ESRD Special Project

ESRD Special Study

Barriers to Outpatient Dialysis Placement

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I. Executive Summary

The Centers for Medicare & Medicaid Services (CMS) contracted with End Stage Renal Disease (ESRD) Network 9/10 for a special study on *Barriers to Outpatient Dialysis Placement* between July 1, 2005 and June 30, 2006. Seven Networks (1, 2, 11, 14, 15, 16, and 18) collaborated on the project.

The overall purpose of this special project was to identify and explore the extensiveness of the barriers to receiving dialysis treatment in an outpatient facility, the impact this has on the quality of patient care, and recommend resolutions. It was estimated that this would take at least three years to complete.

The first year of the project was devoted to developing methods to identify and explore the extensiveness of barriers that prevent patients from receiving dialysis in outpatient dialysis facilities. The TEP and the collaborating Networks identified a number of potential barriers although the extensiveness of these barriers could not be quantified. It was determined that the depth of the barriers could most accurately be determined by gathering information from the Networks, dialysis facilities, and hospitals. The five products which were developed to quantify the potential barriers included the following items : 1) Patient Admission Information Form, 2) Patient Involuntary Discharge Information Form, 3) Barriers to Outpatient Dialysis Placement Facility Survey, 4) Barriers to Outpatient Dialysis Treatment: Brief Hospital Survey, and 5) Barriers to Outpatient Dialysis Treatment: Patient-Level Hospital Survey Data Collection Form. In addition, these standardized methods would identify specific disparities that exist to receiving dialysis in an outpatient facility.

This project, if funded for the second year, would quantify the extensiveness of the barriers to receiving dialysis treatment in outpatient dialysis facilities and would identify disparities that exist to outpatient placement. In addition, if funded for the third year, intervention tools would be developed to encourage outpatient dialysis placement for patients with special needs.

The following tasks were identified as the requirements for the first year of the project:
1) Conduct a focus review of relevant published literature to gain a better understanding of the barriers to outpatient dialysis placement;
2) Convene a Technical Expert Panel (TEP);
3) Develop a method to track admission issues to dialysis facilities as well as a system to determine if there are specific disparity issues that affect outpatient dialysis placement; and
4) Develop survey methods and tools to track barrier issues in outpatient dialysis placement.

A. Literature Review

A literature review of articles relevant to barriers that exist for kidney patients as well as other patients with related issues was conducted. A total of 73 articles were reviewed, summarized, and categorized under the following topics: Payment, Medical Issues, Behavior, Age, Race, Ethnicity, Gender, Socioeconomic Status, Culture, Co-morbidities, and Other Influences. For each citation, there were two additional categories: 1) Article described an admission barrier and 2) Article quantified an admission barrier. Thirty-nine percent of the articles described admission barriers related to kidney patients and only five percent of the articles quantified an admission barrier.

While there is a larger body of literature regarding treatment termination, a review of the literature found limited reporting or quantification of admission difficulties. Payment for treatment, complex medical needs and difficult behavior are the three most commonly reported barriers to outpatient dialysis admission. In addition, the literature provides little guidance for overcoming barriers to admission to dialysis facilities.

Studies have consistently identified disparities in health and health care services. Age, race, ethnicity, culture, gender, socioeconomic status, and co-morbidity are often found in the literature related to other barriers in health care services.

Although federal regulations exist to assure equitable access to dialysis services, little is known about disparities among patients refused access to outpatient dialysis treatment.

B. Convene Technical Expert Panel (TEP)

A Technical Expert Panel was convened to assist the contractor (ESRD Network 9/10) to identify and explore the extensiveness of the barriers to receiving dialysis treatment in an outpatient facility, the impact this has on the quality of patient care, and recommend resolutions.

TEP membership included both ESRD stakeholders who were familiar with placement barriers that exist for dialysis patients and community professionals who had an understanding and experience with disparity issues with patients/clients. Members were chosen by the contractor based on their area of expertise, location and knowledge of either disparities or dialysis patients. The final TEP membership included the following representatives: attorney, ethicist, mental health professional, hospital discharge planner, QIO representative, large dialysis organization representative, independent dialysis facility representative, three disparity experts, including one from a hospital setting, and a dialysis patient. Individual TEP members were approved by CMS.

The first TEP meeting was held in Baltimore on February 9, 2006. The TEP was tasked with developing a methodology to collect data on barriers to outpatient dialysis placement, determining whom the survey should target, and identifying the data elements.

TEP members discussed how to collect data to identify the scope of the barriers to outpatient dialysis placement problem. It was determined that data needed to be captured from both hospital-based inpatient-only dialysis facilities and outpatient dialysis facilities.

Potential barriers were divided into four categories: medical, behavioral, financial, and psychosocial. Patient demographic data collected would include race, ethnicity, gender, and age group. Hospital demographic data collected would include setting (urban, suburban, or rural), profit status (for profit, not for profit, public), and number of hospital beds.

C. Convene Second TEP Meeting

The second TEP meeting was held in Baltimore on May 9, 2006. TEP members reviewed the proposed outpatient dialysis facility survey and methodology and recommended modifications. The purpose of this survey is to understand the scope and limitations of dialysis services offered by dialysis providers.

The hospital survey and methodology were also discussed and modifications were recommended. The purpose of this survey is to understand the scope of the problem to receiving outpatient dialysis placement as it relates to medical, behavioral, financial, and psychosocial barriers.

At the present time, there is no standardized way to track "Outpatient Placement" issues at the Network level. Available data sources to the Networks were reviewed and data challenges were discussed. The Networks will develop a tracking method to use at the Network level.

D. Admission Tracking Method

Often, an admission concern is the result of an involuntary discharge and thus, there is a need to capture information on both admission concerns and involuntary discharges. The collaborating Networks developed draft standardized methods to track admission concerns and involuntary discharge information. The Networks will use SIMS to the extent possible and will add additional keywords in the SIMS Contact to track specific information. In addition, the Networks agreed to gather standardized information on barriers during their contact with facilities and this information would be linked to SIMS.

The Facility and Hospital Surveys would provide additional means to track the extensiveness and the specific barriers to outpatient dialysis placement.

E. Identification of Disparity Issues

The Networks developed a draft standardized report that will identify the following possible disparities related to outpatient placement: Gender, race, age and ethnicity.

The TEP suggested the following categories be used to obtain information from hospitals: Gender, race, age, and ethnicity.

F. Survey Methods and Tools

A Facility Survey was developed that would identify barriers to outpatient placement based upon dialysis patients who have special needs. The special needs categories include obesity, longer treatment time, dialysis while lying on a cart, tracheotomy, ventilator, nursing home resident, isolation, uninsured and underinsured.. .With CMS approval, this form would be piloted and sent to a sample of dialysis facilities in the collaborating Networks.See Appendix F.

Two Hospital Surveys were developed that would identify barriers to outpatient dialysis placement and would quantify the extent of the problem over a given period of time. The short survey would estimate the number of patients experiencing barriers and the general categories of barriers (medical, behavioral, financial, and psychosocial).See Appendix G. Those who completed the short survey would be asked to participate in a prospective survey. The prospective, longer survey would identify more specific barriers in each category and would identify the age, race, gender, and ethnicity of the patients facing barriers. See Appendix H.

Both surveys would gather information regarding patients who were delayed in being discharged from the hospital. The short version would estimate the number of people experiencing delays and the longer, prospective survey would calculate the exact number of days for each patient. The surveys also would gather information about the location of the hospital (urban, suburban, rural), profit status, type of hospital, number of hospital beds, and if the hospital has a Medicare-approved chronic dialysis facility.

These forms would be sent to CMS for approval prior to use.

G. Recommendations to CMS

TEP members agreed that, in their experience, barriers to health care and more specifically, barriers to outpatient dialysis placement do exist for dialysis patients. Seven of the collaborating Networks informally reported that over a three month period patients were not admitted to dialysis facilities for the following reasons: disruptive behavior, special needs, mental illness, noncompliance, financial including illegal immigrants, abusive behavior, violent behavior, history of litigation, and past prisoners. In addition, some Networks noted that corporate lockouts were highly probable.

Network 9/10 developed an Admission Concern Form to use for all calls regarding admission problems. Two other Networks used the form for a period of time and provided feedback on its usage. With their input and the input of the other collaborating Networks, a draft of a new standardized form was completed. (See Appendix C).Although SIMS groups Transfer/Discharge issues together as a category, there is no uniform method to track reasons for discharge, if the discharge was immediate, or if the patient received assistance to locate a new facility. Network 14 had a method to capture this information and some of the other Networks captured some discharge information. Together, the collaborating Networks developed a draft standardized Patient Involuntary Discharge Information Sheet that all of them agreed to use to track discharge issues which directly affect admission issues. See Appendix D. However, there is currently no approved standardized way for all Networks to track the extent of the problem or to encourage dialysis facilities to accept patients who have special needs and may require more time and care. There is great concern that, without intervention from CMS, barriers to outpatient dialysis will continue to rise.

As a result of this special project, the following recommendations are presented to CMS:

1. Provide a standardized, effective method to track outpatient dialysis placement barriers in SIMS. Add additional areas of concern to include Admissions and Involuntary Discharge that would help the Networks track the issues that impact outpatient placement. In addition, activate the reasons for involuntary discharges in SIMS and add the reasons for involuntary discharge to the Patient Activity Report.

If changes are not made to SIMS, the collaborating Networks propose the following approach to standardize a tracking method for outpatient placement barriers: a) Select Other for the area of concern and write Admissions in the Description when the concern is about an outpatient placement barrier, b) Select Patient Transfer/Discharge for the area of concern and write Involuntary Discharge when the concern is about a patient involuntarily discharged from an ESRD provider and c) Track the calls by the keywords in the Description section of the contacts. The Patient Admission Information Form and the Patient Involuntary Discharge Information Form also would be used to gather additional information about the respective concerns and this information would be linked to patient information in SIMS and reports could then be generated.

The collaborating Networks agreed to pilot this approach to standardize the tracking of admission barriers and involuntary discharges in order to quantify and analyze the extensiveness of the barriers and disparities to outpatient dialysis placement.

2. Support the use of the Facility Survey to obtain additional information from outpatient dialysis facilities regarding the barriers that exist to accepting patients with special needs. This information could be analyzed to provide important information regarding barriers from the facility's perspective and assist in the development of resources for the facilities.

3. Support the use of the two Hospital Surveys to obtain additional information from the hospitals regarding the extensiveness of the barriers to outpatient placement. This information could provide needed collaboration between hospitals and the Networks to address the problem of placement which is a source of frustration for many hospitals.

4. Develop a coalition to address the barriers to outpatient dialysis placement. The coalition membership would include the following categories: attorney, ethicist, mental health professional, hospital discharge planner, QIO representative, large dialysis organization representative, independent dialysis facility representative, disparity experts, and a dialysis patient. The tasks of the coalition would include a) Develop a pilot program for the facility survey and the hospital surveys; b) Conduct the pilot program; c) Analyze the data from the pilot program, and d) Make recommendations on resolutions.

5. Fund this special project for the next two-three years to be able to survey facilities and hospitals and to develop tools which would aid in the acceptance of patients with special needs;

6. Develop a method for case-mix adjustment for clinical, behavioral or noncompliance issues;

7. Consider the designation of specialized dialysis facilities with highly trained staff to care for sicker or more difficult patients. These facilities would require higher staff-to-patient ratios and payment could be adjusted accordingly.

H. Conclusion

It is believed that dialysis units are refusing to accept patients who have special needs or behavioral issues for a number of different reasons. Comments from facilities include they are often working short-staffed or without adequate staff, it is difficult to take patients who have time-consuming needs, and they do not want to take "everybody else's problems." Sometimes workers will threaten to quit if difficult patients remain in their care and administrators don't want their "good staff" to leave. The staff may not have received specialized training to work with challenging and special needs patients and associated equipment and they are not confident in treating

them. In addition, facilities fear the possibility of lawsuits, both from patients and from staff if violent situations arise. Also, noncompliance can affect the facility's outcomes that are reported to the Network and to CMS. In spite of all of these reasons, dialysis patients need to receive the best quality of care in the most cost effective manner and that means they need an outpatient dialysis facility for their care.

With CMS approval to gather information from dialysis facilities and hospitals, a greater understanding of the barriers to outpatient dialysis placement, the extent of the problem, and potential disparities that exist will be gained. Networks will have the ability to standardize and track admission data by either making changes to the SIMS program or by following the developed standardized process that would work with what is available in SIMS.

In conclusion, there is a need to track and trend admission data and to be able to address the barrier issues that exist. Interventions need to be developed to assist facilities to accept patients with special needs. Lastly, CMS needs to address the potential lack of motivation at the facility level to accept patients with special needs.

II. Description of Project Activities

The Centers for Medicare & Medicaid Services (CMS) contracted with End Stage Renal Disease (ESRD) Network 9/10 for a special study between July 1, 2005 and June 30, 2006 to identify and explore the extensiveness of the barriers to receiving dialysis treatment in an outpatient facility, the impact this has on the quality of patient care, and recommend resolutions.

A. Scope of Work

The table below lists the specific tasks required by the Scope of Work for this special project. The subsections that follow detail work completed to meet the task requirements.

Task	Task Requirement
1	Develop a work plan.
2	Develop a relationship with the Underserved Quality Improvement Organization Support Center (Tennessee QIO) and other Networks for their input on the barriers to admission.
3	Conduct and prepare a summary report of a focused review of relevant published literature to gain an understanding of the current knowledge on barriers to admission to dialysis facilities.
4	Identify potential members for a Technical Expert Panel (TEP).
5	Convene TEP meeting.
6	Facilitate and document the TEP discussions.
7	Develop a method to track admissions to dialysis facilities as well as a system to determine if there are specific disparity issues that affect admissions to dialysis facilities.
8	Convene a second meeting of the TEP.
9	Facilitate and document the TEP discussions of the second meeting.
10	Develop and submit survey methods and tool(s) to track barrier issues in admissions to dialysis facilities.
11	Prepare final report

B. Task 1. Submit to CMS a detailed work plan within 45 days of date of contract award

The Network submitted a project management plan within 45 days of receiving the contract. This plan served as a guideline to the Network to assure that all tasks of the contract are completed.

After receiving approval for the project, CMS met by conference call with the Network in

August 2005 and requested changes to the scope of the project. CMS offered the following guidance for the project:

- CMS determined that this is to be considered both a disparities project and a barriers to admission project and thus, the timeline needs to be extended for the activities in the project management plan;
- CMS agreed that the project should continue by forming a TEP (to include a representative from the Underserved QIOSC) to discuss the issues. This TEP would assist the Network in creating a survey to be conducted among the hospital discharge planners, state agencies, and other parties relevant to this topic area, such that the Network would be able to collect sufficient information to be able to identify the perceived level of the problem, and the perceived barriers creating it;
- The Network would then assess the data provided in the survey (and present it back to the TEP) and develop a tracking system for CMS to implement within the ESRD Networks to be able to adequately capture information relevant to the dialysis facility admissions difficulties;
- The Networks should not implement any intervention approaches until after the admission tracking system has been implemented and is able to capture adequate data. However, they can begin exploring potential interventions and potentially incorporating information as part of the proposed admissions tracking system;
- Data analysis and further development of interventions to reduce identified disparities (based on data from the implemented Admissions Tracking System) would occur in the second (or possibly the third) year of this project.

C. Task 2. Develop a relationship with the Underserved Quality Improvement Organization Support Center (UQIOSC) at the Tennessee QIO and other Networks for their input on the barriers to admission

The Network began to develop a relationship with the Program Director of the UQIOSC before the special project received final approval. The Director of the UQIOSC became a member of the TEP once approval was received from CMS.

Seven other Networks expressed an interest in collaborating on this project and an initial conference call was held in early September 2005 after the proposed scope of the project was finalized with CMS. During the call, an update of the project was given and the challenges of identifying and tracking the barriers were discussed.

In October 2005, the Patient Services staff from most of the collaborating Networks met by conference call to discuss Network tools that could be used to gather information on identifying the number of patients without placement and the potential barriers. Seven of the Networks said they compare events of involuntary discharge with contacts of discharges in SIMS. Only two of the seven Networks stated they have a standardized way to identify people who lack outpatient placement and two Networks have a specific process for follow up with patients in need of outpatient placement. Three of the Networks have a specific process to follow up with patients who have been involuntarily discharged and three Networks use additional tools to gather information about outpatient placement issues and discharge issues.

All of the participating Networks agreed to track and submit the number of admission concerns that were received during the fourth quarter of 2005. Six of the collaborating Networks reported that at least 44 patients were involuntarily discharged from a unit and were unable to find placement at other dialysis facilities for the following reasons: disruptive behavior, special needs, mental illness, noncompliance, financial including illegal

immigrants, abusive behavior, violent behavior, history of litigation, and past prisoners. In addition, some Networks noted that corporate lockouts were highly probable.

D. Task 3. Conduct a focused review of relevant published literature to gain an understanding of the current knowledge on barriers to admission to dialysis facilities

1. Methods

A MEDLINE search was conducted to review literature related to barriers to receiving dialysis treatment in an outpatient facility. The search term "refusal to treat" yielded 1,744 citations. The search term "transients and migrants" yielded 5,796 results. The combined search terms "refusal to treat" and "dialysis" yielded 45 citations, two of which were promising for review. The combined search terms "transients and migrants" and "treatment refusal" yielded one result that was not relevant upon examination. The combined search terms "transients and migrants" and "dialysis" yielded eight citations, seven of which were promising for review. Science Citation Index was queried for the promising articles, yielding three additional articles. Science Citation Index identifies articles that have referenced a particular article. Articles were obtained and reference lists were reviewed for additional relevant articles. The additional relevant articles were obtained and their reference lists were reviewed for relevant articles. The relevant articles were again obtained. All articles were abstracted and categorized into a customized database.

2. Background

2a. The Outpatient Admission Problem

It is a challenge to provide dialysis services for people with special medical needs or behavioral issues. Facilities may be reluctant to admit patients with complex medical needs that require special services such as ventilators, isolation units, oversized dialysis chairs or extra transfer assistance to dialysis chair due to stroke or other disability. Patients with a history of significant mental illness, substance abuse, noncompliance and/or disruptive or violent behaviors may require more staff time, create staff burnout, or present safety concerns for both other patients and staff. Patients may be refused admittance to an outpatient dialysis facility due to lack of or insufficient insurance coverage. Unauthorized migrants are at particular risk of treatment refusal by outpatient dialysis facilities.[1-14]

2b. Must Facilities Admit All Referred Patients?

Safe, accessible healthcare is a basic human and civil right according to the Americans with Disabilities Act (ADA).[15] However, physicians or private dialysis facilities are not required to accept a patient.[4, 14, 16-20] Forcing private providers to accept a patient would violate the XIIIth Amendment to the United States Constitution. Courts have ruled that if a facility or physician is not in violation of the Civil Rights Act, ESRD regulations, or ADA, they can deny or reject a patient from therapy.[4, 17] However, hospital emergency departments that have accepted Hill-Burton funds at any time, must provide emergency care to all who seek care.[17] As a result, public hospital inpatient dialysis facilities increasingly provide emergency dialysis services for patients who are not admitted to outpatient dialysis centers.[21-23] Inpatient dialysis services are more costly to administer and the hospital may encounter difficulty in transferring the patient for ongoing care.[21, 22]

2c. The Role of ESRD Networks

Hospital discharge planners and other agencies contact ESRD Networks for assistance in placing dialysis patients in outpatient centers if they are unsuccessful in locating a center willing to accept patients. These requests for assistance often relate to patients with medical or behavioral complexities. The Renal Network, Inc. has assisted with placement of patients who are known or have a "reputation" of being noncompliant, mentally ill, verbally abusive, threatening or disrespectful to dialysis staff. Other examples include patients who are frail,

obese, HIV positive, or have a history of stroke or other inability to transfer to the dialysis chair.

ESRD Networks are instructed by CMS to investigate complaints and grievances that may be received from an ESRD patient or personal representative, a family member, a friend, a dialysis facility employee, a physician, a federal or State agency, a patient advocate, or a concerned individual. Currently there is no identified category in the CMS national data system, Standardized Information Management System (SIMS), to track admission concerns and their resolutions. The Renal Network, Inc. has fielded increasing numbers of calls related to admission problems. To examine the prevalence and potential trends of these calls, Network staff began coding admission concerns in the "Other" category of SIMS.

2d. Disparities in Access to Outpatient Dialysis Care

Studies have consistently identified disparities in health and health care services. The Institute of Medicine released a report in 2002 that acknowledged the health gap between minority and non-minority Americans has persisted or widened in recent years.[24] It is well documented that disparities exist in relationship to a number of factors such as race, ethnicity, age, gender, and socioeconomic status. While quality improvement efforts have been successful in reducing disparities in some ESRD outcomes, other disparities persist.[25]

Regulations exist to assure equitable access to dialysis services, however little is known about disparities among patients refused access to outpatient dialysis treatment.

3. Potential Barriers to Admission to Dialysis Facilities

Though a large body of literature regarding treatment termination exists, a review of the literature has found limited reporting or quantification of admission difficulties. Published articles that address the problem of admission often do so within the context of three issues: payment for treatment, complex medical needs and difficult behavior.

3a. Payment Issues as Barriers

The U.S. Census Bureau estimates that 45.8 million people lacked health insurance in 2004.[26] Medicare and Medicaid programs are the primary payors for dialysis treatment. Dialysis treatment costs an average of $63,000/year for Medicare patients.[27] Lack of reimbursement results in patients being shifted to hospital emergency departments and inpatient dialysis facilities since they cannot turn patients away.[21, 23] Capturing data on dialysis services to the uninsured and unauthorized migrant populations is difficult because the United States Renal Data System (USRDS) contains only data for Medicare beneficiaries. Patients with late initiation of dialysis (GFR < 5 ml/min per $1.73m^2$) are more likely to lack insurance (OR=1.55), suggesting lack of insurance is a barrier to dialysis services.[28]

The problem of lack of or inadequate insurance affects both citizens and non citizens.[2, 5, 8, 21, 23, 29-36] The federal government has essentially shifted the burden of providing health care services for undocumented migrants to state and local governments.[2, 36] It is estimated that 10.3 million unauthorized migrants reside in the U.S. Additionally, there are approximately 10.4 million legal permanent resident aliens.[34] Unauthorized migrants are highly concentrated, with 68% residing in eight states: California (24%), Texas (14%), Florida (9%), New York (7%), Arizona (5%), Illinois (4%), New Jersey (4%), and North Carolina (3%).[34] In 1997 Slifkin estimated that unauthorized migrants may account for 5% of the dialysis population.[23] In New York and Southern California, 5-25% of patients in an individual dialysis facility may be unauthorized migrants.[23] Considering that the number of unauthorized migrants has increased markedly,[34] these estimates are likely to be low. Dialysis care for immigrants is not just a problem for these eight states. Since the mid-1990s, the immigrant population has dispersed to regions that previously had few immigrants.[34]

The "Personal Responsibility and Work Opportunity Act of 1996 (Welfare Act) and the "Illegal Immigration Reform and Immigration Responsibility Act" (Immigration Reform Act)

reduced access to the public benefit safety net for legal aliens and barred unauthorized migrants from receiving many federal, state, and local public benefits. It also required states to pass laws in order to provide benefits to unauthorized migrants and allowed states to bar qualified migrants (such as refugees and permanent residents) eligibility to Medicaid programs.[2] Provision of services regardless of citizenship is a humanitarian act, yet dialysis facilities need to protect their financial stability in order to serve their citizen patients.[2]

Immigrants are often blamed for health care budget shortfalls, however most undocumented non-citizens work, have taxes withheld from their wages and pay sales, excise and gasoline taxes.[21, 23, 32] In two New York City hospital dialysis facilities, Coritsidis found the rate of employment was higher in unauthorized migrants compared to citizens. Treatment costs were higher for unauthorized migrants, possibly due to lack of pre-dialysis care.[21] Similarly, unauthorized migrants without funding by the Texas chronic dialysis program had hospital expenses nearly four times greater than unauthorized migrants who have access to such funding.[22]

Care for pediatric undocumented patients is particularly problematic since there is a limited number of pediatric hospitals and pediatric nephrologists. As a result, fewer safety-net hospitals are available to share the burden of caring for undocumented children requiring chronic ESRD treatment. It may not be realistic to expect families to return to their country of origin to pursue ESRD care for their children since developing countries have wide disparities in access to health care. The U.S. Supreme Court has ruled that children have the right to receive a public school education. The same argument may be made for the provision of health care.[36]

There is variation in access to dialysis across states for both documented and unauthorized migrants.[23, 36] In Maryland, coverage is available through the Alien Emergency Medical Assistance (AEMA) program, not through Medicaid. Emergency coverage is permitted for only one emergent condition at a time, complicating payment to dialysis facilities. If patients are on dialysis and then go to the emergency room, they need to reapply for coverage for dialysis.[8] In March 2004, the Maryland Department of Health and Mental Hygiene issued a directive that immigrants on valid visitor visas are not eligible for Medicaid, but must be permanent residents of the state. This creates the situation that visitors must overstay their visa and become unauthorized migrants if they develop ESRD and require dialysis during their stay in the U.S.[8]

Health care services to unauthorized migrants are particularly vulnerable in Arizona due to the Arizona Taxpayer and Citizen Protection Act, effective at the end of 2004. This statute requires all state and local government employees responsible for administration of non-federally mandated public benefits to verify identity, eligibility for the benefits and immigration status, and report to federal immigration authorities any violation of federal immigration law for each applicant. Failure to report federal immigration law violations results in a Class 2 misdemeanor of the government employee and possibly the employee's supervisor if the supervisor is aware that no reporting has occurred.[29] The William E. Morris Institute for Justice has filed a case, Padilla v. Rodgers, challenging the Arizona Health Care Cost Containment System (AHCCCS) and federal government's decision to not pay for outpatient kidney dialysis as an emergency medical service for certain aliens under Medicaid.[37] There is currently an injunction requiring the state Medicaid program (AHCCCS) to pay for dialysis services.[37]

In 2000, the Renal Physician Association (RPA) published their position on dialysis for non-citizens.[2] The RPA suggests that providing ESRD care to non-citizens is likely financially sound so immigrants can continue to work to support their families and to limit costly hospitalizations and invasive procedures.[2] The RPA made six recommendations supporting the provision of care to all patients. The recommendations recognize the burden to specific states for the care of immigrants, and state that the burden should be distributed evenly

among all 50 states. Additionally, the RPA states that nephrologists should not be expected to report undocumented non-citizens due to confidentiality and the fiduciary nature of the patient-physician relationship. Lastly, the RPA urged ESRD Networks to be involved in coordinating the sharing of care of this population.[2]

3b. Medical Issues as Barriers

Medical issues such as significant co-morbidity, terminal illness, unconsciousness, dementia and infectious diseases such as AIDS/HIV are reported in the literature as possible barriers to outpatient dialysis treatment.[1, 6, 7, 9-11, 13, 38-41] More than one Network also stated medical issues were barriers to outpatient treatment. Other possible barriers include morbid obesity or difficulty transferring to dialysis chair.

3b.1 Significant Co-morbidity

Sometimes patients or families do not agree with physicians regarding the appropriateness of starting dialysis for patients with significant co-morbidity, terminal illness, unconsciousness or dementia. In 2000, the RPA issued clinical practice guidelines on shared decision-making in the appropriate initiation of and withdrawal from dialysis.[42] It is recommended that treatment initiation be determined jointly between the patient (or legal guardian) and the physician on the basis of clinical criteria and willingness of the patient.[7, 42, 43] If there is conflict between the patient or their family members and the nephrologist regarding the benefits of dialysis, then treatment should be initiated while continuing to resolve the dispute.[7, 13, 39, 42] It may be difficult to transfer such patients to a chronic outpatient dialysis setting as facilities may be reluctant to accept patients who require substantial care in addition to dialysis due to patient-staff ratios, staff training, and limited availability of non-dialysis related medical equipment in the outpatient dialysis facility.

3b.2 Infectious Disease

The common use of central catheters for vascular access place patients at high risk of infection, therefore infection control is critical in the dialysis setting. Septicemia is the second leading cause of mortality in dialysis patients.[27] Careful adherence to infection control precautions is critical to prevent contamination and spread of infection.[44] A review of literature did not reveal any documentation of refusal to admit patients to outpatient dialysis facilities due to methicillin-resistant Staphylococcus aureus (MRSA), vancomycin-resistant enterococci (VRE) or hepatitis B virus (HBV) infection.

There are many literature references regarding AIDS/HIV patients and access to general health care.[45-51] In Bragdon v. Abbott, a HIV-positive patient sued her dentist for refusing to fill a cavity while she was a patient in his office. The dentist offered to fill the cavity in a hospital if Bragdon covered the extra cost of hospital services.[45, 47] The Supreme Court ruled that HIV infection is a disability under the ADA and that professional judgment of risk is insufficient to deny care under the ADA.[45] Therefore, anti-discrimination law protects individuals with HIV from discrimination in access to healthcare and other public accommodations.[47] AIDS/HIV-infected patients have an even more compelling legal claim of access to care if state anti-discrimination statues include them in the category of handicapped individuals who can not be discriminated against for employment, housing, etc.[47]

Infection with HIV has been reported in the literature as a barrier to outpatient dialysis. In 1992, the Office of Civil Rights investigated 92 dialysis facilities for allegations that they denied transient dialysis care to HIV-positive patients and that some facilities treated patients in isolation units.[11] The social worker attempting to arrange the treatments found that some facility staff plainly stated that their facilities did not provide treatment to HIV-positive patients.[11, 41] In 2003 approximately 11,700 dialysis patients had known HIV nephropathy as cause of renal failure.[27] Refusal to admit a patient due to HIV status violates the ADA, therefore facilities have developed policies and procedures to safely care for these individuals in the dialysis setting.

The Centers for Disease Control and Prevention (CDC) recommend dialyzing hepatitis B surface antigen (HBsAg) positive patients in a separate

room using dedicated machines, equipment, and staff. Additionally, it is recommended that dialysis staff caring for HBsAg patients do not simultaneously provide care to other susceptible patients to reduce the potential for HBV transmission.[44] The CDC does not recommend the isolation of HIV, VRE or MRSA infected patients at this time.[44] However, HBsAg positive patients may have reduced access to care in the outpatient setting due to the limited number of isolation units available.

3b.3 Morbid Obesity

Although not reported in the dialysis literature, morbid obesity may be a barrier to outpatient dialysis admission. Network 9/10 uses an Admission Form to track barriers to outpatient placement and found obesity to be a reason for lack of placement in four cases. Obese patients require longer treatment times in order to receive an adequate dose of dialysis.[52] Facilities may have a limited number of long treatment appointment slots to offer in-coming patients. Additionally, facilities may not have over-sized dialysis chairs available to support the weight and size of morbidly obese patients.

3b.4 Patient Transfer Issues

While no references were located in the literature regarding the inability of a patient to transfer to dialysis chair as a barrier to dialysis admission, not all facilities have patient lift equipment (ex. Hoyer lift) available. Very large or incapacitated patients (such as from stroke) may be difficult for staff to transfer from transporting chair to dialysis chair. Network 9/10 reported on their Admission Form that inability to transfer on one's own was a barrier to receiving outpatient dialysis. The Network found this to be true for some obese patients as well.

3c. Behavioral Issues as Barriers

Patients have a right to a decent minimum of health care and providers have a right to work in a safe environment and to take reasonable precautions to protect themselves from harm. However it is not possible to achieve a risk-free work environment in health care.[19, 46, 53] Some patients are known to be disruptive, abusive, or violent.[1, 3, 4, 12, 19, 20, 38, 43, 54-58] Others are highly noncompliant with treatment recommendations.[1, 3, 4, 12, 14, 20, 38, 54-61] These behaviors may or may not be related to mental health or substance abuse issues.[12, 19, 38, 54, 56-60] Patients have been discharged or barred from a dialysis facility if they are noncompliant or have engaged in hostile, abusive, or violent exchanges with staff or other patients.[1, 3, 4, 12, 19, 20, 38, 43, 54-58, 62] The 2002 Involuntary Patient Discharge Survey organized by the Forum of ESRD Networks found that 0.2% of patients were involuntarily discharged nationally. Leading causes of discharge were non-compliance, verbal threat and verbal abuse (48.7%, 38.4% and 38.2% respectively).[62] Most of the collaborating Networks found that behavioral issues were barriers to outpatient placement.

Patients with developmental disorders and cognitive impairments from stroke, Alzheimer's disease and like conditions may have difficulty understanding, poor short term memory or other difficult behaviors including noncompliance.[1, 38] Dialysis staff and nephrologists should assess patients for root causes of any new, troublesome behaviors. If patients are unable to control their behavior, it may be helpful for staff to share the care of such difficult patients.[1]

Mental illness may be the cause of a patient's difficult or abusive behavior. It is estimated that major depression is prevalent in 20-30% of chronic dialysis patients, compared to 2-4% in the community.[63-65] The presence of depression may be related to the overall physical and emotional symptom burden of the dialysis patient.[66] Despite being common, depression is frequently not treated in the dialysis patient.[64] Depression may be a cause of noncompliance in some patients.[67] The Beck Depression Index and Patient Health Questionnaire are two valid assessment tools that can be used to screen chronic dialysis patients for depression.[68] Psychotherapy and/or careful use of medications may treat depression in this population,[63, 69] however patients may refuse further assessment or treatment.[65]

Other types of mental illnesses such as bipolar disease, schizophrenia, and panic disorders can

disrupt a patient's mood and ability to cope with their chronic illness.[60] Patients can alternate between being cooperative with dialysis treatment and being hostile and abusive to staff.[70] Frequently patients will discontinue mood-stabilizer medication because they believe they no longer require the medication due to side effects or concomitant substance abuse.[71, 72] Because initiation of treatment in these patients may be turbulent and fraught with aggressive outbursts by the patient,[70] facilities may be reluctant to accept new patients with such diagnoses.

Patients may be at risk for violence in their homes or communities. While it is unknown how many dialysis patients present to dialysis facilities with a concealed weapon, health clinics in poor, urban areas where violence is prevalent may have patients who routinely carry weapons for self-protection. A study conducted in an urban sexually transmitted disease (STD) clinic found that 44% of respondents had carried a weapon outside their home for self-defense, and of these individuals, 37% had done so in the prior month. Weapon carriers were more likely to have been victims of violence (ex. weapon pulled on them, beating or rape). Forty-one percent reported experiencing violence in the prior month.[73]

A study of public health workers found that 38% of 364 surveyed workers in sexually transmitted disease (STD), HIV/AIDS and TB clinics had experienced violence from patients. Twelve percent of these incidents involved weapons. [53] Providers have a responsibility to ensure that disruptive behaviors of one patient do not affect other patients in their care.[12, 20] While there is disagreement whether treatment refusal is appropriate if a competent patient does not refrain from difficult behaviors, health care providers do not need to accept violence directed against them.[4, 19, 20, 59, 60]

When patients are labeled as having behavioral issues, their ability to obtain dialysis services elsewhere is limited.[1, 3, 14, 55, 58, 62, 74, 75] The Involuntary Discharge Survey found that only 50% of patients were placed in new dialysis facilities. Twenty-one percent of patients had to use emergency room dialysis. It was unknown where 20.1% received their care after discharge, and 8.1% were categorized as "other" (expired or lost to follow-up).[62]At times the labels are inappropriate, as a patient-staff confrontation may have escalated due to poor staff communication or customer service skills.[14, 75] The TransPacific Renal Network (ESRD Network 17) convened a group of professionals to discuss the issue of inappropriate labeling and involuntary discharge of patients and proposed solutions to assist dialysis facilities in managing difficult patients. Their workgroup developed a set of definitions of behavior or conduct. The workgroup deemed it inappropriate for an entire corporation to exclude a patient from care, recommending instead that referrals and transfers be handled on a case-by-case basis.[14, 75]

There are two court cases, Payton v. Weber and Brown v. Bower, relevant to the issue of treatment refusal and difficult behavior.[16, 17] In the Payton case, the courts ruled that only emergency care was required to be provided by the nephrologist and hospital. Following the case, all dialysis facilities in the area agreed to share the responsibility of providing chronic dialysis for the patient.[20] In Brown, the court ruled that the nephrologist was not obligated to provide care, however the hospital was obligated because it had received funds under the Hill-Burton Act.[17] These cases may not reflect current law because of the 1990 Americans with Disability Act (ADA).[12] Treatment denial due to noncompliance could be considered discrimination based on a psychological disorder. This argument may not hold up however, because the court ruled that Brown was not emotionally or mentally handicapped based on the Rehabilitation Act definition, which is the same definition used for ADA.[12] ADA provides an exception for a person who poses a "significant" direct threat to the safety of others.[20] Verbal abuse is unlikely to meet the threshold to qualify as an exception.[20]

4. Potential Disparities to Admission

No published literature sources were found to quantify potential disparities in outpatient dialysis admission barriers. However, the 2002 Involuntary Patient Discharge Survey found that

patients discharged from dialysis facilities were more likely to be young, male and black compared to the general dialysis population.[62] The data were not analyzed to determine if there were disparities among patients who were identified as not being placed in new dialysis facilities (patients who potentially experienced barriers to admission). Age, race, ethnicity, culture, gender, socioeconomic status, and co-morbidity are often found in the literature related to other barriers to health care services.

4a. Age Disparity

Historically, if patients were not offered dialysis, they were over the age of 50. Now about half of all patients starting dialysis exceed age 65.[7] A Canadian study found advanced age was associated with treatment denial.[6] No articles were located to quantify age disparities in outpatient dialysis admission and no age disparity was associated with late initiation of dialysis.[28]

4b. Race/Ethnicity/Culture Disparity

There are no statistics available to quantify disparities in outpatient dialysis admissions due to race, ethnicity, or culture. Kausz found that Hispanic (OR=1.47) or Asian (OR= 1.66) race was associated with late initiation of dialysis on multivariate analysis compared to Caucasian race, suggesting race may be a potential barrier to dialysis admission. There was no difference among African Americans (OR=1.01).[28] In a study of 458 California patients transferred from private hospitals to a public hospital (not dialysis-related), 45% of transferees where from minority groups, yet only 33% of the county was "non-white.[35]

Unauthorized migrants are vulnerable to outpatient dialysis admission refusal. It has been estimated that 1,000 unauthorized migrants per year may develop ESRD.[21] The majority of unauthorized migrants are Hispanic, with 57% of all unauthorized migrants originating from Mexico and 24% from other Latin American countries.[34]

4c. Gender Disparity

There is no obvious gender disparity in admission to outpatient dialysis. In one Canadian study of patients with poor prognosis and low quality of life, females were more likely to be denied treatment than males.[6] Himmelstein found that patients "dumped" from private hospitals to public hospitals were more often male.[35]

4d. Socioeconomic Status Disparity

There are no published literature sources found to support or refute the notion of a socioeconomic status disparity in admission to outpatient dialysis. Presumably socioeconomic status would impact ability to pay for treatment. In the case of undocumented migrants, low socioeconomic status would likely lead to treatment denial since most are uninsured and work in low-paying jobs.[34] The Himmelstein study found that 63% of hospital transferees (not dialysis-related) had no medical insurance and 21% had Medicaid, suggesting that transferees to the public hospital were most often of low socioeconomic status.[35]

4e. Co-morbidity Disparity

High levels of co-morbidity result in treatment denial,[7, 13, 39] however it is unknown if this denial is in conflict with patient wishes. In the Canadian study by Hirsch, no patients or families disputed the decision to deny treatment.[6] Networks report difficulty in placing ventilator dependent patients, however this has not been published in the literature. In the early 1990s it was reported that HIV-positive patients had difficulty securing transient dialysis, however no recent cases have been cited.[11, 41]

5. Overcoming Barriers to Admission to Dialysis Facilities

The literature provides little guidance for overcoming barriers to admission to dialysis facilities. The RPA position paper on dialysis for non-citizens provides few concrete steps for individual facilities or Networks to follow. The RPA recommends that ESRD Networks be involved in coordinating the sharing of care of uninsured non-citizens within their regions.[2] It would be useful for ESRD Networks to be

trained in the legal provisions of dialysis for migrants in states within their service areas.

The RPA provides specific recommendations regarding the appropriate initiation of treatment including shared decision-making between patient and physician, informed consent, estimation of prognosis, and conflict resolution. They recommend physicians initiate dialysis if conflict regarding the benefit of dialysis occurs between patient (and their legal representative) and physician, while working to resolve the conflict.[42] This guidance may be useful for overcoming barriers to treatment of patients with significant co-morbidity, terminal illness, dementia, etc.

More written guidance is available for reference when dealing with noncompliant or disruptive patients. On October 2-3, 2003, the Dialysis Patient-Provider Conflict: Designing a Collaborative Action Plan with ESRD Stakeholders National Consensus Conference was sponsored by The Forum of ESRD Networks. Twenty-five stakeholders participated in the consensus meeting aimed at addressing dialysis patient-provider conflict (DPC). Majority convergence was achieved for four actions: 1) adopt the setting of national curriculum/standard of education for dialysis technicians; 2) increase reimbursement in keeping with inflation for dialysis so that financially stretched corporations can implement educational and other initiatives for DPC; 3) adopt comprehensive regulations for the procedures and standards for limiting and terminating patient services at a facility; and 4) leverage dialysis units to "make" social workers do what they are supposed to –not be clerical workers.[76] A "DPC Toolbox" of resources was developed and is currently available on the Forum website (www.esrdNetworks.org/dpc.htm). As part of the toolbox, an algorithm titled "Decreasing Patient Provider Conflict Pathway" is provided as guidance to handling conflicts when they arise. Brochures on DPC, tips on cultural awareness and quality improvement tracking tools are all available at the website. Definitions to use for uniform data collection are provided with the tracking tool.[77]

The document "Working with Noncompliant and Abusive Patients" published by the Mid-Atlantic Renal Coalition in 1994 provides an overview of potential causes of patient noncompliance.[1] Consistent adherence to safety policies and high levels of staff training in communication techniques such as reflective listening are approaches to help staff members deal with difficult patients. Proper staff response may help diffuse angry or hostile behavior and reduce the escalation in behavior to threats or acts of abuse or violence.[1, 75] In certain cases, the use of patient-staff meetings, mediation, or behavior contracts may reduce offending behavior.[1, 61, 78] It is also important that nephrologists and facilities consider mental illness or substance abuse as root causes of difficult behavior and work to treat the root cause. If patient terminations from facilities can be reduced, then fewer patients will require subsequent difficult dialysis placement.

6. Summary

A review of the literature has found limited reporting or quantification of admission difficulties. Payment for treatment, complex medical needs and difficult behavior are the three most commonly reported barriers to outpatient dialysis admission. Further study is needed to quantify how often this problem occurs and to examine potential disparities in access to outpatient dialysis treatment in terms of age, race, ethnicity, gender, culture, socioeconomic status or co-morbidity for patients seeking care. Monitoring access to dialysis care will be increasingly important if pay-for-performance becomes the standard method of payment for ESRD treatment.

E. Task 4. Identify potential members for a Technical Expert Panel (TEP)

A Technical Expert Panel (TEP) was identified to provide guidance for the project and identify specific barriers to receiving outpatient dialysis care, analyze the impact these barriers have on quality care, and recommend initial ways these barriers can be removed.

The panel consisted of 11 individuals representing a wide range of relevant fields and expertise. Although none of the gerontologists/geriatricians recommended for the TEP were available, it was determined that a number of the TEP members had extensive work experience with older adults.

The final TEP membership included the following representatives: attorney, ethicist, mental health professional, hospital discharge planner, QIO representative, large dialysis organization representative, independent dialysis facility representative, three disparity experts, including one from a hospital setting, and a patient. Individual TEP members were approved by CMS. See Appendix A.

F. Task 5. Select the date for the TEP meeting

The Network made the logistical arrangements for the meeting on February 9, 2006 in Baltimore and consulted with CMS prior to setting the date to avoid scheduling conflicts.

G. Task 6. Facilitate and document the TEP discussions and prepare a report of the TEP meeting to be submitted to CMS

The Network leadership facilitated the meeting that was held on February 9, 2006 in Baltimore, Maryland.

The TEP was tasked with developing a methodology to collect data on barriers to admission to outpatient facilities, the target audience for the survey, and identification of data elements.

TEP members discussed how to collect data to identify the scope of the problem of barriers to admission to outpatient dialysis facilities. They determined that data should be captured from both hospital-based inpatient-only dialysis facilities and hospital-based outpatient facilities. They identified potential barriers and divided them into four issues categories: medical, behavioral, financial, and psychosocial

It was also suggested that freestanding outpatient dialysis facilities be surveyed to determine staff credentials and staff training in how to handle difficult patients.
See Appendix B.

H. Task 7. Based on the findings of the TEP, develop a method to track admissions to dialysis facilities as well as a system to determine if there are specific disparity issues that affect admissions to dialysis facilities

The TEP recommended that all dialysis facilities be queried regarding the limitations of patients with special needs that they admit to their facility. This information could then form the basis of a list that Networks could use to help patients with special needs find a dialysis facility that could meet their needs. In addition, this survey would help to identify the reasons facilities cannot accept patients with special needs.

The TEP recommended that hospitals also be queried for a specific period of time to understand the extent of the problem of barriers to outpatient dialysis, the type of needs the patients have who are unable to secure a home dialysis facility, and the length of time the patients are without a home facility. In addition, information regarding gender, age, race, ethnicity, and type of barrier would be gathered to identify specific disparities that might exist.

It is recommended that admission concerns also be tracked at the Network level by

1) Identifying patients who are unable to find dialysis placement through contact calls to the Network;
2) Identifying patients who have been involuntarily discharged and do not have a unit to which to transfer by the Patient Activity Report (PAR) event; and
1) Tracking patients who have an event listed as a transfer out without a corresponding transfer in more than 60 days later.

The Networks developed a standardized form to obtain information from facilities regarding admission concern contacts made to the Networks. See Appendix C.

A standardized form was also developed for contacts and events regarding patients involuntarily discharged from facilities. See Appendix D.

These forms will be able to be linked to SIMS. In addition, since SIMS does not identify contacts by the categories of admission concerns or involuntary discharge, these words will be added to the description section for SIMS contacts to enable these concerns to be tracked. Then, for each patient identified in one of these two categories, information regarding age, race, gender, and ethnicity can be gathered to review for disparity issues.

I. Task 8. Convene a second meeting of the TEP

The second TEP meeting was held in Baltimore on May 9, 2006. The Network handled all of the logistical arrangements.

J. Task 9. Facilitate and document the TEP discussions and prepare a report of the TEP meeting to be submitted to CMS

The Network leadership facilitated the TEP meeting on May 9, 2006.

The TEP was tasked with the continuation of the development of the methodology and tools to collect data from dialysis facilities and hospitals regarding barriers to admission to outpatient facilities. See Appendix E.

TEP members reviewed the proposed outpatient dialysis facility survey methodology and form and recommended modifications. The purpose of this survey is to understand the scope and limitations of dialysis services offered by dialysis providers. It was recommended that the Dialysis Patient Provider Conflict (DPC) taxonomy be used when developing survey questions. Each survey question was reviewed and TEP members made suggested changes if needed.

The hospital survey methodology also was discussed and suggested changes were made as needed.

K. Task 10. Develop and submit survey methods and tool(s) to track barrier issues in admissions to dialysis facilities. These methods and tool(s) must be submitted to CMS for approval

With CMS approval, a Facility Survey would be sent to all outpatient dialysis facilities in the collaborating Networks to identify the barriers that exist at the facility level for dialysis patients with special needs. This survey would include the following categories:

- Obesity
- Long treatment duration
- The need to lie on a cart for dialysis
- Patient has a tracheotomy
- Patient uses a ventilator
- Resides in nursing home
- Requires isolation
- Financial (Uninsured/Underinsured, history of nonpayment, homeless)

In addition, the survey would identify limiting factors that affect facilities from taking patients with special needs.
See Appendix F.

With CMS approval, two Hospital Surveys would be sent to a sample of hospitals in the collaborating Networks. Initially, a Brief Hospital Survey would be conducted that would identify the number of patients placed for outpatient dialysis in a month and the discharge placement. In addition, it would identify the number of patients who experience a delay in hospital discharge due to not having a dialysis unit to discharge to and it would rank the primary barriers to outpatient admission from one to four by the following categories: Medical,

Behavioral, Financial, and Psychosocial. See Appendix G.

For hospitals that are willing to participate in a second phase survey, a prospective survey to identify the barriers to outpatient dialysis placement would be sent to them. This Patient-Level Hospital Survey Data Collection Form would identify specific information about dialysis patients over a 90-day period of time. The information sent to the Network would not have identifying patient information. However, it would identify age, race, gender, and ethnicity of patients facing barriers.

In addition, the amount of time it takes for the hospital to locate a dialysis facility to which to discharge the patient will be calculated as well as more detailed information regarding the medical, behavioral, financial, and psychosocial barriers that exist for each patient. See Appendix H.

The surveys also would gather information about the location of the hospital (urban, suburban, rural), profit status, type of hospital, number of hospital beds, and if the hospital has a Medicare-approved chronic dialysis facility.

L. Task 11. Prepare Final Project Report

Additional comments were obtained from CMS and incorporated into this Final Report.

III. Recommendations to CMS

The TEP expressed concerns that admission barriers to outpatient dialysis may intensify with the introduction of pay-for-performance. It was suggested that dialysis facilities may refuse outpatient admission for some patients that have real or potential outcomes that do not meet the desired levels of pay-for-performance financial incentives. Currently there is no method for case-mix adjustment for behavioral or noncompliance issues.

TEP members agreed that barriers to health care and more specifically, barriers to outpatient dialysis placement do exist for dialysis patients. However, there is no standardized way to track the extent of the problem or to encourage dialysis facilities to accept patients who have special needs. In addition, with pay-for-performance tied to quality indicators, there will be little incentive to admit patients who require more care or more time. There is great concern that barriers to outpatient dialysis could rise without any intervention from CMS.

As a result of this special project, the following recommendations are presented to CMS:

A. SIMS Tracking

Provide a standardized, effective method to track outpatient dialysis placement barriers in SIMS. Add additional areas of concern to include Admissions and Involuntary Discharge that would help the Networks track the issues that impact outpatient placement. In addition, activate the reasons for involuntary discharges in SIMS and add the reasons for involuntary discharge to the Patient Activity Report.

If changes are not made to SIMS, the collaborating Networks propose the following approach to standardize a tracking method for outpatient placement barriers: 1) Select Other for the area of concern and write Admissions in the Description when the concern is about an outpatient placement barrier, 2) Select Patient Transfer/Discharge for the area of concern and write Involuntary Discharge when the concern is about a patient involuntarily discharged and 3) Track the calls by the keywords in the Description section of the contacts. The Patient Admission Information Form and the Patient Involuntary Discharge Information Form also would be used to gather additional information about the respective concerns and this information would be linked to patient information in SIMS and reports could then be generated.

The collaborating Networks agreed to pilot this approach to standardize the tracking of admission barriers and involuntary discharges in order to quantify and analyze the extensiveness of the barriers and disparities to outpatient dialysis placement.

B. Facility Survey

Support the use of the Facility Survey to obtain additional information from outpatient dialysis facilities regarding the barriers that exist to accepting patients with special needs. This information could be analyzed to provide important information regarding barriers from the facility's perspective and assist in the development of resources for the facilities.

C. Hospital Survey

Support the use of the two Hospital Surveys to obtain additional information from the hospitals regarding the extensiveness of the barriers to outpatient placement. This information could provide needed collaboration between hospitals and the Networks to address the problem of placement which is a source of frustration for many hospitals.

D. Coalition

Develop a coalition to address the barriers to outpatient dialysis placement. The coalition membership would include the following categories: attorney, ethicist, mental health professional, hospital discharge planner, QIO representative, large dialysis organization representative, independent dialysis facility representative, disparity experts, and dialysis patient. The tasks of the coalition would include 1) Develop a pilot program for the facility

survey and the hospital surveys; 2) Conduct the pilot program; 3) Analyze the data from the pilot program, and 4) Make recommendations on resolutions.

E. Funding

Fund this special project for the next two-three years to be able to survey facilities and hospitals and to develop tools which would aid in the acceptance of patients with special needs;

F. Case-mix Adjustment

Develop a method for case-mix adjustment for clinical, behavioral or noncompliance issues;

G. Specialized Dialysis Facility Designation

Consider the designation of specialized dialysis facilities with highly trained staff to care for sicker or more difficult patients. These facilities would require higher staff-to-patient ratios and payment could be adjusted accordingly.

IV. Conclusion

It is believed that dialysis units are not accepting patients who have special needs or behavioral issues for a number of different reasons. They are often working short-staffed and without adequate staff, it is difficult to take patients who have time-consuming needs, and they do not want to take "everybody else's problems". Or, workers will threaten to quit if difficult patients remain in their care and administrators don't want their "good staff" to leave. The staff may not have received specialized training to work with challenging and special needs patients and they are not confident in treating them. In addition, facilities fear the possibility of lawsuits, both from patients and from staff if a violent situation arose. Also, noncompliance can affect the facility's outcomes that are being reported to the Network, CMS and the public. All or some of these reasons may be real for the facilities. However, if patients are receiving dialysis, they will have the best quality of care in the most cost effective manner if they have a specific dialysis facility to attend.

As the needs of the dialysis population change and grow, facility staff will need training to assist in working with patients with special needs.

The Interpretive Guidelines for ESRD facilities regarding admissions state: "An ESRD facility must comply with provisions of 504 of the Rehabilitation Act of 1973. Specifically, The Rehabilitation Act requires that no otherwise qualified person with a disability be denied access to, or the benefits of, or be subject to discrimination by any program or activity provided by any institution or entity receiving federal funds…The admission policies should delineate which patients will or will not be treated by the facility." The regulations state further "Admission criteria that ensure equitable access to services are adopted by the facility and are readily available to the public." Even with these regulations, it is reported that facilities choose not to admit patients due to noncompliance and inappropriate behavior.

With CMS approval to gather information from dialysis facilities and hospitals, a greater understanding of the barriers to outpatient dialysis placement, the extent of the problem, and potential disparities that exist will be gained. Networks will have the ability to standardize and track admission data by either making changes to the SIMS program or by following the developed standardized process that would work with what is available in SIMS.

In conclusion, there is a need to track and trend admission data and to be able to address the barrier issues that exist. Interventions need to be developed to assist facilities to accept patients with special needs. Lastly, CMS needs to address the potential lack of motivation at the facility level to accept patients with special needs.

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Appendix A

Technical Expert Panel Roster & Contractor Information

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Kathleen Niccum, Ed.D, Director of Patient Services, Project Manager
Jay B. Wish, MD, President
Susan A. Stark, Executive Director

Appendix B

Technical Expert Panel Meeting
February 9, 2006
Meeting Minutes

Technical Expert Panel

Susan Brittman, MPH, Disparity Expert Representative, Tennessee Quality Improvement Organization, Memphis, TN
Godfrey Burns, MD, Disparity Expert Representative, St. Vincent Hospital, New York, NY
Craig Fisher, LCSW, Independent Facility Representative, Fox Valley Dialysis, Aurora, IL
Sandra Fritzsch, RN, JD, Attorney Representative, Delray Beach, FL
Walid Ghantous, MD, Large Dialysis Organization Representative, Riverwoods, IL (absent)
Edwin Hargraves, Patient Representative, Mt. Vernon, TX
Dori Hutchinson, Sc.D., LRC, Mental Health Representative, Boston University Center for Psychiatric Rehabilitation, Boston, MA
Ruth Pudlowski, Discharge Planner Representative, St. Vincent Mercy Medical Center, Toledo, OH
Lana Richmond, MSN, RN, Department of Health Representative, Indiana State Department of Health, Indianapolis, IN
Stella Smetanka, Esq., Ethicist Representative, University of Pittsburgh School of Law, Pittsburgh, PA
Kenni Lou Walker, RN, CCM, MPH, Disparity Expert Representative, Wishard Hospital Services, Indianapolis, IN

CMS Representatives:

Diane Frankenfield, DrPH, Office of clinical Standards & Quality
Jackie Harley, Office of Clinical Standards & Quality
Mary King, Office of Clinical Standards & Quality (absent)

Staff:

Susan Stark, Executive Director, Network 9/10
Jay W. Wish, MD, President, Network 9/10
Kathi Niccum, EdD, Patient Services Director, Network 9/10
Raynel Kinney, RN, CNN, CPHQ, Quality Improvement Director, Network 9/10
Rick Coffin, Program Analyst, Network 9/10
Janeen León, MS, RD, LD, Project Assistant, MetroHealth Medical Center

Collaborating Networks:

Jenny Kitsen, Executive Director, Network 1
Sandra Waring, Quality Management Director, Network 2
Diane Carlson, Executive Director, Network 11

Background

A Technical Expert Panel was convened in Baltimore on February 9, 2006 to assist the contractor (ESRD Network 9/10) to identify and explore the extensiveness of the barriers to receiving dialysis in an outpatient facility, the impact this has on the quality of patient care, and to recommend resolutions. TEP members who attended the meeting included representatives of an independent dialysis facility and a department of health; a dialysis patient; a mental health representative; an attorney; an ethicist representative; disparities experts; and a discharge planner representative. CMS representatives from the Office of Clinical Standards & Quality and representatives from three collaborating networks (Networks 1, 2, and 11) were also in attendance. The TEP was tasked with developing a methodology to collect data on barriers to admission to outpatient facilities, whom the survey should target, and identification of data elements.

The meeting began with a welcome by Susan Stark and self-introductions of all in attendance. Dr. Wish discussed the project background, the role of ESRD Networks, Network responsibilities in terms of quality oversight, handling grievances and complaints, and patient tracking. Ms. Leon presented findings from the literature search to TEP members. Results from the 2002 Involuntary Patient Discharge Survey sponsored by CMS and the Forum of ESRD Networks was discussed by Ms. Carlson from Network 11. A TEP member noted that the patient perceptions of the discharge process and precipitating problem leading to discharge were not included in the data collection. Interest was expressed in reviewing the cases in this project to determine when patients were eventually placed and healthcare costs incurred as a result of the involuntary discharges. Kathi Niccum reviewed two case studies. There was discussion about the responsibility of medical directors, hospitals and dialysis staff in determining the appropriateness of initiating or continuing dialysis treatment and to ensure appropriate referrals for care as needed. Project tasks and data challenges were reviewed. TEP members were shown data screens from the standardized information management system (SIMS). Network 9/10 involuntary discharge and admission data from 2005 were reviewed.

TEP Discussion

TEP members discussed how to collect data to identify the scope of the problem of barriers to admission to outpatient dialysis facilities. Data needs to be captured from both hospital-based inpatient-only dialysis facilities and hospital-based outpatient facilities. Examining Medicare Part A billing data may define some of the problem, but would not capture data for non-Medicare patients including undocumented migrants. It was discussed that access problems are likely worse in areas with certificate of need requirements for dialysis facilities. There was discussion regarding the use of large dialysis organization acute facility data; however this would likely exclude patients without a payer. Lana Richmond, from Indiana State Department of Health discussed that Indiana collects data that defines services offered by the dialysis provider. Some barriers data may be able to be obtained from review of that data. It was discussed that problem behaviors and payment issues are major barriers, and the Indiana data will not quantify these problems.

It was decided that hospitals providing dialysis services would be the best data sources.

Barriers to Admission Tracking Methodology

A prospective study over three months was suggested. It was recommended that a prospective data collection tool be developed and piloted among volunteer Networks. This tool may be best utilized in the form of an Excel spreadsheet. Web-based data collection was considered a possibility. Collaborating Networks would be encouraged to participate and additional Networks would be invited. It was suggested that Networks contact hospitals around days 30 and 60 of data collection to encourage participation and serve as a resource to answer questions about the survey instrument.

Suggested Data Elements

Potential barriers were divided into four issues categories: medical, behavioral, financial, and psychosocial. Hospitals would be asked to identify the number of patients over the course of three months who cannot be placed in an outpatient dialysis facility due to:

Medical Issues
- Obesity
- Ventilator dependency
- Tracheotomy
- Inability to transfer
- Medical instability
- Infectious disease – specify type
- Psychiatric/cognitive disorders
- Substance abuse
- Other – specify

Behavior Issues
- Non-adherence
- Disruptiveness
- Verbally abusive
- Physically abusive
- Other – specify

Financial Issues
- Uninsured
- Underinsured
- Undocumented migrant
- Other – specify

Psychosocial Issues
- Homelessness
- Transportation issues
- Post-incarceration
- Other – specify

Patient demographic data collected would include race, ethnicity, gender, age group. Hospital demographic data collected would include setting (urban, suburban, or rural), profit status (for profit, not for profit, public), and number of hospital beds.

Outpatient dialysis facilities would be surveyed to determine if the provider accepts patients who are obese (> 300 pounds, >500 pounds), require long treatment duration exceeding five hours, unable to dialyze in a chair (require a cart), have a tracheotomy, ventilator dependent, reside in a nursing home, or require isolation.

It was also suggested that freestanding outpatient dialysis facilities be surveyed to determine staff credentials and staff training in how to handle difficult patients.

It was acknowledged that insurance status could be determined from 2728 data. It was recommended that a case mix adjustment be developed for behavioral issues since more time by staff is required.

Next Steps

The next TEP meeting will be held on May 9th in Baltimore. The Network will make the Renal Physicians Association (RPA) and large dialysis organizations aware of the May meeting in the event they would like to have an observer attend. In the meantime, Network staff will develop draft survey instruments, define a methodology to collect that data, develop a data analysis plan, and Networks will discuss further analyzing existing Network data on involuntary discharges and difficult patient placements.

Appendix C

Patient Admission Information Form

1. Call Status:

Today's Date: ____/____/____

Caller Name: _____ **Phone:** _____

Caller is: ☐ Patient ☐ Family

Facility Staff: ☐ Adm ☐ RN ☐ SW ☐ Hospital Staff

☐ Other: _____

Hospital: _____

Potential Unit: _____ **Provider #:** _____

Regarding Patient Name: _____ **SS #** _____

Regarding Facility Name _____ **Provider #:** _____

2. Patient Current Status: *(Check all that apply.)*

☐ Facility Discharge ☐ Doctor Discharge ☐ Hospital Discharge ☐ New Patient

☐ DOB _____ ☐ Sex _____ ☐ Race _____

☐ Home Facility *(Refusing to take back)* ☐ Transfer *(No Facility will accept)*

☐ Prison ☐ Nursing Home

3. Admission Barriers: *(Check all that apply.)*

☐	Behaviors	☐	Finances/Insurance	☐	Undocumented Immigrant	☐	Former Prisoner
☐	Homeless	☐	Medically Unstable	☐	Nursing home resident		
☐	Substance Abuse:	_	Documented Suspected	☐	Cognitive Disorder:	_	Suspected/probable Alzheimer's Diagnosis
☐	Psychiatric Disorder:	_	Suspected/probable Psychiatric diagnosis:	_	Refused psychiatric referral _____		
☐	Special Needs:	_	Obesity Tracheotomy	_	Needs Isolation Ventilator	_	Needs Stretcher
☐	Corporate Lockout	☐	Not enough staff to handle patient	☐	Unit Full	☐	No accepting nephrologist
☐	Other:	_____					

4. Additional Comments:

Appendix D

Patient Involuntary Discharge Information Form

1. **Today's Date:** _____ 2. **Date of Discharge:** _____
3. **Facility Name:** _____ 4. **Provider #:** _____
5. **Patient Name:** _____ 6. **Case #:** _____

7. REASON FOR DISCHARGE: (Check all that apply.)

- ☐ **Nonadherence:** Noncompliance with or nonconforming to medical advice, facility policies and procedures, professional standards of practice, laws and/or socially accepted behavior toward others.
- ☐ **Verbal/written abuse:** Any words (written or spoken) with intent to demean, insult, belittle or degrade facility or medical staff, their representatives, patients, families or others.
- ☐ **Verbal/written threat:** Any words (written or spoken) expressing intent to harm, abuse or commit violence directed toward facility or medical staff, their representatives, patients, families or others.
- ☐ **Physical threat:** Gestures or actions expressing intent to harm, abuse or commit violence toward facility or medical staff, their representatives, patients, families or others.
- ☐ **Physical harm:** Any bodily harm or injury, or attack upon facility or medical staff, their representatives, patients, families or others.
- ☐ **Property damage/ theft:** Theft or damage to property on premises of ESRD facility.
- ☐ **Lack of payment:** Refusal to maintain or apply for coverage or misrepresentation of coverage.
- ☐ **Other** (Specify): _____

8. BEFORE DISCHARGE: (Check all intervention/assistance facility provided.)

☐ Counseled patient on issues of concern	☐ Had meeting with patient & staff	☐ Had staff meeting about issues of concern
☐ Involved family	☐ Doctor talked to patient	☐ Provided resources
☐ Provided counseling	☐ Behavior agreement (request copy)	
☐ Gave patient list of facilities	☐ Called facilities	
☐ Other (specify)_____		

9. IMMEDIATE DISCHARGE:

Was patient given an immediate discharge? ☐ No ☐ Yes
If yes, was patient given assistance to locate another facility? ☐ No ☐ Yes
If yes, what assistance was given: ☐ Gave list of facilities ☐ Called facilities
☐ Other: _____

10. NOTICE OF DISCHARGE: (please request a copy of the notice)

Was patient given 30 days notice? ☐ No ☐ Yes
☐ **O**ther (specify) _____

11. NEW FACILITY INFORMATION:

Does patient have a new facility? ☐ No ☐ Yes: (If yes, please provide facility information below.)

Facility name: _____ Provider #: _____

Appendix E

Technical Expert Panel Meeting
May 9, 2006
Meeting Minutes

Technical Expert Panel

Susan Brittman, MPH, Disparity Expert Representative, Tennessee Quality Improvement Organization, Memphis, TN
Godfrey Burns, MD, Disparity Expert Representative, St. Vincent Hospital, New York, NY (absent)
Craig Fisher, LCSW, Independent Facility Representative, Fox Valley Dialysis, Aurora, IL
Sandra Fritzsch, RN, JD, Attorney Representative, Delray Beach, FL
Walid Ghantous, MD, Large Dialysis Organization Representative, Riverwoods, IL (
Edwin Hargraves, Patient Representative, Mt. Vernon, TX
Dori Hutchinson, Sc.D., LRC, Mental Health Representative, Boston University Center for Psychiatric Rehabilitation, Boston, MA (absent)
Ruth Pudlowski, Discharge Planner Representative, St. Vincent Mercy Medical Center, Toledo, OH
Lana Richmond, MSN, RN, Department of Health Representative, Indiana State Department of Health, Indianapolis, IN
Stella Smetanka, Esq., Ethicist Representative, University of Pittsburgh School of Law, Pittsburgh, PA
Kenni Lou Walker, RN, CCM, MPH, Disparity Expert Representative, Wishard Hospital Services, Indianapolis, IN

CMS Representatives:

Mary King, Office of Clinical Standards & Quality

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Jay W. Wish, MD, President, Network 9/10
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Janeen León, MS, RD, LD, Project Assistant, MetroHealth Medical Center

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Background

A second Technical Expert Panel was convened in Baltimore on May 9, 2006 to assist the contractor (ESRD Network 9/10) to identify and explore the extensiveness of the barriers to receiving dialysis in an outpatient facility, the impact this has on the quality of patient care, and to recommend resolutions. TEP members who attended the meeting included representatives of an independent dialysis facility and a department of health; a nephrologist; a dialysis patient; an attorney; an ethicist representative; disparities experts; and a discharge planner representative. A CMS representative from the Office of Clinical Standards & Quality and a representative from a collaborating ESRD Network (Network 14) were also in attendance. The TEP was tasked with developing a methodology to collect data on barriers to admission to outpatient facilities, to develop a system to determine if there are specific disparity issues that affect admission to dialysis facilities, and to develop a methodology and survey tool to track barriers to admission to dialysis facilities.

The meeting began with a welcome by Susan Stark and self-introductions of all attendees. Dr. Wish discussed the project background. There are currently nine ESRD Networks collaborating on the project.

TEP Discussion

Concern was expressed that admission barriers to outpatient dialysis may intensify with the introduction of pay-for-performance. There is no method for case-mix adjustment for behavioral or noncompliance issues. A TEP member noted that there may be increasing incentive at the dialysis facility level to refuse outpatient admission for some patients because manager bonuses are often tied to quality indicators.

A TEP member indicated that it may be beneficial to create specialized dialysis facilities with highly trained staff to care for sicker or more difficult patients. These facilities would require higher staff-to-patient ratios and payment could be adjusted accordingly.

Data challenges were addressed. Currently available sources of data include CMS forms; patient activity reports; and grievances, complaints, and concerns to ESRD Networks. Networks track the status of patients receiving treatment in Medicare-certified dialysis facility on a monthly basis. TEP members were shown screens from the Standard Information Management System (SIMS) to better understand what data elements are already available to ESRD Networks. This computer system is the best way to collect information, however the current system does not allow for the tracking of more than one area of concern in a straightforward manner. There is no option for outpatient facility admission concerns within the drop-down menu in *Area(s) of Concern* field. As a result, Network 9/10 enters the word "Admissions" as the first word in the *Description* field to allow tracking. A TEP member inquired if the *Time Spent* field captures time from the initial contact only or from all contacts related to the issue. Per Network staff, additional time spent is captured within the *Call History* tab of SIMS, but is not displayed if the form is printed. Ms. Stark noted that the SIMS system is not easily modified and as result, the current system must be used creatively to meet project requirements. Additionally, only admission barriers reported to Networks are captured, so the true scope of the problem is not known and is likely underreported. A TEP member suggested that Networks publicize to dialysis facilities and hospitals that there is interest in this problem and that Networks want to have instances of admissions barriers reported to them. Network staff noted that this may successfully increase admission barrier reporting because in the past letters were sent to facilities regarding the problem of involuntary discharge, and the Network experienced an increase in call volume related to that problem.

Ms. Stark reported that ESRD Networks use a variety of methodologies to collect admission barriers problems since there is no standardized method within SIMS. Following this project, a method of standardized data collection will be suggested in order to capture data over the next year so that Networks can identify the scope of the problem.

TEP members were shown Network 9/10 data regarding involuntary discharges and dangling transferred out status patients. Data is available regarding age and race. Reason codes for involuntary discharges available in SIMS include: a) non-adherence; b) verbal/written abuse, c) verbal/written threat, d) physical threat, e) physical harm, f) property damage/theft, and g) lack of payment. Accuracy of data is unknown, and there are no penalties for inaccurate reporting. Unless a Network receives a large number of patient complaints, it is impossible to know that facilities are misreporting events. Facility data can be compared with patient complaints to determine match, but this does not reveal the full scope of reporting compliance. For this project, aggregate data will be collected, not individual facility-level data.

TEP members discussed that there needs to be a way to stop the trend of involuntary discharges, perhaps by facilities receiving "credit" for providing care to difficult or non-adherent patients. There was discussion regarding the difficulties in developing a case-mix adjustment for patients with medical or behavioral issues. There is no patient-level cost data available within the system; all case-mix adjustment is currently calculated at the facility level. It was noted that most facilities have policies and procedures in place regarding involuntary discharges, but facilities do not necessarily use or follow the policies and procedures. Ms. Stark suggested that an analysis of data on involuntarily discharged and dangling transferred out patients be conducted among all participating ESRD Networks.

Barriers to Admission Tracking Methodology
TEP members reviewed the proposed outpatient dialysis facility survey methodology and form and recommended modifications. The purpose of this survey is to understand the scope and limitations of dialysis services offered by dialysis providers. It was identified that many elements related to facility demographics could be determined through SIMS if the survey is not anonymous. It was suggested that questions in both outpatient facility survey and hospital survey be similar so that results can be compared between groups. Also, it was recommended that the Dialysis Patient Provider Conflict (DPC) taxonomy be used when developing survey questions. Each survey question was reviewed and TEP members made suggested changes if needed.

The hospital survey methodology was discussed at length. It was determined that it will be challenging to identify who to send the survey to within a hospital because in some institutions discharge planners or case managers handle patient disposition and as a result the staff providing dialysis within the hospital may not be aware of disposition barriers. It was suggested that ESRD Network staff contact hospitals to determine where the survey should be sent. Hospital sampling was discussed. Sample size must still be determined, but it was roughly estimated that 10-20 hospitals per collaborating Network would need to be included. The TEP discussed method of recruiting hospitals. It was suggested that partnering with Quality Improvement Organizations may be helpful. Some hospitals frequently contact Networks concerning difficulties in placing patients. It was suggested that these hospitals, plus a random sample of additional hospitals within the network, be included as the hospital sample. Collection of patient-level data will allow identification of disparities in admission to outpatient dialysis. Collecting generalized data from hospitals related to difficult placements is insufficient to identify disparities. It was recommended by the TEP that patient-level hospital data be collected if funding is available to do so. The proposed hospital survey was reviewed and TEP members suggested question changes as necessary.

Next Steps
Network staff will modify the proposed survey instruments, refine data collection methodology, and submit a final report to CMS by June 30, 2006.

Wrap-Up
TEP members were thanked for their participation and the meeting was adjourned.

Appendix F

Barriers to Outpatient Dialysis Placement
Facility Survey

Please answer the following questions below. Do not leave any questions blank.

1. In what state is your facility located? _____

2. In what setting is your facility located? (Check box)
   □ Urban
   □ Suburban
   □Rural

3. What is your facility profit status? (Check box)
   □ For profit
   □ Not-for-profit

4. Is your facility part of a large dialysis organization (ex. FMC, DaVita, etc.) (Check box)
   □ No
   □ Yes

5. Define facility (Check box)
   □ Free-standing
   □ Hospital-based
   π Adjacent to nursing home

6. Average number of patients dialyzed per month? _____

7. Does your facility accept the following types of patients? (Check box)

7a. Obese > 300 pounds	□ No	□ Yes	□Sometimes
7b. Obese > 500 pounds	□ No	□ Yes	□ Sometimes
7c. Treatment duration > 5 hrs	□ No	□ Yes	□ Sometimes
7d. Require dialysis while lying on cart	□ No	□ Yes	□ Sometimes
7e. Have a tracheotomy	□ No	□ Yes	□ Sometimes
7f. Require a ventilator	□ No	□ Yes	□ Sometimes
7g. Reside in a nursing home	□ No	□Yes	□ Sometimes
7h. Require treatment in isolation room	□ No	□ Yes	□ Sometimes
7j. Are uninsured	□ No	□ Yes	□ Sometimes
7k. Are underinsured	□ No	□ Yes	□ Sometimes

8. Record social worker FTE to patient ratio: _____

9. Record credentials of facility social worker(s): _____

10. Describe the training your facility provides staff to deal with patients who exhibit difficult, disruptive, or abusive behaviors. (Take as much space as needed)

Appendix G

Barriers to Outpatient Dialysis Treatment: Brief Hospital Survey

1. In general, how many patients does your hospital place for outpatient dialysis per month? _____

2. As percentages, estimate the disposition of patients needing outpatient dialysis per month:

   _____ % to outpatient dialysis facility where patient last received treatment

   _____% to outpatient dialysis facility where patient will be a new patient

   _____% to nursing home, long term acute care, or rehabilitation facility that provides dialysis treatments

   _____% not placed

3. Estimate the number of patients experiencing a delay in discharge of 3 to 14 days due to difficulty placing in an outpatient dialysis facility:

   per month _____ per 3 months _____

4. Estimate the number of patients experiencing an extended delay in discharge of more than 14 days due to difficulty placing in an outpatient dialysis facility:

   per month _____ per 3 months _____

5. Rank from 1 (largest) to 4 (smallest) the primary barriers to admission to outpatient dialysis among your hospitalized patients.

   _____ Medical barriers

   _____ Behavioral barriers

   _____ Financial barriers

   _____Psychosocial barriers

6. Hospital name: _____

7. State where hospital is located (ex, PA, OH): _____

8. Hospital location: _____ Urban ____ Suburban _____ Rural

9. Hospital status: _____ For profit _____ Not for profit

10. Public hospital? _____ Yes _____ No

11. Number of hospital beds: _____

12. Does hospital have a Medicare-approved chronic dialysis facility? _____ Yes _____ No?

Appendix H

Barriers to Outpatient Dialysis Treatment: Patient-Level Hospital Survey Data Collection Form

1. Hospital name: _____

2. Patient code: _____

3. Patient race: (circle)
   a. American Indian and Alaska Native
   b. Asian
   c. Black or African American
   d. Native Hawaiian and Other Pacific Islander
   e. White
   f. Other – specify: _____

4. Is patient Hispanic?
   a. Yes
   b. No

5. Patient gender?
   a. Male
   b. Female

6. Patient age (years)? _____

7. Date hospital started to place patient in an outpatient dialysis facility? _____

7a. Date patient accepted for placement in outpatient dialysis facility (or last day of data collection)? _____

7b. Number of days until placement in outpatient dialysis established? (Calculate number of days passing between 6a and 6) _____

8. Disposition (circle one)
   a. Outpatient dialysis facility where patient last received treatment
   b. Outpatient dialysis facility where patient will be a new patient
   c. Nursing home, long term acute care, or rehabilitation facility that provides dialysis treatments
   d. Not placed
   e. Patient expired

9. Does patient have a medical barrier to discharge? (circle)
   a. Yes (go to 9a)
   b. No (go to 10)

9a. If 9 is yes, circle all medical barriers that apply:
   a. Obesity
   b. Ventilator
   c. Tracheostomy
   d. Inability to transfer to chair

e. Medical instability
f. Requires continuous cardiac monitoring
g. Infection disease, specify type: _____
h. Severe psychiatric or cognitive disorder
i. Substance abuse
j. Other medical barrier, specify: _____

10. Does patient have a behavioral barrier to discharge? (circle)
a. Yes (go to 10a)
b. No (go to 11)

10a. If 10 is yes, circle all behavioral barriers that apply:
a. History of frequently skipping treatments
b. Disruptive behavior
c. Verbally abusive
d. Verbally threatening
e. Physically threatening
f. Physically abusive
g. Other behavior barrier, specify: _____

11. Does patient have a financial barrier to discharge? (circle)
a. Yes (go to 11a)
b. No (go to 12)

11a. If 11 is yes, circle all financial barriers that apply:
a. Uninsured
b. Underinsured
c. History of nonpayment for dialysis services
d. Undocumented migrant
e. Other financial barrier, specify: _____

12. Does patient have a psychosocial barrier to discharge? (circle)
a. Yes (go to 12a)
b. No (go to 13)

12a. If 12 is yes, circle all psychosocial barriers that apply:
a. Homeless
b. Significant transportation issues
c. Post-incarceration
d. Incompetent without a legal guardian
e. Other psychosocial barrier, specify: _____

13. Primary barrier to admission for this patient (circle one)
a. Medical
b. Behavioral
c. Financial
d. Psychosocial

Hospital to complete once:

1. Hospital name: _____

2. State where hospital is located (ex, PA, OH): _____

3. Hospital location: _____ Urban ____ Suburban _____ Rural

4. Hospital status: _____ For profit _____ Not for profit

5. Public hospital? _____ Yes _____ No

6. Number of hospital beds: _____

7. Does hospital have a Medicare-approved chronic dialysis facility?
   _____ Yes _____ No?