniors and Individuals with Disabilities Program, which was originally established as the Section 16(b)(2) program under the Urban Mass Transportation Act of 1973 and evolved with each subsequent reauthorization legislation. Historically, this program provided capital funding, through the states, for vehicles to be used by private non-profit organizations in meeting the specialized transportation needs of older adults and people with disabilities.

Under the FAST Act, the Section 5310 program continues to fund these “traditional” projects, with other types of projects allowed. At least 55% of program funds are to be used to fund the purchases of vehicles and related equipment, transit-related information technology systems that support services for seniors and people with disabilities, mobility management programs, and purchase of transportation services. The remaining 45% of program funds can also be

used to support capital and operating expenses for new public transportation services and alternatives beyond those required by the ADA, designed to assist individuals with disabilities and seniors. Examples of these types of projects include travel training; volunteer driver programs; building an accessible pedestrian path to a bus stop, improving signage or way-finding technology, incremental cost of providing same day service or door-to-door transportation service, and purchasing vehicles to support new accessible taxi, ridesharing and vanpooling programs.

Under the FTA program, in addition to states, local governmental entities that operate public transportation services and are eligible to receive direct FTA grants under the Section 5311 or 5307 program are now eligible direct recipients for Section 5310 funds. Section 5310 direct recipients vary from state to state. For example, in Maryland, the state continues to be the FTA designated recipient for all Section 5310 funds in Maryland allocated outside of the Washington DC-VA-MD Urbanized Area (UZA), and distributes local Section 5310 subrecipient grants across the state through a competitive selection process, including in Baltimore UZA and the small UZAs in Maryland. The Maryland Transit Administration is a division of state government that both operates regional public transit service—and is the designated recipient of Section 5307 and 5310 funding in the Baltimore Urbanized area—and manages FTA funds allocated to the state.

In the Washington DC-VA-MD UZA, which includes portions of several counties in Maryland, the Metropolitan Washington Council of Governments is the designated recipient. In other states, Section 5310 funds in the urbanized areas are awarded to the Section 5307 designated recipients (urbanized transportation providers), and to the state for distribution in the rural areas.

Funds are apportioned to states based on Census data on the number of older adults and individuals with disabilities, and then allocated by type of service area, with 60% of each state's apportionment allocated to large urbanized areas, 20% to small urbanized areas, and 20% to rural areas. States can transfer small urban or rural allocations to large urbanized areas (but not the other way around).

Under the FAST Act, a total of \$262.95 million were authorized in FY 2016 for these formula grants nationally, increasing annually to \$285.58 million in FY 2020. (These amounts do not include the R2W pilot program.) The federal funding share is 80% for capital projects and 50% for operating assistance.

Although Section 5310 doesn't specifically fund medical transportation, the priority travel needs of many members of the target population means that Section 5310 frequently supports trips for medical purposes, although it may be in the form of a vehicle used to operate transportation service for medical appointments for seniors and individuals with disabilities.

Formula Grants for Rural Areas (49 U.S.C. Section 5311 / FAST Act Section 3007)

The FAST Act re-authorized the Section 5311 - Formula Grants for Rural Areas Program, which provides funding to states and Indian tribes to support rural public transportation (in areas less than 50,000 population). The federal Section 5311 program goals include enhancing access in rural areas to health care (as well as shopping, education, employment, public services, and recreation), so even though Section 5311 isn't specifically targeted to medical transportation, the reality is that transportation to medical appointments is typically a significant part of rural public transportation programs.

States typically provide subrecipient grants to local governments and non-profit organizations that operate or purchase public transportation (as well as intercity bus operators through the 5311(f) program, for which each state must spend 15% of its 5311 apportionment or certify rural intercity bus needs are met). Each state determines how it allocates Section 5311 funds to eligible subrecipients although must do so in a manner that is fair and equitable. Section 5311 funds can be used for operating, capital, or administrative costs. Federal match is a maximum of 50% of net operating expenses and 80% for capital expenses (90% for the cost of vehicle-related equipment attributable to compliance with the ADA or Clean Air Act).

Recipients may use up to 10% of their Section 5311 allocation for the operation of ADA paratransit service for 80% federal share (and up to 20% if certain conditions are met). (Those conditions include doing at least two of the following: 1) actively providing travel training; 2) training all operators in passenger safety, disability awareness, and sensitivity at least every two years; and/or 3) having a memorandum of understanding in place with employers and the American Job Center to increase access to employment opportunities for people with disabilities.) It is worth noting that many 5311-funded services are demand response and thus do not require complementary paratransit.

Annual federal authorization levels for the core Section 5311 program under FAST are \$552.6 million in FY 2016 increasing to \$604.8 million in FY 2020, which excludes the Tribal and Appalachian, and Rural Transit Assistance programs, but including the 5311(f) Intercity Bus program.

Note that states can increase the size of their Section 5311 programs by transferring certain flexible FHWA funds, so the actual amount of federal funding available in each state may be higher than the Section 5311 authorization. Also, states which are eligible for the FTA Section 5340 Growing States program (i.e., have population growth faster than the average across all states) are apportioned additional FTA 5340 funds that can be used for rural public transportation. So the total federal apportionment for 5311 is only an approximation of what states spend on rural public transportation.

Transportation Coordination

FTA encourages maximum feasible coordination of Section 5311 service with other rural transportation services. Rural public transportation services are often rooted in/built around human service transportation needs, including medical transportation. In some communities, Section 5311 services are operated by organizations or government departments with a primary mission to serve particular populations (for example, Area Agencies on Aging, or Community Action Agencies), but which provide transportation services for the general public as well as agency clientele.

Limited funding for rural transportation service, the dispersed populations to be served, and the distances that can be involved in transporting rural residents to medical services means providers are challenged with meeting as many of the needs as they can with limited resources. Rural public transportation is often provided on a demand-responsive basis, and subscription service is a common practice. Orienting services toward meeting human service needs, using human service transportation funding as well as Section 5311, and accommodating general public riders on this service, is one way rural transit providers can make efficient and effective use of resources.

Importantly, the federal program allows rural public transportation programs to apply human service transportation contract revenue to be used either as operating revenue (reducing the net operating expense) or as local match. Historically, Medicaid transportation revenue has been an important source of local match for Section 5311 subrecipients in many states, when rural providers have agreements with Medicaid agencies to provide Medicaid NEMT trips. However, changes in state Medicaid program administration particularly the use of private brokers for NEMT has reduced the opportunity for this coordinated funding, and subrecipients which historically relied on Medicaid funding have sometimes needed to reduce service levels accordingly, or adjust their service coordination approach.

Urbanized Area Formula Funding Program (49 U.S.C. 5307 / FAST ACT Section 3004)

FTA's Section 5307 program supports public transportation in urbanized areas through grant awards to states and other public entities. Funding for large urbanized areas (populations 200,000 or more) is awarded directly to FTA's designated recipient for the urbanized area (often a public transit authority or local government), with funds allocated based on a combination of population, population density, bus revenue vehicle miles, bus passenger miles, fixed guideway revenue vehicle miles, and fixed guideway route miles.

Funding for small urbanized areas (populations 50,000 to 199,999) is allocated based on population and population density, and is awarded to the state, which then awards subgrants to the small urbanized area subrecipients. A state or designated recipient may authorize another public entity to be a "direct recipient" for Section 5307 funds, and a designated recipient in a large urbanized area may also award subrecipient grants.

Section 5307 funds can be used for operating, capital, or administrative costs. Federal match is a maximum of 50% of net operating expenses and 80% for capital expenses (90% for the cost of vehicle-related equipment attributable to compliance with the ADA or Clean Air Act, or bicycle-related project elements). Recipients may use up to 10% of their Section 5307 allocation for the operation of ADA paratransit service for 80% federal share (and up to 20% if certain conditions are met). (As for Section 5311, those conditions include doing at least two of the following: 1) actively providing travel training; 2) training all operators in passenger safety, disability awareness, and sensitivity at least every two years; and/or 3) having a memoranda of understanding in place with employers and the American Job Center to increase access to employment opportunities for people with disabilities.)

Annual federal Section 5307 apportionments under the FAST Act are \$4,508.90 million in FY 2016, increasing to \$4,899.45 million in FY 2020. Additionally, as with the Section 5311 program, the Section 5307 appointments can be supplemented by certain flexible FHWA, as well as the urbanized portion of the FTA Section 5340 Growing States /High Density program, which is \$536.26 million in FY 2016 increasing to \$570.03 million in FY 2020.

Even though Section 5307 funding is not targeted to medical transportation, since it can be used to fund ADA paratransit services, and ADA paratransit can be used to access medical appointments including dialysis, Section 5307 does support medical transportation, although the degree to which is generally not tracked since ADA service must serve all trip purposes without prioritization. Transit agencies may track trips to dialysis based on trip destination.

Department of Health and Human Services— Centers for Medicare and Medicaid

Medicare

People who receive dialysis services are commonly covered by Medicare, the federal entitlement program created in 1965 that provides health coverage for the nation's elderly and disabled populations.³ Most beneficiaries "age into" Medicare coverage, meaning that they are 65 years of age and meet the work requirements to qualify for Social Security (or they are the spouse of someone who meets the work requirements).



³ Medicare consists of several plans or "parts": Parts A and B are often referred to as Original, or Traditional, Medicare. Part C plans, also known as Medicare Advantage plans, are Medicare-approved plans offered by private insurance companies. Part D plans are an alternative to Original Medicare. Along with covering doctors and hospitals, they often cover prescription drugs, too. Part D plans are Medicare-approved private plans that help people who have Parts A and B to pay for prescription drugs.

Other people enter Medicare because they are under age 65 and qualify for Social Security Disability insurance. This second group faces a two-year waiting period for Medicare benefits once their disability benefits begin.

Since 1972, a third group has qualified directly for Medicare with no age restriction or link to Social Security work requirement – these are individuals who have end-stage renal disease and people with ALS (formerly known as Lou Gehrig’s disease). Current estimates indicate that fewer than 1% of Medicare beneficiaries have end-stage renal disease, yet spending on ESRD represents approximately 7% of Medicare’s total expenses.

Although Medicare is the principal source of payment for ESRD and dialysis services, *Medicare does not pay for routine transport of patients to and from dialysis treatment.* Medicare does cover medically necessary ambulance transportation for patients who are deemed by their providers to have no other appropriate or adequate transportation alternatives. (Ambulance service, however, is an extremely costly alternative for the program.) Thus, Medicare patients must look to other sources of support to supplement their own private transportation resources or find alternative supports to facilitate their care. Because a dialysis regimen most often requires multiple weekly trips for patients experiencing severe kidney disease, transportation supports serve as a literal lifeline in patients’ lives.

In 2016, 57 million people were on Medicare, with about two-thirds enrolled in traditional fee-for-service arrangements and one-third in managed Medicare Advantage plans (plans offered by private companies such as HMOs, PPOs, etc.). Since 2004, the number of beneficiaries enrolled in private plans has more than tripled from 5.3 million to 19 million in 2016.⁴

Medicare spending was \$646.2 B in 2015 and accounted for 15% of total federal spending in 2015, according to CMS statistics. More than one-fourth was for payments to Medicare Advantage plans.⁵

ESRD Patients on Medicare

In 2014, there were nearly 630,000 prevalent ESRD patients. (USRDS, 2016) According to the U.S. Renal Data Reporting System, which collects information on ESRD, a sizeable majority of all dialysis patients have Medicare coverage with Medicare as the primary or secondary payer – 89% based on patient data in 2012.⁶

⁴ <http://www.kff.org/search/?s=medicare>

⁵ <http://files.kff.org/attachment/Fact-Sheet-Medicare-Advantage>

⁶ End-Stage Renal Disease Medicare Payment Refinements Could Promote Increased Use of Home Dialysis, GAO, Report to Subcommittee on Health, Committee on Ways and Means, House of Representatives, October 2015

Medicare pays dialysis facilities for treatments—conducted either in a facility or at home—and for training patients to perform home dialysis. Medicare also pays physicians to manage patients' dialysis care and training and to provide education to certain patients with chronic kidney disease.

For individuals eligible for Medicare solely due to ESRD, Medicare coverage generally begins on the first day of the fourth month after patients start dialysis. For individuals who have employer group coverage, Medicare is the secondary payer for the first 30 months of Medicare entitlement, after which Medicare becomes the primary payer.⁷

While Medicare expenditures for beneficiaries with ESRD continued to grow through 2014 and accounted for a disproportionate share of overall Medicare spending, costs on a per patient year basis have changed only modestly in recent years. According to the USRDS, in 2014, Medicare paid for over 490,000 patients with ESRD. Even though the ESRD population remained at less than 1% of the total Medicare population, it has accounted for about 7% of Medicare fee-for-service spending in recent years.

In 2014, the USRDS reported Medicare ESRD per person per year (PPPY) expenditures for patients on hemodialysis of almost \$88,000, peritoneal dialysis of almost \$74,000, and transplant of almost \$33,000.

USRDS aggregate costs of ESRD include only those ESRD beneficiaries covered by the original Medicare fee for service for their Medicare Parts A&B benefits (does not include those enrolled in Medicare Advantage – managed care plans.) However, if a person becomes eligible for Medicare solely due to ESRD, they are generally not permitted to enroll in Medicare Advantage and must use fee-for-service Medicare. Current Medicare beneficiaries who develop ESRD are allowed to remain in their Medicare Advantage plan but generally cannot switch if they were enrolled in fee-for-service Medicare at the time of ESRD onset.

A more accurate picture of total ESRD-related costs would take into account more than just expenditures by the Medicare program. It would include expenses such as those incurred by private insurance carriers when Medicare is the secondary payer, costs during the waiting period for initial Medicare coverage, and as provided by insurance carriers of people living with a functioning kidney transplant following the termination of Medicare coverage. It would also include the beneficiaries' portion of the cost-sharing with Medicare, including the Parts B and D premiums of those enrolled in Medicare solely due to ESRD, the beneficiary's deductible, and their co-insurance amounts for ESRD services⁸.

⁷ GAO, 2015.

⁸ 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.

Data in the USRDS Annual Report shows that total Medicare spending for FFS patients with ESRD reached \$32.8 billion in 2014, an increase of 3.3% from the previous year, accounting for 7.2% of the overall Medicare paid claims costs⁹ (USRDS, 2016).

Medicare Payment Reforms

With increasing costs for treating patients with ESRD, there have been payment reforms in parts of Medicare that may have implications for the costs of end-stage renal disease. For example, beginning in 2005, Medicare patients became eligible for free diabetes screenings. Patients with diabetes constitute almost half of all of the dialysis patients who begin treatment each year. To the extent that screening identifies patients earlier, it may help reduce the number of patients with diabetes who progress to end-stage renal disease. Improving the screening and management of chronic conditions that predispose patients to end-stage renal disease may be a particularly successful strategy in stemming the growth in costs.¹⁰

Medicare's Dialysis Transportation

As discussed above, Medicare does not provide routine transportation for dialysis treatment. Transportation is provided, however, in special cases by ambulance only when other transportation modes such taxi or van could jeopardize the patient's health.

Medicaid

Medicaid is an entitlement program funded jointly by the federal and state governments, which covers a broad range of medical services and supports for individuals and families with low incomes. The Medicaid program is administered in partnership with the states by the Centers for Medicare and Medicaid Services (CMS) within the federal Department of Health and Human Services (HHS).

The federal government covers about 57% of total spending on Medicaid, although funding varies by state. States receive a minimum of 50 cents on the dollar for eligible Medicaid expenses. Poorer states receive a higher federal share to encourage participation in the program and enable them to cover needy residents. For example, Mississippi's federal match is just over 75%, meaning that for every dollar it expends on Medicaid eligible services, the federal government covers 75 cents and the state's share is 25 cents. States also incur administrative expenses associated with operating their Medicaid programs, which the federal government shares, but only at a 50% match.

⁹Reported costs for ESRD patients includes only those beneficiaries covered by Original Medicare, but not those in Medicare Advantage (managed care) plans. Medicare pays for service in Medicare Advantage plans on a risk-adjusted, per-capital basis and not by claims for services. A more accurate picture of total ESRD-related costs would take into account more than just expenditures by the Medicare program.

¹⁰ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3766315/>

The federal government sets a floor and ceiling in terms of who qualifies for Medicaid and what services must or must not be covered (in addition to other program rules and requirements). Between those parameters, states have broad flexibility to design Medicaid program eligibility criteria, covered benefits, and health plan arrangements. All states cover some groups and health services that are beyond those required by the federal government. For example, prescription drugs are not a federally mandated Medicaid benefit, yet all states cover prescription drugs, with various formularies, cost-sharing, and other programmatic features.

As an entitlement program, federal and state payments associated with Medicaid are not capped and cannot be denied to beneficiaries if they qualify for the program and require Medicaid covered services requested by an eligible provider. Nevertheless, access to Medicaid services can be severely limited because of shortages of health professionals in the community or because available providers are unwilling to accept low Medicaid provider payments.

The 2010 Affordable Care Act (ACA) brought substantial changes to Medicaid, by expanding Medicaid eligibility. Prior to the ACA, Medicaid defined eligibility based on categorical membership and poverty. Only children, pregnant women, elderly individuals, disabled individuals, and adults with dependent children were mandatory Medicaid populations, meaning that all states participating in the Medicaid program had to provide enrollment to members of these groups if they met certain income thresholds. States had the ability to expand Medicaid to additional groups through waivers (up to certain income limits) and state-paid enhancement, but poverty alone was not a qualifying event for Medicaid coverage. This left millions of low-income adults out of coverage because they could not qualify for Medicaid, were too young for Medicare, and did not have health insurance options at low-wage or part-time jobs.

The ACA expanded Medicaid to citizens and legal residents (in the U.S. legally for a minimum of five years) under age 65 in families with incomes below 133% percent of the federal poverty level. These individuals made up about half of the country's uninsured.

The Medicaid expansion was challenged in a Supreme Court case,¹¹ with the Court determining that states could not be required to implement the Medicaid expansion as a condition of continuing to operate their existing Medicaid programs and receiving federal financial participation. In effect, this ruling made the expansion of Medicaid optional for each state. As of March 2017, 31 states and the District of Columbia have adopted the Medicaid expansion.

The country's new administration as of January 2017 has indicated that it will make changes to both the ACA and the Medicaid program. This is discussed in more detail in Chapter 8.

¹¹ 2d 450, 132 S.Ct. 2566, *National Federation of Independent Business v. Sebelius*, 2012.

Medicaid regulations stipulate that medical services be provided in the lowest cost manner appropriate for the beneficiary, that services are provided to all eligible individuals in the state, and that those eligible can use the service provider of their choice.¹² Within federal guidelines and certain limitations, states also determine the amount and duration of services offered under their Medicaid programs.

Medicaid Costs

Costs for Medicaid have grown rapidly. According to 2015 CMS data, Medicaid enrollees totaled 75.3 M and spending that year was \$545.1 billion. The program is the largest public health insurance program in terms of enrollment. About 9 million people of the total qualify for both Medicaid and Medicare. These so-called “dual-eligibles” represent low-income elderly and individuals with disabilities who are younger than 65. Medicare serves as the principal source of coverage for dual-eligibles, with Medicaid picking up most of Medicare’s cost-sharing, in addition to other services such as nursing home care, which are not covered by Medicare. Not surprising, dual-eligibles are among the most costly enrollees for both Medicare and Medicaid.

Between Summer 2013 and January 2016, there was a net increase of nearly 15.5 million or 27% enrolled in Medicaid and CHIP (Childrens Health Insurance Program) among the 49 states reporting data for both periods. Much of the growth was in large states in the West that implemented the Medicaid expansion.¹³

Medicaid is the third largest domestic program in the federal budget following Medicare and Social Security, and it has an interesting role in state budgets. With the shared payment with the federal government, Medicaid is both an expense and the largest source of federal revenue in state budgets. Unlike other programs, state spending on Medicaid brings in federal revenues due to its financing structure.¹⁴ Unlike the federal government, however, states face the challenge of needing to balance their budgets. Since Medicaid spending is an entitlement, states often struggle to meet their Medicaid obligations in tough economic times.

States are increasingly using managed care to address Medicaid cost increases. As an alternative to the traditional fee-for-service (FFS) system, states use managed care organizations (MCOs), prepaid health plans (PHPs), or comparable entities that agree to provide a specific set of services to Medicaid members, usually in return for a predetermined periodic payment per enrollee.

¹² TCRP Research Results Digest 109, Impact of the Affordable Care Act on Non-Emergency Medical Transportation (NEMT): Assessment for Transit Agencies, prepared by R.Garrity and K. McGehee, RLS & Associates, Inc., October 2014.

¹³ <http://www.kff.org/medicaid/issue-brief/two-year-trends-in-medicaid-and-chip-enrollment-data-findings-from-the-cms-performance-indicator-project/>

¹⁴ <http://www.kff.org/medicaid/issue-brief/medicaid-financing-how-does-it-work-and-what-are-the-implications/>

Waivers provide the states with flexibility in the design and implementation of their Medicaid programs. The Secretary of Health and Human Services has broad authority to grant waivers of various Medicaid provisions that address coverage, control costs, or result in more efficient service delivery. Waivers have also been used by states in their implementation of non-emergency transportation. For example, the Kaiser Family Foundation reports that two states (Iowa and Indiana) have approved waivers for their Medicaid expansion that include elimination of NEMT.¹⁵

Medicaid Transportation

Non-emergency medical transportation (NEMT) was not specifically included in the original Medicaid legislation. However, provisions in the legislation and the body of case law that has evolved from the legislative language require that each state Medicaid program include provisions for necessary transportation of Medicaid recipients to and from providers of medical services.



In 1978, the transportation requirement was officially added to the Social Security Act as §431.53 *assurance of transportation*.

How states meet the federal mandate to assure necessary transportation to these beneficiaries is determined, in part, by the definition of the term “necessary.” According to an advisory group convened in 1998 specifically to examine non-emergency transportation issues, this is interpreted as:

- Transportation provided is to/from a Medicaid covered service;
- The least expensive form of transportation available is used and is appropriate for the client;
- Transportation is provided to the nearest qualified provider; and
- No other transportation resources are available free of charge.¹⁶

This means that when several modes of transportation are available, states are to use the least costly means of transportation that is appropriate for the particular medical needs of the beneficiary. This is also in keeping with Medicaid’s status as the “payer of last resort.” These Medicaid regulations governing NEMT have impacts for public transit agencies, specifically those that provide ADA paratransit. This is discussed in more detail in Chapter 8.

Given states’ flexibility in implementing their Medicaid program, there is variation in how NEMT is provided. The various NEMT models used by the states include:

¹⁵ Kaiser Family Foundation, The ACA and Medicaid Expansion Waivers.

¹⁶ Fact Sheet: Medicaid Transportation Service National Health Law Program, February 2008.

- In-house management
- Managed care option
- Statewide broker
- Regional broker
- Fee-for-service (FFS) and managed care
- FFS and broker
- Broker and managed care

States' use of brokers, in particular private brokers, has increased in recent years, almost doubling between 2003 and 2012. Currently, 40 of 50 states plus the District of Columbia use brokers to provide their NEMT service.¹⁷

STATE FUNDING

Some states provide state funding to help pay for specific kidney disease-related costs.¹⁸ Delaware, for example, has a Chronic Renal Disease Program funded entirely with state funds.

This program, which began in 1997 and is administered by the state's Department of Social Services, provides a range of services for Delaware residents with ESRD who meet state-defined eligibility criteria. Focused on low-income residents, the program provides financial assistance with medications and nutritional supplements, as well as transportation. Specifically, the program includes reimbursement for transportation for dialysis as well as for transplant services or provides tickets to use the state's public transit service.¹⁹



The program also gives any individual in the program eligibility for the state's ADA paratransit service, regardless of whether they met the regulatory criteria for ADA paratransit. At the outset, this did not add appreciably to the number of registered ADA paratransit riders, but since then, with growth in population as well as the increasing rates of kidney disease as seen nationwide, the dialysis trips contribute significantly to the increasing demand for paratransit service in Delaware.

¹⁷ TCRP Project B-44, Examining Effects of Separate Non-Emergency Medical Transportation Brokerages on Transportation Coordination, Interim Report, by Texas A&M Transportation Institute et. al, 2014.

¹⁸ (National Institute of Diabetes and Digestive and Kidney Diseases at <https://www.niddk.nih.gov/health-information/kidney-disease/kidney-failure/financial-help-treatment#state>

¹⁹ <http://dhss.delaware.gov/dhss/dss/crdprog.html>

LOCAL FUNDING

Local funds are also used to support dialysis transportation. For the FTA transit programs, local funds are required to match the federal dollars.

Additionally, many local governments – cities and counties – provide specialized transportation services for their citizens who have specialized needs because of age and/or disability. These may be a community-level demand-response services or often taxi-based subsidy programs. Given the clientele for the services, many of the trips are for medical purposes, including dialysis.

The City of Phoenix has a locally-funded transportation program specifically for dialysis patients. This program, initiated in 1999 for city residents undergoing dialysis treatment and certified as ADA eligible, subsidizes taxi trips to and from the patients' dialysis facility. Phoenix funds this program with a portion of a dedicated transportation sales tax.



In 2015, the city passed a proposition that increased the 0.4% sales tax for transportation to 0.7% for the next 35 years starting in January 2016, raising the city's sales tax rate to 8.6%. These transportation funds are used for major public transit projects as well as for smaller specialized transportation programs including the taxi-based dialysis transportation program.²⁰

PRIVATE FUNDING

Private organizations that may provide assistance for dialysis treatment include charities and non-profit foundations. Two national organizations focus specifically on helping people with kidney disease and kidney failure: the American Kidney Fund and the National Kidney Foundation. Financial assistance from the American Kidney Fund, for example, specifically includes transportation among the patient needs that it supports.

The National Kidney Foundation has affiliates in various states. The National Kidney Foundation of Michigan provides patients services and resources, among other functions. This includes an emergency fund for one-time help with urgent needs, which specifically includes transportation to dialysis.



²⁰ TCRP Synthesis 119, Use of Taxis in Public Transportation for People with Disabilities and Older Adults, by Elizabeth Ellis, KFH Group, Inc., Transportation Research Board, 2016; and personal communication with the contract manager of the Phoenix dialysis transportation program, March 9, 2017.

The National Kidney Foundation of Maryland also provides funds for emergency transportation needs, with funds provided directly to dialysis centers. This organization recognizes issues with transportation for patients who are lower income:

“For dialysis patients with limited financial means, reliable transportation to and from dialysis can become a major obstacle to treatment, especially if public transportation is used.”²¹

Generally, however, private funding is limited and does not typically address the ongoing, three-times weekly transportation needs of patients on dialysis.

²¹ <http://www.kidneymd.org/kidney-education-research/patient-services>

Chapter 4

The Community Data Tool (Introduction)

INTRODUCTION

As communities struggle with increasing demand for transportation to dialysis treatments, two of the key pieces of information they need to examine are how many current and projected trips the public sector transportation systems in their community need to provide in order to ensure patients are able to access dialysis treatments – and what costs are associated with those trips.

The purpose of this chapter is to:

- Describe the plan for building a community-based data tool to predict demand and cost of public transportation trips to dialysis treatments, and
- Present a summary of the data available with which to construct the data tool including data from both the United States Renal Data System (USRDS)¹ on current ESRD incidence and prevalence rates and information gleaned from the study's surveys.

THE COMMUNITY DATA TOOL

The database tool will be one of the resources included in the project's final report and will provide communities with a method to estimate:

- Current and projected demand for public sector transportation to kidney dialysis, and
- Current and projected cost of this transportation.

The database tool will allow communities to estimate the current and projected number of residents in their community with ESRD and the number travelling to dialysis treatments at dialysis facilities in the community. Based on this information, the tool can be used to predict unconstrained public sector trips currently needed to dialysis and to forecast future demand for dialysis trips.

The current and projected cost of these trips will be estimated either based on local information (current cost per trip for such trips in the community) or using a default value from transit agencies surveyed for the project. Because of the complex and varied ways in

¹ 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.

which public sector trips to dialysis are currently funded, we do not expect the tool to be able to predict funding available to support this transportation.

Much of the data on ESRD incidence and prevalence rates is available through the United States Renal Data System (USRDS), a national data system that collects, analyzes, and distributes information about chronic kidney disease (CKD) and ESRD in the United States. The USRDS data will be supplemented with information found in the literature and gleaned from the study surveys of patients, facility staff and public transportation agencies.

STRUCTURE OF THE DATA TOOL

From the user's perspective, the tool will consist of two screens – one that allows users to input data or override defaults for specific variables and another that reports the results of the data calculations. Exhibit 4-1 provides an example of what the input screen may look like while Exhibit 4-2 provides an example of the output screen.

The tool will be built on a relational database platform such as Microsoft Access that allows us to create background tables of raw data and relational proportions among the variables based on locations, age and race/ethnicity. We considered building a web-based tool but this would require a level of back-end maintenance as well as finding an organization to host it on their website.

We anticipate that, in large part, the data on current and projected demand for kidney dialysis will be available in the USRDS database. While the tool will be based to current data, we anticipate being able to build in a method by which communities can predict for any year into the future (assuming current trends continue). Location, age and race/ethnicity are being used since the USRDS data indicate significant differences in ESRD prevalence counts for these demographic characteristics.

Exhibit 4-1: Sample Input Screen

SAMPLE			
TCRP PROJECT B-45 TRANSPORTATION TO DIALYSIS FACILITIES			
COMMUNITY DATA TOOL - USER INPUT			
<p>Please provide input in the yellow-highlighted boxes for each of the information requests or accept the default values as shown. When your input is reasonable or within a range expected by the tool, the comment box will respond with "o.k." Comments other than "o.k." are meant to provide guidance and, in most cases, will <u>not</u> prevent program execution. However, unreasonable and misleading report values could result.</p> <p>NOTE: First-time users of the Community data tool should read the User's Guide for complete information on the tool including user-defined input, default values, and tool output.</p>			
<p>ABOUT YOUR COMMUNITY</p>			
1. Provide your County	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="background-color: yellow;">Montgomery</td></tr> <tr><td>o.k.</td></tr> </table>	Montgomery	o.k.
Montgomery			
o.k.			
2. Provide your State	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="background-color: yellow;">MD</td></tr> <tr><td>o.k.</td></tr> </table>	MD	o.k.
MD			
o.k.			
3. Do you serve the entire County? If not, what percentage do you serve?	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="background-color: yellow;">100%</td></tr> <tr><td>o.k.</td></tr> </table>	100%	o.k.
100%			
o.k.			
4. Would you consider your community to be: <i>Large Urban Area (1+ plus population)</i> <i>Large City (200,000 - 1M population)</i> <i>Small City (50,000 - 200,000 population)</i> <i>Rural Area (less than 50,000 population)</i>	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="background-color: yellow;">Large Urban Area</td></tr> <tr><td>o.k.</td></tr> </table>	Large Urban Area	o.k.
Large Urban Area			
o.k.			
<p>ABOUT THE MONEY</p>			
5. Provide an estimate of the cost for a public sector trip in your community. If not available, accept the default value	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="background-color: yellow;">\$28.56</td></tr> <tr><td>o.k.</td></tr> </table>	\$28.56	o.k.
\$28.56			
o.k.			
6. Provide the Project Year	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="background-color: yellow;">2020</td></tr> <tr><td>o.k.</td></tr> </table>	2020	o.k.
2020			
o.k.			
ID: <table border="1" style="width: 150px; height: 20px; background-color: yellow;"></table>	Today's Date: <table border="1" style="width: 120px; height: 20px; background-color: yellow;">8/7/2017</table>		

Exhibit 4-2: Sample Output Screen

SAMPLE	
TCRP PROJECT B-45	
TRANSPORTATION TO DIALYSIS FACILITIES	
COMMUNITY DATA TOOL - OUTPUT REPORT	
ESRD PATIENTS IN YOUR COMMUNITY	
1. Estimate of Current Number of ESRD Patients In Community	<input type="text"/>
2. Estimate of Projected Number of ESRD Patients in Community (year)	<input type="text"/>
TRANSPORTATION NEEDS OF ESRD PATIENTS IN YOUR COMMUNITY	
3. Estimate of Current ESRD Patients Travelling to Dialysis Centers	<input type="text"/>
4. Estimate of Projected ESRD Patients Travelling to Dialysis centers (year)	<input type="text"/>
5. Estimate of Current Dialysis Trips Needed on Public Sector - Unconstrained (upper-bound)	<input type="text"/>
6. Estimate of Projected Dialysis Trips Needed on Public Sector - Unconstrained (upper-bound)	<input type="text"/>
PUBLIC SECTOR COSTS	
7. Current Cost of Public Sector Trips Needed - Unconstrained	<input type="text"/>
8. Projected Cost of Public Sector Trips Needed - Unconstrained	<input type="text"/>
ID: <input type="text"/>	Year for Projections <input type="text"/>
Today's Date: <input type="text" value="8/7/2017"/>	

Data Parameters

Following are the data tables/parameters that will be built into the data tool. The sources of these data are described in the next section:

- **Data on current ESRD patients** – by location [county, state, ESRD network²/region, health service area (HSA)³], age, and race/ethnicity factors
- **Data on methods of treatments** – in-center, home, transplant by location (county, state, ESRD network/region, HSA), age, and race/ethnicity factors
- **Change Factors/Trends** - changes in prevalence rates, incidence rates, and methods of treatments – by location, age, race/ethnicity – to predict the future
- **Cost per trip** for dialysis public sector trips by populations size(default)
- **Percentage of trips** that would rely on the public sector

User Inputs

- Community Location/Service Area – County and State – related to HSA⁴
- Percentage of County in Service Area
- Community size (large metropolitan, large city, small city, rural)
- Cost per trip on public sector dialysis trips (if available – if not use default)
- Prediction Year (any year 2015 – current to 2030)

Outputs

- Current and Projected Number of ESRD Patients in Community
- Current and Projected Number of ESRD Patients Travelling to Dialysis Facilities – in-center treatments only
- Current and Projected Number Dependent on Public sector for Transport – Upper Bound
- Current and Projected Dialysis Trips on Public Sector Transportation – Unconstrained
- Current and Projected Cost of Public Sector Trips Needed – Unconstrained

² The USRDS sorts states into 20 ESRD networks or regions of the country.

³ The Renal Data Extraction and Reference (RENDER) system on the USRDS web site enables you to create your own tables using state or county level data.

⁴ Health Service Areas (HSAs) are defined by the [National Center for Health Statistics](#) to be a single county or cluster of contiguous counties which are relatively self-contained with respect to hospital care. There are approximately 824 HSAs. HSAs that crossed state boundaries were split so that all counties from one HSA were in one state. The names of the Health Service Areas are derived from the names of the 2 counties with the highest populations in 2000 within the HSA. Additionally, if there is a major city in one of the counties that name is added in parenthesis.

DATA AVAILABLE FOR THE COMMUNITY DATA TOOL

The community data tool will be built using data from a number of sources:

1. **USRDS** – the primary source of data will be the United States Renal Data System (USRDS), which includes data on current patients with ESRD that are receiving dialysis treatments, their treatment modality, Medicare expenditures, hospitalizations and mortality rates. The data are longitudinal and will also provide trends for projections into the future.
2. **Literature** – even though much of the data reported in the literature is based on the USRDS, there are nuggets of information that will inform trends in the treatment of ESRD – valuable in attempting to predict future demands and costs for dialysis transportation.
3. **Public Transportation Agency Survey** – this survey from our study will provide us with data to create a default value for cost per trip to dialysis treatments.
4. **Patient and Dialysis Facility Survey** – these surveys from the study are the source of information on the percent of dialysis patients that rely on public sector transportation to travel to/from dialysis treatments.

USRDS DATABASE

The USRDS is a national data system that collects, analyzes, and distributes information about CKD and ESRD in the United States. The USRDS is funded directly by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).⁵ Data are reported annually with the most recent annual report, issued in 2016, reporting on 2014 data. We anticipate that by the time we build the data tool in Phase 2 that the 2017 annual report/2015 data may be available. The USRDS data are available from the USRDS online system (RenDER) on national, state and county levels.

Data available from the USRDS that could be used in the development of the tool include:

1. Current Number of people with ESRD and their characteristics (age, race/ethnicity, region, and health service area (HSA).
2. Trends in the Number of ESRD patients and their characteristics – changes in prevalence rates and incidence rates and variations by age and race/ethnicity.
3. Current Methods by which ESRD patients receive dialysis treatment –center versus home-based and variations based on location, age and race/ethnicity.
4. Trends in methods by which ESRD patients receive dialysis treatments.

⁵ All ESRD patients, regardless of insurance coverage and age, are included in the USRDS database. Only claims analyses, such as hospitalizations, costs, and clinical services, are restricted to Medicare patients.

DATA ON NUMBERS, CHARACTERISTICS AND TRENDS - ESRD PATIENTS

Current Incidence Rates – New Cases

- As reported in the USRDS, there were 120,688 newly reported cases of end-stage kidney disease in 2014. The crude (unadjusted) incidence rate was 370 per million/year, representing a slight increase (1.1%) compared to 2013.

Current Prevalence Counts

- While the number of new cases of ESRD has been stabilizing or increasing only slightly in recent years, the number of ESRD prevalent cases continues to rise by about 21,000 cases per year. At the end of 2014, there were 678,383 patients with ESRD receiving treatment (dialysis and/or transplant) – up 3.5% from 2013.

Variations by Location, Age and Race/Ethnicity

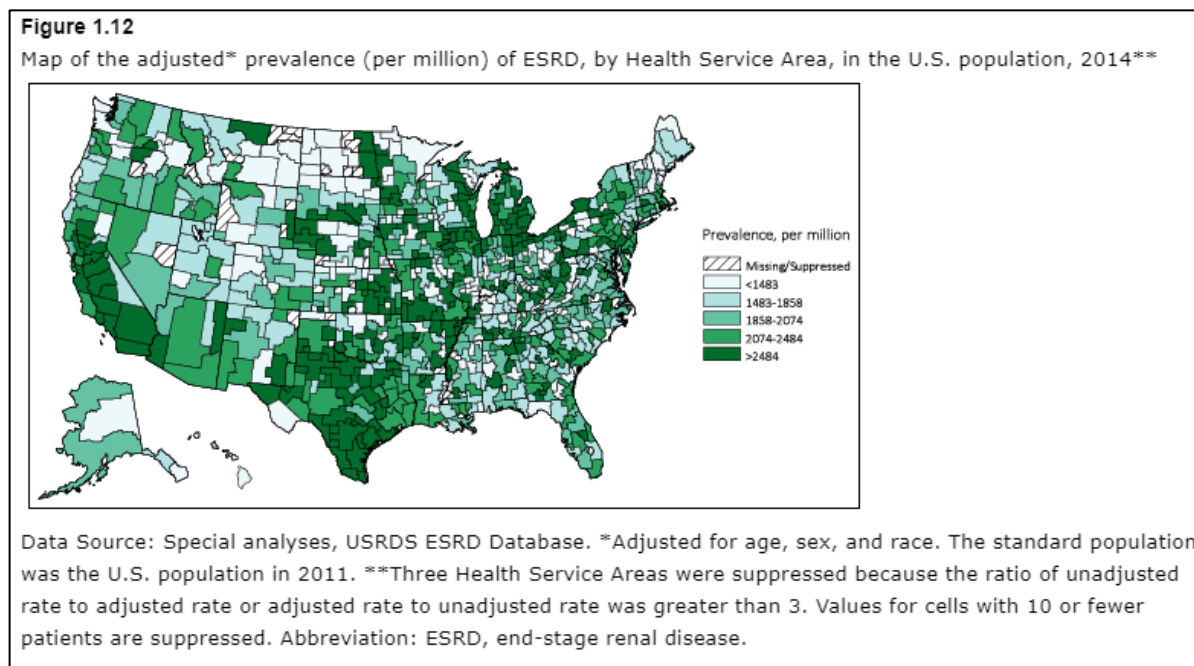
*Location*⁶

- Incidence Rates (new cases) – According to the USRDS, ESRD incidence rates vary substantially among the 18 ESRD Networks and the HSAs. Adjusting for differences in age, sex, and race, the lowest rate was 250 per million/year in the northeast, while the rate in Texas was 73% higher at 432 per million/year. Much of the high incidence in Texas and Southern California is due to the high numbers of Hispanics in these states. Again, according to the USRDS, the adjusted incidence rate of ESRD across 677 HSAs ranged from 83 per million/year to 4,172 per million/year. The rates were generally highest in parts of the Ohio and Mississippi River valleys, the Southeast, Texas, and California, and lowest in parts of New England, the Northwest, and certain Upper Midwest and Rocky Mountain states.
- Prevalence Counts (total patients) – ESRD prevalence rates also vary substantially among the ESRD Networks and HSAs. The USRDS reports that, across 786 Health Service Areas, the adjusted prevalence of ESRD in 2014 ranged from 339 per million to 7,134 per million. Among the 18 ESRD Networks, the age-sex-race-adjusted prevalence of ESRD ranged from 2,339 per million to 1,419 per million. The USRDS cites examples of high ESRD prevalence in 2014 as parts of the Ohio and Mississippi River valleys, Michigan, northern Illinois and parts of Wisconsin along Lake Michigan, Texas, and California while lower prevalence was observed in northern New England, the

⁶ 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

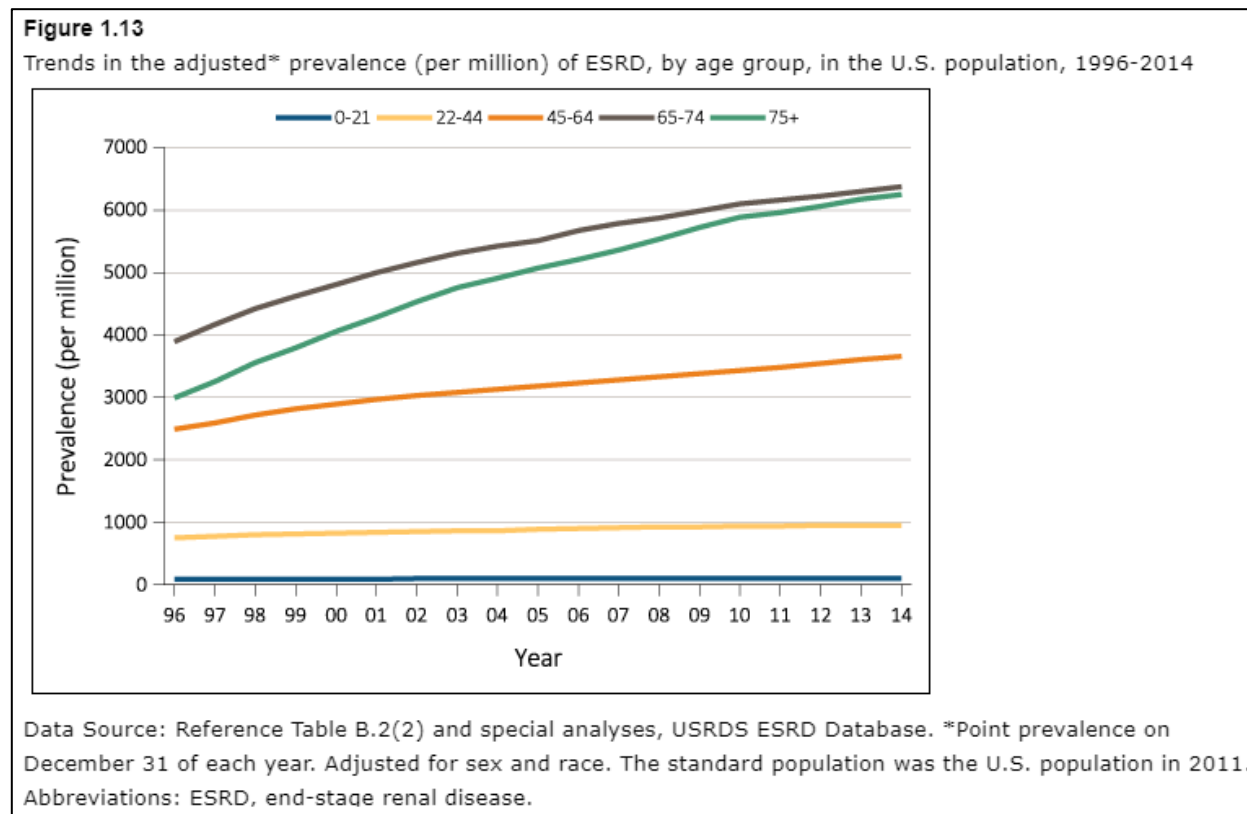
Northwest, and certain Upper Midwest and Rocky Mountain regions. These patterns are roughly similar to patterns of ESRD incidence described earlier. Figure 4-1 (Figure 1.12 from the USRDS 2016 Report) shows variations in prevalence rates across the country in 2014, sorted by HSA.

Figure 4-1: USRD 2016 Annual Report – Prevalence of ESRD in the US Population



Age

- Incidence Rates - Adjusted ESRD incidence rates have been generally stable or fallen for a decade or more across all age groups but differ significantly by age group – as expected, populations in the 65-74 and 75+ age groups have much higher incidence rates than younger age groups.
- Prevalence Counts – Adjusted ESRD prevalence has seen steeper increases among older age groups. These increases over time contrast with the ongoing declines in adjusted ESRD incidence rate across age groups and thus are likely due to longer survival among ESRD patients as well as the fact that patients who are in one age group at incidence necessarily age into older age groups. USRDS reports that, among the age groups, ESRD prevalence per million is highest at 65-74 years. Although those aged 75 and older have the highest ESRD incidence rate, lower prevalence per million is presumably due to higher mortality among ESRD patients in this age group. Figure 4-2 (Figure 1.13 from the USRDS 2016 Report) shows trends in prevalence rates by age groups from 1996 to 2014.

Figure 4-2: USRD 2016 Annual Report – Prevalence of ESRD by Age Group

Race/Ethnicity

- **Incidence Rates** - There are large variations in incidence rates by race/ethnicity. USRDS reports that the rate of incident ESRD is roughly 3-fold higher for Black/African Americans than for other races, and approximately 1.3-fold higher for Hispanics versus non-Hispanics. Of note is the rather dramatic decline in ESRD incidence in the Native American population.
- **Prevalence Rates** - The adjusted prevalence of ESRD continues to rise among whites, blacks, and Asian Americans. However, the remarkable decline in incidence rates among Native Americans has resulted in a 50% decline in the prevalence of ESRD in this population over the past decade. According to the USRDS, in 2014, the prevalence per million was 5,605 among Blacks, 2,101 among Native Americans, 2,198 among Asians, and 1,507 among Whites. Thus, the prevalence of ESRD remains much higher in Blacks than in other racial groups, at nearly 2.6-fold higher than Native Americans and Asians, and nearly 3.7-fold higher than whites. The adjusted ESRD prevalence has continued to rise for both non-Hispanics and Hispanics, though it may be plateauing among Hispanics since 2011. In 2014, the adjusted prevalence was 1,912 per million among non-Hispanics and nearly 58% higher, at 2,958 per million, among Hispanics.

Figure 4-3 (Figure 1.14 from the USRDS 2016 Report) shows trends in prevalence rates by race from 1996 to 2014 while Figure 4-4 (Figure 1.15 from the USRDS 2016 Report) shows trends in prevalence rates by Hispanic ethnicity from 1996 to 2014.

Figure 4-3: USRD 2016 Annual Report – Prevalence of ESRD by Race

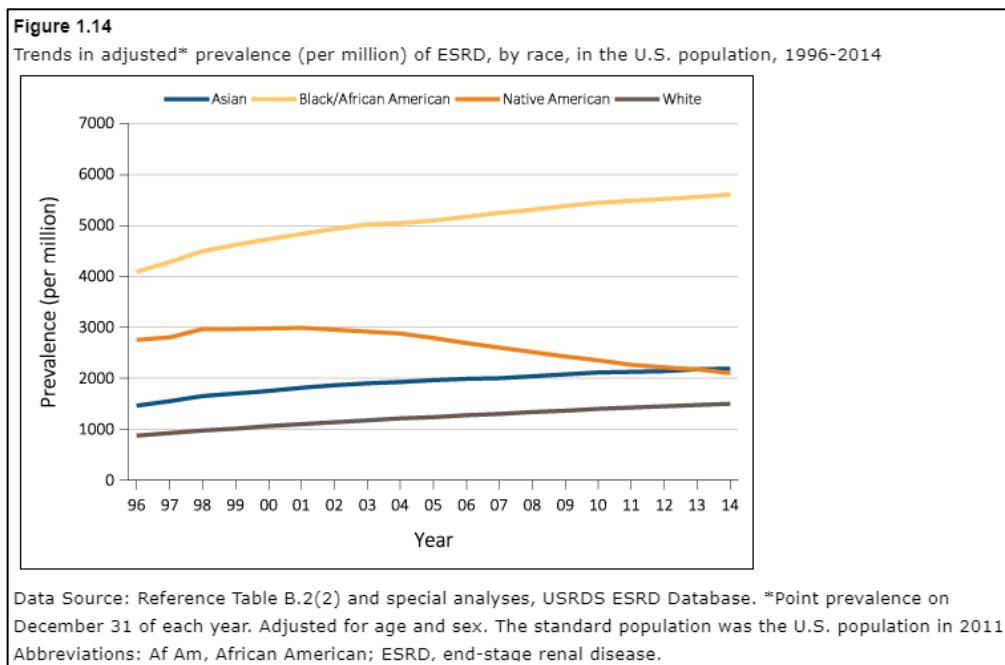
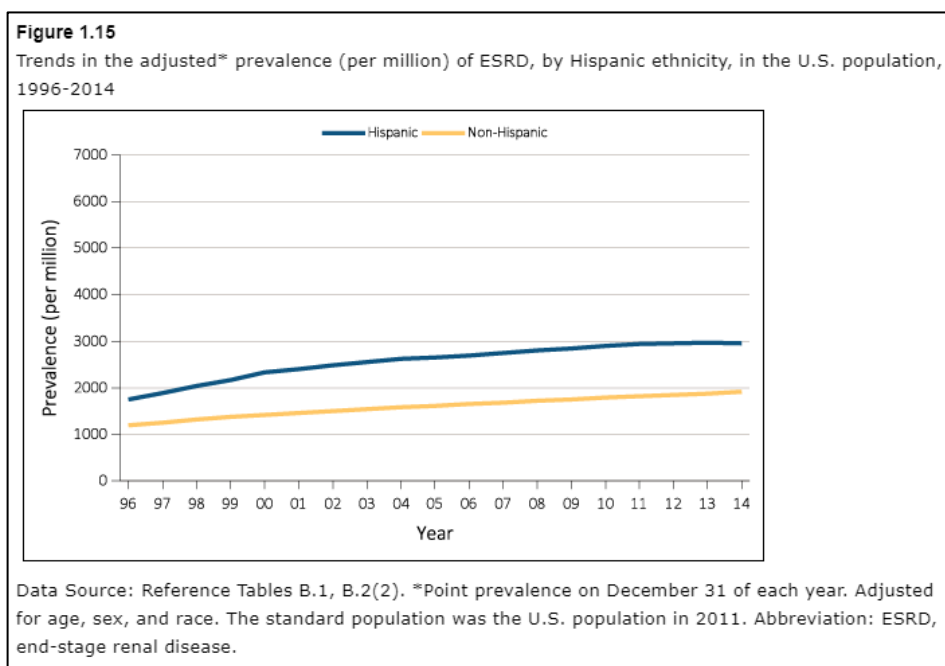


Figure 4-4: USRD 2016 Annual Report – Prevalence of ESRD by Hispanic Ethnicity



Projections

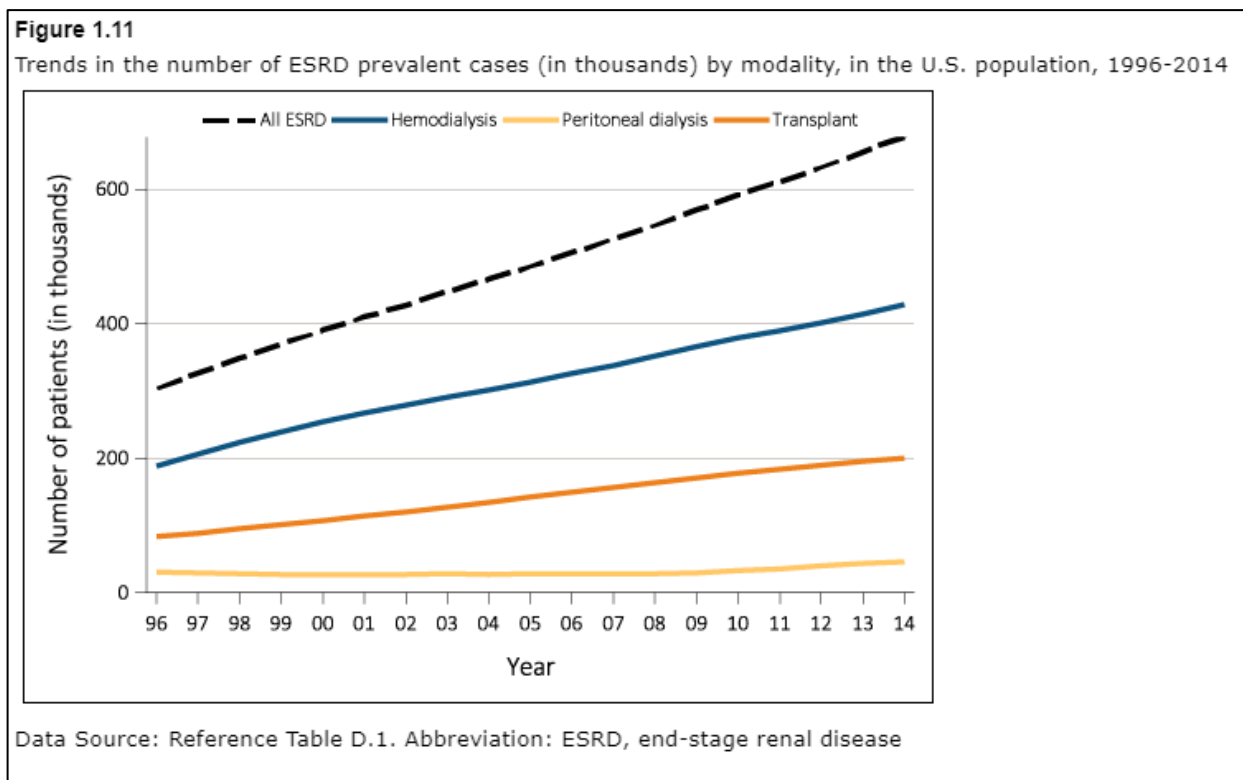
- An increasing lifespan among ESRD patients is likely the main reason for continued growth in the prevalent ESRD population. Overall mortality rates among ESRD (dialysis and transplant) patients continue to decline, with steeper declines in more recent years. In 2014, adjusted mortality rates for ESRD, dialysis, and transplant patients, were 136, 166, and 30, per 1,000 patient-years, respectively. (*USRDS Annual Report, 2016*).
- The projected number of people that will be receiving dialysis in future years is a complicated question. Based on the trend data in the USRDS, the prevalence counts are increasing by 3.3 to 5.1% annually over the last 16 years. Similarly, the unadjusted prevalence rates (cases per million) have been increasing between 2.5-4.1% percent annually over that same period with the adjusted rates increasing 1.2-3.2% annually. Projecting out to 2030 based on this trend in prevalence counts would suggest that there could be a million patients with ESRD in 2030. It is cautioned that there are a number of unknowns that could affect these projections. For example, prevention measure may reduce the incidence rates and prevalence counts while improvements in care could reduce mortality rates and thereby increase prevalence counts. (*USRDS Annual Report, 2016*).

DATA ON CURRENT TRENDS - METHODS OF TREATMENT

There are three different types of dialysis treatment, with the most common being hemodialysis which is provided in commercial or medical facilities three times each week. It is estimated that about 90% of patients requiring dialysis use hemodialysis and the vast majority of these treatments is at centers. Transportation to and from the dialysis facilities then becomes essential to the health – even the survival – of these individuals.

Center versus Home-Based Dialysis

- On December 31, 2014, 63% of all prevalent ESRD cases were receiving hemodialysis therapy, 7% were being treated with peritoneal dialysis, and 30% had a functioning kidney transplant. Figure 4-5 (Figure 1.11 from the USRDS 2016 Report) shows the trends in modality among ESRD patients from 1996 to 2014.

Figure 4-4: USRD 2016 Annual Report – Number of ESRD Prevalent Cases by Modality

- Among hemodialysis cases, 88.0% used in-center hemodialysis, and 1.8% used home hemodialysis. Peritoneal dialysis remains the dominant form of home dialysis.
- Among prevalent ESRD cases, the use of home dialysis (peritoneal dialysis or home hemodialysis) continues to show a rising trend. Home dialysis use overall in 2014 was 73% higher than in 2007. Even so, home dialysis accounted for only 11.6% of all prevalent dialysis patients in 2014 (up from a low of 8.7% in 2008).
- Despite the large relative rise in home hemodialysis, its overall use among incident ESRD patients is low, as only 3.4% of home dialysis patients were treated with hemodialysis in 2014. According to the USRDS, among prevalent cases, home dialysis is increasing, mirroring patterns shown for incident dialysis cases.
- Among new ESRD cases in 2014, 87.9% used hemodialysis, 9.3% used peritoneal dialysis, and 2.6% received a pre-emptive kidney transplant. It seems important that new cases are more likely to use hemodialysis which is generally done in-center (requiring transport to/from).

Variations by Location, Age, Race/Ethnicity

Location

- Geographic Variations -The USRDS indicates that there are wide geographic variations by HSA and Dialysis Networks with respect to modality, especially home dialysis use.
- Incidence Rates (New Cases) – As reported in the URDS, the proportion of incident dialysis cases using home dialysis varied substantially across 677 Health Services Areas, ranging from 0% to 55%. Geographic patterns are not apparent, supporting the likelihood that differences in home dialysis use are largely driven by differences among individual dialysis centers or groups of centers or other factors, rather than by a large-scale regional effect.
- Prevalence Counts (Existing Cases) - As observed for incident dialysis cases, modality use among prevalent ESRD cases varied substantially by region. Use ranged between networks from 54% to 69% for hemodialysis, from 4% to 9% for peritoneal dialysis, and from 23% to 39% for transplantation . The percent on hemodialysis was generally higher and the percent with a transplant was generally lower in networks with higher prevalence of ESRD.
- Home dialysis – As reported in the USRDS, across 763 HSAs, the percent of prevalent dialysis cases using home dialysis ranged from 0% to 83% (interquartile range: 9.5% to 17.2%) in 2014. HSAs with home dialysis use ranging from low to high were found in most regions of the country indicating that the variation may be due to differences in doctors, dialysis centers or other factors rather than regional differences.

Age

- Prevalence of modality use by patient characteristics generally mirror those for incident patients.
- Use of home dialysis, peritoneal dialysis and pre-emptive kidney transplants were markedly more common in younger groups.

Race/Ethnicity

- Uses of peritoneal dialysis and kidney transplant were more common among patients who were white, non-Hispanic and were somewhat less common among Black or Hispanic patients. This implies that use of home dialysis (which is predominantly peritoneal dialysis) is less common among Black, non-Hispanic and Native Americans.

DATA ON CURRENT AND PROJECTED DEMAND, AND COSTS FOR PUBLIC SECTOR TRIPS TO DIALYSIS

Per Trip and Annual Dialysis Transportation Costs on Public Sector

- Our survey estimates that a one-way trip to dialysis centers costs average about \$28.56 and depend on the location of the trip. Trips cost \$35 in large metropolitan centers, \$32.20 in large city agencies, \$29.60 in smaller city agencies and \$26.20 in rural areas. Assuming each patient needs 312 one-way trips a year to dialysis results in an estimate of over \$8,900 annually to serve one person on public sector transportation. (B-45 Transit Agency Survey, 2017).

Demand for Public Sector Transportation to Dialysis Treatment

- Upper Bound Estimate - As noted above, the USRDS reports that, at the end of 2014, there were 678,383 patients with ESRD receiving treatment (dialysis and/or transplant). Of these, 70% of all prevalent ESRD cases were receiving dialysis therapy (about 475,000 patients) while 30% had a functioning kidney transplant. In 2014, nearly 90% of all dialysis patients received in-center hemodialysis. Almost 420,000 patients received in-center dialysis treatments. Assuming that all of these patients are traveling to centers (none of these patients are receiving dialysis at their care facility or if they are the USRDS considers this treatment as “in home” dialysis), this translates into an upper-bound estimate of 131 million one-way trips needed to dialysis centers annually. Of course, not all of these trips need to be provided by the public sector. (USRDS Annual Report, 2016).
- Lower Estimate - If in-center dialysis remains at the same rate, the number of trips to centers will continue to rise in future years. However, in addition to the trend toward an increase in number of ESRD patients needing treatment, there is also a trend toward an increase in home-dialysis. If we assume that home dialysis continues to increase, this means that a lower percentage of dialysis treatments will be done in-center in the future. (USRDS Annual Report, 2016).

Cost of Public Sector Trips Needed to Dialysis

- Assuming that this question relates to costs associated with national transportation costs in the public sector, this can be estimated by determining how many of the upper-bound dialysis trips needed - 131 million annual - would be required of the public sector. Preliminary results from the patient survey and survey of dialysis facilities provide an estimate that about 46% of dialysis patients drive themselves or are driven to dialysis centers by family or friends. These trips use either the patient's or

the family member or friend's personal car. The remaining 54% of patients rely on other modes including public transit, Medicaid and other van services, and these trips – an estimate of 70.8 million trips annually – can be considered trips that need to be provided by the public sector. (Even the tiny percent of patients taking private taxi trips because that is the mode available could prefer a free or less expensive mode for their trips and can be included in the 54% of trips needed.) (B-45 Patient Survey, B-45 Dialysis Facility Survey 2017 and USRDS, 2016)

- Taking this calculation farther, this would mean that the public sector trips to dialysis facilities require over \$2 billion annually. Again, this is an estimate based on the assumption that patients on center-based dialysis travel to all in-center treatments. (B-45 Transit Agency Survey and USRDS, 2016)

Chapter 5

Transit Agency Perspective

INTRODUCTION

The research study's survey of transit agencies had a number of objectives:

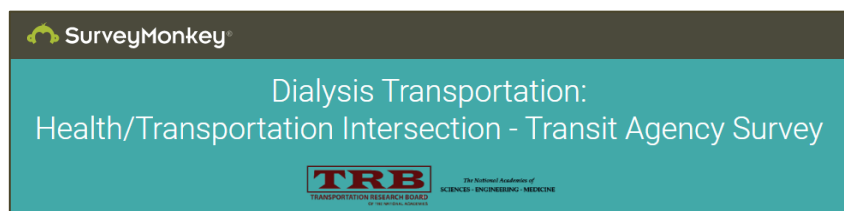
- To collect data on transit agencies' dialysis trips served in Fiscal Year 2016, the estimated cost per trip, and funding sources used for dialysis transportation;
- To determine if the transit agencies had to turn down any dialysis trips and, if so, approximately how many as well as the reasons for the turn-downs;
- To assess any impacts on transit agencies' overall service due to dialysis trip demand; and
- To identify any effective practices or strategies implemented to serve passengers requiring dialysis transportation.

METHODOLOGY

After revisions to survey questions based on review by our consulting healthcare experts and the Panel, we formatted the survey for online completion with SurveyMonkey. The survey was emailed directly to transit agencies in urban areas, using a distribution list we created with email addresses of paratransit managers at urban transit agencies obtained from the American Public Transit Association (APTA) directory and from the National Transit Database (NTD).

For distribution to transit agencies in rural and small urban areas, we sent an introduction to the study and the survey, including a link to the survey, to state program

managers at the states' departments of transportation (these managers oversee federal transit grants, including Section 5311 for rural providers and Section 5307 for small urban providers), with a request that they forward the email to their subrecipients.



We obtained the listing of state program managers through the American Association of State Highway and Transportation Officials (AASHTO) Standing Committee on Public Transportation (SCOPT) and AASHTO's Multi-State Technical Assistance Program (MTAP),

recognizing that there is some overlap between the organizations' membership. We also posted a message ("alert") through MTAP to let state public transportation program managers know about the study and the survey.

To ensure a broad outreach to rural transit providers, we also consulted a listing of state RTAP managers obtained from the RTAP headquarters and added the email addresses of states' RTAP managers to the email distribution list. In a number of cases, the RTAP manager is the same person as the state transit program manager.

The original two-week response period for survey completion was increased by another two weeks at the request of several large transit agencies that needed more time to collect information for their response. At the survey close date, we received 541 responses, 534 of which were usable.¹

SURVEY FINDINGS

Of responding transit agencies, 6% are in large metropolitan areas (over 1 million population), 10% are in large cities (200,000 to 1 million population), 23% are in smaller cities (50,000 to 200,000 population), and the remaining 61% are in rural areas or smaller communities (less than 50,000 population). These four categories are used as surrogates for size of the transit agency as well as to distinguish urban vs. rural agencies, and we used the categories to analyze survey results, anticipating that findings might differ by the size of the transit agency/size of community served. The research project has an interest in differences between urban and rural communities regarding dialysis transportation.

Specialized Transportation/Paratransit Services Provided

The transit agencies were asked what type of specialized transportation or paratransit service they provide, with multiple responses allowed; see Table 5-1.

Agencies in large metro and large city areas are more likely to provide ADA paratransit than agencies in smaller cities and rural areas: almost two-thirds of metro area agencies and almost three-fourths of large city agencies provide ADA paratransit, while only 40% of rural area agencies provide ADA paratransit.

On the other hand, agencies in smaller cities and rural areas are more likely to provide general public demand response transportation (DRT) among their service types. General public DRT is not a common service for metro area and large city transit agencies.

The provision of Medicaid NEMT is more prevalent for transit agencies in rural areas, with 42% providing such service. About one-third of agencies in smaller cities provide Medicaid

¹ We note that respondents did not necessarily answer all survey questions, thus the total respondent count to survey questions often frequently does not equal the number of usable respondents.

NEMT, and approximately one-quarter of large city agencies and only 14% of metro area agencies provide Medicaid trips.

Table 5-1: Type of specialized transportation or paratransit service provided. (Check all that apply).

Response Options	Large Metro Area	Large City	Smaller City	Rural/ Small Community	Total
ADA paratransit	64%	72%	58%	40%	49%
Demand response transportation for seniors and people with disabilities	61%	64%	70%	70%	69%
Demand response transportation for general public	21%	21%	44%	74%	59%
Medicaid non-emergency transportation (NEMT)	14%	23%	36%	42%	37%
Service provided on contract basis to one or more human service agencies	14%	38%	32%	29%	30%
Other	14%	13%	15%	13%	13%
Respondent Count	28	47	108	302	485

Dialysis Trips

The survey asked transit agencies how many one-way trips they provided for dialysis in FY 2016. Recognizing that many agencies were not likely to have an exact count, we indicated that "estimates are OK." ² There was a wide range of answers; see Table 5-2.

Not surprisingly, agencies in metro areas reported larger numbers of dialysis trips, with almost one-third reporting more than 50,000 annual dialysis trips. Transit agencies in the other areas indicated fewer annual dialysis trips, with those in rural and small communities most frequently reporting no more than 5,000 annual dialysis trips.

A number of transit agencies in each of the four categories reported *no dialysis trips*. For those agencies, particularly in the urban categories with ADA paratransit, it is not clear if they are actually reporting no trips for dialysis or if they are indicating that they do not collect trip purpose and therefore do not calculate trips for dialysis.

For many of the 27% of rural area agencies that reported *no dialysis trips* (n=79), we could tell from comments added to the survey that a number of those rural providers did mean *no dialysis trips*.

² ADA regulations prohibit any trip purpose prioritization so ADA paratransit providers generally do not ask for trip purpose. The research team appreciates the efforts of a number of transit agencies that gave us an estimate of the number of dialysis trips by analyzing trip destinations for their ADA paratransit service.

Table 5-2: Number of One-Way Dialysis Trips Provided in FY 2016

Number of Trips	Large Metro Area	Large City	Smaller City	Rural/ Small Community
100,001-500,000	19%	3%	1%	-
50,001-100,000	12%	8%	1%	-
10,001-50,000	27%	21%	15%	3%
5,001-10,000	4%	18%	9%	3%
1,001-5,000	4%	21%	42%	22%
501-1,000	4%	5%	9%	12%
100-500	12%	8%	13%	21%
<100	4%	8%	1%	11%
None	15%	8%	9%	27%
Respondent Count	26	38	96	288

We also asked transit agencies to estimate the percent that dialysis trips represent of all specialized/paratransit trips that they provide, which provides some perspective on the scale of dialysis trip demand. The responses are generally similar across the transit agency categories, except the urban transit agencies report greater proportions of dialysis trips than do the agencies in rural areas; see Table 5-3.

According to the transit agency responses, virtually half of the urban agencies and one-third of rural agencies report that dialysis trips are 10% or more of their total trips; and 21% of the metro area agencies, 18% of large city agencies, and 24% of smaller city agencies reported dialysis trips at more than 20% of all their trips.

Table 5-3: Approximately what percent do the dialysis trips represent of all your specialized transportation/paratransit services?

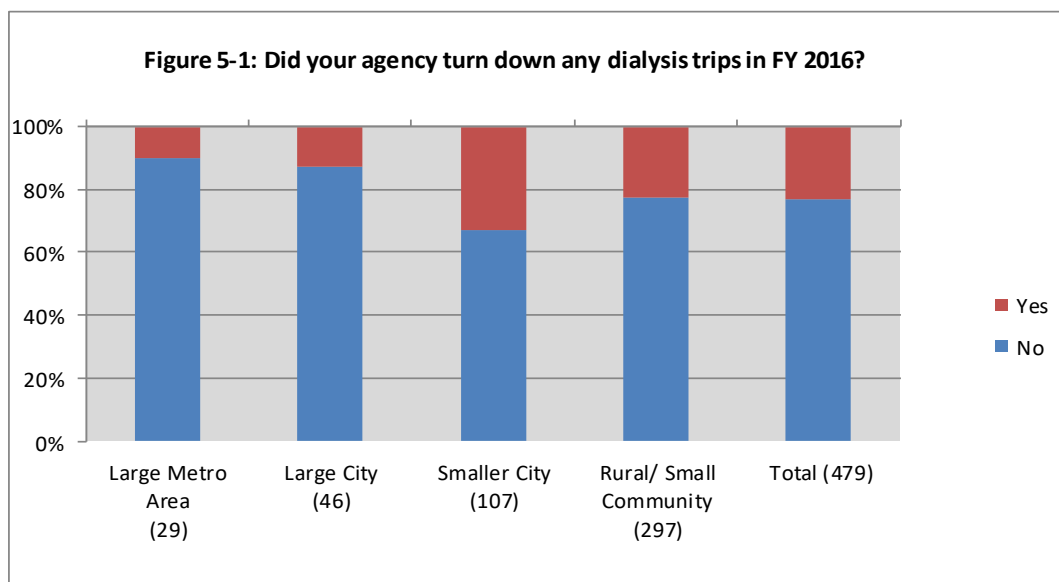
Response Options	Large Metro Area	Large City	Smaller City	Rural/ Small Community	Total
Less than 10 Percent	50%	40%	43%	63%	55%
10-20 Percent	25%	30%	27%	19%	22%
21-30 Percent	13%	13%	10%	7%	9%
31-40 Percent	4%	5%	6%	2%	3%
41-50 Percent	-	-	5%	4%	3%
More than 50 Percent	4%	-	3%	2%	2%
Not Sure	4%	13%	5%	4%	5%
Respondent Count	24	40	99	256	419

Dialysis Trips Denied

We asked the transit agencies if they had turned down any dialysis trips in FY 2016, with the large majority of all the agencies reporting *No*; see Figure 5-1. Particularly for those agencies providing ADA paratransit service, a *No* response would be expected.

Only 10% of the metro area agencies (n=3) indicated turning down any dialysis trips, with the least number of denied trips at 624 and the highest at 10,000. Thirteen percent of large city agencies (n=6) reported turning trips down, ranging from 10 to 1,200 trips.

For smaller city agencies, 33% (n=35) reported that dialysis trips were turned down in FY 2016, from a low of three trips and up to 4,680 trips. And 23% of rural and small community agencies (n=67) reported turning dialysis trips down, from one trip to 1,560 trips.



Reasons for Dialysis Trip Denials

We gave the transit agencies four response options as well as “Other” to explain why they turned down dialysis trips:

- Not enough operating funds
- Not enough vehicles
- Dialysis trip requests were outside the service days and hours
- Dialysis trip requests were outside the service area
- Other

While it was a minority of agencies that reported any turn-downs, the most frequent reason cited by those agencies across the categories is that dialysis trip requests were *outside the agency's service days and hours*.

For the agencies in rural and small community areas, *dialysis trip requests were outside our service area* was the second most frequent and a noteworthy reason reported, which was clear from a number of comments provided by these small agencies, with two quoted below:

We are a tiny agency serving a community that has a population of 15,000 people total, of which approximately 1,800 are seniors and adults with disabilities. We have only had 2 folks who require dialysis, which requires a trip of 2.5 hours driving time one way. We try to accommodate everyone as much as possible but ... we just could not accommodate the trips due to limited resources (personnel, funds, drivers)...

Dialysis treatment is not available in [our island community]. When a person needs dialysis treatment, they have to relocate to the mainland.

Impacts of Dialysis Trip Demand

The transit agencies were asked about the impact of dialysis trip demand on their ability to provide service for other trip purposes; Table 5-4 shows the responses, with multiple responses allowed.

Over one-third – 35% – of responding transit agencies report issues with meeting demand for dialysis trips. This includes 15% reporting that although they meet dialysis trip demand because of ADA regulations, the demand for dialysis trips requires additional service and additional costs. Another 10% of the agencies indicate that dialysis trip demand makes it hard to serve other trips on an average day, and 9% report that they cannot serve other trips during peak periods because dialysis trips require all peak period capacity. Finally, a small 1% but representing five transit agencies report that they no longer serve trips for non-essential purposes because of the demand for dialysis trips.

This question elicited numerous comments under the “Other” option, with about one-quarter of the responding agencies adding comments to this question. Many of the agency comments elaborated on one of the options given, such as this transit agency that noted:

We have added a split shift driver to come in during the peak period because of dialysis trips.

Table 5-4: How has the demand for dialysis trips impacted your ability to provide service for other trip purposes? (Check all that apply)

Response Options	Large Metro Area	Large City	Smaller City	Rural/ Small Community	Total
It has not impacted our ability to serve other trip purposes; we are generally able to serve all our trip demand including dialysis trips.	74%	47%	44%	59%	55%
We meet all trip demand because our service is ADA paratransit, however demand for dialysis trips is requiring additional service and additional costs.	11%	29%	23%	11%	15%
During an average day, it is difficult to serve other trip purposes because dialysis trips are using so much capacity.	11%	4%	20%	7%	10%
During peak times for dialysis trips, it is not possible to serve other trip purposes because demand for dialysis trips uses the capacity.	-	-	18%	9%	9%
Given the demand for dialysis trips, we now limit trip purposes to specifically-defined essential trips only (e.g., medical including dialysis, work, school, etc.) and no longer serve trips for non-essential purposes.	-	2%	-	1%	1%
Other	22%	29%	23%	26%	26%
Respondent Count	27	45	104	292	468

Five respondents gave answers that described problems with scheduling dialysis trips, including, among other problems, that patients are not always ready for their return trip. One of these transit agency respondents said such scheduling problems require:

...significant juggling to accommodate dialysis trips, which then inconveniences other riders and increases staff time [for the adjustments].

Several responses in the “Other” category explained that the agency uses volunteer drivers and that there is difficulty getting enough drivers to meet the demand for dialysis as well as for other medical trips.

And a number of respondents cited the challenges for ADA paratransit service from increasing demand for dialysis trips. According to one transit agency:

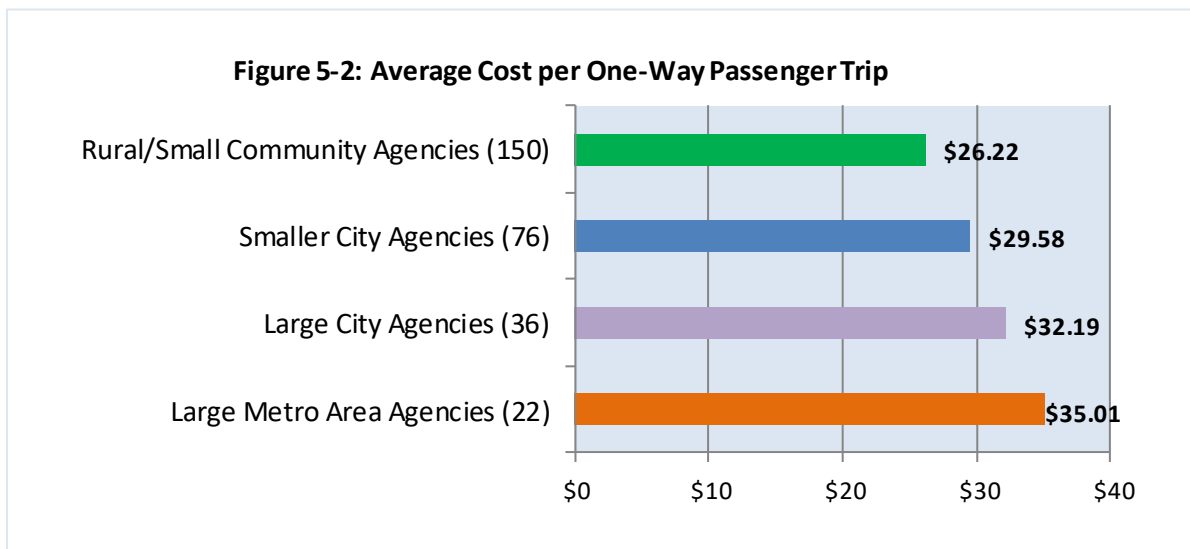
We had a coordinated system [but] Medicaid trips have been removed and more and more people are using ADA paratransit for dialysis because trips provided by the HMOs providers are problematic with long waits and unreliable service so people would rather pay the ADA fare than take a chance of being left at the clinic. This trip dumping puts the burden on the community....rather than the HMOs [that should be providing the transportation].

Costs for Transportation

Average Cost per Trip

The survey asked respondents to report the average cost per one-way passenger trip for their specialized transportation/paratransit trips for FY 2016. Not all agencies answered this question, and we note that some respondents appeared to enter the passenger fare rather than the average per trip operating cost. Thus, figures of \$5 or less were assumed to be the passenger fare and were deleted. And there were a small handful of figures greater than \$200; these also were deleted. The resulting average costs are shown in Figure 5-2. Calculated for all valid responses to the question (n=284), the average cost per trip is \$28.56

One transit agency respondent that did not provide a trip cost figure instead opined about the costs for all its dialysis trips for the year: *"I am sure it is in the tens of thousands of dollars."*



Funding Sources for Dialysis Transportation

Transit agency respondents listed their funding sources, as shown in Table 5-5. The key funding sources are local and state, particularly for agencies in metro areas, large cities and smaller cities. For agencies in rural areas, Federal Section 5311 is the key funding source.

Interestingly, somewhat more than half of the metro area transit agencies reported receipt of Federal Section 5310 funds.

Table 5-5: What funding sources do you use to provide dialysis trips? (Check all that apply)					
Response Options	Large Metro Area	Large City	Smaller City	Rural/ Small Community	Total
Federal Section 5307	19%	21%	36%	1%	12%
Federal Section 5311	15%	12%	31%	61%	47%
Federal Section 5310	54%	26%	32%	19%	25%
State transit funds	27%	60%	41%	44%	44%
State human service agency funds	12%	12%	19%	19%	18%
Local funds	65%	52%	60%	47%	52%
Medicaid funds	19%	17%	29%	36%	31%
Other	23%	24%	23%	25%	24%
Respondent Count	26	42	97	267	432

In addition to the funding source options listed for this question, respondents could also check “Other.” Review of the “Other” responses indicates that more than half reported that the other funding source is either passenger fares or donations.

Additionally, a number of respondents simply added the specific source of state or local funding. And three respondents indicated *Kidney Foundation funding* and two mentioned *United Way funding*.

Other Publicly Funded Providers of Dialysis Transportation

The survey asked respondents to report if there are other publicly funded agencies and providers that serve dialysis trips in their communities, with responses shown in Table 5-6. Medicaid non-emergency transportation (NEMT) providers were most frequently listed when considering all responding transit agencies.

Table 5-6: Are there other publicly-funded agencies or providers in your community that provide dialysis transportation? (Check all that apply)

Response Options	Large Metro Area	Large City	Smaller City	Rural/ Small Community	Total
Yes, Medicaid non-emergency transportation providers	50%	67%	50%	36%	43%
Yes, human service agencies	36%	35%	35%	15%	23%
Probably, but I am not sure	32%	26%	34%	20%	25%
No, I don't think so	14%	7%	14%	41%	30%
Respondent Count	28	43	101	280	452

Effective Practices for Providing Dialysis Transportation

The research study is interested in identifying effective ways to provide dialysis transportation. Towards this end, the survey asked the transit agencies if they have implemented any practices or strategies that result in more effective dialysis transportation for their passengers and for the agency. Responding agencies were almost equally divided between those that said *Yes, we have* (52%) and those that said *No* (48%).

Those answering *Yes* were given a list of seven practices cited in the literature as effective from which to choose. Table 5-7 gives the responses by the four categories of transit agencies, along with the totals across the four categories.

Of the seven listed options for the question, three practices were cited most frequently:

- *Work with dialysis facilities to coordinate patients' treatment times, allowing for grouping of trips for more productive service*
- *Educate dialysis facility staff regarding what we can and cannot do as a transit agency*
- *Educate our dialysis passengers regarding what we can and cannot do to serve their dialysis trips*

The responses by category of transit agency show that working with the dialysis facilities to coordinate patients' treatment times for better grouping of passenger trips is more prevalent for rural agencies and smaller city agencies and, while still practiced, is somewhat less common for metro and large city agencies. It is perhaps easier in a small community to coordinate with dialysis facilities as there might be only a few or maybe just one and therefore easier to develop working relationships with the facility staff.

Table 5-7: Effective practices/strategies for providing dialysis transportation (and please add any others that you use): (Check all that apply).

Response Options	Large Metro Area	Large City	Smaller City	Rural/ Small Community	Totals
Educate dialysis facility staff regarding what we can and cannot do as a transit agency	78%	69%	68%	61%	65%
Educate our dialysis passengers regarding what we can and cannot do to serve their dialysis trips	67%	66%	61%	66%	65%
Increase training for dispatch/scheduling staff and drivers as to dialysis passengers' needs	56%	41%	45%	41%	43%
Provide more flexibility for return trips from dialysis, e.g., allow extra time to wait for passengers	44%	48%	54%	60%	56%
Provide more leeway for dialysis passengers regarding no-shows/late cancels	56%	48%	43%	40%	43%
Work with dialysis facilities to coordinate patients' treatment times, allowing for grouping of trips for more productive service	50%	59%	67%	71%	67%
Work with dialysis facilities or the dialysis passengers so the passengers receive treatment at a dialysis facility closest to their home	28%	28%	32%	32%	31%
Other (please describe). We would very much like to know what you are doing that works!	44%	34%	28%	22%	26%
Respondent Count	18	29	69	158	274

Respondents could also check “Other” and then describe what they are doing that is effective. Many of those describing an “Other” practice or strategy elaborated on one of the practices listed among the choices on the survey, providing more details.

Beyond this, several responses seem worthy of note:

- A non-profit agency in a rural three-county area, serving as the area agency on aging and the public transit provider, is developing a one-call center with a mobility manager with the objective of helping clients, specifically including those on dialysis, navigate transportation. In addition to its own agency-based transportation, the agency is working with volunteers and the faith-based community to provide transportation to meet trip needs for dialysis.
- A transit agency in a smaller city with a user-side/voucher taxi program for its ADA eligible riders provides additional taxi vouchers each month for its riders on dialysis and also waives the waiting period normally in place for ADA riders to use the taxi program. The taxi program gives the riders more flexibility for their return trips, since the trips are scheduled on a real-time basis.
- A transit agency in a large city reports that it schedules as many dialysis patients from the same facility as feasible on the same run, which makes it easier to go back for a patient who was not ready for the originally scheduled return trip, *“since the bus will return again and again.”*
- A large metro area transit agency has found it effective to dedicate one staff member/scheduler just for dialysis transportation.
- A large metro area transit agency has an “open return” policy for three specific trip purposes, including medical trips. Riders wishing an “open return” must inform the scheduler their trip purpose to ensure it fits one of the defined trip purposes and then is to provide an estimated pick-up time for their return trip. If this time changes, the rider contacts the transit agency to re-schedule the trip. If the vehicle happens to arrive before the rider is ready for the return, the rider is not charged with a no-show.

Estimated Annual Costs for Providing Effective Practices and Strategies

We asked the agencies reporting effective practices or strategies for dialysis trips if they could estimate the annual costs for those practices or strategies. Survey results showed that 77 of agencies with effective practices/strategies estimated the associated costs. As shown in Table5-8, a wide range of annual cost estimates was reported.

Table 5-8: Estimated Annual Costs for Providing Effective Practices/ Strategies for Dialysis Transportation

Agency Type	Range	Average	Median
Large Metro Area Agencies (4)	\$1,500-\$4,000,000	\$1,200,375	\$400,000
Large City Agencies (6)	\$500-\$500,000	\$97,000	\$12,500
Smaller City Agencies (20)	\$85-\$250,000	\$27,500	\$6,100
Rural/ Small Community Agencies (47)	\$50-\$312,184	\$29,033	\$2,700

The remaining 121 agencies responding to the question indicated they were not able to provide a cost estimate but checked the following response option:

Not sure of the costs but the practices/ strategies require additional efforts for scheduling, dispatch and other staff compared to efforts for other trip purposes.

Comments

More than 140 agencies responding to the survey added comments at the end, which have been grouped into major themes as shown in Table 5-9. The number of comments associated with each theme is listed, and several sample respondent comments are quoted and shown in italics.

The overriding message from transit agencies is that providing dialysis transportation can be difficult and costly for a number of reasons, including:

- Dialysis trips can be long in terms of distance, often with limited opportunity to group trips for greater productivity.
- Frequently the dialysis passengers are not ready for their scheduled return trip, which means that the driver and vehicle have to wait until the passenger is ready or more often the driver has to leave after the established waiting time (e.g., five minutes) to serve other passengers, which then requires that vehicle or another to go back later for the return trip.
- The treatment schedules for dialysis passengers change, without notification to the transit agency, creating problems for trip scheduling and operations.
- Dialysis passengers often require special attention and care after treatment, so that drivers have to provide more specialized assistance.

A number of the responding transit agencies explained the extra efforts they take to serve their dialysis passengers. One respondent wrote:

“We talk to our [dialysis passengers] and workers at the center to make sure we are doing everything possible to take care of them. We are a small community and drivers get to know and care about all their passengers.”

But not all transit agencies can provide the higher level of support and assistance that dialysis passengers typically need. A transit agency providing ADA paratransit service stated:

Table 5-9: Comments Provided by Survey Respondents, Categorized by Key Issues	Number of Comments
<p>Providing dialysis trips is difficult because passengers are often not ready for the scheduled return trips.</p> <p><i>"The problem we encounter most frequently is that a rider is late getting off dialysis and we have to leave to do other scheduled trips. The rider is then left waiting until the driver is able to go back. I know this is hard on the rider as they are weak or ill and have to spend additional time waiting on a ride."</i></p>	17
<p>Funding is inadequate:</p> <ul style="list-style-type: none"> • Dialysis trips are costly • Impacts on productivity and performance • More funding is needed • Dialysis facilities are located outside the county and the long trips are cost-prohibitive <p><i>"To serve dialysis trips, we have had to put drivers on the road at 4 am, two hours earlier than our previous start time. This places strain on the drivers but also the maintenance team and dispatch team who now need to be ready to react to issues as early as 3:30 am. There is no compensation for this type of operational cost."</i></p>	17
<p>Long trips are required due to distances in rural areas to reach the dialysis facility as well as facilities' scheduling practices for patient treatment times.</p> <p><i>"We have four dialysis centers in our area; it would help if we could transport patients to the closest center to where they live, allowing for more grouping of trips by area and time."</i></p>	16
<p>The transit agency makes extra efforts to provide service for dialysis passengers.</p> <p><i>"We try very hard and put forth the utmost effort to get these patients to their "life dependent" appointments. We assist with scheduling on the side of the patients as well as the dialysis providers to get them to their appointments and home."</i></p>	15
<p>The dialysis facility cooperates with the transit agency regarding scheduling the patients' trips.</p> <p><i>"Dialysis transportation has become a huge issue. The demand is growing but our resources are not. Coordination with the centers is key to trying to provide this service. Chair times need to be set to allow us to get patients to and from their appointments. We have a good relationship with the staff at the center, and they do their best to work with us."</i></p>	13
<p>Providing dialysis trips is difficult because patients' schedules change.</p> <p><i>"Dialysis transportation is high maintenance. We have to work closely with dialysis facilities because their patients' schedules are constantly changing."</i></p>	11
<p>No real problems serving dialysis passengers.</p>	9

Table 5-9: Comments Provided by Survey Respondents, Categorized by Key Issues	Number of Comments
<p>The dialysis facility does not cooperate with the transit agency regarding the scheduling of their patients' trips.</p> <p><i>"The dialysis centers are only concerned with making sure each chair is maximized. The staff puts a lot of pressure on the patients to not be late and are only interested in telling transportation how to get their patients here. They are not at all concerned about ADA and what that means -- no trip priorities."</i></p>	5
<p>Dialysis passengers without Medicaid insurance have problems with the cost of transportation.</p> <p><i>"We have two passengers who must go to a dialysis clinic 30 miles away, however they do not have Medicaid. I have tried to greatly reduce what I would have to charge for their trips to assist them, but they can't even afford the \$20.00 each day that I would have to have (and would still lose money)."</i></p>	4
<p>Transit agency does not or no longer serves dialysis trips.</p>	17

"The structure and policies required for ADA paratransit are the greatest challenge for dialysis patients, particularly for return trips. Policies such as the 30-minute pick-up window and shared-ride nature of the service make it tough, as post-treatment patients are generally physically drained."

One survey respondent listed five bullet points that seem to summarize the challenges of dialysis transportation for transit agencies:

- *"Dialysis changes schedules, for example, for special treatment or holidays"*
- *Patients change schedules--patients must be transported to a medical facility after dialysis, patients leave with family--without notification to the transit agency*
- *Special care is needed with patients on the return trip due to frail status and bleeding*
- *Dialysis patients require trips outside our service area and service hours*
- *The special assistance needs of these passengers go beyond what a public transit driver can provide."*

Another responding transit agency quantified the cost of its dialysis trips, reporting:

"At \$64.40 a trip, it costs us approximately \$20,000 annually to transport a single dialysis patient to and from treatment three days each week. We recoup about \$1,000 in fare revenues for those trips, which are capped at twice the equivalent fixed route fare for the same trip. THIS IS NOT SUSTAINABLE!"

SUMMARY

The survey yielded responses from more than 500 transit agencies: 6% in large metropolitan areas (over 1 million population), 10% in large cities (200,000 to 1 million population), 23% in smaller cities (50,000 to 200,000 population), and the largest number – 61% – in rural and small communities (less than 50,000 population).

Responding agencies provide a range of specialized transportation/paratransit services, with those in metro areas and large cities more likely to provide ADA paratransit and agencies in smaller cities and rural areas more likely to provide general public demand response transportation (DRT). Providing Medicaid NEMT is more prevalent for transit agencies in rural areas, with 42% providing such service. The average cost per trip, according to the survey, ranges from \$26.22 for rural area agencies to \$35.01 for metro area agencies.

Transit agencies estimated the number of dialysis trips provided in FY 2016, with varying numbers reported as would be expected. When asked to estimate the percent that dialysis trips represent of total specialized transportation/paratransit trips, virtually half of the urban transit agencies reported that trips represent 10% or more of all their trips. One-third of the rural area agencies reported that dialysis trips are 10% or more of their total trips. Additionally, 21% of the metro area agencies, 18% of large city agencies, and 24% of smaller city agencies reported dialysis trips at more than 20% of all their trips.

Agencies were also asked if they had turned down any dialysis trips in FY 2016: 77% said *No*, with transit agencies in metro and large city areas more frequently reporting they did not turn down any dialysis trips. This is not unexpected, as these agencies more commonly provide ADA paratransit, with federal regulations prohibiting trip denials for eligible riders.

Over one-third of responding transit agencies – 35% – report issues with meeting the demand for dialysis trips. This includes 15% reporting that although they meet dialysis trip demand because of ADA regulations, the demand for dialysis trips requires additional service and additional costs. Another 10% of the agencies indicate that dialysis trip demand makes it hard to serve other trips on an average day, and 9% report that they cannot serve other trips during peak periods because dialysis trips require all peak period capacity. A small 1% but representing five transit agencies report that they no longer serve trips for non-essential purposes because of the demand for dialysis trips.

About half of surveyed transit agencies (52%) report that they have implemented practices or strategies resulting in more effective dialysis transportation for their passengers and their agency. Three practices were identified most frequently:

- *Work with dialysis facilities to coordinate patients' treatment times, allowing for grouping of trips for more productive service*
- *Educate dialysis facility staff regarding what we can and cannot do as a transit agency*

- *Educate our dialysis passengers regarding what we can and cannot do to serve their dialysis trips*

The many comments added to the survey reveal that dialysis transportation is more complicated and difficult than suggested by some of the survey findings. Comments make clear that demand for dialysis transportation is growing and that the trips require disproportionate attention and resources. Comments from transit agencies across the different sizes of communities referred to:

- Scheduling problems for the return trips from dialysis, as patients are frequently not ready for their return trip, requiring extra efforts to reschedule and provide the trip,
- The extra care and support needed by dialysis patients, particularly after treatment, with several agencies stating that such special assistance is beyond what a transit driver can provide,
- The cost for dialysis trips from the additional efforts required as well as lowered productivity because of longer wait times, extra passenger assistance, limited grouping of passengers due to their passengers' different treatment times and dispersed trip origins, and long travel times to reach dialysis facilities,
- Changing treatment days/times for patients, which then causes scheduling issues for transit agencies.

Some of the growing demand for dialysis trips is not served by transit, as a number of transit agencies report trip requests outside their service hours or their service days. Comments refer to treatment times beginning before 6 a.m. when transit is not yet in service or requests for Saturday trips when transit does not operate.

The comments also highlighted differences between transit agencies in larger cities, particularly those providing ADA paratransit, and agencies in rural and small community areas. Comments from the transit agencies in larger cities providing ADA paratransit and often demand response service for seniors and people with disabilities were more likely to report issues or problems, and several commented about the unfunded shifting of Medicaid NEMT to ADA paratransit. Transit agencies in rural areas more frequently commented that they take the extra efforts needed to serve their dialysis passengers and that they are able coordinate with their community's dialysis facility.

With the growing demand for dialysis transportation, one transit agency suggested what might be an appropriate concluding comment: that it may be “...time for dialysis facilities and transit agencies to gather around the table and find a solution that works.”

Chapter 6

Dialysis Facility Perspective

INTRODUCTION

The research study has included a survey of dialysis facilities, with targeted questions to the facility social workers, with several objectives:

- To collect information about patients' travel modes to and from the facility for treatment and if the patients have problems with transportation;
- To understand the role of the dialysis facilities and their social workers in assisting patients with transportation; and
- To learn if patients who rely on public transportation have issues with transportation that in turn impact patient health.

METHODOLOGY

We worked with the Council of Nephrology Social Workers (CNSW), a professional association of nephrology social workers under the umbrella of the National Kidney Foundation, to administer the survey.



The survey questions, revised after review by our consulting healthcare experts as well as the Panel and the CNSW Executive Committee, were formatted for online completion using SurveyMonkey.

We provided a brief introduction to the study and the survey along with a link to the survey to the Executive Director of the CNSW, who distributed the survey to the CNSW listserve. The dialysis facility social workers were given two weeks to reply; after this two-week time period, we received 262 responses, all of which were usable.

With somewhat more than 600 email addresses of social workers at dialysis facilities in the CNSW listserve, the response rate is estimated at about 40%.¹

¹ The CNSW Executive Director indicated that the Council's listserve has about 700 email addresses of nephrology social workers but not all the included social workers are at dialysis facilities.

SURVEY FINDINGS

Responding social workers represent dialysis facilities in 39 states plus the U.S. territory of American Samoa. The large majority of the represented facilities are located in urban areas, with a smaller number in Census-defined urban clusters, which are population areas adjacent to urbanized areas and can be considered suburban locations. Five of the responding facilities are located in rural areas, which include the respondent in American Samoa.

Figure 6-1 on the following page provides a map depicting the number of responding facilities by state, differentiating their location by urbanized area, urban cluster (suburban), and rural. Note that dialysis facilities in Florida constitute a significant number of all responding facilities, somewhat more than one-third.

The facilities are primarily private, for profit – 75% – with the remaining split between private, not profit (12%) and hospital-based (13%), as shown in Figure 6-2.

Figure 6-2: Type of Dialysis Facility

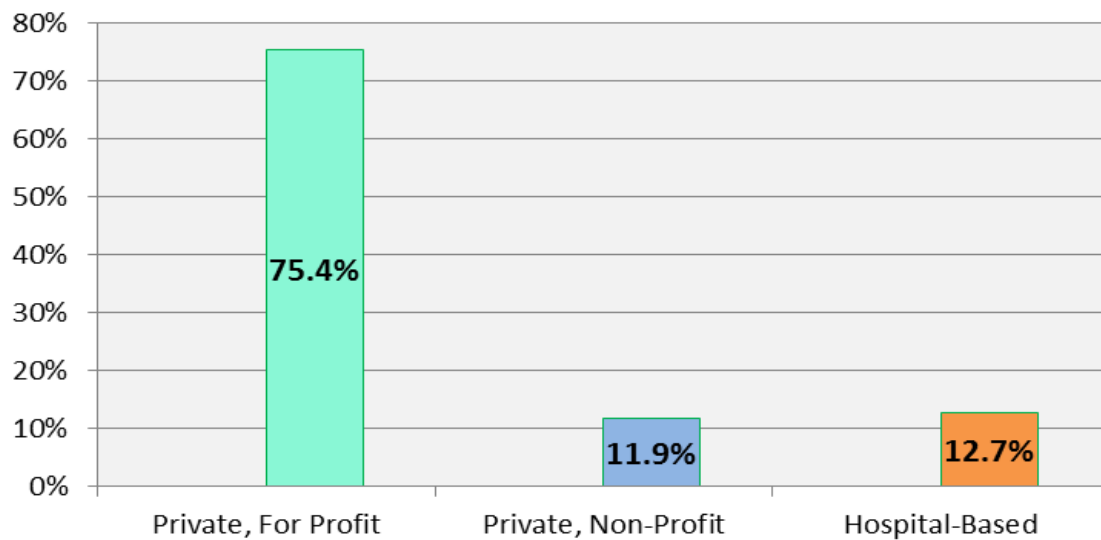
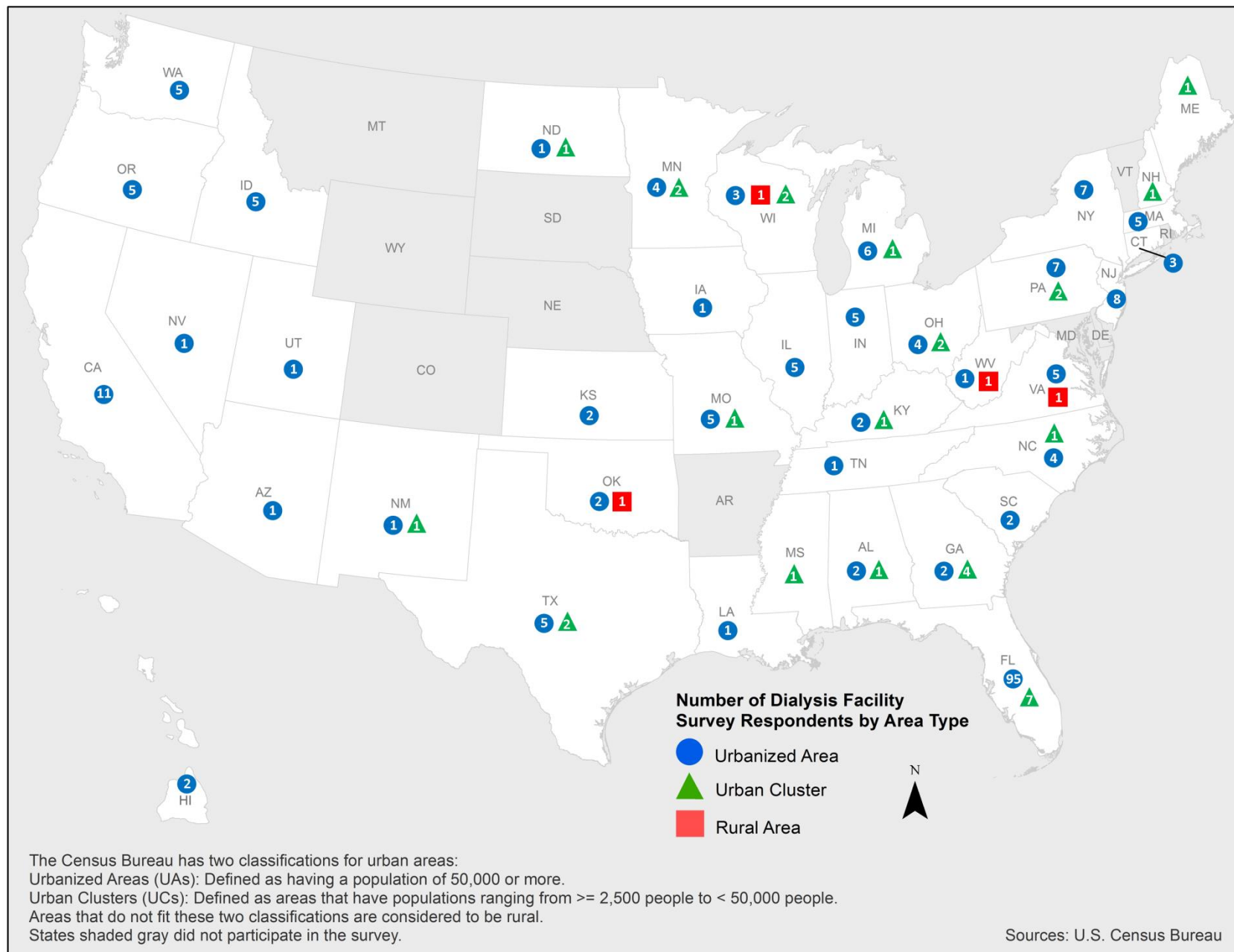


Figure 6-1: Location of Dialysis Facilities Responding to the Survey by State and by Urban/Suburban/Rural Area



The surveyed facilities serve varying numbers of dialysis patients; see Table 6-1. The more typical facilities serve between 60 and 100 patients.

Table 6-1: What is the number of patients currently receiving dialysis treatment at your facility?		
Number of Dialysis Patients	Response Percent	Response Count
1 - 20	6%	15
21 - 40	8%	20
41 - 60	12%	32
61 - 80	17%	44
81 - 100	25%	65
101 - 120	12%	32
121 - 140	7%	19
141 - 160	5%	13
161 - 180	4%	11
181 - 200	2%	5
200+	2%	5
Total Responses	100%	261
Total Respondents	99%	261

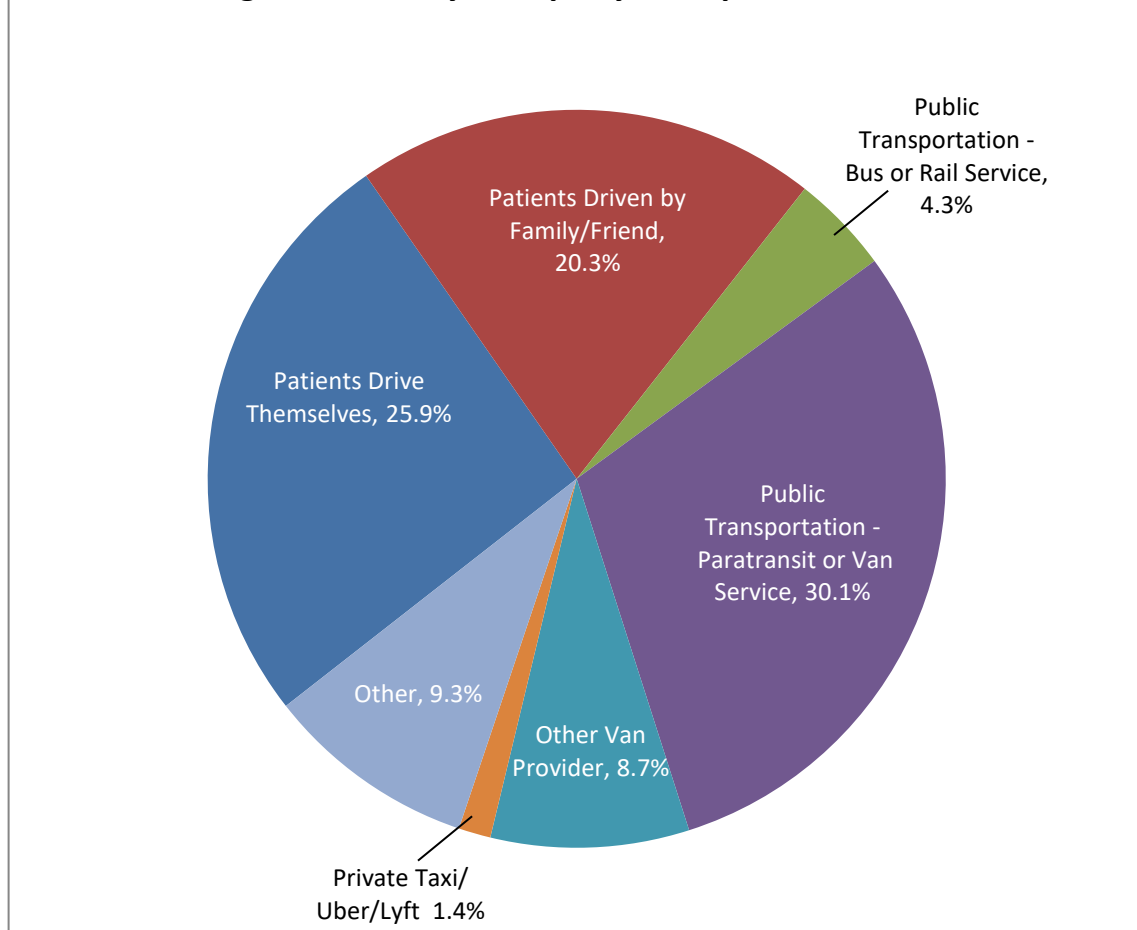
The surveyed social workers were asked about the health insurance of their dialysis patients, with responses showing that 43% of the patients have Medicare, 33% have both Medicare and Medicaid, 12% have Medicaid only, 10% have private insurance and 1% of the patients are uninsured.

Transportation Mode To/From Dialysis Facility

We asked the social workers to indicate the transportation modes their patients use to travel to and from their facility. The predominate modes are:

- Patients drive themselves,
- They are driven by family or friends, and
- They use public transportation paratransit or vans.

We also asked the social workers to estimate the approximate percent of patients using the different modes. Based on the social workers' responses, Figure 6-3 shows the distribution of transportation modes for dialysis trips.

Figure 6-3: Dialysis Trips by Transportation Mode

The survey responses estimate that:

- 30% of trips are provided by public transportation paratransit or van;
- 26% of patients drive themselves;
- 20% of patients are driven by family or friends.

Regarding the remaining modes, the survey responses estimate that 4% take public transportation bus or rail; 9% use another van provider; and 1% use a private taxi or a Transportation Network Company (TNC) such as Uber or Lyft.

The “Other” category shows 9% of the trips. A detailed review of survey respondents’ explanation of the “Other” transportation mode reveals that about half of the “Other” mode is Medicaid non-emergency medical transportation (NEMT). The other half of “Other” is a mix of ambulance transportation, volunteer drivers, an assisted living center or nursing home van, a private duty caretaker, tribal transport, and the VA. Two social workers defined the other mode as “walking” and another two said “bicycle.”

The social workers' responses regarding their patients' transportation modes to and from treatment demonstrate a strong knowledge of how their patients travel. When explaining the "Other" mode, for example, the social workers often provided the name of the Medicaid broker, and one social worker specified that "one patient is transported by the church world service refugee office." Perhaps this knowledge should not be surprising in light of the time and effort that the social workers reportedly spend on patient transportation, a finding illustrated in the comments section of the survey (and detailed later in this chapter).

According to the survey, most dialysis facilities consider patient transportation needs when scheduling treatment, with 74% of social workers responding, *Yes, we consider transportation when scheduling patients*. Another 23% said, *Sometimes*, and just 3% said, *No, we do not take transportation into account for patient scheduling*.

We asked the social workers if they provide assistance with transportation; see Table 6-2. The most frequent types of assistance include providing information about transportation options and helping to arrange transportation, such as helping a patient fill out an application for transportation service and scheduling trips.

A small number of facilities indicated that they provide transportation service (n=6) but they do so only on a "last resort" basis when a patient has no other means. In such cases, a taxicab voucher is provided or, in one case, a social worker noted that Uber is used.

Table 6-2: Does your facility assist patients with transportation to/from the facility for their dialysis treatment? (Check all that apply)

Response Options	Response Percent	Response Count
No, we do not currently provide assistance with transportation.	9.5%	21
Yes, we assist patients by providing information about transportation options.	78.6%	173
Yes, we assist patients by helping to arrange for and schedule transportation.	77.7%	171
Yes, we provide funding/subsidize transportation for patients needing financial help.	5.9%	13
Yes, we help the public transportation provider to group trips by scheduling patients who live near each other for the same treatment time.	8.2%	18
Yes, we provide transportation service for patients who need trips to/from our facility.	2.7%	6
Total Responses (multiple responses allowed)	-	220
Total Respondents	84%	220

Do Patients Have Difficulties with Transportation?

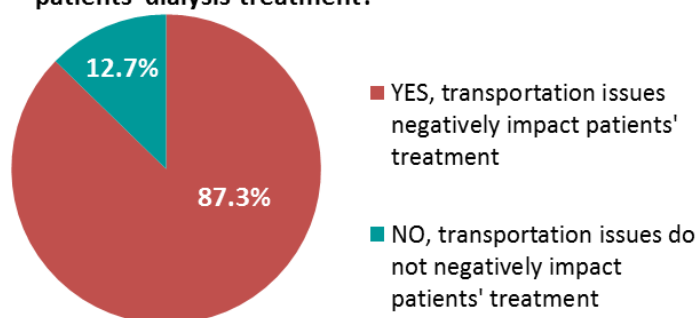
According to the survey, many patients routinely have problems with transportation. Somewhat more than half of the social workers (54%) estimated that more than 20% of their patients have transportation problems. This includes 31 social workers – 14% of respondents to the question – who estimated that more than half of all their patients routinely have transportation difficulties. Responses are shown in Table 6-3.

Table 6-3: Please estimate the percent of your dialysis patients who routinely have difficulties with transportation to and from your facility.		
Percent of Patients	Response Percent	Response Count
Less than 10%	19.4%	42
10-20%	25.8%	56
21-30%	19.4%	42
31-40%	11.5%	25
41-50%	8.3%	18
More than 50%	14.3%	31
Not sure	1.4%	3
Total Responses	100%	217
Total Respondents	83%	217

Do Public Transportation Problems Impact Patients' Dialysis Treatment?

Of particular interest for our research project, we asked if the transportation issues experienced by patients who rely on public transportation buses or paratransit vans have a negative impact on patients' dialysis treatment. Almost 90% (87%) said, *Yes*, with the remaining saying, *No*, as shown in Figure 6-4.

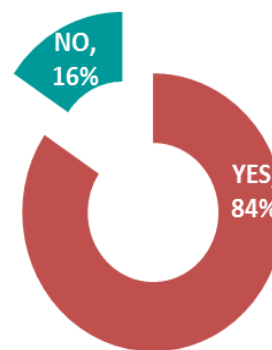
Figure 6-4: For those patients who rely on public transportation buses or paratransit vans, do transportation issues have a negative impact on patients' dialysis treatment?



Those responding *Yes* were then asked two follow-up questions regarding negative impacts of public transportation. Our first question: do patients not receive their full dialysis treatment because they arrive late or leave early?

Two-hundred and twelve social workers answered this question, with 84% saying, *Yes*, their patients' treatment was shortened because the patients arrive late or leave early because of transportation; and the remaining 16% of the social workers said, *No*. (Figure 6-5)

Figure 6-5: Do Public Transportation Issues Result in Shortened Patient Treatments Because They Arrive Late or Leave Early ?



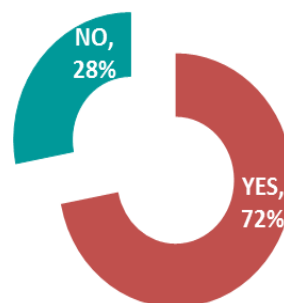
Respondents then estimated the percent of their patients that were impacted in this way in an average month; see Table 6-4. More than two-fifths of the social workers (43%) reported that more than 20% of their patients' treatment is shortened because they arrive late or leave early.

Table 6-4: In an average month, about what percent of patients do not receive their full treatment because they arrive late or leave early?

Response Range	Response Percent	Response Count
No patients are impacted.	4%	8
1% - 10%	33%	69
11% -20%	20%	41
21% - 30%	16%	34
31% - 40%	8%	17
41% - 50%	10%	21
51% - 60%	4%	8
61% - 70%	2%	4
71% - 80%	1%	3
81% - 90%	1%	3
91% - 100%	1%	2
Total Responses	100%	210
Total Respondents	80%	210

Our second question: do patients miss treatments because public transportation is not reliable? Two-hundred and ten social workers answered this question, with 72% saying, Yes, their patients do miss treatments due to unreliable public transportation and the remaining 28% said, No. (Figure 6-6)

Figure 6-6: Do Patients Miss Treatments Because Public Transportation is Not Reliable (e.g., van did not show up)?



Responding social workers then estimated the percent of their patients impacted by unreliable public transportation: more than one-fourth (28%) reported that more than 20% of their patients miss treatments because the transportation is not reliable. See Table 6-5.

Table 6-5: In an average month, about what percent of patients miss treatment due to unreliable public transportation?

Response Range	Response Percent	Response Count
No patients are impacted.	11%	20
1% - 10%	45%	84
11% - 20%	16%	30
21% - 30%	10%	18
31% - 40%	4%	8
41% - 50%	8%	15
51% - 60%	2%	3
61% - 70%	1%	2
71% - 80%	2%	4
81% - 90%	-	0
91% - 100%	1%	1
Total Responses	100%	185
Total Respondents	71%	185

Comments and Summary

The survey concluded with the opportunity for the social workers to add comments, with more than one hundred providing additional insights on dialysis transportation. Table 6-6 categorizes the comments into major themes, showing the count of comments by category along with a number of direct quotes from the social workers that are identified by italics.

These comments summarize the challenges with patient transportation as well as the impacts of those challenges on patients' treatment which in turn impacts patient health and well-being.

The comments also indicate that the dialysis facility social workers spend considerable time dealing with transportation issues, with several suggesting that a preferred approach would be implementation of a transportation service dedicated for dialysis patients, alleviating the stress of transportation for both patients and the dialysis facility social workers and other staff. One social worker wrote:

...it would be nice if dialysis centers were able to have their own transportation company to transport patients which would alleviate a lot of stress on our teammates and patients.

Another social worker suggested that the transportation providers should have a service that catered to dialysis patients since *they have unique considerations*.

The most frequent topic of comments spoke to issues and problems with Medicaid transportation. There were also a number of comments about the lack of transportation for Medicare patients, in particular that such patients often struggle to afford transportation. One social worker wrote:

Having transportation added to Medicare would be a wonderful addition for our dialysis patients.

The social workers also have issues with public paratransit, based on survey comments. At least one comment shows that social workers do not understand the framework in which ADA paratransit operates – that ADA regulations prohibit any prioritization of trips.

Table 6-6: Comments Provided by Survey Respondents, Categorized by Key Issues	
General Comments	Number of Comments
Transportation is a major issue, an ongoing problem and concern.	15
The social workers spend a lot of time dealing with patient transportation. <i>"It is not uncommon that we spend hours a week dealing with problematic transportation issues, which sometimes seems that our position is more transportation manager than social worker with a Master's degree."</i>	14
Limited transportation in rural areas if patients do not have their own transportation. <i>"In a rural area like ours, transportation resources are so limited. The transportation that is available cannot transport patients at typical dialysis times causing patients to have to get off treatment early or start treatment late."</i>	11
Patients on Medicare do not receive transportation. <i>"Most of our patients are on Medicare which does not cover transportation and they cannot afford the private wheelchair van service that can cost up to \$40 per pick-up plus \$3 per mile."</i>	9
Transportation is a big concern and stress for patients. <i>"Transportation problems have a huge impact on our patients. They often report this to be the number one stressor in coping with ESRD."</i>	5
Comments on Transportation Providers	
Medicaid transportation is not reliable.	24
Public paratransit service has problems: <ul style="list-style-type: none"> • days and hours of service are limited; • service area is limited; • the provider cannot cross the county line; • dialysis trips cannot be prioritized. <i>"ADA paratransit services have not been able to prioritize our medically necessary trips that are life sustaining."</i>	10
Taxis are problematic.	2
Transportation for nursing home patients is difficult.	2
Operational Issues That Impact Patients	
Patients have long waits for their trip home. <i>"Some transportation services have patients waiting a very long time after treatment to be picked up. Patients who wait long periods of time after treatment seem to have frequent physical declines."</i>	21
Patients arrive late for treatment.	7
Patients must travel long distances to get to the dialysis unit.	5

Operational Issues That Impact Patients (continued)	Number of Comments
Transportation provider will not wait for patients if they are not ready to leave at the prescheduled time. <i>"The transportation provider waits only five minutes to pick-up patients, even if arriving at the wrong pick up time, and if patients are not ready, they will wait hours before being picked up."</i>	4
Patients start treatment late but end early so they don't miss their ride home. <i>"It is very common to see patients request to come off the machine early for fear they will miss their ride. Our transportation service will only wait five minutes for a patient and when they leave there is no guarantee that they will return. This is very stressful!!"</i>	3
Transportation providers cannot cross city/county/state lines.	3
Scheduling practices mean patients may remain on the van for long periods of time traveling to and/or from dialysis.	2
Cost of Transportation for Patients	
Transportation is expensive, if it is not subsidized by insurance.	11

Significantly, the problems with transportation negatively impact patients' dialysis treatment and therefore their health. According to the survey, transportation providers miss scheduled rides for patients or arrive late at the facility so patients start treatment late. Patients also want to end treatment early so as not to miss their ride home. According to one social worker:

Transportation providers often do not show up or are quite late, both of which tend to decrease the amount of dialysis received by the patient, thereby negatively affecting their health.

Transportation problems also reportedly impact the bottom line for dialysis facilities. Staff that has to stay after hours to wait for patients to be picked up receive overtime pay, and facility performance is marred by treatments missed due to transportation. One social worker commented:

Missed treatments count against the facility but we have no control over the transportation service.

In a few cases, the dialysis facilities provide back-up transportation for their patients when the scheduled provider does not show up or is very late. One survey respondent said that her facility has a pool of donated funds that are used to pay for a taxi trip or to provide bus tickets. Another respondent said her facility will sometime use Uber as a last resort to get a patient home.

Chapter 7

Dialysis Patient Perspective

INTRODUCTION

A survey of dialysis patients was added to the research study to gain information and input from dialysis patients' perspective. Survey questions were designed to collect information from patients who travel to a dialysis facility for treatment and several questions were included for those who have their dialysis treatment at home.

METHODOLOGY

We pursued conduct of the dialysis patient survey with two organizations – the American Association of Kidney Patients (AAKP),¹ and Dialysis Patient Citizens (DPC).² Questions for the survey were reviewed by the Panel as well as our consulting healthcare professionals with revisions made as appropriate. The survey was then formatted for online completion using SurveyMonkey.

The AAKP has a well-developed structure for obtaining patient input, with several options available, each with a cost attached. We choose the option that uses the organization's monthly e-newsletter that reportedly reaches more than 3,000 dialysis patients. We wrote a short paragraph for the e-newsletter, introducing the study, and included a

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Help Remove Roadblocks to Dialysis Transportation - Take This Short Survey & Share Your Thoughts!

A **national study** on **dialysis transportation** is underway and researchers would like to hear from you. The study includes a **short survey** for dialysis patients that will ask how you **get to** and **from** your **dialysis facility** for treatments. The survey has questions for those receiving **in-center dialysis** and those receiving **dialysis at home**.

Survey results will help researchers look at ways to improve transportation for all dialysis patients.

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- Take Dialysis Transportation Survey
- AAKP National Patient Meeting
- IU Researchers Discover New Therapy with Potential to Reverse Damage from AKI
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¹ From the AAKP website: The American Association of Kidney Patients is dedicated to improving the quality of life for kidney patients through education, advocacy and the fostering of patient communities.

² The mission of Dialysis Patient Citizens, according to the organization's website: DPC is a 501(c)(4) non-profit patient organization dedicated to improving dialysis patients' quality of life by developing awareness of dialysis issues, advocating for dialysis patients, promoting favorable public policy and improving the partnership between patients and caregivers. Membership is open only to dialysis and pre-dialysis patients and their families.

direct link to the online survey. Response from the first month (April 2017) was limited, so AAKP ran the article with the survey link again the following month, without charge, and gave the article more prominence in the newsletter. We received 73 responses; findings of this survey are included in this chapter.

We note that the respondents to the survey may not be representative of the larger population of dialysis patients given our survey methodology – an online instrument. This requires that respondents have not only computer technology and skills but also some familiarity with such surveys or at least a willingness to follow a link in an electronic newsletter.

The DPC plans to include some and possibly all our survey questions in the organization's annual survey that is conducted in August. DPC indicated its surveys typically reach a large number of dialysis patients, with more than 500 responses to its 2016 survey. We expect to obtain the results to our survey questions sometime in the fall, at which time we will report the findings, combining results from the two patient surveys.

We also hope to obtain some patient input through our case studies, though that will depend on support from dialysis facilities.

SURVEY FINDINGS

Responding patients were asked their age group. More than half reported ages between 45 and 64 and somewhat more than one-quarter reported ages between 64 and 74, as shown in Table 7-1.

Table 7-1: What is your age group?		
	Response Count	Response Percent
0 to 21	0	--
22-44	5	7%
45-64	37	54%
64-74	19	27%
75 and above	8	12%
Respondent Count	69	100%

We also asked the patients to indicate the size of the community where they live. One-third reported that they live in a large metropolitan area (over one-million population), 14% reported a large city (about 200,000 to one-million population), 30% said a smaller city (about 50,000 to 200,000 population) and 22% indicated a rural area/small community (less than 50,000 population).

Patient respondents were asked the type of dialysis treatment they currently use. As shown in Table 7-2, 75% indicated they use hemodialysis (HD) at a dialysis facility; 18% use peritoneal dialysis (PD) at home, and 7% use HD at home. This reported use of home dialysis is higher than shown by national data. According to the 2016 USRDS Annual Report, in 2014 about 11.6% of prevalent dialysis patients used home dialysis.

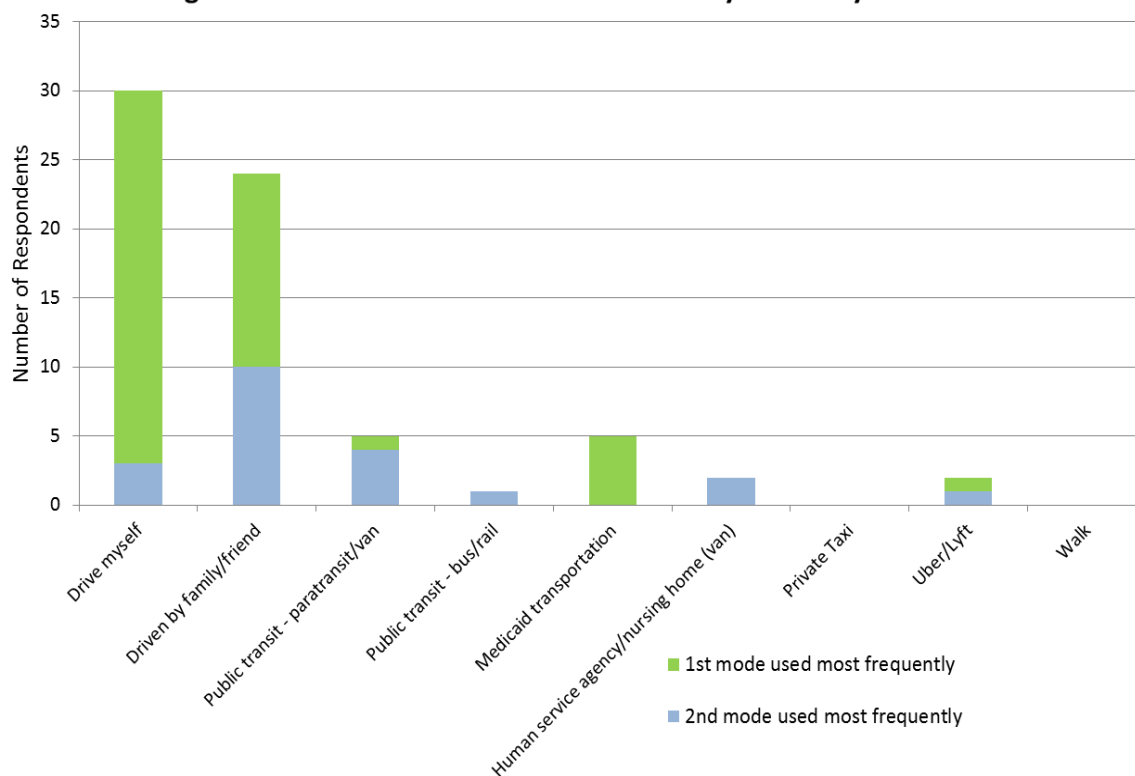
Table 7-2: What type of dialysis do you currently use?

	Response Count	Response Percent
Hemodialysis at a dialysis facility	55	75%
Hemodialysis at home	5	7%
Peritoneal dialysis at home	13	18%
Respondent Count	73	100%

Patients Who Travel to a Dialysis Facility

We asked those patients who go to a dialysis facility which travel mode they use most frequently as well as the second most frequently used mode, with Figure 7-1 showing responses from 48 patients who answered the question.

Figure 7-1: How Patients Travel to Their Dialysis Facility



Patients driving themselves and getting rides from family or friends are the most common primary modes, according to the responding patients. Only one patient indicated that public transit paratransit/van is the most frequently used mode, with another four using the service as a second choice mode. One patient uses public transit bus/rail as the most frequent mode, and five patients use Medicaid transportation as their primary mode.

A comparison of the patients' responses regarding travel mode to their dialysis facility with the modes identified by the nephrology social workers in our dialysis facility survey shows a significant difference: public transit paratransit/van is a minor mode according to the patients' responses. However, according to the social workers, 30% of their patients' trips are by public transit paratransit/van, somewhat more than the 26% of trips by patients who drive themselves and 20% of the trips provided by patients' family or friends.

With a larger number of patients responding to the question – which we hope to achieve with the second patient survey that is planned– information on travel mode may possibly change.

Considerations or Factors Considered in Choosing a Dialysis Facility

The survey asked patients which factors they consider when choosing a dialysis facility for treatment. Respondents clearly chose two factors as more important: *Convenience of the facility's location* was selected most frequently and the *Doctor's recommendation* was the second most frequent factor identified, as shown in Table 7-3.

Table 7-3: Please indicate the considerations or factors that determined which dialysis facility you use for your treatment. (Check all that apply)

	Response Count	Response Percent
My doctor's recommendation	28	54%
My insurance	13	25%
Convenience of the facility's location; it is the closest to where I live	36	69%
Reputation of the facility	11	21%
Other	7	14%
Total Responses (multiple responses allowed)	95	
Respondent Count	52	

Transportation Assistance from the Dialysis Facility

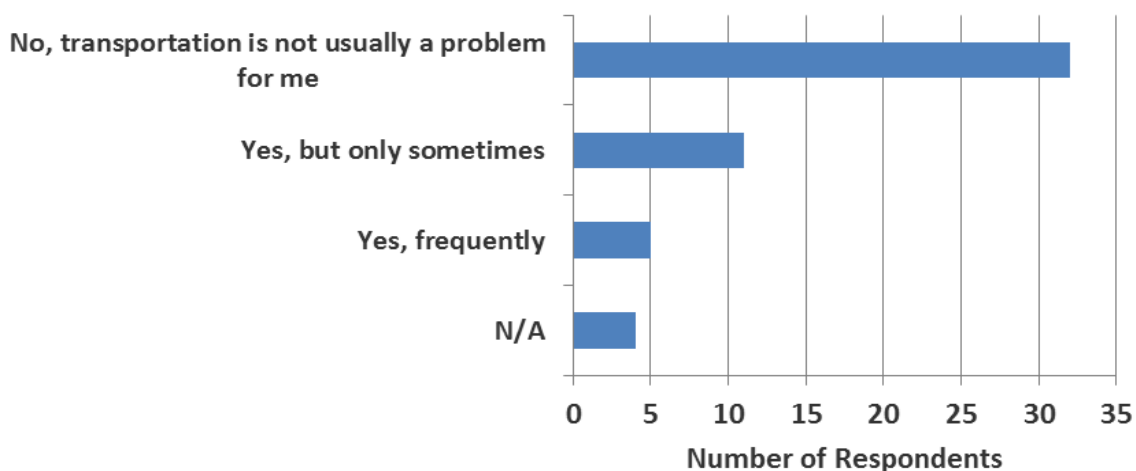
We asked the patients if they had received transportation assistance from their dialysis facility when starting treatment. The most frequent response, from 29 patients, was that assistance with transportation was not needed, not surprising given the number of patients who indicated they drive themselves to dialysis or get rides from family/friends. Twelve patients reported that they were given transportation information by their dialysis facility, and four indicated that their dialysis facility helped arrange and schedule their transportation.

Is Transportation to and from Dialysis a Problem?

When asked if transportation to and from their dialysis facility is currently a problem, most survey respondents reported that it is not usually a problem or the question is not applicable; eleven indicated it's a problem but only sometimes; and five reported that it is frequently a problem; see Figure 7-2.

Of the patients reporting that transportation is frequently a problem, one uses Medicaid as the primary mode and one uses public transit paratransit/van as the primary mode. Two use paratransit as the second mode, and the fifth respondent reported driving to/from dialysis, explaining in the comments that the distance to the dialysis facility is a problem.

Figure 7-2: Is Transportation to/from Dialysis Facility a Problem?



Transportation Impacts on Dialysis Treatment

To assess whether transportation has impacted the patients' dialysis treatment, the survey asked respondents to indicate which among ten possible impacts, if any, had occurred in the past three months due to issues with transportation. The ten impacts included the two we asked in the dialysis facility survey (dialysis treatments are shortened because patients arrive late or leave early and missed treatments because public transportation is unreliable) and mirrored the ten impacts used in the Ride Connection survey of patients.³

³ Improving Transportation for Patients Receiving Dialysis Treatment: A Report on the Findings, Ride Connection, Portland, OR, January 2014.

As indicated in Table 7-4, most of the patients responding to question (40 of 51) reported "not applicable" – that is, they don't have transportation problems. Of the 11 patients that reported impacts, the most frequent included:

- Patients missed a treatment because ride did not show up
- Treatment was shorted because ride arrived late at facility
- Treatment was shortened because patient was worried about missing the ride home
- Treatment was shortened because patient had to leave early to catch the ride home

**Table 7-4: Please indicate if transportation has impacted your dialysis treatment at least once during the previous three months.
(Check all that have occurred at least once in past 3 months.)**

	Response Count
I missed a dialysis treatment because I could not find a ride	1
I missed a dialysis treatment because my ride was canceled or did not show up	5
My dialysis treatment was canceled because my ride was late arriving for my appointment.	1
My treatment was shortened because I was late arriving for my appointment	5
My treatment was shortened because I ended the treatment early since I was worried about missing my ride home	4
I had to leave the dialysis facility before I was ready to leave so I could catch my ride home	4
I was rushed to catch my ride home and, as a result, I had trouble in the vehicle (e.g., bleeding, fainting, etc.)	1
My transportation provider was unwilling to take me home because I was bleeding or had another medical complication	1
I was sent from the dialysis facility to the hospital and had difficulty coordinating my rides	0
I was left waiting at the dialysis facility without a ride home	3
N/A	40
Respondent Count	51

Those patients using Medicaid and public transit paratransit/van reported more transportation impacts on their dialysis treatment than those driving themselves or getting rides from family/friends. However, there were several who get rides from family/friends who did report a few impacts on their treatment due to transportation issues.

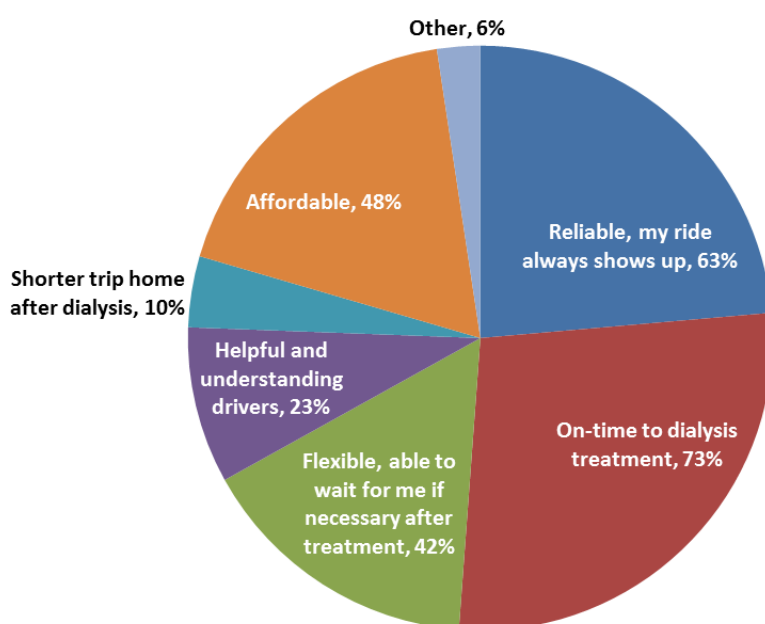
Most Important Characteristics for Dialysis Transportation

We asked the patient respondents to indicate the three more important characteristics for transportation to and from dialysis. According to their responses, the top three are:

- *On-time to dialysis treatment*
- *Reliable - the ride always shows up*
- *Affordable*

Flexible transportation was a close fourth choice.

Figure 7-3: Three Most Important Characteristics for Dialysis Transportation



Patients Who Use Home Dialysis

The survey included three questions for patients who dialyze at home. We received a small number of responses – from 18 patients.

We asked patients the mode of transportation they used during the time they received training for home dialysis. This training typically takes place every weekday for about four weeks. Eight patients reported that they were driven by family/friends; six said they drove themselves; two used public transit bus/rail; and one checked "Other." (The patient clarified that the "Other" mode is ambulance.)

When asked if they had any problems with transportation during the time of their training, eight said "no;" six reported "sometimes;" and three said "yes," they frequently had transportation problems during the time they had training for home dialysis.

The last question asked those on home dialysis if they currently have any problems with transportation for their periodic visits each month to their doctor or the dialysis facility. Eleven said "no," transportation is usually not a problem; four said "yes, sometimes;" and three said "yes, frequently." Of those three patients, two are driven by family/friends and the third is transported by ambulance.

Comments from Patients

Comments from patients who travel to a dialysis center were provided by 17 patients.

Problems with transportation were reported by patients who use Medicaid NEMT and public transit paratransit/van service and, interestingly, by several patients who drive themselves but see other patients having trouble with their transportation service.

Two patients who typically drive themselves commented that low blood pressure after treatment makes that mode of transportation problematic. Nephrologists have concerns about patients driving themselves for that very reason.

Several of the comments are quoted below:

- *"The transportation system companies who arrange the transportation such as _____ are terrible. Oftentimes they make mistakes and cancel your subscription services and such. They need to be monitored much more by Medicaid."*
- *"Some of the transportation providers/business owners and staff are extremely rude and unprofessional and rough handling and uncaring to the health and disabilities of the patients. They cuss at patients. smoke so heavily that respiratory compromised persons such as myself can't breathe. They fail to realize that we are usually weakened after treatments..... Also if we miss our ride home after treatment due to things beyond our control we are left to wait for 2-4 hours before they return to take us home."*
- *"Very concerned that I will not be able to drive myself in the future and will need transportation. I'm aware of all the problems with transportation companies and drivers. It is an added stress to the patient in dialysis."*
- *"I'm glad I can drive myself because when I leave I see people that were done before me waiting for rides."*

There were just a few comments from patients who dialyze at home. A comment from one patient indicated that he had chosen home PD treatment because of the distance he lived from the closest dialysis facility.

SUMMARY

While the number of respondents to our first patient survey was less than we had hoped, the results provide a small window on transportation issues from the patients' perspective. This window, however, should be viewed with recognition that the sample size is small and that the respondents may not be representative of the larger population of dialysis patients.

The survey asked questions of those patients who travel to a dialysis facility for treatment and also of patients who dialyze at home, but our focus is on those who must travel to a facility given their significantly greater need for transportation.

The respondents report much less use of public transportation paratransit/van service than was indicated by our survey of nephrology social workers who reported their patients' mode of travel. Only a small number of patient respondents reported that transportation to and from dialysis is a frequent problem. Perhaps this would be expected given that the predominate modes reported are patients driving themselves and getting rides from family/friends.

Regarding transportation impacts on dialysis treatment, 11 patients out of the 51 responding to the question reported impacts. The most frequently identified impacts result in shortened dialysis treatments (due to late arrivals, leaving early so as not to miss the ride home) and missed treatments because the ride was cancelled or did not show up (in other words, transportation was not reliable). These are the primary problems reported in the literature on transportation problems impacting dialysis patients, and large majorities of social worker respondents to our dialysis facility survey reported that treatments are shortened and missed due to transportation problems.

When we asked patients for the most important characteristics of transportation for dialysis, the top two choices would help address two predominate problems identified for dialysis transportation:

- On-time to dialysis treatment,
- Reliable - the ride always shows up.

Chapter 8

Other Perspectives

INTRODUCTION

Understanding the issues relevant for dialysis transportation requires that the research project consider perspectives beyond those of transit agencies, dialysis facilities and patients, which are documented in the preceding three chapters of this report. Towards this objective, we have undertaken a number of efforts that are reported in this chapter and include:

- Outreach to relevant organizations, including the two listed in the study's RFP – FTA and CMS – for their perspectives and information related to dialysis transportation,
- Review of legislation and healthcare policies, and
- Ongoing discussions with our consulting public health and medical professionals.

ORGANIZATIONS CONTACTED FOR THE RESEARCH PROJECT

Federal Transit Administration (FTA)

Rides to Wellness Demonstration and Innovative Coordinated Access and Mobility Program

The FTA initiated this new funding program, known as Rides to Wellness or R2W, in 2015 specifically targeting transportation to healthcare. It is a discretionary program, funding pilots that aim to improve the coordination of transportation services for access to non-emergency medical care. (The program is discussed in more detail in Chapter 3 of this report.)

R2W grew out of FTA's desire to increase partnerships between health and transportation providers, recognizing that lack of transportation can be a barrier for individuals to get medical treatment particularly for chronic diseases such as ESRD. The FTA defined the goals for the Rides to Wellness program as:

- Increase access to care
- Improve health outcomes
- Reduce healthcare costs

At least one R2W funded project has included dialysis transportation: Northeast Oregon's Public Transit's Rides to Wellness Program. An evaluation of the program analyzed this Rides to Wellness program (implemented as a pilot), documenting the effectiveness of the transportation service, estimating the remaining unmet need for medical transportation, and

provided a business case for the project.¹ The study authors assumed that the transit agency would want to scale up the program and find long-term, sustainable funding sources. The report concludes that the pilot, serving a rural county, is a successful example of the federal Rides to Wellness program and an illustration of use of a pilot as a catalyst for a community to find ongoing funding for an effective and well-received service.

The R2W focus on improving access to healthcare has been bolstered by FTA's recent efforts to re-energize transportation coordination at the federal level through the now-named Coordinating Council on Access and Mobility.

Coordinating Council on Access and Mobility (CCAM)

The FTA has pursued coordination with its sister federal agencies since the 1980s, including the Department of Health and Human Services (HHS), which provides numerous programs with funding for specialized transportation including transportation for healthcare.

Significantly, HHS includes the Centers for Medicare and Medicaid Services (CMS), which administers the Medicaid program and Medicaid's non-emergency transportation (NEMT) benefit in partnership with the states. Medicaid NEMT is a key provider of transportation for dialysis patients.

Building on earlier federal efforts that had established the first coordinating council in 1986, the 2015 federal Fixing America's Surface Transportation (FAST) Act directed the Coordinating Council on Access and Mobility to develop a strategic plan to strengthen interagency coordination and propose changes to federal laws and regulations to eliminate barriers to local transportation coordination.

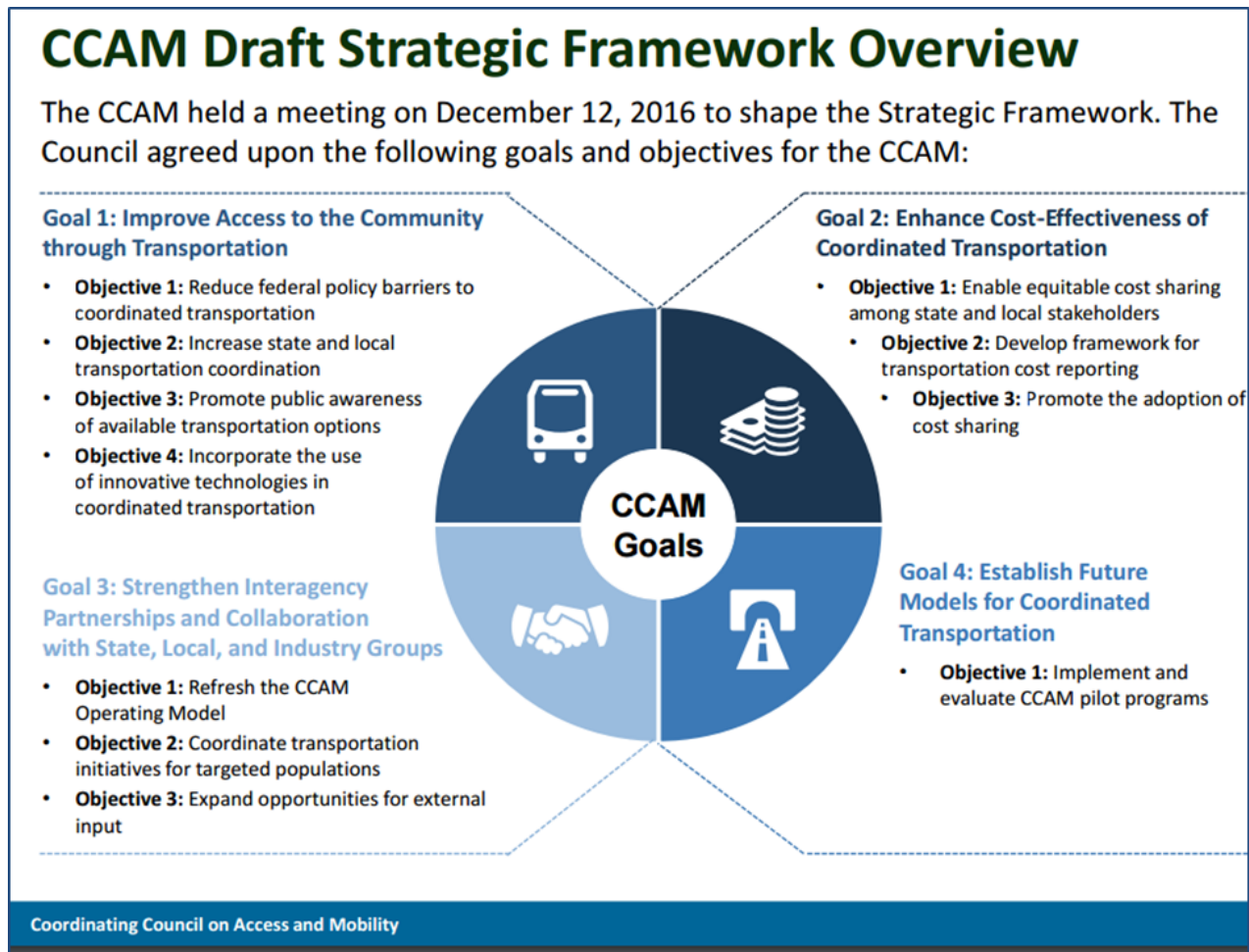
The FTA and its designated staff moved quickly to develop the required strategic plan and then to pursue the goals and objectives developed through the strategic planning process; see Exhibit 8-1, an excerpt from a CCAM February 1, 2017 PowerPoint presentation.

Among CCAM efforts relevant to this research project, FTA staff has held several "listening sessions" that have focused on NEMT.

The first listening session was held in conjunction with CMS for state Medicaid directors in November 2016. This was followed by a session with transportation providers in January 2017 and with state departments of transportation (DOTs) in February 2017.

¹ Gap Analysis and Cost-Benefit Modeling: Northeast Oregon Public Transit's Ride to Wellness Program, pre-pared by Ducote Consulting, LLC, June 30, 2016.

Exhibit 8-1: CCA Strategic Framework, Draft



Minutes from the February 2017 listening session² highlight some of the issues facing attempts to coordinate public transportation with Medicaid NEMT:

- A representative from Washington State's DOT indicated that the state has had problems coordinating ADA paratransit service with Medicaid NEMT, even though the state had developed a method and formula for coordinating trips. Apparently, support from CMS was lacking.
- A representative from the Connecticut DOT indicated similar issues and noted that bringing together state agencies to coordinate NEMT was challenging "due to a lack of resources and political will."

The minutes also include a listing of questions and answers arising from the sessions. Relevant postings are shown below.

² <https://www.transit.dot.gov/sites/fta.dot.gov/files/docs/CCAM-State-DOT-Input-Session-Notes%202.1.17.pdf>

- **"What are the key takeaways from the listening sessions so far?** Many are frustrated by the lack of progress made and are hoping that the strategic plan will bring about real change."
- **"Are state Medicaid agencies willing to participate in state coordinating councils?** The state Medicaid agencies actively participated in the Listening Session hosted by CMS and FTA, demonstrating an interest in coordination. There is natural hesitation among state Medicaid directors because this has not been a typical partnership in the past."
- **"Many states struggle to commingle rides with ADA paratransit program. Will the CCAM address this and provide guidance to states?** Yes, the Council will consider this challenge."
- **"In our state, 75% of Medicaid beneficiaries are covered by managed care plans. How will the CCAM engage managed care plans?** The Council is aware of this challenge and will work with CMS to address it."

Additional listening sessions on NEMT are planned, including one targeting NEMT brokers and one targeting Medicaid beneficiaries

RTAP

The research team spoke about early efforts of the TCRP research project at the spring meeting of the RTAP Board, held in Washington, D.C. in April 2017. At the request of the RTAP Executive Director, an informal briefing was provided, with some preliminary results verbally outlined from one of the study's surveys. There followed a limited discussion of dialysis transportation, and a noteworthy study from Oregon on transportation to healthcare, with a focus on chronic diseases, was identified. (This study is noted earlier in this chapter under the FTA heading.)

Community Transportation Association of America (CTAA)

We reached out to CTAA to ask about the organization's current efforts that might be relevant to the research project and also to see if CTAA might know of any transit agencies that are pursuing services or strategies that might be particularly effective or noteworthy regarding dialysis transportation.

CTAA is closely following the new Administration's plans for changing or replacing the ACA and indicated that it did not plan to get actively involved in the policy debates; but it believes strongly that transportation and mobility must be part of the next health care bill.

CTAA reported that it is working with one of the country's major health insurance companies to plan possible transportation pilots, including one pilot that would specifically address dialysis transportation.

The organization also gave us a couple of suggestions of transit agencies that may have effective or at least interesting practices related to dialysis transportation, and we have followed up as appropriate.

CMS

With support from the FTA liaison on the research project's Panel, we had an informal telephone discussion with CMS staff who have responsibilities for Medicaid NEMT. Several highlights of the draft findings of two of the study's surveys were shared. We talked generally about dialysis transportation as well as the federal framework for Medicaid's NEMT service.

LEGISLATION AND POLICIES

Healthcare in the United States - An Evolving Industry

Healthcare in our country has become a prominent topic for a variety of reasons. Beyond debates current and past, what is worth remembering is the growing attention of the healthcare industry on improved outcomes supported by value-based payment for healthcare services. There is an evolving shift from the more traditional volume-based, fee-for-service model to one where government payments are linked to the performance of healthcare providers.

This attention to healthcare quality, most recently captured by the 2010 Affordable Care Act (ACA), follows many years' experience from cumulative efforts. According to one report, the origins of the quality movement can be traced back as far to the 19th Century doctor "who championed the importance of hand washing in medical care."³

Some of the efforts in the more recent past include, for example, Medicare's Professional Standards Review Organization in 1972, followed by quality control Peer Review Organizations (PROs) in 1983, which could not only identify problems but had the authority to implement solutions and mete out discipline, such as the loss of Medicare billing privileges. (PROs continue to have a role in the ACA.)

³ A Brief History of Quality Movement in US Healthcare, Y. Marjoua and K.Bozic, in Curr Rev Musculoskelet Med, 2012 Dec. 5(4): 265-273.

The years 1995 to 2000 produced several quality improvement initiatives, task forces and reports, including the National Quality Forum in 1999, a non-profit organization with a mission to improve U.S. healthcare quality.

Measuring healthcare quality began with seminal work by Dr. Avedis Donabedian with publication of research in 1966 describing a model that relies on the elements of structure, process and outcome to measure the quality of healthcare provided. This model provides the foundation of current methods used for evaluating healthcare quality.⁴

Efforts in the early 2000's included healthcare reporting systems that enabled quality measurement, such as the 2003 Hospital Inpatient Reporting program, intended to give the public and patients information on healthcare quality so they could make informed decisions about their healthcare. The reporting program was also intended to encourage hospitals and providers to improve in-patient care with the incentive of higher annual updates to their payment rates.

This focus on quality became one of the centerpieces of the ACA, enacted in 2010. The law has various provisions that are designed to change the way care is delivered to Medicare and Medicaid patients as well as to change the provider payment system.

A guiding framework for the federal government agency charged with administering Medicare and Medicaid – CMS – is the “Triple Aim,” a term that originated with a 2008 study by the Institute for Healthcare Improvement (IHI).⁵ The Triple Aim was envisioned as a guide to develop new approaches for healthcare with three components: improve the patient experience; improve population health; and reduce per capita cost. (The shorthand version, often seen in the literature, is *better care, lower costs, and improved health*.) One of the study authors, Dr. Don Berwick, led CMS's implementation of the ACA from 2010 to 2011.

The Affordable Care Act

The Patient Protection and Affordable Care Act of 2010 and the related Health Care and Education Reconciliation Act of 2010 – jointly referred to as the Affordable Care Act or ACA – brought major change to the way that healthcare is delivered and financed in the country. Significantly, the ACA expanded Medicaid eligibility beginning in 2014 to legal residents (for at least five years) under age 65 in families with incomes below 133% percent of the federal poverty level. These individuals made up about half of the country's uninsured. It also created new insurance markets for people who were between 133-400% of the federal poverty level.

⁴ A Brief History of Quality Movement in US Healthcare

⁵ The Triple Aim: Care, Health and Cost, D. Berwick, T. Nolan and J. Whittington, Health Affairs, May 2008, vol. 27, no.3, 759-769.

The ACA provided 100% federal funding for those newly eligible for Medicaid from 2014 to 2016 and then phased down the federal share to 90% by 2020 and beyond. In general, the U.S. Supreme Court upheld the ACA's provisions in 2012 but ruled that states could not be required to implement the Medicaid expansion as a condition of continuing to operate their existing Medicaid programs and receiving federal financial participation. In effect, this ruling made the expansion of Medicaid optional for each state. As of March 2017, 31 states and the District of Columbia have adopted the Medicaid expansion and are known as the *expansion states*.

ACA Accelerates Movement Towards Value-Based Payment Model

Beyond insuring more Americans, the ACA accelerated a movement to change the way healthcare is delivered. Rather than relying on the more traditional fee-for-service (FFS) medicine, where each procedure, exam and prescription has a price, the ACA moves towards a value-based payment model in Medicare, where payments are tied to the quality and efficiency of care provided by health care organizations and professional. The ACA also moves towards “alternative payment models” that make healthcare providers accountable for the outcomes.⁶

This movement includes a focus on preventive care – on taking responsibility for patients’ health when they are in the hospital but also while they are in the community. One of the country’s largest healthcare systems, which is documenting its innovative efforts in this movement, reports that formerly the best scenario for health care systems and providers was “*having lots of sick patients in the hospital*” but now that “*has been turned on its head. Now the ideal is to have lots of healthy people in their homes.*”⁷

The ACA gave the federal government the authority to test new models of healthcare by establishing the Center for Medicare and Medicaid Innovation (CMMI), which was funded at \$10 billion for ten years. This Center is funding a range of demonstrations and model projects. One of its objectives is to tie payments to the quality of care rather than the quantity, with a focus on primary care as well as the social determinants of health. One example in the hospital sector is the Medicare Hospital Readmission Reduction Program, which penalizes hospitals with higher than average readmission rates. In 2016, more than half of the nation’s hospitals returned payments to CMS totaling more than \$500 million.

CMMI’s New Models of Healthcare

The demonstrations and projects are testing new health care payment and service delivery models with an emphasis on care coordination and “patient-centeredness.” There is

⁶ United States Health Care Reform—Progress to Date and Next Steps, by Barack Obama, 8-2-2016 at <http://jamanetwork.com/journals/jama/fullarticle/2533698>

⁷ Disrupting the Status Quo: Northwell Health’s Mission to Reshape the Future of Health Care, by Charles Kenney, CRC Press, 2017.

recognition that the projects could increase costs initially, but over time they are expected to improve quality without increasing spending, reduce spending without reducing quality, or both.

The models being tested are organized into seven categories; see Exhibit 8-2. Several of the demonstrations and projects funded through CMMI deserve mention as they include demonstrations that address dialysis or specifically include transportation for healthcare access. Even innovations that do not currently support transportation may be targets for enhanced enabling services such as transportation since their goals are to advance whole health at the population level.

Accountable Care

The Accountable Care category features groups of doctors, hospitals, and other healthcare providers that come together voluntarily to give coordinated care to Medicare patients. Coordinated care helps ensure patients, especially those with chronic conditions, get the right care at the right time, with the goal of avoiding unnecessary duplication of services and preventing medical errors. An Accountable Care Organization (ACO) that succeeds in both providing high-quality care and spending more wisely will share in the Medicare savings realized. However, if the ACO does not succeed in achieving the established metrics, it must return money. The risk is shared.

Among ACOs is the **Comprehensive ESRD Care Initiative** for Medicare beneficiaries on dialysis. The model "comprehensively addresses the full spectrum of Medicare ESRD beneficiary health care needs by creating financial incentives for dialysis facilities, nephrologists, other Medicare providers, and ESRD stakeholders to coordinate care for these beneficiaries."⁸ This includes the coordination of care "across the full range of clinical and non-clinical support services and across providers and settings."⁹

According to CMS, ESRD beneficiaries comprised 1.2% of the Medicare population in 2013 and accounted for an estimated 6.3% of total Medicare spending, totaling over \$30.9 billion. CMS further reports that the high costs for these patients are often caused by "underlying disease complications and multiple co-morbidities, which can lead to high rates of hospital admission and readmissions, as well as a mortality rate that is much higher than the general Medicare population."¹⁰

⁸ <https://innovation.cms.gov/Files/fact-sheet/cec-py2.pdf>

⁹ Ibid.

¹⁰ <https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2013-Fact-sheets-items/2013-02-04.html>

Exhibit 8-2: CMMI's Innovation Models ¹¹

- **Accountable Care**

Accountable Care Organizations and similar care models are designed to incentivize health care providers to become accountable for a patient population and to invest in infrastructure and redesigned care processes that provide for coordinated care, high quality and efficient service delivery.

- **Episode-based Payment Initiatives**

Under these models, health care providers are held accountable for the cost and quality of care beneficiaries receive during an episode of care, which usually begins with a triggering health care event (such as a hospitalization or chemotherapy administration) and extends for a limited period of time thereafter.

- **Primary Care Transformation**

Primary care providers are a key point of contact for patients' health care needs. Strengthening and increasing access to primary care is critical to promoting health and reducing overall health care costs. Advanced primary care practices – also called “medical homes” – utilize a team-based approach, while emphasizing prevention, health information technology, care coordination, and shared decision making among patients and their providers.

- **Initiatives Focused on the Medicaid and CHIP Population**

Medicaid and the Children's Health Insurance Program (CHIP) are administered by the states but are jointly funded by the federal government and states. Initiatives in this category are administered by the participating states.

- **Initiatives Focused on the Medicare-Medicaid Enrollees**

The Medicare and Medicaid programs were designed with distinct purposes. Individuals enrolled in both Medicare and Medicaid (the “dual eligibles”) account for a disproportionate share of the programs' expenditures. A fully integrated, person-centered system of care that ensures that all their needs are met could better serve this population in a high quality, cost effective manner.

- **Initiatives to Accelerate the Development and Testing of New Payment and Service Delivery Models**

Many innovations necessary to improve the health care system will come from local communities and health care leaders from across the entire country. By partnering with these local and regional stakeholders, CMS can help accelerate the testing of models today that may be the next breakthrough tomorrow.

- **Initiatives to Speed the Adoption of Best Practices**

Recent studies indicate that it takes nearly 17 years on average before best practices - backed by research - are incorporated into widespread clinical practice—and even then the application of the knowledge is very uneven. The Innovation Center is partnering with a broad range of health care providers, federal agencies professional societies and other experts and stakeholders to test new models for disseminating evidence-based best practices and significantly increasing the speed of adoption.

¹¹ <https://innovation.cms.gov/initiatives/index.html#views=models>

There are 37 projects testing the **Comprehensive ESRD Care Initiative**. Available online information does not provide any indication of whether transportation is part of any of the 37 projects, so we contacted CMS staff listed for this initiative in June 2017 for more information, specifically inquiring about transportation. We were told that CMS was not able to share information at this point since data was still being analyzed and that evaluation data for the first year of the model would be available "in fall 2017." We plan to follow up at that time.

Accountable Health Communities

Another initiative is the **Accountable Health Communities (AHC)** Model. This model addresses a gap between patients' clinical care and community services by testing whether healthcare costs can be impacted and healthcare use reduced by addressing the social needs of patients that impact health. The social needs specifically include transportation.

The AHC model is based on evidence that addressing health-related social needs – the social determinants of health – through enhanced clinical-community links can improve health outcomes and reduce costs. Transportation is one of these health-related social needs, without which there may be problems, including an increased risk that individuals may develop chronic conditions; and a reduced ability for individuals to manage those conditions. These in turn will increase healthcare costs and lead to avoidable healthcare use.

While the funding for the AHC model was announced in 2016, CMS did not select organizations to test the model until 2017. According to a press release in April 2017, 32 organizations will be testing the Accountable Health Communities model over a five-year period. Three levels or stages of interventions are to be tested with this model that "promote collaboration between clinical care and community services providers:

- screening community-dwelling Medicaid and Medicare beneficiaries for unmet health-related social needs;
- linking beneficiaries to needed community services; and
- encouraging alignment between clinical and community services to ensure that needed services are available to beneficiaries." The unmet social needs include "housing instability, food insecurity, utility needs, interpersonal violence and *transportation needs*." ¹² [italics added]

We have reached out to the Manager at CMMI's AHC Grant Program office to ask about the role of transportation in the funded pilots and in particular if any of the pilots involve treatment for ESRD, but have not yet heard back.

Other accountable health community initiatives are already underway across the country. For example, the Merced County (CA) Health Department is participating in a partnership with community groups to improve health for residents with cardiovascular disease, diabetes and

¹² <https://innovation.cms.gov/initiatives/ahcm>

related depression that includes improvements in the transportation infrastructure. The California Accountable Communities for Health Initiative is funded by a consortium of health foundations to advance better health and access to social services, including transportation, in six California counties.

Demonstration Model for Patients with Advanced Chronic Kidney Disease

Our research on the CMMI demonstration models found one awarded to the North Shore–Long Island Jewish Health System in New York (now called Northwell Health Systems) for its project called **Health Transitions**, which addresses patients with advanced chronic kidney disease (CKD). This project focuses on patient education and care management to delay ESRD and helps patients make informed choices about treatment options for ESRD. It is also designed to improve the quality of care and reduce costs for Medicare. The demonstration is interesting in that it added palliative care as One of the treatment modalities.

According to the project description, patients must be referred to the program early enough in the progression of their kidney disease so that they may benefit from the program’s interventions. If patients are referred too late, there is little time before they must start dialysis, typically losing the opportunity for an educated choice of modality.

The Healthy Transitions project includes a greater reliance on nurse care managers rather than the nephrologist-based care model, where the nurse care managers can have a more personal relationship with patients and guide them through the complex care system for improved outcomes and better preparation for ESRD, with a goal of ultimately lower costs.

In helping patients navigate the care system, the different modalities for advanced CKD are explained. Regarding the option of home dialysis, the model includes home visits to determine whether the patient has sufficient family support and an adequate home environment to support peritoneal dialysis.

The project specifically includes what it terms *conservative care*, which is the palliative approach and the patient receives no dialysis. According to one of the project’s staff members:

“We cannot offer dialysis to everybody—the 96-year-olds—it’s not the right thing to do. We’re not giving people a dignified end to their life; we’re causing them, very often, a lot of pain and discomfort. The medical science on this has evolved very quickly... What the science has shown now . . . is that for people over 80 who have comorbidities, you live just as long whether you do dialysis or whether you do conservative management.”¹³

¹³ HCIA Round Two Evaluation: North Shore-Long Island Jewish Health System, submitted to CMMI by Mathematica Policy Research, August 2016 at <https://downloads.cms.gov/files/cmmi/hcia2-yroneevalrpt.pdf>

What's Next After the Affordable Care Act?

Changes to the ACA have been debated and, as of July 2017, it is not clear what comes next. One point of interest is that the American Health Care Act in March 2017, the version of reform-and-replace legislation passed by the House of Representatives, kept the CMMI, despite being targeted for elimination in Paul Ryan's health reform proposal, A Better Way.¹⁴

It seems clear, however, that changes to the country's healthcare system will target Medicaid and not Medicare. Congressional bills that have been written as of June 2017 change Medicaid from an entitlement program to either a set a per-person limit on spending or lump sum payment to states. The bills would, in effect, end the Medicaid expansion provided by the ACA, by greatly reducing federal payments for the expansion beneficiaries after 2020. Significantly, the bills give more flexibility to the states to change their Medicaid programs.

According to the Congressional Budget Office's analysis of the American Health Care Act of 2017, enrollment in Medicaid would also drop, as states make it harder to qualify for the program and likely eliminate certain benefits to adjust for the lowered federal contribution.¹⁵

Relationship Between Medicaid NEMT and Public Transit's ADA Paratransit

With the Medicaid program targeted for change, it is possible that the role of Medicaid's NEMT may change. There was a House bill introduced in March 2017 that eliminated the assurance of transportation from Medicaid,¹⁶ however so far the bill has not moved forward.

Recognizing that the role of transportation for Medicaid beneficiary access to healthcare has been firmly established by case law, it is likely that at least some Medicaid patients will continue to be eligible for NEMT. Assuming this is the case, the efforts to pursue coordination between Medicaid NEMT and public transit agencies (and particularly their ADA paratransit services) – which have been underway for many years – will continue.

Medicaid Guidebook in 1998 Suggested a Negotiated Rate for NEMT Trips on ADA Paratransit

Medicaid recognized the ADA paratransit/ Medicaid NEMT connection in the early years of the ADA, as public transit agencies raised the prospect that Medicaid NEMT trips might be shifted to ADA paratransit. A technical advisory group of state Medicaid transportation managers published a guidebook for Medicaid NEMT in 1998, which addressed the possible shifting, recognized that ADA paratransit can charge only twice the fare for fixed route, and

¹⁴ http://abetterway.speaker.gov/_assets/pdf/ABetterWay-HealthCare-PolicyPaper.pdf

¹⁵ <https://www.cbo.gov/publication/52752>

¹⁶ H.R. 1394 introduced by Susan Brooks of Indiana.

suggested that states could negotiate rates with transit agencies for Medicaid NEMT trips on ADA paratransit that are more than the ADA fare.

As explained in the guidebook:¹⁷

The ADA's "requirements have severely strained the fiscal resources of public transportation agencies due to the substantial capital investment and high operating costs of paratransit systems. The limits placed on how much local transportation agencies can charge for their services under ADA regulations is an issue that affects access to public transportation for ADA eligible Medicaid clients. If these limits are determined to apply to trips provided to ADA-eligible Medicaid clients, transportation providers will be less likely to help Medicaid programs develop public transportation alternatives. In recognition of this fact, several regional offices of HCFA [CMS's original name] have sent letters to states informing them that Medicaid can pay transportation providers a negotiated rate based on the cost of providing the service....

One way states can ensure that the fiscal burden of transporting clients is not unfairly placed on ADA-paratransit services is by negotiating rates with the transit agency providing services. The ADA allows agencies to negotiate rates for providing ADA-paratransit services to clients."

CMS Ruling in 2008 Implementing the 2005 Deficit Reduction Act Permits Brokers and a Negotiated Rate for NEMT Trips on ADA Paratransit

While the Medicaid guidebook is no longer in print, the suggestion that states negotiate rates with public transit agencies for Medicaid NEMT trips on ADA paratransit remains a viable option, as provided through CMS's 2008 Final Rule implementing section 6083 of the Deficit Reduction Act of 2005. This ruling allowed states to amend their Medicaid state plans to establish a non-emergency medical transportation brokerage program, and it specifically addressed payment for trips on ADA paratransit. Accordingly, a broker is to pay "no more for public paratransit services than the rate charged to other State human service agencies for comparable services." While this rate will typically not cover the full cost of providing an ADA paratransit trip, it would be more than the rider's fare.

Despite the CMS ruling, such negotiated payment arrangements between state Medicaid agencies and public transit agencies are not common. Forty states and Washington, D.C. use Medicaid NEMT brokers, many of them private entities contracted on a capitated basis. Under a capitation structure, the broker has an incentive to work for the "best deal" it can when selecting and using transportation providers, including public transportation and then getting the "best deal" when paying for Medicaid trips on public transit. This means it is to

¹⁷ Designing and Operating Cost-Effective Medicaid Non-Emergency Transportation Programs – A Guidebook for State Medicaid Agencies, prepared by the Health Care Financing Administration and the National Association of State Medicaid Directors' Non-Emergency Transportation Technical Advisory Group, August 1998

their advantage to pay the ADA fare or even not pay the fare at all rather than to negotiate a rate with the public transit agency.

Medicaid NEMT Use of ADA Paratransit in the Washington, D.C. Region

A recent study in the Washington, D.C. region demonstrates brokers' use of ADA paratransit for Medicaid NEMT trips.¹⁸ One jurisdiction in the region wrote into its contract with the private broker that the broker is to use the regional transit agency's ADA paratransit service as appropriate for beneficiaries with disabilities.

The broker pays the ADA fare for the Medicaid-eligible trips on ADA paratransit, an amount that is generally less than 10% of the full operating cost of an ADA trip provided by WMATA, the region's public transit agency. The jurisdiction then pays WMATA, using local funds, the remaining cost for the trips on ADA paratransit. In calendar year 2015, this amounted to \$51 for each of the 82,000+ Medicaid-eligible trips shifted to WMATA's ADA paratransit.

Had those same trips been provided by the broker, through its network of van providers, the jurisdiction would have paid only its 30% share of the broker's trips (the jurisdiction's federal Medicaid match is 70%), which cost considerably less per trip – on average \$25.75. The net result is that this jurisdiction paid \$4.2 M to WMATA with its local funds when it would have cost the jurisdiction less than \$700,000 of local funds for those 82,000+ trips had they been served through the broker rather than WMATA's ADA paratransit.

Another jurisdiction in the region that provides Medicaid NEMT as an administrative function requires the county Medicaid administrators, who function as county-level brokers, to use ADA paratransit as appropriate for beneficiaries with disabilities, and does not pay the fare; that is the responsibility of the beneficiary. The jurisdiction makes its requirements regarding use of ADA paratransit very clear; see Exhibit 8-3.

The third jurisdiction in the region reportedly indicated to its private broker that it did not want the broker to use ADA paratransit to any extent for Medicaid NEMT trips.

¹⁸ Medicaid Transportation Study of Policy and Practice in the Metropolitan Washington Region, Final Report, prepared for the Metropolitan Washington Council of Governments and the Washington Metropolitan Area Transit Authority, by the KFH Group, Inc., June 2016.

Exhibit 8-3: Excerpt from State Program Guide for County NEMT Administrators/Grantees
(highlighting added)

Necessity of Transportation

Fundamental to the grantees' responsibility to ensure recipients' access to care is the requirement that the transportation be necessary to secure medically necessary care. To this end, grantees are expected to consider alternatives, both of transportation resources and provider resources.

Other transportation resources. First, the grantees are required to determine whether the recipient has other transportation resources available, or whether he/she is dependent on Medicaid-funded transportation to get to medical care. Possible alternative transportation resources include but are not limited to:

- *Public transportation, either fixed-route or **paratransit**. Recipients whose home and provider are within ¼ mile from the closest fixed-route stop, and who have no documented medical reasons why such transportation cannot be used, are expected to use public transportation.*
 - ***When a Grantee asks the recipient if he/she has other means of transportation, eligibility for paratransit is considered as an available resource and can disqualify the recipient for NEMT. If the recipient has been denied eligibility for paratransit services, a copy of the denial should be kept on file;***
 - *For further assistance, Grantees should check with their local public transportation providers for access to online trip planners. A trip planner is a valuable resource to determine the availability of public transportation.*
- *Vehicles belonging to the recipient, others living in the household, or other family members or friends. As appropriate, recipients may be directed to reschedule appointments to be able to make use of this resource, if available; or*
- *Other resources, such as churches, non-profit agencies, or volunteers.*

Grantees are not required to provide funds for the use of public transportation.

Excerpt: Maryland Medical Assistance Program Guide to the Administration of the Transportation Grant Program, Issued June 2014, Department of Health and Mental Hygiene, Medical Care Programs

The Challenges of Coordinating Medicaid NEMT and ADA Paratransit

The examples from the Washington, D.C. region demonstrate one of the challenges for coordinating Medicaid NEMT and ADA paratransit. And that is, a number of state Medicaid agencies follow the Medicaid language specifying that Medicaid agencies are to use the least cost and appropriate transportation mode for Medicaid beneficiaries who need transportation, but do not follow the option of negotiating a rate with the public transit agency that is more than the ADA fare for trips shifted to or taken on the transit agency's ADA paratransit service.

Particularly for private brokers operating under a capitated payment structure, it is to their advantage to shift trips to the public transit agency's ADA paratransit program. Paying the ADA fare – which may range up to \$5 or \$6 depending on the transit agency's fixed route fare – for a Medicaid NEMT trip provided by the transit agency's ADA paratransit service makes better business sense for the broker than using a private wheelchair van provider or a taxi to provide the trip for the beneficiary with a disability.

Another challenge to coordination is the considerable flexibility that states have for providing their Medicaid programs (as long as they stay within the federal guidelines), a reality exemplified in the Washington, D.C. region. The great variation of Medicaid NEMT models across the states and limited examples of coordination with public transit means there is no common template that encourages or facilitates a partnership between Medicaid NEMT and public transit. According to comments and questions from CCAM listening sessions (as reported earlier in this chapter), there is “hesitation among state Medicaid directors” to pursue coordination with public transit since it has not been a “typical partnership in the past.”

There are at least a few examples of state Medicaid agencies that coordinate with public transit. One is from Nevada: the public transit agency in Las Vegas has had an agreement with the Nevada State Medicaid agency that provides for partial reimbursement of Medicaid-eligible trips on the transit agency's ADA paratransit service. The per trip reimbursement is a “calculated cost per ride” which is more than the fare though not the fully allocated operating cost per trip.

Information about such examples might be highlighted through CCAM's coordination efforts to help address the hesitation about coordination with public transit expressed by state Medicaid directors.

A third challenge for the Medicaid-public transit relationship is the ADA and its regulations for paratransit, which make it difficult for public transit agencies to routinely provide the higher level of service frequently needed for riders on dialysis. Two of the ADA's mandated service criteria are relevant to this challenge:

- No trip purpose prioritization: Transit agencies cannot give priority to dialysis trips. This underlies one of the frequent comments provided by respondents to our study's surveys – that the vehicle cannot wait more than five minutes when arriving to pick up a dialysis patient after treatment. A five-minute waiting time policy is standard in the transit industry; after five minutes, the driver is to leave and continue on to serve other riders on his manifest.
- No capacity constraints: A transit agency cannot limit the availability of ADA paratransit service by any of the following (1) Restrictions on the number of trips an individual will be provided; (2) Waiting lists for access to the service; or (3) Any operational pattern or practice that significantly limits the availability of service to ADA paratransit eligible persons. Such patterns or practices include, but are not limited to, (A) Substantial numbers of significantly untimely pickups for initial or return trips; (B) Substantial numbers of trip denials or missed trips; (C) Substantial numbers of trips with excessive trip lengths.

This mandate means that transit agencies have to serve all requests for dialysis trips from eligible riders (and dialysis patients are typically always eligible) and the increasing demand for these trips is challenging transit agencies' capacity and funding, as our survey of transit agencies reveals.

The mandate also requires transit agencies to ensure timely service with trips that are not excessively long. What this means in practice is that the vehicle cannot wait any extra time for dialysis patients – not only because the transit agency cannot prioritize dialysis trips – but also because it must ensure timely service overall to ensure no pattern or practice of late trips. And the mandate also impacts productivity, as it constraints the ability of a transit agency to schedule group trips to or from a dialysis facility as the schedules must be designed so that trips, served in a shared-ride manner, are not too long.

What the Study's Survey Results Contribute to the Discussion

Findings from the study's surveys provide insights on the relationship between Medicaid NEMT and public transit, with a number of transit agency survey respondents commenting about Medicaid NEMT. One large transit agency reported that once the state brought in a private statewide broker, trip and cost shifting to ADA paratransit accelerated. Another transit agency reported that a managed care program was sending trips to its paratransit program, causing capacity issues during peak periods.

Several transit agencies described what they considered to be poor quality Medicaid NEMT service, prompting individuals eligible for both Medicaid NEMT and ADA paratransit to use the agencies' ADA service instead.

Comments about poor quality Medicaid NEMT service were the most frequent category of comments provided by the nephrology social workers in our study's survey. Numerous social workers referred to the unreliability of the service, with late trips to the dialysis facility and sometimes no-shows but especially late pick-ups after treatment. To the extent that their Medicaid-eligible patients are also eligible for ADA paratransit, they may instead shift their medical trips to the transit agency.

The social workers do not necessarily understand the relationship between Medicaid NEMT and public transit, but they do understand, and describe through a number of comments, that there are multiple transportation providers and multiple problems. One social worker reported that implementation of a statewide private broker increased transportation problems for her patients at the same time that the transit agency no longer prioritized dialysis trips because of ADA regulations, and she concluded that the result was "*now everybody get the same bad service.*"

Medicare and Transportation

Unlike Medicaid, Medicare does not provide non-emergency transportation. The one exception is ambulance transport when this level of service is required for the health and safety of the Medicare beneficiary to access a medical appointment.

This means that most dialysis patients on Medicare do not have coverage for routine transportation to get to their treatment.¹⁹ The implications of this are clear from our survey findings. Several rural transit agencies spoke to the difficulties for Medicare patients in finding transportation, as many need accessible service which is costly. One rural transit agency reported that it had used federal New Freedom funding to provide transportation for ten riders on dialysis but funding changes made continuing that service very difficult.

Another rural transit agency explained its dilemma with two passengers on Medicare who need trips to the dialysis facility 30 miles away. The transit agency greatly reduced its fare to assist the individuals but they cannot afford even his reduced fare of \$10 per trip, a rate that is below the operating cost of the trip.

A number of social workers responding to our dialysis facility survey also described financial burdens for patients on Medicare who have trouble affording the cost for transportation, particularly for accessible service. Several social workers quoted the costs for transportation for their patients who must find and pay for transportation for the three-times per week treatment because Medicare does not cover their trips. One social worker wrote that her Medicare patients cannot afford the private wheelchair van service, which cost up to \$40 for

¹⁹ 75% of dialysis patients have Medicare insurance as primary, and about half have Medicaid as secondary insurance. Medicaid NEMT is not always provided for those with secondary Medicaid insurance; The Dialysis Report: Transportation Demand Outstrips Supply, by S. Bogren, Community Transportation, Fall/Winter 2011

the pick-up plus \$3 per mile. Another social worker commented that having transportation added to Medicare would be a wonderful addition for her dialysis patients.

Findings of the patient survey also point to transportation costs as a key concern. Survey respondents were asked to choose the three most important characteristics for their transportation to and from dialysis among six choices; *affordable* was in the top three.

It is worth noting that there is apparently abuse of the Medicare exception for ambulance transportation for dialysis patients. At least two comments to our surveys allude to this, including a social worker responding to the survey from a rural facility. This social worker wrote that “...two patients are using an ambulance service that ‘loosely’ interprets Medicare regulations on [transportation] coverage.”

This misuse of ambulances for non-emergency transportation has actually helped open the door for healthcare providers, including dialysis facilities, to provide transportation for their patients, as now allowed by the December 2016 ruling from the HHS Office of the Inspector General.²⁰ Comments included in the ruling said this about dialysis transportation:

...the safe harbor for local transportation will save federal healthcare dollars for ESRD patients, as “dialysis patients are a population that has been identified as contributing to the increasing costs of nonemergency ambulance transportation and would benefit from local transportation furnished by providers.”

TRANSPORTATION INITIATIVES IN THE HEALTHCARE INDUSTRY

To address transportation issues, some organizations in the healthcare industry have taken matters into their own hands in the recent past. A hospital in NJ (Hackensack University Medical Center) is reported to be the first to partner with Uber to ensure patients get to their appointments. Patients receive reminders about their appointments as well as the need to book an Uber ride from the hospital’s mobile app.

Medstar in Washington, D.C. has also partnered with Uber. Patients can access Uber directly through Medstar’s website. Patients without Internet access can call a patient advocate at the hospital to arrange for the Uber trip.

While Medicare does not provide transportation unless a patient requires an ambulance for medical reasons, some Medicare Advantage plans offer transportation. Blue Cross/Blue Shield (BCBS) is among insurance providers that are getting into the transportation business in partnership with Lyft, a competitor to Uber.

²⁰ Office of the Inspector General of the federal Department of Health and Human Services, 2016 at <https://www.federalregister.gov/documents/2016/12/07/2016-28297/medicare-and-state-health-care-programs-fraud-and-abuse-revisions-to-the-safe-harbors-under-the>

According to news reports and a press release, BCBS will offer free trips to patients in selected Medicare managed care plans who lack reliable transportation. BCBS specifically acknowledges the role of transportation as one of the social determinants of health, stating that its alliance with Lyft will “reduce the number of missed appointments for non-emergency medical care in areas without optimal transportation alternatives servicing health area facilities.”²¹

MEDICAL PERSPECTIVE

Kidney Transplant vs. Dialysis

Patients facing end stage kidney disease who are motivated and have the wherewithal will focus on obtaining a kidney transplant rather than go on dialysis. For other patients who go on dialysis, the difference between facility-based vs. home dialysis is influenced by different factors including whether they lose kidney function suddenly due to acute kidney failure.

Loss of Kidney Function: Gradual or Sudden

When patients lose kidney function gradually, as is the case for the majority of patients, the physician can discuss treatment options, which includes home dialysis.

When a patient loses kidney function suddenly, they are typically hospitalized and hemodialysis is the treatment of choice, given that it is a faster treatment option than peritoneal dialysis for sudden kidney function loss. It is noted that peritoneal dialysis is possible – referred to as Acute Start PD – however, most hospitals are not equipped to handle it and most nephrologists are not well-versed with this treatment.



HD Machines in a Dialysis Facility (KFH photo)

²¹ <https://www.bcbs.com/news/press-releases/blue-cross-and-blue-shield-and-lyft-join-forces-increase-access-health-care>

Once a patient starts hemodialysis, experience shows that the patient stays on hemodialysis, with the majority of patients dialyzing at a facility rather than at home. Home-based hemodialysis is a small percent of patients using home dialysis, although the numbers are increasing.²²

Incident Patients vs. Prevalent Patients

It is important to differentiate between incident patients and prevalent patients when looking at treatment modality. Incident patients – the new ESRD patients – may have the option of using home dialysis; physicians can discuss dialysis options, including home dialysis if medically recommended, when patients need to begin dialysis.

However, prevalent patients – existing patients – who have started hemodialysis in a hospital or a dialysis facility typically do not change their treatment mode and go on home dialysis for a variety of reasons. A change to home dialysis requires that someone educates the patient about the available options and that the patient takes ownership of their treatment.

Survival Rates of ESRD Patients

Patterns of mortality during the first year of dialysis treatment differ substantially by modality and age. More generally, the mortality rate for dialysis patients is 25% within the first year, with the first three months being the most critical. The median survival for patients on dialysis is three years.

Can Use of Home Dialysis Be Increased from Current Practice?

Many factors influence whether a patient goes on home dialysis when starting dialysis, including:

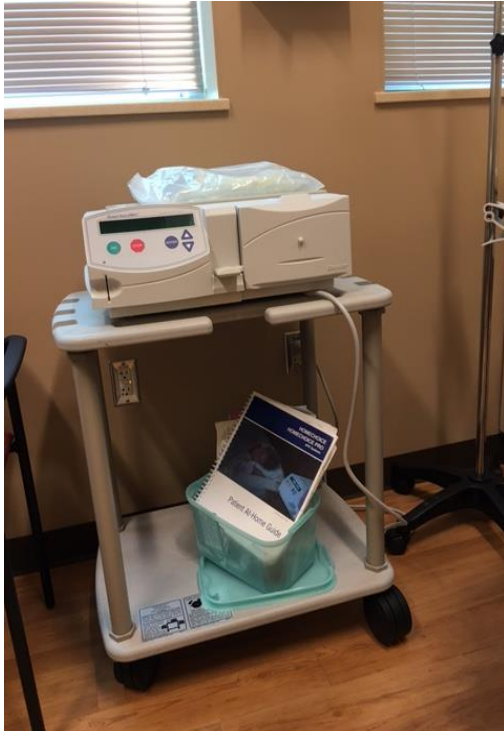
- Whether the patient suddenly loses kidney function, in which case the patient is typically hospitalized where hemodialysis is the treatment of choice; and once a patient starts hemodialysis, experience shows that the patient stays on hemodialysis.
- The physician's recommendation, which is influenced by his or her experience and biases about dialysis modalities.



HD Machine for Home Use (KFH photo)

²² T. Shafi and R. Jaar, Maintaining Patients on Home Hemodialysis: The Journey Matters as Does the Destination, Clin J Am Cos Nephrol, 7-24-2017 at <http://cjasn.asnjournals.org/content/early/2017/07/21/CJN.06890617>

- The patient's preference and capabilities to manage home dialysis.
- The patient's socio-economic status (ESRD patients using in-center dialysis tend to be the more socio-economically disadvantaged patients).



PD Machine for Home Use (KFH photo)

- The “system,” which includes such components as the Medicare payment structure; training locations and training expertise for home dialysis; the fact that starting a patient on peritoneal dialysis (the most common home dialysis method) requires more steps/ medical interventions by medical professionals (starting a patient on hemodialysis is medically less involved). In-center hemodialysis is essentially the default form of dialysis.

- The distance that a patient lives from a dialysis facility can influence the choice; in rural areas where patients live far from a dialysis unit, transportation can influence a patient to use home dialysis.

According to a 2015 GAO report on Medicare payment for dialysis, physicians and other stakeholders have estimated that 15 to 25% of patients could realistically be on home dialysis,

which suggests future increases in use are possible. The report states that in-center hemodialysis, the most common type of dialysis, was used by about 89% of dialysis patients in 2012; the remaining patients received either peritoneal dialysis (9%) or home hemodialysis (2%).²³

What About an Artificial Kidney?

Efforts to create an artificial kidney involve developing a small dialysis machine that would be surgically implanted in the patient's body. A number of such devices are being tested but are likely more than ten years away from widespread use. Implantation would require open surgery with all the concomitant risks of surgery including infection, and only selected numbers of ESRD patients would be able to handle such surgery.

²³ End-Stage Renal Disease Medicare Payment Refinements Could Promote Increased Use of Home Dialysis, GAO, Report to Subcommittee on Health, Committee on Ways and Means, House of Representatives, October 2015

We note an article from April 2017 identified by a Panel member about a "bionic kidney" that is apparently being developed at the University of California at San Francisco and reportedly would be available within a shorter time horizon.²⁴

²⁴ <https://troab.com/worlds-first-bionic-kidney-set-replace-dialysis-just-two-years/>

Appendix A

LITERATURE REVIEW

Summaries of reports and articles identified in the literature are provided below, first, those from the medical literature and, second, those from the transportation literature. Within the two categories, the summaries are ordered by the publication date of the report or article.

From the Medical Literature

Travel Time to Dialysis as a Predictor of Health-Related Quality of Life, Adherence, and Mortality: The Dialysis Outcomes and Practice Patterns Study

L. M. Moist, MD, et. al, American Journal of Kidney Diseases, Vol 51, No 4 (April), 2008: pp 641-650, at https://www.researchgate.net/profile/Hugh-Rayner/publication/5480139_Travel_Time_to_Dialysis_as_a_Predictor_of_HealthRelated_Quality_of_Life_Adherence_and_Mortality_The_Dialysis_Outcomes_and_Practice_Patterns_Study_DOPPS/links/00b4952b1c74919316000000.pdf

This study looked at longer travel time to the dialysis unit which creates a substantial burden for many patients, evaluating the effect of self-reported one-way travel time to hemodialysis on mortality, health-related quality of life (HR-QOL), adherence, withdrawal from dialysis therapy, hospitalization, and transplantation.

Advances in hemodialysis treatment have contributed to improved survival, but patients continue to have impaired health-related quality of life. Many of the contributing factors are difficult to change, such as age, sex, multiple comorbidities, and low income, among others. There are a small number of modifiable variables, such as early referral, correction of anemia, exercise, and, possibly, treatment of depression.

Recent qualitative studies of patient experiences showed a frequent and recurring theme: time involved with both the dialysis treatment and travel affected HR-QOL.

This study used a sample of 20,994 HD patients who completed a patient questionnaire and who were randomly selected from 307 representative dialysis facilities in 7 countries (France, Germany, Italy, Japan, Spain, United Kingdom, and United States) and 319 dialysis facilities in 12 countries (the listed countries plus Australia, Belgium, Canada, New Zealand, and Sweden).

Data for travel time were extracted from 1 of 88 questions completed as part of a patient questionnaire. The following single question was asked: “How long does it take you to get to your dialysis unit or center (1 way)?” Response options included 15 or less, 16 to 30, 31 to 60, and longer than 60 minutes.

Additional questions included: “How do you usually get to dialysis?” Participants responded “yes” or “no” to the following questions: “In the past month of dialysis, have transportation

problems caused you to shorten a hemodialysis session?” and “In the past month of dialysis, have transportation problems caused you to skip or miss a hemodialysis treatment?” A question from the unit practice survey (completed by the nurse manager) also was examined: “In general, when a patient is late for a scheduled treatment, we cannot provide a full treatment,” with responses that ranged from strongly disagree to strongly agree. Patient respondents in the US numbered 2,150; 46.6% traveled 15 min or less, 2.9% traveled 16-30 minutes, 17.2% traveled 31-60 minutes and 3.2% traveled 60+ minutes.

After adjustment for various factors such as age and comorbidities, patients traveling longer than 60 minutes had a 20% greater risk of death compared with those traveling 15 minutes or less.

Adjusted health-related quality of life (HR-QOL) scores were significantly lower for many of the HR-QOL subscales (e.g., general health, pain, mental health, etc.) in those with longer travel times compared with those traveling 15 minutes or less.

The prevalence of skipping or shortening a dialysis session did not differ significantly across travel time to dialysis categories. However, in those with longer travel times, a problem with transportation was a significantly more frequent reason to either skip or shorten a dialysis session. Patients with longer travel times relied more on public and private transportation. In a facility report question, 17% of nurses agreed or strongly agreed that a full dialysis treatment was not provided to patients who arrived late.

The study found that longer travel time to dialysis therapy was associated with lower HR-QOL and a significantly greater risk of mortality. These observations remained large and significant after controlling for possible confounders and in all sensitivity analyses. Also, problems with transportation contributing to both skipped and shortened treatments were more common in those with the longest travel times. These results highlight travel time as a potentially modifiable variable affecting both mortality and HR-QOL.

Cost Comparisons of Peritoneal Dialysis versus Hemodialysis in End-Stage Renal Disease

A. Berger, et al, Am J Manag Care. 2009 Aug; 15 (8):509-18 at <https://www.ncbi.nlm.nih.gov/pubmed/19670954>

This observational study compared healthcare use and costs for patients with ESRD who began HD or PD and were treated between 1/1/2004 and 12/31/2006. A total of 463 patients were included in the study. 12% began treatment with PD and 88% with HD. 50 PD patients were matched with 50 HD patients for the study comparison. The HD patients were more than twice as likely as the PD patients to be hospitalized during the year following their beginning dialysis. Their median healthcare costs over the 12-month follow up period were \$43,510 more than the PD patients (\$173,507 vs. \$129,997).

Study findings suggest that privately insured patients who start dialysis with PD have significantly lower risks of hospitalization and lower total healthcare costs over 12 months than HD patients of similar demographic and clinical characteristics. Prior studies of Medicare enrollees have consistently reported lower healthcare costs among patients who initiate dialysis with PD rather than HD, although the other studies found a small difference than in this study. Authors note that Medicare typically pays less for services than private insurance because of the ability/market power of Medicare to dictate rates.

Differences in this study for total healthcare are costs between the two types of dialysis patients were mostly attributed to differences in the cost of inpatient care. (Apparently from higher incidence of hospitalization.)

Discussion of study limitations: One issue noted is that prior research has shown that 25-33% of PD patients switch to HD compared to only 3-5% of HD patients who switch to PD.

Additional benefits (beyond those found in this study) that have been associated with PD vs. HD include flexible scheduling, fewer needle sticks, and minimizing risk of blood-borne infections. Also PD has been associated with greater patient satisfaction with dialysis care and a reduced burden of kidney disease.

A Comparison of Quality of Life and Travel-Related Factors between In-Center and Satellite-Based Hemodialysis Patients

Diamant, M.J., et al., Clin. J. Am. Soc. Nephrol., 5, 268-274, February 2010, at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2827602/>

Shorter travel times and distance to dialysis clinics have been associated with improved patient outcomes and a higher health-related quality of life (HRQOL). The primary purpose of this study was to compare the HRQOL of patients who received in-center HD with those who received HD in satellite units. The secondary objective was to collect and compare patient responses to travel-related factors and issues relating to conventional HD treatment. It was hypothesized that those who received treatment in satellite units would report a significantly higher QOL.

For patients with ESRD, quality of life is largely determined by the patient's level of physical, mental, and social functioning in the presence of kidney disease.

Authors surveyed 202 patients in England who had completed the questionnaires (101 hospital-based in-center, 101 in satellite clinics). Survey results showed that undergoing dialysis in satellite units was found to significantly decrease the dialysis stress subscale score, on average by 0.385 ($P = 0.037$) after adjustment for age, gender, and diabetes status.

Patients' responses to questions relating to the travel parameters found that those traveling to satellite centers versus in-center had shorter travel times (statistically significant difference in

travel time between the two groups when analyzed categorically). Patients in satellite units also reported a significantly lower cost of transportation.

The method by which patients were transported to and from their dialysis sessions differed between groups as well with a greater proportion of patients in satellite units able to transport themselves to dialysis.

Patients' response to an open ended question indicated benefits with less travel time, reduced driving stress, more time to spend with family and friends, less fatigue and increased energy and decreased cost. "According to patient responses, issues surrounding travel, such as distance and cost, played a large role in determining their perceived QOL. "

The authors conclude that patients who had dialysis in satellite units demonstrated similar characteristics, comorbidities, surrogate outcomes, and most aspects of HRQOL. However, travel time, cost, and receiving treatment in one's own community are important factors that may contribute to a trend toward higher reported HRQOL by patients in satellite dialysis units.

Dialysis Facility and Patient Characteristics Associated with Utilization of Home Dialysis

D. Walker, G. Inglese, J. Sloand, and P. Just, Clin J. Am Soc Nephrol, 5(9): 1649-1654, September 2010

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2974407/>

The authors investigated nonmedical factors that influenced whether patients used home dialysis. Such dialysis is comparable effective and safe and less expensive to society and Medicare than in-center hemodialysis.

Cost-containment is an important consideration for CMS. One option for managing dialysis costs may be to expand the use of home dialysis therapies.

A well-documented literature review proposed that among the principal reasons PD use has been in decline was the rapid expansion of in-center hemodialysis (ICHD) capacity and the aging of the ESRD population.

A multivariate regression model was used to evaluate associations between the use of home dialysis and facility characteristics. Facility characteristic variables: for-profit status of the dialysis facility, chain ownership status, operation of a late shift (defined as starting at 5:00 p.m. or later) and facility size of ≥ 62 patients. Other variables: number of years since a dialysis facility became Medicare certified; patient capacity based on number of machines and number of shifts; whether the facility location was urban or rural; population density of the facility's zip code; and percent of patients 18-54 years of age.

Study results found that facilities located in a more rural area, a geographically larger zip code area, or high-population-density zip codes were associated with lower use of home dialysis. Although many expected home dialysis to be more common in rural settings because of less convenient access to the dialysis facility, the opposite was found, validating previous reports.

The study found no association between profit status and use of home dialysis; however, facilities owned by chain organizations had smaller percentages of home dialysis patients compared with non-chain-owned centers. It also found a significant inverse association between home dialysis use and percent black population within a zip code. For every 1% increase in the black population, the percent of patients treated with home dialysis in a facility declined by 0.03.

In summary: The utilization of home dialysis was positively associated with facility size, percent patients employed full- or part-time, younger population, and years a facility was Medicare certified. Variables negatively associated include an increased number of hemodialysis patients per hemodialysis station, chain association, rural location, and more densely populated zip code, a late dialysis work shift, and greater percent of black patients within a zip code.

Relationship of Missed and Shortened Hemodialysis Treatments to Hospitalization and Mortality: Observations from a US Dialysis Network

C. Obialo et al, in Clin Kidney J. 2012 Aug; 5(4): 315–319 at
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4393476/>

This study explores the frequency of missed and shortened treatments and their impact on mortality and hospitalization. The study used data from 15,340 HD patients treated in facilities operated by non-profit Dialysis Clinics, Inc. and compared the frequency of missed and shortened treatments by gender, race, age and treatment schedules ((MWF) versus (TTS)). Missed or shortened dialysis treatment is universal, but it is disproportionately more frequent in the US-ESRD population

The main observations from this study are that missed and shortened dialysis treatments are more prevalent among the minority populations (African Americans, Hispanic and Native American patients), younger patients aged <55 years and patients who dialyze on the TTS schedule. The frequency of those two non-adherence events is greater than in Europe and Japan. “The adverse relationship between hospitalization and missed/shortened dialysis treatments is unequivocal.”

In a previous single-center study, the authors had reported a high frequency of missed dialysis on Saturdays, which appears to be a nationwide phenomenon that defies logical explanation.

Many patients will often shorten their treatments because they feel poorly, have muscle cramps, have other appointments or do not want to miss their transportation. In a single

center study, the authors used a patient questionnaire to document their reasons for early termination of dialysis or skipped HD. Noted explanations include: family emergencies; transportation- or weather-related issues; feeling poorly; oversleeping; other doctor's appointment; and in a few patients, no reason at all.

The high prevalence of missed/shortened treatments among the US-ESRD population has been blamed for the high mortality rate seen among the US patients. The observation that non-adherence was more prevalent among younger patients aged <55 who had lower mortality than the more adherent elderly would contradict that suggestion. However, the morbidity and mortality effects of missed/shortened dialysis cannot be overlooked. Frequent hospitalization unquestionably contributes immensely to the accelerating cost of ESRD care in the US.

For-Profit Status & Industry Evolution in Health Care Market: Evidence from the Dialysis Industry

Nathan E. Wilson

Working paper no. 314 February 2013 FTC Bureau of Economics at

<https://www.ftc.gov/reports/profit-status-industry-evolution-health-care-markets-evidence-dialysis-industry>

Though long aware of the rising importance of for-profit dialysis providers, scholars and practitioners have not reached a consensus as to what might underpin it. This is concerning for both theoretical and substantive reasons. Theoretically, it limits understanding of the behavioral implications of the profit motive. Practically, it keeps policymakers from developing an accurate sense of whether or not there are benefits to non-profit ownership large enough to justify their tax subsidies.

These benefits are of very substantial magnitude due to the size of the dialysis industry: As a result of the rising prevalence of end-stage renal dialysis, around half a million Americans now regularly need dialyzation, and the bulk of this expense is borne by the taxpayer. Medicare's expenditures on ESRD alone now account for approximately one percent of the entire Federal budget (Ramanarayanan and Snyder, 2012).

Some of the prior literature provides evidence consistent with the idea that for-profit facilities are more efficient at performing hemodialysis treatments.

Physicians view transplantation as the preferred option as it is associated with lower mortality and healthier lives relative to those on dialysis. Unfortunately, the number of ESRD patients vastly outnumbers the number of kidneys available for transplantation. Consequently, 70 percent of ESRD patients are regularly dialyzed.

Effective in 1973, the Social Security Act extended Medicare benefits to all patients diagnosed as having permanently lost kidney function. ESRD is the only catastrophic illness whose care

is financially covered by a national public program regardless of patient age or financial status.

For individuals with ESRD who still have insurance through their employer (or union), the group health plan is the primary payer for the first 30 months, while Medicare is the secondary payer. Once the 30 months have elapsed, Medicare is the principal payer. In 2010 (the most recent year for which data are available), Medicare covered 489,000 ESRD patients, while other payers accounted for an additional 105,000 patients. Similarly, Medicare's expenditures accounted for \$33 billion out of a total of \$47.5 billion.

The Retail Dialysis Industry:

The decision to have Medicare cover ESRD treatment created an industry of facilities dedicated to providing care to qualifying patients. These facilities are differentiated in multiple respects. The most obvious distinction is between those affiliated with hospitals, which often also provide transplantation services, and freestanding centers that primarily exist to provide dialysis services. After taking account of whether or not a center is affiliated with a hospital or not, the chief way in which clinics differ is whether they are operated by for-profit or not-for-profit entities. Clinics are also differentiated by whether or not they are independently owned or part of chains.

In contrast to the mixed results for quality, the existing literature is in broader agreement that for-profit dialysis facilities are more cost-efficient

Author concludes that for profit organization are more efficient. Looking at diversion there is less diversion from for profit to nonprofit facilities than from nonprofit to for profit. This may reflect perceived quality. Or it may result from effort to vertically integrate upstream from referring physicians by the major dialysis chains, which the largest chains are now emphasizing.

Strong Social Support Services, Such as Transportation and Help for Caregivers, Can Lead to Lower Healthcare Use and Costs

G. Shier et al., Health Affairs, March 2013, Vol. 32 Issue 3, p. 544 at <http://content.healthaffairs.org/content/32/3/544.abstract>

CMS has adopted the Triple Aim of better care for individuals, better health for populations, and lower per capita costs to improve healthcare. The Healthcare Innovation Challenges of CMS Innovation are providing resources to achieve the Triple Aim. While efforts are improving, many do not address the key role of social supports in contributing to patients' health safety and well-being. Social supports include homemaker services, *transportation* (italics added), emotional support for patients and caregivers and legal assistance.

Early evidence from 7 care model demonstration suggests that integrating services to address social factors can reduce healthcare use and costs and improve patients' outcomes.

Physicians understand impact of social issues on patients. In a survey of MDs, 85% agreed “unmet social needs – such as nutritious food, reliable transportation, and adequate housing – are leading directly to worse health for all Americans.” This rate increased to 95% among MDs serving patients in low-income urban communities.

There are many community-based services that could be engaged to address social issues with medical consequences. But there is fragmentation with different funding streams between the social services systems and healthcare delivery system which presents a barrier. Provisions of the ACA have the potential to reduce the barriers by providing financial incentives for care coordination, particularly in patient-center medical homes and accountable care organizations. The ACA also created the Community Based Transitions Program to link hospitals and community organizations in an effort to reduce hospital readmissions.

Article identifies 5 innovative programs and 2 models which provide early evidence on how and why to address social issue. Evidence from these suggests that care coordination models with a strong social support services component can provide positive outcomes. Overall cost reductions were observed as well.

Meeting the Triple Aim will require better integrated care....that includes coordination between medical and social services. Such integrated care is particularly important for older patients, those with chronic conditions and those with complex care needs.

Missed or Delayed Medical Care Appointments By Older Users Of Nonemergency Medical Transportation Services

K.E. MacLeod et al, *Gerontologist* 55(6):1026–1037, 2013 at
<http://gerontologist.oxfordjournals.org/content/early/2014/02/17/geront.gnu002.full>

This study examined cancelled trips of Medicaid adults, age 65+, to explore whether there are barriers for elderly people who face particular challenges with age-related declines in health and function. Data from 125,913 trips for 2,913 Delaware clients during 2008-2010 were examined. 75% of the trips were for dialysis and most of these were prescheduled (subscription trips). Results: Over half of canceled trips (study included no-shows with cancels) were attributed to client reasons (e.g., no show, refusal). Client characteristics (e.g., race, sex, functional status) were associated with cancelations; however, these differed based on the cancellation reason. Regularly scheduled trips were less likely to be canceled.

Among all the data, approximately 6% of all trips were canceled.

For those trips that were not prescheduled, i.e., demand, not subscription trips (n= 31,254), 13% were cancelled.

Compared with dialysis trips, other medical encounters were more likely to be canceled by the client. However, wheelchair and stretcher level of service increased the odds of health cancelations and it is not clear if medical appointments were missed or if the condition was elevated to emergency medical services. Trips for substance use encounters were much more likely to be canceled.

Policies: Involving the medical community could assist in reducing missed appointments through better coordination with transportation. In this study, regularly scheduled trips were less likely to be canceled. There is research to indicate that the time between scheduling and the medical appointment is associated with missed appointments, reminders can reduce missed appointments, and that this may be particularly important for older adults whose memory may be declining with age

Engaging medical staff to ensure that patients have transportation for their appointments could improve utilization and reduce longer term costs. Currently, the Affordable Care Act provides an incentive for hospitals to reduce readmissions.

Adherence Barriers to Chronic Dialysis in the United States

Kevin E. Chan, Ravi I. Thadhani, and Franklin W. Maddux
J Am Soc Nephrol. 2014 Nov; 25(11): 2642–2648. Published online 2014 Apr 24.
At <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4214530/>

Study analyzed 44 M HD treatments for 182,536 patients with ESRD in the US over a 5-year period (1/1/2005 – 12/31/2009). Objective was to determine if missed dialysis treatments affected risk of hospitalization, emergency room visit or intensive-coronary care unit (ICU-CCU) admission in the two days after a missed treatment.

Study found:

- Average missed treatment rate was 7.1 days per patient year. The study found that patients missed on average 1.8% of their scheduled HD treatments, which corresponded to 7.1 days when patients were off their schedule.
- Results show that 34.5% of missed treatments occurred on the day before the weekend (on Friday or Saturday) and only 9.8% missed treatments were successfully rescheduled (defined as delivered the next day). Generally, missed treatments were more frequent among younger and non-Caucasian patients.
- The risk of hospitalization, emergency room visit or intensive-coronary care unit (ICU-CCU) admission increased significantly after a missed treatment.
- After a missed treatment:
 - Probability of hospitalization was 5%, but risk was only 1.2% if patient received HD.

- Probability of an ER visit after a missed treatment was 5% and only 1.6% in patients who received HD.
- Probability for ICU-CCU admissions risk was 2% after a missed treatment and 0.5% in patients who were treated
- For ESRD-related complications, odds ratio for a hospital or ER visit after a missed treatment, compared with an attended treatment, was even higher, at 6.39 for urgent hospital dialysis, 17.5 for hyperkalemia, 5.00 for congestive heart failure, and 4.62 for hypertension.

Many patients with ESRD miss their HD treatment and place themselves at increased risk for hospitalization or mortality. Why do patients miss treatments? Several small studies have shown impacts from depression, unreliable transportation, demographic factors, and lack of motivation. But there have been no large-scale studies.

What are the Barriers to Dialysis Care?

Transportation is one: patients who travelled to dialysis via a transportation van and who drive more than 17 minutes to the center were at increased risk to forego their dialysis treatment. Missed treatments also are more prevalent with heavy snow, on any holiday, for patients with gastrointestinal upset, depression, drug or alcohol abuse or chronic pain. Study found that:

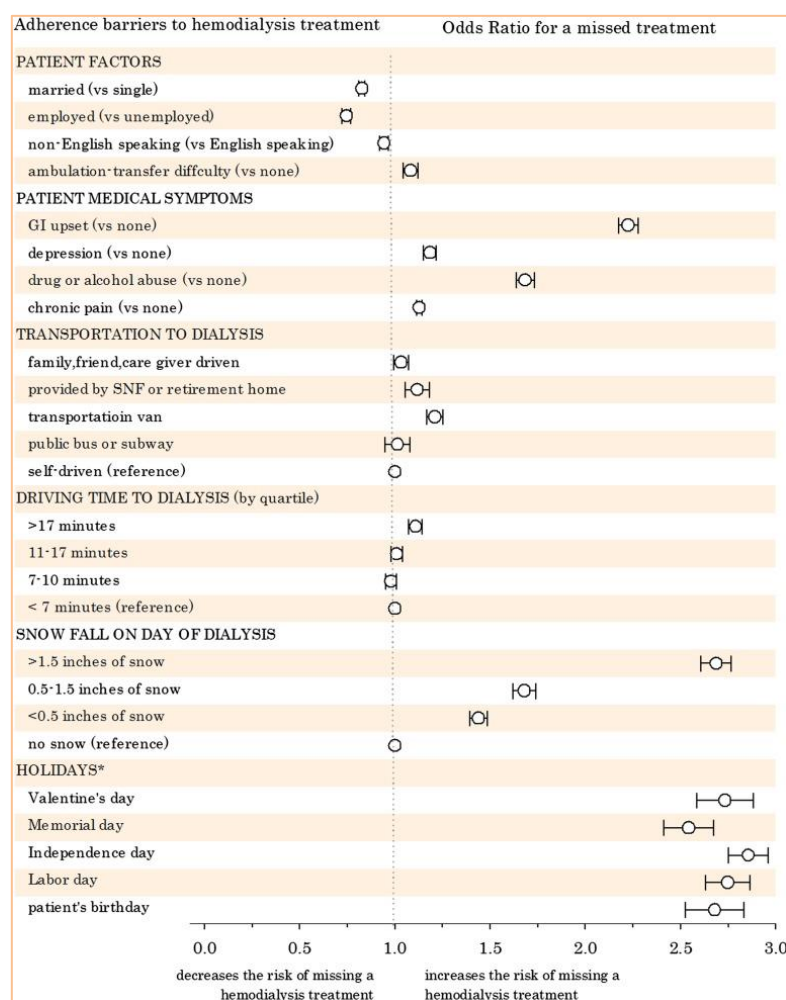
- Improving transportation to dialysis could decrease hospitalizations **by 0.8 days** per patient-year,
- Rescheduling dialysis treatments that occur on holidays could decrease hospitalizations **by 1.7 days** per patient-year, and
- Avoidance of snow days could decrease hospitalizations **by 0.5 days** per patient-year.
- Treatment of residual gastrointestinal upset, depression, drug or alcohol abuse, and chronic pain could decrease hospital admissions **by 2.0, 0.2, 0.4, and 2.7 days** per patient-year, respectively.
- Moving clinics more proximate to where patients live was unlikely to result in meaningful improvements in patient morbidity.

Study reports that there are substantial health risks associated with missing a hemodialysis treatment, and these risks appear larger than previously reported. While improvement efforts have focused on improving medical practices to improve outcomes, there are barriers beyond treatment that impact care, including:

- “Patients with private transportation to dialysis (*i.e.*, self-driven or brought by family member or caregiver) had significantly better attendance and outcomes compared with patients who relied on public transportation (*i.e.*, city bus or transportation van).“
- Patients were also more likely to miss dialysis and end up in the hospital if they were scheduled to dialyze on a holiday, on their birthday, or when the weather was bad.

Such problems may be mitigated by increasing the use of home therapies, or developing treatment schedules that dynamically accommodate the lifestyle and limitations of each patient as opposed to fixed schedules designed to fit a 7-day week. Moreover, efficient rescheduling practices could be developed that balance overall patient flow, but can proficiently reroute appointments to different locations or move appointments earlier or later in anticipation of a major snow storm or last-minute patient cancellation. In addition, there are multiple patient factors that may also impede adherence to dialysis therapies. Untreated depression, psychiatric illness, pain, and gastrointestinal discomfort also increased the risk of missing a treatment. As such, improving medical management in the areas of pain, discomfort, and behavioral health would be beneficial.

*Excerpt: Figure 2-Adherence barriers to hemodialysis care and their association with a missed treatment. Data points to the right of the vertical dotted line (OR>1.0) correspond to an increased risk for a missed treatment. *OR for any holiday, 1.82 (95% CI, 1.79 to 1.86). GI, gastrointestinal; SNF, skilled nursing facility, from Adherence Barriers to Chronic Dialysis in the United States.*



Nephrologists' Perspectives on Dialysis Treatment: Results of an International Survey

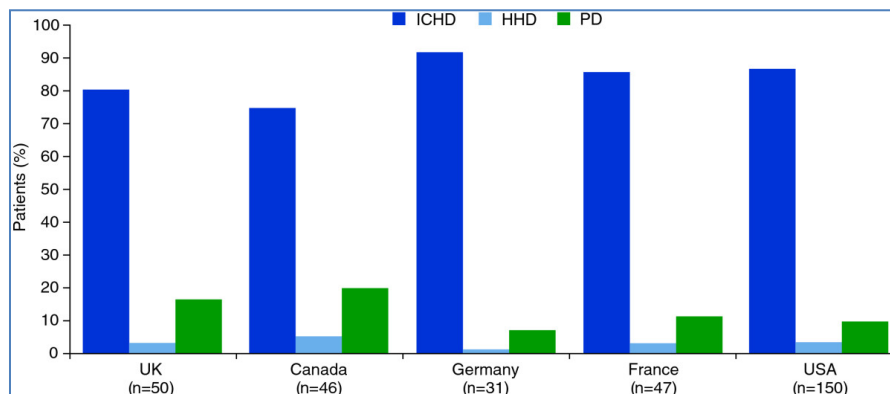
R. Fluck, D. Fouque, and R. Lockridge, BMC Nephrol. 2014, published online Jan. 15, 2014 at <http://bmcnephrol.biomedcentral.com/articles/10.1186/1471-2369-15-16>

Authors surveyed 1500 nephrologists in Europe, Canada and the US, with 324 responses. Survey results show that many nephrologists believe that home HD and high-dose HD (longer and more frequent HD regimens) are better for the patients. But the majority of their patients use in-center HD.

ICHD (in-center HD) was the most common type of dialysis prescribed. Overall, nephrologists reported that 90% of their patients were on ICHD; PD (8%) and home HD (2%) were much less commonly used. This predominance of ICHD was observed across all five countries (see Figure 1 excerpted from the report).

Majority of respondents indicated that increasing the frequency of dialysis beyond three times per week and performing longer nighttime dialysis sessions significantly improves clinical outcomes. Study notes that the survey did not include respondents from Australia and New Zealand where home dialysis are most common.

Except: Figure 1- Proportion of Patients Receiving Different Forms of Dialysis Treatment by Country, Nephrologists' Perspectives on Dialysis Treatment: Results of an International Survey (HHD, home hemodialysis; ICHD, in-center hemodialysis; PD, peritoneal dialysis, n = number of respondents per country)



Medicaid Expansion and Premium assistance: the Importance of Non-Emergency Medical Transportation (NEMT) to Coordinated Care for Chronically Ill Patients

MJS & Co., in Community Transportation, Spring 2014, p. 17-22, at <http://web1.ctaa.org/webmodules/webarticles/articlefiles/NEMTreportfinal.pdf>

NEMT is critical, including for Medicaid beneficiaries newly eligible for Medicaid through the ACA. According to the authors, a previous analysis of National Health Interview Survey data (1999-2009) found that 7% of Medicaid beneficiaries reported transportation as a barrier and 0.6% of those with private insurance reported problems with transportation.

NEMT is currently being threatened in some states (such as Iowa, Pennsylvania, and New Hampshire) which are proposing to waive the NEMT in premium assistance plans (which is one method to expand Medicaid).

Report provides data from a major NEMT provider that managed 48 M rides in 39 states in 2013. The data show that 17.9% of the Medicaid NEMT was provided for dialysis. But the data show variation among states. For example, rides for dialysis were 46% in Mississippi and 42% in Hawaii while the majority of trips in CT and PA were for behavioral health (includes mental health services and substance abuse treatments). The report states “Most Medicaid subsidized rides transport chronically ill beneficiary requiring a more robust, specialized transportation benefit to more intensive and recurring treatments and services.”

Transportation is especially important for dialysis treatment. The report notes that, according to the USRDS, the majority of HD patients rely on others to transport them to and from the dialysis clinic, with 66.8% of patients being driven by others including ambulance. Nearly 8% relied on public transportation such as bus, subway, train or taxi while only 25.3% drove themselves or walked.

Chronic diseases are among the most prevalent, costly and preventable of all health problems.

Allowing states to waive the NEMT requirement runs counter to the overall goal of the ACA.

In-Center Hemodialysis Attendance: Patient Perceptions of Risks, Barriers, And Recommendations

KB Chenitz , M Fernando. JA , in Hemodialysis International. 2014 Ap; 18(2):364-73, at <http://opensample.info/in-center-hemodialysis-attendance-patient-perceptions-of-risks-barriers-and-recommendations>

Authors interviewed 15 dialysis patients who adhered to their treatment schedule and 15 who did not. Average time on dialysis was 2.5 years for the non-adherent group and 7.3 years in the adherent group. A substantial number of patients in both groups understood that missing

HD treatments is dangerous. Generally they did not like the treatment but typically described the treatments as easy.

Patients reported that the most common barriers to hemodialysis were:

- inadequate or unreliable transportation (mentioned in both groups) and
- A lack of motivation to get to dialysis or that dialysis is not a priority (typically mentioned by the non-adherent group).

Regarding transportation:

- The patients interviewed traveled by car, city bus, ambulance or a shared patient van to dialysis.
- Patients who drove themselves, had family drive them, or took the city bus, typically described these modes as efficient and reliable.
- Several patients had to take a van provided by the city of Philadelphia (*note: this is likely the ADA paratransit service*) and “multiple patients” stated inconsistent van pick up and arrival times and long wait times as major obstacles and inconveniences. Some patients even described circumstances in which the van never came at all. “Sometimes I have to sit and wait at least an hour and I have to call and say my ride is not here yet, which makes me late getting there, which makes me late getting on the machine, which makes me late getting off the machine. And then . . . coming to pick you up, if you’re not ready when they get there, they will leave you and you’ll have to sit and wait and wait and wait.” (Adherent patient)

Patient recommendations to improve dialysis attendance included continued education about the risk of poor attendance and more accessible transportation. Patients did not feel that home dialysis would improve adherence. Authors provide three interventions that should be investigated to improve hemodialysis attendance: (1) Improvement of the transportation system, (2) education and supportive encouragement from the health care team, and (3) peer support mentorship.

Expanding Specialized Transportation: New Opportunities Under the Affordable Care Act

W. Fox-Grage and J. Lynott, Insight on the Issues 99, AARP Public Policy Institute, Washington, D.C., January 2015, at <http://www.aarp.org/content/dam/aarp/ppi/2015/AARP-New-ACA-Transportation-Opportunities.pdf>

This AARP brief discusses options under the ACA that could expand specialized transportation. Under Medicaid, the options focus on non-medical transportation since Medicaid already funds NEMT. For Medicare: the ACA does not pay for specialized transportation for Medicare beneficiaries, but it does provide monetary incentives that aim to

reduce hospital admissions, improve care, and contain costs for vulnerable, high-cost Medicare populations.

The following programs offer opportunities to increase transportation services for certain Medicare populations:

Care Transition and Coordinated Care Programs:

The ACA has several programs to improve care transitions when patients move between one care setting or provider to another. Such transitions are essential to ensure patients receive good care when they move, for example, from hospital to home. Another major reason for focusing on better care transitions is to prevent costly hospital admissions and readmissions, particularly for people who are at high risk and who often have multiple chronic conditions. There is recognition that critical elements for improved care transitions should include nonmedical services such as family caregiver supports and transportation.

These programs to improve care transitions include: The Partnership for Patients, Community-based Care Transitions Program (CCTP), Hospital Readmissions Reduction Program, and Accountable Care Organizations (ACOs).

Under the Partnership for Patients, CCTP tests models for improving care transitions and reducing hospital readmissions for high-risk Medicare beneficiaries. CCTP works with the Hospital Readmissions Reduction Program, which penalizes and reduces payments to hospitals for excessive readmissions. Implemented in 2011, 102 sites are participating in the CCTP as of the time this brief was written. The CCTP awardees get a 2-year agreement that may be renewed for 5 years based on successful outcomes of a 20 percent, 30-day readmission reduction. Total funding for CCTP is \$500 million. Only some sites provide transportation.

The ACA is encouraging doctors, hospitals, and other providers to join together voluntarily as Accountable Care Organizations (ACOs) to provide coordinated care to their Medicare patients. The goal is to ensure that patients, especially those with chronic conditions, receive high-quality care while avoiding unnecessary services and preventing medical errors. Successful ACOs receive some of the savings achieved from the Medicare program.

The report describes a case study in Atlanta through the Atlanta Regional Commission that provides some supplemental transportation through a Community-based Care Transitions Program (CCTP) grant to reduce hospital readmission. The ARC partnered with a number of hospitals and the “coaches” found that some patients needed help with transportation, which was provided on a short-term basis. This included transportation for dialysis patients.

End-Stage Renal Disease Medicare Payment Refinements Could Promote Increased Use of Home Dialysis

GAO, Report to Subcommittee on Health, Committee on Ways and Means, House of Representatives, October 2015 at <http://www.gao.gov/assets/680/673140.pdf>

Summary

In 2013, Medicare spent about \$11.7 billion on dialysis care for about 376,000 Medicare patients with ESRD. Some of these patients performed dialysis at home, and such patients may have increased autonomy and health-related quality of life. This report examines (1) trends in home dialysis use and estimates of the potential for wider use, (2) incentives for home dialysis associated with Medicare payments to dialysis facilities, and (3) incentives for home dialysis associated with Medicare payments to physicians.

The percentage of dialysis patients who received home dialysis generally declined between 1988 and 2008 and then slightly increased after through 2012, and stakeholder estimates suggest that future increases in the use of home dialysis are possible. In 1988, 16% of 104,200 dialysis patients received home dialysis. Home dialysis use generally decreased over the next 20 years, reaching 9% in 2008, and then slightly increased to 11% of 450,600 dialysis patients in 2012—the most recent year of data for Medicare and non-Medicare patients

Physicians and other stakeholders estimated that 15 to 25% of patients could realistically be on home dialysis. In the short term, however, an ongoing shortage of supplies required for peritoneal dialysis—the most common type of home dialysis—reduced home dialysis use among Medicare patients from August 2014 to March 2015. Some stakeholders were also concerned the shortage could have a long-term impact.

Medicare's payment policy likely gives facilities financial incentives to provide home dialysis, but these incentives may have a limited impact in the short term. According to the CMS, setting the facility payment for dialysis treatment at the same rate regardless of the type of dialysis gives facilities a powerful financial incentive to encourage the use of peritoneal dialysis when appropriate because it is generally less costly than other dialysis types. However, GAO found that facilities also have financial incentives in the short term to increase provision of hemodialysis in facilities, rather than increasing home dialysis. For example, facilities may be able to add an in-center patient without paying for an additional dialysis machine, because each machine can be used by six to eight in-center patients. In contrast, for each new home patient, facilities may need to pay for an additional machine.

Training: Although CMS recently increased its payment for home dialysis training, it lacks reliable cost data needed to assess payment adequacy. In particular, if training payments are inadequate, facilities may be less willing to provide home dialysis.

Medicare Payment: Medicare payment policies may constrain physicians' prescribing of home dialysis. Specifically, Medicare's monthly payments to physicians for managing the care of home patients are often lower than for managing in-center patients even though physician stakeholders generally said that the time required may be similar. Medicare also pays for predialysis education—the Kidney Disease Education (KDE) benefit—which could help patients learn about home dialysis. However, less than 2 percent of eligible Medicare patients received the benefit in 2010 and 2011, and use has declined since then.

According to stakeholders, the low usage was due to statutory limitations on the categories of providers and patients eligible for the benefit. CMS has established a goal of encouraging home dialysis use among patients for whom it is appropriate, but the differing monthly payments and low usage of the KDE benefit could undermine this goal.

Report

Factors that may have contributed to the decline in home dialysis from 1988 to 2008:

- Increased capacity to provide in-center hemodialysis. Centers may have had a financial incentive to treat patients in facilities rather than at home.
- Demographic changes in dialysis population. Increased age and prevalence of other health issues in the dialysis population may have reduced the portion considered appropriate for home dialysis, e.g., the percentage of dialysis patients with diabetes as the primary cause of ESRD increased from 24.6% in 1988 to 43.1% in 2008.

Medicare payments to facilities likely encourage the use of peritoneal dialysis – the predominate form of home dialysis – over the long term. The payment rate for peritoneal dialysis is the same as the rate for hemodialysis provided in facilities or at home, but the cost of providing peritoneal dialysis is generally lower. (pg.17)

Authors found that on average facilities that provided home dialysis could improve their financial position in the short term by increasing their provision of in-center hemodialysis.

Of two types of home dialysis, the cost of home hemodialysis including training is higher than for peritoneal dialysis.

The adequacy of training payments could affect facilities' incentives for providing home dialysis.

Medicare payments to doctors for dialysis care do not consistently results in incentives for doctors to prescribe home dialysis.

Few patients have used the KDE benefit, which covers choice of therapy (in-center, home or kidney transplant) and management of comorbidities. Low usage is related to payment limits on types of providers allowed to furnish the benefit and on Medicare patients eligible to receive it. Literature and stakeholders have said there is value in predialysis education to help

patients make informed decisions and also indicated that patients who receive it may be more likely to choose home dialysis.

Transportation Requirements and Dialysis Care

Lisa Hall, Rachelle Dubose Caruthers, Sally Gore, in Nephrology News & Issues, December 16, 2016 at <http://www.nephrologynews.com/transportation-requirements-dialysis-care/>

- Missing even one dialysis treatment can cause severe complications and jeopardize patient health
- Because dialysis is a chronic outpatient treatment, patients are responsible for their own transportation.
- A recent evaluation of factors associated with missed dialysis appointments (see Chan, Thadhani, & Maddux, 2014- *study summary included*) found that patients who traveled to dialysis via a transportation van or who drive more than 17 minutes to a clinic were at increased risk of missing their hemodialysis treatment. Missed treatments were also more prevalent when snowfall was heavy. Further, patients with private transportation to dialysis had significantly better attendance and outcomes when compared to patients who relied on public transportation.
- Chenitz et al (2014) interviewed patients using in-center hemodialysis and found that the most commonly reported barriers to hemodialysis were inadequate and/or unreliable transportation. This was true for both “adherent” and “nonadherent” patients. Patient recommendations to improve dialysis attendance included more accessible transportation. (*Study summary included*)
- References to Ride Connection study with key findings provided.
- Emergencies and dialysis transportation.
 - During severe weather, dialysis patients face significant challenges securing transportation to and from treatments. Even when facilities are open and operating, patients may be left stranded. As a result, many patients are forced to either delay dialysis, forego treatment altogether, or seek treatment in hospital emergency rooms. This, in turn, puts patient health at risk and places an additional burden on emergency response personnel and resources.

Barriers:

- Transportation services suspended due to weather conditions
- Lack of drivers
- Transportation company concerns about liability of deploying drivers in unsafe conditions
- Road/bridge closures due to severe weather and/or flooding
- Transportation providers not authorized to take patients across county lines/out of disaster area
- Door-to-door services not available

- Interruption in gasoline availability (supply shortages or power outages)

Possible Solutions:

- Encourage dialysis facilities to secure contracts or memorandums of understanding (MOU) for backup services from traditional and non-traditional resources, including transportation providers.
- Provide dialysis to patients prior to an emergency (when advance notice is possible, such as a severe storm or flooding).
- Look at the option of home dialysis for eligible patients that experience transportation issues.
- Educate patients on the emergency renal diet and sodium/fluid restrictions.
- Help patients to identify alternative sources of transportation (such as family, friends, or community).
- Assist those patients who have no backup plan with possible options, and maintain a list of those vulnerable patients, as they will need extra help during disasters.
- Re-route patients to alternate facilities.
- Identify gas stations that can operate during power outages.
- Develop a plan for gas allocation.
- Encourage early evacuation of individuals with kidney failure if they are on dialysis, along with appropriate family members (where possible), to out-of-area family/friends, or appropriate shelters.
- To minimize triage and transportation issues, designate one regional shelter to house dialysis patients near a dialysis facility that has generator capability, and triage all patients in the shelter to the designated facility.
- Triage, provide urgent care, and evacuate patients to a location where services can be provided on a routine basis in a safe environment.
- If safe, allow patients and staff with appropriate identification to cross roadblocks and travel during curfews to get to and from dialysis.
- Explore transportation assistance available through FEMA in the event of a disaster.
 - The State of Delaware has established guidelines for dialysis transportation during an emergency when the state's Emergency Operations Center (EOC) is activated. The plan defines roles and responsibilities of agencies involved, including Medicaid broker (LogistiCare) which is to take the lead, with DE National Guard as a secondary resource and a Division of Social Services representative to act as liaison with State EOC and who has list of off-hours phone numbers for dialysis centers and LC.

The Big Business of Dialysis Care

Ron Shinkman, Health Care Editor and Journalist, New England Journal of Medicine, article June 9, 2016 <http://catalyst.nejm.org/the-big-business-of-dialysis-care/>

According to the U.S. Renal Data System, 468,000 patients underwent dialysis in 2013. That's a nearly 47-fold increase in 40 years, driven in part by the rise nationwide in diabetes, hypertension, and other chronic conditions. Medicare pays \$34 billion a year for dialysis care, and these patients account for an outsized portion of the program's total expenditures. Dialysis care has improved gradually over the decades. Unadjusted mortality rates among patients dropped nearly 36% between 2001 and 2013.

The two leading dialysis companies are Fresenius Medical Care, based in Germany, and DaVita Healthcare Partners, based in Denver. The two companies control about 70% of the US dialysis market, together operating about 3,900 locations nationwide.

According to the USRDS, it costs about \$88,000/year for a patient to have dialyses treatment. The figure includes dialysis as well as costs of "collateral emergency room visits and hospitalizations."

Dialysis is very profitable for the two companies. DaVita reported an adjusted net income of \$828 M for 2015, up more than \$100 M from 2014; 75% of its cash flow comes from dialysis services. Fresenius netted more than \$1 B in after-tax profit for 2015. The pharmaceutical industry also benefits from dialysis.

With increasing costs for dialysis treatment, Medicare began bundling dialysis care payments in 2011 in an attempt to better control expenses, "paying about \$240 per treatment, or around \$37,000 per year."

[A commenter to the article, Melvin Hodge, replied that a big problem is that patients are not the customers of dialysis companies, they are just part of the product that the companies sell – patient treatments. He said the buyer is Medicare and its policies define the incentives and hence the behavior of the companies. Since 1984, dialysis providers are paid on a per treatment basis for a "bundle" of services. Short treatments earn the same as long treatment and thus offer "high throughput, maximizing revenue and profit." He said the solution is to align the interests of providers and patients by changing the payment basis from payment per dialysis treatment to payment per treatment hour. Providers would then be paid for what is more important to patients – time of dialysis. Medicare could also incentivize providers to emphasize home dialysis because of its lower cost and higher revenue potential. Now, "home dialysis is retarded by industry in-center capacity – which would disappear with hourly payment – and by perceived inadequate training allowance."]

If a dialysis patient has private insurance, the insurance company is required to pay for services for the first 30 months until Medicare become the primary payer. Private payers typically pay least twice the Medicare rates. "DaVita earns its entire dialysis profit from the private insured, even though they represent only about 10% of patients."

Outset Medical, based in California, developed the "Tablo" a device that breaks down the steps of dialysis into simple steps, with prompts given to patients and/or technicians on a

video screen. Reportedly, patients can hook themselves up in about 10 minutes. The company would like the Tablo to make dialysis more pleasant so as to reduce missed treatments which lead to higher hospitalizations.

Report to Congress: Medicare Payment Policy: Chapter 6-Outpatient Dialysis Services

Medicare Payment Advisory Commission (MedPAC), March 2016

<http://www.medpac.gov/docs/default-source/reports/chapter-6-outpatient-dialysis-services-march-2016-report-.pdf?sfvrsn=0>

The Medicare Payment Advisory Commission (MedPAC) is an independent congressional agency established by the Balanced Budget Act of 1997 (P.L. 105-33) to advise the U.S. Congress on issues affecting the Medicare program. The Commission's statutory mandate is broad: In addition to advising the Congress on payments to private health plans participating in Medicare and providers in Medicare's traditional fee-for-service program, MedPAC is also tasked with analyzing access to care, quality of care, and other issues affecting Medicare.

In 2014, about 383,000 Medicare beneficiaries with ESRD on dialysis were covered under fee for service (FFS) Medicare. Since 2011, Medicare has paid for outpatient dialysis services with a “prospective payment system (PPS)” that is based on a bundle of service that includes certain dialysis drugs and ESRD-related lab tests, which were paid for separately before. In 2014, Medicare costs for outpatient dialysis services were \$11.2 B, a 1% increase over 2013 Medicare dialysis costs.

Dialysis Treatment Choices:

The two types of dialysis—hemodialysis and peritoneal dialysis (PD)—remove waste products from the bloodstream differently. Within these two types, patients may select various protocols. Most dialysis patients travel to a treatment facility to undergo hemodialysis three times per week, although patients can also undergo hemodialysis at home.

Because of recent clinical findings, there is increased interest in more frequent hemodialysis, administered five or more times per week while the patient sleeps, and short (two to three hours per treatment) daily dialysis administered during the day. New research also has increased interest in the use of “every-other-day” hemodialysis; reducing the two-day gap in thrice-weekly hemodialysis could be linked to improved outcomes. PD is the most common form of home dialysis.

Each dialysis method has advantages and disadvantages—no one method is best for everyone. People choose a particular dialysis method for many reasons, including quality of life, patients' awareness of different treatment methods and personal preferences, and physician training and recommendations.

The use of home dialysis has grown modestly since 2009, a trend that has continued under the dialysis prospective payment system. Some patients switch methods when their

conditions or needs change. Although most patients still undergo in-center dialysis, home dialysis remains a viable option for many patients because of advantages such as increased patient satisfaction, better health-related quality of life, and fewer transportation challenges compared with in-center dialysis.

Assessment of payment adequacy:

- Dialysis facilities appear to have the capacity to meet demand.
- Between 2013 and 2014 number of Medicare FFS dialysis beneficiaries and dialysis treatments each grew by 2%.
- Quality of care: Using CMS data and quality indicators between 2010 and 2014, rates of ER use modestly increased, while rates of mortality and hospitalizations declined.
- Medicare payments and providers' costs: Based on 2013 to 2014, cost per treatment increased by 1% while Medicare payment per treatment decreased by about 1%. Evidence suggests that payments are adequate. "The Commission recommends that the Congress increase the outpatient dialysis base payment rate by the update specialized in current law for calendar year 2017."

Commission concern:

- The low-volume payment adjustment does not sufficiently target facilities that are both low volume and isolated. Some facilities that receive this payment adjustment are close by other facilities. Other low volume facilities located in isolated areas that are necessary to maintain access should receive enhanced payment.

Better primary care management of the risk factors for kidney disease – especially hypertension and diabetes (which together are the primary cause of 70% of new ESRD cases) – can help prevent or delay the disease. "The Commission has long argued that primary care providers are undervalued in Medicare's fee schedule and has made recommendations to support primary care, which in turn could support better management of kidney disease risk factors." (pg. 153)

Housing, Transportation, and Food: How ACOs Seek To Improve Population Health by Addressing Nonmedical Needs of Patients

T. Frazee et al, in Health Affairs, November 2016 35:112109-2115 at <http://content.healthaffairs.org/content/35/11/2109.abstract>

Addressing nonmedical needs—such as the need for housing and transportation—is critical to advancing population health, improving the quality of care, and lowering costs of care. Accountable care organizations (ACOs) are well positioned to address these needs. The study used qualitative interviews with ACO leaders and site visits to examine how these organizations addressed the nonmedical needs of their patients, and the extent to which they did so.

For the purpose of the study, the researchers defined nonmedical needs as "any patient needs that were not clinical in nature but had the potential to affect health." They defined ACOs as "voluntary groups of providers that collectively are contractually responsible for the total cost and quality of care for a defined patient population."

Findings:

- The authors found that the nonmedical needs most commonly addressed by ACOs were the need for transportation and housing and food insecurity. ACOs identified nonmedical needs through processes that were part of the primary care visit or care transformation programs. Approaches to meeting patients' nonmedical needs were either individualized solutions (developed patient by patient) or targeted approaches (programs developed to address specific needs).
- Organizations that addressed nonmedical needs displayed three types of integration: 1) fully integrated, marked by meaningful organization and service integration across nonmedical and medical care; 2) coordinated, in which services are integrated but organizations are not; 3) segmented where services were not integrated, but organizations were integrated.
- Most ACOs, regardless of whether or not they addressed medical needs, fell into the non-coordinated category, in which neither services nor organizations were significantly integrated. Most ACOs that addressed medical needs were moving toward the coordinated category, in which services but not organizations are integrated. Only a few ACOs were moving toward the fully integrated category, in which both organizational activities and services are highly integrated.
- ACOs struggle with program scalability, with leaders describing instances in which they observed a general need but were only able to provide individual solutions.
- Barriers to developing formal programs to meet patient needs include lack of financial or staffing resources, lack of expertise, and competing clinical priorities.
- ACOs with formalized programs to meet patients' nonmedical needs still struggle with implementation barriers and often lacked resources to implement programs broadly.

Exploring and Data and Metrics of Value at the Intersection of Healthcare and Transportation: Proceeding of a Workshop, June 2016

Theresa Wizemann and Alina Baci, Rapporteurs, Health and Science Division & Transportation Research Board, National Academies of Science, Engineering and Medicine, Washington D.C., 2016.

Chapter 1

There is a promising policy context for healthcare. The cost reimbursement structure for health care delivery has been shifting over time, in part due to the ACA, from a fee-for-service

model to a value-based payments model. In the new context, providers have to work differently to achieve good outcomes and therefore assume a risk for readmission and other avoidable suboptimal outcomes. The ACA has also led to changes in tax-exempt hospital reporting, as it requires changes in the way hospitals deliver a benefit to the community commensurate to their tax exemption.

In early 2016 CMS issued a funding opportunity announcement for testing the “accountable health communities” model for linking clinical and community services. This model centers on testing three interventions that promote collaboration between clinical care and community services providers: (1) screening community-dwelling Medicaid and Medicare beneficiaries for unmet health-related social needs (e.g., transportation); (2) linking beneficiaries to needed community services; and (3) encouraging alignment between clinical and community services to ensure that needed services are available to beneficiaries. The CMS announcement also refers to the agency’s “better care, smarter spending, and healthier people” approach,

Chapter 2

Key highlights:

- The potential benefits of value derived from investing in transportation include reduced or avoided health care costs, social and personal benefits and avoided costs, and changes in health outcomes. (Guenin)

FTA’s Ride To Wellness Initiative: Goals are to leverage public transportation assets and services to improve access to healthcare, improve outcomes and reduce healthcare costs. The initiative is supported by the FAST Act which established a new FTA grant programs with funding over 5 years for services related to NEMT. The Rides To Wellness demo grant program has about \$7 M available to fund promising project and community solutions.

Chapter 3

Key highlights:

- Transportation planning at the time of appointment scheduling can help to alleviate missed appointments, which are a significant source of financial loss for practices. (Arinez, Graxirena)

Chapter 4

Key highlights:

- Funding is an issue of significant concern in rural areas (e.g., state funding for rural transportation is very limited; many rural areas rely on FTA rural funding programs; FTA Section 5311 program funding is limited; programs have experienced delays in receiving Section 5310 dollars; the procurement process is cumbersome; healthcare organizations do not understand the way that rural transit is financed). (Alewine, Phillips, Stock)

Chapter 5

Key highlights:

- Health centers have expressed willingness to participate in trip scheduling at the time of appointment scheduling if it is simple for them. Smart software solutions are needed, and implementation issues (e.g., billing, eligibility rules, cost, time) need to be solved in advance and might require policy reforms. (Guzzetti)
- To compensate for unreliable transportation systems, some health centers appear to be building in buffer time around appointments, which is potentially wasted and costly time. (Stewart)

Chapter 7

Key highlights:

- Education can improve transportation. Transportation providers might not understand what accommodations the patient needs; health care providers often do not know the transportation options available and therefore cannot advocate for patients; and patients are often unaware of or do not understand how to use the transportation that is available in the community. (Dize, Page)
- Ride Connection (Portland, OR)'s Dahlia Dialysis Transportation Pilot project, funded by the Administration for Community Living, in partnership with CTAA, Easterseals, and the n4a.

From the Transportation Literature

TCRP Report 34, Assessment of the Economic Impacts of Rural Public Transportation

J. Burkhardt et al, Ecosometrics, Bethesda, MD, Transportation Research Board, Washington, D.C., 1998 at http://onlinepubs.trb.org/onlinepubs/tcrp/tcrp_rpt_34.pdf

This study assessed the impacts of rural public transportation on local economics by looking at the difference in economic growth in rural counties with public transit versus rural counties without public transit. The authors examined 8 rural transit systems in depth and among other data looked at trips for dialysis. They compared the cost for the dialysis trips provided by the rural provider versus provision by other modes (such as ambulance, private van providers, etc.) and found that that it was more cost effective to have the trips provided by the rural provider than alternative modes.

In a case study in NC, for example, the researchers calculated the benefits of the rural system providing transportation to/from the dialysis centers for 23 patients versus if the patients had to find an alternative means of transportation. The rural system combines dialysis passengers into routes and provides the door-to-door dialysis service for both wheelchair and non-wheelchair patients at a cost of \$10 per round trip. For the 23 dialysis patients, this totals \$35,880 per year. Alternatives, e.g., ambulance for the wheelchair patients, would cost \$127,764 for wheelchair patients and \$65,520 for non-wheelchair patients for a total of \$193,284, about 5.4 times the cost of the NC system. The economic benefits from this rural system's dialysis transportation thus total \$157,404 (\$193,284 alternate transportation less the \$35,880 transit system cost) based on conservative estimates of the costs of providing this service in a comparably safe and effective manner via alternative means.

Regarding trips for dialysis and other medical treatments, access to medical care and other social services enables the individuals to use services that increase their health and quality of life. Dialysis transportation is a particular challenge for rural transportation systems, as it may involve long distance trips that can cross-county or even state boundaries. Dialysis centers are much more often located in urban than rural areas. There are key operational issues of how to ensure full passenger loads and how to productively employ the driver and the vehicle while waiting the three or four hours for patients' treatment to complete.

The study did not look at the improved quality of life of the dialysis patients which was impacted by the transportation.

An Analysis of Transportation Needs for Dialysis Patients in Fairfax County, Virginia

George Mason University School of Public Policy, Fairfax, Virginia, May 2004 at http://schar.gmu.edu/wpcontent/uploads/PDFs/TPOL_Practicum_Reports/TPOLPracticumReport2004.pdf

FASTRAN, a specialized transportation program in Fairfax County VA, requested a study of its dialysis transportation from George Mason University. FASTRAN provided dialysis trips for almost 90 riders. Dialysis transportation was also provided by WMATA's ADA paratransit's service MetroAccess and by the Medicaid NEMT broker, LogistiCare. The researchers conducted a number of tasks, including interviews with stakeholders (e.g., hospital social workers, nephrologists) and surveys of both patients and stakeholders. They also examined the corporate structure, finances and mission of the private dialysis treatment providers, finding that the provision of dialysis services in No. Virginia is "a very competitive industry" and that the major companies providing dialysis "vie for new customers," ... "many of whom are dependent on publicly supported paratransit providers."

The study examined issues of patient placement for dialysis treatment. According to the study, when a patient is hospitalized with acute kidney failure, the hospital assigns a social worker to the patient. The social worker: (1) assists the patient select a dialysis center, (2) places the patient in the selected center, and (3) arranges for patient transportation services to/from the center. To do the third task, the social worker takes into consideration the patient's insurance, where the patient lives or works or goes to school, and the available transportation services.

Insurance can be an overriding factor. Medicare and Medicaid are agency-neutral. Private insurers (e.g. Blue Cross) have contracts with one or more of the dialysis providers. The patient's nephrologist also has a role on placement. These MDs often have contractual affiliations with particular dialysis centers or the corporate owners and may prefer their patients go to one of these affiliated centers.

Survey also showed that 73% of patients have dialysis at a center closest to their home/work/trip origin location. The remaining 27% do not use the closest center thus travel farther than if they went to the closest center.

Why choose the center used? Patients indicated: 57% said because their MD recommended the center; 30% said it was based on the convenience of center location; 5% said because of customer service at the center; 2% said because of insurance; 7% said "other" reason.

The patient survey found the following regarding transportation modes for dialysis (39 respondents):

- FASTRAN transported 39% to dialysis and 38% home from dialysis
- Patients drove themselves: 24% to dialysis and 26% home
- MetroAccess transported 8% to dialysis and 9% home
- Medicaid contractors transported 8% to and 9% home
- Taxis were used for 16% to dialysis and 12% home

Never late to dialysis:

63% said never late – top two providers of this group - 29% used FASTRAN and 18% drove themselves.

Late to dialysis:

5% indicated they were frequently late due to transportation and half of this group used MetroAccess with the other half indicating “other” transportation.

To address forecast of increasing demand for dialysis transportation, the study provided options:

- Increase operational efficiency
 - Among options in this category, implement new technology, e.g., AVL
 - Group dialysis trips by patient location and time. Schedule shifts at dialysis centers with greater considerations for coordinated transportation,
 - Establish limits on trip length for dialysis patients. Set up a zoning structure. A FASTRAN dialysis patient would need to use a dialysis center within patient’s own zone or a neighboring zone. This would reduce trip length and increase productivity.
 - Dialysis providers should consult with transportation providers when locating new facilities.
- Increase revenues or decrease costs
 - Graduated fare structure by distance.
 - Cost sharing between centers and transportation providers
 - Premium services
 - Supplement FASTRAN funding through government programs (e.g., maximize use of S. 5310, look for state funds)
 - Advertising
 - Home dialysis. Perhaps mobile dialysis? Intriguing new concept but not in practice at time of study.

Constraints that limit what paratransit providers can do:

- HIPAA
- ADA
- Dialysis industry structure and facility location
- Insurance
- MD/patient relationship
- Patient preferences
- Social worker transportation knowledge
- Driver training and qualifications

Study recommendations:

- Coordination between dialysis centers and FASTRAN. More formal transportation planning process, especially for new patients, with social workers.
- Coordinate center shift times to more closely meet paratransit providers scheduling needs.

- Dialysis providers should pay more attention to transportation options when planning new center locations
- Advertising
- Land use planning
- Trip zoning
- Incentivize dialysis centers through partnering –FASTRAN could partner with one or more centers giving them enhanced services such as allowing trip changes on short term notice and centers would work with FASTRAN (non-monetary) with such things as advance notice of schedule changes, construction of new centers, consult with FASTRAN before allowing a patient to change shift time or days.
- Technology – e.g., AVL
- Performance tracking
- Encourage patients to carpool
- Patient education
- Last resort options:
 - Trip limits to free up space for essential trips
 - Need based patient prioritization

Medical Transportation Toolkit and Best Practices, 3rd Edition

Community Transportation Association, 2005

<http://www.ctaa.org/webmodules/webarticles/articlefiles/medtoolkit.pdf>

The report is a resource for community transportation providers involved with non-emergency transportation, with 7 chapters. Chapter 7 focuses on “special needs transportation” and in particular dialysis transportation. The report says that dialysis transportation is the most difficult of special needs transportation due to the frequency of trips, the fact that the individuals often have other medical conditions, and their pickup times can vary due to their condition after treatment. The latter is one of the most difficult aspects of dialysis transportation – can be the delay in releasing the patient due to their condition after treatment. There are drugs given to patients during treatment – to keep their blood from clotting – and this makes them susceptible to bleeding for several hours after treatment. If a patient is still bleeding at the time of transportation pick-up, the driver must wait until bleeding stops before taking the patient. Sometimes a patient may start bleeding while on the ride home; in such case, the driver should return the patient to the center or even to a hospital.

Geographic issues:

- Dialysis providers do not open a center without a certain number of patients. Typically it requires 25 patients to make it feasible to open a new center. So in some areas, trips to dialysis center are long, particularly in rural areas.

- Patients usually want to receive treatment affiliated with their doctor. While Medicaid usually requires beneficiaries to use the closest facility, some patients choose to be transported past nearby centers to reach a center chosen by their doctor.

Improving dialysis transportation:

- Dialysis centers could acknowledge that for many of their patients, transportation to/from the center is key to their treatment. “Too often, transportation is treated as an afterthought.”
- Transportation planning – For example could a patient take fixed route to treatment and then specialized service home?
- Scheduling – Dialysis centers can help transportation providers by better scheduling of patients so as to try and group patients from similar areas so they are on the same dialysis shift. Centers could identify patients who are dependent on transportation and live near each other – schedule them on the same shift.
- Dialysis providers could consider their patients’ mobility needs when deciding where to locate new centers.

What can transportation providers do to improve dialysis transportation?

- Group similar passenger trips. One way to do this is to divide the transportation service area into regions and keep runs within those regions. (This is zoning.)
- Transportation provider may need to place restrictions on where passengers can go for treatment. For example, a passenger would use a dialysis center only with his or her defined zone.
- Transportation funding from dialysis providers. Problem for this is the anti-kickback legislation.

Chapter identifies a few places where coordination has benefited dialysis transportation, including Medical Motor Service in Monroe County, NY and the paratransit provider in St. Louis, MO where the Missouri Kidney Program provides funding. Also identifies CountyRide in Baltimore Co, with its partnership program with several hospitals.

Cost Benefit Analysis of Providing Non-Emergency Medical Transportation TCRP B-27 – Web Only Document 29

P. Hughes-Cromwick et al, Altarum Institute, Ann Arbor, Michigan, Transportation Research Board, Washington, D.C., October 2005 at
http://altarum.org/sites/default/files/uploaded-publication-files/05_project_report_hsd_cost_benefit_analysis.pdf

The goal of this study was to compare the costs and benefits, including potentially large net health benefits, of providing NEMT to those who lack access to it.

The study investigated the hypothesis that improving access to healthcare for the transportation-disadvantaged population will lead to improved quality of life and an overall decrease in healthcare costs. Also, the study examined whether this hypothesized net decrease in healthcare costs exceeds the incremental increase in transportation costs.

Findings:

An analysis of nationally representative healthcare datasets revealed that about 3.6 million Americans miss or delay non-emergency medical care each year because of transportation issues. This target population of 3.6 million persons was found to have a higher prevalence of chronic diseases and a higher rate of multiple chronic conditions.

The researchers determined that the most appropriate method of evaluating the benefits of improved access to medical care is cost-effectiveness analysis (CEA). “The CEA method measures the effectiveness-per-unit cost, as opposed to a cost-to-cost comparison. As described in this report, healthcare improvements are worth the amount invested when the cost is reasonable in light of improvements in mortality (enhanced life expectancy) and morbidity (health-related quality of life). Thus, while cost savings are the best possible outcome, cost increases may nevertheless be seen as worthwhile—i.e., cost-effective if they provide sufficient improvement in quality of life, life expectancy, or both. This standard is met for the 8 conditions that are not estimated to be cost saving.”

The researchers examined 12 medical conditions, including ESRD, and found that providing additional NEMT is cost-effective; for four of these conditions, the researchers found that providing additional NEMT is actually cost saving – additional investment in transportation leads to a net decrease in total costs when both transportation and healthcare are examined. These 4 include diabetes (but not ESRD).

For the other 8 conditions, providing NEMT is “highly cost effective” but not cost saving.

The net healthcare benefits of increased access to medical care for the transportation-disadvantaged exceed the additional costs of transportation for all of these conditions (which include ESRD). These benefits include both actual decreases in healthcare costs for some conditions (e.g., emergency care replaced by routine care) and improved quality of life for those who receive access. For three of the chronic conditions (asthma, heart disease, and diabetes), results show net cost savings; for the other four (depression, hypertension, chronic obstructive pulmonary disease, and end-stage renal disease), improvements in life expectancy or quality of life are sufficient to justify the added expense of NEMT.

These results reveal “a major finding and theme of this project: adding relatively small transportation costs does not make a disease-specific, otherwise cost-effective environment non-cost-effective.” For example, a congestive heart failure monitoring program, already evaluated as highly cost-effective, will not become cost-ineffective by only adding incremental

transportation costs. In other words,” in today’s economy, transportation is relatively inexpensive compared with the high and rapidly growing cost of healthcare.”

According to the authors, the literature points to the issue of inadequate transportation that is a key, contributing factor to a lack of access to medical care. But little literature specifically relates transportation barriers to the larger problem of healthcare access.

Florida Transportation Disadvantaged Programs Return On Investment Study

Dr. J. Cronin, Jr et. al, The College of Business, Florida State University, Tallahassee, FL, March 2008 at file:///S:/1618%20%20%20TCRP%20B-45%20Dialysis%20Transportation/Literature/ROI_Florida%20%20%202008.pdf

This report calculates the return on investment to the State of Florida for its transportation disadvantaged program, which funds transportation for defined groups of people with transportation needs. The study looked at the five most common trip types provided by the transportation disadvantaged services which include: medical, employment, nutrition, education and life-sustaining. While it is generally acknowledged that public dollars invested in such programs do not directly “generate” revenues or returns in the traditional sense, there are substantial financial benefits that accrue to the state from its investment. Specifically, these programs benefit Florida based (1) on the economic activity that is generated as a result of five specific activities that are supported and (2) as a result of the state being able to avoid “costs” as a result of the investment.

The benefits associated with transportation disadvantaged programs are not provided in state records. They also are not easily identifiable

One of the primary purposes of transportation disadvantaged funding efforts is to support preventative medical care. Preventative medical care trips assist in keeping low income, elderly, and disabled Florida residents out of the hospital and nursing homes. Moreover, the mobility these programs provide allows such individuals to live healthier lives and to maintain their independence..

Looking just at the medical trips, the authors found the following: The primary purpose of medical trips is to provide preventive medical care to the transportation disadvantaged citizens who have no other way of receiving these services. Given that nursing home costs in Florida average approximately \$5,000 per month, average hospital stays are approximately \$7,900, and adult day care costs range from \$25 to \$100 a day, the benefit that results from providing transportation to preventive medical care is substantial based on the state’s ability to avoid funding assisted living costs. Conservative assumptions were used to identify the return on investment, or payback to the State of Florida. Specifically, if one percent of the trips funded result in an avoided hospitalization (since the individuals received the needed medical care, such as dialysis), the payback to the state is 1108%, or about \$11.08 for each dollar the state invests in the transportation disadvantaged program. The state will also

benefit from healthier citizens and a reduction in the need to invest in such programs as Medicare/Medicaid to fill the need for medical care for these transportation disadvantaged clients.

The Dialysis Report: Transportation Demand Outstrips Supply

S. Bogren, Community Transportation: Fall/Winter 2011, Community Transportation Association of America, Washington, D.C., 2011 at http://www.infrastructureusa.org/wp-content/uploads/2011/12/fall_winter_11_the_dialysis_report.pdf

Trips for dialysis are a growing challenge for community and public transit providers. Demand is increasing and trips distances have grown even as available dialysis center chairs are expanded locally to keep up with the number of patients.

While the typical center-based treatment requires three visits per week, several recent studies have suggested that increased frequency in shorter duration treatments — six times a week for two-and a-half hours — increased overall health and quality of life in patients. This would double the transportation need.

Typically, patients on a Monday-Wednesday-Friday schedule are more likely to be private-paid, particularly those receiving their dialysis in the middle of the day. Conversely, Tuesday-Thursday-Saturday patients and those early morning and later night clients are more likely to be Medicare patients. These are also the dialysis patients more likely to be dependent upon community and public transportation — in the most difficult and costly to serve time slots.

Total Medicare ESRD expenses for 2009 came to \$42.5 billion — or \$82,285 per person per year for hemodialysis patients. Just over 1 percent of Medicare patients have end-stage renal disease, yet these same patients account for more than 8 percent of total Medicare spending.

“The dialysis transportation challenge is so great that major changes in public policy must occur to enable this mobility link to continue. “ (1) The time has come to extend reimbursement for this vital health support service. (2) there must be increased communication between those providing dialysis treatment and transportation.

The crux of the transportation challenge is that the majority of dialysis patients are covered by Medicare, which — unlike Medicaid — does not offer non-emergency transportation as a benefit. Three out of four dialysis patients in the U.S. are Medicare primary, meaning that Medicare sets the reimbursement rate and pays 80 percent of that amount. Reimbursements include one rate for routine dialysis services and another for dialysis medications. This leaves 20 percent of the typical dialysis charges to be paid by a secondary insurer.

For roughly half of the Medicare primary dialysis patients, the secondary insurer is Medicaid, thus creating the so-called dual eligibles. How much of that 20 percent that Medicaid covers depends upon the state. Recent studies indicate that only one in 10 dialysis patients are Medicaid primary, in which case Medicaid pays between 80 percent and 100 percent, depending on the state and its Medicaid plan. Finally, 10 percent of dialysis patients are covered through some form of private insurance.

“Twenty-five years ago when we first launched this service, it seemed to us that 90 percent of the dialysis patients we encountered were on Medicaid,” according to DCT on the Eastern Shore of MD. “Today that equation has flipped, and 90 percent are on Medicare, which is why we’re hurting.” Bill McDonald, executive director of Medical Motors in Rochester, N.Y., has seen the same transition: “We hardly do any Medicaid dialysis anymore, so our focus is on the patients who aren’t Medicaid eligible and who still very much need that ride.”

Some providers have concerns that their general public service is being taken over by dialysis transportation. Some providers receive funding from their local United Way to provide support.

Author states that the key solution for community and public transportation is to develop a funding mechanism for dialysis transportation in Medicare. Currently, Medicare will only reimburse for emergency transportation services —ambulances — and not for non-emergency dialysis transportation.

Community and public transportation managers that were interviewed for this article were asked to roughly estimate the transportation costs incurred for a year of dialysis transports. Most came to a figure in the neighborhood of \$5,000 per patient, per year. When Medicare is paying more than \$82,000 per year per person for dialysis, it does not seem unreasonable to build in a 6 percent increase to provide NEMT.

Final Report to the Texas Department of Transportation and the El Paso County Transportation Program

Center for Interdisciplinary Health Research and Evaluation, College of Health Sciences, University of Texas at El Paso, El Paso, TX, May 2013 at <http://utep.edu/chs/cihre/Files/images/grant%20Awards/FINAL%20REPORT%20DOT%205-10-13%20Final%20EWVAGS.pdf>

This study assessed transportation services for dialysis patients in far west Texas, a rural area of 8 counties and examined how the key stakeholders viewed the transportation services and suggestions for improvement. The study included in-depth interviews with 22 health providers 6 dialysis center administrators, 6 clinic social works and 23 public and private transportation providers’ staff as well as 27 dialysis patients.

The study reports that a patient is assigned to a dialysis clinic by their nephrologist or a social worker. These medical professionals report the following factors used in the assignment: availability of transportation by the patient, the stage of ESRD, availability of seats at the clinic, and distance from the patient's home to the center.

Patient's role in clinic selection: A patient is usually given a list of dialysis clinic to choose from but the following may influence the decision:

- A clinic close to the patient's home may not have space for a new patients
- The patient's nephrologist may not work with the clinic closest to the patient's home which would make monitoring the treatment more difficult
- The patient's insurance provider

Nephrologists' role:

Report states that the main issues related to physician and patient selection of a dialysis clinic is which company is associated to a particular nephrologist. "In most cases, a nephrologist would be reluctant to send his or her patient to a clinic that is not owned by the company he or she works with, because it would make treatment monitoring more difficult."

Dialysis transportation experience: The study assessed a sample of patients' trips and found that 42% of the patients bypassed two or more dialysis clinics on their trip to dialysis before reaching their assigned clinic. "This extra mileage results in high expenditures on fuel, extended driver's time, increases vehicle wear and the decrease in the quality of life of the dialysis patients."

The length of time spent in transportation to/from dialysis is "one of the most common issues affecting the patient's quality of life." Changes to the transportation schedule (late arrival at the clinic, etc.) can have a negative effect on compliance with the treatment which then negatively influences clinic outcomes.

The main problem voiced by study participants including patients and social workers was the waiting time for transportation to/from the dialysis clinics. Some of the patients are transported long distances. Suggestions for improvement:

- Shorten the waiting time. For example, have a certain number of vehicles assigned exclusively to transport dialysis patients, ensuring timely pickups and drop-offs and eliminate the possibility of shortened dialysis treatment time.
- Improve the scheduling system and communication between dispatchers and drivers.
- Add technology – GPS – to allow drivers to change routes if need be.
- Add a buffer of time, e.g., 10-15 minutes, to each pickup from dialysis to ensure patients are stable and ready to leave.
- "Every effort should be made to assign patients to the clinic nearest their residence." To expedite travel time, transportation zones assigned to one single transportation provider should be designed, which would minimize transportation costs, decrease

travel time and most importantly, decrease the waiting time after treatment at the dialysis centers which would improve the patients' quality of life.

Improving Transportation for Patients Receiving Dialysis Treatment: A Report on the Findings

Ride Connection, Portland, OR, January 2014, at http://nationalcenterformobilitymanagement.org/wp-content/uploads/2013/11/RideConnection_DialysisTransportation_ACLStudy_Final-Report.pdf

Ride Connection is a non-profit agency providing specialized transportation service primarily to seniors and people with disabilities in the Portland area. The agency builds on a network of agencies and providers, including volunteers.

Ride Connection initiated a study to identify issues and challenges with transportation and how those impacted individuals' health. With a decision to focus on transportation for dialysis, the study began with an inclusive and participatory planning process which included significant outreach and, included, among others, an advisory committee, focus groups, interviews and surveys of patients and caregivers.

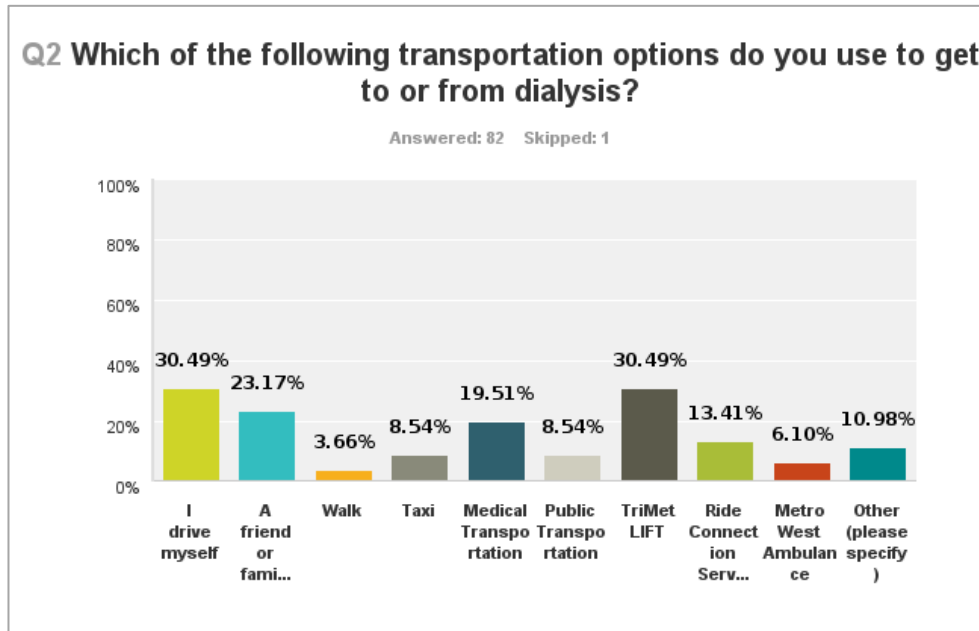
The patient survey asked modes of transportation used for dialysis, with 82 responses showing the top modes as:

- Patient drives 30.5%
- Uses ADA paratransit 30.5%
- Friend or family member drives 23.2%
- Medical transportation 19.5%

The survey asked about transportation problems, categorizing the responses for those who drove themselves to dialysis and those who did not and therefore used other modes. For those that do not drive, the problems identified most frequently include:

- Treatment was shortened because the patient was late for the appointment (33% of non-drivers)
- Treatment was shortened because the patient was worried about missing the ride home (28% of non-drivers)
- Patient was left waiting at the clinic without a ride home (27% of non-drivers)
- Patient missed a dialysis treatment because the ride was canceled or did not show up (25% of non-drivers)
- Patient had to leave the clinic early in order to catch the ride home (23% of non-drivers)
- Patient rushed to catch the ride home and as result had trouble in the vehicle (bleeding, fainting, etc.) (17% of non-drivers)

- Patient missed a dialysis appointment because patient could not find a ride (17%)



Excerpt: Figure 8--Modes of Transportation used by Patient Survey Respondents, Improving Transportation for Patients Receiving Dialysis Treatment, A Report on Findings, pg. 18.

Based on the findings from the planning process, Ride Connection defined “themes.”

The major themes include:

- Flexibility and dependability. For example, one caregiver said: “Transportation service should be based on the individual care needs of each patient, not the scheduling needs and/or financial gain for the transportation company.”
- Waiting and indirect routes. Surveyed patients complained about lack of prioritization for riders who were not feeling well on the ride home.
- Missed rides home.
- Late rides affect dialysis treatment and health conditions. This is a key issue and appears to happen frequently with one-third of non-driving patients surveyed indicating shorted treatment due to being late to the clinic at least once over the 3-month period prior to the study. Less dialysis time has negative health consequences for the patient.
- Affordability.
- Geography and clinic choice. This is a key issue from a transportation perspective; the study found that several patients received dialysis very far from their home. The disconnect between residential location and treatment location results in long and sometimes indirect routes for transportation providers and contributes to delays and waiting that patients experience with transportation.

- Drivers/dispatchers. Transportation staff is not always considerate or compassionate. Some surveyed patients questioned if there was a First Aid kit on board the vehicle in case of bleeding.

The study came up with solutions in 3 categories and a transportation pilot project.

(1) Ride Connection protocol changes:

- Fact sheets, explaining to riders what Ride Connection can and cannot do and explaining to Ride Connection drivers, dialysis patients' rights and responsibilities
- Increase return trip flexibility
- Guaranteed return trip.
 - Allow will-call return or set standards for flexibility of will call
- Re-evaluate no show/late cancel policy, e.g., the Policy should take into consideration health conditions or emergency situations
- Improve scheduling protocol to ensure condition of riders is considered when scheduling each ride
 - Clearly define and prioritize "life-sustaining" trips
 - Expand service hours
 - Increase training options for drivers who transport dialysis patients.

(2) Outreach, Advocacy, Recruitment and Education:

The study suggested a wide range of activities, such as outreach and dialogue with other transportation providers in the community and developing training for dialysis support staff such as a transportation options fact sheet for clinics, social workers etc.

(3) New Program and Collaborations – Transportation Pilot Project:

Study recommended a pilot for a select clinic that would model the best in flexible, reliable and affordable transportation for patients.

Findings show that there are a number of ways that health outcomes of patients are directly and indirectly impacted by barriers or inadequacies with their options for medical transportation. This suggests that improved transportation options would improve health outcomes and also potentially reduce overall healthcare costs by reducing patients' later medical complications

Information provided at the June 2016 National Academies Workshop on Transportation and Healthcare Intersection described the pilot that Ride Connection implemented:

- Elements of the pilot included, for example, a dedicated dispatcher, collaboration with partners, no costs to patients, allowing shared rides, training, and constant communication. A critical aspect of the pilot is a quarterly assessment of the level of service for the patients.
- The average trip costs \$16.32. The cost per ride has been increasing in recent months as the number of paid driver hours needed has increased. At the start, the project

relied heavily on volunteer hours, but the number of volunteer hours has decreased, due in part to overworking of volunteers, slow recruitment, and having only one volunteer coordinator.

- The ultimate goal is improved patient outcomes, and the workshop presented highlighted several key outcomes thus far:
 - Majority of actual dialysis times more closely match the prescription times;
 - Missed appointments have decreased significantly; and
 - Patient health and quality of life have improved, with acknowledgement that quality of life is very difficult to assess, and the pilot relies on qualitative evidence from surveys. Patients have reported that the transportation project has improved their lives and that their stress is reduced by not having to worry about transportation. Meanwhile, clinics are spending less time dealing with transportation issues, they have a better understanding of the transportation options for dialysis patients, and they are better advocates for their patients. All of this leads to saved time and money, according to the presenter.
- The presenters emphasized that collaboration is required for success and said that the educational component alone can help improve transportation. He cautioned against putting too much emphasis on financial return on investment; the focus should instead be a more holistic one, taking into account shared investments and shared values.

Information Provided at International DRT Conference in Breckenridge CO, Sept. 2016:

- Another pilot is planned, with a dialysis center in a rural location. The state of Oregon has provided funding for this pilot.

Impacts of Dialysis Transportation on Florida's Coordinated Transportation Programs

M. Audino and J. Goodwill, National Center for Transit Research, CUTR, Tampa, FL, prepared for the Florida Department of Transportation, April 2014 at <http://www.nctr.usf.edu/wp-content/uploads/2014/05/77951.pdf>

This study looked at the demand for dialysis transportation provided by Florida's specialized transportation programs and its impact of the programs through a survey of the Community Transportation Coordinators, which are businesses or local public transportation providers that are responsible for providing or arranging the delivery of transportation services to the transportation disadvantaged population within their county. The study looked at trips provided by the counties' demand response services and did not include ADA paratransit provided by urban fixed route transit agencies.

The study categorized the state's 67 counties into:

- Rural – 17 counties
- Small urban – 27 counties
- Large urban – 23 counties

Survey was sent to all CTCs. A total of 40 responded, representing 53 of the state's 67 counties.

Regarding dialysis trips, responses were provided by 22 CTCs, which reported a 51% increase in dialysis trips from 2008 to 2012, a five-year period.

Dialysis trips as percent of total trips:

All responding counties – dialysis trips went from 11.9% in 2008 to 15.6% in 2012

Rural counties – reported a decline over the 5 year period of 10.5% to 9.4%

Small urban counties – reported an increase from 8.3% to 13.2%

Large urban counties – reported an increase from 11.6% to 18.1%

Serve all dialysis trips requested?

77% said yes. 23% said no.

Barriers that impact the ability to serve dialysis trips:

- Requested trips were outside the service span
- Insufficient funding
- Vehicle availability

Unique options to serve dialysis trips?

A CTC in a small urban county has implemented a volunteer transportation service and a mileage reimbursement program to help meet demand for dialysis trips.

General observations:

- About one third reported positive relationships with local dialysis facilities

“Best” practices:

- Designate a staff person to represent the CTC in interactions with dialysis facilities and have that person conduct regular and frequent meeting with the facilities. Identify issues and challenges and work with the facilities to address those.
- Maximize group loading.
- Assign the same driver as often as possible.
- Implement a “counseling” program to educate patients/their families/caregiver about the operational issues when patients no-show or late cancel.

Nonemergency Medical Transportation – Updated Medicaid Guidance Could Help States

GAO, Report to Congressional Requesters, February 2016 at <http://www.gao.gov/products/GAO-16-238>

Summary

Medicare provides NEMT via ambulance only when other means of transportation, such as a taxi or wheelchair van, would jeopardize the health of the beneficiary. Medicaid NEMT is generally available for beneficiaries who have no other means of transportation to medical services. States are responsible for the daily operations of their Medicaid programs and have discretion in how they deliver NEMT.

The Centers for Medicare & Medicaid Services (CMS), within the Department of Health and Human Services (HHS), oversees Medicare and Medicaid at the federal level, but this oversight varies by program. CMS generally uses regular program integrity activities—such as claims reviews—to oversee Medicare NEMT. Under Medicaid, CMS also uses regular oversight activities, and these include overseeing states' program integrity activities and periodically issuing guidance. However, some of CMS's guidance is outdated or may be of limited use because of legislative and other changes that affect Medicaid and states' NEMT programs. For example, a 1998 guidebook on NEMT contains outdated information on implementing NEMT transportation broker programs.

These programs also benefit from updated guidance on strategies to ensure compliance with federal requirements while incorporating current practices to meet beneficiaries' needs. Guidance for state Medicaid programs is particularly important because NEMT is at high risk for fraud and abuse; some selected states and stakeholders GAO interviewed reported that updated guidance could be helpful. *Standards for Internal Control in the Federal Government* states that management should ensure adequate means of communicating with stakeholders. Effective communications can take many forms, including guidance. CMS officials reported that the agency is considering assessing whether additional NEMT guidance is needed, but has not set time frames for conducting this assessment.

GAO identified four types of challenges related to Medicaid NEMT and several steps taken by states to address some of these challenges. Challenges reported related to containing costs, maintaining program integrity, contracting with and overseeing vendors, and accessing NEMT.

For example, states reported challenges containing NEMT costs due to increased NEMT utilization and reported implementing practices to help address these challenges. Such practices include setting fixed provider reimbursement fees that remained relatively constant in recent years. Officials from 7 of the 15 selected states and 6 stakeholders GAO interviewed reported that having information on how states administer NEMT and ways to address

challenges could be helpful to states. Some of this information is available; for example, CMS reported collecting information on states' approaches through state Medicaid plans and posting this information on CMS's website. Other organizations, such as the Transit Cooperative Research Program, have or are in the process of collecting such information.

Report

Medicare is a healthcare insurance program administered at the federal level for seniors, certain people with disabilities, and those with ESRD. In 2014, Medicare cost \$613.3 B for 53.8 M beneficiaries,

Medicaid is a joint federal-state health-financing program for low income and medically needy people. For 2014, Medicaid costs were an estimated \$499 B for more than 65 M beneficiaries. The federal government match most state Medicaid expenditures using a statutory formula – the Medical Assistance Percentage rate – based generally on each state's per capita income relative to the national average. Medicare and Medicaid and their NEMT programs are provided under both fee-for-service and managed care payment systems. Under Medicare, NEMT services are allowed to be provided by ambulance to scheduled non-emergency medical services for some beneficiaries. For example, Medicare NEMT may cover ambulance transportation for a beneficiary with ESRD for scheduled, repeated and nonemergency transports to and from dialysis treatments, if ambulance transportation is medically necessary. (pg. 6)

States use different models for provide Medicaid NEMT. These include paying for NEMT on a fee for service basis, contracting with managed care health plans to provide healthcare services including NEMT for a per-member, per-month fee, and contracting with brokers to manage all or some aspects of NEMT on the states' behalf.

CMS began a 3-year Medicare prior authorization demonstration program in Dec. 2014, which requires prior authorization for scheduled repetitive nonemergency trips to test whether prior authorization helps reduce costs while maintaining of improved quality of healthcare. NJ, PA and SC were selected to start this program because of their high use of nonemergency ambulance trips under Medicare and improper payment rates. Plans call for the program to be expanded. Reportedly, some stakeholders in the demonstration states had concerns that patients with ESRD had problems getting NEMT under Medicare. CMS said that Medicare only allows ambulance transportation when it's medically needed. CMS has increased education to beneficiaries and to medical and transportation providers and suppliers to address this.

CMS issued a guidebook in 1998 addressing the design and operation of a cost-effective Medicaid NET program. But this guidebook has outdated information, such as when brokerages can be used. However, the Deficit Reduction Act of 2005 changes the conditions under which states could use NEMT brokerages.

According to CMS officials, some states do not always understand the NEMT benefit in part, per this GAO report because NEMT guidance is not specific to the benefit. Officials in selected states and stakeholders report challenges in containing Medicaid NEMT costs. These individuals report cost increases from 2012-2014 are due to:

- Increased enrollment by Medicaid expansion under the ACA and the economic downturn.
- Program changes such as covering NEMT to more types of services, such as dental and mental healthcare—and greater awareness of the benefit among beneficiaries.

Officials in 9 states and 3 stakeholders (2 counties and 1 transportation broker) reported that certain trip factors make it difficult to contain cost – long distance trips, need for specialized vehicles, and reaching rural locations.

Report provides examples of state practices that could address Medicaid NEMT costs. One of which is: “Wyoming officials reported working with beneficiaries undergoing certain types of treatments such as chemotherapy and dialysis to identify treatment centers closer to their homes.”

Improving Transportation for Patients Receiving Dialysis Treatment

Community Transportation Association of America. Community Transportation 48–51, 2014. <http://web1.ctaa.org/webmodules/webarticles/articlefiles/MedCT14rc.pdf>

This article in the CTAA periodical reports on the dialysis transportation study undertaken at Ride Connection in Portland, Oregon, with excerpts from the Ride Connection report, which is included in this literature review.

Study of Paratransit Services for Dialysis – Maryland Legislative Report

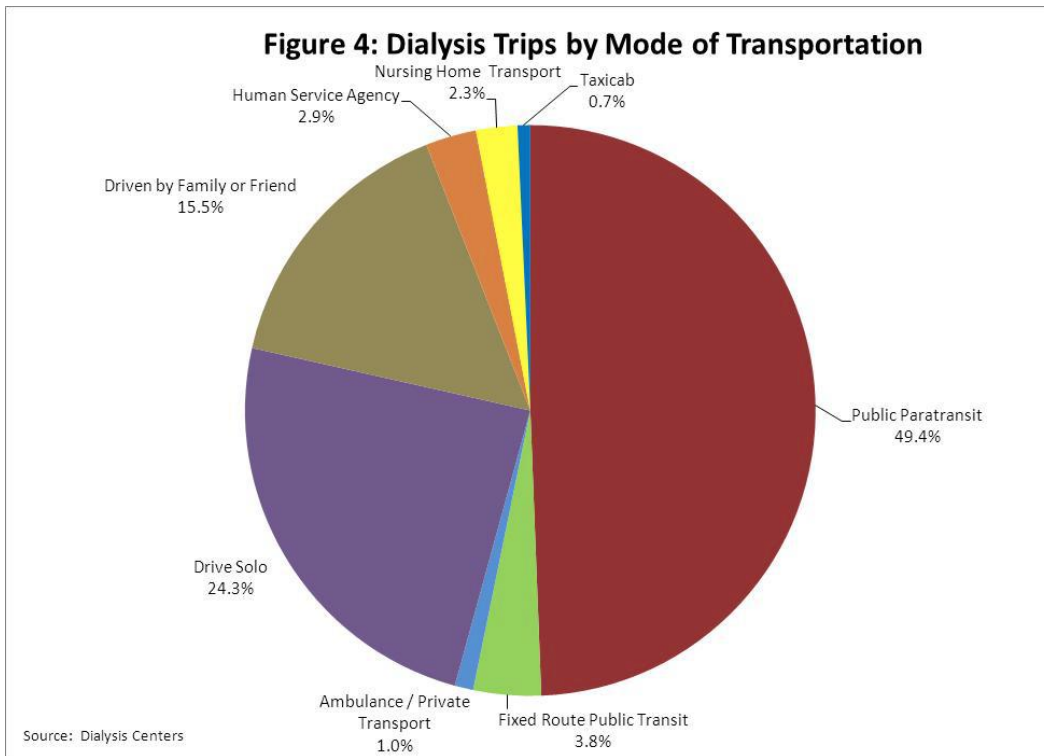
KFH Group, Inc., prepared for the Maryland Dept. of Transportation, Maryland Transit Administration, October 2013

http://web1.ctaa.org/webmodules/webarticles/articlefiles/FinalReport_StudyofParatransitServicesforDialysis.pdf

Legislation was introduced into the Maryland General Assembly in 2013 to provide funding for public transit agencies in the state to meet the growing demand for door-to-door transportation to dialysis centers for patients with ESRD. Rather than legislation, legislators instead requested a study to estimate the demand for paratransit services to dialysis centers and the funding needed if public transit agencies were to meet that demand.

The study included research of ESRD incidence and prevalence in the state as well as a survey of the 114 dialysis centers in the state and of the state’s local transit operators including the major transit agencies in greater Baltimore and the Washington, DC metropolitan regions. The study found that an estimated 8,300 Marylanders receive dialysis at one of the state’s

dialysis centers and that this number is growing 3-4% annually. Of the total 2.6 M estimated trips to dialysis centers in the state, approximately 49% – almost 1.3 M trips annually – are provided by public paratransit, which is broadly defined as including general public demand response, ADA paratransit, Medicaid NEMT, and human service agency transportation. These services are funded by federal, state and local funds. Of the paratransit trips, about 35% are provided by public transit agencies' paratransit services. Of the total 2.6 M trips to dialysis centers, public transit agencies' paratransit serves about 17%.



Excerpt: Study of Paratransit Services for Dialysis – Legislative Report prepared for the Maryland Dept. of Transportation, Maryland Transit Administration, October 2013, pg. 11.

The study further estimated the number of dialysis trips that public transit agencies could not serve due to trips denials because of capacity constraints (most of the smaller transit agencies in the state provide general public demand response service) and because trip requests fell outside of the transit agencies' operating days/hours: 75,000 annual trips. The cost of these additional trips for the transit agencies was then estimated at just over \$2 M annually. Regarding future demand and cost for dialysis transportation for Maryland's public transit agencies, the study estimated that demand could increase from 443,000 current trips to 664,000 annual trips in 2020 as the number of dialysis patients grows; and the total cost to the agencies of providing all current, latent and future dialysis trips in 2020 is over \$27 M, an increase of 43% over current (2013) funding spent by public transit agencies on dialysis transportation.

Medicaid Transportation Study of Policy and Practices in the Metropolitan Washington Region

KFH Group, Inc., prepared for Metropolitan Washington Council of Governments and Washington Metropolitan Area Transit Authority, June 2016

This study documented the provision of Medicaid NEMT in the three jurisdictions of metropolitan Washington, D.C. – the District, Maryland and Virginia – and the overlap of Medicaid NEMT with the region’s public transit agency, the Washington Metropolitan Area Transit Authority (WMATA).

The findings relevant for TCRP B-45 include:

- Medicaid is an entitlement program funded by the federal and state governments, which pays for medical assistance for individuals and families with low incomes. It is the largest source of funding for medical and health-related services for low-income people in the country. The Medicaid program is administered in partnership with the states by the Centers for Medicare and Medicaid Services (CMS) within the federal Department of Health and Human Services (HHS).
- The federal government’s share of Medicaid ranges from 50% to 83%, depending on a number of factors, including whether payment is the medical assistance percentage or the administrative percentage.
- Non-emergency medical transportation (NEMT) was not specifically included in the original Medicaid legislation. However, provisions in the legislation and the body of case law that has evolved from the legislative language require that each state Medicaid program include provisions for necessary transportation of Medicaid recipients to and from providers of medical services. The transportation requirement was then included in rulemaking issued in 1968 and, in 1978, the transportation requirement was officially added to the Social Security Act as §431.53 *assurance of transportation*.
- How a state will meet its federal mandate to assure necessary transportation is determined, in part, by the definition of the term “necessary.” This is defined as:
 - Transportation provided is to/from a Medicaid covered service;
 - The least expensive form of transportation available is used and is appropriate for the client;
 - Transportation is provided to the nearest qualified provider; and
 - No other transportation resources are available free of charge.

The means that when several modes of transportation are available, states are to use the least costly means of transportation that is appropriate for the particular medical needs of the beneficiary. This is also in keeping with Medicaid’s status as the “payer of last resort.”

- The federal payment share for Virginia and Maryland is 50% and 70% for the District (this means the District receives 70% federal funding for its Medicaid program).

- Cost-transferring from Medicaid to ADA paratransit: A significant number of Medicaid NEMT trips in the District in CY 2015 used WMATA's ADA paratransit service for their Medicaid-eligible medical trips rather than using the District's NEMT service administered by a private broker. These trips – numbering 82,404 – cost the District \$51 per trip. If those 82,404 trips had been provided by paratransit providers in the NEMT network administered by the District's Medicaid broker, the District would have paid 30% of trips that cost, on average, \$25.75, with the federal government paying the remaining 70% share. Thus, the District paid, with its local money, \$4.2 M for the Medicaid-eligible trips provided by WMATA's ADA paratransit service whereas if the trips were provided by Medicaid NEMT, the District would have paid less than \$637,000, given its Medicaid program cost-sharing arrangement with the federal government.
- In Maryland, the counties, which administer the Medicaid NEMT program, refer trips to WMATA for Medicaid beneficiaries who are also eligible for ADA paratransit rather than provide those trips on their own NEMT services, where trip costs are significantly less than WMATA's. In this way, the Medicaid NEMT program is fulfilling the requirement to put the trip on the lowest cost provider as judged from the Medicaid program perspective since it does not pay for the trip on WMATA. But WMATA is not the lowest cost provider when judged from the state's perspective, as Maryland must WMATA \$51 for each Medicaid eligible trip provided by WMATA. The average cost of the trips on Maryland's NEMT services ranges from \$32-40 per trip and the federal government would pay its 50% share of those trips.
- Virginia, similar to the District, uses a private broker to administer its Medicaid NEMT program. Reportedly, the broker does not generally refer trips to public transit agencies' ADA paratransit service, as the state expressed concern that significant referrals to ADA paratransit without payment for the real cost of the ADA trips would negatively impact the transit agencies.

From Sweden to Texas via the IHI National Forum: Do-It-Yourself Dialysis

R. Gibney, Institute for Healthcare Improvement, *August 3, 2016*

<http://www.ihf.org/communities/blogs/layouts/15/ihf/community/blog/itemview.aspx?List=7d1126ec-8f63-4a3b-9926-c44ea3036813&ID=287>

A nephrologist practicing in Waco, Texas implemented a do-it-yourself dialysis practice, after learning about the success of the practice in Sweden. Instead of having the dialysis center staff handle the dialysis procedure, interested patients were taught how to start and carry out dialysis themselves at the center, using what the nephrologist calls empowered dialysis, differentiating it from traditional dialysis. The first year of the new program – 2015 – saw very different patient outcomes: Of the 560 patients on traditional dialysis, there were 1,099 hospitalizations and 90 deaths. Of the 191 patients on empowered dialysis, there were only 125 hospitalizations and five deaths. Traditional dialysis patients were hospitalized at a rate of 1.9 hospitalizations per patient compared to 0.7 for the empowered group — more than twice as often.

At the time of the article, the nephrologist's practice had about 280 patients using empowered dialysis in 12 centers in the Waco area. Two of the centers use only the empowerment model, while the others have a mix of the empowered treatment and the traditional treatments.

Medicare and State Health Care Programs: Fraud and Abuse; Revisions to the Safe Harbors Under the Anti-Kickback Statute and Civil Monetary Penalty Rules Regarding Beneficiary Inducements

Office of the Inspector General of the federal Department of Health and Human Services, December 2016 at

<https://www.federalregister.gov/documents/2016/12/07/2016-28297/medicare-and-state-health-care-programs-fraud-and-abuse-revisions-to-the-safe-harbors-under-the>

The Office of the Inspector of the federal Department of Health and Human Services (HHS) issued a final ruling in December of 2016 that, among other things, updates existing “safe harbor” regulations that relate to healthcare providers and local transportation.

As background, the Anti-Kickback Statute provides criminal penalties for individuals or entities that knowingly and willfully offer, pay, solicit, or receive remuneration in order to induce or reward the referral of business reimbursable under Federal health care programs. Because of the broad reach of the statute, there was concern that some relatively innocuous commercial arrangements were covered by the statute and therefore not allowed.

With the ruling, “eligible entities,” which include healthcare providers such as hospitals and clinics and including dialysis centers (but excluding entities that primarily supply healthcare items such as pharmacies), are allowed to fund local non-emergency transportation for patients and shuttle services for patients and others to access medically necessary services and items within specific parameters. The transportation can be free or discounted. Healthcare providers and unrelated businesses may contribute together to provide the transportation.

The ruling defines the details.

Types of transportation: Transportation can be provided on a door-to-door basis. And it can be various modes – buses, taxis, community vans, volunteers, etc. Transportation can also be provided via shuttle transportation, using buses, vans or other vehicles that operate along a fixed route with a fixed schedule. Healthcare providers can provide the transportation or use vouchers or other subsidy methods to provide transportation for patients.

What does local mean? Local transportation is defined at up to 25 miles in urban areas and 50 miles in rural areas. Mileage is measured “as the crow flies.”

Who can be served? Individualized transportation (door-to-door) is to be provided for “established patients.” This means patients who have been served by the healthcare provider which includes, per the ruling, a patient who has made his or her first appointment. The intent of this provision is to offer flexibility to improve patient care but to limit the risk of transportation being used as a recruiting tool or to bring patients in for unnecessary services. However, for shuttle service, transportation can be provided not only to patients but family and friends and even employees of the healthcare provider. Restrictions on marketing the shuttle limit the risk that the shuttle would be used to recruit new patients.

Other details:

- The transportation service cannot be advertised or marketed to patients. The ruling emphasizes this: transportation cannot be used as a recruiting tool. Information about shuttle service, however, can be made available by the healthcare provider with a posting of the schedule and stops.
- The healthcare provider is to establish a set policy regarding the availability of free or discounted transportation and must apply that policy uniformly and consistently. But the OIG declined to mandate specific parameters for such policy other than mandating that it cannot be based on the type of patients’ insurance.
- Paying for transportation serviced: if transportation is available through a private company or driver hired by the healthcare provider, payment cannot be made on a per-patient basis. It can be on a distance/mileage basis. If transportation is provided by public transit or taxi, the transportation would be paid for or reimbursed to individual patients by, for example, taxi vouchers or bus fare.
- Costs for the transportation must be borne by the healthcare provider and not shifted to Medicare, a state healthcare program, other payers, or individuals.

Regarding dialysis providers: Interestingly, comments to the proposed ruling wanted more controls on transportation provided by dialysis providers. Concern was expressed that the larger commercial dialysis providers would increase their business by providing transportation thus hurting smaller providers. This could be addressed by, for example, by allowing dialysis facilities to offer transportation only in certain situations, such as only for patients who have suddenly lack transportation or for those with occasional unreliable transportation. The final ruling, however, does not include such restrictions for dialysis providers. In fact, in commentary that accompanies the ruling, the OIG states that the safe harbor for local transportation will save federal healthcare dollars for ESRD patients, as “dialysis patients are a population that has been identified as contributing to the increasing costs of nonemergency ambulance transportation and would benefit from local transportation furnished by providers.”