

A. Barriers to Outpatient Dialysis Collaborative Project

The Barriers to Outpatient Dialysis Collaborate Project took place over a three-year time period, from 2005 until 2008. A report that summarized all of the activities was sent to all of the participating Networks in July 2009 and is outlined here.

Step 1: CMS Special Project

CMS contracted with ESRD Networks 9/10 for a special study on Barriers to Outpatient Dialysis Placement between July 1, 2005 and June 30, 2006. Nine Networks (1, 2, 9, 10, 11, 14, 15, 16, and 18) collaborated on the project and a Technical Expert Panel assisted with the collaborative process. The purpose of this special project was to identify and explore the extensiveness of the placement barriers to receive dialysis treatment in an outpatient facility, the impact this has on the quality of patient care, and to recommend resolutions. It was estimated that this project would take at least three years to complete.

This summary of some of the outlining problems looked at the issues from both the facility and patient perspective. It was believed that dialysis units were refusing to accept patients who had special needs and/or behavioral issues for a number of different reasons. Responses from facilities regarding their refusal included:

- a) they were often short-staffed or working without adequate staff;
- b) it was difficult to take patients who had time-consuming needs;
- c) non-adherence issues could affect the facility's outcomes as reported to the Network and to CMS; and,
- d) they did not want to take on "someone else's problems."

At times some facility staff threatened to quit if difficult patients remained in their care and administrators acquiesced because they did not want their "good staff" to leave. Moreover, facility staff usually did not receive specialized training to work with challenging and difficult patients, nor with special needs patients, and often they did not feel confident in administering treatment to these populations of patients. In addition, facilities feared the possibility of lawsuits, both from patients and from staff, arising from potential violent situations or incidents. In spite of all of these reasons, dialysis patients still

needed to receive the best quality of care in the most cost effective manner, which meant they needed an outpatient dialysis facility for their care.

A literature review of articles relevant to barriers that exist for kidney patients, as well as other patients with related issues, was conducted. The literature search identified a number of articles related to treatment termination and found a more limited review of admission difficulties. Other topics reviewed that related to discharge and placement barriers included: payment, medical issues, behavior, age, race, ethnicity, gender, socioeconomic status, culture, co-morbidities, and other influences. Of the 73 articles reviewed, 39 percent described admission barriers related to kidney patients and only five percent of the articles quantified an admission barrier. Payment for treatment, complex medical needs and difficult behavior were the three most commonly reported barriers to outpatient dialysis admission. However, the literature provided little guidance for overcoming barriers to admission to dialysis facilities. Studies consistently identified disparities in health and health care services. Age, race, ethnicity, culture, gender, socioeconomic status, and co-morbidity were often 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 who were refused access to outpatient dialysis treatment.

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 Technical Expert Panel 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 were expected to identify specific disparities that exist to receiving dialysis in an outpatient facility. The Networks believed that with CMS approval to gather information from dialysis facilities and hospitals, there would be a greater understanding of the barriers

Step 2: Pilot Project

Although there was no additional funding for the CMS-funded special study described above, eight of the participating Networks decided to participate in a three-month pilot program using the standardized Admission and Discharge Forms developed during the initial project.

The Patient Services Coordinators (PSCs) of Networks 1, 9, 10, 11, 14, 15, 16 and 18 agreed to complete the Admission and Discharge Forms for all contacts related to an involuntary discharge or a barrier to placement issue. It was agreed that this would help quantify the extensiveness of the barriers to receiving dialysis treatment in outpatient dialysis facilities and would identify specific disparities that exist to outpatient placement. The pilot project was conducted from

to outpatient dialysis placement, as well as the extent of the problem. This project concluded that there was a need to track and find trends in admission data to be able to address the barrier issues that exist. Interventions also needed to be developed to assist facilities to accept patients with special needs; however, since this project was not funded for a second year the potential results of the extended study were placed on hold.

January through March 2007. Network 9/10 agreed to collect and analyze the data.

The results of this pilot project showed that the participating Networks had completed forms for 53 calls regarding placement issues and 87 calls regarding involuntary discharges during the three month time period. It should be noted that during the pilot project there were three new Patient Services Coordinators hired at participating Networks. It is expected that some opportunities for gathering the information might have been missed as the new staff were being acclimated to the project. In reviewing the collected standardized information, a number of reasons for discharge and barriers issues became

apparent. A review of the demographic information of both patients discharged and of those seeking placement revealed a number of similar factors. (See Figure 71)

Involuntary discharges were reported to the Networks more

frequently than placement concerns. Behavioral issues were the most frequent reasons for discharge with non-adherence and verbal/written abuse was mentioned most often within the behavioral category. (See Figure 72)

Even though physical threat or physical harm was mentioned no more than 18% of the time, 32% of the patients were given an immediate discharge and 52% were given a 30-day notice.

Figure 71- Reasons for Discharge
Pilot Project – January – March 2007
(More than one category could be chosen)

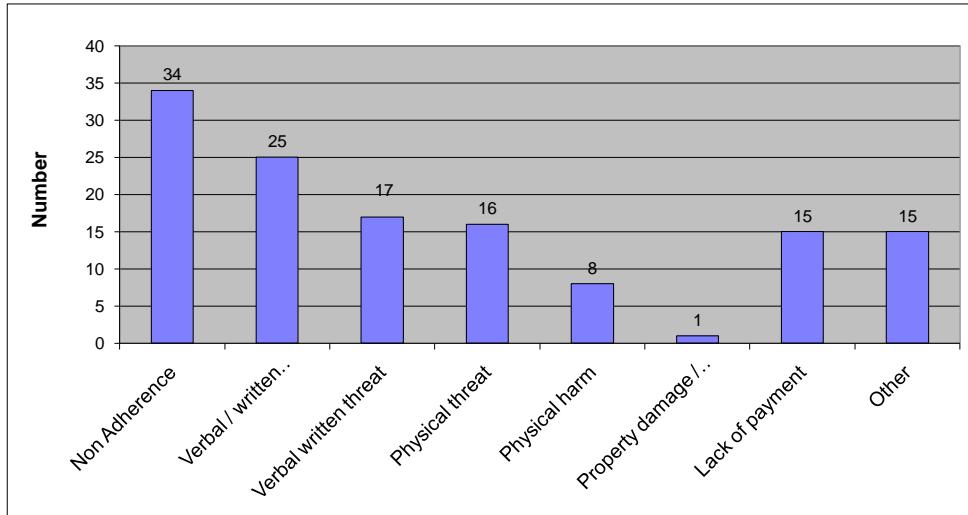
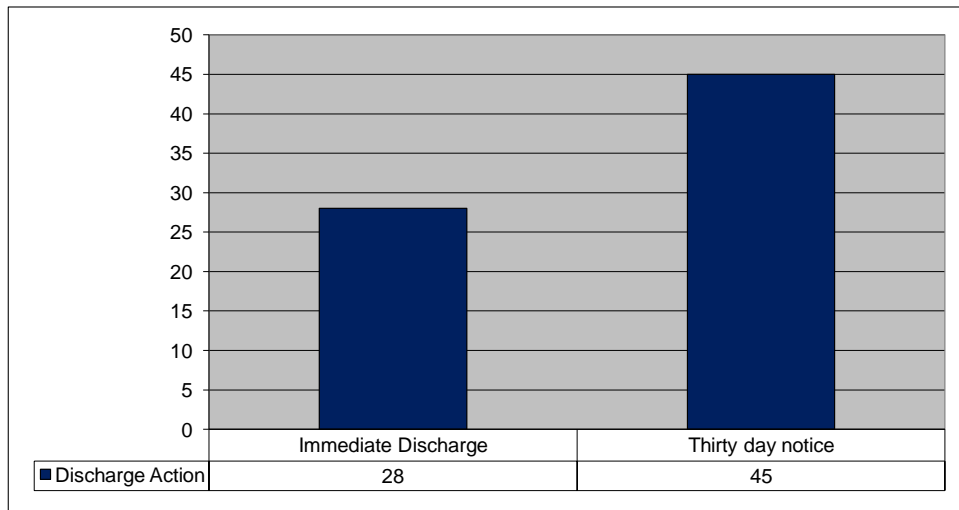


Figure 72 - Involuntary Discharge Actions Pilot Project – January – March 2007

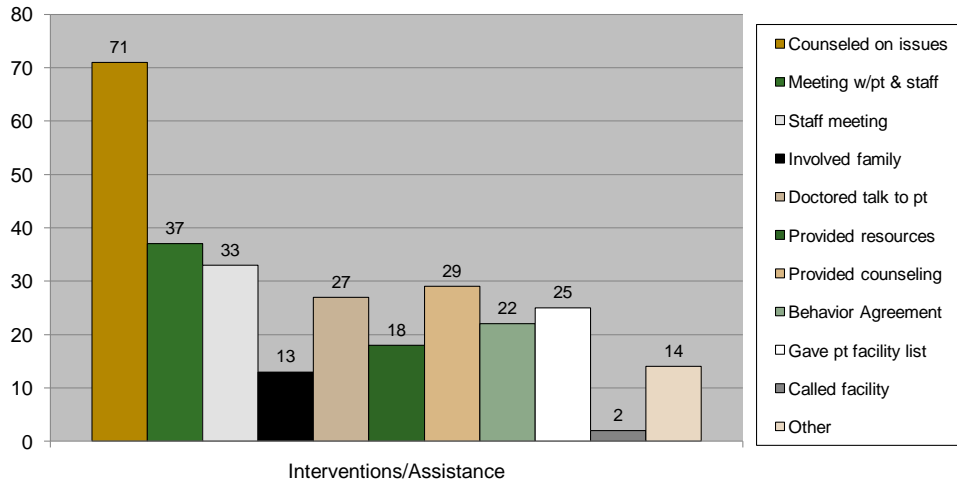


This project did not capture the amount of time facility staff tried to work with patients before the decision to discharge. When Network staff inquired about the various interventions that might have occurred, some facilities were interested in learning more about the interventions on the Network list and requested a copy of the interventions to use in the future. The most frequent intervention repeatedly used by facility staff was to talk to the patient regarding the issue. Rarely did the staff call another facility to help the patient find placement elsewhere. (See Figure 73)

Figure 73 - Interventions Provided Before Discharge

Pilot Project – January – March 2007

(More than one category could be chosen)



The review of demographics of discharged patients showed that when compared to the expected outcomes for age, gender and race the following categories were overrepresented: a) the 18-44 year old age, b) males, and c) blacks. (See Figures 74 – 76)

Figure 74 – Discharge Demographics By Age

Pilot Project – January – March 2007

Age Breakdown (n=87)			
Age	Forms	Percentage of Forms	Network Percentage
< 18	0	0%	1%
18 - 44	26	30%	14%
45 - 64	38	44%	41%
65 - 74	6	7%	22%
75 - Up	5	6%	21%
Unknown	12	14%	0%

Figure 75 - Discharge Demographics By Gender

Pilot Project – January – March 2007

Gender Breakdown (n=87)			
Gender	Forms	Percentage of Forms	Network Percentage
Male	53	61%	55%
Female	22	25%	45%
Unknown	12	14%	0%

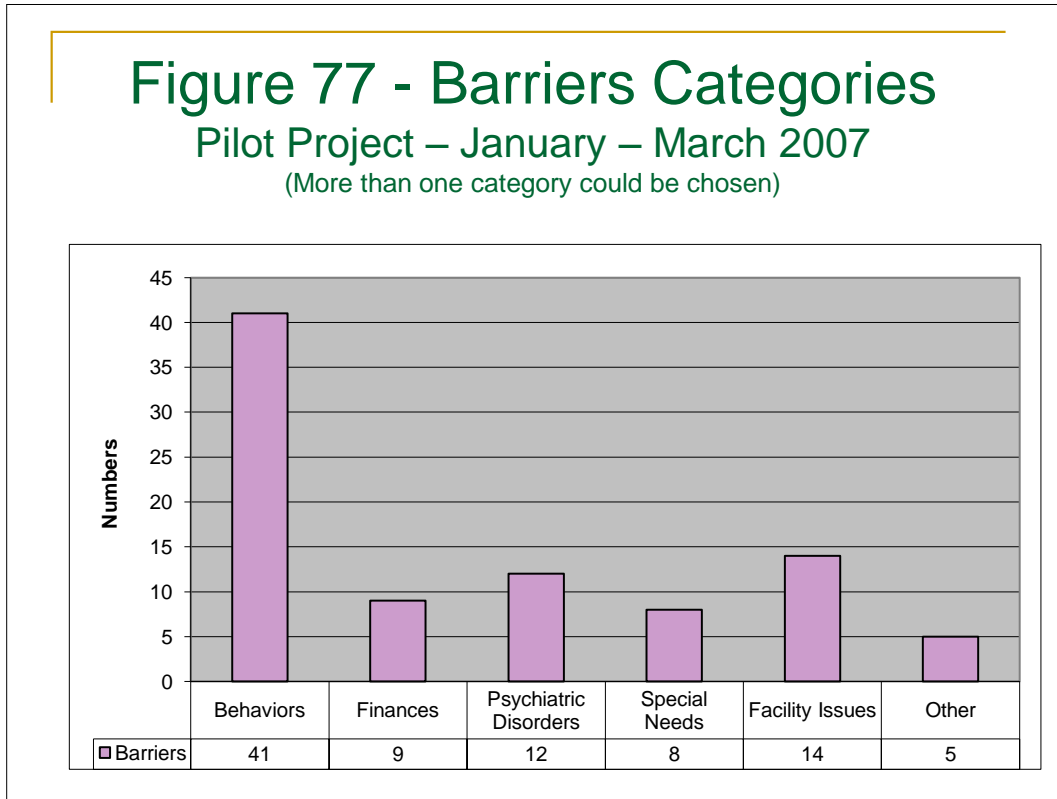
Figure 76 - Discharge Demographics By Race

Pilot Project – January – March 2007

Race Breakdown (n=87)			
Race	Forms	Percentage of Forms	Network Percentage
American Indian	1	1%	2%
Asian	1	1%	3%
Black	38	44%	24%
White	35	40%	69%
Other	0	0%	1%
Unknown	12	14%	0%

Hospital staff and facility staff primarily contacted the Networks about the difficulty in finding placement for a patient at a dialysis facility. Usually the need for placement was for a current patient, and less than five percent of the time was the placement concern about a new dialysis patient.

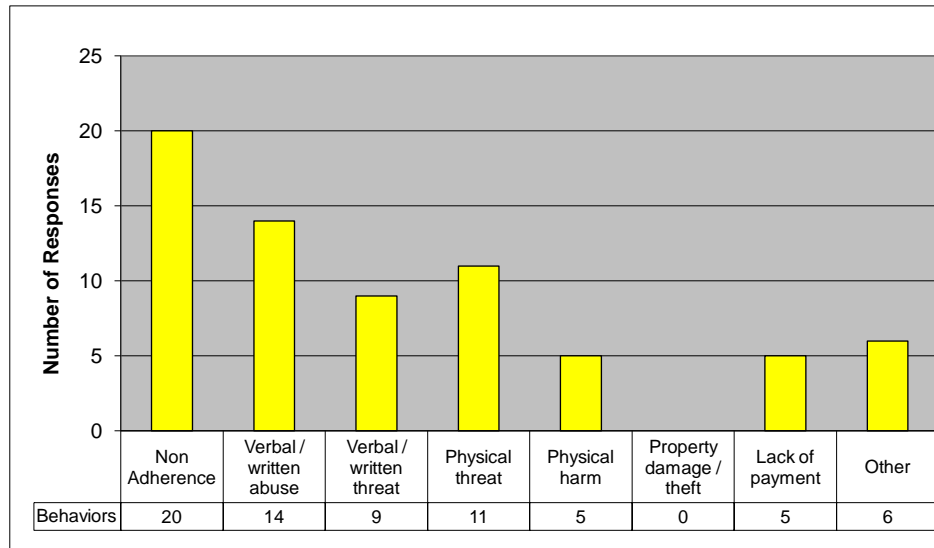
Placement barriers reported to the Networks indicated that behaviors were the most frequent category with facility issues as the second most reported barrier. (See Figure 77)



This project also showed that approximately half of the 53 patients seeking placement had been discharged by their facilities. Behaviors were most often reported as the reasons for discharge with non-adherence reported as the most frequent reason, followed by verbal/written abuse. (See Figure 78)

Figure 78 - Behavior Barriers Pilot Project – January – March 2007

(More than one behavior could be chosen)



Facility barriers, the second highest barriers category, included multiple dialysis units that had denied admission, followed by not having a nephrologist who would accept the patient, and finally corporate denial was cited. (See Figure 79)

Figure 79 - Facility Barriers to Placement

Pilot Project – January – March 2007

Corporate Denial	5
Multiple Units Denial	9
Not Enough Staff	0
Unit Full	0
No Accepting Nephrologist	6

The review of patient demographics for those patients who were experiencing placement barriers when compared to the expected outcomes for age, gender and race were overrepresented in the following categories: a) the 18-44 year old age group, b) males, and c) blacks. (See Figures 80 – 82)-

Figure 80 - Placement Demographics By Age

Pilot Project – January – March 2007

Age Breakdown (n=53)			
Age	Forms	Percentage of Forms	Network Percentage
< 18	0	0%	1%
18 - 44	18	34%	14%
45 - 64	21	40%	41%
65 - 74	3	6%	22%
75 - Up	2	4%	21%
Unknown	9	17%	0%

Figure 81 - Placement Demographics By Gender

Pilot Project – January – March 2007

Gender Breakdown (n=53)			
Gender	Forms	Percentage of Forms	Network Percentage
Male	38	72%	55%
Female	14	26%	45%
Unknown	1	2%	0%

Figure 82 - Placement Demographics By Race Pilot Project – January – March 2007

Race Breakdown (n=53)			
Race	Forms	Percentage of forms	Network Percentage
American Indian	0	0%	2%
Asian	1	2%	3%
Black	18	34%	24%
White	28	53%	69%
Other	0	0%	1%
Unknown	6	11%	0%

The outcomes of the pilot program showed that information regarding involuntary discharges and placement barriers could be consistently gathered across Networks and used to enhance the basic information collected in the SIMS data base, which is used by all ESRD Networks. The discharge profile outcomes were consistent with the Involuntary Discharge Survey of 2002, in which a number of Networks participated in a special project led by Networks 11 and 14. Over time, non-adherence has consistently been the primary reason for discharge, even though CMS has frequently reported that it was not a reason for facilities to discharge patients. The three groups most consistently discharged in the pilot project (younger patients, male patients, and black patients) were also the three groups most consistently noted to be discharged in the 2002 Involuntary Discharge Survey.

The participating Networks agreed to undertake a longer collaborative project and to open it up to other Networks. In addition, the Patient Services Coordinators reviewed and updated the Placement and Discharge forms and agreed to justify the

contact calls regarding discharges with the Patient Activity Reports (PARs) of involuntary discharges (6c).

Step 3: Networks Collaborative Project

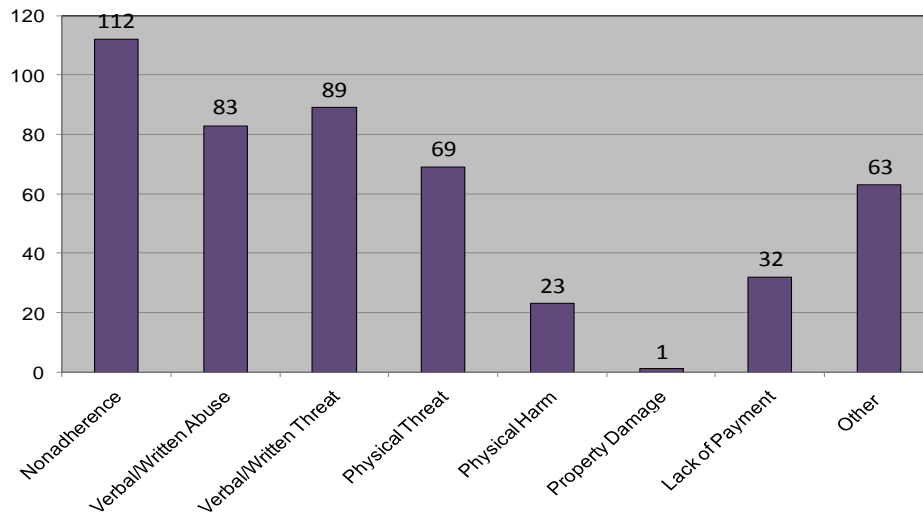
After the pilot project, 12 Networks agreed to participate in a collaborative project to continue to quantify the extensiveness of involuntary discharges and placement barriers as well as to identify disparities that exist to outpatient placement. The following Networks agreed to participate in the project for the year 2008: Networks 1, 5, 6, 9, 10, 11, 12, 13,14,15,16, and 18. Three Networks participated for only part of the year: Network 6 participated until August 2008, Network 16 participated until May 2008, and Network 18 was unable to participate until June 2008. The Patient Services Coordinators agreed to complete the Admission and Discharge Forms for all contacts related to an involuntary discharge or a barrier to placement issue. They also agreed to follow up their contacts by reviewing the Patient Activity Report for the discharge events for accuracy that the discharge event that had occurred. Network 9/10 agreed to continue to collect and analyze the data.

During the entire year of 2008, there were 300 discharge forms completed for calls related to patient discharges. There could be multiple reasons for discharge. Non-adherence was the most frequently identified factor, followed by verbal/written threats. The percentage of time non-adherence was mentioned as a reason for discharge in the pilot project and the collaborative project was similar at approximately 38%. In both the pilot project and the collaborative project, verbal/written abuse occurred approximately 28 % of the time, while verbal/written threats increased by 10% during the collaborative project. (See Figure 83)

Figure 83 - Reasons for Discharge

Collaborative Project - 2008

(More than one category could be chosen)

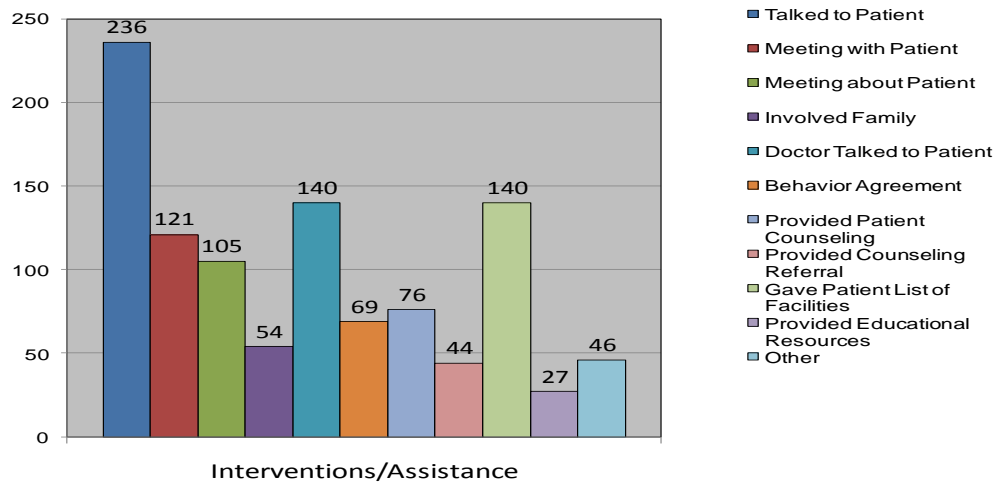


Interventions used to prevent discharge were also captured. The interventions most frequently noted were: talking to the patient about the issue, having the physician talk to the patient, and giving the patient a list of other facilities. In the pilot project, the physician was reported to have talked to the patient about the issue 31% of the time, while in the collaborative project the physician talked to the patient 47% of the time. Also, in the pilot project, the patient was given a list of other facilities 29% of the time and in the collaborative project, the patient was given a list of other facilities 47% of the time. (See Figure 84)

Figure 84 - Interventions Provided Before Discharge

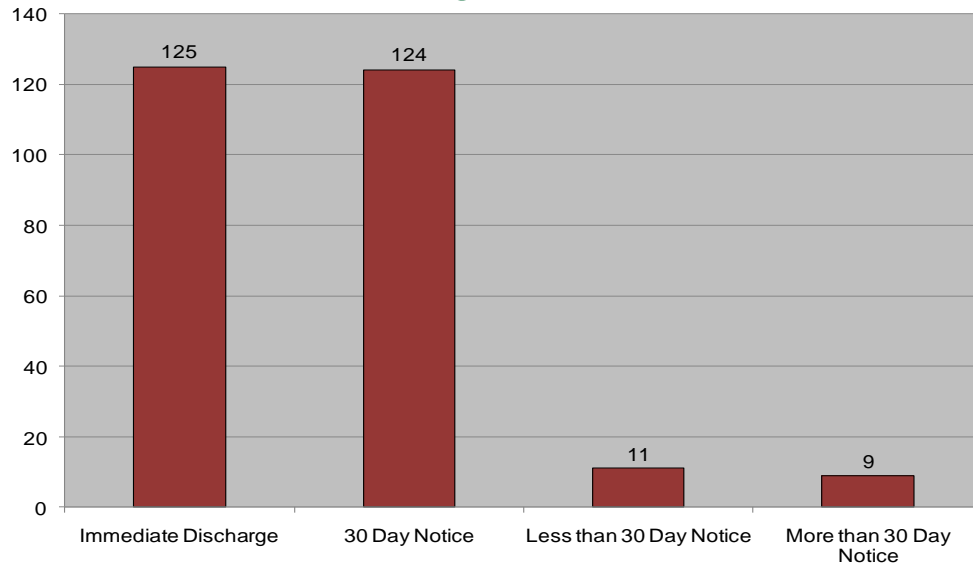
Collaborative Project - 2008

(More than one category could be chosen)



The data showed that 42% of the facilities gave patients an immediate discharge, while in the pilot project 32% of the facilities immediately discharged patients. (See Figure 85)

Figure 85 – Involuntary Discharge Actions



The review of the demographics showed that a disproportionate number of the following groups were discharged: a) the 18-44 year old age group, b) males, and c) blacks. (See Figures 86 – 88)

Figure 86 – Discharge Demographics By Age

Collaborative Project - 2008

Age Breakdown (n=300)			
Age	Forms	Percentage of Forms	Networks Percentage
< 18	1	0%	1%
18 - 44	124	41%	15%
45 - 64	143	48%	42%
65 - 74	22	7%	22%
75 - Up	9	3%	20%
Unknown	1	0%	0%

Figure 87 - Discharge Demographics By Gender

Collaborative Project - 2008

Gender Breakdown (n=300)			
Gender	Forms	Percentage of Forms	Networks Percentage
Male	220	73%	55%
Female	79	26%	45%
Unknown	1	0%	0%

Figure 88 – Discharge Demographics By Race Collaborative Project - 2008

Race Breakdown (n=300)			
Race	Forms	Percentage of forms	Networks Percentage
American Indian	5	2%	2%
Asian	2	1%	3%
Black	166	55%	36%
White	125	42%	58%
Other	1	0%	1%
Unknown	1	0%	0%

During 2008, there were 95 admission forms completed by seven of the participating Networks; the other Networks had not received calls for placement assistance. The category most often mentioned as a barrier was behaviors (primary behavior mentioned was non-adherence, followed by verbal/written abuse). The second highest barriers category was facility issues. (See Figures 89 – 90)

Figure 89 - Barriers Categories

Collaborative Project - 2008

(More than one category could be chosen)

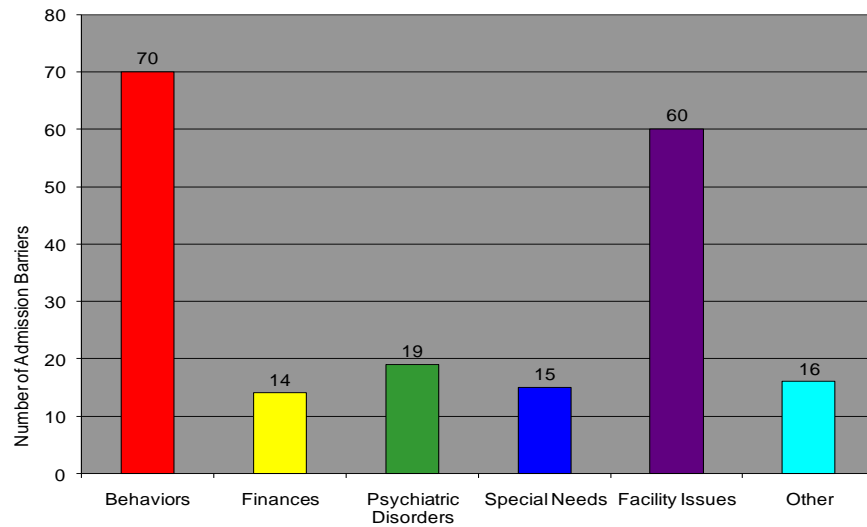
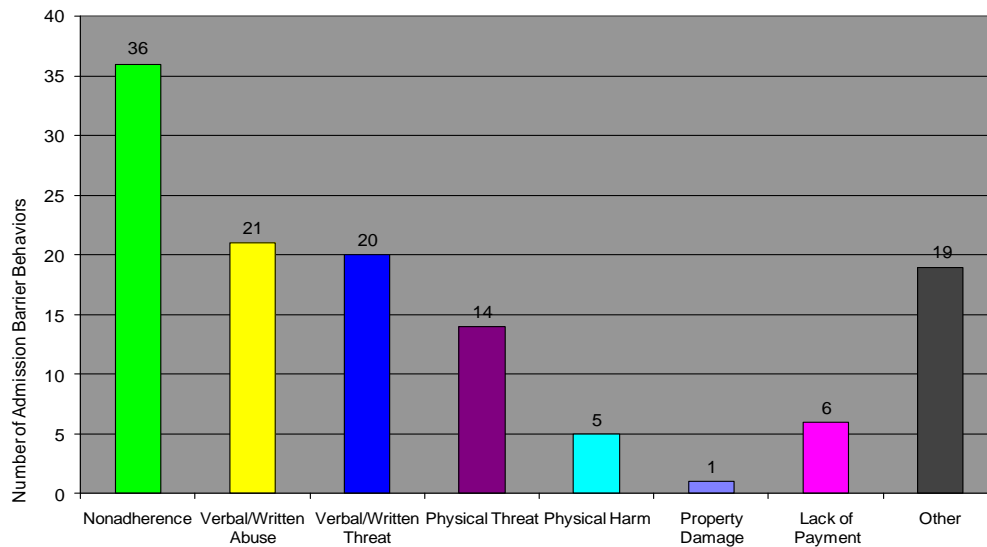


Figure 90 - Behavior Barriers

Collaborative Project - 2008

(More than one behavior could be chosen)



In the pilot project, facility issues were mentioned as a barrier to placement 26% of the time as compared to 63% of the time in the collaborative project.

Multiple units denying placement occurred 53% of the time in the collaborative project compared to 17% in the pilot project. The percentage of time that a nephrologist could not be found to accept a patient occurred 27% of the time in the collaborative project compared to 11% of the time in the pilot project. (See Figure 91)

Figure 91 - Facility Barriers to Placement Collaborative Project - 2008

Corporate Denial	7
Multiple Units Denial	50
Not Enough Staff	2
Unit Full	2
No Accepting Nephrologist	26

The demographics of patients who had difficulty locating placement were consistent with the previous project. The collaborative project showed that there were disproportionately placement barriers for: a) the 18-44 year old age group, b) males, and c) blacks. (See Figures 92 – 94)

These groups are identified in both the pilot project and the collaborative project as being overrepresented given the demographics of the participating networks. Even though the 18-44 year old age group, males, and blacks are consistently overrepresented, one cannot put them all together and state that it is one group, young, black males, that is overrepresented. A correlation between the groups has not been found.

Figure 92 - Placement Demographics By Age Collaborative Project - 2008

Age Breakdown (n=95)			
Age	Forms	Percentage of Forms	Networks Percentage
< 18	1	1%	1%
18 - 44	31	33%	15%
45 - 64	39	41%	43%
65 - 74	7	7%	22%
75 - Up	1	1%	20%
Unknown	16	17%	0%

Figure 93 - Placement Demographics By Gender

Collaborative Project – 2008

Gender Breakdown (n=95)			
Gender	Forms	Percentage of Forms	Networks Percentage
Male	58	61%	54%
Female	29	31%	46%
Unknown	8	8%	0%

Figure 94 - Placement Demographics By Race

Collaborative Project - 2008

Race Breakdown (n=95)			
Race	Forms	Percentage of forms	Networks Percentage
American Indian	1	1%	2%
Asian	0	0%	2%
Black	50	53%	40%
White	27	28%	55%
Other	0	0%	0%
Unknown	17	18%	0%

The results of the collaborative project indicate that some patients are being discharged for reasons not supported by the CMS guidelines and that facilities provide minimal active assistance to discharge patients needing placement at another dialysis facility. In addition, behavior issues have been identified as barriers to outpatient placement and facilities also may play a role in preventing dialysis placement for some patients.

Summary

Overall, both the pilot and the collaborative projects suggest that there is a disproportionate number of black patients, male patients, and patients within the 18-44 year old age range who are involuntarily discharged from facilities and who experience placement barriers.

It is important to learn more about the potential reasons for the disproportionate demographics identified. For example, understanding the reasons that the younger population is more at risk for placement or discharge issues may assist the Networks in developing tools and resources for facilities. Likewise, understanding cultural differences and having tools and/or in-service training programs available for staff may help to address some of the racial barriers.

It also appears that if one facility does not accept a patient for placement, it is now more likely that other facilities will not accept the patient. In addition, nephrologists may be deciding not to accept these potentially challenging patients. This trend is likely to increase with pay-for-performance.

The ability to collect information regarding barriers to placement and involuntary discharges is important to continue and to understand the complexity of the problems. It is believed that many problems may magnify with the coming of pay-for-performance.

Although the Networks as a group are no longer collecting discharge and placement data, individual networks are continuing to collect this information in various fashions. The Center for Medicare and Medicaid Services also has expressed more of an interest in gathering this information and a committee is currently developing a data base that could be added to the Tier 2 level when CROWN WEB becomes fully utilized. In addition, the Patient Services Coordinators will continue to address issues related to placement and discharge.